

Patient-Generated Health Data: Dimensions, Challenges, and Open Questions

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ABSTRACT

In this review, we present an overview of patient-generated health data (PGHD) research, focusing on important aspects that inform and define studies in the area. We start by exploring a fundamental question: what is patient-generated health data? We list the main terms and definitions identified from previous research and generate a set of seven key dimensions for understanding PGHD: (1) the health focus of the study, (2) the type of data, (3) who proposes the use of PGHD, (4) whose data are collected, (5) who are the intended users, (6) how PGHD is collected and used, and (7) the duration of PGHD use. We describe these dimensions and discuss their importance to research PGHD. We then present a discussion of the impact of PGHD and related practices in people's lives and the debates concerning the consequences, both positive and negative, that may arise.

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Introduction

The practices of collecting and using individuals' or patients' personal health data are not new (Cortez *et al.*, 2018) and people have been recording data about themselves for hundreds of years (Rettberg, 2014), often with specific self-management goals (Neff and Nafus, 2016). It is well known that medical practices are essentially information-centric, and the decisions are largely based on patients' data: it is through patients' descriptions of symptoms that healthcare providers can order further tests and provide treatment plans (Loos and Davidson, 2016; Schroeder *et al.*, 2017). To better access and utilize patients' data, numerous studies have advocated patients' active participation as a key factor for enhancing the quality of their healthcare. These studies suggest that patients should have access and contribute to the generation of their health data, and be directly involved in their own healthcare decisions (Shapiro *et al.*, 2012).

Over the past years, individuals' and patients' health data have been increasingly present in public debate: from stories about the benefits of accessing and using these data to reports of privacy breaches and potential negative consequences (e.g., Harwell, 2019; Rowl, 2019; Siegel, 2019). Recently there has been a proliferation of new technologies,

particularly sensor and mobile apps, produced to measure and track different aspects of a person's health and behavior: industry reports state that as of 2018 there were more than 325,000 health related apps available for consumers (Dabbs, 2018). These data are often termed patient-generated health data (PGHD), a research topic that has been increasingly examined by multiple fields of studies, such as Human-Computer Interaction, Computer Science, Health Informatics, Medicine, Psychology, Science and Technology Studies, and Social Sciences, to cite a few.

The use of PGHD is not a new phenomenon; its popularity is associated with the recently increasing interest in patients' data and the rapid development of technologies that can facilitate data collection and use (Consolvo *et al.*, 2008; Cortez *et al.*, 2018). Specifically, two developments have influenced the popularization of PGHD (Neff and Nafus, 2016): the first one is the technology itself. Mobile phones, sensors, and connectivity are pervasive, expanding the presence of technology in our lives and providing the basis for the development of systems that can track a greater number of aspects in a greater frequency and detail. The second development is related to a culture of biomedicalization, or the expansion of "medical jurisdiction, authority, and practices" "through the new social forms of highly technoscientific biomedicine" (Clarke *et al.*, 2003). This culture is related to the increased interest in measuring and medicalizing aspects of life that were not previously medicalized, particularly through new technologies such as sensors and smartphone applications. For example, exercising is not only a habit anymore, it needs to be quantified and measured too (Brown, 2019). Together, these aspects promoted the growth of the social phenomenon of people tracking their own data (Neff and Nafus, 2016), including collecting health data outside of traditional clinical settings from multiple sources and with a rapidly increasing volume (Cortez *et al.*, 2018; Shapiro *et al.*, 2012). Recent movements such as the Quantified Self (Quantified Self, n.d.; Wolf, 2009, 2010) add up to this increased popularity of systems, habits, and research concerning health data generated by patients (and non-patients) as they go about their daily lives.

Many researchers point to a paradigm shift in healthcare from a clinical-centered to a more patient-centric practice, in which patients

have a more active role in their care (Demiris *et al.*, 2008; Grönvall and Verdezoto, 2013a; Hong *et al.*, 2016; Loos and Davidson, 2016; Mamykina *et al.*, 2008; O’Kane and Mentis, 2012; O’Kane *et al.*, 2016; Paton *et al.*, 2012; Zhu *et al.*, 2016). The new view puts patients and their own health data at the center of the healthcare practices. Considering the wide impact and potential benefits of PGHD in healthcare, it is necessary to understand the current landscape and scope of PGHD research, so we can support good practices, work to improve areas that need more attention, promote PGHD benefits, and avoid negative consequences, such as reinforcing negative social stereotypes or increasing health disparities.

In this review we present an overview of the extensive literature related to PGHD, ranging from an attempt to characterize the research to a discussion of the impact of these practices on people’s lives and the debates concerning the consequences, both positive and negative, that may arise. Based on the literature, we identified important dimensions to define the research and design scope, and pinpoint several challenges in researching and developing technologies for PGHD. We defined these dimensions through examining several streams of literature related to PGHD and also through our own previous research in the area.

The remainder of the review is organized as follows. In the first section we summarize the potential benefits of using PGHD and explore vocabularies, definitions, and scopes used in a diverse set of studies on health and health-related data generated and used by patients and non-patients. In the second section we translate this discussion into seven dimensions that can be used to categorize and define the scope of studies related to PGHD. The third section focuses on the main challenges of researching and developing for PGHD. Finally, the fourth section explores important open questions for PGHD research.

1.1 Why Patient-Generated Health Data – The Benefits

PGHD have several benefits to healthcare, including changing healthcare practices to provide more information concerning patients’ health and quality of life (Cortez *et al.*, 2018; Jacobs *et al.*, 2015; Raj *et al.*, 2019). These benefits can impact multiple stakeholders, especially healthcare

providers and patients. In this subsection, we briefly describe the multiple benefits from using PGHD as reported by the literature.

Providers can benefit from PGHD in numerous ways. These data can support personalized care (Cortez *et al.*, 2018; Loos and Davidson, 2016; Zhu *et al.*, 2016), potentially leading to new insights about patients' health status, conditions, or treatment results (Zhu *et al.*, 2016) and improving or facilitating diagnosis and treatment plans (Chen, 2011; Chung *et al.*, 2016, 2019; Jacobs *et al.*, 2015; Loos and Davidson, 2016; Schroeder *et al.*, 2017; West *et al.*, 2016) by providing important measures of lifestyle and personal behavior that may be missed during consultations (Schroeder *et al.*, 2017; Zhu *et al.*, 2016). PGHD can also provide further context about patients' health and health behaviors, reveal unexpected side effects, enable timely and cost-effective interventions (Cheng *et al.*, 2015; Cortez *et al.*, 2018; Frost *et al.* 2011; Loos and Davidson, 2016; Nundy *et al.*, 2014; West *et al.*, 2016), and provide crucial support to continuity of care or patient adherence (Chung *et al.*, 2019; Demiris *et al.*, 2008; Murnane *et al.*, 2018; Nundy *et al.*, 2014). Some studies also describe increased benefits for specific “sub-areas” of healthcare. For example, Grönvall and Verdezoto (2013a) highlight the potential benefits of PGHD for elderly care, e.g., supporting a more independent life outside of clinical settings. Other benefits are related to patient-provider interaction. Sanger *et al.* (2016) mention that PGHD can improve “clinical outcomes and patient satisfaction” (Sanger *et al.*, 2016) by making providers more accountable and improving patients' engagement and self-management. Many studies also argue that these data can improve patient-provider communication and foster shared decision-making (Cheng *et al.*, 2015; Chung *et al.*, 2016, 2019; Cortez *et al.*, 2018; Jacobs *et al.*, 2015; Loos and Davidson, 2016; O’Kane and Mentis, 2012; Schroeder *et al.*, 2017; Zhu *et al.*, 2016).

On the patient side, PGHD are seen as useful for patient empowerment (Ayobi *et al.*, 2017; Demiris *et al.*, 2008; Grönvall and Verdezoto, 2013a; Tang *et al.*, 2012). These data can serve as important memory aids for patients during time-constrained medical consultations (i.e., recording important facts that happen in the sometimes long period between appointments) (Cheng *et al.*, 2015; Jacobs *et al.*, 2015; Loos and Davidson, 2016; Mishra *et al.*, 2019; Nundy *et al.*, 2014;

Tang *et al.*, 2012). They can also provide support in monitoring and mitigating symptoms and delaying or preventing progression of chronic diseases (Chung *et al.*, 2016; Demiris *et al.*, 2008). Additionally, PGHD are believed to enhance patients' knowledge about their health condition, self-awareness, and understanding of their own health, behavior, and lifestyle—aspects that are fundamental for individuals' general wellness and illness management (Choe *et al.*, 2015; Grönvall and Verdezoto, 2013a; Li *et al.*, 2011; Mamykina *et al.*, 2008; O'Kane *et al.*, 2016; Pina *et al.*, 2017). PGHD can also be used to identify possible associations in health events, e.g., identifying the trigger of an allergic reaction (Chung *et al.*, 2019; Karkar *et al.*, 2015a,b, 2017; Pina *et al.*, 2017). In this sense, these data can be used to support patients' reasoning regarding, e.g., their current health status and future trends for their conditions, the relationship between their health status and daily health behaviors, and the important and effective ways to manage illness and health (Barbarin *et al.*, 2016; Johansen and Kanstrup, 2016). Therefore, PGHD can be used to explore alternative approaches of self-management beyond clinical interventions.

1.2 Definitions: Data and Practices

Although PGHD have been extensively studied and frequently mentioned in prior literature, to date there isn't a unified definition for PGHD, largely because of their interdisciplinary nature and multiple fields of inquiry. The following definition was proposed by the Office of the National Coordinator (ONC) for Health Information Technology of the U.S. Department of Health and Human Services in its attempts to explore PGHD opportunities and challenges (Shapiro *et al.*, 2012):

PGHD are 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. PGHD are distinct from data generated in clinical settings and through encounters with providers in two important ways. First, patients, not

providers, are primarily responsible for capturing or recording these data. Second, patients direct the sharing or distributing of these data to health care providers and other stakeholders. In these ways, PGHD complement provider-directed capture and flow of health-related data across the health care system.

As this definition shows, PGHD is a broad and loosely defined term that encompasses health-related data generated by individuals outside of traditional care settings. The data can be in different types: physiological indicators measured by patients (e.g., temperature, weight), lifestyle data (e.g., exercise, diet), quality of life data (e.g., mood, sleep quality), symptoms of medical conditions, or any other information that helps in personalizing patients' situations (Shapiro *et al.*, 2012).

This definition of PGHD overlaps with many other related terms used in the literature, such as “personal health” (Sherman, 2016), “data relevant for healthcare” (Estrin *et al.*, 2016), “personal health experience” (Chen, 2010), “patient-logged data” or “self-logged data” (West *et al.*, 2016). These terms significantly overlap with PGHD but offer slightly different emphases and foci based on the field of study. In understanding and deciding the scope of this review, we first reviewed relevant terms and definitions, particularly the ones commonly used in medical and technology-oriented domains. In this review, we will briefly explore the following terms:

Definitions commonly used in health practices:

- (a) Patient Health Outcomes (e.g., Street *et al.*, 2009) and Patient Reported Outcomes (e.g., Black, 2013; Zhang *et al.*, 2019)
- (b) Journaling (e.g., Zhu *et al.*, 2016)
- (c) Self-management and variants, e.g., personal health information management, home care (e.g., Civan *et al.*, 2006; Davies *et al.*, 2019; Havas *et al.*, 2016; Moen and Brennan, 2005)
- (d) Remote Patient Monitoring (e.g., Cheng *et al.*, 2015; Raj *et al.*, 2019)

- (e) Self-monitoring (e.g., Choe *et al.*, 2014, 2015; Grönvall and Verdezoto, 2013b; Paay *et al.*, 2015; Snyder, 1974)

Concepts originated from Human Computer Interaction (HCI), Computer Science (CS), and Health Informatics:

- (a) Self-tracking and Personal Informatics (e.g., Li *et al.*, 2010, 2011; MacLeod *et al.*, 2013; McKillop *et al.*, 2018; Pina *et al.*, 2017)
- (b) Self-Experimentation (e.g., Karkar *et al.*, 2015a,b, 2017)
- (c) Observations of Daily Living – ODL (e.g., Brennan and Casper, 2015)
- (d) Quantified Self (e.g., Choe *et al.*, 2014; Gregory and Bowker, 2016; Johansen and Kanstrup, 2016; Neff and Nafus, 2016; Quantified Self, n.d.; West *et al.*, 2016; Wolf, 2009, 2010).

1.2.1 Definitions Commonly Used in Health Practices

In medical research, a concept frequently used and close to PGHD is “Patient Health Outcomes.” This term concerns direct outcomes of treatment, such as disease markers (e.g., blood pressure, glucose levels), survival rates, and quality of life measures, such as “functioning and well-being in physical, psychological and social domains” (Street *et al.*, 2009). Street *et al.* (2009) summarize health outcomes in terms of survival rates, cure or remission, decreased suffering, emotional well-being, pain control, functional ability, and vitality. But they also describe proximal outcomes, (understanding, satisfaction, clinician-patient agreement, trust, feeling ‘known,’ feeling involved, rapport, motivation) and intermediate outcomes (access to care, quality medical decisions, commitment to treatment, trust in the system, social support, self-care skills, emotional management) that can lead to the previously mentioned health outcomes (Street *et al.*, 2009). Measuring these outcomes is a common goal and also a challenge. Some of these outcomes can be evaluated through clinical measures, e.g., recovery rate or remission. However, many others require considerable patient input, e.g., emotional well-being, pain levels, and vitality. These are often measured

through data that can be requested by healthcare providers, but that are generated, collected, and provided by patients as part of PGHD.

Similarly, Patient Reported Outcomes (PRO) focus on collecting and measuring the outcomes of healthcare, aiming to increase patient involvement. PROs are a “key measurement of the effectiveness of patient-centered care. PROs include patients’ self-reported symptoms, functional status, and health-related quality of life” (Zhang *et al.*, 2019). They represent patients’ own views about their health status and care and can be used to compare providers’ performances (Black, 2013). Different measurements aim to determine PROs. Many of them are disease specific measures, which “are tailored to the symptoms and impact on function of a specific condition” (Black, 2013). Others are generic PRO measures, aiming to consider general aspects (e.g., self-care) common to multiple medical conditions (Black, 2013). These measures, although self-reported by patients (thus, related to PGHD), are often collected or requested by healthcare providers through questionnaires or questions during clinical appointments.

Journaling is another frequently used term in healthcare. Historically health providers ask patients to write their symptoms and other related information as they go in their daily lives in a journal, so that they can discuss them during appointments (Zhu *et al.*, 2016). Studies in the medical field on chronic diseases also commonly use terms like self-management, or an individuals’ abilities to “manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent to living with a chronic condition” (Davies *et al.*, 2019). “Personal health information management” and “home care” are other terms similar to self-management, both referring to the activities patients perform in their daily lives to manage their health conditions, involving monitoring the status and progress of the condition, treatment adherence and outcomes, and quality of life (Civan *et al.*, 2006; Havas *et al.*, 2016; Moen and Brennan, 2005).

A more provider-oriented term is “remote patient monitoring,” which focuses on near real-time patients’ monitoring, through personal data collection at home and direct transmission of data to providers’ databases (Cheng *et al.*, 2015). Remote patient monitoring often means that

patients have no or low access to, or influence over, the collection and use of their own data.

Finally, a common term rooted in healthcare practices is self-monitoring. Self-monitoring is traditionally used in behavioral psychology as the practice of recording one's own thoughts, feelings, and behavior as part of assessments or treatments in behavior therapy (Choe *et al.*, 2014, 2015). It originally focused on expressive behaviors, i.e., the practice of observing and controlling one's self-presentation (Snyder, 1974). Although commonly applied in health practices, self-monitoring has also been used in research in technology-oriented areas, such as HCI, CS, and health informatics. In this case, it has been used with the connotation of monitoring health parameters, focusing on prevention or early detection of medical conditions (Grönvall and Verdezoto, 2013b). Some of these studies also see self-monitoring as a technique for persuading people to improve health behavior (Paay *et al.*, 2015). Additionally, self-monitoring is often used as a synonym of self-tracking or personal informatics (PI) (Choe *et al.*, 2014; Li *et al.*, 2010; Sanger *et al.*, 2016), one of the currently most used terms for the practice of collecting and using PGHD, especially in HCI and other technology-related areas.

1.2.2 Concepts Rooted in HCI, CS, and Health Informatics

Li *et al.* (2010) introduced the term personal informatics (PI; also called self-tracking) to refer to systems that help people collect and reflect on personal information to gain and improve self-knowledge (Li *et al.*, 2010). The definition includes the collection and use of health data as well as personal finances, emails, and other types of data (Ayobi *et al.*, 2017; Rooksby *et al.*, 2014). Later, Li *et al.* (2011) extended the definition to broadly encompass activities of self-tracking, not only technologies and systems (Li *et al.*, 2011). Self-tracking and PI usually have a characteristic of repetition or periodicity: of repeatedly collecting and reflecting on one's personal data to acquire self-knowledge or achieve a goal (Li *et al.*, 2010). Concerning the data, Li *et al.* (2011) describe that PI data may include data about behavior and physiology, qualitative and quantitative current and historical data, and external data considered to be personally relevant (e.g., weather, if it impacts mood or exercise).

Pina *et al.* (2017) similarly use the term PI, but explicitly focus on health, defining it as the process of tracking behaviors, outcomes, and context to observe and adapt behavior. Their work calls attention to the “personal” part of the term, and they state that many aspects of one’s health impact and are influenced by other people, especially family members. Considering this aspect of who is affected or involved in self-tracking activities for health, Nissenbaum and Patterson’s (2016) taxonomy of health self-tracking lists three different types of actors “involved in the circuits of information flow:” initiators (who initiate the data tracking), data subjects (whose data is tracked), and data recipients (who use the data). In another study using the term PI and explicitly focusing on health, MacLeod *et al.* (2013) highlight the particular goals that patients with chronic or other serious conditions would have: they would be more interested in questions related to episodes (trends, how to prevent and deal with episodes, and consequences), medication (how to change dosage, efficacy, and side effects), and triggers (trends, and how to deal with triggers) than the general population analyzed by Li *et al.* (2010, 2011).

Karkar *et al.* (2015a,b, 2017) rigorously examine the focus on health triggers. They use the term “diagnostic self-tracking,” proposed by Rooksby *et al.* (2014) as a type of self-tracking that refers to “the recording of personal information to diagnose or manage a health condition” (Karkar *et al.*, 2017). Karkar *et al.* (2015b) propose a “self-experimentation” framework, described as a subset of self-tracking based on single case designs or *n*-of-1 trials. They focus on providing some level of scientific rigor to people interested in associations of health-related events, indicators, and symptoms (e.g., if certain food triggers headaches), because often these people perform such analyses without the support of health providers.

Another related term is Observations of Daily Living (ODL), which directly concerns patient’s or individual’s experiences. Brennan and Casper (2015) define ODL as a type of PGHD. ODL consist of patient-defined and patient-generated data that reflect “concepts uniquely defined and uniquely important to the patient,” which are especially useful to indicate idiosyncratically if the person is well or if they should seek healthcare support (Brennan and Casper, 2015). These data come

from the person or her/his environment, and can be as different as indicators of health status (e.g., the presence of pain), indicators of behavior (e.g., eating more when feeling anxious), and “exposures” such as environmental measures (e.g., pollution). These indicators often are not used as symptoms of pathology, but to indicate a “need for action” (Brennan and Casper, 2015). ODL is a term for the data, and not for the practices that generate them.

Finally, a term often conflated with self-tracking or PI, is quantified self (QS) (Neff and Nafus, 2016; Quantified Self, n.d.; Wolf, 2009, 2010). QS originated as a movement of technology enthusiasts who monitor themselves and build technologies to support these activities, based on an interest in self-experimentation and self-knowledge (Choe *et al.*, 2014; Quantified Self, n.d.; West *et al.*, 2016). However, the term evolved to be also used as the general practice of self-tracking (Choe *et al.*, 2014), a “pervasive social trend” (Gregory and Bowker, 2016), and to refer to technologies that support bodily and emotional quantification (Johansen and Kanstrup, 2016) or the cultural movement of self-optimization (Neff and Nafus, 2016). These other meanings may even contradict the original goals of the QS community. Members of the QS community define the movement as a subset of self-tracking that emphasizes self-experimentation or *n*-of-1 studies; they also often gather in meetups to discuss their idiosyncratic experiences. These experiences often include but are not limited to health concerns. Members of the QS movement also often self-define and self-initiate their experiments of data collection and analysis, also highlighting the initiation of PGHD practices (Neff and Nafus, 2016).

Although health is its usual focus, QS is not only about health. Similar to self-tracking, it can also refer to the practices of quantifying other aspects of lives, such as energy consumption or finance. Regarding health, QS includes a wide range of repeated measures such as self-reported mood status, glucose readings from automatic pumps, cognitive performance, etc. (Choe *et al.*, 2014), as well as single time measures such as genetic tests (Gregory and Bowker, 2016). Katz *et al.* (2018) argue that although QS (and they use the term more to refer to self-tracking practices than to a specific community) has many overlaps with chronic disease management, QS does not necessarily involve important

and common concerns of chronic disease management, such as: “the non-elective nature of disease; frequency of treatment decisions; need for continuous monitoring, greater unpredictability of measurements; affective impact of unwanted results due to justifiable fears of health complications; and the critical nature of situated decision-making based on personal data” (Katz *et al.*, 2018).

1.2.3 Defining the Scope of PGHD in This Review

No single term or definition is universally used for PGHD in the literature, and current definitions mostly point to several broad uses. These are only a few terms offered by the literature that are related or overlap with PGHD. Although we searched for literature in several related fields of study, as HCI researchers we primarily approached the PGHD-related literature and its scope from this perspective. While there may be other related terms that were not included in this review, there is no standardized term that works in multiple research areas. As our review of the terminology shows, many related terms cover PGHD, but they either include other types of data, such as non-health data, or data collected during medical consultations, or cover only a subset of PGHD, such as data collected solely by technology. Each term and definition, with differences and similarities, focus on specific aspects in detriment of others. This multiplicity makes it complicated to define the general scope of PGHD, especially considering the varied research areas interested in the theme (e.g., medical vs. technology fields).

We cannot precisely demonstrate the relationship among these terms because their boundaries are fuzzy. From an HCI perspective, we consider PGHD as data collected and used by patients (or their caregivers). Therefore, we do not consider data automatically sent to healthcare providers’ databases, although we analyzed a few papers that use this approach. We also focus on data collected by patients themselves in their everyday lives, not by professionals in clinical settings. For example, we do not include in our review data generated through health assessments requested and conducted by healthcare providers during medical appointments. Since we focus on practices, we include both technologically assisted and traditional manual collection. Although

Table 1.1: Our PGHD space in relation to other terms.

Term	Scope of this review
<p><i>Patient health outcomes and patient reported outcomes</i> – includes direct outcomes of treatment and quality of life measures. Some of these outcomes can be evaluated or generated by healthcare providers, through clinical measures in clinical settings.</p>	<p>Patient health outcomes and patient reported outcomes have many overlaps with PGHD. However, in the scope of this review we focus on data primarily generated by patients (or their caregivers). We do not include data generated through health assessments requested and conducted by healthcare providers during medical appointments.</p>
<p><i>Journaling</i> – the practices of writing down one’s own symptoms and other related information related to one’s daily life in order to later discuss them during clinical appointments (Zhu <i>et al.</i>, 2016).</p>	<p>We consider journaling and self-management as practices that generate PGHD. However, PGHD can encompass more data than these practices traditionally generate, such as data individuals collect for their own health or general wellness management that are not necessarily related to a medical condition, nor to the intent to share this data with healthcare providers.</p>
<p><i>Self-management</i> – individuals’ abilities to “manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent to living with a chronic condition” (Davies <i>et al.</i>, 2019). It refers to the activities patients perform in their daily lives to manage their health conditions (Civan <i>et al.</i>, 2006; Havas <i>et al.</i>, 2016; Moen and Brennan, 2005).</p>	
<p><i>Remote patient monitoring</i> – focuses on near real-time patient monitoring through personal data collection at home and direct transmission of data to providers’ databases (Cheng <i>et al.</i>, 2015). It often means that patients have no or low access to, or influence over, the collection and use of their own data.</p>	<p>The scope of this review focuses only on cases in which patients can at least see some of their data. Remote patient monitoring can generate PGHD, but often it generates data that do not fit the scope we approach in this review: data used or accessed by patients.</p>

Continued.

Table 1.1: Continued

Term	Scope of this review
<p><i>Self-monitoring</i> – traditionally used in behavioral psychology as the practices of recording a person’s own thoughts, feelings, and behavior as part of assessments or treatments in behavior therapy (Choe <i>et al.</i>, 2014, 2015). It originally focused on expressive behaviors, i.e., the practice of observing and controlling one’s own self-presentation (Snyder, 1974).</p>	<p>Similar to self-management and journaling (with which it has many overlaps), we consider self-monitoring as a practice that generates a subset of what we examine as PGHD. However, it can also generate data out of our scope, for example data used in behavioral psychology and behavior therapy.</p>
<p>Also used in research in technology-oriented areas, with the connotation of monitoring health parameters focusing on prevention or early detection of medical conditions (Grönvall and Verdezoto, 2013b).</p>	
<p><i>Self-tracking and Personal Informatics</i> – the practices of collecting personal data on which to reflect (Li <i>et al.</i>, 2010, 2011). Self-tracking or PI are not only about health, encompassing multiple aspects of people’s lives such as finances, social interactions, and productivity (Li <i>et al.</i>, 2010, 2011).</p>	<p>Following Li <i>et al.</i> (2010, 2011), this review considers self-tracking and personal informatics as synonyms. However, we focus only on self-tracking for health. We also consider “secondary tracking” to characterize health-related self-tracking that is not performed by “the self,” as in cases involving families (Pina <i>et al.</i>, 2017).</p>
<p><i>Self-experimentation</i> – described as a subset of self-tracking based on single case designs or n-of-1 trials. It focuses on finding associations between health-related events, indicators, and symptoms (e.g., if certain food triggers headaches).</p>	<p>As a subset of self-tracking, we consider self-experimentation another term for practices that generate some types of PGHD. However, not every PGHD are collected with the intent of testing associations or triggers.</p>

Continued.

Table 1.1: Continued

Term	Scope of this review
<p><i>Observations of Daily Living</i> – Defined as a type of PGHD, ODL consist of patient-defined and patient-generated data that reflect “concepts uniquely defined and uniquely important to the patient” (Brennan and Casper, 2015).</p>	<p>This review considers ODL as a subset of PGHD, because we also include data that is clinically-defined but patient-generated (Brennan and Casper, 2015).</p>
<p><i>Quantified Self</i> – QS is originally a movement of technology enthusiasts who independently monitor themselves and build technologies to support these activities, focusing specifically on self-experimentation, and often gathering in meet-ups to discuss their idiosyncratic experiences (Choe <i>et al.</i>, 2014; Quantified Self, n.d.; West <i>et al.</i>, 2016). The term evolved to be also used as the general practice of self-tracking (Choe <i>et al.</i>, 2014). QS is not only about health, it can also refer to the practices of quantifying other aspects of individuals’ lives (e.g., finances).</p>	<p>In this review, we consider QS as another practice that can generate PGHD. However, QS is not restricted to health, while we focus only on health-related data. Also, the QS community often highlights they perform these activities independent of healthcare providers. In this review, we approach both cases in which individuals collect and use PGHD by themselves as well as cases in which they share the data with their healthcare providers.</p>

technology provides many benefits, patients have been collecting their data for decades and studies that do not focus on technology use may provide valuable insights for future technology development.

We also focus on measures directly related to health, excluding, for example, data related to payments, insurance, or other data patients may generate. Also, although this review describes PGHD use in the context of both medical conditions and general wellbeing, we are especially interested in the former. We focus on data collected and used by patients or individuals and related to a medical condition or health concern they have, even if their healthcare providers do not value these data. We do not include or discuss in this review data automatically and

implicitly tracked while individuals are engaged in activities that may influence but are not directly connected to their health (e.g., online shopping or government data), unless they are explicitly used for health-related issues by the person or caregivers, possibly together with their healthcare providers.

We also consider data that are collected and used by caregivers, as in cases involving families (Pina *et al.*, 2017). In these cases, the data can be collected by both patients and caregivers or only by the latter. For example, PGHD can be collected by older adults and adolescents, but also by caregivers or family members (Hong *et al.*, 2016), collaboratively or not. Table 1.1 presents a comparison between the terms described in the previous subsection and the scope used in this review.

In summary, in this review we considered the following aspects when defining our PGHD scope:

- (1) We include data related to a medical condition or to general wellness, excluding management of other life aspects, such as finances, unless this data is used explicitly for health-related interests;
- (2) Data can be directly related to a medical condition, general health, or wellbeing; or provide context for patients' health-related interests;
- (3) Data collection can be patient- or provider-initiated, but patients (or their caretakers) are responsible for collecting the data outside of traditional clinical settings;
- (4) Data can be collected by the patient, caregivers, or both;
- (5) Data can be primarily used by patients (and/or their caregivers), healthcare providers, or both patients and providers. Although we analyzed a few papers focusing on data intended for exclusive use by healthcare providers, we focused on studies in which patients (or their caregivers) could access at least part of the data;
- (6) Data can be both technology and manually generated;
- (7) And data can be intended to be used in the short and long term.

These aspects helped us delimit the space of our review. However, even within this roughly delimited space, defining the PGHD scope is not straightforward. The ONC definition (Shapiro *et al.*, 2012) is a good summary, but we propose further analysis. Based on the analyzed literature, particularly on the definitions explored in the previous subsection, we derived the following questions to define the space of PGHD research and technology around key aspects:

- (1) What is the focus of the study? Is it strictly medical-related, or does it relate to general health and lifestyle?
- (2) What types of data are used? How are they used? What data can be considered PGHD?
- (3) Who initiates or proposes (or is intended to initiate or propose) the use of PGHD? Patients? Healthcare providers? Other actors?
- (4) Whose data are collected? Is the person a patient? Is the person tracking her/himself?
- (5) Who is intended to use the data? Who uses the data? Patients? Healthcare providers? Others?
- (6) How are the data generated? What means are used to collect and use PGHD? Are the data collected with or without the use of technology?
- (7) For how long are the data expected to be used? How long are the data actually used?

Based on these questions, we generated a set of seven dimensions important for understanding the space of PGHD: (1) the health focus of the study, (2) the type of data, (3) who proposes the use of PGHD, (4) whose data are collected, (5) who is intended to use the data, (6) what are the mechanisms of PGHD collection and use, and (7) what is the duration of PGHD use. The next subsection describes each of these dimensions and how different studies approach them. We argue that it is important to consider these seven dimensions when researching and developing technologies and solutions focusing on PGHD.

1.3 Overview of This Review

We primarily draw on the research literature published in the ACM digital library and PubMed repositories. We chose the ACM Digital Library because it contains papers from most of the relevant conferences and journals related to HCI and technology-oriented research, e.g., CHI, CSCW, Pervasive Health. As this study is primarily pursued from the HCI perspective, it is necessary for us to include papers published in ACM. We chose PubMed because it covers a wide range of medical and health studies that are particularly relevant for PGHD. Many studies in technology-oriented areas focus on technology design and the use of such technologies by healthcare consumers, while medical and health studies focus on supporting clinical practices. Analyzing these two repositories allows us to include both the patients' and providers' views and address their individual challenges in using PGHD. We did not intend to provide a comprehensive review of technologies and design approaches focused on PGHD collection and use, such as pervasive or mobile computing. Other reviews have explored the common features and design challenges of health and wellness applications (e.g., Consolvo *et al.*, 2014; Tentori *et al.*, 2012). Instead of examining aspects of the engineering design and features of technologies, since our focus in this review is from an HCI perspective we examine the data, the practices of collecting and using these data, and the consequences of this use. However, readers should be aware that there is much more relevant literature scattered among other medical, nursing, public health, mental health, science and technology studies, social sciences, media studies, and other general conferences, journals, and repositories. Due to the broad applications and diverse relevant concepts of PGHD, it is not feasible for us to comprehensively review all existing literature in this highly multidisciplinary area. In this review, we aimed to describe the current PGHD space, articulate a set of important dimensions to consider when researching and developing within this space, and discuss the main challenges identified in prior literature regarding PGHD. Although as HCI researchers we have a special interest in technology support, our focus in this review is broader than studies proposing new technologies, since people use health-related data in varied ways, and often without technology support.

To identify representative papers to include in this review, we performed multiple searches in the two databases, using combinations of different keywords, such as quantified self, patient-generated data, self-tracking, personal informatics, self-experimentation, personal data, self-monitoring, self-management, log, journal, diary, daily living, patient-reported, combined with health-related words such as health, healthcare, patient, illness, chronic, disease, conditions, symptoms, and outcomes. However, due to the broadness of the research space, each individual research query resulted in a large number of irrelevant studies, and many important studies did not appear in the results. As mentioned in the earlier subsection, PGHD literature is broad and interdisciplinary, with different terms used in different areas to refer to the same concept. This complex space makes it extremely difficult to conduct a comprehensive and systematic review. Instead of going through all the research results and attempting to review a complete list of papers, we opted to conduct a narrative review in which we selected relevant papers identified through our initial search, incorporated papers we are aware of in this area, and further searched for papers citing the key literature in the area. Besides these searches, we also draw on our own research experiences and those of our colleagues and fellow researchers, as well as from the list of references of several key publications.

Our general inclusion criteria for the papers analyzed in this review also included studies, pilot studies, and case studies focused on:

- (a) Data collection and use to support medical conditions or health-related concerns;
- (b) Health-related data used by patients or individuals, caregivers, and/or healthcare providers;
- (c) New technology solutions, such as wearable devices or self-tracking systems;
- (d) Individuals (both patients and caregivers) outside of traditional clinical settings; to understand their healthcare needs and their use of PGHD (e.g., interviews with patients or users, social media analysis, surveys);

- (e) Healthcare providers; to understand their views and experiences concerning PGHD use (e.g., interviews with healthcare providers, observation studies).

Based on this literature review, we identified seven important dimensions to define the research and design scope in researching and developing technologies for PGHD. We defined these dimensions through examining representative key literature in the area, emphasizing challenges in defining the term and the scope around PGHD. We articulate these dimensions to create a general guideline for researchers and developers to better study and understand the opportunities and challenges in studying PGHD.

The remainder of this review is organized as follows: Section 2 describes each dimension and their classifications, highlighting the challenges in classifying the papers; and Section 3 presents different open challenges related to PGHD, including the consequences of using these data for patients, caregivers, and healthcare providers.

2

Dimensions of PGHD

Based on the scope of PGHD described in Section 1 and on critical aspects or concerns outlined in prior research, in this section we discuss seven important dimensions for understanding PGHD. We identified these dimensions through the review to define the scope of PGHD and refined them based on the analysis of the papers discussed in this review. This set of dimensions is not intended to be comprehensive and there may be other aspects that ought to be considered. However, these are important dimensions for defining the scope of PGHD studies and systems that we suggest should be considered when researching and developing PGHD-related technologies and solutions.

The first dimension concerns the health focus: if the study or system is directly related to a specific medical condition or focusing on general wellbeing. The second dimension focuses on the most common types of data that are considered PGHD, from data directly related to the characteristics of an illness or health concern, to general contributing data, or to contextual data. The third dimension considers the initiation of data collection and use; more specifically, it focuses on who proposes the collection and use of PGHD for addressing the individual's care. The fourth dimension concerns the relation between the person collecting the

data, and the person whose data is collected, who may or may not be the same person. The fifth dimension discusses the users of these data, whether it is the individual being tracked, the healthcare providers, the caregiver, or a combination of multiple stakeholders. The sixth explores how studies approach PHGD collection and use; whether they focus on studying individuals' daily practices to gather insights for technology design, or on designing and evaluating new technologies. Finally, the seventh dimension discusses the temporal aspect of PGHD, i.e., how long and how frequently individuals are expected to use these data.

2.1 Health Focus

As the name of PGHD suggests, health data is a central focus of its scope. However, health is a broad term, which could refer to different illnesses or health-related concerns, general health and wellness, or physical or mental health. The first dimension focuses on the type of health focus of PGHD use, i.e., if the research study addresses specific medical conditions or health concerns (diagnosed or not) or if it approaches health through a more general and preventative perspective. This dimension serves as a fundamental guide for many other dimensions of PGHD use, influencing the goals of PGHD use, the stakeholders involved, the type of data being collected, the duration of data use, and how the data are used. This subsection focuses on the conditions/wellness aspects examined and the goal of the studies, aiming to describe how papers are using PGHD in specific disease contexts, or in preventative health or general wellbeing.

2.1.1 Related to a Specific Disease or Condition

Katz *et al.* (2018) highlight the differences between tracking health data in a disease versus non-disease context. First, diseases are non-elective: once one has the disease, one must deal with it. In many cases, particularly in chronic illness contexts, dealing with the condition involves tracking specific health indicators that are specifically crucial for this disease. The classic example is diabetes: once the person has diabetes, she needs to monitor glucose, diet, and exercise to avoid complications.

As a result, for many patients, engaging with PGHD may not be a choice, but rather a necessary step in managing their illness. Second, making informed decisions, such as establishing a treatment plan, involves using health data generated by patients themselves, especially regarding how treatments might affect and improve (or not) their daily living. And third, experiencing or living with an illness often affects the emotional aspect of health data usage, potentially reinforcing feelings such as fear, depression, shame, and guilt (Ancker *et al.*, 2015; Ayobi *et al.*, 2017; Costa Figueiredo *et al.*, 2017, 2018; Eikey and Reddy, 2017; Katz *et al.*, 2018). People often face their health and their relationship with “measuring devices” in different ways. One particular difference is between “an individual that must make daily measurements for a long time to monitor a life-threatening disease and someone doing preventive check-ups few times a year” (Grönvall and Verdezoto, 2013a).

The characteristics of some medical conditions point to or dictate the use of PGHD more than others. We focus on health-related data generated outside of traditional clinical settings that are often used to make decisions and changes outside of or in between clinical visits. Therefore, PGHD tend to have a chronic orientation. Chronic illnesses stand out because patients need to manage symptoms, measures (e.g., glucose measures, blood pressure values), and triggers. Therefore, patients often need to track their data as part of their care, and health providers can use these data to adapt or maintain the current treatment. Tracking personal information is in fact suggested for many chronic conditions (Ancker *et al.*, 2015). In addition, chronic illness care is moving more towards home care in order to better address individual needs of patients, which increases the importance of PGHD (Chung *et al.*, 2016).

The majority of PGHD research and technologies focus on chronic illnesses. Because of the long-lasting nature of the conditions and the activities that often occur outside of clinical visits, PGHD are particularly useful for such illnesses. However, as mentioned before, medical practices are dependent on information provided by patients, so the potential of PGHD is not restricted to chronic illnesses. Studies within the PGHD scope address diverse health concerns, such as support for the care of high risk infants (Cheng *et al.*, 2015; Liu *et al.*, 2011;

Tang *et al.*, 2012), physical and recovery therapy for different types of injuries and conditions (Bagalkot and Sokoler, 2011; Ploderer *et al.*, 2016), support for monitoring the recovery of surgery wounds at home (Sanger *et al.*, 2013, 2016), stress (Adams *et al.*, 2014; Morris *et al.*, 2010), etc. Table 2.1 lists the main health conditions or concerns encountered in the studies analyzed for this review. We categorized them in chronic, degenerative, mental health, rehabilitation, other, and not specific. The unique nature of each of these categories needs to be considered when developing or researching PGHD solutions (e.g., the long-lasting characteristic of chronic illnesses, the progressive characteristic of degenerative conditions, the stigma associated with mental health, and the recovery process involved in rehabilitation). However, each condition will also present its own characteristics, important health indicators to monitor, challenges, and opportunities for technology support. People can also experience these conditions in different ways. Therefore, when intending to support a specific medical condition through PGHD, it is necessary to consider not only broader aspects related to the illness, but also its specificities, especially people's daily experiences.

Papers that address multiple conditions (categorized under not specific) often approach health illnesses from different categories, including some that do not appear isolated in other examined studies. For example, in MacLeod *et al.*'s (2013) study, participants had asthma, diabetes, depression, epilepsy, fibromyalgia, gastroesophageal reflux disease, hereditary angioedema, low blood pressure, migraines, and osteoarthritis. We opted to not extract the conditions from these studies in Table 2.1 to show only the ones that were the main focus of each study.

Different goals, which often coexist, may trigger the use of PGHD in the context of a medical condition. Based on the literature, we list below the main reasons for using PGHD identified in the context of a medical condition or concern. The list provided below is an attempt to summarize potential reasons for PGHD use identified in different health contexts.

To manage symptoms The goal of PGHD use is more directly related to chronic diseases, since self-management is often expected and seen as an essential part of care (Chen, 2011; Grönvall and Verdezoto, 2013a).

Table 2.1: Summary of health conditions addressed by the analyzed papers.

Category	Conditions (number of analyzed studies)
Chronic	Asthma (1), Cancer (2), Chronic kidney disease (1), Chronic pain (1), Diabetes (17), Diabetes in pregnancy (1), Heart conditions (1), Hypertension (2), Irritable bowel syndrome (5), Juvenile idiopathic arthritis (1), Obesity (4), Hepatic encephalopathy (advanced liver disease) (1), Chronic fatigue (1), Endometriosis (1), HIV (1), Migraines (2), Vulvodynia (1), Chronic diseases (1), Multiple chronic conditions (1)
Degenerative	Multiple sclerosis (1), Neuromuscular disease (1), Parkinson (3)
Mental health	Bipolar disorder (5), Eating disorders (1), Amnesia (1)
Rehabilitation	Hip replacement rehab (1), Stroke rehabilitation (1), Vestibular rehabilitation (1)
Other	Eye health (1), Fertility challenges (2), High-risk infants (3), Sleep behavior (2), Smoking (1), Stress (2), Whiplash disorder (1), Post-discharge surgical site infection (2), Anxiety in autism (1)
Not specific	Physically-oriented conditions (1), More than one condition (10), No disease (3), Rare diseases (1)

Many projects aiming to support this type of PGHD use focus on managing vital signs, health behavior, and disease indicators (often proposing new technologies to support these activities), so patients can understand and adapt themselves and their behavior to their condition (Ayobi *et al.*, 2017; Grönvall and Verdezoto, 2013a). Often, PGHD for managing a chronic condition is expected to be a continuous task.

Management also includes avoiding complications when the goal is to identify early signs of something undesirable. For example, Sanger *et al.* (2013, 2016) studied the use of PGHD to assess and early identify signs of post-discharge surgical site infection, Ganapathy *et al.* (2017) approached PGHD to avoid readmissions due to hepatic encephalopathy in patients with advanced liver disease, and Weaver *et al.* (2007) explored

the use of PGHD to identify severe and potentially life-threatening toxicity levels in patients receiving chemotherapy. These approaches often aim to identify changes in the patient's state early enough to intervene and avoid worsening the condition.

Finally, management can also include improving the current health status or recovering from a health condition. Rehabilitation is an important case of management focusing on recovery (e.g., studies approaching stroke Ploderer *et al.*, 2016, hip replacement Bagalkot and Sokoler, 2011, and vestibular rehabilitation Huang *et al.*, 2014). This focus usually requires the patient to follow a set of specific exercises that need to be accompanied or evaluated by health providers. Johansen and Kanstrup (2016) presented an interesting example of using PGHD for the recovery of whiplash disorder: a psychological intervention for pain confrontation, aiming to “challenge the way patients associate experiences of pain and emotional distress with disability” so they would progressively reduce the fear of re-injury and thus more actively participate in their recovery through self-management (Johansen and Kanstrup, 2016). In this case, the focus of using PGHD for recovering was not the injury recovery itself, but psychological mechanisms that challenge or prevent recovery.

Management needs depend the condition, population, and context. For example, although diabetes has main characteristics and symptoms, it has different demands for pregnant women (e.g., requires closer monitoring) (Ballegaard *et al.*, 2008; Blondon and Klasnja, 2013), children (e.g., when parents are responsible for the care) (Toscos *et al.*, 2012a,b), and when it coexists with other chronic conditions (e.g., the care for one of them can negatively impact the other) (Ancker *et al.*, 2015; Lim *et al.*, 2016). Studies focused on avoiding complications may need to consider real-time feedback, who is going to review the data in real time, what are the actions to be taken when a complication is identified, and how to deal with false positives or false negatives. Studies on recovery need to explore how to deliver guidance, how patients and providers interact, how providers monitor patient's adherence, how patients understand the exercises and solve doubts, and how both discuss patient evolution and, potentially, discharge. Additionally, studies aiming to support management of health conditions need to consider not only the basic management needs of the disease, but also the target (and

untargeted) population and the context around them, including how PGHD technologies and practices would or would not fit in their daily lives (Ballegaard *et al.*, 2008).

To keep a record This reason for using PGHD encompasses tracking health-related data to keep a record either for healthcare providers or for the self. Some patients track PGHD mostly because their health providers asked, either in general, such as asking patients to track symptoms, or for more specific cases, such as instructing patients to track food consumption to gain approval for bariatric surgery or gastric pacemaker implantation (Ancker *et al.*, 2015; Chung *et al.*, 2016). This reason for PGHD use also includes cases in which a patient experiences a symptom and decides to record the information to show to their doctors. This focus is important because it demands that technologies and practices approach both patients' and providers' needs concerning PGHD in order to support them and their interaction through the data. Finally, besides creating records for interacting with healthcare providers, individuals may want to keep records of PGHD for themselves. For example, Rooksby *et al.* (2014) describe people may track for documenting pleasure activities, while Ayobi *et al.* (2017) describe patients using PGHD to evidence that they are doing everything they can to manage their condition. In both cases the documentation practices are directly related to individuals' emotional experiences.

To identify triggers and solutions This goal for PGHD use refers to finding relationships between symptoms and triggers (e.g., which food causes a flare in IBS symptoms Karkar *et al.*, 2015a,b, 2017), identifying which solutions have best results (e.g., exercising to reduce endometriosis pain McKillop *et al.*, 2018, or identifying the best combination of medications Bardram *et al.*, 2013, Frost *et al.* 2011). It does not necessarily imply an actual diagnosis: people may track to try to diagnose a health condition, including when they disagree with their providers (Rooksby *et al.*, 2014). Self-experimentation is based on this reason for PGHD use (Karkar *et al.*, 2015a,b, 2017). Karkar *et al.* (2015a,b, 2017) developed a framework based on single-case experimental designs to support patients in performing self-experimentation with their data to

identify their specific triggers. They approached self-experimentation primarily in the context of irritable bowel syndrome, a condition in which triggers differ for different patients (Karkar *et al.*, 2015a,b, 2017). Another context in which finding triggers and solutions is useful is bipolar disorder, a condition that requires experimenting with medications, coping habits, and behaviors to find an adequate treatment (Frost *et al.*, 2013). Avoiding possible triggers also fits in this category. Felipe *et al.* (2015) describe the case of chronic pain, in which PGHD could be useful for automatically detecting and warning patients of potentially dangerous symptoms, suggesting ways to counteract them in real time. Although providers had mixed feelings about this use (i.e., they believe it could cause dependence on the surveillance provided by the system), it would provide patients the chance to divert their focus from pain and toward other activities (Felipe *et al.*, 2015). Other types of conditions in which this use of PGHD can be especially important are the ones considered rare. In this case, there is a lack of information available, even to health providers, so PGHD collection and use becomes fundamental for the patients to understand their situation, manage their everyday lives, and interact with health providers and others (Felipe *et al.*, 2015; MacLeod *et al.*, 2013). Finding relations is a reason for PGHD use that demands support for the tests people need or want to perform. It also demands an increased rigor from technologies and practices so patients can correctly identify relations and interpret results, especially when they are looking for relations without the support of health providers.

To gather evidence and gain recognition This reason for PGHD use focuses on gathering evidence for patients, for healthcare providers, and for others (Felipe *et al.*, 2015; Schroeder *et al.*, 2018), particularly when the health condition is “invisible” (Felipe *et al.*, 2015) or “enigmatic” (Davies *et al.*, 2019; McKillop *et al.*, 2018). First, it is used to acquire recognition for individuals themselves: it works as a means for self-validating one’s own experiences, especially in the context of complex chronic conditions, which have different manifestations of symptoms and can create more uncertainty (e.g., migraines) (O’Kane *et al.*, 2016; Park and Chen, 2015; Schroeder *et al.*, 2018). Second, this reason for using PGHD is important to communicate one’s own experiences to

others and thereby gain social recognition and support (Mishra *et al.*, 2019; Park and Chen, 2015). In this context, PGHD can support easing the emotional load of many diseases and health concerns (e.g., infertility, eating disorders, migraines). This use of PGHD is also important in the case of rare diseases, in which patients must play the role of advocates and researchers (Davies *et al.*, 2019; MacLeod *et al.*, 2015). In addition, as suggested by Neff and Nafus (2016), using PGHD with this goal can help develop knowledge about conditions traditionally neglected by traditional health institutions, e.g., HIV in the 80s and chronic fatigue. In this context, self-tracking data aggregated across a population with an enigmatic disease “can provide a novel view of the disease, can help enhance scientific knowledge about the disease, and can help bridge the gap that exists between the patient experience of these enigmatic conditions and their current medical understanding” (McKillop *et al.*, 2018).

2.1.2 Related to Wellbeing or Preventative Health

Besides managing specific illnesses or health conditions, PGHD can also be used to manage a person’s general health or promote general wellness. These uses are often “tightly coupled with behavioral change” (Grönvall and Verdezoto, 2013a), and focus on a larger population, who are most often not patients. The most common examples are exercise and diet tracking. Estrin *et al.* (2016) use the term “data relevant for health care” to highlight the possibility of this other use, where the person may not be a patient, but can still perform tracking activities on their own with health-related goals (Estrin *et al.*, 2016).

In this scenario, tracking can be used to increase activity level (Consolvo *et al.*, 2008; Lin *et al.*, 2006), understand one own’s own body (e.g., track menstrual cycles Epstein *et al.*, 2017), encourage more water intake for health purposes (Chiu *et al.*, 2009), improve sleep quality (Choe *et al.*, 2015), etc. We analyzed papers examining varied health behaviors and wellbeing aspects, such as diet and exercise (2), exercise only (15), diet only (5), water consumption (1), emotions (3), breath and heart rate (1), child development (1), and multiple wellbeing aspects (6).

The goals associated with using PGHD for preventative health or general wellness are more aligned with the general goals for personal informatics described by Li *et al.* (2010), the reasons for self-tracking suggested by Rooksby *et al.* (2014), and the motivations for tracking suggested by Epstein *et al.* (2015). Based on the literature, we list below the main reasons for using PGHD in the context of preventative health or general wellbeing. Again, the provided list is an attempt to summarize the reasons identified in the analyzed papers.

Improving health and health behaviors Improving health and health behaviors is the main reason for using PGHD in the context of general wellness, which is often accomplished through behavior change techniques (Epstein *et al.*, 2015; Li *et al.*, 2010; Rooksby *et al.*, 2014). It relates to the primary goal for PI suggested by Li *et al.* (2010) and the behavior change goals suggested by Epstein *et al.* (2015). The most common goals are related to gaining, losing, or maintaining weight; therefore, many papers focus on diet and exercise. Another example could be using PGHD to increase water consumption (Chiu *et al.*, 2009).

Monitoring or documenting This reason often coexists with the previous one. It focuses on monitoring and documenting one's own health, but without a concrete goal in mind. As Rooksby *et al.* (2014) define, it concerns simply observing one's activities. Examples can include tracking menstruation days and symptoms to understand one's cycle (Epstein *et al.*, 2017), emotions (Hollis *et al.*, 2015), and the development of a child (Kientz *et al.*, 2009).

Curiosity or trend It is not uncommon for people to track health data out of curiosity, either about their measurements or about new technologies or gadgets (Epstein *et al.*, 2015; Rooksby *et al.*, 2014). They enjoy tracking; they want to know how much they walk, how many hours they sleep, and how many calories they spend in a regular day. They like gadgets and want to try new technologies. A person who is initially motivated by curiosity may start tracking for other reasons, including to improve health or a specific health behavior.

Competition or collaboration Competition and collaboration are often common mechanisms for engaging people in self-tracking. Although they are not goals or reasons for using PGHD, we decided to include competition and collaboration because some people only start tracking to take part in a competition, in the first case, or because they want to accompany someone else, in the second case. Competition is the case of campaigns in the workplace or schools, where people join to compete or win a prize (Gorm and Shklovski, 2016; Xu *et al.*, 2012). This involves people tracking to collect rewards, score points, or unblock achievements as they compete against themselves, friends, or strangers. Competition organizers have their own interests (e.g., to improve public health or reduce health insurance costs), but for some participants the initial reason for using PGHD may be the competition or involved prizes, and they may not have started collecting and using PGHD without the competition (Rooksby *et al.*, 2014). This reason for PGHD use can also relate to people joining self-tracking activities to support others, in a collaborative rather than competitive way (Chiu *et al.*, 2009). For example, Katule *et al.* (2016) used the concept of intermediaries (i.e., family members or close friends who would mediate the use of healthcare technologies during the health intervention) to motivate the beneficiaries (i.e., the patients) and facilitate the collection and use of PGHD. They used this strategy to try to improve the engagement of a population with low socio-economic status and who is unfamiliar or intimidated by such technologies and health interventions (Katule *et al.*, 2016). In this case, the intermediaries started using PGHD to support the beneficiaries, who were overweight or pre-diabetic. In both competition and collaboration, the interaction with others is important and it is the main initial reason for collecting and using PGHD. Although competition and collaboration can be specific reasons for starting using PGHD, they can and often do change over time.

Similar to using PGHD in the context of a specific health condition, these reasons for using PGHD for general wellness are not mutually exclusive; rather, they can overlap, coexist, or evolve into others. For example, a person who starts tracking only to receive prizes (competition or collaboration) in a competition may decide to keep tracking to lose weight or to run a marathon (improve health behaviors).

2.2 Type of Data

The second dimension focuses on the data collected and used. Many different types of data can be considered PGHD. Shapiro *et al.* (2012) classify PGHD types as (i) patient's vital signs measured by devices (e.g., glucose, temperature, weight, blood pressure), (ii) self-reported lifestyle data (e.g., exercise, water intake, medication), (iii) self-reported "perceived quality of life data" (e.g., pain level, mood, social interactions), and (iv) other data not directly health-related that help providers understand patients' cases and needs (Shapiro *et al.*, 2012). Using a different classification, MacLeod *et al.* (2013) categorize tracked data related to (i) episodes (prevention, trends and patterns, dealing with episodes, consequences), (ii) triggers (factors that may cause symptoms and episodes, dealing with triggers, trends and patterns), (iii) medication (dosage, efficacy, side effects, and elimination), (iv) status (current status of the condition), and (v) history (the progress of the condition) (MacLeod *et al.*, 2013).

The same data can also be used in different contexts and for different reasons. For example, data such as water intake, sleep, and diet can be used in the context of a health condition or for general well-being, depending on the focus of the tracking: diet can be tracked by a person who wants to eat healthier or maintain the weight for general health (Maitland and Chalmers, 2011; Schaefbauer *et al.*, 2015), but it can also be tracked by a person with diabetes who has specific concerns about diet (Blondon and Klasnja, 2013), or by a person with IBS to identify whether a specific food triggers an episode (Karkar *et al.*, 2017). Water intake can be tracked to incentivize healthy water consumption (Chiu *et al.*, 2009) or by a person with kidney disease who needs to limit liquid intake (Havas *et al.*, 2016). Additionally, people may use technologies that are not necessarily focused on health for health and well-being reasons (Rooksby *et al.*, 2014), suggesting that other types of data that are not directly health-related (e.g., weather) can also be useful for people concerned about their health.

Considering this broadness of data that can potentially be used for health, a general classification of the data according to their purpose seems more adequate for this review: (i) data specific related to a health

condition or concern, (ii) general data that can be used in the context of multiple health conditions and for wellness and preventative health, and (iii) context data, which is not strictly related to a health issue, but can give supporting information for users.

2.2.1 Data for a Specific Illness or Health Concern

Researching and developing solutions for a specific disease or health concern involves tailoring the data collection and use for that specific case. Some conditions require close monitoring of specific data or primary disease indicators (Ayobi *et al.*, 2017; Loos and Davidson, 2016) such as water intake in kidney disease (Havas *et al.*, 2016), diaper use in pre-term infants care (Cheng *et al.*, 2015; Liu *et al.*, 2011; Tang *et al.*, 2012), sleep in juvenile idiopathic arthritis (Pina *et al.*, 2017), or number of bowel movements in hepatic encephalopathy (Ganapathy *et al.*, 2017), etc. In these cases, designers and researchers traditionally turn to current scientific knowledge about the condition they are exploring to identify which data is relevant to track (McKillop *et al.*, 2018). The same is true for using PGHD for general wellness: depending on the focus of PGHD use, there will be primary indicators that are specific to that context, such as sleep duration when focusing on sleep habits (Choe *et al.*, 2015; Kay *et al.*, 2012).

These data can be simpler to manually collect, such as pictures of wounds (Sanger *et al.*, 2013) or dirty diapers (Cheng *et al.*, 2015), automatically collected such as steps number gathered by sensors (Zulman *et al.*, 2013), or more complicated measurements such as fetal heart bits and uterine contractions that need specific machines and processes to collect (Grönvall and Verdezoto, 2013a).

2.2.2 General Health Data That Are Not Disease Specific

Other types of data are more general and useful for a broad range of conditions. A clear example is diet, which, besides being a common focus in preventative health or general wellness, is important, in different ways, to diabetes (Desai *et al.*, 2019; Raj *et al.*, 2019), irritable bowel syndrome (Karkar *et al.*, 2015a,b, 2017; Schroeder *et al.*, 2017), obesity (Katule *et al.*, 2016; Lee *et al.*, 2006; Tsai *et al.*, 2007;

Zulman *et al.*, 2013), eating disorders (Eikey and Reddy, 2017), etc. The same is true for mood, exercise, water intake, sleep. Since these represent essential human needs, multiple tracking activities are designed to capture them, and people track them with various goals and reasons for using PGHD. For example, Emmons and McCullough (2003) focused on a specific health condition, i.e., neuromuscular disease, but their intervention was not focused on the primary disease indicators; rather, they focused on the patient's emotional state. Choe *et al.* (2015) examined sleep behavior, and mention that most of the factors impacting people's sleep are not the specific measures of the target behavior (sleep measures, such as sleep duration), but contributing factors, such as meals, exercise, caffeine, etc. Finally, Bussone *et al.* (2016) describe how most of their participants were more interested in tracking information that was indirectly related to their condition (i.e., HIV), such as emotions and food, rather than specific to it.

2.2.3 Contextual Data

Many studies included data that are neither primary disease indicators, nor primary indicators of the wellness aspect in question, nor general health data. These studies often name these data as “contextual,” and use this contextual information to help patients make sense of their health data. For example, Grönvall and Verdezoto (2013a) suggest the collection and use of other data, such as the locations the person visited during the day, and other routine and contextual information, to support data understanding. For example, data about one's appointments may support users to recall what they were doing when they experienced a symptom. Raj *et al.* (2019) argue that contextual data are an important addition to clinical measures or disease indicators that can “help people connect disease management with different aspects of their lives” (Raj *et al.*, 2019). Because care management at home is “highly context-dependent” (Grönvall and Verdezoto, 2013a), including this type of data would better support self-reflection and help explain why the data are how they are (Smith *et al.*, 2007). Sanger *et al.* (2016) highlight that contextual metadata are important to health providers as well, for example patient reliability and anxious tendencies can be

useful to providers for better understanding patients' experiences during treatment.

Contextual data vary widely; they can involve information about patients' location (Felipe *et al.*, 2015; Luo *et al.*, 2019), travels they made (Blondon and Klasnja, 2013), events they attended (Bentley *et al.*, 2013; Murnane *et al.*, 2018), the weather (Bentley *et al.*, 2013) etc. One pervasive piece of contextual data is also one of the simplest ones: comments associated to the measurements. Many studies and technologies add the possibility for users to add comments concerning the measures (Aarhus *et al.*, 2009; Ayobi *et al.*, 2017; Bagalkot and Sokoler, 2011; Felipe *et al.*, 2015; Johansen and Kanstrup, 2016). This type of contextual data can be important to understand the circumstances around each specific measurement (Aarhus *et al.*, 2009; Bentley *et al.*, 2013).

Data for the specific illness or health concern being studied are the most obvious type of data to consider when studying PGHD. However, health conditions, health concerns, and wellness are not isolated issues. They interact, impact, and are impacted by multiple aspects of a person's life. Therefore, it is important to explore, and consider in the design of PGHD systems, different types of data that may be useful or contribute to the experiences of not only patients, but also other involved stakeholders.

2.3 Who Initiates Data Collection

As the scope and definitions related to PGHD we discuss in Section 1 suggests, it is important to consider who initiates data collection activities of PGHD: the patient (or individual), the healthcare provider, or others, such as insurance companies or hospital administrators. This is an important dimension that serves as basis to explore the use of the data and design of technology. The initiation of PGHD collection (particularly patient- or provider-initiated) may directly influence how these data are used and the collaboration between patients and providers (Chung *et al.*, 2016; Zhu *et al.*, 2016). For example, some authors highlight the importance of "physicians' willingness" or "provider buy-in" to the success of developing and using PGHD technologies (Loos and Davidson 2016; Nundy *et al.*, 2014), while others describe

patients think that systems recommended by providers are too rigid (MacLeod *et al.*, 2013).

Despite its potential impact on the success of PGHD use, this dimension is often hard to classify. First, while one can assume that most papers describing preventative health or wellness systems focus on patients using PGHD by their own initiatives, the papers focused on medical conditions are less clear. Second, when the paper focuses on understanding the practices of patient populations with different medical conditions, the initiative of collecting and using PGHD varies from case to case (i.e., some patients start using PGHD because their healthcare providers suggested it, while others decided on their own to use these data) (MacLeod *et al.*, 2013). Because of these aspects, this dimension is characterized here in 3 groups: provider-initiated, patient-initiated, and other-initiated (e.g., researchers, government policies, insurance companies). We included papers describing caregivers starting the use of PGHD within patient-initiated PGHD use, because, despite their specific challenges (approached in the next dimensions), their main interests are commonly aligned with patients' interests (especially when compared with providers and others initiating PGHD use).

2.3.1 Provider Initiation

Considering that patients' data are fundamental to healthcare, it is not unusual for providers to ask patients to track health indicators, especially when patients have chronic conditions. For example, provider-directed tracking is widespread in irritable bowel syndrome to investigate which foods trigger symptoms (Schroeder *et al.*, 2017). Other examples of conditions in which provider-directed tracking is common are diabetes (Frost and Smith, 2003) and hypertension (Ballegaard *et al.*, 2008).

Studies describe different reasons why providers would propose that patients track PGHD, whether to: support diagnosis, foster patient engagement, manage treatments, assess medication effects, determine patient state, manage chronic conditions or persistent symptoms after procedures or during rehabilitation, discuss barriers preventing patients to achieve health goals, and gain approval for procedures (Chung *et al.*, 2016; Zhu *et al.*, 2016). Healthcare providers usually have

a very specific goal when asking patients to track health indicators, and thus these data are valuable to them. However, this value is not the same when patients initiate the tracking (Zhu *et al.*, 2016). Zhu *et al.* (2016) report that providers did not find PGHD tracked through patients' initiation useful, often considering the data incomplete or irrelevant, and other studies (Grönvall and Verdezoto, 2013a; Nundy *et al.*, 2014; Sanger *et al.*, 2016) describe how providers prefer to target specific sub-populations or individuals to ask for PGHD (e.g., individuals with uncontrolled diabetes or with poor health history).

Providers' initiation impacts patients' use of PGHD as well, especially when provider guidance involves the direction to use specific technologies. MacLeod *et al.* (2013) observed that systems recommended by providers are often more rigid and structured, providing less flexibility. In this context, although providers' authority can work as a motivation for the patient to track (Zhu *et al.*, 2016), this lack of flexibility may cause frustration and even abandonment (MacLeod *et al.*, 2013). The authority may, however, provide a good incentive for patients who have in the past lacked motivation to track. However, if patients already track on their own and for their own reasons, a conflict of expectations with their providers, concerning what, how, and how often to track, for example, may arise (see Section 3).

2.3.2 Patient Initiation

When the focus is on wellness and preventative health, people usually initiate PGHD use without the advice of health providers; this is because they are not acting as patients, but rather as individuals motivated to gain self-awareness, self-knowledge, and improve their health behaviors (Rooksby *et al.*, 2014). For example, a person may decide to collect diet data in order to eat healthier and reduce heartburn. A person in this situation often does not look to a healthcare provider to help change their eating habits. However, when PGHD are used for a medical condition or health concern, a patient may self-initiate PGHD collection and use for other reasons, such as to develop self-management skills, curiosity (e.g., to determine if the treatment is working), to better

collaborate with providers and answer their questions, to change or stop medications, or to change treatment plans (Zhu *et al.*, 2016).

Patients who are diagnosed with a specific disease may start using PGHD to gain more information on their health conditions, such as if they feel they did not have enough from the health providers or to translate the information they receive into terms they can relate to (MacLeod *et al.*, 2013). Patients can also start tracking to show doctors proof of their experiences and thereby to form a basis for questioning prescribed treatment or medication (Chung *et al.*, 2016). For example, Ayobi *et al.* (2017) report on patients with multiple sclerosis who had reservations concerning their health providers and decided to take medications their providers were skeptical about. These patients decided to explore their condition by themselves to better adjust to life with a degenerative disease. This example indicates how PGHD can be involved in tensions between patients and providers regarding issues such as expectations, trust, liability, and data completeness and accuracy (see Section 3). Individuals may also initiate PGHD tracking aiming to diagnose or to help in the diagnosis of a condition.

2.3.3 Other Stakeholders

Many studies do not make it clear who initiates or suggests the use of PGHD. Often it is likely that the researchers who designed the study proposed PGHD collection and use. If there is a health provider in the research team, this could mean that the suggestion of using PGHD emerged from the providers, at least during the study. However, often it is not clear how it would happen in a real scenario.

Other actors who can influence the initiation of PGHD use are hospitals, workplaces or school administrations, insurance companies, or even governments, particularly through campaigns and health promotion programs. Studies approaching this context usually focus on the impact of such campaigns on participants, describing benefits (e.g., the social component stimulating participants) (Vyas *et al.*, 2015) or possible negative consequences (e.g., moral accounting, privacy, social pressures, and impact on non-participants) (Gorm and Shklovski, 2016). For example, Zulman *et al.* (2013) analyzed a workplace insurance-incentivized

program, reporting that some participants felt forced to participate due to financial incentives, or excluded for having fewer resources or less access to healthy activities. These cases of others initiating the use of PGHD add a new layer in the power structure involved in PGHD use, which can bring both positive consequences, such as increasing the incentives and range of health programs, which may favor positive health consequences (Vyas *et al.*, 2015), and negative ones, such as imposing other moral and social pressures on the users, which can ultimately undermine their efforts and participation (Gorm and Shklovski, 2016; Zulman *et al.*, 2013).

2.4 Whose Data Are Collected

Although many terms in Section 1 use the word “self” to describe the activities of PGHD collection and use (e.g., self-tracking, self-management, self-monitoring), the person collecting the data and the person whose data are collected are not necessarily the same. Neither it is necessarily an individual activity. The presence of different actors and their characteristics introduce other challenges into PGHD use. This subsection focuses on the “data subjects” (Nissenbaum and Patterson, 2016), discussing why their different perspectives matter and how studies in the area have approached them.

2.4.1 People Tracking Their Own Data

One person tracking or monitoring herself is the basic and most studied case of PGHD use, and forms the basis of most devices and interventions. Studies thus often focus on supporting people’s individual PGHD use, how to better embed these activities in people’s daily lives (Aarhus *et al.*, 2009; Epstein *et al.*, 2015; Rooksby *et al.*, 2014), and how to encourage routine use and avoid abandonment (Clawson *et al.*, 2015; Epstein *et al.*, 2016; Figueiredo *et al.*, 2017). These studies are often more directly related to the personal informatics model and the barriers people face in each of its stages (i.e., preparation, collection, integration, reflection, and action) (Li *et al.*, 2010). Many studies also discuss the

consequences (positive or negative) of collecting and reflecting on PGHD (Ancker *et al.*, 2015; Ayobi *et al.*, 2017; Eikey and Reddy, 2017).

However, although PGHD technologies, such as self-tracking systems, focus on the data of an individual, the impact of examining data of the “self” can be social and collaborative. In fact, tracking, and consequently using PGHD, is more often a social and collaborative activity than a personal one (Murnane *et al.*, 2018; Rooksby *et al.*, 2014). This is exemplified by research concerning data sharing (Jacobs *et al.*, 2015) and collaborative programs, such as workplace campaigns (Gorm and Shklovski, 2016; Vyas *et al.*, 2015; Zulman *et al.*, 2013). Other studies also describe how people turn “individual” self-tracking activities into collaborative sensemaking efforts (Costa Figueiredo *et al.*, 2017). Moreover, PGHD technology, like other technologies in our society, is not neutral; it is always embedded in a “social ecology” (Kranzberg, 1995), which includes discourses that can powerfully influence individuals, such as discourses concerning gender and racial representation (Epstein *et al.*, 2017; Fiore-Gartland and Neff, 2016; Murnane *et al.*, 2018). In this sense, although self-tracking and PGHD are often described in terms of the individual, they are also part of social situations and “beliefs about how societies function” (Neff and Nafus, 2016). For instance, Costa Figueiredo *et al.* (2018) discuss how self-tracking for fertility may reproduce discourses concerning gender (e.g., that every woman menstruates and that only the people who menstruate are women), fertility (e.g., that an infertile woman is not “normal”), women’s representations (e.g., that women need to be stereotypically feminine), and social roles (e.g., that it is a woman’s role to have children). Eikey and Reddy (2017) approach similar questions in the context of eating disorders and food tracking apps, discussing how the culture of the thin body ideal can be embedded in weight loss apps. Lupton (2013a,b) examines the use of self-tracking technologies through a critical lens, discussing aspects of healthism (which values people who are willing and have the resources to take the responsibility for their health as “ideal citizens”) and control of the body, such as how self-tracking technologies demand users to perform self-surveillance and imply that those who do not engage in such activities are “inferior or morally deficient” (Lupton, 2013b). These broader societal influences (discussed in Section 4) are

important to this dimension because even when PGHD refer to the data subject and data receiver as the same person (the person is performing data collection on herself and reflecting on it), there is still a broader social context that makes self-tracking and monitoring a social activity.

2.4.2 Others Tracking the Person

Although health tracking is often primarily seen as an individual activity (e.g., *self-tracking*, *self-monitoring*), it often involves others tracking the person, whether in collaboration with them or not (Hong *et al.*, 2016; Murnane *et al.*, 2018; Pina *et al.*, 2017). For example, families usually are collectively involved in PGHD use, especially with children who have chronic illnesses (Hong *et al.*, 2016; Kumar *et al.*, 2016; Pina *et al.*, 2017; Raj *et al.*, 2019). Pina *et al.* (2017) describe “second-hand tracking,” which refers to when a different person tracks the “self.” They describe primary and secondary caregiver roles, where the primary is more involved in caring, monitoring, and exchanging information with health providers (Pina *et al.*, 2017). The secondary (e.g., the second parent, a sibling, another family member) assists the primary (Pina *et al.*, 2017). Ancker *et al.* (2015) propose that the benefits of this division of labor include a reduction of burden on individual caregivers and the possibility of expertise development for them.

When a person cannot collect and use PGHD, such as in the case of high-risk infants (Cheng *et al.*, 2015; Liu *et al.*, 2011; Tang *et al.*, 2012), caregivers become fully responsible for these activities. In this context, Pina *et al.* (2017) emphasize the importance of recognizing the impact of caregiving (through the use of PGHD) on the other family members. When children get older, their role should transition to a more active one, involving collaboratively collecting their own data with their parents. Toscos *et al.* (2012a) highlight the importance of parents’ engagement in child diabetes management. However, they also describe potential adverse effects on children: an excessive focus on measuring blood glucose by the parents may cause a feeling of excessive surveillance in the children (Toscos *et al.*, 2012a,b). These conflicts become more visible when children become adolescents, aggregating or exacerbating issues of self-esteem, lack of trust, privacy, and independence

(Toscos *et al.*, 2012b). In this context, Hong *et al.* (2016) claim that technologies need to support both adolescents and parents in different ways, and to create and support the notion of partnership between them. A similar context may be observed in the case of older adults: PGHD practices may be performed collaboratively (Caldeira *et al.*, 2017) or even entirely without the intervention or participation of the elderlies, generating confusion or even intimidation (Ballegaard *et al.*, 2008).

These approaches extend data collection and use beyond the self, expanding the focus of PGHD from an individual activity performed by a single person towards a collaborative effort. However, most of the current technologies and practices do not offer sufficient support for these other actors (Pina *et al.*, 2017). Understanding these collaborative practices and each person's role in PGHD collection and use is fundamental to support these populations.

2.5 Who Uses the Data

Who uses the data is one of the most important dimensions because it directly influences how the data should be presented, potential sharing mechanisms, and who will be directly involved in using PGHD. This dimension refers to the “data recipients” of Nissenbaum and Patterson's framework (Nissenbaum and Patterson, 2016) and who uses the data largely influences the usefulness of the data. Based on the literature, this subsection discusses four main possibilities of data recipients within this dimension: (i) only patients are intended to use the data, (ii) only providers are intended to receive and analyze the data, (iii) both providers and patients have access to and use the data, and (iv) caregivers or others close to the patients use the data.

Some examples of well-defined intended users are: (i) Frost *et al.* (2011), who clearly state “we are presenting a system to help with the treatment of patients who have bipolar disorder, which aims for both the patients, the clinicians and the relatives” (Frost *et al.* 2011), and (ii) Dohr *et al.* (2012), who describe their prototype system was “designed for newly diagnosed diabetes patients, working in conjunction with physicians” (Dohr *et al.*, 2012). However, though it is often possible to assume through the text, few papers clearly state whom the authors

envision or expect to use the collected data. In addition, some studies are harder to classify within this dimension, especially when they approach multiple patients with different conditions (e.g., MacLeod *et al.*, 2013). This subsection describes data use by patients, close others or caregivers, and healthcare providers. We do not discuss data use by institutions (e.g., hospital administrations and health insurance companies), since the studies reviewed in this paper did not explicitly focus on this aspect (although it is mentioned and acknowledged by some of them).

2.5.1 The Intended Users of PGHD Are Patients

The use of PGHD solely by patients is directly related to the quantified-self movement and the popularization of commercial self-tracking technologies (Choe *et al.*, 2014; Neff and Nafus, 2016; Quantified Self, n.d.). When concerning health, often “quantified-self” encompasses taking control of one’s own health (Neff and Nafus, 2016). In fact, among the main benefits attributed to self-tracking and PGHD use is patient empowerment (Ayobi *et al.*, 2017; Demiris *et al.*, 2008; Grönvall and Verdezoto, 2013a).

Studies focusing on wellness and preventative health more commonly focus on “patients” as the sole users of PGHD, since the “patients” are not necessarily under clinical care, and thus health providers are not necessarily involved. However, even in studies focusing on specific health conditions, patients can be the sole users of the PGHD. Diabetes is a good example of a health condition commonly explored by studies that center the patient as the intended user of PGHD (e.g., Blondon and Klasnja, 2013; Katz *et al.*, 2018; O’Murchu and Sigfridsson, 2010), potentially because researchers and developers consider diabetes straightforward enough that patients can manage their care with little provider intervention. Other conditions these studies investigate vary, including: IBS (Karkar *et al.*, 2015a, 2017), eating disorders (Eikey and Reddy, 2017), whiplash disorder (Johansen and Kanstrup, 2016), stress (Morris *et al.*, 2010), smoking (Paay *et al.*, 2015), etc.

This use of PGHD can be particularly important for gathering evidence and recognition: patients can, besides understanding their condition, better explain their symptoms to others, such as health providers

(e.g., some participants in MacLeod *et al.*, 2015 study), family members, friends, or coworkers (Felipe *et al.*, 2015; Mishra *et al.*, 2019). Other positive consequences of this use of PGHD, as described by Gregory and Bowker (2016), can be seen in the context of sleep issues: patients can analyze their sleep patterns at home, a much more familiar and much less overwhelming place than sleep monitoring rooms. The case of the “home-made artificial pancreas” also exemplifies an ingenious use of PGHD by patients (Neff and Nafus, 2016; Ramirez, 2015): a couple used the wife’s well-known patterns of eating, exercising, glucose measures in a continuous glucose monitor, and her implanted insulin pump to avoid nighttime hypoglycemia by automatically triggering insulin during the night. Despite some controversy concerning risks and liability of “do-it-yourself” approaches, these examples illustrate how PGHD can inspire the development of user-driven technologies that attend to user’s specific needs (Neff and Nafus, 2016).

However, especially in the context of health conditions or concerns, patients may want to involve providers (Karkar *et al.*, 2017). When PGHD is solely used by patients, these data can contribute to information overload for them (Barbarin *et al.*, 2016): people may feel confused with the amount of data and face challenges trying to reflect on them (Li *et al.*, 2010, 2011). Interpretation may be complicated, and patients may generate wrong conclusions from the data (Karkar *et al.*, 2017). Healthcare providers collaboration can “influence how people make decisions about what, when, and how long to track; how to interpret the resulting data; and what to do based on the results” (Chung *et al.*, 2019). However, if patients decide to take these data to doctors, often the technologies may not support collaboration (Chung *et al.*, 2016, 2019).

2.5.2 The Intended Users of PGHD Are Providers

Although a possible way to distinguish PGHD from data collected in clinical settings is that patients are responsible for *collecting and deciding to share* the data (Loos and Davidson, 2016), some studies focus on only providers using the data. Only a few studies analyzed for this review discuss healthcare providers as the only actors intended to

use PGHD. In these cases, the patient collects the data and directly sends it to the provider, without receiving the data back for reflection (apart from during medical appointments). Some studies in this context describe interventions based on telephony systems, in which patients receive calls or messages with questions that they answer and send to their health providers (Anhøj and Møldrup, 2004; Farzanfar *et al.*, 2007; Nundy *et al.*, 2014; Weaver *et al.*, 2007). Even mobile applications can fit in this category when they only acquire data from patients and transmit these data to providers, with no access to the collected data on the patient's side (Pinsker *et al.*, 2008). Other examples are studies focusing on wearables for physiotherapy, when the patient has no or very limited access to the data before the medical appointment (Huang *et al.*, 2014; Ploderer *et al.*, 2016).

These studies often include the proposal of a system or technology and an intervention based on it. They commonly focus on patient compliance, early identification of worsening symptoms or behaviors, and treatment outcomes. This type of intervention most often initiated by health providers: all the papers analyzed for this review that fit in this category were also categorized as initiated by providers in the dimension referring to who initiates PGHD use. Not all studies in which providers propose data tracking will focus only on the providers' use of data, but it makes sense that the ones that describe health providers as the only recipients also assume or suggest that they would be the ones to propose the activities to the patients.

2.5.3 Both Patients and Providers Use PGHD

One of the possible benefits of PGHD is to improve patient-provider collaboration (Cheng *et al.*, 2015; Jacobs *et al.*, 2015; O'Kane and Mentis, 2012; Schroeder *et al.*, 2017), since it can combine patients' expertise in their routine, lifestyle, and illness experience, with providers' medical knowledge and expertise (Chung *et al.*, 2016; Schroeder *et al.*, 2017). For these reasons, some studies explore how to leverage PGHD for both actors. We classified as "both" any study that approaches data sharing between patients (and others) with healthcare providers.

However, the technologies patients use typically are not designed to support collaboration with providers (Chung *et al.*, 2016, 2019).

Some systems and studies explore collaboration between patients and providers using PGHD more directly, e.g., (Aarhus *et al.*, 2009; Cheng *et al.*, 2015; Chung *et al.*, 2019; Kumar *et al.*, 2016; Schroeder *et al.*, 2017). These approaches offer visualizations, communication platforms, and support for using the data in both contexts. In an interesting approach, Kumar *et al.* (2016) started from two systems that focused on patients and providers separately: consumer continuous glucose monitors and the Electronic Health Records (EHR). They then combined the two to integrate PGHD with clinical practices, providing pattern and thresholds identification, and triggering communication between patients and providers. Other systems were not designed for collaboration, but end up used this way: Grönvall and Verdezoto (2013a) describe two PGHD interventions that focused on sending patients' data directly to providers for their assessment of patients' conditions, however, because patients had access to the data, they ended up using their data for their own reflections and learning processes, helping them to understand their condition. Similarly, although many patients track their data on their own, often they turn to healthcare providers' expertise when they have difficulties in analyzing their data or in deciding if and what actions are necessary (Chung *et al.*, 2019). However, Chung *et al.* (2016, 2019) argue that current commercial personal informatics systems often do not support collaboration among patients and providers. They found that patients try to overcome this barrier by creating boundary negotiating artifacts to support collaboration.

Despite the possible benefits and the efforts of research on collaboration between patients and providers through PGHD, many conflicts and tensions arise when trying to support both needs (Sanger *et al.*, 2016). Some of these challenges are: differences in goals and expectations (O'Kane and Mentis, 2012), time and resource pressures (Chung *et al.*, 2016, 2019), type of data each actor needs and wants (Jacobs *et al.*, 2015; Vandenberghe and Geerts, 2015), and the involvement of multiple providers (Grönvall and Verdezoto, 2013a; Kumar *et al.*, 2016; O'Kane and Mentis, 2012). These conflicts can generate dissatisfaction,

disengagement, and even system abandonment, especially among patients (Chung *et al.*, 2016; MacLeod *et al.*, 2013).

2.5.4 Caregivers Use PGHD

Besides patients and providers, other actors may use or interact with PGHD. Although health tracking at an individual level is important, many aspects of health or health-related behaviors affect and are affected by other people (Pina *et al.*, 2017). This is closely related to the dimension discussing whose data are collected: when the tracked person is not the one who is collecting the data, it is natural that the person collecting the data will also primarily use the data. This can be done collaboratively or not (Grönvall and Verdezoto, 2013a). So, this subsection encompasses data used exclusively by: caregivers (that is, the person whose data is collected does not use it); or the patient (or person whose data is collected) alongside caregivers (e.g., caregivers monitoring data from newborns Cheng *et al.*, 2015 vs. caregivers collectively monitoring the medical condition of a teenager Hong *et al.*, 2016).

Grönvall and Verdezoto (2013a) call the group of people involved in collaborative care a “care network.” Families and informal caregivers are the most common example, which the authors call the “intimate care network.” Barbarin *et al.* (2016) argue that families often share chronic illness experiences and play a fundamental role that can impact patients’ outcomes. As previously described, Katule *et al.* (2016) used intermediaries (i.e., family members or close friends who would intermediate the use of healthcare technologies during the health intervention) to motivate and help the beneficiaries (i.e., the patients). This strategy has the potential to support populations that may be unfamiliar with or intimidated by the technology or health intervention (Katule *et al.*, 2016).

This collaborative PGHD use can bring many benefits. Among them, Ancker *et al.* (2015) discuss aspects of labor division, highlighting that one family member can specialize in information management while the others perform supporting activities, alleviating the burden on the patient. Grönvall and Verdezoto (2013a) suggest that this context

of shared information contributes to feelings of security and safety. However, according to Barbarin *et al.* (2016), family members are not as researched in PGHD-related studies. Grönvall and Verdezoto (2013a) share a similar opinion, affirming that technologies are usually developed to focus on two actors, the patient and provider, and lack support for families and other close members of the care network.

Pina *et al.* (2017) highlight the importance of identifying ripple effects. They found, for example, that parents want to know how the behavior (e.g., sleep quality or mood) of one person in the family would impact the others. In a similar vein, Cheng *et al.* (2015) included in their system focused on preterm infants a screening questionnaire to monitor mothers' postpartum depression. The system used the data to calculate a threshold and warn the patient and provider (Cheng *et al.*, 2015). However, while this screening was used to send the alert, parents did not have access to the data in a way that supported their reflection. In another example of PGHD's influence on the lives of the intimate care network, Neff and Nafus (2016) described the Nightscout project, in which parents of children with diabetes modified a continuous glucose monitor to display data on a smartphone or smartwatch, rather than on the original clinical device. Parents could then monitor their child's glucose when they are away, such as when they are at a friend's house. The Nightscout project also supported parents' social lives, since they could freely monitor their child's glucose readings using an everyday consumer device, rather than one with a clinical appearance. This user-developed approach did not consider measurements from other family members, only those from the patient. However, it considered how the measurement routine impacts the relatives' lives. The Nightscout project illustrates how a seemingly small change such as the device that displays a patient's data can have ripple effects that pervade the lives of their caregivers.

Despite the benefits, the use of PGHD by others introduces further challenges. First, the amount of data can quickly become overwhelming for patients and caregivers (Pina *et al.*, 2017). Second, members of the care network may interpret the data differently according partially to their health literacy (Barbarin *et al.*, 2016; Hong *et al.*, 2016; Liu *et al.*, 2011). Hong *et al.* (2016) suggest that technologies should

allow both patient and family assessment of symptoms to avoid conflicts of interpretation and also to contribute to providers' decision-making. Another significant challenge is privacy (Schaeffbauer *et al.*, 2015; Hong *et al.*, 2016; Pina *et al.*, 2017; Toscos *et al.*, 2012b), which involves different needs depending on the affected population: young children, adolescents, older adults, etc. Pina *et al.* (2017) claim that privacy issues may prevent families from using PGHD technologies. Finally, it is important to account for caregivers' motivation, support, division of labor, and access, in order to avoid problems due to the apparent disconnection between who performs the data work and who benefits from it (Grönvall and Verdezoto, 2013a; Liu *et al.*, 2011; Pina *et al.*, 2017; Tang *et al.*, 2012).

2.6 Mechanisms of Data Collection and Use

This dimension concerns studies' orientation towards the mechanisms supporting PGHD collection and use. Although technology provided many benefits to PGHD use, patients have been collecting their data for decades and studies of people's health management practices may provide valuable insights for future technology development. In this context, we characterized the analyzed papers in two categories: studies focused on (i) studying people's current daily health management practices and experiences (with or without technology use) to inspire future technology design, or (ii) proposing and evaluating new technology solutions for PGHD.

2.6.1 Studying Daily Practices for Technology Design

Many studies focus on individuals' daily health management practices, often aiming to gain insight into how technology can better support them. In some studies on how patients manage their information, patients (by the descriptions offered in the papers) mainly use paper (Chen, 2010, 2011). Paper diaries are common tools for keeping a log of health measures, such as weight, medication compliance and effects, and general symptoms (Cortez *et al.*, 2018). Zhu *et al.* (2016) report that in their

study about half of the providers preferred paper-based data tracking over the use of technology.

Other studies aim to understand people's practices, often regardless of the means they use, to identify design implications for improving or developing new technological tools (Ayobi *et al.*, 2017; Ballegaard *et al.*, 2008; Costa Figueiredo *et al.*, 2017; Epstein *et al.*, 2017, MacLeod *et al.*, 2013, 2015; Murnane *et al.*, 2018). These studies are usually exploratory and qualitative, making use of interviews or other means of collecting users' opinions, such as using surveys (with open-ended questions) and online forum data. In a different approach concerning PGHD without technology support, Figueiredo *et al.* (2017) found, through a quantitative study, a possible relation between relying on memory to self-track PGHD and a decreased likelihood of routine tracking.

2.6.2 Designing and Evaluating Technologies

The use of PGHD is not new in the literature; however, much of the technology that helped to popularize the term and practices is recent (Cortez *et al.*, 2018). In this sense, many studies approach PGHD through a technology point of view, proposing or evaluating a new technology, or investigating the impacts and benefits of new systems. Many of these technological solutions are proposed to support existing practices that traditionally rely on paper-based PGHD, such as diabetes (e.g., O'Murchu and Sigfridsson, 2010; Sanger *et al.*, 2016; Schroeder *et al.*, 2017). These systems often focus on facilitating information recovery and meaning making (e.g., Hodges *et al.*, 2006). Other systems focus on automating data collection to reduce the burden of tracking (Rooksby *et al.*, 2014). Within this category, wearable technologies stand out as the primary solution, particularly the ones focusing on physical therapy or injury recover (Huang *et al.*, 2014; Ploderer *et al.*, 2016). Another type of technology focuses on self-experimentation, aiming to bring some level of rigor to people's analysis of data, particularly of triggers (e.g., Karkar *et al.*, 2015a,b, 2017). Other systems focus more on collaboration, aiming to facilitate the interaction among different actors: patients, families, caregivers, different health providers. These

technologies aim to connect clinical and non-clinical environments, facilitating transitions between them (Demiris *et al.*, 2008).

Technologies are also designed to support clinical interventions. In this context, mobile applications are commonly used because mobile phones are ubiquitous, personal, and offer enough technological capabilities to support a diverse set of possible interventions (Morris *et al.*, 2010; Stawarz *et al.*, 2014). These studies do not necessarily propose new technologies; rather, some of them propose the use of existing systems, while others assess the use of existing technologies that people choose without health professionals' advice.

In any of these cases (i.e., proposing new technologies or analyzing the use of existing ones), one important factor to consider is how technologies fit people's daily lives. Some studies focus particularly on evaluating features or the feasibility of a new system (e.g., Hodges *et al.*, 2006; Jang *et al.*, 2014; Kim *et al.*, 2017; Lane *et al.*, 2014; Nachman *et al.*, 2010). Others present a deeper examination of how the approached technologies will impact routines, workflows, and social lives. For example, Grönvall and Verdezoto (2013a) highlight the differences of perceptions between "general devices, wellness devices, and illness devices," and how these perceptions impact patients' appropriation of the devices (Grönvall and Verdezoto, 2013a). Ancker *et al.* (2015) argue that some people may not be interested in new technologies because they already found comfortable solutions. Also, as discussed by Katule *et al.* (2016), some users may express a general resistance to technology use. Some studies also consider how technologies fit healthcare providers' workflow, particularly when the technology aims to intermediate patient-provider collaboration (Loos and Davidson, 2016). Other studies consider that technology can potentially restrict what users can do, reducing their agency (Neff and Nafus, 2016; Purpura *et al.*, 2011; Rooksby *et al.*, 2014; Simm *et al.*, 2016; Woolgar, 1990) and try to offer more freedom to users, often through customization (e.g., Luo *et al.*, 2019; Maitland and Chalmers, 2011; Mamykina *et al.*, 2006; O'Murchu and Sigfridsson, 2010; Simm *et al.*, 2016). One noteworthy example is O'Murchu and Sigfridsson's (2010) system, focused on diabetes, in which the users create their own data categories and associations between them.

In summary, technology is not required for PGHD research, as suggested by the many studies focusing on people's practices in managing their health and wellness. When studies specifically include technology, in addition to proposing and evaluating new systems, they may also focus on practices people already adopt in their daily lives. Rooksby *et al.* (2014) argue that research in health and research in HCI differ on the use of technologies: the first often explores the use of existing, commercially available, consumer trackers, while the second usually focuses on proposing or evaluating a new prototype of technology. Aligned with Rooksby *et al.*'s (2014) claim, this review identified the same two approaches concerning technology (i.e., studies proposing a technology and studies focusing on people's use of technologies they have chosen). However, we did not find the division between health and HCI studies as clear and defined as described by Rooksby *et al.* (2014).

2.7 Duration of PGHD Use

This dimension concerns how long people are expected to use PGHD. Two categories emerged based on our review: repeated use over a long period of time; and repeated use for a limited time. Issues arose in characterizing this dimension as well: many studies do not clearly indicate how long they expect people to use PGHD. In general, if the study is about a chronic condition and the technology does not focus on training or on a specific 'stage' of the condition, we considered the duration as ideally repeated for a long period of time. For example, studies focusing on diabetes but not on post-diagnosis training (e.g., Blondon and Klasnja, 2013; Nachman *et al.*, 2010; O'Kane and Mentis, 2012), asthma (e.g., Anhøj and Møldrup, 2004), hypertension (e.g., Ballegaard *et al.*, 2008), and chronic pain (e.g., Felipe *et al.*, 2015) were classified in this category. On the other hand, studies on conditions like post-surgical infections (e.g., Sanger *et al.*, 2013, 2016), pre-eclampsia (e.g., Grönvall and Verdezoto, 2013b), and high-risk infants (e.g., Cheng *et al.*, 2015; Liu *et al.*, 2011; Tang *et al.*, 2012), which have a clearer time limitation, the duration of PGHD use was classified as repeated for a limited time.

The case of one-time measures Before introducing the two categories, it is worth mentioning a type of data that may create some debate on whether it should be considered PGHD or not: one-time measures. While some authors include one-time measures, such as genetic tests, as PGHD (Gregory and Bowker, 2016; Zhu *et al.*, 2016), others reinforce repetitive use as a definitional characteristic (Li *et al.*, 2010). Besides genetic tests, this case also includes family history and laboratory and image tests requested by the patients without healthcare providers' direction. These data can be used alongside other data to provide context to treatments or, in more sparse evaluations, to check how “well” patients are (Ancker *et al.*, 2015). However, first, most of these data are not generated by patients (e.g., genetic, laboratory, and image tests are generated by specialists in clinical settings), although patients may need and want to manage them alongside their PGHD. And second, these data do not need to be collected and used with significant repetition. No study analyzed in this review specifically and exclusively focused on one-time measures. Besides, our focus in this review is on data that are generated outside of traditional clinical environments. For this reason, we did not include one-time measures. Nevertheless, one-time measures appeared within some studies (e.g., Ancker *et al.*, 2015) among other data that patients tracked.

2.7.1 (Ideally) Repeated for a Long Period of Time

Studies of chronic disease management often suggest a prolonged use of PGHD, since patients need to deal with the conditions for their lifetime. The idea is that PGHD can be used to improve symptom management, understand and comply with treatments, and navigate all the changes these diseases bring to people's lives (Hong *et al.*, 2016). However, despite the importance of tracking PGHD, people frequently abandon technology and tracking practices because these activities can become a burden over long period of time (Adams *et al.*, 2014; Blondon and Klasnja, 2013; Mamykina *et al.*, 2008; Zhu *et al.*, 2016) (other reasons for abandoning PGHD use, such as lack of novelty or poorly designed technologies, are discussed in Clawson *et al.*, 2015; Epstein *et al.*, 2016). It is important to consider how the measurements will fit

into the person's routine so it will be easier for them to develop the habit and collect data over a longer period of time, without requiring an excessive focus on tracking (Grönvall and Verdezoto, 2013a). Figueiredo *et al.* (2017) analyzed the aspects that influence routine self-tracking through a national survey data and found that a recent emergency visit and the use of technology were associated with a higher likelihood of routinely adopting self-tracking activities. The authors hypothesize that a recent severe health event can make people more diligent with their health and thus motivate them to consistently track PGHD, and the use of technology may facilitate this use (Figueiredo *et al.*, 2017).

Many chronic diseases can achieve a stable phase when patients reach a level of understanding of how disease impacts their daily activities and how to manage it (Chen, 2010). However, some authors highlight that even in these cases there is always the possibility of crisis; in such moments having PGHD may help patients better cope with the sudden crisis (Blondon and Klasnja, 2013). These authors then suggest that patients should continuously use PGHD, but in different ways and with different intensities depending on the stage of the disease (Blondon and Klasnja, 2013).

Finally, many preventative health or general wellness studies also fit in this category (although they often do not explicitly state their expectation for the duration of use). This expected duration can be related to their main goal: to support behavior change and maintain healthy behavior. In this context, Ancker *et al.* (2015) argue that developers of self-tracking technologies seem to assume that "patients have unlimited enthusiasm for tracking their own health data via technology, that these data are objective facts with unambiguous interpretations and applications, and that healthcare providers welcome such data in their assessment of a patient's health status" (Ancker *et al.*, 2015). However, life is more complicated, and people abandon self-tracking technologies for a variety of reasons, such as expectation mismatches, meeting goals, technology failure, and changes in health status (Clawson *et al.*, 2015).

2.7.2 Repeated for a Limited Time

Some studies suggest PGHD use for a limited time. These studies usually focus on health concerns that are not lifetime oriented and may end after a period of time, such as pre-eclampsia (Grönvall and Verdezoto, 2013a) and the care of high-risk infants (Cheng *et al.*, 2015; Liu *et al.*, 2011; Tang *et al.*, 2012), which lasts during pregnancy (maximum of 9 months but often less) and in the first years of preterm children respectively (around 2 years). In these cases, since patients perform these monitoring activities only during treatment or while the condition persists, they are usually motivated to comply with the treatment. The limited time they need to track their measures can reduce the feeling of burden, because they know they will not need to do it for the rest of their lives. In some cases, PGHD use can give patients the chance to undergo their treatment and monitoring at home, where they feel more comfortable and do not need to alter their daily work and life activities, such as taking care of their children, practicing their hobbies, or any regular activity that is performed outside the hospital. The pre-eclampsia case is a good example (Grönvall and Verdezoto, 2013a): PGHD and the telemonitoring system provided women the chance to avoid being hospitalized or visiting the hospital every day. Other cases that do not necessarily require indefinite time are the ones in which people are only trying to identify triggers, for example, the studies on self-experimentation (Karkar *et al.*, 2015a,b, 2017).

Other than short-term health conditions, PGHD for limited time use can also serve as a training mechanism for people who are newly diagnosed with chronic diseases. For example, Frost and Smith (2003) describe the development of a system for training patients newly diagnosed with diabetes. Mamykina *et al.* (2008) also describe a system for diabetes self-management, arguing that it “is particularly well suited for individuals newly diagnosed with diabetes who are forced with the challenge of examining and altering elements of their daily routines.” These patients need to learn how to cope with their new condition, and it is likely that they do not know details about the disease. Since the beginning of their treatment is probably one of the most challenging times, patients need more information and support from providers during this

time (Ayobi *et al.*, 2017; Desai *et al.*, 2019; Mamykina *et al.*, 2008). PGHD could be used to facilitate this interaction, providing relevant information to providers and improving patients' knowledge about their situation. Thus, PGHD can be used for a short period of time to serve the specific goal of learning and training immediately post diagnosis, even for those with lifelong conditions.

In this context, PGHD can also be used for a limited time to support people in better understanding and embracing their condition (Ayobi *et al.*, 2017; Chung *et al.*, 2019; MacLeod *et al.*, 2013). For example, Ballegaard *et al.* (2008) describe the case of women with diabetes who knew the amount of insulin they needed to take based on the serving size of their kitchenware, their routine meals, and their feelings. These patients incorporated disease management into their lives in such a way that they no longer needed to actively and routinely track their data. However, the same authors mention that one of the participants was no longer able to feel fluctuations in her glucose levels due to her pregnancy. Because of that, she felt the need to track her glucose levels again (Ballegaard *et al.*, 2008). Similarly, Desai *et al.* (2019) describe that experts and novice users evaluate the burden associated with self-tracking in different ways. They suggest that “users may be more willing to endure high self-tracking burden for the purpose of learning and exploration over a short time.” However, this level of burden would be unfeasible for continuous everyday tracking, and technologies aiming to support such a level of engagement should “prioritize convenience of use and integration with daily practices” (Desai *et al.*, 2019).

3

Challenges

The seven dimensions discussed in the previous section are important to define the scope of a PGHD study or system. This section focuses on discussing the main open challenges described by studies in the area: (i) patient-provider collaboration through PGHD; (ii) the use of PGHD for complex conditions; (iii) the relation of goals and possible negative consequences; (iv) reflection and action, and instances in which they can be negative; (v) access to PGHD technologies; and (vi) intended and unexpected users of PGHD. These challenges often present complex issues that are not easily addressed. We will end each subsection with design implications described in the analyzed papers that can potentially, if partially, address each challenge.

3.1 Patient-Provider Collaboration

One of the main benefits of using PGHD is to support and improve patient-provider collaboration (Andersen and Moll, 2017; Ballegaard *et al.*, 2008; Cheng *et al.*, 2015; Chung *et al.*, 2016; Cortez *et al.*, 2018; Jacobs *et al.*, 2015; Loos and Davidson, 2016; O’Kane and Mentis, 2012; Schroeder *et al.*, 2017; Zhu *et al.*, 2016). PGHD are expected to support patients in better communicating their symptoms and experiences, and

providers in triage, diagnosis, and treatment decisions (Jacobs *et al.*, 2015; Loos and Davidson, 2016; Schroeder *et al.*, 2017). These aspects could contribute to better patient-provider communication, which is often connected to patient satisfaction, understanding, and compliance (Loos and Davidson, 2016; O’Kane and Mentis, 2012). These benefits are especially relevant in care that requires more collaboration between patients and providers, such as diabetes (O’Kane and Mentis, 2012) and cancer care (Jacobs *et al.*, 2015; Weaver *et al.*, 2007). However, as Schroeder *et al.* (2017) argue, attempts to use PGHD to improve patient-provider collaboration in clinical environments often end with both patients and providers dissatisfied. The following subsections discuss factors that influence these results.

3.1.1 Expertise

Patients’ expertise is a source of challenges to effective patient-provider collaboration through PGHD. Although it is known that patients have their own specific expertise, particularly about their daily experiences of disease management (Ballegaard *et al.*, 2008; MacLeod *et al.*, 2015), researchers and healthcare providers have concerns about patients’ interpretation of their own data. This concern can be related, for instance, to patients’ health literacy (Liu *et al.*, 2011; Tang *et al.*, 2012) or fear and negative feelings related to health (Ancker *et al.*, 2015; Barbarin *et al.*, 2016). The way the information is presented in PGHD tools combined with some patients’ imprecise understanding of percentages (Gigerenzer *et al.*, 2007) can also contribute to researchers and providers’ concerns regarding patients’ expertise. Patients can also have difficulties in understanding cause and effect (Vandenberghe and Geerts, 2015) and be influenced by confirmation bias (Karkar *et al.*, 2017; Raj *et al.*, 2019).

Expertise can be a concern for providers as well. Studies found that PGHD and data visualizations may create an “unfamiliar territory” for providers, generating feelings of anxiety and fear of not being able to interpret the results correctly (Schroeder *et al.*, 2017; Vandenberghe and Geerts, 2015; West *et al.*, 2016). Each provider has their own specialty, but identifying correlations within data (e.g., between symptoms and

triggers) may require the expertise of different specialists, who may not be available. Moreover, the systems used to collect PGHD often have different data visualizations, and providers may not be familiar with every existing PGHD system. In addition, providers are also concerned with the potential information overload and the time needed to understand the PGHD during their visits (Murnane *et al.*, 2018; Sanger *et al.*, 2016; Schroeder *et al.*, 2017; West *et al.*, 2016).

These challenges may directly impact trust within patient-provider collaboration. Providers may not trust that patients can correctly interpret their data by themselves. Some providers are also concerned that patients may develop obsessive tracking behaviors or that patients can fake data (Ancker *et al.*, 2015; Grönvall and Verdezoto, 2013a; Schroeder *et al.*, 2017; West *et al.*, 2016). Patients often think their providers will not use their PGHD or feel dissatisfied when providers do not use the data the way they expected (Desai *et al.*, 2019; Murnane *et al.*, 2018; Sanger *et al.*, 2016; Schroeder *et al.*, 2017; West *et al.*, 2016). Patients can also receive inconsistent recommendations from different providers, (Schroeder *et al.*, 2017; Zia *et al.*, 2016), which impacts patients' trust. Because of these concerns, it is important that systems aiming to support patient-provider collaboration through PGHD also focus on literacy of both parts, balancing expectations, and supporting mutual trust (Schroeder *et al.*, 2017).

3.1.1.1 Design Implications

On the providers' side, some studies suggest focusing on understanding clinical reasoning, using formats similar to the ones providers are accustomed to (Sanger *et al.*, 2016; West *et al.*, 2016), incorporating questions and questionnaires they already use, and using standard data formats and data visualizations (Vandenberghe and Geerts, 2015; West *et al.*, 2016). Such features would potentially support providers in making sense of data by reducing the mental effort of learning new data visualizations and representations (West *et al.*, 2016). Similarly, PGHD systems could provide timeline visualizations, compare a patient's data against a population or demographic average, and provide statistical pre-validation to verify whether measurements fall within the normal

range of the person's demographic (Sanger *et al.*, 2016; West *et al.*, 2016). In addition, PGHD systems could also foreground data useful for diagnosis and treatments (Schroeder *et al.*, 2017), reducing the need to search in the system to find such information and partially tackling the problems of information overload. Considering many providers prefer to use PGHD for triage instead of diagnosis (Sanger *et al.*, 2016), PGHD systems should consider supporting the use of PGHD for this purpose as well (Cheng *et al.*, 2015).

For patients, mitigating burden and information overload are important aspects for supporting expertise building. Many studies provide more pragmatic implications for reducing burden, such as technologies should respectfully and flexibly schedule the frequency of data collection (e.g., avoiding triggering data collection multiple times in a day or in inappropriate times) and automatically collect data when possible (e.g., using computer vision or personal data traces from smartphones and other devices) (Ancker *et al.*, 2015; Barbarin *et al.*, 2016; Gorm and Shklovski, 2016; Liu *et al.*, 2011; Mishra *et al.*, 2019; Paay *et al.*, 2015; Tsai *et al.*, 2007). Other studies approach other ways to simplify data collection by, for example, using photos instead of detailed manual tracking (Chung *et al.*, 2019).

Besides allowing easy data collection, PGHD systems should focus on understandability and learning (Ballegaard *et al.*, 2008), providing guidelines for patients to interpret health data (Barbarin *et al.*, 2016). They should provide tutorials and informational materials that support patients in developing the necessary knowledge to track (e.g., how to track each measure) and interpret the data (e.g., what the results provided by the system mean) (Ballegaard *et al.*, 2008; Schroeder *et al.*, 2017). Many studies also focus on providing insights for data visualizations: PGHD systems should provide visualizations that are simple and easy to understand and learn, but at the same time allow exploration, active information seeking, and access to more specific and detailed knowledge when users desire it (Ancker *et al.*, 2015; Ballegaard *et al.*, 2008; Costa Figueiredo *et al.*, 2017; Schroeder *et al.*, 2017). Some studies also suggest that information should be presented in creative ways (in terms of content, interaction, and technology) to maintain attention, because information already known by the users can be easily

ignored (Paay *et al.*, 2015). Other studies aim to provide more structured guidance, such as supporting patients in conducting self-experimentation consistently in order to bring rigor to PGHD explorations (Karkar *et al.*, 2015a,b, 2017) or investigating the potential of real-time measurements and dynamic data visualizations for real-time feedback (Ayobi *et al.*, 2017; Felipe *et al.*, 2015; Johansen and Kanstrup, 2016; Paay *et al.*, 2015; Vandenberghe and Geerts, 2015). Those are valid and useful approaches, but other studies also suggest caution on technology supervision and pre-defined design solutions, in order to avoid limiting self-management and agency (Ayobi *et al.*, 2017; Felipe *et al.*, 2015).

Many papers also suggest supporting individual and collaborative knowledge creation (Barbarin *et al.*, 2016; Costa Figueiredo *et al.*, 2017; Grönvall and Verdezoto, 2013a; Liu *et al.*, 2011; MacLeod *et al.*, 2015; Vandenberghe and Geerts, 2015). For example, data visualizations, analytics, and summarization techniques could support collaborative exploration (e.g., by patients and providers) to reflect on the data and gain critical insights (Schroeder *et al.*, 2017; Zhu *et al.*, 2016). Studies have also been exploring collaboration among patients, especially in online health forums, where people seek information from other patients who are facing similar experiences. These interactions contribute to sense-making and reassurance, particularly when individuals face complex health conditions (Huh, 2015; Costa Figueiredo *et al.*, 2017; Mamykina *et al.*, 2015; O’Kane *et al.*, 2016; Sillence, 2013). PGHD systems could draw inspiration from these interactions and facilitate peer support and collaborative sensemaking (Costa Figueiredo *et al.*, 2017). For example, studies could explore, upon user consent (i.e., clearly asking consent and easily allowing withdrawal of consent), the possibility of identifying and matching users with similar experiences based on their interests or on the data they decide to share. Although such strategies could potentially stimulate collaboration, it is also important to consider that even when people have similar symptoms and experiences, the same solution or treatment may have different results, particularly with highly individualized health conditions (Costa Figueiredo *et al.*, 2017; O’Kane *et al.*, 2016). For these reasons, many studies argue that it is necessary to include health providers in this process, and PGHD alone

cannot replace the expertise and care provided by healthcare providers (MacLeod *et al.*, 2013; Simm *et al.*, 2016).

Finally, different types of data visualization are recommended for supporting patients and providers. For example, patients may not be interested or may have difficulties in using data visualizations to support healthcare practices, such as using statistical validations to verify if measures fall within the normal range for the demographic (Sanger *et al.*, 2016; West *et al.*, 2016). Since patients may also need different data visualizations for different situations, MacLeod *et al.* (2015) suggest the following different data visualizations: a non-technical overview, a quick summary for hospital emergency visits, a view with the most relevant information for new healthcare providers, and the patient's complete history. Besides these different visualizations, features that allow patients and providers to individually review and possibly annotate the data before appointments would support both sides in preparing for the consultation, improving their confidence in collaboratively discussing PGHD during the appointment (Schroeder *et al.*, 2017).

3.1.2 Conflicting Expectations

Patients and providers have different needs, what generates persistent tensions and challenges for the adoption and use of PGHD (Sanger *et al.*, 2016). Often, they have conflicting expectations, different perspectives on how they want to collaborate, and lack understanding of each other's goals (Chung *et al.*, 2016, 2019; Jacobs *et al.*, 2015; O'Kane and Mentis, 2012; Raj *et al.*, 2017; Sanger *et al.*, 2016; Zhu *et al.*, 2016). Patients often start tracking to gain in-depth knowledge about their conditions, so they can share this information with providers. However, providers often do not utilize the data patients collect on their own (Zhu *et al.*, 2016), especially when the PGHD tools selected by patients do not support providers' work during medical consultations. Besides, providers generally want to empower patients to understand their own data, but they may not have the capacity to review each data point, or to effectively use the data to inform treatment plans (Cheng *et al.*, 2015; Chung *et al.*, 2016; Raj *et al.*, 2017).

Many patients expect their data to be used to inform diagnosis, treatment, detection of triggers, and to support medical decisions. Instead, providers often use PGHD for triage (i.e., identifying earlier which patients need to schedule an in-person appointment and preventing unnecessary visits), although providers also have concerns about under- and over-triage (Sanger *et al.*, 2016). Other patients expect direct communication with providers when PGHD show potentially worrying results. In contrast, providers worry about being overloaded by patients' information. Since they also have other pressing tasks to work on, they are often unable or unwilling to answer to every concern derived from PGHD (Liu *et al.*, 2011; Sanger *et al.*, 2016).

Other conflicting expectations might result from the primary goals of using PGHD. For example, in a study about elderly care, Ballegaard *et al.* (2008) found that providers were interested in effective telemedicine, and in avoiding patients' hospitalization, improving compliance, and supporting documentation. In contrast, elderly patients and relatives were interested in supporting a "normal everyday life, spending time with friends and family, continuing the activities they cherished the most" (Ballegaard *et al.*, 2008). Similarly, in a study about chronic pain, Felipe *et al.* (2015) describe patients' willingness to transfer responsibility to the technology, allowing it to monitor their stress while they focus on their daily activities. Physiotherapists, in contrast, wanted patients to take an active approach to their recovery, so they would not develop a limited understanding of emotions by focusing solely on stress (Felipe *et al.*, 2015).

Providers also want to decide when and which patients should use PGHD (Felipe *et al.*, 2015; Grönvall and Verdezoto, 2013a; Nundy *et al.*, 2014; Sanger *et al.*, 2016). Besides information overload, staff needs, and liability issues (Sanger *et al.*, 2016), some providers may also object to patients seeing their data and data visualizations because of the potential stress resulting from receiving bad news (e.g., signs of the worsening of a health condition, signs that a treatment is not working). In these cases, healthcare providers would prefer to provide such bad news in a more humanized way (Hong *et al.*, 2016), aiming to avoid misinterpretations of data (Felipe *et al.*, 2015) or increased stress (Sanger *et al.*, 2016). This may be especially critical for patients with

severe, progressive, or terminal diseases. However, patients often have conflicting expectations concerning prioritization and response times (Sanger *et al.*, 2016).

Finally, there are conflicting expectations between patients and providers about the potential results of PGHD use. Schroeder *et al.* (2017) and Desai *et al.* (2019) describe patients' dissatisfaction with providers' use of their data: patients complained that the recommendations or evaluations they received seemed to change based on which provider analyzed the data. In other words, the same data generated different recommendations depending on who analyzed them, which could be due to multiple factors, such as providers' background, data quality, or poor standardization. Moreover, patients can also resist providers' interpretation or struggle to incorporate recommendations into their lives, and therefore may prefer to evaluate the data focusing on their personal history and experience, and determine their own actions (Ancker *et al.*, 2015; Ballegaard *et al.*, 2008; Desai *et al.*, 2019).

3.1.2.1 Design Implications

Studies of patient-provider collaboration often try to ensure that both patients and providers benefit from PGHD (Andersen and Moll, 2017; Chung *et al.*, 2019; Vandenberghe and Geerts, 2015). However, these conflicting expectations are challenging and hard to address. In such complex scenario of conflicting expectations and liability and accuracy concerns, some studies suggest establishing an agreement with patients to clearly determine the necessary types of data, the frequency and timeliness of providers' response, the presence or lack of real-time data analysis, and the circumstances in which immediate care is necessary (Kumar *et al.*, 2016; Sanger *et al.*, 2016). For example, Kumar *et al.* (2016) used verbal and written communication in the beginning of the study to avoid both liability issues and conflicting expectations. The study setup defined that the study did not comprise real-time data assessment and that providers would not be reliable for identifying whether patients' measures reached thresholds in real-time (e.g., if the glucose values collected through the continuous glucose monitor reach a dangerous level). In a similar vein, Sanger *et al.* (2016) suggest making

communication preferences explicit, by, for instance, establishing and publicizing “guidelines about appropriate content and timeliness of provider responses” (Sanger *et al.*, 2016). But the authors also suggest considering giving patients the possibility to “escalate their request” if providers do not answer within the agreed time or if the answer does not meet agreed expectations (Sanger *et al.*, 2016). This type of clear agreement at the beginning could help to set realistic expectations for patients and providers.

Supporting patient-provider smoother collaboration may partially tackle this issue of conflicting expectations. Implications for improving collaboration include: (i) features that allow patients and providers to annotate and review the data individually before appointments to support their confidence and help both sides prepare for consultations (also helpful to support expertise building); (ii) features that allow patients and providers to create and configure personalized templates for PGHD collection and use, (iii) designs that support co-interpretation and interaction with visualizations both in collocated and remote consultations, and (iv) social features that include healthcare providers (Chung *et al.*, 2016, 2019; Liu *et al.*, 2011; Schroeder *et al.*, 2017). Finally, some studies suggest PGHD technologies should support patients in finding specialists (MacLeod *et al.*, 2015) and include satisfaction with care measures whose results are shared with providers through the technology to alleviate the challenge of directly confronting doctors (Jacobs *et al.*, 2015). This last aspect needs to be carefully considered to avoid creating conflicts between patients and providers. Another potential suggestion is to provide guidance on how to approach providers and ways to customize data collection to include their needs (especially in patient-initiated data tracking).

3.1.3 Liability and Accuracy Concerns

The simple existence of data creates challenges: once there are data, patients want providers to review them reliably, often expecting real-time assessment (Kumar *et al.*, 2016; Sanger *et al.*, 2016; Toscos *et al.*, 2012b). Providers then become concerned with liability for missed diagnoses. And, since a health condition often affects a whole family,

and therefore patients may want to include PGHD from other people besides themselves, providers do not want to be responsible for acting on data from people who are not their patients (Cheng *et al.*, 2015).

In addition, providers often perceive PGHD as unreliable or of poor quality (Ancker *et al.*, 2015; Chung *et al.*, 2019; Nundy *et al.*, 2014; West *et al.*, 2016). This can be attributed to, for example, patients' "lack of diligence, the moral valence of the data (with patients unwilling to 'admit' undesirable numbers), and fear of consequences" (Ancker *et al.*, 2015). Grönvall and Verdezoto (2013a) describe an example in which participants manipulated self-reported measures (drinking more water to change the result of a urine test) to avoid going to the hospital. In such cases, if this person had a complication, would the providers be held responsible for the incorrect diagnosis?

Another reason that providers do not trust PGHD is its incompleteness. Patients may choose to track measurements based on their knowledge of their illness and personal preferences. However, these data may be unnecessary or incomplete (Schroeder *et al.*, 2017; Tang *et al.*, 2012; West *et al.*, 2016), which makes them not useful for providers (Zhu *et al.*, 2016). These gaps in data may be due to differences in and lack of communication about information sharing preferences between patients and providers (Jacobs *et al.*, 2015; O'Kane and Mentis, 2012). There are also conflicting reports on the type of data providers want: some studies report that although visualizations are useful for communicating with patients, providers want to see raw data (O'Kane and Mentis, 2012; Vandenberghe and Geerts, 2015). Others argue that the massive amount of raw data that can be generated makes it infeasible for providers to have a holistic view of patients, suggesting the use of data trends rather than raw data (Tang *et al.*, 2012).

Finally, providers have concerns about whether the data produced by new technologies are accurate, reliable, and securely transmitted. Although some self-tracking tools and devices fall under the types of applications that require FDA approval (Paton *et al.*, 2012), the lack of regulation for many of these tools raises concerns (West *et al.*, 2016). Providers do not want to be accountable for faults in technology or false results (Cheng *et al.*, 2015; Loos and Davidson, 2016; Nundy *et al.*, 2014; Sanger *et al.*, 2016; West *et al.*, 2016), which can occur for

various reasons: uncalibrated or poorly calibrated devices, technology or algorithm errors, improper protocols for collecting or testing data, lack of guidelines for measuring bio-values, and other contextual or unknown factors that can affect results (Grönvall and Verdezoto, 2013a; West *et al.*, 2016; Zhu *et al.*, 2016). Cheng *et al.* (2015) faced a technology problem in their study that affected data used by patients and providers. They reflect on the risks of something similar happening outside of the context of a research study: who would be responsible for the accuracy of the data? And more, if technology fails, can providers be held accountable for malpractice claims? (Cheng *et al.*, 2015).

3.1.3.1 Design Implications

Due to the conservative nature of medicine (Vandenberghe and Geerts, 2015), it is natural that healthcare providers express concerns about technologies used outside of clinical settings. Vandenberghe and Geerts (2015) suggest that healthcare providers should be involved in the design and validation of PGHD technologies. Such validation studies could make the capabilities and limitations of PGHD systems more transparent, so that healthcare providers could have more information before using these systems or suggesting that patients use them (Vandenberghe and Geerts, 2015). Moreover, Loos and Davidson (2016) report that healthcare providers see FDA approval and compliance with standards for health data privacy (e.g., the Health Insurance Portability and Accountability Act – HIPAA) as important factors for trusting PGHD systems.

Other studies propose giving metadata to healthcare providers to help them in determining data accuracy, particularly in the context of high-risk health conditions. For example, West *et al.* (2016) suggest PGHD systems should capture information about the calibration of their sensors and associate it with the data, so healthcare providers can better evaluate if they can trust the measurements. Providing context about the moment of data collection is another way to address trustworthiness of tracked data. Standard protocols are available for accurately collecting health indicators. For example, the European standard protocol to measure blood pressure at home describes the

correct position of the equipment and states that the person should be in a quiet room, comfortably seated, in silence, immobile with the arm resting on a table, and the results, alongside the time they were collected, should be immediately recorded (Parati *et al.*, 2010). Healthcare providers would benefit from knowing, for example, the time of the measure, if the patient followed the protocol, where the patient was, and what the patient was doing at the time the data was recorded (Grönvall and Verdezoto, 2013a,b; West *et al.*, 2016). Such systems should also reinforce guidelines and protocols, which would address some concerns from healthcare providers (Ballegaard *et al.*, 2008; Schroeder *et al.*, 2017). West *et al.* (2016) also suggest the use of cryptographic approaches to prove the measures were taken in the recorded time in order to avoid post-hoc data fabrication (e.g., recording that a result was measured in the past).

In a similar vein, supporting providers in recognizing obsessive behavior (e.g., collecting too much or unrelated data) could also influence their decision to use PGHD and their trust in the measurements patients record (MacLeod *et al.*, 2015). Not all patients will benefit from specific PGHD strategies, so providers should have options to (i) choose the patients they want to use PGHD (Nundy *et al.*, 2014), and (ii) treat the other patients with the same quality of care (Loos and Davidson, 2016; Veinot *et al.*, 2018). This would allow prioritization of patients based on both patients' and providers' needs (Sanger *et al.*, 2016). Contextual information about both the data and how these data influence users' thoughts and emotions could again be beneficial for supporting patient prioritization (Ayobi *et al.*, 2017; Ballegaard *et al.*, 2008; Felipe *et al.*, 2015; Sanger *et al.*, 2016; Schroeder *et al.*, 2017; Vandenberghe and Geerts, 2015; West *et al.*, 2016; Zhu *et al.*, 2016).

Although these strategies can partially address liability and accuracy issues of PGHD use, these problems cannot be fully addressed by technology alone; they require attention and potentially changes to current work practices and workflow.

3.1.4 Workflow

As previously mentioned, many researchers point to a paradigm shift in healthcare from a clinical-centered to a more patient-centered practice. This shift emphasizes the change in the patient role from passive recipient of care to active participant. Providers are still responsible for providing healthcare services, understanding the diseases and conditions, investigating symptoms, and identifying and gathering important information from patients. However, with PGHD use they may also receive data generated by patients. It may look like a small change, however it can significantly impact different aspects of providers' work, particularly their workflow. This aspect is critical, since providers "buy-in" may define the success of the system (Nundy *et al.*, 2014). Moreover, many studies argue that for providers to effectively use PGHD, the data need to be integrated into their workflow, including integration with Electronic Health Records (Kumar *et al.*, 2016; Liu *et al.*, 2011; Nundy *et al.*, 2014; Sanger *et al.*, 2016; West *et al.*, 2016; Zhu *et al.*, 2016).

Information overload and time commitment are common challenges for integration: providers worry they will receive excessive amounts of data that will consume too much of their limited time, reducing the quality of direct patient care (Chung *et al.*, 2019; Loos and Davidson, 2016; Murnane *et al.*, 2018). Appointments are already short, and if the provider spends most of the time trying to understand pages of data, it will negatively impact patient care. Providers also express concerns about being burdened by messages and data outside of appointments or work time, preferring to receive PGHD during clinic appointments (Andersen and Moll, 2017; Cheng *et al.*, 2015; Loos and Davidson, 2016; Nundy *et al.*, 2014; Schroeder *et al.*, 2017; West *et al.*, 2016; Zhu *et al.*, 2016). Furthermore, within the current payment format, analyzing PGHD is currently not incentivized, meaning providers cannot be reimbursed for this work (Kumar *et al.*, 2016; Sanger *et al.*, 2016; Zhu *et al.*, 2016).

Another challenge of integrating PGHD into providers' workflow is related to continuity of care. Care, especially for patients with multiple conditions, may be spread across different health providers with

different specializations. PGHD has the potential to help patients communicate information across these different providers (Ancker *et al.*, 2015; Kumar *et al.*, 2016; Liu *et al.*, 2011; Sanger *et al.*, 2016; Tang *et al.*, 2012); however, the workflow of the different health providers may pose barriers to achieve this benefit. PGHD systems need to consider that different providers (e.g., paramedics, nurses, general practitioners, specialists, etc.) make decisions regarding the same patient under different situations and constraints (Chung *et al.*, 2019). Interoperability and lack of standards are challenges for such use of PGHD across different health providers. Even when focusing on a single specialty, differences in providers' daily practices and habits may pose barriers to the use of PGHD in clinical practice (Luo *et al.*, 2019; West *et al.*, 2016).

Finally, West *et al.* (2016) highlight the potential impact of PGHD on the work processes and ways “that clinical evidence was ordered, structured, and represented,” particularly concerning the timeline of patients' events: providers describe creating a mental timeline that includes the chronological order and duration of events to identify potential relations of symptoms and possible causes. In this sense, if PGHD systems do not support the creation of such timelines, the introduction of PGHD could impact not only the practice workflow, but also providers' mental models of their practices.

3.1.4.1 Design Implications

One of the most common, important, and potentially difficult to implement recommendations is the need to integrate PGHD in healthcare providers' existing tools (e.g., EHR), workflows, and dissemination channels (Barbarin *et al.*, 2016; Sanger *et al.*, 2013, 2016; Vandenberghe and Geerts, 2015; West *et al.*, 2016; Zhu *et al.*, 2016). Besides understanding clinical reasoning and use formats providers are accustomed to (Sanger *et al.*, 2016; West *et al.*, 2016), changes in the workflow are often required for successful implementation of PGHD into clinical practices.

Monitoring PGHD can impact significantly on healthcare providers' workflow. Sanger *et al.* (2016) report that most of their participants saw clinical nurses as best positioned to take on this task. The team members involved in the study identified nurses as already performing

the tasks that were more similar to monitoring PGHD. However, they mention nurses are already overworked and that there should be one nurse dedicated to monitoring PGHD, so the study participants suggested creating a new nursing role to take on this task. In a contrasting example, Nundy *et al.* (2014) report that most physicians they approach would rather directly and personally receive PGHD immediately before appointments with patients. Therefore, in order to support providers' workflow, PGHD systems should build on existing sociotechnical systems (Sanger *et al.*, 2016), which depend on organizational culture and structure, healthcare providers' specialties, and existing processes and protocols. Even when building on such sociotechnical systems, including PGHD into providers' practices still demands some changes in the workflow (e.g., creating a new role). These changes would need (i) to be introduced incrementally (Sanger *et al.*, 2016), and (ii) to include educating or developing a new culture around PGHD (Andersen and Moll, 2017).

Other changes in the workflow can be even more complicated. For instance, a major change that could impact PGHD use is to create ways to bill PGHD usage, since providers currently cannot be paid for this work. Therefore, it is necessary to review policies to incentivize providers to effectively use PGHD (Kumar *et al.*, 2016; Sanger *et al.*, 2016; Zhu *et al.*, 2016). However, such changes are complex and beyond the scope of technology.

Considering continuity of care, some studies point to customization. PGHD systems should allow each provider to choose which data, as well as how often and in what format, they want to receive from patients, and guide patients to accurately collect these data. Such features could support patients' awareness of each providers' needs and support them in collecting more complete, accurate, and clinically relevant data (Jacobs *et al.*, 2015; O'Kane and Mentis, 2012; Sanger *et al.*, 2016; West *et al.*, 2016; Zhu *et al.*, 2016). Besides allowing customizable data collection and visualization according to the needs of each provider, PGHD systems should also enable providers to share data with colleagues in a flexible way (e.g., defining the length of the data shared) to better support continuity of care (Vandenbergh and Geerts, 2015).

3.2 Complex Conditions

Many PGHD studies focus on conditions such as diabetes (e.g., Farmer *et al.*, 2005, 2007; Nachman *et al.*, 2010; Smith *et al.*, 2007), hypertension (e.g., Bardram *et al.*, 2013), and asthma (e.g., Anhøj and Møldrup, 2004), which can be considered common illnesses (Ayobi *et al.*, 2017; MacLeod *et al.*, 2015). These conditions often present well-defined symptoms, treatments, and self-care practices. Consequently, technology can be tailored to support their care (MacLeod *et al.*, 2015). When the condition is rare, poorly understood, or more complex, the challenges are intensified.

Diseases that are rare (affecting small parts of the population MacLeod *et al.*, 2015) or enigmatic (involving “heterogeneous symptoms, unexplained differences in treatment responses, and lack of symptom specificity”) (McKillop *et al.*, 2018) often lack standard disease representation, creating challenges to patients, providers, and technology designers. These aspects create a sense of invisibility and uncertainty that increases feelings of disbelief, depression, and isolation (Felipe *et al.*, 2015; Johansen and Kanstrup, 2016; MacLeod *et al.*, 2015; Young and Miller, 2019). In the cases of progressive or terminal diseases, the use of PGHD may constantly remind patients of the life-threatening character of their illness, potentially contributing to feelings of fear, depression, and helplessness (Ayobi *et al.*, 2017; Barbarin *et al.*, 2016; Jacobs *et al.*, 2015). In this context, data that portray decline are particularly delicate. Mishra *et al.* (2019) describe how patients with Parkinson’s disease would like to see their decline data framed in terms of actionable insights, so they could adopt a “planful problem-solving” orientation. Such orientation has been associated “higher health-related quality of life” in the context of Parkinson’s disease. However, actionable insights must be carefully considered to avoid being contradictory (e.g., symptoms rapidly fluctuate so recommendations could drastically change) or unhelpful (Bentley *et al.*, 2013; Mishra *et al.*, 2019), which could even reinforce unrealistic expectations.

Other conditions are complex because they are very idiosyncratic: these diseases’ mechanisms are often not entirely understood, and the

health indicators, symptoms, triggers, and treatments change considerably from person to person. In these cases, self-tracking becomes an individual endeavor, requiring people to create their own personalized solutions (Costa Figueiredo *et al.*, 2017, Frost *et al.*, 2011; Huh and Ackerman, 2012; Jacobs *et al.*, 2015; O’Kane *et al.*, 2016; Park and Chen, 2015; Young and Miller, 2019). This is also the case of people who have multiple chronic conditions (e.g., a patient who has diabetes and hypertension simultaneously). Although the individual conditions are often well-known, the cumulation of them brings extra challenges. The conditions can impact each other, often presenting conflicts, such as the medication for one worsening the other (Ancker *et al.*, 2015; Grönvall and Verdezoto, 2013a). Similar to other complex conditions such as cancer (Jacobs *et al.*, 2015), care becomes more fragmented and the management of information more burdensome. Finally, some conditions, such as HIV (Bussone *et al.*, 2016) and bipolar disorder (Murnane *et al.*, 2018), are not only complex but also highly stigmatized. Studies highlight the importance of security (“the safety of a user’s personal information, and the measures taken to protect it against unwanted access” Bussone *et al.*, 2016) in the case of such conditions in order to help users protect themselves from discrimination (Bussone *et al.*, 2016; Murnane *et al.*, 2018).

Complex conditions pose increased challenges to PGHD research, which can include: smaller populations with which to work, populations spread across different locations, poorly defined guidelines for care, significantly smaller numbers of specialists with which to work, and significantly higher emotional burden for patients. However, despite that, PGHD can potentially result in significant benefits for these patients: it can help by bringing visibility and social recognition to their conditions (Felipe *et al.*, 2015; Johansen and Kanstrup, 2016; MacLeod *et al.*, 2015; Murnane *et al.*, 2018; Park and Chen, 2015), providing self-validation to patients experiencing them (Felipe *et al.*, 2015; O’Kane *et al.*, 2016), increasing feelings of agency and control when facing complex, rare, or degenerative illnesses (Ayobi *et al.*, 2017; Bussone *et al.*, 2016; Felipe *et al.*, 2015; Paton *et al.*, 2012; Snyder *et al.*, 2019), understanding individual and personalized patterns (Costa Figueiredo *et al.*, 2017; Park and Chen, 2015; Young and Miller, 2019), and even advancing

knowledge of the disease by providing more data on illness experiences (MacLeod *et al.*, 2013; McKillop *et al.*, 2018; Neff and Nafus, 2016; Young and Miller, 2019). Considering this, it is important to approach such health issues so they will not be “left out of the health design space” (MacLeod *et al.*, 2015) and patients can experience PGHD’s benefits.

3.2.1 Design Implications

Rare, poorly understood, degenerative, or more complex conditions present multiple challenges that go well beyond the use of PGHD. Ayobi *et al.* (2017) suggest that self-tracking and PGHD technologies by themselves are not enough to support care for complex and degenerative diseases. They suggest using a mix of personalized self-care activities and different self-tracking practices and tools, encompassing support for healthy lifestyles (e.g., fitness), disease monitoring (e.g., information and knowledge), mental health management (e.g., life-journaling), and reflective thinking (Ayobi *et al.*, 2017).

In the context of complex conditions, PGHD can support personal daily activities, such as exercising, healthy eating, and taking medications (Mishra *et al.*, 2019), or to provide crowdsourced information about specialists that treat the specific condition, since they can be challenging to find (Young and Miller, 2019). But these data may also have other potential benefits. PGHD can stimulate patients to perceive themselves as experts who are knowledgeable about their conditions, which can support engagement with self-management and self-care practices (Felipe *et al.*, 2015; MacLeod *et al.*, 2015; Murnane *et al.*, 2018; O’Kane *et al.*, 2016). To approach these aspects, two studies of complex conditions (i.e., vulvodynia Young and Miller, 2019 and Parkinson’s disease Mishra *et al.*, 2019) highlight the importance of personalization and flexibility in PGHD collection and use. Both suggest that PGHD technologies aiming to support patients with these conditions should allow patients to track whatever health indicators and contextual data they consider meaningful and support them in identifying correlations between them and their symptoms, treatment efficacy, and disease progression (Mishra *et al.*, 2019; Young and Miller, 2019). Technologies should support these

self-experimentation activities (Karkar *et al.*, 2015a,b, 2017) both in “the very short term (e.g., a matter of hours to track medication effect) and the very long term (e.g., for years to track progression)” (Mishra *et al.*, 2019). Other suggestions are to identify people with similar experiences and support collective sensemaking (Costa Figueiredo *et al.*, 2017; Murnane *et al.*, 2018; Young and Miller, 2019). Finally, Mishra *et al.* (2019) also discuss the role of PGHD in predicting disease progression, by using, for example, machine learning algorithms. They describe how some users would like to have this information so they can better plan for decline. However, the authors emphasize it is necessary to explore how to frame PGHD in order to support positive coping strategies, even when the data suggest irreversible decline (Mishra *et al.*, 2019).

Besides supporting self-knowledge, self-validation, and gathering evidence for themselves, PGHD could also potentially contribute to advancing general knowledge about the disease and providing evidence to others, such as healthcare providers, family members, friends, or coworkers (Felipe *et al.*, 2015; MacLeod *et al.*, 2015; Murnane *et al.*, 2018; Young and Miller, 2019). To support this aspect, MacLeod *et al.* (2015) recommend that PGHD technologies provide multiple different data visualizations to be used according to the need and the people involved. For example, the system could provide visualizations focusing on laypeople (e.g., to be used as evidence or to improve illness visibility among coworkers), or support emergency visits to the hospital (e.g., a quick medical summary that can be easily understood in the context of an emergency), or provide information to new providers (e.g., when a patients’ healthcare provider change, or for consultations with a different provider while a patient is traveling) (MacLeod *et al.*, 2015). Similarly, Felipe *et al.* (2015) suggest different levels of disclosure for providing evidence of the disease or its symptoms to others in different social contexts and levels of interaction (e.g., family members vs. with coworkers vs. with strangers). Other studies (Luo *et al.*, 2019; Murnane *et al.*, 2018) argue that such different visualizations or levels of disclosure must be personalizable and modifiable, because even similar types of relationships (e.g., patient-provider relationships) differ for each individual and change over time. The aesthetics of the devices may

also play a role in avoiding stigmatization and supporting normalization of self-monitoring (Ballegaard *et al.*, 2008; Bussone *et al.*, 2016; Grönvall and Verdezoto, 2013a; Paay *et al.*, 2015; Shih *et al.*, 2015; Simm *et al.*, 2016). In addition, it is important to avoid generating a feeling of over-empathy that can be seen as “pity or lack of respect” (Felipe *et al.*, 2015). Some studies also highlight the possibility of using PGHD tools to support advocacy practices towards visibility and effective and ethical awareness among the general public, especially in the cases of rare and stigmatizing conditions (Felipe *et al.*, 2015; MacLeod *et al.*, 2015; McKillop *et al.*, 2018; Young and Miller, 2019).

Another potential issue that PGHD can partially tackle is related to the individual’s care network, i.e., the people who play different roles in the care of an individual (MacLeod *et al.*, 2015). PGHD could support communication and collaboration between patients and their care network (e.g., family members, friends) (Mishra *et al.*, 2019; Murnane *et al.*, 2018) and even help caregivers to accept the diagnosis or progression, supporting them to collaborate with the individual when they feel ready (MacLeod *et al.*, 2015). MacLeod *et al.* (2015) also approach the care network fatigue faced by people living with rare health conditions, describing it as something that technology could help to address by helping the patient communicate about the disease and thereby expand their care network. A larger care network can reduce the burden or fatigue placed on each individual or caregiver (MacLeod *et al.*, 2015). They recommend a “slow discovery process” in which individuals with a rare disease would gradually release information to new people (e.g., friends or other family members). These people would then “slowly transition from a general level of awareness (understanding what the condition is, building empathy) to a specific level of understanding (how to be helpful)” (MacLeod *et al.*, 2015).

Finally, Mishra *et al.* (2019) also discuss how PGHD, particularly data automatically collected with sensors, “can help people combat their own unconscious tendencies towards avoidance and face the reality of their condition” (Mishra *et al.*, 2019). Besides contributing to helping patients face their illness and avoid denial, PGHD systems could also support problem-solving strategies to contribute to patients’ self-management practices (Mishra *et al.*, 2019).

3.3 Goals

PGHD can be used for different goals, and each of them impacts patients' practices and outcomes. For example, encouraging people to engage in healthy behaviors involves a different approach than asking them to stop doing something unhealthy (Paay *et al.*, 2015). And using PGHD for self-experimentation entails different approaches to collection and interpretation of data than using PGHD for health management and control of known health indicators (e.g., glucose) (Chung *et al.*, 2019). Thus, goals play a fundamental role in PGHD practices and their consequences and results.

Li *et al.* (2011), based on Powers (1973), describe four levels of goals, from abstract to specific ones: system concept, principle, program, and sequence (Powers, 1973). System concept goals relate to ideals, such as an idealized self. Principle-level goals encompass the goals used to achieve an ideal (e.g., an idealized self), such as physical fitness. Program-level goals are used to achieve principle-level goals, as exercising four times a week to be physically fit. Finally, sequence-level goals are specific actions performed to reach program-level goals (e.g., enrolling in a gym and reserving time in your schedule to exercise 4 times a week). Li *et al.* (2011) report that program-level goals are more suitable for Personal Informatics (PI) because they are not as abstract as system concept- and principle-level goals, and are thus more actionable. They report that some people use PI to achieve principle-level goals, but tools only help in achieving the program-level goals necessary to reach the principle-level ones. However, this relationship (program- and principle-level goals) may be more complex.

First, people often do not distinguish among the different levels of goals, the inter-relation among them, or how they are aligned with self-tracking and PGHD use. As Li *et al.* (2011) also describe, if the person does not know what program-level goals are necessary to achieve their principle-level goal, they cannot act towards it. For example, if a person wants to use PGHD to prevent night-time cramps (principle-level) but she does not know what causes the cramps (program-level), she cannot effectively act towards the goal. Besides hindering action, this issue can also emotionally impact the person, leading to frustration

(Katz *et al.*, 2018). This negative consequence can happen both in the context of a health condition and in the context of preventative health or general wellbeing. However, the non-elective characteristic of a disease may intensify the involvement of the person and the resulting consequences (Katz *et al.*, 2018; Pina *et al.*, 2017).

Second, PGHD technologies may focus on or (unintendedly) reinforce the search for system concept and principle-level goals that are not practical to track (Karkar *et al.*, 2017). Because of these technologies, people may pursue abstract goals that cannot be achieved through tracking, or at all (Costa Figueiredo *et al.*, 2018; Snyder *et al.*, 2019). Additionally, PGHD practices are embedded in broader social contexts that can be directly related to system concept-level goals. So, besides aiming for abstract goals, people may turn to self-tracking and PGHD to achieve unrealistic, idealized goals based on societal patterns and pressures. Self-tracking tools can emphasize and support the belief that persistent tracking will ultimately lead to goal achievement (Costa Figueiredo *et al.*, 2018; Snyder *et al.*, 2019). The search for an idealized body is the clearest example of this, but it can also include other idealizations such as the “good” patient (Ancker *et al.*, 2015), the “healthy” person (Purpura *et al.*, 2011), or the “perfect” family (Costa Figueiredo *et al.*, 2018). Searching for these idealizations can easily turn into frustration, stress, guilt, and dependence (Ancker *et al.*, 2015; Costa Figueiredo *et al.*, 2018; Eikey and Reddy, 2017; Katz *et al.*, 2018; Lengelle *et al.*, 2016; Snyder *et al.*, 2019).

Another important aspect is that the goal may not always be positive. For example, in certain eating disorders, the person is always trying to lose weight, even when it is prejudicial or even life-threatening (Eikey and Reddy, 2017). According to Martin and Tesser (1996), people who connect “lower-order” goals (e.g., program-level) to higher-order ones (e.g., system concept level) tied to well-being or identity (e.g., weight to happiness) are more likely to ruminate instead of reflect (Martin and Tesser, 1996). This would put them in cyclical negative thought patterns, which can reinforce problematic goals. Other goals may not be achievable through tracking or at all (Costa Figueiredo *et al.*, 2017, 2018). Often PGHD research focuses on domains in which people have some level of control over what is tracked and analyzed (e.g., physical

activity, food choices) (Epstein *et al.*, 2017). In other domains, however, people have little to no control over the data. This is the case of tracking menstruation or fertility, when people are able to primarily observe their measures, with little to no means to change them (Costa Figueiredo *et al.*, 2017, 2018; Epstein *et al.*, 2017). In these cases, stimulating a narrative that persistent action will ultimately pay off (e.g., when using PGHD to try to conceive) may be harmful to users (Costa Figueiredo *et al.*, 2018).

3.3.1 Design Implications

Supporting users to identify actionable and doable goals for PGHD use is a central challenge. To tackle these issues, some studies highlight the importance of involving healthcare providers (Epstein *et al.*, 2017; Karkar *et al.*, 2017) to support users in identifying program-level goals. In these cases, PGHD systems should offer ways to summarize and export data (concisely and following standard formats) to share with healthcare providers (potentially through integrations with digital health records) (Epstein *et al.*, 2017), so patients and providers can identify actionable goals together. However, as discussed in the previous section, PGHD is not always used in collaboration with healthcare providers. In these cases, studies suggest PGHD systems need to account for and support appropriate baselines (Pina *et al.*, 2017), different goals, and migration between goals (Epstein *et al.*, 2015, 2017). Section 2 described some common reasons for using PGHD that could be coded within PGHD systems. However, caution is necessary when encoding fixed goals in PGHD systems to avoid reinforcing a “narrow conception of what it means to be healthy or fit” (Purpura *et al.*, 2011).

In this context, some studies focus on supporting users to individually identify their goals through data analysis. Li *et al.* (2011) describe how people often start tracking to discover what might be adequate goals to pursue, as a way to “(1) determine what actions they should take to fix a problem or (2) establish a ‘baseline’ of their activities to determine whether they have a problem” (Li *et al.*, 2011). In these cases, users tend to collect multiple different types of data until they identify which ones are more adequate or necessary to their principle-level goals.

Li *et al.* (2011) call this the “discovery phase” of reflection: when users want to reflect to identify program-level goals. In order to support these users, Li *et al.* (2011) suggest that upon identifying users are in this stage systems should collect data automatically whenever possible, storing large amounts of data. Such features would help reduce the burden of data collection, supporting the user in exploring their data to identify their actionable goals (Li *et al.*, 2011). However, some studies suggest that large amounts of data can contribute to information overload, which can prevent users from identifying program-level goals (Choe *et al.*, 2014; Raj *et al.*, 2019).

In this context, Niess and Woźniak (2018) describe a model for tracking goal evolution (focusing specifically on fitness tracking) that explores how people translate qualitative goals (e.g., regain former fitness level) into quantitative goals that can be tracked (e.g., exercise two hours per day). They argue that current systems provide arbitrary pre-selected quantitative goals to users (e.g., walk 10,000 steps) without providing a clear connection of these numerical goals to the users’ desired consequences for health and wellbeing. For this reason, they suggest tracking applications should initially ask users about their qualitative goals and then propose quantitative goals that are directly connected to them. Also, trackers should make the connection between qualitative and quantitative goals explicit to the users, and expose how the data is gathered, how the metrics are developed, how trackers define which quantitative goals to suggest to users, and what are the anticipated benefits of achieving these goals (Niess and Woźniak, 2018).

Similar to Niess and Woźniak’s (2018) approach, Raj *et al.* (2019) suggest using sensemaking processes to guide the identification of users’ information needs. These information needs could then be used to guide data collection, supporting individuals to identify personal patterns and derive actions from them. The authors highlight the usefulness of this approach for self-experimentation, suggesting that PGHD systems should include a pre-experimentation stage “where patients collect multiple streams of data including factors and outcome measures, rank these factors through retrospective analysis and sensemaking, and conduct experiments based on the prominence of the factors” (Raj *et al.*, 2019).

Other studies propose approaches to avoiding negative goals and experiences. Costa Figueiredo *et al.* (2018) suggest PGHD tools should analyze how the user engages with data and potentially suggest cycles of reduced or no tracking to avoid negative experiences and cyclic negative thought patterns. Other studies also question if PGHD systems should encourage less tracking or lapses (Eikey and Reddy, 2017; Gorm and Shklovski, 2016; Johansen and Kanstrup, 2016; Karkar *et al.*, 2017; Murnane *et al.*, 2018). Eikey and Reddy (2017) analyzed how weight loss apps may reinforce or help in recovering from eating disorders, highlighting aspects and features of these apps that should be improved to support more positive attitudes towards the body and health. For example, using colors associated with the caloric budget should be tied to users' goals (as opposed to always represent eating less calories as green) and even include more nuanced representations than just green and red (as opposed to displaying the same red color regardless of how much users exceed the calorie budget) (Cordeiro *et al.*, 2015; Eikey and Reddy, 2017). Finally, PGHD systems, particularly the ones focusing on issues as socially loaded as diet and weight, should avoid focusing solely on numbers and try to reinforce "healthy behaviors like eating nutrient-rich foods and a variety of foods" (Cordeiro *et al.*, 2015; Eikey and Reddy, 2017).

Beyond avoiding negative goals, it is necessary to analyze which goals are reinforced. Purpura *et al.* (2011) discuss that systems focusing on persuading the user often provide fixed preconceived "social" goals. These social goals may conflict with users' personal goals or even harm them (e.g., losing weight for people with eating disorders). They suggest systems should encourage mindfulness (similar to Ayobi *et al.*'s, 2017 suggestions for the multiple sclerosis context) and help users to establish self-reliance, as for example helping them to develop an internal locus of control. They also call for improvements in the evaluation of these systems, suggesting such evaluations should consider not only the features and intended goals but also the unintended consequences of these features and goals, in order to assess the "true impact of the system on the user" (Purpura *et al.*, 2011). Finally, they argue that "it is important to not focus solely on restoration to an ideal state but also

on the revelations that users achieve while using the product,” which is directly related to reflection (Purpura *et al.*, 2011).

3.4 Reflection

Reflection is a central concept in PGHD research (Choe *et al.*, 2010; Epstein *et al.*, 2015; Li *et al.*, 2010, 2011; Rooksby *et al.*, 2014). Personal informatics, which is a main concepts related to PGHD, is defined as the practice of collecting and reflecting on data about oneself to acquire self-knowledge or achieve a goal (Li *et al.*, 2010). Reflection is seen as a means to bring awareness of one’s status, expose patterns and trends, generate meaningful insights, and lead people to new understandings about themselves in order to support positive changes (Choe *et al.*, 2010; Grönvall and Verdezoto, 2013a; Li *et al.*, 2010). In this context, two issues arise: (i) the connection between data and reflection, and (ii) as argued by Baumer *et al.* (2014), the apparent underlying assumption that reflection is valuable and positive.

Regarding the first issue, there is an ongoing debate regarding the apparent assumption of some studies that seeing data will automatically trigger reflection, and this reflection will generate action presumably different and better than what has been done before (Baumer *et al.*, 2014; Mols *et al.*, 2016; Purpura *et al.*, 2011). However, the connection between data and reflection is not always so straightforward. To tackle this challenge, studies propose approaches to support and stimulate users’ self-reflection. Some approaches focus on visualizations (Choe *et al.*, 2015; Johansen and Kanstrup, 2016; Morris *et al.*, 2010; Raj *et al.*, 2019; Schroeder *et al.*, 2017; Snyder *et al.*, 2019; Tang *et al.*, 2012), some consider the trade-offs between manual and automatic tracking (Choe *et al.*, 2015; Chung *et al.*, 2019; Grönvall and Verdezoto, 2013a; MacLeod *et al.*, 2013; Tang *et al.*, 2012), some focus on providing more information, especially contextual information, to users (Grönvall and Verdezoto, 2013a; Hodges *et al.*, 2006; Vandenberghe and Geerts, 2015), and others focus on supporting reflective thinking skills through social interaction (Mamykina *et al.*, 2008).

The second issue – the fact that reflection may not always be positive – has lately gained prominence in HCI, with studies suggesting

that reflection may also be connected to more negative thought cycles (van Dijk *et al.*, 2015; Hollis *et al.*, 2015; Lengelle *et al.*, 2016). In some cases, awareness and constant thinking about one's behavior can be harmful (Harrington and Loffredo, 2011) and inhibit problem-solving and acting (Lengelle *et al.*, 2016). Rooksby *et al.* (2014) describe how tracking is related to a person's self-esteem and can exacerbate issues such as body image and aging (e.g., to aggravate negative attitudes towards the body), potentially reinforcing negative emotional response. Along the same line, Baumer *et al.* (2014) discuss the "dark side of reflection," highlighting aspects such as bitterness revival, the act of "continually focusing on negative life events and using them to justify current behavior" (Baumer *et al.*, 2014). Studies in the HCI and PI areas have also described users experiencing negative emotions when self-tracking (Ancker *et al.*, 2015; Costa Figueiredo *et al.*, 2017, 2018; Eikey and Reddy, 2017; Gross *et al.*, 2017; Katz *et al.*, 2018; Williams, 2015), which can be related to maladaptive reflection processes, indicating that these activities may contribute to both negative and positive experiences.

Trapnell and Campbell (1999) describe reflection as one type of a broader concept, self-awareness, which is the "capacity to become the object of one's own attention; to focus one's attention inward toward the self; to actively identify, process, and store information about the self" (Morin, 2017). Reflection is the type of self-awareness with which people have a generally positive experience. The other type of self-awareness, related to negative experiences, is called rumination: anxious, perseverative attention towards the self, particularly focused on negative aspects (Trapnell and Campbell, 1999). Both reflection and rumination can be triggered by having and analyzing new information about oneself, for example, by using PGHD. Considering this, triggering reflection could instead trigger rumination, leading to negative and even harmful experiences to users, which are potentially worsened by "feedback loops" or "self-fulfilling prophecies" (Paton *et al.*, 2012).

Considering this, it is necessary to carefully consider the consequences of designing to inspire self-reflection. There is a trade-off to consider: too much automatization, such as when only providers use the data or when systems focus on reaction, and not reflection

(Adams *et al.*, 2015), may not generate the self-knowledge necessary to patients' self-management and empowerment. However, reflection can be risky in some situations and can turn into rumination, triggering negative experiences that can harm patients. Some aspects that may contribute to rumination are the goals users pursue (e.g., goals that may not be achieved, or goals that the user cannot control), as discussed in the previous subsection. Others are related to who the envisioned users of PGHD technologies are, how these technologies impact unexpected users, and who is left out. The next subsections focus on these aspects.

3.4.1 Design Implications

We identified five main types of recommendations for supporting reflection in the analyzed studies: (i) providing direct opportunities for reflection, (ii) offering customization, (iii) using predictions, (iv) avoiding negative consequences, and (v) considering temporal aspects.

First, many studies suggest implications to provide explicit opportunities for intentional reflection and to help make sense of data in an actionable way (Tang *et al.*, 2012). For example, studies suggest providing actionable insights about the data, such as presenting trends and highlighting important data points (Barbarin *et al.*, 2016; Morris *et al.*, 2010; Shih *et al.*, 2015), questioning outliers (Liu *et al.*, 2011), or highlighting contextual triggers and most helpful actions (Morris *et al.*, 2010). Concerning self-experiments, studies propose testing for the identification of thresholds, suggesting users perform re-tests with more confidence, or providing guidance to consult health providers regarding the interpretation and validity of the results (Felipe *et al.*, 2015; Karkar *et al.*, 2017; Sanger *et al.*, 2016; Schroeder *et al.*, 2017). Other studies suggest balancing automatic and manual collection (Consolvo *et al.*, 2008; Liu *et al.*, 2011; Simm *et al.*, 2016; Tang *et al.*, 2012), and providing "explicit opportunities for feedback and reflection" (Tang *et al.*, 2012) when using sensors to automatically gather PGHD. In order for these recommendations to work, it is important to support users' understanding and knowledge building. Therefore, some studies suggest translating medical language to common terms and considering users' language and literacy barriers (Ayobi *et al.*, 2017;

Liu *et al.*, 2011). Similarly, other studies highlight the importance of patients' and providers' collaboration in the interpretation of the data (Schroeder *et al.*, 2017; Vandenbergh and Geerts, 2015).

Second, customization and personalization are suggested by multiple papers to support meaningful, tailored reflection (Ayobi *et al.*, 2017; Barbarin *et al.*, 2016; Bussone *et al.*, 2016; Chung *et al.*, 2019; Costa Figueiredo *et al.*, 2018; Felipe *et al.*, 2015; Jacobs *et al.*, 2015; Li *et al.*, 2010; Liu *et al.*, 2011; Luo *et al.*, 2019; MacLeod *et al.*, 2013; McKillop *et al.*, 2018; Mishra *et al.*, 2019; Morris *et al.*, 2010; O'Kane and Mentis, 2012; O'Murchu and Sigfridsson, 2010; Paay *et al.*, 2015; Raj *et al.*, 2019; Sanger *et al.*, 2016; Schroeder *et al.*, 2017; Simm *et al.*, 2016; Tang *et al.*, 2012). The use of sensemaking processes to identify information needs, as proposed by Raj *et al.* (2019), can also be useful to support customization. In a different but related approach, Chung *et al.* (2019) suggest automatically configuring tracking tools according to individuals' goals through an initial walkthrough process. Such a process could reduce customization burden and at the same time support patients' health goals and reflection. Other design implications that can be useful for supporting reflection include personal recommendations based on customized and personal data or on the person's current stage towards the goal or type of engagement with data (Costa Figueiredo *et al.*, 2017, 2018; MacLeod *et al.*, 2013; Morris *et al.*, 2010; Paay *et al.*, 2015). Concerning recommendations and guidelines, different studies suggest generating them based on cases similar to the users' specific situation, instead of a general guideline based on a general (and potentially not representative) population (Bussone *et al.*, 2016; Costa Figueiredo *et al.*, 2017, 2018; Liu *et al.*, 2011; Paay *et al.*, 2015; Pina *et al.*, 2017; Sanger *et al.*, 2013; Shih *et al.*, 2015). Some authors also emphasize the differences between recommendations and rigid pre-defined automated solutions. Designers should avoid the latter because they may reduce patients' agency and downplay the need to interact with providers to interpret the data (Ayobi *et al.*, 2017; Schroeder *et al.*, 2017; Vandenbergh and Geerts, 2015).

Third, more recent studies have been suggesting or exploring the use of simulations or predictions to infer future states from past states (Desai *et al.*, 2019; Hollis *et al.*, 2018; Mishra *et al.*, 2019;

Raj *et al.*, 2019; Springer *et al.*, 2017). For example, Desai *et al.* (2019) developed a smartphone application that provides “personalized meal-time forecasts of anticipated changes to BG levels in response to meals” aiming to support meal-time decision making. Such features could help users to visualize the potential impact of a meal on their blood glucose levels and decide if they want to take an action in real-time (i.e., to continue or to change the meal). Such strategies can potentially support reflection by directly pointing to possible consequences of users’ health habits. However, similarly to the trade-offs between manual and automatic tracking, providing such predictions can result in over-reliance on technology and algorithm results. For example, Hollis *et al.* (2018) investigated how algorithmic feedback may influence users’ evaluations of their own emotions. They reported that users might defer to an algorithm’s classification of their own emotional experience over their personal judgment of that experience.

Therefore, the fourth type of recommendation considers how to avoid negative consequences and rumination patterns when designing for reflection. Some studies suggest motivating users to explore alternative solutions through, for example, transferring known self-management practices to new contexts (Johansen and Kanstrup, 2016) or through mindfulness (Ayobi *et al.*, 2017). In their work, Costa Figueiredo *et al.* (2018) suggest accounting for different personal contexts, personality traits, and relationships with data (i.e., more positive or more negative) because people may need different types of support depending on how they engage with their own health data. Similarly, it would be beneficial to identify rumination processes and try to provide support for breaking these negative thought cycles, triggering more positive engagements with data at the appropriate time (Costa Figueiredo *et al.*, 2018).

In a different approach, Johansen and Kanstrup (2016), based on Bandura’s self-efficacy construct (Bandura, 1997), focused on promoting functional recovery through confrontation. They suggest that technologies should focus on showing “how momentary actions contribute to maintaining a healthy balance with symptoms.” This approach may be useful to gain insights on how to deal with rumination cycles (Johansen and Kanstrup, 2016). However, this approach should be

carefully considered, because confrontation may also generate negative results, which can deepen the negative thought patterns of rumination.

Supporting and promoting self-compassion (Neff, 2003) could be another way to potentially avoid or interrupt self-rumination, helping users to overcome negative engagements with data. In a similar context, Mishra *et al.* (2019) suggest that sparse or intermittent tracking may help patients with progressive diseases, who may constantly look for symptoms of decline (e.g., Parkinson's disease), to “distinguish disease symptoms from chance occurrences” (Mishra *et al.*, 2019). Other studies suggest that PGHD technologies should allow users to collect positive experiences in order to avoid creating an overly negative data history (Luo *et al.*, 2019; Simm *et al.*, 2016).

Additionally, in order to avoid reinforcing obsessive behavior, studies suggest setting and informing “normal limits and acceptable fluctuations in the data” (Liu *et al.*, 2011), limiting the tracking periodicity of delicate measures (e.g., weight gain/loss measured once a month to avoid fixation with natural day-to-day fluctuations) (Tang *et al.*, 2012), supporting the care network to help identifying and avoiding obsessive behavior (Grönvall and Verdezoto, 2013a), and avoiding focusing solely on increasing performances by considering natural fluctuations in results, motivation, and engagement (Ayobi *et al.*, 2017). Studies suggest that systems should avoid comparisons with “optimal” values or predefined ideals (Ancker *et al.*, 2015; Mamykina *et al.*, 2008; Purpura *et al.*, 2011). Instead, reflection could be done in non-judgmental, subjective ways, allowing users to define their personal meanings and values, supporting curiosity, mindfulness, and self-discovery (Ancker *et al.*, 2015; Ayobi *et al.*, 2017; Purpura *et al.*, 2011).

Finally, temporal aspects can also influence reflection through PGHD (e.g., reflection may be different in the short and long term Li *et al.*, 2010). Supporting evolving needs, disease progression, and adjustments of care can also benefit reflection (Jacobs *et al.*, 2015; Luo *et al.*, 2019; Pollack *et al.*, 2016; Schroeder *et al.*, 2017), particularly in the long term. Barbarin *et al.* (2016) use the sociological concept of “narrative reconstruction” to suggest that the use of PGHD for reflection needs to account for “better-to-worse-to-better rhythms,” highlighting the importance of putting downturns in perspective and account for people's

changing life stories. In this context, it is necessary to consider the role of gaps and lapses beyond focusing on stimulating resuming tracking (Clawson *et al.*, 2015; Costa Figueiredo *et al.*, 2018; Epstein *et al.*, 2015, 2016; Murnane *et al.*, 2018). Some authors suggest considering changes in motivation over time and due to specific happenings. For example, Pina *et al.* (2017) suggest that tracking should be deprioritized during a crisis, when the whole family focuses on the sick child. Johansen and Kanstrup (2016) suggest providing ways to engage and disengage with devices. Karkar *et al.* (2017) suggest that people can designate gap days in an experiment. Gorm and Shklovski (2016) consider if it would not be important to “change the game often and sometimes stop counting” (Gorm and Shklovski, 2016). Costa Figueiredo *et al.* (2018) describe problematic scenarios of engagement with data that could benefit from breaks. These reports can indicate the need to not only account for lapses but also study if they are beneficial in some cases.

3.5 Access to PGHD Technologies

In the realm of PGHD, an important challenge refers to who has access to PGHD technologies and practices. There is increasing discussion of demographic issues of PGHD technologies such as self-tracking tools and wearables: these technologies often serve populations with a higher socio-economic status (SES) (since they can afford the technologies), and can exclude the populations that might need them the most, such as people with low access to healthcare and low socioeconomic status (Ancker *et al.*, 2015; Hecht *et al.*, 2018; Karkar *et al.*, 2017; Katule *et al.*, 2016; Loos and Davidson, 2016; Nundy *et al.*, 2014; Pollack *et al.*, 2016; Veinot *et al.*, 2018). Veinot *et al.* (2018) state that, despite researchers’ aspirations to improve healthcare and well-being and reduce the burden of disease, especially for populations that need it the most, health informatics interventions “pose a particular risk of producing intervention-generated inequalities by disproportionately benefiting more advantaged people”. According to them, health informatics interventions can generate inequality if they are more effective, accessible, adopted, and adhered to among advantaged groups. The relation of obesity and SES is a good example: while people with lower SES

tend to have poorer diets and higher likelihood of obesity, technological interventions targeting these health aspects tend to benefit more people with higher SES (Cameron *et al.*, 2015; Darmon and Drewnowski, 2008; Ogden *et al.*, 2010). Technological solutions, in general, are typically more adopted by people with higher SES. Similarly, incentivized programs based on healthcare and corporation interventions are also more accessible for people who have health insurance, use preventative care, are employed, or have more time and resources (Veinot *et al.*, 2018; Zulman *et al.*, 2013). All these aspects benefit people with higher SES, higher education, higher health literacy, higher technological use, and who are young and live in cities.

Accessibility and adoption can also impact on how providers view patients: providers can see patients that use PGHD as more engaged in their healthcare, which may influence on their attitude towards the patient (e.g., being more supportive vs. having a generally worst communication) (Loos and Davidson, 2016). If these technologies are more adopted by advantaged groups, they can potentially increase the disparities of care, and even reinforce bias and differences in patient-provider communication based on, for example, race, age, education, or SES (Johnson *et al.*, 2004; Loos and Davidson, 2016; Street, 2007).

3.5.1 Design Implications

Veinot *et al.* (2018) discuss how health informatics interventions can produce “intervention-generated inequality” (IGI) and propose means to mitigate them. For example, for intervention-generated inequalities originating from differential efficacy (i.e., when interventions are more effective for groups with higher SES) they suggest emphasizing the implementation of “upstream” informatics interventions, i.e., interventions that focus on factors at the structural and environmental level (Veinot *et al.*, 2018). For instance, interventions aiming to promote healthy eating and exercise need to tackle environmental aspects that can prevent low SES groups from achieving the expected benefits, such as food prices or availability and access to exercise facilities. Parker *et al.* (2012) and Maitland *et al.* (2009) approached such issues concerning healthy eating, describing how participants had difficulties in finding healthy

foods in their communities. In this context, Parker *et al.* (2012) created a system for individuals to share their ideas for healthy eating within their community to encourage community activism, exposing structural challenges such as the “imbalance of power between food vendors and the residents of predominantly African American communities” (Parker *et al.*, 2012). Parker *et al.* (2012) also partnered with a local nonprofit organization, which can help tackling IGI originated from differential access (i.e., when interventions are more accessible to more advantaged groups) (Veinot *et al.*, 2018). Other suggestions for addressing the same challenge of technology access are to partner with public libraries and keep using older technologies (e.g., SMS) in interventions instead of only approaching the most recent (and expensive) technological solutions (Veinot *et al.*, 2018). When partnering with healthcare providers, particularly through traditional clinical settings, it is important to give them options to provide the same quality of care for patients that may not have access to the technologies necessary to use PGHD or that may have structural and environmental barriers to using such data (Loos and Davidson, 2016; Nundy *et al.*, 2014; Veinot *et al.*, 2018).

In this context, it is important to consider who will have access to the technology in order to avoid increasing social disparities or reinforcing social bias. However, it is also important to develop systems and interventions that directly target health disparity (Veinot *et al.*, 2018), such as, for example, proposing systems that address health conditions and preventative health issues particularly amongst the groups who experience them disproportionately more (Parker *et al.*, 2012). More than addressing the needs of disadvantaged populations to avoid IGI, such interventions could propose approaches to directly reduce inequalities. Some studies propose to support community activism and advocacy concerning health (Katule *et al.*, 2016; Parker *et al.*, 2012; Veinot *et al.*, 2018). Parker *et al.* (2012) suggest that researchers should understand and consider the broader context of how health and wellness fit in people’s lives. They argue that health should not be considered only as an individual effort of changing behaviors. Health interventions should “explicitly confront the community, cultural, and society-level forces that shape the conditions in which people live” (Parker *et al.*, 2012). For example, Maitland *et al.* (2009) describe how participants felt

motivated to change health behaviors but faced many structural and environmental challenges concerning time and tight work schedules, lack of space, and financial uncertainty. Therefore, Maitland *et al.* (2009) conclude, “any attempt to motivate to change should be paired with an equal attempt to facilitate change” (Maitland *et al.*, 2009).

3.6 Expected and Unexpected Users

PGHD are based on different measurements, for example, steps, bio-values, weight, calories, symptoms. These measurements only make sense when compared to a scale: a temperature is only considered low when compared to the “normal” body temperature. A number by itself would not be capable of “characterizing” health or disease. These scales are created based on the measurements of a population. Using the temperature as an example, in order to define the “range of normal body temperature,” Carl Wunderlich recorded more than 1 million readings from 25,000 patients, establishing the interval of temperatures that were considered “normal” and, consequently, the ones outside this interval “suggested disease” (Pearce, 2002).

A similar issue happens with all measures used in PGHD practices, especially in the increasingly popular self-tracking systems and technologies. These measures can be created based on a limited population, and this population will then represent the total. This can negatively impact populations not represented in the measure and scale definitions. Self-tracking technologies often do not describe what the characteristics of the population used to create the scales were (Neff and Nafus, 2016), so we do not know to which extent they are representative. Considering that technologies in other fields have generated debates on bias and fairness (e.g., cameras that did not detect African-American faces or detected Asians blinking when they were not (Rose, 2010), artificial intelligence systems that prefer men’s resumes to women’s resumes Dastin, 2018, criminal systems biased against African-Americans Dressel and Farid, 2018) this is a relevant concern. In the health domain, similar problems are possible concerning the measures people will compare themselves against. For example, the 10,000 daily steps number recommended by most commercial pedometers did not have any particular

health rationale, but it is widely adopted as a good exercise target. However, it can be prejudicial to some people, such as older adults (Caldeira *et al.*, 2017) or people who have suffered injuries (Neff and Nafus, 2016). People may feel pressured to achieve that number despite their physical limitations (Ayobi *et al.*, 2017). These issues become even more complex with the recent increased application of data science methods to behavioral or social media data, focusing on creating predictive models of illness. These approaches tend to disproportionately include data from advantaged groups (e.g., who have access to technologies and internet), skewing the “composition of the dataset that is used to generate the models of illness and health needs” (Hecht *et al.*, 2018). If these models are then applied to the broader population, they can increase disparities in healthcare, contribute to discrimination, and even put people’s lives at risk (Hecht *et al.*, 2018).

In addition, PGHD systems often do not describe what a “normal” (or average) measure is for different people with different health status or conditions (Neff and Nafus, 2016). One-size-fits-all solutions will never match with every person (Ancker *et al.*, 2015; Grönvall and Verdezoto, 2013a; Simm *et al.*, 2016; Stawarz *et al.*, 2014), but some health concerns have a huge variability and using the same single scale can be very problematic (Costa Figueiredo *et al.*, 2017, 2018; Murnane *et al.*, 2018; Park and Chen, 2015; Pina *et al.*, 2017; Snyder *et al.*, 2019). In this scenario, self-tracking and PGHD may contribute to negative feelings in people both by reinforcing over-tracking, aiming to achieve a measure that does not represent the person’s reality, and by not recognizing themselves in the measures offered to them. And more vulnerable populations (e.g., individuals with mental health conditions such as depression and obsessive-compulsive behavior and individuals facing terminal diseases) are potentially more susceptible to experience rumination and negative engagements with data, particularly when they connect their goals to their identity or self-worth in extreme ways (Costa Figueiredo *et al.*, 2018; Eikey and Reddy, 2017; Liu *et al.*, 2011; Murnane *et al.*, 2018; Snyder *et al.*, 2019).

It is also important to consider the populations that are not the targeted user groups, but that might be impacted by the use of PGHD tools. For example, Eikey and Reddy (2017) studied the use of regular

weight loss apps by women with eating disorders. These women were not the intended population for the apps, but they were also using them, and consequently, they were also using the same scale to judge themselves. In this scenario, design decisions that support healthy behavior in the target population may negatively impact other users that were not foreseen by the technology.

3.6.1 Design Implications

It is not unusual that health interventions, including the ones using PGHD, opt for a one-size-fits-all approach in order to benefit or support the majority of people. However, people have different health experiences. Consequently, users of PGHD technologies will be differently impacted by the design of these technologies (Eikey and Reddy, 2017).

First, the standard measures used to define averages or “normal” range of values should be defined based on data from a more diverse population to improve the representativeness of the results. In addition, PGHD technologies could also define different scales for different situations, experiences, and health statuses (Costa Figueiredo *et al.*, 2018). Showing scales, average values, and standard measures based on a population that is more similar to the user, and showcasing the inherent variability of values, can improve users’ recognition and support balanced expectations concerning their own results. It is also fundamental to account for exceptions, making it clear to the user that her results may be different from the expected even if they are using an appropriate scale (Costa Figueiredo *et al.*, 2017). Kendall *et al.* (2015) suggest that PGHD technologies could initially use typical scales and variances based on other users’ data or existing literature and gradually personalize the results and visualizations based on the user’s personal data, scale, and variance. However, if predictive models are created based on PGHD such as behavioral or social media data, it is necessary to rigorously discuss and address the broader impacts of using personal data of large numbers of individuals, such as issues concerning privacy, security, and discrimination (Hecht *et al.*, 2018). Furthermore, systems should expose how users’ personal data and other population data are gathered, how the metrics and scales are developed based on them

(Niess and Woźniak, 2018) and how representative such data and scales are. Other studies emphasize the importance of making the system logic (i.e., algorithm transparency) and the variability in the measures explicit in order to make the limitations of the quantification process clear to the end users (Costa Figueiredo *et al.*, 2017, 2018; Gorm and Shklovski, 2016; Niess and Woźniak, 2018; Sanger *et al.*, 2016; Schroeder *et al.*, 2017). For example, Liu *et al.* (2011) recommend that a system's interface include uncertainty notification and feedback, notifying the user of the presence of uncertainty and providing mechanisms to deal with it.

Customization and better and nuanced support for personalized goals (as discussed in the previous subsections) can also help in addressing the needs of different people (Eikey and Reddy, 2017). It is also necessary to analyze the potential consequences of the adopted design strategies. For example, gamification for health could potentially improve motivation. However, since data can cause strong emotional responses, using gamification can appear to “trivialize important tasks, and ‘losing’ in a game might amplify negative emotions” (Ancker *et al.*, 2015). Similarly, reminders can be useful for compliance, but they can also: contribute to negative feelings of constantly remembering the disease (Ancker *et al.*, 2015), feed obsessive behaviors (Costa Figueiredo *et al.*, 2018; Eikey and Reddy, 2017), or trigger the exact behavior the person is trying to avoid (Paay *et al.*, 2015). Competition is another controversial feature: some studies describe users would like such features (Paay *et al.*, 2015; Vyas *et al.*, 2015), while others describe negative consequences (Gorm and Shklovski, 2016; Zulman *et al.*, 2013).

Although some studies focusing on behavior change suggest showing the user what they would immediately lose (Consolvo *et al.*, 2009; Paay *et al.*, 2015), others suggest approaches less focused on negative results. For example, some studies suggest highlighting success (e.g., short-term improvements) and aspects of normalcy (in specific cases of diseases), while helping in recognizing periods of stabilization and stagnation of symptoms and framing discouraging patterns within actionable suggestions, resources, or inspiring stories to avoid or reduce distress (Ayobi *et al.*, 2017; Barbarin *et al.*, 2016; Felipe *et al.*, 2015; Johansen and Kanstrup, 2016; Pina *et al.*, 2017). Other studies highlight that it is not necessary to shame or make users feel bad about their data when they

do not achieve a specific result (Consolvo *et al.*, 2008; Cordeiro *et al.*, 2015; Eikey and Reddy, 2017; Purpura *et al.*, 2011). Other recommendations are to be mindful when using moral accounting (e.g., in workplace competitions) to support the benefits but respect people's privacy and work balance, and to consider using more holistic approaches of social ecology and health promotion (Gorm and Shklovski, 2016).

Finally, it is critical to carefully consider who the users are – not only the “ideal” target user but also unexpected users that may use the system. In this sense, it is important to consider contextual factors, the broader social context, and how they influence users' behaviors, thoughts, and emotions (Costa Figueiredo *et al.*, 2018; Eikey and Reddy, 2017; Paay *et al.*, 2015). Additionally, it is necessary to consider who will have access to the technology by analyzing whether it can increase social disparities or reinforce social bias, targeting structural and environmental aspects, and dedicating effort to develop equity-focused interventions and technologies (Veinot *et al.*, 2018).

Considering that it may be challenging to identify and address the needs of all potential users of a system, it has been clear that we need multidisciplinary and diverse teams in all stages of the process of designing and developing PGHD technologies (Sanger *et al.*, 2016). Liu *et al.* (2011) also highlight the need to deploy and evaluate the impact and effectiveness of the technologies in real scenarios, so we can understand how they fit in users' personal and cultural context. Other studies emphasize the need for experimental studies and larger field deployments to evaluate the potential benefits and understand how such technologies might be adopted and impact communities (Ballegaard *et al.*, 2008; Morris *et al.*, 2010).

Some issues, however, need much more than technology support. This is the case, for example, of incentivized health programs, promoted by health insurance companies and based on step counts, and its effect on the healthcare of people with disabilities. In such cases, policies are often necessary to avoid discrimination and the increase of health disparities (Zulman *et al.*, 2013). These and other issues related to populations, particularly the ones related to quantification and representation, are intrinsically connected to the broad social context in which designers, developers, users, and technology are embedded.

4

Open Questions for PGHD Research

The previous section described the main challenges related to PGHD technologies and research. These challenges are often entangled with complex issues that are not easily addressed. We presented the main design implications described in the analyzed papers that can potentially address each challenge. However, many of these issues are beyond the scope of technology, and it is unlikely (and maybe not feasible) that technology can solve these problems. Adapting a classic law of software engineering (Brooks, 1987): technology is no silver bullet for societal problems. Considering this, we end this review with several open questions for PGHD research regarding the wider sociocultural context in which the design of PGHD technologies is embedded.

4.1 The Complex Social Context

Digital technology tools are socially constructed (Gorm and Shklovski, 2016) and “sociocultural products located within pre-established circuits of discourse and meaning” (Lupton, 2015). Thus, PGHD technology and activities are immersed in broader socio-cultural contexts and “beliefs about how societies function” (Neff and Nafus, 2016). When people use these practices, they are not isolated; rather, they are embedded in

and influenced by broader social phenomena such as biomedicalization, quantification, empowerment, and societal ideals.

Biomedicalization refers to the expansion of “medical jurisdiction, authority, and practices,” “through the new social forms of highly technoscientific biomedicine” to aspects of our lives that were not previously medicalized (Clarke *et al.*, 2003). According to Neff and Nafus (2016), biomedicalization generated a mental model that sees medicine as the main explanation for how people behave: they report that it seems easier to explain people’s behavior by neuron interactions than to consider the impact of society and culture on people’s lives. This phenomenon, alongside with the current technological advances, expands the areas of life that can be measured, making “close measurement of the body both conceivable and desirable,” and propitiating the growth of the movement of people tracking themselves (Neff and Nafus, 2016). Biomedicalization is also intrinsically related to quantification: “the production and communication of numbers” (Espeland and Stevens, 2008).

Quantification is directly related to PGHD practices since many of the measures and health indicators tracked by individuals are based on the quantification of bodily or emotional observations (e.g., *number* of steps, *level* of pain, *number* of days a feeling is experienced, *hours* slept, *duration* of physical activity). Quantification processes naturally involve some levels of meaning loss, especially when measuring and quantifying a physical or bodily phenomenon (in contrast with objects or countable things). The result of these processes will always be a reduction: a partial representation of a person or observation in data, and not the whole person or observation (Nafus, 2016). This reduction is a natural process, due to the need to define boundaries and parameters to delimit the observation so it is possible to distinguish it (Snyder *et al.*, 2019). For example, devices’ sensors measure steps through algorithms involving generalizations and approximations: the sensors do not measure the length of each of the user’s strides, not even the users’ average (although averages can be configurable in some devices). However, this created measure often becomes the representation of the larger observation: the user’s activity level (Sherman, 2016). In this sense, the measure is capable of redefining the thing being measured

(Espeland and Stevens, 2008; Sherman, 2016). In addition, after the measure exists, it acquires an authoritative role (Espeland and Stevens, 2008; Sherman, 2016), while the real limitations of quantifying the physical phenomenon disappear behind the final number (Espeland and Stevens, 2008; Lupton, 2013a; Sherman, 2016; Verran, 2011). Body data is then viewed as objective, neutral, scientific and a true representation of the body (Lupton, 2013a).

After the number exists and is presented to the user, the measure acquires its own form and demands users to deal with it. Espeland and Stevens (2008) argue that numbers naturally have authority and tend to discipline human behaviors. These numbers then impact the definition of “what is normal,” often conflating “normal” in a statistical connotation (i.e., shape and properties of measures said to follow a normal distribution) with “normal” in a moral sense (Espeland and Stevens, 2008; Neff and Nafus, 2016). The numbers then become the ideal goal that indicates if a person achieved “good” health (Sacramento and Wanick, 2017), or her “best-self” (Bietz *et al.*, 2016). Consequently, the “outliers” – the people that do not fit in the norms or whose data are not aligned with the ideal – may suffer with anxiety, fear, and disapproval (Ancker *et al.*, 2015; Ayobi *et al.*, 2017; Costa Figueiredo *et al.*, 2018; Eikey and Reddy, 2017; Espeland and Stevens, 2008; Gorm and Shklovski, 2016; Lupton, 2013a; O’Kane *et al.*, 2016). This issue becomes even more problematic when linked to principle or system-concept level goals, connecting the pursuit of the measure to self-identity or self-worth. In this context, “health” becomes a euphemism for what is believed to be desirable, contributing to feelings of stress, judgment, guilt, and shame (Neff and Nafus, 2016).

This “best-self” aspect is highly influenced by societal ideals and pressures, such as gender, family, work, health, and beauty. Nafus (2016) highlights that data and data collection have often been used to consolidate cultural and economic powers. She cites the description of the “unblushing American” (“a young, married, white, urban, northern, hetero-sexual, protestant father of college education, fully employed, of good complexion, weight, and height, and a recent record in sports” Goffman, 1986), who is a rare creature, but is often the standard used to generate the measures and technologies and, consequently, the one

with which we will compare ourselves (Nafus, 2016). In this context, it is always important to consider whether the measurements and the technology based on them are not reproducing social constructions that may be problematic or harmful.

These social constructions include power relationships. One of the reported benefits of self-tracking and PGHD is patient empowerment through an increased sense of control and agency (Ayobi *et al.*, 2017; Barbarin *et al.*, 2016; Cortez *et al.*, 2018; Farmer *et al.*, 2005; Grönvall and Verdezoto, 2013a; MacLeod *et al.*, 2015; Mamykina *et al.*, 2008; Snyder *et al.*, 2019). PGHD technology often gives people a plan—something that they can do when facing health issues, especially complex ones. Thus, using PGHD can be seen as an act of challenging existing power relationships between patients and providers (Aarhus *et al.*, 2009). However, some scholars call attention to the possibility that this promise of control becomes a burden “disguised as empowerment” (Neff and Nafus, 2016). Neff and Nafus (2016) contrast the use of PGHD technologies as a supplement for care or as its substitute. They argue that the increasing reliance on self-tracking technologies and PGHD use by patients may end up shifting labor costs to patients: issues that are the responsibility of institutions through paid labor may be shifted to patients, who would perform the tasks for free, sometimes even against their will. In this sense, although these technologies can empower people, they can also feel like an obligation, demanding patients to take responsibility for their health. Patients would be expected to not only monitor their health but also to track and take actions based on their data. As Schüll (2014) reports about choice, especially in contemporary capitalist societies, “modern individuals are not merely ‘free to choose’ [...] but obliged to be free, to understand and enact their lives in terms of choice” (Schüll, 2014). Lupton (2013b) argues that this can potentially disempower patients, by making tracking and acting on one’s own health a required process and, thus, out of patients’ control if they want to do it or not. In this sense, no action would be associated with failure, while “doing something” would lead to the improvement.

This complex social context opens several questions regarding the role of PGHD research and technology. One of these fundamental questions is what is the role or responsibility of design in balancing

users' trust and expectations regarding PGHD technologies? Moreover, we believe PGHD systems and practices can be beneficial to people, but these technologies need to be transparent about (i) their real capabilities, and (ii) the complex social norms that influence them. In this context, how can PGHD technologies convey to users the limitations inherent to the quantification process in a meaningful way? Also, how can PGHD technologies be more representative to the varied groups (expected and unexpected) that may use them? Beyond being more representative, how can PGHD technologies support users in determining if a recommendation is appropriate to their reality? Or, more broadly, how can PGHD technologies avoid reproducing social constructions that may be problematic or harmful to different groups of users? Finally, in order to approach such questions, should we focus on universal PGHD technologies that will reach a broader public or should we design for particular and diverse experiences?

4.2 The Evolving Scope of Health

Researchers now have a much broader view towards health. Health is broader than treating medical illness: it can involve improving health and wellness (in the absence of any medical illness), or even further stretched to other factors such as social wellness, emotional wellness, and several more. These new evolving and more inclusive views towards health mean that we will likely have to embrace new data, new challenges, new stakeholders, etc. which requires us to keep an open mind in designing PGHD.

This evolving health scope demands strategies that avoid reinforcing limited definitions of health (Eikey and Reddy, 2017; Purpura *et al.*, 2011). Instead of solely trying to “fix” a health condition, PGHD technologies should include both physical and emotional factors (not only symptoms) and fit people's daily lives, accounting for natural changes, hidden work, and supporting sustaining everyday lives as a whole (Ancker *et al.*, 2015; Ayobi *et al.*, 2017; Ballegaard *et al.*, 2008; Barbarin *et al.*, 2016; Costa Figueiredo *et al.*, 2017, 2018; Felipe *et al.*, 2015; Gorm and Shklovski, 2016; Jacobs *et al.*, 2015; Kendall *et al.*, 2015; O'Kane *et al.*, 2016; Pina *et al.*, 2017). Some of the implications

described in the previous section can contribute to supporting broader views of health. For example, accounting for appropriate baselines and analyzing whether the goal is realistic and positive (providing users information and actionable suggestions) can avoid limited pre-defined goals that can harm some populations. Studies also suggest avoiding both comparisons with “optimal” values and the use of persuasion to achieve a predefined ideal (Ancker *et al.*, 2015; Mamykina *et al.*, 2008; Purpura *et al.*, 2011). Fixating on an “optimal” result or behavior may contribute to the negative consequences of pursuing an unrealistic “best-self” (Bietz *et al.*, 2016) heavily loaded with societal pressures and stereotyped roles (Ancker *et al.*, 2015; Costa Figueiredo *et al.*, 2018; Eikey and Reddy, 2017; Epstein *et al.*, 2017). Instead, reflection should be done in non-judgmental, subjective ways, allowing users to define their personal meanings and values, and supporting curiosity, mindfulness, and self-discovery (Ancker *et al.*, 2015; Ayobi *et al.*, 2017; Purpura *et al.*, 2011). It is also important to acknowledge that treats (e.g., going over the calorie budget to celebrate an achievement) and gap days might be part of what it means to be healthy in a person’s life (Costa Figueiredo *et al.*, 2018; Eikey and Reddy, 2017; Gorm and Shklovski, 2016; Luo *et al.*, 2019; Pina *et al.*, 2017). In addition, supporting and promoting self-compassion (Neff, 2003) could be one way to potentially avoid or interrupt self-rumination, helping users to overcome negative engagements with data, and stimulating different attitudes towards the body.

Supporting only a medical and narrow view of health can be problematic at different levels. In this sense, Murnane *et al.* (2018) position PGHD within broader social ecology systems, particularly considering long term care. They proposed a model of the sociotechnical ecology surrounding serious mental illness management, which considers the “personal data practices that encompasses the range of people, organizational units, and broader sociocultural norms and values that influence and are influenced by the condition and care of a central individual” (Murnane *et al.*, 2018). This model describes different layers of relations that surround the individual, including closely involved ties (e.g., family, friends, professional or informal caregivers), indirect institutional influencers (e.g., workplace, health insurers, community organizations,

schools), broader sociocultural context (e.g., societal norms, government policies, ideologies, economic trends), and a temporal layer that represents how healthcare and health needs change throughout the course of a person's life. This model locates PGHD within its broader sociocultural context, highlighting the multiple levels of interaction that involve or impact both PGHD use and a person's health management. Moreover, it highlights the role PGHD systems play across these layers and how it may impact individuals' health, care practices and social structures (Murnane *et al.*, 2018).

In a related approach, Kaziunas *et al.* (2019) explored community forms of care in communities struggling with significant health disparities. In their work, they emphasize the role of the broader sociocultural context, challenging common assumptions of health informatics interventions regarding “empowering” or “engaging” users through technology, particularly considering people in “infrastructural shadows” (Kaziunas *et al.*, 2019). The authors propose “the analytic sensibility of precarious intervention to capture the ways in which design in a setting of systemic health disparities requires grappling with experiences of infrastructural brokenness that are not easily resolved or repaired, but routinely negotiated” (Kaziunas *et al.*, 2019). This concept of precarious interventions would help in recognizing commonly overlooked workarounds, which can be distressing or dangerous, as necessary care work required to survive or access healthcare for people living with systemic health challenges in vulnerable socioeconomic and political realities. This approach foregrounds that health is broader than the aspects commonly approached by technology design, highlighting “problematic assumptions embedded in the design of health technology that reduces care to an issue of information transfer or a site for promoting user empowerment and engagement” (Kaziunas *et al.*, 2019).

These two approaches highlight that not only should we avoid reinforcing limited definitions of health through PGHD (Eikey and Reddy, 2017; Purpura *et al.*, 2011), but we also need to position PGHD within the larger sociocultural context in which we are embedded. They call attention to the limits of “human-centered and techno-solutionist approaches to design” that may not recognize that technical solutions

cannot fully address systemic challenges and infrastructural breakdowns (Kaziunas *et al.*, 2019).

These practices point to the need to support broader views of what health and healthcare mean. In this sense, how can PGHD technologies support broader views of health even when the system is intended to support the management of a specific health condition? Studies such as Murnane *et al.* (2018) and Kaziunas *et al.* (2019) suggest that PGHD practices and technologies should be positioned within the broader sociocultural context in which they are embedded. This leads to other important questions like: how can PGHD technologies acknowledge and support the different sociocultural levels of interaction that influence and are influenced by them? How can PGHD technologies support people in infrastructure shadows? As Veinot *et al.* (2018) describe, health interventions based on technology can increase health disparities, since people living within infrastructure breakdowns are often excluded from such interventions due to systemic problems (Kaziunas *et al.*, 2019). In this context, is it possible to use PGHD technologies to fix infrastructure breakdowns without increasing health disparities? Finally, following Maitland *et al.*'s (2009) suggestion that “any attempt to motivate to change should be paired with an equal attempt to facilitate change,” how can we use PGHD technologies to support health advocacy and change?

4.3 The Design Culture

Many of the criticisms of self-tracking are related to its potential to influence users to follow predetermined, potentially harmful, behaviors disconnected from their own needs (Purpura *et al.*, 2011; Schüll, 2014). This is related to an earlier discussion regarding the power of technology in “configuring the user” (Woolgar, 1990): machines “configure the user” by defining who the user is and delimiting the user’s possible actions. The configuration of a singular user makes it easier to organize the messiness of the world in a way that can be approached by technology, especially in the domain of PGHD and self-tracking for health, where very little can be anticipated (Nafus, 2016). Aiming to make the processes easier for users, designers tend to reduce options and simplify tasks, which can

also limit the opportunities for reflection and opportunistic tracking, like self-experimentation (Ayobi, 2018; Neff and Nafus, 2016; Purpura *et al.*, 2011; Schüll, 2014). And finally, the market pressures demand tools to be developed and released in a short time to avoid competition (Woolgar, 1990). Combining all these factors, the configuration, often subtle and unnoticed, can turn to a sort of coercion, leading users to engage in activities that are not always beneficial to their health (Purpura *et al.*, 2011).

Many designers are aware of the shortcuts, simplifications, and generalizations they need to do to release a product. These aspects are often part of almost inflexible limitations of their work that often cannot be solved by current technology. Nevertheless, the impact of technology cannot be overlooked. Although designers cannot solve all the social issues surrounding the technology they are developing, these consequences need to be acknowledged, understood, and avoided or alleviated when possible. Social norms can be intractable, but may be possible to consider, embrace, or co-adapt in design (Gross *et al.*, 2017). In this context, we, as designers, need to be critical about different aspects and dimensions of PGHD, such as who defines the data to be collected, what data will be gathered, how these data will be used, what the consequences of PGHD use are, and who will benefit (Suchman, 2006). This is not meant to hinder technology production, but to encourage responsible development, especially in areas as heavily loaded with social values and pressures as health. The previous section presented some useful implications, but it is important to highlight that “the technology field alone is not equipped for such a task – multidisciplinary partnership is crucial” (Calvo and Peters, 2014).

In this context, beyond technology itself, the design process also matters. Different studies have proposed implications that focus on how PGHD technologies are envisioned, planned, and developed. These studies emphasize the need for analyzing the real-life use of PGHD and integrating the user in the development. In general, a common suggestion in this direction is to have multidisciplinary, diverse teams that include, listen, consult, and apply patients’ and users’ knowledge and needs in the projects (Ancker *et al.*, 2015; Ayobi *et al.*, 2017; Ballegaard *et al.*, 2008; Barbarin *et al.*, 2016; Jacobs *et al.*, 2015;

Paay *et al.*, 2015; Sanger *et al.*, 2016; Tang *et al.*, 2012; Veinot *et al.*, 2018). Ballegaard *et al.* (2008) highlight that people have the right to influence and safeguard their interests in technology development, that technology professionals are not neutral, and that the more technology becomes ubiquitous, the more we need detailed knowledge of and experiences with the activities we are trying to support. These recommendations focus on reducing the user/designer separation (Suchman, 2002) by truly including users, so they can help to define the problems and solutions alongside healthcare and technology professionals. This would support a better understanding of users' needs, non-needs, and how technology can positively or negatively impact their lives. However, these recommendations are not new, so, why do we keep facing the challenges they intend to tackle?

Some authors suggest that we need to go one step further and invest more in larger field deployments studies to evaluate the impact and effectiveness of the technologies in real scenarios, so we can understand how they fit and impact the user's personal and cultural context (Ballegaard *et al.*, 2008; Liu *et al.*, 2011; Morris *et al.*, 2010). Communities need also to be more deeply approached, since PGHD is seldom a strictly personal activity. Using participatory approaches or action research (e.g., Hayes, 2014; McIntyre, 2007; Schuler and Namioka, 1993; Rohde *et al.*, 2017) may be useful to better consider the dynamic social contexts in which PGHD systems are embedded. Complementarily, Kaziunas *et al.* (2019) highlight the use of critical design literature as a means to expose and interrogate the limits of technology design in accounting for the complexity of systemic challenges and infrastructure breakdowns, particularly in the context of vulnerable socioeconomic and political communities.

Finally, there is another aspect that needs to be considered: users' agency. Users are not naïve creatures, blindly following everything technology tells them (Suchman, 2006). In fact, the quantified-self movement started as the opposite: technology enthusiasts aiming to create personalized solutions (and not follow general and normative approaches) to improve themselves, including their health (Neff and Nafus, 2016). Many studies describe workarounds people have created to adapt the tools and create their individualized solutions and processes

(Bietz *et al.*, 2016; Gross *et al.*, 2017) or even to overcome systemic infrastructure breakdowns (Kaziunas *et al.*, 2019). Gross *et al.* (2017) argue that “the blurry relationship between health goals and social norms, as well as the gap between what sensors sense and what actually happened, creates ambiguity,” and many users, aware of the limits of the technologies in capturing “reality,” often use this gap in active and creative ways (e.g., faking data by tricking devices to count more steps) (Gross *et al.*, 2017). As it can be seen in other contexts, every story of oppression can also be seen as a story of resistance, depending on how you look at it (Kumar *et al.*, 2018). In the PGHD context this creates another duality: technologies that discipline the users, causing stress and dependence in some, and technologies that allow users to create creative solutions to maintain their agency. In this context, it is important to make visible and account for the fact that the same tools and activities can have nearly opposing consequences. This will help us avoid the “double bind of agency” (Kumar *et al.*, 2018): to overlook users’ agency and treat them as puppets of technology, or to glorify agency, dangerously ignoring the fact that the technology should be improved. This knowledge is critical for designers, developers, and researchers, since the decisions we make can directly impact the lives of many people. As Calvo and Peters describe, “to enter an age of ubiquitous computing while turning a blind eye to the influence of technology on wellbeing is to accept a kind of convenient ignorance of the real impact of our work and thus to limit our success as designers and developers” (Calvo and Peters, 2014).

Recently, a group of researchers released a manifesto calling for more actions to mitigate the negative impact of computing (Hecht *et al.*, 2018). They suggest starting through research: by changing the peer-review process to try to force deeper considerations of the negative impact of research and technology development. This suggestion calls attention to our current technology and research culture, which emphasizes and focuses on the good side of the story in order to get market, funding, papers. In this sense, our own technology culture makes part of the social context impacting PGHD use and potentially reinforces or even generates negative consequences to the users we intend to support and help. And since technology is spreading to even more sensitive aspects

of our lives (e.g., health), the need to discuss such issues and to include as many more affected stakeholders as possible increases. As described previously, social norms can be intractable, but may be possible to mitigate (Gross *et al.*, 2017). We need to consider not only the external social norms but also our own research culture and practices.

Considering this, an important question for PGHD research is: how do our own research and design practices influence the PGHD technologies we study and develop? And how can we improve our own research culture and practices? Hecht *et al.* (2018) proposed noteworthy suggestions for the peer-review process, which represents a critical part of our research culture. How can we implement such suggestions and go beyond them to approach other fundamental aspects such as funding? Finally, considering that in some cases technological interventions may create more challenges and their consequences can be difficult to predict, we need to develop a critical capacity for identifying when technological interventions are and are not appropriate. Therefore, a question that should always be considered by anyone researching and developing for health support: when is a technological solution appropriate and when should they NOT be proposed?

4.4 Final Remarks

As our review shows, PGHD is a rather elusive term that is difficult to define. Many different dimensions need to be considered when researching and developing PGHD-related technologies and solutions. The use of PGHD presents various challenges, such as incorporating such data in healthcare providers' workflows, supporting effective collaboration between patients and providers, allowing reflection, and supporting different user groups without harming unintended users or people who cannot access such technologies. Many of these challenges are directly related to the health context, which is diverse, personalized, emotionally loaded, and embedded in and impacted by sociocultural norms, beliefs, and systemic challenges. Many of these aspects cannot be solved solely through technology, and some of them can be worsened by it. With new technology developments and new approaches towards health and wellness, both the types of data that are considered PGHD and the

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technologies that are designed to support the use of these data are constantly evolving and thus deserve further, continued, and careful research. It is our hope to bring the promised benefits of PGHD to the right users, allowing the co-adaptation of technology and social context in order to incorporate broader approaches to health, to carefully consider the impacts of any new technology, and to approach the described design challenges not only from the perspective of the end product, but throughout the whole design process.

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