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#### **Editorial**

## The Medium and the Message: Fitting Sound Health Promotion Methodology Into 160 Characters

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#### **Related Article:**

Comment on: http://mhealth.jmir.org/2014/4/e51/

## Abstract

Text messaging health promotion projects continue to proliferate due to their relative low-cost, simplicity, non-intrusiveness, and proven effectiveness in several randomized controlled trials. In these past trials, participants have typically been recruited through traditional means, received the text messaging intervention, and then completed evaluation. In this issue of the *Journal of Medical Internet Research*, Sheoran et al have demonstrated how use of text messaging alone can be a feasible method for all three stages: recruitment, intervention, and evaluation. Use of text messages without any other modes of communication could be a key to population-level dissemination and wider uptake of health promotion messages. However, in the rush to utilize new technologies and in the brevity of 160 characters, it should not be forgotten that quality, rigour, and careful development remain essential in any health promotion practice.

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#### **KEYWORDS**

text messaging; mobile phone; health promotion; program evaluation

## Introduction

There are now 96 mobile subscriptions for every 100 people on the planet [1], and text messaging (SMS, short message service) remains one of the most common uses of mobile phones, particularly for young people in the United States [2]. Consequently, text messaging is being increasingly used as a health promotion tool, as highlighted recently by Sheoran et al in the *Journal of Medical Internet Research* [3]. As technologies develop and projects in this field proliferate, it is vital that quality research continues to be conducted to maximize the quality of interventions, to refine the methods used, and to evaluate impact. While the major benefit of text messaging interventions is their ability to reach people in a non-intrusive way, most trials published to date have bookended the text messaging intervention itself with traditional recruitment methodologies such as face-to-face or clinic-based recruitment and traditional evaluation methodologies such as focus group discussions or questionnaires [4-6]. While this might have been considered necessary initially to provide scientific rigour, the cost and effort of going through these methods negates the key benefits and simplicity of the technology. However, it is possible to use text messages as the sole method of communication in an intervention; to identify and recruit participants, to deliver the intervention, and to evaluate the project. *The Hookup* provides an example of a sexual health promotion project using text messaging in all of these three ways.



## Text Messaging to Recruit Participants

Text messaging health promotion and research efforts have often relied on starting with face-to-face recruitment [4]. However, this may not be necessary and means that some of the benefits of mobile-delivered health promotion or research are lost—in particular it is more costly, time-consuming and inconvenient for both researchers and participants. Instead, researchers could utilize text messaging to recruit people with whom they have never had any contact with in any other form.

One of the greatest advantages in using text messaging to recruit participants is the feasibility for population-wide dissemination and translation of research into practice; a much lower level of engagement is needed than for other contact methods. This may be particularly salient for young people; other evaluation methods such as postal mail and landline communication have limited reach for this demographic group and may recruit only the most motivated young people. Through mixing technologies and approaches, it may be possible to reach different people who do not normally engage in research. The Hookup's recruitment approach was opt-in, via text messages [3]. They advertised the service widely at schools, adolescent health centers, and online but had no direct contact with potential participants. Other programs have attempted to attract users through in-person enrollment at festivals or street intercept, and use of mass media [5, 7-9].

Probably the most effective and efficient way to recruit participants via text messages is to partner with a telecommunications company or mobile phone provider. This allows individuals' mobile phones to be accessed in large numbers from existing databases with very little effort [10,11]. However, as discussed in depth by Gold et al, this can be problematic when the priorities of the private company and the public health or research organization do not align [11]. A particular concern is that researchers become dependent on a third party (the private telecommunications company) to conduct their research; for example in one study 316 text message surveys were not delivered due to a mid-study block by a local mobile phone provider [12], and in another study the telecommunications company elected to censor the content of sexual health promotion messages [11]. Other important potential limitations to using text messaging to recruit participants are that engagement with the program may be lower, initial participation rates may be lower, and it may not be possible to validate participant characteristics (eg, age and gender) [11,13].

## Text Messaging as the Intervention

Sheoran et al report that *The Hookup* project was successful, with 90% of respondents reporting a positive change to their behavior such as testing for sexually transmitted infection (STI) or condom use [3]. This work supports the findings of several previous trials and reviews [4,5,14-17]. However, despite the success of text messaging interventions in sexual health promotion, there remains important research gaps in this area. While several studies have shown impact using text messaging, this does not mean that all text messaging programs will be

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effective; significant work is needed to develop effective content. As Ybarra et al, pointed out "many researchers seem to view text messaging as the intervention itself instead of simply a delivery mechanism... Like other interventions, however, the content is a central driver of the behavior change."[18] There has been limited use of behavior change theory to guide message development in many previous studies [15]. The impact of important variables on the success of a project; including the timing, frequency, duration, tailoring, and interactivity of text messaging has not been fully explored [4,17]. Furthermore, while mHealth sexual health promotion interventions show great promise in developing countries [19], to date there are no reported RCTs in this setting.

Lim et al

## Text Messaging to Evaluate the Intervention

When evaluating a text messaging health promotion intervention, typical outcomes include process measures such as acceptability of the intervention and impact measures such as changes in knowledge and behaviors. Process measures can use a combination of data on number of subscribers, response rates and dropout rates, which should be collated throughout the project. Additionally, participants may be asked to report their opinions about the program generally and the content specifically. Impact measures can also utilize self-report data (eg, in the *Hookup* participants reported whether they had changed their behavior).

Common methods used previously to collect these self-report data include focus group discussions and surveys [5,8,20]. However, as Sheoran et al describe, in an intervention where the only contact researchers have with participants is via text messages this may not be feasible. Online evaluation is considerably simpler than 10 years ago now that many recipients can switch from a text message to an online survey instantly on a single device using Web-enabled mobile phones. However, this may bias participation to those who own smartphones and exclude those who choose only to engage with the program via text messaging. An alternative is to use text messages themselves to collect self-report questionnaire data.

Text messaging data collection in research is well established [12,21-24]. This method is effective, low-cost and useful, and achieves good response rates compared to other survey delivery methods [12,22,25,26]. The major limitation of text messaging data collection is the number of characters; the 160 character limit can make it difficult to provide sufficient detail to pose clear and valid questions. However, several studies have compared text messaging questionnaire responses to retrospective reports by more traditional survey methodologies and have demonstrated reliability over time in responses [12,22,25].

An additional benefit of text messaging data collection is that it allows the possibility of using frequent (eg, daily) real-time diary-style data collection. This may improve the reliability of data beyond retrospective questionnaires through decreasing recall bias and is particularly useful for rapidly fluctuating measures (eg, mood)[12,22,27,28]. One concern is that frequent

prompts to complete data collection may influence behavior by serving as a reminder about the behavior in question; for example, one study's participants reported that participating in a weekly text messaging sexual behavior survey made them want to have sex more often [22].

No matter how they are collected, self-report data are subject to certain biases and limitations [29]. Objective biological measures (eg, STI test results) would improve validity. Mobile technologies may be a pathway to achieving this; a consortium in the United Kingdom are working to develop mobile phone enabled point-of-care STI diagnostics for STI which link directly to mobile networks [30]. Other novel technological tools for evaluating the impact of a health promotion project include direct and objective mobile data collection via an app, wearable cameras, or other electronic devices such as accelerometers [31,32]. However, these sorts of devices may not be appropriate or acceptable for measuring sexual health related behaviors.

### Discussion

Text messaging interventions have demonstrated effectiveness in several trials, however, there is still much to learn about how to maximize their impact. As these programs are more broadly implemented, it is important to maintain rigour in development and evaluation. When moving beyond research into health promotion practice, the burden of poor funding and shortage of research-trained staff can prohibit the conduct of high quality evaluation via other methods. Thankfully as discussed above, the text messaging tool lends itself to practical and low-cost intervention delivery, recruitment, and evaluation.

Text messaging health promotion is an exciting area offering many opportunities in implementation and evaluation, but it is vital to ensure we are not leaving behind the theory and evidence that has been carefully developed and tested on other platforms. Even though a text message is only 160 characters long, it does not mean that work in this field requires less careful consideration. While text messaging is a highly promising tool, it is important to remember that text messaging itself is not the answer but only a mode of delivery. Whatever medium we use, we still need to be certain that we are recruiting the right people, delivering the right message, and measuring the right things to conduct successful and rigorous research and health promotion.

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#### **Conflicts of Interest**

None declared.

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#### **Original Paper**

## Consumers' Perspectives on National Health Insurance in South Africa: Using a Mobile Health Approach

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## Abstract

**Background:** Building an equitable health system is a cornerstone of the World Health Organization (WHO) health system building block framework. Public participation in any such reform process facilitates successful implementation. South Africa has embarked on a major reform in health policy that aims at redressing inequity and enabling all citizens to have equal access to efficient and quality health services.

**Objective:** This research is based on a survey using Mxit as a mobile phone–based social media network. It was intended to encourage comments on the proposed National Health Insurance (NHI) and to raise awareness among South Africans about their rights to free and quality health care.

**Methods:** Data were gathered by means of a public e-consultation, and following a qualitative approach, were then examined and grouped in a theme analysis. The WHO building blocks were used as the conceptual framework in analysis and discussion of the identified themes.

**Results:** Major themes are the improvement of service delivery and patient-centered health care, enhanced accessibility of health care providers, and better health service surveillance. Furthermore, health care users demand stronger outcome-based rather than rule-based indicators of the health system's governance. Intersectoral solidarity and collaboration between private and public health care providers are suggested. Respondents also propose a code of ethical values for health care professionals to address corruption in the health care system. It is noteworthy that measures for dealing with corruption or implementing ethical values are neither described in the WHO building blocks nor in the NHI.

**Conclusions:** The policy makers of the new health system for South Africa should address the lack of trust in the health care system that this study has exposed. Furthermore, the study reveals discrepancies between the everyday lived reality of public health care consumers and the intended health policy reform.

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#### **KEYWORDS**

health systems reform; public consultation; South Africa; National Health Insurance (NHI); health systems strengthening (HSS); WHO building blocks; social media, GINI Index

#### Introduction

In the South African health system, there is a severe divide between the public and private sectors [1]. The proposed National Health Insurance (NHI) scheme aims to bridge existing health inequalities and offer equal access to affordable, quality health care to all citizens, regardless of their socioeconomic status [2]. The escalating gap between the rich and the poor in South Africa is underlined by the Gini index over the last decades (65.0 in 2011 vs 59.3 in 1993) [3,4], which indicates that the disparity is wider than under apartheid [5-7]. The country spends 8.5% of its gross domestic product on its health care system [8], with a poor outcome [9] that is emphasized by a low life expectancy (57 years in males vs 60 years in females) [8] and a high neonatal mortality rate (19 per 1000 live births in 2009) [10-12].

The South African health system is characterized not only by a two-tiered system, but also by escalating costs [13]. The major share of financial and human resources in the health care sector is currently located in the private health sector, which covers only a relatively wealthy minority of the population [2]. While public health care is mainly tax funded and partly by service fees, private health care is financed by privately insured people, medical schemes of public servants, governmental subsidiaries, and public grants. Furthermore, while the costs in the private health sector almost doubled between 1996 and 2003, resulting in increased premiums for private health care users, spending in the public sector decreased [14,15]. Whereas the public annual expenditure is estimated at US \$248 per capita, it is US \$1002 for the private group [2]. In addition, a major part of public health sector spending is directed towards human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) and tuberculosis (TB) treatment, to the neglect of other medical areas. The health outcome of people in the private sector differs from the public sector: in 2005 the infant mortality rate (under 1 year) was 4.1 fold higher in the public sector in comparison to the private sector (74 deaths per 1000 live births versus 18 deaths per 1000 live births) [16]. The figure differs across provinces within South Africa and is, for example, 2.6 fold higher in the Eastern than in the Western Cape [17]. Within a decade the maternal mortality rate increased 6.5 fold from 100 deaths in 100,000 pregnancies in 1998 to 650 deaths in 100,000 pregnancies in 2007 [18]. Adding to the decline in the quality of public health services are the poor governance and management of hospitals, public underfunding, mismanagement, shortages of health professionals, and deteriorating infrastructure [1,2,8,19,20]. South Africa also needs to invest in training health professionals, an area that is currently underdeveloped and neglected [19]. The use of measures that optimize efficiency and enable treatment of patients according to their needs [21], such as the triage score [22], are also proposed [23].

The NHI of South Africa seeks to provide universal access to health care, as is promoted by the WHO [24]. Phased in over a period of 14 years, it will lead to major changes in delivery structures, administration, and management systems [2]. These changes are associated with high costs [25], which are estimated at US \$33 billion by 2025 [26]. Since different socioeconomic groups have diverse expectations of public health care, South

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Africans need to be well prepared for major health system changes to ensure their support [20]. Another major concern is the proposed intention to run the health system from the national tier, thus centralizing it [26].

According to Frogner [19], South Africa could reduce the burden of disease by 14.2 million disability adjusted life years (DALYs) and gain up to 184,085 lives by avoiding premature death under a single payer system like the NHI. But this goal can be achieved only if service provision, equity, and efficiency are improved [9]. Currently the NHI is at the Green Paper stage [26], defined as a first-draft document. It is being circulated among interested parties with the intention that they participate in a process of consultation and debate. However, the implementation of the NHI is associated with various logistical and political concerns [1,27]. Hence, it is important to establish public support by reaching and including, as broadly as possible, the opinions of members of the society [28]. Participation can influence service planning, information development, and dissemination as well as the attitudes of service users and providers [29]. It has also been found to have a positive effect on quality and coverage of health care as well as health outcomes [29,30]. As a result, public and patient involvement is increasingly being mainstreamed by various governments [31,32]. It also has the potential to be an important tool for accountability.

A government's effectiveness is linked to its ability to develop, implement, and enforce measures that ensure the enforcement of policies [32]. This entails the professionalism of the public service, the functioning of governmental departments and agencies, as well as the absence of corruption [33,34]. In addition, it is necessary to establish valid indicators for policy performance [35].

Public consultations not only constitute a civil right in terms of the South African Constitution [36], they may enable enhanced understanding of complex policy changes [37] and can be used to highlight, precisely, the gaps between lived reality and proposed policy [38-40]. The knowledge gained from public consultations can assist [41], as in this case, policy makers to facilitate the overhaul of the health system and to implement the process of a new policy [40,42]. To this end, an electronic consultation process was initiated by a non-governmental organization (NGO) and the People's Health Movement of South Africa.

The WHO proposes a "building blocks" framework for health systems strengthening (HSS) [43]. The aim of such strengthening is to provide effective, equitable, and high-quality health care as well as to maximize its accessibility [43,44]. Although the WHO building block framework does supply health sector actions for strengthening health systems, the blocks in fact appear static and are not interrelated [45]. Also, the blocks do not specifically address either the role of the population in this process, or the underlying social and economic determinants of health, or the substantial interactions that exist across each component [46]. This is because the building blocks provide an outline for the "hardware" but not for the "software" required to apply ideas and interests, relationships and power, norms [47], values, and human rights to the strengthening process [48]. A practical approach to HSS may, however, be

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applied through the use of systems thinking [49], which is a means of gaining understanding of the dynamics and the relationships of various stakeholders that would be essential for successful interventions.

The study analyzed the views on a health system policy of consumers—as the system's major stakeholders. Health systems are meant to be complex adaptive systems that aim to provide improved health as well as social and financial protection as they respond to the expectations and current needs of a population [45]. As a result, in addition to the WHO building blocks, an HSS policy for this country would require the promotion of dynamic networks of diverse stakeholders, the ability to work across subsystems, and the means of inspiring learning and research [49].

Despite consensus on the need of HSS worldwide [50], there is little agreement on which strategies to use in its implementation. The performance of different health systems varies even at the same level of health expenditures or income per capita. These variations are influenced by determinants such as leadership, institutions, system design, and technologies [51].

Public consultation and participation are valuable tools to draw on in support of the successful implementation of new policies and in order to reduce any disparities between intended policies and everyday lived reality. Up to the present, only a few electronic public consultations related to health policies have been published [52]. Governments have not been very active in seeking citizens' input over the Internet, even though it has become widely accepted by society as a way of conducting everyday life. The advantages of involving the public in decision making are to promote the goals, bind individuals and groups together, support civic and political identity, and create competence and responsibility [53].

Mobile devices that provide social interaction technology applications are ideal for regions such as South Africa with its low Internet and computer penetration, but high coverage on mobile phones [54]. Among social interaction technologies, Mxit is by far the most popular one [55]. More than 6.5 million South Africans run this free instant messaging application on their mobile phones [56-58]. Therefore, it was chosen as a tool to reach health care consumers nationwide.

The objective of the study was to understand the experiences and perceptions of public health care users regarding the current health care system and to relate these to the intended reform. The six WHO building blocks were employed as an overarching framework for HSS, and a qualitative research approach was adopted by using a theme analysis to illustrate and interpret the survey data.

This paper outlines health consumers' views of the current system and whether they are congruent with the proposed improvements of the NHI and the six building blocks for HSS. Since findings may be deployed by policy makers to fine-tune implementation of policy and to fill gaps between public concerns and policy reform, they should facilitate the process of the consumer-orientated overhaul of the health system.

## Methods

Due to the high coverage of mobile phones in South Africa [54], an e-public consultation via Mxit was chosen using mobile devices [55,57]. This public electronic consultation was initiated to raise awareness and facilitate the incorporation of the public's health needs and concerns into the bill. To ensure the understanding of the participants, short advocacy messages were sent to inform them about the purpose of the consultation and the use of the obtained information to shape the NHI health policy reform. By taking the survey, the participants agreed that their anonymized comments would be used for analysis. Data collection and data analysis were handled separately. All data were rendered anonymously, so that messages could not be traced back to the sender. The study was approved by the Ethics Committee of the University of Cape Town.

The Green Paper was made available on the South Africa National Health Insurance website so as to raise awareness and stimulate public feedback. Mxit donated free advertising for the NHI consultation. An advertisement was sent to 60,000 Mxit users. Nearly 900 participants showed interest in contributing towards the NHI policy. The survey was carried out between November 30 and December 24, 2011. In total, 582 people participated in the survey by submitting answers to the six guestions. The questions asked, and their linkage to the six building blocks of the WHO, are illustrated in Table 1. Table 2 displays how many answers were retrieved for each question. In addition, a ranking of the major themes of the survey users was carried out.



Table 1. Overview of the questions and statements addressing the South African health care consumers in the survey.

WHO building block	Survey question
Health Service Delivery	The South African Constitution protects the right to health for all people living in SA. Free access to health care services is your right.
Health Workforce	Do you spend hours waiting in line at the clinic every month? South Africa's public hospitals/clinics need more staff, for example, nurses, doctors, and pharmacists.
Health Information	Prevention is cheaper than treatment! The SA government must provide more health promotion and illness prevention education.
Medicine and Technology	Please give suggestions on how you would like health care services in your community to be improved through the NHI?
Health Care Financing	In SA, over 85% of the population relies on public health care, while only 15% can afford private health care. Yet each sector has almost the same amount of money to spend!
Leadership and Governance	Corruption is a major problem everywhere! How can we prevent corruption from happening in the NHI?

#### Table 2. Semi-quantitative analysis.

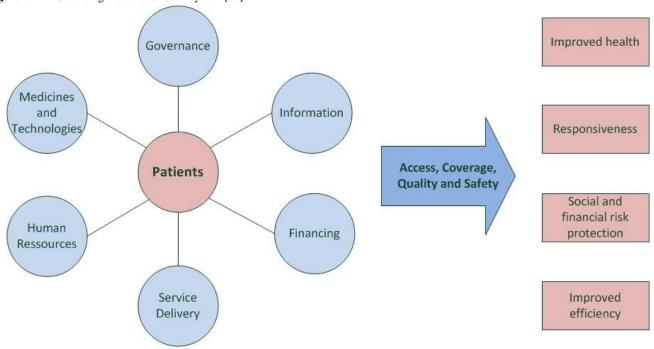
Building block and related question	Obtained answers	Ranking of major themes
Service delivery: SA constitution right to free	522	1 Good quality of health care provision
health care		2 Equal health care for all
		2 Treated with respect and dignity
		3 Trust in government
Workforce: waiting times hospitals and shortage	534	1 Waiting time too long
of staff		1 Improve attitude of staff
		2 Improve training of staff
Information: prevention is cheaper than treatment	496	1 Information campaigns (pros and cons)
		2 Affordability of prevention
		3 Better education of people
Medicine and technology: suggestions for improve-	516	1 Improved infrastructure
ment		1 Improved staff performance
		2 Accessibility of health care providers
Financing: public versus private health care	494	1 Allocation of funds for public health care
		2 Quality of public versus private health care
		2 Affordability of health care
Leadership and governance: Corruption	524	1 Prevention of corruption, law enforcement
		2 Request for reduction of corruption
		3 Introduction of ethical standards for health care professionals
		3 Emphasis on right job qualification

A qualitative analysis [59-61] was performed on the responses. Messages were "cleaned" by deleting space holders and re-allocating the answers to the appropriate questions where necessary. Replies were coded until a saturation of themes was reached, and no new topics emerged. The qualitative data took the form of phrases but were mainly embedded in free-flowing text. Analysis of free-flowing text requires methods that reduce the text to codes [61]. Codes were analyzed by using NVivo as a qualitative data analysis tool, and these were mapped to both NHI themes and the framework of the WHO building blocks (Figure 1). Overall, the dataset should provide a picture of how reform of national health policy is perceived by the public.

Data were analyzed in the light of the research questions: (1) What are the experiences and perceptions of health care users in South Africa?, (2) How would health care users like to see the system improved under the NHI?, and (3) What are the strengths and weaknesses of the WHO building blocks in the light of the answers obtained from the public consultation?

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## Results Overview

The results are linked to the WHO's six building blocks of a health system. The consumers' perspectives are analyzed according to whether the claims of health care users are included in the NHI scheme as planned and if these demands are addressed in the WHO building blocks.

#### **Health Service Delivery**

Health service delivery is a key element in a health care system and a fundamental contributor to the health status of a population [62]. According to the WHO, health service delivery is defined as the delivery and management of safe and quality health services. Resources should be efficiently used and not wasted [63]. The question was phrased as "The South African Constitution protects the right for all people living in South Africa. Free access to health care services is your right".

The NHI does provide a leadership concept to address the existing inequalities and poor health outcomes in the country as stated by health care consumers in the survey: "Some clinics are dirty and people also suffer from all those germs", "As South Africans we need to get the right treatment to stay alive", "They do provide it but the quality is extremely poor", and "Government must improve health condition in rural areas". The survey leads the respondents to the matter of human rights, so that some responses read "I have a right for healthy living" or "a healthy country equals to a healthy economy, more jobs are created and less poverty". Comments such as "the right of health care must be provided by public institutions and not by private ones" or "If it is a free medical services why do we have to pay medical expenses at hospitals?" expressed the view that government is responsible for providing health care for free without charging service fees. Critical voices raise the concern: "What is a right when you are treated with no respect and

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humanity", "How reliable is the confidentiality between the patient and the health practitioner?", and "It is true, but the government still lacks to find people who really care about our health and who do not judge".

According to the WHO, accountability involves enforcement, such as the imposition of sanctions, the provision of rewards for performance, performance around the actual supply of services, evaluation and monitoring of performance, and financing to ensure that adequate resources are available to deliver essential services [46]. The WHO suggests two types of indicators for measuring governance: rule-based and outcome-based [43]. Rule-based indicators, or so-called formal procedure measurements, are undertaken when a country has appropriate policies, strategies, and approaches for health system governance. The NHI is an approach towards implementing a system based on rule-based indicators. Outcome-based indicators assess whether procedures are being effectively implemented or enforced. The health care users would appreciate the future implementation of outcome-based indicators, although such indicators are not outlined in the NHI. Health care consumers criticize the weak law enforcement and quality control they have experienced, and there is a strong demand from them for better outcome-based rules, monitoring and surveillance; for example, "Quarterly audits might be helpful" and "Have people from department to come and check every day".

The NHI demonstrates leadership and governance by emphasizing existing inequalities and how to overcome them in a certain timeframe. Yet an existing lack of confidence in the health system is expressed by the respondents: "This statement is our right but I find the government is failing to do this" and "It is a right but everybodies rights are being abused". This failure of trust will have to be remedied.

#### **Health Workforce**

The workforce is a key element in a health system. It is defined as "people engaged in actions whose primary intent is to enhance health" [43], which includes physicians, nurses, pharmacists, etc. The health workforce is a topic in the NHI and in the WHO building blocks. In the survey, health consumers were asked about waiting times in hospitals and the staffing level of the health workforce.

The analysis of responses revealed that the attitude and training of the health workforce as well as the waiting time are major concerns. The attitude of employees regarding their workplace environment relates to the emotions, level of satisfaction, and their overall outlook. It is often directly related to a high or low level of morale in the workplace. Respondents targeted different disciplines: administration ("The receptionist must always be there"), doctors ("Doctors are more occupied with their own affairs than to treat patients"), and nurses ("The rude treatment [by] the nurses is unethical"). Nurses are more widely discussed, probably because respondents have more intense contact with nurses than with other staff members. The responses express the desire for a more patient-oriented service. From some of the respondents' points of view, the staff seem to be more focused on their own affairs than on reacting to the patients' needs.

A good health outcome is largely dependent on the knowledge, motivation, and skills of the health care workforce [45,64], while data support the view that there is a connection between the number of health professionals relative to patients and health outcomes. According to the survey, health care users experience long waiting times in public hospitals but not in private ones. They state that private hospitals have more health professionals available, that they are better trained, better paid, and better motivated to care for people. In addition, they criticize the attitude of the staff in public hospitals: they take breaks that are too long, are absent, are less concerned about their work and the patients, and have been observed "shouting", "not being empathetic with the patients", "not been supervised", and "not well trained".

A number of responses relate to the training of staff as in the following quote: "Nurses should be trained to take care of patients". Health care users insist that staff have to receive proper and regular training to fulfill their duties. They also believe that only health workers with a high level of job satisfaction can deliver the best outcome for patients: "The government should keep health workers happy". Other statements, such as "Health care service is insufficient and [so is] the level of training of health care workers", suggest that South Africa is not investing enough money to train health professionals and needs to upgrade the quality of service [19]. Since the attitude of the health workforce can be linked to their motivation and work satisfaction, high quality of care cannot be provided unless issues related to demotivated staff are comprehensively addressed [65]. This requires attention if the health system is to be strengthened. Financial incentives, career development, and the quality of management are core factors affecting motivation [66]. Other important elements are adequate resources and appropriate infrastructure [67].

The importance of waiting times for the health care consumers is underscored by the following two quotes: "In public sector patients wait over 12 hours", and "I never spend less than 4 hours in a clinic". Different explanations are given for lengthy waiting times: "Long waiting time due to break time for staff", "The waiting time is too long because the shortage of staff", and "Long waiting time because everything is free".

Yet a few respondents report no waiting time. As the data were anonymized, we do not know if this applies to private or public facilities or if the respondents live in a well-serviced area. Waiting times between 4 hours and 12 hours and more are not acceptable to health care users, especially when people are severely sick and urgently need attendance and treatment [68,69]. The government and the individual service providers are asked to reduce these long waiting times and provide quicker help.

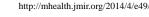
Interestingly, health care consumers asked for the implementation of ways to improve treatment efficiency. Separate queues for different diseases are suggested: "for eg influenza in the winter, HIV and TB". Related to this matter of efficiency, triaging scales are not mentioned as a tool, in the NHI or in the WHO building blocks. Yet they could prove useful in reducing waiting times for severely sick patients and offer more rapid and adequate treatment [23] based on the severity of diseases or illnesses [21]. In countries where they have been introduced, they have been well received by health care consumers and by service providers [22,70]. They would also prove beneficial in South African emergency departments [23].

According to the NHI guidelines, managers should be allocated the necessary authority to achieve planned objectives and should also be held accountable for overall performance and results [2]. Patients report a lack of management and supervision: "Supervise nurses [to stop] long tea breaks", and "Improve treatment performance by better training". The respondents complain about insufficient supervision and lack of action taken. In addition, they report waste of resources: "Check how resources are spent and not how much is being spent".

The attitude of the staff is addressed in the Green Paper of the NHI, where it is portrayed as less service- and patient-oriented than is desirable [2]. Responses in this study also indicate that the level of care is perceived as not centered on the patient's needs: it is not effective ("received the wrong medication and treatment") and is not timely ("sometimes I am going home without any treatment and medication").

Clearly the delivery of health care service through the health workforce needs improvement and scaling up, but it remains traditionally driven, with a paternalistic approach [71]. A shift to an approach more in line with partnership could help to improve service quality [39]. The NHI should foster improvement in levels of trust [72], as well as better relationships between health care consumers and health care providers, and between clinician and patient relationships, in order to improve health outcomes.

The NHI aims to establish a higher quality of service through compliance with the Office of Health Standards: "It will have three units, namely: inspections, norms and standards [...]. It



will set norms and standards and undertake the inspection of all health facilities" [2]. However, an area of particular concern is service delivery by the health care workforce [73] and the fact that the NHI plan outlines neither how patient-centered care is to be achieved nor how the regular teaching of health care professionals is going to take place. Based on the responses, neither effective monitoring nor an evaluation of human resources is currently taking place, nor is the assessment of health facilities working adequately. The scaling up of these areas of expertise and service could enhance efficiency as a means of HSS [65].

To estimate if the number of health professionals is adequate, a more thorough analysis must be done by calculating the number of health workers available in a region relative to the total population. The WHO recommends at least 23 health care professionals (physicians, nurses, midwives) per 10,000 people for selected primary health care interventions [46]. Data on the South African health work force in 2011 display 7.7 physicians per 10,000 people and for nursing and midwifery, 40.8 per 10,000 [8]. This exceeds by a total of 48.5 per 10,000 the recommended limit of 23 per 10,000 health care professionals. This fact may be understood to underline the need for better service efficiency, although the uneven distribution of health care professionals between the public and private sector has to be considered.

In the relevant WHO building block, high-quality health services are mentioned, centered on the patient's need and given in a timely fashion [46]. The way to achieve this is proposed by indicators, mainly related to the amount of available human resources. However, the means of improving interdisciplinary work relations are not elaborated. A more holistic approach to enhanced collaboration between different actors [65] could be helpful in strengthening and improving the health system in South Africa.

#### **Health Information**

The survey question, "Prevention is cheaper than treatment! The South African government must provide more health promotion and illness prevention education", is linked to the theme of health information. Analysis revealed a number of concerns: affordability ("Prevention should be affordable"), government involvement ("The government is doing enough but the people are ignorant", "The government is not doing enough"), and the need for a better information policy ("People have less knowledge about prevention", "The government must try hard to inform the people comprehensively"). Youth are also a matter of concern ("Most of the youth is illiterate", "Teenagers do not use condoms").

For people coming from a lower socioeconomic background, resources for obtaining information are scarce. Consequently, they have to rely on whatever information is provided by the municipality or government. Health care users should have access to reliable, usable, understandable, and comparative data and information [43]. They should be informed about health risks so as to avoid contracting diseases. A sound and reliable information policy to support and educate patients is a milestone to establish efficient decision making among the population [46]. The communication and dissemination of information are

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crucial to an effective prevention campaign. A lack of information or access to relevant information was observable in our study ("What is NHI?"), indicating the need for a well-functioning information system [43].

Affordability for the sake of prevention was raised by the respondents. The provision of prevention must be offered based either on the individual's ability to pay or be free of charge [14]. Further, people need to be informed about preventative measures and strategies. Respondents expressed different views about prevention. Some are convinced that prevention campaigns are successful provided that people are educated ("Education is necessary to run a successful prevention program", "Teach ignorant people live a healthier life"). Others state that people cannot be taught to adhere to a different lifestyle ("Education does not seem to help. Teens still get pregnant").

According to the NHI Green Paper [2], prevention campaigns for non-communicable diseases are mainly driven by four risk factors: smoking, alcohol, poor diet, and lack of exercise. Yet multiple other burdens exist [74] that need to be dealt with to improve overall health [73]. Prevention campaigns are associated with various obstacles in South Africa, such as vast rural areas that have poor communication links and a high rate of illiteracy [75].

Participants also conveyed their belief that "the government is doing enough to educate the people". They point out that a range of prevention programs has been carried out, but people still do not behave accordingly. Hence, they conclude that people cannot be educated and prevention campaigns are a waste of time and resources. Comments like these should sensitize the government to the need to demonstrate the results of prevention campaigns by publishing and advertising data about achieved goals [76].

#### **Medicine and Technology**

The question "Please give suggestions on how you would like health care services in your community to be improved through the NHI" was related to the building block for medicine and technology. Analysis of responses revealed the respondents connecting primary and secondary health care ("24 hours emergency ambulances and emergency rooms"), recognizing intersectoral health care ("Government must provide educated social workers"), and special care ("Employ counsel[1]ors"). They envisage health care through the life course with improved accessibility ("A bus service for pensioners"), besides hospitals' diverse health care settings ("Provide a nurse at each school"), and improvements in existing services ("ambulances must better work together and be better organized"), and staff performance ("By training the nurses to take good care of patients", "Would like the nurses to work with their hearts").

They requested the scaling up of services and medication availability ("Enough medication in hospital is needed"). Even intersectoral cooperation between public and private health care providers was suggested to achieve a better quality of care ("private doctors should work together with normal doctors").

The maintenance of hospitals and "cleaner hospitals" are frequently mentioned together with the demand for a broad scaling-up initiative of health care facilities. Responses focus on existing clinics ("Better care and longer opening hours"),

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mobile clinics ("Providing everywhere mobile clinics"), as well as new facilities ("More hospitals are needed because public and private hospitals are full"). Access barriers emerge as another topic: "People in rural areas are not taken care of", "There is no clinic close to them and there is a lack of water and electricity", and "A basic health care facility should be in every community". These demands refer to the need for capacity enhancement [65]. The answers highlight the difficulty the population experiences in gaining access to an adequately equipped health care provider able to answer to their medical needs. According to our survey, the availability and accessibility of health care facilities for public health consumers must be improved.

The respondents expressed wishes similar to those of patients from developed countries, such as the United Kingdom [39]: easier access to primary health care services, more complementary therapies, and longer clinic opening hours. Where there is a contrast between the respondents' wishes and those expressed in developed countries, it lies in those in the developed countries articulating their desire to have the choice of health service providers, to be actively involved in treatment decision processes, to discuss treatment options, and to have their expectations met [77]. In accordance with UK health care users [39], however, the respondents of our survey expressed their wish to have good and equal services everywhere and available to all.

Most of the public health care consumers' requests are taken up in the NHI and the WHO building blocks. Under the question "suggestions", people asked for better access to basic medicines and adequate equipment. Also requested were additional service provisions such as mobile ambulances and better logistics such as the management of ambulance vehicles.

A well-functioning health system ensures equitable access to essential medical products, vaccines, and technologies [46]. The requirements and indicators are outlined in the WHO building blocks. Underpinned by the answers of the respondents, the current SA public health system does not offer equitable access to medical products, vaccines, and technologies. As the data were anonymized, we cannot obtain information about where people report better service quality. But the answers demonstrate that both a lack and uneven distribution of resources appears in rural areas in comparison to urban settlements.

#### **Health Care Financing**

The mismatch of resources between private and public sectors is addressed in the question regarding health care financing and is also elaborated in the Green Paper of the NHI [2]: "In SA, over 85% of the populations rely on public health care, while only 15% can afford private health care. Yet each sector has almost the same amount of money to spend!".

The consumers surveyed for this study describe the purpose of public health care as follows: "Public health care is important for poor people who cannot afford private health care". Responses touched on matters of affordability ("A lot of people cannot afford health care"), equality ("If the quality of the health care would be equal, no private health care would be needed"), and funding ("money for the public sector should be

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reallocated"). The service quality of private health care is regarded as superior to public health care ("People that can afford private health care get better services and are treated better", "Private health care has a higher standard. So most people do prefer it", "Public health care has always been a mockery to us because of its poor standards").

Concerning out-of-pocket payments and service fees, some stated that "they must pay in some public clinics", but others said that "the people in SA get the health service for free". As suggested by such contradictory answers, the service fees of public health care providers seem not to be handled equally across the country. Apart from the difficulties of accessing health care providers, especially in rural areas, it is essential that lower income groups not be required to make out-of-pocket payments [78]. Financial risk protection is one of the important elements of HSS [65]. The exemption of service fees and the re-engineering of primary health care to improve accessible and affordable health care are proposed in the NHI [2].

The implementation of the NHI should achieve universal coverage, aiming to allow health care users the access to affordable health care services [24,43,79]. A country-wide survey in South Africa that examined household expenditures in relation to out-of-pocket payments showed a regressive profile: the lower the family income, the higher the possibility of experiencing catastrophic household expenditures [15,80]. The NHI Green paper provides an overview of how the new health system will be financed in the near future and funds allocated according to need. The financial system is being conceptually divided into three interrelated functions: revenue collection, fund pooling and purchasing, and provision of services [2]. All three elements were addressed by the responders. They emphasized that they want to experience a more equal and affordable health care system. It is planned to achieve universal coverage through a prepayment health financing mechanism. The payments should be pooled and can come from a combination of sources (fiscus, employers, individuals) [2]. The improvement in resourcing is characterized as an urgent intervention and will be phased in over a period of 7 years. It is estimated that currently 70% of the outpatient and 80% of the inpatient care patients are uninsured [2].

The topic of equality was raised concerning income groups, disease groups (HIV- not HIV-infected), and public and private health care providers having an unequal distribution of financial and human resources. The separation of funds between private and public health care and the contribution to the health care system, depending on personal income are discussed in the survey. Some of the respondents stated that they were not aware of the huge difference in health care expenditures between the private and public sector ("Did not know before how funds are spent"). They requested that people be informed about the existing differences and how to overcome them. Some respondents said that "we all have to get private health care", as the quality of private health care is considered to be better than in the public sector.

This becomes evident in statements such as "The government should improve the standards for public health care". Reasons for this, among others, can be seen in the underfunding of public

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health care: "The public health care does not get enough funds" and the fact that more professionals per patient are working in the private sector than in the public sector [2]. "The amount spent in the private health sector relative to the total number of people covered is not justifiable and defeats the principles of social justice and equity" [2]. Hence a reallocation of funds between the private and public sector is mandatory.

According to the WHO, health financing refers to the "function of a health system concerned with the mobilization, accumulation and allocation of money to cover the health needs of the people [...] to ensure that all individuals have access to effective public health and personal care" [43]. In line with the WHO's guidelines, co-payments or out-of-pocket payments will be abolished with the NHI. Financial access barriers should be removed. The WHO suggests equity through receiving exemptions or subsidized services and medicines [43]. This should allow people to use needed services without experiencing impoverishment, a method characterized as financial risk protection. Pooled funds are needed where the rich cross-subsidize the poor, and the healthy subsidize the sick population. The respondents target this topic in the following quotes: "Those who can afford more, should pay more" and "Money for the public sector should be reallocated". It will be one of the major tasks facing the new health system to restructure its financing mechanism and perform a reallocation of funds: the private sector needs to cut back costs, while the funding for the public sector has to be increased to upgrade existing facilities and offer accessible and affordable health care to the majority of the population [2]. It will be a major challenge to achieve the proposed reallocation of funds, and a great deal of lobbying is required to achieve consensus among the different stakeholders [79].

#### Leadership and Governance

The WHO, defining the role of the government and the relationship of other actors in order to protect the public interest, describes it as stewardship [43,46]. The existence of strategic political frameworks in combination with effective oversight and accountability are requested [46]. Corruption can impede the delivery of effective and high-quality health care to the people who would benefit most [81]. The World Bank defines corruption as "the abuse of public office for private gain". Corruption comes in four main types: theft, bribery, misinformation for private gain, and bureaucratic or political corruption [81].

Health care consumers were asked how to prevent corruption in the health system and their responses raised concerns regarding the corruption they are experiencing. They said, for instance, "Reduction of corruption is necessary". Participants proposed solutions to address this problem. Ethical standards should be implemented: "Corruption is unethical. Honesty should be made a value" and "People in high positions must be honest". In order to achieve such ethical standards, the "right qualifications and experiences" of those working in the health care sector were deemed to be essential. This implies that protocols around hiring staff should be improved. Participants also recommended that "Prevention through work[ing] as a community police force". And they called for the supervision and punishment of those in charge: "The people in charge should be accountable and the money deducted from their salary".

According to the study's results, a new ethical approach for those employed in the health care sector should be introduced, with its stated values demonstrating a high standard of ethical commitment. Some respondents commented that the current state of the health system mirrors the corruption taking place in government: "Prevention by starting at the government", "Hire qualified people and not politicians", "Eliminate nepotism and corruption will disappear", and "Hire people who know the job and are not your relatives...in this corrupt system of government". A lack of trust in government emerged, thus indicating that it is believed that a change in society would have to take place [33,82] before major improvements would happen in the public health care sector.

The participants asked for the employment and selection of people who were more honest. In order to make people accountable for their actions, they suggested additional audits to expose corruption. The responses display a clear understanding of what actions health care users expect to be taken to address this problem. The majority expressed the feeling that corruption could probably be reduced if the necessary steps were taken but that it cannot be eliminated.

The Green Paper of the NHI does not explicitly address corruption, and consequently, there are no measures described to deal with it. The reform of governance, the autonomy of hospital management as well as overall and individual accountability are mentioned, but outlines on how to provide more efficient supervision of staff and management are missing. Ethical values might be included in the final bill, but it is vital to also incorporate means to reduce corruption, improve surveillance, and to hold individuals to account since corruption is regarded by consumers as a serious problem in the SA health system.

## Discussion

#### **Principal Findings**

The analysis of the answers to the survey answers revealed a public request for improved service efficiency, equity, affordability, and equal allocation of resources between the public and the private sector. These findings substantiate the need for reform and fit with the aims of the NHI. The current state of the health system is described from the patient's perspective as neither accountable nor efficient. There is a shortage of medicines, uneven distribution of health services, and poor availability of equipment and of intersectoral services. Basic service management appears to be inadequate. The respondents in this study are concerned about the quality of care they are receiving. In general, people judge the quality of care to be better in private hospitals with quicker treatment and less waiting time. The staff in private health care is described as being better organized, more attentive, and more patient oriented in comparison to staff in public health care.

The expectations of health care users are in accordance with those of other countries [39,42,48,77]. Most of the existing and well-documented health inequalities and inefficiencies within

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the South African population are addressed by the NHI. However, several themes were identified that are not covered, such as the need to fight corruption, the implementation of underlying ethical values for health care professionals, regular surveillance, and indicators for improved health services. These public concerns could be incorporated into the final bill. An enhanced understanding of the goals and timeframe of the NHI should be advertised by the government, as a lack of information to the public becomes evident in the analysis. The NHI, to be implemented gradually over a 14-year period, faces major challenges as various stakeholders are involved in this process. Public health care users perceive the need for changes in the current system, but as is underlined by their comments, they need to understand how these changes are going to happen.

The WHO's six building blocks identify the key elements of a health system to strengthen health systems. They should lead to improved health, equity, responsiveness, social and financial risk protection, and more efficiency. These building blocks were used as a lens to analyze responses and relate them to the reform of the South African health systems. However, while a health system embraces all organizations, institutions, resources, and people whose primary purpose is to improve health [43], the interactions and interrelations of actors and stakeholders, and measures for improved intersectoral work performance are not elaborated on in the building blocks. Health consumers in South Africa, on the other hand, suggest advancing the intersectoral relationships within the health system. Interestingly, they ask for a more holistic approach and capacity enhancement to establish an efficient working health system [45,65].

The building blocks provide a description of tools that are necessary to strengthen health systems; however, they provide no outline of the soft skills and measures such as values and norms. This is the underlying capital on which a health system runs efficiently and successfully. Each country is asked to implement these soft skills and norms. From the consumers' perspective, soft skills, interaction techniques, and training of health care professionals need improvement in South Africa. The application of measures for monitoring performance would also prove helpful in enhancing overall performance. Public consultation processes are not often applied in health policy processes, although they constitute a civil right in terms of the South African constitution [36]. The active participation and understanding of the population is needed to restructure the health care system successfully [20]. The health care users in our survey make valuable suggestions as to what can and should be improved in the health system. Up until now, consultation campaigns have not been well-established tools to support health policy changes. The answers obtained could be used by health care decision and policy makers to highlight existing gaps between the lived reality and the set goals, thus aiming to achieve health system strengthening through a patient-centered, outcome-based approach [48].

#### Limitations

Some limitations arise regarding the study design: the survey is not representative of the South African population as Mxit is mainly used by a younger population (average 15-35 years) with a different race stratification than in the South African population. For example, there was a higher number of colored people (colored is one of four population groups used by Stats SA, with the others being black African, Indian/Asian, and white): 26% colored people as Mxit users versus 8.9% of the total population. We have no insight into the number of different races that participated in this survey.

#### Conclusion

The data obtained in the survey of the People's Health Movement are useful for further studies and provide insight into the public's views. These data have been used according to Robson [83] as a real world challenge facing limited time and resources combined with the necessity to address a current problem. These data could be used to highlight existing gaps between the lived reality and the set goals in health care, in order to achieve health system strengthening.

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#### **Conflicts of Interest**

None declared.

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#### Abbreviations

DALYs: disability adjusted life years HSS: health systems strengthening NGO: non-governmental organization NHI: National Health Insurance SA: South Africa WHO: World Health Organization

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**Original Paper** 

# Accuracy, Consistency, and Reproducibility of the Triaxial Accelerometer in the iPod Touch: A Pilot Study

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## Abstract

**Background:** The use of a mobile consumer communicative device as a motion analysis tool for patients has been researched and documented previously, examining the triaxial accelerometer embedded in such devices. However, there have been few reports in the literature testing the sensitivity of an embedded triaxial accelerometer.

**Objective:** Our goal in this study was to test the accuracy, consistency, and reproducibility of the triaxial accelerometer in the iPod Touch.

**Methods:** In this pilot study, we subjected the triaxial accelerometer in the iPod Touch to a free fall from a height of 100 cm in order to test its accuracy, consistency, and reproducibility under dynamic conditions.

**Results:** The resultant vectorial sum acceleration was mean 0.999 g (standard gravity; SD 1.51%; 95% CI 0.99-1.01), indicating very high accuracy and sensitivity under dynamic conditions.

**Conclusions:** Our results highlighted the reproducibility of the capability of the triaxial accelerometer in the iPod Touch to capture data accurately and consistently. Thus, the device has huge potential as a motion analysis tool for measuring gait and studying balance and mobility in patients before and after surgery.

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#### **KEYWORDS**

accelerometry; tri-axial accelerometer; iPod Touch

## Introduction

The world is witnessing a huge increase in the mobile electronic devices that are used in everyday activities. The 4th generation iPod Touch manufactured by Apple Inc. is one such device that has had a tremendous impact on our lives, serving as a communication device, as well as a mobile personal assistant. This device is equipped with a built-in triaxial gyroscope and accelerometer, which have been shown by multiple researchers to be capable of detecting, with good accuracy, daily activities such as walking, jogging, sitting, and even playing cricket [1-4]. Recent literature also supports the reliability of various

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smartphone devices in the measurement of gait parameters and as an analytical tool to study balance and mobility [5-7].

The built-in triaxial accelerometer in an iPod comes in the form of a microelectromechanical system (MEMS). MEMS is the technology of very small devices. MEMS are made up of subcomponents between 1 to 100 micrometers in size (ie, 0.001 to 0.1 mm), and generally range in size from 20 micrometres (20 millionths of a meter) to 1 millimeter (ie, 0.02 to 1.0 mm). They consist of a central unit that processes data (the microprocessor) and several components that interact with the surroundings such as microsensors like accelerometers and gyroscopes. MEMS accelerometers allow measurement of the

instantaneous acceleration of an object, compared to gravity at any given time, in a free-fall reference frame both in the static and dynamic motion characteristics. They generally allow measurement of the acceleration in 3 axes, hence the name triaxial accelerometer.

However, the sensitivity of the MEMS accelerometer intalled in the iPod has not been determined with a sufficient level of accuracy, consistency, and reproducibility in the literature. Recently, a small-scale pilot study demonstrated consistent sensitivity values in measuring instantaneous accelerations in a steady state across multiple iPods [8]. The testing for sensitivity, accuracy, and reproducibility of the MEMS accelerometer in the iPod under a dynamic state had not been performed before. We therefore embarked on this study to determine the accuracy, consistency, and reproducibility of the built-in MEMS triaxial accelerometer housed within an iPod Touch by determining its vectorial sum acceleration when subjected to a free fall drop from a height of 100 cm and to compare the results with the established standard of 1 g (standard gravity, equivalent to 9.81 m/s<sup>2</sup>) under these circumstances.

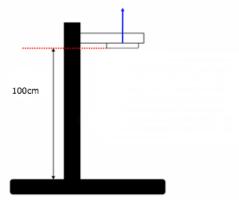
## Methods

#### Overview

A single 4th generation iPod Touch mobile device was used to collect instantaneous acceleration in a free fall state from a height of 100 cm. The device was secured to a protective non-elastic string and placed on the under surface of a leveling block measured 100 cm from the ground with the z-axis in approximately -1 g recording position, which corresponds to the screen facing upward towards the ceiling (Figure 1).

Prior to the start of the experiment, we calibrated the triaxial accelerometer software (Accel4Pros) pre-installed in the iPod. The Accel4Pros triaxial accelerometer software captures acceleration range within -2.3 g to +2.3 g with a data capture frequency of 20 data per second or 20 hertz. We then dropped the iPod towards the ground while the program was running; 30 trials of free fall were performed. Following each trial, the acceleration data were stored on the device in Comma Separated Value format and exported via Internet to a remote email account where it was downloaded and interpreted using Microsoft Excel.

**Figure 1.** This is a diagram of the set-up for the iPod Touch free fall test showing the distance of travel of 100 cm. The i-Pod Touch is secured to a non-elastic string (blue arrow) to ensure that it is always held with the Z-axis in approximately -1G recording, corresponding to the screen facing upward, on the undersurface of the levelling block.



#### **Statistical Analysis**

Triaxial accelerometer data analysis was carried out prior to performing the statistical analysis. The mathematical formula for calculation of vectorial sum acceleration, r, using acceleration data from the triaxial accelerometer, is the root square of the sum of  $(X^2 + Y^2 + Z^2)$ , as shown below:

$$r = \sqrt{(X^2 + Y^2 + Z^2)}$$

where r=vectorial sum acceleration

X=acceleration change along X-axis between 2 data points

Y=acceleration change along Y-axis between 2 data points

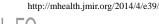
Z=acceleration change along Z-axis between 2 data points

From the acceleration data captured during each free fall, we used Microsoft Excel software to generate the following representative graph (Figure 2).

Segmentation was performed to remove irrelevant noise waveforms from the representative graph in order to identify the waveform that is representative of the actual free fall. In Figure 2, we identified data point Z1 as the data point in time immediately prior to the fall in a stationary position, while Z2 is the immediate data point in time when falling. (See Figure 3 for a magnified view of the segment within the dotted line in Figure 2).

The change in acceleration detected by the triaxial accelerometer within the iPod in the Z-axis is the absolute difference in value between data point Z1 and data point Z2. Figure 4 illustrates the acceleration data in the Excel spreadsheet within the dotted line for all 3 axes.

From Figure 4, we could then identify the corresponding acceleration data changes in the X- and Y-axis. By using the formula shown, we then determined the vectorial sum acceleration measured by Accel4Pro during the free fall. Using the same process for all the 30 trials, we ended up with the resultant mean vectorial sum acceleration, which then allowed



#### Khoo Chee Han et al

us to proceed to perform the statistical analysis on all the acceleration data obtained.

Below is a simple illustration of how we performed the mathematical calculation to obtain the mean acceleration captured by the triaxial accelerometer housed in the iPod, using the acceleration data from Figures 2-4. Following is an example of a calculation for vectorial sum acceleration, r:

 $= \sqrt{(0.002558 + 0.000239 + 1.014915)}$  $= \sqrt{(1.017712)}$ = 1.008817 g

Z axis acceleration changes = 0.967764 + 0.039666 = 1.007430Y axis acceleration changes = 0.034229 - 0.018772 = 0.015457Descriptive statistics (mean and standard deviation) were generated for the sensitivity of the device as well as comparing the acceleration data for all 3 weeks.

Vectorial sum acceleration,  $r=\sqrt{(X^2 + Y^2 + Z^2)}$ 

X axis acceleration changes = 0.043315 + 0.007267 = 0.050582

Figure 2. A representative graph generated from the acceleration data (the segment within the dotted line represents the period of time before and after the free fall test; Z1 is data point in time immediately prior to fall on stationary position and Z2 is the immediate data point on falling).

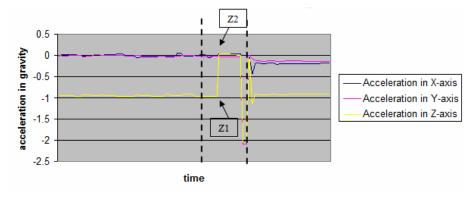
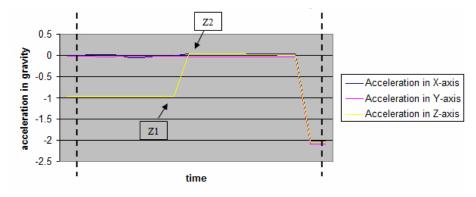


Figure 3. A magnified segment view of the section within the dotted lines.





**Figure 4.** The acceleration data within the dotted line represents the duration of time prior to and after the fall captured by the triaxial accelerometer within the iPod Touch (Z1 is the acceleration data immediately before the fall and Z2 is the acceleration data at the beginning of falling).

				-
	Calibrated X	Calibrated Y	Calibrated Z	
	-0.0022012	-0.0147136	-0.9657045	
	-0.0022012	-0.0147136	-0.9657045	
	0.01350006	-0.0244029	-0.973456	-
	0.01350006	-0.0244029	-0.973456	
	-0.0481149	-0.0224498	-0.9652925	
	-0.0481149	-0.0224498	-0.9652925	Acceleration Data at Z1
_	-0.0072672	-0.0187724	-0.9677644	. /
	-0.0072672	-0.0187724	-0.9677644	×
	0.04331573	-0.0342296	0.0396666	▼.
-	0.04331573	-0.0342296	-0.0396666	• Acceleration Data at Z2
	0.04444488	-0.0311931	0.03577561	receleration Data at 22
	0.04444488	-0.0311931	0.03577561	
	0.04261383	-0.0321239	0.02103562	
	0.04261383	-0.0321239	0.02103562	
	0.04384979	-0.0309795	0.00438828	-
	0.04384979	-0.0309795	0.00438828	-
	-2.029072	-2.0925792	-2.0408083	-
	-2.029072	-2.0925792	-2.0408083	-

## Results

The resulting descriptive statistic of mean acceleration for all the 30 trials of free fall was represented using a scatter plot as shown in Figure 5.

The acceleration data captured for all 30 trials (Table 1) showed us that the mean acceleration from the trials was very accurate and consistent as evidenced by the very small standard deviation of 1.58% from a mean acceleration of 0.999 g with a 95% confidence interval of 0.993488-1.004761 (Figure 6). Week-to-week acceleration data were also found to be very consistent and accurate, indicating the reproducibility of the acceleration data captured across different times and under different conditions.

 Table 1. Mean accelerations and standard deviations of the device as a function of the device orientation.

	1 <sup>st</sup> tests (G)	2 <sup>nd</sup> tests (G)	3 <sup>rd</sup> tests (G)
Trial 1	1.002297	0.984672	0.984208
Trial 2	0.995306	0.999181	1.010951
Trial 3	1.008817	0.994424	1.014362
Trial 4	1.006725	1.019200	1.007173
Trial 5	0.999943	0.983010	1.012857
Trial 6	0.995615	0.964196	0.997752
Trial 7	0.981492	1.000802	1.013392
Trial 8	1.027264	1.006944	1.005093
Trial 9	1.002452	1.008590	0.979668
Trial 10	0.960244	1.000500	1.006613
Mean (SD)	0.998016 (0.017646)	0.996152 (0.015566)	1.003207 (0.012279)
Overall mean (Sl	D)		0.999125 (0.015094)



Figure 5. A scatter plot for all the 30 free fall trials.

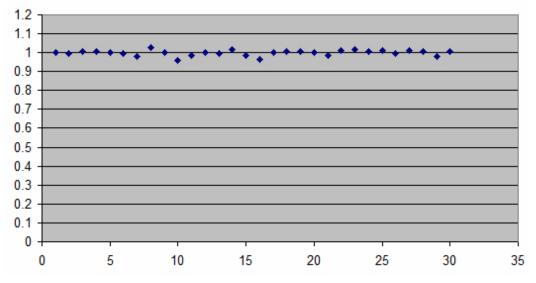
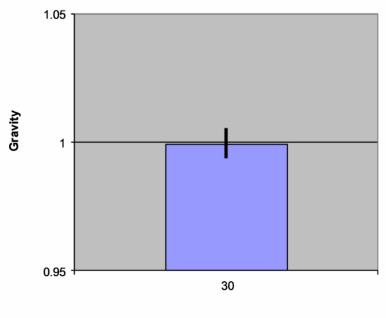


Figure 6. The mean vectorial sum acceleration with 95% CI 0.99-1.01.





## Discussion

#### **Principal Findings**

The use of mobile electronic devices in daily life has increased worldwide. Apple's 4th generation iPod touch is one such device that has had a tremendous impact on our lives, serving as a communication device, as well as a mobile personal assistant. The built-in triaxial gyroscope and accelerometer in such devices has been shown by multiple researchers to be capable of detecting daily activities with good accuracy [1-4]. Recent literature also supports the reliability of various smartphone devices in measuring gait parameters and as an analytical tool to study balance and mobility [5-7].

Our work to determine the accuracy, sensitivity, and reproducibility of a triaxial accelerometer embedded in a 4th generation iPod Touch in relation to gravity under free fall

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conditions represents a pilot study for using the iPod Touch triaxial accelerometer waveforms data in a circular pattern to help clinicians recognize common gait patterns. Amick et al [8] showed recently that in a static state, the accelerometer in the iPod is capable of capturing acceleration accurately. Thus, we believe our methodology is the first of its kind in subjecting the iPod Touch to free fall testing from a height of approximately 100 cm in a controlled environment. We compared our results with the established standard of 1 g (equivalent to 9.81 m/s<sup>2</sup>) under these circumstances. Our results showed that the free fall acceleration data captured by the triaxial accelerometer indicated that the iPod displays a very high accuracy and sensitivity under dynamic conditions to capture acceleration data.

#### Conclusions

In our opinion, the triaxial accelerometer embedded within mobile consumer communication devices has huge potential as

a motion analysis tool based on its highly accurate and sensitive acceleration data output. The direction of future work should focus more on performing research involving multiple devices subjected to more complex motions over a longer duration, taking advantage of the ability to detect subtle changes in acceleration accurately. In view of its high sensitivity and accuracy under dynamic conditions, our results show that the 4th generation iPod Touch can be used in the clinical practice of joint reconstructive surgery to objectively evaluate gait changes of each patient before and after undergoing joint arthroplasty surgery.

#### **Conflicts of Interest**

None declared.

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#### Abbreviations

**MEMS:** microelectromechanical system

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# Development and Evaluation of an iPad App for Measuring the Cost of a Nutritious Diet

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## Abstract

**Background:** Monitoring food costs informs governments of the affordability of healthy diets. Many countries have adopted a standardized healthy food basket. The Victorian Healthy Food Basket contains 44 food items necessary to meet the nutritional requirements of four different Australian family types for a fortnight.

**Objective:** The aim of this study was to describe the development of a new iPad app as core to the implementation of the Victorian Healthy Food Basket. The app significantly automates the data collection. We evaluate if the new technology enhanced the quality and efficacy of the research.

**Methods:** Time taken for data collection and entry was recorded. Semi-structured evaluative interviews were conducted with five field workers during the pilot of the iPad app. Field workers were familiar with previous manual data collection methods. Qualitative process evaluation data was summarized against key evaluation questions.

**Results:** Field workers reported that using the iPad for data collection resulted in increased data accuracy, time savings, and efficient data management, and was preferred over manual collection.

**Conclusions:** Portable digital devices may be considered to improve and extend data collection in the field of food cost monitoring.

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#### KEYWORDS

portable digital device; iPad; healthy food; food cost

## Introduction

The cost of nutritious food is a key factor influencing food access, choice, and therefore impacts on health [1]. Socially and economically disadvantaged populations have greater rates of nutrition related diseases. Monitoring the cost and availability of a nutritious basket of food can provide useful information to assess both economic and physical access to nutritious food in a region, as well as changes in affordability over time, and is

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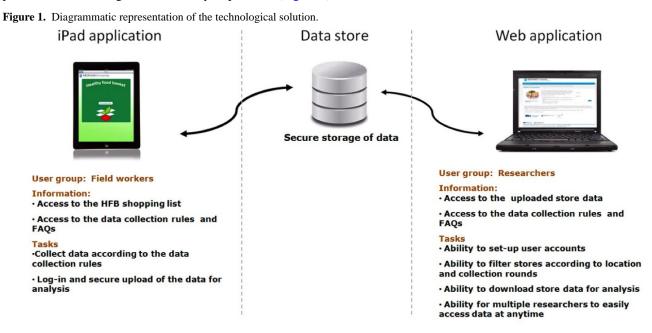
vital information to assist in informing policy. Healthy food baskets are a tool implemented regionally to reliably achieve this. A range of healthy food baskets have been developed internationally to assess and monitor the cost of an ideal nutritious diet [2-5]. Healthy food baskets have been deemed to be an effective instrument to assess economic food access [6]. The Victorian Healthy Food Basket (VHFB) is a shopping list of the specific quantities of 44 commonly consumed foods that, as a whole, meet the nutrient requirements of four reference

families for a fortnight [7]. Checking the price of these items at supermarkets makes it possible to calculate the cost of a nutritious diet, monitor changes over time, and compare the cost of healthy diet to income data to assess affordability. In Australia the distance between a store and the nearest capital city can be over 2000 km [3], creating a need for efficient mechanisms for the collection of data. We focus on a study in the state of Victoria, Australia, covering 115 stores over 27 geographically and demographically distinct areas with a total population of 2,525,534.

Practical implementations of healthy food baskets rely significantly on data collection. Traditional approaches to collecting data on the cost of items in a healthy food basket involve simple, manual data collection techniques, including pen and paper at the source of observation. This data is then entered into computerized spread sheets for the purpose of data analysis. This form of data collection and management can be inaccurate, labor-intensive, and therefore inefficient [8-11]. Newer technology developments such as portable digital devices (Personal Digital Assistant [PDA] and smart touch devices) and wireless technologies have opened many opportunities for the way we collect, store, manage, and share survey data. These advances are making data collection and sharing faster, easier, and more accurate [8-11].

An iPad app aimed to enhance the quality and efficacy of the research and was complemented by a Java Server app that provides a data management and analysis platform (Figure 1).

The Java Server app is built using Model View Controller (MVC) and Inversion of Control (IoC) design patterns that employ Struts2 technology to generate interactive webpage content, with persistence to a database achieved using Hibernate JPA. The app is currently deployed on an Apache Tomcat server using a PostgreSQL database. The iPad app was developed to incorporate instructions for data collection as well as data entry fields with quality controls (Figure 2). Upon completion of the data entry, the field workers upload the shopping lists to the central data store, eliminating the need for manual data entry. The app was implemented with the ability to seamlessly manage data capture and data upload even when connectivity to the mobile network is not available. The iPad app had basic error validation and prevention mechanisms such as a format for price, quantity, and address fields. Error messages were displayed if users entered data that did not match the agreed formats, drop-down boxes so that users were limited to a set of valid data options, and if users were not able to upload prices/data from stores that did not have a completed data set. The app was freely available from the Apple App Store with conditions for use for research purpose highlighted as a condition of the download. While anyone is able to download the app, only those trained in rule for data collection and use of the iPad are given user accounts by the research team to upload their data to the central Web-based store. This paper describes the development and process evaluation of the iPad app for the collection of healthy food basket data.





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Figure 2. Home screen healthy food basket iPad app.

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<del>ç</del>	11:10 AM Home	100%
😹 N	10NASH University	
	Healthy food basket	
	Healthy Healthet	
	This project was undertaken by Monash University. Funding for this work was provided by the Centre for Excellence in Intervention and Prevention Science (CEIPS), an initiative of Department of Health, Victoria.	
	Palermo C, Wilson A. Development of a healthy food basket for Victoria. Australian and New Zealand Journal of Public Health. 2007;31:360-3.	
	Term of Use	
	Home Store Help Settings	

## Methods

The iPad app was piloted to test for user-friendliness. All field workers (n=6) who were selected to pilot the technology were invited to be part of the evaluation. They all had previous experience with the paper-based, manual data collection processes and consented to be interviewed to evaluate the new technology.

A process evaluation was conducted using semi-structured interviews with five field workers (83% response rate) at the completion of the pilot. The focus of the process evaluation was

on the quality and efficiency of, and satisfaction with, the technology and perceptions of improvements from previous paper-based methods (Table 1) [11]. The short interview explored the experience of using the iPad app for data collection and entry. Interviews were audio-recorded and notes taken. Interviews were analyzed by one author (DPS) using an approach whereby audio-recording and notes were reviewed, text coded, and grouped into categories against the process evaluation questions [12]. The analysis was verified by another author (CP) through independent review of notes from interviews.

Table 1. Interview questions asked from field workers and the focus of inquiry for process evaluation.

Questions of inquiry	Inquiry logic
Approach to data collection using the iPad app	Quality of app, visual appeal and functionality
Strengths of data collection using the iPad app compared to paper-based	Efficiency – ease of use, perceived ease compared to paper-based collection
Challenges with data collection and entry using the iPad app	Satisfaction - overall with app and compared to manual collection
Recommendations for future improvement of iPad app	



### Results

#### Accuracy

Field workers commented that the iPad app resulted in more accurate data collection with fewer discrepancies. Collecting data in a paper format at the store and entering the data later into an excel file was tedious, error prone, and time-consuming.

When I used to enter data .... I would have about 15-20 stores piled up and start entering them one after the other and you could easily miss a decimal point or an item. But with the iPad ... I actually made less mistakes when entering prices... [Field worker number 4].

#### Efficiency

The field workers reported that another significant benefit of portable digital device was the time savings made. Compared to the previous paper-based model, field workers found the ability to upload the data directly from the app saved time. Compared to paper-based data collection, using the iPad app was reported to be a fast, easy, and convenient way to collect data whilst in the supermarkets.

I would have to go home and then enter data... Sometimes I had to wait until the file is shared with me. With the iPad, once I have collected the data in the store the work is done. It saves a lot of time. [Field worker number 1]

#### Ease

The field workers commented that the iPad app was easy to use and they were able to be familiar with the available functionality quickly and with minimal training. Participants commented that having access to the data collection rules in the iPad reduced the need to manage multiple sheets of paper. Field workers recorded that the time taken to collect and upload data was between 45-60 minutes. This varied from previous paper-based collection which took 70-90 minutes in total and was a two-step rather than one-step process. Field workers described entering data using the iPad for the first time took longer than when using pen and paper. However, after the first store the time taken was the same as that of the paper and pen. They explained that this was due to the need to become familiar with the new technology.

I looked at the user guide for about 5 mins and was ready to go. It's very easy to use. [Field worker 1] We didn't even look at the guide, the orientation we had was good enough. [Field worker 2]

#### Discussion

The development of this novel iPad app for the collection of food cost data was perceived to provide a more efficient and accurate form of data collection compared to previous manual-based systems.

Improved data accuracy is a major advantage for using portable digital devices. Previous studies have shown that error validation, prevention, and workflow improvements (such as taking away the need to double handle data entry) in the surveys designed for digital devices significantly reduce the errors seen when data is collected using manual techniques [8,9]. Adding further error prevention and validation mechanisms such as range checks, real-time visibility of missing data, and automatic capture of store addresses using GPS capabilities of the devices are planned for the immediate future. Price scanning using the portable device may also be investigated.

While views of the five field workers in this study are likely to be transferable to others using portable devices for data collection, the small sample size and focus on process evaluation are acknowledged as limitations in the breadth and depth of evaluation data.

There remains a need for a national food and nutrition monitoring system in Australia [14]. The electronic support systems of the healthy food basket could form part of this system. This research provides some evidence to support the idea that using portable digital devices for data collection in the nutrition research area can result in increased data accuracy, time savings, and efficient data management and sharing. The iPad app is available free to use for research purposes (contact corresponding author for more information).

#### Acknowledgments

Funding for this work was provided by the Centre for Excellence in Intervention and Prevention Science (CEIPS), an initiative of the Department of Health, Victoria.

#### **Authors' Contributions**

SQ together with AS identified the idea of the iPad app for the collection of the data. AK, SE and DPS supported researchers CP and HT to complete the development. CP and DPS tested the app and conducted and analyzed interviews from field workers. CP oversaw project and drafted manuscript. All authors were involved in drafting and approved the final version of the manuscript.

#### **Conflicts of Interest**

None declared.

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#### Abbreviations

IoC: Inversion of Control (IoC) MVC: Model View Controller PDA: Portable Digital Assistant VHFB: Victorian Healthy Food Basket

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# User Preferences and Design Recommendations for an mHealth App to Promote Cystic Fibrosis Self-Management

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## Abstract

**Background:** mHealth apps hold potential to provide automated, tailored support for treatment adherence among individuals with chronic medical conditions. Yet relatively little empirical research has guided app development and end users are infrequently involved in designing the app features or functions that would best suit their needs. Self-management apps may be particularly useful for people with chronic conditions like cystic fibrosis (CF) that have complex, demanding regimens.

**Objective:** The aim of this mixed-methods study was to involve individuals with CF in guiding the development of engaging, effective, user-friendly adherence promotion apps that meet their preferences and self-management needs.

**Methods:** Adults with CF (n=16, aged 21-48 years, 50% male) provided quantitative data via a secure Web survey and qualitative data via semi-structured telephone interviews regarding previous experiences using apps in general and for health, and preferred and unwanted features of potential future apps to support CF self-management.

**Results:** Participants were smartphone users who reported sending or receiving text messages (93%, 14/15) or emails (80%, 12/15) on their smartphone or device every day, and 87% (13/15) said it would be somewhat or very hard to give up their smartphone. Approximately one-half (53%, 8/15) reported having health apps, all diet/weight-related, yet many reported that existing nutrition apps were not well-suited for CF management. Participants wanted apps to support CF self-management with characteristics such as having multiple rather than single functions (eg, simple alarms), being specific to CF, and minimizing user burden. Common themes for desired CF app features were having information at one's fingertips, automation of disease management activities such as pharmacy refills, integration with smartphones' technological capabilities, enhancing communication with health care team, and facilitating socialization within the CF community. Opinions were mixed regarding gamification and earning rewards or prizes. Participants emphasized the need for customization options to meet individual preferences and disease management goals.

**Conclusions:** Unique capabilities of emerging smartphone technologies (eg, social networking integration, movement and location detection, integrated sensors, or electronic monitors) make many of these requests possible. Involving end users in all stages of mHealth app development and collaborating with technology experts and the health care system may result in apps that maintain engagement, improve integration and automation, and ultimately impact self-management and health outcomes.

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#### **KEYWORDS** cystic fibrosis: qualitative research: mobi

cystic fibrosis; qualitative research; mobile health



### Introduction

#### Background

Despite the well-documented need for improved adherence to prescribed medical treatments for chronic health conditions [1,2], interventions targeting treatment adherence have had modest results, and typically demonstrate small effect sizes [3]. Behavioral interventions tend to be time- and resource-intensive and are disconnected from standard medical care. Researchers have attempted to address these challenges by using technology for adherence promotion, initially through educational or interactive videogames [4] and more recently via text messaging-based medication reminder systems [5,6]. Unfortunately, barriers including the length of time it takes to develop and evaluate technology-based interventions using a static platform can result in programs that are outdated, obsolete, and clinically ineffective [7]. Behavioral interventions that use technologies or are delivered via the Internet have begun to address some of these common limitations, with evidence of improved treatment adherence [8]. Apps for smartphones and other mobile devices represent a promising avenue for further innovation in mHealth adherence promotion.

The use of mobile technologies is widespread and growing rapidly, and is increasingly intersecting with individuals' health management. Smartphone ownership continues to rise: 91% of American adults now have a cell phone and over half (56%) own a smartphone [9]. A 2012 Pew Internet poll reported that one-half of smartphone owners look up health information on their phones and 19% have at least one health-related app [10]. Consistent with this growth, there has been a surge in mobile technologies to support health, and it is not surprising that researchers are increasing their efforts to integrate mHealth technology into adherence promotion interventions.

#### **Trends in mHealth Intervention Research**

Early evidence suggests that there is a high level of patient interest in mHealth interventions [11-13]. Text messaging has been an early focus of mHealth research and has shown modest, short-term benefits for adherence in multiple illness groups [14-19]. However, in contrast to the relatively common use of text messaging in adherence promotion research, dissemination has been slow: fewer than 10% of cell phone owners have signed up to receive health-related text messages [10], of which only a portion are related to adherence promotion. Moreover, as technologies advance, text messaging reminders may not be dynamic or interactive enough to sufficiently engage participants and impact health behaviors. There is a need to develop apps that utilize the advanced technological capabilities of smartphones to more effectively integrate behavioral strategies known to improve treatment adherence for people with chronic medical conditions [20].

Advances in mobile technologies permit researchers to develop automated mHealth interventions targeted to individuals' specific treatment regimens and personal characteristics that can facilitate self-management in multiple ways [21]. For example, smartphones with embedded or external sensors can track and provide real-time feedback on the occurrence of particular behaviors or events, context awareness can trigger

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delivery of behavioral intervention at appropriate times or locations, and social networking functions can facilitate communication between patients and providers or among family members [21-23]. Integrating interactive features at this level has the potential to boost the efficacy of mHealth interventions in diseases with complex daily management needs. However, currently available mHealth apps largely focus on educational content or provide basic monitoring or reminding functions [24] and tend not to use the unique features and capabilities of mobile platforms (eg, context sensors, graphical data visualization, real-time data collection, and feedback) to their maximum potential [23,24]. With so many possibilities, a critical first step is to determine which design features have sufficient empirical evidence of efficacy, user interest, and potential to support chronic disease self-management. To maximize engagement with the software, it is essential for app developers to involve participants in the process of developing content and features that appeal to them [25]. In recent years, this idea of "user-centered design" [26] has begun to gain strength, and a handful of studies have reported user preferences for apps to promote health behaviors [27-30].

#### **Study Aims**

Thus, the goal of this study was to involve individuals with cystic fibrosis (CF) in guiding the development of future mHealth apps for adherence promotion via mixed-methods research. Given the ever-expanding capabilities of smartphone technology, our purpose was to identify which potential app features would be of greatest interest to individuals with CF to support their daily disease management needs. We hypothesized that a primarily young adult sample of smartphone-owning individuals with CF would be interested in an app for smartphones or mobile devices to support disease management, and that they would recommend various strategies to maximize the relevance and utility of mHealth apps to support adherence to CF treatments.

## Methods

#### Participants

Potentially eligible patients were identified from the patient roster of the adult CF clinic at a large, urban hospital in the mid-Atlantic United States. Clinic staff emailed all patients with email addresses on file to introduce the study and to offer an opportunity to opt-out of being recruited to participate. Study staff then telephoned potentially eligible participants to verify eligibility, describe the study in detail, answer questions, and obtain verbal informed consent. Eligibility requirements included age 18 years or above, diagnosis of CF, currently treated at the hospital's adult clinic, prescribed at least one pulmonary medication (eg, inhaled mucolytic, inhaled or oral antibiotic therapy, hypertonic saline), and own or use a mobile device (eg, smartphone, tablet). For informational purposes, 235 clinic patients were emailed general information about the study, with an option to call the study team to opt out of being recruited for the study. Two people opted out of further contact at this stage. To actively recruit potential participants, study staff attempted to contact 72 patients randomly selected from the list of people who had been emailed. Of those we attempted

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to contact, 44 were not able to be reached by telephone. Of the 28 with whom we made contact, four were ineligible (one not diagnosed with CF, two not prescribed any CF medications, and one not a smartphone owner) and two declined to participate due to time restrictions and feeling that "my CF is atypical". The remaining 22 indicated interest in participating and 19 consented to participate (three were unable to be reached to obtain consent after indicating interest); 16 people (84%) subsequently provided qualitative data via telephone interviews (technical problems resulted in 15 audiotaped interviews available for coding), and 15 (79%) completed an online survey. Recruitment was stopped once sufficient data had been collected for the study team to identify the core concepts and themes, without additional information being gained from new participants; this is known as reaching thematic saturation [31].

#### Cystic Fibrosis as an Exemplar Condition for mHealth Apps

Apps for health behavior promotion may be most appealing and useful for people who need help or support managing a chronic medical condition [28]. Yet, little is known about the needs and wants of people with most chronic conditions [27,29].

CF is an exemplar chronic condition for which mHealth apps could have potential relevance. CF is a chronic, progressive, obstructive pulmonary disease with a complicated and demanding treatment regimen. For people with CF, decreased lung function, pulmonary exacerbations, and being underweight are associated with increased mortality and morbidity, and with decreased quality of life. Just 35 years ago, a child born with CF had a median predicted survival of 14 years; today it is over 40 years and more than half of those with CF are now adults [32]. The increased survival of individuals with CF is attributable to advances in the medical treatment of CF; however, the complex CF management regimen is extremely demanding. On average, it takes adults with CF nearly 2 hours to complete seven therapies per day [33]. A typical daily treatment regimen includes chest physiotherapy and inhaled medications to break down and expel mucus from the lungs, and oral antibiotics and nebulized antibiotics (every other month) to prevent and treat infections. The majority of individuals with CF are also prescribed multiple daily vitamins, nutritional supplements, pancreatic enzymes to take with snacks and meals, and a diet high in calories, fat, and sodium. As people with CF age, they are a greater risk for diagnosis of CF-related diabetes that requires carbohydrate tracking. Most prescribed CF medications are classified as specialty drugs, and obtaining refills requires extra authorizations and paperwork that must be coordinated between clinicians, pharmacists, and insurers. Because of the risk of cross-infection, it is recommended that people with CF not have in-person contact with others with CF. Between these infection control guidelines and the relatively small population with CF, many people have never met another person with CF. This often leads to a sense of isolation and lack of social support from others who understand firsthand their treatment burden [34-36]. Because care is provided at specialty CF clinics, many individuals with CF travel long distances for routine care, making social support from providers and in-person adherence counseling challenging.

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The motivation and organizational skills required to consistently follow this demanding regimen can lead to suboptimal CF management [37], which has implications for increased morbidity and health care utilization [38]. Given the widespread and growing use of smartphones and mobile devices, mHealth technologies represent a promising avenue for automated yet individually tailored interventions to support adherence to the complicated, time-consuming CF management regimen [14]. Moreover, the complex treatment needs of CF make it an exemplar condition for which to develop mHealth apps that could serve as a model for other chronic conditions.

#### Procedures

Human subjects research approval was obtained from the institutional review board. After providing oral consent, participants completed a 30-45 minute semi-structured telephone interview with study staff. The interviews were digitally recorded and transcribed to facilitate coding and interpretation. Participants were also emailed a secure link to a password-protected Web-based survey to be completed within 2 weeks. Participants were compensated US \$50 for completing the interview and online survey.

#### Measures

#### Quantitative Survey

Participants completed a series of questions developed by the research team for this study, adapted from the Pew Research Center's Internet and American Life Project survey [10]. To assess overall smartphone/device use, participants were asked to rate the frequency with which they engage in 14 behaviors using their smartphone or mobile device (eg, send or receive email, access a social networking site, look up health or medical information). Response options were on 5-point Likert scale from "never" to "every day". They were also asked to rate how difficult it would be to give up their smartphone or mobile device on a 4-point scale ranging from "not at all hard" to "very hard". For more detail regarding mHealth apps, participants were asked to indicate all categories of health-related apps (eg, exercise/fitness, diet/calories, medication management) they currently have on their smartphone/device and the names of the specific apps, if any. Participants also provided demographic data (eg, age, income).

#### Qualitative Interview

A trained research assistant administered a semi-structured interview, using a naturalistic inquiry approach with open-ended probes on the following topics: experiences with general and health-related apps, likes and dislikes of previously used apps, current use of apps in relation to CF management, and perspectives on mobile privacy and security. Participants were also prompted to discuss their thoughts about the following potential features of an app for CF management: medication/treatment reminders, tracking completed medications/treatments, earning rewards or prizes for completing medications/treatments, communicating or exchanging messages through the app (with the CF treatment team and family members), social networking with other people with CF, behavioral comparisons or competitions with other people with

CF, games related to CF management, and any other app features they would like to see developed.

## **Data Analysis**

Descriptive data were calculated from the quantitative Web survey using Stata software, version 8.2, and qualitative data were coded from interview transcripts using NVivo software, version 10. To identify themes and develop an initial coding guide, five interview transcripts were collaboratively reviewed by the research team, which consisted of three clinical health psychologists, one clinical psychology graduate student, and one research coordinator. Two study team members coded the remaining transcripts using the initial coding guide. Discrepancies and coding scheme modifications were resolved through group discussion in an iterative fashion, repeated every five interviews until thematic saturation was reached. Inter-rater reliability between coders was determined by percent agreement and *kappa* coefficient.

Table 1. Participant characteristics (n=15)<sup>a</sup>.

# Results

## **Participant Characteristics**

Of the 16 study participants, 15 completed the Web survey, the characteristics of whom are summarized in Table 1. Participants reported that they used their smartphones/mobile devices to do the following activities every day: 93% (14/15) send or receive text messages, 80% send or receive emails, 80% (12/15) access the Internet, and 73% (11/15) access a social networking site. In addition, 64% (9/14; one missing response) and 47% (7/15) reported frequent use of gaming apps and real-time chat apps, respectively. Approximately one-half of participants (53%, 8/15) reported currently having at least one health-related app on their smartphone/device, the majority of which were related to diet or exercise.

Demographic characteristics	n (%)
Age, years, mean (SD) (range)	30.2 (5.9) (21-43)
Race, % Caucasian	15 (100%)
Gender, % female	7 (47%)
Marital status, % married/partnered	11 (73%)
Education, % college degree or beyond	11 (77%)
School, % currently attending	2 (13%)
Work, % full or part time	11 (73%)
Annual income, % ≥US \$100,000	9 (60%)
Insurance status, % private	12 (80%)

<sup>a</sup>One of the 16 study participants did not complete the online survey.

## **Qualitative Themes**

A total of 16 interviews were conducted before thematic saturation was reached. Of the 16 interviews conducted, 15 transcripts were available. For one interview, the recorder failed but detailed notes were reviewed for content. Agreement between the two primary coders was high (97.3% agreement, SD 3.8) and inter-rater reliability was acceptable, in the moderate range (Cohen's  $\kappa$ =47%, SD 0.43).

Participants discussed their preferences and concerns for potential future mHealth apps to promote adherence to CF treatments. One of the clearest overarching messages was the desire for an app tailored to the unique, complicated experience of having and managing CF. For example, one 24 year-old female said, "...the chronic illness community as a whole is kind of lacking apps geared toward them because we live a completely different lifestyle than someone who is not ...chronically ill... who doesn't have the [same] kind of daily medical struggle or regimen". A common challenge of using available health-related apps is that they may or may not fit with CF treatment goals. For instance, nutrition or diet apps are typically designed for weight loss, which is in stark contrast to CF nutrition guidelines that call for high calorie, fat, and sodium

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intake and often weight gain. The same respondent explained, "I found that most of those are geared towards losing weight and I wanted to be gaining weight and...it wouldn't...let me input a higher goal weight for me...I find that a lot of...health-related apps are generally limited to the general public".

Within the context of a "wish list" for features designed for CF-specific mHealth apps, four cross-cutting themes representing the key functions that study participants would find useful or appealing in a CF-related app emerged from the coded transcripts: (1) information at one's fingertips, (2) automation of functions and integration with other technologies, (3) communication with health care providers, and (4) socialization within the CF community (described below, with representative quotes in Tables 2-5). Of note, there was not unilateral agreement about the potential benefits of each theme, and we present quotes reflecting both preferences and participant concerns about each theme. Participants also discussed strategies to enhance motivation through an app and shared their opinions about app design issues (eg, navigation, security, customization). Finally, participants shared ideas for specific functions or features of a CF mHealth app that they would find useful in their everyday CF management (Table 6).

## Theme 1: Information at One's Fingertips

One common preference of study participants was to have a central, accessible resource for information about CF in an mHealth app (Table 2). Participants were interested in accessing information on three levels: educational, personal, and outcomes. Because most educational or informational health resources currently available through apps are designed for the general population, providing information specific to CF was highly valued (Quote 2A). Participants also emphasized wanting easy access to their personal medical data, such as recent lung function values, current prescriptions, and hospitalization history, either synced from an electronic medical record or manually inputted for later reference (Quotes 2B-C). However, some people raised concerns about privacy issues when storing all health data in a central location (Quote 2D). Many were also interested in an app tracking their CF management behavior and health status over time to identify trends and associations between adherence and personally relevant outcomes (eg,

physical symptoms, lung function, mood). Potential benefits of behavior tracking included giving insights into their own self-management patterns, increasing motivation, and facilitating informed communication with health care providers (Quotes 2E-F).

## Theme 2: Automation and Integration

Many participants emphasized the importance of obtaining maximum useful output from an app with a minimal amount of input required (Table 3). They wanted "smart" functions that would passively capture data, thus requiring less input, and be highly relevant and responsive to their circumstances. For example, respondents recommended medication alarms that would adjust to changes in the regimen or their current activity or daily schedule (Quotes 3A-C). Many were also in favor of apps to automate the process of ordering prescriptions or refills for specialty medications, which often requires substantial time, paperwork, and coordination between providers and pharmacies (Quotes 3D-E).

Table 2. Participant preferences, concerns, and illustrative quotes regarding Information at One's Fingertips theme.

Preference	Concern	Quote
General CF information		
Educational resource for self and others (family, friends)	Generic information not useful, must be CF specific	A: "Sometimes I'll [wonder when] something happens health-related to me, 'Is that normal for everyone oris that happening to me because I have CF?' And it's hard to find particular sources where I can find that out." [Age 35, Female]
Personal CF information		
Central, accessible storage for personal CF data (eg, medical history, prescriptions)	Privacy, data security	B: "I think that CF can be kind of overwhelming and it's really nice to have one central location to keep important information and data." [Age 34, Female]
		C: "Whenever you go to [a] doctor [they ask], 'What's your current list of medications?'It'd be nice to have the whole historyand then have a place for notes for how well it worked." [Age 48, Female]
		D: "I am not going to put medical information in one place unless I know that I can control who sees it." [Age 31, Male]
Individual behavioral and health	outcomes	
Self-monitor adherence and health status data over time	Cannot guarantee accuracy of self-report, risk for dishonesty	E: "If you had an app that [tracked medication] dosesthat said I missed 16 doses [on] 16 morningsthat might be a little bit of a wake-up call for me." [Age 38, Female]
		F: "I like being able to seewhere I fall on the [PFT] chart and correlate that with how I'm feelingso if this app can track when I do my meds, when I do my treatments, and I correlate it to how I'm feeling maybe I'll discover something like, 'Oh, I feel the best when I do my vest at 1 pm instead of 8 pm.'" [Age 24, Female]



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Table 3. Participant preferences, concerns, and illustrative quotes regarding Automation and Integration theme.

Preference	Concern	Quote
Alarms and reminders for treatmen	nts	
Reminders for new, unusual, cyclical prescriptions	Don't need alarms for common or routine treatments	A: "Last week they had me on a medication that I am not normally on, and I had to take that twice a day, so something [to remind me] might be helpful because[for the medications I am normally on] I pretty much know the drill I've been taking them my whole life, but for stuff like that where it's not part of my normal routine that could be helpful." [Age 23, Male]
Motivating or persistent alarms	Alarms can feel like nagging, are easy to "snooze" or ignore	B: "It needs to find the right line between annoying and not annoying…it needs to be just the perfect amount of annoying that I'll actually do it." [Age 24, Female]
Well-timed reminders	Alarms that sound at inconve- nient times	C: "The problem with alarm apps is that they tell you once and then you cansnoozeor just end it, andif there's a problem with taking the medication right then, that's not good. For instance, if you're driving you snooze and 5 minutes later it goes off again and you're still drivingit would be really good if it could[remind you later when] you're not moving anymore." [Age 30, Male]
Pharmacy refills		
Automatic, triggered by available medication data (eg, new or pre- vious fills, adherence data)	Refill barriers: forgetting, late requests, time-consuming calls, pre-authorizations	D: "The biggest thing for me would be the ability to manage medica- tionsall in one placeIf I need to refill prescriptions, being able to potentially do it straight from my phone with the ability to tie into wherever I get my medicine from so that when I do need to renew it or refill it, it's the click of a button or scanning of a bar code in the phoneIf I could have one central location that had all of my prescriptions that dealt with cystic fibrosis in one spot and I could refill them from that spot, that would make life a lot easier." [Age 31, Male]
		E: "A lot of people need reminders when they need to refill their prescription sokeeping track of how many [doses of medication] do I have left?Keep track of when I filled that and automatically populate 30 ampulesthen it counts down every time you use, being able to track when you're supposed to order your medication again." [Age 27, Male]

## Theme 3: Communication

Opportunities to seek or share medical information with other people were frequently mentioned (Table 4). Participants were interested in using an mHealth app to communicate with their health care provider between clinic visits and to improve care by giving providers access to personal CF data through the app (Quotes 4A-B), although concerns were raised with the quality of app-based communication compared to live or telephone contact (Quote 4C). On the other hand, many perceived health or behavior tracking as a mechanism to enhance communication with their CF providers by providing relevant data (Quotes 4D-F). Participants also discussed ways that an mHealth app could facilitate efficient conversation within the health care system, such as to promote care coordination among different providers or between prescribers and pharmacies (Quotes 4G-H). Finally, some respondents envisioned mHealth apps that could promote communication within families, for example to help parents monitor adolescents' CF treatment adherence, although this was less appealing for adults (Quotes 4I-K).

## Theme 4: Socialization

Study participants often saw a social networking component as a possible solution to the widespread sense of isolation among people with CF (Quote 5A; Table 5). Respondents almost unanimously agreed that a closed social network separate from existing public social networks or platforms was important, not only for privacy, but also to build a community of people with similar experiences (Quotes 5D-F). Many emphasized the uniqueness of their individual experiences or CF genotype and wanted highly filtered networks based on their demographic and health status to maximize the benefit of socializing, which may not otherwise be possible given their rarity of CF (Quote 5G). Social networking was perceived to be appealing for family members or partners of people with CF, as well (Quote 5H-I). While several respondents saw potential benefits in sharing personal experiences and data via a social network (Quotes 5J, L), concerns were raised about privacy (Quotes 5M). Many respondents also discussed the risk of feeling saddened by the high rate of mortality and illness in the CF community and wanting to limit contact with others to avoid these reminders (Quotes 5B, C, K).



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 Table 4. Participant preferences, concerns, and illustrative quotes regarding Communication theme.

Preference	Concern	Quote
With medical team		
Contact with CF providers be- tween visits	May not be as responsive as tradi- tional telephone or email contact, don't want to replace human con- tact with providers	A: "I'm not always in a place where I can call them, so if I can just shoo a textthat would be convenientIf they want me to do something out of the ordinaryI want to [ask], 'How exactly did you want me to do this? " [Age 23, Male]
		B: "If there is an impending exacerbation coming up, being able to com municate with them about that and do aplan of action." [Age 35, Female
		C: "In the everyday world [electronic communication] just seems to be replacing talk and conversation and you know, communicating that way I don't want that to happen [with my doctors]." [Age 35, Female]
Sharing health data with CF providers can facilitate informed conversations during medical visits	Discomfort with medical team having high level of monitoring ability	D: "Obviously they're the experts, butit's empowering togo into an appointment with salient data." [Age 34, Female]
		E: "If you started to get sick and the nurse says, 'Well how have you been doingtaking these medications?'Being able to say, 'Yeah, here is what I've been doing.'would be a nice function to have." [Age 31, Male]
		F: "I don't know if I'd want it butit would be good for them to seehow much you did a treatment in a week. I feel like they probably should see that but you might not want them to." [Age 21, Female]
Vithin health care system		
Care coordination between CF team and subspecialists or other providers		G: "My regular doctorputs me on [a medication] for high blood pres- surethen I need to go talk to my CF doctor to make sure this isn't goin to screw up my [CF medication] so that they know what I'm onif there a waywhen I'm up at CF clinic and they change my regimen you coul use the app and it will automaticallysend it to my regular doctorso am not manually having to remember to send stuff back and forth." [Ag 48, Female]
Between pharmacy and CF team to submit prescriptions, authorize refills		H: "I could have a list of medications and submit a refill request to my doctors [through the app]ideally it would integrate with the pharmacy appand have the ability to say, 'You're out of refills on this,'and it could notify my doctor [directly] instead of notifying [my pharmacy] to notify my doctor." [Age 28, Male]
Vith family		
Parents would find it valuable to help monitor teens' adherence	While potentially helpful for oth- ers, adults did not need a new communication channel	I: "It might be good for parents tobe able to see when the medication is being taken and when the treatments are being done." [Age 30, Male]
		J: "I would use other more direct messages." [Age 28, Male]
		K: "I would probably continue to communicate with them the way I already do." [Age 33, Female]



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Table 5. Participant preferences, concerns, and illustrative quotes regarding Socialization theme.

Preference	Concern	Quote
With other people with CF		
Novel opportunity to network, given prohibitions on face-to- face contact	Could feel discouraged or guilty seeing others doing better or worse than you	A: "Because people with CF can't be in the same room as each other,being able to see someone else with CF is much more profound than just exchanging emails with some anonymous person." [Age 28, Male]
		B: "I don't like hearing about CF people that aren't doing well. I have a hard time distancing myself from it. It's hard having to filter through all this sadness to get kind of connected with someone." [Age 26, Female]
		C: "I didn't really like it only because some people had it worse than me and if it kind of brought me down because I felt like this is where I'm heading and I just didn't like thatSo I don't know if I'd really want to talk to any other people with CF, I don't want to like be depressed." [Age 32, Male]
Access to people with similar experiences	Variability within CF does not guarantee shared experiences	D: "At some point in our lives, we feel inadequate and we're not as good as normal people so this gives us our own sense of community that way we can relate topeople who are like us." [Age 27, Male]
		E: "It's always nice to know another mom that has CF, like, 'How do you juggle getting your child out to school versus doing your treatment?', you know that sort of same situation." [Age 38, Female]
		F: "The ability to ask questions to a larger community regardingissues or problems that you may be having from a CF standpointA CF to CF community[is] what I found lacking, that I didn't have when I was growing up." [Age 31, Male]
		G: "There's like 1800 different kinds of CF right now and they're still dis covering more, so it's never going to be a specific thing unless you could somehow logyour exact genesand then maybe connect with people that have the exact same ones." [Age 30, Male]
Social support opportunities for families, partners, caregivers of people with CF	Challenge to maintain other per- son's privacy or anonymity if organized through app of person with CF	H: "I think that support for the family and friends is importantfor people who have CFtalking to significant others of people who have CF." [Age 28, Male]
		I: "Something toconnect friends and family so that they understand the disease a little bit more, and maybe they canconnect with you on a different level." [Age 32, Male]
Comparisons for motivation		
Self-monitoring in context of others with CF	Discouraging if not meeting goals, doing worse than others	J: "To build a communitywould help provide people a better incen- tivemore of the 'We're in this together.' Someone else has worked 12 hours a day but they're still doing their medicine, you know I can." [Age 28, Male]
		K: "Sometimes you don't want to be comparing yourself to other CF-ers because it is depressing like, 'She has worse lung function than me but she is never sick, why is that?'It can be tough because no two cases are the same and yet we allhave similar therapies so it can be frustrating to see a better outcome than yours if you are doing all the same things if not more." [Age 24, Female]
Potential for motivation and rein- forcement from peers	Concerns about anonymity and privacy, ability to be identified	L: "If you're going to see somebody that is doing pretty well and you cantalk to them about how they handle it or what their regimen is, then maybe you can pick up things from them or share with them what you do." [Age 35, Female]
		M: "If I were to have my data compared to the wholeI wouldn't want them to say, 'Oh there's someone named [removed] that didn't do treatments today.' " [Age 26, Female]

## **Other Potential Motivators**

In addition to the four themes discussed above, participants were also prompted to discuss other possible app features that could be potential motivators. Opinions were mixed regarding

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XSL•FO RenderX the usefulness of gamification, behavioral comparisons, and competitions to enhance motivation among app users. One point of agreement was the importance of comparing adherence behaviors rather than clinical indicators (eg, lung function, weight), because individuals have more control over their

behaviors than their health outcomes. Some participants discussed potential benefits of comparing their adherence behaviors with others, such as, "it may be helpful...if other people are able to share how they're able to do it or...motivate you to do a better job" [age 38, female]. However, many did not imagine feeling motivated by comparing their data or competing with other people, from whom they may be very different. One respondent described her disinterest in competitions, "I'm shooting for the best I can be, not the best that other people can be" [age 33, female]. Others raised concerns about negative feelings, such as guilt, from comparing oneself to others: "If I see someone who [has a very poor disease state], I'm going to start feeling guilty because I do not have that" [age 27, male]. Another participant discussed possible discouragement, "you wouldn't want to make somebody feel horrible about themselves if they're maybe not...doing everything they should be doing" [age 35, female].

The use of prizes to motivate health behavior was also controversial. Some respondents were eager to earn rewards for completing CF treatments, especially those that were tailored to their interests or that benefitted the CF Foundation, while others did not feel that material prizes would sufficiently motivate them. One 24 year old female participant expressed her ambivalence about rewards, "Day after day it's hard...it's your health and your life, and that should be motivation enough, and well...sometimes, gosh darn it, it isn't."

## **App Design Recommendations**

Participants shared suggestions for app design features that would meet their needs and preferences for a CF management app (Table 6). For example, to address preferences related to automation and integration, study participants described app features that would automatically suggest optimal times for CF tasks based on all available information by syncing with other apps or using other smartphone technologies such as motion detection or other sensors. Some participants imagined systems to automatically provide medication reminders or refill prescriptions using data stored in the calendar or pharmacy app. Another described the potential benefits of video chatting for communication with others with CF, "The video thing that is a way for CF patients to interact with each other kind of face-to-face, which...we're not allowed to do" [age 27, male]. Participants raised several points about the app design and usability. A central issue for many was ease of use, with minimal burden or effort to input medical data or set up scheduled alarms. Participants described frustration with other apps having "tedious" data entry and access processes [age 33, female] that limited the app's usefulness. One participant acknowledged the long-term benefits of entering personal data up-front, "that may take …back end [effort] on the user's part, like on my part it may take me importing account information... but I don't mind doing that if it makes it easier in the long run" [age 31, male]. Yet the overarching sentiment was to use automated processes for passive data collection to reduce requirements for user effort.

Clear, intuitive navigation was important, with the ability to easily search data within the app. Participants wanted graphical displays to be presented in digestible, easily understood, and mobile-friendly visual formats. Simple features, such as a basic alarm or medication reminder system, were generally not of interest; rather, participants favored app designs that integrated multiple functions within a single, cohesive program. As one participant described her vision, "I don't want a bazillion apps...it would be so great to have an all-in-one where, I could keep track of my calories and also my exercise, and also, 'Well, I did saline three times today, gold star for me.'...all compiled into one [app] so I can quickly look at this one app and see an overview of my progress or my lack of progress...so if it could be presented in an orderly and efficient fashion all in one place would be great" [age 24, female]. However, with so many possible features within a single app, several participants also emphasized the need for customization options, such as selecting which features to use and privacy settings. For example, some participants were comfortable with their CF providers being able to track their adherence or refill data, while others wanted to limit access. Some were interested in social networking, while others would prefer not to use that feature. Given the heterogeneity in participant preferences and concerns about app features, the option to turn individual features on and off will be very important to ensure acceptability and use of an app. Finally, a common recommendation was to sync the app across multiple devices so that the data and functionality could be updated and accessed not only from a smartphone, but also from other mobile and desktop devices via the Internet and the cloud.



 Table 6. Suggested app features related to cross-cutting themes.

Feature	Theme			
	Information at One's Fingertips	Automation and Integration	Communication	Socialization
Searchable CF-specific medical wiki-resource with video clips and interactive resources	•			
Sensors to assess lung function (spirometry), sweat chloride, medication, or treatment adher- ence	•	•		
Graphical displays of adherence behaviors and outcomes (eg, symptoms, spirometry, mood) over time, visualize links between treatments and outcomes	•		•	
"Smart" goal-setting guidance based on medical team's treatment plan and tracked adherence or outcome data		•	•	
"Genius" suggestions for personalized behav- ioral incentives (eg, for adherence) based on Web-browsing or purchasing history		•		
Timed serial alarms for consecutive series of treatments		•		
"Genius" treatment scheduler / adherence prompt based data from other apps: personal schedule (calendar events), current location (GPS), activ- ity level (motion detection)		•		
Recognize new or cyclical (month-on, month- off) prescriptions (eg, via linked pharmacy app) and automatically set up reminder/alarm		•		
Automatic medication refill requests sent to pharmacy based on passively collected adher- ence data (eg, sensors on medication packaging, self-reported administrations)		•	•	
Schedule and sync medical appointments with existing calendars (eg, Outlook or Google calendar appointment requests)		•	•	
Barcode/Q-code scanner to access CF-specific information about medications or food, to track adherence to treatments, to request prescription refills	•	•	•	
Direct contact buttons (call, email, text) to reach CF team, one for emergencies, one for rou- tine/non-urgent contact			•	
Video chat – with CF team, pharmacy, other people with CF		•	•	•
Two-way messaging with CF team – Q&A with providers, providers contact patient via app if behavioral/outcome monitoring indicates health concern		•	•	
Connect with others with CF with similar expe- riences or characteristics via searchable database of participant profiles				•
CF-specific social networking platform, can opt into sharing personal data to public sites		•		•

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# Discussion

## **Principal Findings**

Based on the thoughtful and realistic input of potential end users (ie, smartphone-using individuals living with CF), this study provides direction for future development of patient-oriented mHealth apps for CF adherence promotion. It should be noted that participants were asked to comment on their experiences and their "wish lists" and not an already developed app. This afforded them the opportunity to be blunt about preferences without concern about negatively commenting on the work of the investigators. Moreover, in contrast to other studies on patient perspectives [39,40], the primary topic of inquiry was desired design features, not educational content. Study participants largely expressed excitement and interest in potential future mHealth apps designed to facilitate CF management. Participants emphasized the importance of having easy access to health information, automating app functions to avoid creating additional burden, integrating smartphones' technological capabilities to increase efficiency for time-consuming disease management tasks, and facilitating timely and meaningful communication with others with CF or health care providers. However, important concerns about the usefulness, appeal, and security these issues were also raised. Given the opportunity to brainstorm future app features, respondents described inventive, creative, yet realistic functions that have the potential to ease the burden of daily disease management and facilitate healthy behavior patterns. While this study focused on individuals with CF, the key themes, concerns, and ideas raised are likely relevant to people with a number of chronic medical conditions with complex and burdensome management regimens.

## **Common Themes in mHealth App Preferences**

Several of the themes voiced by this study's participants echoed the preferences of other research related to user preferences for mHealth apps. Perhaps most universal are the desire for low-burden, high-payoff apps and the need to be able to customize app content and features to fit individual health needs and wants [27-29]. Across people with and without chronic conditions, these were nearly universal and should be applicable to most mHealth app designs.

Specific content and functionality also had some similarities to findings from other research. Participant interest in communicating via an app with health care providers in this study was consistent with similar themes in studies with people with type 2 diabetes [27] and HIV [29], highlighting the importance of patients desiring greater access to their health care team. The other studies did not discuss using the app to facilitate communication and cooperation among health care providers and other services such as pharmacies. However, this was suggested by the participants with CF, perhaps due to the multiple systems involved in the treatment of CF and the burdensome process of ordering specialized medications and equipment. Qualitative research to guide mHealth apps for more general health behaviors has called for automated processes to track and provide feedback about physical activity and diet [28,30]. This is similar to the adherence behavior monitoring

components discussed in this study. The ability of smartphones to passively collect, store, and synthesize behavioral data may be helpful across numerous health behaviors and populations.

Like the current study, the study on apps for individuals with HIV reported a theme related to automated medication prompts based on current contextual sensing (eg, geolocation) [29], while individuals without chronic conditions were less optimistic about how this technology could support their health behavior goals [28]. It may be that the highly structured, time-intensive, and location-specific (eg, specialized equipment at home or medical facility) daily demands of chronic condition treatment regimens benefit more from personalized prompts than do the more flexible health behaviors of generally healthy adults. In contrast to the samples of people with CF or type 2 diabetes [27], young adults without a chronic medical condition were less interested in social networking opportunities around supporting health behaviors such as eating or exercise [28]. Social networking may be particularly attractive to people with chronic medical conditions who feel alone in their disease or who are seeking guidance or support from others in similar situations. Individuals without chronic health conditions may receive adequate support from other sources and not desire health behavior-specific support from other online users. Alternatively, people with chronic conditions may not feel comfortable sharing their health behavior data via general social networks that reach people to whom they may not have disclosed their diagnosis; sharing information about health behaviors may be much more socially acceptable for people without chronic conditions (eg, tweeting today's bike ride distance, posting a photograph of tonight's healthy dinner) [28]. It appears that particular features like context sensing and social networking have greater appeal for chronic condition management and should therefore be considered independently for each population developing its own mHealth app.

## Making Use of Available Technologies

Ever-evolving smartphone technologies make many of the recommendations and themes of this study's participants plausible. Given the prevalence of social networking in general and the CF-specific challenges of social isolation, it is unsurprising that app-based socialization with other people with CF was a major focus for many participants. The potential for feeling isolated is elevated in CF due to the guidelines to reduce risk for infection by eliminating close contact with others with CF [34]. Widespread social networking and communication features common to smartphones, including text, talk, and video messaging, can be easily employed to create previously impossible opportunities for socialization and support among people with CF and their families. Similarly, many participants imagined the benefits of having an app that could reduce the arduous and time-consuming tasks of refilling complex prescriptions or that could enhance care coordination between multiple medical providers, pharmacies, and insurers. By capitalizing on existing technologies, these challenges could be easily resolved. For example, a personal mHealth app could sync with apps for pharmacies and integrate with patient-provider electronic medical record portals to automate these processes and efficiently use already available resources and infrastructure.

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Internal and external sensors in smartphones are also increasingly available for use with future mHealth apps. For example, mHealth systems have been developed that use machine learning, or the context sensing capabilities of smartphones, to provide psychological interventions in timely, relevant, and highly personalized ways [22,41]. Sensors that are native to smartphones, including GPS geolocation, motion detection, voice recognition, and calendar event monitoring, are available for coordination with mHealth apps. External sensors could also be integrated to detect other data about individuals' behavior or context, such as physical activity via electronic pedometers or medication adherence via electronic medication monitors [42]. For people with pulmonary conditions like CF, data from an external peak flow meter could be used to track and provide feedback on patterns of lung function [43]. Although these technologies exist, they have not been maximally used for personalized behavioral interventions related to chronic illness management [21-24]. Thus, there remains great potential to take advantage of sophisticated tools in the development of patient-centered mHealth apps. Moreover, even as smartphones have growing capability to collect numerous types of monitoring data, little attention is being given to the most effective and user-friendly ways to provide feedback to both the user and health care team. As noted by many participants in this study, tracking health behaviors with clear graphs and visualizations is likely of great interest and benefit.

## **Stakeholder Input in the Design Process**

To successfully create and evaluate the impact of mHealth apps for chronic illness management, many stakeholders need to be included from the start and throughout the development and evaluation process [26]. The themes of integration and ease of use identified in this study highlight the need for apps to provide a clear perceived benefit to the user in order to keep them engaged. Although many mHealth apps are available, repeated use is extremely low [44-46]. For example, an analysis of a dietary self-monitoring app with photography and feedback found 2.6% of users were considered "active" and user feedback was rare, with only 15.4% of uploaded photos receiving a single "like" from other users [44]. It is critical to create apps that are not only initially appealing but also maintain engagement over time, in order to have optimal benefit for users or improve health outcomes. As evidenced in the current study, end users (in this case, individuals with CF) are critical to informing the direction, content, format, and focus of eventual apps [25,26]. Including the target population end users in all stages of mHealth development allows developers to harness patients' experiences, perspectives, preferences, and-perhaps most underutilized and undervalued-their creative imaginative solutions to the everyday challenges with which they are intimately familiar. When recruiting potential end users into a study like this one, it is critical to include participants with varied characteristics in order to maximize the likelihood that their feedback will apply to many types of people.

A common theme in this study was the desire for integration of app functions across various health care providers and services. To achieve an integrated product, it is recommended that app developers should coordinate with representatives from multiple sectors of the health care system (eg, pharmaceutical companies, pharmacies, insurers, medical providers). To ensure that the app features are integrated in a way that is consistent with behavioral theory and evidence [47], psychologists and behavioral scientists should be consulted [20]; additionally, they could advise on research design and evaluation. Finally, technology experts, including computer scientists and engineers, and experts in privacy and security, are also crucial to executing the app or mHealth program effectively. Not included in this study, but also important to survey, would be family members and other supporters of individuals with the chronic condition for whom the app is designed, as well as health care teams, pharmacists, and insurers whose activities could be impacted or touched by app features such as those described in this study.

## **Strengths and Limitations**

As with all mixed-methods research, this study has strengths and limitations. This study gathered rich qualitative data and was able to quantitatively characterize the demographic, clinical, and behavioral profiles of a sample of adults with CF, a chronic condition with a complex and burdensome treatment regimen. The qualitative data were coded by two independent raters, and the inter-rater reliability coefficient kappa was in the moderate range. The kappa statistic takes into account the possibility of agreement due to chance. While this is useful for categorical data, it relies on the assumption that a coder who is unsure what code to select will rely on chance or guess randomly. This is highly unlikely for qualitative coding because coders often have some background information to guide selection and thus results in a conservative underestimate of agreement for qualitative data [48]. Thus, paired with the high percent agreement between raters, the moderate kappa is acceptable.

Participants were varied in age, disease status, and adherence behaviors, yet all were smartphone users who would be potential consumers of an mHealth app. Though small, the sample size was adequate for the purpose of this study to inform directions for mHealth app development with a user-centered design, and we were able to identify a number of common themes and to reach saturation. Participants were actively recruited, which resulted in a sample that better represented the clinic population than had we relied on participants to volunteer in response to advertising. Nevertheless, individuals who agree to participate in research may be more motivated or knowledgeable about their condition than those who decline or do not respond to invitations to participate, which may have an impact on study outcomes. While CF is an exemplar for a complicated management regimen, it is a rare disease with many unique aspects that may not generalize to other illnesses.

## Conclusion

Finally, apps create a large amount of data for both patients and providers, but little is known about how the data will be received and used by providers in clinical care. It will be important to include health care providers and other stakeholders in future research to determine their needs, preferences, and uses of mHealth apps for chronic condition management.

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## **Conflicts of Interest**

None declared.

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## Abbreviations

CF: cystic fibrosis

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# Mobile Technologies: Expectancy, Usage, and Acceptance of Clinical Staff and Patients at a University Medical Center

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# Abstract

**Background:** Despite their increasing popularity, little is known about how users perceive mobile devices such as smartphones and tablet PCs in medical contexts. Available studies are often restricted to evaluating the success of specific interventions and do not adequately cover the users' basic attitudes, for example, their expectations or concerns toward using mobile devices in medical settings.

**Objective:** The objective of the study was to obtain a comprehensive picture, both from the perspective of the patients, as well as the doctors, regarding the use and acceptance of mobile devices within medical contexts in general well as the perceived challenges when introducing the technology.

**Methods:** Doctors working at Hannover Medical School (206/1151, response 17.90%), as well as patients being admitted to this facility (213/279, utilization 76.3%) were surveyed about their acceptance and use of mobile devices in medical settings. Regarding demographics, both samples were representative of the respective study population. GNU R (version 3.1.1) was used for statistical testing. Fisher's exact test, two-sided, alpha=.05 with Monte Carlo approximation, 2000 replicates, was applied to determine dependencies between two variables.

**Results:** The majority of participants already own mobile devices (doctors, 168/206, 81.6%; patients, 110/213, 51.6%). For doctors, use in a professional context does not depend on age (P=.66), professional experience (P=.80), or function (P=.34); gender was a factor (P=.009), and use was more common among male (61/135, 45.2%) than female doctors (17/67, 25%). A correlation between use of mobile devices and age (P=.001) as well as education (P=.002) was seen for patients. Minor differences regarding how mobile devices are perceived in sensitive medical contexts mostly relate to data security, patients are more critical of the devices being used for storing and processing patient data; every fifth patient opposed this, but nevertheless, 4.8% of doctors (10/206) use their devices for this purpose. Both groups voiced only minor concerns about the credibility of the provided content or the technical reliability of the devices. While 8.3% of the doctors (17/206) avoided use during patient contact because they thought patients might be unfamiliar with the devices, (25/213) 11.7% of patients expressed concerns about the technology being too complicated to be used in a health context.

**Conclusions:** Differences in how patients and doctors perceive the use of mobile devices can be attributed to age and level of education; these factors are often mentioned as contributors of the problems with (mobile) technologies. To fully realize the potential of mobile technologies in a health care context, the needs of both the elderly as well as those who are educationally disadvantaged need to be carefully addressed in all strategies relating to mobile technology in a health context.

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## **KEYWORDS**

survey; mobile health; mobile apps; health care; privacy; data protection; patients; medical staff; staff attitude

# Introduction

## **Mobile Phones and Health Care**

The widespread use of mobile devices such as smartphones and tablets, or more specifically, mobile devices able to run various types of application software (apps) does not stop at health care; apps running on such devices provide users with health information, measure their bodily functions, remind them about taking their medication, or support diagnostics. According to current findings by Tran et al (2014), in medicine, the use of mobile phones in a medical setting is increasingly coming into the focus of (international) research [1]. Studies performed in these contexts often deal with, and identify chances as well as challenges and risks of using health apps and medical apps in health care [2-4].

The use of mobile devices in daily clinical practice does not only touch on questions regarding technical feasibility, structural framework conditions, or political aspects, rather, using or refraining from using these devices should always be an individual choice of the clinicians. Based on a longitudinal study where we surveyed medical doctors working at the Hannover Medical School at two points in time, specifically the summer of 2012 and spring of 2014, we were able to confirm that the use of mobile devices in professional settings is rapidly increasing, both when collaborating with colleagues as well as when interacting with patients [5]. This increase does not only cover the increased frequency of use, but also the expansion of the areas of application where mobile devices are used. Our findings also show that there have been only marginal changes regarding concerns voiced by the staff regarding the use of smartphones and tablets. In contrast to [5], where we only evaluated how the use of mobile devices in a professional setting had changed between 2012 and 2014, this time around we also wanted to include patients. Specifically, we wanted to determine whether there are any notable differences in how patients and doctors view the use of mobile devices when it comes to using them in a health related context.

## **Narrow Perspectives of Previous Studies**

Many publications only consider a relatively narrow perspective, for example, the patients' [6,7], or doctors' [8,9] point of view, or a specific field of application [10] when looking at the challenges and potentials of using mobile devices in a clinical context. Also, these studies often only look at whether mobile devices work for a specific intervention or area of application, rather than at the general question of what makes their use attractive for potential users or which factors may keep potential users from using the devices. Thus, one may miss the chance of painting a comprehensive picture of the acceptance and use of mobile devices in medical settings, which would be necessary for letting both groups, patients as well as medical professionals, participate and benefit from mobile technical innovations during the care process. Only when including these aspects is it possible to account for the qualms doctors, as well as their patients, may have regarding the use of mobile devices in medicine.

## The Objectives

Our objective was therefore to obtain a comprehensive picture of how mobile smart devices are perceived in medical contexts, and how they are used in reality. The evaluation therefore covers not only the purposes for which both doctors as well as their patients are already using mobile smart devices, but also concerns they may have or challenges they perceive when using such technology. In this context, it was also of interest whether medical professionals have a different view with respect to the use of mobile technology or toward the perceived dangers.

# Methods

## **Multi-Perspective Approach**

Based on a multi-perspective approach, doctors working at Hannover Medical School, a maximum care university hospital located in northern Germany, as well as patients being admitted to this facility, were surveyed about their acceptance of mobile devices in medical settings and how they made use of this technology. This study was registered with the institutional review board of Hannover Medical School (trial number 1206-2011).

## **Doctors' Survey**

Data regarding doctors were obtained based on a standardized and anonymous online survey that was performed between February 6th and March 12th, 2014. All doctors employed by Hannover Medical School during this time span were invited to participate. Following the first call for participation, two reminders were sent to those who had not yet participated. Altogether, 206 out of 1151 eligible doctors participated in the survey, corresponding to a response rate of 17.90%. The sociodemographic data of those who answered are representative of the overall population of doctors working at Hannover Medical School [11]. Table 1 describes the sociodemographic data for the sample (206/1151) we obtained.



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#### Table 1. Sociodemographic data of the physicians (206/1151) who answered the survey.

Sociodemographic data of the physicians		Number of physicians who an- swered survey=206,
		n (%)
Gender		
	Male	135 (65.5)
	Female	67 (32.5)
	Not specified	4 (1.9)
Age (years)		
	18-25	1 (0.5)
	26-35	80 (38.8)
	36-45	92 (44.2)
	46-55	23 (11.2)
	56 and older	6 (2.9)
	Not specified	5 (2.4)
Work experience (years)		
	None	4 (1.9)
	1 up to 2	11 (5.3)
	2 up to 4	31 (15.0)
	4 up to 6	26 (12.6)
	6 up to 10	35 (17.0)
	10 up to 20	69 (33.5)
	20 up to 30	20 (9.7)
	30 and longer	7 (3.4)
	Not specified	3 (1.5)
Role		
	Chief physician	1 (0.5)
	Consultant	75 (36.4)
	Attending	25 (12.1)
	Junior doctor	99 (48.1)
	Not specified	6 (2.9)

## **Patients' Survey**

A systematic random sample of adult patients presenting at the central admissions point of Hannover Medical School was used to perform the patient specific survey. Patients below 18 years of age were not included in the survey, since at Hannover Medical School, children and adolescents are not admitted via the central admissions point, but through the separate admissions point of the pediatric clinic. The survey was performed on five days (over periods of two to four hours per day) between November 12th, 2013 and December 10th, 2013. During the survey, altogether N=558 patients entered the central admissions point and every second patient (279/558) was asked whether he or she was willing to participate in the survey. The survey was performed in the form of oral interviews, and the survey personnel consisted of 7 students of the University of Applied

Sciences and Arts at Hannover who had been instructed about how to perform the interviews; specifically how to go through the questions; to provide explanations when needed, but to refrain from using suggestive explanations; and to avoid touching on personal matters such as specifics of a patient's condition. Altogether, 213/279 individuals were willing to participate and were thus included in the survey, corresponding to a utilization rate of 76.3%. Main reasons for not participating were language problems, as well as patients being called in too soon to finish the survey.

The demographics (age, gender, etc) of the patients included within the survey (Table 2) were comparable to the demographics of the overall patient population (provided in anonymized form by the hospital's administration) encountered at the admissions point during the survey.

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Table 2. Demographics of the patients (n=213) participating in the survey.

Sociodemographic data of the	patients	n (%)
Gender		· · · · · · · · · · · · · · · · · · ·
	Male	115 (54.0)
	Female	85 (39.9)
	Not specified	13 (6.1)
Age (years)		
	18-25	18 (8.5)
	26-35	30 (14.1)
	36-45	26 (12.2)
	46-55	30 (14.1)
	56-67	47 (22.1)
	68 and above	47 (22.1)
	Not specified	15 (7.0)
Educational level		
	Primary school	2 (0.9)
	Lower secondary school	37 (17.4)
	Intermediate secondary school	73 (34.4)
	Upper secondary school	84 (39.4)
	Not specified	17 (8)
Condition		
	Acute	73 (34.3)
	Chronic	123 (57.7)
	Not specified	17 (8.0)

## Instruments Used During the Survey

## Questions Used for Doctors

Although different means were used for administering the surveys for patients and doctors, in accordance with our objectives, the design of the questionnaires used for surveying both patients and doctors was largely similar. Depending on the question, answers were either given as "yes" or "no", as a choice between various options, or as free text answers.

The electronic questionnaire used for surveying the doctors contained 15 items (see Multimedia Appendix 1) that were relevant for the presented evaluation. Another 12 items that were also included in the questionnaire focused on a slightly different subject area and are thus not included here.

Among others, two questions dealt with whether the participant had access to a mobile device, and if so, which type of device was available. Another seven questions covered current and desired usage scenarios (including one question with free text answers where the participants could state which, if any, apps they were already using), as well as possible concerns arising from the use of mobile devices in a medical context. In addition, the participants were given an opportunity to voice their opinion or make remarks by entering text in a text entry field. They were also asked to provide information about their age and gender,

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as well as their professional experience (none, 1 up to 2 years, 2 up to 4 years, 4 up to 6 years, 6 up to 10 years, 10 up to 20 years, 20 up to 30 years, 30 years, and more), as well as their professional function (chief physician, consultant, attending, junior doctor). There was also one field where the participants could enter remarks.

## **Questions Used For Patients**

The questionnaire employed for the oral interviews of the patients contained 17 items (see Multimedia Appendix 2). Again, the first two questions covered availability of a mobile device, as well as the type of device (if one was available). Another five items covered current and desired use of mobile devices with respect to medical and health issues. An additional five items were included to obtain information about the participants' attitude toward mobile devices being used by their attending physicians. There were also four questions regarding age, gender, as well as the school-leaving qualification, and whether the patients were seeking help for an acute or a chronic condition. This was of interest since various factors, including but not limited to, age and educational level may influence access to mobile technologies, as well as the level of competence individuals exhibit when dealing with such technologies [12-14]. Also, patients with chronic conditions are often rated as "experts" when it comes to their condition, dealing with the condition on a daily basis, medication for their condition, etc

[15,16]. In this light, we were therefore interested whether, and, if yes how, the answers provided regarding use and appraisal of mobile devices in a medical context differed between patients presenting with acute or chronic conditions. According to [15], chronic conditions are defined as the "...result of an ongoing process of degenerative changes in the somatic or psychological status". Nevertheless, in literature, there is no uniformly recognized definition of the amount of time needed to make an acute condition chronic, and numbers often range between 3 and 6 months [17,18]. In the context of our evaluation, we decided to use a duration of at least 6 months to define a "chronic condition".

## **Statistical Methods**

GNU R (version 3.1.1) was used for statistical evaluation. Fisher's exact test, two-sided, alpha=.05 with Monte Carlo approximation, 2000 replicates, was applied to determine dependencies between two variables. For the patient survey, calculations were performed following the assumptions outlined in section "Instruments", specifically for age, gender, education, and disease status. For evaluating the data obtained from the doctors' survey, regarding professional function, the values obtained for chief physicians and consultants were aggregated since there was a low response rate from chief physicians. In addition, regarding the educational level of the patients, those who had attended primary school or lower secondary school were also aggregated since the number of patients who had only finished primary school was low.

# Results

## **Doctors' Survey**

At the time of our second survey in 2014, the majority of doctors who had answered owned one or more mobile devices (168/206, 81.6%). There were (78/206) 37.9% of them that admitted to using the device for work purposes (without knowing how often they did so, since we did not ask for how frequently they used the devices). Another (77/206) 37.4% deem it highly probable that they would be using such a device for work in the future, (46/206) 22.3% believe this to be unlikely in the near future. Whether a mobile device is already used in a professional context does not depend on age (P=.66), professional experience (P=.80), or professional function (P=.34). However, this changes when looking at gender versus professional use of

mobile devices (P=.009), with (61/135) 45.2%, use is more common among male participants than among female doctors, where only (17/67) 25% of those who had answered the survey were already using mobile devices for their work.

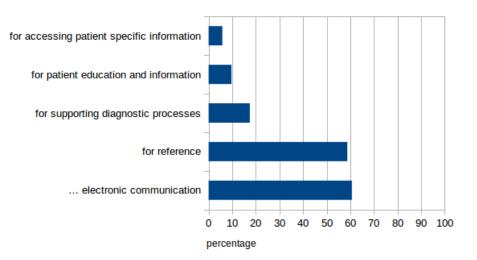
The majority of doctors who were using at least one mobile device for work had purchased or received the device(s) privately; only 12 had received a device from their employer. While a larger number of participants owned an iPhone, Android based phone, or Blackberry (158/168, admitting to professional use of mobile devices, 69/158), there is also a considerable number of those who own an Android or iOS based tablet PC (80/168, admitting to professional use of mobile devices, 46/80). Other mobile phones or tablets are negligible (7/168), and many doctors (69/168) own more than one device. Main application areas were sending emails (125/206, 60.7%) or looking up medical information (121/206, 58.7%). Almost every fifth participant admitted to using their devices during contact with patients, for example, for showing information to their patients or as a diagnostic aid (Figure 1 shows this information).

The types of apps that had been installed by the participating physicians, primarily, also mirror these activities; the interviewees stated that they used apps for literature searches, medication databases, or apps provided by medical journals. In the free text answers, there were two mentions of professional online networks for doctors where users can discuss specific cases.

Concerns regarding the use of mobile devices during physician-patient encounters were mainly voiced with respect to the safety of patient data (129/206, 62.6%), hygiene (80/206, 38.8%), and credibility of the provided content (67/206, 32.5%). For these three aspects, there were no differences between those already using mobile devices in the course of their work and those not (yet) using mobile devices for professional purposes. In contrast, the latter group worries more about the technical reliability of the devices than those already using them, and the significance between both groups is significant (P=.03). Only a few physicians were concerned about patients not having access to such technologies or being unfamiliar with it (17/206,8.2%). Too much time being required for familiarizing oneself with mobile technology or lack of interest were of little consequence for the use of mobile devices in a professional context (6/206, 2.9%).



Figure 1. Activities the mobile devices were used for by the participating physicians.



## **Patients' Survey**

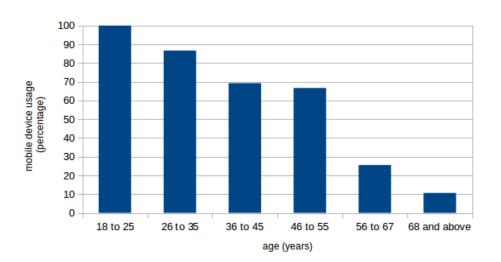
Over half of the participating patients (110/213, 51.6%) already use a smartphone and/or a tablet PC (mainly iPhones or Android devices, iPhone; 30/110, 27.3%; Android phones; 66/110, 60.0%). Availability and use of mobile devices presents itself differently within different age groups (Figure 2 shows this information).

Apart from the association between age and ownership/availability of a mobile device (P=.001), there is also a significant correlation between education and ownership of such a device (P=.002), also see Table 3.

Table 3. Ownership of a mobile device versus educational level.

School-leaving qualification	Absolute number of participants who own a mobile device	Percentage per school-leaving qualification, % (n)
Primary or lower secondary school	11	30 (11/37)
Intermediate secondary school	39	53 (39/73)
Upper secondary school	52	62 (52/84)
Not specified	23	

Figure 2. Availability/ownership of mobile devices within different age cohorts.



## Patients' Use of Mobile Devices

There were (53/110) 48.2% of patients who owned a mobile device, and provided any information about their health related

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usage of the device, that stated that they were using it for looking up health related information, and for managing their own health data. In this respect, chronically ill patients do not differ from those presenting with an acute condition. Main activities where

the devices are used in a health context are the search for information about symptoms and specific health conditions (43/53, 81%), or specific diagnostic methods as well as treatments (36/53, 68%), as well as looking up desired and adverse effects of specific medications, medical devices, and therapies (28/53, 53%). The devices are also often employed for searching for doctors (39/53, 74%) or pharmacies (37/53, 70%). Less often do those surveyed use their devices for communicating (via email, chat, etc) with their doctors (14/53, 26%), insurance companies (12/53, 23%), or other health care service providers (10/53, 19%).

When asked about what they would like to use a mobile device for, independent of whether they already own and use such a device or not, searching for doctors (106/213, 49.8%) and pharmacies (76/213, 35.7%), as well as looking up information about symptoms and specific health conditions are mentioned most often (82/213, 38.5%). Compared to the numbers above, communication with physicians gains importance (73/213, 34.3%). The use case patients mention least often is trying to establish a diagnosis on their own (18/203, 8.9%; Figure 3 shows this information).

Of those owning a smartphone or tablet PC, (43/110) 39.1% have one or more health related apps installed on their device. Specific apps mentioned by the participants include fitness apps (four apps), apps provided by insurers (one app), apps for obtaining the heart rate (two mentions), weight loss apps (one app), as well as vision tests (one app), and apps for specific pharmacies (five mentions). Looking at the apps mentioned by the participants, it becomes clear that the apps they mention are health apps rather than medical apps, if one follows the definition of health apps and medical apps taken from [19], where Albrecht et al recommend a differentiation between the terms "health app" and "medical app", based on the definitions of "health" given by the World Health Organization in 1946, where health is defined as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" [20]. Apps with a purpose that follow this definition of health can therefore be counted as "health apps", and this also includes fitness and wellness related apps, and the apps mentioned by our participants clearly fall into this category.

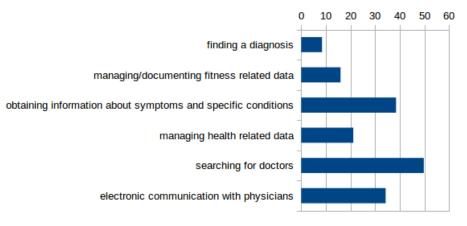
In contrast, although apps that deal with the prevention of diseases, injuries, or support diagnostics and treatment could also be covered by the term "health apps", they should more fittingly be labeled as "medical apps", such apps clearly touch on areas typically covered by health care professionals, and thus, assigning the label "medical app" seems more appropriate to underline their diagnostic and therapeutic aspects [19]. None of the apps mentioned by the patients participating in our survey meets this definition of a "medical app".

Apart from their own use behavior, we also asked whether they have any reservations about using the devices, and whether they are comfortable with doctors using mobile devices during patient-physician interactions. The majority tolerated communication related use during such interactions. There were (180/199) 90.5% (who answered this question) that consider it acceptable if doctors use the devices to illustrate something. Almost three quarters of the participants (155/197, 78.7% of those who answered this question) have no problem if doctors use a mobile device to inform themselves about their condition.

In the context of physicians using mobile devices while treating them, those surveyed were particularly worried about data protection. Roughly every fifth participant (45/202, 22.3%) did not want their doctors to save or process their individual health related data on a mobile device, whereas (145/202) 71.8% considered it acceptable.

This is also mirrored by answers given regarding general use of mobile devices in the context of health and illness. Again, data protection was the aspect about which the participants had the greatest reservations (113/213, 53.1%). They worried less about the technical reliability of the mobile devices (28/213, 13.1%) or susceptibility of the software (31/213, 14.6%). There were 11.7% (25/213) that were worried that the devices might be too complicated to use in a health context, most of these among those participants who did not yet own or have access to such devices (20/25).

Figure 3. Health related activities patients would like to perform with their mobile devices.





# Discussion

## **Principal Results**

The physicians who participated in the survey mirror the widespread use of mobile devices; in this group, four out five (168/206, 81.6%) own a smartphone or tablet PC. In contrast, only every second patient (110/213, 51.6%) in our survey uses such a device, although the usage rate is equally high in the younger age groups, and only tapers off with increasing age of the participants, and especially for pensioners. Altogether, although addressing mobile smart devices in a broader sense, our findings for both groups mirror those of [21], where age and gender were strong predictors of advanced smartphone use in Germany, but also other European countries as well. And while one may argue that at least age wise, our sample of patients may not quite be representative of the overall population in Germany (with younger persons being somewhat underrepresented), due to our method of recruitment, we believe the participants to at least be representative for the typical patient population that doctors at a maximum care facility such as Hannover Medical School have to deal with in Germany.

Mobile devices are rarely used during direct contact between doctors and patients; rather, patients as well as physicians use them for looking up health related information or information about specific conditions. Although about half of the patients do not yet use a mobile device, the majority of patients would not object to doctors using mobile devices. Most of the patients have no problem with physicians using mobile devices to inform themselves about the patients' condition, and about half of the physicians in our survey actually do so. Similarly, the vast majority of patients would have no objections to doctors using their device for patient education and providing or illustrating information, but in fact, less than 10% of physicians (20/206, 9.7%) use the devices for this purpose. Patients are more critical of doctors using their devices for storing and processing patient related data; every fifth patient has qualms about this, but approximately 5% of doctors (10/206, 4.8%) using a mobile device in the line of their work also use it for this purpose.

From our results, it is clear that the majority of patients do not have problems with doctors using mobile devices while caring for them. About one third of patients would like to be able to contact their doctors via electronic communication methods (email, chat, etc) using their smartphone or tablet PC. In view of the high rate of acceptance of mobile devices, the question arises whether the full potential of mobile technologies in physician-patient contacts, and the care process, is being realized. Problems with data protection and data security probably play an important role when it comes to explaining the slow progress in introducing mobile devices in this context. Both physicians as well as patients are worried about protection and security of sensitive patient data. Although one may suspect a seasonal effect on the answers, due to recent revelations about surveillance and cyber-espionage, data protection and privacy issues have always been on the political agenda.

Participants of both groups voiced only few concerns about the credibility of the content provided by the software or about the technical reliability of the devices (Figure 4 shows this information). There were only few doctors (17/206, 8.3%) who would refrain from using mobile devices during patient contact because they thought patients might be unfamiliar with or might not have access to such technology. All the same, 11.7% (25/213) of the surveyed patients expressed concerns that the use of smartphones and tablet PCs might be too complicated when it comes to health issues.

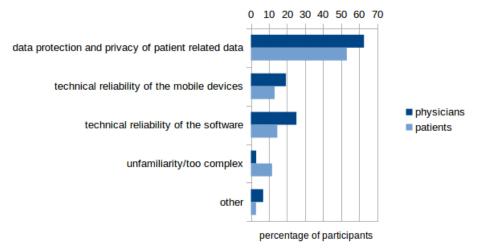
Our results support the claim that for patients, age and education play an important role in the use of mobile devices. They clearly show the digital divide that is so often mentioned in literature for older people, as well as educationally disadvantaged individuals [12,13]. Concerns about using mobile technologies in a medical context are often associated with whether patients are familiar with using mobile devices; those who own a mobile device clearly differ from those who do not have access to such a device. Still, another aspect also needs to be considered; access to and familiarity with computers with Internet access or mobile devices that also provide access to various (online) sources of information does not yet say anything about whether users can competently use this technology. Age, gender, and education are often mentioned as factors that contribute to either competent use or problems with such technologies, although this influence will probably lessen over time [12,13]. Considering the sociodemographic data available for the participating patients, it is clear that the majority of patients presenting at the central admissions point are of higher age, and there is also a considerable number of patients with lower and intermediate levels of education. Therefore, to fully realize the potential of mobile technologies in a health care context, one should include both the elderly as well as those who are educationally disadvantaged in all considerations, and implement measures to carefully introduce them to using these technologies in a safe manner.

For professional users, in spite of their prevalence, there has so far been little research supporting the use of mobile smart devices, a point also noted (albeit for emergency medicine) in [10]; available studies with similar aims regarding use of mobile devices by physicians are often either somewhat dated, at least considering the rapid developments in mobile technology [22-24], or they only consider a narrow angle [25,26].

Altogether, our findings, as well as the scarcity of literature on the matter, emphasize the need for further research into the use of mobile devices in medical settings, independent of which user group one considers, in order to fully realize the potentials mobile technologies can offer in medicine, while respecting users' needs, hopes, and concerns.



Figure 4. Concerns voiced by the participants about using mobile devices in a clinical setting.



#### Conclusions

In conclusion, to ensure successful integration of mobile technologies in health care, in addition to expanding research, providers of medical content should be urged to closely check the requirements for their digital products, to ensure that they can be used in a safe manner, and to adapt their products to the needs of the specific users groups they target. Our results suggest that the use of mobile devices during physician-patient contact will increase in the years ahead. Currently, only one out of five doctors consider it unlikely that he will use a mobile device for his work in the near future; for patients, usage rates will probably also increase as the younger generation, often called "digital natives", moves up. Still, even though future patients and doctors will be increasingly familiar with mobile technologies, it is of utmost importance to educate them about how to safely use it.

## Acknowledgments

We would like to thank the participating patients and physicians for their help. Special thanks also go to the students of the University of Applied Sciences of Hannover for conducting the patient survey at the central admissions point. The analysis was financed solely based on institutional funds of the Hannover Medical School. We acknowledge support by Deutsche Forschungsgemeinschaft for the publication costs.

## **Conflicts of Interest**

None declared.

## Multimedia Appendix 1

Relevant questions of the questionnaire used for the doctor's survey.

[PDF File (Adobe PDF File), 7KB - mhealth\_v2i4e42\_app1.pdf]

## **Multimedia Appendix 2**

Questionnaire used during the patient's survey.

[PDF File (Adobe PDF File), 9KB - mhealth\_v2i4e42\_app2.pdf]

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## Abbreviations

**apps:** application software **PC:** personal computer

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# **Original Paper**

# Nurses' Use of Mobile Devices to Access Information in Health Care Environments in Australia: A Survey of Undergraduate Students

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# Abstract

**Background:** The growth of digital technology has created challenges for safe and appropriate use of mobile or portable devices during work-integrated learning (WIL) in health care environments. Personal and professional use of technology has outpaced the development of policy or codes of practice for guiding its use at the workplace. There is a perceived risk that portable devices may distract from provision of patient or client care if used by health professionals or students during employment or WIL.

**Objective:** This study aimed to identify differences in behavior of undergraduate nurses in accessing information, using a portable or mobile device, when undertaking WIL compared to other non-work situations.

**Methods:** A validated online survey was administered to students while on placement in a range of health care settings in two Australian states.

**Results:** There were 84 respondents, with 56% (n=47) reporting access to a mobile or portable device. Differences in use of a mobile device away from, compared with during WIL, were observed for non-work related activities such as messaging (P<.001), social networking (P<.001), shopping on the Internet (P=.01), conducting personal business online (P=.01), and checking or sending non-work related texts or emails to co-workers (P=.04). Study-related activities were conducted more regularly away from the workplace and included accessing University sites for information (P=.03) and checking or sending study-related text messages or emails to friends or co-workers (P=.01). Students continued to access nursing, medical, professional development, and study-related information away from the workplace.

**Conclusions:** Undergraduate nurses limit their access to non-work or non-patient centered information while undertaking WIL. Work-related mobile learning is being undertaken, *in situ*, by the next generation of nurses who expect easy access to mobile or portable devices at the workplace, to ensure safe and competent care is delivered to their patients.

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## KEYWORDS

undergraduate nurse; mobile; work integrated learning



# Introduction

The rapid evolution of digital technology in health care environments has created new challenges for learning and teaching (L&T). While increasing access to mobile or portable devices has enabled opportunities for promoting learning at the workplace in real-time [1-3], there is the risk that portable devices may distract from patient or client care if used by health professionals or students during employment or work-integrated learning (WIL) [4-6]. Undergraduate nurses undertake one third of their course in a range of health care settings. Experiential learning provides students with the opportunity to link theory with practice and augments learning, in situ. Previous studies have indicated that access to mobile or portable devices at point of care, may be cause for concern regarding patient or client safety [4-8], professional identity [9,10], or workforce development opportunities [11,12]. However, there is little research regarding the frequency of use or the type of information accessed on mobile devices by undergraduate nurses during WIL.

The reported use, effectiveness, and impact of eHealth and mobile devices internationally is similar to the Australian situation. Systematic reviews demonstrate that evidence is required to guide clinicians and develop frameworks for use in clinical environments [13,14]. The Australian National E-Health Strategy identified that a health workforce skilled in information communication technology (ICT) was a key area for driving change that could transform health care delivery [15]. Furthermore, the Workforce Development Strategy [16] emphasized the need for more creative and effective use of ICT and the need to improve the digital literacy of health professionals. Studies have found that although health profession students report ubiquitous use of computers, it is not translated into ICT competency [17,18]. Inclusion of ICT literacy development in all undergraduate nursing programs is a requirement of the Australian Nursing and Midwifery Council [19]. National strategies and registered health profession bodies contend that educational preparation of student nurses in ICT literacy at an individual level is critical for ensuring competency that is reflected at a systems level in health care environments.

Gray and colleagues [20] reviewed the implementation and effectiveness of clinical informatics education for future health professionals and concluded that a more sophisticated and scholarly approach to further pedagogical enquiry into clinical informatics education was required. Lindley and Fernando [5] asserted that curriculum content and L&T approaches at a systems level needed to improve preparation of students for their future careers.

The second global survey on eHealth [21] identified a range of challenges that mobile technology posed at individual, organization and systems levels. Due to the complexity of the health sector, integrating mobile technologies into routine health care practice at point of care has been slow [21]. There is a range of factors that impact at an individual, organization, and systems level [22-24]. Environmental factors include institution and organization governance, policy and ICT architecture, or

infrastructure that prohibit or reduce access to mobile or portable devices at the workplace [7].

Previous studies have focused on the technology available rather than the learning afforded by its use [2]. Students can now engage and capture, in real-time moments they regard as significant for learning [25] which are then used to scaffold understanding or build knowledge [26,27]. Mobile learning (mLearning) in the workplace enables a student-centered approach whereby an effective and efficient response can be obtained as they arise [2]. Students can merge the nexus of theoretical learning, while developing skills to augment their learning by accessing web-based resources such as YouTube clips, text or images for medication management or nursing diagnosis information. Additionally, informal learning at point of care creates opportunity for patient-centered, participatory care that could improve health outcomes by enabling access to resources and individualized treatment plans [28,29]. Mobile learners have considerable control over their learning, they can share, store, re-purpose, and re-use objects and artifacts for use in discussion, reflection, or peer review later at a more suitable place or time [30,31]. While mLearning also offers opportunities to access expert advice or opinion on a global scale, there are challenges and risks associated with introducing L&T innovation into the workplace.

Perceived risks associated with using mobile devices in the workplace have been investigated. Potential distraction from patient care while using a mobile device in situ, is well documented [5-7,20,32]. However, the benefits of accessing L&T information by using mobile devices at the point of care have been less thoroughly researched. Mather and colleagues [33] found there were a number of human factors that reduced the capacity of clinical supervisors in effectively using mobile learning approaches during WIL. These include intrinsic and extrinsic motivations [34,35], social presence, peer disapproval [33], or infection control [36,37]. The need to further explore the limited implementation of mobile learning using mobile devices has emerged leading to this study. This paper reports on the results of an online survey administered to undergraduate nurses in a range of health care settings. The aims of the survey were: (1) to advance understanding of how mobile devices are used to access information at, and away, from the workplace; and (2) to determine differences in accessing information by students during WIL or away from the workplace.

# Methods

## **Study Design**

This cross-sectional study captured self-report of undergraduate nurses' access to Internet or device-based resources, using a mobile or portable device at, and away, from the workplace. The study involved administration of a survey to undergraduate nurses, while they were in clinical practice during January 2014, at a range of health care settings in two Australian states.

#### **Ethical Approval**

Minimum risk ethics for this research was approved by the University of Tasmania Human Research Ethics Committee,



approval number H0013729. Consent was implied by completion of the survey.

#### **Participant Recruitment**

Eligible participants were identified through consultation with lecturers from the University. All participants were undertaking WIL and were recruited via email. Two reminder request emails were sent at two week intervals following the initial request.

## **Data Collection**

Of the 22 survey items relating to utilization of mobile devices to access information, 15 were from a validated tool developed by McBride, LeVasseur and Li [6]. Professional experience placement (PEP) was the term used in the survey to describe WIL. 'Away from PEP' was defined as when the student was not undertaking placement as part of their studies and 'During PEP' meant the student was undertaking workplace learning or clinical placement hours in a health care setting as part of their study. Five-point Likert scale questions (Scale of 1-5: 1: Never, 2: Once per day, 3: 2-5 times per day, 4: >5 times per day, 5: Not applicable) were used to determine frequency of use when away from and while undertaking WIL.

## **Data Analysis**

The survey data were imported into IBM SPSS (Version 21) for analysis and frequencies were investigated. Chi-square tests were utilized to explore differences between those who had access to a mobile device and those who did not. Differences in responses to scales for 'Away from PEP' and 'During PEP' were explored using Wilcoxon signed ranks tests. All tests were two-sided and differences were accepted at P<.05 significance level.

# Results

## Participants

A total of 476 students undertaking WIL were offered the opportunity to participate in the online survey and 84 responded (18% response rate). There were 37 respondents (44%) who participated in WIL in New South Wales, and 38 (45%) in Tasmania. Of those respondents, 45 (54%) were in their first year of nursing study. Furthermore, 44 respondents (52%) undertook WIL at tertiary health care facilities and the remainders were dispersed at district hospitals or community-based facilities.

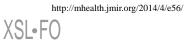
A filter question requiring access to a mobile or portable device (Do you have current access to a mobile technology device?) rendered 37 respondents ineligible to complete the second section of the questionnaire. Table 1 presents demographic information for all respondents and those who had access to a mobile device. No differences were found in access to mobile devices for gender ( $\chi 2_1 = 0.0, P = 1.0$ ), ethnicity ( $\chi 2_1 = 0.0, P = 1.0$ ) or geographic location ( $\chi 2_1=0.8, P=.4$ ). There were insufficient expected cell frequencies to establish associations for age group, level of education, and focus of health care organization. Additionally, there was no difference between the two groups when the categories were collapsed to investigate associations between access to a mobile device and type of WIL (tertiary or other health care) organizations. Final year students were more likely to have access to a mobile or portable device than first year students (n=23, 77% versus n=24, 53%,  $\chi 2_1$ =4.2, P=.04).



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Table 1. Demographic information of respondent access to a mobile or portable device.

		All respondents	Access to a portable or mobile device
Demographic descriptor		N=84 <sup>a</sup>	N=47 <sup>a</sup>
Gender			
	Male	19 (23%)	14 (30%)
	Female	56 (67%)	33 (70%)
	Missing; non respondents	9 (11%)	0 (0%)
A			
Age	-21	10 (120/)	4 (09/ )
	<21 21-30	10 (12%)	4 (9%)
		22 (26%)	13 (28%)
	31-40	20 (24%)	15(32%)
	41-50	13 (15%)	8 (17%)
	>51 Missing	10 (12%)	7 (15%)
	Missing	9 (11%)	0 (0%)
Language, other than En	glish spoken at home		
	Yes	24 (29%)	14 (30%)
	No	51 (61%)	33 (70%)
	Missing	9 (11%)	0 (0%)
Level of education prior			
	Secondary	20 (24%)	9 (19%)
	Vocational certificate	21 (25%)	15 (32%)
	Undergraduate degree	26 (31%)	18 (38%)
	Post graduate	8 (10%)	5 (11%)
	Missing	9 (11%)	0 (0%)
State where student unde	ertook WIL		
	NSW	37 (44%)	23 (49%)
	TAS	38 (45%)	24 (51%)
	Missing	9 (11%)	0 (0%)
Year of study			
	First year	45 (54%)	27 (57%)
	Final year	30 (36%)	20 (43%)
	Missing	9 (11%)	0 (0%)
Focus of care of health or	ganization		
- sous of care of hearth of	Major hospital	44 (52%)	31 (66%)
	District hospital	11 (13%)	5 (11%)
	Primary care	5 (6%)	2 (4%)
	RACF	3 (4%)	2 (4%)
	Multipurpose	2 (2%)	1 (2%)
	GP	3 (4%)	3 (6%)
	Mental health	4 (5%)	2 (4%)



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	All respondents	Access to a portable or mobile device
Demographic descriptor	$N=84^{a}$	N=47 <sup>a</sup>
Other	3 (4%)	1 (2%)
Missing	9 (11%)	0 (0%)
Access to portable or mobile device		
Yes	47 (56%)	
No	12 (14%)	
Missing	25 (30%)	

<sup>a</sup>May not equal 100% due to rounding

## **Use of Mobile Devices**

Differences in participant reports of behavior in accessing information away from and during WIL were found for several variables (Table 2). Activities were categorized into work, non-work, and study-related tasks. Work-related activities were patient-centered activities that occurred at point of care, or related to education or professional development. Non-work related activities involved communication and personal tasks that were not of the nature or scope required in the workplace.

## **Non-Work Related Activities**

Differences in access to information using a mobile or portable device away from or at the workplace, were reported for 6 out of the 7 items grouped in non-work related activities. Non-work related uses of portable devices were more frequent when students were away from the workplace. These included messaging (median 4 vs median 2, T=49.5, P<.001), social networking (median 4 vs median 1, T=48.5, P=.01), shopping on the Internet (median 2 vs median 1, T=17.5, P=.01), conducting personal business online (median 2 vs median 1, T=48.0, P=.01), and checking or sending non-work related texts or emails to co-workers (median 2 vs median 1, T=43.0, P=.04).

## **Study-Related Activities**

Study-related activities that were conducted more regularly away from the workplace included browsing on the Internet (median 4 vs median 3, T=16.5, P<.001), or accessing University sites for information (median 4 vs median 3, T=63.0, P=.01).

Checking or sending study-related text messages or emails to friends or co-workers also occurred (median 3 vs median 2, T=43, P=.01).

## Away From Work-Integrated Learning

There were no differences found away from or during WIL for accessing work-related activities such as accessing drug, nursing, and medical information or professional education and development resources. Students reported infrequently accessing study-related text or email messages from academic supervisors, or submitting assessment tasks using a mobile or portable device. Respondents also used a mobile or portable device as a clock or a stopwatch (median 4 vs median 2, T=61.5, P=.01) more regularly away from the workplace.

## **During Work-Integrated Learning**

Participants reported that during WIL they did not shop on the Internet; check or post on social networking sites; play online or games loaded on the device; conduct personal business online; or check/send personal text messages or emails to co-workers. Access to work-related protocols and mobile apps that assist with patient or client care were more likely (once per day) to be accessed during WIL.

## **Non-Access**

Respondents reported they did not access sites for patient handouts and teaching, communicating with other members of the health care team to coordinate patient or client care, or to play games.



Table 2. Utilization of portable or mobile devices during work integrated learning.

Use of portable or mobile devices to access information	Away from PEP Median, (Range)	During PEP Median, (Range)	P value
Work-related activities			
I access work-related drug references	3 (1-5)	3 (1-5)	.94
I use it to communicate with other members of the health care team to coordinate patient or client care	1 (1-5)	1 (1-5)	.94
I access work-related protocols	1 (1-5)	2 (1-5)	.90
I access work-related apps that assist patient or client care	1 (1-5)	2 (1-5)	.75
I access sites for patient handouts and teaching	1 (1-5)	1 (1-5)	.53
I use the device as a calculator for nursing/medical formulas	2 (1-5)	2 (1-5)	.52
I access sites for professional education and development	3 (1-5)	3 (1-5)	.23
I access work-related nursing/medical information	3 (1-5)	3 (1-5)	.21
Non-work related activities			
I check/send personal text messages or emails to family or friends	4 (1-5)	2 (1-5)	<.001
I check/post on social networking sites (Facebook, Twitter, Snapchat etc)	4 (1-5)	1 (1-5)	.01
I shop on the Internet	2, (1-5)	1 (1-5)	.01
I conduct personal business online (eg paying bills, banking)	2 (1-5)	1 (1-5)	.01
I play games loaded on the device <sup>a</sup>	1 (1-5)	1 (1-5)	.05
I check/send personal text messages or emails to co-workers	2 (1-5)	1 (1-5)	.04
I play online games	1 (1-5)	1 (1-5)	.84
Study-related activities			
I browse (eg use a search engine Google, Safari etc) for information to assist with			
progression of my studies <sup>a</sup>	4 (1-5)	3 (1-5)	<.001
I check/send study related text messages or emails to friends or co-workers	3 (1-5)	2 (1-5)	.01
I access University related sites (eg MyLO) to assist with progression of my			
studies <sup>a</sup>	4, (1-5)	3, (1-5)	.01
I check/send study related text messages or emails to my academic supervisors <sup>a</sup>	2, (1-5)	2, (1-5)	.26
I access study related sites (eg library, journal articles) to assist with progression of my studies <sup>a</sup>	3, (1-5)	2, (1-5)	.03
I submit assessment tasks <sup>a</sup>	2, (1-5)	2, (1-5)	.44
Other activity			
I use the device as a clock or stopwatch <sup>a</sup>	4, (1-5)	2, (1-5)	.01

<sup>a</sup>Non-validated question.

# Discussion

## **Principal Findings**

This study demonstrated differences in accessing the Internet or device-based resources using a mobile or portable device at, and away, from the workplace by undergraduate nurses. Undergraduate nurses reported there was a range of non-work related Internet-based activities they avoided during WIL. Predominantly these activities related to social networking with family or friends, shopping, or conducting personal business online. McBride, Le Vasseur, and Li [6] and others [4, 7,20,32] indicated that risks to patient or client safety could be attributed to individual level distraction at point of care. While distraction

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may occur while using a mobile or portable device during WIL [4,6], this study found it was unlikely due to student nurses' accessing non-work related sites.

The research indicates that through lack of access to mobile devices or resources there were lost opportunities to engage with patients or clients at point of care. Undergraduate nurses reported they never accessed patient handouts for teaching or communicating with other members of the health care team to coordinate patient care. At registration there is an expectation that students are work-ready [38,39]. There is an expectation that students will develop professional identity during their course and during their final year, during WIL, they will develop the knowledge, skills, attitudes, and behavior that demonstrate

competency for registration [10]. A key role for nurses is providing patients with health education, and with guidance, final year students may initiate and engage patients in improving their health literacy. A lack of access to web-based resources at point of care can hinder or undermine this development of professional identity [9,10]. Additionally, senior undergraduate students could be involved with coordination of patient care if they had the opportunity. Self-management education at point of care creates opportunity for shared understandings that can improve health outcomes of patients or clients by enabling access to resources and individualized treatment plans [28,34]. Modeling of professional behaviors required as a graduate nurse, including access to web-based self-management or health education resources, could promote work-readiness of students and minimize transition shock [38,39].

There was no demonstrated difference in behavior for accessing work-related drug references, nursing or medical information, and professional education and development. Undergraduate students continue to study when they are not at the workplace. The convenience of enabling access to mobile or portable devices *in situ* could promote habits that support continuing professional development and life-long learning which are requirements for continuing registration [40,41].

Differences were found in browsing for information, accessing study or University related sites, which predominantly occurred away from WIL. The convenience and ease of using a mobile device supported student-centered learning [2,41] away from and during WIL. Although no differences were found, mobile devices were used for contact with academic supervisors and submission of assessments. Access to mobile devices enables the activity of learning to be user-controlled [2]. The convenience and ease of learning in real-time at point of care challenges traditional pedagogy. Utilization of mobile devices to access a range of study information has implications for learning at systems, organizational and individual levels that need to be acknowledged and addressed through curriculum design and organizational policy. Addressing educational preparation in ICT competency and guidance in safe and appropriate use of mobile learning in the classroom, prior to undertaking WIL, could assist with the development of professional identity. Policy development to guide undergraduate students and health profession staff about effective and competent use of mobile devices in situ could also ameliorate the risk of distraction at point of care.

While away from the workplace students tend to use mobile or portable devices to monitor time. This behavior was less likely during WIL, suggesting that undergraduate students did not access their mobile device to conduct patient observations such as pulse or respiration assessments. Institution or organization policy that dissuades the use of mobile or portable devices during WIL may be a factor for regulating use [33]. Concerns about cross infection between patients could also prohibit the use of a mobile device for this intimate patient activity [36,37].

Respondents indicated that communicating with family, friends, co-workers, and study were more likely to be accessed than playing online games loaded on the device while away from or during WIL. Communication or maintenance of meaningful

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relationships may contribute to lack of interest in playing games using a mobile device. The predominance of females in the cohort may also have negatively skewed the result as females are less likely than males to game [42].

#### Limitations

This study had several limitations. The first included the low response rate. This may have occurred because although the survey was anonymous, it may have contributed to students feeling that if they did not respond appropriately there was a chance of disadvantage with their studies. Additionally, survey fatigue of students may also have contributed to a lower level of engagement with completion of the survey. Respondents were recruited from one university and may attend WIL at partner health care organizations that have guidelines impacting the conduct by students during WIL, which could reduce the generalizability of the findings. Of the questions asked, 7 relating to access to study options were not validated. In these cases the sentence construction was similar to the validated questions, however their actual reliability is unknown at this time. Finally, as this survey has been administered by staff at the teaching university there is the possibility of social desirability bias, the tendency to respond to questions in a known socially acceptable manner.

## **Future Directions**

Further examination of preferred mobile or portable devices used for L&T by undergraduate nurses is warranted. Review of higher education institutional and health care organization policy relating to mobile devices could reveal there is a need to change to allow students to prepare for their future profession in accessing learning objects or resources while they are undertaking WIL. Concurrently, there is a need to ensure ICT architecture and infrastructure at organizations supports L&T at the workplace. Curriculum design to incorporate appropriate and safe use of mobile devices is necessary to promote diffusion of this informal method of L&T into the workplace. Over time, responsible use of mobile devices to minimize risk could create a cultural shift that will enable safe use for L&T *in situ* at point of care.

#### Conclusions

Exploration of access to information using a mobile or portable device by undergraduate nurses away from and during WIL contributes to the discourse about the challenges of using these devices at systems, organizational, and individual levels. This study found that undergraduate nurses limited their access to non-work or non-patient-centered care while undertaking WIL. Furthermore, the risk of distraction was unlikely due to student nurses' accessing non-work related sites (4,6). The use of mobile devices for study purposes occurred during WIL, but was more frequent away from the workplace. This suggests students were focused on developing competency in patient care while in the workplace. Acceptance of access to mobile devices as a legitimate L&T tool during WIL is imperative. To support this aim there is a need to promote professional identity and facilitate L&T by including guidance for appropriate mobile learning behavior in the curriculum. The development of best practice guidelines or policy to minimize risk and enable improvement

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of health outcomes of patients at point of care is necessary. Undergraduate students are the next generation of nurses. This study showed they can discern appropriate mobile device use. Over time, nurses will expect easy access to mobile learning resources to enable them to deliver safe and effective health care to patients.

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## **Conflicts of Interest**

None declared.

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## Abbreviations

ICT: information communication technology L&T: learning and teaching mLearning: mobile learning WIL: work-integrated learning



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**Original Paper** 

# A Low-Intensity Mobile Health Intervention With and Without Health Counseling for Persons With Type 2 Diabetes, Part 1: Baseline and Short-Term Results From a Randomized Controlled Trial in the Norwegian Part of RENEWING HEALTH

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## **Related Article:**

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# Abstract

**Background:** Self-management support for people with type 2 diabetes is essential in diabetes care. Thus, mobile health technology with or without low-intensity theory-based health counseling could become an important tool for promoting self-management.

**Objectives:** The aim was to evaluate whether the introduction of technology-supported self-management using the Few Touch Application (FTA) diabetes diary with or without health counseling improved glycated hemoglobin (HbA<sub>1c</sub>) levels, self-management, behavioral change, and health-related quality of life, and to describe the sociodemographic, clinical, and lifestyle characteristics of the participants after 4 months.

**Methods:** A 3-armed randomized controlled trial was conducted in Norway during 2011-2013. In the 2 intervention groups, participants were given a mobile phone for 1 year, which provided access to the FTA diary, a self-help tool that recorded 5 elements: blood glucose, food habits, physical activity, personal goal setting, and a look-up system for diabetes information. One of the intervention groups was also offered theory-based health counseling with a specialist diabetes nurse by telephone for 4 months from baseline. Both intervention groups and the control group were provided usual care according to the national guidelines. Adults with type 2 diabetes and HbA<sub>1c</sub>  $\geq$ 7.1% were included (N=151). There were 3 assessment points: baseline, 4 months, and 1 year. We report the short-term findings after 4 months. HbA<sub>1c</sub> was the primary outcome and the secondary outcomes were self-management (Health Education Impact Questionnaire, heiQ), behavioral change (diet and physical activity), and health-related

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quality of life (SF-36 questionnaire). The data were analyzed using univariate methods (ANOVA), multivariate linear, and logistic regression.

**Results:** Data were analyzed from 124 individuals (attrition rate was 18%). The groups were well balanced at baseline. There were no differences in HbA<sub>1c</sub> between groups after 4 months, but there was a decline in all groups. There were changes in self-management measured using the health service navigation item in the heiQ, with improvements in the FTA group compared to the control group (P=.01) and in the FTA with health counseling group compared with both other groups (P=.04). This may indicate an improvement in the ability of patients to communicate health needs to their health care providers. Furthermore, the FTA group reported higher scores for skill and technique acquisition at relieving symptoms compared to the control group (P=.02). There were no significant changes in any of the domains of the SF-36.

**Conclusions:** The primary outcome,  $HbA_{1c}$ , did not differ between groups after 4 months. Both of the intervention groups had significantly better scores than the control group for health service navigation and the FTA group also exhibited improved skill and technique acquisition.

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#### **KEYWORDS**

self-care; quality of life; diabetes mellitus, type 2; randomized controlled trials; telemedicine; mHealth; mobile apps; counseling; complex intervention; life style

## Introduction

People with type 2 diabetes have an increased risk of cardiovascular morbidity and mortality, but the multifactorial risk can be reduced by changes in diet, exercise, and education often combined with antihypertensives, statins, and oral glucose-lowering agents or insulin-lowering drugs [1-3]. However, type 2 diabetes is a complex disease for the individual and clinicians [4]. Furthermore, severe comorbidity may decrease the capacity for self-management and patients with a macrovascular comorbidity, such as heart failure, or other diseases not related to the diabetes (eg, depression and chronic pain) may place a lower priority on their diabetes treatment [5]. Moreover, the co-occurrence of multiple diseases is associated with obesity [6] and weight loss through behavioral change may be an essential part of the treatment [7], although findings regarding the benefits of weight loss are inconclusive [8,9].

Intensive long-term interventions related to lifestyle and obesity in patients with type 2 diabetes have achieved some effects on weight loss and improved glycemic control, but these were not enduring [10]. The treatment is also more complex when type 2 diabetes is of longer duration. Due to costly treatment, it may become necessary to differentiate between those in need of a low- or high-intensity intervention, thereby offering the patients the lowest level of effective management [11] and reducing the costs. This approach is in accordance with the Norwegian Coordination Reform, which aims to transfer treatment services from hospitals to local centers in the municipalities [12]. At present, most patients with chronic diseases are treated in primary care where they are educated to improve their self-management, which is an important activity for the successful attainment of personal health goals, and to communicate with health professionals [13]. Furthermore, the development of self-management support is recommended by international guidelines because it has also been shown to have an effect on glycemic control [14,15].

Computer-based solutions may support self-management in everyday life and research shows that mobile health tools in particular may improve glycemic control, although the findings are inconclusive [16-18]. Furthermore, few telemedicine studies have detected effects on cognitive, behavioral, or emotional outcomes [17], and few studies have measured self-management using appropriate questionnaires. Some interventions combine self-monitoring with professional support, which is based primarily on the monitoring of results by health care providers, with subsequent counseling and advice [18-22]. More research is needed in this area to determine the effects on both clinical outcomes and self-management, and to assess the benefit of providing health counseling to support patients in the implementation and maintenance of the necessary behaviors required to manage their diabetes [15].

The European Union collaborative project REgioNs of Europe WorkING together for HEALTH (RENEWING HEALTH) was set up to evaluate innovative telemedicine tools on a large scale using a specially designed framework, the Model for the Assessment of Telemedicine (MAST) [23]. The present study is from the Norwegian part of the RENEWING HEALTH network. Results from the 4-month intensified part of a 1-year intervention are presented in the present paper.

The primary aim of this paper was to assess whether the use of a mobile health self-management intervention, the Few Touch Application (FTA) diabetes diary [24], with and without a theory-based health counseling intervention, was superior to usual care in terms of glycated hemoglobin  $A_{1c}$  (Hb $A_{1c}$ ) levels, self-management, behavioral change (diet and physical activity), and health-related quality of life after 4 months. Further, the secondary aim was to describe sociodemographic, clinical, and lifestyle characteristics of persons volunteering to participate in such a lifestyle intervention.

## Methods

#### **Study Design**

This study was a block randomized controlled trial (RCT) [25] with 3 parallel groups: 1 control group and 2 intervention groups using the FTA diary during the 1-year study in which 1 of the

2 groups received a strengthened intervention with health counseling. The groups are described in detail in the study protocol [26]. We had a longitudinal design with 3 assessment points: baseline, after 4 months, and after 1-year follow-up. Further, the patients' registrations in the FTA diary were recorded continuously and transferred securely to a server for research purposes.

## **Participants**

We used broad eligibility criteria: age  $\geq 18$  years, diagnosed with type 2 diabetes a minimum of 3 months before inclusion, HbA<sub>1c</sub>  $\geq$ 7.1%, able to use the FTA system, and capable of understanding and completing the questionnaires. The exclusion criteria were mental or physical conditions that interfered with the protocol [26]. HbA<sub>1c</sub> measurements needed to be available to the researchers within a 1-month window (ie, 2 weeks before or after randomization) to control the eligibility criteria [27]. Participants were recruited to the study by several routes. Firstly, through general practitioners who accepted an invitation by letter after being supplied with standard information about the protocol. Secondly, at educational "diabetes start courses" which were arranged by the health care specialist for patients newly diagnosed with diabetes, and from local public health clinics in the municipalities. Finally, a few participants were recruited through media advertising. People who stated their willingness to participate were given a letter that contained a brief summary of the study and an invitation to obtain more in-depth information at start-up group meetings arranged by the research team, each of which included a maximum of 10 participants. The participants were also allowed one-to-one meetings if group meetings were not feasible for practical reasons. The participants were randomized after they signed the informed consent form.

## **Study Setting and Data Collection**

Participants were from the Northern and Southeastern part of Norway because the project originated from research teams in these regions and the inclusion of participants was conducted in local start-up group meetings in the regions.

The recruitment period lasted from March 2011 to October 2012. The measurement points were at baseline, after 4 months, and after 1 year. The short-term follow-up was performed between August 2011 and January 2013.

After 4 months, all the participants were invited to attend the first follow-up meeting to complete the questionnaires. They were also asked to visit their general practitioner for measurement of their HbA<sub>1c</sub> levels and collection of data from their medical records. Preferably, the general practitioners completed the patients' case record form at the same time as the questionnaires ( $\pm 14$  days) and returned them to the researchers in a prepaid addressed envelope. Participants who could not attend the follow-up meeting were sent the questionnaires by mail to their postal address with a prepaid addressed envelope to return them to the study center.

#### Randomization

We used a computer-generated block randomization system, which was developed and administered by the Unit of Applied Clinical Research, Institute of Cancer Research and Molecular

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Medicine, Norwegian University of Science and Technology, Trondheim, Norway, to ensure a good balance between the numbers and confounding factors in each of the 3 groups. The blocks were small and their sizes varied. The procedure is described in detail elsewhere [26].

## Power

Power analyses were performed before recruitment to estimate the sample size required based on the HbA<sub>1c</sub> level as the primary outcome. The sample size was estimated to be 34 individuals in each group with a decrease in the HbA<sub>1c</sub> level of 0.35%, a significance level of 5%, a standard deviation (SD) in the outcome variable of 0.5, statistical power of 80%, and a 2-tailed significance test. To compensate for dropouts, the sample size was set to 50 in both intervention groups and 50 in the control group (total=150).

#### **Control Group**

The control group received usual care according to the Norwegian clinical guidelines [28]; patients with type 2 diabetes are recommended to consult their general practitioner every 2-6 months and to have a more thorough consultation once a year with measurements of their blood pressure, serum lipids, glucose, HbA<sub>1c</sub>, weight, body mass index (BMI), etc. The treatment target for HbA<sub>1c</sub> in Norway is  $\leq$ 7.0% [28].

## Intervention

In addition to the usual care provided by their general practitioners, the participants randomized to the intervention arms received either the FTA diary only or the FTA diary and health counseling, which are described subsequently and in more detail in the published protocol [26].

#### **Few Touch Application Intervention**

Both intervention groups were given a smartphone with the FTA diary for type 2 diabetes system installed. The participants were generally not able to use the app on their own smartphone because it required a specific phone model to operate properly. They were encouraged to replace their current mobile phone with the smartphone provided for the study and use it in everyday life as an ordinary mobile phone and as a diabetes diary. The smartphone provided was a HTC HD Mini based on the Windows Mobile 6.5 operating system, and the blood glucose meter was the OneTouch Ultra Easy from LifeScan. The phone and the blood glucose meter were linked using Bluetooth wireless communication so that glucose measurements were automatically transferred to the diabetes diary part of the FTA on the phone. The FTA and smartphone intervention lasted for 1 year. The FTA is a self-management tool that comprises 5 main elements accessible to the user: (1) the blood glucose data management system, (2) food habits data management system, (3) physical activity data management system, (4) personal goal-setting system, and (5) general diabetes information look-up system [24]. The blood glucose results were transferred directly from the blood glucose monitoring system to the app via Bluetooth. The diet and physical activity systems enabled an easy way of entering such data manually into the diabetes diary by the user.

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# Few Touch Application With Health Counseling Intervention

In addition to the FTA intervention described previously, the participants in this group were offered health counseling with a diabetes specialist nurse for 4 months from baseline. The health counseling was based on motivational interviewing [29], the transtheoretical model [30], and a problem-solving model [11]. The nurse also supported the participants in their use of the FTA, specifically the various elements of the tool and how to take advantage of the app. The participants received 5 telephone calls from the nurse during the first 4 months, each of which lasted for an average of 20 minutes. A schedule for each conversation was developed before the study by an interdisciplinary research team [26]. In addition, the participants could contact the diabetes specialist nurse via a secured text messaging system using their smartphones when necessary [31]. The nurse responded to the messages at least twice each week. The monitoring of the sessions showed that 38 of 50 participants (76%) completed the whole program (all 5 modules), whereas 12 participants conducted 4 modules or less. Of these, 4 participants completed 4 of 5 health counseling sessions, 2 completed 3 of 5 sessions, 4 completed 2 of 5 sessions, and 2 completed 1 of 5 sessions.

#### Training

Both the FTA group and the FTA with health counseling group were trained to use the mobile phone-based system at the start-up meetings, which included a demonstration of the diabetes diary [26]. They were also provided with a manual that contained instructions on the use of the smartphone, whereas the instructions for the FTA were supplied in the form of a paper-based handbook and on a universal serial bus (USB) memory stick. In addition, the consent form informed the participants about the diary and its specific procedures. A telephone support service was available to answer questions and to help the participants with technical aspects during weekdays from 9:00 to 15:00. The participants in the FTA with health counseling group were given additional training about how to send and receive secure messages to the diabetes specialist nurse.

### Measures

We used a broad evaluation based on a complex intervention framework [32] and MAST [23]. The Consolidated Standards of Reporting Trials (CONSORT) statement for reporting of RCTs [33], CONSORT for pragmatic trials [25], and the eHealth checklist [34] were used. The primary and secondary outcomes are described in Table 1, as well as the time points for the assessments. RENEWING HEALTH established a common minimum dataset of sociodemographic and clinical characteristics for all regions in the project (Table 1). Depressive symptoms were defined based on a total Center for Epidemiologic Studies Depression Scale (CES-D) score ≥16 [35]. Behavior change was measured with diet [36,37] and physical activity [38,39] questionnaires, and with the Health Education Impact Questionnaire (heiQ) [13]. Participants who reported a minimum of 60 minutes per week of moderate to vigorous activity were categorized as physically active. Detailed descriptions of the measures and the national and international validations of the measures are given in the published protocol [26]. The Diabetes Empowerment Short-Form scale [40] (described in the protocol) demonstrated a ceiling effect; thus, the data collected using this scale were not analyzed.



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Table 1. Data collected at baseline and after 4- and 12-month follow-ups.

Measurements	Baseline	After 4 months	After 12 months
Sociodemographic variables			
Demographics, marital status, education, work situation <sup>c</sup>	Х		
Clinical characteristics			
Related to disease, self-monitoring blood glucose, late complications (foot ulcer, eye)	Х		
Comorbidity <sup>c</sup> (EU minimum dataset)	Х		
Smoking and alcohol habits <sup>c</sup>	Х		Х
Self-reported questionnaires			
Health-related quality of life (SF-36) version 2.0 [41] <sup>b,c</sup>	Х	Х	Х
Depression (CES-D) [35]	Х	Х	Х
Self-management (heiQ) [13] <sup>b</sup>	Х	Х	Х
Physical activity (from HUNT) [38] and motivation (transtheoretical model) [39] <sup>b</sup>	Х	Х	Х
Diet [36,37] <sup>b</sup>	Х	Х	Х
System Usability Scale [42] <sup>d</sup>		Х	
Service user technology acceptability (SUTAQ) <sup>c,d</sup>			Х
Participation in other courses/programs during the study <sup>e</sup>			Х
In-depth interviews			
Participants' perceptions of the intervention <sup>d</sup>			Х
From general practitioners' medical records			
Diabetes medication	Х		
Change in medication		Х	Х
Medication in general			Х
Height <sup>c</sup>	Х		
Weight, blood pressure, and waist circumference <sup>c</sup>	Х		Х
HbA <sub>1c</sub> <sup>a</sup>	Х	Х	Х
Lipids	Х		Х
Hypoglycemic events	Х	Х	Х
Cardiovascular complications	Х		
Use of health care, expenses <sup>c</sup>		Х	Х
General practitioners classification of diseases			Х
Mobile user log			
Log data from FTA <sup>d</sup>	Х	Х	Х

<sup>a</sup> Primary outcome.

<sup>b</sup> Secondary outcome.

<sup>c</sup> EU minimum dataset.

 $^{\rm d}$  Only the groups receiving a mobile phone (FTA and FTA with health counseling).

<sup>e</sup> Such as swimming, cooking, weight reduction.

### **Blood Samples and Clinical Data**

Information about the  $HbA_{1c}$  level, weight, height, blood pressure, and medication were obtained from the medical records

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7.1% of total cases). The blood pressure was measured according to the standardized instructions (ie, the clinicians used the correct cuff size and the patient was sitting for a 5-minute rest before 3 measurements were obtained with 1-minute intervals) and the mean of the last 2 measurements was recorded. The waist circumference was measured at the umbilical level.

# Blinding

Blinding of participants was not possible because the participants were aware of their group allocations. The general practitioners were not blinded because the participants were encouraged to discuss the progression of their glucose measurements, diet records, and activity logs with them. The assessment of the participants' eligibility according to the inclusion criteria and the smartphone use training were performed by the research team. The researchers were part of the project team; thus, they also knew the groups to which the participants were allocated as did the technical support team.

### **Statistical Analysis**

The baseline sociodemographic, clinical, treatment variables, and lifestyle characteristics were expressed as counts with percentages for categorical variables or means and SDs for continuous variables. The differences in mean change from baseline to 4-month follow-up between the groups were analyzed using 1-way analyses of variance (ANOVA) for both the primary outcome (HbA<sub>1c</sub>) and the secondary outcomes (heiQ and SF-36). Further, change in both primary (HbA<sub>1c</sub>) and secondary outcomes (heiQ and SF-36) were modeled with univariate linear regression models. To correct for possible confounding effects, we adjusted for age, gender, education, comorbidity, work situation, BMI, depression, and regions from different parts of Norway using multiple linear regression. For baseline measurements, all 3 groups were compared using the Kruskal-Wallis test.

Data that were not available were considered missing and the results were based on the intention-to-treat approach. The trend in the use of the app was described with number of glucose measurements and other keystrokes in the app. *P* values <.05 were considered statistically significant. All tests were 2-sided. The analyses were performed using SPSS version 21 (IBM Corp, Armonk, NY, USA).

### **Ethics and Safety**

The study was approved by the Regional Committee for Medical and Health Research Ethics. All participants gave their written informed consent before study start. The ethical guidelines and rules were followed with the intention to do well and prevent harm or risks.

The participants' entries in the FTA diabetes diary app were recorded continuously and transferred to a secure server at 1 of the study sites (Tromsø). A comprehensive risk analysis of the technology was performed before the start of the study to ensure that privacy and security issues were addressed in an appropriate manner and the data were kept at the responsible research institutions [26]. Through the informed consent form, participants were made aware of the possibility of hypoglycemia related to behavioral change and they were informed to contact their general practitioner according to their instructions.

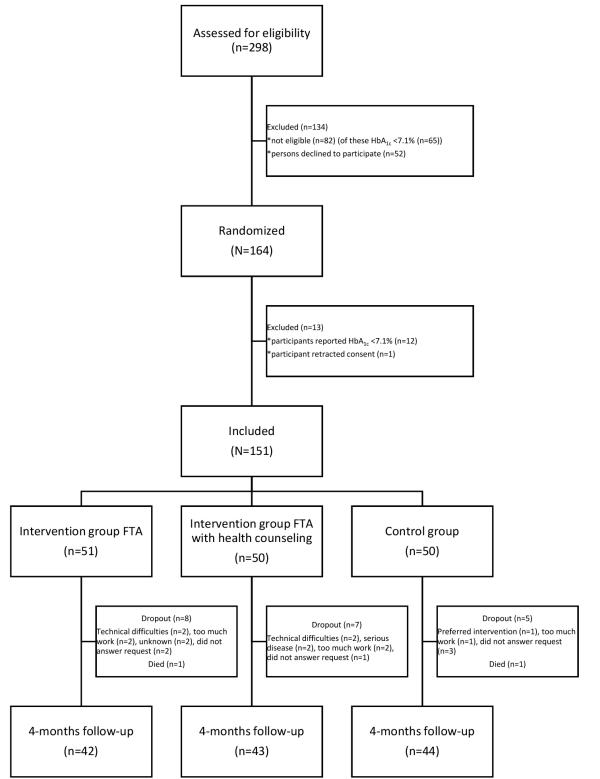
# Results

# Overview

In total, 298 individuals were assessed for eligibility (Figure 1), 65 of which were excluded because of HbA<sub>1c</sub> levels <7.1%, 17 were not eligible due to other reasons, and 52 declined to participate. In total, 164 participants were randomized of which 151 were included in the study because 12 participants had HbA<sub>1c</sub> <7.1% at the time of inclusion and 1 retracted consent.



Figure 1. Flow diagram showing the design of the study.



### **Baseline Characteristics of the Groups**

There were no statistically significant differences between the groups in terms of the baseline variables, except for rheumatism and depressive symptoms (Table 2). Significantly more participants in the FTA group had rheumatism compared with both of the other groups (n=11, 4, and 3 in the FTA, FTA with health counseling, and control groups, respectively, P=.03). More individuals had depressive symptoms (a CES-D score

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 $\geq$ 16) in the control group (n=17) compared with the FTA group (n=10) and the FTA with health counseling group (n=7, *P*=.045).

Of the 151 participants, the mean age was 57 years (SD 12), 62 (41.1%) of participants were women, and 83 (55.0%) had less than 12 years of education. The mean HbA<sub>1c</sub> was 8.2% (SD 1.1) or 66 mmol/mol (SD 12), the mean BMI was 31.7 kg/m<sup>2</sup> (SD 6.0), and 58.1% (75/129) were obese [43]. Only 9 of 131 participants (6.9%) did not receive glucose-lowering medication.

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In total, almost half of the participants (72/151, 48%) reported disease. 2 or more comorbidities and 36 of 151 (23.8%) reported heart



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 Table 2. Baseline characteristics of the control group and the 2 intervention groups.

Variables	Intervention group	ps	Control group
			(n=50)
	FTA	FTA with health counseling	
	(n=51)	(n=50)	
Sociodemographic characteristics			
Age (years), mean (SD)	58.6 (11.8)	57.4 (12.1)	55.9 (12.2)
Gender (female), n (%)	17 (33)	25 (50)	20 (40)
Educational background <12 years, n (%)	26 (51)	26 (52)	31 (62)
Clinical characteristics			
HbA 1c (%), mean (SD)	8.1 (1.1)	8.2 (1.1)	8.3 (1.2)
HbA <sub>1c</sub> (%),median (range)	7.8 (7.1-12.4)	7.9 (7.1-11.3)	7.9 (7.1-11.6)
HbA <sub>1c</sub> (mmol/mol), mean (SD)	65 (12.1)	66 (12.2)	67 (12.7)
Comorbidity (≥2), n (%)	28 (55)	22 (44)	22 (44)
BMI (kg/m <sup>2</sup> ), mean (SD)	32.4 (6.5)	30.7 (5.6)	32.0 (6.0)
BMI range, n (%)	5(0.0)	(0.0)	()
Normal (18.50-24.99)	2 (4)	7 (16)	4 (10)
Preobese (25.00-29.99)	17 (38)	13 (30)	11 (28)
Obese class I (30.00-34.99)	13 (29)	14 (32)	15 (38)
Obese class II (35.00-39.99)	8 (18)	6 (14)	6 (15)
Obese class III (≥40)	5 (11)	4 (9)	4 (10)
Missing data, n	6	6	10
Weight (kg), mean (SD)	98 (23)	91 (20)	96 (25)
Missing data, n	6	4	9
Height (cm), mean, (SD)	173 (10)	171 (10)	172 (11)
Missing data, n	6	6	10
Blood pressure (mm Hg), mean (SD)			
Systolic	136 (16.9)	132 (13.7)	134 (14.5)
Diastolic	81 (8.2)	79 (8.6)	82 (9.4)
Missing data, n	8	7	16
Duration of diabetes (years), mean (SD)	11.2 (7.3)	9.6 (8.4)	9.4 (5.5)
Missing data, n	3	5	5
Ireatment variables			
Glucose-lowering medication, n (%)			
No medication	3 (7)	2 (4)	4 (11)
Only oral agents	20 (44)	27 (57)	16 (42)
Only injections	9 (20)	7 (15)	3 (8)
Combination oral/injections	14 (30)	11 (23)	15 (40)
Missing data, n	5	3	13
Self-monitoring blood glucose, n (%)	48 (94)	45 (90)	49 (98)
Lifestyle characteristics			
Smoking (yes), n (%) Physical activity, n (%)	5 (10)	12 (24)	7 (14)

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Variables	Intervention g	roups	Control group (n=50)
	FTA (n=51)	FTA with health counseling (n=50)	
Little or not engaged in physical activity	31 (63)	34 (68)	33 (66)
Some to very engaged in physical activity	18 (37)	16 (32)	17 (34)
Missing data, n	2	0	0

#### **Characteristics in Responders Versus Nonresponders**

When comparing distribution of variables at baseline and at 4 months in responders versus nonresponders, there were no

significant differences between the groups. Hence, our analyses of dropouts vs nondropouts indicated that attrition did not change the distribution between the groups at baseline (Table 3).

 Table 3. Differences between responders and nonresponders at 4 months.

	Responders at 4 months	Nonresponders <sup>a</sup> at 4 months	
Variables	(n=118)	(n=33)	Р
Age (years), mean (SD)	57.9 (10.7)	55.3 (15.9)	.52 <sup>b</sup>
Gender (female), n (%)	47 (39.8)	15 (46)	.56 <sup>c</sup>
Education <12 years, n (%)	68 (57.6)	15 (46)	.21 <sup>c</sup>
HbA <sub>1c</sub> (%), mean (SD)	8.2 (1.1)	8.2 (1.1)	.74 <sup>b</sup>
BMI (kg/m <sup>2</sup> ), mean (SD)	31 (6.0)	34 (5.9)	.09 <sup>b</sup>
Missing data (BMI), n	7	15	
Comorbidities ≥2, n (%)	58 (49.2)	14 (42)	.49 <sup>c</sup>
Diabetes duration (years), mean (SD)	10 (7.0)	9 (7.8)	.20 <sup>b</sup>
Missing data (diabetes duration), n	9	4	

 $^{a}$  Nonresponders (those without HbA $_{1c}$  at 4 months).

<sup>b</sup> Between-group differences tested with Mann-Whitney test.

<sup>c</sup> Between-group differences tested with chi-square test.

#### **Primary Outcomes and Estimations**

In total, 118/151 (78.2%) participants provided  $HbA_{1c}$  data at 4 months. There were no statistically significant differences in  $HbA_{1c}$  level changes from baseline between the 3 groups (*P*=.65)

after 4 months (Table 4). Adjustments for age, gender, and education did not affect the estimates.

The mean HbA<sub>1c</sub> level declined in all groups: -0.41 (95% CI -0.71 to -0.11) in the FTA with health counseling group, -0.23 (95% CI -0.47 to 0.01) in the FTA group, and -0.39 (95% CI -0.75 to -0.03) in the control group.

Table 4.	Changes in	HbA <sub>1c</sub>	between	baseline and	4 months.
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Groups	Base	Baseline		nths	Mear	Mean change	
Intervention	n	Mean (95% CI)	n	Mean (95% CI)	n	Mean (95% CI)	
FTA	51	8.1 (7.8, 8.4)	40	7.8 (7.5, 8.0)	40	-0.23 (-0.47, 0.01)	
FTA with health counsel- ing	50	8.2 (7.9, 8.5)	39	7.8 (7.4, 8.2)	39	-0.41 (-0.71, -0.11)	
Control	50	8.3 (8.0, 8.6)	39	8.0 (7.6, 8.4)	39	-0.39 (-0.75, -0.03)	

### **Secondary Outcomes**

We obtained data from 124/151 (82.1%) participants who provided self-reported data at 4 months. We found that there was significantly improved self-management between baseline

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XSL•FO RenderX and 4-month follow-up with respect to 2 heiQ domains for at least 1 intervention group compared to the control group (Table 5). The participants in the FTA group reported significantly higher scores than the control group (P=.01) for health service

navigation indicating an improved ability to discuss their health needs with their provider. Moreover, the FTA with health counseling group reported significantly higher scores than both the control group and the FTA group (P=.04) also after the scores were adjusted for age, gender, and education level to account for possible confounders (Table 6).

For the skill and technique acquisition domain, which indicates that the participants possess the skills and techniques required to relieve symptoms and manage health challenges, the FTA group reported significantly higher scores than the control group (P=.02) after adjusting for age, gender, and education level in the linear regression analyses. However, there were no differences between the FTA with health counseling group and the other 2 groups (P=.11). The difference between the FTA group and the control group was also found after adjusting for age, gender, and education level.

We fitted linear regression models for the health service navigation domain and the skill and technique acquisition domain and the following explanatory variables: duration of diabetes, comorbidity, work situation, BMI, depression, and regions from different parts of Norway. None of these explanatory variables were statistically significant.

There were no statistically significant differences in the changes between baseline and 4-month follow-up for health-related quality of life (SF-36) within or between the 3 groups or for changes in diet and physical activity (results not shown).

The trend in the use of the app was not particularly different between the 2 intervention groups regarding either the number of blood glucose measurements (Figure 2) or number of keystrokes (Figure 3). The degree of use was lowest during the first month; it increased slightly during the second month and remained at about the same level during the third and fourth months.

Domain and group	Base	Baseline		4 months		Mean change	
	n	Mean (95% CI)	n	Mean (95% CI)	n	Mean (95% CI)	
Skills and technique acquisition			,				
FTA	51	2.95 (2.82, 3.07)	40	2.98 (2.81, 3.15)	40	0.02 (-0.12, 0.16)	
FTA with health counseling	50	2.87 (2.75, 2.99)	41	3.04 (2.90, 3.19)	41	0.17 (0.04, 0.29)	
Control	50	2.92 (2.83, 3.02)	43	2.92 (2.76, 3.07)	43	-0.04 (-0.18, 0.09)	
Health service navigation							
FTA	51	3.14 (3.00, 3.28)	40	3.21 (3.04, 3.37)	40	0.02 (-0.10, 0.14)	
FTA with health counseling	50	3.08 (2.95, 3.20)	41	3.27 (3.11, 3.42)	41	0.22 (0.07, 0.37)	
Control	50	3.13 (2.98, 3.27)	43	3.20 (3.05, 3.35)	43	0.00 (-0.11, 0.12)	

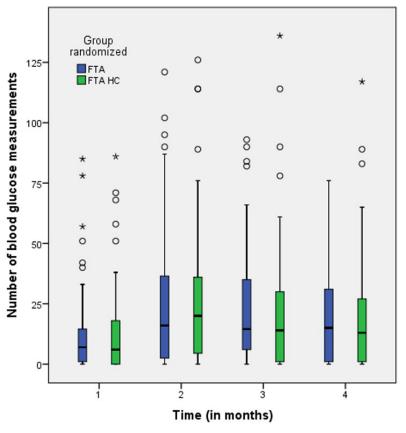
 $\label{eq:table_formula} \textbf{Table 6.}\ Linear\ regression\ analysis\ with\ crude\ and\ adjusted\ values\ for\ HbA_{1c}\ and\ heiQ\ domains\ from\ baseline\ to\ 4-month\ follow-up.$ 

Group	n	Unadjusted		Adjusted <sup>a</sup>	
		Estimated $\beta$ (95% CI)	Р	Estimated $\beta$ (95% CI)	Р
HbA 1c					
FTA	40	.02 (40, .44)	.91	.03 (40, .46)	.90
FTA with health counseling	39	.18 (24, .60)	.40	.16 (27, .58)	.47
Control (ref)	39				
heiQ domains					
Skills and technique acquisition					
FTA	40	-0.21 (-0.39, -0.03)	.02	-0.22 (-0.40, -0.03)	.02
FTA with health counseling	41	-0.14 (-0.33, 0.04)	.13	-0.15 (-0.34, 0.03)	.11
Control (ref)	43				
Health service navigation					
FTA	40	-0.21 (-0.39, -0.04)	.02	-0.23 (-0.41, -0.05)	.01
FTA with health counseling	41	-0.20 (-0.38, -0.02)	.03	-0.19 (-0.37, -0.01)	.04
Control (ref)	43				

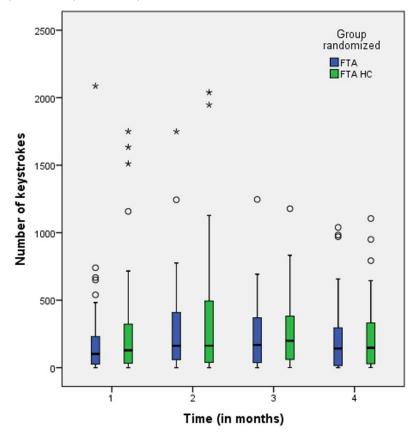
<sup>a</sup> Adjusted for age, gender, and education.

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**Figure 2.** Number of blood glucose measurements during the first 4 months for the 2 intervention groups: Few Touch Application (FTA) and FTA with health counseling (HC). Time 1 (baseline): n=90; time 2: n=83; time 3: n=80; and time 4: n=79.



**Figure 3.** Number of keystrokes during the first 4 months for the 2 intervention groups: Few Touch Application (FTA) and FTA with health counseling (HC). Time 1 (baseline): n=90; time 2: n=83; time 3: n=80; and time 4: n=79.





#### **Adverse Events**

No adverse events or important unintended effects were reported. Two persons died during the study, but these events were not related to the intervention or the study overall.

# Discussion

We found no significant changes between groups for the primary outcome measure HbA1c, although there were declines in the control group and in the intervention groups from baseline to 4-month follow-up. However, to the best of our knowledge, this is the first study to describe an effect of an electronic diabetes diary (FTA) in persons with type 2 diabetes in terms of their self-management and confidence in their capacity for health service navigation which may indicate an improved understanding of how to access health care to meet their needs. In addition, we found that the participants developed skills and technique acquisition, indicating that they improved their skills in relieving symptoms and gaining better health (according to heiQ) [13]. The FTA with or without health counseling from the diabetes specialist nurse appears to be a supporting tool that improved perceived self-management and it may have mitigated the burden caused by the illness.

The reasons for the lack of effect on the primary outcome of  $HbA_{1c}$  between groups are not clear, but several explanations are possible.

First, the HbA<sub>1c</sub> level declined in all groups, thus the FTA intervention with or without health counseling may not be sufficiently effective, at least in the short term, to encourage a sufficient change in lifestyle to cause a further decrease in HbA<sub>1c</sub>. It is also reasonable to question what outcome measures could be used to better judge the effectiveness of self-management interventions and to evaluate behavior change [40,44]. The participants in our study had a mean diabetes duration of approximately 10 years and approximately 60% were obese, 50% reported 2 or more comorbidities, and only 7% did not receive glucose-lowering medication. In total, 31% of the participants were treated with both oral medication and injections, indicating that they had serious disease, which makes it difficult to reduce HbA1c with a low-intensity lifestyle intervention. Thus, a higher intensity intervention may be required that considers the complexity of chronic conditions, whereas the low-intensity intervention used in our study provided less support and less frequent contacts with the health care providers [11,26]. However, after we adjusted for BMI, comorbidities, and medication, we found no indications that the effect differed between those with high and low BMI or disease burdens. Irrespective of these findings, one may nevertheless speculate whether a low-intensity intervention is appropriate for people who have been living with diabetes for a long time and if it is realistic to think that lifestyle changes can result in improved self-management and weight reduction. More recently, research has indicated that contact in clinical practice through telemedicine should be increased over time [18]. Many patients need closer support with structured interventions to help them attain the goals that they chose [15].

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The FTA intervention could also have been too time-consuming because it required daily recordings of blood glucose, diet, and physical activity, and even more for the group that received additional health counseling. However, the app was accessed via the smartphone distributed in the project and it could be used as their own and when convenient. Another aspect of interest in this intervention is the health psychology models used in the health counseling and the proper use of theories in mHealth in general. Different directions within health psychology may also suit different people. More research within this area is needed. A transdisciplinary research approach is necessary in this matter and this is an area in which technology and psychology have to cooperate closer in the future.

Blinding of participants and health care personnel was not possible and the decline in the HbA<sub>1c</sub> level in all groups, including the controls, may be attributed to the Hawthorne effect, particularly the attention the participants received when joining the study, which may have increased their self-confidence with respect to their diabetes management. They may also have received special attention from their general practitioners because "their patients" were included in a lifestyle intervention with modern technology [45]. Furthermore, according to the study design, a run-in period prior to randomization could have helped to stabilize the HbA1c level before the study started, but we lacked the resources and the time for this additional process. However, a run-in period could also have led to increased dropouts, which in turn could have threatened the external validity if only participants that were highly motivated by a telemedicine intervention were randomized. In addition, expectations about the project and the possible intervention could have increased during a run-in period; thus, the participants who were disappointed about not receiving the expected intervention might have caused further dropouts and threatened a successful randomization due to dropouts from causes other than usual [46-49]. To address this challenge, a stepped wedge trial design, in which all participants received the intervention gradually could have compensated for the dilemma of withholding the intervention and the related Hawthorne effect. However, the design would then have been expensive because of the length of the intervention and the demands of collecting data [50]. More research is needed to optimize intervention-based research designs for patients with diabetes, as discussed previously [51].

It was also interesting that several participants wanted to attend the study although they were not eligible according to the eligibility criterion of  $HbA_{1c} \ge 7.1\%$ , as indicated in the flow diagram. This suggests that even though they were within their recommended treatment goals, they felt the need for professional support to facilitate a lifestyle change in addition to their use of medication. This should be taken into consideration when deciding the inclusion criteria and using  $HbA_{1c}$  as a primary outcome in future research.

With respect to the self-management measures, we found that the participants in both intervention groups reported significantly better scores for the heiQ health service navigation domain, whereas the intervention group that received FTA also reported significantly better scores in the skill and technique acquisition

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domain. Increased skill and technique acquisition may indicate an increased ability to reduce symptoms and manage health challenges, including the use of management devices. Furthermore, the health service navigation domain indicates that communication with health personnel is improved and that the communication is more specific to the patient's own health needs [13]. It appears that the participants' self-management skills and ability to make contact with health personnel increased during the intervention, whereas typical well-being domains, such as emotional well-being, social integration and support, and positive and active engagement in life, remain unchanged after 4 months. These results extend the findings of Nolte [44] by confirming that self-management courses appear to improve these skills in patients with chronic diseases.

The strengths of this study are that it was an RCT with 3 arms of equal size and few differences between groups and equal dropouts. The control group provided an opportunity to compare the standard treatment with a mobile health intervention based on theory. According to the power calculation based on the HbA<sub>1c</sub>, the sample size was acceptable and it provided sufficient support for the primary outcome, but the sample and subgroups were still small and they did not allow subgroup analysis as desired.

Another limitation is that the participants and their general practitioners were not blinded, indicating there was greater opportunity for the participants to influence the results. For example, the control group could have used similar apps. However, the app was meant to be shared with others, such as health care personnel, and the participants were expected to communicate and clarify their needs. This could have affected the intervention groups, but also the controls.

Finally, technology is developing rapidly. When the inclusion period was extended to recruit sufficient participants, the smartphone used was gradually lagging behind the latest smartphone software released onto the market. We found that an immediate transfer of the app to another mobile software system was too demanding, despite the risk of reduced interest in the app. The use of new software could have changed the intervention because the participants would also have been able to use the smartphone for calls and a more user-friendly phone could have changed perceptions of the app's accessibility and usability.

The significant differences between the randomized groups were slightly uneven with respect to the distribution of rheumatic diseases and depression. Both of these diseases and their treatments can affect self-management and influence the HbA<sub>1c</sub> levels. However, the estimates did not change after adjusting for these variables. As mentioned earlier, the randomization procedure was generally successful with 3 equal groups at baseline and the dropouts were distributed almost equally among the groups.

The use of the FTA diabetes diary with or without additional health counseling improved self-management in terms of the ability to navigate health services and the skills required to reduce symptoms. The app and the health counseling did not help to reduce the  $HbA_{1c}$  levels of the participants in the intervention groups compared with those who received usual care.

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## **Conflicts of Interest**

None declared.

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## Abbreviations

BMI: body mass index
CIP: Competitiveness and Innovation Framework Programme
CONSORT: Consolidated Standards of Reporting Trials
FTA: Few Touch Application
HbA1c: glycated hemoglobin A1c
heiQ: Health Education Impact Questionnaire
MAST: Model for the Assessment of Telemedicine
RCT: randomized controlled trial
RENEWING HEALTH: REgioNs of Europe WorkING together for HEALTH
USB: universal serial bus

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**Original Paper** 

# A Mobile Health Intervention for Self-Management and Lifestyle Change for Persons With Type 2 Diabetes, Part 2: One-Year Results From the Norwegian Randomized Controlled Trial RENEWING HEALTH

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# Abstract

**Background:** Self-management is crucial in the daily management of type 2 diabetes. It has been suggested that mHealth may be an important method for enhancing self-management when delivered in combination with health counseling.

**Objective:** The objective of this study was to test whether the use of a mobile phone–based self-management system used for 1 year, with or without telephone health counseling by a diabetes specialist nurse for the first 4 months, could improve glycated hemoglobin  $A_{1c}$  (Hb $A_{1c}$ ) level, self-management, and health-related quality of life compared with usual care.

**Methods:** We conducted a 3-arm prospective randomized controlled trial involving 2 intervention groups and 1 control group. Eligible participants were persons with type 2 diabetes with an HbA<sub>1c</sub> level  $\geq$ 7.1% ( $\geq$ 54.1 mmol/mol) and aged  $\geq$ 18 years. Both intervention groups received the mobile phone–based self-management system Few Touch Application (FTA). The FTA consisted of a blood glucose–measuring system with automatic wireless data transfer, diet manual, physical activity registration, and management of personal goals, all recorded and operated using a diabetes diary app on the mobile phone. In addition, one intervention group received health counseling based on behavior change theory and delivered by a diabetes specialist nurse for the first 4 months after randomization. All groups received usual care by their general practitioner. The primary outcome was HbA<sub>1c</sub> level. Secondary outcomes were self-management (heiQ), health-related quality of life (SF-36), depressive symptoms (CES-D), and lifestyle changes (dietary habits and physical activity). Data were analyzed using univariate methods (*t* test, ANOVA) and multivariate linear and logistic regression.

**Results:** A total of 151 participants were randomized: 51 to the FTA group, 50 to the FTA-health counseling (FTA-HC) group, and 50 to the control group. Follow-up data after 1 year were available for 120 participants (79%). HbA<sub>1c</sub> level decreased in all groups, but did not differ between groups after 1 year. The mean change in the heiQ domain skills and technique acquisition was

significantly greater in the FTA-HC group after adjusting for age, gender, and education (P=.04). Other secondary outcomes did not differ between groups after 1 year. In the FTA group, 39% were substantial users of the app; 34% of the FTA-HC group were substantial users. Those aged  $\geq$ 63 years used the app more than their younger counterparts did (OR 2.7; 95% CI 1.02-7.12; P=.045).

**Conclusions:** The change in  $HbA_{1c}$  level did not differ between groups after the 1-year intervention. Secondary outcomes did not differ between groups except for an increase in the self-management domain of skill and technique acquisition in the FTA-HC group. Older participants used the app more than the younger participants did.

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#### **KEYWORDS**

self-care; mobile applications; cellular phone; telemedicine; counseling; motivational interviewing; diabetes mellitus, type 2; hemoglobin A1c protein, human

# Introduction

Type 2 diabetes is a complex disease [1,2] with an increasing prevalence worldwide [3,4]. Multifactorial treatment is necessary to improve long-term outcomes as stated in treatment guidelines [1,5,6]. Still, many do not meet the recommended goals for diabetes care [7-9]; in Norway, research has shown that only 20% attain the target for metabolic control for glycated hemoglobin  $A_{1c}$  (HbA<sub>1c</sub>), blood pressure, and lipid level, although the quality of care has improved [8]. New treatments are evolving rapidly and self-management is crucial in daily disease management and to prevent macro- and microvascular complications [2,10,11].

The field of technology-supported health care is growing and offers new ways of self-management education and support. Mobile phones are essential in people's lives today and may serve as a platform for a variety of self-management tools, such as apps. However, the current reviews are inconclusive and the effects of mobile health (mHealth) remain unclear [12-16]. The studies included in these reviews are heterogeneous and have used different mobile phone-based interventions and lengths of follow-up, and people with type 1 and type 2 diabetes are often included in the same studies. In most interventions, patients are monitored by health care personnel in contrast to interventions in which self-management is based on self-monitoring and self-care [14,17]. Despite this, mHealth is recognized as a potential addition to usual care in that some studies have found positive short-term effects on glycemic control, although the effects of the intervention decreased with time [15]. mHealth apps have also been shown to be effective without support from health care personnel, which may reduce health care costs [14].

Apps for mHealth interventions are often combined with health counseling, but the research related to these complex interventions is inconclusive because of heterogeneity in the types of studies [17,18]. Earlier research has shown that phone counseling is feasible, convenient, low cost, and may be an alternative to frequent visits [17,18]. In countries such as Norway, people in rural areas may have less access to specialized health care. A recent Coordination Reform has reorganized the delivery of health care, with more responsibility transferred from specialist health care to primary health care services and with more emphasis on self-management. The

application of innovative technologies may be a supplement to this reform [19].

Few studies have used the combination of a mobile phone app for self-management supported by health counseling via telephone. Studies often include monitoring with real-time feedback from health care personnel, which may lead to the investigation of dimensions other than self-management. However, an intervention based largely on the patient's initiative to self-manage at a frequency that does not interfere with daily life should be feasible in today's society [20].

Earlier reviews noted the lack of integration of behavior change theory into mHealth research and recommended that interventions should be theory-based [13,17]. Motivational interviewing is a technique in health counseling [21] and a well-known clinical method recommended for use in Norwegian guidelines for persons with diabetes [5]. Research has also indicated an effect of motivational interviewing on persons with type 2 diabetes trying to attain behavior change in lifestyle-related issues [22-24]. Further, some studies have tailored health counseling to the patient's stage of readiness to change according to the transtheoretical model of stages of change [25] and have demonstrated effects for persons with type 2 diabetes with the use of this model [26,27]. In the present study, both techniques were used in the health counseling.

The current study is the Norwegian part of the European Union collaboration study RENEWING HEALTH (REgioNs of Europe WorkING together for HEALTH), which comprises telehealth interventions in different health care and home settings [28]. The short-term findings after 4 months are described elsewhere [29].

The aim of this study was to determine if the use of a mobile phone–based self-management system for 1 year, with or without telephone health counseling by a diabetes specialist nurse for the first 4 months, could improve  $HbA_{1c}$  level, self-management, and health-related quality of life compared with usual care. The primary outcome was glycemic control, as assessed by the  $HbA_{1c}$  level. Secondary outcomes were self-management and health-related quality of life, depressive symptoms, and lifestyle changes (dietary habits and physical activity).



# Methods

# **Trial Design**

We conducted a 3-armed prospective randomized controlled trial (RCT) with a 1:1:1 allocation ratio using block randomization to 1 of 2 intervention groups or to a control group. The allocation has been described in detail elsewhere [30].

### **Participants**

All participants lived in their homes and received usual care by their general practitioner (GP). They were eligible if they were aged  $\geq 18$  years, had an HbA<sub>1c</sub> level  $\geq 7.1\%$  (54.1 mmol/mol), and were capable of completing questionnaires in the Norwegian language. They also had to be cognitively able to participate and to use the system and devices provided, although prior familiarity with mobile phones was not necessary. The majority of participants were recruited through 2 study centers in the southern and northern parts of Norway in collaboration with their GPs. Some participants were recruited from local public health clinics in the municipalities, through diabetes courses held by the specialist health providers for those newly diagnosed with type 2 diabetes, and through advertisement in The Norwegian Diabetes Association's media. The HbA1c level was set to  $HbA_{1c}$  >7.0% (53 mmol/mol); that is, above the treatment target according to the Norwegian guidelines [5]. Written informed consent was obtained from participants after detailed information about the project was provided by the research team during the start-up meetings. Data collection was obtained through self-reported questionnaires and from medical records at the GPs' offices. Randomization was performed consecutively.

There were 3 assessment points: baseline (time of randomization) and at 4 and 12 months after randomization. For the follow-up assessment, participants were invited to meet with the research team for data collection (questionnaires). Those not able to attend the follow-up meetings were sent questionnaires and a prepaid envelope to be returned by mail to the study center. All patients were asked to visit their GP for measuring of their HbA<sub>1c</sub> level and weight at the same time ( $\pm$ 14 days) after they had filled in the questionnaires.

#### Interventions

#### **Overview**

The Norwegian study in RENEWING HEALTH was a 1-year intervention to increase self-management comprised of 3 intervention groups: the Few Touch Application (FTA) intervention group, the FTA with health counseling (FTA-HC) intervention group, and the control group [30].

All participants in the 3 groups received usual care by their GP according to national guidelines [5]. This included at least 1 thorough annual visit to their GP for measurement of  $HbA_{1c}$  level, blood pressure, blood lipid concentrations, waist circumference, body weight to calculate a body mass index (BMI), screening for late complications, lifestyle advice, and treatment adjustments. Additional visits were recommended to

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monitor  $HbA_{1c}$ , fasting glucose, weight, and blood pressure every 2-6 months according to the needs of the patient and to support self-management medical treatment.

#### Control Group

The participants randomized to the control group received usual care [5].

### Few Touch Application Intervention

In addition to usual care, these participants received a mobile phone with the FTA self-management system. The FTA system provided the user with a diabetes diary app designed to increase self-management through awareness, overview of relevant factors, and motivational feedback through symbols such as smiling faces and color codes in the app [31]. The participants measured blood glucose level with a glucometer (LifeScan OneTouch Ultra Easy), which enabled automatic transfer of the measurement to the diary mobile app through a wireless Bluetooth connection and provided visual graphs, trend reports, and feedback through color coding (below normal, normal, and above normal). The app also consisted of a food habit registration system, a physical activity registration system, a personal goal-setting system, and a general information system. The user entered information about food intake, physical activity, and personal goals manually. Training was in person; a paper manual and a universal serial bus (USB) memory stick with further information were provided to participants. Technical support was available all weekdays between 9 am and 3 pm and was provided by technical staff of the project.

# Few Touch Application With Health Counseling Intervention

In addition to the mobile phone, FTA system, and usual care, the participants in the FTA-HC group received health counseling for the first 4 months of the project period. The health counseling was based on the transtheoretical model of stages of change [25] and a problem-solving model [32], and used motivational interviewing as a counseling technique [21]. The health counseling in the present study was part of the mHealth intervention. The counseling was delivered as a booster at the start of the intervention. This may have enhanced participants' identification with the intervention and may have resulted in more autonomous participation and better compliance [22].

A diabetes specialist nurse delivered the health counseling. She had special training and additional education in diabetes, was supervised by a clinical psychologist, and received support from a dietician when needed. Diet is an important element in the app. The nurse used a client-centered style for enhancing behavior change by helping the patients to explore and resolve ambivalence related to aspects of self-management. We provided a low-intensity intervention with a short counseling duration with few contacts between the patient and health counselor [32]. The counseling was delivered through phone-based conversations each month for 4 months, 5 in total after randomization (with the start-up call), and with no refresher contact thereafter. The calls lasted for 20 minutes (mean) and contained 5 structured modules developed to support self-management and the use of the FTA. The health counseling is described in more detail elsewhere [29,30]. A few days before

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the call, the diabetes specialist nurse sent a standardized text message through a secure system that allowed the participants to respond or send questions. The plan in the future is that the health personnel get access through their patients' registrations through a care portal for discussions and increased user participation in treatment (Figure 1).

The participants were recruited to the project because of an  $HbA_{1c}$  above the national recommendations ( $HbA_{1c}$ >7.0%, 53 mmol/mol) [5] and, therefore, they were recommended to measure their blood glucose as a part of their self-management irrespective of insulin use. Most participants not using insulin had been recommended by their GP or diabetes nurse to measure a monthly 24-hour profile of their blood glucose and as such to be aware of their normal blood glucose levels.

Use of the FTA system in GP consultations was an option for the intervention groups; however, the participants had to take the initiative.

### Measures

## **Demographics**

Demographic information were self-reported and included age, gender, education, employment status, and cohabitation (including those married and those living with a partner), and are described in detail elsewhere [29,30].

## **Clinical Measures**

Clinical characteristics included  $HbA_{1c}$ , weight, BMI, blood pressure, diabetes duration, comorbidities, complications, medication treatment, hypoglycemia, self-monitoring, and lifestyle variables (smoking, diet, and physical activity). Data were obtained from the GPs or self-reported (diabetes duration, comorbidity, hypoglycemia, self-monitoring, and lifestyle). Of these, only HbA<sub>1c</sub> and weight were collected at the 1-year follow-up.

# **Primary Outcome**

Change in HbA<sub>1c</sub> level after 1 year was chosen as the primary outcome because it is the main target measure when treating diabetes and is frequently used when evaluating interventions [15]. HbA<sub>1c</sub> data were collected through the GPs and were assessed primarily with the Siemens DCA Vantage Analyzer a maximum of 2 weeks before or after the follow-up to reduce measurement bias [30,33].

# Secondary Outcomes

The Health Education Impact Questionnaire (heiQ) [34] was used to assess self-management. This measure contains 40 questions on a 4-level Likert scale, grouped into 8 domains: positive and active engagement in life, health-directed activity, skill and technique acquisition, constructive attitude and approaches, self-monitoring and insight, health service navigation, social integration and support, and emotional well-being. This measure evaluates patient education and self-management interventions for people with chronic conditions. Higher scores reflect greater self-management, except for emotional well-being in which the scale is reversed. The heiQ is a validated measure for evaluating the effectiveness

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of health education and coping skills, and has been translated into Norwegian and several other languages [34,35].

To evaluate lifestyle and lifestyle changes, we investigated the participants' dietary habits including recommended food items and traditional Norwegian dietary habits [36], and engagement in physical activity based on intensity, frequency, and duration [37]. The Short-Form 36v2 Health Survey (SF-36) was used to measure overall health-related quality of life [38]. This survey has been translated into Norwegian and validated and tested in a Norwegian setting [39]. Depressive symptoms were measured by the Center for Epidemiologic Studies Depression Scale (CES-D) [40] using a cutoff of  $\geq 16$ , which indicated that those below the threshold reported no depressive symptoms. For the demographic and clinical measures, a common dataset was provided from the RENEWING HEALTH project administration and data were gathered according to a protocol provided from the project administration [41]. In the analysis, age was dichotomized with a cutoff at  $\geq 63$  years, the age of early retirement in Norway. Further details about measures have been published in the study protocol [30].

# Use of the Few Touch Application

Registrations of the use of the FTA system were collected continuously through automatic data transfer to a secure server and into a usage log. For the FTA-HTC group, further education on usage of the app was supported by the diabetes specialist nurse. A dichotomous variable of substantial or not substantial use of the FTA was made retrospectively based on the usage log. To be categorized as a substantial user, the participant had to be an active user for at least 6 months. An active user was defined as one who had performed  $\geq$ 5 blood glucose measurements during each of these 6 months and who had  $\geq$ 50 interactions in the parts of the diary not including collection of data (eg, viewing data or accessing general information).

# Sample Size

An a priori power calculation indicated that 34 participants in each of the 3 groups would be sufficient to detect significant changes in the primary outcome  $HbA_{1c}$  level with an effect size of .35, a significance level of 5%, a standard deviation (SD) of the outcome variable of 0.5, statistical power of 80%, and a 2-tailed significance test. The sample was set to 50 in each of the 3 groups to allow for dropouts and 151 participants were included in total.

### Randomization

Block randomization was performed through the Center of Randomization at the Unit for Applied Clinical Research at the Norwegian University of Science and Technology in Trondheim using the Web Case Report Form.

# Ethics

The Regional Ethics Committee South East approved the protocol and all participants provided written informed consent before randomization.

# Blinding

The study could not be blinded for the participants or GPs and health providers because of the nature of the intervention, which

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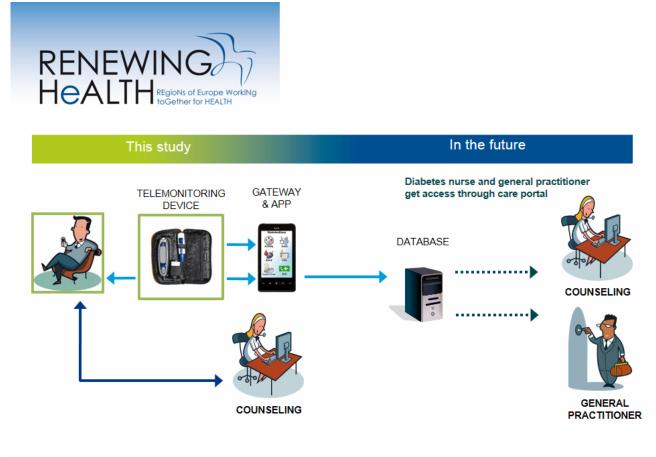
required overt participation [42]. The participants could use the device at visits to their GP as part of usual care. The research team was involved in the assessment of eligibility, data collection, training of patients to use the devices, and follow-up. Thus, those who delivered technical support had to know which group the participants were allocated to.

# **Statistical Methods**

The baseline characteristics are reported as mean and SD (continuous variables) and counts and percentages (categorical variables). Data not available were considered to be missing and the results were based on intention-to-treat. Baseline differences between groups were assessed with 1-way ANOVA (continuous measurements) and chi square tests (categorical

Figure 1. Self-management with the FTA supported by health counseling.

data). Within-group changes were analyzed using Student t tests. Multiple linear regression and logistic regression analyses were used to control for possible confounding factors. The final models were adjusted for age, gender, and educational level. Changes in medication (glucose-lowering agents), BMI, depressive symptoms (CES-D), diabetes duration, and comorbidities were added one by one to the final models to investigate the possible confounding effects. When the preceding covariates were not statistically significant, they were not presented in the final model to increase statistical power and precision of our estimates. All tests were 2-sided. P values <.05 were considered significant. All analyses were performed using SPSS version 21 (IBM Corp, Armonk, NY, USA).



# Results

# **Participant Flow**

Through the recruitment period, 298 persons were assessed for eligibility; 134 persons were not included, 52 did not wish to participate, and 82 did not meet the eligibility criteria (Figure 2). Of these, 65 had an HbA<sub>1c</sub> level below the threshold of 7.1% (54.1 mmol/mol), 6 had type 1 diabetes, 4 had interfering comorbidities, and 7 did not fulfill the eligibility criteria for other reasons. Randomization was performed for 164 persons (Figure 1), but 12 were excluded because of an HbA<sub>1c</sub> level below the 7.1% (54.1 mmol/mol) threshold. One person

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withdrew consent, leaving a total of 151 participants to be included in the study; 51 were allocated to the FTA intervention, 50 to the FTA-HC intervention, and 50 to the control group.

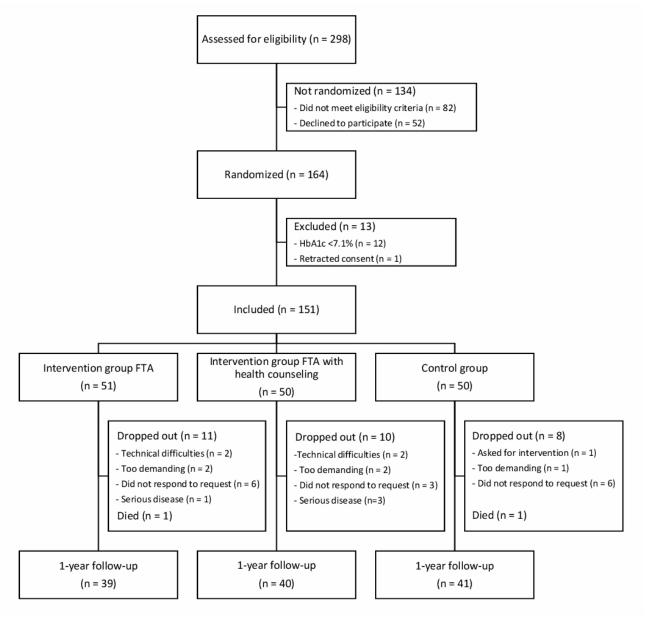
Inclusion and randomization started in March 2011 and ended in September 2012. The first complete participant dataset was finalized in April 2012 and the follow-up data was finalized in October 2013.

After the 1-year follow-up, there was a total dropout attrition rate of 21% (31/151), with an equal distribution in the groups. Baseline analysis revealed no difference between those lost to follow-up and those who completed the study for all variables. For the primary outcome (HbA<sub>1c</sub> level), data were obtained for

a total of 120 participants after the 1-year follow-up: 39 in the FTA group (dropout attrition 24%, 12/51), 40 in the FTA-HC group (dropout attrition 20%, 10/50), and 41 in the control group (dropout attrition 18%, 9/50). For the secondary self-reported

outcomes, data were included from 119 participants, 38 in the FTA group, 40 in the FTA-HC group, and 41 in the control group.

#### Figure 2. Flowchart of enrollment.



# **Demographic and Clinical Characteristics**

The demographic and clinical baseline characteristics of the participants have been described in detail elsewhere [29]. Overall, the mean age was 57 years (SD 12), 62 of 151 (41%) were female, and 51 of 151 (34%) had >12 years of education (Table 1). The mean HbA<sub>1c</sub> level was 8.2% (SD 1.1), 66 mmol/mol (SD 12.3), and the mean BMI was 31.7 kg/m<sup>2</sup> (SD

6.03). None of the variables listed in the tables differed significantly between groups at baseline. However, a higher proportion of persons in the control group reported depressive symptoms compared with the other 2 groups. The numbers (percentages) of participants whose score exceeded the cutoff value of  $\geq$ 16 in the CES-D were 17 of 50 (35%) in the control group, 10 of 51 (20%) in the FTA group, and 7 of 50 (14%) in the FTA-HC group (*P*=.04).



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 Table 1. Demographic and clinical characteristics at the baseline (N=151).

Characteristics	Ν	FTA (n=51)	FTA-HC (n=50)	Control group (n=50)
Demographics				
Age (years), mean (SD)	151	58.6 (11.8)	57.4 (12.1)	55.9 (12.2)
Gender (female), n (%)	151	17 (33)	25 (50)	20 (40)
Education <sup>a</sup> , n (%)	151			
<12 years		26 (51)	26 (52)	31 (62)
12 years		4 (8)	10 (20)	3 (6)
>12 years		21 (41)	14 (28)	16 (32)
Employment status <sup>b</sup> , n (%)	148			
Employed		22 (44)	31 (63)	26 (53)
Unemployed		13 (26)	11 (22)	17 (35)
Retired		15 (30)	7 (14)	6 (12)
Cohabitation status (cohabiting), <sup>c</sup> n (%)	151	37 (73)	36 (72)	37 (74)
Clinical characteristics				
HbA 1c				
HbA <sub>1c</sub> (%), mean (SD)	151	8.1 (1.1)	8.2 (1.1)	8.3 (1.2)
HbA <sub>1c</sub> (mmol/mol), mean (SD))	151	65 (12.0)	66 (12.0)	67 (13.1)
HbA <sub>1c</sub> (%), median (range)	151	7.8 (7.1-12.4)	7.9 (7.1-11.3)	7.9 (7.1-11.6)
HbA <sub>1c</sub> (mmol/mol), median (range)	151	62 (54-112)	63 (54-100)	63 (54-103)
Weight (kg), mean (SD)	132	98 (23.1)	91 (20.3)	96 (25)
BMI kg/m <sup>2</sup> , mean (SD)	129	32.4 (6.5)	30.7 (5.6)	32.0 (6.0)
Systolic blood pressure (mmHg), mean (SD)	121	136 (17.9)	132 (13.7)	134 (14.5)
Duration of diabetes (years), mean (SD)	138	11.2 (7.3)	9.6 (8.4)	9.4 (5.5)
Comorbidities, n (%)	151			
0		6 (12)	8 (16)	10 (20)
1-2		33 (65)	32 (64)	32 (64)
≥3		12 (23)	10 (20)	8 (16)
Late complication: foot ulcer, n (%)	151	11 (22)	8 (16)	4 (8)
Late complication: eye, n (%)	151	7 (14)	3 (6)	9 (18)
Treatment variables, n (%)				
Glucose-lowering agents, n (%)	131			
Diet only		3 (7)	2 (4)	4 (11)
Oral agents only		20 (44)	27 (57)	16 (42)
Injections only <sup>d</sup>		9 (20)	7 (15)	3 (8)
Combination of oral agents and injections		14 (30)	11 (23)	15 (40)
Hypoglycemia (self-reported), n (%)	148	23 (46)	19 (39)	27 (55)
Self-monitoring blood glucose, n (%)	151	48 (94)	45 (90)	49 (98)
Lifestyle variables, n (%)		5 (10)	10 (0.1)	
Smoking (yes)	151	5 (10)	12 (24)	7 (14)
Physical activity (physically active) <sup>e</sup>	149	18 (37)	16 (32)	17 (34)

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Characteristics	Ν	FTA	FTA-HC	Control group
		(n=51)	(n=50)	(n=50)
Daily servings of fruit and vegetables	148	2.8 (1.6)	2.9 (1.7)	3.8 (2.7)
Poultry >3 servings per month	146	33 (67)	26 (52)	28 (60)
Meat >3 servings per month	143	44 (88)	44 (92)	41 (91)
Fish >3 servings per month	148	41 (82)	38 (78)	37 (76)

<sup>a</sup> Education: some high school or less (<12 years), high school graduate (12 years), or some college or more (>12 years).

<sup>b</sup> Employment status: employed (state employee, private employee, self-employed, or employed part-time); unemployed (student, military duty, homemaker, unemployed, or unable to work); and retired.

<sup>c</sup> Cohabitation status: living alone (not married, divorced, separated, or widowed); and cohabiting (married or living with someone).

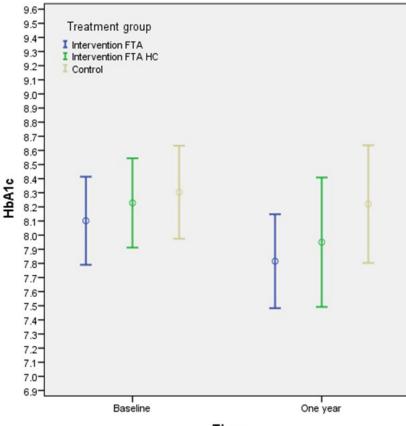
<sup>d</sup> Injections were both insulin and other blood glucose–lowering injections.

<sup>e</sup> Physically active: those with >60 min per week at an intensity of "being short of breath" or higher intensity.

### Primary Outcome Measure: HbA<sub>1c</sub> Level

The change in HbA<sub>1c</sub> level did not differ significantly between the 3 groups after 1 year. However, HbA<sub>1c</sub> level declined within all groups and none of the participants in any of the groups reached their pretest levels at the 1-year follow-up (Figure 3). Adjusting for age, gender, and educational level did not affect the change in  $HbA_{1c}$  level nor did inclusion of possible confounders, such as changes in medication (glucose-lowering agents), BMI, depressive symptoms (CES-D), diabetes duration, and comorbidities (Table 2).

Figure 3. Mean HbA1c levels (95% CI) at baseline and 1-year follow-up (N=119).



Time



Table 2. Mean HbA<sub>1c</sub> level, body weight, and heiQ domains at baseline and 1-year follow-up, and changes for those with 2 measurements.

Variables by group	n	Baseline, mean (95% CI)	1-year follow-up, mean (95% CI)	Change, mean (95% CI)
HbA <sub>1c</sub> (%)				
FTA	39	8.1 (7.72, 8.53)	7.8 (7.48, 8.15)	-0.31 (-0.67, 0.05)
FTA-HC	40	8.1 (7.76, 8.43)	8.0 (7.49, 8.41)	-0.15 (-0.58, 0.29)
Control	41	8.4 (7.97, 8.76)	8.2 (7.77, 8.61)	-0.16 (-0.50, 0.18)
HbA <sub>1c</sub> (mmol/mol)				
FTA	39	65 (61,70)	62 (58,66)	-3.4 (-7.4,0.6)
FTA-HC	40	65 (61,69)	63 (58,68)	-1.6 (-6.3,3.1)
Control	41	68 (64,72)	66 (62,71)	-1.7 (-5.4,2.0)
Weight (kg)				
FTA	33	96.3 (87.99, 104.64)	95.0 (87.54, 103.22)	-1.3 (-3.05, 0.43)
FTA-HC	34	89.7 (82.45, 96.90)	88.9 (82.28, 95.67)	-0.7 (-2.29, 0.84)
Control	36	94.3 (85.31, 103.22)	93.0 (84.44, 101.36)	-1.2 (-2.75, 0.54)
Positive and active engagement in life				
FTA	38	3.23 (3.08, 3.38)	3.19 (3.04, 3.34)	-0.04 (-0.18, 0.09)
FTA-HC	40	3.20 (3.08, 3.31)	3.22 (3.08, 3.36)	0.02 (-0.15, 0.19)
Control	41	3.12 (2.95, 3.29)	3.09 (2.94, 3.24)	-0.03 (-0.19, 0.13)
Health-directed activity				
FTA	38	2.78 (2.52, 3.04)	2.82 (2.60, 3.05)	0.04 (-0.16, 0.25)
FTA-HC	40	2.78 (2.57, 2.99)	2.81 (2.57, 3.04)	0.03 (-0.16, 0.21)
Control	41	2.71 (2.51, 2.92)	2.81 (2.58, 3.04)	0.10 (-0.08, 0.27)
Skill and technique acquisition				
FTA	38	2.92 (2.79, 3.04)	2.88 (2.69, 3.06)	-0.04 (-0.20, 0.12)
FTA-HC	40	2.89 (2.75, 3.02)	3.08 (2.96, 3.21)	0.19 (0.05, 0.33) <sup>a</sup>
Control	41	2.95 (2.83, 3.06)	2.94 (2.77, 3.12)	-0.01 (-0.14, 0.13)
Constructive attitudes and approaches				
FTA	38	3.17 (2.98, 3.36)	3.13 (3.00, 3.26)	-0.04 (-0.21, 0.13)
FTA-HC	40	3.23 (3.09, 3.38)	3.33 (3.19, 3.47)	0.10 (-0.02, 0.21)
Control	41	3.19 (3.02, 3.36)	3.19 (3.02, 3.36)	0.00 (-0.13, 0.13)
Self-monitoring and insight				
FTA	38	3.06 (2.95, 3.15)	3.09 (2.98, 3.19)	0.04 (-0.07, 0.15)
FTA-HC	40	3.09 (2.99, 3.18)	3.18 (3.06, 3.30)	0.09 (-0.01, 0.19)
Control	41	3.14 (3.03, 3.24)	3.15 (3.02, 3.28)	0.01 (-0.12, 0.13)
Health service navigation				
FTA	38	3.14 (2.97, 3.31)	3.03 (2.86, 3.20)	-0.11 (-0.25, 0.04)
FTA-HC	40	3.06 (2.91, 3.20)	3.14 (2.96, 3.31)	0.08 (-0.03, 0.20)
Control	41	3.16 (3.00, 3.33)	3.27 (3.09, 3.44)	0.11 (-0.05, 0.26)
Social integration and support				
FTA	38	3.04 (2.87, 3.21)	2.93 (2.77, 3.09)	-0.11 (-0.23, 0.02)
FTA-HC	40	3.02 (2.86, 3.17)	3.02 (2.86, 3.19)	0.01 (-0.09, 0.11)
Control	41	2.94 (2.74, 3.15)	2.95 (2.74, 3.16)	0.01 (-0.14, 0.16)
Emotional well-being				

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Variables by group	n	Baseline, mean (95% CI)	1-year follow-up, mean (95% CI)	Change, mean (95% CI)
FTA	38	2.99 (2.77, 3.20)	2.98 (2.76, 3.20)	-0.01 (-0.16, 0.13)
FTA-HC	40	2.99 (2.81, 3.17)	3.04 (2.84, 3.25)	0.05 (-0.12, 0.22)
Control	41	2.81 (2.57, 3.05)	2.87 (2.64, 3.11)	0.07 (-0.11, 0.24)

<sup>a</sup> Change was statistically significant (*P*<.05).

#### **Secondary Outcome Measures**

# Weight

Body weight was slightly reduced in all 3 groups at the 1-year follow-up, although not significant (Table 2). However, the change in weight did not differ between groups at the 1-year follow-up.

# Health Education Impact Questionnaire

Table 2 presents the mean scores for the 8 heiQ domains and the mean changes at the 1-year follow-up. Except for skill and technique acquisition in the FTA-HC group, no statistically significant changes were found between groups. However, as shown in Table 3, there were significant differences in the changes in 1 of the 8 domains between the control group and 1 of the intervention groups.

**Table 3.** Changes in  $HbA_{1c}$  level, skill and technique acquisition, and health service navigation for the intervention groups versus the control group, unadjusted and adjusted for age, gender, and educational level in multiple linear regression analysis.<sup>a</sup>

Group	Unadjusted B	95% CI	Р	Adjusted B <sup>a</sup>	95% CI	Р
HbA <sub>1c</sub> (%)						
FTA	-0.15	-0.68, 0.37	.57	-0.22	-0.75, 0.32	.42
FTA-HC	0.01	-0.51, 0.53	.97	0.01	-0.52, 0.54	.97
Control (ref)						
HbA <sub>1c</sub> (mmol/mol)						
FTA	-1.7	-7.4, 4.1		-2.4	-8.2, 3.5	.42
FTA-HC	0.1	-5.6, 5.8		0.1	-5.6, 5.9	.97
Control (ref)						
Skill and technique acquisition						
FTA	-0.04	-0.24, 0.16	.71	-0.03	-0.22, 0.17	.79
FTA-HC	0.20	0.004, 0.40	.046	0.21	0.01, 0.40	.04
Control (ref)						
Health service navigation						
FTA	-0.21	-0.41,-0.02	.03	-0.19	-0.38, 0.01	.06
FTA-HC	-0.02	-0.21, 0.17	.82	-0.004	-0.19, 0.19	.97
Control (ref)						

<sup>a</sup> This table presents 3 final multiple linear regression models, all adjusted for age, gender, and education.

After adjusting for age, gender, and educational level, the mean change in skill and technique acquisition was still significantly higher in the FTA-HC group (B=0.21; 95% CI 0.01-0.40; P=.04). The mean change in health service navigation was significantly smaller in the FTA group before but not after adjusting for age, gender, and educational level (B=-0.19; CI -0.38 to 0.01; P=.06) compared with the control group.

When analyzing the effect of depressive symptoms independently of group allocation, we found that those who reported depressive symptoms (CES-D score  $\geq 16$  at baseline, indicating more depressive symptoms) reported a higher change in heiQ than those who did not report such symptoms. Both analyses of change in heiQ after 1 year were adjusted for age and gender. In the domains of positive and active engagement

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in life, the results were B=0.24, (95% CI 0.01-0.46; (P=.04) and for social integration and support were B=0.22 (95% CI 0.03-0.41; P=.02).

#### Health-Related Quality of Life and Depressive Symptoms

There were no significant differences in any of the 8 subscales or in the 2 summary component scores of the SF-36 between the 3 groups at the 1-year follow-up in both the unadjusted and adjusted analyses. The change in depressive symptoms measured with the CES-D did not differ significantly between groups for the total score (continuous variable) or for the number/percentage of participants with a score greater than the cutoff of  $\geq 16$  both before and after adjustments.



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# Changes in Reported Physical Activity and Nutritional Habits

There were no significant differences between the groups in self-reported levels of physical activity (inactive to active or opposite). The changes in the intake of fruits and vegetables, meat, chocolate, and fish after 1 year did not differ between the 3 groups (results not shown).

# Use of the Few Touch Application and Health Counseling

Of those randomized to the FTA group, 20 of 51 (39%) were categorized as substantial users. In the FTA-HC group, 17 of 50 (34%) used the FTA part of the intervention substantially, and all these people attended  $\geq$ 4 health counseling sessions; 42 of 50 (84%) attended  $\geq$ 4 sessions of health counseling regardless of their FTA use.

Analyses of substantial versus nonsubstantial users of only the FTA, regardless of the intervention groups, did not reveal any statistically significant differences between groups regarding SF-36, heiQ, or depressive symptoms (CES-D). However, participants aged  $\geq$ 63 years were more likely to be substantial users of the app (OR 2.7; 95% CI 1.02-7.12; *P*=.045) compared with younger participants.

## **Adverse Events**

No serious adverse clinical events were reported from enrollment to the 1-year follow-up. However, a few undesired technical events were reported, such as trouble with the Bluetooth pairing required for automatic transmission of data from the glucometer to the app in the mobile phone. This may have been stressful for those affected and has been shown to lead to less satisfaction and decreased use of the technology in a previous study [13]. The project could not pay for mobile use if the participants were traveling abroad and some participants experienced high mobile costs for use of the mobile phone app in other countries (because of different rates for different network operators). However, we did inform all participants of this risk before they entered the trial.

# Discussion

Although HbA<sub>1c</sub> level declined in all groups, the change did not differ significantly between either of the intervention groups and the control group after 1 year. However, the mean HbA<sub>1c</sub> level did not increase to the baseline level in any of the 3 groups. We found no effects on secondary outcomes other than a significant positive change in self-management reflected by the skill and technique acquisition scale in the FTA-HC group. Interestingly, participants aged  $\geq$ 63 years were more likely to use the app.

In this study, we conducted a low-intensity mHealth intervention based on self-management with a mobile app and with a health-counseling booster for the first 4 months in one of the intervention groups. Previous reviews have investigated follow-up and intervention duration, and have found a trend of decreasing intervention effect over time [15,18]. Although interest in mHealth interventions may decrease over time [17,43], it has been shown previously that regular contact with

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clinical practice may improve glycemic control [15,16] and positive outcomes in general [17]. The participants in our study had only the health counseling intervention in one of the intervention groups at the beginning of the study and a more intense intervention during the 1-year follow-up or booster appointments could have strengthened their self-management and behavior change.

The finding that the FTA-HC intervention group tended to have a greater change in self-management, as shown by the increase in skill and technique acquisition, may mean that they had an increased ability to reduce their symptoms related to type 2 diabetes and to manage their health effectively, including greater skills for using technical aids. A lack of effect in the other domains of self-management could indicate that our intervention did not reach those at highest risk of a decline in health [44]. The degree of self-management may be less in people with type 2 diabetes compared with those with type 1 diabetes because of the intensity of treatment and need for self-measuring of blood glucose levels by those who are insulin dependent [15]. However, some type 2 diabetes insulin users are also in need of a similar self-management intensity. Reviews are inconsistent about whether mHealth is more effective in people with type 1 or type 2 diabetes [15,20]. Most of our participants reported that they were self-monitoring their blood glucose level at the start of the study, suggesting that they were already self-managing at some level irrespective of insulin use.

The HbA<sub>1c</sub> level is widely used for evaluation of interventions, but its relevance to self-management has been questioned in the past few years [15,18] because the focus on glycemic control may not always reflect the degree of self-management. To date, few mHealth studies evaluating self-management have included a self-management outcome with appropriate measures [35,45]. The choice of outcome measures is critical. The emphasis in the present study is on self-management and the primary outcome, HbA<sub>1c</sub>, may not reflect the relevant self-management outcomes for the participants. In this study, we found that many participants did not know their HbA<sub>1c</sub> level at enrollment and many had a too low HbA<sub>1c</sub> to be included.

Interventions are often designed without sufficient knowledge about the target group and without a theoretical framework [46]. Although this study used both theory and thorough analyses of the literature beforehand, more research about how to design and implement behavior change interventions is needed. An interesting framework has been developed with a behavior change model with essential conditions such as capability, opportunity, and motivation, including intervention strategies addressing these conditions specifically [46]. If a self-management intervention should improve HbA<sub>1c</sub>, it must first effectively improve healthy eating, physical activity, and adherence to medication. Therefore, we need to know how we can support and effectively motivate a person's readiness for behavior change. Future research must include the users as part of the team when developing appropriate interventions tailored to their needs [11,46,47].

Lack of findings in many behavior change studies may also relate to a lack of key components in available apps for persons

with type 2 diabetes. Apps should be designed in the context of the current guidelines for treatment of type 2 diabetes to increase self-management [12,13]. It has been shown previously how integrated daily use is more likely if the self-management components are offered in a mobile phone app, and electronic diaries are thought to improve self-management [48], as in this study. Further, solutions are provided to reduce the potential for erroneous imputations for functions such as transfer of blood glucose data [12,13]. However, the perceived benefits must outweigh the effort of using the app, especially because self-management is an ongoing process that requires many iterations every day [2]. The most frequent component offered in mobile phone apps is blood glucose measurement, but education in self-monitoring of blood glucose [12] and in the use of the application [13,15] is often lacking.

There are also other possible explanations for the lack of difference in the change in  $HbA_{1c}$  levels between groups. A total 39% of participants were substantial users of the app during the 1-year follow-up. The lack of effects on predefined outcomes may also relate to low use of the FTA, partly caused by outdated technology at the end of the study. The actual use of a mHealth intervention may reflect the external validity better than does the rate of dropouts [43]. In this study, attrition occurred in participants who did not use the intervention or used it infrequently. The common limit for threatened external validity is a 20% dropout rate [49], but high dropout attrition is expected in trials investigating innovative technology because of technical difficulties and cumbersome user interfaces. Our attrition rates are relatively small in comparison with others [43].

Traditionally, the RCT is the gold standard for clinical trials. In this study, we achieved successful randomization with no statistically significant differences between the 3 groups at baseline. Moreover, all patients were recruited from the primary health care system, which may increase the generalizability of our results [18]. During this study, new and improved versions of mobile phones hit the market and participants reported this as the reason for some of the cases of low use of the mobile phones given to the participants. Outdated equipment may be a problem when using RCTs for testing mobile interventions because of the often-prolonged inclusion process. In future research within the digital area, we should consider other designs and evaluation methods that have a shorter turnover than RCTs.

Some of the results were unexpected, such as the increased use among the older participants (aged  $\geq 63$  years). In previous research, a lack of effect was attributed to a fear of technology with increasing age [14], although others have suggested that compliance may be higher in older people [20]. Our findings suggest that age may not be the barrier that many expect. Generalization of the results of this single trial must be made with caution because of the participants' motivation and preferences for entering the study. It is preferable that the characteristics of those interested in mHealth interventions in the target population should be investigated before the study starts [50].

In summary, we have successfully conducted a low-intensity RCT to test a mobile diabetes self-management system with and without health counseling. There were no significant differences in the change in  $HbA_{1c}$  between the intervention groups and the control group. Skill and technique acquisition increased in those who received health counseling in addition to the self-management app. This may be important to their daily self-management of diabetes. Our findings indicate that age may not hinder the use of technology, as suggested by earlier research, but further research is needed to confirm this finding.

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#### **Conflicts of Interest**

None declared.

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# Abbreviations

BMI: body mass index
CES-D: Center for Epidemiologic Studies Depression Scale
FTA: Few Touch Application
FTA-HC: FTA with health counseling
GP: general practitioner
HbA1c: glycated hemoglobin A1c
heiQ: Health Education Impact Questionnaire
mHealth: mobile health
RENEWING HEALTH: REgioNs of Europe WorkING together for HEALTH
SF-36: Short-Form 36v2 Health Survey

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# **Original Paper**

# Dietary Approaches to Stop Hypertension: Lessons Learned From a Case Study on the Development of an mHealth Behavior Change System

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# Abstract

**Background:** Evidence-based solutions for changing health behaviors exist but problems with feasibility, sustainability, and dissemination limit their impact on population-based behavior change and maintenance.

**Objective:** Our goal was to overcome the limitations of an established behavior change program by using the inherent capabilities of smartphones and wireless sensors to develop a next generation mobile health (mHealth) intervention that has the potential to be more feasible.

**Methods:** In response to the clinical need and the growing capabilities of smartphones, our study team decided to develop a behavioral hypertension reduction mHealth system inspired by Dietary Approaches to Stop Hypertension (DASH), a lifestyle modification program. We outline the key design and development decisions that molded the project including decisions about behavior change best practices, coaching features, platform, multimedia content, wireless devices, data security, integration of systems, rapid prototyping, usability, funding mechanisms, and how all of these issues intersect with clinical research and behavioral trials.

**Results:** Over the 12 months, our study team faced many challenges to developing our prototype intervention. We describe 10 lessons learned that will ultimately stimulate more effective and sustainable approaches.

**Conclusions:** The experiences presented in this case study can be used as a reference for others developing mHealth behavioral intervention development projects by highlighting the benefits and challenges facing mHealth research.

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# **KEYWORDS**

mHealth; chronic disease; behavior change



# Introduction

### Background

Cardiovascular disease remains the leading cause of morbidity and mortality in the United States [1]. Despite well-characterized drivers-diet, physical activity, obesity-and effective treatments for its key risk factors, such as hypertension, the burden continues. Several decades of research have produced successful behavior change interventions that promote a healthier approach to diet and physical activity with notable highlights in the field of hypertension. The Dietary Approaches to Stop Hypertension (DASH) and its more comprehensive successors, the PREMIER and POWER lifestyle modification programs [2-4], promote a lifestyle approach to blood pressure control that emphasizes a diet rich in fruits and vegetables with moderate portions of low-fat dairy and lean protein, along with increased physical activity and reduced sodium intake. These well-validated studies provide an ample evidence base for the effectiveness of lifestyle modification for hypertension control, but to date remain underused. Multiple factors underlie the underuse of evidence-based interventions, including the intense resources required to replicate the intervention, the substantial user burden required to participate, and the low engagement of participants over time [5,6]. Researchers and dissemination partners who attempt to promote evidenced-based strategies to large populations are quite familiar with factors limiting uptake of behavior change interventions, not just for hypertension control, but for health promotion in general.

#### **Clinical Problem**

We imagine an "average" primary care patient named Dawn. Dawn is 35 years old, is overweight, works in a sedentary office environment, and gets little leisure-time exercise. Her primary care provider has been following Dawn's low grade hypertension over the past three office visits (last blood pressure reading was 145/85). In the current clinical environment, comprehensive hypertension control programs based on DASH, PREMIER, and POWER are not widely available in most practices; as such, no referral to a lifestyle program is made. With the few minutes available, the provider reviews her usual diet and physical activity habits, recognizes need for improvement, perhaps prints out a "DASH hypertension control" reference booklet from her electronic medical record and hands it to Dawn with directions to read it before the next visit in 3 months.

### Potential of mHealth for Behavioral Interventions

In the current health care setting of episodic physician visits, low provider knowledge/confidence of behavioral health promotion, insufficient ancillary support services, and nearly non-existent behavioral data feedback from patients, mHealth offers a promising means of delivering effective lifestyle interventions. Mobile technologies such as smartphones and wireless sensors, along with the dynamic software that powers them, have the ability to deliver behavioral interventions in a simple, personalized, and objective manner. Below, we present our rationale as to why smartphones can be a powerful modality for delivering mHealth behavioral interventions for hypertension control. (1) Smartphones can be embedded into patients' lives

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and are increasingly common. More than half (56%) of Americans report owning a smartphone, up from 46% in 2012 and 35% in 2011 [7]. They can deliver health interventions-educational and/or motivational-in the patient's usual context. It is the patient-driven customization to their personal lifestyle that is critical. (2) They can also deliver engaging, multimedia content that goes far beyond the traditional patient education booklet described above, which is still the dominant resource in the average clinician's repertoire. (3) Smartphones can integrate with new wireless devices that can collect patient data such as blood pressure, weight, and physical activity to drive tracking and feedback loops for discrete data and wirelessly sync with smartphones [8,9]. The automatic collection of data by these devices dramatically reduces the need for tedious data entry, allowing patients to focus their efforts on engaging with the app's tracking and feedback systems [10]. Data are also collected objectively, compared to self-reported data, providing more accurate feedback for patients and information for the health care team. (4) Smartphones are able to deliver personalized feedback and data visualizations to facilitate a potentially more meaningful relationship with the data [11,12], a motivational concept based on several key theories of persuasion and change including the Elaboration Likelihood Model and traditional operant conditioning [13,14], and (5) utilize GPS and other mapping functionalities such as Foursquare to customize the intervention to the patients' local environment. (6) Smartphones can embed alerts, reminders, or game-based motivational tools into mobile apps, weaving these tools into the daily fabric of patient's lives and promoting engagement with behavior change interventions, and (7) serve as hubs for social interventions using platforms like Patients Like Me or Facebook, or social networking forums built specifically for the intervention [9].

Unfortunately, most lifestyle apps for conditions such as hypertension do not effectively leverage the evidence base or smartphones capabilities [15]. In an October 2013 brief search of the DASH-like apps available on Google Play for Android and the Apple app store for iOS, apps related to DASH were primarily information resources, providing tips about hypertension and treatment or shopping lists and recipes. While these apps can be interactive (eg, tailored shopping lists), they did not leverage the multiple communication channels afforded by smartphones to help patients follow the behavior change plan or have comprehensive self-monitoring capabilities to track weight and physical activity, which are all integral components of hypertension management.

The purpose of this case study is to describe our experience developing a behavioral blood pressure reduction mHealth system designed from the outset to leverage the unique capabilities of smartphones and wireless sensors to facilitate learning, utilization, engagement, and motivation. Throughout our description, we will highlight lessons learned with a focus on current and potential future research pathways.

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# Methods

# **Creation of DASH Mobile**

In response to the clinical need and the growing capabilities of smartphones, our study team decided to develop DASH-inspired behavioral hypertension reduction mHealth system. DASH was successfully migrated to an Internet version over a decade ago [16]. The Internet program has been studied and has demonstrated significant, albeit less dramatic, effects compared to the original, more intensive in-person version. However, the Internet version was limited by poor participant engagement over time and has not been disseminated widely [16]. For our DASH mobile system, one of the first decisions was to build our program from scratch. Starting with the fully developed Internet version would serve to constrain our design and limit the system's flexibility. Therefore, the DASH Mobile development project reimagined the behavioral hypertension trial evidence using this guiding question: "How would we design an app that can deliver the underlying behavioral-based blood pressure reduction concepts using the tools of mHealth"? In retrospect, this decision represents one of the key lessons learned: creating some distance from traditional approaches to behavior change delivery formats designed for historical technological environments is critical to developing tools that can fully leverage the technology. Next, we began the process of team assembly, identifying funding, and planning our step-wise development process as will be explained in the following sections. Our goal was to design a first generation, minimally viable product that would be ready for efficacy and feasibility testing within one year. While one year may appear long compared to rapid industry prototyping lifecycles, the complexities of academic bureaucracies (institutional review boards, etc), funding mechanisms, multidisciplinary teams, academic calendars and student participation, and lack of mHealth development experience in academic medical centers may slow the development cycles.

# Assembly of the Team and Acquiring Start-Up Funding

The first step was to assemble the appropriate team [17]. The required expertise was broad including primary care, behavior change, nutrition, computer science, design, human-computer interactions, usability, videography, and informatics. Funding is a scarce resource on academic medical campuses, but multidisciplinary, technology-driven projects are more likely to be developed, evaluated, maintained, and successfully built upon with adequate start-up funding. The relatively slow funding cycle and careful ramp-up of new technologies in academia creates further drag on this type of innovation [6]. Funding early in the development cycle provides several advantages, including creation of a more interactive, industry-quality user interface (UI), more options for linking data collection devices, and a pilot study among a larger sample of participants allowing for sufficient preliminary data to drive the next steps in the research process and successfully compete for highly competitive, limited traditional grant opportunities. While funding mechanisms such as the National Institutes of Health (NIH) Small Business Innovation Research program exist to enable innovation of projects designed for the marketplace, in our experience, smaller funds with shorter and simpler application cycles are potentially better suited to early mHealth development stages. In the case of DASH mobile, our work was sponsored by two pilot grants: one from our university and another from a local technology consortium incubator (Center for Integration of Medicine and Innovative Technology).

#### **Approaches and Frameworks**

mHealth is an exciting new tool for developing health behavior change interventions, but it is just a tool. Careful thought needs to be given to the behavioral framework that will support and ultimately drive the technology facing the patient. While many frameworks exist, there are several that warrant highlighting as important touch points for our intervention design. The first is Michie's COM-B behavior change [18], which organizes behavior change into three components: Capability, Opportunity, and Motivation. This is a reformulation of decades of behavioral research and is a useful system for categorizing potential drivers of behavior and behavioral intervention design. Another organizing force in our development was the increasingly influential persuasion science literature. Leaning heavily on the work of Cialdini, the persuasion literature has advocated for the development of behavior change tools that take greater advantage of the peripheral route in the Elaboration Likelihood Model [13]. Messages processed through the mind's peripheral route are filtered through heuristics that do not involve more complex central processing and are sensitive to external signals from the environment as guides to decision making. Approaches that promote behavior change by tapping into these automatic, almost reflex responses that individuals can have to stimuli could and should be combined with traditional cognitive behavior interventions. We used these complementary frameworks as a lens for the design and implementation of the DASH mobile system, which we believe will be critical to the success and ultimate efficacy of our mHealth system.

#### **Starting the Development Process**

The first major design decision is determining the scope and key components of the mHealth intervention. Scoping decisions included the following questions and answers.

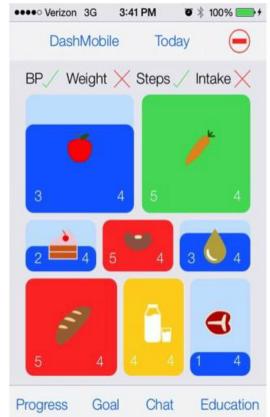
# Would This Be a Standalone App or Would We Include a Coaching/Counseling Component?

We ultimately decided to include a human-based mHealth coach component to our system in order to capitalize on the capabilities of a human counselor to dynamically interact with a patient during a conversation, tailoring the conversation to the issues at hand in real time [19,20]. Motivational interviewing was selected as the counseling framework because its iterative, dynamic, and flexible approach based on client feedback is particularly well suited to human interaction. Motivational interviewing is a psychologically based health behavior change counseling method suited for those ready to take action and, importantly, also for people who are ambivalent about change [21]. A counselor trained in motivational interviewing techniques aims to work with a person's core values and beliefs, resolve the person's natural ambivalence, and express their own internal motivations to change [21]. Interventions using

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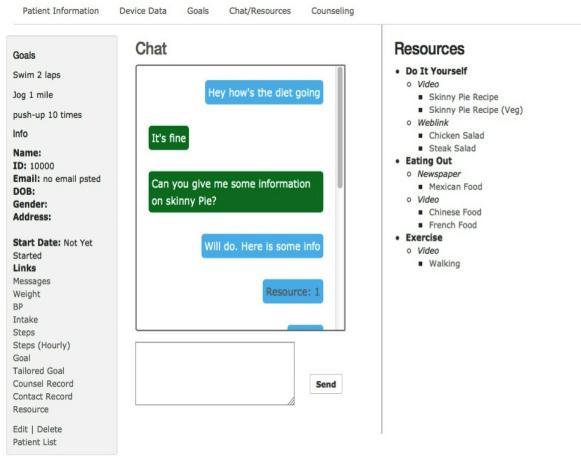
motivational interviewing have demonstrated efficacy for changing lifestyle behaviors among patients with a range of diverse sociodemographic characteristics [22,23]. In addition, the use of a human coach may also be leveraged to increase sustained use with the mHealth system [24]. With these principles in mind, we decided to build a comprehensive mHealth solution that involved a patient-facing smartphone app and coach-facing Web-based portal (Figures 1 and 2). In order to preserve the potential scalability of our mHealth system, we built features into the system that allow the human coach to have both synchronous and asynchronous communication with a patient.

Figure 1. Screenshot from DASH Mobile: Self-reported DASH diet interface.





#### Figure 2. Screenshot from DASH Mobile: Prototype DASH e-coaching portal.



# Who Would Be the mHealth Coach?

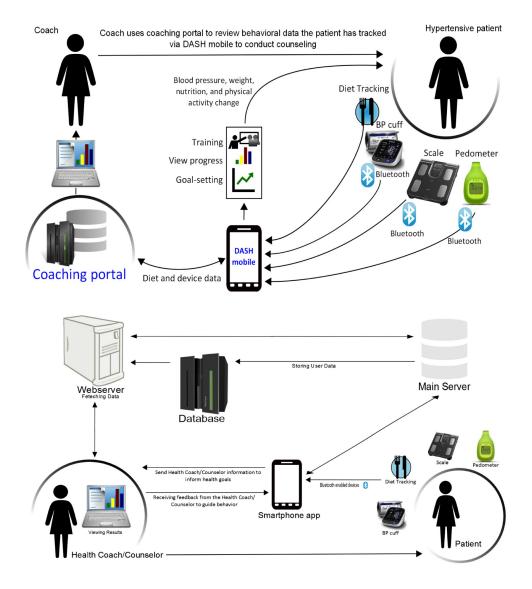
This is an important and complicated question. In the end, we wanted to avoid an mHealth coach who would be unlikely in real world settings due to misaligned skillsets and high cost (eg, physicians and nurses). However, we were also unsure how well an mHealth coach with specific training in counseling might perform. As such, we selected a Master's level student as the mHealth coach, although we anticipate adapting this role to the level of a health coach, navigator, or community health worker using standardized training and scripts. This decision was also based on funding considerations, given that our initial pilot funding precluded hiring a professional counselor but was suited to providing training in the core concepts of motivational interviewing, education about the behavioral topics, and opportunities to practice counseling along with provision of feedback.

## How Would the Devices Communicate?

To minimize barriers to sustainable data entry and avoid draining patient motivation, we made the decision to use wireless device data capture whenever possible. The decision to use a blood pressure monitor, weight scale, and pedometer with wireless communication capabilities included expensive and complicated software development, but we felt strongly that reducing tracking burden was an important principle of sustainable mHealth interventions. In addition, we decided to avoid hardware that required a home Internet connection, as this would exclude patients who use the phone as their primary connection to the Internet. Ultimately, we decided to integrate a Bluetooth blood pressure machine, scale, and pedometer, allowing the patient's data to be relayed from the device to the phone and then to the Internet (see Figure 3).



Figure 3. Schematic model of linkages between users, data, and devices of the DASH mobile app.



# What Hardware Would a Patient Need to Use the System?

Whether to build the smartphone portion of the system in iPhone or Android operating systems was another early decision. We decided to pursue both for their differing strengths: the iPhone operating system is often more compatible with wireless health devices, yet Android systems are equally if not slightly more popular than iPhone systems [7]. At present, we require that patients own a functional Android or iPhone smartphone with a data plan, as we believe to provide either of these components would represent an unrealistic delivery model for broad implementation of our system.

# What Core Behavior Change Techniques Should We Include?

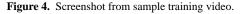
The list of potential behavior change techniques is enormous and the COM-B, Elaboration Likelihood Model, and other frameworks we were employing are robust—supporting the implementation of many specific behavioral tools [25,26]. In order to achieve our "minimally viable product", we needed to

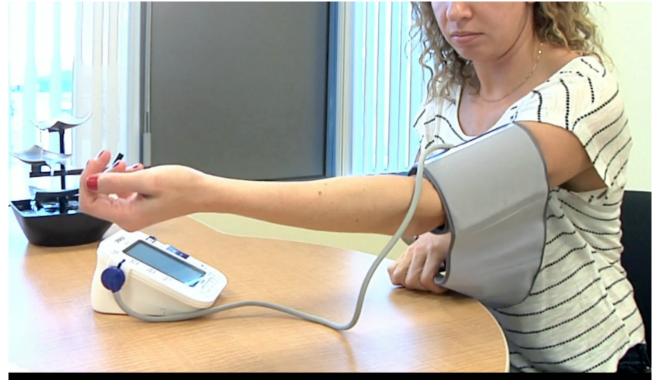
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focus on a small core set of functionalities. Cross-referencing the best evidence with the realities of mHealth and behavioral hypertension management, we selected the following core features: (1) automated tracking and feedback, (2) multimedia training and educational clips, and (3) mHealth coach synchronous and asynchronous communication based on principles of motivational interviewing. The wireless devices would provide the automated tracking of weight, physical activity, and blood pressure, while feedback with DASH diet adherence would be acquired through self-report using a simple smartphone interface (Figure 2). The goal setting would be negotiated via mHealth coach communication and tracked via the smartphone. The multimedia training and educational content would be a combination of short videos (Figure 4) and short slide sets ( $\leq 2$  minutes). We developed original content as well as sourced content from external educational reference materials. The mHealth coaching would be delivered using a motivational interviewing-based guide (manuscript under review), with the synchronous communication occurring via FaceTime, Skype, or Google Hangout video calls when feasible or telephone. The guide is meant to be highly structured, providing

section-by-section scripted content with examples of wording and questions, but flexible enough to allow the counselor to follow up on participants' answers to allow for a natural conversation and to build rapport. Synchronous communications capitalize on the inherent capabilities of a human coach who explores important motivational interviewing-based concepts (eg, level of self-efficacy and importance in changing behavior), elucidate relevant multilevel factors that may influence behavior (eg, time, money, community), and conduct collaborative goal setting targeted to the participant's level of motivation. Synchronous coaching sessions are alternated with shorter asynchronous sessions to review progress, discuss new goal attainment strategies as needed, and provide additional tailored education if requested by the participant. Overall, we sought to strike a balance between the more time-consuming synchronous sessions when the e-coach discusses new behaviors and less time consuming asynchronous sessions checking in about behavioral progress.





## **Building an Initial Prototype**

While there are established procedures for design specifications in health technology [27,28], in this small-scale health development project, a simplified approach in which we enumerated system capabilities and used them to drive the initial prototyping was a useful starting point. Using the functionality requirement decisions described above, the prototype development began by identifying "use case scenarios", which are detailed descriptions of how the system will be used in various settings and whether the design specifications are different under various clinical conditions. For example, one use case scenario would describe how the app will function if the patient is expected to access it daily, weekly, etc. Then, employing rapid iterative design methods we create mock-ups of the user interface [29]. Mock-ups allow visualization of how a user would interact with the components of the app. In the UI wireframes, we were able to compare various strategies for tracking dietary intake, visualizing blood pressure and weight data, setting up libraries of relevant information and links, framing the self-management training tutorials, and plan more advanced functions for future versions of our system like motivational alarms, social networking, and GPS-based alerting. In the simulated UI environment, the study team quickly mocked

usability feedback from 3 test users who reflected the ultimate target patient population (hypertensives with smartphone access). While a complete description of this user-centered design process is beyond this scope of this paper, some examples of design considerations driven by the test users included (1) lack of clear feedback that their device data was being received and processed (eg, "No way of knowing whether the reading went through"), (2) UI improvements, for example, the addition of 1/2 portion sizes, (3) integration of serving size references directly into the tracking tool icons (eg, "I'm always referring to the website on the education tab to figure out my serving sizes"), and (4) new features such as tracking water and sleep. This feedback and subsequent design modifications encountered during the iterative UI design phase were critical to enhancing development efficiency, usability, and usefulness of the DASH mobile system.

up what various ideas might look like and evaluated their

usability on the smartphone interface. We then elicited additional

#### **Development of the Systems Architecture**

A flexible, scalable, and integrated "back end" is equally important to an evidence-infused "front end" of any mHealth system. The seamless integration of the UI, mHealth coaching portal, sensing devices, and multimedia content all depend on

an underlying architecture to support the system functionality. All of our "back-end" decisions were guided by the following six mHealth platform criteria: (1) a generic database, (2) a scalable Web server, (3) integrated smartphone data collection tools (ie, Bluetooth), (4) a stable server for receiving data, (5) support for big data analytics, and (6) security considerations.

An interactive platform between coach and patient is needed. However, a single system that allows direct communication between coach and patient does not exist. To address this issue and respect the above criteria, we created a Web server to access patient data, process requests, communicate with a patient, display patient data, store patient information, and analyze patterns in a central database. We developed a smartphone application that could interact and provide feedback to the user without storing data locally on the phone or the app to maximize data security. To further support data security, only encrypted and nameless data would be transmitted to the mobile app. To tie these systems together, we built a central server that communicates with the app and collects data for storage, from which the Web server can retrieve and run data analysis.

Figuring out how the data will move through the system—from phone, to server and back again—and the respective security considerations is an active area of research in mHealth [30,31]. All data visualizations on the phone accessed from the server are not locally stored on the smartphone. In addition, considerations regarding what personally identifiable information are linked to the study data needs to be taken into account. Figure 3 represents the final "back-end" architecture of DASH mobile that demonstrates each of these principles and decisions.

# Results

# Lessons Learned

Imagine now that our primary care patient Dawn comes back for her 3-month follow-up appointment. Both she and her provider have forgotten about the DASH diet brochure. Fortunately, in the meantime, the provider's practice has gained access to the DASH mobile system. The provider e-prescribes the app to Dawn through the electronic medical record, which triggers an automated mailing of the integrated Bluetooth scale, blood pressure cuff, and pedometer to Dawn's home and a secure message to her (via a patient portal in the electronic health record) with a hyperlink to download the app. Dawn receives the package the next day, downloads the app to her own personal smartphone, and begins the set-up process. Within minutes, Dawn begins watching videos on her phone to learn how to use the system and is contacted that week by the practice health coach to arrange a video call to discuss expectation and goals of the system and arrange future counseling sessions over the coming months.

Over the past 12 months, our study team has faced many challenges to developing this future experience for Dawn, and we have learned are the following 10 lessons. (1) To truly leverage mHealth, you need to be willing to break from tradition and re-imagine behavior change tools in a connected environment, from the outset. At the same time, not everything

XSL•FO RenderX is done better via mHealth. Each decision, each functionality, and each device need to be evaluated through the multidisciplinary team lens and justified as to why it needs to be rebuilt in an mHealth approach. (2) Development teams need broad membership—crossing several disciplines—informatics, computer science, behavioral science, and clinical medicine. Each group needs equal footing throughout the design process to ensure a product that is robust to the variation in real world implementations. Giving presentations at academic conferences within and outside one's discipline also helps to inform intervention development by inviting a range of multidisciplinary perspectives. (3) Behavior change frameworks such as COM-B, Elaboration Likelihood Model, and others can be useful scaffolds for organizing the design specifications and potential mHealth behavior change tools; however, developers should be ready to be responsive to new frameworks developed specifically for mHealth interventions as they emerge [32]. (4) Clearly identifying the scope of the initial prototype and matching it to the design specifications ensures efficient development timelines and allows for well-defined iteration cycles. (5) Involving humans such as coaches in mHealth systems is still often critical to a robust intervention, but the pros and cons of doing so need to be carefully evaluated. (6) Decisions around supported platforms, human and technology resources, and workflows should be explicit as they dramatically affect potential future scalability and dissemination potential. The target population, their characteristics, resources, and capabilities should be kept in mind when making these decisions. (7) While the behavior change literature and frameworks enumerate many possible tools, prototypes should focus on evidence-based core tools first in order to ensure rapid development of a minimally viable product and allow for evidence-guided iteration cycles. (8) It is important to keep the prototyping lightweight and simple, particularly in academic environments where resources are often thin. This allows for quick assessments and alterations of the developer's execution of the design specifications. (9) Whenever possible, it is best to build the prototype in a flexible, scalable fashion as there can be many pivots and evolutions of the system as the development process unfolds. Having a flexible architecture allows for adoption of new data inputs, new devices, and new workflows without massive redesign of the system. This also allows for maximum adaptability for taking on new behaviors or health conditions as opportunities arise (eg, emerging clinical needs, new funding announcements). (10) Engaging with the technology transfer/commercialization experts at your institution early allows you to prepare for inevitable conversations with potential industry partners and for identifying growing intellectual property and inventorship rights.

# Discussion

# **Future Plans**

This case study describes our experience developing a behavioral blood pressure reduction mHealth system designed to leverage the unique capabilities of smartphones and wireless sensors to facilitate learning, utilization, engagement, and motivation. Our DASH-inspired prototype is focused on initial functionality, content delivery, tracking, and communication

with the e-coach. Using this minimally viable product, we are now engaged in usability studies to collect more data about the usability and usefulness of each component of the system and will use these data to improve the app through iterative development [33,34].

Our project is entering its first series of pilot trials, which are a critical first test of its feasibility and preliminary efficacy. Unlike commercial health apps and systems, an mHealth system originating from the medical community requires validation of its clinical efficacy prior to widespread implementation and dissemination. We will conduct short pilots with flexible methodology that allows continued iterative improvement. In addition, we have created an mHealth behavior change architecture that serves as a platform for other common behavior change sensitive conditions such as medication adherence, cancer prevention and control, and diabetes.

#### Conclusions

mHealth represents an important turning point in behavioral change interventions. The availability of a context-sensitive, wireless sensor-integrated delivery platform that is literally in the hand of the patient nearly all the time represents a potentially important disruptive force. Researchers need to carefully integrate behavior change best practices, mHealth technologies, and flexible, learning design processes to maximally leverage this potential and substantially change our ability to improve our patients' behaviors for hypertension and other common chronic conditions.

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# **Conflicts of Interest**

None declared.

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# Abbreviations

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**DASH:** Dietary Approaches to Stop Hypertension **UI:** user interface

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# Preferences for a Mobile HIV Prevention App for Men Who Have Sex With Men

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# Abstract

**Background:** The Centers for Disease Control and Prevention recommends that sexually active men who have sex with men (MSM) in the United States test for human immunodeficiency virus (HIV) at least three times per year, but actual testing frequency is much less frequent. Though mHealth is a popular vehicle for delivering HIV interventions, there are currently no mobile phone apps that target MSM with the specific aim of building an HIV testing plan, and none that focuses on developing a comprehensive prevention plan and link MSM to additional HIV prevention and treatment resources. Previous research has suggested a need for more iterative feedback from the target population to ensure use of these interventions.

**Objective:** The purpose of this study is to understand MSM's preferences for functionality, format, and design of a mobile phone-based HIV prevention app and to examine MSM's willingness to use an app for HIV prevention.

**Methods:** We conducted focus group discussions with 38 gay and bisexual men, with two in-person groups in Atlanta, two in Seattle, and one online focus group discussion with gay and bisexual men in rural US regions. These discussions addressed MSM's general preferences for apps, HIV testing barriers and facilitators for MSM, and ways that an HIV prevention app could address these barriers and facilitators to increase the frequency of HIV testing and prevention among MSM. During focus group discussions, participants were shown screenshots and provided feedback on potential app functions.

**Results:** Participants provided preferences on functionality of the app, including the type and delivery of educational content, the value of interactive engagement, and the importance of social networking as an app component. Participants also discussed preferences on how the language should be framed for the delivery of information, identifying that an app needs to be simultaneously fun and professional. Privacy and altruistic motivation were considered to be important factors in men's willingness to use a mobile HIV prevention app. Finally, men described the potential impact that a mobile HIV prevention app could have, identifying individual, interpersonal, and community-based benefits.

**Conclusions:** In summary, participants described a comprehensive app that should incorporate innovative ideas to educate and engage men so that they would be motivated to use the app. In order for an app to be useful, it needs to feel safe and trustworthy, which is essential when considering the app's language and privacy. Participants provided a range of preferences for using an HIV prevention app, including what they felt MSM need with regards to HIV prevention and what they want in order to engage with an app. Making an HIV prevention app enjoyable and usable for MSM is a difficult challenge. However, the usability of the app is vital because no matter how great the intervention, if MSM do not use the app, then it will not be useful.

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#### Goldenberg et al

#### **KEYWORDS**

MSM; HIV; mobile phone app; mHealth; HIV prevention

# Introduction

Gay, bisexual, and other men who have sex with men (MSM) account for a disproportionate burden of incident human immunodeficiency virus (HIV) infections in the United States. Although MSM make up less than 2% of the population, in 2011, 62% of new HIV infections in the United States were among MSM [1]. In order to address this, the Centers for Disease Control and Prevention (CDC) recommends that MSM test for HIV infection at least three to four times per year [2]. Identification of new HIV infections is the first step in the cascade of HIV care [3]; however, less than 20% of MSM are testing at least three times per year [4]. HIV interventions that use multipronged approaches and incorporate biomedical, behavioral, and structural strategies to target HIV prevention among MSM are most effective [5]. In an age of advancing technology and increasing mobile phone use [6,7], Internet-based interventions and mHealth (the use of mobile phones for medical or public health supported interventions) have become a popular vehicle for a variety of health interventions [6,8,9] and may be a useful mechanism for bringing multifaceted HIV prevention strategies to scale [10,11].

Most existing mHealth HIV interventions have used mobile technology through the use of short message service (SMS) texting to provide HIV risk-reduction messages [12-15] and to improve adherence to highly active antiretroviral treatment [16-21]; many of these SMS-based interventions have been proven to be effective [19]. HIV interventions using mobile phone apps are also becoming increasingly popular. In their evaluation of the availability of HIV-prevention mobile apps, Muessig et al identified 55 unique mobile apps that address HIV prevention and care; however, these apps were not frequently downloaded and were not highly rated by their users [22].

In order to increase the uptake and use of apps used for HIV prevention, Muessig et al suggests that app developers collect input from the target audience through a process that identifies app preferences and evaluates the app [22]. In response to this, we conducted formative qualitative research with MSM to understand likely scenarios for app use, to identify preferences regarding functionality, format, and design, and to determine MSM's willingness to use an HIV prevention mobile app. This would be the first app to guide MSM in building a comprehensive prevention plan and link them to HIV testing, HIV prevention services, and treatment resources.

# Methods

#### **Study Population and Recruitment**

This study was approved by the Emory University Institutional Review Board. From August-December 2013, we recruited gay and bisexual men using flyers and Facebook advertisements. Flyers were posted in venues in Atlanta and Seattle where gay and bisexual men frequent (eg, restaurants, bars, coffee shops, gyms). Facebook advertisements targeted men living in Atlanta, Seattle, and rural regions who reported being interested in men in their profiles. In Atlanta, men recruited through Facebook have been reported to be comparable behaviorally to men recruited through other venues [23]. Rural locations were determined by postal codes using the US Census Bureau's data and definition of rural (ie, population density <1000 people/square mile) [24]. The flyers and advertisements provided a link to an online screening survey through SurveyGizmo to determine study eligibility. Eligibility criteria included (1) age 18 years or older, (2) male, (3) self-identification as gay or bisexual, (4) current residence in Atlanta, GA, Seattle, WA, or in a rural US county, (5) never having tested positive for an HIV test, and (6) having ever owned a mobile phone. Eligible participants were contacted to participate in a focus group discussion (FGD).

#### **Study Procedures**

We completed four in-person FGDs (two in Atlanta and two in Seattle) and one online FGD (OFGD) [25] with rural men. The OFGD used a chatroom-based format using Adobe Connect, a real-time Web-based meeting client. Adobe Connect allows for participants to view a variety of customizable windows, including a window for discussion, where they can communicate and type responses to questions as though in a chatroom. Other windows allowed the moderator to share screenshots and poll participants on app preferences. Participants were also able to contact the moderator privately if they had questions or comments that they did not want to express to the group.

Each in-person FGD lasted approximately 1.5 hours, and the OFGD lasted approximately 2 hours. FGDs were conducted by 2 trained facilitators (one in Atlanta and one in Seattle) who were familiar with the goals of the mobile HIV prevention app. All FGDs addressed men's general preferences for apps, HIV testing barriers and facilitators for MSM, and ways that an HIV prevention app could increase the frequency of HIV testing and prevention among MSM. During FGDs, participants were shown screenshots and provided feedback on eight potential app functions: (1) information about HIV testing options and creating a testing plan (Figure 1), (2) use of the phone's calendar for reminders of upcoming HIV testing dates, (3) a map of HIV testing sites, (4) location-based reminders for HIV testing when near a testing center (Figure 2), (5) non-location-based reminders for HIV testing, (6) rating and reviewing HIV testing centers and other venues, including a review on how gay-friendly the venue is (Figure 3), (7) tracking of sexual behaviors over time with a summary describing results (Figure 4), and (8) documentation of HIV testing results (Figure 5). Participants also provided suggestions for how to improve each function and the app overall, identifying additional functions that should also be included.



Figure 1. Screenshot for creating a testing plan.



Figure 2. Screenshot for location-based reminders for HIV testing.







Figure 3. Screenshot for rating and reviewing HIV testing centers and other venues.

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Figure 4. Screenshot for tracking of sexual behaviors.





Figure 5. Screenshot for HIV testing documentation.

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## **Data Analysis**

In-person FGDs were audio-recorded and transcribed verbatim, and the OFGD was automatically downloaded to a readable text file. Analysis was conducted using MAXQDA, version 10. A team of 4 data analysts conducted a thematic analysis, examining both inductive and deductive themes within the transcripts. After multiple close readings, the team created a preliminary codebook of all salient themes. Provisional definitions were given to each code and 3 analysts applied each code to a single transcript. The coded transcripts were merged for comparison and code definitions were revised based on coding disagreements. Once the final codebook definitions were established, 3 data analysts consistently applied the codes to all of the transcripts. All transcripts were double-coded with 2 analysts each coding the same transcript. Transcripts were then merged and codes were reconciled; differences among coders were resolved by consensus.

After multiple purposeful and focused readings of coded text, thick descriptions were created for each theme. The descriptions identified common concepts, patterns, and unique ideas

expressed in the FGDS. Themes were analyzed separately based on location and were compared and contrasted between groups.

# Results

# Overview

In total, 38 MSM (all identifying as gay or bisexual) participated in this study. Demographics varied based on location (Table 1). Participants in Seattle had an older mean age (39 years) than in Atlanta (29 years) or rural regions (30 years). Racial composition of participants varied; Atlanta was the only site with African American participants (35% of Atlanta participants, 6/17). Participants in Seattle were more likely to have ever taken an HIV test (Seattle: 91%, 10/11; Atlanta: 88%, 14/16; Rural: 70%, 7/10), but participants in Atlanta were more likely to have taken an HIV test within the past 3 months (Atlanta: 57%, 8/14; Seattle: 10%, 1/10; Rural: 14%, 1/7). Participants discussed 16 themes that were incorporated into the codebook (Table 2). There was some geographic variation in discussions of these themes, especially regarding preferences about the language and tone of the app. There was less variability for other preferences, such as the functionality and content of the app.



Table 1. Participant demographics.

	Atlanta (n=17)	Seattle (n=11)	Rural (n=10)	Total (n=38)
Age in years, mean (range)	29 (23-40)	39 (19-63)	30 (19-41)	32 (19-63)
Race, % (n)				
White/Caucasian	58.8 (10)	80.0 (8)	80.0 (8)	68.4 (26)
Black/African American	37.5 (6)	0.0 (0)	0.0 (0)	15.8 (6)
Other	6.3 (1)	20.0 (2)	20.0 (2)	13.2 (5)
Sexual orientation, % (n)				
Gay/Homosexual	87.5 (14)	90.9 (10)	90.0 (9)	86.8 (33)
Bisexual	12.5 (2)	9.1 (1)	10.0 (1)	13.2 (5)
Has ever taken an HIV test, % (n)	87.5 (14) <sup>a</sup>	90.9 (10)	70.0 (7)	83.8 (31)
How many HIV tests have you had in the last 12 months? Mean (range) <sup>b</sup>	2.1 (1-4)	0.8 (0-3)	0.7 (0-2)	1.4 (0-4)
How long ago was last HIV test <sup>b</sup> , % (n)				
<3 months ago	57.1 (8)	10.0 (1)	14.3 (1)	32.3 (10)
3-6 months ago	35.7 (5)	30.0 (3)	28.6 (2)	32.3 (10)
6-12 months ago	7.14 (1)	0.0 (0)	14.3 (1)	6.5 (2)
>1 year ago	0.0 (0)	30.0 (3)	28.6 (2)	16.1 (5)
>5 years ago	0.0 (0)	30.0 (3)	14.3 (1)	12.9 (4)
Where received an HIV test, % (n) $^{\rm b}$				
СВО	78.6 (11)	80.0 (8)	42.9 (3)	71.0 (22)
Doctor's office	71.4 (10)	50.0 (5)	42.9 (3)	58.0 (18)
At home	21.4 (3)	20.0 (2)	14.3 (1)	19.4 (6)
Other	14.3 (2)	20.0 (2)	14.3 (1)	16.1 (5)

<sup>a</sup>One participant did not answer, total n=16.

<sup>b</sup>Among participants who ever had an HIV test.



App preferences	General discussions about what participants like/do not like about the apps that they use
Beyond HIV testing	STI testing, PEP, PrEP, linkage to care (for HIV and STIs), mental health, other health issues; include discussions in support of and opposed to including additional information; include any discussion of HIV/STI prevention that goes beyond the original suggested purpose of the app; DO NOT include sex diaries, gay yelp
Credibility/ Authority	Discussions about trusting the app and the information that it is providing, credibility of the app and sources behind information (eg, CDC, doctors, universities), reliability of how the app reports results, whether or not an authoritative tone is more trustworthy, concerns regarding abuse of the app
Customization/ Personaliza- tion	Discussions of ways that the app can be customized or personalized to fit the needs of different app users; discussion of anything optional or described as "this should be optional"; Code when a participant states "this is not something that would work for me, but I can see this working for people in general" – statements that express how different users may want to interact with the app differently
Design/ Functionality	Any reference to the layout of the app, functions that should or should not be included in the app (and why), usefulness of functions, relevance of functions, comments about how cluttered it is, images, etc; ease of use, simplicity; statements describing if it is "simple", "straight forward", "confusing" etc; battery life, data usage
Education	All discussions of HIV/STI and health education/information, including discussions of how the app does or can educate, why education is important, etc; the type of education/information that participants want; how they want to receive education/information
Interactive engagement	Engagement with the app rather than simply receiving information (eg, discussions of putting information into the app via quizzes, diaries, etc.), discussions of how the app already includes or can include more interactive engagement, the importance of interactive engagement, the impact of interactive engagement on motivation to use the app
Perceived impact	How participants described the impact that the app could have on HIV testing, HIV risk, and sexual health, including both the individual impact and the community impact; the ability for the app to help start conversations about HIV, the ability for the app to improve HIV prevention, HIV testing behaviors, safer sex behaviors, etc
Privacy/ Confidentiality	Any discussions/concerns about privacy, confidentiality, or security; concerns that insurance companies may get infor- mation about the app; legal concerns regarding HIV transmission
Relatable vs professional	Discussions of whether or not the tone/language of the app should be relatable or professional and why
Sharing data	Willingness or unwillingness to share data with the program developers; sharing data as a way to enhance the app, as a way to get information back about yourself and/or community, for research, as a way to give back to the community; any motivation for sharing data or not sharing data; DO NOT code when discussions of sharing on social networking sites
Social networking	Using the app for the purpose of networking with the others; "check-ins"; connections to Facebook, online dating sites, or other networking sites; using the app for communication with others in a social network, advertising on social networking and/or online hook-up sites, sharing information with individuals (friends, partners, etc)
Stigma	Discussions about HIV stigma and homophobia and how the app can impact stigma
Target population	Discussions about the target population and app audience demographics, including sexual orientation (and outness), age, race, rural vs urban, Spanish speakers, etc; comments about how "gay" to make the app, ie, "don't make it too gay"
Testing barriers/ Facilitators	Discussions about current barriers and facilitators for regular HIV testing for MSM, including access to testing, knowing where testing sites are located, feeling safe/unsafe when going to get tested, anonymous testing vs required reporting, etc
Willingness/ Motivations	Expressions of willingness (and unwillingness or reluctance) to download and/or use the app, explanations of why willing (or unwilling) to download and/or use the app; statements about whether or not there is a perception that others would be willing to use the app, discussions of what would motivate (or not motivate) someone to download and use the app regularly

# **Functionality**

#### Education

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In all FGDs at all study sites, participants recognized an educational component of the app as being vital to HIV prevention: "A real important aspect of prevention is education...it needs to have an educational element so that people who might be questioning whether or not they should go and get tested, they can" (FGD1, Atlanta). Participants identified the types of information that they would want to receive about HIV testing options, including education about

accuracy of tests, where to get tested, home-testing (especially instructions on what to do if someone receives a positive test result after administering a home test), and information about window periods of HIV tests. This education about the types and availability of HIV tests was perceived as useful because it would help guide men in decision-making about which type of test is best for them:

For people who have maybe not got tested before, are not really confident about it, some sort of pro/con list for each [HIV test]... So someone just doesn't

have to look at this and make a decision on their own. [FGD2, Atlanta]

I really like the take a [testing preference] quiz option. So if you have absolutely no idea, you could go through and it will prompt you for which one might be the best for you. [FGD2, Atlanta]

Men also felt that education about HIV should go beyond HIV testing to include information about linkage to HIV care, sexually transmitted infection (STI) information, STI treatment, safer sex tips (especially among sero-discordant couples), pre-exposure prophylaxis (PrEP), non-occupational post-exposure prophylaxis (nPEP), and current HIV research. Men felt that this additional information would provide a more comprehensive education about HIV prevention and was perceived as more "relevant" to the general MSM population because it would benefit all MSM, regardless of HIV status.

Though education was considered important, participants also stated that an HIV prevention app would need to provide more than just information in order to engage app users:

Some sort of a reason to use the app is really important...having all the information on there is good but you could also Google HIV testing centers. I mean, it's possible. The information wouldn't all be in the same place. But having a reason to do it is good...with the testing options, if you could order from there, it would give you like a coupon for 10%, 15% off of a swab kit or something. [FGD1, Atlanta]

#### Interactive Engagement

Participants stated that interactive engagement where app users needed to input information into the app (eg, through sex diaries) could help "keep people coming back using the app" (FGD2, Atlanta). Participants stated that the most frequently used apps involve some kind of "user input" that "gives somebody a reason to go into the app and do stuff on it... it's not strictly information based" (FGD1, Atlanta). Based on this idea of increased engagement, many participants suggested interactive game-like functions as a more enjoyable way to receive information.

Although men were interested in functions that involved interactive engagement, they also recognized that inputting information into an app requires a lot of "commitment" and that the novelty of inputting the information could wear off after a period of time. To address this, participants stated that feedback from inputting information into the app would enhance engagement:

I downloaded the Kinsey survey app...it never gave you end results...it was interesting in a sense to me personally. I don't use it as much anymore because the interest wore off because there was no actual use out of it. Something like this [HIV app] I would probably use because it would be interesting for me to see what the results turned into. [FGD2, Atlanta]

Many participants described wanting community information to "compare it to everyone else that's using the app" (FGD2, Atlanta): I would love if these data were actually aggregated and researched...I would love to see a summary of my city and just in terms of averages or something...[For example], last month the average gay man in this zip code in Seattle had X number of different partners. [FGD4, Seattle]

Participants also expressed wanting feedback about personal behaviors:

I also like this too to see statistics [based on your behaviors]...you were drunk or high 3 out of 10 times [that you had sex...that isn't something that I would necessarily remember or think about. But then if you see something like this and it's like you were drunk or high the past 9 out of 10 times, it's like oh. I like to see where you're at and just personal feedback where maybe some of the other apps might not actually let you see the results. [FGD2, Atlanta]

Well I love seeing these kind of info-graphics and digestible things about me that I don't know already so something that can tell me cool facts about me without me already knowing that in advance is kind of neat. [FGD4, Seattle]

Participants felt that receiving this feedback on personal behaviors could help with HIV prevention by increasing self-awareness of one's own HIV risk:

I think people will sometimes tell themselves this person seems clean, this person seems healthy, he says he doesn't have HIV, we don't have a condom as kind of ways to rationalize it. And then they could be recording and tracking all of that and an app would be able to tell them, "you're engaging in high-risk sexual behavior." And I think, as obvious as it might seem, like oh, you just had bareback sex last night with someone you met online. Of course you should realize, but people I think do that and we would have an app to be able to send that message. They're sitting down and they say, this voice of science and authority in medicine says you are putting yourself at risk of exposure to HIV. [FGD2, Atlanta]

It's easy to say "I am an adult, I know what I'm doing," but that isn't always true. Some people NEED to know the truth about their choices. [OFGD, rural]

App feedback was perceived as even more useful if men were then linked to services based on their behaviors; for example, participants suggested that if an app user reported a lot of unprotected sex, they could be provided with more information about HIV testing.

#### Social Networking

An additional recommendation for making the app more interactive was to incorporate social networking. Participants described using various types of social media (eg, Facebook, Twitter) as well as online hook-up sites and apps (eg, Grindr) and explained how social media could be used with HIV prevention. Some participants talked about sharing their status or sharing the fact that they got tested on sites like Facebook.

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Participants described how sharing this information through social media could encourage testing:

I think sharing it is a good way to get the word out and to encourage your friends to go or you to go. If you see that four friends got tested in the past week or two weeks or whatever, then you might be more inclined to go yourself. [FGD1, Atlanta]

I think [posting that you got tested on Facebook] is a really good idea because every time I get tested, I post it on Facebook. I don't post the results but I ask all my friends, do you know if you're HIV positive or not? I just got tested and I usually give the address of where I went. [FGD2, Atlanta]

Posting information about testing on social media was also perceived as a way to reduce stigma around HIV and MSM:

It might be nice to...have the option of putting out a message on Twitter or Facebook so you can say, "I just got tested, I know my status"...a lot of the voting, blood drives, they give you a little sticker that says I just did something and you feel good about it because you were responsible, did something you were supposed to do. And I think there's usually not a lot of that around HIV testing because of the stigma around HIV or around men who sex with men when in reality, there's lots of people out there getting HIV tests all the time. And it could be a social message to put out there. [FGD2, Atlanta]

# Language and Tone

Participants identified a need to present information in the app using simple language that is straightforward and concise: "I'm just thinking of things for lower intelligence levels, like writers for the newspaper are supposed to write on a fourth grade level" (FGD1, Atlanta). There was disagreement about the preferred tone of an app, with participants explaining the importance of two preferences for language: friendly and sexy versus professional and authoritative. In Seattle, participants proposed using sexier and "playful" language and content:

What is it that would make it fun to use or what would be a way to deliver the information in a way that people would actually want to digest it?...I'm thinking of a very extreme idea, but...what is it that gay men like? Well, they like sex. They like porn...what if instead of a clinician delivering the information, what if you actually have a video of two hot guys having sex and one guy is talking to the camera and he's showing someone how to put on a condom properly and it's not some clinical bullshit, it's a hot guy with a hard on about to have sex, putting on a condom the right way. [FGD3, Seattle]

Friendly, fun, and humorous language that is more subtle when addressing HIV and risk behaviors was described as less stigmatizing and less judgmental:

These [risky behaviors] are public health concerns and they need to be subversive and they need to be kind of a joke...because I don't want to be preached

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at. As a gay man, I am subjected to enough external guilt about what I do and how often I do it and how I do it and with whom that I really don't want extra guilt about I haven't been tested in however long or I'm engaging in risky behaviors because the purpose is not to criticize, the purpose is to change the behavior and to get people the health care that they need. So I think you really have to put a premium emphasis on being sneaky about it and subversive. [FGD3, Seattle]

On the other hand, participants in all locations identified wanting respected and trustworthy information and language: "We don't want something 'cute' we want something authoritative...something that promotes security and trust" (OFGD, rural). Authoritative language was perceived as increasing the credibility of the app and the information that the app provides.

#### **Target Population**

Participants expressed differing opinions regarding the app's target population with variation occurring within cities and within groups. Some participants recommended functionality specifically targeting gay men, while others expressed concerns about making the app "too gay". Men felt that if the app targets gay men, then it would exclude some men and "would make it definitely not attractive to the bisexual/straight community" (OFGD, rural). Multiple participants across FGDs stated that if the app has a more general target population, then it may reach a wider population of men who may not be getting tested for HIV:

I just want to bring up a point...for lack of a better word, not to make this too gay, I think a lot of the problem of people not getting tested is they think HIV is a gay disease... A lot of people who don't have that information are probably more in the closet or they live somewhere where they can't be who they are or they're not gay and they're something else on the spectrum and they don't want to necessarily read articles from [an Atlanta LGBT news source] or something similar on this sort of app...it can focus on that LGBT community but maybe not be so overt about it, just to encourage as many people to use it as possible. [FGD1, Atlanta]

Some participants identified the app as "universal" and therefore suggested that it should not specifically target the gay community. Men suggested that the app could be advertised for gay men and used by gay men, but that the app itself does not need to have content or language that exclusively targets the gay community.

Some rural men especially felt that the app should not target just gay men and expressed concerns that this would be "discriminatory" and "make gays feel more in the spotlight" (OFGD, rural). However, rural men also felt that targeting MSM was important because it "targets the high risk area" and "it is targeted to those who will most likely be looking for the information" (OFGD, rural). Participants in other FGDs also identified the importance of including content that is specifically aimed at gay, bisexual, and other MSM, such as providing

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resources on gay-friendly testing locations, providing health information on gay sex, incorporating gay blogs or local gay news sources, aggregating collected data to provide fun HIVand sex-related statistics on the gay community etc.

## Willingness to Use the App

#### **Overview**

Participants varied in their willingness to use the app and share data; this variation occurred both between and within groups and study sites. Some men said that they would not be willing to share very personal and private data with the app, especially data related to sexual experiences and HIV status:

I think the information that [the app] is asking is way too much, private. I would never submit those kind of information to an app. I don't trust the privacy of that. If you ever put your email address in there, you never really know. [FGD1, Atlanta]

Uncertainty about inputting information and sharing data were specifically related to privacy and concerns about who would be able to access the information. Some men were concerned about the potential for negative consequences if private health information or data about sexual experiences were accessed by others:

To me it looks like an information-gathering thing...almost like a big brother. This government has access to everything on your phone in one way or another...But if your insurance starts to deny you based on you being too promiscuous because they've got information on the average gay men has sex however many times a month. And that's what it's going to get to when the prices of insurance start going up and things like that. It gets more and more difficult. They already do it with cars. You know, you can get an insurance rate based on that little thing you plug under your dash. [FGD1, Atlanta]

However, many participants also expressed a willingness to use the app and share data. Participants stated that men may be willing to share data if the app promotes altruistic motivations for engagement. One such form of altruistic motivation is sharing data for the purpose of research or to help health organizations: "I think the value of this information...if you opted to share that information anonymously that would be very helpful for health organizations to know what's going on" (FGD3, Seattle). Men also suggested using altruistic motivations by providing financial incentives to HIV organizations when men input and share data with the app:

I think altruism is a good thing to build with apps. There's one on My Quiz where...for every question you get right they donate a pound of rice to the third world or something like that. So, facts about HIV, whenever you do it there's a donation made by one of the sponsors to the AIDS Foundation or some research association...I think the altruism could be a way to incorporate more engagement. [FGD4, Seattle]

#### **Privacy and Discretion**

Though participants expressed many concerns about privacy, some participants explained that if they trusted the app and the app's creator, then they may be more willing to share private information. Men also explained the importance of discretion with an HIV prevention app aimed at MSM: "There's a degree of discretion that someone might want with the content...If they're looking at these things...they're not going to be doing it just at home" (FGD3, Seattle).

One suggestion was to be careful about icons and language, so that if others were to gain access to an app user's phone, they would not identify what the app is:

I could imagine if someone gets an HIV positive result, they're not going to want that to be something that oh, my little sister picks up my phone and sees this. So I would just be very thoughtful about how you designed those features... I think that would be critical to make sure that that's done in a way that minimizes the risk of any type of exposure that people don't want. [FGD2, Atlanta]

I've had friends ousted on various social media and apps so and even just having the icon of Grindr on someone's phone, it's a very distinct tell...I can only imagine if I wasn't out that would be something that I would be very concerned. I don't know if I would keep an app like that on my phone at all, just because I wouldn't want to be found. [FGD4, Seattle]

Discretion was considered to be especially important when sending push notifications to the phone:

I think the wording of [push notifications] would be pretty important not to have anything about HIV testing or something pop up on your screen. Your phone could be wherever. [FGD1, Atlanta]

I am often times in meetings and it's often me who's projecting up on a giant computer. The last thing I want is the schedule plus alert saying that it's time for me to get an AIDS test. [FGD3, Seattle]

Participants also recognized the importance of password-protected data and suggested using a separate password for the app.

#### Perceived Impact of the App

Participants discussed a perceived impact that the app could have for individuals who use the app, for sexual partnerships, and for the MSM community as a whole. For individuals, men recognized that the app could be a useful personal tool that "provides a lot of accountability" (FGD2, Atlanta) for one's sexual health and sexual decision-making, increases personal awareness and "self-analysis" of one's behaviors, assists with ownership over health behaviors, and could help men make "active attempts to stay healthy" (FGD3, Seattle). As a way to promote self-care for individuals, participants recognized that the app could have a useful impact by connecting individuals to resources, tracking sexual behaviors, and tracking HIV test results; these functions could help to increase self-awareness and could be "psychologically useful" (FGD3, Seattle). In this



regard, participants saw the app as doing more than just encouraging HIV testing; they perceived it as a "useful life tool" (OFGD, rural). As a link to resources, participants identified the app as useful to all MSM, but also as something that could be especially useful to MSM who live in regions that do not have a lot of gay-friendly HIV services: "I think in some places, the places that are more rural, this would actually be even more useful because there's less general knowledge of services" (FGD2, Atlanta).

The app was also seen as a useful way to discuss HIV with partners and friends and to help identify others who are also "taking the proactive steps" (FGD1, Atlanta). Participants stated that if others had this app on their phone, then they would not necessarily assume that they were HIV-negative, but they would identify that person as someone who is "more responsible" in terms of their sexual health. Men also stated that the app could be used as a tool for conversations with partners about HIV and that men would like to share dates of HIV tests and results with their partners through the app.

For the community, participants recognized that an HIV prevention app could help promote a culture where self-care around sexual health is a priority and is normalized: "If the goal of the [calendar and reminder] function is to promote a new culture where the testing is part of our self-care, [the function] is important because it'll encourage the culture to start to form over time" (FGD3, Seattle). Participants also discussed the importance of the app in promoting a nonjudgmental and sex-positive space for men to discuss issues of sexual health within communities:

The gay community that really needs something like this is very social about this conversation and having like a little Facebook where everybody gets to log on and call each other sluts would actually be fun and for the people who really need this functionality, they're talking about it amongst each other anyway, I think. [FGD3, Seattle]

The app was not perceived as something that would exist on its own, but rather a tool that could be used in conjunction with the HIV prevention efforts that are already occurring in the MSM community:

We used to go out to the bars with literally safety pins and hand them out and give them to people and it was something that as a community we did as an outreach to educate people...but I don't see a lot of that, and when I see a profile of somebody that's 22 years old that's HIV positive online, my thinking is what are we doing as a community that we failed this person?...it's a hard disease to get and it's easy to avoid and if you just have the right information. And I think that we're not getting that out there...so this app really what it should be doing is augmenting what we as a community are already doing, which means we as a community maybe need to also think about how we can deal with this because it boggles my mind. 22 years old and HIV...we celebrate birthdays as a community, we sober up as a community, we celebrate

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momentous times in our life as a community, so why are we not coming together for this? [FGD3, Seattle]

# Discussion

### **Principal Findings**

In summary, participants described a comprehensive app that should incorporate innovative ideas to educate and engage men to increase motivation to use the app. Participants also suggested using existing social media platforms to engage MSM in HIV prevention. In order for an app to be useful, it needs to feel safe and trustworthy, which is essential when considering the app's language and privacy. Regardless of precautions that may be taken, some men may not feel comfortable inputting personal information in an app; however, if the app proves to be credible and has safeguards to ensure discretion and privacy, then MSM may be more willing to use it. Men also expressed a willingness to share data anonymously if it would contribute to research about their community or help AIDS service organizations. These findings suggest that if an HIV prevention app can be developed so that MSM will be motivated to use it, then it may be able to simultaneously address individual, interpersonal, and community-based needs for HIV prevention.

Our findings are similar to results from other studies examining MSM's preferences for app use. Others have identified similar desires for sex education and links to resources, such as STI and HIV testing, gay-friendly providers, and resources for MSM who are living with HIV [26-28]. Participants' discussions of the use of social networking for HIV prevention augment previous reports about effective interventions based in social media sites, such as Facebook [29,30]. These studies use Facebook as a means to provide an intervention, but participants in this study suggested using an app that links with existing social media to encourage increased use. Expressed preferences also align with guidelines for mHealth practices [31], which suggest that mHealth interventions use scalable platforms, offer sustainable possibilities, address a willingness for app use, encourage continued engagement, provide connections to social networks, and measure social network and/or geographic data [31].

Many of the participants' suggestions are based on what they want in an app, but this often also aligned with what men might need for HIV prevention; for example, participants expressed a desire for increased accountability to improve HIV risk-reducing behaviors and encouragement for increased HIV testing. Many of the participants' suggestions also addressed how to make the app more fun (eg, games, sexy content). Although these suggestions might not be as directly related to what men need for HIV prevention, they are still useful. Making an HIV prevention app enjoyable and usable for MSM is a challenge; however, the usability of the app is vital because no matter how great the intervention, if MSM do not use the app, then it will not be useful.

Identifying the appropriate language to make an app enjoyable yet usable may be challenging, as sometimes participants' suggestions were contradictory. Participants expressed wanting the language and tone of the app to simultaneously be professional, credible, and trustworthy, while also including

language that is more sexy, fun, and nonjudgmental. This variety in app preferences, especially regarding language, identifies a need for customizable app options. One possibility for addressing these contradictory app preferences is to build the app using two different options for language and allow app users to customize their app by choosing the voice or tone that they want their app to have. However, this option may not be feasible as it would require twice as much work for building the app. A more cost-effective option may be to incorporate more formal or clinical language for some features (eg, for a description of HIV tests), but more informal or conversational language for other features (eg, for behavioral assessments). Based on these findings, we learned that it is important to find the right balance of language in the app so that it is sexy and fun, but not so much that it discredits the feeling of authority of the app. According to participants, it is also important that the language be nontechnical and easy for anybody to understand. Formal language should still be simple and nonjudgmental.

#### Limitations

There are some limitations in this study. These qualitative findings may not be transferrable to a larger population of MSM. Only 16% of participants in this study identified as black/African American, all of whom were in the Atlanta FGD. The greater recruitment of African American MSM in Atlanta is reflective of Atlanta's population [32], but more direct targeting for young African American MSM may have been useful to ensure the inclusion of the population most at risk for HIV [1,33]. Furthermore, MSM who identify as gay or bisexual and include that they are seeking other men on Facebook may not represent MSM in general. However, recruitment occurred in two different cities where populations, culture, and HIV efforts vary. This

study also included rural MSM nationwide; rural MSM face unique challenges related to HIV, such as a lack of resources or increased stigma [34-39]. We found some geographical variation in responses but also agreement among participants in different locations. Additional FGDs, especially with rural men, may have provided greater variation. FGDs with rural men were limited by the online environment. Men participating in these groups needed to have access to a computer with Internet. Furthermore, the facilitator was unable to use nonverbal cues to assist with probing questions. Despite these limitations, the OFGD was useful for capturing a population that would have otherwise not been able to participate in this study and the OFGD supplemented the in-person FGDs by highlighting the similarities and differences in opinions that MSM have in other regions throughout the United States.

# Conclusions

Bringing HIV prevention services to scale for MSM is a critical prevention priority [5,40]. At a time when mobile phone use has become the norm in the United States [7] and mHealth is advancing and becoming a more popular medium for HIV prevention interventions [11,22], it is important to understand preferences for mobile apps to deliver public health interventions. In order for an HIV prevention app that targets MSM to be useful, it needs to address the challenges and barriers that MSM face with HIV testing and HIV prevention, while also appealing to the community as a fun, trustworthy, and easy-to-use app. Participants suggested that if successful, this type of intervention could have a great impact on HIV prevention. However, in order to be successful, additional efforts must be made to address MSM's wants and needs regarding HIV prevention and interventions based in mobile technology.

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# **Conflicts of Interest**

None declared.

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# Abbreviations

CDC: Centers for Disease Control and Prevention FGD: focus group discussion HIV: human immunodeficiency virus MSM: men who have sex with men OFGD: online focus group discussion nPEP: non-occupational post-exposure prophylaxis PrEP: pre-exposure prophylaxis SMS: short message service STI: sexually transmitted infection



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# Parent-Targeted Mobile Phone Intervention to Increase Physical Activity in Sedentary Children: Randomized Pilot Trial

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# Abstract

Background: Low levels of moderate-to-vigorous physical activity are associated with adverse health consequences.

**Objective:** The intent of the study was to determine the feasibility and efficacy of a 12-week physical activity promotion program targeting children, which was delivered to parents through mobile phones.

**Methods:** Potential participants were recruited through advertisements placed in the newspaper, local hospitals and schools, and an email listserv. Sedentary children aged 6-10 years were randomly assigned to a minimal (MIG) or intensive (IIG) intervention group. Parents in the MIG were given a goal to increase (within 1 month) and maintain their child's activity at 6000 pedometer steps/day above their baseline levels and to monitor their child's steps daily. Parents in the IIG were given the same steps/day and monitoring goals, in addition to text messages and articles containing additional behavioral strategies (based on the Social Cognitive Theory) designed to promote their child's physical activity. The intervention components were delivered via mobile phone. Anthropometrics, body composition, and questionnaires were administered in a clinic. Children wore a New Lifestyles pedometer (NL-1000) each day throughout the intervention and parents were to monitor their child's step counts daily.

**Results:** Out of 59 children who screened for the study, a total of 27 children (mean age 8.7, SD 1.4 years; 56%, 15/27 female; 59%, 16/27 African American) were enrolled and completed the study. Overall, 97.90% (2220/2268; 98.20%, 1072/1092 for MIG; 97.60%, 1148/1176 for IIG) of expected step data were successfully entered by the parent or study coordinator. Parents in the MIG and IIG were sent approximately 7 and 13 text messages per week, respectively, averaged over the course of the study. IIG parents accessed an average of 6.1 (SD 4.4) articles over the course of the intervention and accessed a fewer number of articles in the last month compared to the first 2 months of the study (P=.002). Children in both the MIG and IIG significantly increased their physical activity, averaged over 12 weeks, by 1427.6 (SD 583.0; P=.02) and 2832.8 (SD 604.9; P<.001) steps/day above baseline, respectively. The between group difference was not statistically significant (P=.10; effect size=.40), nor was the group by time interaction (P=.57). Regardless of group assignment, children who significantly increased their physical activity enjoyment (P=.003). The number of behavioral articles accessed by IIG parents was significantly correlated with change in children's steps/day (r=.575, P=.04). Changes in children's steps/day were unrelated to changes in their body composition, mood, and food intake.

**Conclusions:** Parent-targeted mobile phone interventions are feasible, yet more intense interventions may be needed to support parents' efforts to increase their children's physical activity to levels that approximate national recommendations.

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## **KEYWORDS**

mobile health; physical activity intervention; child; parents; pedometers; text messaging

# Introduction

Low levels of moderate-to-vigorous physical activity are associated with adverse health consequences. Specifically, epidemiological studies demonstrate that low levels of physical activity are positively associated with childhood obesity [1]. Accumulating evidence suggests that total physical activity levels and time spent in moderate-to-vigorous physical activity are inversely associated with cardiovascular disease (CVD) and diabetes risk factors [2-9]. Therefore, increasing intensity of physical activities or time spent being physically active may have a significant impact on reversing excessive adiposity in children and reducing their risk of developing chronic disease.

Parents have an important role in teaching and encouraging their children to be physically active. For example, cross-sectional and prospective studies provide evidence that parental support and rules, as well as physical activity modeling and co-participation, are positively associated with objectively measured moderate-to-vigorous physical activity levels in children [10]. In addition, favorable parental perceptions of neighborhood safety and reports of frequent family trips to the park are related to parental reports of children's increased time in free play [11]. Despite these correlational findings, reviews of interventions for children in which physical activity promotion was the main component, or at least one of the intervention components, concluded that family-based interventions have not yet demonstrated strong evidence of effectiveness [12-15]. However, the authors of the reviews noted that many of the family-based interventions have had methodological limitations, including failure to use randomized comparative interventions, high dropout rates, and/or a reliance on self-reported outcome assessments [12-15]. These limitations, coupled with the fact that family-based approaches have shown great success with weight management in children [16-18], suggest that there is a need to improve upon the methods used in family-based interventions targeting physical activity promotion in children.

There has been an increase in the use of mobile phones as an intervention delivery strategy. Mobile phones contain several features appealing to researchers. Mobile phones are portable, which provides the opportunity to collect real-time data [19] and to aid in self-monitoring [20]. Furthermore, participants view text messages as more convenient and effective than other types of communication [21], text messages can be personalized and can augment behavior change strategies [22], and mobile phone-based interventions have been shown to be cost-effective compared to alternative interventions [23]. Several different mobile phone-based interventions have been designed to increase physical activity in children. These interventions were either solely focused on increasing physical activity [24] or

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offered a physical activity component as part of a larger intervention (eg, weight loss, diabetes management) [25-29]. Importantly, reviews [30-32] have concluded that mobile health interventions can increase physical activity in children, though few mobile phone-based interventions have been conducted. To date, none of these mobile phone studies have delivered the physical activity intervention exclusively to parents. Therefore, interventions delivered through mobile phones promise a novel approach to family-based physical activity promotion.

Few family-based interventions have exclusively targeted children's physical activity [33-37]. These studies have not consistently produced positive results. Mobile phone-based interventions are promising, yet to the best of our knowledge, no childhood physical activity study has delivered a mobile phone-based intervention exclusively to the child's parents with the intent of increasing the child's physical activity. In addition, the clustering of risk factors for CVD develops between 6 and 9 years of age [38], providing an appropriate target age-range for intervention. Therefore, the primary aim of this pilot study, "P-Mobile", (trial registration NCT01551108) was to determine the feasibility of delivering a physical activity promotion program targeting 6-10 year old children that is delivered to parents through mobile phones. A second aim was to determine whether or not the intervention could elicit objectively determined increases in children's physical activity.

# Methods

#### Participants

Children who were 6 to 10 years of age, physically capable of exercise, and sedentary were eligible for the study. A parent or legal guardian of each participating child was eligible if they owned a mobile phone with Internet access and text message capabilities. Children were excluded if they were diagnosed with a serious medical disorder (eg, cancer within the last five years, cardiovascular disease). Families were compensated US \$200 for their time, mobile phone data use, and travel costs. All study procedures were approved by the Pennington Biomedical Research Center Institutional Review Board.

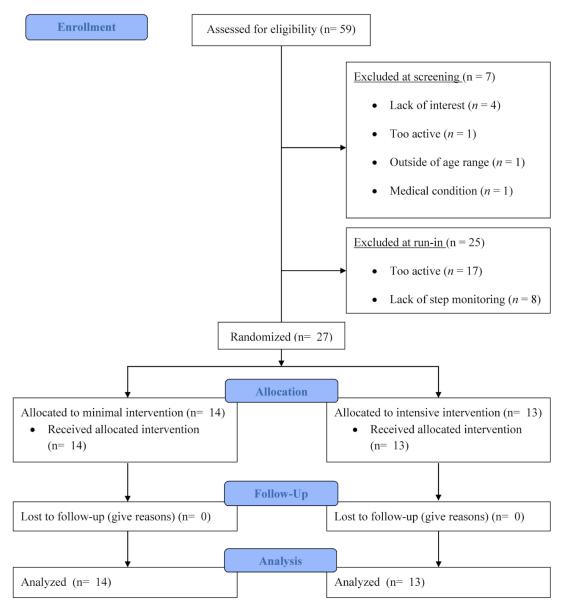
#### Procedures

Potential participants were recruited through advertisements placed in the newspaper, posted in local hospitals and schools, and delivered through a Pennington Biomedical Research Center email listserv targeting registered individuals interested in participating in research. Once self-identified, one parent completed an initial telephone screen to determine eligibility for themselves and their child. If the parent-child dyad was eligible following the phone screen, they attended a clinic screening visit at the Pennington Biomedical Research Center (Louisiana). The dyad was oriented to the study and then written

informed consent was obtained from the parent and written assent was obtained from the targeted child. The baseline assessment (see Measures below) was then conducted. At the end of the clinic visit, the targeted child was fitted with a pedometer (New Lifestyles 1000/NL-1000), the parent was required to use their mobile phone to respond to a text message sent from the study coordinator, and the parent had to access the study website. The dyad was sent home with the following instructions: the child was to engage in their normal level of activity and the parent was instructed to use their mobile phone to access the study website [39] to record their child's step count each night after the child laid down to go to bed. This website was formatted for a mobile phone and contained a webpage to enter the date and the child's step count. Following the clinic visit, the dyad was sent home to begin the 7-day run-in period the following morning. The run-in period was designed to assess

the targeted child's baseline physical activity levels and the parent's compliance with monitoring the child's step counts. The dyad was eligible for the study if girls averaged <9500 steps/day or boys averaged <12,500 steps/day (sex-specific cut points indicative of sedentary behavior in children) [40] and parents entered at least 5 days of step counts into the study website across the 7-day run-in period (evidence of ability to comply with data recording requirements). The dyad was not made aware of these eligibility criteria so that they did not alter their behavior in order to qualify for the study. Those dyads meeting eligibility criteria at the end of the run-in period were randomly assigned to either the minimal (MIG) or intensive (IIG) intervention group. Among the 59 dyads showing interest, there were 27 dyads eligible for the study, 14 were randomized into the MIG and 13 into IIG (Figure 1).

#### Figure 1. Study flowchart.



#### Interventions

## Overview

This study was a randomized comparative behavioral trial of a minimal versus an intensive intervention delivered to parents via mobile phone with the purpose of increasing physical activity in sedentary children. A block randomization procedure was generated by a study statistician (HH) utilizing SAS software, with a block size of four. The randomization sequence was placed in sealed, numbered envelopes. The clinic coordinator opened the next envelope in the sequence after a participant successfully completed all eligibility criteria. Children in both study groups were instructed to wear a study-provided pedometer every day during the course of the 12-week intervention.

## **Minimal Intervention Group**

Parents in the MIG were given access to a version of the website (formatted for a mobile phone) in which they could view their

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child's daily step goal, monitor their child's step counts, and receive monthly nutrition tips (Table 1). The website provided parents with a target steps/day goal for their child, which was intended to increase their child's physical activity by 1000, 3000, and 6000 steps/day above the child's individualized baseline during the first, third, and fourth week of the intervention, respectively. The additional 6000 steps/day above the baseline level was to be maintained from weeks 4-12. This total increase of 6000 steps/day above baseline was selected to approximate the current national recommendation of 60 minutes of physical activity per day for children [40]. Parents in the MIG were instructed to use their mobile phone to access the study website to record their child's step count each night after the child laid down to go to bed (Figure 2). Parents in the MIG were also sent monthly healthy nutrition tips via text message targeting the child in order to provide these families with potentially health promoting information.

Table 1. Components of the minimal (MIG) and intensive (IIG) intervention groups.

Intervention component	MIG	IIG
Access to mobile phone formatted website	X	X
6000 steps/day goal	Х	Х
Daily step monitoring	Х	Х
Monthly nutrition tips	Х	
Weekly behavioral articles		Х
Behavioral text messages		Х
Steps/day graph		Х

Figure 2. Mobile phone screenshot showing pedometer step count entry on P-Mobile website.

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#### Intensive Intervention Group

Parents in the IIG were given access to a version of the website in which they could view their child's daily step goal, monitor

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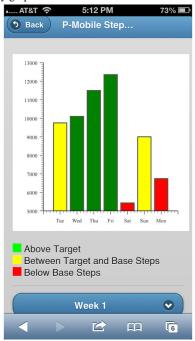
their child's step counts, view a steps/day graph, and read weekly behavioral articles, and they also received text messages. The step monitoring and steps/day website components and goals were identical to the MIG. The steps/day graph was

color-coded to illustrate how their child's daily steps compared to the target step goal: red bars represented days in which the child's step count was below baseline, yellow represented step counts between baseline and the goal, and green represented step counts at or above the goal (Figure 3). Behavioral strategies based on the Social Cognitive Theory (Table 2) were adapted from previous interventions [41-43] and were delivered through weekly articles posted on the website (Figure 4) and via text messages. The average length of each behavioral article was 621 words. Each text message was  $\leq 160$  characters. Text messages were designed to prompt parents to encourage their child's physical activity (eg, "This is a reminder for your child to be physically active!"), remind parents of behavioral concepts presented in the articles (article tip; eg, "A slip is a time where your child goes several days without reaching their activity goal. Try to stop slips as soon as you can."), and motivate parents to foster behavioral change in their child (eg, "By engaging in regular physical activity, your child will reduce their risk of gaining weight.").

Table 2. Behavioral articles provided to parents in the intensive intervention group (IIG).

Week	Title	Content	
1	Self-monitoring	Parental monitoring of child activity, role of parent in child's activit increase steps/day by additional 1000.	
2	Making time for exercise	Goal setting, scheduling time for activity, what is moderate intensity activity, maintain increased step/day of additional 1000.	
3	Increasing activity outdoors	Benefits of outdoor play, role of the parents in child's physical activity, increase steps/day by additional 2000.	
4	Increasing activity indoors	Cues to activity, changing the home environment, increase steps/day by additional 3000 (achieve $\geq 6000$ steps/day above baseline).	
5	Checking-in #1	Identify barriers to achieving goal.	
6	Problem solving	5-step problem-solving process.	
7	Rewarding your child	Principles of positive reinforcement, rewards for increased activity.	
8	Reducing sedentary time	Defining and identifying sedentary behavior, ways to reduce sedentary behaviors, substituting physical activity.	
9	Checking-in #2	Identify barriers to achieving goal.	
10	Lifestyle exercise	Incorporating activity that is part of daily living.	
11	Parental modeling/social support	Parents as a role model for physical activity, obtaining social support from family members.	
12	Relapse prevention	Defining and anticipating slips and relapses, ways to respond to slips.	

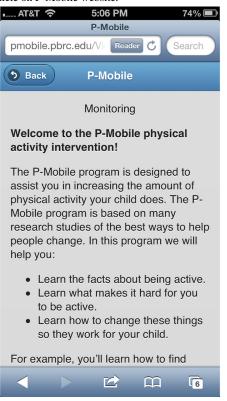
Figure 3. Mobile phone screenshot showing steps/day graph on P-Mobile website.





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Figure 4. Mobile phone screenshot showing an article on P-Mobile website.



#### Measures

#### **Overview**

All measures, with the exception of the pedometers and the Home and Neighborhood Environment Questionnaire, were assessed at baseline and 12-weeks. The assessment staff was not blinded to the participant assignment.

#### Pedometer

Children in both groups were asked to wear a NL-1000 pedometer for the duration of the study. The device has a 7-day memory and steps are also digitally displayed on an immediately accessible screen. The NL-1000 contains the same internal mechanism as the NL-2000, which has been previously validated for counting steps in children [44]. Children were instructed to wear the pedometer during all waking hours except during water-based activities.

#### Anthropometrics

Height and weight were measured with the child dressed in normal street clothes, but without shoes and socks. Height was measured to the nearest 0.1 cm using a wall-mounted stadiometer (Holtain Ltd, Crymych, Dyfed, United Kingdom). Weight was measured to the nearest 0.1 kg using a digital scale (Indiana Scale Company model GSE 450). Waist circumference was measured to the nearest 0.1 cm at the natural waist, with clothing moved out of the way. The circumference was taken twice, with a third measurement taken if the first two were more than 0.5 cm apart. Body mass index (BMI) was calculated by dividing the participant's average weight in kilograms by the square of their height in meters (kg/m<sup>2</sup>). BMI was converted to a *z*-score using gender and age data from the Centers for Disease Control and Prevention, to account for the fact that children of

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this age are still growing. Blood pressure and pulse were taken after the participant sat quietly for 5 minutes.

#### **Body Composition**

The Tanita Body Composition Analyzer (model TBF-240) was used to estimate body fat. The child stood on the scale with bare feet, and impedance data were recorded using a laptop computer. The Tanita has a mean difference of -1.0% with DXA and is considered to be very reliable in children [45].

#### Questionnaires

Children completed two questionnaires, with the assistance of a study staff member to ensure the child understood all questions. Parents were allowed to be present during the questionnaire administration if the child preferred. The 12-item Physical Activity Enjoyment Questionnaire (PACES) [46] was used to assess the level of a child's enjoyment of various physical activities. The Child Depression Inventory-Short Form (CDI-S) [47] contains 10 items to assess symptoms of childhood depression and was used to measure self-reported depressed mood.

Parents completed three questionnaires. The Sedentary Behavior Questionnaire was completed to describe the amount of time their child spent watching TV, playing video games, playing on the computer, and doing other sedentary activities. The Home and Neighborhood Environment Questionnaire, adapted from the Neighborhood Impact on Kids study [48,49], assessed parent's perceptions of their home and neighborhood environment, including safety, availability of destinations, and suitability of the neighborhood for walking and physical activity. The Food Frequency Questionnaire (FFQ) [50] was completed to describe their child's food intake, including information about macro/micronutrients and food group servings.

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## **Statistical Analysis**

Weekly steps/day means analyzed across all 12 weeks of the study were analyzed using a repeated measures analysis of variance. Change in the secondary outcome data (eg, BMI, body composition, questionnaires, website usage, etc) were analyzed using dependent samples t tests. Correlation coefficients were used to assess the relationships between secondary outcome measures and steps/day data. Effect sizes were calculated using Cohen's d. All statistical analyses were conducted using SAS version 9.3.

# Results

# **Baseline Characteristics**

Characteristics of the participating children are summarized in Table 3. A total of 27 children (mean age 8.7, SD 1.4 years;

Table 3. Baseline demographic characteristics for all children.

56%, 15/27, female; 59%, 16/27, African American) successfully completed the run-in period and were randomly assigned to the MIG (n=14) or IIG (n=13). The sample of 27 children had a mean BMI equal to 23.1 (SD 7.7) kg/m<sup>2</sup>, a mean BMI *z*-score equal to 1.5 (SD 1.0), a mean BMI percentile of 85.6 (SD 20.2) kg/m<sup>2</sup>, and mean waist circumference equal to 72.4 (SD 18.1) cm. Participating children across both intervention groups averaged 8621.8 steps/day and the difference in steps/day between the intervention groups was not statistically significant (MIG: 9042.5 vs IIG: 8168.6, *P*=.25). The only significant difference between intervention groups was percent of reported calories consumed from protein (MIG: 16.7% vs IIG: 19.1%; *P*=.047).

Characteristic	All children	Minimal intervention	Intensive intervention
	(N=27)	(n=14)	(n=13)
	n (%) or mean (SD)	n (%) or mean (SD)	n (%) or mean (SD)
Age (years)	8.7 (1.4)	9.1 (1.3)	8.3 (1.5)
Gender (% female)	15/27 (56%)	7/14 (50%)	8/13 (62%)
Ethnicity (% African American)	16/27 (59%)	8/14 (57%)	8/13 (62%)
Height (cm)	138.1 (10.7)	140.0 (8.3)	135.9 (12.9)
Weight (kg)	45.5 (19.7)	44.5 (18.3)	46.5 (21.9)
$BMI^{a} (kg/m^{2})$	23.1 (7.7)	22.3 (7.4)	24.1 (8.1)
BMI z-score	1.5 (1.0)	1.3 (0.9)	1.7 (1.0)
BMI percentile	85.6 (20.2)	83.7 (21.0)	87.6 (20.1)
Waist circumference (cm)	72.4 (18.1)	70.5 (17.0)	74.5 (19.7)
Body fat percent	31.1 (11.2)	29.0 (10.3)	33.4 (12.1)
CDI-S <sup>a</sup>	47.1 (9.2)	47.3 (8.9)	46.8 (9.9)
Physical activity enjoyment	66.6 (7.0)	67.5 (7.9)	65.6 (6.2)
Sedentary time (weekday hours)	5.1 (4.0)	4.9 (4.1)	5.4 (3.9)
Sedentary time (weekend hours)	8.3 (5.4)	8.2 (5.0)	8.4 (5.9)
TV in room	16/27 (59%) yes	5/14 (36%) yes	11/13 (85%) yes
Total calorie consumption	1587.1 (647.5)	1520.6 (628.7)	1658.7 (685.1)
Steps/day	8621.8 (1955.0)	9042.5 (1930.5)	8168.6 (1953.2)

<sup>a</sup>BMI: body mass index

<sup>b</sup>CDI-S: Child Depression Inventory-Short Form

# Website Data

Parents across both groups logged into the website an average of 76.7 (SD 20.1) times over the course of the study (6.3 times/week). Parents were instructed to enter their child's step counts daily, and parents in the MIG and IIG, respectively, entered 44.20% (520/1176) and 62.80% (686/1092) of their child's step counts daily as instructed. Parents could also enter step count data for up to 7 days past the date the activity occurred. Another 40.60% (478/1176) and 27.00% (295/1092) of data was entered on a subsequent day for a total of 84.80%

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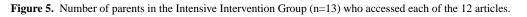
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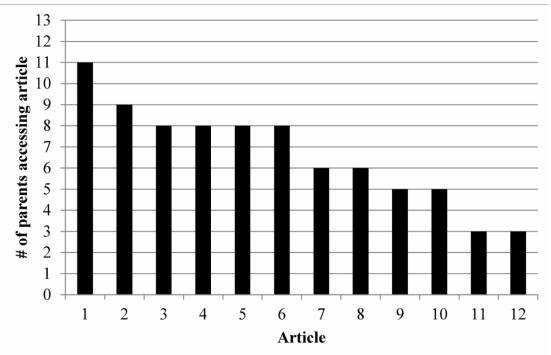
(997/1176) and 89.80% (981/1092) of step counts being entered by the parents in the MIG and IIG, respectively. The remaining 13.40% (158/1176; MIG) and 7.80% (85/1092; IIG) of the data were entered by the study coordinator because either the parents sent this information to the coordinator (via text message) or because the study coordinator contacted the parents (via phone) to retrieve missing data when identified. Overall, 97.90% (2220/2268; 98.20%, 1155/1176 for MIG; 97.60%, 1066/1092 for IIG) of expected step data were successfully entered by the parent or study coordinator.

Figure 5 shows the number of parents in the IIG who accessed each of the weekly behavioral articles. Approximately 38% (10/27) of the parents accessed 9 or more articles, 23% (6/27) accessed between 4 and 8, and 38% (10/27) accessed less than 4 articles, with two parents never accessing an article. Overall, IIG parents accessed 70% (8/12) of the articles in Month 1, 60% (7/12) in Month 2, and 37.5% (5/12) in Month 3. Article

accessing decreased significantly over the course of the study (P=.002).

Parents in the IIG visited the steps/day graph an average of 25.3 (SD 24.5) times over the course of the study (2.1 times/week). There was a clear dichotomy in access, with six participants accessing the graph fewer than 8 times, and seven accessing the graph more than 21 times.





## **Text Messages**

Parents in the MIG were sent 1-2 text messages and parents in the IIG were sent 7-8 text messages per week during the first 6 months of the study. However, daily text message reminders were implemented after the first four participants completed the study in an attempt to increase compliance with parent monitoring of the child's daily steps. Therefore, parents in the MIG and IIG were sent approximately 7 and 13 text messages per week, respectively, averaged over the course of the study.

Parents in the MIG sent 162 (0.96/week) and parents in the IIG sent 419 (2.7/week) text messages over the course of the study. Approximately half of the text messages sent by parents in both groups were communications with the study coordinator regarding missing step data. The other text messages sent by

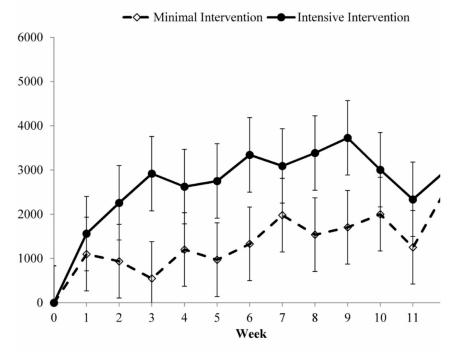
the parents were related to equipment/resource issues (eg, pedometer, website), requests for further information (eg, spontaneous questions, scheduling), or responses to a text message they had received.

#### **Step Counts**

All randomized children attended the Week 12 visit and thus completed the 12-week study. Figure 6 graphically illustrates the weekly changes in steps/day for the two intervention groups. Children in the MIG and IIG both demonstrated significant increases across the 12 weeks by 1427.6 (SD 583.0; P=.02) and 2832.8 (SD 604.9) steps/day (P<.001) above baseline, respectively. The between-group difference was not statistically significant (P=.10) yet the effect size was d=.40. The group by time interaction was not significant (P=.57).



Figure 6. Average change in child's steps per week by intervention group.



#### **Secondary Analyses**

Table 4 shows that none of the changes in body composition variables, including BMI, BMI z, waist circumference, body fat percent, and fat free mass were significant (all P values >.22). Further, there were no significant within or between-group differences in the parent proxy-reported measures, including sedentary behavior and food intake, or child self-reported physical activity enjoyment, and depressive symptoms (all P

values >.38). Therefore, the data from the groups were combined to assess the relationship between the change in these secondary outcome measures and change in steps/day. The correlation between change in physical activity enjoyment and change in steps/day was statistically significant (r=.469; P=.003). For participants in the IIG, a significant correlation (r=.575, P=.04) was observed between the number of articles accessed by the parent and average change in their child's steps/day.



Table 4. Change in outcome variables from baseline to 12 weeks.

	Minimal intervention	Intensive intervention	<i>P</i> value (between group differences)
	mean (SD)	mean (SD)	
Height (cm)	1.5 (1.0)	1.6 (1.1)	.843
Weight (kg)	0.94 (2.1)	1.4 (1.7)	.536
BMI <sup>a</sup> (kg/m <sup>2</sup> )	-0.86 (1.1)	0.28 (1.0)	.369
BMI z-score	0.016 (0.19)	0.00 (0.14)	.773
BMI percentile	1.01 (6.1)	0.27 (1.9)	.455
Waist circumference (cm)	0.85 (4.0)	1.3 (2.8)	.764
Body fat percent	-0.24 (1.9)	0.69 (2.4)	.275
CDI-S <sup>b</sup>	-1.1 (4.0)	-3.4 (8.4)	.378
Physical activity enjoyment	-0.09 (0.17)	-0.01 (0.29)	.391
Sedentary time (weekday hours)	0.0 (3.2)	-0.59 (3.9)	.617
Sedentary time (weekend hours)	-1.2 (4.0)	-1.1 (5.5)	.941
Total calorie consumption	96.2 (682.4)	-310.6 (569.1)	.200
% calories from fat	-1.8 (6.7)	-0.06 (7.2)	.483
% calories from protein	0.78 (2.6)	0.59 (2.3)	.976
% calories from carb	1.0 (5.7)	-0.37 (7.2)	.323
Steps/day <sup>c</sup> , mean (SE)	1427.6 (583.0)	2832.8 (604.9)	.102

<sup>a</sup>BMI: body mass index

<sup>b</sup>CDI-S: Child Depression Inventory-Short Form

<sup>c</sup>Represents the average change in weekly steps/day across 12 weeks

# Discussion

#### **Principal Results**

The P-Mobile study demonstrated that it is feasible to deliver a child-targeted physical activity promotion program to parents through their mobile phones. Feasibility was demonstrated by parental utilization of the components of the intervention, including entering their child's step counts, responding to text messages, and accessing the behavioral articles. The intervention also resulted in increased physical activity in both study groups. Step counts increased significantly in both the MIG and the IIG over the course of the 12-week intervention. These findings suggest that mobile phone-based physical activity promotion interventions delivered to parents have the potential to be utilized and may positively affect physical activity levels in children.

Parental use of the intervention components varied by the component assessed. Concerning step count data, only half of the parents complied with the study requirement to enter step counts each night. This required the study coordinator to prompt parents for about half of the data and enter 10%-15% of the data. Therefore, the large volume of step data entered was the result of combined efforts by both the parents and the study coordinator, which may be difficult for participants and burdensome on study staff to sustain over a period longer than 12 weeks. Bluetooth capable activity monitors (eg, FitBits, Jawbone, Garmin Vivofit, etc) may lessen this burden and increase compliance. Concerning text messages, on average,

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parents in the IIG received approximately 13 automated text messages per week. This level appears to be tolerable because only one parent (4%, 1/27) requested a decrease in the frequency of text messages. Parents sent between 1 and 3 text messages per week to the study coordinator, but this was largely related to obtaining missing step data. Text messaging appears to be an acceptable form of communication, but it did not appear to be utilized by parents to increase their child's physical activity levels. Concerning articles, accessing article content was positively associated with change in steps/day for families in the IIG. However, accessing article content decreased significantly over the course of the study. This finding is consistent with Internet-based studies reporting incrementally reduced usage of websites across the study duration [51,52] and suggests that this type of intervention may not be ideally suited for all parents. In sum, although the components of the intervention were utilized, they were not utilized as anticipated. Based on our results, future studies should find ways to maintain consistent engagement of participants in mobile phone-based interventions because performance is positively associated with engagement.

The P-Mobile study demonstrated that children in both the MIG and IIG significantly increased steps/day above baseline levels. The intervention where parents received additional behavioral strategies and text messages (IIG) resulted in steps/day increases that were two-fold greater than steps/day levels reported with only daily monitoring and goal setting (MIG). Though this difference was not statistically significant, suggestion of a

moderate treatment effect was observed. However, the children in P-Mobile were unable to achieve the study goal (increasing 6000 steps/day above individualized baseline levels) directed to their parents. Children in the MIG were able to reach approximately 24%, while children in the IIG were able to reach approximately 50% of this goal. A 6000 steps/day increase from baseline levels would have amounted to ~13,500 steps/day for girls and ~16,000 steps/day for boys. Surveillance studies of free-living behavior demonstrate that only 25% of girls and 15% of boys aged 6-10 years achieve this level of habitual daily physical activity [53]. Therefore, the goals promoted herein were achievable, but require intervention support for those not habitually inclined toward a physically active lifestyle. Given the results of the current study combined with those of previous investigations, it suggests that interventions need to be further strengthened in order for sedentary children to achieve this level of activity. Interventions can potentially be further strengthened by engaging both parents (eg, providing behavior strategies to both parents, encouraging both parents to exercise with their child), incorporating siblings into the intervention (eg, delivering the intervention to all children in the family), and/or gathering real-time data (eg, through ecological momentary assessment) to better understand the physical activity patterns to determine optimal times/ways to incorporate physical activity in each individual child's life [54]. A potential downside to such strengthening efforts is the possible increase in staff and participant burden, and the potential for increased non-compliance due to the more intense strategies and requirements. Further research will help illuminate the optimal approach to using this technology to promote children's physical activity by targeting parents. For example, a multiphase optimization strategy [55,56] can be used to develop the ideal approach from the many intervention components (eg, pedometers, text messages, lesson plans, etc) of P-Mobile.

# **Comparison to Prior Work**

Family-based studies that have used pedometers to increase physical activity in children have typically delivered the intervention through group sessions [57-60]. A consistent finding across these interventions is that they realize increases in children's physical activity [15], anywhere from ~1500 [59,60] to ~3000 [57] steps/day above baseline levels. One study showed a significant differential increase of ~1000 steps between the intervention and control groups [58]. In two studies that utilized mobile phones to deliver behavioral change strategies and pedometers as monitoring tools to increase physical activity in children [24,29], neither resulted in significant within or between-group differences in steps/day. P-Mobile showed increases in physical activity for children in both groups (~1400 to ~2800 steps/day) and resulted in differences between groups (~1400 steps/day) that are within the range of values of similar

family-based interventions that delivered the intervention through face-to-face contact. To our knowledge, P-Mobile is the only mobile phone-delivered physical activity intervention in children that has resulted in significant within group increases in steps/day. Therefore, it appears that mobile phone interventions can be delivered to parents and result in increases in physical activity in their children. Our findings are in need of replication with larger samples, over longer durations, and with more diverse populations.

# Limitations

The P-Mobile findings should be interpreted within the context of the study's limitations. One major limitation was the small sample size. This may have provided insufficient power for detecting statistical significance between the observed group differences. The study had 17% power to detect differences and would have needed a sample size of 105 children/group to detect a 1400 steps/day difference. In addition, the study was limited to only 12 weeks; therefore, the long-term effectiveness of the study is unknown. The mobile phone components utilized in this study were limited to text messages and accessing a website through the mobile phone. Smartphones offer increased functionality, such as specially designed apps that could have fostered automated uploading of step data, thereby reducing participant burden and potentially increasing utilization. Apps also allow for location-based services that can be used to assist participants in identifying nearby facilities conducive for physical activity. Concerning measurement, although we used an objective measure of activity, pedometers do not capture all activity such as biking and swimming, and dietary intake was assessed using the FFQ, which is known to provide biased estimates compared to gold standard techniques, such as doubly labeled water. Finally, P-Mobile did not contain a control group. Our comparison group, the MIG, increased their average steps/day across the study, while control groups in previous studies have not significantly increased steps/day or have resulted in decreased steps/day [61,62].

#### Conclusions

P-Mobile was able to demonstrate that it is both feasible and effective to deliver a physical activity promotion program utilizing mobile phones. The study also showed that parents can be the exclusive targets and thus agents of their children's behavior change. Our findings add to the literature indicating that pedometers can be used to help increase physical activity in children. Our program relied on text messages, a website, involved few families, and was of a moderate duration. Researchers can build upon this foundation to develop more effective mobile phone-based interventions targeting childhood physical activity.

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# **Authors' Contributions**

RLNJr conceived and designed the study, interpreted the data, drafted, and critically revised the manuscript. AMM, HRA, and JMSJr acquired and interpreted the data, and critically revised the manuscript. RM, HH, and WDJ conducted the statistical analyses and critically revised the manuscript. STB and CT-L designed the study, interpreted the data, and critically revised the manuscript. TSC conceived the study, interpreted the data, and critically revised the manuscript. All authors provided final approval.

# **Conflicts of Interest**

HRA, a co-author, developed the software that was utilized in the study.

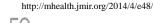
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## Abbreviations

BMI: body mass index
CDI-S: Child Depression Inventory-Short Form
CVD: cardiovascular disease
FFQ: Food Frequency Questionnaire
IIG: intensive intervention group
MIG: minimal intervention group
NL-1000: New Lifestyles 1000 pedometer
PACES: Physical Activity Enjoyment Questionnaire
P-Mobile: Parent-Targeted Mobile Phone Intervention to Increase Physical Activity in Sedentary Children
TBF: Tanita Body Composition Analyzer

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# Short Paper

# The Hookup: Collaborative Evaluation of a Youth Sexual Health Program Using Text Messaging Technology

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# Abstract

**Background:** The Hookup is a collaborative project reaching young people in California with valuable sexual and reproductive health information and linkage to local resources. Due to limited access to subscriber contact information, it has been a challenge to evaluate the program.

**Objective:** The aims of this study were to determine the feasibility of using text messaging (short message service, SMS) as an evaluation tool for an educational text message-based program and to evaluate the program itself.

**Methods:** All subscribers of The Hookup were sent four survey questions via SMS about age, gender, location, referral source and behavior change. An incentive was offered for completing the survey and an opt-out option was provided in the initial message.

**Results:** All existing subscribers of The Hookup (N=2477) received a request to complete the survey using the SMS application on their mobile phones. A total of 832 (33.6%) subscribers responded to the initial question and 481 (20%) answered all four questions. Of the responses, 85% were received in the first two hours of the initial request. Respondents who answered the question about behavior change, 90% reported having made some positive change since subscribing to Hookup, including getting tested for STDs and HIV.

**Conclusions:** The survey methodology initiated a high response rate from The Hookup subscribers. The survey was able to provide data about subscribers in a short time period at minimal cost. The results show potential for using mobile SMS applications to evaluate SMS campaigns. The findings also support using SMS to provide young people with sexual health prevention messaging and linkage to health services.

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# **KEYWORDS**

sexual health; STDs; HIV; mobile phone; youth; SMS; text messaging; program evaluation

# Introduction

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Mobile phone use has exploded in the United States (US) and across the world in the last decade, providing a cheap, easy and

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fast way to communicate with others. Five billion text messages (short message service, SMS) are sent daily in North America [1]. The volume of texting among teens has risen from 50 texts per day in 2009 to 60 texts in 2011 for the median teen texter.

Of all teens, 63% say they exchange text messages with people everyday. This far surpasses the frequency with which they use other forms of daily communication [2,3].

Preliminary data has shown that SMS can be used successfully to increase knowledge around reproductive health issues [4,5], as well as to promote short-term behavior change for sexual and reproductive health [6-8]. Behavior changes included intent to use condoms, increased access to reproductive and sexual health services, including sexually transmitted disease (STD) and HIV testing, and intent to have fewer sex partners.

A study in South Africa used a randomized controlled study design to test whether SMS messages could motivate people to test for HIV [9]. Participant interactions were conducted via SMS and multimedia message service (MMS). The study found that 10 motivational-style SMS/MMS messages encouraged a statistically significant amount of people to test for HIV as compared to the control group. Another randomized control study in Australia, which used SMS as a health promotion tool, found a significant increase in STD knowledge and STD testing in the intervention group as compared to the control [10].

There exists a small yet limited database of using SMS for sexual health research in the context of randomized control trials [11]. Such information has typically been collected through surveys and interviews conducted face to face, by telephone, or online. These methods have the disadvantage of being costly and time consuming. According to a recent meta analysis, half of all online surveys received less than a 26% response rate, with the majority of responses (96.5%) taking two weeks to arrive [12,13]. Additionally, response rates to telephone surveys have continuously declined over the past decade [14, 15].

As SMS is the most commonly used mobile app worldwide, extremely fast and highly reliable [16], known to be opened and read in short time after delivery [17], this study aimed to discover if SMS could be a feasible tool to use to collect user data, particularly from a program concerning sensitive content around sexual and reproductive health for teens.

Designed and implemented as a partnership between California Family Health Council (CFHC) and youth+tech+health (YTH) in April 2009, The Hookup is a California statewide sexual health text messaging service for adolescents between the ages of 13 and 24. The goals of the program are to connect users with relevant and accurate sexual and reproductive health information, and serve as a convenient, confidential resource for accessing local clinics that offer free or low-cost sexual and reproductive health services.

By sending the word "Hookup" as a text message to 61,827, young people subscribe for weekly sexual health tips. Subscribers can also enter the word "Clinic" plus their zip code to obtain local clinic referrals for youth-friendly, free and low cost STD/HIV testing, and reproductive health services. Subscribers are also linked to Teensource, a youth-focused sexual health website, for further information. All content for the messages is developed through inputs from the youth community and reviewed by internal medical, sexual health, and adolescent experts. Promotion of the Hookup was conducted through outreach in school-based health centers, other

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community-based partnerships using print materials, social media, and through the Teensource website. To increase sign-ups, we distributed branded youth-selected collateral such as lip balm, palm cards, condom tins, and keychains. While the program staff has access to subscribers' cell phone numbers, this access is for the sole purpose of sending The Hookup messages. This has posed a challenge in evaluating the program, and led to the design of an SMS-based survey tool.

# Methods

#### Aims

The aims of this study were: (1) to assess the feasibility of using SMS as an evaluation tool for a text message-based sexual health program for California youth, and; (2) to evaluate the effectiveness of the program itself.

#### Feasibility of SMS Evaluation

At the time of the survey in January 2011, The Hookup had 2477 subscribers receiving weekly messages. The evaluation team, comprised of members from the community, CFHC and YTH, identified and developed the survey questions (Textbox 1) adhering to the 160 character limitation of a standard text message in the United States. Additional elements included: specific format of responses "Text \_\_\_\_"; examples to avoid confusion "Like \_\_\_\_"; requirement for respondent to be concise.

The evaluation format included an introductory text message with an opt-out option, four survey question messages and a concluding message. The first three questions had limited response options, while the fourth question was open-ended. The text evaluation was conducted on the day and at the same time that the usual weekly messages were released. In order to increase response rates, the team offered an incentive in the form of a draw for US \$50 Target gift cards for 10 subscribers who completed the survey.

All responses were exported from the SMS platform to excel to conduct the analysis and included phone number, date/time of response, and body of response. The evaluation team additionally tracked response time for completing the survey and compared it to traditional survey data collection methods.

#### **Evaluation of The Hookup**

The three main questions that the evaluation of the program looked to answer were: (1) are we reaching target population (California youth)?; (2) are our promotion efforts successful?; and (3) are our messages effective?

Throughout the program, YTH collected aggregate process data during the first year of operations to track overall program usage. This included the number of new subscribers, opt-outs, and clinic searches. In order to evaluate the program by answering the evaluation questions, in 2011 YTH and CFHC designed and conducted the following survey to understand the demographics of the population, how they heard about the program, and potential impact in terms of behavior change. For the program evaluation, The Hookup subscribers were asked to answer four questions about their age and gender, location, referral source, and behavior change efforts using an SMS survey via their mobile phones (Textbox 1).

#### Textbox 1. Survey questions.

Hookup: No tip this week. Your turn to help the Hookup! 4 questions coming your way. Answer all and you can win prizes. Text stop 2 end.

Hookup: 1st a little about u. Text back GUY or GIRL then ur age. Like 'GIRL 16' or 'GUY 20'. Msg&rates apply.

Hookup: We want to know if we're reaching youth all over CA. Text back ZIP then ur zipcode to tell us where ur at! Like 'ZIP 94117'. Msg&rates apply

Hookup: How'd u get hooked up with the Hookup? A friend tell u? Teacher? Saw a poster? Text back HOOKED and ur reason, like 'HOOKED my bff'. Msg&rates apply

Hookup: How has the Hookup changed u? Text back CHANGE then ur change or something new, like 'CHANGE STD test last week'. Msg&rates apply.

Hookup: Thx 4 helping us make Hookup better 4u! Stay tuned 2 learn if u won our raffle 2 win \$25 iTunes card. Back 2 ur regular tips next week! Msg&rates apply.

# Results

#### **Feasibility of SMS Evaluation**

In total, 2477 Hookup subscribers were invited to participate in the survey, of those 832 (33.6%) responded and 58% (482) completed the full survey (responded to all four questions). Of all responses received, 85% were received within two hours, 13% were received within the subsequent 22 hours, for a total of 98% of responses received within 24 hours.

Respondents were lost with each subsequent question, 22% were lost at second question, 34% at third and 50% at fourth question (cumulative).

#### **Evaluation of The Hookup**

# Question 1: Are We Reaching Target Population (california Youth)?

Analysis of the responses showed that of the people who responded, over 90% were in the age range of 14-21 with 92% girls and 8% boys. Of the people who responded, 95% lived in zip codes that were California-based. The results appear to indicate that The Hookup is reaching the target population of California youth with a higher female than male representation. This finding has guided improved program promotion to reach males.

#### Question 2: Are Our Promotion Efforts Successful?

Due to the multi-faceted promotion plan, the question assessing how users heard about the Hookup was left open-ended. The responses reflected the program's promotion efforts. The main sources of referral to the campaign were: teachers/school (40%), friend (25%), posters/stickers/tattoos (22%), and online/web (10%). This has resulted in enhancing school-based partnerships for The Hookup promotion, as well as increased web-based promotion efforts.

#### Question 3: Are Our Messages Effective?

Of the respondents who answered the question about behavior change (n=482), 90% indicated that they had made some behavior change since they started receiving the text messages, including using condoms (33%), increased knowledge and awareness (24%), initiation of birth control (15%), and getting tested for HIV and other STDs (15%).

# Discussion

#### **Principal Results**

Feasibility of SMS Evaluation: with traditional data collection methods facing modern day challenges, using text messaging for short surveys can be an effective and efficient method. This study demonstrates the feasibility of using text messaging for evaluating health campaigns in terms of response rates, turnaround time, and ability to reach the target audience. As compared to online surveys, the response rate was comparable and the turnaround time was much faster [12,13].

Evaluation of The Hookup: the data collected correlates with key Hookup program objectives, raising awareness/knowledge, increasing safer sex and condom use, and getting tested for STD/HIV among youth in California. The findings on sources of referral to Hookup indicate that teachers and other school staff have been key in promoting the uptake of this program among youth.

#### Limitations

The challenges to using SMS as a survey tool include fitting questions and potential responses within the 160 character limit of text messaging and accounting for the loss of respondents as the number of questions increase. Our findings indicate the need to keep the surveys short and the questions clear to minimize drop-out rates. Additionally, the methodology may have presented a selection bias in those who chose to respond, potentially posing a threat to validity. Although preliminary calculations indicate that this method could be cost-effective, more in-depth study is needed to conduct a cost-effective analysis of text messaging for program evaluation.

#### Conclusions

Using SMS messaging for prevention has high potential for reaching young people consistently and supporting their decision making process around their sexual and reproductive health. SMS messaging shows immense potential to increase access to free and low cost health care, and increase knowledge in the United States among hard to reach populations such as adolescents. With text messaging being seen as a low cost, viable method of reaching communities with valuable information and critical resources, this study sheds some light on actual field experience through a functioning statewide campaign, as opposed to a pilot demonstration project.

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Additionally, SMS is an innovative and effective tool for conducting evaluations of SMS-based programs.

#### Acknowledgments

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#### **Conflicts of Interest**

None declared.

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#### Abbreviations

**CFHC:** California Family Health Council **SMS:** short message service **STD:** sexually transmitted disease **YTH:** youth+tech+health

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**Original Paper** 

# Qualitative Feedback From a Text Messaging Intervention for Depression: Benefits, Drawbacks, and Cultural Differences

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# Abstract

**Background:** Mobile health interventions are often standardized and assumed to work the same for all users; however, we may be missing cultural differences in the experiences of interventions that may impact how and if an intervention is effective.

**Objective:** The objective of the study was to assess qualitative feedback from participants to determine if there were differences between Spanish speakers and English speakers. Daily text messages were sent to patients as an adjunct to group Cognitive Behavioral Therapy (CBT) for depression.

**Methods:** Messages inquired about mood and about specific themes (thoughts, activities, social interactions) of a manualized group CBT intervention. There were thirty-nine patients who participated in the text messaging pilot study. The average age of the participants was 53 years (SD 10.4; range of 23-72).

**Results:** Qualitative feedback from Spanish speakers highlighted feelings of social support, whereas English speakers noted increased introspection and self-awareness of their mood state.

**Conclusions:** These cultural differences should be explored further, as they may impact the effect of supportive mobile health interventions.

**Trial Registration:** Trial Registration: Clinicaltrials.gov NCT01083628; http://clinicaltrials.gov/ct2/show/study/NCT01083628 (Archived by WebCite at http://www.webcitation.org/6StpbdHuq).

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#### **KEYWORDS**

mobile health; depression; text messaging; culture; digital health; cognitive behavioral therapy; disparities; mental health; behavior change

# Introduction

# Health Interventions Using Mobile and Digital Technologies

Mobile and digital technologies provide opportunities for increasing patient engagement and monitoring. Health interventions delivered through text messaging and other

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telecommunications have shown promising results in a variety of studies addressing varied health issues. Examples of targets include smoking cessation [1-3]; diabetes [4]; treatment of sexually transmitted infections; supporting community-based HIV/AIDS health workers; and improving primary care attendance [5]. In the area of mental health, texting has been used to assess and treat serious mental illness [6], schizophrenia [7], and depression [8]. Text messaging is increasingly seen as

a valuable provider tool because it is widely available, used with relatively low cost and ease, can be applied to a range of health and mental health conditions [9], and can reach underserved populations [10]. Latinos and African Americans are more likely than other racial/ethnic groups to gather health information through their phones [11], which suggests that this medium may be an ideal tool to reach these populations that experience detrimental health disparities [12].

While evidence of efficacy of text messaging-based interventions is growing, mobile health research and intervention development are still in early stages. Now it is important to build knowledge about the user experience from the perspectives of diverse populations to understand if and how interventions impact people. While a focus on clinical outcomes is also crucial, these outcomes cannot be achieved if we do not understand how people interact with digital health interventions. For example, there are limited studies that explore the role of culture and culture-specific messaging in digital health interventions [5]. When developing an intervention, particularly one that is standardized utilizing technology, we tend to assume that it will act similarly for all people who use it since they are receiving the same information and experience; however, the information provided via digital health technologies may be perceived differently based on one's worldview or cultural values, which may modify the experience. A cultural difference that has been the subject of extensive study has been the comparison of the individualistic framework that is common in the United States in contrast to the collectivist framework that is more typical of other parts of the world. An individualist perspective values autonomy and frames the individual as the agent of change and success, whereas a collectivist perspective is relational in nature and emphasizes maintaining harmonious relationships and fitting into a larger social structure [12]. Culture is by no means the only factor that could influence how individuals perceive an intervention, but in a diverse country like the United States, it merits attention along with other factors such as age, gender, socioeconomic status, and education.

#### **In-Between Session Messaging**

An area of clinical practice that could benefit from the use of messaging technologies is the time between psychotherapy visits in order to increase engagement and ultimately improve outcomes [13,14]. In-between session messaging can increase self-awareness, skill building, as well as perceived support. Aguilera and Muñoz [8] reported initial findings on a text messaging adjunct to cognitive behavioral therapy, and noted that Spanish speakers reported feeling support and cared for, while English speakers mainly reported increased self-awareness.

This paper will present findings from qualitative data gathered from patients about their experiences receiving text messages as part of their cognitive behavioral therapy for depression. We will identify positive and negative feedback as well as highlight how culture may play a role in the perception of the text messaging intervention.

# Methods

#### **Development of the System**

The development and initial testing of this system were reported previously in more detail [8]. Patients in a group cognitive behavioral therapy for depression (based on Health Management of Reality, HMOR, and Building Recovery by Improving Goals, Habits, & Thoughts, BRIGHT, manuals) [15,16] in an urban public sector clinic were asked if they wanted to receive text messages as part of their participation in therapy. The live intervention consists of four four-week modules that focus on thoughts, behaviors, interpersonal issues, and health. Patients were asked if they were interested in using text messaging as part of their group therapy to aid in their completion of their "homework", which consisted of mood monitoring, as well as monitoring of thoughts, activities, social interactions, and healthy activities. Participants were also given the option to continue receiving text messages after they "graduated" from the therapy, which most patients (17/20, 85%) accepted. For those who did not own a phone, we provided a prepaid mobile phone (~US \$10) and provided a prepaid service during the study for a cost of US \$25 a month that included unlimited phone calls and text messages. We taught participants who did not know how to use text messaging how to respond to messages. If a patient did not know how to text, a clinician or research assistant sat with that person to help them find where the text messages were stored and orient them to the specific functions of their phone. We would also send a sample message and walk them through the process of responding to the message. If they were not successful on the initial try, we would attempt again until they felt comfortable replying. We would then ask them to find a text message from their messages list, and to try to reply to a message that was sent previously. The next week, we would check in with patients who were having difficulty responding, to try to troubleshoot issues and go through the steps again. Participants who still had difficulties after the third try had a difficult time engaging in the intervention. Some were still able to read the messages, but not respond to them. Some patients took to the texting very quickly, while others, especially older patients, demonstrated more difficulty.

Recruitment occurred in two stages with the first half of participants recruited from 2010 through 2011, and the second round recruited from February to December of 2013. During the first round of recruitment, basic messaging included a daily mood monitoring message ("What is your mood right now on a scale of 1-9?"), sent at random times, and a thematic question sent in the evening (8 p.m.), asking patients to report their quantity of positive thoughts, pleasant activities, social interactions, and healthy activities (eg, "How many positive thoughts have you noticed today?", "How many positive social interactions did you have today?", etc.). These four areas were the focus of the group therapy for four weeks at a time during the 16 weeks of the treatment.

The second round of participants received the same mood question and also received a thematic question or a "tip" that was different everyday, but was consistent with the theme for that month. Additionally, the second round of participants

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received reminders to attend their therapy session and also had the option of receiving medication reminders if they chose. The groups enrolled participants on a rolling basis, and patients graduated from the group after completing all four modules and after displaying low stable symptom levels; thus, patients sometimes stayed longer than the standard 16 weeks.

After two and four months of receiving text messages, 20 of the 39 patients answered open-ended questions about their positive and negative experiences receiving text messages. This questionnaire also asked them to rate their agreement on a 1-5 scale (do not agree to strongly agree) to two questions asking whether receiving messages made them feel close to the group, and whether receiving messages made them more likely to attend sessions. Those who completed these surveys were significantly older (mean 55.73 vs 49.27), attended significantly more sessions (mean 20 vs 7), and were available to provide feedback in person after using it over time (see Table 1). As shown in Table 1, other demographic variables, including initial Patient Health Questionnaire - 9 (PHQ-9) scores, were not significantly different. There were 15 participants that replied in Spanish and 5 replied in English. Most participants were women (n=13). Of the 5 English speakers, 1 was Latina, 1 was African American, and 3 were Euro-American. All of the Spanish speakers were Latino/a from either Mexico or countries in Central and South America. All patients had a diagnosis of depression and at least one other chronic physical illness (ie, diabetes, cardiovascular disease, chronic pain, etc). Average PHQ-9 scores at the start of therapy were 10.94, which reflects moderate depression symptoms. There were 17 that had their own phones and 12 of the 20 had used text messaging prior to participating in the study. The website used to send and receive automated messages is now called HealthySMS [17].

Table 1. Respondent characteristics.

	Respondents	Nonrespondents
	n=20	n=19
Response rate to SMS, %	47	42
Age	55.73	49.27 <sup>a</sup>
Sessions attended	20	7.27 <sup>a</sup>
Use SMS <sup>b</sup> prior, n (%)	13/20 (65)	12/19 (63)
Learned SMS <sup>b</sup> for study, n (%)	7/20 (35)	6/19 (32)
Continued, n (%)	17/20 (85)	0/19 (0)
PHQ9	10.94	10.24

 $^{a}P < .05$ 

<sup>b</sup> SMS = short messaging service

#### **Participants Responses to Open-Ended Questions**

Participants provided written responses to questions about their experiences after two to four months of receiving the messages. The qualitative study sample was asked open-ended questions about what they liked about receiving text messaging ("What did you find helpful or positive about the text messages you received?"), what they did not like ("What were the downsides of receiving the messages or what did you find unhelpful?"), what they would suggest to improve the text system ("What other kinds of messages would you find helpful?", "How else might text messaging improve your health care?"), and reasons they did not respond to the texts, when applicable, ("For the times you did not respond, what were some of the reasons?"). These responses were transferred verbatim into Excel, where the data were analyzed for concepts and possible themes using the open coding method of grounded theory by three separate raters. Concepts were delineated and codes were derived from the data and modified throughout this process of reading and rereading the data [18]. All raters discussed disagreements in ratings until all three reached a consensus. This inductive process enables the data to speak and codes to emerge organically. Through this open coding process, themes were identified and responses were clustered accordingly. As themes

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emerged, consistencies and inconsistencies were noted and are described below [19].

## Results

#### Helpful, Positive Messages

When we asked participants, "What did you find helpful or positive about the text messages you received?", their responses clustered around three distinct themes: (1) prompts of self-reflection, (2) feeling cared for and supported, and (3) appreciating having reminders to take medication and to attend their scheduled group therapy sessions. Differences surfaced between the themes reported by Spanish and English speakers. As shown in Table 2, the most commonly reported feedback was that text messages prompted self-reflection and awareness (11/20, 55%). Other feedback included reports of feeling cared for (8/20, 40%), liking reminders (7/20, 35%), being cheered up (6/20, 30%), being behaviorally activated (3/20, 15%), and liking the ease of using texts (1/20, 5%). There were significant differences between language users, with Spanish speakers reporting feeling cared for more often than English speakers. There were no significant differences for other categories.

When comparing English and Spanish speakers with regards to demographic characteristics, there were no statistically

significant differences, but it is possible that the detection of differences was limited by a lack of power due in particular to a small English speaking sample. In addition to eliciting qualitative feedback, we also asked patients whether they felt that receiving text messages made them feel closer to the group. Most patients agreed that receiving messages made them feel closer to the group with an average rating of 4.5 (out of 5).

#### Table 2. Language comparison.

		Total	English	Spanish
		N=20	n=5	n=15
Female, n (%)		13/20 (65)	2/5 (40)	11/15 (73)
Response rate, %		47	61	42
Age		56	58	55
Sessions attended		20	27	17
Use SMS <sup>b</sup> prior, n (%)		13/20 (65)	4/5 (80)	9/15 (60)
Learned SMS <sup>b</sup> for study, n (%)		7/20 (35)	1/5 (20)	6/15 (40)
Continued, n (%)		17/20 (85)	4/5 (80)	13/15 (87)
PHQ9		10.94	6.2	12.92
Sessions attended		20	27	17
Average rating (1-5)				
	Did messages make you feel closer to the group?	4.51	4.00	4.67 <sup>a</sup>
	Did messages make you more likely to at- tend?	4.51	4.00	4.67
What do you like?				
	Prompts reflection, n (%)	11/20 (55)	4/5 (80)	7/15 (47)
	Feel cared for, n (%)	8/20 (40)	0/5 (0)	8/15 (53.33 <sup>a</sup> )
	Reminders, n (%)	7/20 (35)	0/5 (0)	7/15 (47)
	Cheers you up, n (%)	6/20 (30)	0/5 (0)	6/15 (40)
	Activates (behavioral), n (%)	3/20 (15)	0/5 (0)	3/15 (20)
	Easy, n (%)	1/20 (5)	1/5 (20)	0/15 (0)

<sup>a</sup>P<.05

<sup>b</sup> SMS = short messaging service

#### **Self-Reflection and Awareness**

Nearly all English speakers reported that they valued the prompts for self-reflection, while only one third of the Spanish speakers valued it. As one English speaker put it,

They made me stop and think for a moment about how I was feeling and why I was having those feelings. My life is so crazy I need a reminder to think about how I feel. [Female English speaking participant]

Others noted that it gave them the ability to look "in the proverbial mirror" or that "they forced me to 'check in' with myself". A final example of the self-reflection when receiving a text was provided by a patient who said, "They made me stop and think for a moment about how I was feeling and why I was having those feelings". The English speakers were highly consistent in their responses that receiving texts increased self-awareness and reflection.

Some Spanish speakers also mentioned benefits of self-reflection. For example, one woman stated that, "Me a ayudado a ser y pensar positivo", "They help me be and think more positively". Another participant also mentioned self-reflection, but also referred to the group saying,

Me recuerda sobre lo que hablamos en el grupo. Recuerdo de la rehabilitación y de los demàs, (They remind me about what we discussed in group. I remember my rehabilitation and about the other group members.) [Female Spanish speaking participant]

These responses from Spanish speakers refer to self-reflection, but as a whole were less focused on self-awareness. They highlighted the fact that receiving messages reinforces the themes of the weekly therapy session and reminds them of the group interaction process. Spanish speakers often mentioned that receiving messages helped them feel better and focus on themselves, yet the theme was not as central as it was for the English speaking participants.

#### **Perceptions of Support**

Differences also appeared in the number of people who mentioned that receiving text messages increased feelings of support. No English speakers offered that they felt supported; however, a majority of Spanish speakers stated that receiving the text messages during the week made them feel cared for and supported. For example, one participant stated, "Te hace sentir que alguien se preocupa por ti". "It makes you feel like someone is concerned about you". This suggests that the therapeutic relationship is strengthened via the receipt of the messages. This was echoed by a 41-year-old woman who said she likes "saber que alguien le interesa saber como estuvo mi día y me hace sentir un poco mejor si mi día fue mal", "knowing that someone cares how my day was makes me feel a little bit better, particularly if I had a bad day". This feeling of being cared for enabled a sense of hope and support,

Ustedes están poniendo esperanza en que uno siga adelante. Están pendientes. (You are providing hope so that one continues moving forward. You are watching out for us.) [Female participant]

Table 3. Correlations between patient characteristics and qualitative feedback.

Here, the text messages were experienced by users as a way to let their therapists know how they are doing, making the technology an extension of the therapeutic relationship.

A Spanish speaking patient summed up the various positive aspects reported about the intervention, stating, "te hace pensar en ti, te hace sentir que alguien se preocupa por ti, te recuerda tus medicinas, te evalùa constantemente, ayuda a estar active, me impulso a usar un cell", "it makes you think about yourself, it makes you feel that someone is concerned about you, it reminds you to take your medications, it evaluates you constantly, it motivated me to use a cell phone".

#### **Demographic Correlates of Qualitative Themes**

In order to assess whether demographic characteristics are related to the type of feedback that patients provided, we conducted correlational analyses of age, sex, language, and previous use of text messaging with the various positive themes that arose. As seen in Table 3, speaking Spanish is related to increased feelings of being cared for, and previous use of text messaging is negatively related to feeling behaviorally activated by receiving text messages.

	Reflect	Care	Remind	Activates	Easy	Cheer up
Age	0.12	-0.15	-0.06	0.25	0.19	-0.22
Female	-0.03	0.17	-0.34	0.02	-0.31	0.25
Spanish	-0.29	0.47 <sup>a</sup>	0.42	0.24	-0.40	0.38
Used SMS <sup>b</sup> before	-0.33	0.04	-0.04	051 <sup>a</sup>	0.19	-0.13

 $^{a}P < .05$ 

<sup>b</sup> SMS = short messaging service

#### **Downsides of Texting**

When the participants were asked about the downsides of receiving text messages, the most common response was that there were none, and that they actually appreciated the messages. An aspect that some participants disliked or had difficulty with was an inability to respond due to being busy (eg, while at work). A patient mentioned, "que interrumpen si estas trabajando", "they interrupt if you are working", and another stated that, "sometimes you had a delayed response from me, I might have been preoccupied".

Another set of problems that arose was technical in nature. These were mostly related to people not being able to access or respond to text messages, "El problema es que no se usar con facilidad los textos, como contestar con mas informacion". "The problem is that I don't know how to use text with ease, how to respond with more information". A way that we attempted to address this problem was that we asked people to only respond with a number to the mood question, while others could also add additional text to provide context to the mood rating. A 70-year-old woman reported, "tenia que leérmelos mi hijo", "my son had to read them for me", referring to the difficulty accessing the messages in the phone and to the small text.

When we asked participants, "What other kinds of messages would you find helpful?", "How else might text messaging

XSL•F() RenderX improve your health care?", the vast majority reported "none" or "nothing else". Others had suggestions for specific messages such as suggesting free or inexpensive activities in the community, as well as varied messages that were less repetitive. A patient even made a list of motivational messages that he suggested including in the set of messages (eg, "Vive tu vida, no vivas la vida de los demás". "Live your life, don't live the life of others". "Confía en ti mismo, ese es el primer paso de tu éxito". "Believe in yourself, it is the first step in your success".).

#### Discussion

#### **Qualitative Feedback From Participants**

The qualitative feedback obtained from participants in a text messaging intervention for depression showed that the intervention yielded positive experiences that resulted in reports of self-awareness, skill building, and feelings of being cared for and supported. The main criticisms of texting included receiving messages at inopportune times and some technical difficulties for those that were unfamiliar with the technology.

#### **Cultural Differences**

An interesting cultural difference arose when comparing the responses about what was deemed positive about receiving text messages. Spanish speakers more often mentioned that receiving messages made them feel cared for and supported, while English

speakers never mentioned this benefit, but stated that the messages were a way to help them be more aware of their mood states. A possible explanation for this difference is that Spanish speakers may place a stronger value on collectivism and relational connections than English speakers, who may value agency and independence more [20]. Another possibility is higher educational levels among English speakers may result in more exposure to technology and different understandings of how technology works and who the messages are coming from, even though all participants were told that messages were sent automatically and not by individuals. Higher levels of education confer increased health literacy [21], as well as familiarity with technology [5]. Unfortunately, we do not have systematic data assessing educational background; however, we can note that at least two of the English speakers had a college education and all had at least a high school level of education compared to Spanish speakers, who mostly had only an elementary level education (most only to 6th grade).

The role of supportive accountability in technology interventions has previously been discussed with technological interventions [22]; however, the role of culture in moderating the support felt by users of technological interventions has not been considered. This is an interesting difference that should be explored further, as this is a limited sample, but points to the potential of culture as a moderating influence. Technology-based interventions should assess cultural and demographic differences that may shape the user's experience. This knowledge can also help further personalize interventions and possibly increase engagement. It is also possible that the intervention may have felt equally supportive cross-culturally by the participants, but that support is communicated more among people who are more collectivistic. Even that difference may show the difference in salience of support cross culturally.

Problems that users experienced included not being able to respond to a message because they were busy, as well as technical difficulties. These are important limitations to consider, but they are also addressable. The issue of bad timing of messages can potentially be solved by narrowing the window at which messages are sent with a feature that enables clients to block off times when text messaging cannot come through, so that they are not bothered when they know they do not want to be interrupted. The issue of technical difficulties, such as the inability to access messages and making messages basic and readable, are more challenging. Some ways to address these problems included keeping the messages and response options simple, so that individuals at various skill levels can still participate. The increased ubiquity of smartphones will also aid in this, as there are more accessibility friendly features that can enlarge or even read text out loud. A continuing challenge is making technology-based interventions available to those with limited tech-savviness and literacy.

#### Limitations

The data were collected from participants who stayed in therapy long enough to provide responses in person, so results are skewed toward those who are engaging in therapy. People who attended one session and did not return did not provide feedback,

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which could be helpful for highlighting more of the negative aspects of receiving text messages.

The sample size was small, which limits generalizability. In particular, the number of English speakers was only 5, compared to 15 Spanish speakers, which reduces the confidence in the language differences. However, the consistency of English speaking respondents at least merits further study of this question in future research.

Another potential limitation is the focus on text messaging, which is a basic technology. The lessons we are learning from the use of standard text messaging can transfer to other messaging platforms and applications for use when smartphones are more ubiquitous. For instance, the crowdsourcing of messages could be an effective precedent in delivering personalized messages going forward. The fact that most people in this study did not provide suggestions to improve the system may reflect a lack of knowledge of the potential of technology. Many people may not realize the possibilities of technology and are limited in providing suggestions, but those who do provide suggestions are a potentially valuable resource.

#### Conclusions

Based on our developmental research, we have found that it is useful to take the time to teach people how to use the technology and see them be successful. It is also important to keep things simple so that more people can engage. Text messaging is simple enough for people to engage in for long periods of time, and it can provide important information for clinicians. Interventions can also have tiered levels of interaction. For example, we asked for mood, but gave the option to add additional context about that mood rating. Some people provided this, while others did not. Responding with a number is relatively simple, but adding text is more complicated, particularly with older phones or for people with eyesight difficulties. People with less previous use of technology have a higher barrier to entry, but may be more likely to engage and get more out of technological tools. Learning to use a new technology seems to build self-efficacy, and it is still a novel task with a high likelihood of engagement as long as they pass the threshold of feeling comfortable with using it.

It is important to ask about what people like and dislike about a digital health intervention. This helps steer developers of the technology to possible mechanisms of action in an intervention. Technology-based adjuncts seem to be extensions of a clinical and therapeutic relationship. Just as there are cultural nuances in the delivery of live psychosocial interventions [23], technology-based interventions should also consider the role of culture in shaping perceptions. It is likely that the relationship that a clinician has with their clients will serve as the basis for engagement with technology. Text messages may also be a particularly salient medium of communication for depressed Latinos, as they report feeling isolated and receiving a message reminds them that someone cares.

The results from this study show that there is potential for utilizing digital health technologies such as text messaging as an adjunct to mental health practice, but that people may experience digital health interventions differently based on

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demographic and cultural differences. It is important to take these diverse values into account as we disseminate digital health interventions to underserved and low-income populations that have high need.

#### **Conflicts of Interest**

None declared.

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#### Abbreviations

PHQ-9: Patient Health Questionnaire - 9

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# Texting Teens in Transition: The Use of Text Messages in Clinical Intervention Research

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#### **Related Article:**

This is a corrected version. See correction statement: http://mhealth.jmir.org/2015/1/e13/

# Abstract

**Background:** The rapidly growing population of young adults living with congenital heart disease (CHD), currently challenging ill-prepared cardiac care systems, presents a novel population in which to consider the use of mHealth. This methodological study was part of a larger study that tested the effectiveness of a clinic-based nursing intervention to prepare teens for transfer from pediatric to adult cardiology care. The intervention included creation of a MyHealth Passport and subsequently SMS (short message service) text messages between the intervention nurse and study participant.

**Objective:** Our aim was to determine (1) the preference of teens with CHD to be contacted via text message following the nursing intervention, (2) the effectiveness of texting to collect data regarding the use of MyHealth Passport after participation in the intervention, (3) the nature of the texting interaction, and (4) the risks and benefits of texting.

**Methods:** Participants were recruited through the intervention study (n=24) by either choosing to receive information from the study coordinator through text message, or texting a question to the study nurses. Inclusion criteria were age 15-17 years, diagnosed with moderate or complex heart disease, and currently being followed by the Division of Cardiology at Stollery Children's Hospital. Exclusion criteria were heart transplantation and/or less than a 6th grade reading and comprehension ability. Text message transcripts were analyzed by qualitative inductive content analysis.

**Results:** Two-thirds of teens (16/24, 67%) chose text messaging as their preferred contact, making them eligible for the study. Texting was effective in collecting information regarding the MyHealth Passport; all but one teen had their MyHealth Passport on them, and many reported carrying it with them wherever they went. All teens reported showing their MyHealth Passport to at least one person. Seven themes were identified in the texting transcripts: mixing formal and informal language, the passive teen, interaction with health care providers, texting teens in transition, texting as a mechanism to initiate other forms of communication, affirmation, and the nurse as an educator. Benefits of texting were identified as flexibility, ability to respond over time, information presented in byte-sized amounts, and information directly related to patient questions. Risks of texting were identified as the possibility that interactions may not be in-depth, distraction of teen and researcher, and invasiveness.

**Conclusions:** Text messaging was useful in collecting data regarding the use of the MyHealth Passport. Text messaging resulted in conversations with the teens that were sometimes in-depth and meaningful, especially when combined with other communication modalities. Using text messaging in a manner resulting in full conversations with the patients requires more study and may benefit from protocols and the use of solid theoretical foundations that would standardize the interaction so that more conclusions could be drawn.

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#### **KEYWORDS**

teens; congenital heart disease; text messaging; SMS; qualitative research

# Introduction

Mobile health (mHealth), the delivery of health-related services through mobile communication, is gaining interest in the research community [1]. Texting-based interventions have been evaluated in many areas including violence and neglect [2,3], asthma control [4,5], human immunodeficiency virus/acquired immune deficiency syndrome and sexual health [6-15], exercise and weight control [16-24], diabetes management [25-29], smoking cessation [30-38], oral health [39], increasing attendance at clinics [40-44], communication of medical results [45], screening [46], and mental illness support [47-54]. Few studies deal exclusively with adolescents [8,9,11,20,22,23,26,28,29,31,32,49], and none have examined adolescents living with congenital heart disease (CHD). Additionally, few studies feature two-way discussion between researcher and participant [7,14,15] as the primary method of communication; most studies use an automated text messaging system or send standard messages with varying levels of personalization. There are some studies that include two-way discussions, but these studies do not focus exclusively on this type of interaction.

There is a rapidly growing population of young adults living with CHD; these individuals challenge ill-prepared cardiac care systems [55]. CHD is the most common birth defect and is present in 8-9 of every 1000 newborns [56,57]. Historically, affected individuals died in childhood. Advances in health care currently enable many of these children to survive into adulthood, resulting in increased pressure on the health system to provide care to this emerging population [58]. The situation is further complicated by the fact that over half of these young adults do not attend their follow-up appointments [59] and that many individuals with CHD are ill-informed about their heart conditions and health care [60]. Some young adults hold the misconception that they were cured in childhood [61]. Cardiac care services have begun to address these issues by creating transition programs with the intent of encouraging the movement of adolescents and young adults with chronic medical conditions from pediatric to adult care [62]. Transition, in this instance, is not viewed as a one-time event, but rather a multidimensional process to foster self-management through childhood and adolescence [63].

The objective of Texting Teens in Transition, as part of the larger Congenital Heart Adolescents Participating in Transition Evaluation Research (CHAPTER) Study, was to determine the nature of texting by teens in the context of clinical intervention research. The CHAPTER study is a single site, cluster controlled

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trial conducted to test whether a nurse-led clinic-based intervention, in addition to usual care, resulted in better "transition readiness" than usual care alone [64]. The CHAPTER study intervention focused on increasing patient knowledge [65-68] and promoting self-management skills [69-71]. During the intervention, a MyHealth Passport was created in addition to activities to increase knowledge and self-efficacy, including review of the teen's cardiac anatomy, discussion of potential complications, introduction of transition resources (eg, websites), and application of learning through three scenarios and the setting of one education goal.

The MyHealth Passport is a Web-based program in which teens enter information regarding their health care including diagnosis, test results, and physician names [72]. The final document is printed onto a wallet-sized card. The MyHealth Passport fosters knowledge and self-management. By creating the document, the teen learns more about their diagnosis and how to manage their condition. Additionally, the document itself is used by the teen to more effectively interact with health care providers, which is a necessity for self-management. Thus it was important to keep the MyHealth Passport with them. Text messages were used to invite teen commentary regarding their use of the MyHealth Passport.

This paper presents the qualitative analysis of the text messages that determined (1) the preference of teens with CHD to be contacted via text message following the CHAPTER study intervention, (2) the effectiveness of texting to collect data regarding the use of the MyHealth Passport, (3) the nature of the texting interaction, and (4) identified risks and benefits of texting.

# Methods

#### **Study Design**

Participants for this study were recruited through the larger CHAPTER Study. From that study, participants were specifically recruited to this Texting Teens in Transition study in one of two ways. At enrollment in the CHAPTER study, the participants were asked if they wished to receive information from the CHAPTER team through text, email, or phone. Participants were enrolled in Texting Teens in Transition if they indicated a preference to be contacted by text message. Second, at the end of the nurse-led intervention, participants were again invited to indicate their preference between text, email, or phone contact with one of the study nurses following the nurse-led clinical intervention. Participants in the CHAPTER study who indicated a follow-up preference other than text messaging are

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not included in this paper as it did not relate to the texting interaction. Participants were recruited between January 2011 and May 2012. Inclusion criteria were 15-17 year olds with moderate or complex heart disease [73], who were followed by the Division of Cardiology at the Stollery Children's Hospital. Teens who had undergone heart transplantation and/or who were below a grade 6 reading and comprehension level were excluded.

#### Procedure

At the end of the nurse-led clinical intervention, the nurse welcomed the teen to text back with any questions. The nurse also informed the teen that if the teen had not already contacted the study team in the week following the CHAPTER Study intervention, one of two study nurses (usually the nurse who had interacted with the teen in clinic) would send the participant a text message at the time to which they agreed. If the nurse did not get a response, she sent another text message the following day. If there was still no response, the nurse made no further attempts to contact the teen. The teen was welcome to text back at any time and begin participation. All interactions began with the nurse addressing any questions the teen had. "Do you have any question?" was the scripted question used to gather data in the group that did not text in with a question. Next, specific questions were asked of the teen regarding the MyHealth Passport. The questions were (1) "Where is your MyHealth Passport now?" and (2) "Have you used your MyHealth Passport or shown it to anyone else?" The interaction was to be predominantly guided by the teen after the nurse gathered the above data. Throughout the study, every effort was made to text the teens outside of school hours.

Texting interactions took place on a smartphone used for the study. When the texting interaction between the teen and the nurse was complete, the nurse selected all text messages through the Edit feature (see Figure 1) and forwarded them to the same smartphone. This text message that contained all of the texts was then anonymized before emailing the script of the texting interaction to the research coordinator for data management (see Figure 2). The text messages were then combined into one document and uploaded to a secure server. The messages on the phone were then deleted. The texting transcriptions constituted the study data for analysis as did the field notes (FN) that the nurse recorded after the intervention.

Figure 1. Edit feature.





Figure 2. Consolidated texts, anonymized and emailed.



#### **Data Analysis**

The text message transcripts and field notes were analyzed by 2 members of the research team (GR and RB). Code categories and subcategories were identified as per qualitative inductive content analysis [74-76]. The unit of analysis consisted of each texting interaction, defined in this study by at least one reciprocated message between the teen and the nurse. These data were then analyzed for latent content, including temporal separation of messages, formality of language, and sentence formation, as well as manifest content.

#### **Ethical Considerations**

This study was approved through the Health Research Ethics Review Board at the University of Alberta. Both the teen and a parent provided signed informed consent. Identifying information was removed from texts prior to analysis.

# Results

#### Overview

Of the teens enrolled in the larger study, two-thirds (16/24, 67%) indicated a preference to be contacted by text message, making them eligible for this substudy. A quarter of teens (6/24, 25%) chose email and 2/24 (8%) chose telephone. Successful contact varied with the highest percentages of contact being established with participants in the texting group (Table 1).

The teens' preference for texting was also determined by the extent of the texting interactions; they ranged in length from seven messages at the shortest, to 62 messages at the longest. This number included the teen's and nurse's texts. The average number of text messages in one interaction was 28. Most interactions were completed on the day contact was initiated. With 3 participants, the interactions occurred over the course of 2 days. All contact with the teens took place between 3:45 pm and 9:00 pm.

Table 1. Preference of contact modality indicated by teen and contact made by modality.

Contact modalities	Preference indicated by teen, n (%)	Contact made, n (%)
Text	16/24 (67)	13/16 (81)
Email	6/24 (25)	4/6 (67)
Telephone	2/24 (8)	0/2 (0)

#### **MyHealth Passport**

#### Where is Your Passport Right Now?

All but one of the 24 teens in the study (92%) had their MyHealth Passport on their person; these teens reported that

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they carried the passport in their wallet or pocket wherever they went. Participant CH-007 noted: "[In my] Wallet, it was with me skiing today actually". The participant who did not have the MyHealth Passport with him knew where it was and reported that he did not keep it with him because he did not have a wallet:

Nurse: Thats great! Where is your passport right now?

CH-058: i have it in my room in a safe area where it wwont get wrecked

Nurse: Do you ever carry a wallet with you?

CH-058: no not realyy though i probably shoul

Nurse: Well think about bc then you would have a place for your passport.

CH-058: ya good idea

Also of note was one teen who kept the MyHealth Passport in their pocket, but who subsequently reported putting the MyHealth Passport in his wallet:

Nurse: Where is your health passport right now?

Nurse: The one we did together last Monday. I remember putting it in your back pocket.

CH-061: In my back pocket lol

*Nurse: That same back pocket? Or in the pocket of the pants you are now wearing?* 

CH-061: In the ones Im wearing right now

Nurse: Good work!! Has it made it to your wallet? Or maybe you dont carry your wallet with you all the time?

CH-061: Yeah I wear it all the time

# Have You Used Your MyHealth Passport or Shown It to Anyone Else?

All teens reported that they had shown their MyHealth Passport to at least one person, and over half (7/13, 53.8%) of the teens had shown it to at least 2 people. One particular example was interesting because of what the teen considered to be a small number of people: CH-059: "Umm not to too many people maybe like 10-15 people". Most teens showed their MyHealth Passport to family (69%) or friends (46%): CH-006: "I love showing it to people who mean a lot to me :)". Only one teen

Table 2. Instances of informal language in texting interactions.

indicated that they had used it in a health care setting. CH-063: "...only for doctor appointment when they ask what meds I take". This was to be expected, as the text messaging occurred only 1 week after the MyHealth Passport had been created with the teen. One teen reported showing her MyHealth Passport to her coworkers. Using the MyHealth Passport in a work environment was a use of the MyHealth Passport not initially apparent to the researchers but one that could be useful for teens.

#### **Nature of the Texting Interaction**

#### Formality of Language

Both formal and informal language was used by the nurses and teens, often within the same text message. Some teens opted to use full sentences that conveyed more formal language. For example, one teen, whose friend was with her during the clinic intervention with the nurse, reflected on her experience as follows: CH-006: "...We had a long talk on the way home it was a very positive opportunity for both of us". Other teens opted to use shorter sentences and abbreviations of words. CH-017: "K thank you". Most teens used a combination of formal and informal language throughout the interaction.

Our analysis of the texting interactions identified six categories of informal language: contractions, abbreviations, emoticons, text talk, multiple punctuation, and informal words. Both nurses and participants used contractions. Abbreviations were also common and included those that are in common general use (eg, OK) and more unique abbreviations such as birth control, which was shortened to "BC". Text talk was the shortening of words and phrases frequently used in text messaging such as "LOL", "NM", or "u" for the word "you". Text talk was mostly used by the participants as were emoticons. Teens also used informal words such as "Ya" and "Umm…" in their text messages. Multiple punctuation was exclusively used by the nurses, for example, "Excellent! Spring break, eh!?!". Table 2 summarizes the informal language used by the nurses and participants.

Informal language	Nurse (n=72)	Participant (n=78)
	n (%)	n (%)
Contraction	52 (72)	27 (35)
Abbreviation	14 (19)	19 (24)
Emoticons	0 (0)	10 (13)
Text talk	2 (3)	13 (17)
Multiple punctuations	4 (6)	0 (0)
Informal words	0 (0)	9 (11)

#### Correctness of Language

Spelling, grammatical, and typing errors were coded. Both nurses and participants appeared to express and understand ideas without difficulty despite the errors, but understanding of the texting interaction was not assessed. Spelling errors were deviations from the conventionally accepted spelling of a word, excluding errors caused by typographical errors (see below). Spelling errors occurred only two times. This was expected as most phones have spellcheck and autocorrect functions.

Grammatical errors were errors of syntax or morphology in the composition of clauses, phrases, and words. Such errors were common for both nurses and participants and are summarized in Table 3.

Typing errors occurred in 5 of the nurses' messages and 11 of the teens' messages. There were three categories of typing errors. The first was the omission of a letter unlikely due to a spelling error or text talk (eg, "shoul" for the word "should") and accounted for 25% of typing errors. This is in contrast to when letters were dropped purposely to shorten words in text messages such as "till" for "until". The second category was repetition of a letter within a word, such as "bbrought" or "wwont" and accounted for 37.5% of typing errors. The last category was the insertion of an improper word into a sentence and accounted for 37.5% of typing errors. This phenomenon sometimes occurred when a typing error was made and the phone's autocorrect allowed the incorrect word as it was the correct spelling of another word, for example, "Can u plead get me the information for the Edmonton clinic".

Table 3. Presence of grammatical errors by both researchers and teens.

Grammatical errors		Nurse (n=113)	Participant (n=345)
		n (%)	n (%)
Errors of capitalization			
Omission		7 (6)	68 (20)
Improper use		3 (2.5)	0 (0)
Errors of punctuation			
Omission			
	Period	34 (30)	146 (42)
	Comma	35 (31)	99 (29)
	Apostrophe	0 (0)	13 (4)
	Dash	0 (0)	2 (1)
Improper use			
	Period	1 (1)	0 (0)
	Comma	0 (0)	4 (1)
	Dash	13 (11)	0 (0)
Missing words			
Verb		3 (2.5)	1 (0.3)
Preposition		2 (2)	0 (0)
Pronoun		3 (2.5)	1 (0.3)
Subject		0 (0)	1 (0.3)
Miscellaneous			
Verb-tense agreement		1 (1)	1 (0.3)
Plural		2 (2)	0 (0)
Starting sentence with a conjunction		4 (3.5)	3 (1)
Homonym confusion		0 (0)	4 (1)
Use of pronoun in place of adverb		1 (1)	1 (0.3)
Use of improper preposition		2 (2)	0 (0)
Use of pronoun in place of adjective		1 (1)	0 (0)
Reverse word order		1 (1)	0 (0)
Adjective used instead of adverb		0 (0)	1 (0.3)

#### No or Few Questions

Although invited, and even strongly encouraged, to contact the nurse with any questions or concerns regarding the clinic session, no teen contacted the nurse in the 7 days following the intervention. In all cases, it was the nurse who initiated contact with the teen. This was also true for email and phone interactions. Even when prompted with a scripted question, "Do you have any questions for me?", only one teen responded with a question.

CH-061: Hey CH-061: I have a question for you Nurse: Let me hear it! Nurse: And then Ill text you a question. You go first.

CH-061: Ok lol its just kinda but Im I able to drink energy drinks?

Nurse: Good question.

CH-061 also asked questions about pain he was experiencing.

*Nurse: So anything else I can help you with. Any questions?* 

CH-61: Umm yeah I have one question..... sometimes I have a sharp pain it my lower stomach and I dont know what it is.

The nurse asked a few questions about the pain and then referred the teen to their general practitioner to follow up with any concerns.

The lack of questions received from teens led the nurse to ask if the participant would like more information on a topic related to their particular clinic intervention in 46% of conversations. For example, one teen had previously asked a nurse in the CHAPTER intervention if they were able to get a tattoo. The nurse used the texting interaction to expand on some of the risks associated with tattoos. Nurse: "I did find out a bit more about tattooing and the risk of endocarditis. Can I email that to you?" These nurse-initiated prompts led to more dialogue with the teen in all but one case. In this instance, the teen had to go to a basketball banquet and ended communication after the nurse asked if the teen wanted more information on cardiomyopathy. Communication with this teen was not re-established.

The theme of No or Few Questions was exemplified by one teen's reported actions regarding his CHD. According to the 2007 American Heart Association guidelines regarding bacterial endocarditis prophylaxis [73], this teen no longer required antibiotics when going to the dentist. During the clinic intervention, the nurse realized that the teen was not sure about antibiotics so she had suggested that the teen ask his mom what the pediatric cardiologist had most recently recommended. The nurse followed up on this during the texting interaction:

*Nurse: Did you have a chance to ask your mom about whether you are to have antibiotics?* 

Nurse: When you go to the dentist.

CH-058: yes i did she said i always have to take them cause off what i have but i didnt take any today

Nurse: You went to the dentist today?

CH-058: ya for a filling

CH-058: i had a dentist appointment today

*Nurse: And who decided that you wouldnt have antibiotics thus time?* 

Nurse: This time?

CH-058: no idea i was just bbrought to the dentist i had no idea i was going until this morning

This teen's apparent lack of initiative was not observed in the texting interactions with other teens in this study.

#### **Interaction With Health Care Providers**

#### **Overview**

During the clinic intervention, nurses also provided information regarding how to communicate effectively with health care providers (HCPs). This was a point for follow-up during the texting interaction. Seven of the texting interactions (54%) concerned interaction with HCPs.

Analysis of the texting data indicated that one of the teens continued to have difficulty remembering the medical term for their CHD. During the texting interaction, the nurse encouraged her to use an abbreviation to more easily communicate with HCPs. Nurse: "Why don't you just say T-G-A. That is the short form for Transposition of the Great Arteries. What do you think about that?" The nurse followed up with the teen on the telephone to have her practice pronouncing the name of her heart condition and encouraged the teen to use this terminology in her next clinic visit. Additionally, five of the interactions in some way focused on following up with the teen regarding their ability to connect with general practitioners and adult CHD cardiologists as needed. One teen was headed to summer camp, and the nurse highlighted the importance of having her family doctor's phone number should problems arise.

Nurse: One more thing - did you find [primary physician's name] phone # to put on your health passport? CH-017: Oh i will Nurse: Good! Do it while you remember. CH-017: Yes Nurse: Ok - that's all for now. Thanks!

Although no teens initiated a second texting interaction with the nurse for the purpose of asking questions, one teen texted the nurse when she returned to the hospital for a diagnostic test. She had completed questionnaires from the CHAPTER Study and wanted to return them directly to a study team member. The nurse contacted the research coordinator to retrieve the questionnaires from the teen and also made contact with the teen while she was waiting for her test to follow up on concerns that the teen had shared during the clinic intervention and texting.

#### **Texting Teens in Transition**

Because text messages can be responded to at any time, the teens transitioned through their after school and late afternoon activities while responding to the nurse-initiated text messages. To analyze temporal aspects of text messages, the unit of analysis was a conversation that began with the intervention nurse introducing themselves and ended with the nurse saying goodbye to the teen. There were 14 of these conversations. Regarding time of day, the earliest time for the texting interaction to begin was 2:56 pm and the latest start time for texting between the teen and the nurse was 7:40 pm The end time of the interaction ranged from 5:30 to 9:40 pm.

Both teens and nurses took advantage of their ability to respond over time. Conversations were an average of 67 minutes in length, and there was an average of 20 text messages an hour



in each conversation. Teens were able to take part in many activities such as time with friends, sporting activities, attending events, and driving while fitting the text messaging in between these activities. For example, a nurse was able to schedule the interaction around a teen's social activity. Nurse: "Can I give you a quick call to hear you say TGA?" CH-003: "Kk but can u call me at 9 bec i am at my friends right now". The nurse was then able to call at 9 pm to continue the interaction.

Likewise, the nurses were engaged between work and home activities during the late afternoon and early evening texting interactions. Research field notes written by GR, the nurse who did most of the texting interactions indicated that she was involved in various activities when the texting occurred:

As I was texting back and forth with CH-016 I came up with a journal article title: "Texting teens in transition" – they are in transition in their life and they are also texting you as they move from place to place, activity to activity and I am texting them as I am moving through life – in the grocery store, walking home,...watching my niece run a race. [FN CH-016]

#### Texting as a "Jumping-off Point"

In the data, there were occurrences of the nurses supplementing texting communication with the teens via email (15% of interactions), phone calls (8% of interactions), and websites (8% of interactions). For example, when a teen wanted to see what a baby with a heart condition looked like, the nurse guided the participant to a blog where a family chronicled their experience of having a child with the same heart condition as the participant.

#### CH-061: How are you?

*Nurse: Good. Wanted to check to see if you ever looked at that website about the baby with* [cyanotic congenital heart lesion] *- your heart problem.* 

#### CH-061: Yeah I did thanks for that

The nurse then used this jumping-off point to ask the teens some questions to deepen the interaction:

Nurse: What did you think of it? Any surprises?

CH-061: Yeah I was surprised to see that I was just like that

Nurse: How did that make you feel seeing the little baby with all the tubes?

CH-061: I was really sad! :(

Nurse: Did you talk to anyone about this?

CH-061: No

*Nurse: How are you feeling now?* 

CH-061: What do you mean? Like about the baby? Nurse: About having had such a big operation when

you were a baby?

CH-061: I feel like I was scary for my family and friends

Additionally, during the interaction with the teen who could not pronounce the name of her CHD, the nurse followed up with phone call to engage the teen in pronouncing the name of

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her heart condition. These examples illustrated that texting was not always appropriate but served as a reliable method to initiate other forms of communication. The nurse also emailed some teens in conjunction with the texting, including emailing information about selected topics, as relevant.

#### Affirmation

Affirmation of the teens was a recurrent theme in the texting data. One teen was affirmed for his insight after commenting on how the disease (during his infancy) had negatively affected his family CH-61: "I feel like I was scary for my family and friends" Nurse: "Yes- you would given them a big scare! That's a good insight." The nurse affirmed 2 (15%) teens for their apparent maturity, 2 (15%) for asking appropriate questions, 2 (15%) for demonstrating insight, and 8 (62%) for having the MyHealth Passport in their wallet. The following quote demonstrates a common affirmation given by the nurses. Nurse: "It was good to meet with you. I was impressed by your understanding of your [condition], meds, need for follow-up...Keep up the good work!"

#### Education

Due to the fact that all but one of the teens did not ask questions of the nurse without prompting, information was provided to 6 of the participants (46%) in a more educational fashion with information tailored to what had occurred during the in-person CHAPTER Study intervention. Topics suggested for further education included understanding the nature of their CHD, birth control, tattoos, heredity of a cardiac disease (8%), dental visits (8%), alcohol intake (8%), health care systems (8%), and use of energy drinks (8%). Even the inheritability of CHD, a potentially sensitive issue for the teens who generally did not realize that there was a chance that their offspring could be born with CHD, was addressed:

Nurse: One piece of information that you can put away for the future is about the chances of your kids having a heart problem.

Nurse: Its a little higher that I told you. I asked [pediatric cardiologist] about it.

CH-007: Okay sounds goof

Nurse: Do you want me to tell you more about this or do you want to talk with your doctor next time?

CH-007: Ya should be fun

Nurse: Ok well text back if you have questions

CH-007: You can tell me more sure thanks. So its a high chance they[offspring] will have it[CHD]?

*Nurse: No not a high chance.In fact its a high chance they wont have it.* 

CH-007Okay thats what i thought, thats good!

Nurse: 85-90% that their hearts will be fine.

CH-007: Good to hear, thanks

Nurse: But with a 10-15% chance of having a heart problem you will want talk about this when you thinking about having kids. Ok?

CH-007: Ya ofcourse

Given the back and forth nature of the texting interactions and the reality that teens were likely simultaneously texting others, the messages were sometimes out of sequence or did not seem to fit (eg, Ya should be fun posted twice; see Figure 3). In this situation, the nurse made sure that the teen was open to more information by offering the teen to "text back if you have questions". This was also reflected in the nurse's field note:

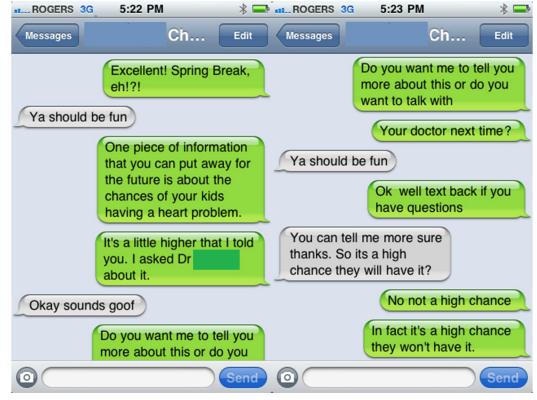
As I was texting CH 007 I was trying to imagine what kind of setting he was in. He had been skiing today – so is he in the car? Is he hanging out with friends? At home? Is this the time or is he in a place, physical and otherwise, to be talking about heart related things? He was upbeat in his responses to me and at one point I felt that he texted me the wrong response – "Ya should be fun" right after I was trying to figure out if he was open to hearing more about genetics

#### Figure 3. Out-of-sequence texts.

and his CHD. I was willing to back off and then the next text showed his openness to hearing more: "You can tell me more sure thanks. So its a high chance they will have it?" [FN CH-007]

This interaction and other similar interactions were mostly guided by the nurse instead of being guided by the teen as planned but with sensitivity to the teen's openness to education that may be beneficial to the teen. Again, the nurse reflected on this in a field note:

I felt satisfied with how the texting interactions unfolded and I was able to put a positive spin on the numbers which I felt was appropriate given the nature of our interaction (texting during Spring Break) and his age and stage of life. I believe that our goal is to plant the seed for his future consideration. [FN CH-007]



#### **Benefits and Drawbacks of Texting**

#### **Benefits and Risks**

Through analysis of the interaction between youth and the nurse in texts, benefits and drawbacks were identified in terms of the use of texting as a communication modality.

Contact by texting was established among 81% of study participants. Both the teen and the nurse made use of texting and its associated ability to respond in the immediate or over time. Of note, many interactions took place over several hours with both parties responding at a time convenient to them. For example, many teens were able to work in the interactions between daily activities. CH-061: "Its not heart related[?]" Nurse: "Not likely. That's why I asked about your bowels. But if you are concerned [patient's primary cardiologist] would be

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the one to see." CH-61: "Ok thanks but I got to go I'm about to go work out haha". Another benefit is that the information was delivered in "byte-sized" amounts that were directly related to teen's questions; the ability for the teen to guide discussion with their questions allowed for the discussion of a wide variety of topics.

#### Drawbacks

Drawbacks were also discovered upon analysis of the study transcripts. Because texting has inherent limits on the number of characters in each message, it may not always be a good medium for in-depth conversations; however, as seen above, in-depth interactions (although perhaps truncated comments) were possible. Accordingly, nurses often supplemented text messages with information delivered through other communication modalities. Another drawback identified was

that participants may have been distracted during the interaction as they were able to continue other activities while texting, thus contributing to some of the shorter back and forth interactions. Nurse: "Did I ask you if anyone else in your family has a heart problem like your? Cardiomyopathy?" CH-63: "No sorry but I have to go my basketball banquet really soon so I need to change and drive there". Nurse: "Ok - off you go!!" The last drawback that was found in the data is that the interaction could be perceived as invasive. The field note following this interaction indicated that the nurse felt bad that she had been texting with the teen as he was getting ready to go to a special event. Review of all of the texting data demonstrated that the nurse only sometimes asked the teen if it was a good time to text. On a positive note, as soon as the teen indicated that they had to move on to another activity, the nurse was receptive and terminated the interaction quickly as seen in the above example.

### Discussion

#### **Principal Findings**

The use of text messaging has potential to contribute to communication between health care providers and teens and young adults. This study does not claim that texting is the best modality for follow-up, but rather seeks to begin the investigation of using texting in the pediatric cardiac population as a potential tool augmenting communication and patient monitoring. The majority of participants in this study could be contacted by text messaging and texting was the preferred mode of follow-up among teens. This seems to indicate that texting could be an appropriate modality of contact with this population and warrants further study. Texting also served well as a method of collecting data on how effective the clinic-based intervention was at promoting use of the MyHealth Passport. Data were collected easily at the convenience of the teen and nurse, and because this data was already in electronic form, they were easily captured for analysis.

Despite the ubiquitous nature of texting among adolescents, all of the texting interactions in this study were initiated by the nurse even when the teens were advised that they were welcome to text the nurse with any questions. Additionally, during the nurse-initiated texting interaction, the teens had no or few questions and required further interaction with the nurse to deepen the conversation. This could be indicative of the interaction being nurse driven rather than teen driven. Given the considerable risk of teens with CHD being lost to follow-up [77,78], however, and the grave implications this has for their future health outcomes [79], this convenient and preferred method of interaction warrants further investigation in the context of intervention research and evaluation of transition programs in pediatric cardiology.

In regards to the nature of the texting interaction, this study adds to the literature. Although the original plan of the study was to interact completely through text message, it was found that some of the interactions resulted in the use of email, blogs, telephone, and other modes of communication. This finding is useful because it suggests that texting may serve as an initial mode of contact and as a way to connect teens to other resources, what we have called a "jumping-off point". This being said, the

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information shared between the nurse and the teen within text messages was varied and important. Topics discussed included reviewing the name of the teen's heart condition, birth control, tattoos, heredity of heart conditions, dentist visits, alcohol and energy drinks, and seeing a baby with the same heart condition. As various topics were addressed during a texting interaction, we were assured that texting was an appropriate medium for such specific education.

#### Limitations

Although this study provides useful information, it does have limitations. First, this study includes non-uniform interactions with a limited sample of 13 participants. For this reason, the findings are not representative of teens with CHD in general but offer information regarding the usefulness and viability of this type of texting interaction.

Second, this study required that teens had access to a cell phone. This was not a problem for the participants in this study but could be an issue for those working with disadvantaged populations. The same is also true for populations that do not consider cell phones appropriate for teenagers for social or cultural reasons. Researchers working with these populations may consider providing low-cost cell phones to their participants for health-related communications only, as has been done in other studies [7,14,15].

There is some question of whether or not these types of interactions, with a full back-and-forth interaction between nurse and teen, could benefit from more established protocols as two knowledge syntheses suggest [80,81]. Findings from this qualitative analysis provide direction for a protocol about the content of and approach to texting teens following a clinic-based intervention to facilitate their readiness for transition from pediatric to adult care. This guideline will provide nurses with direction for interacting with teens who may not respond well to open interaction, such as the passiveness demonstrated by the teens in this study. Implementing and evaluating established protocols for texting may allow studies to draw more powerful conclusions. Identifying a solid theoretical framework to inform the texting interactions is needed and supported by a related meta-analysis [80].

While this study does appear to indicate that texting can result in more in-depth interactions than have previously been reported in studies involving text messaging [1-6,8-13,16-54], this type of intervention is unlikely to be feasible in its current state at a large-scale organizational level. The interactions in this study were open-ended, featuring full discussions between the teen and the nurse that occurred in the late afternoon and early evening, differing from many of the studies that have occurred in the area that are mostly automated. There is some doubt as to whether this open-ended type of texting interaction is feasible because of the time and staff necessary to provide this service to all patients transitioning from pediatric to adult cardiology. There are several ways to lessen the demands of implementing such an intervention. Those wishing to implement a program using full back-and-forth interactions may consider automating some of the interaction. The research of Reback et al [14,15] included both pre-written automated messages and real-time personalized text messages to study staff. In this study,

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automated texting was used both to establish contact with participants through an introductory message and to also deliver pre-written educational messages. This type of strategy would reduce time and labor constraints and would also allow for more in-depth interaction than automated texting alone. Additionally, we recommend that the nurse determine the teen's openness to text during the day, for example, during the lunch break at school or another part of the school day when the teen can direct some attention to the text messages. More research with larger sample sizes is needed to explore the feasibility of text messaging in clinical settings.

This study identified possible risks of using text messaging in this manner. In addition to the benefits and drawbacks discussed, there is the issue of confidentiality. Although this study encountered no known breach of confidentiality, there is an inherent risk in communicating through non-secure channels. The authors of this study would recommend that there be some teaching about security and mobile devices before communicating with teens through text messaging. Teens would benefit from using pass codes on their mobile devices and deleting messages after the interaction has been completed. Content management systems to which texting data are immediately transferred are being developed [82]. Another risk is that teens feel that they do not have a choice about engaging in the texting interaction given the immediacy of the modality. The CHAPTER Study protocol now includes a question by the nurse at the beginning of the texting interaction ("is this a good time to 'talk'?") with a special point made to ensure that the teen is not driving while texting.

One final ethical concern is the possibility that a serious issue or concern could be raised in a text and the youth is not available for, or engaged in, follow-up or is not reachable perhaps due to their being mobile and/or engaging in texting only in a brief moment or engaging in truncated conversation. This did not prove to be a problematic issue in this study; however, the brevity of texting and the mobility in which it is often used, potentially renders subsequent follow-up difficult. But as a tool for maintaining communication with youth with chronic illness, texting appears to add augmentative value to clinical follow-up, particularly for populations that value this flexible modality of communication.

#### Conclusion

Text messaging offers an important augmentative method of communicating with patients that could assist in care monitoring and follow-up. In this study, text messaging was useful for collecting data about the effectiveness of the clinic-based intervention with teens with CHD. Text messaging also resulted in conversations with the teens that in some cases were reasonably in-depth and meaningful to their health and well-being, especially when combined with other forms of communication. The use of text messaging, in a manner that results in full conversations with the patient, requires more study and could benefit from protocols and a solid theoretical foundation that would ground and potentially standardize the interaction so that firmer conclusions of this novel intervention could be drawn. Toward that end, this study offers evidence of benefit and viability.

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#### **Authors' Contributions**

All authors made substantial contributions to the development of this manuscript and have given final approval of the version for publication. ASM was the study PI and oversaw all aspects of the study conceptualization, design, implementation, analysis, and reporting. GR, one of the intervention nurses and qualitative research expert on the project oversaw the generation and analysis of texting data and field notes. RB assisted with data analysis and wrote the first draft of the paper. All authors contributed to the write-up of the results and discussion.

#### **Conflicts of Interest**

None declared.

#### **Multimedia Appendix 1**

Poster presentation 2012.

[PPTX File, 9MB - mhealth\_v2i4e45\_app1.pptx]

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#### Abbreviations

CHD: congenital heart disease



**CHAPTER:** Congenital Heart Adolescents Participating in Transition Evaluation Research **FN:** field notes **HCPs:** health care providers

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**Original Paper** 

# Enabling Psychiatrists to be Mobile Phone App Developers: Insights Into App Development Methodologies

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# Abstract

**Background:** The use of mobile phones, and specifically smartphones, in the last decade has become more and more prevalent. The latest mobile phones are equipped with comprehensive features that can be used in health care, such as providing rapid access to up-to-date evidence-based information, provision of instant communications, and improvements in organization. The estimated number of health care apps for mobile phones is increasing tremendously, but previous research has highlighted the lack of critical appraisal of new apps. This lack of appraisal of apps has largely been due to the lack of clinicians with technical knowledge of how to create an evidence-based app.

**Objective:** We discuss two freely available methodologies for developing Web-based mobile phone apps: a website builder and an app builder. With these, users can program not just a Web-based app, but also integrate multimedia features within their app, without needing to know any programming language.

**Methods:** We present techniques for creating a mobile Web-based app using two well-established online mobile app websites. We illustrate how to integrate text-based content within the app, as well as integration of interactive videos and rich site summary (RSS) feed information. We will also briefly discuss how to integrate a simple questionnaire survey into the mobile-based app. A questionnaire survey was administered to students to collate their perceptions towards the app.

**Results:** These two methodologies for developing apps have been used to convert an online electronic psychiatry textbook into two Web-based mobile phone apps for medical students rotating through psychiatry in Singapore. Since the inception of our mobile Web-based app, a total of 21,991 unique users have used the mobile app and online portal provided by WordPress, and another 717 users have accessed the app via a Web-based link. The user perspective survey results (n=185) showed that a high proportion of students valued the textbook and objective structured clinical examination videos featured in the app. A high proportion of students concurred that a self-designed mobile phone app would be helpful for psychiatry education.

**Conclusions:** These methodologies can enable busy clinicians to develop simple mobile Web-based apps for academic, educational, and research purposes, without any prior knowledge of programming. This will be beneficial for both clinicians and users at large, as there will then be more evidence-based mobile phone apps, or at least apps that have been appraised by a clinician.

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**KEYWORDS** smartphone application; mobile application; creation

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## Introduction

Over the past decade, there have been massive developments in Web-based and Internet technologies, with the introduction of smartphones. Smartphones are a new generation of mobile phone technology that have created a revolution in the current telecommunications market [1]. Smartphones are currently equipped with immense computing capabilities that allow individuals to access the Internet on the go and have the capabilities to facilitate more than just the voice and text-based communications of cellular phones. In fact, they are generally now being regarded as handheld computers, rather than just cellular phones [1]. It was perhaps the release of Apple's iPhone in 2007 that sparked a major revolution in the telecommunications and information technology arena. What was also regarded as pivotal in the advancement of mobile phone technology was the launch of the Apple App Store in July 2008 [2]. The app store enabled users to download mobile phone-based apps that allowed for additional capabilities on the phone, rather than their being used only as tools for accessing the Internet.

More recent studies have looked at medical students' and trainees' ownership, usage, and perspectives towards mobile phone use. In Payne's 2012 study [2], a total of 257 medical students and 131 junior doctors were surveyed. The study showed a significantly high level of mobile phone ownership in that cohort. In addition, the majority of participants in their cohort owned between 1-5 medical-related apps. Compared to other platforms, iPhone users were more likely to own apps. Both the medical students and the trainee doctors had similar usage of apps, with most of them using apps for 20-30 minutes per day. The most frequently used apps include disease diagnosis, management, and drug reference apps. In a 2014 pilot study [3], Payne investigated the impact of implementation of a hospital-specific mobile phone app to a cohort of British junior doctors. The investigators created an iPhone app that contained mainly disease management and antibiotic dosing guidelines specific to a hospital and tested the app among 39 foundation year doctors for a total duration of 4 months. Their results showed that participants felt generally positive towards the availability of having such an app, with 68% indicating that the app helped them save significant time in clinical activities.

It is well known that anyone can publish a medical app and that the app stores do not routinely do a rigorous review of the accuracy of the app's content prior to publication [4]. Given the fact that mobile phones are used by the majority of interns on a daily basis in performing their job, there is thus a need for more guidance and advice with regards to the information provided within each app to ensure that the information provided within is accurate and credible [5]. Previous studies [6-8] have demonstrated a lack of evidence base for apps for asthma self-management; prevention, detection, and management of cancer; and for cardiopulmonary resuscitation. If clinicians were more involved and took ownership of creating their own apps, there would be less concern about the evidence contained within apps. Recent studies have highlighted the need for clinicians to be more involved in the mobile phone app development process. A recent research article highlighted a simple methodology for creating an app using only an Internet browser and a text editor, but this does not eliminate the challenges faced by clinicians [9]. The methodology shared previously might help overcome the fears of clinicians who are keen to develop their own apps but lack technical skills. However, there may be still some resistance given the fact that some coding in computer programming language would still be required. In addition, there are limited features that could be integrated in the app based on the methodology that was shared previously.

The objective of the current research is to share two freely available methodologies for developing Web-based mobile phone apps, without needing to know any programming language. Furthermore, these methodologies allow not just programming of a Web-based app, but also integrating multimedia features within the app. The application and feasibility of these two methodologies are illustrated using an app developed by the authors.

## Methods

#### WordPress

There are currently two methodologies that can be used to create HTML5 mobile Web-based apps, without the need of any technical programming knowledge. The first option is using the WordPress portal [10], which has been commonly known to the general public as a blogging site. WordPress is online, open source website creation tool. When applied to medicine, all clinicians would need to do is to create an account, register for a domain name, and modify the content using the graphic user-interface that it offers (Figure 1). Text-based content integration is possible by dragging and dropping the appropriate content into the posts or pages. Multimedia features like videos can be uploaded to the library and automatically integrated into the page. The user can also generate forms, and filled forms can be directed to a clinician's email address. When the portal is launched on a normal computer, it is a full-fledged website, but on a mobile phone, it is automatically displayed as an app (Figure 2).



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Figure 1. The graphic user interface of WordPress.

Mastering F	lsychiatry	New Post 🧧 Mastering 🛛
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Comments Feedback	emotional disorders. Psychiatry offers medical students a unique experience because psychiatric diagnosis is established by clinical interview but not based on a laboratory test or an X-ray. Medical students may need time to adjust to this specially because it involves treatment modality such as psychotherapy or electroconsidave therapy which are not found in other medical or surgical disciplines.	Page Attributes
Appearance	The duration of undergraduate posting in psychiatry is 6 weeks and it poses a challenge for medical	Parent
Users	students to master psychiatric knowledge and skills in a short period of time. The old ideology was to study a large psychiatric textbook. Medical students often realise that much time has elapsed without	(no parent)
Tools	consolidating their knowledge prior to the examination, leading to partic attacks. Some students study textbooks published in the UK and US but these books may contain treatment recommandations which are not interant to the Singane context. We believe that this new book, Mastering Psychiatry. A core	Template
Settings	Textbook for Undergraduate overhaits will be one of the most accessible, creative and practical books in undergraduate psychiatry to bridge the gaps of revision and application of includege in the	Default Template 💲
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Figure 2. How WordPress automatically converts an online portal into a Web-based app.

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#### **iBuildApp**

## **Mastering Psychiatry App**

The other methodology for developing a Web-based mobile app is by using online mobile Web-based app builders like iBuildApp [11]. Its graphic user interface would help in the immediate integration of text-based content, videos, and even rich site summary (RSS) feeds (for clinicians to retrieve information from a dedicated server). The authors have created a dedicated video to give clinicians an overview of the features (Multimedia Appendix 1) provided by current online app builders. The application of the above two methodologies has been illustrated through the development of the "Mastering Psychiatry" Web-based app. The Web-based portal and Web-based mobile phone app were developed between February and June 2012.

For the online portal (developed using WordPress), apart from the provision of a newly written textbook that integrates local clinical guidelines specific to Singapore, we included other features that could help augment student's educational needs.

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These included videos demonstrating how to assess patients for a particular psychiatric disorder and how to elicit basic psychopathologies. In addition, an interactive multiple-choice survey was integrated that students could use for rapid revision of the multiple-choice component at their end for posting examinations.

For the Web-based app (developed using iBuildApp), we designed it to be a handy reference for students to use in their clinical settings. The app included the same content as was available on the online portal but was further subclassified into four individual tabs.

With regards to the deployment of the app, all of the students who were up for their clinical psychiatry posting were provided with information about the portal and the Web-based app on the first day of their clinical posting. A 10-minute demonstration of the features of both the online portal and the native app was conducted by the first author, MWBZ, on the first day of their clinical posting.

With ethics approval from the National University of Singapore, a user perspective survey was administered to the students right after completion of their end of posting clinical assessment. Participation in the survey was entirely voluntary, and a participant information handout was provided to all the participants prior to the start of the survey.

# Results

Our online portal and Web-based mobile phone app were launched on July 15, 2012, via direct dissemination of the Web links to the portal and to the mobile phone app. Since inception until today, there have been a cumulative total of 21,991 views of the online portal and a cumulative total of 722 users who have used the mobile app, based on our analytics. A cumulative total of 185 students took part voluntarily in the user perspective survey.

The majority of the students (141/178, 79.2%) students were 22 years old. More than half (121/227, 53.3%) used an Apple iOS device, whereas 21.6% (49/227) used an Android device. The majority of the students (124/186, 66.7%) had between 1-5 medical apps on their mobile phones. The purposes of the medical apps they had previously downloaded were mainly for educational purposes, as well as for usage in clinics and wards. The demographics of the sample population who took part in the survey are shown in Table 1.

The majority of the students (177/186, 95.2%) indicated that having a psychiatry mobile phone app would be useful. Similarly, a majority suggested that it would be particularly useful if the app contained textbook content and clinical videos. More than half of the students (105/184, 57.1%) agreed that having an app for psychiatry would be helpful, and 71.4% (132/185) also agreed that it would be a good companion to a traditional textbook. Table 2 gives an overview of students' perspectives towards the app and its content.



 Table 1. Student's baseline demographic information.

Demographic variable	n	%
Mobile phone ownership		
No	3	1.3
iPhone	121	53.3
Google Android	49	21.6
iPad	24	10.6
Android tablet	8	3.5
Laptop / Notebook computer	22	9.7
Medical-related app		
No	40	21.5
1-5 apps	124	66.7
6-10 apps	15	8.1
11-15 apps	3	1.6
>15	4	2.2
Purpose of medical-related app		
Education – Revision	40	14.8
Education – Learning	74	27.4
Clinical (wards)	84	31.1
Clinical (clinics)	55	20.4
Others	17	6.3
Gender		
Male	100	54.1
Female	85	45.9
Age in years		
20	1	0.6
21	12	6.7
22	141	79.2
23	11	6.2
24	12	6.7
>25	1	0.6



Table 2. Student's perspectives about app content and usefulness.

Perspectives	n	%
Having mobile phone app for learning psychia	try	
Absolutely useless	2	1.1
Useless	7	3.8
Of some use	93	50.0
Useful	60	32.3
Very useful	24	12.9
Usefulness of mobile phone app in psychiatry		
Absolutely useless	1	0.5
Useless	5	2.7
Of some use	73	39.7
Useful	86	46.7
Very useful	19	10.3
Good companion to book		
Absolutely useless	4	2.2
Useless	11	6.0
Of some use	38	20.5
Useful	94	50.8
Very useful	38	20.5
Having textbook contents in mobile phone app	s	
Absolutely useless	4	2.2
Useless	8	4.3
Of some use	53	28.7
Useful	84	45.4
Very useful	36	19.5
Having clinical OSCE videos in mobile phone a	apps	
Absolutely useless	2	1.1
Useless	12	6.4
Of some use	49	26.2
Useful	81	43.3
Very useful	43	23.0

# Discussion

#### **Principal Findings**

The advantages of the website and app builder tools are that they enable clinicians to build their own apps that can be used for academic pursuits, education, and research. The initial findings in our study showed that a significant group of students were also amenable to trying out newer modalities of technologies, such as mobile phone technologies, to help them fulfill their educational needs on the go. The user perspective survey results showed that a high proportion of students valued the textbook and OSCE videos features in our app. A high proportion of students also agreed that a self-designed mobile phone app would be helpful for psychiatry education.

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XSL•FO RenderX Due to the lack of previous research studies in this area, the interpretation of our results can be based only on a prior study on the development of a mobile phone app integrating guidelines for family physicians. Waldmann and Weckbecker [12] designed a Web-based app, very similar to ours in conception, that enabled teaching medical students more about primary care guidelines. In their Web-based app, a total of 15 guidelines from the German College of General Practitioners and Family Physicians (DEGAM) were included. Their study of 14 student testers showed that students preferred the Web-based app compared to a printed hard copy guideline. It was noted that students used the app much more frequently and made use of their waiting periods to go through the guidelines. They highlighted how the simple Web-based app helped to create an interest among students and helped them acquire valuable

knowledge on the go or during down time. This might account for the initial results that we obtained, using the two methodologies that we described. Our students appeared to be similar to the cohort studied by Waldmann and Weckbecker [12], as they were receptive towards what we developed and perceived our Web-based self-developed psychiatry app as a useful tool for mastering psychiatry on the go. This reinforces the fact that our methodologies indeed do work and can equip psychiatrists with additional technological skills.

#### **Strengths and Limitations**

The main strength of the current study is that we managed to assess the feasibility of enabling psychiatrists to be app developers and tested the student response to a self-developed app. Given that clinicians could regulate the content within the app if desired, and if there were collaborations between a group of clinicians, there would likely be some fundamental critical appraisal of app content. This is in line with Faye [13] who proposed that, in order to overcome the issue of the lack of apps that have been reviewed by appropriate authorities, we must demonstrate that the apps are evidence-based. One option involves having university or health care organizations creating their own in-house apps. It has been believed that developing in-house apps has inherent advantages, as the apps can help address specific shortfalls in clinical education, or specific deficiencies in competencies of either medical students or residents. Another suggestion would be for either university or health care organizations to have their own set of peer-reviewed apps. Other advantages of in-house apps are the low cost of development and the speed at which an app can be built. The speed of developing an app can be critical, especially if it has been planned for acquisition of information during a crisis. Finally, the advantages of using the website and app builders

we described are that the apps created would be cross-compliant across various platforms and devices.

The limitations of the two methodologies we described include the fact that the number of interactive features that can be deployed are limited to what is in the app library online. Another limitation is that users would not be able to locate their app in the conventional app store, so dissemination of the availability of the app might be affected. Our sample size is relatively small and this is mainly due to the limited number of medical traineeship places available locally. In addition, our results are mainly derived from an Asian cohort and hence cannot be generalized to a Western cohort. We acknowledge that the response rate to our questionnaire is not 100%, as students might have skipped questions and not answered all the questions. In addition, we note that students might have given multiple responses to certain questions on a paper-based questionnaire, accounting for the varying total sample size for each question. It might be more ideal to consider allowing our students to fill in a Web-based online questionnaire with restricted responses to each question. We examined students' perspectives from a sample that comprised mainly students with access to a smartphone. However, we do acknowledge that there are students with financial difficulties who might not have a smartphone, and hence our results might have an inherent bias.

#### Conclusions

These Web and app-building methodologies can enable busy clinicians to develop simple mobile Web-based apps for academic, educational, and research purposes, without any prior knowledge of programming. This will be beneficial for both clinicians and users at large, as there will then be more evidence-based apps, or at least apps that have been appraised by a clinician. We hope that more work can be done in the future to address the limitations in the current study.

#### **Authors' Contributions**

MWBZ contributed the original idea, designed the Web app, compiled the Multimedia Appendix and drafted the initial manuscript. CSSH and RCMH drafted the final manuscript. All authors read and approved the final manuscript.

#### **Conflicts of Interest**

None declared.

#### **Multimedia Appendix 1**

Demonstration of Web-based mobile app with native app interface created by online application toolkits.

[MOV File, 12MB - mhealth v2i4e53 app1.mov]

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#### Abbreviations

**iOS:** Apple operating system **OSCE:** objective structured clinical examination

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# Application of Low-Cost Methodologies for Mobile Phone App Development

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# Abstract

**Background:** The usage of mobile phones and mobile phone apps in the recent decade has indeed become more prevalent. Previous research has highlighted a method of using just the Internet browser and a text editor to create an app, but this does not eliminate the challenges faced by clinicians. More recently, two methodologies of app development have been shared, but there has not been any disclosures pertaining to the costs involved. In addition, limitations such as the distribution and dissemination of the apps have not been addressed.

**Objective:** The aims of this research article are to: (1) highlight a low-cost methodology that clinicians without technical knowledge could use to develop educational apps; (2) clarify the respective costs involved in the process of development; (3) illustrate how limitations pertaining to dissemination could be addressed; and (4) to report initial utilization data of the apps and to share initial users' self-rated perception of the apps.

**Methods:** In this study, we will present two techniques of how to create a mobile app using two of the well-established online mobile app building websites. The costs of development are specified and the methodology of dissemination of the apps will be shared. The application of the low-cost methodologies in the creation of the "Mastering Psychiatry" app for undergraduates and "Déjà vu" app for postgraduates will be discussed. A questionnaire survey has been administered to undergraduate students collating their perceptions towards the app.

**Results:** For the Mastering Psychiatry app, a cumulative total of 722 users have used the mobile app since inception, based on our analytics. For the Déjà vu app, there has been a cumulative total of 154 downloads since inception. The utilization data demonstrated the receptiveness towards these apps, and this is reinforced by the positive perceptions undergraduate students (n=185) had towards the low-cost self-developed apps.

**Conclusions:** This is one of the few studies that have demonstrated the low-cost methodologies of app development; as well as student and trainee receptivity toward self-created Web-based mobile phone apps. The results obtained have demonstrated that these Web-based low-cost apps are applicable in the real life, and suggest that the methodologies shared in this research paper might be of benefit for other specialities and disciplines.

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#### **KEYWORDS**

education; technology; mobile phone apps; cost-effectiveness

## Introduction

The worldwide prevalence of mobile phones has made them a very useful and innovative platform for the provision of patient care [1], as well as in helping clinicians with management decisions. Over the past few years, mobile phones have advanced drastically in terms of both their functionality and design, and they are currently more than what used to be a simple call and messaging device [1]. They have literally been transformed into sophisticated personal mini-computers.

Previous reviews have highlighted the worldwide prevalence and the global acceptance of mobile phones and commercial mobile apps by medical students, trainees, and interns. In 2012, a questionnaire-based survey was distributed amongst interns in the Republic of Ireland [2], and it has demonstrated that mobile phones are being used daily by the interns to perform their job. There have been numerous literatures demonstrating the acceptability of mobile phone usage in education for medical students. A survey questionnaire conducted at the University of Birmingham, United Kingdom, highlighted that students generally find mobile phones useful as educational aids, with at least 84% believing so. This has been replicated in other studies, which highlighted that there has been a high level of mobile phone ownership and usage amongst medical students and junior doctors [3].

Along with the enhancements in mobile phone functionality, there has been an increased number of educational mobile phone apps made available for users to download and install. However, it is a well-known fact that anyone could publish a medical app, and the app stores do not routinely do a rigorous review of the accuracy of the content of the mobile app prior to publication [4]. Although mobile phones have been used by the majority of interns on a daily basis in performing their job [4], there still needs to be more guidance and advice with regards to the accuracy and the credibility of the information provided within the apps [5]. Despite the high usage of mobile phone and its apps, the development of mobile phone apps by professionals will incur a huge cost. Very often, clinicians and researchers have to wait for and hope to be successful in securing grants to finance the developmental costs. Apart from the concerns about the high cost associated with development, another concern lies with the fact pertaining to how evidence-based apps are. Most of the current apps available have been developed by external vendors and developers, and are lacking inputs from clinicians who have a vast amount of knowledge and expertise in their specialized fields. Recent studies have highlighted the need for clinicians to be more involved in the mobile phone app development process and a research article highlighted a simple methodology of creating an application using just an Internet browser and a text editor [6]. The methodology shared seemingly seemed to help overcome the fears of clinicians, but the methodology shared previously does require clinicians to have some fundamental technological knowledge. Also, the previous methodology shared does not enable clinicians to

include more multimedia features in the app. Zhang MWB et al [7] recently shared two methodologies of app development using a blogging site as well as an online app builder. The limitation of Zhang MWB et al [7] recent publication lies within the fact that the costs associated with using these tools have not been explicitly declared. In addition, the methodology shared by Zhang MWB et al [7] will still require users to have constant access to the Internet in order to access the apps. As the apps are not in the respective app stores, it might be hard for dissemination of the apps as well.

Thus, taking these variables into consideration, we wish to elaborate on the previous methodologies shared by Zhang MWB et al [7]. Therefore, the objectives of the current research article are to: (1) highlight a low-cost methodology that clinicians without technical knowledge could use to develop educational apps; (2) clarify the respective costs involved in the process of development; (3) illustrate how limitations pertaining to dissemination could be addressed; and (4) to report initial utilization data of the apps and to share initial users' self-rated perception of the apps.

## Methods

#### Low-Cost Mobile Phone App Development

Zhang MWB et al [7] previously described two methodologies that could be deployed for mobile app creation. In this paper, we wish to highlight a particular methodology that could enable clinicians to develop mobile apps that resemble native mobile phone apps developed by professionals, with minimum costs involved.

There are various online Web-based mobile phone app builders such as Conduit Mobile [8] and IbuildApp [9]. The advantages of using online Web-based mobile app builders are that its graphic user interface will help in the immediate integration of text-based content, videos, questionnaires, and other multimedia features. These multimedia features include built-in photo-taking capabilities as well as e-commerce capabilities. An overview of the features that could be integrated using an online application builder is exemplified (Figures 1 and 2). Integration of content was simple. All users have had to do is select the appropriate interactive feature and then key in the relevant information.

The methodology described above would enable clinicians to devise cost-effective apps. A summary of the costs involved and the features included for each price plan provided by these online app builders have been summarized in Table 1. Mobile site visits imply that users could access the application via a Web-link.

The authors will describe the development of two educational apps, one for undergraduate education and another for postgraduate education using the cost-effective methodologies as described above.



XSL•FC

Zhang et al

Table 1. Cost of online mobile app builders.

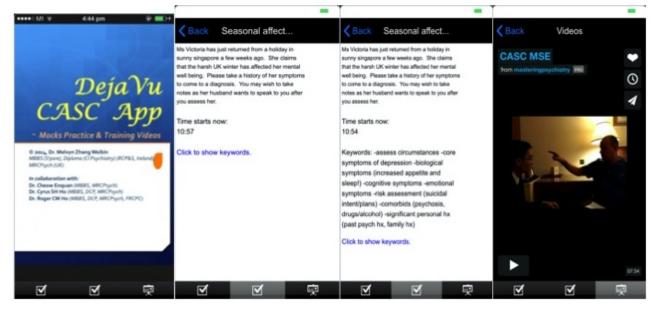
Online app builder	Cost involved	Features
Conduit Mobile	US \$0 /month	up to 5 mobile app downloads
		50 mobile site visits per month
Conduit Mobile	US \$33/month	unlimited app downloads
		unlimited mobile site visits
		app submission to stores
IBuildApp	US \$5.99/month	100 app downloads
		unlimited mobile site visits
IBuildApp	US \$23.40/month	3000 app downloads
		unlimited mobile site visits
		expert submission to app stores

## Figure 1. Development of Web-based mobile phone using online app builder.

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	④ Add Content			?	< Untitled	
	Social	General Content	Multimedia	Contact & info	- Psychiatry, we teach you how to master it -	
	Facebook	News	Photos	About us	2 years ago	
	Twitter	Calendar	Videos	Contact us	Share	
	Tinstagram	Resources	💽 Audio	💡 Мар	Welcome to the online companion to	
		Collection	LiveAlbum	Forms	Mastering Psychiatry: A Core Textbook for undergraduates!	
		Loyalty Card			If you are using a Smart Phone (iPhone / Blackberry / Android / Windows OS), please make use of this link to assess our	
		Web page			application directly on your smartphone.	
		Coupons			(Your smartphone / tablet screen must be in Portrait orientation)	



#### Figure 2. Overview of the app.



# Differentiating "Mastering Psychiatry" and the "Déjà vu" Apps

## The "Mastering Psychiatry" Mobile Phone App

Zhang MWB et al [7] has previously described the application of this methodology in their recent paper. An online mobile app builder was used to develop the initial version of the app, including various features such as the core textbook information, clinical interviewing videos, and questionnaires. All the information was coded into the online builder using basic HTML5 programming language. The determination of the relevant content to be included was based on the experiences of the authors in undergraduate education, and also based on careful evaluation of the existing textbook based mobile app in the mobile app stores. With regards to the dissemination of the mobile app information, students who posted to the National University of Singapore, Psychological Medicine program were provided with information of the mobile app on the first day of their clinical posting.

## The "Déjà vu" Mobile Phone App The "Déjà vu" CASC (Clinical Ass

The "Déjà vu" CASC (Clinical Assessment of Skills and Competencies) app was developed between January 2014 and April 2014. The developmental approach involved 4 developmental phases, which included: (1) understanding trainee requirements; (2) system development; (3) system evaluation; and (4) system deployment. In terms of user requirements, the authors postulate that the core requirements of a CASC app for trainees would need to include each one of the following in Textbox 1.

The postulation of what to be included in the mobile app was based on the experiences of the authors in the recent diet of the postgraduate examination.

In consultation with the author RCMH, the following core interviewing approaches have also been identified to be essential as presented in Textbox 2.

Textbox 1. Core requirements for trainees.

- 1. Inclusion of Mock examination stations with timers (either 7 minutes or 10 minutes timers).
- 2. Timers to include additional 60 seconds preparation time, to allow trainees to practice recalling vital information and write them down prior to the commencement of any station.
- 3. Inclusion of mock stations (30 in total) that are adaptations of old College stations with variants in the constructs, or are new stations crafted based on information from the Royal College of Psychiatrists Mental Health Leaflets.
- 4. Ability of app to enable trainees to link up with others for video-conferencing.
- 5. Ability of app to enable trainees to practice stations in a timed mock examination way with fellow trainees from their trust.
- 6. Inclusion of instructional videos that demonstrate to trainees core approaches for a specific variety of stations.



Textbox 2. Core interviewing approaches.

- 1. How to break bad news
- 2. How to deal with angry patients
- 3. How to perform a mental state examination
- 4. How to handle an explanation station
- 5. How to deal with disinhibited patients
- 6. How to deal with patients who are refusing to engage with Psychiatry
- 7. How to perform a risk assessment
- 8. How to deal with patients who are not forthcoming
- 9. How to handle patients with learning disabilities
- 10. How to perform cognitive assessment

With regards to system deployment, this was initially an issue as none of the authors are currently based in the United Kingdom, and hence, would not have access to the trainees within each of the trusts. Therefore, the deployment of the mobile phone app was done via a commonly accessed online forum, known as "Revise Now". The author, MWBZ, posted a message under the forum topic 'courses and books' on April 13<sup>th</sup> 2014, giving trainees a Web-link to access the mobile phone app. In addition, the mobile phone app was also deployed locally in Singapore to fellow trainees via direct email dissemination.

Subsequently, as the online app builder allows for the generation of an application programming interface (API) for download, the author, MWBZ managed to submit a version of the mobile app to the Android Play Store and has been published since October 27<sup>th</sup>, 2014. In order to be published on the mobile app stores, MWBZ has had to set up a developer account and upload the API, along with images of the app. Publication to the iTunes store was similar, though the cost of the developer account was vastly different. The costs were US \$25 per annum for an account with Android Play, but US \$300 per annum for an account with the iTunes store.

The application could be found in the android play store by searching for the following keywords "MRCPsych, CASC."

## Acquiring Utilization Data and Initial Perspectives

Utilization data was tracked using the analytics provided by the online app builders. With regards to initial perspectives, the authors, with ethics approval from the National University of Singapore, conducted a user-perspective survey looking into the perception of the mobile app, mainly by undergraduate students. Participation in the survey was entirely voluntary and a relevant participant information handout was provided to all the participants prior to the start of the survey.

## Results

## The "Mastering Psychiatry" Mobile App

The online portal and the Web-based mobile phone app were launched on July  $15^{\text{th}}$  2012 via direct dissemination of the Web-links of the mobile app. Based on our analysis, since

## The "Déjà vu CASC" Mobile App

Since the date of deployment of the Déjà vu CASC mobile app and up until November 7<sup>th</sup> 2014, there has been a cumulative total of 154 downloads of the mobile app from the Web-link that was provided to the students.

For the user' perceptive survey about the "Mastering Psychiatry" app launched locally in Singapore, a total of 185 undergraduates have taken part in the survey. Most of them used an Apple IOS device (121/227, 53.3%), whereas 21.6% (49/227) used an android device. The average age of the sample was 22 (141/178, 79.2%). A cumulative total of 51.7% perceived that the mobile app to augment undergraduate education is helpful. Approximately 71 of the students agreed that mobile apps would make a good companion to a conventional textbook.

## Discussion

## **Principal Findings**

From our current knowledge, this is one of the first few studies to describe how using an online application builder might be a low-cost methodology of mobile app development, with interactive features embedded within the app. Based on the utilization data for both the undergraduate and the postgraduate apps, it showed that both groups are receptive towards a self-developed mobile app. Therefore, our current study has demonstrated that clinically relevant content for mobile phones could be developed by clinicians and clinical teachers using low-cost, non-technical methodologies. The results obtained indicate that these Web applications could be used in real-life and hence may suggest that these low-cost methodologies are feasible for conveying knowledge to other health professionals.

Despite the rapid advancement in Web 2.0 technologies as well as mobile phone technologies, there is still a paucity of technology-related papers published about how lost-cost methodologies could be used by clinicians to self-create mobile phone apps. The only study identified thus far is previously published by Waldmann UM and Weckbecker K (2013) [10], who have described how they have formulated a Web-based

guideline app and have piloted it and demonstrated that students were receptive towards such a self-developed app. Zhang MWB et al [7] have described two separate methodologies that clinicians could use to develop mobile apps, but have not disclosed the costs involved. It is hoped that this current paper will share more insights about the relevant costs involved. Also, the limitations of Zhang MWB et al's [7] previous paper was that there was perceived difficulties in accessing the mobile apps, as they are not made available on the mobile app store. In our current paper, the authors have shared how the respective online app builders could help to make the mobile app available on the respective app stores. Zhang MWB et al [7] also mentioned that their findings are only generalized to their local context of students in Singapore. In the current paper, by using a low-cost method to create a postgraduate application, the authors have managed to demonstrate the utility of a self-created mobile app worldwide.

The authors in this paper have described a low-cost methodology that could enable clinicians to develop their own in-house mobile app. This might help mitigate the concerns raised by Thomas LL (2013) [11] in his previous editorial reply, which proposed that there ought to be a systematic self-certification model developed for peer-review of mobile apps. By empowering clinicians with techniques of mobile app development, and hopefully enticing them with the low-costs associated with development, more apps made available on the application would fulfill the quality of information based on Health on the Net Foundation (HON) criteria. The criteria specifies that all relevant medical information included in any mobile app in the application stores should be attributed to an author, with the training level of the author disclosed. In addition, the purpose of the mobile app, confidentiality of the information, date of the information as being created and modified, and the contact details and disclosures should all be specified within the application.

The main strength of the current study is that we managed to demonstrate how educational mobile apps could be developed using low-cost methodologies and without any technical knowledge. It is obvious that if clinicians take more ownership of creating mobile apps, the app will be more evidence based and there will be enhanced quality of information within the app. Our current study has empowered both undergraduates and postgraduate psychiatry students and trainees to have an opportunity to make use of the latest innovations in technologies, using a low-cost methodology. As well, the initial results also demonstrate the feasibility of adopting this methodology in creation of mobile apps for education and for other disciplines. In addition, the provision of the application on the app store would imply that users do not need a continuous Internet to access the relevant content.

Nevertheless, several limitations remain in the current study. The authors have not formally evaluated the perspectives of non-Asian users of self-created mobile apps. The authors have addressed the previous limitations pertaining to the difficulties associated with the access of the mobile app, by making the app available on one of the app stores. However, the authors have not mentioned their experience with making the mobile app available on other stores, such as iTunes. It should be noted that different app stores have different criteria for acceptance of mobile apps and there might be a chance one store would accept and another might reject the proposal. This would limit the distribution of the mobile app across multiple computing platforms. Another limitation would be the lack of conducting focus groups before deciding what would be the most appropriate contents to be integrated within the respective mobile apps.

## Conclusions

This is one of the few studies that has demonstrated that clinically relevant content for mobile phones could be developed by clinicians and clinical teachers using both low-cost, and non-technical methodologies. The results obtained have demonstrated that these Web-based low-cost mobile apps are applicable in real life, and suggest that the methodologies shared in this research paper might be of benefit for other specialties and disciplines. In addition, it is hoped that more clinicians will be willing to consider using our methodology and create their own mobile apps, and by pooling the results of several studies together, we will have more rigorous evidence of the effectiveness of self-created mobile phone apps.

## **Authors' Contributions**

MWBZ contributed the original idea, designed the Web applications, compiled the multimedia figures and drafted the initial manuscript. EQ, CSSH, NBY, and RCMH drafted the final manuscript. All authors read and approved the final manuscript.

## **Conflicts of Interest**

None declared.

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## Abbreviations

**API:** application programming interface **CASC:** Clinical Assessment of Skills and Competencies

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**Original Paper** 

## SMARTHealth India: Development and Field Evaluation of a Mobile Clinical Decision Support System for Cardiovascular Diseases in Rural India

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## Abstract

**Background:** Cardiovascular disease (CVD) is the major cause of premature death and disability in India and yet few people at risk of CVD are able to access best practice health care. Mobile health (mHealth) is a promising solution, but very few mHealth interventions have been subjected to robust evaluation in India.

**Objective:** The objectives were to develop a multifaceted, mobile clinical decision support system (CDSS) for CVD management and evaluate it for use by public nonphysician health care workers (NPHWs) and physicians in a rural Indian setting.

**Methods:** Plain language clinical rules were developed based on standard guidelines and programmed into a computer tablet app. The algorithm was validated and field-tested in 11 villages in Andhra Pradesh, involving 11 NPHWs and 3 primary health center (PHC) physicians. A mixed method evaluation was conducted comprising clinical and survey data and in-depth patient and staff interviews to understand barriers and enablers to the use of the system. Then this was thematically analyzed using NVivo 10.

**Results:** During validation of the algorithm, there was an initial agreement for 70% of the 42 calculated variables between the CDSS and SPSS software outputs. Discrepancies were identified and amendments were made until perfect agreement was achieved. During field testing, NPHWs and PHC physicians used the CDSS to screen 227 and 65 adults, respectively. The NPHWs identified 39% (88/227) of patients for referral with 78% (69/88) of these having a definite indication for blood pressure (BP)-lowering medication. However, only 35% (24/69) attended a clinic within 1 month of referral, with 42% (10/24) of these reporting continuing medications at 3-month follow-up. Physicians identified and recommended 17% (11/65) of patients for BP-lowering medications. Qualitative interviews identified 3 interrelated interview themes: (1) the CDSS had potential to change prevailing health care models, (2) task-shifting to NPHWs was the central driver of change, and (3) despite high acceptability by end users, actual transformation was substantially limited by system-level barriers such as patient access to doctors and medicines.

**Conclusions:** A tablet-based CDSS implemented within primary health care systems has the potential to help improve CVD outcomes in India. However, system-level barriers to accessing medical care limit its full impact. These barriers need to be actively addressed for clinical innovations to be successful.

RenderX

**Trial Registration:** Clinical Trials Registry of India: CTRI/2013/06/003753; http://ctri.nic.in/Clinicaltrials/showallp.php?mid1=6259&EncHid=51761.70513&userName=CTRI/2013/06/003753 (Archived by WebCite at http://www.webcitation.org/6UBDlrEuq).

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#### **KEYWORDS**

clinical decision support systems; mobile health; developing countries; community health worker; primary health care; cardiovascular disease

## Introduction

Cardiovascular diseases (CVD) are the major cause of premature death and disability worldwide and are rapidly rising in many low- and middle-income countries (LMICs) [1-3]. In India, CVD risk factor levels are high in rural populations, which currently constitute 70% of the total population, and CVD is now the leading cause of adult deaths in many rural communities [4,5]. Despite the availability of evidence-based guidelines for the prevention of CVD, the use of simple, affordable, preventive treatments (eg, smoking cessation strategies, aspirin, low-cost statins, ACE-inhibitors, and beta-blockers) is very low in these communities [6]. Even the use of secondary preventive drugs is low among people with known coronary heart disease (CHD) or stroke [7]. Multiple barriers exist at different levels of the health systems, including lack of health care facilities, limited access to health care providers, and high out-of-pocket costs for consumers [8].

Several systematic reviews have consistently shown that clinical decision support systems (CDSS) are able to improve effectiveness of care [9-15]; however, the vast majority of evaluations have been conducted in high-income countries. Given the vastly different health systems and infrastructure, the effectiveness of CDSS in LMIC settings is unclear [16]. As a result of infrastructure limitations for fixed-line information technology solutions, implementation of CDSS in these settings could be enhanced by building them into accessible and affordable mobile device-based platforms. A few recent reviews in LMICs concluded, however, that the current evidence for their effectiveness is limited mostly to isolated interventions with intermediary outcomes, such as cost savings, improved data quality, monitoring and supervision, and improved quality of care [17-22]. One of the reviews advocated mobile health (mHealth) solutions that are integrated within existing health system structures and recommended the use of end-to-end solutions ranging from point-of-care support through to high-level system elements such as shared electronic records and processes to manage drug supply chain [17].

India has a 3-tier health care system, with a subcenter at the village level, primary health center (PHC) at the mandal level (a group of approximately 10 villages), and a community health center (for every 4 PHCs) at the district level. The PHC, often led by 1 doctor, is expected to provide comprehensive primary health care for up to 30,000 residents. This leads to massive unmet demand, placing considerable strain on PHC resources and consequently on the quality of care provided. In this context, there is an urgent need for different workforce strategies. One promising solution is to expand the capacity of nonphysician

health care workers (NPHWs) by training and provision of appropriate tools [23]. Within each village, 1 local female resident, with approximately a grade 10-level education, is appointed as an accredited social health activist (ASHA) for every 1000 residents. ASHAs receive performance-based remuneration under India's National Rural Health Mission program. On average, they work for 2-3 hours each day, with a primary focus on maternal and child health. Their services are provided primarily through outreach village household visits, which provide an ideal environment for additional opportunistic health screening activities and reaching sectors of the community that may not readily access the PHC. A trial conducted in this region demonstrated that a simple algorithm administered in the community by NPHWs increased the identification of people at high risk of cardiovascular events (ie, individuals with a history of heart attack, stroke, or angina) who would be eligible for proven preventive drug therapies [24]. This suggests that this workforce can be trained to effectively identify people at high risk and refer them appropriately for medical care.

In this paper, we describe an innovative strategy called Systematic Medical Appraisal Referral and Treatment in India (SMARTHealth India) that comprises (1) a mobile device–based CDSS for CVD risk management, (2) task-shifting traditional physician roles to NPHWs, and (3) integration of the overall system within government PHC infrastructure in rural India. Our objectives were (1) to develop a valid CVD risk assessment and management algorithm based on best practice national and international recommendations, with a focus on blood pressure (BP) management and (2) to assess the utility, preliminary effectiveness, and acceptability of the system among community members, NPHWs, and PHC physicians.

## Methods

## Ethics Statement

The study was approved by the ethics committee of the Centre for Chronic Disease and Control, New Delhi, and the University of Sydney, New South Wales, Sydney. Informed, written consent was obtained from all participants contributing data in the study. This is a registered study (CTRI/2013/06/003753).

## **Clinical Decision Support System Development**

Plain language clinical rules were developed based on a synthesis of recommendations from Indian and international screening and management CVD guidelines. World Health Organization (WHO)/International Society of Hypertension (ISH) risk charts calibrated for use in India were used for assessment of 10-year risk of a fatal or nonfatal cardiovascular

event (eg, myocardial infarction or stroke) [25]. Only those conditions for which information could be collected in the primary care settings were programmed into the algorithm.

Overall, this resulted in 28 inputs and 42 calculated variables in the algorithm (Textbox 1).

Textbox 1. Variables and conditions for use of WHO/ISH risk charts in this algorithm.

Variables used in the WHO/ISH risk chart:

- Age
- Sex
- Smoking status
- Presence or absence of diabetes
- Systolic blood pressure
- Total cholesterol

Individuals at high cardiovascular risk include the following:

- Presence of established cardiovascular disease
- Without established cardiovascular disease and:
  - Systolic blood pressure ≥160 mm Hg
  - Diastolic blood pressure ≥100 mm Hg
  - Total cholesterol (TC) ≥320 mg/dL
  - Low-density lipoprotein cholesterol (LDL-C) ≥240 mg/dL
  - TC/High-density lipoprotein cholesterol (HDL-C) >8

Risk is considered to be underestimated in the presence of any of the following conditions:

- Taking antihypertensive therapy
- Obesity (including central obesity)
- Family history of premature coronary heart disease (CHD) or stroke in first-degree relative (male <55 years, female <65 years)
- Raised triglyceride level (>2.0 mmol/L or 180 mg/dL)
- Low HDL cholesterol level (<1 mmol/L or 40 mg/dL in males, <1.3 mmol/L or 50 mg/dL in females)
- Fasting dysglycemia
- Raised resting heart rate (heart rate >100 beats per minute)

If age is between 18 and 40 years, risk is determined at age imputed at 40 years; if age is ≥79 years, risk is determined at age imputed at 79 years.

Depending on the availability of cholesterol testing, low and high information risk equations were programmed with the algorithm automatically defaulting to the appropriate equation depending on the data available. Once risk was assessed, management recommendations were derived based on Indian CVD-related guidelines (Textbox 2). These plain language rules were then built as a java-based application into a mobile tablet computer using the Android 4.1 operating system. Both English and local language (Telugu) versions were developed. Based on ASHA literacy levels, a 7-inch screen size was chosen to maximize utility but still maintain the portability afforded by smaller mobile phone–size screens.



Textbox 2. CVD risk management outputs and targets programmed in the algorithm.

BP-lowering medication indications:

- Established CVD
- BP ≥160/100 mm Hg
- BP  $\geq$ 140/90 mm Hg and 10-year CVD risk >20%
- BP  $\geq$ 130/80 mm Hg and 10 year CVD risk >30%
- TC  $\geq$  320 mg/dL or LDL-C $\geq$  240 mg/dL or TC/HDL-C>8

Lipid-lowering medication (statins) indications:

- Established CVD
- Established diabetes
  - Previous diagnosis of diabetes
  - Fasting blood glucose  $\geq 126 \text{ mg/dL}$
  - Random blood glucose ≥200 mg/dL
- TC  $\geq$  320 mg/dL or LDL-C $\geq$ 240 mg/dL or TC/HDL-C>8
- BP ≥160/100 mm Hg
- 10-year CVD risk >30%
- Age  $\geq$ 40 years and 10-year CVD risk >20% and any 1 of the following:
  - TC ≥200 mg/dL
  - LDL-C≥120 mg/dL

Antiplatelet medication indications:

- Established atherosclerotic CVD
- TC  $\geq$ 320 mg/dL or LDL-C $\geq$ 240 mg/dL or TC/HDL-C>8
- BP ≥160/100 mm Hg
- 10-year CVD risk >30%

Target treatment levels for BP:

- BP <130/80 mm Hg for those with any of the following:
  - Established CVD
  - Established diabetes
  - TC  $\geq$  320 mg/dL or LDL-C $\geq$  240 mg/dL or TC/HDL-C>8
- BP <140/90 mm Hg for all others

Target treatment levels for lipids:

- TC <160 mg/dL, LDL-C<80 mg/dL, and HDL-C>45 mg/dL for those with established CVD
- TC <180 mg/dL, LDL-C<100 mg/dL, and HDL-C>45 mg/dL for those with diabetes
- TC <200 mg/dL, LDL-C<120 mg/dL, and HDL-C>40 mg/dL for all others

The app takes the user through a 4-step process (patient registration, past medical history and medications, risk factor measurements, and treatment advice). For BP measurement, the ASHA/physician used a Bluetooth-enabled automatic monitor to wirelessly upload readings to the computer tablet. Blood glucose, cholesterol (if available), height, and weight are manually entered. The treatment advice page provides the 10-year CVD risk of the participant, lifestyle and referral

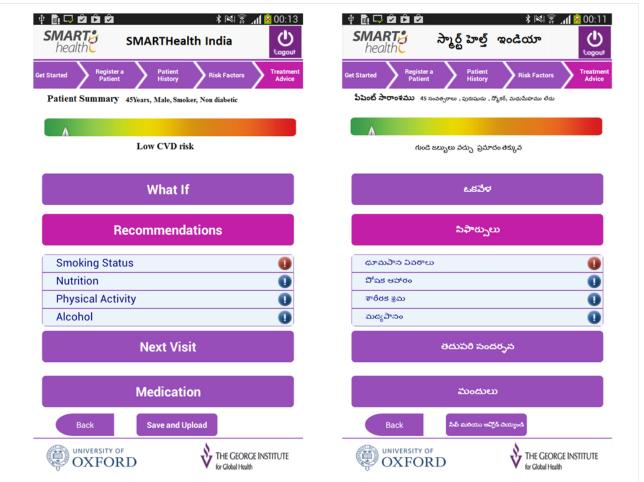
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recommendations for the ASHA, and medication recommendations for the physicians (Figure 1).

Data are stored locally on the tablet and are securely uploaded to a server hosted at the coordinating research institute using Open Medical Record System (OpenMRS) version 1.9. Data uploads occur asynchronously whenever there is an adequate network connection available.

Figure 1. Treatment advice screen of the app in English and Telugu (local language).



## Validation Testing of the Clinical Decision Support System Tool

The algorithm was validated using a 2-step process following methods used in previous studies [26].

Step 1 was a comparison with an independently coded program. Each of the 42 calculated variables in the algorithm was tested using deidentified data from 200 individuals involved in the Andhra Pradesh Rural Health Initiative [24]. A research fellow independently coded the plain language algorithm rules into SPSS statistical software package [27] and the outputs generated from the CDSS and SPPS programs were compared. In an iterative process, outputs were examined, programming modifications were made, and variables were retested to ensure they were programmed correctly.

Step 2 was physician-based validation. A random sample of 100 patient cases was constructed again using deidentified data from the Andhra Pradesh Rural Health Initiative [24]. A physician, who was not involved in the algorithm development, independently reviewed these cases. She assessed 10-year CVD risk for each case using paper WHO/ISH risk charts and manually reviewed the Indian guidelines to provide management advice. Agreement was then assessed between the CDSS and the physician's recommendations.

Once all adjustments were made, a larger deidentified primary health care dataset comprising 1000 patients was then tested in

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both the CDSS and SPSS programs. Agreement between the outputs obtained from the 2 programs was again assessed.

## **Field Testing**

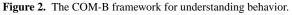
The CDSS was field-tested in 11 villages and 3 PHCs in the West Godavari district of Andhra Pradesh, India. A 5-day and 1-day training course was provided for ASHAs and physicians, respectively. Following this, ASHAs conducted village-based opportunistic CVD risk assessments for a minimum of 20 households per village over a 1-month period, while doctors did the same in the PHC setting. Anyone identified by the ASHA to be at high CVD risk was provided with a referral card to attend the local PHC.

#### **Evaluation and Analysis**

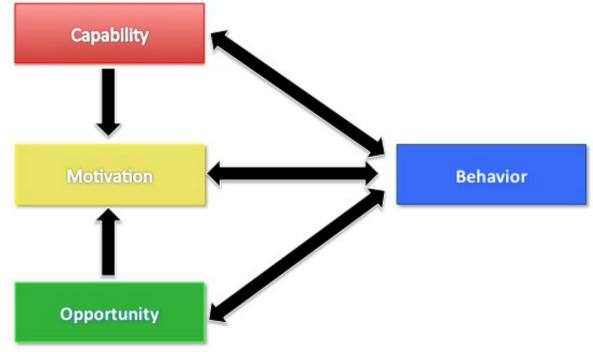
A mixed methods evaluation was conducted. Quantitative and qualitative components were equally weighted and combined simultaneously to obtain an understanding of the likely effectiveness, acceptability, and feasibility of the CDSS. Deidentified clinical data and "loggers" that recorded usage data from each page in the tablet were collected. Although the study was not designed for the purpose of evaluating effectiveness, clinical data were analyzed to assess the number of patients identified as high risk provided with appropriate management by the doctor, with a particular focus on BP management. A follow-up survey was also conducted for the high-risk patients referred to the PHC to assess the numbers

who attended and the numbers who initiated treatment. Quantitative analyses were performed using SPSS version 21 (IBM Corp, Armonk, NY, USA).

At the end of the study, all physicians and ASHAs participated in an in-depth interview evaluation and selected community members participated in 4 village-based focus group discussions (separate male and female groups). Interviews were semistructured and conducted by a researcher experienced in these field settings who was proficient in English and Telugu. The COM-B theory of behavior change (Figure 2) was used to design and analyze the interview data [28]. This theory looks at 3 interrelated domains which are linked to behavior change: *capability* refers to a physical and psychological capacity to engage in an activity, *motivation* refers to automated and reflective brain processes that energize and direct behavior, and *opportunity* refers to all the physical and social factors that lie outside of the control of an individual that influence change [28].



A systems lens to the behavior change was considered and the manner in which intervention influenced the behavior of several different actors (patients, ASHAs, and doctors) to improve CVD risk detection and management was evaluated. Interviews covered the following domains: (1) staff roles and responsibilities; (2) patient, ASHA, and doctor satisfaction with using the tablet; (3) staff knowledge and skills; and (4) impact of CDSS on usual work routines. Interviews were professionally transcribed, translated to English, and thematic content analysis performed [29]. Transcripts were open-coded to key thematic domains using NVivo 10 (QSR International, Melbourne, Australia) and these were interpreted with reference to the COM-B model. The broader research team met regularly to corroborate these themes and collective knowledge on health systems in India and elsewhere was drawn upon to better understand the impact of the intervention.



## Results

## Validation of the Tool

For the initial 200 patient dataset, there was initial agreement between the CDSS output and output from the SPSS program for 29 of 42 calculated variables (69%). The causes for the discrepancies were primarily due to misinterpretation of the plain language rules by the software engineer, some minor programming errors in both the CDSS and SPSS versions, and incoherent logic when dealing with missing values. These errors were rectified and the algorithm was then retested resulting in 100% agreement.

For the physician review of 100 cases, there was perfect agreement between the physician-calculated 10-year CVD risk

and the CDSS output. For management recommendations, initially there were 4 cases of disagreement which were chiefly due to a difference of opinion for treatment of CVD patients with normal BP or cholesterol levels. Minor adjustments were subsequently made to the algorithm. Once all final adjustments were made, the algorithm was revalidated using the 1000-patient dataset and perfect agreement was obtained.

## **Field Testing: Quantitative Evaluation**

The recruited ASHAs were diverse in age, schooling, work experience, and English literacy (Table 1). The 3 doctors were similarly diverse in age (29-44 years), years of clinical experience (4-20 years), and time working in the PHC (2-11 years).

Table 1. Characteristics of health workers (ASHAs) in the study (N=11).

Variable	n (%)
Age group	
20-29 years	5 (45)
30-39 years	5 (45)
40-49 years	1 (9)
Gender	
Female	11 (100)
Schooling	
Primary (completed grade 5)	5 (45)
Secondary (completed grade 10)	6 (55)
Higher (completed grade 12)	—
English communication	
Read and write	8 (73)
Cannot read or write	3 (27)
Working as ASHA <sup>a</sup>	
2 or less years	2 (20)
2 to 4 years	4 (40)
4 to 6 years	0 (-)
6 to 8 years	4 (40)
Average working hours per day <sup>a</sup>	
2 or less hours	7 (70)
2 to 4 hours	2 (20)
4 to 6 hours	1 (10)
Use of cell phone	
Personal	4 (36)
Shared with other family members	7 (64)

<sup>a</sup> One missing response.

ASHAs and physicians opportunistically used the CDSS to assess 227 and 65 individuals, respectively. All staff achieved the minimum screening targets except for 1 ASHA whose tablet was damaged during the study period. Patient characteristics are highlighted in Table 2. ASHAs tended to screen a larger proportion of female patients compared with the doctors; conversely, the doctors tended to screen a larger proportion of patients who were already taking BP-lowering therapy when compared with the ASHAs. A much higher than expected proportion of participants screened by ASHAs reported a history of peripheral vascular disease (PVD) suggesting problems with interpretation of this question on the tablet device. On further review of this issue, it became clear that some ASHAs were assigning this diagnosis if the patient reported any leg pain rather than a doctor-confirmed diagnosis. Thirteen participants were classified at high CVD risk on this basis alone.

Table 2. Cardiovascular risk factor profile for participants screened by ASHAs (n=227) and doctors (n=65).

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Variable	Screened by ASHAs (n=227)	Screened by doctors (n=65)	P value
Age (years), mean (SD)	51.4 (13.1)	55.3 (11.6)	.03
Female, n (%)	152 (67)	24 (37)	<.001
Current smoker, n (%)	30 (13)	23 (35)	<.001
Past history, n (%)			
Angina/heart attack	36 (16)	7 (11)	.43
Stroke	2 (1)	2 (3)	.22
Peripheral vascular disease	22 (10)	1 (2)	.03
Diabetes	31 (14)	13 (20)	.24
Medication history, n (%)			
Blood pressure lowering	44 (19)	29 (45)	<.001
Lipid lowering	1 (0)	2 (3)	.13
Antiplatelet	6 (3)	2 (3)	>.99
Nondiabetics with an elevated capillary blood glucose, a n (%)	37 (16)	7 (11)	.33
SBP (mm Hg), mean (SD)	129 (22)	131(17)	.48
DBP (mm Hg), mean (SD)	80(12)	83(12)	.08
Weight (kg), mean (SD)	57.9(16.3)	62.3(14.7)	.05
BMI (kg/m <sup>2</sup> ), mean (SD)	24.2(4.6)	24.1(4.8)	.88
10-year adjusted cardiovascular risk, n (%)			
<10% risk	122 (54)	36 (55)	.89
10-20% risk	17 (7)	8 (12)	.22
20-30% risk	8 (4)	2 (3)	>.99
30-40% risk	6 (3)	1 (2)	>.99
>40% risk	2 (1)	2 (3)	.21
Clinically high risk <sup>b</sup>	20 (9)	7 (11)	.63
CVD	45 (20)	9 (14)	.36
CVD and CHR	7 (3)	_	.35

<sup>a</sup> Elevated capillary blood glucose defined as random glucose  $\geq 200 \text{ mg/dL}$  or fasting glucose  $\geq 126 \text{ mg/dL}$ .

<sup>b</sup> Defined as presence of raised blood pressure (>160/100 mm Hg), without established CVD.

For those patients referred to a physician, approximately one-half visited the PHC doctor as opposed to a private practitioner. Two management gaps were identified (Figure 3). Only 35% (24/69) who had a clear indication for initiating BP-lowering medication actually visited a doctor within 1 month of screening. Although all 24 patients who accessed either a government or private doctor were recommended BP-lowering medicines, only 42% (10/24) reported still taking medication at 3-month follow-up. The majority (70%, 7/10) of those that were adherent at 3 months had visited a government doctor. Other CVD medications potentially indicated, such as antiplatelet and lipid-lowering medications, were not prescribed to any patients despite indications for 1 of these in 24 patients. Because the decision support tool only provided treatment recommendations for CVD risk management, the only advice provided for those with elevated glucose (n=31) or those with a past history of diabetes (n=9) who were not at elevated CVD risk was that they see the doctor for further testing. We did not capture any further information on the management practices of these patients. Patients diagnosed with PVD by the ASHAs but lacking any other data to suggest high CVD risk (n=13) were excluded from further analyses.

Of the patients assessed by doctors (Figure 4), 45% (29/65) were already taking BP-lowering medications but target levels were reached in only 48% (14/29). Among those not on medications, 31% (11/36) were recommended for treatment by the CDSS. The physician commenced all these patients (n=11) on BP-lowering treatment.

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Figure 3. Assessment and management pathway for patients screened by the ASHA (n=227).

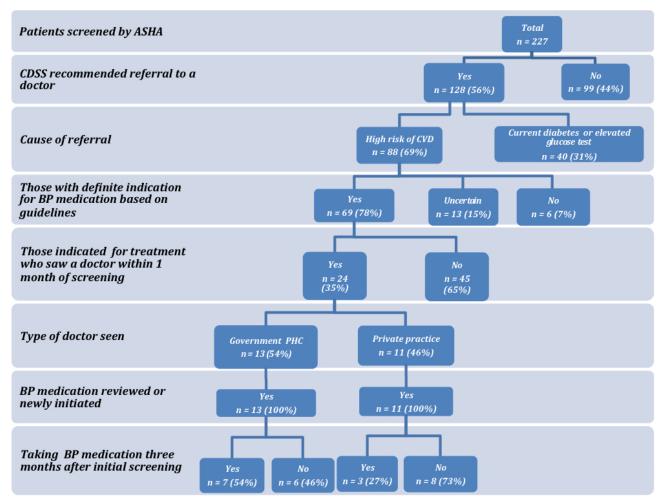
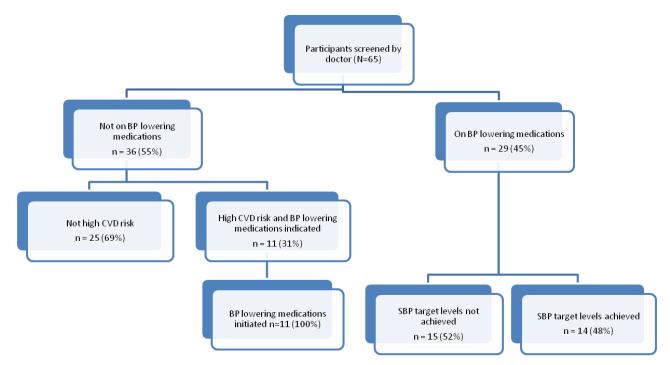


Figure 4. Blood pressure management in participants screened by the physician (n=65).



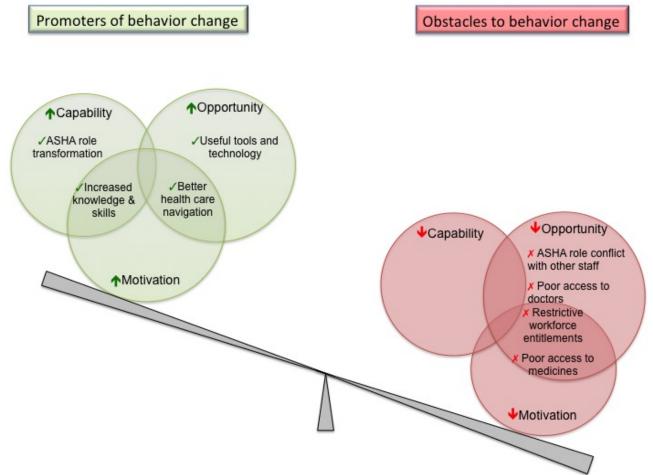
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## **Field Testing: Qualitative Evaluation**

All physicians and ASHAs participated in interviews and 4 community focus groups were conducted (2 male and 2 female groups). Interviews lasted for approximately 60 to 90 minutes. Three interrelated interview themes emerged: (1) the intervention strategy had potential to transform prevailing health care models, (2) task-shifting of CVD screening to the ASHA was the central driver of change, and (3) despite high

acceptability, *actual* transformation was substantially limited by system-level barriers such as access to doctors and medicines. These themes are expanded subsequently in the context of the COM-B model. Figure 5 is a diagrammatic representation of themes identified that both enhanced (green circles) and inhibited (red circles) behavior change. These are further broken down into the 3 domain areas of capability, opportunity, and motivation. Where a theme is in the overlapping areas, it means that this theme influenced 2 domains.

Figure 5. Illustration of the interview themes in context of the COM-B model.



## Potential to Change Prevailing Health Care Models

## Acquisition of New Knowledge and Skills: Increased Capability and Motivation

Although ASHAs had some knowledge about CVD, few had received formal training in this area. Mostly, their role had been confined to assisting other staff in collecting BP information; however, in this setting ASHAs became proficient in not only performing risk factor measurements, but also in interpretation of the results:

Earlier, I just used to go and measure BP, but with this tablet, I came to know what was a normal reading and how the actual reading differs from normal readings. [ASHA 1, 31 years]

Several ASHAs considered that the training and support provided in this project improved their knowledge and that the tablet itself offered a novel mechanism for dissemination of this

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knowledge to the community. The doctors found that the training and support enhanced their awareness of guideline recommendations for lifestyle and medication management of cardiovascular risk. They described how this system increased their confidence in providing treatment advice based on the overall risk score.

## Tools and Technology: Increased Opportunity

Overall, patients and providers received the technical aspects of the tablet and the CDSS positively. Several ASHAs described initially feeling anxious and some were skeptical of their ability to use electronic devices. However, these sentiments rapidly dissipated and by the third day of the initial training course, the majority were using the tablet device confidently:

First, we were afraid that there was the need to handle computers and touch screens, but later after training, we were able to understand it. After we did

*1 or 2 tests, it became easy, and we can do it better now.* [ASHA 11, 29 years]

Over the course of the field implementation, this confidence noticeably grew and most ASHAs described how the tablet was able to facilitate skills expansion into areas they previously would not have considered possible:

For people at my level to inform others about their health conditions is really a fortunate thing. Usually for these things, only specialists can talk about them. But with this tablet we are able to tell them what are the present levels and what would be future levels (of risk), and to what extent one needs to take care... [ASHA 11, 29 years]

For the doctors, the tablet appeared to enhance workflow and was viewed as a time-saver. It also increased their confidence in communicating with patients. One doctor also described how the patient perceptions of the value of the tool enhanced the quality of the health care interaction:

It's wonderful. I got better results than I expected...If patients see the risk bar, they understand very well that they have a high risk of CVD...We gained knowledge from this percentage display too...This is 100% beneficial to the doctor. [DOCTOR 2, 48 years]

There were detailed accounts from all those interviewed on the optimal ways to communicate risk. Of all the mechanisms used in the tablet to express risk (color, percentage score, and "what if" scenarios to show risk changes), there was a strong preference for the use of color, particularly for a population with low levels of literacy:

If it (the arrow) is turned...if it becomes red, then it is danger...Red signs are kept on the road as danger... [Male community focus group 1]

Although overall the use of a tablet was favorably received, a number of technical limitations were also encountered which would affect larger scale use. Hardware limitations included limited battery life, screen damage, challenges with Bluetooth pairing, and inaccurate rendering of the local language font (Telugu) in the tablet. Although continuous network connectivity was not necessary, there were some villages with very limited connectivity that led to prolonged delays in the transmission of the data to the central server.

## Removal of Barriers to Navigating Health Care: Increase Opportunity and Motivation

A major transformative element of the strategy was its ability to reduce access barriers. The community positively received village-based screening:

We do not have transportation facility, no autos—it is like living in a jungle, and so we are happy that she (ASHA) is around. She is not only taking care of fevers...but also testing our sugar and blood pressure... [Male community focus group 2]

Most ASHAs highlighted ease of access to households. Only 1 ASHA described isolated pockets in her village that were not accessible because the residents came from a higher caste. Similarly, most community participants who were recommended

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for referral to the doctor appeared very receptive. Several ASHAs described a duty of care to reach men, which represents a substantial departure from the current maternal and child health–focused role. However, some ASHAs found it challenging to screen male community members due to long working days and were reticent about doing after-hours screening. Despite these reservations, men highlighted that accessibility after hours was considered a highly valued service. Most men visited the ASHA's residence during the evenings and did not express any inhibitions with this.

# ASHA Task-Shifting Role as the Central Driver of Change

#### **Role Transformation: Increased Capacity**

ASHAs described feeling welcomed by the community in their new role and described a sense of respect at being given additional responsibilities in this project. Community participants also expressed satisfaction with the convenience and reduced costs of village-based screening by the ASHA:

We know there are expenses involved with these tests. So, if it is done here, there is no expenditure for us...I never thought I had sugar problems, but when I came to her (ASHA), she tested me and found that I had sugar up to 360... [Female community focus group 2]

Importantly, community members expressed high levels of confidence in the ASHAs ability to perform this role:

Once I got examined by a nurse in town and she did an excellent job. And here she (ASHA) examines me even better than that nurse... [Male focus group 1]

This role extended from screening to also engaging patients in management advice for lifestyle actions. One focus group participant commented on his decision to cease tobacco use and alcohol consumption following advice from the ASHA:

I have been drinking alcohol and used to fall down and I stopped it now because I was told by my (ASHA)...Most of us have now stopped smoking bidi, cigarette... [Male focus group 1]

One doctor also described how the "frontline" role of the ASHA placed them in an ideal position to motivate patients to make lifestyle changes and for treatment monitoring:

In my opinion, ASHAs can motivate lifestyle changes. If she is a good working ASHA, she can also monitor whether they are taking (medicines) or not... [DOCTOR3, 29 years]

All physicians interviewed viewed the system of ASHAs referring patients to the PHC for medication as being a highly useful strategy to maximize their limited resources. One physician used the project to look at systematically incorporating the expanded ASHA role into PHC activities. A key part of this was a continuous reporting mechanism whereby he monitored the duties of his ASHAs in screening and following patients for regular medications.

## Role Conflict: Diminished Opportunity

Although there was a high level of support for these new roles played by the ASHAs, there was potential for unintended consequences. Although motivating patients to take lifestyle action was well received, a few ASHAs expressed apprehension in communicating the CVD risk score. Disclosure of such information could be perceived as being too sensitive and, therefore, was considered to be the responsibility of the doctor or someone more qualified:

...I felt that if I tell patients (of their risk score) they may be afraid. I will give them a referral card and tell them to go to the doctor...the doctor has to tell... [ASHA 2, 30 years]

At the core of this issue was not the communication of risk per se, but concerns about the lack of follow-up support if someone was identified as high risk. For those ASHAs that were less comfortable with this role, follow-up review by the doctor and confirmation that they had performed the risk assessment accurately were key elements that would increase confidence.

There were also accounts of role conflict with other senior NPHWs, in particular auxiliary nurse midwifes (ANMs). ANMs are in charge of village subcenters. They are more highly trained, receive higher remuneration, and carry broader responsibilities in delivery of PHC activities than ASHAs. Although most ASHAs worked well with ANMs, there were some accounts of hostility from the ANM:

...she (the ANM) scolded me and said that I am giving too much importance to this work...I said I am doing both jobs...and it is my problem...but I made 1 mistake...I regretted not showing this tablet to her... [ASHA 6, 32 years]

Most ASHAs, however, felt that if the ANM was actively informed about the program and if existing work duties were not compromised then potential conflict with ANMs would be minimized.

## Workforce Conditions and Entitlements: Diminished Opportunity and Motivation

Despite the untapped potential of the ASHA workforce to perform expanded roles, insufficient remuneration, lack of job security, and availability of other more lucrative employment opportunities in non-health-related areas constitute critical threats to sustainability of this workforce:

There were 4 ASHAs initially working in this village, but now 1 member has left to work in Kuwait and another member has left due to insufficient salary...It (the job) is good but the salary is insufficient.... Despite 6 years of experience it is still not permanent... [ASHA 1, 31 years]

The departure of ASHAs from the village places additional pressures on the remaining ASHAs. Although the government targets are set at 1 ASHA per 1000 population, this is not always reached:

Earlier 3 ASHAs used to work here and now 2 have left...I used to look after 1000 people and now I have to look after all 2700 people. [ASHA 2, 30 years]

## Broader Health System Barriers to Actual Health Care Transformation

# Drug Access and Adherence: Diminished Opportunity and Motivation

Although the ASHAs recognized the importance of identification of high-risk individuals and confirmed the feasibility of incorporating this program in their daily schedule, there was some apprehension about the success of the program due to the availability of medications. ASHAs described a gap in care postreferral, where the patient would need to visit a doctor and, if required, would have to take medications. Private consultation costs (if any due to referral by the PHC doctor) and the availability of medicines at the PHC were the most prominent barriers identified:

...My doing testings for BP or sugar is quite acceptable to them. But, for all those ailments, there is a need to give medication. If medication was also supplied, it would become a full-fledged program. [ASHA 9, 33 years]

Free medicines are available for the patients at the PHCs, but they need to be prescribed first by the doctor. Community participants suggested that dispensing of medicine in the village would greatly improve the service. Another potential implication was that by increasing access to more comprehensive screening there would be downstream pressures on the PHC physicians to treat ever-increasing numbers of people with limited medication supplies.

## Doctor Access: Diminished Opportunity

Although the intervention strategy has great potential to overcome navigation barriers via ASHA-led household screening assessments, there were substantial "downstream" barriers uncovered in relation to access to doctors. ASHAs expressed the nonavailability of the medical officer at PHC during the patient's visit and conflicting advice from the medical officer would lessen the confidence of the community in the ASHAs:

If we refer somebody and if the doctor examines them, then the patients would respect us and it will be good...if it is not done, there may be a problem. If the doctor won't examine or is not available when we send patients, then we will lose impression. [ASHA 1, 31 years]

One community participant described how she was recommended for referral for treatment of her elevated blood pressure. She went to the government PHC on 2 occasions with the expectation of commencing treatment; however, on both occasions there were no doctors present at the clinic. The lack of availability of doctor services and perceived hostility by nondoctor PHC staff leads community members to seek care in the private system. Large out-of-pocket costs can ensue as a consequence:

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People are pawning household utensils to afford going to private clinics...Even if we go to the government hospital, their treatment of patients is bad...As long as the doctor is around, nurses behave, once the doctor is gone they do not care and all of them also go away...They sometimes ask us to go to other private hospitals...How can poor people afford that? [Female focus group 2]

## Discussion

## **Principal Findings**

This field evaluation of a multifaceted mHealth strategy to improve CVD risk screening and management found that such a strategy can be successfully developed and integrated with the current tasks performed by ASHAs and physicians. Drawing on behavior change theory, the strategy showed promising signs of enhancing ASHA capability and motivation to perform village-based CVD risk screening and provided new opportunities for these workers to perform an expanded role. The strategy also appeared to increase opportunities for patients by increasing access to screening facilities within the home at times that are more convenient. Equally important, treatment gaps were also identified by the tool, which resulted in appropriate management by the doctors. The evaluation also highlighted important constraints once high-risk individuals were referred to the local PHC for treatment. Only one-third of patients referred visited a local physician and only approximately one-third of those who were advised medication by the physician were still taking medication after 3 months. Reasons for poor engagement with the health system are not clear, but might include poor accessibility to physicians, costs associated with travel to visit a doctor, remoteness of the place of stay, proper counseling about lifelong therapy with drugs, and out-of-pocket costs for these drugs [30]. These critical issues of access to care and use of medication are similar to other studies conducted in this setting [30-32]. Although the numbers are too small to make any definitive conclusions, a greater proportion of patients managed by the public system were adherent to recommended treatments at 3 months compared with those seen privately. This suggests that both provider and patient-level factors may manifest differently in the public versus private systems. There were also additional potential constraints related to insufficient remuneration and role conflict with other nonphysician health staff. Addressing these key barriers is likely to be essential for mHealth strategies to be successfully taken up in the Indian government primary health care sector.

The findings highlight that mHealth interventions cannot exert their effect in isolation of prevailing health system context. The Innovative Care for Chronic Conditions (ICCC) Framework [33] stresses that health care is a complex interplay of different actors, requiring end-to-end solutions that address constraints and enhance opportunities at multiple levels. Labrique and conceptualized mHealth colleagues [34] as а systems-strengthening tool integrated within the context of the broader health system. They described 12 common mHealth applications, including interventions focused on health behavior change, diagnosis, data collection and health records, health

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worker training, human resource management, supply chain management, and financial transaction. The authors recommend that mHealth projects deploy multiple intervention types to maximize success. When placed in this context, the SMARTHealth India strategy encompasses many, but not all, of these areas. An increased emphasis on human resource management, supply chain management, and financial transactions appear to be critical areas for expansion of the platform that will address some of the critical barriers highlighted in this study. Taking all these factors into account, 5 key actions have been identified to optimize the SMARTHealth India strategy:

- 1. CDSS tool enhancements: Simplification of the user interface, proper language font installation, and greater emphasis on the use of color for communicating risk to the patients are key technical issues that need addressing. Collaboration with local mobile phone operators to boost signal strength in villages with weak network connectivity could also greatly improve data use. There is also a need to ensure more accurate capture of medical history by asking questions in a more standardized fashion. The tablet provides an ideal vehicle for incorporation of multimedia resources to facilitate this. NPHWs could demonstrate short animations during their routine visits to obtain a more informed and consistent medical history (eg, regarding heart attack, stroke). This also provides an opportunity to provide a more interactive health education vehicle for patients.
- 2. Changes to the workflow of PHC staff to increase access: Potential strategies include engaging another intermediary work force (nurse, pharmacists) in the PHC other than the doctor, changes to the working arrangements of the doctors, and bringing the doctor to the village rather than the village to the doctor via structured community visits. Overcoming access blocks are likely to make a substantial impact on patient confidence and satisfaction with the PHC system and reduce financial impact associated with use of private practitioners.
- 3. Addressing drug supply chain barriers: Close engagement with local, district, and national government authorities is necessary to ensure that medicines on the national approved essential medicines list are reliably able to be accessed at the PHC level. Providing PHC medical officers and pharmacists with increased powers to indent these medicines and provision of mobile health applications to easily monitor critical resource shortages are potentially important solutions. As a result of this study, a closer collaboration with the ministry of health at the national, state, and district levels has been initiated and negotiations to ensure adequate CVD medication supply to the PHCs are currently underway. Future initiatives might incorporate prescription of a limited range of essential drugs by community-based NPHWs, similar to strategies widely adopted for the management of human immunodeficiency virus (HIV) infection [35].
- 4. Innovative strategies to improve treatment adherence: Addressing upstream system barriers to treatment adherence is important, but the sharp fall in persistence with treatments once initiated dramatically negates any benefits afforded by those treatments. Scalable strategies to increase

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knowledge, self-monitoring, repeated prompts, care coordination, and cost barriers are key factors that need addressing [36]. Although the evidence base is still immature, technological strategies such as text message systems have been shown to improve adherence in a variety of settings [37]. Attention to local context, however, is important. Most residents in Indian rural communities do not use text messages as a usual mode of communication and the most promising health strategies in this setting have been with the use of interactive voice messaging systems [38]. Voice messages can be used to support better use of medicines, treatment follow-up, and support with health behavior change such as smoking cessation. Voice systems can also be used with doctors and ASHAs to establish recall and reminder systems.

5. Remuneration and training and support for ASHAs: The detailed accounts of workforce constraints faced by ASHAs and doctors highlight the fact that human resource support must be incorporated as a core element to any strategy. Large-scale training of a community workforce to conduct household screening is not likely to be feasible under the workforce conditions experienced in this study. The expanded responsibilities associated with this role also have potential to divert the ASHAs from performing their usual maternal and child health duties. Addressing this issue also requires close collaboration with local, district, and national government authorities. Discussions are currently underway with the Indian government's National Rural Health Mission to explore establishment of a dedicated noncommunicable disease ASHA workforce, drawing on the successful model utilized with maternal and child health programs. Based on these study findings, key factors to address in the establishment of such a workforce will include review of training requirements (including use of mHealth remote learning platforms), payment structures such as performance-based remuneration, improved management structures within the PHC, and integration rather than competition with other workforces such as ANWs.

This evaluation was highly exploratory in nature and examined a single screening encounter by the health worker and management by the physician. Rather than a representative sample, the study used convenience sampling whereby people residing in the villages were opportunistically selected based on the proximity or convenient accessibility to the physicians or ASHAs. Because the physician also screened patients from outside the 11 villages that were included in the study, it was not logistically possible to get follow-up information from these patients. It may be argued that general education and training for the ASHAs regardless of the technology could improve CVD risk screening, but it would almost inevitably need a more intensive formal training program in combination with continuous education to re-enforce the learned skills. The motivation for this study is to test an overall intervention strategy that aims to integrate health care between ASHAs and doctors. If successful, this could eventually be delivered at scale for a fraction of the cost of more traditional workforce strategies. The technology simplifies the process and facilitates the delivery of the information to the community through the health workers and physicians. A few ongoing trials are testing the difference

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in effectiveness using an electronic decision support system and a paper-based version of the tool [39]. These studies may shed light on the relative merits of computer- versus paper-based tools; however, it is clear that a paper-based tool lacks the systems-integrating element that a mHealth intervention can provide. The main focus of the study was to understand the acceptability and feasibility of the strategy in preparation for a more robust, large-scale evaluation. mHealth interventions are frequently criticized for being nonrepresentative in nature, dominated by pilot studies, and not focused on scalable solutions. Although this is certainly true, the critical insights learned from this exploratory study highlight the importance of detailed scoping work before undertaking large and expensive evaluations.

The findings reported in this study are likely to be relevant to other LMICs with similar health system contexts. The WHO Package of Essential Noncommunicable Disease Interventions [40] provides a comprehensive vehicle in which to take a systems approach to mHealth strategies. This package explicitly recommends investment in early disease detection using affordable technology, pharmacological and nonpharmacological management of risk factors, and provision of affordable medicines for treatment and prevention [40]. Such features, if successfully implemented at all levels of the health care system, have the potential to bring about transformative changes to health care access and quality. A key element underpinning the successful and scalable implementation of the WHO package is workforce transformation. Although there is well-established literature on the effectiveness of task-shifting the physician role to NPHWs in HIV/AIDS care settings [41], there have been few studies conducted to date that have focused on the transformative role of NPHWs in managing CVD, although some studies have shown evidence that it has helped in managing single risk factor management [42,43]. This study goes some way to outlining that similar success from task shifting for noncommunicable disease management may be possible, but only if viewed within a broader health system context.

## Conclusions

This feasibility study provides initial insights on the acceptability and preliminary effectiveness of a tablet-based DSS to improve CVD detection, prevention, and management in an Indian primary health care setting. It incorporates a technological solution with innovative workforce strategies to address the growing CVD epidemic in India. Despite great promise for mHealth interventions to improve access to effective health care, there remains considerable uncertainty about how this can be successfully achieved. Appreciation of the broader systems issues and integration of mHealth strategies within this broader context are essential factors in maximizing impact from such approaches. The intervention strategy will be optimized based on the recommendations from this study and it will be tested for clinical- and cost-effectiveness in a large randomized trial in a similar setting [44]. If found to be successful, the findings are likely to advance knowledge on scalable strategies to improve access to effective health care for underserved populations worldwide.

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## **Conflicts of Interest**

None declared.

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## Abbreviations

ANM: auxiliary nurse midwife ASHA: accredited social health activist BP: blood pressure CDSS: clinical decision support system CHD: coronary heart disease CVD: cardiovascular disease HDL-C: high-density lipoprotein cholesterol LDL-C: low-density lipoprotein cholesterol LMICs: low- and middle-income countries mHealth: mobile health NPHW: nonphysician health care worker PHC: primary health care center PVD: peripheral vascular disease TC: total cholesterol

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**Original Paper** 

## Digital Technology Ownership, Usage, and Factors Predicting Downloading Health Apps Among Caucasian, Filipino, Korean, and Latino Americans: The Digital Link to Health Survey

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## Abstract

**Background:** Interventions using mobile health (mHealth) apps have been effective in promoting healthy lifestyle behavior change and hold promise in improving health outcomes to thereby reduce health disparities among diverse racial/ethnic populations, particularly Latino and Asian American subgroups (Filipinos and Koreans) at high risk for diabetes and cardiovascular disease. Latinos and Asian Americans are avid digital technology owners and users. However, limited datasets exist regarding digital technology ownership and use, especially among specific racial/ethnic subgroups. Such information is needed to inform development of culturally tailored mHealth tools for use with lifestyle interventions promoting healthy behaviors for these at-risk racial/ethnic populations.

**Objective:** The intent of the study was to examine (1) digital technology ownership and usage, and (2) factors predicting downloading health apps for Caucasian, Filipino, Korean, and Latino American subgroups.

**Methods:** A cross-sectional survey conducted in August 2013 through December 2013 recruited 904 participants (Caucasians n=172, Filipinos n=250, Koreans n=234, and Latinos n=248), age >18 years, from California community events, clinics, churches, and online. English, Spanish, and Korean surveys were administered via paper or online. Descriptive statistics characterized the sociodemographics and digital technology ownership/usage of the 904 participants. Differences among groups in categorical variables were examined using chi-square statistics. Logistic regression was used to determine factors predicting downloading health apps.

**Results:** Overall, mean age was 44 years (SD 16.1), with 64.3% (581/904) female. Only 44.7% (404/904) of all participants reported English as their primary language (Caucasian 98.3%, 169/172; Filipino 67.6%, 169/250; Korean 9.4%, 22/234, and Latino 17.7%, 44/248. Overall, mobile phone ownership was 92.8% (839/904). Compared to all groups, Koreans were more likely to own a mobile phone (82.8%, 194/234), computer (91.4%, 214/234), or tablet (55.2%, 129/234), whereas Latinos (67.5%, 167/248; 65.3%, 162/248; 24.4%, 61/248, respectively) were least likely. Internet access via mobile phones (90.5%, 818/904) was higher than computers (78.6%, 711/904). Odds of downloading health apps increased with college (OR 2.62, 95% CI 1.44-4.80) or graduate school (OR 2.93, 95% CI 1.43-6.00) compared to some high school; and family history of heart attack (OR 2.02, 95% CI 1.16-3.51). Odds of downloading health apps were reduced with: race/ethnicity, Latino (OR 0.37, 95% CI

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0.20-0.69), and Korean (OR 0.52, 95% CI 0.31-0.88) compared to Caucasians; increasing age (OR 0.96, 95% CI 0.95-0.97); and completing paper surveys (OR 0.50, 95% CI 0.34-0.75).

**Conclusions:** This survey study uniquely targeted specific racial/ethnic subgroups. Results indicated that despite a narrowing racial/ethnic "digital divide", some disparities still exist, particularly among racial/ethnic groups with less education and whose primary language is not English. Findings will be used to inform development and evaluation of culturally tailored mHealth apps for use with interventions promoting healthy behavior change for Filipinos, Koreans, and Latinos.

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## **KEYWORDS**

digital technology; mobile health apps; mHealth; Latinos; Filipinos; Koreans; cross-sectional survey

## Introduction

Disparities exist among racial/ethnic populations, such as Latino and Asian American subgroups (eg, Filipinos and Koreans) who suffer from high rates of obesity, diabetes, and hypertension [1-5]. Healthy People 2020 recommends three key strategies for improving health outcomes and narrowing health disparities: (1) providing equitable access to health information, (2) improving health communications, and (3) providing quality health care [6].

Digital technology (mobile phones, tablets, and computers) holds great promise in helping reduce health disparities. It has been embraced as a means of facilitating health care services, such as providing electronic medical records, real-time health information, and remote delivery of preventive health interventions [7]. In particular, mobile phones and mobile health (mHealth) apps have the potential to overcome barriers to health care access, health information, and facilitate positive health outcomes [8,9]. For example, mobile phones can deliver lifestyle interventions promoting physical activity and health nutrition via mHealth apps that provide virtual health education, goal setting, social support, positive feedback, and coaching [10-12]. Moreover, mHealth apps that support self-monitoring of physical activity and dietary intake have been effective in promoting health behavior change and subsequent health outcomes (eg, weight loss) [13-15].

The theory of planned behavior supports the use of mHealth apps as a lifestyle intervention strategy. It posits that intent can be linked to personal motivation and is one of the most important predictors for behavior change [16]. Perceived control through self-monitoring of one's behavior can motivate health behavior change, bolstering self-efficacy in one's ability to succeed, thereby providing positive feedback to further improve health behaviors.

Encouraging evidence indicates the "digital divide" is narrowing between racial/ethnic minorities and the general population. Due to the proliferation, convenience, and affordability of digital technologies, racial/ethnic minorities have become avid mobile phone owners and users. Among the estimated 272 million US mobile phone users, penetration is highest for Asian Americans (78%) and Latinos (77%) [10,17].

Thus, coupling proven intervention strategies with mobile technologies, such as mobile phones and mHealth apps may be an effective and cost-effective means to promote healthy behaviors and improve health outcomes, particularly for at-risk

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racial/ethnic populations. Of the 17,000 commercially available mHealth apps, many are low cost or free, and offered in multiple languages (eg, Spanish) [13,18]. Approximately 30% of mobile phone users download at least one health app and of these health apps, 60% are related to diet and exercise [10,19].

However, a knowledge gap exists in the sparse datasets describing digital technology ownership and use among racial/ethnic subgroups, particularly information regarding the downloading of health apps for tracking health behaviors [9,10]. Asian Americans and Latinos are two of the largest and fastest growing US racial/ethnic minority populations [20]. Nonetheless, non-English speaking Asian Americans and Latinos were not specifically targeted in previous digital technology ownership and usage surveys [17,21]. Such information is important to facilitate the design and development of lifestyle interventions using mHealth apps to self-monitor health behaviors. This innovative strategy could promote healthy behavior change and thereby improve health outcomes for racial/ethnic populations at risk for lifestyle-related diseases.

Therefore, we conducted the Digital Link to Health (DiLH) study—a cross-sectional survey of diverse racial/ethnic groups, targeting Filipino, Korean, and Latino Americans at high risk for diabetes and cardiovascular disease. Results regarding gender difference in lay knowledge of type 2 diabetes are reported elsewhere [22]. The objective of this paper was to examine (1) types and extent of digital technology (mobile phones, computers, and tablets) ownership and usage (Internet access, social media, and health app), and (2) factors predicting the downloading of health apps among these populations. Results will help inform the development of culturally tailored mobile phone-delivered lifestyle interventions that use health apps—potentially improving health outcomes, and thus reducing health disparities for these at-risk racial/ethnic groups.

## Methods

## Study Design, Sample/Setting, Recruitment

The DiLH cross-sectional survey was conducted from August 2013 through December 2013 to develop a culturally tailored mobile phone-based diabetes prevention program for at-risk Filipinos, Koreans, and Latinos. Therefore, these specific racial/ethnic groups were over-sampled. The University of California, San Francisco, Institutional Review Board approved the study. A total of 1039 participants were recruited from the San Francisco Bay Area and San Diego community events, community clinics, churches, and online through Craigslist. A

sample of 904 participants who were 18 years or older, self-identified as Caucasian, Filipino, Korean, or Latino, and with no history of diabetes were included in the final analysis. Excluded from analysis were individuals with missing data on gender (n=1), ethnicity/race (n=23), or identified as other Asian (n=53) or other race (n=58).

## **Data Collection**

The DiLH survey required 15 minutes to complete. The English DiLH survey was first pilot-tested among 10 participants. The survey was then forward and back translated into Spanish and Korean following published translation guidelines [23]. The English, Spanish, and Korean surveys incorporated revisions identified from the first pilot test and were pilot-tested a second time with 10 participants each.

Prior to administering the survey, bilingual staff screened potential participants. Surveys were administered either on paper or online (SurveyMonkey) and available in English, Spanish, or Korean. Participants independently completed the survey. Bilingual staff answered questions or assisted with the paper survey (ie, verbally administering the survey in preferred language). For those who preferred to complete the survey digitally, a link was available through Craigslist to the secure online SurveyMonkey site. Those who completed a paper survey were offered a complimentary tote bag. Those who completed the online survey had the option of entering a US \$25 gift card raffle.

## Measures

The DiLH survey included questions regarding demographics, medical and family history, physical activity level, self-reported health status, and cardiovascular risk perceptions. Digital technology ownership was assessed by a "yes" or "no" answer to the question, "Do you currently own: a mobile phone (smartphone or non-smartphone), computer or laptop, and iPad or other type of tablet?" Digital technology usage (at least 1 time/week) was based on "yes" or "no" answers to questions pertaining to (1) mobile phone and/or computer usage, (2) Internet access via mobile phone and computer, (3) text messaging, and (4) email, Facebook, and/or Twitter usage. The primary outcome measure was determined by a "yes" or" no" answer to, "Do you have any health apps on your mobile phone or iPad/Tablet?" Participants were also asked to list any health apps they used. An investigator (SA) categorized and coded health apps as physical activity, diet/nutrition, health monitoring for blood pressure or blood glucose, or health information (eg, WebMD).

## Analysis

Data analysis was conducted using SPSS 22.0. Descriptive statistics characterized sociodemographics, digital technology ownership and usage for Caucasians, Filipinos, Koreans, and Latinos. After overall analyses determined that there was a significant difference in a categorical variable among the four race/ethnic groups, post hoc analyses were employed to determine between group differences for race/ethnicity, age, gender, marital status, education, years lived in the United States, language, survey type, and digital technology ownership and usage variables. One-way analysis of variance (ANOVA) was used to examine group differences in age. Chi-square analyses examined differences among the four racial/ethnic groups in the categorical variables. Binary logistic regression analyses were done to identify independent predictors associated with downloading a health app. A backward stepwise multiple logistic regression was run to determine the optimum combination of predictors associated with downloading a health app, where predictors remaining in the model showed significant unique contributions. Predictor variables considered for inclusion in the model were: race/ethnicity, age, gender, marital status, years lived in the United States, education, primary language is English, body mass index, smokes cigarettes, history of high blood pressure or high cholesterol, family member with diabetes, family member with myocardial infarction (MI), physical inactivity, perceived risk for MI, perceived risk for diabetes, self-reported health status, discussed diabetes with provider, and type of survey completed (online vs paper). These selected variables were added to the model because previous studies showed health behaviors differed based on these variables [5,24-28]. Statistical significance was set at  $P \le .05$ .

## Results

## **Demographics**

Table 1 provides demographic characteristics for 904 self-identified Caucasians, Latinos, Filipinos, and Koreans. Overall, mean age was 44 (SD 16.1) years. Koreans were the oldest (50, SD 14.3 years) and Filipinos were the youngest (41, SD 18.1 years). Overall, there were almost twice as many female (64.3%, 581/904) as male (35.7%, 323/904) participants. A total of 27.4% (247/904) of the participants had high school or less education. A majority of participants (87.5%, 788/904) were either native born or had lived  $\geq$ 10 years in the United States. Among the racial/ethnic minority groups, Filipinos (67.6%, 169/250) were more likely to report English as their primary language compared to Latinos (17.7%, 44/248) and Koreans (9.4%, 22/234).



Table 1. Demographics and digital technology characteristics by race/ethnic groups.

Variable		All	Caucasian	Filipino	Korean	Latino	Overall
		N=904	n=172	n=250	n=234	n=248	
		n (%)	P value				
Age, years, mean (SD)		44 (16.1)	45 (16.1)	41 (18.1)	50 (14.3)	42 (14.0)	.001
Gender							.01
	Female	581 (64.3)	125 (72.7)	160 (64)	133 (56.8)	163 (65.7)	
	Male	323 (35.7)	47 (27.3)	90 (36)	101 (43.2)	85 (34.3)	
Marital status <sup>a</sup>							<.001
	Married or cohabitating	524 (58.1)	68 (39.5)	117 (47.2)	189 (80.8)	150 (60.5)	
	Single or divorced	378 (41.9)	104 (60.5)	131 (52.8)	45 (19.2)	98 (39.5)	
Education <sup>a</sup>							<.001
	High school or some high school	247 (27.4)	19 (11.0)	33 (13.3)	41 (17.5)	154 (62.6)	
	College or some college	515 (57.2)	109 (63.4)	187 (75.1)	136 (58.1)	83 (33.7)	
	Graduate school	139 (15.4)	44 (25.6)	29 (11.6)	57 (24.4)	9 (3.7)	
Years lived in Unite	d States <sup>a</sup>						<.001
	<10 years	113 (12.5)	5 (2.9)	32 (12.8)	43 (18.5)	33 (13.4)	
	≥10 years	501 (55.6)	23 (13.4)	133 (53.2)	182 (78.1)	163 (66.3)	
	Native born	287 (31.9)	144 (83.7)	85 (34)	8 (3.4)	50 (20.3)	
Primary language En	ıglish	404 (44.7)	169 (98.3)	169 (67.6)	22 (9.4)	44 (17.7)	<.001
Type of survey							<.001
	Online	250 (27.7)	105 (61)	49 (19.6)	58 (24.8)	38 (15.3)	
	Paper	654 (72.3)	67 (39.0)	201 (80.4)	176 (75.2)	210 (84.7)	

<sup>a</sup>Some variables have missing data, percentages are based on the n of each individual variable per group.

## **Digital Technology Ownership**

Overall, mobile phone ownership among all four groups (92.8%, 839/904) was almost twice that of landline phone ownership (54.8%, 165/904). Table 2 presents the adjusted digital technology ownership percentages by racial/ethnic groups, controlling for age, gender, marital status, education, years lived in the United States, language, and survey type. Landline ownership was highest among Filipinos (65.9%, 165/250) and lowest among Koreans (44.4%, 104/234). In contrast, mobile phone ownership was highest among Koreans (97.8%, 229/234) and lowest among Filipinos (89.0%, 223/250). However, smartphone ownership was highest among the Asian groups: Koreans (82.8%, 194/234) and Filipinos (81.7%, 204/250) compared to Caucasians (69.6%, 120/172) and Latinos (67.5%, 167/248).

## **Digital Technology Usage**

Among study participants, 96.1% (869/904) were mobile phone users. Internet access was higher via mobile phone (90.5%, 818/904) than computer (78.6%, 711/904). Table 2 also presents the adjusted digital technology usage percentages after controlling for demographic covariates. Mobile phone use was similar among all groups with no significant between group

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differences (overall P=.24). Regarding Internet access, Koreans were the most likely to access the Internet via mobile phone (95.7%, 224/234) and computer (96.7%, 226/234), compared to Caucasians (93.2%, 160/172 and 77.6%, 133/172) and Filipinos (88.2%, 221/250 and 78.7%, 197/250) respectively. Internet access was lowest for Latinos via mobile phone (85.4%, 212/248) and computer (61.0%, 151/248). Compared to all the other groups, Filipinos were the most likely to use: text messages (85.9%, 215/250), email (93.1%, 233/250), Facebook (87.4%, 219/250), and Twitter (48.0%, 120/250). Texting was similar between Caucasians (78.3%, 135/172), Latinos (79.8%, 198/248), and Koreans (79.7%, 186/234) (overall P<.093). Overall, groups preferred to use Facebook over Twitter by a ratio of 2 to 1.

Overall, 57.5% (520/904) of participants downloaded any type of app on their mobile phone or tablet. However, only 19.8% (179/904) of participants downloaded a health app. More Koreans (69.6%, 163/234) downloaded any type of app on their mobile phone or tablet compared to Caucasians (58.6%, 101/172), Filipinos (59.6%, 149/250), and Latinos (43.7%, 108/248) (overall P<.001). However, Koreans (17.8%, 42/234) and Latinos (12.1%, 30/248) were less likely than Caucasians (25.5%, 44/172) and Filipinos (24.7%, 62/250) to download

health apps (overall P<.028). Notably, prevalence of any downloaded app and health app were similar for Caucasians

(58.6%, 101/172 and 25.5%, 44/172, respectively) and Filipinos (59.6%, 149/250 and 24.7%, 62/250, respectively).

Table 2. Adjusted digital technology ownership and usage percentages by race/ethnic group.

Variable	All (N=904)	Caucasian (n=172)	Filipino (n=250)	Korean (n=234)	Latino (n=248)	Overall
	n (%)	n (%)	n (%)	n (%)	n (%)	P value <sup>c</sup>
Digital technology ownership <sup>d</sup>						
Landline phone	485 (54.8)	84 (49.3)	159 (65.9)	103 (44.4)	137 (57.2)	<.001
Mobile phone <sup>a</sup>	825 (92.8)	160 (93.7)	215 (89)	228 (97.8)	222 (91.5)	.01
Smartphone	622 (75.8)	115 (69.6)	181 (81.7)	183 (82.8)	144 (67.5)	<.001
Computer/laptop	713 (80.8)	140 (81.8)	193 (80.4)	224 (96.6)	156 (65.3)	<.001
iPad or tablet	340 (39.0)	60 (35.4)	98 (40.9)	124 (55.2)	59 (24.4)	<.001
Digital technology usage <sup>d</sup>						
Use mobile phone <sup>a,b</sup>	795 (96.1)	154 (92.7)	217 (96.7)	218 (98.2)	207 (96.1)	.24
Use Internet via smartphone <sup>b</sup>	547 (90.5)	107 (93.2)	168 (88.2)	157 (95.7)	115 (85.4)	.02
Use Internet via computer <sup>b</sup>	692 (78.6)	133 (77.6)	187 (78.7)	225 (96.7)	146 (61)	<.001
Use text <sup>b</sup>	672 (81.2)	130 (78.3)	192 (85.9)	177 (79.7)	172 (79.8)	.09
Use email <sup>b</sup>	683 (90.7)	145 (89.5)	198 (93.1)	199 (96.2)	141 (82.2)	.001
Use Facebook <sup>b</sup>	456 (78.9)	112 (86.4)	156 (87.4)	87 (65.1)	101 (73.9)	.002
Use Twitter <sup>b</sup>	100 (38)	22 (42.4)	42 (48)	25 (43.4)	12 (18)	.011
Download any apps	509 (57.5)	100 (58.6)	144 (59.6)	161 (69.6)	106 (43.7)	<.001
Download health apps	175 (19.8)	44 (25.5)	60 (24.7)	41 (17.8)	30 (12.2)	<.03

<sup>a</sup>Mobile phone=non-smartphones+smartphones.

<sup>b</sup>At least 1x/week in the last month.

<sup>c</sup>Adjusted for age, gender, marital status, education, years lived in the United States, language, survey type.

<sup>d</sup>Some variables have missing data, percentages are based on the n for each individual variable per group.

## **Factors Predicting Health App Downloads**

Table 3 presents results of a backward stepwise multiple logistic regression in predicting health app downloads controlling for demographic covariates. Only five out of the 18 variables remained in the final model. For each 1-year increase of age, the odds of downloading a health app were reduced by 4.0% (adjusted OR 0.96, 95% CI 0.95-0.97; P<.001). The odds of downloading a health app were reduced by 63% for Latinos (adjusted OR 0.37, 95% CI 0.20-0.69; P=.002) and 48% for Koreans (adjusted OR 0.52, 95% CI 0.31-0.88; P=.02) compared to Caucasians; and 50% for completing paper surveys (adjusted OR 0.50, 95% CI 0.34-0.75; P=.001) compared to online surveys. The odds of downloading a health app were 2.62 times greater for those who attended some or more college (adjusted OR 2.62, 95% CI 1.44-4.80; P=.002), and 2.93 times greater

for those who attended graduate school (adjusted OR 2.93, 95% CI 1.43-6.00; P=.003) compared to those who had high school or less education. Those having a family member with a myocardial infarction (MI) had 2.02 times greater odds of downloading a health app (adjusted OR 2.02, 95% CI 1.16-3.51; P=.013) than those not having a family member with an MI.

## **Popular mHealth Apps**

Participants downloaded 187 health-related apps: 107 addressed diet, weight, and exercise, and 81 addressed health information. Participants could list more than one health app. The most popular downloaded mHealth apps were related to diet, weight, and exercise. The top downloaded mHealth apps were: The Calorie Counter, Lose It, and My Fitness Pal. The top downloaded health information apps were: Web MD and Kaiser Permanente apps.



Table 3. Multivariate logistic regression model for factors predicting the download of mobile health apps (N=848).<sup>a</sup>

Variable		Adjusted OR	95% CI	P value
Age (years)		0.96	0.95-0.97	<.001
Race/ethnicity				.002 <sup>b</sup>
	Caucasian	reference		
	Filipino	0.89	0.54-1.48	.66
	Korean	0.52	0.31-0.88	.02
	Latino	0.37	0.20-0.69	.002
Education				.005 <sup>b</sup>
	High school or some high school	reference		
	College or some college	2.62	1.44-4.80	.002
	Graduate school	2.93	1.43-6.0	.003
Family member with MI <sup>c</sup>		2.02	1.16-3.51	.013
Type of survey				.001
	Online survey	reference		
	Paper survey	0.50	0.34-0.75	

<sup>a</sup>Backward elimination step-wise multiple logistic regression (Wald). Variables entered in initial model: race/ethnicity, age, gender, marital status, years lived in the United States, education, primary language is English, body mass index, smokes cigarettes, has high blood pressure, has high cholesterol, family member with diabetes, family member with heart attack, physical inactivity, perceived risk for MI, self-reported health status, discussed diabetes with provider, and survey type completed.

<sup>b</sup>Overall *P* value.

<sup>c</sup>MI: myocardial infarction.

## Discussion

## **Principal Findings**

This study sought to examine digital technology ownership and usage among Caucasians, Filipinos, Koreans, and Latino Americans, and factors predicting health-seeking behaviors, specifically mobile phone health app downloads. Most large survey studies examining digital ownership and use focus on the general US English-speaking population. Moreover, Asian and Latino Americans subgroups are often characterized and analyzed as one aggregated group [4,29]. This survey study was unique in that it targeted specific racial/ethnic subgroups (Filipinos and Koreans) among whom less than half (44.7%, 404/904) considered English as their primary language.

Our findings support previous studies indicating that the "digital divide" between racial/ethnic groups is narrowing [8,30,31]. However, despite the increasing uptake of digital technology in the United States, we noted disparities still existed in our racial/ethnic groups, particularly among those who were older, had less education, and where English was not the primary language. In general, mobile phone ownership and Internet access was more equitable across groups, while online access and health-seeking behaviors (ie, health app downloads) demonstrated a wide variability.

## **Digital Technology Ownership**

The Pew Internet and American Life Project reported increasing computer and mobile phone ownership, with smartphone ownership increasing even faster [21]. While some Latino

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groups lag behind Caucasians in computer ownership (possibly due to affordability), mobile phone ownership is pretty much level among all racial/ethnic groups. Our overall mobile phone ownership (92.8%, 839/904) was similar to the Pew survey report of 91%. However, in comparison to the 58% reported by Pew survey for the general US population, all racial/ethnic groups in our study exhibited higher mobile phone ownership—with Koreans and Filipinos ranking highest, followed by Caucasians and Latinos. This supports the gradual demise of the digital divide as the convenience and affordability of digital technologies increase [30-33].

Evidence indicates that Asian Americans are the most avid owners and users of digital technology compared to all racial/ethnic groups [33]. In our study, Koreans were the most likely to own a mobile phone, computer, and/or iPad/tablet compared to Caucasians and Filipinos, while Latinos were the least likely to own these devices. Based on previous studies, higher education and income was correlated with digital technology ownership and usage, whereas age had an inverse correlation [8,9,34]. Koreans in our study were the most educated and oldest, while Latinos were the least educated and youngest, leading us to believe that education and income may have a stronger influence on digital ownership and use than age. Future research should examine additional factors contributing to ownership and use among race/ethnic subgroups.

## **Digital Technology Usage**

Internet access via mobile phones may be replacing computers due to a combination of convenience, functionality, and affordability, particularly among low-income populations

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[30,34]. The 2013 Pew Internet report found 63% of Americans access the Internet using mobile phones [35]. Moreover, one-third indicated their mobile phone is their primary Internet access, thus replacing computers as their primary access device. Similarly in our study, Internet access was higher via mobile phone than by computer among Caucasians, Filipinos, and Latinos. One exception was Koreans, who accessed the Internet equally by mobile phone and computer. Perhaps this is because Korean computer ownership was highest compared to all other groups. Nevertheless, mobile phone Internet access is increasing among multiple racial ethnic subgroups. Thus, digital technology tools, such as mHealth apps could empower individuals to take a more active role in their health care promoting health behavior change [9].

Social media survey reports indicate Asian Americans are the predominant online users of social networking sites worldwide [31,33]. For example, in a survey among the top 10 nations using Facebook, Filipinos (93.9%) were reported as the highest-ranked Facebook users [36]. In our study, Filipinos were the highest-ranked users of Facebook, Twitter, and text messaging. In contrast, Koreans were more likely to use email and text than other social media sites. This difference may be due to the inverse association of digital technology use with age [8,21,34]. Koreans on average were the oldest users of social media compared to Filipinos who were the youngest. In addition to this age bias, US digital technology use is skewed by native language, that is, most social media users are English dominant or bilingual [30]. The Pew Internet survey reported that the majority of Latinos (86%) who used social media sites were primarily English speakers. In contrast, only 17.7% (44/248) of Latinos in our study reported English as their primary language. However, a majority of the Latinos in our study reported using text, email, and Facebook (possibly in their native language), indicating an increased trend toward social media networking via mobile phone among non-English speaking Latinos, supporting a narrowing digital divide. Further research exploring the use of social media preferences among non-English speaking racial/ethnic groups is warranted.

Health information seeking behavior, such as downloading health apps is recognized as a vital activity in the "preparation stage" toward health behavior change [37]. National surveys found 75% of Americans use online sources for health information, illustrating health information is becoming more accessible, and health consumers are becoming more proactive [38,39]. Moreover, about 33% of Americans used mobile phones to access health information. Among mobile phone users, 20% downloaded at least one health app to track or manage their health. Reports indicated the most popular downloaded health apps addressed diet, weight, and exercise [11]. Our findings were similar wherein 19.8% (179/904) of participants downloaded at least one mobile health app. The top downloaded health apps in our study were for diet, weight, and exercise: The Calorie Counter, Lose It, and My Fitness Pal.

Factors predicting health app downloads included: race/ethnicity, age, education, family history of heart attack, and type of survey completed. Among the racial/ethnic subgroups, English-speaking and younger age groups (specifically Filipinos) were more likely to download mobile health apps than older and predominately

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native-speaking Koreans and Latinos. National surveys reported that individuals most likely to download health apps were younger individuals with higher education, while the least likely were Latinos [31,34]. Although language was not a predictor variable in our study, other studies found most US digital technology users were English dominant or bilingual, compared to non-English dominant users [9,28,30]. Since most US mobile health apps are in English, this may have deterred the predominately non-English speaking Latino and Korean groups from downloading health apps. Further research should assess potential psychographic drivers predicting the download of health apps, such as language preference, attitudes, and beliefs regarding culturally tailored health apps.

Having a family history of heart attack was also a predictor for downloading health apps. Participants with a family history of heart attack were two times more likely to download health apps than those without. Perceived risk for heart disease has been found to influence positive health behavior changes [25]. This may have motivated many of our study participants to download health-tracking apps. Curiously, a family history of diabetes was not a significant predictor for health app downloads, especially among Latinos and Filipinos who are at high risk [3,4]. Future research should explore this paradox, as well as examine mHealth apps as possible moderators for positive health behavior change, particularly among at-risk racial/ethnic populations.

Online survey participants in our study were younger by almost 6 years compared to paper survey participants. In general, previous findings indicated younger online survey participants were more likely to download health apps than older paper survey participants [21,34]. However, one study found older adults were more likely to seek health information than younger individuals [8]. A possible explanation is that younger individuals tend to be healthier than their older counterparts and thus, may be less likely to seek health information. It is also possible older participants search for health information on the Web, but do not download health apps as frequently as the younger, more tech savvy participants. However, further study is warranted to ascertain the reason for this age disparity.

#### **Strengths and Limitations**

Several strengths and limitations for this study are noted. First, Asian Americans and Latinos are two of the largest and fastest growing US racial/ethnic minority populations, destined to be part of the majority by 2050 [20]. This survey study addresses the knowledge gap and adds to the body of science by way of datasets describing the digital technology ownership and use among specific Asian American subgroups (Filipinos and Koreans) and Latinos who have been largely overlooked in preventive health research. Moreover, our survey study was unique in that it targeted specific racial/ethnic subgroups whose primary language was not English. Second, the large sample size of diverse populations strengthens the validity of our findings that is representative of the US regions we sampled. However, our survey data was self-reported and the cross-sectional design prevents examination of causal relationships. Compared to national surveys, our study sample was comprised of specific racial/ethnic groups from the Western

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United States, with a younger age profile. Although the generalizability of our findings is limited, findings of the large diverse sample of Caucasians, Filipinos, Koreans, and Latinos from Northern and Southern California confirmed that a majority of these Latino and specific subgroup Asian populations were avid owners and users of digital technologies.

## Conclusions

Our study supports previous findings indicating the "digital divide" between racial/ethnic groups is narrowing. However, notable variability and some disparities still exist in digital technology ownership and usage reflecting pre-existing socioeconomic, cultural and difference in language proficiency. More importantly, results for this study add to the body of knowledge for digital technology ownership and use among specific Asian American subgroups and Latinos, including those whose primary language is not English.

Results indicated, although overall mobile phone ownership and usage in this California survey was similar among all groups, mobile phone ownership however, was significantly higher among participants than in national surveys. Digital technology ownership and usage varied by age and education, with younger and more educated individuals more likely to own and use digital technologies and download health apps.

In contrast to the more equitable distribution of digital technology ownership among our survey groups, the use of mobile health apps exhibited a wider variability and disparity, particularly in terms of age and race/ethnicity. Non-English speaking Latinos and Koreans groups were less likely to download health apps compared to predominantly English-speaking Caucasian and Filipinos. Moreover, downloading of health apps decreased with older age. Future research should explore factors influencing the use of digital technologies, specifically, health app use among racial/ethnic populations, particularly those with less English proficiency.

Finding from this study could be used to inform the design and development of culturally relevant self-monitoring mHealth apps for Filipinos, Koreans, and Latinos. Using health apps as a self-monitoring/tracking tool has the potential to promote health behavior change to improve health outcome and thereby mitigate health disparities among these at-risk populations. Recent studies evaluating lifestyle interventions using mobile technologies that allow for more proactive engagement through self-monitoring of health have found them to be effective in promoting healthy behavior change and disease management [40,41].

The narrowing digital divide between racial/ethnic populations is a first step. The next step is to develop culturally appropriate mHealth apps that are relevant, engaging, and tailored to today's aging and diverse racial/ethnic health care consumer. Finally, the effectiveness of culturally appropriate mHealth apps to improve health outcomes for these at risk populations should be evaluated. This important research will provide evidence that mHealth apps could serve as innovative and interactive pathways to improve tomorrow's health care outcomes and consumer well-being.

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## **Conflicts of Interest**

None declared.

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## Abbreviations

**DiLH:** Digital Link to Health **MI:** myocardial infarction

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## **Original Paper**

## The Long Way From Government Open Data to Mobile Health Apps: Overcoming Institutional Barriers in the US Federal Government

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## Abstract

**Background:** Government agencies in the United States are creating mobile health (mHealth) apps as part of recent policy changes initiated by the White House's Digital Government Strategy.

**Objective:** The objective of the study was to understand the institutional and managerial barriers for the implementation of mHealth, as well as the resulting adoption pathways of mHealth.

**Methods:** This article is based on insights derived from qualitative interview data with 35 public managers in charge of promoting the reuse of open data through Challenge.gov, the platform created to run prizes, challenges, and the vetting and implementation of the winning and vendor-created apps.

**Results:** The process of designing apps follows three different pathways: (1) entrepreneurs start to see opportunities for mobile apps, and develop either in-house or contract out to already vetted Web design vendors; (2) a top-down policy mandates agencies to adopt at least two customer-facing mobile apps; and (3) the federal government uses a policy instrument called "Prizes and Challenges", encouraging civic hackers to design health-related mobile apps using open government data from HealthData.gov, in combination with citizen needs. All pathways of the development process incur a set of major obstacles that have to be actively managed before agencies can promote mobile apps on their websites and app stores.

**Conclusions:** Beyond the cultural paradigm shift to design interactive apps and to open health-related data to the public, the managerial challenges include accessibility, interoperability, security, privacy, and legal concerns using interactive apps tracking citizen.

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## KEYWORDS

mHealth; mobile apps; open data; prizes and challenges

## Introduction

## The Federal Government and Open Data

The Open Government Directive and Digital Government Strategy of the Obama Administration call for innovative approaches to increase participation, collaboration, and

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transparency of government operations, especially with mobile phone apps [1,2]. At the center of the initial efforts is a website [3], a new platform to publish government datasets, for an overview of the platform see [4]. Federal departments, among them the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), the Food and Drug Administration, and the Substance Abuse and Mental Health

Services Administration under the umbrella of the Department of Health and Human Services (DHHS), move so-called high-value datasets in machine-readable format on to the Internet for public consumption.

The effort to promote the availability and reuse of the datasets is combined with the open innovation platform Challenge.gov, see for example [5,6]. Using a policy instrument called Prizes and Challenges, developer contests such as the Health 2.0 program invite civic hackers as well as professional problem solvers to reuse health-related public sector data and crowdsource solutions in the form of mobile phone apps [2]. Both initiatives are designed to create public awareness, but also to promote external innovations based on citizen needs. While citizen-driven ideas can be highly individual, and the development of mobile apps themselves is usually limited to professionals with highly specialized skills and coding knowledge, in the aggregate they can add value to larger parts of the population and ensure more effective reuse of open data [7]. The invention and acquisition process itself is usually not part of the scope and responsibility of government's core mission to deliver public health. Government organizations are missing the design skills, need to jump through legal hoops, and in part have to rethink their approach of informing and educating the public given these new types of technological platforms.

The uptake of the release of health-related datasets, the use of contests and prizes to promote the datasets, and ultimately the implementation and promotion of the innovative outcomes such as mobile phone apps is facing significant institutional barriers unique to the public sector context [7]. The top-down political mandate has freed up agency resources to dive into mobile app development, create best practices for commercial as well as private mobile app review processes, and might set new standards for government-wide development of mobile apps, as demanded by the Chief Information Officer (CIO) Council [8]. However, existing rules and regulations need to be taken into account, which challenge the development and release process, especially of health mobile apps.

# **Current Use of Mobile Health Apps in the United States Federal Government**

The result of these managerial and political developments is a set of currently 33 mobile apps promoted on the Department of Health and Human Services' mobile website, an overview of all apps is available (see Appendix for DHHS) [9]. The apps were developed and promoted by 12 different agencies that are part of DHHS. Among them are, for example, the Agency for Health Care Research and Quality, the CDC, National Cancer Institute, NIH, National Library of Medicine, and the Centers for Medicare and Medicaid Services.

All apps are either replicating information that is already available on the agency's website or provide access to a searchable database of symptoms, diseases, or health-related alerts. The content supports the mission of government organizations, most agencies have to inform and educate the public by providing neutral, reliable, and trustworthy information. Similar to previous phases of e-Government development, mobile apps in public health agencies are still at

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an early maturity level and focus mostly on representing already existing agency content, delivered through an innovative platform [10,11].

There are nine apps that go beyond a mere information and education function, and focus on supporting behavioral change, such as the National Institute of Cancer QuitPal app or the WordWeather app from the National Cancer Institute that help smokers quit their habits. The apps provide health-related information, but also interactive elements, such as calendar functions with reminders, financial goals, or behavior tracking functionalities. There are two of those apps that are targeting a specific audience, and are using gaming technologies. These apps focus on younger patients, such as teenagers, and are designed to offer "a better option for idle hands" [12,13]. As an example, the NIH's Brrd Brawl App banks on the popularity of the mobile phone app Angry Birds, and tries to attract younger demographics to help defend against what the app calls "cold turkeys" to protect the farms against invading penguins to stay in a "never-ending survival mode" [14].

A set of apps focuses on another specialized audience, health care and emergency management professionals. There are four of the apps that provide health-related alerts about outbreaks or medication warnings that are pushed to health care professionals to keep them up to date. As an example, the CDC's Influenza app pushes information about the national flu activity out, and provides information about the latest recommendations to help professionals with diagnosis and treatment options. Similarly, the National Library of Medicine provides the LactMed app for nursing mothers to help them understand medical information about medication and dietary supplements. This adds to a series of commercial mobile apps designed for use by health care professionals in their work with patients [15].

Only three apps allow patients to actively share personal health information regarding the phases of their disease with their online social networks, such as sharing to social media sites or sharing of information by email. The goal of the social networking sharing functions is to increase social awareness for the evolution of the patients' symptoms, treatments, and outcomes in order to increase cognizance, and by extension, social support.

An app focuses on higher levels of e-government, and provides information about direct transactions with government agencies. The Open Payments Mobile for Industry app of the Centers for Medicare and Medicaid Services is designed to help manufacturers keep track of, store, and view financial payments of industry partners. However, the app does not allow for actual mobile payment transactions.

The analysis of the existing government-owned and -promoted mobile health apps shows a surprising trend toward simple provision of government-vetted information. Apps with higher levels of interactions are rare. There are very few opportunities for citizens to directly interact with the content, to track individual health-related behavior, or for bidirectional exchanges with other patients, supporters, or health care professionals. The guiding research question is therefore, what are the drivers, and most importantly, the barriers for the development and adoption

of health-related mobile apps in government, and what are the adoption pathways federal agencies follow?

# Methods

# Using an Interpretative Approach

Much of the nature of the research question of intraorganizational institutional factors leading to the development and ultimately the implementation of mobile apps in government is qualitative in nature. It requires narratives to explain the internal decision making processes, the problems public managers encounter when they start to review interactions of patients-and regular citizens-through their personal data in combination with government data. It is therefore necessary to use an interpretative approach to gain a deeper understanding of each individual agency's context in which it is operating, as well as their specific situations and specialized internal data. The cumulative insights from a variety of agencies facing the same problems as agencies working with health-related personal data help to open the black box of internal managerial decision making.

# **Data Collection**

The research design relies on an instrumental case study approach to help inform the adoption of mobile apps by government agencies in general [16], and to derive implications for mobile health apps specifically. A qualitative research design helps to understand the meaning of real-world conditions and perspectives of public managers who are tasked with the development and implementation of mobile health apps. While the outcomes are observable on their agencies' websites, it is impossible for the researcher to adequately understand the internal situational context and emerging legal conditions that have led to the observable Internet practices.

The aim is to explain events leading to outcomes, and let concepts emerge from the insights provided by the interview partners. The sample includes 35 public managers in agencies of the US Federal Government actively involved in the development of mobile apps in 2012-2013. At the time, ten agencies were actively implementing either in-house designed apps, or outsourced the development to their contractors. In addition, 25 federal agencies actively solicited ideas from the public for the reuse of their datasets available on a data sharing platform [17]. While not all agencies expected mobile apps as a result, many civic hackers and professional coders designed mobile apps. The collection of field-based data aims to accurately capture the contextual decisions across the federal government as a whole, and the individual barriers specific agencies were experiencing.

## **Data Analysis**

The initial open-ended questions were hand-coded using the qualitative data analysis software QSR NVivo [18]. The initial categories that were represented in the interview questions included, historical evolution of the decision to develop mobile health apps, drivers for these decisions and initial barriers for the development, and the subsequent implication process. The transcripts were coded line-by-line, and the social and managerial processes emerged from this coding process. They

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were then matched to the phases of e-Government adoption [19], and new categories evolved to help explain the current stage of mobile app development in the US Federal Government.

This iterative data analysis process provides the opportunity to integrate different sources of data, interpret the results, and explain the complexity of the field setting and diversity of the participating government agencies. Following Glaser and Strauss [20], the interpretative data analysis process results in explanations of real-world social behavior. Drivers and barriers are derived "bottom-up" in the form of grounded categories and concepts.

# Results

# **Three Pathways to Mobile Apps Development**

The qualitative data show that public managers follow three different pathways to develop mobile health apps. These pathways include: (1) in-house development and contracting out to external vendors, (2) top-down policy mandates to develop at least two mobile apps, and (3) running government contests to ask the public to solve public management problems and relying on civic hackathons. However, government agencies face significant barriers as soon as mobile apps are developed that have to be addressed before apps are officially confirmed and promoted on the agency's website. These barriers include: (1) legal terms of use issues with Apple's mobile store, (2) accessibility and compliance issues, (3) data privacy issues, and (4) security issues.

#### **Adoption Pathways**

# Pathway 1, In-House Experimentation and Contracting Out

Mobile health app development started at different times and for different needs in the US Federal Government. Some agencies noticed that with the diffusion of smartphones with Internet access, their agencies' websites had become unusable to view on certain mobile devices, such as iPads. As one of the interview partners explains,

It started because we created a website for teachers to teach with the records of the [agency] in their classrooms. We had lots of requests from teachers who were using the website that they were getting all sorts of iPads in their schools and they were interested in using the website as an app with students. [Interview Partner]

The driver was therefore mainly an adjustment to changing technology standards, rather than internal agency needs or an external policy directive.

The goals of many agencies are not specifically to develop an interactive mobile app that provides a new service, instead the native mobile app development oftentimes coincides with the upgrade of the existing agency website design to a responsive mode, for example, using the programming technology markup language HTML5. As an example, one public manager explained that mobile apps are not standalone solutions for his agency. Instead,

We are moving toward HTML5 on all of our major websites, using active code, that can scale nicely to the mobile devices. It is more than just applications for us. [Public Manager]

Other agencies already have their own developers in-house who are developing website features to be accessible across several platforms, such as PC, mobile, and tablets. Agencies used their in-house Drupal developers, who are reusing free and open-source code already developed elsewhere, and adjusted it to the needs of the agency. Using in-house resources allows agencies to be flexible and quicker. However, one public manager points out, "I think down the road we might be contracting out the operation in maintenance and future development".

In other agencies, similar internal initiatives were started by entrepreneurs [21], or internal trailblazers, even ahead of the official Digital Government Directive that directed agencies to invest in mobile accessible websites and mobile apps. As one public manager in one of the public health agencies explains,

One day I was in a doctor's office, and when you are in the waiting room of a doctor's office, they give you a form to fill out, they ask you to list all of the medications and the dietary supplements that you take. While I was filling out that form it occurred to me how hard it is to remember everything that you take and to have really accurate information to be able to share with your doctor. So, I came back to the office and I talked to my supervisor and colleagues about this idea of a mobile app that would allow people to track all of the dietary supplements that they take, so that when they went to the doctor's office, they would have a more accurate list of everything they take, and that would in turn allow for more accurate communication and more complete communication between the patient and the healthcare provider. In addition to that, we also develop fact sheets on dietary supplements that are science-based, and we wanted to increase our outreach. We also decided to put these fact sheets in the app as well. [Public Manager]

Here, the app allows for the reuse of already existing scientific evidence that the agency has to distribute to the public, but added an innovative interactive feature that supports patients' needs beyond the mere display of information that is already available on the agency's website.

However, these internal, bottom-up initiatives come at a cost, and are oftentimes met with resistance,

I have been trying to push folks to do mobile since the iPhone came out and the department has a lot of the challenges that is within government's culture. Remember folks have pretty much just been doing websites and putting everything on the web. Now that we are seeing a paradigm shift, it's kind of hard to folks to say how do we put our stuff on mobile, or how do we start accepting the new paradigm shift. And some folks just might not know what to do. This is new to them. [Public Manager]

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This paradigm shift involves a cultural change, and oftentimes a change to the approach of how government passively pushes information to a mobile app that goes beyond the information and representation function many agencies see as their main mission. Citizens have long made the shift. A recent Pew study shows that as of 2014, 90% of US American adults own a cell phone, 58% own a smartphone, and 42% own a tablet [22].

Other agencies adjusted more easily to the paradigm shift,

[...] because we had very strong support from the highest level of the organization, that made it very helpful. So for the first year to get this done, we didn't get a lot of pushback other than from other business areas, because we are including phone numbers in the tool. And, politically a lot a people did not know about it because it was done at a very high level and very quietly, because we wanted to get it out the door quickly. We had the support of the CCO, one of the deputy commissioners, and the commissioner himself, because it was one of the goals to reach citizens who use mobile devices. [Public Manager]

#### A public manager points out that mobile apps,

...seemed like the next logical step. We know that more and more people are using their phones to do conversations and socializing, and if they want information, they want it now. They are not going to wait. If they have a question at the grocery store, they are not going to wait until they go home and remember to go to the website [23] and look it up. They are going to look it up while they are standing there. So, launching the mobile version of Ask Karen seemed to be the next logical step. [23] [Public Manager]

This website [23] is a service that is already hosted by a vendor, and consequently the agency outsourced the design of a mobile app to the already trusted vendor instead of acquiring internal personnel resources to rebuild the app from scratch. Similarly, patients need health-related information at their fingertips in the moment they walk into a pharmacy and need to explain their symptoms, or want to know the inspection scores of a restaurant, which are, for example, provided by the "DON'T EAT AT\_\_\_\_" app [24]. Searches are highly situational, context specific, and results need to be reliably delivered just in time in the right format that is easy to interpret by nonprofessionals.

Overall, the first pathway mostly leads to reuse of already existing agency content to make it available on all technological platforms through which citizens access the agency's information.

# Pathway 2, Top-Down Policy Mandate Triggers Development

The majority of federal agencies follow the second pathway. Triggered by top-down policy mandates in the form of a presidential executive directive, a new digital strategy agenda, and follow-up guidance for the implementation of mobile apps issued by the federal CIO, agencies start to develop mobile apps. Initially, the Digital Government Strategy focused on the improvement of customer-facing services for mobile use [25].

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To accomplish this goal, each federal agency had to identify two existing customer-facing services and optimize them for mobile use. It is therefore not surprising that the majority of the existing apps focus on "low-hanging fruits", such as apps that mainly provide previously vetted information and education functionalities. An additional executive order laid out directions to make open government data available in machine-readable format so that government datasets can be accessible on data sharing websites [3,17,26]. Follow-up guidance from the CIO's office provided agencies with best practices to create an increased awareness of the potential of mobile apps [8,27].

For most agencies, these policies triggered the first internal discussions and experiences with mobile apps, as one of the public managers explains,

It wasn't much of a conversation to start the mobile apps. In conjunction The White House had a directive that they wanted everybody to have something mobile by the end of the year. We actually have a whole slew of tools that we will be offering over the next few years. [Public Manager]

And another interview partner adds,

Now since the government has passed the Digital Government Strategy mobile will be part of your product line. Prior to that mobile was viewed as like, "Ah, it's like a fad, or it's something nice to have, but it's not part of our core product line". With our website, that we are launching, mobile will be part of that core experience. [Interview Partner]

Agencies that had not previously gained experience in converting their content and services to be accessible through mobile apps needed the external intervention through a top-down mandate, and the follow-up instructions, to start the internal development process.

# Pathway 3, Civic Hackathons and Contests

Health data contests and open innovation challenges are the third pathway government agencies are taking to build mobile apps for their agency, see for example [6,28]. The federal government is using a new policy instrument called Challenges and Prizes to promote contests on an online platform [2,29]. Contests are designed to encourage idea generation processes by involving "unlikely" audiences who are usually not in contact with the agency, who have specialized knowledge about a health area, or skills to provide solutions to public management problems.

While some agencies have very concrete needs, others use the platform to allow for a free flow of innovative ideas from

citizens into the agency, as one of the public managers at NIH states,

There are two ways to (come up with innovations or solutions to problems), either unsolicited applications where we just allow the applicants to come up with the problem and the solution that they want to claim it to. And then we have other means where we have a call for applications in a given area. Say if you wanted to see more applications in say electronic health records, we have a call out saying we are interested in funding applications in these areas. [Public Manager]

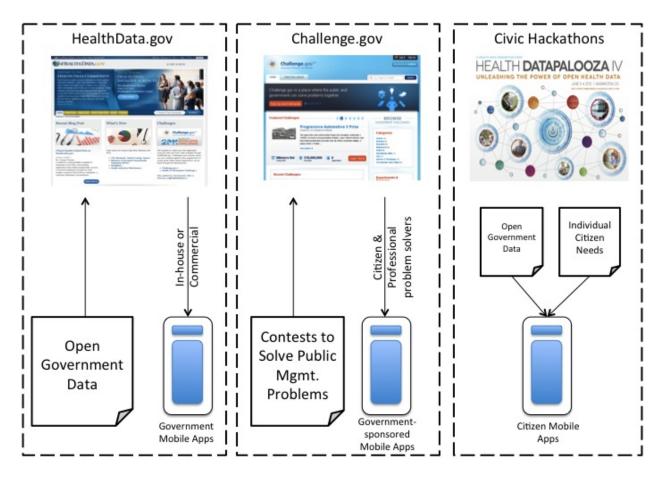
The outcomes of open innovation contests vary across agencies. Many agencies use contests as a way to pull citizens into their health datasets, and as a result, they create a wider awareness for the availability of the datasets. These outcomes are what Mergel et al [5] called "low hanging fruits". The actual development of marketable health-related apps is secondary, especially because agencies are usually not allowed to promote the externally developed apps through their websites. While this is a relatively negative view on the use of contests to develop mobile health apps, the major outcomes of contests and prizes in government need to be evaluated based on their effects that are realized outside of government, and are not part of the scope of this paper. However, as an example, DHHS sees the importance in these external idea generation contests as opportunities for economic development,

There is a project called "MyCancerGenome". A doctor was the finalist on the project. Since becoming a finalist of that project, she has actually won a number of other innovation competitions. She has been the finalist in a bunch of projects. She's raised quite a bit of money, and as a result has been able to take a project and develop it further. [DHHS Interviewee]

Another prominent example organized outside the federal government is the annual Health Data Palooza hackathon [28]. Hackathons are events—in this case—initiated by government agencies to invite large numbers of programmers to collaboratively reuse government datasets and program mobile apps. The event is designed to create health-related innovations that oftentimes result in mobile health apps. However, government organizations rarely adopt the apps created by third parties for legal reasons.

In summary, Figure 1 shows the three main pathways of mobile health apps adoption, the data sources, and outcomes.

Figure 1. Three pathways of mobile health apps development. Mgmt. = Management.



# **Barriers for the Adoption of Mobile Apps in Government**

# Main Challenges

The main challenges of adopting and successfully introducing mobile apps in government focus on legal issues, accessibility and compliance issues, as well as the collection and protection of individual patient data. Initially, cultural and change management issues occurred in several agencies, however these were mitigated as soon as the presidential top-down mandate made discussions and decisions obsolete. The search for government information with the help of mobile apps is significantly different from the search on a desktop computer. Data need to be available in the same moment citizens need them, for example, when they are making buying decisions at a car dealership, they want to know about safety ratings; when they are about to buy new lighting or light bulbs for their house, they need the information as they are standing in the aisle of a home improvement store; or when they are listening to a warning on the radio regarding a food recall. What all of these issues have in common is that mobile apps need to deliver different types of Internet interactions with government data, searches are highly situation-based and context-specific. As a consequence, the results need to be reliable, delivered just in time in the right format, and easy to interpret.

# Barrier 1, Legal Challenges

Legal challenges in the public health sector occur on a different scale and magnitude than in other agencies. For every step of the development—or codevelopment process with the public—public managers have to involve counselors to clarify the risks, the type of data that are published or released to the public through the app, and the way the agency is collecting data from citizens. A public manager describes the lengthy process to gain consent within his agency,

We had wanted to do [a contest] for years actually. And as a regulatory agency we live under certain laws and regulations that other agencies don't. So, an agency like the General Service Administration GSA, National Aeronautics and Space Administration, or National Oceanic and Atmospheric Administration, who have as part of their mission, reaching out to people, to have them take advantage of the data that they have collected. Our mission is protecting human health and the environment and except under a couple of laws, we actually don't have the legal responsibility for making that data available to the public. Now, we have always felt as an agency, we have a moral and ethical need to make that data available, and we have done so, really since the beginning of the Web. We were restricted from contests, based on our Office of General Counsel, our lawyer's interpretation of

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certain regulations that we had to live under as a regulatory agency. But then Congress passed the new law that gave broad challenge authority across the entire federal government and we worked together with our office, OEI, Office of Environmental Information, with the Office of Public Affairs, with GSA, and with our general counsel, to make sure that this fit within the other regulations that we had to live with, and they approved for the first time, our doing a contest. So we launched the contest, we had a couple of codathons where we had Environmental Protection Agency (EPA) people either at the codathon, or available by phone to talk with people about the data. We deployed a number of new Web services to let people access our data securely, and then, went live and voted on the winners. [Public Manager]

The outcome of using challenges and prizes to run contests then leads to the next legal challenge, when government agencies have to promote third-party mobile health apps on their official agency website. When agencies are taking the pathway to host codathons or post contests on Challenge.gov, the legal hoops they have to jump through are higher than during the development process of their own apps. While the vetting and review process is the same as for in-house apps, the agency allows the free promotion of a third-party app for a certain amount of time only. Here is how one public manager explains the process,

There were no monetary prizes in our contest, so the people who submitted with the [obligation] that, for one year after they won, the application had to be available for free. And that during that time, we would promote it on our website. But then after that time, they could surcharge with work, it was their choice after that. [Public Manager]

The main legal challenge, however, occurs in the negotiations with the Apple App Store outside of government. Apple's App Store is subject to California law, and Apple's terms of service agreements had to be adjusted to comply with federal law. A public manager explains the process,

It took us a while to get [the app] released, but that had to do with difficulties we had with Apple's Terms of Services. It had language in there that was not acceptable to the federal government. It took quite a while before Apple eventually added language to their standard terms of service that made it possible for us to legally get the app up in the App Store. [Public Manager]

The language changes included indemnity clauses or determination which courts can handle disputes.

Agencies moving their apps to the App Store were the first to run into barriers that had to be worked out, but eventually also led to procedural changes in Apple's app developer licensing process to accommodate the needs of the federal government. Agencies who had outsourced the app development did not experience the same challenges, because their external developers had a business license, Our very first challenge was that when we were developing this app, we were one of the very first mobile apps to come out of the federal government, and so, even Apple did not know what to do with us when we applied for the developer license. I really wanted our app to be listed in the app store as developed by the Office of Dietary Supplements at the NIH, not by our contractor who was doing the work, because I wanted our app to have more, it just looks better. People would trust it more if the app was listed as developed by the government. Apple had never had a federal government agency apply to develop an app, they had only had a few apps from other federal government offices, but they were listed as developed by their contractor. It took about two months with Apple to get them to understand our needs were different than the needs of a private company or a private individual who was developing an app, and we, at the federal government did not have some of the documents they wanted from us, we don't have a business license, we don't have a contract. You know, we're the federal government. That was one of the very first obstacles we had, until I was able to find a human being at Apple, and talk with them. They had a federal office that I didn't even know about, and they changed a few things so that in the future people didn't have the issues that we had. [Public Manager]

# Barrier 2, Accessibility Issues

mHealth accessibility issues emerged as one of the critical factors that had to be considered in the strategic planning, design, and development process. All federal agencies have to adhere to the accessibility guidelines for electronic and information technology as described in Section 508 of the Rehabilitation Act [30]. However, when agencies started to explore mobile health apps, there were no guidelines available specifically for mobile and smartphones, so that the existing guidelines for website development were used as guidance. The only guidance the Digital Government Strategy provides pushes agencies to develop for all mobile platforms, and test the apps before they are released to the public, "...develop secure, device-agnostic mobile applications, provide a development test environment to streamline app delivery, foster code-sharing, and validate official government applications" [25] (no page). Accessibility includes several different aspects that include a variety of citizen needs on a continuum between disability accessibility to platform preferences, "Whenever someone says accessibility in government, they generally think of Section 508, access for users of low vision, but also, considering accessibility in terms of the mobile access to government data, accessibility on different devices, and broadband access".

Given the lack of initial guidance, public managers had to make sure that their interpretation of the laws, regulations, and current standards for Web development are applicable to mobile apps. A public manager at NIH explained,

Unfortunately, the guidelines are not really clear yet for mobile devices. So we tried to treat it like a

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website, and tried to make it as 508 compliant as we possibly could. [Public Manager]

Compliance officers and users were invited to test the final app. A public manager described the internal process to assure that the features are accessible to screen readers,

To promote accessibility, we have been meeting with our internal 508 Accessibility Office. I've actually personally sat with them while they have done their testing and sat through their experience. We are big on user experience in our area, and we like to actually experience what the user experiences, so I sat with one of our employees who happens to be blind and uses a screen reader on his iPhone, and I got to experience what he experiences. We actually have things to make improvements for the next round, based on what we experienced in his feedback. [Public Manager]

Another agency established Section 508 standards as the minimum,

We try to strive for better than that, because we aim for accessibility, not just mere 508 compliance. We actually have an accessibility expert on staff that has been able to train the other quality assurance testers to test not just for Section 508 compliance, but for just general accessibility. One of the biggest things you can do on any platform is use the standard user interface controls. The minute you start designing your own, creating your own button objects rather than using or even tweaking the standard button objects, you create a whole new problem for yourself. And now you have to also develop means for the screen reader to recognize and read that item. The approach I described I'd say will get you about 95 to 98% of the way there, if not all the way there. There are certain things that you can do with regards to how you order things on the screen, but we tend to solve that problem separately just by trying to use really good user experience design practices. [Public Manager]

Accessibility, therefore, incorporates a broad interpretation of access by, and inclusiveness of, all citizens no matter what their technological preferences are or their capabilities to access the content.

While some mobile phone platforms already have accessibility features built in, such as magnification, other platform providers do not offer these yet, and public managers have to make decisions based on the law. If a platform does not provide the features, development is prioritized toward those platforms that comply with Section 508, giving a lower priority to platforms that lack the features,

I have been developing a lot for the Web, but with a mobile phone it was different. The phones are having those accessibility features built in, we can try to develop towards those. The problem is there are no standards yet in the accessibility space for mobile phones. My worry there is you develop for one phone,

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and then it doesn't work for the way the accessibility has been done on another phone. It's still a very evolving issue. It is one that is important. It's important simply because we want to serve citizens on a moral and ethical level, and it's important because we have a legal responsibility under the Section 508 of the Rehabilitation Act to design our information technology systems. [Public Manager]

Given the apparent lack of standards, guidance, and the vast differences in what the individual mobile platforms are offering, it is therefore no surprise that agencies develop for the iPhone first, and later on adapt the initial app for other platforms. Another consequence is that the first round of apps is mostly text-based, does not include many interactive features, and is a safe solution to comply with the presidential mandate, as one public manager explains,

What we are trying to do is be device agnostic as much as possible. That is why for our first launch, we are making this into a mobile optimized page. All you have to do is from any mobile device, more specifically from iPhone, any Android device, or tablet, iPad and Blackberry, you open up the browser that's in within your phone, you type in our URL, and it should automatically detect your device, and render the appropriate dimensions or size for that device. [Public Manager]

#### **Barrier 3, Privacy Issues**

Privacy and security issues in the development process of mobile health apps play a central role for all agencies. The terms are oftentimes used in tandem without clarifying the difference. As an example, the Digital Government Strategy adopted the following language, "As good stewards of data security and privacy, the Federal Government must ensure that there are safeguards to prevent the improper collection, retention, use, or disclosure of sensitive data such as personally identifiable information (PII)" [25] (no page). Consequently, public managers tend to use the terms interchangeably. However, these are two distinct concepts. Privacy focuses on the personally identifiable information of data solicited and stored through the app from citizens, and security issues focus on the safe archiving and the prevention of improper release of the data to third parties or the public in general. Both issues are important mechanisms to manage and reduce organizational risks for the federal government according to the National Institute of Standards and Technology's risk management framework [31].

Privacy issues arise as soon as an agency actively solicits and collects information from mobile health app users. Given that the majority of agencies are using mobile health apps to provide information to citizens simply through a different channel than the known and trusted agency website, there is usually no need to collect personally identifiable information. However, every time a citizen downloads an app from the agency's site or through an app store, the Internet Protocol (IP) address of the phone is recognized in the same way as a visit to an agency's website results in the delivery of the IP address to the host and a traceable record. A public manager explains the process,

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We are not asking for information from [citizens], we are not asking for Global Positioning System (GPS) coordinates, so there is no reason there to have any concerns over privacy per se. Your phone is just like a desktop. I don't think a lot a people understand that, you have an IP address. But, we are not tracking users or anything like that, we do have statistics where we have aggregate data just like we would on a website. But other than that, there's no privacy issue. [Public Manager]

A public manager at the EPA explains the process of how data from the agency that feeds into the mobile app are stored, and how the app provides it to the users. Information is only collected in direct relationship to the app itself, and the agency tracks the number of downloads, deletions from the App Store, and how often the app is used,

The way that we developed our apps is, we would load everything into a database that we have control over, which is public accessible, and then, even our apps, all accessed any information we needed with Web services that we designed, and so we designed the security into them. They would only take connections from our applications. We wanted to track usage, While I can track downloads and deletions for instance from the Apple iStore, if I wanted to track usage, I have to be able to count how many times [the app is] used. We don't keep any information, like phone identification, or anything that would identify a person. All we keep track of is the number of times that the Web service was called. [Public Manager]

Those apps that are actively helping citizens to track their own data or store individual medical information are of greater concern. The solution to the problem emerged over time, public managers decided to develop apps so that personally identifiable information is only stored on the citizen's phone without transmission to the agency. Responsibility to protect citizens' privacy and security of their own data is therefore put on the shoulders of the users themselves. A public manager explained that they looked for evidence in other corners of the government system, and replicated those efforts,

There is a bit of ambiguity right now, whether, having the person's full name and email address, even if voluntary provided, is considered a personally identifiable collection of information, a system of records. It makes it pretty challenging, but we figured that there were precedents in terms of public comment on regulations online, and folks participated in the White House's social media sites, and they also provide email addresses and names. [Public Manager] However, as mobile experiences are evolving, and agencies start to experiment with higher levels of interactions, more complex data combinations, and more features for their apps, more privacy issues will have to be resolved,

When we came out with what we call our version 1 of our app that version only lived locally on someone's device. So that there were no security issues, because any information that they put into the app would only stay on their phone. We never saw it, we couldn't see it, it didn't sync, anything like that. We have since as of this past winter launched version 2 of our app, and this new version rather than being a native app in the Apple Store, it is a mobile web app, and it can sync between devices from Apple to Android to Blackberry to iPad, to desktop, to iPad, all over the place. In order to be able to sync like that between devices, and to have people's data synced, the user has to create an account, with their username, which is their email address, and a password. That means that we are now storing their data in the cloud so to speak. All of a sudden we had privacy issues that we had to think about. We weren't collecting personal identifiable information, but everything was being encrypted, so we can't see what a user, what dietary supplements the user is taking for example. [Public Manager]

Working in collaboration with the agency's privacy officer, the solution was to encrypt citizen data.

Overall, agencies that only use mobile health apps to recycle content from their website, and do not track or pull in information from citizens, are not concerned with privacy issues. This topic only becomes relevant when agencies open their own datasets and let citizens reuse data. In summary, data collection from citizens falls into six different categories and depends on the type of app, all apps collected IP addresses. Apps providing answers based on locations ask for the submission of longitude and latitude data to match the GPS location with government scores, for example, for sanitation scores. Apps that are designed to alert citizens of impeding risks, for example, for dietary supplements or food recalls, are oftentimes designed so that citizens have to opt in and names, email addresses, as well as the location of the phone are submitted to the agency. Apps with higher levels of interactions, for example, apps that are tracking patient data are usually storing the citizen input directly on the phone, and therefore prevent all privacy issues that might arise in case data are transmitted to the agency. The following table provides an overview of the type of data entry, the data collected by each app, and where the data are stored.



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Table 1.	Summary of persona	ally identifiable information c	collected through mobile health a	ops.
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Type of data entry	Collected by type of app	Data stored
IP address	Collected by all apps	Submitted to agency
Longitude, latitude (GPS location)	Ask for submissions (for example, feedback on sani- tation scores, check ins)	Submitted to agency
Email address, name	Apps issuing alerts	Submitted to agency
Patient data (symptoms, medication, dietary supple- ments)	Apps tracking intake, dosage, phases of symptoms, changes over time	Stored on phone only
Individual health information (smoking habits, eating/in- takes, physical activity)	Apps promoting behavioral changes	Stored on phone only
Individual scores	Game apps	Stored on phone, opt-in to share with social networks

# Barrier 4, Security Issues

Security concerns include two dimensions, first, government provided content needs to be stored securely, and if possible, in a separate database that can be continuously accessed by mobile apps used by the public. Second, for those apps through which citizens are submitting information to the government, these data points need to be encrypted and safeguarded. The Digital Government Strategy provides guidance for authorization and encryption of agency data provided to the public, but leaves the protection of citizen data and devices as a responsibility of the citizens, "data owners can focus more effort on ensuring the safe and secure delivery of data to the end customer and fewer resources on securing the device that will receive the data" [25] (no page).

The main goal is to reduce the risk for government itself, and agencies are following OMB's risk assessment instructions to protect personally identifiable information [32]. Web sites and mobile apps are going through a rigorous security process, as well as periodic reviews. However, as outlined earlier in the paper, agencies only adopt one-way interactions (citizens with government data), mostly decided not to ask for user data, avoid e-transactions, and focus on the protection of their own content in-house, as the NIH interview partner highlights,

# It's all the information is on a server here at the NIH. So it's very protected. It's not just out there. [Interview Partner]

The biggest obstacle occurs for those agencies that are providing apps that collect data from citizens on a voluntary basis; however, the solution is similar to the previously discussed privacy issues,

The users' data that they're recording needed to be stored. One option was to create a Web service on our end, on our servers that would store this data. However that raised a lot of security concerns, in the sense that now we have to actually build in a lot a extra security for this to protect that data on our infrastructure. What we decided to do was to have the user store that data locally. In addition to resolving the security and privacy issues, it also made things a lot snappier for the user, because now they didn't have to reach out to a server, or necessarily

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have Internet access in order to use the app to just store data locally. [Public Manager]

Agencies that are planning for more complex apps in the future need to include solutions to meet these needs,

We do know that there's going to be a need at some point for the apps to reach out and grab or store personal data, so that's why on our end we got an API that's on our developer site. One of the current projects we have got right now is to add authentication capabilities using Open ID, etcetera. So that if we need to either make data available that requires authentication, or we have data sets that are read right, such as one that where an app can actually say, send data to us, we can do so securely. [Public Manager]

Others stay on the lowest level of adoption and rely on the existing security protection, and do not veer away to iPhone or Android platforms, instead, relying on Blackberry that already provided the needed security checks,

Security just depends on the application itself. We haven't moved away from Blackberry, and that's been our standard for some time. Until we do, I don't know of any major security issues any more than if you do a web application. [Public Manager]

# Discussion

# **Solving the Paradox**

Solving the paradox of openness, customer-centric design of health-related mobile apps, and the federal policy to prevent the collection, retention, use, or disclosure of sensitive data, such as personally identifiable information, has resulted in 33 DHHS-sponsored mHealth apps [25] (no page). Most of the apps, however, are so-called native apps that are replicating the Web presence of content public agencies already provide to their stakeholders through their regular e-Government presence. These findings are in line with Cucciniello and Nasi's findings [33] that show that public health innovations are especially challenging governments, and that medical apps lack quality.

This push tactic of disseminating information to the public is fully in line with the agency's mission, as the following

statement of an interview partner from the Office of Dietary Supplements at the NIH says,

Our office supports research on dietary supplements, and then we disseminate the results of that research out to the public. We try to get more science-based information about dietary supplements out to the American public. [Interview Partner]

Besides other established dissemination channels, such as newsletters or the website itself, apps allow the agency to actively push the information to the citizens, instead of waiting for citizens to stumble upon the information during a Web search.

This study shows for the first time-to the best of the author's knowledge-the strategic and managerial decisions that have to be made before government agencies are able to even experiment with these simple apps that purely focus on representation, education, and informing the public. Previous research on the adoption of new technologies in government has shown that adoption patterns usually follow a similar adoption curve, first, government agencies start with simple versions of the new platforms, and, in the process, work out all the internal barriers, such as uncertainty about legal issues and considerations on how to apply the existing regulations, such as the compliance with Section 508 of the Rehabilitation Act or data protection and security issues, see for example [19]. What is surprising is that none of the interview partners pointed to restrictions of the Health Insurance Portability and Accountability Act. Instead, they simply avoided the collection of patient data, and handled mobile app development in a conservative manner.

Only after the internal issues have been satisfactorily determined, and existing rules are adapted to the new technology standards, agencies might be willing to explore more complex versions of new technologies, in this case interactive mobile health apps [10,11,19]. What is currently observable in this specific sample is the experimentation of what Rogers labeled "early adopters", who served as internal trailblazers and saw initial opportunities to start transforming their agencies content to a new technological platform [34]. With the introduction of an external intervention in the form of a new top-down policy, the majority of agencies followed the mandate, but not necessarily out of an internal need, other successful apps, or a push from citizens to move into mobile.

This article, therefore, contributes to the existing literature on new technology adoption in government and provides microlevel insights into the internal decision-making processes that lead to the adoption of mobile apps, and, by that, helps to open the black box of government.

# Limitations

This study focused on a very specific sample, federal-level agencies in the US Government in their early adoption phases of mobile health apps. It excluded by design other levels of government, as well as citizen apps, that are not hosted or promoted by the government. Citizen-designed apps are not subject to the same regulations and standards as federal government agencies. Innovations, especially when it comes to data entry, tracking, and sharing, are therefore much more prevalent in other sectors, but were not part of this study, and the insights are therefore limited to this specific sample.

# **Conflicts of Interest**

None declared.

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### Abbreviations

CDC: Centers for Disease Control and Prevention CIO: Chief Information Officer DHHS: Department of Health and Human Services EPA: Environmental Protection Agency GPS: Global Positioning System GSA: General Service Administration IP: Internet Protocol NIH: National Institutes of Health

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# **Original Paper**

# Enhancing Knowledge Flow in a Health Care Context: A Mobile Computing Approach

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# Abstract

**Background:** Advances in mobile computing and wireless communication have allowed people to interact and exchange knowledge almost anywhere. These technologies support Medicine 2.0, where the health knowledge flows among all involved people (eg, patients, caregivers, doctors, and patients' relatives).

**Objective:** Our paper proposes a knowledge-sharing environment that takes advantage of mobile computing and contextual information to support knowledge sharing among participants within a health care community (ie, from patients to health professionals). This software environment enables knowledge exchange using peer-to-peer (P2P) mobile networks based on users' profiles, and it facilitates face-to-face interactions among people with similar health interests, needs, or goals.

**Methods:** First, we reviewed and analyzed relevant scientific articles and software apps to determine the current state of knowledge flow within health care. Although no proposal was capable of addressing every aspect in the Medicine 2.0 paradigm, a list of requirements was compiled. Using this requirement list and our previous works, a knowledge-sharing environment was created integrating Mobile Exchange of Knowledge (MEK) and the Easy to Deploy Indoor Positioning System (EDIPS), and a twofold qualitative evaluation was performed. Second, we analyzed the efficiency and reliability of the knowledge that the integrated MEK-EDIPS tool provided to users according to their interest topics, and then performed a proof of concept with health professionals to determine the feasibility and usefulness of using this solution in a real-world scenario.

**Results:** . Using MEK, we reached 100% precision and 80% recall in the exchange of files within the peer-to-peer network. The mechanism that facilitated face-to-face interactions was evaluated by the difference between the location indicated by the EDIPS tool and the actual location of the people involved in the knowledge exchange. The average distance error was <6.28 m for an indoor environment. The usability and usefulness of this tool was assessed by questioning a sample of 18 health professionals: 94% (17/18) agreed the integrated MEK-EDIPS tool provides greater interaction among all the participants (eg, patients, caregivers, doctors, and patients' relatives), most considered it extremely important in the health scenario, 72% (13/18) believed it could increase the knowledge flow in a health environment, and 67% (12/18) recommend it or would like to recommend its use.

**Conclusions:** The integrated MEK-EDIPS tool can provide more services than any other software tool analyzed in this paper. The proposed integrated MEK-EDIPS tool seems to be the best alternative for supporting health knowledge flow within the Medicine 2.0 paradigm.

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# **KEYWORDS**

knowledge sharing; health care; mobile computing; Medicine 2.0; collaborative interaction; social computing

# Introduction

# Background

The way we communicate with the world is changing every day because of advances in wireless technologies. Mobile devices such as cell phones, netbooks, and tablets allow us to establish permanent connection and interaction with other people, almost anywhere. This communication allows people to constantly exchange knowledge among themselves. Indeed, most daily human activities have been transferred from personal computers to mobile devices [1]. People chat on their phones wherever they are, share snapshots of interesting places taken with smartphones, and regularly send and receive text messages.

The dissemination of wireless devices and their increasing use have created a huge network that has changed the way people communicate. These interactions seem to have no limits with regard to space and time. An Internet connection is often the only requisite for people to be able to work, interact, or entertain themselves, anywhere and at any time [1]. Nowadays, the interactions among people are easier, faster, and more frequent than they were just a few years ago. The interval between messages in asynchronous communication has become inconspicuous to regular users. Moreover, people are now more open to interact with other people they do not know to help them address a specific problem. These spontaneous links are weak and they are usually lost at the end of the activity [1].

# Medicine 2.0

The new interaction scenario can be considered to be a part of what has been called *cyberculture* [2]. This scenario encompasses people and objects in an immense and interconnected environment that is changing the way people interact with the spaces; thus, the world takes on new dimensions [3]. This new interaction paradigm has also reached the health care area, where information technology is changing medical practice and research, and empowering those who need quick access to supporting health information. It includes a long list of participants who play several roles in health care processes. This networked scenario has been called *Medicine 2.0* [4], and it can be understood as:

Web-based services for health care consumers, caregivers, patients, health professionals, and biomedical researchers that use Web 2.0 technologies, semantic Web, or virtual-reality tools to enable and facilitate specifically social networking, participation, apomediation, collaboration, and openness within and between these user groups. [5]

There is a powerful knowledge flow in the health care scenario (see Figure 1) and the Medicine 2.0 principles, services, and applications are used to support it. When knowledge flow and these interactions are lacking—particularly toward patients and their families—it may have a negative effect on patients and prolong recovery time [6]. Medicine 2.0 tries to mitigate this

situation by generating a social environment where people are more interconnected and available to support one another.

In Figure 1, we can identify 3 groups of participants: sick people/patients, supporting people, and biomedical researchers. These participants create different pieces of knowledge and develop different degrees of expertise that can eventually be shared with others in need of external support.

The patients are those undergoing treatment who are eventually able to provide information about their own illness, symptoms, physical and psychological reactions, and previous diseases and treatments [7]. During treatment, several subgroups are involved (health staff such as doctors, nurses, and other health professionals) who are responsible for diagnosing and treating patients. They have solid and reliable domain knowledge that can be shared to support not only patients, but also their families and caregivers. Such knowledge is useful to clarify doubts and concerns about a disease and its treatments, and instructing the supporting people on how to deal with the patients.

We also have patients who have already recovered, but are still being monitored. This is typical when people are in long-term care (eg, cancer treatment). These patients are a special kind of knowledge provider because they can share information on the disease and its treatment in an easy, informal, and understandable way. This is particularly important for other patients and their families and friends, all of whom usually appreciate the support of people who have been in a similar situation.

Understanding this knowledge-sharing scenario can help software engineers to create new types of solutions. If these pieces of knowledge can freely flow among all members of this huge network, we can create collective knowledge that can and should be harnessed to streamline the treatments and care procedures, improving the quality of life for patients.

As shown in the model defined by Eysenbach [4], 5 major concepts that emerge from Web 2.0 were applied to health care: social networking, participation, apomediation, collaboration, and openness. These emerging and recurring concepts, which are the basis of Medicine 2.0 [4], will outlive the specific tools and services that should be offered to the end users (ie, people participating in health care processes).

The term "social network" has become very popular with the growth of tools intended to manage relationships or disseminate news (eg, Facebook, Google+, and Twitter). These tools, which are based on the principles of Web 2.0, can be used in a medical scenario to facilitate interactions among participants, thus helping prevent diseases through the dissemination of health information and motivating users to take responsibility for their own health situation.

However, the real meaning of social networking is the interactions among a set of actors who may have different kinds of relationships with one another. A social network may have a few or many members (ie, nodes) and 1 or more types of

relationships (ie, edges) between the members [8]. By analyzing and understanding how and when people interact with one another, we can determine the propagation of diseases [9-14], how science is developed [15], and how it could be improved through appropriate alliances [16]. The analysis of social networks can help disseminate information, determine the quality of a piece of information, and enable collaborative filtering. People are usually less reluctant to accept a piece of information when it is offered by a community member as opposed to an unknown person. Typically, it is assumed that relevant people are linked to reliable information as well. These links among people can be used to turn an information campaign into a success (eg, to alert about a new treatment, problems with a medication, an epidemic season, or regular exams).

Figure 1 shows how knowledge flows through interactions among the members of a particular health care community. The links among participants allow each piece of knowledge to be enhanced, updated, or transformed during each interaction.

In Medicine 2.0, the main concept directly related to social networking is participation. Members of a community are free to participate, connect, and cooperate with one another, which is reflected by the various levels of people's participation. Consequently, this generates unique and unprecedented opportunities for engaging patients in their own health care activities, in the construction of knowledge regarding a treatment, and in connecting people using informal and formal knowledge.

This complex network leads to another concept of Medicine 2.0. Apomediation represents the access to knowledge without intermediaries such as health professionals giving "relevant" information to a patient [4]. Eysenbach [4] stated:

In the age of Web 2.0, there is a special form of disintermediation: an information-seeking strategy in which people rely less on traditional experts and authorities such as gatekeepers, but instead receive guidance from apomediaries; that is, networked collaborative filtering processes. The difference between an intermediary and an apomediary is that an intermediary stands between the consumer and the information, focusing on the need for a mediating agent to receive, validate, and pass on the information. By contrast, apomediation means that there are agents (eg, people or tools) who stand by to guide a consumer to high quality information and services without being a prerequisite for obtaining that information or service. [17,18]

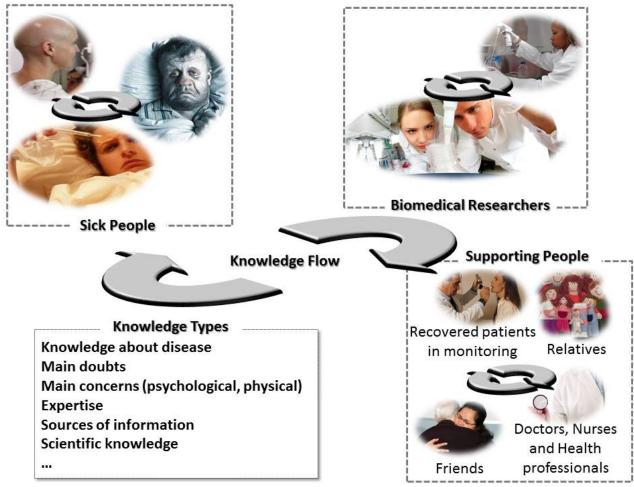
Collaboration is the fourth major concept linked to Medicine 2.0. It represents the actions that allow the connection of communities that follow similar goals or have similar interests. Finally, the openness concept is related to the interoperability (for data and services) among the software systems used by the participants in health care activities according to the interaction paradigm proposed in Medicine 2.0.

We believe that mobile computing is an important driver for Medicine 2.0 because of the widespread use of mobile devices and their ability to capture contextual information. By contextual information, we mean the meta-information that can be used to trigger knowledge exchange between 2 people (eg, information that specifies the location or the proximity of people who are looking for knowledge that another person can provide them). Based on positioning information (ie, contextual information), mobile devices can provide relevant data about the place where users are located, the events that are occurring there, and other community members who are nearby at that time.

According to the Medicine 2.0 paradigm, the use of mobile devices and contextual information can enhance the interactions and knowledge exchange among members of a health care community. To validate this hypothesis, we developed and evaluated a software environment that uses mobile devices (particularly smartphones) and contextual information for such a purpose. In this paper, we identify the current status in apps that support Medicine 2.0 and describe and validate the proposed system.



Figure 1. Knowledge flow in a medical scenario that adheres to Medicine 2.0.



# Methods

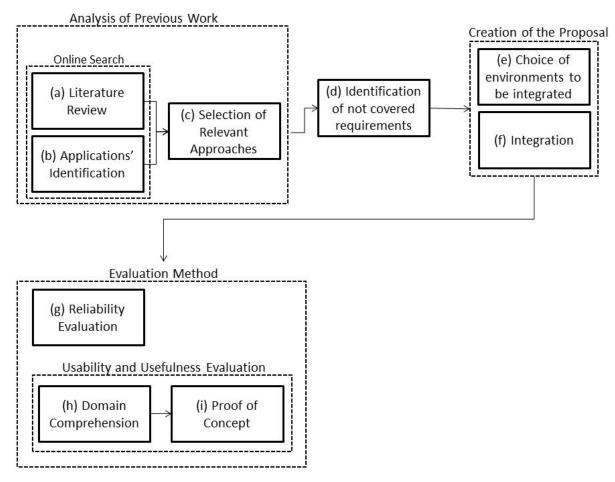
# **Creation of the Computational Solution**

The conception of the knowledge-sharing environment involved an evolving process that included several steps (Figure 2). First, we analyzed previous works to determine the current state of knowledge sharing as a support to the health care process. In particular, we reviewed the scientific literature and analyzed the main software apps that could be used to address the problem of knowledge sharing in a medical scenario. Then we identified a set of scientific proposals and apps, considering also the main themes addressed by Medicine 2.0. Based on this analysis, we identified the requirements of the health care scenario that have not been addressed by the reviewed proposals. An initial knowledge-sharing environment for mobile devices was developed based on the previous works and the requirements of Medicine 2.0 that were not addressed by the proposals presented in the literature or on the market. The development process involved 2 steps: the selection of already implemented and complementary products and the integration of the selected tools.

The resulting knowledge-sharing platform underwent a twofold evaluation. First, we analyzed the efficiency and reliability of the answers (ie, knowledge provision) that the system gave to people asking questions about illnesses or treatments and the identification of experts' locations. Second, we evaluated the suitability of the environment to support knowledge acquisition and exchange in a particular domain. We also performed a proof of concept to determine the feasibility of applying this solution to a real-world scenario.



Figure 2. The creation process of the knowledge flow solution.



# **Analysis of Previous Works: Literature and Apps**

# **Online Search**

A search to identify works related to knowledge exchange in health care scenarios with themes from Medicine 2.0 and eHealth was conducted in January 2013. Initially, we only considered scientific works published in proceedings, book chapters, and journal articles over the previous 3 years (Figure 2). The keywords used in this search were mHealth, health care, eHealth, mobile, collaboration, social network, apomediation, participation, knowledge dissemination, and Android. Other nonmedical sources were used in subsequent searches; in particular, publications from the Institute of Electrical and Electronics Engineers (IEEE) Computer Society Library were also considered. The keywords used for these subsequent searches were mHealth, health care, eHealth, medical service, knowledge dissemination, and opportunistic collaboration.

After collecting the relevant publications, we extended the search to include mobile apps that could be used to support some of the main concepts of Medicine 2.0 (Figure 2). We performed a search within Apple iTunes [19] and the Google Play Store [20] using the following terms: eHealth, health care collaboration, medical collaboration, medical knowledge dissemination, health care knowledge dissemination, and opportunistic collaboration. In both software repositories, we searched primarily for freeware apps because they could

eventually be integrated into other solutions (without cost to the end users) to build a knowledge-sharing environment. We also looked for tools and projects related to knowledge exchange using mobile devices that were not specifically designed for health care, but that could be used to support Medicine 2.0.

We also searched for services by using the keywords "Web services" and "health." This search gave us primarily social networks designed to support patients or health professionals.

# Selection of Relevant Approaches

#### Overview

The articles, apps, and programs obtained in the previous step were analyzed from the standpoint of the 5 major themes of Medicine 2.0 (ie, social networking, participation, apomediation, collaboration, and openness).. Those that did not support at least one of the key Medicine 2.0 themes were excluded. For the apps, only freeware tools were chosen for a more detailed analysis. Applying these selection criteria, we built a study corpus composed of 32 relevant articles (describing solutions and projects) and 133 mobile apps. This is step c Figure 2.

These were carefully reviewed to determine whether the following themes were supported or not. The themes were defined based on both the recommendations for supporting Medicine 2.0 apps and our experience in developing these types of apps.

# Social Networking

By using the identification of relationships and interaction types, we can characterize the relationships among members as, for example, 2 members who are family members, coworkers, neighbors, patients, caregivers, or patients undergoing treatment. More than 1 relationship type can characterize the link between 2 people. Distinguishing the types of relationships between community members and the frequency of their interactions is required to understand what is going on in a community.

Analysis of the network structure identifies the roles that are present in a social network, the number of members per role, and the interaction links. On the basis of these findings, the size and structure of the community can be established.

Analysis of an egocentric network recognizes people linked to a particular member, the roles of these people, the relationship types, and the frequency of interactions with the observed member.

In social network analysis, several graph metrics are used (eg, centrality, density, and distance between members). Using predefined graph metrics, we analyzed the proposals to determine if they provide functionalities to calculate these graph metrics.

Identification of relevant members allows relevant members of a community to be identified (eg, leaders or experts). Usually, the life of these networks depends on these people. Counting on an important number of relevant people helps keep the community alive. The relevance is a qualification given by the community members based on the attitude and value of the contributions of each person.

Identification of content and main topics analyzes the content that triggers the members' interactions and, based on the findings, the main subjects discussed in the community are determined.

#### **Participation**

Asynchronous communication allows 2 or more community members to interact sending messages or data intermittently rather than in a steady stream. For example, emails, SMS or file transferring, where users do not need to be connected in the same time to communicate to each other. Differently, we have Synchronous communication (synchronous communication), as in chats or telephone/voip calls, where all the users need to connect to communicate.

Using the service mechanisms for encouraging participation, we can implement incentive mechanisms focused on encouraging participation inside a community. There are several approaches for implementing these incentives, such as social incentives (eg, status and power) and intangible rewards (eg, esthetic improvement or public recognition). Depending on the current needs of the community, adaptive rewards can also be implemented.

Participation also involves the service promotion of various kinds of participation. Some communities support particular activities that a member (or group of members) offers to other community members (eg, physical or virtual resources, online or face-to-face meetings, or specialized talks). Counting on

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services that support these kinds of (special) participations helps keep the community alive and helps it to evolve based on its own interests.

Security and privacy of the user's personal information protects community members from unauthorized use of their personal information. It also considers information about the users' activities in the network.

Information protection allows users to define levels of visibility for their information (eg, public or private information, information accessible only to friends or family).

Interest identification allows identification of the interest areas of a community member. Thus, a software application can facilitate knowledge exchange among people with similar interests.

Expertise identification identifies the expertise area of each community member. This information can then be used by a supporting application to suggest potential experts on a specific topic.

Attention level provides status awareness, indicating the current availability of a certain community member (eg, available, busy, or disconnected). Typically, this awareness mechanism can support synchronous and asynchronous interactions among these people.

# Apomediation

Autonomous operation is a self-management service that provides supporting information to people who require it. The information delivered by this service is based on the pieces of knowledge generated by the community.

Apomediation considers that knowledge is neither centralized nor held by intermediaries, such as experts or authorities. By using decentralized environment, we evaluated the presence of services that allow people to produce, keep, and consume the shared knowledge in a decentralized way.

Informal learning supports people learning through active participation in the community. Typically, this service supports people interaction and information exchange. Sometimes this learning process involves unofficial information sources.

Source credibility indicates the credibility level of a person based on the opinion of other community members. People with high credibility are asked questions more frequently by other community members in need of external support.

Message credibility indicates how much support (credibility) a certain message has. The credibility of the community member who delivered the message tends to be more relevant for other community members compared to the formal citations.

Information filtering allows relevant information to be selected based on a filtering process that usually considers several criteria. This filtering process can be carried out using several strategies (eg, applying information retrieval techniques or through the collaborative participation of community members).

Detection of opinion leaders identifies people who are leaders of opinion. Typically, these people polarize and segment the

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community opinions; therefore, their interventions should sometimes be mediated.

# Collaboration

Location awareness allows computing devices to determine their location in indoor and outdoor environments. This is particularly useful to promote face-to-face meetings between people (eg, in a hospital).

Contextual information implements other awareness mechanisms that provide relevant information to understand, to perceive, to feel or to be conscious of events, objects or sensory patterns (in addition to the user's location) such as user presence and availability, or similarity of users' profiles.

Opportunistic collaboration support provides communication and interaction support for users who have decided to start a spontaneous computer-mediated interaction (eg, based on topics of common interest).

#### Openness

Various content formats allow an application to use different data and media formats, ensuring data interoperability among supporting services or applications.

Semantic integration allows a software system to perform data integration using semantic mechanisms, facilitating knowledge searches and inference processes.

Transparency represents the ability to access data easily, regardless of its original sources and the application that created it.

Free access indicates that no charges will be made for accessing the shared knowledge or for getting external support.

By using this analysis, we could identify functionalities that were not covered by current approaches of knowledge sharing in medical scenario. These services were used to build the comparative study between the proposals in the literature and apps review, and to guide the development of a new supporting system, described subsequently. The results of this comparison are detailed in the section Results.

# **Creation of the Proposal**

Aiming to provide complete support for knowledge flow in medical scenarios (as shown in Figure 1) and to use contextual information to enrich the access and creation of knowledge, we designed a new knowledge-sharing supporting system. The first intention was neither to create a completely new solution, nor to use closely tied tools that could make future extension of the system difficult. Instead, we opted for the integration of already implemented solutions. To determine which software to integrate, we defined a set of requirements the candidate systems had to satisfy:

- 1. The source code is available (open or granted) to enable future customizations.
- 2. Complete documentation available and development teams willing to collaborate by providing technical support when needed.
- 3. The existence of projects with scientific and academic background, where the new customizations related on

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knowledge sharing and advances made on them could be continued by future research efforts.

- 4. A product that is already being used in the health domain.
- 5. Possibility of integration with other products.
- 6. The integrated products should address most themes of Medicine 2.0.

With this criteria, we based our proposal on the integration of mobile exchange of knowledge (MEK) [21,22] and the Easy to Deploy Indoor Positioning System (EDIPS) [23].

# **Evaluation of the Integrated Knowledge-Sharing Solution**

## Goal

The goal of the evaluation was twofold: to assess the correctness of the answers provided by the integrated MEK-EDIPS tool (ie, evaluate the system's reliability) and to identify the intended use (ie, usability and usefulness evaluation).

# Reliability Evaluation

In this stage, we analyzed MEK and EDIPS separately. For MEK, which is a peer-to-peer (P2P) platform for disseminating information, we simulated some scenarios for information sharing using 6 smartphones. These phones had similar configurations and features. Based on the knowledge exchanges performed in the simulated scenarios, we calculated the precision and recall metrics (Figure 3).

The simulated scenarios represented different ways of sharing knowledge, starting with a simple exchange that involved only 2 peers. The network was gradually increased one by one until a network with 6 mutually interacting nodes was achieved. In this evaluation phase, we used 30 pieces of knowledge from various areas of interest.

In MEK, a piece of knowledge is any resource that can be exchanged, such as a piece of text, or an archive with its description. Two evaluations were performed for each scenario, involving different people. The first scenario involved the exchange of knowledge pieces without attached files. In the second scenario, the pieces of knowledge had attached files ranging from 1 to 5 MB. The analyses of the knowledge dissemination were performed based on the following metrics:

- 1. Number of failed connections. This metric indicated the number of interaction attempts for which no matching peers were found.
- 2. Number of connections without transfer. This quantifies the number of times that a device found a peer, but no knowledge exchange occurred.
- 3. Number of successful transfers. This metric is similar to the previous one; however, it counts the number of times that knowledge was exchanged between peers.

For the EDIPS, a mobile application that identifies the presence and location of people in indoor environments, the evaluation process was quite different. The EDIPS evaluation was conducted on the third floor of the Computer Science Department of the University of Chile. It has an area of 1320  $m^2$  (55 m × 24 m) with 6 Wi-Fi access points. The devices used

in this evaluation were smartphones and all possessed HTC Diamond Touch 2.

This evaluation analyzed the efficiency of the user location prediction made by the system. The location prediction error

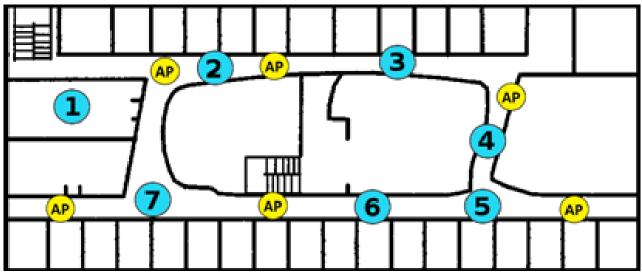
Figure 3. Precision and recall metrics.

was the distance (in meters) between the user's actual location and the position estimated by EDIPS. Figure 4 shows the map of the physical infrastructure where the evaluation was performed. We calculated an average location error by using 25-35 samples at each point.

$$precision = \frac{|\{relevant \ knowledge\} \cap \{knowledge \ retrieved\}|}{|\{knowledge \ retrieved\}|}$$

$$recall = \frac{|\{relevant \ knowledge\} \cap \ \{knowledge \ retrieved\}|}{|\{relevant \ knowledge\}|}$$

Figure 4. Map of the testing area with Wi-Fi access points (AP) and the estimated measuring locations (1-7) [19].



# Usability and Usefulness Evaluation

# Phases

This suitability evaluation was done in 2 phases. During the first phase, where we analyze the domain, we identified knowledge acquisition as a main limitation in a health scenario. In this phase, we also collected data to understand how health professionals acquire knowledge, what they consider important information during treatment, and how their patients learn about a disease and its treatment. In the second phase, we tried a proof of concept of the MEK-EDIPS tool, where we presented the system to health professionals and they assessed it.

# **Domain Comprehension**

To evaluate the domain comprehension, a goal, question, metric (GQM) [24] template was used. Based on this template, we analyzed the knowledge acquisition process in a health scenario, especially during a treatment, for the purpose of evaluating the efficiency of the knowledge acquisition process, and the reliability of the sources and the services used by professionals and patients with respect to (1) main information sources and usage frequency, (2) importance level of information in a treatment, (3) effort required to acquire information from the

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patient, and (4) usability and reliability level of the information consumed by patients from the viewpoint of health professionals.

All the participants were volunteers. First, we explained the study and all its stages and some health professionals agreed to participate in it. The sample was analyzed by gender, age, profession, expertise area, institution where the person works, main work area (clinical, research, management, or other), experience (calculated in years since graduation), time (in years) that a participant had been working at the current institution, and education level.

No training was needed for this study. All participants received the link to an online questionnaire that included questions in different areas.

The questions about sources of knowledge acquisition identified the main resources used to acquire new knowledge and the frequency the health care workers accessed them. The types of resources were classroom/face-to-face courses, distance courses, lectures, textbooks, scientific articles, discussion with more experienced professionals, discussion with less experienced professionals, discussion with professionals outside of my area, presentations in scientific meetings, empirical observation of other professionals, specialized websites, study groups

(face-to-face or virtual), social networks or media (eg, Facebook, Twitter, LinkedIn), and others (specified by the participant). The frequency of access to these information sources were at least once a year, 2-6 times a year, 1-3 times a month, 1-3 times a week, or daily.

The questions about importance of information in a treatment identified the significance of information provided by patients during a treatment and were rated as not important, somewhat important, important, very important, or extremely important. The types of information considered in the questionnaire were symptoms, doubts about the disease, fears about medication or treatment stages, physical reactions, psychological reactions, previous diseases, treatments already undertaken, routines, hobbies and information about private life, religious beliefs and superstitions, details about work (eg, location, infrastructure, and level of violence), details about residence (eg, location, infrastructure, basic sanitation, transportation, and level of violence), educational and cultural background, and others.

The questions about ease in acquiring information from patients asked how easy it was to get prior information from patients. The answers were difficult, somewhat easy, easy, very easy, or extremely easy.

The questions about usability and reliability of the information consumed by patients identified the most common information sources used by patients and how the health care workers evaluated the reliability of these sources. The usage level was rated as very little, little, regular, frequent, or very intensive. The source's reliability was rated by health care workers as unreliable, not very reliable, reliable, very reliable, or extremely reliable. The types of information source used by patients were divided into scientific publications, other health professionals, friends and relatives, known people who have had the disease, friends and relatives of people who have had the disease, social networks or media, specialized virtual communities, webpages and other Internet materials, and others.

The following specific question was posed to the participants about general feelings about knowledge exchange: Do you believe that greater interaction among patients, health professionals, researchers, recovered patients, and caregivers brings benefits to a patient's treatment and quality of life? For this question, participants could answer yes or no. In this phase, we only wanted to understand the knowledge exchange scenario; we did not control or measure the quality of the knowledge exchanges or determine the efficiency and effectiveness of this process.

## **Proof of Concept**

After collecting information to understand how professionals acquire knowledge, what they consider important information during a treatment, and how their patients learn about their disease and its treatment, we did a proof of concept. In this qualitative study, conducted in January 2013, we presented the knowledge-sharing environment to health professionals for evaluation. As defined in GQM [24], this study was to analyze the functionalities of the system for the purpose of evaluating the support provided to the knowledge flow in a health scenario with respect to possible uses of the environment by different actors in a hospital, its applicability in a health scenario, and the possibility of recommendation and use, from the viewpoint of health professionals, in the context of the MEK-EDIPS proposal.

The participants were the same as in the knowledge acquisition evaluation. They received brief training, where we described the MEK-EDIPS environment and its main services. Then participants answered a questionnaire about the knowledge-sharing program (Textbox 1).

Although the sample was characterized by different attributes, the most relevant ones were the experience level, particularly the time (in years) since graduation and the time (in years) that working at the current institution, education level, and the main area of work (eg, clinical, research, management, or others). The attributes that delineate this experiment (ie, the dependent variables) are possible use (questions 1, 2, and 5) and increase of knowledge flow (question 4).

We hypothesize that there are recognized possibilities for using the integrated MEK-EDIPS tool (ie, its use is considered important and would be recommended) and that the integrated MEK-EDIPS tool can increase knowledge flow in a health scenario.

In this study, the hypotheses about possible use and knowledge flow are equally important. In the same way, its usage is only relevant if there really is better knowledge flow among actors.



Textbox 1. The questionnaire used to analyze the benefits of MEK-EDIPS environment in knowledge sharing

(Q1) Possible uses of the environment by different actors in a health care process: For each possible use, the interviewees rated the importance level as a little important, somewhat important, important, very important, or extremely important. The potential end users of the system are as follows:

- Patients and relatives: Obtain information on the disease for additional understanding and, consequently, better treatment.
- Patients and relatives: Comfort of knowing, meeting, and collaborating with people who are going through (or that have gone through) the same illness.
- Patients and relatives: One way to get information that is more reliable than that obtained from the sources they normally use.
- Health professionals: Possibility to expand their knowledge more easily through access to scientific articles, experimental results, and treatments shared by other colleagues.
- Health professionals: Obtaining information that may help in the treatment that is usually omitted in consultations (eg, major doubts, unreliable data the patient may be relying on, reactions, or beliefs).
- Researchers: Collecting information or results to help them create new hypotheses for further research.
- Managers: Improve the provision of health information. The knowledge-sharing environment can identify the areas most people are interested in. The system can also support knowledge exchange and detect areas where there are information gaps.

(Q2) Other usage possibilities: The interviewees could indicate any other kind of usage different from that previously mentioned.

(Q3) Advantages and disadvantages of using the platform: The interviewees could indicate the environment's strengths and weaknesses.

(Q4) Impact of the system: The participants were asked to answer the following question: Do you believe that this environment can increase the flow of knowledge in the medical scenario? The participants answered using a 5-point scale, where 1=no and 5=absolutely.

(Q5) Users' acceptance of the system: The participants were asked to answer the following question: Would you use the platform or recommend its use? The participants answered using a 5-point scale, where 1=never and 5=absolutely.

(Q6) Free space for any comments: This space allowed the participants to indicate any other information that they considered relevant about the usage of the proposed environment.

# MEK-EDIS: The Integrated Environment to Aid Knowledge Exchange

# Mobile Exchange of Knowledge

The main purpose of MEK is to disseminate knowledge in a proactive and viral way. In this paper, we consider knowledge to be any information, such as images, texts, or audio, that can be scanned or created digitally. Figure 5 shows how the environment allows the interconnection of devices and the exchange of pieces of knowledge between them. This communication process uses Bluetooth. This design decision was made because this network protocol is present in most mobile devices and its usage is widespread. Moreover, no communication infrastructure is required to use it.

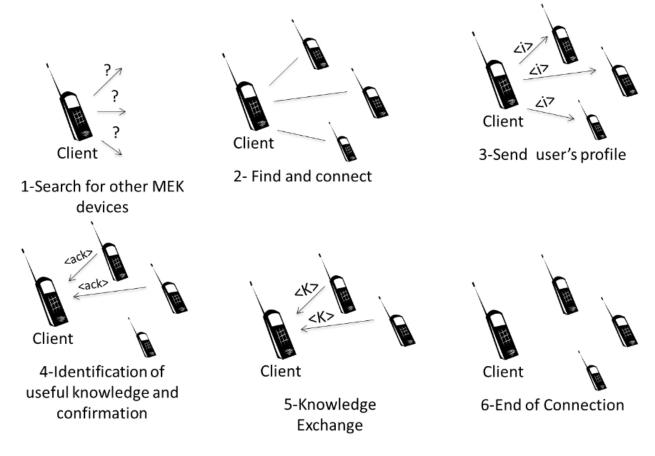
Our motivation for developing this proposal came from the hypothesis that people who have easy access to information become a great source of knowledge, thus avoiding the constraint of having just one person or group as an information source. Therefore, MEK aims to increase the exchange of knowledge among people, forming a network composed of users sharing the same interests.

After installing MEK on a smartphone, users have to identify their interests by filling in a small form, indicating their areas of interest, relevant keywords, and other information that will be used to build their personal profile. This profile will be then used to support knowledge exchange processes. The interest areas are based on a preset taxonomy, structured as a tree. After building the user profile, users could subscribe to knowledge topics delivered to their mobile phone. This knowledge will be rated according to the previously mentioned tree and the keywords from the user in the system to help improve knowledge classification.

For knowledge exchange, the MEK system of a device periodically scans for other mobile phones in the vicinity that are running the application. When another device is found, the profiles of the local users, their areas of interest, and keywords are exchanged. If there are any matches, the selected knowledge is sent to the requester (see Figure 5).



Figure 5. How knowledge is exchanged in Mobile Exchange of Knowledge (MEK) [22], where is information about user's profile, <ack> is acknowledge and <k> is a piece of knowledge.



# Easy to Deploy Indoor Positioning System

The EDIPS [23] is a mobile application that maps the position of several people in a closed environment. This system uses a mix of inertial navigation and wave analysis to perform the positioning process..

#### **Inertial Navigation Systems**

The inertial navigation positioning method uses inertial sensors (eg, gyroscopes and accelerometers) to capture the movement of a user in indoor environments. A positioning system that is based solely on these sensors becomes imprecise over time because the sensors carry a margin of error that accumulates whenever a new measurement is made. Nevertheless, it is an excellent support tool that can be combined with other techniques to achieve simplicity and accuracy.

#### Wave Analysis

The wave analysis positioning method is based on the analysis of a network's signal strength. It uses multiple reference points that emit signals to a receptor device, which then (based on the wave properties) infers its position in the physical environment. The 3 common techniques for wave analysis are proximity detection, signal triangulation, and fingerprinting.

Proximity detection uses device detectors that are placed on previous known positions. When a resource is identified by one of these detectors, its coordinates are reported to a component in charge of mapping the device. Although this strategy could be very accurate for detecting objects in motion, it requires the

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use of specialized hardware and significant effort to prepare the environment where the positioning system would be used.

Signal triangulation uses the geometric properties of the triangle to estimate the position of a resource in a 2-dimensional scenario. The estimation process uses 3 reference points with a known location from which signals are emitted. The signals are then surveyed by the device whose location is to be estimated. By estimating the distance between the device and each reference point and triangulating the signals, it is possible to pinpoint the resource in the area within a fairly reasonable margin of error. The advantage of this method is that it usually requires little setup effort to be used in an indoor environment.

Fingerprinting estimates the position of a resource in the environment, comparing the signal strengths detected by the receptor device against a set of prestored signals that correspond to different points in the physical area. This strategy usually has 2 phases: the online and the offline phase. In the online phase, several signal samples are collected from multiple reference points at the physical locations. This information is used to make a grid, where each cell is characterized by the set of signal strengths that can be detected at the location. In the online phase, the signal strengths captured by a device are then compared to the information preset in the offline phase. Comparing both sets of signals, the method estimates the current position of a mobile user. The problem with this strategy is the significant effort it takes to produce the grid. This method uses only the existing infrastructure at a site (eg, Wi-Fi access points).

EDIPS uses a combination of inertial navigation, triangulation, and fingerprinting. During the offline phase, the signal strengths are calculated based on only the Wi-Fi access point (as reference points) and a signal propagation model [23]. Based on this information, a discretization of the physical space is automatically performed. A grid with fixed-sized cells is overlapped onto the blueprint of the physical area. Every cell has preloaded the expected signal strengths assigned by the signal propagation model. By comparing the current signal strengths captured by a mobile device with the signals preloaded in the system, it is possible to determine the user location with minimal effort. EDIPS has fast deployment with an acceptable degree of precision (between 2 and 6 m) that makes it suitable for finding people in most indoor scenarios (eg, hospitals). Based on this application, the knowledge exchange can then be done through face-to-face interactions.

# **The Integration of Tools**

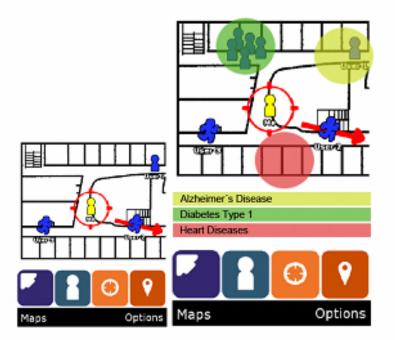
# **Conceptual Integration**

Both MEK and EDIPS have different functions, although when combined they can increase their potential. Both applications work in a loosely related way; that is, the collaboration between users is on-demand and involves a short time period [25]. For instance, the devices of 2 users would remain connected only during the time required to perform the matching of user interests and the knowledge exchange. For the integration of these tools, a mechanism for information exchange between these systems was proposed. It enriches the information from each application and supports collaboration. MEK provides information on the exchange of knowledge, while EDIPS contributes with the positioning of the participants involved in the exchange at the time it is performed.

Further analyses can be done by both applications with the information obtained from both of them. MEK may perform analyses involving the positioning of the participants, and it can highlight the location and amount of knowledge that has been exchanged at a certain location, for example. EDIPS can also interpret the data received from MEK and enrich it with points on the map representing knowledge areas (see Figure 6). It can be used to identify groups that have the same interests, the usual locations of these groups, and how people move in a certain physical area (eg, in a hospital). A breakdown of locations with their exchanged knowledge can be shown on EDIPS maps. This kind of visualization is appropriate to show from which users and in which areas one is more likely to find a piece of knowledge for a certain category.

This MEK-EDIPS integration can also be used in several contexts, especially in the health care scenario. The next section describes the use of this knowledge-sharing environment for various purposes in hospitals and clinics.

Figure 6. Screenshots of original EDIPS (left) and EDIPS incorporating information provided by MEK (right) [25].



# **Example Scenarios**

Health care is one possible scenario where the integrated MEK-EDIPS tool can be used. This scenario involves people who play several roles: physicians and other health professionals, patients (adults or children), patients' families and friends, recovered patients, and managers of health centers. All these people are considered and supported by the proposed

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environment. The following example illustrates the support that can be provided by MEK-EDIPS to participants in a health care scenario.

Mary is undergoing breast cancer treatment. Today she is being consulted by her physician, Dr Silva, who identifies new symptoms and some unrecognized reactions. While Mary is waiting for a chemotherapy session, she uses MEK-EDIPS to receive information about her disease and reports from other

women who also undergoing treatment for breast cancer. She takes the opportunity to ask a question about metastasis.

The chemotherapy session starts, her mobile phone is off. Her husband takes this time to learn about the usual fears of patients with breast cancer in his own phone. He asks some questions about it and through the integrated MEK-EDIPS tool he identifies Helen, a breast cancer survivor, who is under monitoring. Helen is available to contact and his device indicates that she is across the corridor, close to him. He walks across the hall, presents himself, and asks his questions. During this face-to-face conversation with Helen, his phone is receiving and sending pieces of knowledge about his main interests, "psychological effects of cancer" and "symptoms of depression."

Simultaneously, a nurse elsewhere in the hospital identifies erroneous information about an alternative HIV treatment. She reports it and then enters the correct information. She also answers Mary's question about metastasis.

During lunch break, Dr Silva identifies a group of experts at a nearby table through the integrated MEK-EDIPS tool. He goes to their table to clarify some concerns about Mary's new symptoms and reactions. In the same restaurant, Dr Koothrappali, who has just come from an important conference, is telling other doctors via his phone some news about treatment options.

By using all the information exchanges supported by the integrated MEK-EDIPS tool, Dr Wilson, the hospital manager and head of the Oncology Department, recognizes that there are many questions about breast cancer. People who interact about this issue (asking questions or providing pieces of knowledge) are usually in the hospital on Mondays from 2 pm to 3 pm. Therefore, he organizes some lectures every Monday at 2:30 pm and distributes leaflets and notices to the health staff to identify the main questions from their patients.

# Software Integration

The data integration between the 2 app (MEK and EDIPS) was possible through the exchange of extensible markup language (XML) files with the contextual information captured by each. This data format was chosen because it is lightweight, structured, and standardized, thus facilitating data interoperability. The proposed integration between MEK and EDIPS is depicted in Figure 7.

Both apps must be running simultaneously on the user's mobile device. While MEK uses contextual information to perform knowledge exchange, EDIPS maps the position of other users. MEK searches for knowledge that may be useful to the user. When a piece of knowledge is found, the exchange is performed; that is, a copy of the found knowledge is transferred to the user's mobile device. To perform this exchange, MEK needs to know the knowledge categories (from its taxonomy) that the user is interested in and some personal information from the user profile.

When the exchange occurs, MEK performs 2 tasks. The first task is to communicate with EDIPS to request the position of the device sending the knowledge. Once this information arrives, MEK performs the second task, which is the construction of the XML file with the information about the occurrence/location of the exchange. This metadata and information about the time when the transfer occurred and the participants in the exchange are stored in the XML file. A part of the XML file is shown in Figure 8.

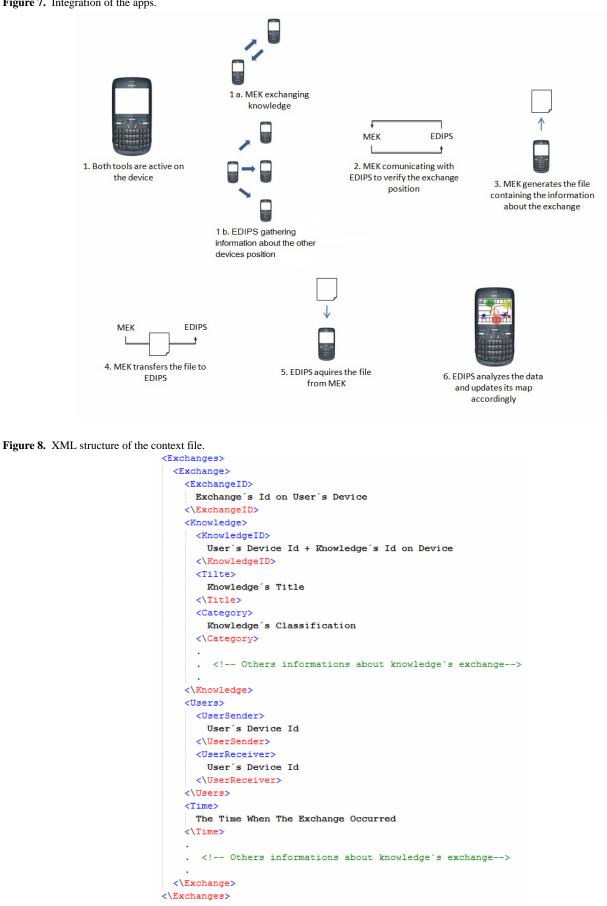
The XML file can also be used as an input for EDIPS, providing additional information for updating its map and for MEK for the identification of groups of interest and statistics about knowledge exchange. Once the exchange occurs, MEK can run analyses about which location has the highest exchange rates. With this information, one can find out which areas have more users with similar interests.

The file generated in the previous step is relayed to EDIPS, which then takes the necessary data to improve its mapping. EDIPS also runs analyses of the data to add awareness information to the map. Boundaries for areas of interest may also be produced; that is, EDIPS can mark with different colors on its map the locations that concentrate a large number of people with a particular interest. Figure 6 shows 3 groups: light green, dark green, and red, which represent people interested in Alzheimer disease, type 1 diabetes, and heart disease, respectively. All this information will be displayed on the EDIPS screen, providing data to the end users in a visual and easy-to-understand manner.



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Figure 7. Integration of the apps.



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# Results

# **Analysis of Previous Work**

## **Overview**

The apps and articles selected to be part of the study corpus were grouped into 4 categories: social networking, mobile applications, online tools, and academic literature. We found social networking apps that would only be useful for patients and other apps that would only be useful for health professionals, but the main goal of both clusters was the exchange of experiences among users.

Some apps for patients focused on searching for people who have the same diseases, with the aim of sharing experiences among them. Furthermore, there were apps for treatments and activities that could help find information for patients and their families. Some apps for health professionals were used to exchange experiences related to patient's medications and the discovery of new treatments.

## Social Networking Tools

In the social networking area, the following tools were selected: Everyday Health [26], PatientsLikeMe [27], HealthVault [28], and Sermo [29].

Everyday Health [26] is a social network geared toward patients. The user can search for other people with the same interests in the health area and exchange experiences with them. The user states his/her interests when registering by choosing from a preset list of interests.

PatientsLikeMe [27] is a social network catering to patients. Users can search for other users with the same interests. Once found, one can follow other users to see what they have posted. There is a forum area to support interactions among users. It is mainly used to clarify questions and share experiences.

HealthVault [28] is a Microsoft tool that is based on a social network designed to facilitate learning in the health care area. The tool allows users to record personal information and medical records that can be accessed by authorized people or health centers in the event of emergencies.

Sermo [29] is a social network for health care professionals. It is for finding new procedures and exchanging experiences and results of disease treatments. To register with it, a user needs a credential that proves expertise in health care professional services. For this reason, the application was not formally considered in the evaluation process.

# Mobile Apps

For mobile apps, we chose AsthmaMD [30] and Epocrates [31]. These apps take advantage of the diffusion capabilities of mobile devices to connect health professionals with patients (eg, to find a second opinion on a patient's disease). In the case of Epocrates, it can also be used to help people find information about medications, dosages, and their collateral effects.

AsthmaMD [30] is a free application for mobile devices that allows users to register their asthmatic activities, medications, and the causes of their crises, much like a diary. This

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information can be shared with other users. Using this information, it is also possible for users to generate a graph with activities that can be shared with their doctors and stored in their health records. The application also promotes the openness of these files so that researchers can study the cases for scientific purposes. For this reason, the files are all anonymous.

Epocrates [31] is a large online database for mobile devices. This tool includes data on medication dosage, indications for the use of drugs, laboratory tests, adverse reactions, pharmaceutical information, and other clinical data and papers on the topic. As Epocrates focuses on drug information (and not in collaboration or information sharing among professionals), we did not include it in the comparison.

#### **Online Tools**

The third area of related works involved online tools that help patients search for a second medical opinion or advice from a health specialist. In this area, we selected an online tool named Doctle [32]. After registration, the user can initiate a new medical consultation to obtain an opinion or advice. This service is not free. Doctle [32] is an online tool that allows patients to get a medical consultation via the Internet. Although registration is free, the user has to pay to set an appointment or send his/her medical history to the physician.

### Academic Literature

The academic literature category reported on initiatives for helping improve people's well-being. These research works introduced tools or frameworks with a scientific reasoning [33-37].

HOMEVMI [33] is a tool that can give advice to its users and deliver alerts regarding their lifestyle. The advice is personalized according to the user's input and other conditions identified by sensors connected to the patient.

Wei and Yang [34] designed an app that allows patients to access the server of a hospital to retrieve information or suggestions on diseases and symptoms. Physicians can also monitor their patients using the system.

Benavides et al [35] described a mobile application that uses Bluetooth to discover and record users who are interested in similar health topics. This can be used to infer the proximity of those people, to detect contact between 2 people, the duration of the contact, and he geolocational data. The contact data are then used to evaluate the potential spread of an infectious disease—a transmission vector represents the proximity to infected agents.

Ramos et al [36] reported on an app for mobile devices that enhances communication between doctors and patients who live in distant areas with difficult access.

MobiClique [37] is middleware for mobile social networking. This tool allows for studying the behavior of mobile social networks and interactions among people, based on opportunistic communication by using Bluetooth.

# **Comparison of Functionality**

We compared the functions provided by these systems and the

objectives of the software. The findings of the comparison process described previously as well as the integrated MEK-EDIPS tool are presented in Tables 1 and 2.

Table 1. Current social networking tools, mobile apps, and online programs: Analysis from Medicine 2.0 perspectives.

Requirements	Work <sup>a</sup>							
	Everyday Health	PatientsLikeMe	HealthVault	Doctle				
Social networking								
Relationships and interaction types	-	_	_	_				
Network structure	+	+	_	_				
Egocentric network	+	+	_	_				
Graph metrics	N/A	N/A	N/A	_				
Relevant members	+	+	_	_				
Content and main topics	+	N/A	_	_				
Participation								
Asynchronous communication	+	+	+	+				
Synchronous communication	-	_	_	_				
Mechanisms for encouraging participation	_	+	_	_				
Promotion of various kinds of participation	-	-	_	_				
Security and privacy of the user's personal in- formation	+	+	_	+				
Information protection	+	-	N/A	_				
Interest identification	+	+	_	_				
Expertise identification	-	-	_	_				
Attention level	-	-	N/A	_				
Apomediation								
Autonomous operation	+	+	_	_				
Decentralized environment	+	+	_	_				
Informal learning	+	+	+	N/A				
Synchronous communication	-	-	N/A	_				
Message credibility	N/A	N/A	N/A	_				
Information filtering	N/A	N/A	N/A	_				
Detection of opinion leaders	-	-	N/A	_				
Collaboration								
Location awareness	-	-	_	_				
Contextual information	+	+	N/A	-				
Opportunistic collaboration	+	+	-	-				
Openness								
Content formats	-	N/A	N/A	-				
Semantic integration	N/A	N/A	N/A	-				
Transparency	+	+	-	-				
Free access	+	+	+	-				

<sup>a</sup>+: the application incorporates the attribute; -: the attribute is not incorporated; N/A: the attribute analyzed was not found or it was not mentioned in the paper or website of the tool.

Table 2. Proposed works: Analysis from Medicine 2.0 perspectives.

Requirements	Work <sup>a</sup>								
	HOMEVMI	Ramos et al [36]	Benavides et al [35]	MEK-EDIPS					
Social networking									
Relationships and interaction types	+	_	_	+					
Network structure	_	_	+	_					
Egocentric network	_	N/A	+	+					
Graph metrics	_	_	N/A	_					
Relevant members	+	_	N/A	+					
Content and main topics	_	_	_	+					
Participation									
Asynchronous communication	+	+	_	+					
Synchronous communication	_	+	-	+					
Mechanisms for encouraging participation	+	_	-	+					
Promotion of various kinds of participation	+	_	-	+					
Security and privacy of the user's personal in- formation	N/A	-	-	+					
Information protection	N/A	N/A	-	+					
Interest identification	N/A	_	-	+					
Expertise identification	+	_	-	+					
Attention level	_	_	-	+					
Apomediation									
Autonomous operation	+	+	_	+					
Decentralized environment	+	_	-	+					
Informal learning	+	_	-	+					
Synchronous communication	N/A	_	_	+					
Message credibility	N/A	_	_	+					
Information filtering	-	_	-	+					
Detection of opinion leaders	_	_	-	+					
Collaboration									
Location awareness	N/A	N/A	-	+					
Contextual information	+	+	+	+					
Opportunistic collaboration	-	_	-	+					
Openness									
Content formats	N/A	+	_	+					
Semantic integration	-	_	_	+					
Transparency	+	+	_	+					
Free access	N/A	N/A	+	+					

 $^{a}$  +: the application incorporates the attribute; -: the attribute is not incorporated; N/A: the attribute analyzed was not found or it was not mentioned in the paper or website of the tool.

We can see in Tables 1 and 2 that the presented works do not support the social networking and the participation. The MEK-EDIPS provides a good support to these requirements, as to the others.

For the integrated MEK-EDIPS tool, the focus is on knowledge dissemination. The users' relationships and interactions types can be information exchange, chatting, or face-to-face meetings. The user can identify the frequency of his/her interactions, who participates in them, when they occur, and the type of

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communication (egocentric network). Network structure and Graph metrics are requirements missed in MEK-EDIPS, because this solution does not provide mechanisms to analyze the complete social network. It was not part of its design goals, but the social information can be easily exported to a social network analysis tool, as example Gephi.. The most relevant members can be identified by the frequency of participations; therefore, relevance is related to the degree of cooperation. The categories of a taxonomy and keywords used by users to describe the resources and their own interests are related to identification of content and main topics interactions.

The integrated MEK-EDIPS tool provides both asynchronous and synchronous communications. This solution does not have very sophisticated mechanisms for encouraging participation—it is achieved in a proactive way because people have learning needs and gaps in their knowledge. Receiving useful information provides interesting benefits, such as clarifying and filling in the knowledge gaps, or it can be used to find and interact with people who have the same interests or are experts in these areas.

The integrated MEK-EDIPS tool promotes some kinds of participation, such as information sharing, validation, chatting, and face-to-face meetings. Because the main goal of the integrated MEK-EDIPS tool is the dissemination of information, none of the user's personal information is available (security and privacy), and his/her resources can be public or private (information protection). As explained previously, this solution allows the identification of the users' areas of preference (interest identification) and the identification of experts (expertise identification). In connection with MEK, information sharing is transparent to users, whereas in EDIPS, the user can be invisible if one does not wish to be interrupted or identified (attention level).

The conceptual base of MEK is apomediation. The users determine information creation and provision (autonomous operation) in a decentralized environment, using their mobile devices. The learning process is fully participative and collaborative. It involves the use of official and unofficial sources (informal learning), and the crowd evaluates them in a continuous process (synchronous communication). All the content is provided for and by common people, mostly nonexperts, based on their own understanding or experiences (message credibility). During this process of information creation and dissemination, all the members of this huge network filter useful information (information filtering), validating, and commenting on each resource. Opinion leaders can be detected by the frequency of their collaboration and participation.

Indoor location awareness is the main focus of EDIPS. It allows identification of people in a physical space, and following and interacting with people who are in close proximity. The integration with MEK enables the identification of people with similar interests. The contextual information used to enrich content and empower collaboration is as follows: time (when the knowledge was created, an interaction occurred, or people passed by a specific location), spatial information (usually maps), areas of interest, and information content. In its creation, MEK was based on opportunistic collaboration.

The integrated MEK-EDIPS tool uses any data that can be scanned or digitally created; for example, images, text, or audio (content formats). The information type can be identified using a common taxonomy (semantic integration). If this information is available in the knowledge sharing application, it is considered to be accessible data (transparency) that can be shared for free (free access).

After analyzing the proposals that are part of the study corpus, it is possible to say that there is no work supporting a complete knowledge flow among the participants in the health care process, according to the guidelines given by Medicine 2.0 principles. This evidence leads us to expect an interesting contribution from the integrated MEK-EDIPS tool as a supporting tool for the entire knowledge flow process (as shown in Figure 1).

# **Reliability Evaluation**

# **MEK and EDIPS**

We evaluated the MEK capability to support knowledge sharing among participants in the health care process. We tested the capability of EDIPS to locate people in order to promote face-to-face interactions among them, based on their common interests.

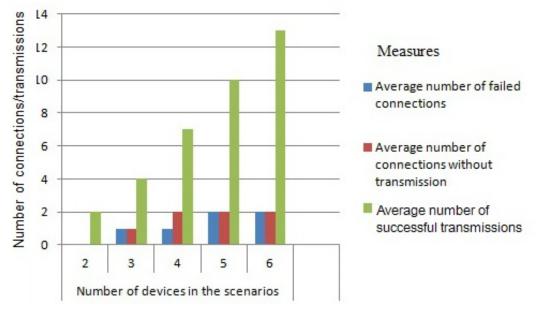
# **MEK Evaluation**

Figure 9 shows the results obtained in the reliability evaluation of MEK. The x-axis represents the number of devices used in each scenario described previously, whereas the y-axis shows the average number for each measurement.

In these tests, the precision rate was 100% and recall rate was 80%. As shown in Figure 9, the number of failed connections or connections without transmission was very low compared to the successful knowledge exchange interactions.



Figure 9. Results of reliability evaluation of MEK.



# **EDIPS** Evaluation

The results obtained in the EDIPS positioning evaluation are presented in Table 3. The average distance error across all 7

testing locations was <6.28 m, an acceptable distance if we are trying to find people based on such information.

Location	Error distance (m), mean (SD)
1	4.57 (2.02)
2	3.63 (2.07)
3	6.25 (1.12)
4	5.74 (2.31)
5	6.28 (2.15)
6	6.16 (2.63)
7	4.27 (1.83)

# Usability and Usefulness Evaluation

# Sample Characteristics

To understand how professionals usually acquire knowledge, what they consider important information during a treatment,

and how their patients learn about their diseases and cures, we gave a questionnaire to a sample of health professionals. In this study, 18 health professionals participated: 14 females and 4 males. We present their ages, occupations, the place where they work (some researchers work in hospitals), and their experience (in years) in Table 4.



Table 4. Participants' characteristics (N=18).

Characteristics	n (%)
Gender	
Male	4 (22)
Female	14 (78)
Age (years)	
≤30	8 (45)
31-40	3 (17)
41-50	5 (28)
>51	2 (11)
Occupation	
Physician	7 (39)
Medical student (in final year)	1 (6)
Physiotherapist	1 (6)
Nurse	5 (28)
Psychologist	1 (6)
Dentist	2 (11)
Nursing assistant	1 (6)
Workplace	
Clinic	10 (56)
Research institute or university	2 (11)
Other	6 (33)
Experience (years)	
<5	6 (33)
5-10	5 (28)
11-15	2 (11)
16-20	1 (6)
21-25	1 (6)
>25	3 (17)

Although there is an imbalance in the age and gender of the participants because participants are not distributed equally using these variables. It is not a problem because these variables are not particularly important for this experience. We were looking for people with some relevant professional expertise in different health care areas. For this study, the variables related to expertise (ie, experience, academic background, and occupation) are more relevant. Concerning the occupations, we preferred professionals who interacted directly with patients, performed clinical work, and other kinds of assistance.

In all, 13 participants were specialists in some of the following areas: mental health and psychosocial care/emergency, trauma orthopedics, pediatrics, anesthesiology, family and community medicine, nephrology, organ donation and transplants, or pathology. Moreover, 56% (10/18) of our sample worked directly with the treatment of diseases (clinic), 11% (2/18) in research, and 33% (6/18) had other kinds of assignments, such as intensive care units or emergency and pathology diagnosis.

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Regarding the participants' experience (Table 4), 39% (7/18) had more than 10 years of experience, 28% (5/18) had between 5 and 10 years, and 33% (5/18) had less than 5 years of experience. Concerning their academic background in addition to being an MD, 33% (6/18) held a PhD degree, 11% (2/18) held a Master's degree, 33% (6/18) held a specialized training or residency, 17% (3/18) were graduate students, and 5% (1/18) had a technical degree. Taking into account these characteristics, we considered it to be a valid sample.

# Domain Comprehension: How Professionals and Patients Learn

Using this sample, we understood how the participants (and their patients) create knowledge and identified some characteristics of this process (eg, frequency, main information sources, and source reliability). The participants answered the questions presented in the questionnaire and also provided extra information about this process. The main information sources with their most common usage frequency are:

- 1. Classroom/face-to-face courses: Most participants use this information source, but with low frequency (at least once a year).
- 2. Lectures: Similar to the previous one, many people sporadically use this knowledge source.
- 3. Discussion with professionals outside my area and specialized websites: Both sources are used most commonly from 1 to 3 times per month.
- 4. Scientific articles and discussion with less experienced professionals: These sources are frequently used (most commonly from 1 to 3 times per week).
- 5. Textbooks and empirical observation of other professionals: These are the most frequently used knowledge sources. Both are most commonly used daily or almost daily.

Table 5 presents the main information sources used by health professionals to create, validate, or update knowledge, and the frequency with which they used those sources.

Resource used in knowledge acquisition	Usage frequency, n (%)									
	>1 time/year	2-6 times/year	1-3 times/month	1-3 times/week	Daily					
Classroom/face-to-face courses	13 (72)	2 (11)	0 (0)	2 (11)	0 (0)					
Distance courses	5 (28)	2 (11)	1 (6)	0 (0)	0 (0)					
Lectures	1 (6)	11 (61)	3 (17)	2 (11)	0 (0)					
Textbooks	0 (0)	3 (17)	5 (28)	4 (22)	5 (28)					
Scientific articles	0 (0)	3 (17)	5 (28)	6 (33)	3 (17)					
Discussion with more experienced profession- als	0 (0)	3 (17)	5 (28)	5 (28)	4 (22)					
Discussion with less experienced professionals	1 (6)	3 (17)	2 (11)	6 (33)	4 (22)					
Discussion with professionals outside of my area	1 (6)	4 (22)	6 (33)	2 (11)	4 (22)					
Presentations in scientific meetings	4 (22)	7 (39)	1 (6)	0 (0)	1 (6)					
Empirical observation of other professionals	2 (11)	5 (28)	1 (6)	4 (22)	5 (28)					
Specialized websites	0 (0)	3 (17)	6 (33)	4 (22)	4 (22)					
Study groups (face-to-face or virtual)	2 (11)	5 (28)	4 (22)	1 (6)	1 (6)					
Social networks or media	4 (22)	1 (6)	4 (22)	0 (0)	3 (17)					
Other	0 (0)	2 (11)	0 (0)	0 (0)	0 (0)					

#### Table 5. Sources of participants' knowledge acquisition (N=18).

During a treatment, it is important that the health professional can get information from the patient to understand their health situation. Table 6 shows the importance level of information about a certain element of a patient's disease or treatment according to the opinions of the participants.

Symptoms were rated by the participants as extremely important information, the treatments already undertaken were considered to be very important, and religious beliefs and superstitions and details about work were regarded as important issues. Moreover, the participants mentioned other kinds of relevant information, such as the quality of family relationships or the social behavior of the patient.

The participants were also asked about how easy it is to get important information from the patient. The results obtained indicate that it is not a difficult task (Table 6). The main difficulties were related to access to personal information; for example, details about work or residence, or information about the private life of the patients.



Table 6. Ratings of importance of information for a treatment and difficulty gathering information from patients (N=18).

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Relevant topics for a treatment	Impor	rtance, n (	%) <sup>a</sup>			Difficul	ty, n (%)				
	1	2	3	4	5	1	2	3	4	5	
Symptoms	0 (0)	0 (0)	0 (0)	0 (0)	16 (89)	1 (6)	2 (11)	5 (28)	5 (28)	3 (17)	
Doubts about the disease	0 (0)	0 (0)	2 (11)	3 (17)	11 (61)	0 (0)	2 (11)	9 (50)	3 (17)	2 (11)	
Fears about medication or treatment stages	1 (6)	0 (0)	2 (11)	5 (28)	8 (44)	1 (6)	3 (17)	8 (44)	2 (11)	2 (11)	
Physical reactions	1 (6)	0 (0)	1 (6)	4 (22)	10 (56)	0 (0)	3 (17)	6 (33)	3 (17)	3 (17)	
Psychological reactions	0 (0)	1 (6)	1 (6)	4 (22)	10 (56)	0 (0)	3 (17)	9 (50)	2 (11)	1 (6)	
Previous diseases	0 (0)	0 (0)	2 (11)	5 (28)	9 (50)	0 (0)	3 (17)	4 (22)	5 (28)	3 (17)	
Treatments already undertaken	0 (0)	0 (0)	3 (17)	7 (39)	6 (33)	0 (0)	4 (22)	5 (28)	2 (11)	4 (22)	
Routines, hobbies, and information on private life	0 (0)	1 (6)	6 (33)	3 (17)	6 (33)	1 (6)	5 (28)	7 (39)	0 (0)	2 (11)	
Religious beliefs and superstitions	1 (6)	1 (6)	9 (50)	3 (17)	2 (11)	1 (6)	2 (11)	8 (44)	2 (11)	1 (6)	
Details about work (eg, location, infras- tructure, and level of violence)	0 (0)	0 (0)	9 (50)	2 (11)	5 (28)	0 (0)	6 (33)	7 (39)	2 (11)	0 (0)	
Details about residence (eg, location, in- frastructure, basic sanitation, transporta- tion, and level of violence)	0 (0)	0 (0)	8 (44)	3 (17)	5 (28)	1 (6)	6 (33)	7 (39)	1 (6)	0 (0)	
Educational and cultural background	1 (6)	2 (11)	7 (39)	1 (6)	5 (28)	0 (0)	2 (11)	8 (44)	2 (11)	3 (17)	
Other	0 (0)	0 (0)	0 (0)	0 (0)	4 (22)	0 (0)	2 (11)	2 (11)	0 (0)	0 (0)	

<sup>a</sup>1=Not important, 2=somewhat important, 3=important, 4=very important, 5=extremely important.

<sup>b</sup>1=Difficult, 2=somewhat easy, 3=easy, 4=very easy, 5=extremely easy.

According to the health care professionals' opinions, the most reliable information sources for the patients are were their friends and relatives, or people who have the same disease (both recorded very frequent use). Although they are the most frequent mechanisms to solve patients' doubts, they are not considered reliable sources (Table 7). When asked for other sources, the sample mentioned newspapers and magazines, which are also not reliable sources. The participants were asked if they believe that greater interaction among patients, professionals (eg, doctors, nurses, aides), researchers, recovered patients, and caregivers (eg, family and friends) could benefit the acquisition, validation, and exchange of knowledge on the patient's disease or treatment. Of the total participants, 94% (17/18) answered yes and 6% (1/18) said no.

Table 7. Reliability level of information sources according to health care professionals.

Information source	Reliability level, n (%) <sup>a</sup>						Frequency of access to the information source, n (%) <sup>b</sup>				
	1	2	3	4	5	1	2	3	4	5	
Scientific publica- tion	0 (0)	0 (0)	2 (11)	7 (39)	4 (22)	4 (22)	2 (11)	0 (0)	1 (6)	1 (6)	
Other health pro- fessionals	0 (0)	0 (0)	9 (50)	2 (11)	3 (17)	0 (0)	6 (33)	4 (22)	1 (6)	3 (17)	
Friends and rela- tives	3 (17)	4 (22)	6 (33)	0 (0)	0 (0)	0 (0)	1 (6)	3 (17)	4 (22)	6 (33)	
Known people who have had the disease	2 (11)	3 (17)	7 (39)	2 (11)	0 (0)	1 (6)	1 (6)	1 (6)	6 (33)	5 (28)	
Friends and rela- tives of people who have had the disease	3 (17)	5 (28)	6 (33)	0 (0)	0 (0)	1 (6)	1 (6)	2 (11)	4 (22)	6 (33)	
Social networks or media	5 (28)	6 (33)	2 (11)	0 (0)	0 (0)	1 (6)	6 (33)	2 (11)	2 (11)	3 (17)	
Webpages and other Internet materials	1 (6)	7 (39)	5 (28)	0 (0)	0 (0)	1 (6)	3 (17)	3 (17)	4 (22)	2 (11)	
Specialized virtu- al communities (focused on the disease)	2 (11)	1 (6)	8 (44)	3 (17)	0 (0)	4 (22)	3 (17)	4 (22)	2 (11)	1 (6)	
Other	0 (0)	2 (11)	0 (0)	0 (0)	0 (0)	0 (0)	1 (6)	0 (0)	0 (0)	0 (0)	

<sup>a</sup> 1=unreliable, 2=not very reliable, 3=reliable, 4=very reliable, 5=extremely reliable.

<sup>b</sup> 1=very little use, 2=little use, 3=regular use, 4=frequent use, 5=very frequent use.

# **Proof of Concept**

The integrated MEK-EDIPS tool was presented to the participants. Then, they determined how important it would be to use integrated MEK-EDIPS tool to support certain activities of the members of a health care community (Table 8).

The use of the integrated MEK-EDIPS tool was considered extremely important to support the activities presented in Table

8. The participants mentioned that the integrated MEK-EDIPS tool facilitates the search for professional content. Moreover, 67% (12/18) would like to use or would recommend the use of this environment. Therefore, this supports our hypothesis that there are recognized possibilities for using the integrated MEK-EDIPS tool and the use is considered important and would be recommended.



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 Table 8. Importance of the integrated MEK-EDIPS tool in the health scenario.

Activities to be supported	Level of importance, n (%)							
	A little im- portant	Somewhat im- portant	Important	Very impor- tant	Extremely impor- tant			
For patients and relatives								
Obtaining information on the disease, additional understand- ing, and, consequently, better treatment	0 (0)	1 (6)	3 (17)	4 (22)	7 (39)			
Facilitating the interaction with people who are going through, or have gone through the same illness	0 (0)	0 (0)	4 (22)	4 (22)	7 (39)			
Improving the reliability of the information that they get. This is an expected result because the shared information is read and evaluated by a larger number of people (some of them could be specialists)	0 (0)	3 (17)	2 (11)	3 (17)	7 (39)			
For health professionals								
Possibility to more easily expand their knowledge by obtaining additional scientific information, articles, results of experi- ments, and procedures provided by specialists in an area of interest	0 (0)	3 (17)	1 (6)	2 (11)	9 (50)			
Obtaining information that may help in the treatment, but that is usually omitted in consultations; for example, major doubts, unreliable data the patient may rely upon, reactions, beliefs, etc	0 (0)	1 (6)	3 (17)	2 (11)	9 (50)			
For researchers								
Collecting information or results to help them create new hypotheses and do further research	0 (0)	1 (6)	4 (22)	2 (11)	8 (44)			
For managers								
Improving the provision of health information based on the identification of the most interesting topics for patients and health professionals	0 (0)	1 (6)	4 (22)	2 (11)	8 (44)			

The participants were asked if they believe that this environment can increase the knowledge flow in health environments. They used a 5-point scale to indicate their answer, from 1=never" to 5=always." The results indicate that 22% (4/18), 11% (2/18), and 39% (7/18) of participants think it can increase knowledge flow sometimes, often, and always, respectively. This supports our hypothesis that the integrated MEK-EDIPS tool can increase the knowledge flow in a health scenario.

The participants indicated that the proposed environment has strengths and limitations. The most important strengths were:

- 1. Improvement of doctor-patient interaction.
- 2. Optimization of time in communication with patients. Consequently, this time can be used to better evaluate the patients and choose the best treatments.
- 3. Clarification of professional doubts quickly, thereby reducing the risks of forgetting to look for an answer.
- 4. Support for new doctors who may be reluctant to ask someone with more experience.
- 5. Helping healthy people get data about health, and also act in disease prevention.
- 6. Knowledge dissemination to be made easier, and allows the exchange of ideas and diffusion of scientific knowledge.
- 7. Improvement of the use in home care services.
- 8. Acquiring of knowledge in a more accurate and efficient way, because other professionals check the accuracy of the shared information.

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9. Exchanging of relevant information, especially on rare and serious diseases.

The participants also mentioned several limitations of the proposed environment . These included a possible lack of privacy, inexperience in the use of the system could be a problem to lay users, there is no guarantee that the information sources are reliable, there are technical limitations if the users utilize a smartphone without Android or Windows Phone, and the hardware requirements for using the system could restrict its usage for socioeconomically disadvantaged people.

# Discussion

# **Principal Findings**

In this work, we analyzed how the flow of knowledge occurs in a health care scenario and the benefits that it brings to the people involved. Considering the Medicine 2.0 paradigm, we analyzed the scientific proposals and software apps that could contribute to support this new health care paradigm.

The review of previous work unveiled the current landscape and their main proposals and limitations. This review process also allowed us to build a list of requirements that can be used to guide the design and development of future solutions. Because none of the analyzed solutions supported all of the main

concepts involved in Medicine 2.0, we decided to develop a software environment that did support them.

Using a requirement list, the authors' previous works, and taking advantage of the mobile computing paradigm, we developed a knowledge-sharing environment based on the integration of MEK [21,22] and EDIPS [23]. The suitability of this platform to support social networking, participation, apomediation, collaboration, and openness was evaluated with a sample of health professionals. The results obtained indicate that the proposed tool can be used to support most activities considered by health professionals as important in Medicine 2.0.

A precision rate of 100% and a recall rate of 80% were obtained in the proof of concept performed with the health professionals. Simulated situations for spontaneous collaboration among some of the participants were defined. In all cases, the participants were able to identify the physical location of their collaborator using the positioning service provided by the system. The maximum average error of this positioning service was 6.28 m.

According to the participants', the proposed environment is both usable and useful. Of the total participants, 94% (17/18) agreed that the tool facilitates the knowledge flow among members of a health community (eg, patients, caregivers, doctors, and patients' relatives). Most of them rated the use of the tool as extremely important in such a scenario. Of the total participants, 72% (13/18) thought that the system helps increase the knowledge flow, and 67% (12/18) would like to or would recommend its use. After comparing MEK-EDIPS to the other related apps and proposals, we believe that the integrated MEK-EDIPS tool is a good solution to facilitate the knowledge flow.

Concerning the support for knowledge sharing, the wireless communication mechanism used by the proposed integrated MEK-EDIPS tool is safe. The knowledge is only exchanged among devices running the system. In other words, there is no risk of a piece of knowledge being exchanged indiscriminately with other devices because the devices were accidentally paired by Bluetooth. However, this is an opportunistic collaborative approach, which, based on similar profiles, is characteristic of virally spread information. In this case, we cannot guarantee information reliability, inappropriate, abusive information, or erroneous content may be disseminated on the P2P network. At the same time, this problem can be attenuated by report functionalities and the removal of the content from the devices. Users can infer the accuracy of the information by analyzing the reliability of the information sources or feedback provided by other users.

In a knowledge-sharing network, we have members with different expertise and levels of education acting in different scenarios. Consequently, they have different languages and use specific vocabularies and terms. For example, biomedical researchers, doctors, and patients/lay people have different terms and understandings for the same concept. In our approach, all content can be classified as a concept of taxonomy and related to a set of tags. Moreover, we use different ways to recommend pieces of knowledge, envisioning a decrease in this problem. The different recommendation aspects are reported by Souza et al [21].

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# Limitations

The integrated MEK-EDIPS tool has some limitations. For instance, it is focused on knowledge dissemination in a collaborative way among people involved in a particular treatment. In a health care scenario, there are solutions that incorporate other elements that were not considered in the proposed environment; for example, specialized components of the Internet of Things [38,39] and environmentally assisted living [40,41] paradigms. Solutions addressing computing paradigms usually involve specialized devices, which is exactly what we were trying to avoid.

If the tool is not available for all operating systems, the users have various restrictions regarding the type of device that they can use. The system uses Bluetooth to support the knowledge exchange; therefore, it can do it only if the involved devices are in communication range (iet, the distance between the information provider and the consumer is not more than 10 m).

In the systematic review, we excluded all apps that were not freeware because commercial products were out of the scope of this work. This does not exclude the possibility of finding commercial products similar to the proposed environment.

Concerning the experiments, although we consider our sample to be valid for the previously explained reasons, it is small and may not represent the whole population. Because we based our study on free participation (ie, we invited a large number of health professionals who could freely refuse or accept to participate in our experiment), it is typical to have low participation rate. Usually, a sample based on free participation is more responsible and dedicated. In this initial assessment, we preferred using a small but involved sample.

For the same reason, we did not involve patients in this initial assessment. Considering that we would only do a proof of concept study, the participation of health professionals, who have intensive contact with patients was deemed appropriate. This proposal does not address the social aspects involved in the health scenario or in the knowledge exchange process. For instance, it is common that people with high levels of depression have no desire to interact with other patients or learn new things. Consequently, these people would not take advantage of our solution. Moreover, the proposed solution assumes that the users know how to utilize smartphones. This could represent a problem for elderly people. Related aspects that should also be addressed in the future are information privacy and trustworthiness. The main limitation of this proposal is the lack of a formal evaluation of its impact in a real scenario. However, this is an activity that is currently being addressed.

#### **Conclusions and Future Work**

The proof of concept performed with health professionals gave us an interesting insight into the potential impact and limitations of this proposal. The integrated MEK-EDIPS tool could be used to support the different actors that participate in a health care process and also to make the search and retrieval of scientific knowledge easier. The impact of the system, as a support for people in a Medicine 2.0 scenario, was considered good by the participants in the proof of concept. Participants also considered the proposal as useful and usable. Although the system has

strengths and weaknesses, its limitations have low relevance compared to the advantages that can be provided. Therefore, we envision that the proposed integrated MEK-EDIPS tool is a good first step toward the development of solutions supporting Medicine 2.0. As future work, we will formally evaluate the integrated MEK-EDIPS tool in a real-world scenario to more accurately understand its strengths and weaknesses. Moreover, we will include Wi-Fi support to MEK, as a way of increasing the distance in which a knowledge exchange can be made between 2 devices. Thus, we will extend the coverage area of this tool.

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# **Conflicts of Interest**

None declared.

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# Abbreviations

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**EDIPS:** Easy to Deploy Indoor Positioning System **GQM:** goal, question, metric

http://mhealth.jmir.org/2014/4/e17/

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**IEEE:** Institute of Electrical and Electronics Engineers **MEK:** mobile exchange of knowledge **XML:** extensible markup language

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