

## Patient-Generated Health Data: Opportunities and Challenges

### Introduction

It is no secret that the emergence of the digital age has influenced the way humans interact with one another. This pertains not only to social interactions amongst friends and family, but also to historically less balanced relationships, such as physician-client interactions. In recent years, there has been a growing interest from the public to use electronic and digital tools for the purposes of adding, collecting, managing, and monitoring information related to one's health. This self-collected information is referred to as patient-generated health data (PGHD). Innovative digital and electronic data collection tools have pushed the focus of health care towards patient-centered care, in order to improve the safety, quality, and efficiency of health care delivery.<sup>1-3</sup>

Patient-generated health data goes by a variety of different names including “user-generated data”, “person-generated data” and “patient-generated health information”. For the purposes of this paper, the main term to be used will be patient-generated health data. While no official definition of patient-generated data exists, a widely used definition comes from The Office of the National Coordinator for Health Information Technology (ONC), which defines patient-generated health data as “health-related data created, recorded, or gathered by or from patients (or family members or other caregivers) to help address a health concern”.<sup>4</sup>

Health information of patient were traditionally created by medical health professions (e.g. physicians) and written down in medical records. These medical professionals made their decisions based on information they received from patients during medical appointments and various health assessments. However, while health information may have been obtained from the patient, it reflected the voices of the medical professional, rather than the patient.<sup>2,5</sup>

PGHD differs from the traditional method of health data collection in many respects. First PGHD is data that is created or generated by patients, or their family members or caregivers.<sup>3</sup> Second, PGHD often represents real-time data – information regarding their immediate, current health state.<sup>4,5</sup> Third, the methods of collection (handwritten notes, medical devices, apps, wearables, health trackers, home medical devices) typically occur outside the scope of clinics and medical appointments.<sup>5</sup>

Patients have long since been considered experts of their own health, and are able to provide a more comprehensive history of their health. This is distinct from the traditional mode of data collection by physicians, which represents a snapshot taken at that particular point in time (i.e. during the appointment).<sup>3,4,5</sup> Evidence has demonstrated that the use of PGHD leads to increased patient engagement and improved communication between physicians and patients.<sup>4,5</sup> This creates a more balanced relationship amongst the two parties and results in greater patient satisfaction.<sup>4,5</sup> Improvements in the way physicians and their patients interact have the potential to benefit health care systems by improving health outcomes and reducing health care costs, which would ultimately result in a healthier population.<sup>4</sup> Data sharing amongst patients and their health care providers can lead to better decision-making, creation of care plans tailored more closely to the individual patient, more personalized care feedback, and patients taking control of their health.<sup>2-7</sup>

## What is captured by Patient-Generated Data?

Before getting into the details of PGHD, it is important to understand the kind of information it encompasses. Patient-generated health data includes any information that is produced by the patient his or herself (or by their caregiver). Ultimately, the amount of information a patient can generate is endless and does not necessarily include information that represents health in the traditional biomedical sense. The information that could be captured include, but is not limited to, clinical data (e.g. blood pressure, insulin levels), medication history, other health history (e.g. past and current diagnoses and symptoms, prior health assessment results, previously administered health tests), lifestyle choices such as activity levels (e.g. number steps taken per day) and diet (e.g. calories consume), demographic information (e.g. age, ethnicity), biometrics (e.g. fingerprints, DNA), and social and cognitive data (e.g. changes in mood, mental health).<sup>1,3</sup> As long as the patient produces the information and feels that the information being collected is relevant to their health, it is considered to be PGHD.

One form of PGHD that is regularly collected across many countries (e.g. New Zealand, United Kingdom, Sweden, Netherlands) are patient reported experiences measures (PREMs) and patient reported outcome measures (PROMs).<sup>8</sup> The Canadian Institute of Health Information defines PROMs as “measurement instruments that patients complete to provide information on aspects of their health status that are relevant to their quality of life, including symptoms, functionality and physical, mental and social health”.<sup>9</sup> These measurement tools can be generic or disease-specific. PROMs are used to understand the effect different health care services and treatments have on a patient’s health status or quality of life.<sup>9</sup> PREMs, on the other hands, are measurement instruments that help capture the perception patients have about their health care and its services.<sup>1</sup> These tools are usually in the form of surveys and questionnaires, available in an online or paper-based format, that are administered to patients at health care institutions (e.g. hospitals, clinics).

## Methods of Collection

Due the advent of the internet, mobile apps, and various other technologies and digital tools, there are more ways than ever before to collect, store, share, and track patient-generated health and wellness data.<sup>1,10</sup> Such technologies and digital tools include mobile apps, wearables, connected devices, and personal health records.

**Surveys and Questionnaires.** As previously mentioned, PGHD can be collected via surveys and questionnaires. This method is widely used in health care systems and has expanded to include online-based formats in addition to paper-based ones. As the information collected by surveys come directly from patients, this constitutes as patient-generated health data. Such surveys and questionnaires are often used to collect PREMs and PROMs. These tools have been designed with the patient in mind, but they are variable in whether they included patient involvement. Many tools possibly reflect what health care institutions and researchers consider important. This does not necessarily mean the information being collected is not important or insightful, and in fact, there are many tools that have been validated by patient populations. However, more patient involvement in the design and development of such tools could provide an opportunity to make these tools better. Further discussions on the opportunities related to PGHD will be presented later in this paper.

**Mobile Apps.** Worldwide, individuals have access to a wide range of mobile apps, and the health information these mobile apps collect are variable. One example is Apple's Health App, which allows individuals to track information about their activity levels (e.g. steps taken and distance travelled), sleeping habits (e.g. what time one wakes up or goes to bed), and nutrition (e.g. what percentage of your diet comes from carbs).<sup>11</sup> Such information (such as distance travelled) is collected automatically and does not require any effort on the part of the individual, making it not only convenient but easy.<sup>4,11</sup> Other information must be manually recorded, such as diet information (e.g. water and food intake, calories consumed), and changes in your blood pressure or insulin levels.<sup>2</sup> Depending on the app and the related technology available, this information can be uploaded (e.g. incorporated into an EMR) and made available to one's health care provider. Individuals can also show allow their provider to view the information straight from the app itself, by bringing their device along to appointments. These self-monitoring devices enable patients not only to track progress and share information that may otherwise be missed between doctor's visits, but also helps them to self-manage their health.<sup>4,10</sup>

**Connected Devices.** There are also connected medical devices, such as home monitoring equipment that can track and keep records patient results. Like information collected from mobile apps, the results from connected medical devices could easily be sent to health care providers via Bluetooth technology or be stored manually for one's own individual purpose.<sup>5,10</sup> These connected devices include equipment such as blood pressure monitors. Like mobile apps, connected medical devices allow patients to self-monitor their health and could acts as a medium that automatically stores information.

**Wearables.** Wearables can include health/fitness trackers such as FitBit, or watches like Samsung Gear. Wearable technology includes sensory components that can be used to track physiological information such as heart rate. This information can consequently be used to diagnose, manage, analyze, and treat diseases. Wearables are designed to be small, and unobtrusive in everyday life, making them ideal to store information. Additionally, much like mobile apps, wearables includes the element of convenience for everyday use.<sup>5</sup>

**Personal Records.** Another way to electronically store and share PGHD is by using personal records. The two most predominant forms are personal health records (PHRs), owned by the patient; and electronic health records (EHRs), owned by a health care institution (such as hospitals). Many PHRs give patients the ability to store their data, as well as share it. This permits individuals to maintain ownership of their own data, but still share the very same information with health care providers.<sup>5</sup> When patients are not owners of their data, there are existing methods that allow them to view some of their information, though this is not a standard practice at all institutions. It is possible for patients to view their information via patient portals, which are online websites that gives patients access to their personal health information. Patient portals can be accessed using a username and a password.<sup>4</sup>

## Benefits and Opportunities

Patient-generated health data is not a new phenomenon. Individuals have always collected information about their health, whether it included writing down symptoms, keeping a list of their medications, or tracking what they eat.<sup>4</sup> What has changed is public interest in PGHD and a desire to incorporate this data to reflect that interest. Using PGHD presents various opportunities and challenges, which will be discussed below. Matters are further complicated by the involvement of many stakeholders. While the data is generated by the patients, it affects more than just the patients themselves. It affects the health

care providers who make health care decisions; health care institutes who decide to use PGHD as part of their health care delivery; developers and vendors who design and produce technology and devices to aggregate and disseminate PGHD; researchers who wish to use PGHD for their projects and create best practices around collection and dissemination; and policy-makers charged with creating regulations about security, privacy, and confidentiality about personal health information. The involvement of so many key players – and it *is* important to have all these players involved – creates numerous opportunities for PGHD, but also generates many challenges.

**Research and Data Donation.** There is an opportunity for patients to engage in “data donation”, a concept whereby patients provide permission for their data to be used for research purposes.<sup>12</sup> It is possible for the PGHD of numerous individuals to be stored in databases, which can then be made accessible to researchers to use for their projects. Such databases could be used to recruit potential participants for studies, or the data could simply be analyzed to draw different conclusions and support various hypotheses.<sup>12</sup> It is possible that such methods could prove to be more efficient than traditional ways of seeking out participants for studies.<sup>4</sup> In order to be a successful endeavor, it is vital to understand what patients’ expectations are when they decide to donate their data and share it with researchers and/or clinicians.<sup>12</sup> Once expectations are identified, key players need to be engaged and work collaboratively to build upon those expectations. This may include developing models and frameworks based on evidence-based best practices, as well as introducing legislation to ensure patient confidentiality and privacy. Such a scenario would entail research and health care institutions, patients, clinicians and researchers, and policy-makers to work together to ensure everyone’s interests are taken into account and determine the most successful approach.

**Health Care Providers and Clinical Decision-Making.** Using PGHD during the course of everyday health care delivery allows users (whether they are patients or health care providers) to capture a more complete picture of an individual’s health.<sup>1,3</sup> The potential of incorporating PGHD into medical records would provide more comprehensive health assessments of patients, which can ultimately aid in physician decision-making.<sup>10,12</sup> Studies have looked at the impact that PGHD data has on clinical trials, with evidence suggesting that these patient-focused studies can lead to new and unique insights into health and disease that can help inform clinical decision-making.<sup>1</sup> This could prompt changes or adjustments to current care plans and help create or lead to more appropriate treatment plans. Additionally, the sharing of this information between health care providers and patients can lead to earlier diagnoses, more timely interventions, and an increase in patient adherence to treatment plans.<sup>5</sup> Using PGHD essentially aids health care providers to fill in the gaps and include information that they may have missed between doctor’s visits – thus improving the accuracy of the data stored in a patient’s medical record.<sup>1,4,10</sup> Allowing physicians to capture this extra information also offers a more holistic view of a patient’s health, which can ultimately improve health outcomes and a patient’s quality of life over time.<sup>3,4</sup>

**Care Coordination.** Sharing PGHD with health care providers can help reduce duplication of tests, aid in the coordination of health care services, and help mitigate safety risks. For example, health care providers could have immediate information about your allergies; and one’s current medication regime, which can reduce adverse pharmacological interactions and allow for quicker comparison amongst medications. There is a public health benefit of using PGHD as a part of every day delivery, as research has demonstrated that it can help facilitate prevention and promotion strategies.<sup>1,2</sup> This can ultimately result in improved health outcomes, and reduced health care costs.<sup>1-5,10</sup>

**Patients.** PGHD intake is not only useful for physicians, health institutions, and health systems; it is useful for the patient. Evidence has demonstrated the use of PGHD leads to increased physician-patient communication, patient engagement, patient satisfaction, and patient experience.<sup>5</sup> By using digital tools to capture and share their data, patients become more empowered and are better able to manage their own health.<sup>4,5</sup> They can engage in a process of self-managing and self-monitor their health, including writing down and tracking changes in their symptoms, and other health-related outcomes (e.g. blood pressure, insulin levels).<sup>3</sup> By playing a more active role in their health care, patients can also improve their health literacy and gain a better understanding of all aspects related to their health.<sup>1,3,4,5</sup> The sharing of health information can also help encourage a process of shared decision making between physicians and patients.<sup>4</sup> If a patient better understands his or her own health and is able to engage in the decision-making process, they are more likely to adhere to treatment plans.<sup>5</sup>

**Multiple Tools.** Above, we discussed the various methods of collection for PGHD. With such a wide range of possibilities, patients are able to choose a platform that they are most comfortable with using. Convenience and simplicity make a huge difference and it is important for these technological and digital tools to be as user-friendly as possible. Evidence has demonstrated the benefit of using some of these tools. For example, there are some mobile health apps that have been approved for medical use, and evidence has demonstrated that the use of mobile apps leads to increased patient engagement and improved health outcomes.<sup>4</sup> The takeaway here is that there is a real opportunity for the use of digital tools (like mobile apps) for PGHD collection. However, it should be kept in mind that appropriate regulatory bodies should approve the use of these technologies, that patient populations validate them, and that they demonstrate their effectiveness in academic studies.<sup>5</sup>

## Challenges

While there are many opportune uses of PGHD, they do not come without their challenges. As mentioned above, PGHD affects more than just patients, and the involvement of so many key parties creates numerous challenges. Many of these key players are also concerned about many of the same issues, which will be discussed at length below.

**Standardization.** While incorporating PGHD into patients' medical records creates an opportunity to provide a more comprehensive and holistic picture of one's health, it does not come without barriers. As previously mentioned, PGHD can be collected from numerous digital tools, but finding ways to incorporate data from multiple sources could prove to be difficult. There is challenge in as to how large volumes of information from multiple sources could be appropriately merged and integrated. These various technologies would have very different interoperability and security functions, would present and collect data in different ways, and would vary in their terminology of the health language.<sup>12,13</sup> Furthermore, it is a consuming process to look through the existing technological and digital tools and understand the kinds of data they collect. After all, there are now hundreds of thousands of tools that exist, and that number is only growing. Matters are further complicated by the fact that these large pools of data need to align with physician and researcher interests to ensure that the data being collected is meaningful and actionable. Finally, these tools need to be validated for use.<sup>12</sup> Many of the aforementioned difficulties are related to the lack of technical and legal standardization processes related to PGHD, and the lack of such processes affect all parties involved.<sup>13</sup>

**Data Ownership.** One of the most common and important challenge of PGHD is the idea of data ownership. Essentially, who owns the data? It sounds like a simple question, but the reality is ownership

of PGHD is not very clear, and different key players have different opinions.<sup>13</sup> Do patients (or their caregivers) own their own data? Do health care institutions who house the data own them? Or do vendors, who create the resource/infrastructure and allow the information to be collected in the first place, own the data? In addition to the question of data ownership, it serves to question what can be done with that data. Could, for instance, vendors sell patient-generated data to hospitals and clinics so providers can access their clients' information? Could vendors charge patients to use their infrastructure or view their own data? Furthermore, if data is transferred from one party to another or from one system to another (e.g. from a patient to an EHR system), then who is the rightful owner of the data? The patient who inputs his or her own data, the developer of the EHR system, the owner (i.e. the hospital) of the systems, or even varying combinations of these parties?<sup>5</sup>

Since there are such differing views as to who owns PGHD, and who has the right to access, share, and use it, it becomes challenging to create consistent regulations in this area.<sup>4</sup> This poses a huge challenge for policymakers and governments, who need to keep the interests of all involved parties in mind.

**Patients.** Patients have serious and very valid concerns related to privacy, security, and confidentiality. Such concerns include the reliability of their device/digital tool to hold their information but also distribute it when necessary. They are rightly concerned about third party access to their information or secondary use of their information – especially without their consent and permission – which may deter them from using such digital tools, no matter how great the benefit.<sup>10</sup> Many patients are not against having their information used for other purposes (such as research) but would like to be aware of what their data is being used for, provide consent or permission for use of their data, and have certain identifying information removed.

Patients require assurances that their information remains confidential and is only being used and accessed by those who have permission.<sup>4</sup> This could include being able to track their own data as it moves from one system to another, having the ability to view who has accessed and seen their information, tracking any changes or adjustments that have been made by other parties, setting up patient authorization rules before sharing information with others, and having authentication methods to view the information themselves.<sup>3,4</sup> However, while the risks may lessen by putting some of these measures in place, some risks will still remain. For example, there will always be authentication issues no matter what method of collection you decide to use (wearables, mobile apps, online digital tools), including having your identity stolen, your device stolen, or having your information hacked – which in the digital world, are very real and plausible scenarios.<sup>4</sup> Since these are very real and persistent issues, these challenges may deter patients from sharing, collecting, or storing their health information on digital health tools, or giving permission to others to do so.<sup>6,10,12</sup>

In addition to who will have access to their data, and whether it has been stored and shared securely, patients have further concerns with what will be done with their data. The information that they collect needs to be meaningful not only for health care providers, but also for themselves. Patients want to ensure that they are collecting their data for a purposeful reason. It is important for patients to know their information is valued, that whoever received them (e.g. health care providers, researchers) have seen their information and are making their decisions and/or conclusions based on that information.<sup>1,3,5,10,13</sup>

**Multiple Platforms.** Earlier, we discussed the various tools that patients could use for their PGHD intake. While the variety of choices provide an opportunity for patients to choose platforms they are most comfortable with, the platforms themselves come with their own challenges. For example, while patient

portals enable patients to view certain health information, the platform does not permit patients to enter their own data. Many digital tools and mobile apps are not user-friendly and may require training individuals on how to use them.<sup>3</sup> These devices could also contain issues such as complicated health terminology or even varying health terminology between different devices. Furthermore, it is likely that all these tools can be integrated into the various health information systems used by health care institutions. Finally, data privacy rules would differ between these tools, making the sharing of this information more complicated.<sup>3,10</sup>

*Mobile Apps.* While there are many technological and digital tools, this paper will be taking a closer look into mobile devices as an example to further illustrate the above concerns. In 2016 alone, there were about 165,000 health related mobile apps available in the iOS and Android platforms.<sup>5</sup> It begs the question – which app should individuals be using and for what purpose? Furthermore, because there are so many, and there is a real lack of regulation for apps – some of them may actually prove to cause more harm than good. Furthermore, research has demonstrated that there is a high rate of device-abandonment, meaning consumers eventually stop using the digital tool.<sup>12</sup> Even if a patient decides to use a certain mobile app – there is no guarantee that researchers and health care providers would accept the results of these apps, especially when there are no standardization procedures in affect and they need to take liability issues into consideration.<sup>3,13</sup> Aside from self-monitoring purposes, there is some debate of whether or not using mobile apps is helpful. In order to be truly useful, these apps need to be user-friendly and there needs to be a method of integrating the PGHD collected into hospital systems and patient records.<sup>5</sup>

**Access.** Throughout this paper, there has been an emphasis on the potential of PGHD to be captured using various health technologies. However, it is important to keep in mind that not everyone are able to acquire these technologies.<sup>4</sup> Technological and digital devices are costly and additional health and wellness tools could end up being additional costs (e.g. paying for certain mobile health apps). Furthermore, individuals will have varying levels of both literacy and technological literacy, which may pose a further challenge of using digital technologies for the purpose of capturing, using, collecting, and sharing PGHD.<sup>1,4,6,13</sup> Additionally, as previously mentioned, generated the data may not mean an individual has access to that data, depending on who is assigned as legal owners of that data.<sup>13</sup> Vendors create infrastructure that house patient data – and could potentially use this for commercial services, leaving patients, providers, and institutions to access PGHD for a price.

**Research.** As with all information coming into a research setting, the accuracy and validity of the data being generated must be accounted for.<sup>1,4</sup> Incomplete or unreliable data could deter researches from using PGHD and dissuade them from making decisions and conclusions based on that data. Furthermore, while having a variety of platforms to choose from enables patients to choose a collection method they are most comfortable with, that comfort does not necessarily translate into a tool that is readily accepted by researchers and health care providers. It is not enough to have a platform to collect the data – there needs to be a method (or a system/tool in place) that could analyze the data in a way that is meaningful and/or actionable for researchers. The PGHD needs to be compiled and presented in a way that ensures clarity of the patient data.<sup>4,10</sup> Additionally, there needs to be a standardized approach in the way PGHD is collected, stored, submitted, shared, and used.<sup>3</sup> Such standardization processes can include the types of PGHD data that is being collected, incorporating patient-friendly vocabulary, and the processes by which this information is integrated into EHRs.<sup>6</sup> Additionally, devices

and tools involved with PGHD intake needs to be standardized as well, providing some proof of scientific legitimacy to ensure that such approaches are based in evidence.

**Health Care Providers.** Physician compliance may pose an additional challenge to PGHD intake. For many valid reasons, providers may choose not to review PGHD, or take such data into account when making decisions for their patients. Like researchers, health care providers have concerns regarding incomplete or unreliable data, which could deter them from keeping an open mind about using PGHD. Physicians require clarity about the data being sent to them.<sup>10</sup> If providers are concerned about the data being collected, or the data they receive, it is unlikely they will use that data to make health care related decisions. Health care providers are also concerned about data provenance, or in other words, the original source of the data.<sup>4,5</sup> Providers need assurances that the information they receive originates directly from the patient and that this information was not altered in any way.<sup>3</sup> Ultimately, physicians need to have trust in the digital tool being used – which may not always be the case.<sup>5</sup> If accepting PGHD intake is part of the provider's practice or line of duty, they will be liable for reviewing that information and making sound decisions with that information in mind – leaving them in a place where they may not be able to live up to patient expectations.<sup>4,5,10</sup> Furthermore, they will also be liable if they make decisions based on information that turns out to be inaccurate, creating additional deterrence for providers to incorporate PGHD to their practice.<sup>4,11,13</sup>

**Data Overload.** As mentioned above, challenges of PGHD intake are not limited to patients. Health care and research institutions need to have the correct infrastructure in place to support the intake of PGHD.<sup>4</sup> This includes the types of tools that are being used (e.g. EHRs), providing adequate employee training, having a purposeful and actionable use for the PGHD they are collecting, and taking the potential of additional workload into account.<sup>3,4,10</sup> In fact, data overload is a serious problem that could be faced by various systems and stakeholders.<sup>1,10,13</sup> Receiving a voluminous amount of data can contribute to an increase in one's current workload, leading to a more stressful work environment, which may ultimately deter individuals from incorporating PGHD into their decision-making.<sup>4</sup> To combat such issues, PGHD data should be presented in a manner that allow for simple analysis or reduces the need for researchers and/or providers to manually analyze these large volumes of information.<sup>3,5</sup> This also means that investments need to be made for infrastructure and technologies that could store the large volume of information, present it in an appropriate manner, and allow for quick and easy analysis of the data.<sup>4</sup> In addition to the aforementioned measures, both researchers and providers need to trust the accuracy and validity of the PGHD and the digital tools they receive the data from.<sup>12</sup>

## Conclusion

At present, while there may not be any set definition and it may go by a variety of different names, the concept of PGHD data is not new. Patients have been collecting information about themselves, including health-related information, for a long time. It makes sense that they wish for this information to be used to a greater extent than it has previously been used – and for their data to be useful not only for themselves, but for others as well. As patients are the generators of this data, it makes sense, intuitively, for them to have a say in what happens with the data, who can view and access it, and who should be permitted to make adjustments or additions to it. Evidence has demonstrated mixed results in using PGHD – with some literature demonstrating increased patient empowerment, satisfaction, and outcomes. Improved patient-physician communication, greater patient involvement in decision making, and better adherence to care plans are other positive findings. However, on the other side of the debate, there are concerns about the accuracy and validity of the data being collected, or the tools

being used to collect and present them. Patient abandonment of technology, increased workloads for researchers and providers, and issues about data provenance are other concerns. We must keep in mind the very real challenges of PGHD. Many countries have existing legislature that protect an individual's personal health information – but it is uncertain whether PGHD could – or should – fall under this umbrella. After all, with the advent of digital and technological tools, which didn't necessarily exist to the extent that they do today, it makes it difficult to be entirely positive that current laws and regulations adequately encompass and take into account all the various challenges of collecting, storing, and using PGHD. The use and incorporation of PGHD is nonetheless promising. It will require collaboration amongst various different parties to decide how to best approach this avenue and what changes need to be made to ensure it effectively and safely reaches its potential. The opportunities are vast and will be interesting to explore. For now, as it is *patient*-generated health data, a good first step is to concretely figure out what they desire, and where they wish for this to lead.

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