

Mobile Personal Health Records: Research Agenda for Applications in Global Health

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Abstract

Health threats, such as HIV/AIDS, maternal health and SARS, are global in nature, as their impact goes beyond the borders of any one nation. This has compelled a global approach to combating these threats, commonly by multinational partnerships among many different types of institutions. Although diffusion of mobile technology in the developing world has been successful, and personal health records on mobile devices (mPHRs) have shown effectiveness in certain health-related contexts, they have not been widely used to address health threats globally. The purpose of this article is to discuss six areas in which research on mPHRs can be used to address global health issues.

1. Introduction

As global interconnectedness increases, addressing health problems from a purely national standpoint becomes inefficient. For example, health problems such as diabetes and obesity in the developed world, and influenza and AIDS in the developing world have reached the point where the problem transcends national boundaries, compelling some level of co-operation among nations, if they are to be effectively addressed. Advances in technology has contributed to the ability to address healthcare problems that are global in scope, harnessing the efforts of an interdisciplinary group such as physicians, technologists and researchers, to benefit people regardless of nationality. Global health, as this area is referred to, entails the cross-national, multi-disciplinary collaboration on health and wellness issues of trans-national interest, in particular issues that impact rural populations, under-developed countries [7,40].

One tool that has successfully been applied to healthcare in some contexts is the Mobile Personal Health Record (mPHR). mPHRs are mobile applications developed to enable the patient to record

and view health- or disease-relevant data [4]. These tools offer much promise in the case of chronic disease management. mPHRs allow the patient to record symptoms, and view and act upon their health data, or choose to share this data with a healthcare worker so they may better assist in providing their services. mPHRs have shown to be successful in various areas, such as diabetes [52], yet a lack of these tools is noticeable in addressing chronic disease problems from a global approach. As much of the developing world implements the wireless technology infrastructure, coupled with the increasing accessibility for mobile devices in these regions, this creates opportunity to deliver healthcare services directly to chronic disease patients all over the world. The potential for these tools is underlined by successes in providing mobile technologies to healthcare workers [11,17,23,55], as well as patient-centric applications using video [49] and SMS [51], yet development and dissemination of mPHRs not been a large focus of global health initiatives. The challenge remains, then, as to what approaches would best facilitate the delivery of mPHRs and support to chronic disease patients in need, so that human health and system-level benefits are achieved? In the interest of guiding development of mPHRs to address these and other global health issues, this article will propose several research questions relevant to this area.

2. Background

2.1. Global health

The global approach to addressing health concerns has arisen from the realization that co-ordination among individual nations is much more effective at addressing problems than individual nations alone. The global diffusion of HIV/AIDS, a popular example, has compelled healthcare systems and governments to adopt a concerted approach in addressing health issues. Other examples of issues

relevant to global health the disease-specific, such as malaria and tuberculosis (TB), or perhaps strengthening services available to pregnant and nursing women, or rural populations in developing nations. As well, the global health approach has not been limited to governments alone. Academics, philanthropists, universities, healthcare organizations, charities, and many other types of individuals and organizations are now contributing to health issues that are global in scope. The concerted approach in addressing these issues are now referred to as *global health*, and entities whose mission is to address one or several of these issues are referred to as Global Health Initiatives (GHIs).

Although there is no universal agreement on the definition of global health, there are some common factors between these definitions. First, global health focuses on issues that are of interest across borders, whether these borders are physical (i.e. between countries) or between disciplines (e.g. healthcare and agriculture). For example, obesity is considered a concern in most developed countries and hence may be considered a global health problem. Second, global health is not only concerned with diseases but rather with the wellness of humans. This makes an issue such as adequate child nutrition a global health issue. Third, global health acknowledges the mutual health related effects between populations. These mutual effects make it essential to focus on under-developed populations because problems arising in these populations can eventually affect other more populations. For example, although SARS started in China, it soon turned into a world problem.

Koplan [40] further characterizes global health in relation to the similar international health and public health concepts. With regard to geographic reach, global health encompasses issues that transcend international boundaries and can impact health in some way. Global cooperation among nations and disciplines are embraced in either preventing or clinically treating these diseases. Finally, a major objective of global health should be health equity among nations.

Despite these conceptual issues, consensus exists as to major global health issues, regardless of national boundaries. Among these are heart disease, diabetes, malaria, HIV/AIDS, tuberculosis, maternal and neonatal issues, as well as others [72].

2.2. Ehealth, mhealth and mPHRs

As technology advances, it is inevitable that new innovations are eventually applied to healthcare. Healthcare practitioners have used radio, television and telephone to healthcare, to enhance opportunities

typically for communicating over long distances. Information and communication technologies (ICTs), however, offer a whole new capability for healthcare. Although telemedicine has been applied to facilitate distance communication among practitioners and patients, they are merely integrated into existing processes, without too much opportunity in changing the process. ICTs, however, give opportunity to change healthcare processes, so that new possibilities and efficiencies may be reached. The goal of ehealth [26] is to achieve these possibilities through the safe application of technology to healthcare, so that gains in performance can be realized by changing its processes.

The advent of mobile devices, infrastructures and associated technologies has predictably led to yet more capabilities for healthcare. The concept of mhealth refers to the use of the various mobile technologies in healthcare, for the same purpose of generating improvement and reaching new capacities. Among the drivers of mhealth are the reduction of cost in mobile devices and services, as well as the dissemination of mobile and wireless infrastructures. In particular, these devices and infrastructures now are more prevalent in the developing world than they are in the developed world [74]. Hence, opportunities exist to address health issues with a global approach can be aided, facilitated, or otherwise implemented through mobile technology.

Applying mobile technologies to combat global health issues has resulted in success. Current ehealth and mhealth applications that address global health issues concern aiding healthcare workers with data collection and patient tracking [43], decision support [3], education and training [66]. Patient centric applications are used to motivate individuals to seek care [65], and adhere to treatment [75].

Regardless of the current successes, evidence concerning the use of mobile personal health records (mPHRs) is underrepresented in the context of global health. Personal health records (PHRs) refer to records that contain health-relevant information about each patient, such as personal information, health history, healthcare utilization, or disease specific symptom data [4]. The data in a PHR is owned by the patient, and the patient may choose to share this data with healthcare providers. Although the term can refer to records regardless of format, they have been implemented electronically (ePHRs [4]), and subsequently on mobile devices (mPHRs [4]). In certain contexts, they have been successful at enhancing communication between patients and healthcare providers [30], and allowing the patient to self-monitor and self-manage their own chronic conditions [12].

3. Discussion on research areas

As previously argued, the potential of mPHRs in addressing global health issues is demonstrated through its success in other contexts, as well as the increasing accessibility of these devices the world over. This unrealized potential reveals opportunity for GHIs to explore the ways in which mPHRs can be applied, in the realization of their stated goals. This section will discuss several research areas, in which knowledge accumulation will facilitate the successful and impactful implementation of mPHRs to address various global health issues. Table 1 (below) summarizes these issues.

3.1. Applications

Perhaps the most obvious direction for global health mPHR research should be the applications of the technology. This area includes, but is not limited to disease-specific applications, applications to increase and enhance service delivery, and applications to link healthcare consumers to healthcare workers, practitioners and services. Many of the global health initiatives (GHIs) seek to address specifically defined issues. Some mainstream examples include: the Global Fund, which supports programs that are specific to HIV, AIDS, TB and malaria [76]; PEPFAR, which exists to “save the lives of those suffering with AIDS” [77], and the GAVI alliance, who seeks to provide vaccines to those without access [27].

Although there are other areas that are being addressed by national government, the potential exists for a global approach to address many other diseases. For example, diabetes is regarded as an epidemic in western society [14,15]. Diabetes is an area that has shown promise in the effectiveness of mPHRs in allowing patients to monitor and change behavior, thereby empowering them to act in a way that benefits their quality of life [71]. Rates of Inflammatory Bowel Diseases are high in developed countries such as Canada, yet are increasingly drawing on healthcare systems of the developing

world [13]. Gi BodyGuard [16] is an application for mobile devices that allows the individual to track data that is clinically relevant to the disease, such as stool qualities, episodes of pain, food, water and medication intake. The data stored in this application can be used by the individual to gain more knowledge of the nature of the disease. The application is free for anybody to use.

Apart from specific diseases, GHIs focus on other issues such as the delivery of healthcare services to those who need it. For example, one of the focuses of the Canadian International Development Agency (CIDA) is to provide for the maternal health needs of women and young children by focusing on nutrition, and improving service delivery at a local level [19]. Rural health initiatives are being conducted by ACCESS Health International, who believes that “all people, no matter where they live, have a right to access high-quality, affordable healthcare” [78].

Aside from purely patient-centric applications, mPHRs can be integrated with electronic medical records (EMRs). EMRs refer to the records that are owned and utilized by doctors, clinic, and health organizations, rather than those owned by the patients [46], stored in electronic form. The EMRs can include demographics, test results, images, symptoms, and other relevant information. When data from the PHR, for instance disease symptom activity, is shared by the patient, it can be represented to the physician in a way that is useful for their ability to provide quality care [25].

The provision of mPHRs is not enough to guarantee benefits. In promoting adoption of mPHRs, several challenges must be addressed by the GHI [35]. Technical issues such as security and interoperability (discussed later), usability [48], and the value of the mPHR to the patient must be addressed. Policy barriers, such as the handling of personal health information, are exacerbated in contexts where international issues are a factor. Literacies for computers, mobile devices, and health, may need attention, especially in developing nations. Failure to address these and other barriers can result in developing mPHRs that patients do not use, rendering them ineffective at their intended purpose.

Research Area	Description
Applications	Disease specific areas, Integration with EMRs/EHRs/, Training
Local Relevance	Negotiating cultural differences, Developing local capacity
Epidemic Intelligence	Disease reporting, Vaccine uptake prevalence, Transnational data transmission, Privacy and security, Global usefulness of data, Authorization, GPS integration
Devices and Infrastructure	Cloud computing applications, wireless transmission standards
Integration	Internationalization, Interoperability, Substitutability, Security, Privacy, Addressing Policy Issues, Platforms and Standards
Global Health Initiatives	Conceptual clarity for “global health”, Tracking Global Health Initiatives, Governance

Table 1: Six research areas for mobile personal health records for global health issues.

In short, the mPHR increases the ability of the patient to collect, analyze and share data associated with diseases and healthcare system utilization. Further benefits are possible when the user shares the data with healthcare practitioners. A multitude of mPHRs exist, each designed with their own purpose, whether it be disease specific, or otherwise. Much like an mPHR, GHIs too are created with specific purposes in mind, which are typically codified in their mission, values and goals. Research continues to be the basis of developing effective tools that will be used by the population, and demonstrating the benefits of interventions similar to mPHRs in their respective contexts [37]. As GHIs rise to the various global health challenges, the mPHR is a potential vehicle for the realization of their goals.

3.2. Local relevance

The local relevance of the various initiatives has been a challenge to GHIs, as many organizations that undertake GHIs are from outside the local region. It is argued that GHIs can be based on values of the culture in which it is originating [73]. In the case of Western society, these may include rationality and efficiency, for examples. These values may not be compatible with the values of the local health system, the healthcare providers, or the patients. It is argued that imposition of these types of system onto populations with incongruent cultures amounts to a form of parochialism, imperialism, domination, and colonialism. In short, homogenous global solutions to healthcare problems may be rendered ineffective due to local social, cultural, and regulatory factors.

These examples underline the ineffectiveness of a monolithic approach to global health. Instead, a complex interplay among global health stakeholders should be expected, characterized by a process involving negotiation and diplomacy [39].

Various mechanisms have been proposed in order to ensure the acceptance of these global health initiatives at a local level. Central to this is the notion that true and lasting partnerships must be formed among global health players. Schools in the global north should partner with institutions in the global south, to both build capacity in the south, and develop an understanding of the context by faculty in the north [60]. As well, increasing capacity to develop and launch technologies in the global south will further ensure that local needs are understood and met by those involved in technology development for patient use, research, and other uses [20,29].

Aside from knowledge, it is important that technological resources are available to the local

populations, contributing to their own capacity to develop and utilize technology and innovations [29]. Various cases have successfully developed HIV interventions for mobile phones in South Africa [20]. Open-source platforms, which do not cost anything to access or change, have played a large role in the capacity of developing nations to develop their own technologies [20].

3.3. Epidemic intelligence

Epidemic outbreaks represent a serious concern for global health. This is because despite an epidemic can start in single remote area, it can spread across borders to threaten communities worldwide. The world has witnessed several epidemic outbreaks in recent years. For example, the outbreak of SARS in 2003 started in China and soon spread infecting more than eight thousand people in seventy three countries [67]. The H1N1 influenza epidemic in 2009 spread to 213 countries resulting in about 17 thousand deaths [68]. Epidemic outbreaks are possible because it may take a long time to collect the indicators of traditional indicator-based surveillance from healthcare facilities and issue a global warning of this epidemic [32]. Therefore, it is necessary to find new methods that allow the rapid gathering and dissemination of epidemic information. Epidemic intelligence systems (EIS) are relatively new expert systems that gather unstructured data (e.g. health related data from different sources) and synthesize these data to provide early warnings of possible epidemic outbreaks [6]. PHRs can represent an important source of epidemic information. For example, health records can provide information about an increase in number of patients suffering from a certain disease, and vaccine failures in dealing with this disease [38]. This information may indicate a possible epidemic outbreak and can be used in issuing early warnings. Although traditional EHRs can provide this information, they have several limitations. First, there is a lack of inter-operability between EHR is different hospitals which may limit EIS capability to synthesize epidemic information. Second, epidemics represent a global threat and hence epidemic information needs to be collected from different countries with different regulations and speaking different languages which may limit the capability of EIS to use this information. Finally, epidemics can start in rural and under developed areas where hospitals lack EHR systems making it impossible to provide epidemic information. Because of these limitations, PHRs represent a more viable source of epidemic information. PHRs are standardized and can be accessed by different healthcare providers and

hence can be used by EIS systems to gather epidemic information. PHRs can be accessed from anywhere, and hence patient information can be entered even in rural areas. Finally, PHRs are owned by the individual and may pose less restrictions on the transport of information across borders.

Despite the possible usefulness of PHR in epidemic intelligence, they impose several technical and social challenges that should be addressed in research. The first challenge is related to the privacy and security of patient information [2]. PHR systems contain sensitive and private health information, which raises the question of how to gather epidemic related information without threatening patient privacy? This question is important because privacy and security represent a real patient concern and may negatively affect individuals' and communities' acceptance and adoption of the use of PHR systems for epidemic intelligence [64]. Furthermore, the usefulness of global health information, and particularly epidemic information depends on the dissemination of information across borders and the synthesis of health information from different countries, hence patient information will move between different jurisdictions with different privacy and security regulations which may further threatens patients' privacy and hinder the adoption of such systems. Therefore, research should focus on how to organize the access to patient information globally. For example, should there be a global body responsible for regulating access to patient information? And how can these regulations be enforced?

Another challenge that is related to access to patient information is how to standardize the interface between EIS and PHR systems. There should be a clear and standardized interface that enables EIS systems to access relevant patients' information and to anonymize this information to avoid threatening patients' privacy and security [54]. This gathered information then needs to be mined for epidemiological information, and therefore appropriate data mining algorithms need to be developed for this purpose[18].

Finally, for surveillance purposes, it is not enough to gather epidemiological information. Geographical information should also be gathered in order to link different patients' information together. For example, it is impossible to measure an increase in flu infection in a certain area without being able to link infection and location together. Traditionally, geographical information systems (GIS) were used to create this link [36,50,59]. Therefore, research should focus on the integration of GIS with PHR to achieve this association and the issues that rise because of this

integration (e.g. how to report patients' locations without threatening their privacy).

3.4. Devices and infrastructure

The main goals of PHR include enabling individuals to access and manage their health information from anywhere and enabling the sharing of data among providers [64]. In order to accomplish these goals, PHR systems require building and maintaining an appropriate and efficient infrastructure capable of storing, processing, and transporting the huge amount of data that characterize PHR systems [24,33,64].

Building the infrastructure for healthcare information systems has been of great interest and concern. This is because of the diversity of the infrastructure required which includes servers, storage, network components, and security infrastructure as well as the huge cost associated with this infrastructure. For example, in 2001, it was recommended to spend fourteen billion dollars in building healthcare information systems infrastructure in USA for ten years [41] which is comparable to required funding in other countries. When we consider global healthcare, the complexity and cost of infrastructure grows exponentially because of the need of the infrastructure to support and process gigantic amount of data (e.g. for epidemical intelligence) and transport data across borders and across systems of different standards and languages. Moreover, the cost of installing the infrastructure may not be available for all countries in the World. For example, the health expenditure of poor African countries is as low as \$12 per person [69], which hinders the development of the appropriate infrastructure.

In order to mitigate the enormous cost associated with healthcare information systems, several solutions have been proposed. The first solution is utilizing cloud computing in healthcare information systems especially by providing healthcare infrastructure as a service (IaaS) [5]. Using cloud computing decreases the cost associated with building and maintaining infrastructure while providing individuals with the capability to access the healthcare system ubiquitously. In the context of PHRs, research should address several areas related to cloud computing. Firstly, what is the appropriate framework for using cloud computing for PHR systems? For example, should private or public clouds be used for PHR systems? And what are the regulations that should govern access to cloud based PHR systems? Another important issue related to cloud computing is how to maintain the privacy and

security of patient data? In cloud computing, data can reside anywhere in the cloud and hence stringent security and privacy policies should be adopted to ensure the security of patient information[42].

Another issue to the infrastructure problem is wireless systems. Mobile communications do not require the expensive infrastructure required by wired communications and hence can assist in the rapid deployment and adoption of PHR systems in rural and under-developed societies. Mobile communications have been successfully used for healthcare and non-healthcare applications in rural areas to overcome infrastructure shortage problem. For example, mobile phones have been used to educate HIV patients in countries like Malawi and Uganda [1]. It has also been used to send radiology images to central systems remotely [28]. For none healthcare applications, mobile payment (m-payment) has been widely adopted in under developed countries such as Kenya [47]. For PHR systems, we expect similar acceptance of the use of mobile technology, not only because of the lack of appropriate infrastructure, but also because of the prior success of mobile applications which will enhance users' attitudes towards using mobile PHR systems.

3.5. Integration

Integration of the PHR into other technologies is widely regarded as a feature that adds value to patients, healthcare practitioners, and healthcare systems [34,53,63]. Specifically, integration facilitates communication between patient and provider, ensures completeness of the medical record, or allows for the portability of data if a patient were to change health providers, for example. Technologies that do not have the ability to freely share data run the risk of creating information silos that can't interact with other systems, creating duplication of work, lack of perspective on external systems, and likely frustration of system users [10]. In the case of mPHRs, they are typically integrated with electronic medical records (EMRs), which are held by a physician or healthcare organization, or electronic health records (EHRs), which are shared among several healthcare organizations. PHRs can be integrated to several degrees with EMRs or EHRs, appropriately determined as required by the application [64]: standalone PHRs do not integrate with any other software; tethered PHRs give limited access to patient information contained in the EMR or EHR, commonly read-only access to certain features; interconnected PHRs allow for a greater two-way communication of data. Although full

integration is often regarded as the ideal situation, it is also the hardest to achieve.

GHIs should be aware of several concepts that contribute to a software's ability to integrate with others systems. Among these are interoperability, substitutability, internationalizability, security and privacy. Interoperability of systems pertain to their ability to communicate with other systems and coordinate work [31]. In addition, mPHRs that are substitutable will allow for greater innovation and sharing of data [44,45]. For example, if a patient adopts one mPHR, and proceeds to enter data into it for some time, it is harder for that patient to switch to another mPHR, even if that other product had features that would allow for greater benefits to the patient. Unless the applications are substitutable, the patient is faced with the decision to continue to use the first mPHR, or to switch to the second mPHR and lose all of their data. Substitutability entails the ability of the user to switch applications freely while continuing to use the same data. This in turn will allow incremental innovation take place, as newer improved products can be adapted more readily by users.

Internationalizability refers to the ability of software to adjust to different language and cultural contexts as needed [61]. This ability would be essential in global health, as GHIs often need to integrate processes beyond single cultures and languages. Other than translating languages, this may expand into currency, weights, measures, and special symbols [61].

Security and privacy, although related, are two distinct concepts. Whereas security is the quality of ensuring that an asset is protected from harm [21], privacy refers to preventing access to information by unauthorized parties [56]. When integrating systems, external parties are provided access to valuable resources. This must be done appropriately, in a way that ensures that only the parties intended can access the system, and that these parties access only the resources necessary. The storage and use of personal health information (PHI) in mPHR is highly regulated in some jurisdictions, therefore these concerns may be amplified [2].

As global health entails both interdisciplinary and intercultural work, the need for integration of mPHRs developed or utilized by GHIs is clear. Existing platforms for technology development, such as OpenMRS [70] and OSCAR [79], and standards for data interchange, such as HL7 [81] and those based on ICD-10 [80] can be taken advantage of.

3.6. Global health initiatives

Important in establishing the benefits of GHIs is the ability to demonstrate that the GHI has had a positive impact on healthcare systems, or patients, in accordance with its stated mission. In interacting with any healthcare system, it cannot be automatically assumed that resources will directly translate to benefits. On the contrary, system level interventions may exacerbate existing problems, lead to system breakdown, potentially impacting the health, wellbeing and safety of the patients and populations involved.

When establishing the benefits of GHIs on a system level, researchers first must define what exactly constitutes a GHI. As previously mentioned, the definition of a Global Health Initiative (GHI) is hard to define, yet they are commonly characterized by their focus on diseases that have a supranational impact, desire to improve healthcare systems in developing nations, or some other healthcare related purpose involving more than one nation. This conceptual uncertainty makes it difficult to define what exactly constitutes a GHI [9,58]. Indeed, several large GHIs, namely the GAVI, Global Fund, World Bank MAP, and PEPFAR comprise of the majority of global health resource expenditure [9,58]. However, there are many smaller GHIs that focus on issues that are more obscure than HIV/AIDS, TB and malaria. These include sleeping sickness [62] and hookworm [57], for examples. Further, many universities offer degrees in Global Health, and as part of the learning, conduct what may be considered small scale GHIs, or participate in partnerships with organizations that do. It would make sense that these would fall under the definition of GHI, but certainty is needed. Further complicating this issue are organizations that exist to transfer knowledge and technology, whose value may be harder to monetize. As existing definitions refer largely to the raising and distribution of funding [8], it is not clear if organizations that provide benefits other than money may be considered GHIs.

To encourage uptake of mPHRs in global health areas, the wider knowledge of the benefits of GHIs must be established. This will require researching the measurable aspects of GHIs, such as treatment uptake, and descriptive elements, such as critical success factors. First, the definition of a GHI must be conceptually clear. This must be done to classify organizations as GHIs, and by extension, to identify resources expended in the interest of global health. As the benefits from providing the more intangible resources are clear, the authors favor a definition that is inclusive to organizations that provide resources other than monetary. Second, studies assessing the

prevalence of GHIs should be continued. As conceptual clarity increases, and more GHIs are identified, the accumulation of knowledge on the impact of GHIs will contribute to understanding GHIs, their critical success factors, and other knowledge useful for their success.

Finally, the configuration of these initiatives with respect to their governance model and strategy must be considered [22]. When conducting partnerships, issues concerning business models, competencies and strategies will drive the organizations that are chosen to collaborate. Strategic issues include the combination of resources and skills, trust among partners, and fit between the goals of each organization, and understanding of local infrastructures.

4. Conclusion

This paper discusses six research areas in which mPHRs are applied to global health issues. These research areas are: applications that are disease-specific and otherwise; ensuring local relevance of initiatives; using mPHRs for the collection of data for epidemic intelligence; innovative devices and infrastructures; integration with other technologies; and issues with global health initiatives that can apply these technologies. Despite the challenges with mPHRs, they remain a viable option for addressing the various global health concerns of today.

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