Patient-Generated Health Data: Dimensions, Challenges, and Open Questions
Other titles in Foundations and Trends® in Human–Computer Interaction

*Human-Food Interaction*
Rohit Ashok Khot and Florian Mueller
ISBN: 978-1-68083-576-2

*10 Lenses to Design Sports-HCI*
Florian Mueller and Damon Young
ISBN: 978-1-68083-528-1

*Values and Ethics in Human-Computer Interaction*
Katie Shilton
ISBN: 978-1-68083-466-6

*Research Fiction and Thought Experiments in Design*
Mark Blythe and Enrique Encinas
ISBN: 978-1-68083-418-5
Patient-Generated Health Data: Dimensions, Challenges, and Open Questions

Mayara Costa Figueiredo
University of California
Irvine, USA

Yunan Chen
University of California
Irvine, USA

Full text available at: http://dx.doi.org/10.1561/1100000080
Foundations and Trends® in Human-Computer Interaction
Volume 13, Issue 3, 2020
Editorial Board

Editor-in-Chief
Desney S. Tan
Microsoft Research

Youn-Kyung Lim
Korea Advanced Institute of Science and Technology

Editors
Ben Bederson
University of Maryland

Madeline Balaam
KTH Royal Institute of Technology

Eun Kyoung Choe
University of Maryland, College Park

Andy Cockburn
University of Canterbury

Karrie Karahalios
University of Illinois at Urbana-Champaign

Bilge Mutlu
University of Wisconsin-Madison

Marianna Obrist
University of Sussex

Nuria Oliver
Telefonica

Sameer Patil
Indiana University Bloomington

Orit Shaer
Wellesley College

Koji Yatani
University of Tokyo
Editorial Scope

Topics

Foundations and Trends® in Human–Computer Interaction publishes survey and tutorial articles in the following topics:

- History of the research community
- Theory
- Technology
- Computer Supported Cooperative Work
- Interdisciplinary influence
- Advanced topics and trends

Information for Librarians

Foundations and Trends® in Human–Computer Interaction, 2020, Volume 13, 4 issues. ISSN paper version 1551-3955. ISSN online version 1551-3963. Also available as a combined paper and online subscription.
# Contents

1 Introduction  
1.1 Why Patient-Generated Health Data – The Benefits  
1.2 Definitions: Data and Practices  
1.3 Overview of This Review  

2 Dimensions of PGHD  
2.1 Health Focus  
2.2 Type of Data  
2.3 Who Initiates Data Collection  
2.4 Whose Data Are Collected  
2.5 Who Uses the Data  
2.6 Mechanisms of Data Collection and Use  
2.7 Duration of PGHD Use  

3 Challenges  
3.1 Patient-Provider Collaboration  
3.2 Complex Conditions  
3.3 Goals  
3.4 Reflection  
3.5 Access to PGHD Technologies  
3.6 Expected and Unexpected Users  

Full text available at: http://dx.doi.org/10.1561/1100000080
4 Open Questions for PGHD Research

4.1 The Complex Social Context ................................ 97
4.2 The Evolving Scope of Health .............................. 101
4.3 The Design Culture ........................................... 104
4.4 Final Remarks .................................................. 108

References ......................................................... 110
Patient-Generated Health Data: Dimensions, Challenges, and Open Questions

Mayara Costa Figueiredo¹ and Yunan Chen²

¹University of California, Irvine; mcostafi@uci.edu
²University of California, Irvine; yunanc@ics.uci.edu

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.
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)
Introduction

(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).
1.2. Definitions: Data and Practices

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
1.2. Definitions: Data and Practices

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
Introduction

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

| Term                                                                 | Scope of this review                                                                                                                                 |
|----------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------|
| Patient health outcomes and patient reported outcomes – 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. | 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. 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. 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. |
| Journaling – 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 et al., 2016). |                                                                                                                                                        |
| Self-management – 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). It refers to the activities patients perform in their daily lives to manage their health conditions (Civan et al., 2006; Havas et al., 2016; Moen and Brennan, 2005). |                                                                                                                                                        |
| Remote patient monitoring – focuses on near real-time patient monitoring through personal data collection at home and direct transmission of data to providers’ databases (Cheng et al., 2015). It often means that patients have no or low access to, or influence over, the collection and use of their own data. |                                                                                                                                                        |

Continued.
### Table 1.1: Continued

| Term                              | Scope of this review                                                                                                                                                                                                                                                                                                                                 |
|-----------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| **Self-monitoring** – 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 et al., 2014, 2015](http://dx.doi.org/10.1561/1100000080)). It originally focused on expressive behaviors, i.e., the practice of observing and controlling one’s own self-presentation ([Snyder, 1974](http://dx.doi.org/10.1561/1100000080)). 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](http://dx.doi.org/10.1561/1100000080)). | 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. |
| **Self-tracking and Personal Informatics** – the practices of collecting personal data on which to reflect ([Li et al., 2010, 2011](http://dx.doi.org/10.1561/1100000080)). Self-tracking or PI are not only about health, encompassing multiple aspects of people’s lives such as finances, social interactions, and productivity ([Li et al., 2010, 2011](http://dx.doi.org/10.1561/1100000080)). | Following [Li et al. (2010, 2011)](http://dx.doi.org/10.1561/1100000080), 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 et al., 2017](http://dx.doi.org/10.1561/1100000080)). |
| **Self-experimentation** – 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). | 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. |
Table 1.1: Continued

| Term                                      | Scope of this review                                                                                                                                 |
|-------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------|
| **Observations of Daily Living** –        | 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). |
| 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). |                                                                                                                                                   |
| **Quantified Self** – 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 et al., 2014; Quantified Self, n.d.; West et al., 2016). The term evolved to be also used as the general practice of self-tracking (Choe et al., 2014). QS is not only about health, it can also refer to the practices of quantifying other aspects of individuals’ lives (e.g., finances). | 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. |

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);
1.3. **Overview of This Review**

(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.
Aarhus, R., S. A. Ballegaard, and T. R. Hansen (2009). “The eDiary: Bridging home and hospital through healthcare technology”. In: ECSCW 2009. London: Springer. 63–83.

Adams, A. T., J. Costa, M. F. Jung, and T. Choudhury (2015). “Mindless computing: Designing technologies to subtly influence behavior”. In: Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing. ACM. 719–730.

Adams, P., M. Rabbi, T. Rahman, et al. (2014). “Towards personal stress informatics: Comparing minimally invasive techniques for measuring daily stress in the wild”. In: Proceedings of the 8th International Conference on Pervasive Computing Technologies for Healthcare. ICST (Institute for Computer Sciences, Social-Informatics and Telecommunications Engineering). 72–79.

Ancker, J. S., H. O. Witteman, B. Hafeez, T. Provencher, M. Van de Graaf, and E. Wei (2015). “You get reminded you’re a sick person: Personal data tracking and patients with multiple chronic conditions”. Journal of Medical Internet Research. 17(8): e202.

Andersen, T. O. and J. Moll (2017). “SCAUT: Using patient-generated data to improve remote monitoring of cardiac device patients”. In: Proceedings of the 11th EAI International Conference on Pervasive Computing Technologies for Healthcare. ACM. 444–447.
References

Anhøj, J. and C. Møldrup (2004). “Feasibility of collecting diary data from asthma patients through mobile phones and SMS (short message service): Response rate analysis and focus group evaluation from a pilot study”. Journal of Medical Internet Research. 6(4): e42.

Ayobi, A. (2018). “Informing the design of personal informatics technologies for unpredictable chronic conditions”. In: Extended Abstracts of the 2018 CHI Conference on Human Factors in Computing Systems. ACM. DC02.

Ayobi, A., P. Marshall, A. L. Cox, and Y. Chen (2017). “Quantifying the body and caring for the mind: Self-tracking in multiple sclerosis”. In: Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems. ACM. 6889–6901.

Bagalkot, N. and T. Sokoler (2011). “MagicMirror: Towards enhancing collaborative rehabilitation practices”. In: Proceedings of the ACM 2011 Conference on Computer Supported Cooperative Work. ACM. 593–596.

Ballegaard, S. A., T. R. Hansen, and M. Kyng (2008). “Healthcare in everyday life: Designing healthcare services for daily life”. In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. ACM. 1807–1816.

Bandura, A. (1997). Self-Efficacy: The Exercise of Control. Macmillan.

Barbarin, A. M., P. Klasnja, and T. C. Veinot (2016). “Good or bad, ups and downs, and getting better: Use of personal health data for temporal reflection in chronic illness”. International Journal of Medical Informatics. 94: 237–245.

Bardram, J. E., M. Frost, K. Szántó, M. Faurholt-Jepsen, M. Vinberg, and L. V. Kessing (2013). “Designing mobile health technology for bipolar disorder: A field trial of the Monarca system”. In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. ACM. 2627–2636.

Baumer, E. P. S., V. Khovanskaya, M. Matthews, L. Reynolds, V. Schwanda Sosik, and G. Gay (2014). “Reviewing reflection: On the use of reflection in interactive system design”. In: Proceedings of the 2014 Conference on Designing Interactive Systems. ACM. 93–102.
References

Bentley, F., K. Tollmar, P. Stephenson, et al. (2013). “Health mashups: Presenting statistical patterns between wellbeing data and context in natural language to promote behavior change”. ACM Trans. Comput.-Hum. Interact. 20(5): 30:1–30:27.

Bietz, M. J., G. R. Hayes, M. E. Morris, H. Patterson, and L. Stark (2016). “Creating meaning in a world of quantified selves”. IEEE Pervasive Computing. 15(2): 82–85.

Black, N. (2013). “Patient reported outcome measures could help transform healthcare”. BMJ. 346.

Blondon, K. S. and P. Klasnja (2013). “Designing supportive mobile technology for stable diabetes”. In: Design, User Experience, and Usability. Health, Learning, Playing, Cultural, and Cross-Cultural User Experience. Berlin, Heidelberg: Springer. 361–370.

Brennan, P. F. and G. Casper (2015). “Observing health in everyday living: ODLs and the care-between-the-care”. Personal and Ubiquitous Computing. 19(1): 3–8.

Brooks, F. P. (1987). “No silver bullet”. IEEE Computer. 20(4): 10–19.

Brown, D. (2019). “Fitbits, Apple Watches and smartphones can actually hurt your workout”. URL: https://www.usatoday.com/story/tech/2019/05/15/fitbits-apple-watches-and-smartphones-can-actually-hurt-your-workout/1186522001/.

Bussone, A., S. Stumpf, and G. Buchanan (2016). “It feels like I’m managing myself: HIV+ people tracking their personal health information”. In: Proceedings of the 9th Nordic Conference on Human-Computer Interaction. ACM. 1–10.

Caldeira, C., M. Bietz, M. Vidauri, and Y. Chen (2017). “Senior care for aging in place: Balancing assistance and independence”. In: Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing. ACM. 1605–1617.

Calvo, R. A. and D. Peters (2014). Positive Computing: Technology for Wellbeing and Human Potential. Cambridge, Massachusetts: The MIT Press.

Cameron, A. J., A. C. Spence, R. Laws, K. D. Hesketh, S. Liolet, and K. J. Campbell (2015). “A review of the relationship between socioeconomic position and the early-life predictors of obesity”. Current Obesity Reports. 4(3): 350–362.
Chen, Y. (2010). “Take it personally: Accounting for individual difference in designing diabetes management systems”. In: Proceedings of the 8th ACM Conference on Designing Interactive Systems. ACM. 252–261.

Chen, Y. (2011). “Health information use in chronic care cycles”. In: Proceedings of the ACM 2011 Conference on Computer Supported Cooperative Work. ACM. 485–488.

Cheng, K. G., G. R. Hayes, S. H. Hirano, M. S. Nagel, and D. Baker (2015). “Challenges of integrating patient-centered data into clinical workflow for care of high-risk infants”. Personal and Ubiquitous Computing. 19(1): 45–57.

Chiu, M.-C., S.-P. Chang, Y.-C. Chang, et al. (2009). “Playful bottle: A mobile social persuasion system to motivate healthy water intake”. In: Proceedings of the 11th International Conference on Ubiquitous Computing. ACM. 185–194.

Choe, E. K., J. A. Kientz, S. Halko, A. Fonville, D. Sakaguchi, and N. F. Watson (2010). “Opportunities for computing to support healthy sleep behavior”. In: CHI ’10 Extended Abstracts on Human Factors in Computing Systems. ACM. 3661–3666.

Choe, E. K., B. Lee, M. Kay, W. Pratt, and J. A. Kientz (2015). “SleepTight: Low-burden, self-monitoring technology for capturing and reflecting on sleep behaviors”. In: Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing. ACM. 121–132.

Choe, E. K., N. B. Lee, B. Lee, W. Pratt, and J. A. Kientz (2014). “Understanding quantified-selfers practices in collecting and exploring personal data”. In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. ACM. 1143–1152.

Chung, C.-F., K. Dew, A. Cole, et al. (2016). “Boundary negotiating artifacts in personal informatics: Patient-provider collaboration with patient-generated data”. In: Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing. ACM. 770–786.
Chung, C.-F., Q. Wang, J. Schroeder, et al. (2019). “Identifying and planning for individualized change: Patient-provider collaboration using lightweight food diaries in healthy eating and irritable bowel syndrome”. *Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies*. 3(1): 7:1–7:27.

Civan, A., M. M. Skeels, A. Stolyar, and W. Pratt (2006). “Personal health information management: Consumers’ perspectives.” In: *AMIA Annual Symposium Proceedings 2006*. 156–160.

Clarke, A. E., J. K. Shim, L. Mamo, J. R. Fosket, and J. R. Fishman (2003). “Biomedicalization: Technoscientific transformations of health, illness, and U.S. Biomedicine”. *American Sociological Review*. 68(2): 161–194.

Clawson, J., J. A. Pater, A. D. Miller, E. D. Mynatt, and L. Mamykina (2015). “No longer wearing: Investigating the abandonment of personal health-tracking technologies on craigslist”. In: *Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing*. ACM. 647–658.

Consolvo, S., P. Klasnja, D. W. McDonald, and J. A. Landay (2014). “Designing for healthy lifestyles: Design considerations for mobile technologies to encourage consumer health and wellness”. *Foundations and Trends in Human-Computer Interaction*. 6(3–4): 167–315.

Consolvo, S., D. W. McDonald, and J. A. Landay (2009). “Theory-driven design strategies for technologies that support behavior change in everyday life”. In: *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM. 405–414.

Consolvo, S., D. W. McDonald, T. Toscos, et al. (2008). “Activity sensing in the wild: A field trial of ubifit garden”. In: *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM. 1797–1806.

Cordeiro, F., D. A. Epstein, E. Thomaz, et al. (2015). “Barriers and negative nudges: Exploring challenges in food journaling”. In: *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems CHI Conference 2015*. 1159–1162.
Cortez, A., P. Hsii, E. Mitchell, V. Riehl, and P. Smith (2018). *Conceptualizing a Data Infrastructure for the Capture, Use, and Sharing of Patient-Generated Health Data in Care Delivery and Research Through 2024 (White Paper)*. Office of the National Coordinator for Health Information Technology.

Costa Figueiredo, M., C. Caldeira, E. V. Eikey, M. Mazmanian, and Y. Chen (2018). “Engaging with health data: The interplay between self-tracking activities and emotions in fertility struggles”. *Proc. ACM Hum.-Comput. Interact.*

Costa Figueiredo, M., C. Caldeira, T. L. Reynolds, S. Victory, K. Zheng, and Y. Chen (2017). “Self-tracking for fertility care: Collaborative support for a highly personalized problem”. *Proc. ACM Hum.-Comput. Interact.* 1(CSCW): 36:1–36:21.

Dabbs, M. (2018). “Does your mobile medical app need FDA approval?” *Reinvently.* URL: https://reinvently.com/blog/mobile-medical-application-approval-fda/.

Darmon, N. and A. Drewnowski (2008). “Does social class predict diet quality?” *The American Journal of Clinical Nutrition.* 87(5): 1107–1117.

Dastin, J. (2018). “Amazon scraps secret AI recruiting tool that showed bias against women”. *Reuters.* URL: https://www.reuters.com/article/us-amazon-com-jobs-automation-insight-idUSKCN1MK08G.

Davies, T., S. L. Jones, and R. M. Kelly (2019). “Patient perspectives on self-management technologies for chronic fatigue syndrome”. In: *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems.* ACM. 1–13.

Demiris, G., L. B. Afrin, S. Speedie, et al. (2008). “Patient-centered applications: Use of information technology to promote disease management and wellness. A white paper by the AMIA knowledge in motion working group”. *Journal of the American Medical Informatics Association: JAMIA.* 15(1): 8–13.

Desai, P. M., E. G. Mitchell, M. L. Hwang, M. E. Levine, D. J. Albers, and L. Mamykina (2019). “Personal health oracle: Explorations of personalized predictions in diabetes self-management”. In: *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems.* ACM. 1–13.
van Dijk, E. T., F. Beute, J. H. Westerink, and W. A. IJsselsteijn (2015). “Unintended effects of self-tracking”. In: *Human Factors in Computing Systems-Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems (CHI’15)*.

Dohr, A., J. Engler, F. Bentley, and R. Whalley (2012). “Gluballoon: An unobtrusive and educational way to better understand one’s diabetes”. In: *Proceedings of the 2012 ACM Conference on Ubiquitous Computing*. ACM. 665–666.

Dressel, J. and H. Farid (2018). “The accuracy, fairness, and limits of predicting recidivism”. *Science Advances*. 4: 1.

Eikey, E. V. and M. C. Reddy (2017). “It’s definitely been a journey: A qualitative study on how women with eating disorders use weight loss apps”. In: *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. ACM. 642–654.

Emmons, R. A. and M. E. McCullough (2003). “Counting blessings versus burdens: An experimental investigation of gratitude and subjective well-being in daily life”. *Journal of Personality and Social Psychology*. 84(2): 377.

Epstein, D. A., M. Caraway, C. Johnston, A. Ping, J. Fogarty, and S. A. Munson (2016). “Beyond abandonment to next steps: Understanding and designing for life after personal informatics tool use”. In: *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*. ACM. 1109–1113.

Epstein, D. A., A. Ping, J. Fogarty, and S. A. Munson (2015). “A lived informatics model of personal informatics”. In: *Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing*. ACM. 731–742.

Epstein, D. A., N. B. Lee, J. H. Kang, *et al.* (2017). “Examining menstrual tracking to inform the design of personal informatics tools”. In: *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. ACM. 6876–6888.

Espeland, W. N. and M. L. Stevens (2008). “A sociology of quantification”. *European Journal of Sociology/Archives Européennes de Sociologie*. 49(3): 401–436.
References

Estrin, D., A. P. Hanika, and D. Nafus (2016). “Open mHealth and the problem of data interoperability”. In: Quantified: Biosensing Technologies in Everyday Life. The MIT Press. Chapter 9.

Farmer, A., O. Gibson, P. Hayton, et al. (2005). “A real-time, mobile phone-based telemedicine system to support young adults with type 1 diabetes”. Informatics in Primary Care. 13(3): 171–177.

Farmer, A., A. Wade, E. Goyder, et al. (2007). “Impact of self-monitoring of blood glucose in the management of patients with non-insulin treated diabetes: Open parallel group randomised trial”. BMJ: British Medical Journal. 335(7611): 132.

Farzanfar, R., S. Frishkopf, R. Friedman, and K. Ludena (2007). “Evaluating an automated mental health care system: Making meaning of human-computer interaction”. Comput. Hum. Behav. 23(3): 1167–1182.

Felipe, S., A. Singh, C. Bradley, A. C. Williams, and N. Bianchi-Berthouze (2015). “Roles for personal informatics in chronic pain”. In: Proceedings of the 9th International Conference on Pervasive Computing Technologies for Healthcare. ICST (Institute for Computer Sciences, Social-Informatics and Telecommunications Engineering). 161–168.

Figueiredo, M., C. Caldeira, Y. Chen, and K. Zheng (2017). “Routine self-tracking of health: Reasons, facilitating factors, and the potential impact on health management practices”. AMIA Annu. Symp. Proc. 2017: 706–714.

Fiore-Gartland, B. and G. Neff (2016). “Disruption and the political economy of biosensor data”. In: Quantified: Biosensing Technologies in Everyday Life. The MIT Press.

Frost, J. and B. K. Smith (2003). “Visualizing health: Imagery in diabetes education”. In: Proceedings of the 2003 Conference on Designing for User Experiences. ACM. 1–14.

Frost, M., A. Doryab, M. Faurholt-Jepsen, L. V. Kessing, and J. E. Bardram (2013). “Supporting disease insight through data analysis: Refinements of the Monarca self-assessment system”. In: Proceedings of the 2013 ACM International Joint Conference on Pervasive and Ubiquitous Computing. ACM. 133–142.
Frost, M. G., R. Hansen, K. Szaántó, and J. E. Bardram (2011). “The MONARCA self-assessment system: Persuasive personal monitoring for bipolar patients”. In: 5th International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth) and Workshops. 204–205.

Ganapathy, D., C. Acharya, J. Lachar, et al. (2017). “The patient buddy app can potentially prevent hepatic encephalopathy-related readmissions”. Liver International: Official Journal of the International Association for the Study of the Liver. 37(12): 1843–1851.

Gigerenzer, G., W. Gaissmaier, E. Kurz-Milcke, L. M. Schwartz, and S. Woloshin (2007). “Helping doctors and patients make sense of health statistics”. Psychological Science in the Public Interest. 8(2): 53–96.

Goffman, E. (1986). Stigma: Notes on the Management of Spoiled Identity. New York: Touchstone.

Gorm, N. and I. Shklovski (2016). “Steps, choices and moral accounting: Observations from a step-counting campaign in the workplace”. In: Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing. ACM. 148–159.

Gregory, J. and G. C. Bowker (2016). “The data citizen, the quantified self, and personal genomics”. In: Quantified: Biosensing Technologies in Everyday Life. The MIT Press.

Grönvall, E. and N. Verdezoto (2013a). “Beyond self-monitoring: Understanding non-functional aspects of home-based healthcare technology”. In: Proceedings of the 2013 ACM International Joint Conference on Pervasive and Ubiquitous Computing. ACM. 587–596.

Grönvall, E. and N. Verdezoto (2013b). “Understanding challenges and opportunities of preventive blood pressure self-monitoring at home”. In: Proceedings of the 31st European Conference on Cognitive Ergonomics. ACM. 31:1–31:10.

Gross, S., J. Bardzell, S. Bardzell, and M. Stallings (2017). “Persuasive anxiety: Designing and deploying material and formal explorations of personal tracking devices”. Hum.-Comput. Interact. 32(5–6): 297–334.
Harrington, R. and D. A. Loffredo (2011). “Insight, rumination, and self-reflection as predictors of well-being”. The Journal of Psychology. 145(1): 39–57.

Harwell, D. (2019). “Is your pregnancy app sharing your intimate data with your boss?” Washington Post. url: https://www.washingtonpost.com/technology/2019/04/10/tracking-your-pregnancy-an-app-may-be-more-public-than-you-think/.

Havas, K., A. Bonner, and C. Douglas (2016). “Self-management support for people with chronic kidney disease: Patient perspectives”. Journal of Renal Care. 42(1): 7–14.

Hayes, G. R. (2014). “Knowing by doing: Action research as an approach to HCI”. In: Ways of Knowing in HCI. Ed. by J. S. Olson and W. A. Kellogg. New York, NY: Springer. 49–68.

Hecht, B., L. Wilcox, J. P. Bigham, et al. (2018). “It’s time to do something: Mitigating the negative impacts of computing through a change to the peer review process”. ACM FCA. url: https://acm-fca.org/2018/03/29/negativeimpacts/.

Hodges, S., L. Williams, E. Berry, et al. (2006). “SenseCam: A retrospective memory aid”. In: UbiComp 2006: Ubiquitous Computing. Berlin, Heidelberg: Springer. 177–193.

Hollis, V., A. Konrad, and S. Whittaker (2015). “Change of heart: Emotion tracking to promote behavior change”. In: Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems. ACM. 2643–2652.

Hollis, V., A. Pekurovsky, E. Wu, and S. Whittaker (2018). “On being told how we feel: How algorithmic sensor feedback influences emotion perception”. Proc. ACM Interact. Mob. Wearable Ubiquitous Technol. 2(3): 114:1–114:31.

Hong, M. K., L. Wilcox, D. Machado, T. A. Olson, and S. F. Simoneaux (2016). “Care partnerships: Toward technology to support teens’ participation in their health care”. In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. 5337–5349.
Huang, K., P. J. Sparto, S. Kiesler, A. Smailagic, J. Mankoff, and D. Siewiorek (2014). “A technology probe of wearable in-home computer-assisted physical therapy”. In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. ACM. 2541–2550.

Huh, J. (2015). “Clinical questions in online health communities: The case of “see your doctor” threads”. In: CSCW: Proceedings of the Conference on Computer-Supported Cooperative Work. 1488–1499.

Huh, J. and M. S. Ackerman (2012). “Collaborative help in chronic disease management: Supporting individualized problems”. In: CSCW: Proceedings of the Conference on Computer-Supported Cooperative Work. 853–862.

Jacobs, M. L., J. Clawson, and E. D. Mynatt (2015). “Comparing health information sharing preferences of cancer patients, doctors, and navigators”. In: Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing. ACM. 808–818.

Jang, A., D. L. MacLean, and J. Heer (2014). “BodyDiagrams: Improving communication of pain symptoms through drawing”. In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. ACM. 1153–1162.

Johansen, S. K. and A. M. Kanstrup (2016). “Expanding the locus of control: Design of a mobile quantified self-tracking application for whiplash patients”. In: Proceedings of the 9th Nordic Conference on Human-Computer Interaction. ACM. 59:1–59:10.

Johnson, R. L., D. Roter, N. R. Powe, and L. A. Cooper (2004). “Patient race/ethnicity and quality of patient-physician communication during medical visits”. American Journal of Public Health. 94(12): 2084–2090.

Karkar, R., J. Fogarty, J. A. Kientz, S. A. Munson, R. Vilardaga, and J. Zia (2015a). “Opportunities and challenges for self-experimentation in self-tracking”. In: Adjunct Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing and Proceedings of the 2015 ACM International Symposium on Wearable Computers. ACM. 991–996.
Karkar, R., J. Zia, R. Vilardaga, et al. (2015b). “A framework for self-experimentation in personalized health”. *Journal of the American Medical Informatics Association: JAMIA*. 23(3): 440–448.

Karkar, R., J. Schroeder, D. A. Epstein, et al. (2017). “TummyTrials: A feasibility study of using self-experimentation to detect individualized food triggers”. In: *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. ACM. 6850–6863.

Katule, N., M. Densmore, and U. Rivett (2016). “Leveraging mediated interactions to support utilization of persuasive personal health informatics.” In: *Proceedings of the Eighth International Conference on Information and Communication Technologies and Development*. ACM. 19:1–19:11.

Katz, D., B. Price, S. Holland, and N. Dalton (2018). “Data, data everywhere, and still too hard to link: Insights from user interactions with diabetes apps”.

Kay, M., E. K. Choe, J. Shepherd, et al. (2012). “Lullaby: A capture & access system for understanding the sleep environment”. In: *Proceedings of the 2012 ACM Conference on Ubiquitous Computing*. ACM. 226–234.

Kaziunas, E., M. S. Klinkman, and M. S. Ackerman (2019). “Precarious interventions: Designing for ecologies of care”. *Proceedings of the ACM on Human-Computer Interaction*. 3(CSCW): 113:1–113:27.

Kendall, L., D. Morris, and D. Tan (2015). “Blood pressure beyond the clinic: Rethinking a health metric for everyone”. In: *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*. ACM. 1679–1688.

Kientz, J. A., R. I. Arriaga, and G. D. Abowd (2009). “Baby steps: Evaluation of a system to support record-keeping for parents of young children”. In: *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM. 1713–1722.

Kim, D.-Y., S.-H. Hwang, M.-G. Kim, J.-H. Song, S.-W. Lee, and I. K. Kim (2017). “Development of Parkinson patient generated data collection platform using FHIR and IoT devices”. *Studies in Health Technology and Informatics*. 245: 141–145.

Kranzberg, M. (1995). “Technology and history: Kranzberg’s laws”. *Bulletin of Science, Technology & Society*. 15(1): 5–13.
Kumar, N., N. Jafarinaimi, and M. Bin Morshed (2018). “Uber in Bangladesh: The tangled web of mobility and justice”. Proc. ACM Hum.-Comput. Interact. 2(CSCW): 98:1–98:21.

Kumar, R. B., N. D. Goren, D. E. Stark, D. P. Wall, and C. A. Longhurst (2016). “Automated integration of continuous glucose monitor data in the electronic health record using consumer technology”. Journal of the American Medical Informatics Association: JAMIA. 23(3): 532–537.

Lane, N. D., M. Lin, M. Mohammod, et al. (2014). “BeWell: Sensing sleep, physical activities and social interactions to promote wellbeing”. Mobile Networks and Applications. 19(3): 345–359.

Lee, G., C. Tsai, W. G. Griswold, F. Raab, and K. Patrick (2006). “PmEB: A mobile phone application for monitoring caloric balance”. In: CHI ’06 Extended Abstracts on Human Factors in Computing Systems. ACM. 1013–1018.

Lengelle, R., T. Luken, and F. Meijers (2016). “Is self-reflection dangerous? Preventing rumination in career learning”. Australian Journal of Career Development. 25(3): 99–109.

Li, I., A. K. Dey, and J. Forlizzi (2011). “Understanding my data, myself: Supporting self-reflection with ubicomp technologies”. In: Proceedings of the 13th International Conference on Ubiquitous Computing. ACM. 405–414.

Li, I., A. Dey, and J. Forlizzi (2010). “A stage-based model of personal informatics systems”. In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. ACM. 557–566.

Lim, C., A. B. L. Berry, T. Hirsch, et al. (2016). “It just seems outside my health: How patients with chronic conditions perceive communication boundaries with providers”. In: Proceedings of the 2016 ACM Conference on Designing Interactive Systems. ACM. 1172–1184.

Lin, J. J., L. Mamykina, S. Lindtner, G. Delajoux, and H. B. Strub (2006). “Fish’N’Steps: Encouraging physical activity with an interactive computer game”. In: Proceedings of the 8th International Conference on Ubiquitous Computing. Springer. 261–278.
Liu, L. S., S. H. Hirano, M. Tentori, et al. (2011). “Improving communication and social support for caregivers of high-risk infants through mobile technologies”. In: Proceedings of the ACM 2011 Conference on Computer Supported Cooperative Work. ACM. 475–484.

Loos, J. R. and E. J. Davidson (2016). “Wearable health monitors and physician-patient communication: The physician’s perspective”. In: 2016 49th Hawaii International Conference on System Sciences (HICSS). 3389–3399.

Luo, Y., P. Liu, and E. K. Choe (2019). “Co-designing food trackers with dietitians: Identifying design opportunities for food tracker customization”. In: Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems. ACM. 1–13.

Lupton, D. (2013a). “The digitally engaged patient: Self-monitoring and self-care in the digital health era”. Social Theory & Health. 11(3): 256–270.

Lupton, D. (2013b). “Quantifying the body: Monitoring and measuring health in the age of mHealth technologies”. Critical Public Health. 23(4): 393–403.

Lupton, D. (2015). “Quantified sex: A critical analysis of sexual and reproductive self-tracking using apps”. Culture, Health & Sexuality. 17(4): 440–453.

MacLeod, H., K. Oakes, D. Geisler, K. Connelly, and K. Siek (2015). “Rare world: Towards technology for rare diseases”. In: Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems. ACM. 1145–1154.

MacLeod, H., A. Tang, and S. Carpendale (2013). “Personal informatics in chronic illness management”. In: Proceedings of Graphics Interface 2013. Canadian Information Processing Society. 149–156.

Maitland, J. and M. Chalmers (2011). “Designing for peer involvement in weight management”. In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. ACM. 315–324.

Maitland, J., M. Chalmers, and K. A. Siek (2009). “Persuasion not required: Improving our understanding of the sociotechnical context of dietary behavioural change”. In: 3rd International Conference on Pervasive Computing Technologies for Healthcare. 1–8.
Mamykina, L., E. D. Mynatt, and D. R. Kaufman (2006). “Investigating health management practices of individuals with diabetes”. In: *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM. 927–936.

Mamykina, L., E. Mynatt, P. Davidson, and D. Greenblatt (2008). “MAHI: Investigation of social scaffolding for reflective thinking in diabetes management”. In: *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM. 477–486.

Mamykina, L., D. Nakikj, and N. Elhadad (2015). “Collective sense-making in online health forums”. In: *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*. ACM. 3217–3226.

Martin, L. L. and A. Tesser (1996). “Some ruminative thoughts”. *Advances in Social Cognition*. 9: 1–47.

McIntyre, A. (2007). *Participatory Action Research*. SAGE Publications.

McKillop, M., L. Mamykina, and N. Elhadad (2018). “Designing in the dark: Eliciting self-tracking dimensions for understanding enigmatic disease”. In: *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*. ACM. 565:1–565:15.

Mishra, S. R., P. Klasnja, J. MacDuffie Woodburn, *et al.* (2019). “Supporting coping with Parkinson’s disease through self tracking”. In: *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM. 1–16.

Moen, A. and P. F. Brennan (2005). “Health@Home: The work of health information management in the household (HIMH): Implications for consumer health informatics (CHI) innovations”. *Journal of the American Medical Informatics Association: JAMIA*. 12(6): 648–656.

Mols, I., E. van den Hoven, and B. Eggen (2016). “Informing design for reflection: An overview of current everyday practices”. In: *Proceedings of the 9th Nordic Conference on Human-Computer Interaction*. ACM. 21:1–21:10.

Morin, A. (2017). “Toward a glossary of self-related terms”. *Frontiers in Psychology*. 8: 280.

Morris, M. E., Q. Kathawala, T. K. Leen, *et al.* (2010). “Mobile therapy: Case study evaluations of a cell phone application for emotional self-awareness”. *Journal of Medical Internet Research*. 12(2): e10.
Murnane, E. L., T. G. Walker, B. Tench, S. Voida, and J. Snyder (2018). “Personal informatics in interpersonal contexts: Towards the design of technology that supports the social ecologies of long-term mental health management”. *Proc. ACM Hum.-Comput. Interact.* 2(CSCW): 127:1–127:27.

Nachman, L., A. Baxi, S. Bhattacharya, et al. (2010). Jog falls: A pervasive healthcare platform for diabetes management. *Pervasive Computing.* Berlin, Heidelberg: Springer. 94–111.

Nafus, D. (2016). *Quantified: Biosensing Technologies in Everyday Life.* The MIT Press.

Neff, G. and D. Nafus (2016). *Self-Tracking.* The MIT Press.

Neff, K. D. (2003). “Self-compassion: An alternative conceptualization of a healthy attitude toward oneself”. *Self and Identity.* 2(2): 85–101.

Niess, J. and P. W. Woźniak (2018). “Supporting meaningful personal fitness: The tracker goal evolution model”. In: *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems.* ACM. 1–12.

Nissenbaum, H. and H. Patterson (2016). “Biosensing in context: Health privacy in a connected world”. In: *Quantified: Biosensing Technologies in Everyday Life.* The MIT Press.

Nundy, S., C.-Y. E. Lu, P. Hogan, A. Mishra, and M. E. Peek (2014). “Using patient-generated health data from mobile technologies for diabetes self-management support: Provider perspectives from an academic medical center”. *Journal of Diabetes Science and Technology.* 8(1): 74–82.

Ogden, C. L., M. M. Lamb, M. D. Carroll, and K. M. Flegal (2010). “Obesity and socioeconomic status in adults: United States 1988–1994 and 2005–2008”. In: *NCHS Data Brief No 50.* Hyattsville, MD: National Center for Health Statistics.

O’Kane, A. A. and H. Mentis (2012). “Sharing medical data vs. health knowledge in chronic illness care”. In: *CHI ’12 Extended Abstracts on Human Factors in Computing Systems.* ACM. 2417–2422.
O’Kane, A. A., S. Y. Park, H. Mentis, A. Blandford, and Y. Chen (2016). “Turning to peers: Integrating understanding of the self, the condition, and others’ experiences in making sense of complex chronic conditions”. *Computer Supported Cooperative Work (CSCW)*. 25(6): 477–501.

O’Murchu, N. and A. Sigfridsson (2010). “TiY (tag-it-yourself)”. In: *Proceedings of the 8th ACM Conference on Designing Interactive Systems*. ACM. 57–60.

Paay, J., J. Kjeldskov, M. B. Skov, L. Lichon, and S. Rasmussen (2015). “Understanding individual differences for tailored smoking cessation apps”. In: *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*. ACM. 1699–1708.

Parati, G., G. S. Stergiou, R. Asmar, *et al.* (2010). “European society of hypertension practice guidelines for home blood pressure monitoring”. *Journal of Human Hypertension*. 24(12): 779–785.

Park, S. Y. and Y. Chen (2015). “Individual and social recognition: Challenges and opportunities in migraine management”. In: *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing*. ACM. 1540–1551.

Parker, A., V. Kantroo, H. R. Lee, M. Osornio, M. Sharma, and R. Grinter (2012). “Health promotion as activism: Building community capacity to effect social change”. In: *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM. 99–108.

Paton, C., M. Hansen, L. Fernandez-Luque, and A. Y. S. Lau (2012). “Self-tracking, social media and personal health records for patient empowered self-care. Contribution of the IMIA social media working group”. *Yearbook of Medical Informatics*. 7: 16–24.

Pearce, J. M. S. (2002). “A brief history of the clinical thermometer”. *QJM: An International Journal of Medicine*. 95(4): 251–252.

Pina, L. R., S.-W. Sien, T. Ward, *et al.* (2017). “From personal informatics to family informatics: Understanding family practices around health monitoring”. In: *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing*. ACM. 2300–2315.

Full text available at: http://dx.doi.org/10.1561/1100000080
Pinsker, M., K. Schindler, J. Morak, et al. (2008). “Experiences using mobile phones as patient-terminal for telemedical home care and therapy monitoring of patients suffering from chronic diseases”. In: *Computers Helping People with Special Needs*. Berlin, Heidelberg: Springer. 1305–1312.

Ploderer, B., J. Fong, A. Withana, et al. (2016). “ArmSleeve: A patient monitoring system to support occupational therapists in stroke rehabilitation”. In: *Proceedings of the 2016 ACM Conference on Designing Interactive Systems*. ACM. 700–711.

Pollack, A. H., U. Backonja, A. D. Miller, et al. (2016). “Closing the gap: Supporting patients’ transition to self-management after hospitalization”. In: *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*. ACM. 5324–5336.

Powers, W. T. (1973). *Behavior: The Control of Perception*. Chicago, IL: Aldine.

Purpura, S., V. Schwanda, K. Williams, W. Stubler, and P. Sengers (2011). “Fit4Life: The design of a persuasive technology promoting healthy behavior and ideal weight”. In: *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM. 423–432.

Quantified Self (n.d.). “Quantified Self - Self Knowledge Through Numbers”. *Quantified Self*. url: https://quantifiedself.com/.

Raj, S., J. M. Lee, A. Garrity, and M. W. Newman (2019). “Clinical data in context: Towards sensemaking tools for interpreting personal health data”. *Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies*. 3(1): 22:1–22:20.

Raj, S., M. W. Newman, J. M. Lee, and M. S. Ackerman (2017). “Understanding individual and collaborative problem-solving with patient-generated data: Challenges and opportunities”. *Proc. ACM Hum.-Comput. Interact.* 1(CSCW): 88:1–88:18.

Ramirez, E. (2015). “Do it yourself pancreas: An access conversation with Dana Lewis & Scott Leibrand”. *Access Matters*. url: https://medium.com/access-matters/do-it-yourself-diabetes-bd1ea1adf034.

Rettberg, J. W. (2014). *Seeing Ourselves Through Technology: How We Use Selfies, Blogs and Wearable Devices to See and Shape Ourselves*. Springer.
Rohde, M., P. Brödner, G. Stevens, M. Betz, and V. Wulf (2017). “Grounded design—A praxeological IS research perspective”. *Journal of Information Technology*. 32(2): 163–179.

Rooksby, J., M. Rost, A. Morrison, and M. C. Chalmers (2014). “Personal tracking as lived informatics”. In: *Proceedings of the 32nd Annual ACM Conference on Human Factors in Computing Systems*. ACM. 1163–1172.

Rose, A. (2010). “Are face-detection cameras racist?” *Time*. url: http://content.time.com/time/business/article/0,8599,1954643,00.html.

Rowl, C. (2019). “Quest Diagnostics discloses breach of patient records”. *Washington Post*. url: https://www.washingtonpost.com/business/economy/quest-diagnostics-discloses-breach-of-patient-records/2019/06/03/aa37b556-860a-11e9-a870-b9c411dc4312_story.html.

Sacramento, I. and V. Wanick (2017). “mHealth and the digital cyborg body: The running apps in a society of control”. In: *Mobile e-Health*. Springer. 39–70.

Sanger, P., A. L. Hartzler, W. B. Lober, and H. L. Evans (2013). “Provider needs assessment for mPOWEr: A mobile tool for post-operative wound evaluation”. In: *Proceedings of AMIA Annual Symposium*. 1236.

Sanger, P., A. Hartzler, R. J. Lordon, et al. (2016). “A patient-centered system in a provider-centered world: Challenges of incorporating post-discharge wound data into practice”. *Journal of the American Medical Informatics Association: JAMIA*. 23(3): 514–525.

Schaefbauer, C. L., D. U. Khan, A. Le, G. Sczechowski, and K. A. Siek (2015). “Snack buddy: Supporting healthy snacking in low socioeconomic status families”. In: *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing*. ACM. 1045–1057.

Schroeder, J., J. Hoffswell, C.-F. Chung, J. Fogarty, S. Munson, and J. Zia (2017). “Supporting patient-provider collaboration to identify individual triggers using food and symptom journals”. In: *CSCW: Proceedings of the Conference on Computer-Supported Cooperative Work*. 1726–1739.
Schroeder, J., C.-F. Chung, D. A. Epstein, et al. (2018). “Examining self-tracking by people with migraine: Goals, needs, and opportunities in a chronic health condition”. In: Proceedings of the 2018 Designing Interactive Systems Conference. ACM. 135–148.

Schuler, D. and A. Namioka (1993). Participatory Design: Principles and Practices. CRC Press.

Schüll, N. D. (2014). Addiction by Design: Machine Gambling in Las Vegas. Princeton University Press.

Shapiro, M., D. Johnston, J. Wald, and D. Mon (2012). Patient-generated health data (White Paper). Office of Policy and Planning, Office of the National Coordinator for Health Information Technology.

Sherman, J. (2016). “Data in the age of digital reproduction: Reading the quantified self through Walter Benjamin”. In: Quantified: Biosensing Technologies in Everyday Life. The MIT Press. 27–42, Chapter 2.

Shih, P. C., K. Han, E. S. Poole, M. B. Rosson, and J. M. Carroll (2015). “Use and adoption challenges of wearable activity trackers”. In: iConference 2015 Proceedings.

Siegel, R. (2019). “LabCorp discloses data breach affecting 7.7 million customers”. Washington Post. url: https://www.washingtonpost.com/business/2019/06/05/labcorp-discloses-data-breach-affecting-million-customers/.

Sillence, E. (2013). “Giving and receiving peer advice in an online breast cancer support group”. Cyberpsychology, Behavior and Social Networking. 16(6): 480–485.

Simm, W., M. A. Ferrario, A. Gradinar, et al. (2016). “Anxiety and Autism: Towards Personalized Digital Health”. In: Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems. ACM. 1270–1281.

Smith, B. K., J. Frost, M. Albayrak, and R. Sudhakar (2007). “Integrating glucometers and digital photography as experience capture tools to enhance patient understanding and communication of diabetes self-management practices”. Personal Ubiquitous Comput. 11(4): 273–286.
References

Snyder, J., E. Murnane, C. Lustig, and S. Voida (2019). “Visually encoding the lived experience of bipolar disorder”. In: Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems. ACM. 1–14.

Snyder, M. (1974). “Self-monitoring of expressive behavior”. Journal of Personality and Social Psychology. 30(4): 526–537.

Springer, A., V. Hollis, and S. Whittaker (2017). “Dice in the black box: User experiences with an inscrutable algorithm”. In: The AAAI 2017 Spring Symposium on Designing the User Experience of Machine Learning Systems. AAAI.

Stawarz, K., A. L. Cox, and A. Blandford (2014). “Don’t forget your pill!: Designing effective medication reminder apps that support users’ daily routines”. In: Proceedings of the 32nd Annual ACM Conference on Human Factors in Computing Systems. ACM. 2269–2278.

Street Jr, R. L., H. Gordon, and P. Haidet (2007). “Physicians’ communication and perceptions of patients: Is it how they look, how they talk, or is it just the doctor?” Social Science & Medicine. 65(3): 586–598.

Street, R. L., G. Makoul, N. K. Arora, and R. M. Epstein (2009). “How does communication heal? Pathways linking clinician–patient communication to health outcomes”. Patient Education and Counseling. 74(3): 295–301.

Suchman, L. (2002). “Located accountabilities in technology production”. Scand. J. Inf. Syst. 14(2): 91–105.

Suchman, L. A. (2006). Human-Machine Reconfigurations: Plans and Situated Actions. New York, NY: Cambridge University Press.

Tang, K. P., S. H. Hirano, K. G. Cheng, and G. R. Hayes (2012). “Balancing caregiver and clinician needs in a mobile health informatics tool for preterm infants”. In: 6th International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth) and Workshops. 1–8.

Tentori, M., G. R. Hayes, and M. Reddy (2012). Pervasive Computing for Hospital, Chronic, and Preventive Care. Hanover, MA: Now Publishers Inc.

Full text available at: http://dx.doi.org/10.1561/1100000080
References

Toscos, T. R., S. W. Ponder, B. J. Anderson, et al. (2012a). “Integrating an automated diabetes management system into the family management of children with type 1 diabetes: Results from a 12-month randomized controlled technology trial”. *Diabetes Care*. 35(3): 498–502.

Toscos, T., K. Connelly, and Y. Rogers (2012b). “Best intentions: Health monitoring technology and children”. In: *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM. 1431–1440.

Trapnell, P. D. and J. D. Campbell (1999). “Private self-consciousness and the five-factor model of personality: Distinguishing rumination from reflection”. *Journal of Personality and Social Psychology*. 76(2): 284.

Tsai, C. C., G. Lee, F. Raab, et al. (2007). “Usability and feasibility of PmEB: A mobile phone application for monitoring real time caloric balance”. *Mobile Networks and Applications*. 12: 173–184. DOI: 10.1007/s11036-007-0014-4.

Vandenberghe, B. and D. Geerts (2015). “Sleep monitoring tools at home and in the hospital: Bridging quantified self and clinical sleep research”. In: *9th International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth)*. 153–160.

Veinot, T. C., H. Mitchell, and J. S. Ancker (2018). “Good intentions are not enough: How informatics interventions can worsen inequality”. *Journal of the American Medical Informatics Association*. 25(8): 1080–1088. DOI: 10.1093/jamia/ocy052.

Verran, H. (2011). “Number as generative device: Ordering and valuing our relations with nature”. In: *Inventive Methods: The Happening of the Social*. Routledge.

Vyas, D., Z. Fitz-Walter, E. Mealy, A. Soro, J. Zhang, and M. Brereton (2015). “Exploring physical activities in an employer-sponsored health program”. In: *Proceedings of the 33rd Annual ACM Conference Extended Abstracts on Human Factors in Computing Systems*. ACM. 1421–1426.

Weaver, A., A. M. Young, J. Rowntree, et al. (2007). “Application of mobile phone technology for managing chemotherapy-associated side-effects”. *Annals of Oncology*. 18(11): 1887–1892.
West, P., R. Giordano, M. Van Kleek, and N. Shadbolt (2016). “The quantified patient in the doctor’s office: Challenges & opportunities”. In: Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems. ACM. 3066–3078.

Williams, K. (2015). “An anxious alliance”. In: Proceedings of the Fifth Decennial Aarhus Conference on Critical Alternatives. Aarhus University Press. 121–131.

Wolf, G. (2009). “Know thyself: Tracking every facet of life, from sleep to mood to pain, 24/7/365”. Wired. url: https://www.wired.com/2009/06/lbnp-knowthyself/.

Wolf, G. (2010). “The data-driven life”. The New York Times. url: http://www.nytimes.com/2010/05/02/magazine/02self-measurement-t.html.

Woolgar, S. (1990). “Configuring the user: The case of usability trials”. The Sociological Review. 38(1_suppl): 58–99.

Xu, Y., E. S. Poole, A. D. Miller, E. Eiriksdottir, R. Catrambone, and E. D. Mynatt (2012). “Designing pervasive health games for sustainability, adaptability and sociability”. In: Proceedings of the International Conference on the Foundations of Digital Games. ACM. 49–56.

Young, A. L. and A. D. Miller (2019). “This girl is on fire: Sensemaking in an online health community for Vulvodynia”. In: Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems. ACM. 129:1–129:13.

Zhang, R., E. R. Burgess, M. C. Reddy, et al. (2019). “Provider perspectives on the integration of patient-reported outcomes in an electronic health record”. JAMIA Open. 2(1): 73–80.

Zhu, H., J. Colgan, M. Reddy, and E. K. Choe (2016). “Sharing patient-generated data in clinical practices: An interview study”. In: AMIA. Annual Symposium Proceedings. 1303–1312.

Zia, J., C.-F. Chung, K. Xu, et al. (2016). “Tu1422 inter-rater reliability of healthcare provider interpretations of food and gastrointestinal symptom paper diaries of patients with irritable bowel syndrome”. Gastroenterology. 150(4, Supplement 1): S900.
Zulman, D. M., L. J. Damschroder, R. G. Smith, et al. (2013). “Implementation and evaluation of an incentivized internet-mediated walking program for obese adults”. *Translational Behavioral Medicine*. 3(4): 357–369.