

## Accessing the Value of Patient Generated Health Data

**Prashad R\***

Faculty of Health, York University, Canada

**\*Corresponding author:** Prashad R reshma.prashad@gmail.com

Faculty of Health, York University, Canada

**Tel:** 416-899-0218**Citation:** Prashad R (2018) Accessing the Value of Patient Generated Health Data. J Hosp Med Manage Vol.4 No.1:1

### Abstract

Chronic illnesses are on the rise in Canada and are expected to rise even further within the next five years. Ineffective management of chronic conditions leads to poor quality of life for patients and even premature death. In addition, chronic illnesses costs the Canadian Healthcare system approximately \$68 billion dollar annually. The effective management of chronic illnesses is crucial for the sustainability of the healthcare system. mHealth is anticipated to be a powerful mechanism in facilitating patient engagement and empowerment. Given the strong uptake of smart phones/other interactive technologies over the last decade, the potential exists for this to be leveraged as a patient engagement tool for the effective management of chronic conditions. This paper seeks to investigate/explore the clinical and financial value of health data generated from mobile devices and other interactive technologies.

**Keywords:** Patient generated health data; Mobile applications; mHealth; Decision making; Predictive analytics

**Received:** January 18, 2018; **Accepted:** January 29, 2018; **Published:** February 25, 2018

### Introduction

Chronic illnesses are a major problem in Canada. According to Statistics Canada, the estimated cost of caring for complex patients is \$68 billion dollars annually [1]. Approximately 52.7 percent of the total cost of healthcare in Canada is spent on chronic illnesses [1]. Ineffective management of chronic conditions can have major consequences such as poor quality of life for the patients' affected, premature death and increased healthcare spending. Patient engagement and empowerment are cited as effective ways of promoting self-management, thereby preventing exacerbations and reducing costs. Accordingly, the proactive management of chronically ill patients is vital for their engagement and empowerment.

Preliminary evidence shows [2] that patient self-management leads to better health outcomes for complex patients. mHealth is a powerful mechanism to facilitate patient engagement and empowerment. Chronically ill patients usually receive care in ambulatory settings by primary care providers; however due to the rise in chronic illnesses the primary care providers' role is shifting to one of facilitator. This changes expectations about the management of chronic illnesses from a provider centric model

to a patient focused model. To facilitate clinicians' proactive management of chronically ill patients, data is needed for their decision making about potential changes to treatment plans including medication changes and follow up visits.

The usage of technology has increased significantly in the healthcare industry. However, the data has been primarily collected by healthcare professionals at the point of care. Given the growing usage of technology by patients, there are significant benefits that can be harnessed from the data collected by patients. Currently, care is provided based on the data collected from episodic interactions with care providers; this data does not accurately represent the patients' health status. In many cases, it was shown that several interactions with care providers were required before a patient received the appropriate care. This is both costly to the healthcare system and results in unnecessary complications that affect a patient's quality of life. The implications of not utilizing patient-generated data have a significant impact on both clinical and financial outcomes. In terms of clinical outcomes, patients are not benefitting from the proactive collection of data that provides clinicians with a better picture of their health status. The collection of patient's data over a longer period is shown to help providers gain a

better understanding of the patients' health status and facilitates proactive care which results in a better quality of life for patients.

In terms of financial outcomes, healthcare organizations are not benefitting from the collection and utilization of patient-generated data. Proactive data collection can facilitate care in the community versus costly care in acute care organizations that results when patients' health status deteriorate significantly (due to a lack of proactive care) and cannot be handled in the community. There is potential for significant cost savings as a result of proactive management of patients; this is particularly the case for patients with multiple chronic conditions. In 2005-2008, the cost of caring for patients with multiple chronic diseases was \$192.8 billion, many of these patients can benefit significantly from proactive management of their conditions which can result in reductions in acute care readmissions. Chronic diseases have a profound impact on society, both in terms of health outcomes and economic burden.

### Problem statement

There has been a significant impact on both financial and human resources as a result of the millions of Canadians affected by chronic illnesses. Therefore, significant efforts have been undertaken by key stakeholders over the last decade to explore the best ways to provide proactive and ongoing care and engage and empower patients' to become active participants in their own care. The engagement and empowerment of complex patients is essential for improvement in the quality of their lives and the reduction of unnecessary healthcare spending. The current engagement and empowerment approaches undertaken are narrow in their focus; only episodic care data is collected at the point of care. Episodic care data does not provide a complete picture of the patients' health status nor does it provide the opportunity for their care providers to be proactive in monitoring their health. Discussed in this paper are new approaches to patient engagement and empowerment utilizing mHealth and other interactive technologies to capture patient generated health data to facilitate this.

### Aims of this research

Through the use of a scoping review, this paper will examine whether patient generated health data (PGHD) has the value (clinical and financial) to positively influence the management of chronic conditions.

### Research questions

The research questions arose from a scan of the literature to determine whether clinicians can utilize patient generated health data to proactively engage and empower chronically ill patients to manage their illnesses. The research questions were: what is patient generated health data? Is data generated from interactive technologies (devices such as Fitbit, iPhone Apps, Apple watch Apps, other Android devices Apps) credible? Is there value (clinical and financial) in collecting patient generated health data? Can the collection of patient generated health data promote self-management through patient engagement and empowerment?

## Scoping Review Methodology

Through the use of the Arksey and O'Malley scoping review methodology [3], this paper will summarize and report the relevant findings on the value of patient generated health data and identify future research directions. The scoping review approach was chosen as the research topic is context specific, this approach allows for the relevant literature from multiple sources to be easily identified. The scoping review approach refines the literature results-it identifies relevant ones and ignores non-relevant ones [3].

### Scoping review findings

**What is patient generated health data?:** There was a lack of consensus in the literature on the definition of Patient Generated Health Data (PGHD). According to Kim et al. [2], the Office of the National Coordinator for Health Information Technology defined PGHD as follows "health-related data created and recorded by or from patients outside of the clinical setting". The following were commonly cited as "health data" activity levels, vital signs, symptoms and medication effects [3,4]. These were also cited as commonly collected "health data" in clinical settings; however one author extended this definition to include dietary intake. However, it was noted that given the proliferation of mobile devices, applications and other interactive technologies that this data set can increase significantly over the next few years. Additionally, some sources [5] cite that the amount and frequency of the data captured will significantly increase as well.

**Is data generated from mobile devices and other interactive technologies credible?:** Some sources cited [2,5] that there was a "reasonable" amount of credibility in the data captured by patients through their devices and other interactive technologies. Data sets such as heart rate, activity levels and glucose levels were fairly accurate and could be of benefit to clinicians. However, there are data quality concerns with the accuracy of data sets such as vital signs and medication effects that will require significant improvements through collaborations with clinicians to ensure that nuances such as age and gender is considered when flagging "abnormal" to patients. Some of the challenges in this domain were attributed to the mobile devices and interactive technologies applications or software as opposed to the hardware.

**Is there value (clinical and financial) in collecting patient generated health data?:** Some sources cited [2,5] that there was a "reasonable" amount of value or "anticipated value" in capturing patients' clinical data from mobile devices and other interactive technologies; however it was noted that the challenges outlined above in terms of the nuances about age and gender will need to be resolved before optimal benefits can be realized from some of the data sets. Contrary to the confidence in clinical data, there is more cynicism around the perceived financial value. Many of the sources cited [5,6] the "lack of evidence" as the basis for their cynicism. They argued that majority of the positive evidence reported thus far has been from pilot studies; therefore further research is necessary beyond the pilot studies to confirm consistent value. They also cited that a framework or guidelines

is necessary to define what constitutes financial benefits. They argued that once the challenges (outlined above) were resolved they anticipate that significant financial benefits can be realized.

**Can the collection of patient generated health data promote self-management through engagement and empowerment?:**

There was a high level of agreement that patient generated health data can promote self-management as a result of patient engagement and empowerment, however it was noted that there has to be a two way data exchange between patients and their providers and vice versa between providers and their patients for optimal results to be realized. It was noted that healthcare providers need to be transparent with patients before optimal results can be realized. This includes patients' having the ability to access their health information, it was stated that these tools have the potential to enhance patients decision making capacity.

## Discussions

The findings from this review have implications for all stakeholders including clinicians, patients, their families and researchers.

### Opportunities and challenges

**Patients and their caregiver's opportunities: Empower patients to better manage their health:** Patient generated health data has a significant potential to empower patients and their caregivers to better manage their health. Mobile devices and other interactive technologies can be utilized by patients to self-manage their chronic conditions; however it is necessary that patients are educated by their care providers on the nuances (in relation to age and gender) of the results and their relevance to them.

Some pilot studies demonstrated positive results in utilizing mobile devices to educate, engage and empower patients with diabetes to manage their blood sugar levels. For example, patients that submitted their glucose data through a mobile phone application and was monitored by a group of clinicians and researchers demonstrated significant confidence in managing their glucose levels over a longer period of time compared to those that did not participate in the study [6]. The goal was to empower patients to self-manage their chronic conditions and collaborate with clinicians when necessary to prevent exacerbations which can lead to costly emergency department visits and hospital admissions.

**Supports shared decision making:** Patient health data generated through mobile devices and other interactive technologies has the ability to empower patients and their caregivers to become active participants in decision making processes about their care, their values and preferences. Patients and their caregivers can work collaboratively with their providers to make decisions about their care, for example patients can determine whether it is more convenient for them to report data to their providers on a weekly basis or monthly basis depending on how their self-management is working for them. Patients can also provide feedback to providers on how a certain medication is working and whether they prefer one over the other given their reactions. In addition to the decision making about care, patient can also

utilize PGHD to express their values and preferences to their care providers. One study results revealed that patients had a specific value around the use of blood products in their care that was important to them. Patients can also express their religious preferences around diet, which has an impact on the type of treatment they receive for a specific illness.

**Provides clinicians with a better understanding of patient's health over a longer period of time:**

The utilization of mobile devices and other interactive technologies can provide clinicians with the ability to track a patient's health status over longer duration due to the ease of capturing the data. This is of importance especially for chronically ill patients; the data collected over a longer period can help a clinician that may be interested in tracking a patient's cholesterol over a longer period of time to determine the impact of a prescribed medication. The clinician maybe interested in knowing whether a specific dosage is effective or needs to be adjusted. The capture and sharing of patient generated health data provides better opportunities to detect smaller variances in patients' biometric data as opposed to data generated at the point of care that mostly reflects the patients' health status at that time. Many sources cited [2,5,6] this as the most promising area of benefit to both patients and providers alike.

**Reduce the time, effort and costs associated with visiting a clinician in person:**

Improved efficiency was cited as a significant benefit of PGHD, in some of the pilot studies patients reported high satisfaction rates with having the ability to have data being auto-generated and submitted from their mobile devices and other interactive devices to their clinician's health information systems. Patients cited the reduction in the time and costs associated with visiting a clinician in person as a significant incentive for continuing to utilize this type of service. Patients also expressed satisfaction with the ease of use in comparison to having to manually record the data and then submit it to their clinicians. Patients noted that they were significantly more motivated with using the mobile devices and other interactive technologies.

**Patients and caregivers challenges: High rates of abandonment:**

One of the challenges cited was long term non-compliance with data submissions. High rates of abandonment were reported in some pilot studies; however the consensus appears to be skewed towards higher rates of abandonment for acute illnesses versus chronic illnesses. Researchers expressed concerns about this given the significant upfront investments by clinicians to facilitate patients' automatic submission of data to their health information systems. The literature review revealed that more studies are needed in this area to confirm the accuracy of this finding.

**Concerns about data privacy and security:** One of the additional challenges in achieving buy in from patients are concerns about the privacy and security of their data. Patients are concerned about where their data is stored, who has access to it, and how secure the transmission of their data is between their devices and their clinicians receiving information systems. Both clinicians and researchers acknowledge patients concerns about this and

noted that technologies have progressed significantly in ensuring secure data transmission. However, it was recommended that clinicians provide education to patients on this prior to enrolling them in these types of programs. The goal is to be transparent with patients to alleviate some of their anxieties about this.

**Lack of technology or low digital literacy levels:** Another concern cited by both clinicians and researchers is the lack of technology utilization in some groups of chronically ill patients. The lack of technology utilization was attributed to either age or a lack of resources to afford the technologies required to participate in these types of programs. Additionally a lack of or low digital literacy levels were noted in some patient groups, this was expressed as a concern due to the inability to accurately interpret instructions provided. It was recommended that clinicians offer mobile devices and other interactive technologies if possible to support patients' participation in these programs, as it may be less costly in the long term if patients participate in them versus in person visits. It was also recommended that patients with a lack of or digital literacy levels be trained to utilize the technologies to ensure their equitable participation if they are interested in doing so.

**Clinicians' opportunities: Enable clinicians to make timelier and more informed decisions:** Health data generated from mobile devices and other interactive technologies is cited as a potentially powerful tool in enabling clinicians to make timelier and more informed decisions. Comparatively episodic data currently collected by clinicians do not provide the opportunity for timely decisions because the patient needs to be present for that data set to be generated. On the other hand, patients do not need to be present for data to be generated from a mobile device or other interactive technologies. The faster access to the patient's data can facilitate clinicians' ability to make timelier and more informed decisions. Additionally, the volume of data generated from mobile devices and other interactive technologies enables clinicians to have a more comprehensive view of the patients' health status, thereby facilitating more informed decisions. This also has the potential to reduce the amount of time spent waiting for additional testing, which causes delays and inefficient use of clinician's time.

**The creation of individual treatment plans:** The accessibility to a higher volume and larger data sets has the potential to facilitate the creation of individual and customized patient treatment plans. Clinicians can benefit from improved collaboration with patients, thus allowing for a better understanding of the patients' health status and personal circumstances. This can facilitate the creation of a customized treatment plan that is more favorable to the patient's lifestyle and personal circumstances. Improvements in patients' compliance were observed when customized treatment plans were created for some patient groups.

**Reduced emergency department visits and hospital readmissions:** Health data generated from mobile devices and other interactive technologies were attributed to reductions in emergency department visits and hospital readmissions. This was a result of proactive management of the patients' conditions by their care providers and increased self-management by patients.

Patients' ability to self-manage was previously proven to reduce emergency department visits and hospital readmissions, however this was enhanced by the utilization of mobile devices and other interactive technologies. Data generated from mobile devices and other interactive technologies provides clinicians with additional data to proactively manage their patients, thereby reducing the frequency and severity of exacerbations.

**Reduced healthcare costs:** Patient generated health data enables clinicians to provide proactive care; this is shown to reduce the frequency and severity of exacerbations. This decline in exacerbations can result in millions of dollars of savings to the healthcare system [1].

**Clinicians' challenges: Potential negative impact on clinical workflows:** There are many benefits to the utilization of health data generated from mobile devices and other interactive technologies; however despite this, there are some challenges as well. One of the challenges seen in pilot studies is the negative impact on clinical workflows. Patient generated data adds a large volume of data to be reviewed by clinicians; this can negatively impact their workflows due to the time required to evaluate the large data sets.

**Management of patient expectations:** One of the other concerns about utilizing mobile technologies and other interactive devices is the management of patient's expectations. Patients' expectations can be heightened given the capacity to submit their data 24 hours per day and 7 days per week, this has proven to be challenging for many providers. As a result, researchers have recommended that clinicians set expectations with their patients prior to their involvement in these types of programs. However, clinicians will need to explain the delicate balance between an emergency and a non-emergency to patients to ensure that this does not become burdensome to them.

**Potential for increased liability:** Given the delicate balance between an emergency and a non-emergency, clinicians are concerned about the potential for increased liability due to adverse events. This is precisely why researchers recommend that clinicians inform their patients in advance about availability expectations. Additionally, it is also recommended that clinicians educate patients about the symptoms and the situations in which they need to seek the help of emergency services. Clinicians are also advised to inform patients of this in writing to prevent misunderstandings.

## Conclusions

There are many benefits that can be realized through the utilization of health data generated from mobile devices and other interactive technologies. However, there is currently limited evidence to support the utilization of PGHD for the proactive management of chronic conditions, patient engagement and reductions of healthcare costs. Despite the inconclusive evidence that currently exists, the implications of not utilizing patient-generated data can have a significant impact on both clinical and financial outcomes. In terms of clinical outcomes, patients are not benefitting from the proactive collection of data that

can provide their clinicians with a better picture of their health status. The collection of a patient's data over a longer period is shown to help providers gain a better understanding of the patients' health status and facilitates proactive care which results in a better quality of life for patients.

In terms of financial outcomes, healthcare organizations are not benefitting from the collection and utilization of PGHD. Proactive data collection can facilitate care in the community versus costly care in acute care organizations that results when patients'

health status deteriorate significantly and cannot be handled in the community. There is potential for significant cost savings as a result of proactive management of chronically ill patients. Chronic diseases have a profound impact on society, both in terms of health outcomes and the economic burden. Provider-centric processes that capture episodic care data in organizations should be transformed to consumer-centric processes that capture patients care data both across the continuum of care and from external sources such as from mobile devices and other interactive health technologies.

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