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Title:
Patient Generated Health Data: Looking Towards Future Healthcare.

Abstract:
Patient generated health data (PGHD) refers to health-related data namely, physiological, health history, and lifestyle data created by patients or their caregivers to address a health concern. It has the potential to reconfigure the way healthcare is provided and managed via a patient-centred digital reimagining of healthcare. These data have emerged due to several socio-technical factors: the proliferation of self-monitoring and wearable technologies, the ubiquitous nature of smartphones and the growing public desire to digitally track, measure and understand various aspects of our being. For many, PGHD represents a significant data-pool from which healthcare professionals can garner fresh insights about the health status of individuals and populations from a data-driven perspective. This chapter will explore the uses and benefits of PGHD as society looks towards the future of healthcare.

Keywords:
Patient generated health data; digital health; wearable technology; health technology; data-driven healthcare.

Introduction

Patients generating data about their health is not a new phenomenon. Since the development of early self—monitoring devices such as the weighing scale and thermometer, and later the home-pregnancy test, glucometer and blood pressure monitor, patients have long been capturing data about their health. But the thing that is new, very new in fact, is the profound transformation of these traditional data due to rapid digitization. The digitization of health-related data is occurring at the nexus of several interrelated socio-technical factors namely the development of broadband infrastructure, advancements in smart technology allowing for affordable smartphones, the proliferation of wearable sensing devices and the growing public desire to track, measure and understand various aspects of our being. At an individual level, the digital data footprint may be considered as ‘small data’. However, when we consider it in terms of the potential contained in longitudinal datasets from large sections of the population we think in terms of unlocking the value from ‘big data’. The promises of these ‘big data’ are
receiving heightened attention as healthcare systems and industry pursue data-driven models of care that can provide health management stakeholders with actionable information that drives a more proactive healthcare model to ease the financial and resource burdens associated with aging populations and the prevalence of chronic disease. The term patient generated health data (PGHD) has emerged from the discourses regarding use of data in healthcare. Shapiro and colleagues defined PGHD as “health-related data – including health history, symptoms, biometric data, treatment history, lifestyle choices, and other information – created, recorded, gathered, or inferred by or from patients or their designees to help address a health concern” [1]. It is clear that this refers to a very wide spectrum of data types and sources and a detailed discussion of all would be beyond the scope of this chapter. The focus of this chapter, therefore, will be in the benefits of digitally generated PGHD from wearable sensors and mHealth applications from the perspective of both patient and health care professionals.

The focus on digitally generated PGHD corresponds with the ‘digital patient culture’ that is developing at a staggering pace. In 2018, it is estimated that 135 million wearable units will be shipped worldwide – up from 9.7 million units in 2013 [2]. In terms of ownership, approximately 29% of Americans have a wearable device, while in the UK research has shown that 3 million wrist-worn wearable units were sold in 2015, up 118% on 2014 [3,4]. As wearable devices are frequently accompanied by a dedicated application (app), of equal importance to the wearable industry is the growing number of smartphone users, which is forecasted to reach 2.08 billion worldwide by 2019 [4]. These upward trends are also seen in relation to mHealth app market with between 165,000-259,000 apps now available for download [5,6]. Furthermore, the remote patient monitoring market is also expanding at an enormous rate. A recent report shows a 44 percent rise in the number of patients been remotely monitored to 7.1 million in 2016, which is set to grow to 50.2 million by 2021 [7].
The report also found that the number of mHealth monitoring devices with integrated wireless connectivity increased from 3 million in 2015 to 4.9 million in 2016 allowing for greater interoperability with wearable and smartphone technologies [7]. As the digital health ecosystem concretizes, the optimal circumstances for the rapid digitization of PGHD is fast establishing. The knock on social effect is that a new type of health consumerism is also emerging – one where individuals are keener than ever to adopt a more technologically driven personalized approach to health which is creating opportunities to collect health-related data that is unparalleled to any period in history.

Society is on the cusp of fully realizing the digital patient and the nature and potential of the PGHD they produce is demanding our attention, especially when solutions to ease the climate of uncertainty in healthcare remain elusive. In this context, new questions arise in relation to the future of healthcare; how will PGHD disrupt our conceptions of patienthood or the healthcare professional? Will traditional healthcare practices suffice as patients demand more emphasis being placed on the data they generate as they go about their daily lives? If PGHD is to become part of the healthcare fabric, what are the key barriers facing their integration? And, what, if any, are the potential benefits of leveraging digitally produced PGHD for healthcare, patients and healthcare professionals? The following sections will attempt to open up a space for new discussions regarding the potential benefits of PGHD in a time when society is faced with a pressing need to rethink the future of healthcare.

**PGHD – What are the Benefits?**

For so long, patients were only expected to share one type of information with their HCP – how they were feeling. However, as digitally produced PGHD gain traction, patients will be armed with a plethora of self-data to utilize in their daily healthcare routines. The following
sections will try to unpack some of the potential benefits that could arise from leveraging PGHD for patients and HCPs.

- **Patient Engagement**

Patient engagement has gained significant attention in healthcare policy and research in the past decade. Evidence suggests that increased patient engagement enhances the quality of patient safety, reduces healthcare costs and improves health outcomes [8,9]. The increased emphasis on engaging patients comes at a time when there is a growing acceptance that HCPs are only one of the integral cogs required to tackle illness, health and wellbeing. Patients are now expected to play an essential role in the management of their health and their engagement is central to achieve it. Recent approaches to reforming the provision of healthcare such as patient-centred and personalized care are examples of the turning tide towards trying to effectively engage patients in their care. The philosophy underpinning these approaches centres on transforming the patient’s role from a passive recipient of care to that of an engaged and active participant. An engaged patient is one who feels empowered to partake in collaborative discussions about the trajectory of their care and is one who is empowered to take control in the management of their health with the support of their HCP [10].

But patient engagement is a complex matter, it requires the intertwined responsibility of the patient, the HCP and the healthcare system to all function in harmony. The problem is however, HCPs are often left as the sole drivers to engage patients - consultations frequently involve information flows that are one-way, from the HCP to the patient, without collaborative dialogue which only further deepens the culture of patients as passive recipients of care [10]. Achieving satisfactory levels of engagement has proven problematic globally [11]. The breakdown in patient engagement is seen more so in chronic disease populations –
studies have shown that 50% of patients do not take medications as prescribed, while low patient adherence to pulmonary and cardiac rehabilitation is also a growing issue [12–16]. So, how can PGHD help with patient engagement?

Proponents of PGHD believe that as patients increasingly participate in the collection of PGHD, they will be enabled to achieve a more active status in their health. For example, when a patient decides to collect self-data they impart on themselves an element of mastery and control that was not there before as it is they (or their caregiver) and not the healthcare professional who is generating their health data. By taking on this responsibility they are no longer a passive recipient waiting to be assessed and told what to do. Instead they are self-assessing and self-directing. Interestingly, within the very practise of collecting PGHD, another form of patient engagement emerges as a by-product of the patients’ motivation to capture these data. In other words, a patient who is motivated to capture self-data is, in a sense, a patient who is already engaging with their healthcare. Thus, as a generation of patients start to capture PGHD, they are simultaneously self-activating their engagement with their health [17], and, in a sense, initiating a virtuous cycle.

Patient self-activation relates to the idea of the engaged patient explained above – but instead of the HCP leading the engagement of patients, self-activated patients are driven by their own motivation, knowledge, skills and confidence to make decisions in the management of their health [18]. For HCPs, the self-activated patient will provide them with an opportunity to venture down previously unexplored avenues to discuss engagement in a more person-centred manner. For instance, patients who are motivated to collect PGHD through digital devices might be more willing to explore these technologies as a medium for delivering person-centred treatment plans and engagement strategies. Moreover, as self-activated patients (or their caregiver) turn their motivation to acting on these data, such as sharing it with their HCP or demanding their integration into an EHR, levels of self-efficacy will
improve as patients demonstrate an increasing confidence to partake in discussions and decisions regarding the trajectory of their health based on their PGHD.

Patients increasingly want to be more involved in the healthcare decision-making process [19]. Healthcare has responded to this need by placing a stronger emphasis on shared decision making (SDM) as mechanism to further engage patients in their healthcare. SDM refers to a dialogue centred on sharing information between the HCP and the patient – the HCP provides options, describes the risks and benefits, and the patient is encouraged to express their preferences and values; a consensus is then collaboratively reached on how to proceed [20,21]. SDM is important as it can increase patient knowledge, lower anxiety regarding the care process and creates greater harmony between the patients’ values and preferences and the course of their care [22].

- PGHD and the Interappointment Period – Bridging the Gap

Patients manage their health primarily in the home. As Sara Riggare pointed out in her landmark paper on her personal experience of dealing with illness, she spends 1 hour a year receiving her neurological care and the other 8,765 hours self-managing her Parkinson’s disease [23]. Clinical visits are thus episodic, and HCPs are increasingly recognizing that the intermittent data captured by clinical assessments only offers a snapshot of the patient’s health. The main issue is the interappointment period, as it represents a time when understanding the patient’s health status is beyond the resources of many HCPs. Finding solutions to help fill this knowledge gap has been receiving significant consideration in recent years particularly as healthcare systems have begun implementing chronic disease management strategies that aim to shift care provision from being purely an acute based endeavour to a more integrated model of care that focuses on leveraging Primary care resources in an effective manner [24,25].
As the shift is happening, the need to understand the health status of patients outside the clinical environment is high on the agenda. The use of self-monitoring devices such as the blood pressure monitor and glucometer were early attempts to gather data about patients outside of the clinic. The logic of these devices is that patients would be engaged by the information to help positively influence and support their self-management strategies. The data captured from these devices however, only provides the patient and the HCP with disease-specific information. These data answer the ‘What?’ but not the ‘How?’ and the ‘Why?’ Attempts to answer the ‘Why?’ usually happen through further tests and assessments or conducting a more detailed patient interview placing further financial and time burdens on patients as well as on the resources of HCPs and healthcare systems.

However, when we consider the ubiquitous nature of smartphones and wearable technologies, the spatial and temporal boundaries for the collection of patient data are widening. Answering the ‘How and Why?’ can be supported by PGHD as they can reduce the interappointment knowledge gap particularly by providing HCPs with access to previously unattainable lifestyle and psychosocial data. These data include: activity, sleep, mood, smoking or alcohol habits, exercise, diet, calorie intake to name just a few. Each discrete PGHD element on their own have value, but it is the combination of data points where the greatest promise is envisioned. An example of this would be potential benefits to be gained from combining PGHD with already existing medical record data. Carolina’s Healthcare system in the US has recently launched an ‘app’ that enables patients to integrate their fitness and wellbeing data from approx. 70 discrete devices directly into their care management plan via their personal health record [26]. The platform also facilitates the aggregation of longitudinal PGHD, which is an important aspect as it provides a broader context for data generated by disease-specific monitoring devices.
For example, a patient visits their GP after noticing their blood pressure (BP) has been higher than normal for the past two weeks. Upon speaking to the patient, the GP suspects that the patient has not been as active as usual so they access the patient’s activity data and discover that has indeed been reducing steadily for the past month. Furthermore, the GP might notice that the patient’s disposition is not their usual so they access the patient’s mood data and observe that they have been logging depressive mood ratings for the past two months. The GP might be able to deduce here that as the patient’s mood lessened so too did their activity levels, which may have affected their BP levels. The point is, by having access to more nuanced PGHD such as lifestyle and psychosocial data, HCPs can leverage otherwise unattainable contextual information to fill in the knowledge gaps relating to the ‘How and Why?’ questions. Looking forward, leveraging PGHD to fill in the interappointment gap will extend to ensuring patient safety; PGHD can help HCPs to holistically understand patient responses to new medications - patient reported outcomes combined with physiological PGHD will have an important role to play if, and when, adverse reactions occur. Finally, the more PGHD points HCPs can access the less clinical visits they will require, especially with the establishment of eHealth eco-systems that include video-consultations, electronic health records, patient portals and ePrescribing all of which will facilitate the remote alteration of treatment plans.

- Can PGHD help lower Health Insurance?

Vehicle telematics is not a term often cited in healthcare literature but it is a well-known concept in the auto-insurance world. Vehicle telematics refers to the collection, transmission and analysis of data generated from an on-board unit (OBU) fitted to a motor vehicle [27]. For decades, auto-insurance premiums were based on demographic measures such as driver’s
age, occupation, place of residence, car type, engine size or expected mileage. With the use of OBUs however, auto-insurance companies are now basing premiums on real-time dynamic measures of driver behaviour; for example, actual miles travelled, acceleration, deceleration (including braking habits), time spent on the road, trip duration, location and driving style – this is referred to as pay-how-you-drive insurance (PHUD) [27,28].

PHUD insurance relies on monitoring aspects of the driver’s performance to create safer driving practices through the provision of constructive feedback from their insurance company regarding safer driving techniques. The ultimate aim is to identify the low risk drivers from the high-risk ones by mining driver data to determine if a customer’s driving behaviour justifies a lower or higher insurance price [29]. The benefits of PHUD go beyond purely the financial; environmentally, reduced fuel consumption and optimized traffic patterns are possible outcomes while socially, increased driver education through constructive feedback has the potential to lower driving related fatalities and the associated healthcare costs of motor accidents [30].

Insurance models such as PHUD should be of interest to Governments, healthcare systems, consumers and patients particularly in a time when out-of-pocket healthcare expenditure and private health insurance premiums are on the rise [31]. When you consider the role of vehicle telematics data in the auto-insurance industry, it is not hard to imagine the role PGHD can have for health insurance customers and providers. As auto-insurers adopt OBUs to monitor their driver’s behaviour, it should come as no surprise that other industries have begun investigating the potential of wearables and self-monitoring devices to measure their customer’s health behaviours and lifestyles.

On the back of the Affordable Care Act passed by the Obama administration in 2010, companies were granted permission to spend up to 30% of their annual insurance premiums
on rewards for healthier behaviour [32]. Thusly, similar trends to those in the auto-insurance industry have started to emerge elsewhere in the private sector primarily through the establishment of workplace employee wellness programs that leverage health data from wearable technology as part of their employee health insurance models. Such programs are implemented to incentivise healthier behaviours in their employees to improve overall staff productivity while lowering health insurance premiums. In 2013 for example, US company Cigna launched a pilot program with four of its US based employer health plan clients [33]. Employees were provided with a wearable that tracked activity and calories burned amongst other physiological data. The data was then shared with health coaches who worked with the employees to adjust and motivate them to create healthier habits. Employees could earn points based on reaching healthy behaviour targets, the more points they gained the further discounts they received on their premiums [33].

More recently, UnitedHealthcare are the latest insurers to offer wearable devices to their customers through their wellness program Motion [34]. Customers will use a Fitbit Charge 2 to track their progress across three domains of Motion’s program: Frequency, Intensity and Tenacity (F.I.T). Customer’s daily progress is tracked and if daily goals are reached, they can earn financial credits which can be applied to their policy. Customers can earn up to $4 per day in credits as they achieve their F.I.T targets with a maximum of $1500 of credits achievable in a year. For example, customers are rewarded if: they can reach 300 steps in five minutes an hour a part six times per day (Frequency); achieve 3000 steps in thirty minutes once a day (Intensity); or complete 10,000 steps per day (Tenacity) [34].

The evolution of behaviour based health insurance can be driven by PGHD. As increasing numbers of customers track their health, health insurers can plug into already existing data as means to attract a new customer base. Providers could incentivise customers, who already track or a willing to track, by offering the prospect of lower premiums if they have, or can
adopt, healthier behaviours. Mining customer’s PGHD will allow insurers to create fairer customer profiles, where traditional factors such as age, gender and area of residence, are not the main criteria for determining risk. This would pave the way for personalised health insurance policies and premiums which would help create a more competitive health insurance market.

Much like the PHUD policies, health insurance driven by PGHD can have a positive impact beyond cheaper premiums; if customers are willing to share data regarding their healthcare resource utilization, insurers can work with Governments and healthcare systems to offer insights into what types of patients are utilizing what services and when they are utilizing them (not only when, in terms of everyday use but also when, in relation to their life-span or disease journey) – these insights could inform more effective healthcare budgeting as well as enhancing the allocation of resources. Finally, if insurers create collaborative programs with the input of healthcare systems and allied health groups, consumers will have access to expert medical advice and support regarding the creation of healthier behaviours based on their PGHD. This type of health insurance eco-system would close the loop so speak with respect to scaling the management of individual health to population health. As increasing numbers of customers are empowered to manage their health through person-centred health insurance, healthier behaviour change becomes possible at the populations level which could help tackle the social costs associated with lifestyle-related diseases.

- The Wider Research Potential of PGHD

Another major benefit that can be derived from PGHD is its potential as a research resource that can be used to expand our knowledge base regarding human behaviour and performance. If large populations of people are generating longitudinal data over time, and are willing to contribute this data to a shared database that can be mined we can greatly expand our
understanding of human behaviour, and its relationship with health. Our current understanding of human behaviour and its relationship with health is derived from periodic questionnaire methodologies, a strategy that only provides a snapshot of behaviour. PGHD offers the potential to provide a very rich picture of how people feel and behave on a longitudinal level. If this data is taken alone, we can learn a lot about patterns of behaviour and perceived health or mood of the population, giving us greater understanding of the health and social care needs of a population. If we can link this PGHD with other clinical, or even genetic data, then we can derive greater understanding of the relationships between different domains of measurement of health. In particular, we can understand the interplay between lifestyle/behaviour and biomedical/genetic markers of health.

**Emerging Issues**

The integration of PGHD into the daily healthcare routines is of course not without its barriers, however. This section will explore some of the key emerging issues facing the use of PGHD.

- Changing Roles and New Conversations

As more and more patients introduce PGHD into their day-to-day healthcare regimes, traditional forms of information exchange in the clinic and hospital will undoubtedly change as well. With their PGHD in hand, patients will expect conversations about their data and how they can be used to inform decisions. Correspondingly, HCPs will find themselves entering unfamiliar territory as patient preferences turn to data-centric consultations. PGHD can have a positive impact on aspects, such as SDM, by engaging the patient to have an authoritative voice in the consultation. However, patients who collect PGHD will be informed about the capabilities of these data and in many cases, much more informed than
their HCP. Thus, no longer will the HCP be the de facto leader of consultations - the patient, by virtue of being an authority on their data, will naturally begin to steer consultations with the expectation that their HCP will collaborate in these discussions. Moreover, as patients tap into the ‘Doctor Google’ phenomenon, they will begin to couple their PGHD with health information further empowering them to offer options regarding their course of care or at minimum, to challenge those provided by their HCP.

The shifting cultures of health responsibility discussed above are enabling patients to be more assertive in deciding the appropriateness of care provision they receive which has been discussed elsewhere regarding the co-production of healthcare [35,36]. With the introduction of PGHD into everyday clinical practices, patients and HCPs will organically begin to co-produce more empathetic care pathways brought about by the digitization of health data. However, to unlock the true potential of PGHD, HCPs need to improve their literacy regarding PGHD in order to evaluate how best to use these data in their patient’s treatment and to offer patients an informed decision concerning how they can effectively use PGHD in their care.

- Creating Actionable PGHD

As the research regarding health-related data has evolved, two interchangeable terms have emerged in the literature, “actionable data” and “actionable information”. These terms are used to describe user-friendly data that can be acted upon by the end-user in a manner that has a practical value whilst meeting their particular needs (Kumar et al. 2013; Foldy et al. 2014; Hood & Price 2014; Woods et al. 2016). An issue facing the integration of PGHD into clinical use will be determining what constitutes practical value for the key stakeholders. But determining practical value will rely on other factors, such as identifying the needs of patients
and HCPs across the various contexts and scenarios of use. With the increasing potential for people to bring their PGHD into the clinical setting, of central importance, will be understanding how PGHD can be integrated into the workflows of HCPs in a manner that is empathetic to the resources and culture of their clinic. For instance, six months of activity data would hold little practical value to a GP if the data cannot be easily visualized and interpreted within the constraints of a ten-minute consultation. Other questions arise when we think about the relevancy aspect of the actionable data argument. Each disease or illness require information from discrete types of data to help HCPs to make decisions; more work is required in terms of PGHD to understand what are the information needs of HCPs per disease. Gaining this insight could also be used to educate patients about the types of data relevant to their health profile - if patients are only bringing relevant PGHD to their clinical visits, this may help to reduce the occurrence of data-overload for HCPs.

Another aspect that will affect the actionability of PGHD for HCPs will be their integration with electronic health records (EHR). In countries where EHRs are operational, questions relating to the interoperability of PGHD remain mostly unanswered as do questions concerning the ways in which HCPs will make clinical decisions based on the synthesises of medical information and PGHD. Progress is being made however, with PGHD programs such as the one on-going in the Carolina Healthcare system mentioned earlier. Elsewhere, the University of California Davis Health System have recently begun a PGHD initiative called “Integrating Patient-Generated Health Data to Improve Health” [41]. The program involves integrating 1.4 million PGHD points captured from diabetes and better blood pressure initiatives from patient-connected devices and integrate the PGHD points into their EHR system. Going forward, learning from on-going PGHD programs like Carolina’s will help shed light on issues relating to interoperability and workflow. We shouldn’t forget about those countries without operational EHRs for they far outweigh their counterparts. Creating
actionable information for HCPs in this context will rely heavily on finding solutions that allow PGHD to be utilized when it cannot be seamlessly integrated with already existing medical records. This will be a complex issue to overcome given the embeddedness of the paper-based culture in many healthcare practices.

From the patient perspective, health literacy will have a massive bearing on the actionable nature of PGHD particularly when we consider that lower levels of health literacy have been shown to negatively impact patients’ ability to self-manage [42]. A core component of a person’s health literacy is their health numeracy skills. Health numeracy refers to “the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical and probabilistic health information needed to make effective health decisions [43]. Given that many wearable and self-monitoring devices are accompanied by an app and furthermore, that the greater number of app-based data visualizations are numerical and graphical, health numeracy emerges as an important attribute for people to have if they are using PGHD as part of their health routines. For instance, if an individual is capturing weekly BP data, seeing these measurements will be of little use if they do not understand the significance of the numbers which will leave them without the vital knowledge that would otherwise empower them to act upon this data safely and appropriately. To avoid the risk of endangering patients, ensuring that users are: (a) made aware of the necessity for health numeracy skills and (b) supported to develop adequate levels of health numeracy, should be a priority for healthcare systems and HCPs as the use of PGHD evolves.
Conclusion

The on-going digital health phenomenon has witnessed mobile and smart devices, including sensor technology, become common place technologies in people’s daily routines. As their adoption grows, the numbers of people self-tracking are helping to create a significant pool of PGHD that is progressively catching the attention of healthcare and HCPs alike. This chapter has discussed several benefits associated with leveraging PGHD in healthcare while also exploring some of the emerging issues that should be considered as research in the area evolves. Understanding how small data sets such as PGHD will impact social institutions has immediate and future advantages especially in a time when data-driven solutions are showing great promise to propel service innovation. Indeed, for many, data is the fuel source that will power future societies but before then many questions still need to be answered particularly concerning the human factors element of data use. Ultimately, unlocking the potential of small data, such as PGHD, is more of a social problem than it is a technological one and unless data-driven solutions can meet the needs of end-users across the multiple contexts they occupy, it may, unfortunately, be a long time before we can deliver on the promises of big or small data.
References


