

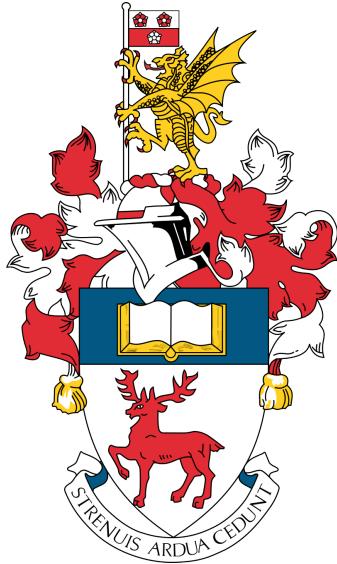
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University of Southampton  
*Health Sciences & Web Science*

THESIS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

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**The Quantified Patient in the Doctor's Office:  
Understanding Clinical Workflows for Using Patient  
Self-Tracked Data**

Doctoral thesis of:  
**Peter West**

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October 2019



UNIVERSITY OF SOUTHAMPTON

## ABSTRACT

FACULTY OF ENVIRONMENTAL AND LIFE SCIENCES

Thesis for the degree of Doctor of Philosophy

### THE QUANTIFIED PATIENT IN THE DOCTOR'S OFFICE: UNDERSTANDING CLINICAL WORKFLOWS FOR USING PATIENT SELF-TRACKED DATA

Peter West

*Fitbit* and *Apple Health* are two popular consumer technologies amongst a growing plethora of health wearables and smartphone apps. These devices have empowered a new kind of patient – the *quantified patient* – to collect data on diverse aspects of their own health. From heart rate and physical activity, to sleep and mood, these data have the potential to help clinicians diagnose disease, personalise treatments to individual patients, and avoid delivering unnecessary medical procedures. Realising this potential is vital as we enter an era of ageing population, chronic disease epidemics, and soaring healthcare costs. However, these *self-tracked data* are new to medicine, so it is unknown how clinicians might use such unfamiliar data.

This research aimed to understand clinicians' experiences with self-tracked data in their clinical workflows, such that future use of such data can be enabled through appropriate technology design and consideration of clinicians' work practices. Interviews were conducted with 13 clinicians of a broad spectrum of clinical roles, including cardiology, general practice, and mental health. This was followed by workshops with five clinicians in the co-design of a software-based tool for using self-tracked data within the management of chronic heart conditions. These studies revealed that there are common clinical workflows for using self-tracked data, delineating a process of evaluating data usability while collaborating with the patient to ensure mutual understanding. However, constraints of the clinical settings and of data usability presented barriers to this workflow, limiting the potential for self-tracked data. The co-designed prototype unveiled several design principles for overcoming these barriers, reflecting the importance of clinicians' participation in future research of self-tracked data. This research contributes an understanding of the diverse opportunities for self-tracked data and design principles for overcoming the barriers to using such data in a future data-driven medicine.



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## DECLARATION OF AUTHORSHIP

---

I, Peter West, declare that this thesis, entitled "The Quantified Patient in the Doctor's Office: Understanding Clinical Workflows for Using Patient Self-Tracked Data", and the work presented in it are my own and has been generated by me as the result of my own original research. I confirm that:

1. This work was done wholly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. Parts of this work have been published as:
  - (a) Manuscripts:

West P, Giordano R, Van Kleek M, and Shadbolt N (2016) The quantified patient in the doctor's office: Challenges and opportunities. Paper presented at *The Conference on Human Factors in Computing Systems* in San Jose, US on 7–12 May. New York: ACM pp. 3066–3078. **CHI'16 Honourable Mention Award.**

West P, Van Kleek M, Giordano R, Weal M, and Shadbolt N (2017) Information quality challenges of patient-generated data in clinical practice. *Frontiers Public Health* 5 p. 284.

West P, Van Kleek M, Giordano R, and Weal M (2018) Common barriers to the use of patient-generated data across clinical settings. Paper presented at *The Conference on Human Factors in Computing Systems* in Montreal, Canada on 21–26 Apr. New York: ACM pp. 484:1–484:13.

## (b) Talks:

West P, Giordano R, Van Kleek M, and Vass J (2015) The quantified self and clinical decision making. Presented at *King's Fund Digital Health and Care Congress* in London on 16–17 June.

West P (2017a) Health self-tracking: How can doctors use your data? Presented at *NExT++ Workshop: AI Solutions to Information Rich Open Problems* in The National Supercomputing Center, Wuxi, China on 26–27 Sep.

Giordano R, Tamime RA, and West P (2018) Enabling trust, accountability, and routine use of AI-enabled healthcare. Presented at *NExT++ Workshop: AI in Health and Finance* in Nanjing University of Science & Technology, Jiangsu, China on 1–2 Nov.

## (c) Posters:

West P, Giordano R, and Van Kleek M (2015) The Quantified Self and clinical decision making: understanding clinical decision bias and errors when using quantified self data. Presented at *Health Services Research Network Symposium* in Nottingham, UK on 13–14 Jul.

West P (2017b) Self-tracked data in clinical settings. Presented at *WSTNet Web Science Summer School* in Saint Petersburg, Russia on 1–7 Jul.

West P (2017a) Health self-tracking: How can doctors use your data? Presented at *NExT++ Workshop: AI Solutions to Information Rich Open Problems* in The National Supercomputing Center, Wuxi, China on 26–27 Sep.

Signed: .....

Date: .....

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---

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## I INTRODUCTION

---

In 2014, the UK government launched the *Personalised Health and Care 2020 Framework*, a policy that set out to improve healthcare by learning from data about the health of individual citizens (National Information Board, 2014). The policy stated that moving towards data-driven medicine will ensure clinicians are better informed when making decisions about patients. In turn, diagnoses and treatments could become personalised towards patients to promote better care and prevention of chronic diseases.

Achieving data-driven medicine will require access to detailed data about individual patients' health, habits, and experiences (Swan, 2012b). Medical records are an obvious place to start looking for such information, but in reality, these tend to only document the small snapshots of patients' lives within clinical settings (Neff and Nafus, 2016). For personalised medicine to achieve its full potential, clinicians need to discern intimate details of their patients' routines and habits outside of clinical settings (Swan, 2012b). Where can such detailed data come from?

### 1.1 SELF-TRACKING FOR HEALTH

A potential source of detailed health data lies within the culture of *self-tracking*, the collection of data about oneself (Neff and Nafus, 2016). Self-tracking has a long history; in the 18th century, Benjamin Franklin used notes to track and reflect on his thirteen virtues (Franklin and Bigelow, 1868). Today, health tracking has advanced from paper notes to wearable sensors, which continuously and automatically track personal activities, fitness, and health. Wearables such as Fitbit and Apple Watch (Figure 1) have become fashionable consumer technologies and, with over 200 million wearables expected to be sold in 2019, they have galvanised a well-being economy (The International Data Corporation, 2016). Health apps such as Strava



**Figure 1.** The *Apple Watch*, a smartwatch capable of tracking physical activity, heart rate, and location. The left photo shows the watch face, and the right photo shows the sensors for measuring heart rate. Photos by Wiyre Media.

and MyFitnessPal have flourished in this new well-being economy, with over half of smartphone owners using a health app (Krebs and Duncan, 2015).

Health apps and wearables can document aspects of health more diverse and detailed than traditional clinical measurements, including physical activity, heart rate, and symptom severity (Gilleade and Fairclough, 2010). The devices follow their owners wherever they go, either on their wrist or in their pocket (Neff and Nafus, 2016), and therefore generate data describing daily activity patterns (Chiuzzi et al., 2015) and first-hand descriptions of patient experience (Hong et al., 2016) over long periods of time. Controversially, some workplaces have used wearable sensors to track the wellness of employees, which reportedly encouraged greater physical activity and health promotion (Chung et al., 2017). Some therefore suggest that self-tracking could reduce healthcare costs associated with monitoring chronic illness (Dubberly et al., 2010) and contribute towards personalised and preventative medicine (Swan, 2012b). Already, in the US, some healthcare providers allow patients to upload self-tracked data to their electronic health records to “maximize resources and target interventions toward patients who will benefit most” (Hernandez, 2014).

Despite these developments, studies have documented a wide range of difficulties in establishing routine use of such data in clinical settings (Deering et al., 2013). When self-tracking tools were used for managing irritable bowel syndrome, one study discovered that lack of standardisation within the data made it difficult for clinicians to interpret the data (Chung et al., 2015). Self-tracking devices and techniques often have unknown reliability and validity, with most wearable-device manufacturers providing no empirical evidence of the efficacy of their devices (Piwek et al., 2016). Moreover, people who self-track typically do so intermittently and without scientific rigour, creating incomplete and unreliable data (Karkar et al., 2017). These challenges to using self-tracked data in clinical decisions may, in some cases, outweigh the potential benefits (Piwek et al., 2016). Indeed, a study of health apps for managing diet found clinicians worried that data from these apps were unreliable and fell short of clinical standards (Kim et al., 2016).

This raises questions about how clinicians could use self-tracked data. Can self-tracked data be safely and reliably used in clinical settings? What are clinicians’ workflows to determining how and where such data could be used? While prior studies of self-tracking in medicine have yielded insights about self-tracking in *specific* clinical settings, such as irritable bowel syndrome (Chung et al., 2015) and dieting (Kim et al., 2016), little is known about the workflows and scope for using self-tracked data across different clinical settings. Identifying *common* workflows and opportunities for using self-tracked data in different clinical settings promises to uncover ways to enable practitioners and designers to jointly address or prioritise challenges to their use. Thus, this research aimed to investigate the opportunities, challenges, and workflows for using self-tracked data in diverse clinical settings.

### 1.2 RESEARCH QUESTIONS

This research sought to investigate the following three questions:

- RQ1. *What are the opportunities for and barriers to using self-tracked data in clinical settings?* This question aimed to identify how self-tracked data could improve healthcare and challenges to their use.
- RQ2. *What are the common workflows of clinicians when using self-tracked data?* This question aimed to discover sequences of processes that clinicians follow when a patient presents self-tracked data.
- RQ3. *What are the design needs of clinicians for using self-tracked data in clinical settings?* This question aimed to construct design principles for enabling the opportunities for self-tracking, overcoming the barriers to their use, and operating within clinical workflows.

### 1.3 SCOPE AND CONTRIBUTIONS

As shown in Table 1, this thesis presents three novel contributions: a framework for understanding the opportunities and challenges for self-tracked data within clinical settings, a workflow model for understanding how clinicians work with self-tracked data, and a set of principles for designing self-tracking technologies to be more effective within clinical settings. These findings contribute to a formative understanding of the clinical use of self-tracked data. The first two contributions have been published in the *Frontiers Journal of Public Health* (West et al., 2017) and the *Conference on Human Factors in Computing Systems* (West et al., 2018) respectively.

At this nascent stage of self-tracking research, it is important to unpack the term ‘self-tracking’. It has several meanings, which could create ambiguity in this research. For the purpose of this research, self-tracking encompasses all practices of documenting health-related information that a person may engage in using techniques not typical of clinical settings. This includes the use of wearable technologies such as Fitbit, health apps such as Google Fit, and hand-written notes and diaries. This thesis pays particular attention to electronic technologies because of their increasing popularity. Hand-written journals and health diaries are also

**Table 1.** The three research questions and contributions of this thesis, listed with subsequent publications.

Research question	Contribution	Publication
1: What are the opportunities for and barriers to using self-tracked data in clinical settings?	Opportunities and challenges for self-tracked data	West et al. (2017)
2: What are the common workflows of clinicians when using self-tracked data?	A clinical workflow model for using self-tracked data	West et al. (2018)
3: What are the design needs of clinicians for using self-tracked data in clinical settings?	Design principles for self-tracking technologies	Unpublished

considered as these are often undertaken by patients without instruction from their clinicians (Neff and Nafus, 2016). Forms of self-tracking not directly relating to health, such as financial expenditure or location tracking, are not considered.

Telemonitoring and telehealth devices, implantable medical devices, and other apps and devices designed as medical devices are excluded from consideration. While these devices are of tremendous importance to the future of medicine, they are already the subject of intensive clinical research; see, for example, Oudshoorn (2008) on cardiac telemonitoring devices. Instead, this thesis focuses on self-tracking techniques oriented towards the consumer and that have not been the subject of significant clinical research. There is not always a clear distinction between self-tracking practices that are and are not of a clinical nature. For instance, health diaries have a history of use in medicine (Richardson, 1994) but are also frequently used without instruction from a clinician (Neff and Nafus, 2016). For this reason, self-tracking techniques will be discussed with respect to the context they have been used in and how this differs from typical clinical practice.

The terms *patient-generated health data* and *citizen-generated data* are commonly used synonymously with *self-tracked data* but are used in different contexts. Patient- or consumer-oriented literature, where data are seen to empower patients or provide self-knowledge, typically use the term ‘self-tracked data’ (Neff and Nafus, 2016). In contrast, clinical-oriented research, where data are seen to provide information for diagnoses and treatments, typically refer to ‘patient-generated health data’ (Accenture, 2018). The latter restricts itself to individuals as patients, whereas the former is a practice one undertakes whether they are a patient or not (Neff and Nafus, 2016). Policy-makers and think-tanks are increasingly using the term ‘citizen-generated data’, again generalising data gathering beyond patients to encompass all citizens (PHG Foundation, 2018). This thesis opts to use the term ‘self-tracked data’ because it is sufficiently generalised to encompass all individuals who collect health data, regardless of if they could be classified as a patient or not.

The *patient* is an important actor in self-tracking; they are the data gatherers, data owners, and the ones who may understand the most about their data. There has been a plethora of published empirical works studying the role of self-tracking from patients’ perspectives, some of which provide important grounds for discussion in Chapter 2. However, *clinicians’* perceptions of self-tracked data have, thus far, seldom been considered. The systematic review in Chapter 5 identified only 35 published empirical works that considered clinicians’ perceptions of self-tracked data. This is in contrast to the several hundred papers that considered patients’ perspectives which were excluded from the review. Therefore, this research emphasises *clinicians’* perceptions of self-tracked data to better situate itself in this gap in self-tracking research.

Diverse clinical roles are considered in this thesis, each embodying particular needs and workflows, including general practitioners, nurses, cardiologists, and audiologists. Within this thesis, the word ‘clinician’ is used to generally describe members of these roles. While ‘physician’, ‘doctor’, or ‘health professional’ may also

be appropriate words, a ‘clinician’ is specifically a health professional who works with and treats patients (Tumulty, 1970) so was most appropriate for this thesis. A related limitation of this work is that the findings may not apply to roles not considered, so the word ‘clinician’ should be taken to only include roles that were considered. This work therefore provides an initial insight into a sample of clinical roles that could provoke research in more specific areas.

Clinicians’ attitudes towards self-tracked data are affected by the work practices and funding models of health services, which differ by country. As revealed by the literature review in Chapter 5, most existing studies of self-tracked data have focused on healthcare within the US where, for example, health insurance has implications for using self-tracked data (Ancker et al., 2015b). Conversely, clinicians interviewed in this research all work within the UK and therefore reflect the workflows common in the UK. Hence, while this research contributes a new understanding of self-tracking from the clinician’s perspective, it does so with a view of UK clinical work practices.

#### 1.4 INTERDISCIPLINARY APPROACH

Understanding the effects of technological tools within clinical environments calls for the use of multiple disciplines, including Health Science and Computer Science. Each discipline has its own methodological and epistemological approaches, which limits how research from multiple disciplines can be synthesised (Repko, 2011). This thesis does not take a standpoint from any single discipline and instead opts for an interdisciplinary perspective. The following definition of interdisciplinary research has been put forward by the National Academies in the US:

Interdisciplinary research is a mode of research by teams or individuals that integrates information, data, techniques, tools, perspectives, concepts, and/or theories from two or more disciplines or bodies of specialized knowledge to advance fundamental understanding or to solve problems whose solutions are beyond the scope of a single discipline or field of research practice. – *Committee on Facilitating Interdisciplinary Research, Committee on Science, Engineering, and Public Policy (2004)*

The interdisciplinary *Web Science* perspective is useful in this case, as it concerns itself with the study of technology (in particular, the World Wide Web) within disciplines other than Computer Science. Helder et al. (2008) states:

Despite the Web’s great success as a technology and the significant amount of computing infrastructure on which it is built, it remains, as an entity, surprisingly unstudied. – *Helder et al. (2008)*

Self-tracking is inherently related to the Web; the information recorded via smartphones and wearables will typically be transmitted and stored via the Web. Thus, many research concerns of the Web apply to self-tracking, including the effect of technology on society (and vice versa), information privacy, policy, and technology design (Berners-Lee et al., 2006).

### 1.5 STRUCTURE OF THIS THESIS

This thesis is structured as nine chapters. Chapters 2–4 outline the background and methodological considerations for this research. Chapter 2 provides a history of self-tracking and critiques of its use in clinical settings. Chapter 3 constructs the theoretical framework used for this research, outlining three core concepts: *The Quantified Self*, patient empowerment, and the workflow elements model. Chapter 4 presents the methodology, which comprised three studies grounded in the paradigms of participation, technocratic, and empiricism.

Chapters 5–7 present the methods and findings for the three studies. Chapter 5 presents the first study, a systematic literature review that revealed opportunities for self-tracked data in healthcare settings and several barriers to introducing such data. Chapter 6 presents the second study, comprising interviews with clinicians which uncovered common workflows for working with self-tracked data. Chapter 7 presents the third study, a participatory design approach which engaged clinicians in the design of a tool for using self-tracked data, revealing their design needs for self-tracking technologies.

Chapter 8 then distils the novel contributions of this research to the field of self-tracking, before Chapter 9 concludes with potential future research.

## 2 BACKGROUND

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This chapter provides the background to this research in four areas. First, a brief history of self-tracking is given. Second, several visions for self-tracking are described. Third, prominent critiques of self-tracking are outlined. Finally, design considerations for healthcare technologies are discussed.

### 2.1 HISTORY OF SELF-TRACKING

Beginning with Benjamin Franklin's tracking of his thirteen virtues, self-tracking has a long history. This section gives a brief history of self-tracking, from Franklin's diaries to the popularisation of consumer health technologies.

#### 2.1.1 18th-19th Century: Early Record-Keeping

Forms of self-tracking are evident throughout the 18th and 19th centuries. Benjamin Franklin (1706-1790) kept accounts of his daily activities in the form of tables and notes (Neff and Nafus, 2016). Each day, Franklin would record his faults in his diary, structured around the thirteen virtues he forth for himself (Franklin and Bigelow, 1868, p. 227):

**Temperance:** Eat not to dullness. Drink not to elevation.

**Silence:** Speak not but what may benefit others or yourself. Avoid trifling conversation.

**Order:** Let all your things have their places. Let each part of your business have its time.

**Resolution:** Resolve to perform what you ought. Perform without fail what you resolve.

**Frugality:** Make no expense but to do good to others or yourself; i.e. waste nothing.

**Industry:** Lose no time. Be always employed in something useful. Cut off all unnecessary actions.

**Sincerity:** Use no hurtful deceit. Think innocently and justly; and, if you speak, speak accordingly.

**Justice:** Wrong none, by doing injuries or omitting the benefits that are your duty.

**Moderation:** Avoid extremes. Forbear resenting injuries so much as you think they deserve.

**Cleanliness:** Tolerate no uncleanliness in body, clothes or habitation.

**Tranquillity:** Be not disturbed at trifles, or at accidents common or unavoidable.

**Chastity:** Rarely use venery but for health or offspring; never to dullness, weakness, or the injury of your own or another's peace or reputation.

**Humility:** Imitate Jesus and Socrates.

Franklin's autobiography describes how his diary was structured:

I made a little book, in which I allotted a page for each of the virtues. I ruled each page with red ink, so as to have seven columns, one for each day of the week, marking each column with a letter for the day. I crossed these columns with thirteen red lines, marking the beginning of each line with the first letter of one of the virtues, on which line, and in its proper column, I might mark, by a little black spot, every fault I found upon examination to have been committed respecting that virtue upon that day. – *Franklin and Bigelow (1868)*

TEMPERANCE.

Eat not to dullness;  
Drink not to elevation.

	Sun	Mon	Tue	Wed	Thu	Fri	Sat
T.	●						
S.	● ●	●		●		●	
O.		●	●		●	●	●
R.			●			●	
F.		●			●		
I.			●				
S.							
J.							
M.							
C.							
T.							
C.							
H.							

**Figure 2.** The table on which Franklin recorded his virtues for a week (Franklin and Bigelow, 1868), separated into columns for each day and rows for each virtue. Dots were drawn for each fault. A virtue is described above (this table shows *temperance*).

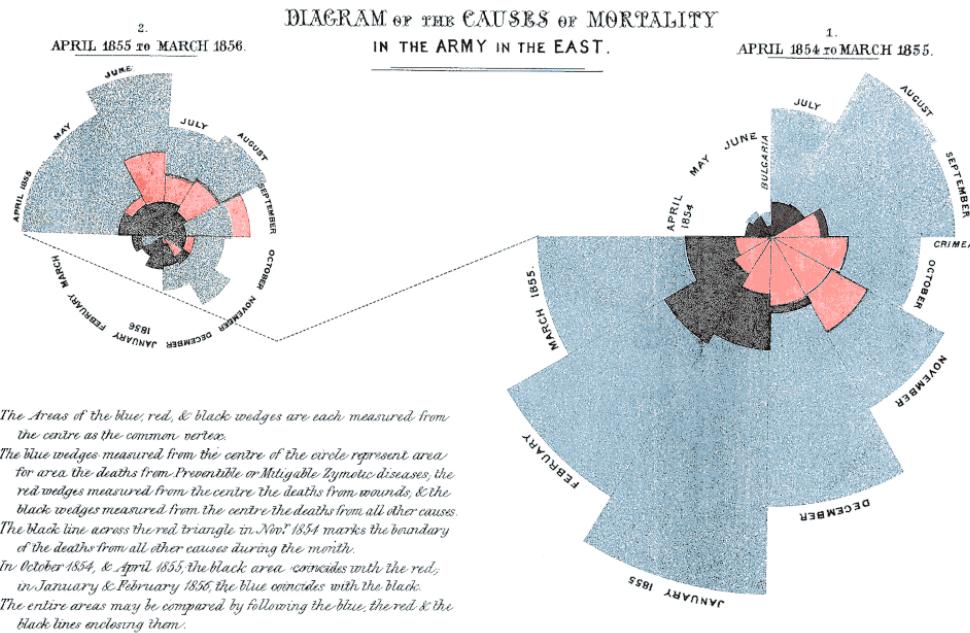
Figure 2 illustrates what a page from Franklin's diary may have looked like, comprising a table of his thirteen virtues over a one-week period. As described by Franklin, going back over these tables could help him judge his past decisions and help improve his future ones (Franklin and Bigelow, 1868).

Forms of diaries such as Franklin's were common in the 18th and 19th Century and have been compared to the modern-day use of Twitter to "account, reflect, communicate, and share with others using media of the times" (Humphreys et al., 2013). People of this era commonly used diaries to record aspects of one's health. McCarthy (2000) quotes the 1873 pocket diary of Jane Briggs Smith Fiske, a woman from New England who had suffered from illness for several years:

**26 January 1873:** "Cold disagreeable day. Felt very badly all day long and lay on the sofa all day. Nothing took place worth noting."

**27 January 1874:** "I was very ill all day and only brightened up at night because friends came. Made snaps and doughnuts. Began taking Dr Gallinger's medicine."

Later in Fiske's life, she gave birth a boy. Fiske would record her son's weight in her diary every month (McCarthy, 2000). She continued to keep notes in her diary for nearly forty years, comprising records of her health, confessions of emotions, and intimate details of her routines. Like many people of the 19th century, her diary became a companion and a mechanism for coping with the loneliness of life in the remote settlement in which she lived (McCarthy, 2000).



**Figure 3.** For each month of the Crimean War, Nightingale charted preventable deaths (blue), deaths from wounds (red), and deaths from other causes (black). The chart showed that most deaths were preventable, provoking adoption of better sanitation practices.

Despite suffering from ill health, it is unlikely Fiske would have shared her diary with her doctor. In this era, pocket diaries were explicitly private and were seen to be a place to write “without the fear of inducing worry or the necessity of explaining circumstances” (McCarthy, 2000). Indeed, the information within Fiske’s diary was deeply intimate and personal (McCarthy, 2000). However, the record-keeping of another woman – a nurse named Florence Nightingale – was being shared with doctors, and was precipitating a revolution in medicine.

During the Crimean War (1853–1856), Nightingale kept detailed records of sick patients, finding that for every soldier who died from injury, seven died from preventable diseases caused by poor sanitation (McDonald, 2001). To draw the attention of physicians and policy-makers, Nightingale charted the causes of mortality over each month (see Figure 3), showing that most deaths were preventable. When shown to policy-makers, her visualisations provoked the immediate adoption of better sanitation practices. Historians believe improved sanitation to have been the most significant contribution to reducing mortality during the war, from 69 per 1000, to 18 (Cohen, 1984). At the end of the 19th century, *information* had become indispensable, driving the discoveries of disease causes and dawning the practice of *evidence-based medicine* (McDonald, 2001).

#### 2.1.2 20th Century: Emergence of Health Self-Knowledge

Modern forms of self-tracking build on everyday primitive measurement tools such as the weighing scales (Crawford et al., 2015). During the early 20th century, weighing scales were only common in physicians’ offices and one’s weight was specialist medical knowledge. However, demand for domestic weighing scales surged as people began to associate weight with health and longevity. Manufacturers

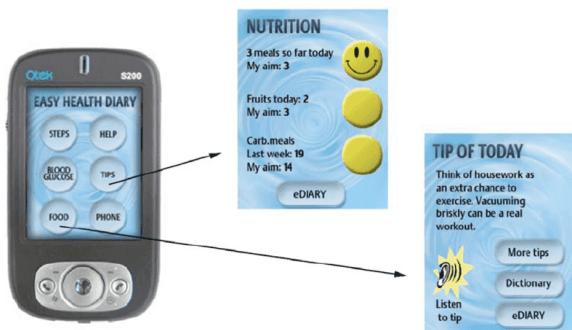
marketed domestic weighing scales as “bathroom scales”, reinforcing the idea that weighing oneself should be part of a daily private and intimate bathroom routine (Crawford et al., 2015). As weight became attributed to self-worth and health, attitudes shifted “from what this person weighs, to what you should weigh and what you could be” (Schwartz, 1986, p. 165). Tracking one’s own weight became an important form of self-knowledge (Crawford et al., 2015).

Notions of self-knowledge were historically important within medical practice. During the 20th century, clinicians routinely asked patients about their knowledge of their symptoms and experiences (Have, 1991). But patients often forgot events which took place or when events occurred (Lingard et al., 2001). In the absence of reliable memories of events, clinicians depended on guesswork and collecting new information (practices which remain necessary today) (Topol, 2012). The need for reliable longitudinal data about patient experience led nurses to adopt *health diaries*, paper diaries for patients to document their symptoms, triggers, and coping strategies. These facilitated immediate data entry when a patient experienced a noteworthy event, mitigating recall errors (Richardson, 1994). Health diaries thus formed intimate chronological records of a patient’s own knowledge of their life over long periods of time, making them suitable for managing long-term and symptomatic health conditions (Richardson, 1994).

Despite the advantages of paper diaries over recall, patients often left their health diary at home and waited until the end of the day to fill in their day’s activities (Stone et al., 2002). This delay in completing the diary led to recall errors in the recorded data (Hyland et al., 1993). Patients were observed backfilling entries to give the appearance of good compliance or faking entries to obscure their actual well-being (Mazze et al., 1984). One study found only 11 per cent of chronic pain patients completed their paper diaries within the instructed half-hour window of pain events, with around 75 per cent of dates and times of entries falsified (Stone et al., 2003). Patient compliance usually declined over time, with use of the diary averaging around 32 per cent of days within the diary period. Thus, whilst paper diaries improved clinicians’ ability to understand a patient’s condition over time, they were often deemed too unreliable for routine clinical use (Mazze et al., 1984).

### 2.1.3 Late 20th Century: Dawn of the Digital Age

During the later decades of the 20th century, digital technologies began to emerge. Personal computers became commonplace within the home, and portable electronics, such as personal organisers and personal digital assistants were rapidly becoming affordable. Unseen today, the personal digital assistant (PDA) was a popular household item during the 1990s until they were made obsolete by smartphones in the 2000s. A typical PDA comprised a simple hand-held computer with various applications, including a calendar, to-do list, and address book. During this era, health diaries saw a convergence with digital technology. Electronic health diaries often worked on PDAs and achieved much higher adherence than paper diaries because patients generally kept their PDA with them at all times (Arsand et al., 2007).



**Figure 4.** *Easy Health Diary* is an electronic health diary for managing Type-2 diabetes. It captures blood glucose, physical activity, and nutrition data through a user interface presented on a PDA (Arsand et al., 2007).

*Easy Health Diary* (Figure 4) was one such diary which aimed to improve long term diarising for patients with Type-2 diabetes (Arsand et al., 2007). Before PDAs became popular, diabetes management typically relied on paper health diaries which patients usually filled in poorly (Stone et al., 2002). Patients who used Easy Health Diary found it a more positive experience because it was easier to use and integrated with daily routines, in turn leading to higher compliance over paper health diaries (Arsand et al., 2007). Because of their portability and affordability, digital electronics became a cornerstone of patient diarising.

The rise of digital technology cultivated a novel tool for health applications: sensors. The late 20th century saw the invention of hand-held cameras, accelerometers, digital thermometers, and the Global Positioning System (GPS). Initially, these sensors were prohibitively complex and expensive for non-experts, but a small community of patients and technology evangelists began to use them for collecting information relating to their health (Bottles, 2012). In the 1980s, Steve Mann began developing such sensors into a wearable headset to record video wherever he went (Mann, 1997). Figure 5 shows how the development of this technology changed over time, reducing in size from its original bulky shape. Mann's work was hugely influential in the development of wearable cameras, which are now well suited to monitoring diet and sedentary behaviour (Doherty et al., 2013).

Meanwhile, personal computers became affordable and abundant within hospitals. Healthcare providers began to use IT systems to store and transfer medical records, giving rise to electronic medical records (EMRs) (Boonstra and Broekhuis, 2010). EMRs promised to improve healthcare by presenting health information in a consistent structure, preventing records from getting lost and facilitating the transfer of records between health providers (Hersh, 1995). The Institute of Medicine predicted that every clinician would be using EMRs by the year 2000 (Institute of Medicine, 1991). But integrating EMR systems into healthcare services was complex and adoption of EMRs was slow. Many hospitals continued using paper records into the 21st century (Boonstra and Broekhuis, 2010).



**Figure 5.** Steve Mann's development of wearable computing (Mann, 1997): (a) 1980 model with camera and CRT display, (b) mid-1980s model with improved technology, (c) early 1990s model with smaller headset and large computer on a belt, (d) mid-1990s model with smaller headset and computer on belt, (e) late 1990s model with much smaller headset and computer hidden under the user's t-shirt.

#### 2.1.4 The 2000s: Rise of Ubiquitous Health Technologies

The beginning of the 21st century saw rapid technological advancements in medicine. The computer had equipped clinicians with a way to quickly review patient histories, keep track of prescriptions, and access disease research (Acharya and Panth, 2015). EMRs had become the foundation of healthcare systems, overcoming problems of illegible handwriting and records getting lost (Acharya and Panth, 2015). Moreover, mobile technology became cheap and abundant, enabling clinicians to interact with patients across the globe without requiring them to be physically at the clinic (Konschak et al., 2013).

The use of mobile technology in healthcare formed the field of *mHealth*, defined by the World Health Organisation as “the provision of health services and information via mobile technologies such as mobile phones and PDAs” (Belluck, 2017). *mHealth* had been described as a coming digital revolution of healthcare, enabled by mobile devices with sensors for measuring one’s gait, to sensors for transmitting blood pressure to clinicians (Konschak et al., 2013). These technologies facilitated improved disease management, empowered patients in their care, and provided care to those without easy access to hospitals:

Mobile technology is helping with chronic disease management, empowering the elderly and expectant mothers, reminding people to take medication at the proper time, extending service to underserved areas, and improving health outcomes and medical system efficiency. [...] Remote monitoring devices enable patients with serious problems to record their own health measures and send them electronically to physicians or specialists. This keeps them out of doctors' offices for routine care, and thereby helps to reduce healthcare costs – West (2012)

The advancement of mobile technology gave rise to the fields of *telemedicine* and *telehealth*, which aimed to monitor and manage patients’ health conditions using telecommunication technologies. In many cases, these technologies had been found to improve patient outcomes in chronic condition management. For in-

**Table 2.** Potential cost savings from adopting mHealth technologies, from Konschak et al. (2013).

Condition	Location	Technology	Outcome
Diabetes	Pennsylvania	Post-discharge remote monitoring	42% drop in overall cost per patient
Diabetes	Cleveland	Cell phone-sized wireless transmitter transfers vital signs to electronic health record	71% increase in number of days between office visits
Congestive heart failure	Trans-European-Network-Home-Care Management System	Remote monitoring of patients who received implantable cardiac defibrillators	35% drop in inpatient length of stay; 10% reduction in office visits; 65% drop in home health visits
Chronic obstructive pulmonary disease	Canada	Remote monitoring of patients with severe respiratory illness	Reduced hospital admissions by 50%; acute home exacerbations by 55%; hospital costs by 17%

stance, in a US hospital, remote monitoring of heart failure patients led to a reduction of hospital readmission rate, from 47 per cent to 6 per cent (Kulshreshtha et al., 2010; Konschak et al., 2013). Consequently, telemedicine technologies have been associated with reductions in healthcare costs, as shown in Table 2. Yet, telemedicine has not always shown success; a metaanalysis of studies of telemedicine in heart failure show nonsignificant reductions in cost, with two studies even showing telemedicine associated with increased mortality (Anker et al., 2011).

As smartphones became abundant, healthcare technologists turned to mobile apps as a way to advance healthcare. One such app, WellDoc, was (and still is) a leading diabetes management app that transmits patients' glucose levels to their clinicians and gives real-time feedback to patients (Konschak et al., 2013). The app has undergone a controlled randomised clinical trial, which showed that it improved the effectiveness of diabetes management (Quinn et al., 2011), reducing emergency hospital visits and stays by 58 per cent (WellDoc, 2011). It received FDA approval and clinicians now frequently prescribe it for managing of diabetes. WellDoc showed the potential for mHealth to solve complex problems associated with chronic condition management and reducing healthcare costs by reducing the use of health services (Konschak et al., 2013).

Today, around 80 per cent of clinicians are using mobile technology to provide patient care, including viewing patient information and giving patients medication information (HIMSS, 2015). Telemedicine and mHealth technologies became of particular interest to healthcare providers in developing countries where patients are typically very far away from hospitals. Around 59 per cent of people in developing countries use an mHealth technology, compared with only 35 per cent in developed countries (PricewaterhouseCoopers, 2014). Unlike developed countries, where mHealth is transforming healthcare, mHealth is developing health-

**Table 3.** The Quantified Self community website (Quantified Self Labs, 2011) lists over 500 self-tracking products in a diverse range of categories. This table lists each category relating to health, with an example and total count of tools within the category.

Category	Example	Count
Health	<i>Withings Bodyscale</i> : wireless body fat monitor and scale.	185
Fitness	<i>Fitbit</i> : wearable tracker which records steps and heart rate.	124
Lifelogging	<i>Momento</i> : app for journaling text, photos, or locations.	122
Goals	<i>42Goals</i> : app for tracking, charting, and evaluating goals	87
Lifestyle	<i>Be Like Ben</i> : track accomplishing Ben Franklin's 13 virtues.	76
Medicine	<i>PatientsLikeMe</i> : website for sharing experience of health conditions.	60
Mood	<i>MoodPanda</i> : mood tracking website and mobile app.	59
Location	<i>Foursquare</i> : app for tracking places visited.	57
Productivity	<i>Equanimity</i> : a meditation timer and tracker app.	55
Food	<i>my-calorie-counter</i> : online calorie counter and diet journal.	54
Sleep	<i>Wakemate</i> : device that records sleep state.	34
Relationships	<i>LoveVibes</i> : app for measuring sexual activity.	19

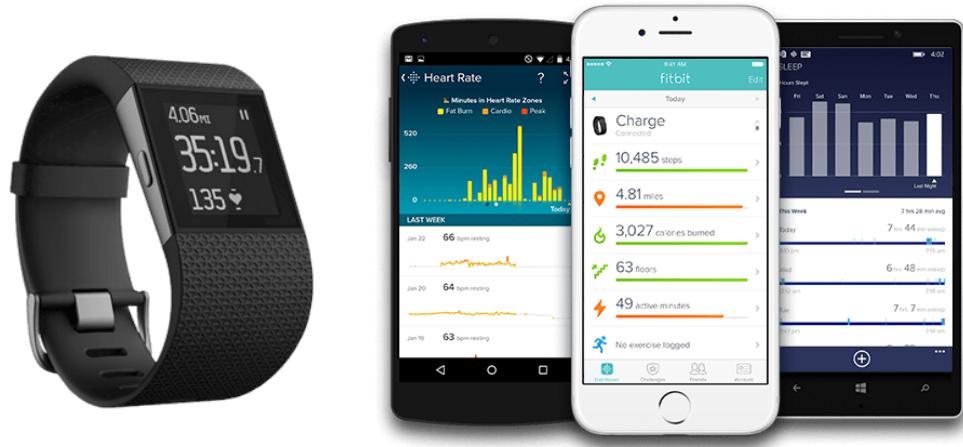
care as a possible cost-effective alternative to building hospitals which only serve people in the local area (Konschak et al., 2013).

#### 2.1.5 The 2010s: Democratisation of Medicine

As sensor technologies became cheap and abundant, everyday technologies such as smartphones and wearable devices became capable of recording metrics relating to health (Lupton, 2016). GPS receivers could measure how far a person walked (Fry, 1999), light sensors could measure a person's heart rate (Grajales and Nicolaescu, 2006), accelerometers could measure physical activity (Naqvi et al., 2012), and cameras could record diet (Doherty et al., 2013). It was now trivial for non-experts to use sensors to track their health, shifting the average person who self-tracks from the technologically experienced 'geek' to the layperson looking to gain insight into their own behaviours and improve their health (Choe et al., 2014).

Just prior to 2010, the *Quantified Self* had been formed by a movement of people towards quantifying and better assimilating their behaviours, thoughts, and feelings for meaningful insight and positive behavioural changes (Lupton, 2016). In 2013 around 69 per cent of Americans tracked at least one indicator of health (such as weight or symptoms) on paper or digitally (Fox and Duggan, 2013), and by 2017 around 77 per cent of Americans owned a smartphone, a rise from 35 per cent in 2011, with about a fifth of smartphone owners having a health app installed (Pew Research, 2017). The Quantified Self community burgeoned, and today is responsible for meet-ups in over a hundred cities worldwide to discuss ways that self-tracking products can be used (Grant, 2017).

Driven by consumers' desire for self-knowledge, the market for health-oriented technology has prospered, outpacing innovation within medicine (Topol, 2012). Unbounded by the regulations of medical appliances, there has been a boom in



**Figure 6.** The *Fitbit Surge* wrist-worn fitness tracker (left) can track heart rate, sleep patterns, physical activity, and location. The *Fitbit* smartphone app (right) is available for most smartphones and allows visualising activity, heart rate, and sleep data from the *Fitbit* wearable tracker.

consumer sensor devices for measuring diverse new forms of health-related information (Neff and Nafus, 2016). There are over 160,000 health apps available to download for smartphones (Jack, 2017) and the Quantified Self community website (Quantified Self Labs, 2011) lists over 500 self-tracking products in a diverse range of categories (see Table 3). One such product, the *Fitbit Surge*<sup>1</sup> (Figure 6), is worn on the wrist and automatically tracks heart rate, sleep patterns, physical activity, and distance moved. It connects with a mobile app to display self-tracked data as progress towards daily goals and plots over time. By 2017, a substantial number of people owned a Fitbit device, with over 3 million sold in first quarter 2017 (Fitbit, 2017). Fitbit and other similar tools made self-tracking accessible to the general population by simplifying the collection of data about health and presenting data in simple, easy-to-understand formats (Fausset et al., 2013).

When, in September 2014, Apple unveiled their Apple Watch<sup>2</sup>, CEO Tim Cook proclaimed that they had created a “comprehensive health and fitness device” that would help people live better lives (Apple, 2014). Worn as a wristwatch, the miniature computer would track physical activity and heart rate and consequently reveal to the wearer metrics about their health. While their product was not the first wearable health device on the market (by this point the aforementioned Fitbit had already become popular), Cook’s launch of the Apple Watch conjured a standing ovation, and the hype that followed precipitated 2.3 million sales in its first week (Vincent, 2015). This was a turning point in consumer health; devices for quantifying one’s own health had become fashionable and ubiquitous, galvanising a new well-being economy. By 2019, the number of wearable devices sold is expected to surpass 200 million (The International Data Corporation, 2016), with consumers ranging from babies to pensioners (Wang et al., 2017).

<sup>1</sup>Fitbit Surge wearable fitness tracker – <https://www.fitbit.com/us/surge> [Accessed 5 Jan 2019]

<sup>2</sup>Apple Watch smartwatch – <http://www.apple.com/uk/watch> [Accessed 5 Jan 2019]

Recent technology advancements have enabled rapid research into biological aspects of the development of health conditions, including the presence of certain genes and cell compositions (von Mutius, 2009). The cost of sequencing an individual's genome was, by 2001, around \$100 million US dollars. But by 2015, this cost had shrunk to around \$1000 (National Human Genome Research Institute, 2016). Personal genomics services became popular amongst people curious about their risks of certain diseases, traits they may have, and their heritage. One such popular service, *23andme*<sup>3</sup>, enabled customers to see their possible risks of celiac disease, Parkinson's, and Alzheimer's.

Identifying biomarkers could help personalise the treatment of patients (Szeffler et al., 2012). A large study of asthma biomarkers found that sufferers of severe asthma exhibited different symptoms to mild asthma patients, including depression, anxiety, and acid indigestion, suggesting the mechanisms involved in severe asthma may be different (Shaw et al., 2015). Moreover, biomarkers may be predictive of certain conditions. Multiple genes have been found to be involved in the onset of asthma, and this knowledge could lead to superior asthma prediction and management (Los et al., 1999). It is hoped that knowledge around biomarkers will lead to developing personalised treatment strategies (Shaw et al., 2015).

Genomics services and fitness trackers are spurring the democratisation of healthcare (Topol, 2012). Patients are becoming consumers and increasingly wanting empowerment within their own healthcare (Konschak et al., 2013). Prompted by patients' demand for democratised healthcare, one recent area of digital transformation within healthcare is the *Personal Health Record* (PHR), defined by Wyatt et al. (2016) as:

a digital tool that helps people to maintain their health and manage their care. It may do this by enabling them to capture their own health and care data, to communicate with health and care services, and/or to have access to their care record.

Distinct from EMRs, PHRs focus on the patient's overall health, rather than just the clinical notes about the patient (Huba and Zhang, 2012). These records typically allow a patient to access and contribute to them (Konschak et al., 2013). PHRs could address the fragmentation of health information across healthcare providers by consolidating patients' clinical information with their self-collected health information (Estrin and Sim, 2010). Moreover, PHRs could enable prompt viewing of blood test results, secure communication with health professionals, appointment booking, and ordering repeat prescriptions (Wyatt et al., 2016). PHRs thus became an important milestone for health services towards digitisation of health services and continuity of care (Iakovidis, 1998).

Visions for PHRs began as early as the 1990s. Iakovidis (1998) described the potential for early electronic health records to have greater involvement of patients towards prevention and health promotion as technology becomes more accessible and abundant. Such records would accrue over a patient's lifetime to support continuity of care and, in turn, improve quality and efficiency of health care delivery

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<sup>3</sup>23andme personal genomics service website – <https://www.23andme.com> [Accessed 13 Dec 2018]

(Iakovidis, 1998). A perceived challenge to PHRs at the time of the review was fragmented data and interoperability problems (Iakovidis, 1998), a problem which remains to this day (Wyatt et al., 2016). Indeed, clinicians have had difficulty integrating common PHR systems into their workflows because of heterogeneous data structures and inconsistent data representations (Liu et al., 2011). Liu et al. (2011) suggests that such challenges must be overcome before successful adoption of PHRs can occur, reinforcing the need for human-computer interaction literature to inform the field of medical informatics.

### 2.1.6 Today: A Change-Averse Healthcare

Patients increasingly expect digital healthcare (Konschak et al., 2013). Doctors opt for EMRs over paper, patients track their health using their phones, and online genomics services let anyone find out their risks of chronic health conditions. Yet, despite these technological advances, medicine remains in many ways antiquated. Fax machines, long abandoned by most industries, remain an integral part of healthcare information practices (Konschak et al., 2013). The NHS is the world's largest purchaser of fax machines, with over 8000 fax machines in use within the health service (Bracken et al., 2017). This, combined with patients still needing to fill out paper forms (Fallows, 2014), means patient information tends to be fragmented across hospitals, clinics, and organisations (Bates et al., 2001). Clinicians can rarely access complete information about patients, leading to medical errors and adverse events (Donaldson et al., 2000).

A 2016 review of PHRs found low adoption of PHRs within health and social care settings, mostly limited to individual care organisations focusing on specific communities, such as long-term health conditions (Wyatt et al., 2016). Despite PHRs promising to improve the methods of care by empowering patients and promoting self-management (National Information Board, 2014), PHRs have rarely stretched beyond enabling secure communication and information sharing with health professionals (Wyatt et al., 2016). Even in these cases, PHRs have typically not met patient expectations, with PHRs generally limiting patients to accessing subsets of their health information and being unable to upload their own patient-generated health data (Wyatt et al., 2016). With the low adoption, PHRs have yet to address the fragmentation of health information (Wyatt et al., 2016). Low adoption led Google to shut down their PHR, Google Health, in 2013 (Dolan, 2011) and Microsoft shut down HealthVault in 2019 (Truong, 2019). A 2019 review of PHRs in the context of managing complex health conditions in children found only a minority of studies of PHRs have examined organisational issues, so information governance and interoperability of PHRs remain largely unknown (Diffin et al., 2019).

Medicine has been described as “the most entrenched change-averse industry in the US” (Christensen et al., 2000). In other industries, like airlines, banking, and shopping, digital transformation has provided efficiency boosts and cost savings (Konschak et al., 2013). Investment in digital health in the NHS could reduce expenditure by 11 per cent (London and Dash, 2016). Hence, governments worldwide

are working towards policy for healthcare innovation. In 2018, the UK government banned the NHS from purchasing new fax machines, citing the danger of patient privacy (fax rarely encrypts information) (BBC News, 2017). Future legislation is likely to focus on leveraging technology to improve efficiencies in healthcare, reduce costs, and improve care (National Information Board, 2014).

Topol (2012) suggests there is a need for a transformation of medicine to expedite innovation, reflecting the inundation of digital technologies which have transformed how humans communicate. Economist Joseph Schumpeter's argued these kinds of 'creative destruction' are essential facts of capitalism, where the "process of industrial mutation incessantly revolutionizes the economic structure from within, incessantly destroying the old one, incessantly creating a new one" (Schumpeter, 1942). Topol (2012) therefore argues that rapid digital innovation outside of medicine will transform medicine, including the practices of clinicians, the organisation of hospitals, the life sciences industry, and approaches to regulation. However, industry-led digital innovations have often been considered unethical or inappropriate for application within medicine, such as the commoditisation of personal data by Facebook (Cadwalladr and Graham-Harrison, 2018) and the marketing of technologies towards over-generalised populations (Spiel et al., 2018). These critiques of digital health technologies are discussed later in this chapter.

## 2.2 VISIONS FOR SELF-TRACKING

Since 1950 the worldwide average life expectancy has increased by two decades, from 48 in 1950 to 68 in 2010 (Bloom et al., 2011). This increased longevity, along with declining fertility and ageing of the 'baby boom' generation, is leading to an ageing population. The proportion of the world's population over age 60 is projected to increase from 11 per cent today, to 22 per cent in 2050 (Bloom et al., 2011). This is predicted to place a strain on healthcare as more people require access to health services (Etzioni et al., 2003). At the same time, health services within the UK are already under increasing pressure to save costs during financial austerity, reducing access to health services and shifting the financial burden of health onto citizens (Karanikolos et al., 2013). Within the US, the cost of delivering care has increased strikingly over the past few years; in 2017, it cost almost \$27,000 for the average insured family, a rise of 22 per cent over 2013 (Girod et al., 2017).

With this ageing population and financial austerity, the UK (Kelsey, 2013) and the US (Fox, 2015) are pursuing advancements to healthcare efficiency through *personalised medicine*, moving away from the 'one size fits all' treatment and care approach towards specialised treatments, tailored towards individuals based on their risks of disease or responses to therapy (Harvey et al., 2012). Personalised medicine promises to improve the care of patients while ensuring healthcare systems become more efficient (Forum, 2015). Such a healthcare revolution will require new kinds of data which centre on individuals and specific populations (Gaw, 2016). One potential source of this data is consumer self-tracking tools.

**Table 4.** Fitbit is a popular wearable health tracker which has been the subject of diverse studies relating to health. This table lists a variety of these studies.

Clinical context	Reference
Alcohol dependency	Abrantes et al. (2017)
Sleep and cardiac functioning	de Zambotti et al. (2016)
Therapy for depression	Chum et al. (2017)
Sleep activity in major depressive disorder	Cook et al. (2017)
Weight loss	Espinoza et al. (2017)
Reducing sedentary behaviour in breast cancer survivors	Nguyen et al. (2017)
Monitoring complications of childhood cancer survivors	Le et al. (2017)
Monitoring circadian rhythm measurement	Lee and Hong (2017)
Preventing sedentary behaviour in the chronically ill	Mercer et al. (2016)
Supporting activity in patients with mental illness	Naslund et al. (2016)
Measuring activity of children with congenital heart disease	Voss et al. (2017)
Prostate cancer	Rosenberg et al. (2016)
Increase physical activity for adolescents with ADHD	Schoenfelder et al. (2017)
Stroke rehabilitation	Klassen et al. (2017)

Wearable sensors and smartphones are pervasive and automated, enabling them to track daily activities and habits (Chiauzzi et al., 2015) and first-hand descriptions of patient experiences (Hong et al., 2016). Data from such devices could constitute evidence about individual patients for providing a more personalised and patient-centric approach to healthcare (Swan, 2012b). The Fitbit wearable tracker has been the subject of a plethora of studies demonstrating its use for diverse forms of health management, including managing weight loss and stroke rehabilitation (see Table 4). In one study, Chung et al. (2015) found self-tracked data provided detailed and precise information about irritable bowel syndrome patients' routines and enabled personalisation of treatment plans, in turn improving the outcomes of management. For heart failure patients, diary mobile apps for recording symptom intensity and triggers for each day led to earlier reporting of health changes and reduced hospital stay duration (Eastwood et al., 2007).

The potential for self-tracked data to personalise care and reduce costs has provoked several hospitals to partner with software companies to develop their own mobile apps (Chung et al., 2015). Many clinicians have been eager to utilise consumer technology to promote better health across the population, monitor and change patients' behaviours, and contribute to the field of preventive medicine (Lupton, 2013). In the UK, the *Personalised Health and Care 2020* policy envisions that patients will be able to contribute their own self-tracked data to health records, which will improve the quality of care, decrease healthcare costs, and empower patients (National Information Board, 2014).

Collectively, the deluge of self-tracked data could help understand the health of small, specific populations. Published clinical studies frequently exhibit biases in their population samples; the elderly and ethnic minorities are often excluded and males are typically represented disproportionately more than females (Murthy

et al., 2004). A drug for treating vascular disease, Plavix, was recently found to be ineffective for around 2–14 per cent of the population (Food and Drug Administration, 2010). Individuals with a particular genetic variant – more common within particular racial minorities – have a reduced metabolism of Plavix (Food and Drug Administration, 2010). Missing this sub-population during the earlier drug trials could be explained by the omission of those with genetic variants and the use of the same dose for every participant (Topol, 2012). Moreover, the financial motives of pharmaceutical companies to generate evidence which supports selling a new drug can bias researchers towards seeking a positive result (Ioannidis, 2005). Topol (2012) argues that the life science industry is motivated to focus on larger and more general populations, rather than smaller populations, causing those small populations to be delivered tests or treatments which are unnecessary and ineffective; “what constitutes good evidence-based medicine today is what is good for a large population, not for any particular individual” (Topol, 2012).

Understanding health conditions within smaller and minority populations is, therefore, a critical goal for personalising medicine (Harvey et al., 2012). Swan (2012b) explains that *big data* – enormous quantities of unstructured and semi-structured data – is ubiquitous in most sectors of the economy and analysing these data is critical for producing meaningful health insights. Large-scale data collection could generate new knowledge of disease and drug responses (Swan, 2012a) and facilitate early warnings of disease in patients (Swan, 2012b). These studies could complement traditional clinical trials for conducting health research:

Massive datasets allow not only population-level analyses, but also sub-population-level and personal-level analyses. Such datasets enable the discovery of personalized risk factors, which take into account the various additional variables that might confer susceptibility or resistance to a given risk factor. Identifying personalized risk factors holds the promise of giving people more effective information about how to prevent disease, and doing so in a way that is more compelling for them to act upon because it is targeted to them specifically as opposed to the “average person.” – Barrett et al. (2013)

Data from self-tracking devices has thus been described as “the most underutilised resource in ambulatory healthcare,” and their integration into care promises to allow tailored treatment towards individuals, more informed clinical decisions, and a shift from treatment to prevention (Appelboom et al., 2014b). It could contextualise genomic markers and help understand diseases in sub-populations (Neff and Nafus, 2016). Self-tracked data, along with data from health records, health diaries, EMRs, telemonitoring, and genome markers, might drive a change from traditional medicine to clinicians treating digitised patients:

Whether it is mapping the mind to awaken an individual who has been minimally conscious for several years, or mapping the genome of a person to diagnose an idiopathic, life-threatening condition or prevent an otherwise inevitable, premature death from cancer or heart attack, the technological capabilities are with us now – and emerging at a breakneck, unprecedented pace, eventually leading to the ability to print organs and even to control aspects of the mind. Humans digitizing humans is the ultimate life changer. – Topol (2012)

Whilst Topol pushes for expeditious technological advancements – even advocating for a creative destruction of medicine (Topol, 2012) – several concerns around such technologies have been raised. The next section discusses these concerns in the context of self-tracking.

### 2.3 CRITIQUES OF SELF-TRACKING

Whilst self-tracking has been posited as a way of delivering more personalised medicine, it is not without its limitations. This section considers three prominent critiques of self-tracking.

#### 2.3.1 Self-Tracking for ‘Everyone’: One-Size-Fits-All and The Worried Well

Self-tracking could unleash an era of personalised medicine, yet the vast majority of self-tracking tools are designed for people who are already ‘healthy’, such as those trying to exercise more (Spiel et al., 2018). Companies design these devices for the largest available market and measure success in profit, not health outcomes (Goldacre, 2013). Self-tracking products are often marketed to *everyone* but tend to be designed for the largest heterogeneous group of people, commonly privileged people who are young, affluent, healthy, white, and heterosexual (Spiel et al., 2018; Kirkpatrick, 2016). The irony is that those who are most likely to benefit from self-tracking are probably *not* the privileged. The elderly, the impoverished, and minority groups are at the greatest risk of developing chronic illness (Kanjilal et al., 2006). But because of privacy, cost concerns, lack of access, and computer illiteracy, these groups of people are often unable or unwilling to engage with self-tracking technology (Pearson et al., 2011). Moreover, most academic research observing self-tracking use focuses on computer-literate people in affluent areas, with little research focusing on broader populations (Ancker et al., 2015a). In one small study, high-school aged Latina girls were given self-tracking devices, but found them too noticeable as a status symbol, did not understand the need for them, did not have the tools and skills to interpret information, and did not have the necessary internet connectivity to use them (Lee and Dey, 2014). These populations remain under-represented in studies of self-tracking (Ancker et al., 2015b), which limits the generalisability of their findings.

Accordingly, self-tracking tools have mostly served to satisfy the positive feelings of the privileged who are already fit, the so-called ‘worried well’ (Gabriels and Moerenhout, 2018). These tools prescribe normative values for what is an acceptable health status or achievement, merely drawing on the designers’ perception of what is ‘healthy’ or ‘desirable’ (Spiel et al., 2018). The goals imposed on users are the same for everybody (Spiel et al., 2018). Fitbit, for example, reports that an increase of steps each week is good and encouraged, while a decrease is bad and discouraged. This disregards that as a person ages they will experience mobility issues and their physical activity will decrease. Fitbit negatively judges people for this natural and expected decline (Spiel et al., 2018). This one-size-fits-all approach of consumer self-tracking tools – where the devices are not calibrated to individu-

als or sub-populations – is therefore likely to lead to unreliable data which do not represent the person's activities (Alabi and Coady, 2014).

In the life sciences industry, companies often act with self-interest, particularly with respect to how drugs have been marketed by the pharmaceutical industry. Vast sums of money are spent on marketing new drugs and medical devices directly to patients, particularly in the US where advertising drugs has become commonplace in print, on television, and digitally (Goldacre, 2013). Patients who see adverts for drugs (commonly advertised as discounted or more effective than an alternative) are more likely to believe they need medication, more likely to request drugs they see advertised, and more likely to be prescribed medication (Kravitz et al., 2005). These treatments are often unnecessary and can risk side effects and anxiety about one's health, revealing the dangers of marketing directly to consumers (Goldacre, 2013). Likewise, the marketing of consumer health technologies, such as health apps and wearables, risks increased anxiety or obsession with one's health (Lupton, 2013). Marketing prescription drugs and medical devices directly to consumers is prohibited by UK law (Medicines and Healthcare Products Regulatory Agency, 2014), but 'health' products may be advertised with few restrictions. For instance, Fitbit recently partnered with the popular UK reality TV show, *The X Factor*, to have contestants wear and endorse their products for promoting health and fitness (Hobbs, 2016). In parallel to the marketing of medications, effective marketing of consumer health products could lead to anxiety about one's body or body dysphoria (Van den Bulck, 2015), and the belief that everybody requires improvement:

These technologies do not facilitate a better life: they define it, without oversight, without transparency, using emotional design tricks to engage in a progressive re-definition of what it means to be human. – *Spiel et al. (2018)*

This relates to the impact of primitive weighing scales discussed at the beginning of this chapter; as weight became attributed to self-worth and health, attitudes shifted "from what this person weighs, to what you should weigh and what you could be" (Schwartz, 1986, p. 165). Lupton (2013) suggests self-tracking devices could eventually be seen as body enhancements used to 'extend the capacities of the body' towards a 'perfect body'.

### 2.3.2 The Need for Regulation

Devices used within medicine are strictly controlled and subject to regulations. Medical devices must undergo clinical trials to ensure they are effective and safe, usually through Randomised Controlled Trials (RCT). RCTs are considered the "gold standard" in clinical evidence because the outcomes of empirical research are critical to patient safety (Kabisch et al., 2011). Without the assurances of medical device regulations, devices could report unreliable information or behave unpredictably and lead to fatal consequences (Hunink et al., 2014).

However, unlike medical devices, clinical regulations do not apply to consumer health products. With designers and manufacturers under no obligation to seek clinical validation of their products, one study found that fewer than 0.4 per cent

of pain apps provided any scientific evidence of the efficacy of their products (Lalloo et al., 2015). While this has proliferated rapid innovation of health apps and wearables (Topol, 2012), it has meant that many products available have questionable claims, seeking to improve the health of users with no scientific basis.

Consumers often validate consumer health products by finding evidence from low-quality studies in obscure journals, blogs, or forums (Topol, 2012). These studies are typically conducted without clinical expertise, have only one participant (often the experimenter), have limited generalisability, and lack a control condition (Mehta, 2011; Choe et al., 2014). One such study – the *Buttermind* experiment (Roberts, 2011) – sought to investigate if eating butter in the morning enhanced brain function. The study was run by a blogger on the Quantified Self website who had experienced faster arithmetic after eating 50 grams of butter each day. Forty-five participants were split into three groups: the first consumed a portion butter every day, the second consumed coconut oil every day, and the third ate their usual diet. During the weeks before and after the experiment, participants ate normally. Participants completed an online arithmetic test every day. The findings revealed improved brain function for those who consumed butter, but not those who consumed coconut oil. The author concluded that butter consumption *did* improve brain function. However, the method used has come under scrutiny, in particular because the method was vague, had a small sample size, lacked adjustment of IQ, and lacked verification of self-tracked data (Swan, 2012a). Moreover, the experiment was not blind so the findings may reflect a placebo response (Swan, 2012a). Therefore, these findings are not considered rigorous enough to support the clinical recommendation of butter consumption (Vandenbergh and Geerts, 2015).

Many such studies of self-tracking draw parallels with studies of ‘complementary and alternative medicines’ (CAMs), such as herbal remedies and homoeopathy (Gorski and Novella, 2014). CAMs have poor evidence of efficacy (Nahin and Straus, 2001; Gorski and Novella, 2014), and yet are enjoying a growing industry; around 40 per cent of Americans having tried some form of CAM (Barnes et al., 2008). The primary concern with CAM is patients may opt for poorly supported forms of treatment over treatments which have received clinical validation, needlessly exposing patients to the risks of inadequate disease control (Söllner et al., 2000). The corollary argument is that effective marketing of self-tracking tools could lead consumers to favour those tools over sound medical advice, in turn leading to poorer health outcomes (Price et al., 2014), and despite these tools lacking sufficient clinical validation (Lalloo et al., 2015).

Recent studies have revealed widespread inaccuracies in consumer health technologies (Ringrose et al., 2017). Such inaccuracies result from device limitations (Loveday et al., 2015), the patient using the device incorrectly (Pearson et al., 2011), the patient’s inappropriate choice of tool (Rapp and Cena, 2014), or the patient’s lack of objectivity when recording data (Chung et al., 2015). In one study, doctors wished to understand the location behaviour of patients but discovered that GPS

instruments used were not suitable for accurate indoor tracking (Loveday et al., 2015). Doctors rejected the data because patients spent most of their time indoors. Hersh et al. (2013) suggest that such poor data quality is a serious caveat to clinical practice, citing missing, erroneous, uninterpretable, and inconsistent data.

Responding to calls to regulate consumer health technology, the US Food and Drug Administration (FDA) has begun approving consumer self-tracking devices for clinical trials, citing the importance of quantifiable analysis of physical activity to physiological monitoring (Food and Drug Administration, 2014). The recently appointed FDA commissioner, Dr Scott Gottlieb, is promoting digital technologies as empowering consumers to make better decisions about their health, enabling more efficient clinical practice, and addressing public health crises (Gottlieb, 2017). While obtaining ‘medical device’ certification remains a difficult and expensive task, Gottlieb is enacting legislation to make it easier to get approval by taking a risk-based approach to evaluating technology:

We are considering whether and how, under current authorities, we can create a third-party certification program under which lower risk digital health products could be marketed without FDA premarket review and higher risk products could be marketed with a streamlined FDA premarket review. Certification could be used to assess, for example, whether a company consistently and reliably engages in high-quality software design and testing (validation) and ongoing maintenance of its software products. Employing a unique pre-certification program for software as a medical device could reduce the time and cost of market entry for digital health technologies. – *Gottlieb (2017)*

Device manufacturers have reacted favourably to Gottlieb’s move towards reducing the burden of FDA approval (Deahl, 2017). Since the statement, Apple was successful in gaining FDA clearance for their Apple Watch 4, which includes an electrocardiogram (Food and Drug Administration, 2018). However, several clinician and patient groups have suggested FDA approval requirements do not go far enough, and moves to lighten requirements could endanger patient safety (Pear, 2017). In particular, manufacturers can bypass FDA approval if they can prove their device is similar to an existing regulated device; this is how Apple received FDA clearance for their Apple Watch 4 without running a clinical trial (Chen, 2018). Critics have questioned Gottlieb’s motivations to reduce the barriers to market medical devices, with Gottlieb previously on the board of several large device manufacturers in the US (Pear, 2017). While critics acknowledge that self-tracking technologies are generally regarded to be low-risk, therefore not requiring the stringent requirements of, for instance, implantable devices, they argue that devices could generate inaccurate or incorrect data, which could lead doctors to make incorrect decisions and risk patient safety (Leap, 2017).

### 2.3.3 Patient Privacy in the Health Information Economy

Self-tracked data often document intimate and private aspects of a person’s life, so keeping such data private and secure is an important challenge healthcare providers (Neff and Nafus, 2016). Recent events have unveiled a thriving market for

personal data, with social media giants such as Facebook unintentionally<sup>4</sup> making available user data to clandestine political agencies (Cadwalladr and Graham-Harrison, 2018). In 2018, it was revealed that a UK political firm, Cambridge Analytica, was using social media data to generate targeted advertisements in support of particular political agendas, including Donald Trump (Davies, 2015) and the *Vote Leave* campaign prior to the UK EU referendum (Cadwalladr and Townsend, 2018). These events have brought to light a vast market for personal information as a tradable commodity (Cadwalladr and Graham-Harrison, 2018).

Within medicine, there is a growing underground market for stolen patient data and there are fears that patient data can be used for identity and insurance fraud (Humer and Finkle, 2014). In the UK, around 58 per cent of consumers are concerned that health data could be stolen when in the hands of wearable or health app companies (Accenture, 2017). Despite 84 per cent of these consumers having a greater trust in clinicians to keep data secure (Accenture, 2017), there have been over 400 recent data breaches in the US with millions of patients affected (Office for Civil Rights, 2018). Table 5 lists ten of the most severe breaches.

In 2015, an HIV clinic in the UK accidentally publicised details of over 700 patients via their email newsletter. The clinic was fined £180,000 for the breach (Information Commissioner's Office, 2016). In 2017, the NHS was attacked by *WannaCry* 'ransomware' software, which encrypted information stored on unsecure computers containing patient records, making them inaccessible until a ransom was paid to the assailants (O'Dowd, 2017). While this did not appear to be an attack specifically targeting health records, it showed that NHS IT systems were routinely insecure and vulnerable to attack (Gayle et al., 2017).

Other sinister uses for self-tracking have emerged. Allen (2008) describes a worry that governments could use lifelog data for surveillance and that past lifelog data could be made 'permanent' with individuals having no control over their data. While O'Hara et al. (2008) suggest many of these concerns relating to government surveillance are overblown, at least one company has asked employees to track their sleep, heart rate, stress, and work performance to determine how they can work more effectively (Bottles, 2012). These may be seen as unwanted forms of surveillance, representing an Orwellian future of corporate information gathering in an 'information economy' (Whitaker, 2000).

Perhaps a greater fear, especially within medicine in the US, is that the data could end up in the hands of health insurance companies, whose motives are to decide premiums based on the person's health problems and past decisions the individual has made (Neff and Nafus, 2016). One insurance company has distributed armbands to thousands of policyholders revealing individuals who were at high risk of diabetes (Olson, 2014). While policyholders consented to this, a person's perceived privacy of self-tracked data may change over time. Policyholders may become less willing to share data which indicates, for example, reduced physical

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<sup>4</sup>Facebook claimed the harvesting and sale of personal details from 30 million Facebook users was undertaken by a University of Cambridge lecturer without Facebook's permission, while the lecturer argued that Facebook used him as a scapegoat (Weaver, 2018).

**Table 5.** The ten largest US health data breaches currently under investigation (Office for Civil Rights, 2018).

Entity	Entity type	Individuals affected	Date reported	Type of breach	Location of breach
Bon Secours Health System Inc.	Healthcare Provider	651,971	Aug 2016	Unauthorized Access/Disclosure	Network Server
CA Department of Developmental Services	Health Plan	582,174	Jun 2018	Theft	Paper/Films
MSK Group	Healthcare Provider	566,236	May 2018	Hacking/IT Incident	Network Server
LifeBridge Health, Inc.	Healthcare Provider	538,127	May 2018	Hacking/IT Incident	Network Server
Peachtree Orthopaedic Clinic	Healthcare Provider	531,000	Nov 2016	Hacking/IT Incident	Network Server
Airway Oxygen, Inc.	Healthcare Provider	500,000	Jun 2017	Hacking/IT Incident	Network Server
SSM Health St. Mary's Hospital - Jefferson City	Healthcare Provider	301,000	Jul 2018	Improper Disposal	Paper/Films
Women's Health Care Group of PA, LLC	Healthcare Provider	300,000	Jul 2017	Hacking/IT Incident	Desktop Computer, Network Server
Oklahoma State University Center for Health Sciences	Healthcare Provider	279,865	Jan 2018	Hacking/IT Incident	Network Server
Med Associates, Inc.	Business Associate	276,057	Jun 2018	Hacking/IT Incident	Desktop Computer

activity because of their undisclosed depression. As Neff and Nafus (2016) describe, one's perception of privacy depends on what the data describes and who will see it:

What makes data 'private' is the line-up of people or institutions 'in context' for issues related to the data and the body to which the data refers. You might not share with your doctor the fight you had with your husband because it is too personal and out of context, but you might not share with your husband what you share with your doctor and, de facto, your insurance company, for exactly the same reason. – *Neff and Nafus (2016)*

Some countries have legislated that once information is entered into a clinical system, it must be afforded protection from sharing without the patient's consent. Legislation such as the Health Insurance Portability and Accountability Act (HIPAA) in the US protects patients' rights to privacy over their data within a medical domain by regulating how and where data are stored, with heavy penalties for violations (US Department of Health and Human Services, 1996; Petersen and DeMuro, 2015). The act provides federal protection for health information stored by any organisation or person who works with patients (Konschak et al., 2013).

It is unknown how HIPAA will apply to self-tracked data, which are diverse and often stored in the cloud (Konschak et al., 2013). The FDA's recent relaxation (Gottlieb, 2017) of regulation of consumer health technologies could lead to reduced consideration of patient privacy in future clinical approval of such technologies. One recent example is the *digital pill*, a medication which has a sensor embedded within it which informs clinicians when the patient takes the medication (Belluck, 2017). The FDA's approval of this drug may help clinicians to address problems of medication non-compliance common with prescriptions, affecting approximately half of patients and costing around \$100 billion per year (IMS Institute for Healthcare Informatics, 2013). However, some have considered these digital pills to be a form of surveillance, which could foster mistrust between the patient and the clinician (Belluck, 2017). Moreover, a recent announcement has confirmed the FDA will not regulate the data generated by self-tracking devices (Lecher, 2015), and there could therefore be few limitations on how self-tracked data get used by the companies that hold them.

#### **2.4 DESIGN CONSIDERATIONS FOR SELF-TRACKING IN MEDICINE**

With the digital transformation of healthcare, it has become increasingly important to understand how information systems can be designed to be safe and practical. This section explores how clinical records are read, types of problems which may be introduced by self-tracking in medicine, and how information design could help overcome these problems.

A clinician's interpretation of information, such as a medical record, often follows a familiar pattern. Interviews with physicians have revealed that physicians will usually start by looking for a summary of the patient and their case; they may have to leaf through several summaries to identify an adequate description (Nygren and Henriksson, 1992). Documents are then searched through to find the most relevant for that time, often by looking at the printed date (Nygren and Henriksson, 1992). For paper records, finding information can be slow and difficult because of poor organisation; doctors have been observed using the colour of pages to quickly determine date, with older pages appearing yellow (Nygren and Henriksson, 1992). Electronic medical records may offer improved organisation of documents through structured data, as well as improved legibility, integration with other information sources, tailored output, and simultaneous access (Nygren et al., 1998).

Despite electronic records facilitating quicker searching and improved legibility, they have introduced other problems. Data entry can be slower because of the need to input structured information and clinicians have described a loss of design control, with design decisions increasingly made by programmers rather than clinicians (Nygren et al., 1998). Nygren et al. (1998) describe a potential impact to clinician-patient relationship, with computers creating physical barriers between clinician and patient. Indeed, through observing how clinicians use EMRs, Frankel et al. (2005) discovered two barriers to the effective use of computers within exam

rooms. First, when focused on a computer-based task, clinicians did not listen to or make eye contact with patients, making patients feel left out of the consultation. Second, EMRs added additional tasks, such as typing information into a computer and requiring greater cognitive load to process the larger wealth of available information. Similarly, Alsos et al. (2012) observed the use of EMRs on mobile devices and found that clinicians were poor at maintaining eye contact and easily distracted by the device. Alsos et al. propose that the impact of computer systems on verbal and non-verbal dialogue negatively affected the effectiveness of consultations, patient outcomes, and patient compliance. From these studies of EMRs on doctor-patient interactions, form factor and user interface have been found to impact eye-contact and verbal and non-verbal communication (Chen et al., 2011). Complex user interfaces requiring close attention by the clinician increased cognitive workload for the clinician, exacerbating barriers to eye-contact and communication.

Finding and interpreting data from clinical records can be difficult and time consuming, often because of the large volume of disorganised information, or because notes are specific to the needs to one specialist or profession (Wyatt and Wright, 1998). Such issues can arise because the responsibilities for maintaining records can be ambiguous, with nobody maintaining indexes or keeping records in order, even within a single institution (Wyatt and Wright, 1998). Clinicians have raised concerns that entering self-tracked data into records could exacerbate disordered information, with increased workload for clinicians in an already overloaded practice (Neff and Nafus, 2016, p. 136-147). Indeed, doctors reportedly do not have time to evaluate and interpret self-tracked data, with less than five minutes following consultations to review such data (Chung et al., 2015). Such time-pressured use of data inevitably leads to rapid decision-making; nurses in emergency rooms, for example, must make decisions rapidly, often using intuition (Cioffi, 1997). Croskerry (2005) refers to this as Flesh and Blood decision making:

Clinicians do not take to reclining armchairs to cogitate and consider their options at length, but instead respond to omnipresent time pressures and resource availability with expeditious decision and action. To make a Flesh and Blood decision is to think on one's feet and go with clinical intuition. – (Croskerry, 2005)

In such time and resource constraints, decisions tend to be more automated, increasing the likeliness of errors and biases (Kahneman, 2012). Graber et al. (2002) highlight an ideal data interpretation may involve calculations and adjustments of probabilities as more data is interpreted. Realistically, clinicians are unlikely to think like this:

The probability of the initial hypothesis is adjusted upwards or downwards using test results to calculate a new probability using Bayes' theorem. Unfortunately, few clinicians are skilled in using Bayes' theorem, and in practice it is probably more common for tests to be interpreted without taking into account the characteristics (sensitivity and specificity) of the test itself. – (Graber et al., 2002)

Studies have shown errors are common when interpreting data in time constraints. A study conducted at a Utah hospital found highest percentage of negligent ad-

verse events occurred in patient rooms and emergency rooms, where there was high task complexity, uncertainty, multiple concurrent tasks, rapidly changing plans, and high workload (Thomas et al., 2000). In a study of students, participants' immediate perceptions of treatment acceptability influenced how they interpreted graphs of treatment effectiveness (Spirrison and Mauney, 1994). Data interpretation can be influenced by one's emotion (Ambady and Gray, 2002), how a question is framed (Cheng et al., 2012), and by how long ago one had lunch (Danziger et al., 2011). Substitution errors are also common, such as confusing the drug brands *Norflex* and *Norflox* (Pincus and Ike, 1992). Croskerry (2003) proposes that such biases and errors are covert and subtle, making them more difficult to observe and making clinicians unaware of them, which, Croskerry suggests, is perhaps why they are not on the list of serious reportable events<sup>5</sup>. Understanding how data are interpreted under time pressured environments is therefore important to designing safe displays of information.

Previous technology failures in clinical environments have led to incorrect diagnoses, malfunctions, and patient deaths (Leveson and Turner, 1993). In the 1980s, a radiation therapy machine called *Therac-25* massively overdosed six people in part because of poor interaction design (Leveson and Turner, 1993). When the operator pressed the button to deliver a dose of radiation, a fault in the software caused the user interface to display meaningless error codes and the machine to shut down. With no meaningful visual feedback, some operators assumed nothing was happening and repeatedly reattempted to deliver the dose. Unknown to the operators, each attempt delivered a dose of radiation to the patient which caused the preventable injuries and deaths of several patients. The problems related to poor interaction design, poor documentation, poor risk analysis, and complicated design.

A review of 130 studies of use of EHRs found barriers associated with design, including low contrast text, small font sizes, and poor navigational design (Archer et al., 2011). Patients with specific diseases who tried interpreting their records found problems caused by flashing and animations, cluttered displays, and poor perception of the colour red (Archer et al., 2011). Moreover, there remain usability issues around data entry in mobile apps. Thimbleby et al. (2015) found erroneous number input to be common on mobile devices. Mobile data entry could exacerbate existing errors with entering drug names, such as the aforementioned substitution of *Norflex* and *Norflox* (Pincus and Ike, 1992). Liu et al. (2011) suggest that a consideration of using information from mobile devices in clinical records must be to highlight potential input errors. Mobile devices also present challenges for data structure and representation. Self-tracking apps and devices rarely share the same representations and often use bespoke representations whose meaning depends on the manufacturer, such as "physical activity points" (Becker et al., 2014), and

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<sup>5</sup>List of Serious Reportable Events – [http://www.qualityforum.org/Topics/SREs/  
List\\_of\\_SREs.aspx](http://www.qualityforum.org/Topics/SREs/List_of_SREs.aspx) [Accessed 3 Oct 2019]

more advanced data visualisations have been found to have steep learning curves, particularly when visualising many data sources (Choe et al., 2014).

Despite these challenges, computerised records have long been proposed as a way to improve ability of doctors to retrieve information quickly (Nygren et al., 1998). The field of *Information Design* offers a solution to electronic record design challenges by considering how people interpret information, including visual cues to highlight salient data, layout of information, appropriate comparisons, and suitable typography for correct and efficient reading (Wyatt and Wright, 1998). Structured graphical representations, in particular, have been shown to reduce time to interpret data when allowing highlighting of correlations, anomalies, triggers, and undesirable behaviour and comparisons with other patients or goals (Swan, 2012c; Rapp and Cena, 2014). Frankel et al. (2005) suggests that the sensible organisation of data is important to reduce the time and effort of finding relevant information and reduce the training needs. Whooley et al. (2014) propose three methods for representing data more effectively: *binary*, in which a person has or has not done something, *structured*, for example tables and graphs which display relationships between multiple variables, and *abstract*, which are generally artistic and not structured.

Projects which have utilised Information Design have benefited from improved understanding by users. *LifeLines* is one such product, which displays personal histories and biographical data – such as medical records – on a multi-faceted timeline (Plaisant et al., 1995). Trends and anomalies are highlighted and discrete events marked by icons to ensure that salient information can be quickly interpreted. *LifeLines* has been applied to clinical records to show patient conditions and clinical events over a patient's life time on a single timeline (Plaisant et al., 2003). The display enabled viewing a patient's record at a glance, and found a 61 per cent speed improvement for complex tasks (Wang et al., 2008).

An important part of information design is the inclusion of stakeholders in design, such as clinicians, researchers, and clerks (Wyatt and Wright, 1998). Shneiderman and Plaisant (2006) propose that regular observations and interviews of users, recording usage of the tool with instruments, and asking users to log their comments, problems, and insights gathered can form an important evaluation of the tool and basis for improvement. Wright et al. (1998) propose several design rules for clinical records informed by information design:

- Ensure the context is clear, including the date and main purpose of consultation.
- Headings should be informative and specific, such as 'eating problems' instead of 'symptoms'.
- Enable quick data interpretation by limiting information under each heading, but having more headings.
- Records should highlight salient or abnormal points and indicate where important data are.

- Information should be organised to suit more than the needs of one profession. Information for specific profession should be visually separate (such as in a box).
- White space should be used to clearly organise the record into sections.

The design of technology within healthcare has taken lessons from past mistakes, motivating some fundamental requirements for modern healthcare information systems (Leveson and Turner, 1993). New technologies, such as self-tracked data, will need to ensure the safety of patients by drawing on these design lessons (Konschak et al., 2013). Leveson and Turner (1993) provide several safety-critical design rules as lessons-learned from Therac-25:

- Do not be overly confident in the software;
- Do not solely rely on software for safety;
- Do not design a system where a single error can be catastrophic;
- Do design for the worst case;
- Do log incidents as part of a quality control process;
- Do undertake a thorough risk assessment;
- Do ensure systems are thoroughly documented;
- Do ensure systems are thoroughly tested;
- Do keep the designs simple;
- Do ensure that software engineers are trained for working on safety-critical systems and human factors; and,
- Do ensure that users of the systems are involved in resolving problems.

Konschak et al. (2013) propose the following design rules for healthcare IT systems, which build on the lessons learnt from EMR and mHealth systems:

- Do undergo testing and quality assurance with designers and users working cooperatively;
- Do ensure data are easily, accurately, and reliably retrievable;
- Do ensure data displays are simple and intuitive;
- Do design the system to enhance clinicians' workflows by, for example, automating menial tasks and not increasing cognitive workloads;
- Do ensure data are transferable to other systems and organisations; and
- Do ensure the system is accessible at all times.

Technology does not always solve problems and occasionally introduces new problems. Thus, these recommendations share a common goal of ensuring that the systems are usable in a safe way by health professionals. One area of research which places humans at the centre of design is Human-Computer Interaction (HCI). HCI goes beyond the software implementation of information systems to consider how they are used by people (Rogers, 2012). Classical literature in HCI theory has demonstrated that the usefulness of a computer-based system in a given context is determined by its form factor (the size, shape, and other key physical characteristics), visual display of information, user interface (the design of a tool to allow a

human to interact with it), and usability (the extent to which a product achieves specific goals) (Rogers, 2012, p. 21). Thus, as described in the next chapter, this research adopts approaches grounded in HCI to understand how clinicians may use self-tracked data.

### 3 THEORETICAL FRAMEWORK

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This chapter outlines the theoretical framework used for this research. The framework served three purposes: to focus the scope of research within the field of self-tracking, to identify good approaches to researching and understanding this topic, and to identify the generalisable findings towards the end of this research. This chapter first describes the underlying concepts before constructing the theoretical framework for this research.

#### 3.1 UNDERLYING CONCEPTS

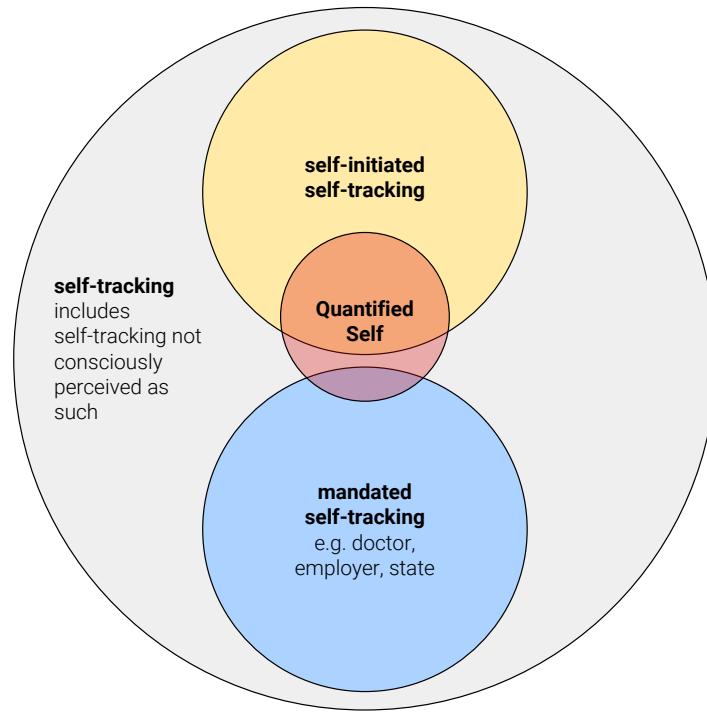
This section examines three concepts which form the basis for the theoretical framework. The first is the *Quantified Self*, which helps to understand the motivations of those who engage in self-tracking. The second is patient empowerment, which describes the movement of patients having greater roles and responsibilities in their care management. The third is the workflow elements model, which provides a way to study and understand the processes actors perform within a system.

##### 3.1.1 The Quantified Self

This thesis concerns the clinical use of health data generated by individuals; these individuals are often collectively referred to as the *Quantified Self* (Lupton, 2016). This section draws on HCI research of the Quantified Self to understand why patients engage in self-tracking, how they practise self-tracking, and the role ‘quantified patients’ have in clinical workflows. In defining the Quantified Self, Lupton (2016) explains an ethos around self-tracking tools and practices:

While the Quantified Self overtly refers to using numbers as a means of monitoring and measuring elements of everyday life and embodiment, it can be interpreted more broadly as an ethos and apparatus of practices that has gathered momentum in this era of mobile and wearable digital devices and of increasingly sensor-saturated physical environments. – Lupton (2016)

As self-tracking has become more abundant, the term *Quantified Self* has become synonymous with several forms of self-tracking, including self-initiated self-tracking, where a person decides to voluntarily self-track, and mandated self-tracking, where a person has been instructed to self-track (Boesel, 2013). This is underpinned in Boesel’s model of the Quantified Self, shown in Figure 7, which represents how the community of the Quantified Self overlaps with the self-initiated and mandated self-trackers. The breadth of different kinds of self-tracking has led some to suggest that the Quantified Self goes beyond the scope of health; “quantified self is not just about health and wellness, it’s about your consumer habits all throughout your day, from what sites you surf, what you buy, to what you like to brag about on your Facebook and Twitter” (Taylor, 2012). However, Boesel (2013) argues that Quantified Self refers to self-tracking with the interrogation of exper-



**Figure 7.** Taxonomy of types of self-tracking, based on Boesel (2013), displayed as a Venn diagram of self-tracking communities. Quantified-selfers include those who decide to initiate self-tracking (self-initiated) and those who are instructed to (mandated).

iences, and includes those who are mandated to self-track by, for example, their clinician. Boesel suggests these contrasting understandings of the Quantified Self reflect the different objectives of entrepreneurs, who define Quantified Self as the market towards which they develop and target devices, and researchers, who define Quantified Self by the practices of self-tracking.

These different perceptions of the Quantified Self represent unique motivations to engage in self-tracking; while early quantified-selfers typically self-tracked because of a desire to know more about oneself (Morris and Aguilera, 2012), having an illness or being given medical advice has become a growing motivation to self-track (Bottles, 2012). Within the field of HCI, a recent review of Quantified Self community meetings identified a diverse range of motivations for self-tracking, ranging from improving one's health and managing a health condition, to becoming more knowledgeable about one's body to make better health decisions (Choe et al., 2014). For others, the motivations to self-track may be more opportunistic, because they have the technical capability to do so easily (they self-track because they can) (Mehta, 2011). Table 6 lists thirteen different motivations identified by Choe et al. (2014).

Motivation to self-track has become a well-studied topic within HCI, with a common conclusion that a person's motivation to pursue and continue self-tracking often depends on the purposes for which they started self-tracking (Epstein et al., 2016; Choe et al., 2014; Rapp and Cena, 2014). For example, a person's motivation to self-track will often hinge on finding answers to questions about their health; without finding these answers, 'tracking fatigue' can set in and

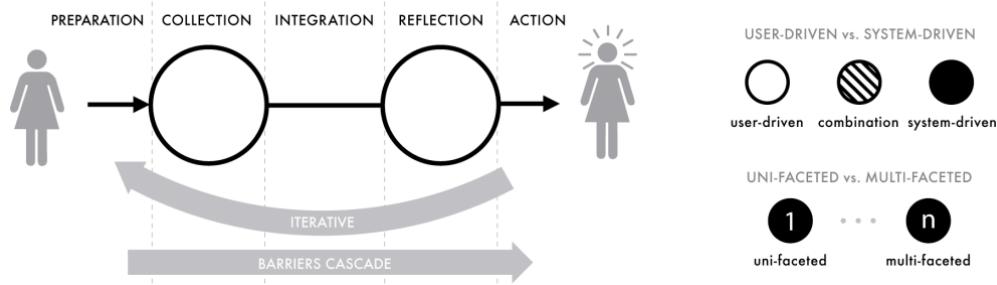
**Table 6.** There are diverse motivations for quantified-selfers to engage in self-tracking. This table lists thirteen motivations, with examples, derived from Choe et al. (2014).

Category	Example
<b>To improve health</b>	
Cure/manage condition	Track blood glucose to hit the target range
Achieve a goal	Track weight to get back to the ideal weight of 135 pounds
Find triggers	Log triggers that cause atrial fibrillation
Answer a question	Track niacin use and sleep to identify how niacin treats symptom
Identify relationships	Track relationship between exercise, muscle mass, and body fat
Execute treatment plan	Log food, exercise, and panic to plan for panic attack
Better health decisions	Record healthy and unhealthy things to make better decisions
Find balance	Log sleep, exercise, and time to get back from erratic lifestyle
<b>To improve other aspects of life</b>	
Maximize work	Track use of time to identify ways to improve efficiency
Be mindful	Take selfie every day to capture each day's state of mind
<b>To find new life experiences</b>	
Curiosity or fun	Log frequency of 'puns' to see frequency and reasons for them
Explore new things	Track every street walked in Manhattan to explore all of the city
Learn interesting thing	Track heart rate and see what can be learned from it

self-tracking is often abandoned (Epstein et al., 2016). Tracking fatigue is exacerbated by the cost of collecting, possessing, and sharing data (Epstein et al., 2016). Moreover, a person life circumstances can change, or they may feel they learnt enough, so no longer need to self-track (Epstein et al., 2016).

Li et al. (2010) formalised self-tracking practices in a stage-based model, in which people prepare for data collection, undergo data collection, integrate the data with other tools, reflect on it, and take action (see Figure 8). Rapp and Cena (2014) suggested that the reflection stage is a key source of problems because of difficulties in exploring and interpreting information. After failing to answer questions people will stop self-tracking, meaning such endeavours to self-track are short-lived (van Berkel et al., 2015). Satisfying curiosity is therefore an important motivator for quantified-selfers, and without this, data may be incomplete or unreliable. Thus, when self-tracked data are used within clinical settings, understanding a patient's motivation to self-track may be a critical component in deciding how such data can be used.

To encourage patient adherence to self-tracking, designers of self-tracking devices often impose rewards or punishments for achieving or failing to achieve goals or benchmarks (Rapp and Cena, 2014). For example, apps often encourage users to publish their data via social media to foster competition and behaviour changes (Dontje et al., 2015). Kamal et al. (2010) document that self-reflection can result from sharing self-tracked data on social media, thus causing social pressure to accomplish goals. Rapp and Cena (2014) describe this as guilt control, which motivates users to achieve their goals. However, the effect is modest and tempor-



**Figure 8.** Stage-based model of self-tracking by Li et al. (2010). An individual begins by preparing for data collection, then undergoes data collection, integrates the data with other tools, reflects on it, and finally takes action.

ary, and people frequently still pursue short-term objectives even if they lead to long-term harm (Rapp and Cena, 2014).

Some who self-track are concerned they are perceived as obsessive (Mesko, 2015), and clinicians echo concerns that self-tracking practices may indicate a patient's obsession with some aspect of their health (Ancker et al., 2015b). Gilleade and Fairclough (2010) suggest that if designers do not take into consideration any obsessive or hypochondriac tendencies of users, the resulting data will not accurately describe the person. However, studies have shown that clinicians do not always need to interpret the data to understand more about the patient's condition; understanding the user's intentions of self-tracking and their understanding of data may itself provide enough insight into the patient's condition (Morris and Aguilera, 2012).

This thesis extends the Quantified Self, as defined by Lupton (2016), to the *Quantified Patient*: a patient within the Quantified Self, or an individual who has engaged in self-tracking so their health-related experiences may be interrogated, either by themselves or by clinicians. Aligning with the work of Choe et al. (2014), the Quantified Patient may decide to self-track voluntarily, or at the instruction of clinicians, representing a broad array of motivations for self-tracking (Choe et al., 2014). For the purpose of this thesis, the Quantified Patient takes Boesel's viewpoint that quantified-selfers "don't just self-track; they also interrogate the experiences, methods, and meanings of their self-tracking practices, and of self-tracking practices generally" (Boesel, 2013).

### 3.1.2 Patient Empowerment

The concept of *patient empowerment* is crucial to this thesis. This research draws on the work of Holmström and Röing (2010) around empowerment and patient-centred care models. In their work, Holmström and Röing reviewed 40 published articles on empowerment to establish the core concepts of patient empowerment and patient-centredness. For this thesis, these concepts help to understand the driving force behind self-tracking and the reasons patient self-tracking could support clinical decisions. Feste and Anderson (1995) define patient empowerment as follows:

The empowerment philosophy is based on the assumption that to be healthy, people must be able to bring about changes, not only in their personal behaviour, but also

**Table 7.** Comparison of provider-centred and patient-centred healthcare from Konschak et al. (2013).

Provider-centred	Patient-centred
Fragmented care	Teams of providers that include patients and families
Primary care physician is the gatekeeper	Coordinated care across organisations; primary care physician as advocate or coach
Paternalistic care	Patient-centred care
Little focus on data	Information technology critical
Acute-care focused	Preventative and chronic care focused
Little attention to cost	Focus on value with protocols and practice standards designed to achieve the best outcome for the lowest cost

in their social situations and the organisations that influence their lives. – *Feste and Anderson (1995)*

The terms *patient empowerment* and *patient-centredness* are frequently used synonymously, although Holmström and Röing make a subtle distinction in their usage. Literature on patient-centredness tends to focus on sharing power, while literature on patient empowerment tends to focus on clinicians *surrendering* power (Holmström and Röing, 2010). Both concepts have the common goal of sharing power with the patient, and their success depends on effective communication between doctor and patient (Holmström and Röing, 2010).

Historically, *provider-centred* health has been the norm, with the clinician exercising power over the patient (Parsons, 1939). Clinicians make decisions and provide care while patients receive care. In this asymmetry, patients with chronic illness often find care a disempowering experience, leading to patients demanding greater control of their care (Dubberly et al., 2010), greater access to information held about them within inaccessible medical records (Wicks and Little, 2013), and greater control over their health information (Ancker et al., 2015a). Over time, a drive towards patient-centred care has seen patients become empowered as partners in their healthcare decisions and increasingly seen as “experts on their own bodies, symptoms, and situation” (Holmström and Röing, 2010). Konschak et al. (2013) describe several identifying differences of patient-centredness over traditional provider-centred healthcare (see Table 7), including a greater focus on patient information, a shift towards preventative care, and increased coordination with other healthcare organisations (Konschak et al., 2013).

Part of the motivation behind patient-centred care is the capabilities of modern everyday technologies. Technology advancements have made available home medical devices for managing diabetes (Topol, 2012) and heart arrhythmias (Matchar et al., 2010), while the Internet has enabled people to research diseases and medications (McMullan, 2006). Many patients have begun to record their own health

information so they can take the role of maintainer and controller of their health information and care (Lupton, 2013), leading to a larger role of the patient in medical decision-making (Ben-Zeev et al., 2015). With patients becoming more knowledgeable about their health, the patient's role has shifted from a passive recipient of health information, to an active consumer of health information, empowering patients to have greater participation in clinical consultations (McMullan, 2006). Lupton (2013) suggests that, for these reasons, self-tracking will empower patients in their care by causing a shift away from clinical paternalism towards participation between clinician and patient. Patients may accept, or demand, a larger role in their health decisions, in turn dismissing the clinical paternalism common within many clinical settings (Ben-Zeev et al., 2015).

Choe et al. (2014) suggest patients may be motivated to self-track to manage their condition, achieve goals, manipulate coping strategies, and find triggers of symptoms, particularly when there is a clinical dialogue when using these tools. Patients' abilities to identify trends in their own behaviours and symptoms could therefore galvanise the empowerment of patients in clinical decisions about their care (Ben-Zeev et al., 2015). For example, Bentley et al. (2013) showed that allowing people to link various health and well-being data together empowered people to reflect on and change their own behaviours. When mood, diet, and weather were presented together, subjects gained insight into the causes of bad moods, which encouraged behaviour changes to avoid those situations. Subjects also found they walked less on particular days of the week, were happier when are less tired, and slept better when exercised more. Consequently, users were "empowered to see the trade-offs that they face in daily life in new ways that are difficult to spot on their own" (Bentley et al., 2013).

Modern technology has meant sufferers of heart arrhythmias no longer require frequent hospital visits to ensure their blood thinners are not causing a risk of bleeding (Wolf et al., 1991). Instead, a patient can use a portable device to test themselves (Camm et al., 2010), which has been demonstrated to be effective at regulating medication doses while improving patient satisfaction (Matchar et al., 2010). These technologies have empowered patients to become more knowledgeable about their health and able to control it (McMullan, 2006). Similarly, online health communities have prompted shifts in power. *PatientsLikeMe* is one such online community, where people with similar illnesses share and discuss their health data and request that clinicians answer questions, offer next steps, and provide preliminary diagnoses based on self-reported data (Morris and Aguilera, 2012). This is an atypical form of clinical consultation, where the patient leads the consultation with their own collected information, demonstrating a shift of patients' trust from their clinicians to their peers (Topol, 2012). Empowering patients in such online communities could reduce the healthcare costs of people with rarer health conditions, while empowering patients in their own care (Steele, 2011).

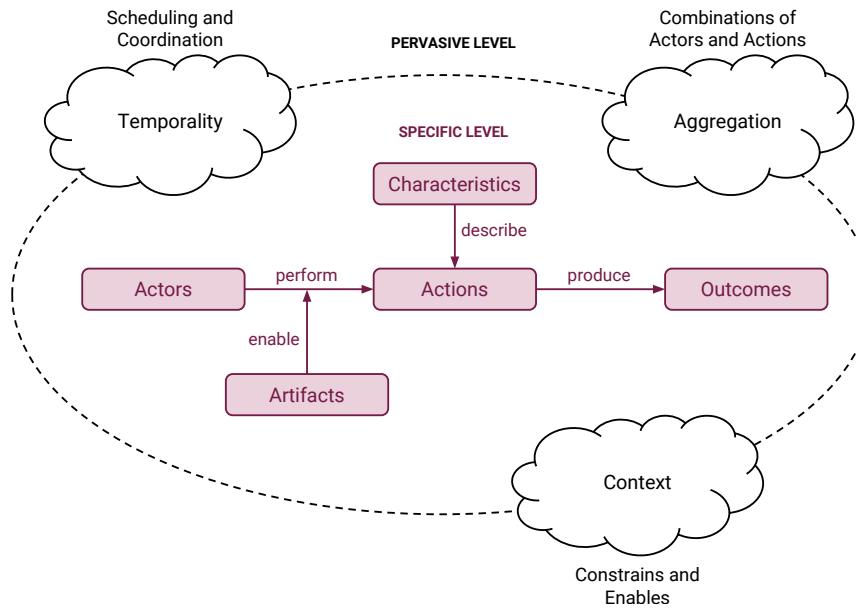
However, not all patients desire a greater role in their care. Patients live with the burdens of their illness; the burdens of symptoms and treatment can negatively

impact one's physical, social, financial, and psychological well-being (Eton et al., 2012). Such negative impacts can have detrimental consequences to health and care, including poor adherence to prescribed treatments, poor quality of life, and higher mortality (May et al., 2009). The shift towards self-care is further exacerbating this by creating new responsibilities for patients, including maintaining a diet, taking medication, scheduling clinical appointments, and exercising (Gallacher et al., 2011). With these added responsibilities, patients have become 'co-workers' or 'subordinates' who are assigned technically or organisationally demanding tasks (May et al., 2014). Contemporary HCI literature has argued that self-tracking in medicine is part of this shift of subordination, in which patients take on the responsibility of data collection that was traditionally the clinician's responsibility, in turn placing a greater burden on patients and reminding them they are sick (Ancker et al., 2015b). Such effects of self-tracking may lead to changes in their condition; for example, Choe et al. (2014) found that patients who tracked their emotions changed their emotions, both negatively and positively, due to their tracking and being more aware of, for example, being anxious. Self-tracking tools could, therefore, have negative psychological and physiological effects on their users.

Patient empowerment and patient-centredness remain important topics of research towards the future of healthcare. While many patients will wish to have a greater stake in their care, many patients will prefer the traditional paternalistic model. While some argue that such patient-centred medicine could allow tailoring treatment and care to the patient's individual needs, evidence towards such improvements are inconsistent (Lee and Lin, 2010), and clinician-patient interaction is still today considered asymmetric (Pilnick and Dingwall, 2011). Nevertheless, Holmström and Röing (2010) conclude that patient empowerment and patient-centredness have the potential to improve the quality of healthcare systems by ensuring patients have a voice in their care. This thesis will use the work of Holmström and Röing to establish the role of patient empowerment in self-tracking, and, in turn, explore the potential impact of patient empowerment towards clinical workflows when working with self-tracked data.

### 3.1.3 Workflow Elements Model

When multiple people complete similar tasks as part of their occupations – such as clinicians using self-tracked data (West et al., 2016) – there are often similarities in their *workflows* (Unertl et al., 2010). Workflows are "systems that help organisations to specify, execute, monitor, and coordinate the flow of work cases within a distributed office environment" (Burton et al., 1989). Thus, to understand how self-tracked data are used by clinicians, this thesis considers workflows by drawing on the *workflow elements model* (Unertl et al., 2010). The workflow elements model was developed by Unertl et al. (2010) from a systematic review of 127 articles on workflows, and it provides a basis for constructing workflows, defining the actors, and scoping the applications of the workflows.



**Figure 9.** The workflow elements model (Unertl et al., 2012) comprises a pervasive layer (around the outside) and a specific layer (on the inside).

As illustrated in Figure 9, the model comprises two layers: the pervasive layer and the specific layer. In the pervasive layer, there are three components which consistently affect the specific layer: *context*, which constrains and enables the workflow within workspaces and organisational settings, *temporality*, which includes how time impacts tasks and coordination of events, and, *aggregation*, which defines the relationships and interactions between different actors and tasks. Meanwhile, the specific level defines *actors*, who are the people performing actions, *artefacts*, which are the tools actors are using, *actions*, which are the actions being performed, *characteristics*, which are the characteristics of those actions, and, *outcomes*, which are the products of the actions.

Despite the diverse and distinct tasks undertaken in different clinical settings (Unertl et al., 2012), clinicians across these settings share common goals, such as mitigating risk and harm and engaging patients in their care (Bowens et al., 2010). Prior work has revealed workflows for using EMRs which work around clinical time constraints, disruption to current practice, and legal concerns (Boonstra and Broekhuis, 2010). Thus, analysing the workflows of clinicians' using health information could help uncover common barriers to using self-tracked data.

A few studies in HCI have identified workflows for using self-tracked data in clinical settings. West et al. (2016) observed that, when deriving a diagnosis using self-tracked data, clinicians across different roles followed a workflow comprising steps of information discovery, evaluation, generating hypotheses, and then systematically ruling-out hypothetical causes of the patient's condition. This step-by-step workflow aligns with the clinician's aim to minimise risk to the patient. In a study evaluating an interface for viewing step-count data from Fitbit in clinical settings, a workflow was followed by a clinician comprising three phases (Kim et al., 2017). First, data were 'skimmed,' in which the clinician viewed the provided information

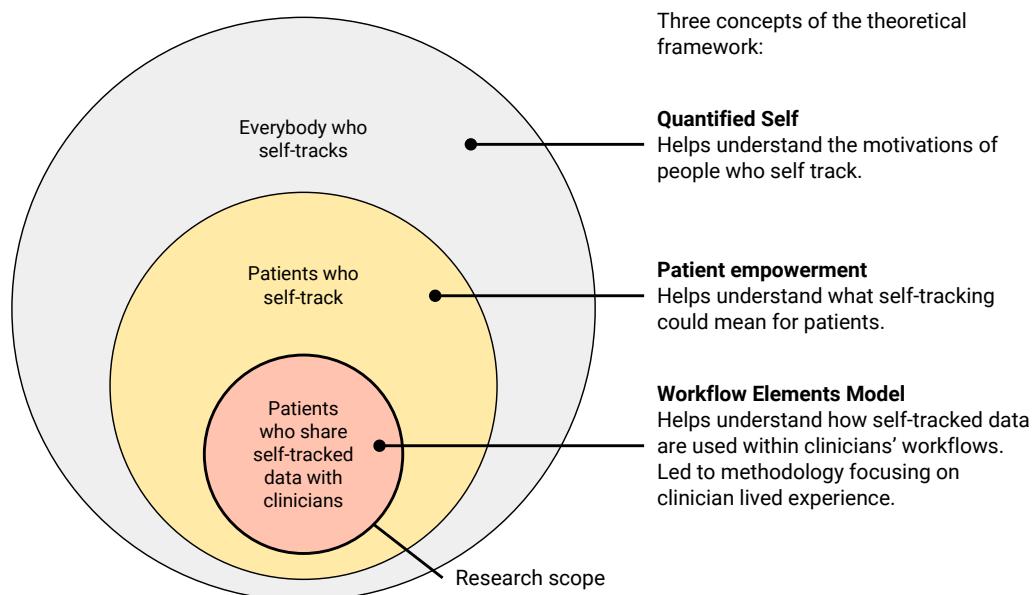
**Table 8.** Application of the workflow elements model (Unertl et al., 2012) to using self-tracked data in clinical settings.

	<b>Component</b>	<b>Description</b>	<b>Application to self-tracked data use</b>
<b>Pervasive</b>	context	workspace/organisational factors	clinical settings
	temporality	impact of time to tasks	time constraints of clinical consultation
	aggregation	relationships actors and tasks	patient empowerment; shared decision-making
<b>Specific</b>	actors	people performing actions	clinicians and patients
	artefacts	tools actors are using	self-tracked data
	actions	actions being performed	data interpretation; decision-making
	characteristics	characteristics of those actions	cooperative and risk-mitigating
	outcomes	products of the actions	improved mutual understanding

and interpreted them with respect to prior known information about the patient. Second, the clinician asked questions about the data, such as what the patient was doing during data collection, and goals were set for the patient. Third, the clinician would wait until the end of the consultation to enter the goals into the interface. The three phases involved conversing with the patient, which suggests that successful workflows for using self-tracked data will include doctor-patient collaboration. Mentis et al. (2017) observed doctors using Fitbit data recorded by patients, also revealing that the use of self-tracked data is a collaborative process, in which doctors and patients work towards a mutual understanding of the data.

The workflow elements model includes consideration of collaboration, cooperation, and conflict (Unertl et al., 2012). The *actors* in the workflow can thus be seen as both clinicians and patients cooperatively working to understand the self-tracked data (the *artefact*). Chung et al. (2016) propose such data act as a boundary artefact, where collaboration around shared information requires knowledge and expertise from both clinicians and patients, who may have different views. However, prior work has shown that clinical settings can be challenging environments for using information, with fragmented health information impeding efforts to interact and collaborate with information (Unruh et al., 2010).

When designing for a group of people, such as clinicians, understanding how those people work is critical for ensuring the designed artefact will be useful and safe. This thesis expands ‘workflow’ to include precursor events to the ‘use’ of self-tracked data, including making judgements on their quality and suitability for a given clinical situation. This builds on the work of Mentis et al. (2017) to contextualise doctor-patient collaboration in using self-tracked data as part of this workflow. The shared concerns of doctors and patients, such as mitigating risk (West et al., 2016) and engaging patients in their care (Mentis et al., 2017), could mean some workflow activities are common across clinical settings. Based on these studies, Table 8 documents the application of the workflow elements model to self-tracked data use. This will be the basis for understanding workflows throughout this thesis.



**Figure 10.** The theoretical framework comprised three concepts: The Quantified Self, patient empowerment, and the workflow elements model. Each concept helped understand problems of increasingly focused scope, from considering *everybody* who self-tracks, down to those who specifically share self-tracked data with their clinicians.

### 3.2 CONSTRUCTING THE THEORETICAL FRAMEWORK

To research the role of self-tracking in clinical settings, the concepts of the Quantified Self, patient empowerment, and workflow elements model were consolidated to form a theoretical framework. Figure 10 shows how each concept was used to understand increasingly focused problems, from considering *everybody* who self-tracks, to focusing only on those who share self-tracked data with their clinicians.

The first and broadest problem of this research was to understand the context of self-tracking, namely, who partakes in self-tracking and why. The *Quantified Self* helped to understand the motivations of those who engage in self-tracking and was crucial to establishing the research questions and scope. As this research began to focus on clinical environments, rather than self-tracking as a whole, it became important to focus on the motivations of patients specifically. *Patient empowerment* describes the movement of patients having greater roles and responsibilities in their care management, which helped to establish the role of patient empowerment in self-tracking, and, in turn, helped classify *quantified patients* as those who decide to self-track voluntarily or at the instruction of clinicians, representing a broad array of motivations for self-tracking.

While both the Quantified Self and patient empowerment helped to understand the practices of self-tracking, the research also needed an understanding of how clinicians would work with self-tracked data. The *workflow elements model* provided a way to study and understand the actors, artefacts, actions, characteristics, and outcomes of workflows. The workflow elements model, in consolidation with the Quantified Self and patient empowerment, therefore formed the backbone for understanding workflows throughout this thesis.

## 4 METHODOLOGY

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Self-tracked data could help personalise and improve healthcare, but it is largely unknown how such data could form part of clinicians' workflows. This chapter therefore sets out a procedure to investigate the three research questions defined in Chapter 1:

- RQ1. *What are the opportunities for and barriers to using self-tracked data in clinical settings?*
- RQ2. *What are the common workflows of clinicians when using self-tracked data?*
- RQ3. *What are the design needs of clinicians for using self-tracked data in clinical settings?*

This chapter first describes the philosophical approach behind this research. Then, a three-study procedure is outlined, comprising a systematic literature review, interviews, and a participatory design study.

### 4.1 PHILOSOPHICAL APPROACH

Three research philosophies pertain to this research: *participation*, which concerns the inclusion of subjects within the research; *empiricism*, which concerns the use of observation to understand what is true; and, *technological paradigms*, which concern the development of technologies. Each philosophy is described below with regard to their relevance in this research.

#### 4.1.1 Participation

A central aim of this research is to understand the lived experiences of clinicians when using self-tracked data. A dominant method for understanding people is the testing of hypotheses within an environment to observe the effects on people (Chalmers, 2013). However, there is a view that subjects of such conventional studies are frequently marginalised because the researcher – who is in charge – has the greatest power, limiting the voice and influence of subjects (Cornwall and Jewkes, 1995). Participatory research seeks to involve subjects as collaborators within the research to help provoke questions to ask and to guide the collection and analysis of data (Creswell, 2009). This democratises research, allowing both the researchers and subjects to influence research as equals, thereby advocating action for marginalised peoples (Guba, 1990). Cornwall and Jewkes (1995) explain that this participation balances the power between the researchers and subjects:

A primary step in the process of [participatory research] is creating spaces in which people can be 'empowered' to engage in a process through which they can identify and confront their problems. This may involve contracting people into exercises which facilitate reflection and analysis as a step towards collaboration, which may later evolve into more collegiate processes of mutual learning. – Cornwall and Jewkes (1995)

For researching healthcare technologies such as self-tracking, now may be a crucial time to ensure clinicians are empowered within research and technology design. There is a growing gap between what clinicians *need* from technology and what they *get* (Orlikowski, 1992). Clinicians' satisfaction with electronic medical records is falling, but the satisfaction amongst IT professionals is rising, showing that designers are possibly neglecting the needs of clinicians and causing a mismatch between the technology and their workflows (Shaha et al., 2015). Attempts by technology designers to improve the effectiveness of NHS information systems have resulted in difficult, poorly organised, and expensive technologies which remain under-used because designers failed to align the technology's design with clinicians' needs (Waterson, 2014). These systems have been expensive, running into millions (Bowers, 2006) or even billions (Syal, 2013) of pounds.

This growing gap between what clinicians need from technology and what they get has several possible causes. First, system designers may fail to recognise the organisational cultures of healthcare services by, for example, underestimating the complexity of healthcare workflows (Littlejohns et al., 2003). Second, healthcare services are customers to technology manufacturers, so designers aim to please the administrators and managers (who are seen to be the 'buyers') but neglect the needs of clinicians (Littlejohns et al., 2003). Third, the delivery of a cost-effective product is often prioritised above usability, leading to difficult-to-use information systems (Shaha et al., 2015). These circumstances may be exacerbated by recent economic conditions, where efficiency has been emphasised in the development of information systems (Kensing and Blomberg, 1998). Ironically, many decisions made to improve efficiency and reduce costs have contributed to the poor integration of technology within clinicians' work practices and, in turn, have reduced the efficiency of health services, increased costs, and created risks of patient harm (Shaha et al., 2015).

As a consequence, clinicians' interests have been neglected and clinicians have lost power over the development of information systems (Kensing and Blomberg, 1998). Without carefully considering clinicians' perspectives, introducing self-tracked data to healthcare could exhibit a comparable gap between technology and the needs of clinicians. Eliciting clinicians' concerns and experiences could reveal any risks to patient safety or potential disruptions that self-tracked data could cause (Neff and Nafus, 2016). Yet, while self-tracking tools have had substantial research focused on their benefits for *consumers*, there is little research focused on *clinicians'* perspectives (Neff and Nafus, 2016). Morris and Aguilera (2012) express urgency at involving clinicians in the development of self-tracking tools so the scientific community can better understand the relationship between such technology, patients, and clinicians.

A popular participatory approach is *participatory design*, which aims to empower subjects in the design and development of technological systems (Schuler and Namioka, 1993). Participatory design combines the views, input, and skills of workplace practitioners in design and decision-making processes (Computer Pro-

fessionals for Social Responsibility, 2005). It grew from a Scandinavian labour union movement for workers to have greater democratic power over their work environment (Abras et al., 2004), which nurtured a “human, creative, and effective relationship between technology and the human activities that provide technological systems with their reason for being” (Suchman, 1993). Participatory design has thus been viewed as a political movement away from the paternal power of technology designers, towards democratic cooperation of designers, users, and citizens (Abras et al., 2004). At the core of participatory design is the collaboration of designers and users within design workshops, which are meetings where open discussion and creativity is encouraged (Schuler and Namioka, 1993). When participatory design is applied within research (as it has been in Chapter 7 of this thesis), the researcher’s role is typically the designer, which reinforces the democratised power of participants to influence the research (Sanders, 2003).

Chapter 3 discussed notions of empowerment and democratisation with respect to patients and clinicians collaboratively using self-tracked data. With the growth in chronic illness and the technological ability for patients to self-track information, many patients are demanding greater influence in their health decisions; patients are becoming empowered (Holmström and Röing, 2010). Much like the empowerment of patients in healthcare decision-making, the empowerment of clinicians in design promises to provide meaningful insights by working towards a mutual understanding of the world (Chung et al., 2016). Indeed, prior work has found that involving workplace practitioners in design promotes idea generation and more innovative concepts (Mitchell et al., 2016). Including users within such designs ensures the final products are useful and usable, and mitigates potential dangers to patients which the designers alone may not have considered (Schuler and Namioka, 1993). Moreover, by involving clinicians in the design of a tool, this will go beyond just “asking users what they want” (Di Mascio et al., 2014) by allowing clinicians to express knowledge which they cannot put into words, such as routines and attitudes (Greenbaum and Madsen, 1993). Therefore, to understand the lived experiences of clinicians, a fundamental grounding of this thesis is the role of clinicians as participants and collaborators within the research.

#### 4.1.2 Empiricism

Empiricism is the foundation of science, comprising the formulation, testing, and modification of hypotheses by observation, measurement, and experimentation (Chalmers, 2013). Gaskell (2000) states that “empirical research methods derive from the application of observation and experience to a research question rather than being grounded in theory alone.” Knowledge in empiricism is *a posteriori*, that is, it is formed from experience (Markie, 2017). This is distinct from *a priori* knowledge, which is formed from reason and independent of experience, such as through mathematics (for example,  $3 + 1 = 4$ , or  $4 = 2 + 2$ ). Biologist Edward Wilson states that empiricism is important for generating objective knowledge and forms part of “the organised, systematic enterprise that gathers knowledge about the world and condenses the knowledge into testable laws and principles” (Wilson,

1999, p. 57). He proposes that empirical study ensures findings have several essential characteristics of scientific work. First, the work is *repeatable*, such that the experiments or observations may be made again. Second, the findings have *economy*, meaning the information is abstracted to its simplest form. Third, the findings are *measurable*, that is, measured using standards such that generalisations are unambiguous. Fourth, the work uses *heuristics* to provide additional tests for the principles used. Finally, the findings have *consilience*, meaning they are consistent with other scientific explanations.

The aim of this research was to understand how self-tracked data may be used within clinical settings. While there is intense scientific research on understanding how consumers of self-tracking tools can monitor their own health (von Entress-Fürsteneck et al., 2016) and how self-tracking can be technologically achieved (Chu and Lin, 2017), there are few studies which focus on *clinicians'* experiences of using these forms of data (Neff and Nafus, 2016). There was therefore insufficient theory to form *a priori* knowledge of how clinicians would conduct their work with self-tracked data on a day-to-day basis. With insufficient theory, rational deduction of how clinicians use these data was likely to produce a flawed understanding because it would not encapsulate the experiences of clinicians in their work settings. For instance, consider an app for managing diet which shows daily calorie intake as a line chart. A consumer wishes to lose weight, and their doctor is trying to offer guidance based on data collected by the app. A design rule for such an app might be to keep the chart simple so the consumer can understand it without training; in common software engineering vernacular, this heuristic is known as “keep it simple, stupid” (Lampson, 1983). If it were deduced that tools for clinicians should follow this heuristic, it is likely these tools will be oversimplified. Such oversimplifications have led to real-world challenges with using electronic medical records (Jenkins and Wilson, 2007).

Therefore, this work focused on generating *a posteriori* knowledge from the empirical study of clinicians' experiences with self-tracked data. Specifically, this work emphasised the importance of understanding their *lived experiences*, because these reflect their experiences in everyday work settings. The methods used within this research are *qualitative*, which means clinicians' behaviours and workflows will be observed to describe phenomena within how they work (Pope et al., 2000). Qualitative methods comprise the continual reflection about and interpretation of the relationships between people and artefacts in the participants' settings (Creswell, 2009). Typically, research data are collected as text or images through methods such as interviews and then analysed using *thematic coding*, where themes are identified within the data and interrelated to deduce an understanding of the research problem (Creswell, 2009). For example, thematic coding of interview transcripts may reveal a set order of activities in which participants engage, revealing a narrative for the research problem.

Thematic coding was applied to interview and workshop transcripts throughout this research for identifying narratives of clinician work practices. Because

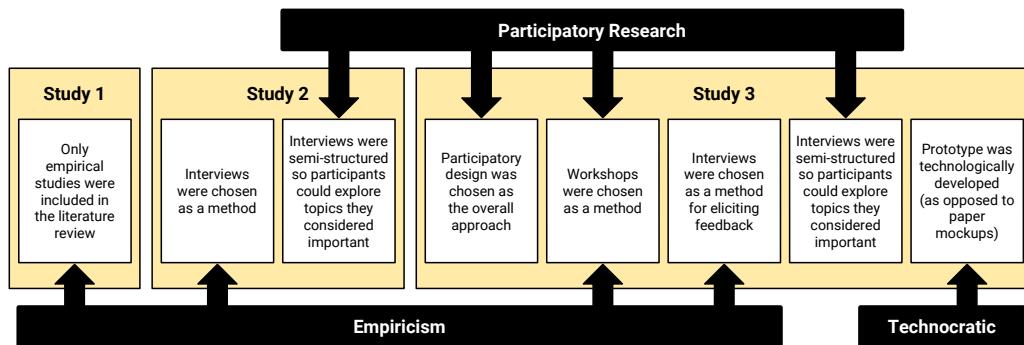
coding is interpretive, my background in computer science could have led to a bias in favour of technological solutions when interpreting research data. Chapter 2 discussed several healthcare technology failures, each with causes relating to the designer's failure to consider the needs of users. For this reason, the codes which I interpreted were fed back into the participatory design approach through implementing feature artefacts and prototypes, which allowed clinicians to provide feedback on my interpretations of their problems.

#### 4.1.3 Technological Paradigms

This research views technology through two paradigms: *technocratic* and *scientific*. A paradigm is a distinct philosophy to conducting research comprising “a basic set of beliefs that guide action” (Guba, 1990). The technocratic paradigm views computer science is a branch of engineering, rather than science (Eden, 2007). This is in contrast to the scientific paradigm of computer science, in which knowledge about how computers behave is sought through formal deduction and scientific experimentation (Dodig-Crnkovic, 2002). The technocratic approach to software design and development is common while scientific endeavours rarely take place within the software development (Eden, 2007). This reflects that the training of computer scientists has historically been closer to that of engineers than scientists (Pressman, 2005). New digital technologies, such as self-tracking tools, have therefore mostly been understood from a technical point of view and have been elusive to other disciplines (Halford et al., 2013). Describing the technocratic paradigm, Eden (2007) states:

Computer science is a branch of engineering which is concerned primarily with manufacturing reliable computing systems, a quality determined by methods of established engineering such as reliability testing and obtained by means of a regimented development and testing process. – Eden (2007)

Consequently, early models of software development used engineering approaches to project management, comprising several sequential stages: a *requirements* stage where stakeholders are met to establish their needs, a *design* stage to plan the software architecture, an *implementation* stage to program the software, a *verification* stage to test the software, and a *maintenance* stage which serves as a commitment to ensure the software continues to operate correctly. Typically, stakeholders would only be extensively involved at the start of the project during the *requirements* stage (Bell and Thayer, 1976). This means that adequate testing during the *verification* phase is essential to ensuring software fulfils the needs of the stakeholders. This normally involves testing suites which repeatedly execute small parts of the program and compare the output with the expected output, in turn generating statistical data to measure the product’s efficacy (Pressman, 2005). A parallel can be drawn between the empirical approach to gaining *a posteriori* knowledge about the world through experience, and the technocratic approach to gaining *a posteriori* knowledge about software through testing (Newell and Simon, 1976). While this research favoured a participatory approach, the technocratic paradigm influenced the technological approach within the participatory design process. Software



**Figure 11.** Adopting participatory research, empiricism, and technocratic paradigms led to several decisions in the design of each study. The arrows indicate how each philosophy led to decisions within each study; for example, embracing participatory research led to the decision to use participatory design as the overall approach to Study 3.

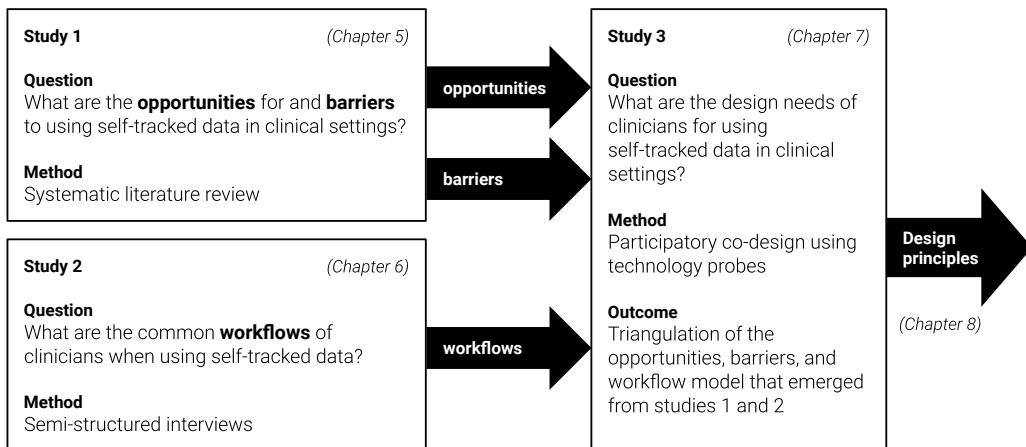
artefacts and prototypes were tested by having clinicians use them, generating *a posteriori* knowledge about how the software fulfils its objectives and helping to understand how clinicians work with self-tracked data.

#### 4.1.4 Subsequent Methodological Decisions

Adopting the aforementioned philosophical approaches led to several decisions in designing the research approach design, as illustrated in Figure 11. Participation was a central philosophy and shaped the methods used in studies 2 and 3. In both studies, semi-structured interviews were used as a research method, which permitted the researcher or participant to probe topics most important within the context of the unique lived experiences of that participant (Louise Barriball and While, 1994). In Study 3, participatory design was used as a research method to reach a mutual understanding between the participants and researcher. By having participants engage in the design process as equals with the researcher, the study could generate findings representative of the participants' lived experiences. Empiricism was adopted to ensure this research resulted in findings which describe phenomena with truth and reliability. For Study 1 (systematic literature review), only papers which reported empirical studies were included. Studies 2 and 3 used interviews and workshops, in which participants were empirically observed in responding to questions and interaction with artefacts. Finally, the technocratic principle motivated the mockups developed in Study 3 to be developed into a technological tool, thus generating new knowledge about how the tool could be used by clinicians in their work practices.

## 4.2 OVERVIEW OF RESEARCH APPROACH

This research focuses on three research questions with each requiring a bespoke research method, as shown in Figure 12. These methods are briefly described below, with more in-depth descriptions provided in later chapters. Each of the three studies carried through the knowledge gained in the previous study, which has been a fundamental concept within recent participatory design research (Clemensen et al., 2016). For example, in the participatory design of a clinical intervention for



**Figure 12.** The research approach comprised three studies, each building on the outcomes of the last. The research draws on these studies to construct a set of principles for designing self-tracking tools for clinical use.

foot ulcers, Clemensen et al. (2016) described a process where “each step in the process was planned according to the results and ideas that were created during the former activity.”

#### 4.2.1 Study 1: Systematic Literature Review

The first study aimed to address RQ1: *What are the opportunities for and barriers to using self-tracked data in clinical settings?* A systematic literature review was conducted in which prior studies of self-tracking technologies were reviewed to identify current opportunities and barriers for using self-tracked data in clinical settings. Chapter 5 details the systematic literature review approach and findings.

#### 4.2.2 Study 2: Interviews

The second study aimed to address RQ2: *What are the common workflows of clinicians when using self-tracked data?* Thirteen clinicians of diverse roles were interviewed about their experiences with and perceived uses of self-tracked data. These semi-structured interviews were structured around high-level questions to elicit insights into the kinds of clinical settings in which self-tracked data may be useful and how they might be used, thereby providing new evidence for an improved understanding of the opportunities and barriers for self-tracked data among a diverse range of clinical settings. By interviewing clinicians directly, the findings reflect the clinicians’ lived experiences, which is crucial for understanding how self-tracked data would realistically be used in real clinical settings (Manen, 1990). Chapter 6 describes the protocol and findings for this study.

#### 4.2.3 Study 3: Participatory Design

The third study aimed to address RQ3: *What are the design needs of clinicians for using self-tracked data in clinical settings?* As described in Section 4.1.1, the participation of clinicians was important for understanding their design needs. Thus, a participatory design method was used to probe this question, which comprised mockup workshops in which clinicians engaged in designing a technology probe

for using self-tracked data in clinical settings. The findings from the participatory design helped triangulate the opportunities, barriers, and workflow model identified in the prior studies. Chapter 7 describes the protocol and findings for this study.

#### 4.3 ETHICAL CONSIDERATIONS

The interviews and workshops involved human participants, so ethical considerations were made before conducting these studies. The University of Southampton ethics board approved the studies under ERGO number 22500. This project had no significant risks; the subject matter and data collected were not sensitive so posed little impact in the event of an incident during this study. The prototype created in the participatory design process served as an artefact for engaging participants in discussion and will not be integrated into clinical practice and does not constitute a medical device. Any ‘patient’ data presented to participants for the purpose of demonstrating the tools were synthetic and not real patients’ data. Potential participants were provided with an information sheet describing the studies (Appendix A), and only those who signed a consent form (Appendix B) took place in the studies. Pseudonyms were used to identify participants in data. Participants were audio recorded and were asked to not reveal any personally identifiable information about themselves or others. Only my supervisors and I have access to the recordings and transcripts.

## 5 OPPORTUNITIES AND BARRIERS FOR SELF-TRACKED DATA

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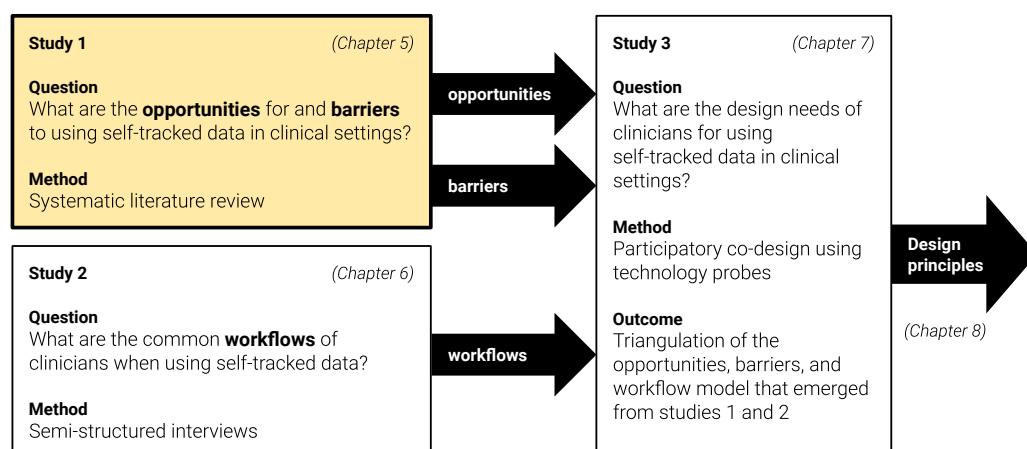
This chapter details a systematic review of empirical studies around self-tracking. As illustrated in Figure 13, the purpose of this review was to address the first research question: *what are the opportunities for and barriers to using self-tracked data in clinical settings?* This chapter begins by describing the method used and follows by presenting the findings in two areas: opportunities and barriers. The findings in this chapter have been published in the *Frontiers Journal of Public Health* (West et al., 2017).

### 5.1 METHOD: SYSTEMATIC LITERATURE REVIEW

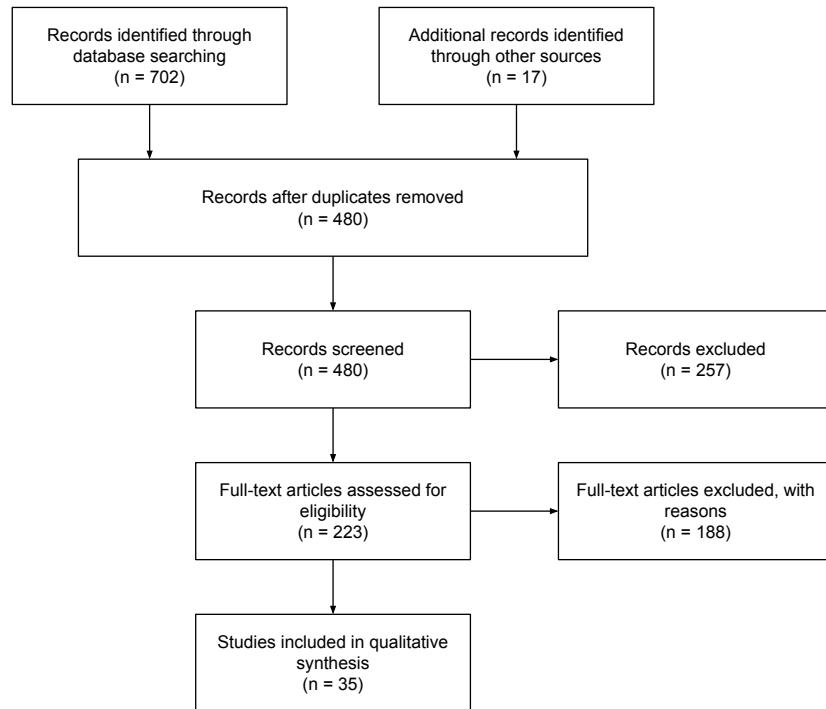
The systematic review was guided by the *Preferred Reporting Items for Systematic Reviews and Meta-Analysis* (PRISMA), which dictates an evidence-based procedure and audit trail for conducting literature reviews (Moher et al., 2009). Figure 14 illustrates the order in which work was conducted. First, databases of publications (*records*) were searched, and resulting records were combined with other known records. Duplicates and records not conforming to the inclusion criteria were then removed. This section describes these stages in detail.

#### 5.1.1 Literature Search Strategy

Because this research spanned multiple disciplines, including health science and computer science, a variety of databases of high-quality journals and conferences were searched (see Table 9). A search query was constructed around self-tracking in clinical scenarios, shown in Figure 15. The query included synonyms for *self-tracked data*, such as *life-logging*, *quantified self*, and *patient-generated health data*. The query used wild-cards to match similar words (for example, *track\** matches tracked and tracking) and Boolean operators to constrain results to records with sufficient



**Figure 13.** Study 1 focused on identifying the opportunities and barriers for using self-tracked data in clinical settings.



**Figure 14.** The procedure of the literature review illustrated as a PRISMA flow chart (Moher et al., 2009), with the number of records at each stage.

```

(
  "clinic*" OR
  "medic*" OR
  "physician*" OR
  "health professional*" OR
  "doctor*" OR
  "*care professional*" OR
  "provider*"
)
AND
(
  "self track*" OR
  "self quant*" OR
  "activity track*" OR
  "lfc log*" OR
  "lifelog*" OR
  "quantified self" OR
  "quantified patient*" OR
  "patient generated data" OR
  "patient generated health data" OR
  "consumer wearable"
)
AND
(
  "study" OR
  "interview*" OR
  "observ*" OR
  "role-play" OR
  "perspectives"
)
  
```

} Papers must be related to *clinical* use of self-tracked data

} Papers must relate to *self-tracking* and related concepts

} Papers must use *empirical* methods which capture clinicians' lived experiences

**Figure 15.** Search query used for the systematic review. The first component specifies that papers must relate to clinicians' use of self-tracked data, the second component specifies that papers must relate to self-tracking, and the third component restricts results to those that use empirical methods.

**Table 9.** Databases searched for the review of empirical studies of self-tracking in clinical settings.

Database	Discipline	Records
JSTOR	Multidisciplinary	12
EBSCOhost (MEDLINE)	Medicine	129
PubMed	Medicine	15
Web of Science	Multidisciplinary	151
Scopus	Multidisciplinary	426
ACM DL	Computing	40
<b>Total</b>		702

relevant terms. The search yielded 702 results across all databases. A further 17 were added to the sample from prior background reading, leading to a total of 719 records. After removal of duplicates, 480 records remained.

### 5.1.2 Inclusion Criteria

Records were included based on the following criteria:

1. *The work must represent original empirical work.* This excluded opinion pieces, literature surveys, and papers which re-reported results of already published studies.
2. *The article must have been peer-reviewed.* This excluded accounts of self-experimentation and studies lacking scientific rigour such as those found on blogs (Roberts, 2011).
3. *The subject matter must pertain to data collection by a person using consumer or personal tools.* This included wearable fitness trackers, mobile apps, and paper diaries but excluded telemonitoring, implantable devices, and other forms of data or technology used in clinical settings. Studies relating to patient-reported outcomes were also excluded, as these data were usually retrospective forms of information gathering (Stull et al., 2009), rather than pervasive self-tracking.
4. *Findings must pertain to clinicians' perspectives of using self-tracked data.* The review focused only on studies in which clinicians accessed, used, or otherwise interacted with self-tracked data. This excluded papers solely concerned with self-tracking for self-reflection or self-improvement because these only pertained to the person who was self-tracking. Studies about using self-tracking for research or 'big data' and the efficacy of self-tracking tools were excluded as these did not relate to clinicians' perspectives.

The title and abstract for each paper were read to check conformance to these criteria, resulting in thirty-five papers. Of the papers excluded, 140 did not consider clinicians' perspectives, 33 were not empirical, 11 did not pertain to patient self-tracking, and three concerned big data only.

A subset of ten random studies (28.6%) were independently re-assessed for eligibility by two additional researchers and compared for agreement. A percent agreement of eligibility was then calculated.

### 5.1.3 Critical Appraisal of Quality

A sample of ten papers (28.6%) which met the inclusion criteria were critically appraised by two independent reviewers using the *Joanna Briggs Institute Qualitative Assessment and Review Instrument* (JBI-QARI). The instrument comprises a checklist for assessing studies against their methodological quality and mitigation of bias in study design, conduct, and data analysis (Lockwood et al., 2015). A comparison of appraisal instruments by Hannes et al. (2010) found JBI-QARI particularly well suited to qualitative studies, which made it an appropriate instrument for this systematic review.

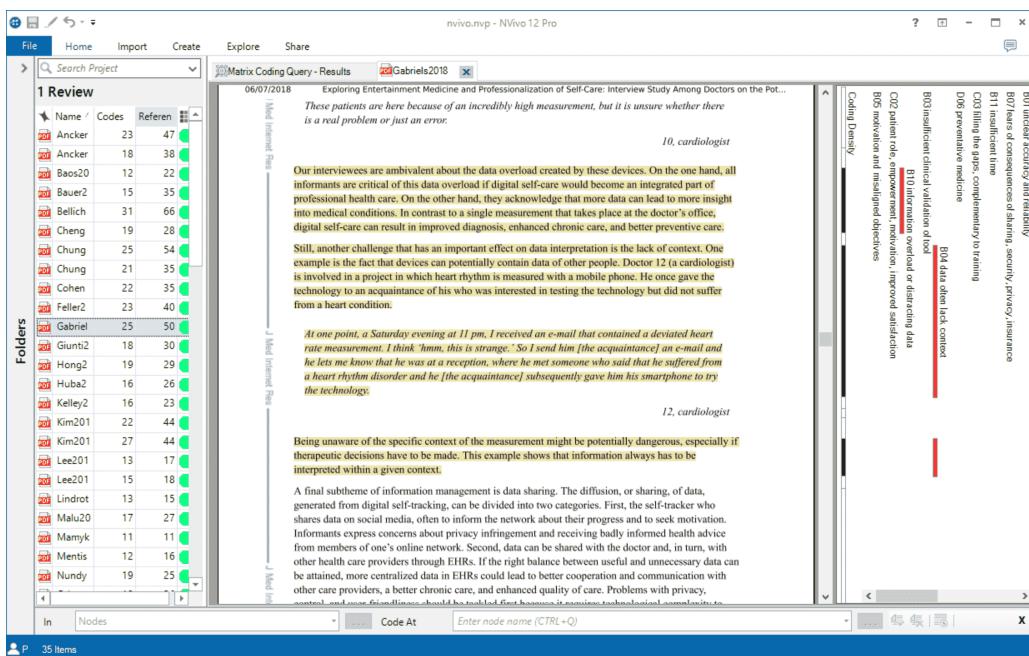
To ensure that the sample of papers reflected a broad range of publication sources – including computer science conferences and health science journals – a maximum variation sampling technique was used, where reviewers picked studies with the aim of ensuring a diverse sample (Palinkas et al., 2015). This was used instead of a random sample, which would have likely favoured the CHI conference and JMIR journal which dominated the field. The reviewers independently checked each paper against the JBI-QARI checklist. Disagreements were resolved through discussion, and where it was not possible to resolve, the criterion response was marked ‘unclear’.

Whilst the JBI-QARI checklist is used by other studies (Koh et al., 2011) as a means of study inclusion, this review opted not to include papers on the basis of the checklist because of the need to include formative work. Inclusion of such formative work ensured that the studies encompassed a broad range of clinical contexts. Instead, the critical appraisal afforded an understanding of the quality of studies which was used to contextualise the data analysis.

### 5.1.4 Data Analysis

The manuscripts were read to identify and tabulate clinical setting, study rationale, methods, and key conclusions from each article on self-tracking in clinical settings. The manuscripts were then thematically coded to identify common themes in the literature. Among these themes, several opportunities for self-tracked data and barriers to their use emerged. Themes were iterated and consolidated into two sets: opportunities and barriers. Coding was accomplished using the qualitative analysis software package NVivo 12, which allows the coding of digital articles and analysis of those codes (see Figure 16).

A subset of ten random studies (28.6%) were independently re-analysed for themes by two additional researchers. Themes were collaboratively contrasted and compared to identify equivalence and calculate an agreement rating. Disagreements were resolved with discussion.



**Figure 16.** NVivo 12 was used to code digital articles and analyse codes. This screenshot shows an article under analysis, with noteworthy parts of the text highlighted. The map on the right shows codes corresponding to highlighted text. The list of articles with coding statistics is shown on the left.

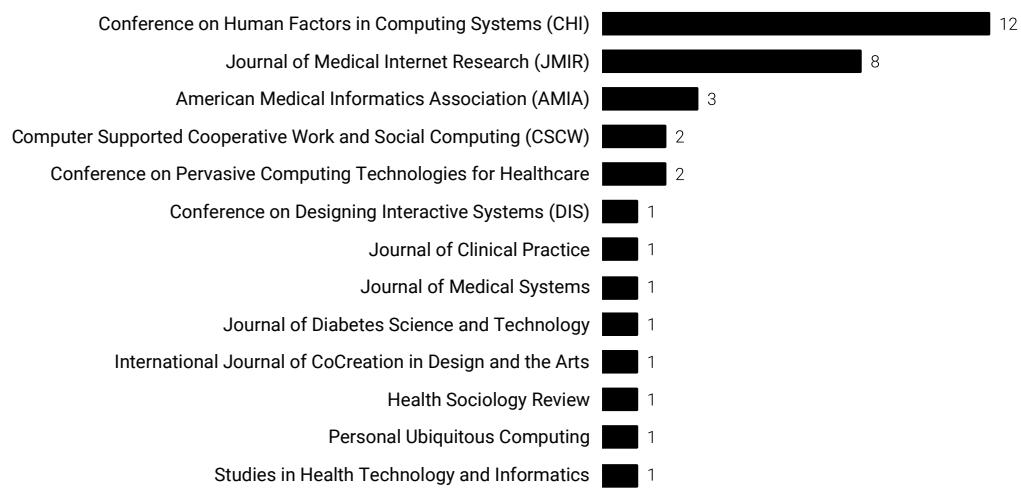
## 5.2 OVERVIEW OF REVIEWED STUDIES

Following study selection, re-assessment for eligibility by two reviewers yielded a 90 per cent agreement rate (nine of the ten papers). The reviewers had differing opinions on the inclusion of Bauer et al. (2018), whose study methodology primarily focused on the development of an app rather than eliciting the perspectives of clinicians. The reviewers resolved to keep the study because it presented clinician perspective as a secondary finding. Thirty-five studies were taken forward for analysis.

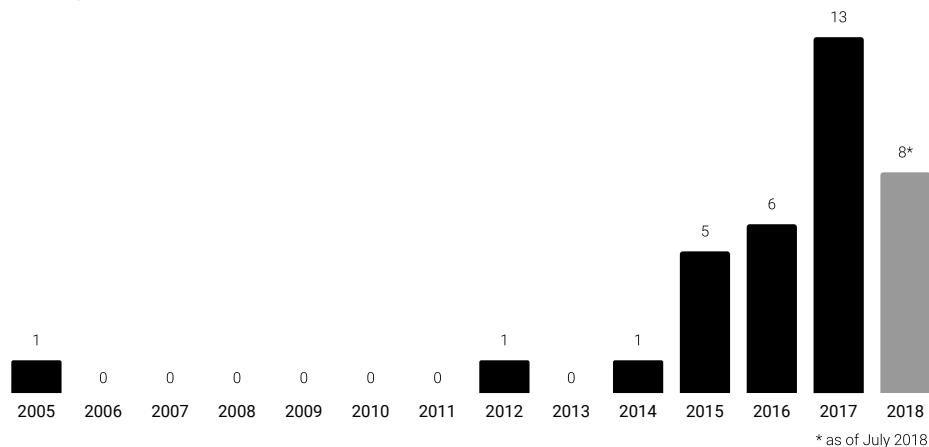
While most studies focused on managing long-term conditions, such as heart failure and breast cancer, other studies focused on using self-tracked data in disease prevention and hospitalisation, demonstrating a broad scope for applying self-tracked data within clinical care. Studies argued the importance of bespoke self-tracking tools, including for identifying triggers of irritable bowel syndrome (Chung et al., 2015, 2016), for managing multiple chronic conditions (Ancker et al., 2015a,b), for monitoring itching conditions (Lee and Hong, 2017), for managing Parkinson's (Mentis et al., 2017), and for promoting healthy sleeping (Ravichandran et al., 2017; Vandenbergh and Geerts, 2015). These studies used a variety of qualitative methods to capture clinician perspectives of self-tracked data, including interviews, surveys, and field observations. The number of participants in many of the studies was small (often between two and four participants). Nevertheless, the outcomes of those studies are considered in this chapter against their methodological limitations.

Of the 35 included studies, 18 were published in peer-reviewed journals and 17 were published in peer-reviewed conference proceedings. Over half of the studies ( $n=20$ ) were published in two publications: twelve in the *Conference on Human Factors in Computer Systems* and eight in the *Journal of Medical Internet Research* (see Figure 17). These two publications encourage interdisciplinary work around health and technology. The number of studies around self-tracked data has increased by year, particularly within the last two years (see in Figure 18). The earliest study was published in 2005 while most ( $n=21$ ) were published in 2017 and 2018. Every study was conducted within developed countries; about a third ( $n=23$ ) in the US, and only one in the UK (see Figure 19). The findings of this review are therefore likely to show a bias towards the work practices of health services in the US, which is likely to have practices which differ to other countries (for example, fear of personal litigation is more prevalent in the US than the UK).

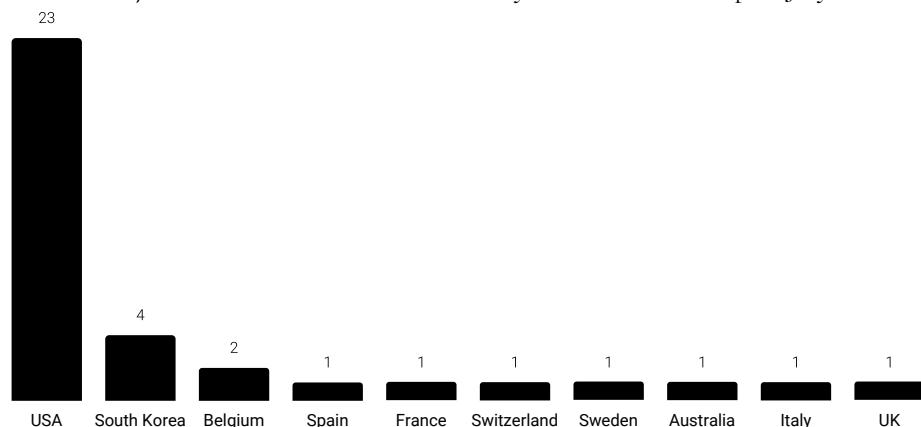
Most studies had reasonable conformance with JBI-QARI (see Table 10), but certain checklist criteria failed on most papers. For example, very few papers fulfil the criteria "there is a statement locating the researcher culturally". This is possibly because many papers were from computer science and the checklist targets health science where there is a greater responsibility for reporting ethics and validation (Lockwood et al., 2015). Applying the checklist as a inclusion criteria of papers could have eliminated many papers from Computer Science, which would



**Figure 17.** Number of studies included in the systematic review per publication. Over half of the studies ( $n=20$ ) were published in two publications: *Conference on Human Factors in Computer Systems* ( $n=12$ ) and *Journal of Medical Internet Research* ( $n=8$ ).



**Figure 18.** Number of studies included in the systematic review per year. Most studies were published in 2017 and 2018. The value for 2018 only includes studies up to July 2018.



**Figure 19.** Number of studies included in the systematic review per country. Most studies were conducted within the USA, and all were conducted within developed countries.

**Table 10.** Conformance of the sample of studies to the JB-QARI checklist. Ticks (✓) indicate that reviewers agreed the study conformed to the criterion and crosses (✗) indicate that reviewers agreed the study did *not* conform to the criterion. Question marks (?) indicate that the reviewers could not come to an agreement.

Checklist question	Ancker et al. (2015a)	Bauer et al. (2018)	Chung et al. (2015)	Hong et al. (2018)	Mamykina et al. (2016)	Mentis et al. (2017)	Nundy et al. (2014)	Piras and Miele (2017)	Wallace et al. (2017)	Zhu et al. (2016)
1. There is congruity between the stated philosophical perspective and the research methodology	✓	✓	✓	✓	?	✓	✓	✓	✓	✓
2. There is congruity between the research methodology and the research question or objectives	✓	?	✓	✓	?	✓	✓	✓	✓	✓
3. There is congruity between the research methodology and the methods used to collect data	✓	✗	✓	✓	✗	✓	✓	✓	✗	✓
4. There is congruity between the research methodology and the representation and analysis of data	✓	?	✓	✓	?	✓	✓	✓	✗	✓
5. There is congruity between the research methodology and the interpretation of results	✓	✗	✓	✓	?	✓	✓	✓	✓	✓
6. There is a statement locating the researcher culturally or theoretically	✓	✓	✗	✗	✓	✗	✓	✗	✗	✗
7. The influence of the researcher on the research, and vice-versa, addressed	✗	✗	✗	✗	✓	✗	✗	✗	✗	✗
8. Participants, and their voices, are adequately represented	✓	✗	✓	✓	✗	✓	✓	✓	✗	✓
9. The research is ethical according to current criteria or, for recent studies, there is evidence of ethical approval by an appropriate body	✓	✗	✗	✓	✓	✓	✓	✓	✗	✓
10. Conclusions drawn in the research report flow from the analysis, or interpretation, of the data	✓	✓	✓	✓	✓	✓	✓	✓	✗	✓

have been unacceptable in this interdisciplinary study (Williams et al., 2019). As described by Williams et al. (2019):

In the case of qualitative research, checklists offer only a blunt and arguably ineffective tool and potentially promote an incomplete understanding of good ‘quality’ in qualitative research. Current framework methods do not take into account how concepts differ in their application across the variety of qualitative approaches and, like checklists, they also do not differentiate between different qualitative methodologies. – Williams et al. (2019)

The findings from the checklist are therefore only indicative of the quality according to conventional health science methodology (Lockwood et al., 2015). Despite this, the checklist affords an understanding of the overall quality of research around patient-generated health data. In particular, within much of the current literature there is clear congruity between philosophical perspectives and the research methodology. This perhaps because computer science venues such as CHI and health science venues such as JMIR are consistent in expecting methodologies backed up by prior work.

The pitfalls of studies tended to pertain to methodological design. For example, Wallace et al. (2017) performed poorly within the checklist because it was reporting preliminary work in an ‘extended abstract’ format, which required less detail about the methodological design and ethical approval process. Despite this, the paper still offers formative work into PGHD in the context of sleep, and was thus considered important to keep. For another study, Bauer et al. (2018), the two reviewers found the results unclear and were unable to agree on whether the paper had congruity between the research objective, methodology, and analysis of data. This paper focused on the development of an app in the context of a clinical trial, and elicitation of clinician perspectives on PGHD appeared to be a secondary objective. Similarly, the study by Mamykina et al. (2016) appeared to elicit clinician perspectives as a secondary objective, which did not align with the methodological design.

While the studies did cover a broad range of clinical work settings, such as irritable bowel syndrome and heart failure, they typically had only a few perspectives from a small number of clinicians and rarely compared self-tracked data use over different clinical settings. There are many clinical work settings which were not reflected in the findings, so the findings will not necessarily apply to clinical settings not considered. Additionally, the sparsity of high quality studies limits the generalisability of this review and prevented any quantitative analysis of findings. This reflects a need for new empirical work which includes clinicians from different roles. With the field of PGHD rapidly expanding, higher quality studies are likely to rapidly emerge, enabling a deeper systematic review in the future.

Overleaf, Table 5.2 lists each included study with their characteristics and outcomes.

**Table II.** Results of systematic review of empirical studies in clinical settings. The clinical context, country, methods, participants, focus, and outcomes are listed for each study.

Reference	Clinical context	Country	Methods	Clinical participants	n	Focus	Relevant outcomes
Ancker et al. (2015a)	multiple chronic conditions	USA	Interviews	nurse practitioners, internists, family doctors, ER doctors	7	Self-management using electronic or paper methods	Suspicions of patient's concealing data; difficult to share information; self-tracking perceived as invisible work; missing information contributes to medical errors
Ancker et al. (2015b)	multiple chronic conditions	USA	Interviews	nurse practitioners, internists, family doctors, ER doctors	7	Self-management using electronic or paper methods	Self-tracking seen as obsessive; self-tracking reminded patients of illness; clinical data trusted over self-tracked data
Baos et al. (2005)	migraine	Spain	Surveys	primary care physicians	22	Structured migraine diary completed by the patient	Deepens doctor patient communication; improved patient satisfaction
Bauer et al. (2018)	PTSD, bipolar disorder	USA	Interviews	care managers	5	SPIRIT mobile app	Technology may not be accessible to non-tech-savvy or less-well-resourced people
Bellicha et al. (2017)	obesity, type-2 diabetes, hypertension	France	Interviews	senior physicians	11	Electronic activity trackers	Unclear about the clinical validity of tech; insufficient time to use data; information overload; improves patient education
Cheng et al. (2015)	high-risk infants	USA	Interviews, observation	paediatric health specialists, community paediatricians, clinicians	15	Estrellita mobile system for collecting data about pre-term infants	Self-tracked data creates liability for the doctor; difficulty finding appropriate medical staff willing to use self-tracked data
Chung et al. (2015)	IBS, obesity	USA	Interviews	physicians, nurses, dietitians	21	Mood diaries, MyFitnessPal, Fitbit	Bridges the gaps between consultations; encourages communication; patients may track wrong data
Chung et al. (2016)	IBS, obesity	USA	Interviews	physicians, nurses, dietitians	21	Self-management using paper, excel, and other self-tracking methods	Encourages doctor patient relationship; bridges gaps between consultations; concerns about patient's motives to self-track
Cohen et al. (2016)	asthma, overweight, Crohn disease, primary care	USA	Interviews	primary care physicians, nurses	12	Smart devices and consumer tech	Patients are empowered; bridges gaps between consultations; data presentation needs to be flexible
Feller et al. (2018)	type-2 diabetes	USA	Participatory design, interviews	dietitians	10	Clinicians perspectives on Glucolyzer, a system for analysing glycaemic response	Encourages doctor-patient relationship; empowers patients; bridges gaps between visits; time/skill needed to interpret data
Gabriels and Moerenhout (2018)	cardiology	Belgium	Interviews	general practitioners	12	Digital self-tracking for enhancing self-care	Patients are empowered; bridges gaps between consultations; concerns about patient's motives to self-track; difficult to identify high quality data

(Continues overleaf)

Reference	Clinical context	Country	Methods	Clinical participants	n	Focus	Relevant outcomes
Giunti et al. (2018)	multiple sclerosis	Switzerland	Focus groups, interviews	physicians, physiotherapists, occupational therapists, sports therapists	12	Apps for physical therapy	Encourages doctor patient relationship; bridges gaps between consultations; concerns about insurers accessing information
Hong et al. (2018)	paediatric oncology	USA	Participatory design, interviews	oncologists, nurse practitioners	11	Symptom tracking via mobile phones	Bridges gaps between consultations; concerns about patient's motives to self-track
Huba and Zhang (2012)	emergency care, primary care, physical therapy, geriatrics	USA	Interviews	hospital doctors, private practitioners, pharmacists, alternative medicine providers	21	Working with self-tracked data from word processors and on paper	Clinicians from different specialisms need data presentations which support their workflow
Kelley et al. (2017)	mental wellness	USA	Focus groups	psychiatrists, primary care, women's health, and health promotion doctors	14	Mobile health apps, wearable devices, and paper journals	Time constraints to using data; concerns about provenance
Kim et al. (2016)	dieting	South Korea	Interviews, observations	internists, otorhinolaryngologist, family doctors, obstetricians, gynaecologists, rehabilitation doctors	6	Perspectives on a clinician web interface for analysing food data	Encourages doctor patient relationship; patients are empowered; bridges gaps between consultations
Kim et al. (2017)	sleep management, chronic condition management	South Korea	User-centred design, interviews, surveys	otorhinolaryngologist, family doctor, rehabilitation specialists, urologists	4	Misfit device, which logs steps and sleep data	Doctor and patient collaborate to interpret information; concerns about patient's motives to self-track
Lee and Hong (2017)	mental health	South Korea	Interviews	mental health experts	3	MindTracker approach, which uses tangible interaction and clay for tracking emotion	Encourages doctor patient relationship; bridges gaps between consultations
Lee et al. (2017)	itching	South Korea	Interviews	dermatologists	2	Wearable for monitoring itching	Encourages doctor patient relationship; bridges gaps between consultations
Lindroth et al. (2018)	cancer rehabilitation	Sweden	Interviews, observations	nurses	4	Mobile app for patients to self-report their symptoms	Encourages doctor patient relationship; patients are empowered; bridges gaps between consultations
Malu and Findlater (2017)	mobility impairment	USA	Interviews	therapists	10	Wearables and exergames for health and fitness	Patients are empowered; bridges gaps between consultations; concerns about patient's motives to self-track
Mamykina et al. (2016)	diabetes (type 1 and 2)	USA	Interviews	experienced diabetes educators	2	Printed or on-screen charts	Bridges gaps between consultations
Mentis et al. (2017)	Parkinson's	USA	Interviews, observations	neurologists	2	Activity trackers	Encourages doctor patient relationship

(Continues overleaf)

Reference	Clinical context	Country	Methods	Clinical participants	n	Focus	Relevant outcomes
Nundy et al. (2014)	diabetes, primary care	USA	Survey, interviews	primary care physicians, endocrinologists	12	Mobile technologies for diabetes	Encourages doctor patient relationship; patients are empowered; bridges gaps between consultations; concerns about patient's motives to self-track
Orlowski et al. (2018)	mental health	Australia	Participatory design, interviews	mental health nurses, social workers, psychologist	8	Mobile technologies for mental well-being	Patients are empowered; bridges gaps between consultations; concerns about patient's motives to self-track
Piras and Miele (2017)	type-1 diabetes	Italy	Interviews	paediatrician, diabetes doctors, diabetes nurses	6	Clinician-pushed self-tracking	Educes patients; bridges gaps between consultations; concerns about patient's motives to self-track
Raj et al. (2017)	paediatric diabetes	USA	Interviews, focus groups, observations	paediatrician, diabetes educators, endocrinologists	8	Paper logs and self-created visualisations	Encourages doctor patient relationship; concerns about patient's motives to self-track
Ravichandran et al. (2017)	sleep management	USA	Interviews	sleep experts	5	Sleep sensors	Patients are empowered; bridges gaps between consultations
Schroeder et al. (2017)	irritable bowel syndrome	USA	Interviews	IBS specialists	10	Food and symptom journal	Encourages doctor patient relationship, patients are empowered
Schroeder et al. (2018)	migraine	USA	Interviews	family doctors, headache clinic nurses, primary care doctors	6	Paper journals and patient-created spreadsheets	Encourages doctor patient relationship; patients are empowered; bridges gaps between consultations
Vandenberghhe and Geerts (2015)	sleep management	Belgium	Interviews, observations	sleep experts	8	Wakemate, which monitors sleep patterns	Encourages doctor patient relationship; poor interoperability
Wallace et al. (2017)	sleep management	USA	Survey, user study	sleep experts	3	SleepCoacher, a mobile app	Encourages doctor patient relationship; bridges gaps between consultations
West et al. (2016)	hospital, primary care	UK and USA	Interviews	general practitioners, hospital specialists	10	Printed charts	Simulates doctor patient communication; concerns about patient's motives to self-track; concerns about data quality
Zhu et al. (2016)	physical therapy, primary care	USA	Interviews	physical therapists, internists, primary care doctors, psychologists, paediatric nephrologists	9	Paper and technology based tracking	Encourages doctor patient relationship; concerns about patient's motives to self-track
Zhu et al. (2017)	mental health	USA	Interviews, observations	psychologists, psychotherapists, counsellors, occupational therapists	10	Paper and technology based sleep diaries	Empowers patients; allows remote monitoring

Initial thematic analysis of the studies resulted in nineteen themes comprising seven opportunities and twelve barriers. Re-assessment of these themes by two independent reviewers across a sample of ten papers yielded agreement of 84 per cent (16 of 19 themes). The reviewers disagreed on the opportunities *Patient Empowerment* and *Patient Education*, and on the barrier *Misaligned Motivations*.

The reviewers at first suggested that the opportunities *Patient Empowerment* and *Patient Education* overlap to the point that they should be merged into a single theme around patient empowerment. However, upon discussion, it was agreed that education is not always perceived as resulting from increased patient empowerment, but rather an effect of patients having access to their data. Thus, these themes have been kept separate. The reviews disagreed that *Obsession* was a sub-theme of the barrier *Misaligned Motivations*, but instead a separate theme. Upon discussion, we resolved to keep *Obsession* as a subtheme in keeping with prior literature (West et al., 2016; Ancker et al., 2015a).

### 5.3 OPPORTUNITIES FOR SELF-TRACKED DATA

Seven themes around opportunities for self-tracked data emerged: bridging the gaps between consultations, enhancing doctor-patient collaboration, patient empowerment, motivating patients, patient education, overcoming recall biases, and collecting ecologically valid measurements. These themes are listed in Table 12 according to the studies they appeared within. Each of these themes is described below by most prominent first.

#### 5.3.1 Bridging the Gaps Between Consultations

Most prominently within the studies was the concept that self-tracked data described patients' health outside of clinical consultations. Typically, a clinician only has information about a patient collected within brief and infrequent clinical consultations, leaving large periods of time between those consultations where no data exist. Findings from the review support the principle that self-tracking over long periods of time could generate data to 'bridge the gaps' (Neff and Nafus, 2016) between clinical consultations.

Bridging the gaps may be advantageous for managing chronic illnesses, which typically takes place over years. Managing chronic illnesses is often difficult because little is known about the condition and habits of patients between consultations (Chung et al., 2015). Hence, a rationale behind many of the included studies was to find new ways of gathering information about a patient while they go about their daily activities. Interviews with clinicians who manage patients with irritable bowel syndrome (IBS) revealed that self-tracked data helped understand patient preferences and routines, allowing care to be tailored to individual needs (Chung et al., 2015). Similarly, Cohen et al. (2016) found self-tracked data fostered a "deeper and more accurate understanding of a patient's illness [...] because it helps clinicians identify and understand how patients' symptoms varied over longer periods

**Table 12.** Occurrence of opportunity themes in each study.

Reference	Bridging the Gaps Between Consultations	Enhancing Doctor-Patient Collaboration	Patient Empowerment	Motivating Patients	Patient Education	Overcoming Recall Biases	Collecting Ecologically Valid Measurements
Ancker et al. (2015a)			✓				
Ancker et al. (2015b)			✓				
Baos et al. (2005)	✓	✓	✓		✓		
Bauer et al. (2018)*							
Bellicha et al. (2017)	✓	✓	✓	✓	✓		
Cheng et al. (2015)	✓	✓	✓				
Chung et al. (2015)	✓	✓	✓	✓	✓	✓	
Chung et al. (2016)	✓	✓					
Cohen et al. (2016)	✓		✓				
Feller et al. (2018)	✓	✓			✓		
Gabriels and Moerenhout (2018)	✓		✓				
Giunti et al. (2018)	✓	✓		✓			
Hong et al. (2018)	✓						
Huba and Zhang (2012)	✓						✓
Kelley et al. (2017)				✓			
Kim et al. (2016)	✓	✓	✓		✓		
Kim et al. (2017)	✓	✓				✓	
Lee and Hong (2017)	✓	✓	✓		✓		
Lee et al. (2017)	✓	✓	✓				✓
Lindroth et al. (2018)	✓	✓	✓				
Malu and Findlater (2017)	✓		✓	✓			
Mamykina et al. (2016)	✓						
Mentis et al. (2017)		✓					
Nundy et al. (2014)	✓	✓	✓	✓		✓	
Orlowski et al. (2018)	✓		✓				
Piras and Miele (2017)	✓		✓				
Raj et al. (2017)		✓					✓
Ravichandran et al. (2017)	✓			✓	✓		✓
Schroeder et al. (2017)		✓	✓				✓
Schroeder et al. (2018)	✓	✓	✓	✓	✓		
Vandenbergh and Geerts (2015)		✓					
Wallace et al. (2017)	✓	✓					
West et al. (2016)	✓	✓					
Zhu et al. (2016)		✓					
Zhu et al. (2017)	✓		✓	✓			
<b>Total studies</b>	23	21	16	10	8	5	2

\* While Bauer et al. (2018) fulfilled the inclusion criteria, they did not report on clinician's perceived opportunities of self-tracked data in their paper, hence this row is empty.

of time.” Self-tracked data therefore helped clinicians identify problems that might otherwise go unnoticed (Cohen et al., 2016).

For some long-term illnesses, data about a patient’s daily routines were seen to be essential for understanding the patient’s condition. For example, successful migraine management requires longitudinal data about a patient’s possible triggers and habits (Schroeder et al., 2018). In a study of self-tracking of migraines, clinicians encouraged patients to use symptom tracking tools to collect longitudinal data, which, in turn, supported clinicians in deciding diagnoses and treatments (Schroeder et al., 2018). Similarly, for managing itching conditions, self-tracking provided clinicians with information on scratch counts and locations (Lee et al., 2017). These data would have otherwise been unavailable from their brief consultations with a patient, particularly because some itching conditions were not visible on the skin and were not detectable within clinical contexts (Lee et al., 2017). Self-tracked data enabled detection and improved understanding of these conditions, and therefore enabled better diagnoses and treatment (Lee et al., 2017).

In some studies, clinicians were apprehensive about using self-tracked data to inform diagnoses and treatment decisions. For instance, a study within paediatric oncology found clinicians would not typically use self-tracked data to inform major treatment decisions (Hong et al., 2018). However, self-tracked data were still valued and sought-after to inform decisions for supportive care to alleviate symptoms of treatment (Hong et al., 2018). Similarly, West et al. (2016) found hospital doctors would use self-tracked data to understand the patient’s well-being but would be unlikely to use such data for making a diagnosis or deciding on a procedure. In both studies, clinicians were seen to weigh the perceived reliability of information against the risk of the decision, thereby limiting the use of self-tracked data to lower-risk decisions (West et al., 2016; Hong et al., 2018).

### 5.3.2 Enhancing Doctor-Patient Collaboration

Amongst many of the studies, self-tracked data enhanced collaboration between doctor and patient, enabling clinicians to better understand the patient’s condition (Chung et al., 2016). For example, in studies of diet management, self-tracked data triggered communication between clinicians and patients, in turn enabling a more thorough history taking (Kim et al., 2016). Similarly, in IBS management, Schroeder et al. (2017) found that self-tracked data enabled patients and providers to combine their knowledge, which deepened the communication about possible triggers and treatments. An absence of these kinds of data limited conversations to what the provider had found in their own investigations (Schroeder et al., 2017). In hospital settings, West et al. (2016) found doctors willing to use self-tracking data as a communication tool to help explain patient symptoms or gather information about recent history. In sleep management, Kim et al. (2017) described this as a *data-driven consultation*, where clinicians iteratively learn about patients through conversations about their self-tracked data.

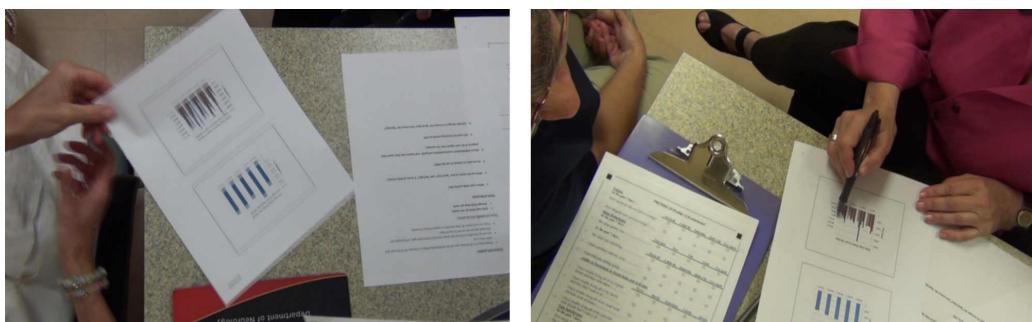
Self-tracked data sometimes overcame clinicians’ fears that a patient had made mistakes in their self-management. In a study of diabetes management, one doctor

assumed a patient's symptoms resulted from a poor decision by the patient, but information about the patient's condition revealed other factors to be the cause (Nundy et al., 2014). Self-tracked data improved clinicians' understanding of patients' subjective experiences of their condition, in turn improving trust in the patient (Nundy et al., 2014). Similarly, in IBS management, symptom and behaviour logs helped doctors understand the patient's perspective of their condition and their priorities (Chung et al., 2015).

Self-tracked data also enabled patients to understand their clinicians' perspectives. In IBS management, doctors shared their interpretation of self-tracked data with patients to help them understand medical recommendations (Schroeder et al., 2017). In this scenario, self-tracked data were seen to serve an educational role (Schroeder et al., 2017). Similarly, for diabetes management, helping a patient understand how certain meals can have high or low glycaemic impacts can motivate the patient to change their habits to improve their condition (Feller et al., 2018).

In many of the studies, self-tracked data appeared to improve the mutual understanding of both the clinicians and patient. The clinician learns about the patient's experiences of their illness and the patient learns about the clinician's perceptions of the illness. This mutual understanding better enables reaching mutually agreeable goals. For example, in itching management patients are often unaware of their scratching behaviours (such as scratching during sleep) (Lee and Hong, 2017). Using self-tracked scratch behaviour data can provide evidence of patients unknowingly scratching and causing wounds, thus forming a mutual understanding of the causes of problems (Lee and Hong, 2017).

Amongst the studies, clinicians often described the patient's presence as important when interpreting self-tracked data. This often took a collaborative form: both the clinician and the patient would co-interpret the data to ensure they understood the data reliably (Kim et al., 2017) and efficiently (Bellicha et al., 2017). During co-interpretation, clinicians could gather information to contextualise the data. In a study of Parkinson's management, the clinician and patient co-interpreted self-tracked activity data (see Figure 20) to understand the patient's lived experiences; these were important for understanding whether the patient considered, for example, their data outliers as a cause for concern (Mentis et al., 2017). During cancer rehabilitation, a patient's presence during interpretation was considered essential to contextualise self-tracked symptoms, namely, to understand what the patient may have been doing at the time of the symptoms; this context made the information suitable for entering into the patient's electronic patient record (Lindroth et al., 2018). Raj et al. (2017) (paediatric diabetes management) described co-interpretation as a process of co-constructing meaning of the patient's life experience and their problems. In this exchange, the clinician and patient would argue their interpretations of the data until they reached a mutual understanding (Raj et al., 2017). The outcome of co-interpretation was a better understanding of the patient's goals (Schroeder et al., 2017), their life experiences



**Figure 20.** In Mantis et al. (2017), clinicians and patients collaborated to form an understanding of their self-tracked data.

(Mantis et al., 2017), their thoughts on their treatment plan (Schroeder et al., 2017), and their reasoning for wanting to change their treatments (Zhu et al., 2016).

### 5.3.3 Patient Empowerment

Many studies showed that self-tracking behaviours can empower patients in their care. Good self-tracking practices can lead to patients identifying trends between behaviours and symptoms, enabling patients to be more autonomous (Chung et al., 2015). For managing diabetes, obesity, and hypertension, clinicians saw developing patient autonomy as important to improving patients' knowledge of their condition and their adherence to medical advice (Bellicha et al., 2017). Similarly, in Type-1 diabetes management, self-tracking was seen to engage patients in educating themselves about their health, in turn letting them understand the "tricks of the trade that can be reused autonomously by patients" (Piras and Miele, 2017). However, some debated the potential costs of patient autonomy. Gabriels and Moerenhout (2018) found cardiology clinicians were concerned that they would need to accept a new role under the patient, who becomes the manager for their care. Echoing this, Cohen et al. (2016) found doctors in chronic condition care and primary care concerned that patients may become demanding of certain interventions, such as drug prescriptions. However, some doctors in the cardiology study were comfortable with this arrangement, stating that such autonomy means greater patient empowerment and subsequent improvement of the quality of care (Gabriels and Moerenhout, 2018).

A related downside to self-tracking found within the review was the potential burden on patients. In IBS management, Ancker et al. (2015b) described patients being reminded they were sick every time they used their self-tracking tools. In sleep management, doctors were concerned that giving patients the responsibility to fill in a sleep diary could cause patients to stress over their sleep patterns, which exacerbates their sleep problems (Zhu et al., 2017). In these cases, the responsibility of self-tracking and consequent patient empowerment can have a counter-productive effect on the condition they are trying to manage. Furthermore, some studies raised that the responsibility of tracking constitutes work for the patient. Ancker et al. (2015a) described self-tracking for multiple chronic condition management as 'invisible work' for patients, which can leave patients feeling unrewarded for their efforts. In cancer rehabilitation, clinicians were left

unsure whether self-tracking empowers patients or burdens them with additional work (Lindroth et al., 2018), while in cardiology, clinicians worried that empowerment itself adds to the burden of responsibilities on patients, potentially leading to distress and hypochondria (Gabriels and Moerenhout, 2018). To address this, clinicians in migraine management suggested self-tracking should take place only as long as beneficial for tracking the patient's condition, after which self-tracking should be stopped to prevent the burden on the patient (Schroeder et al., 2018). Doctors suggested that to overcome the perceived burden of tracking, patients should stop tracking bad moments and track good moments instead so that they focus on positive aspects of their treatment (Schroeder et al., 2018).

#### 5.3.4 Patient Education

A common characteristic of self-tracking found within the studies was its role as an educator. Self-tracking gave patients an improved knowledge of their own health, such as the relationship between behaviours and symptoms or the effectiveness of their management plan. In a study of chronic condition management, activity tracking data helped improve patients' perceptions of their exercise intensity and its impact on their health (Bellicha et al., 2017). For diet management, clinicians stated that food records contributed to the patient's awareness of their food consumption and strengthened the impact of their doctor's advice (Kim et al., 2016). In mental health, self-tracked data on well-being helped patients understand medical advice and take ownership of their health outcomes (Orlowski et al., 2018). Similarly, for migraine management, self-tracking improved patients' understanding of their health and led to improved satisfaction with their medical care (Baos et al., 2005).

#### 5.3.5 Motivating Patients

Several studies pointed out that the educational aspect of self-tracking served to motivate patients to take greater responsibility for their health. In a study of migraine management, clinicians said that tracking triggers and symptoms motivated patients to change their behaviours, in turn improving their symptoms (Schroeder et al., 2018). Similarly, in sleep management, Ravichandran et al. (2017) found that clinicians perceived self-tracking to create an awareness of the importance of sleep hygiene, which motivated patients to improve their sleep patterns. Another study in sleep management found that tracking sleep activity led patients to feel more accountable for their actions and motivated to comply with medical advice (Zhu et al., 2017). Discussing self-tracked data with patients was perceived to motivate them to continue self-tracking. In a study of IBS management, clinicians reviewed data with patients to highlight why self-tracking was important, in turn motivating patients to engage in their management plan (Chung et al., 2015). A study in diabetes management found that tracking blood sugar led to patients engage in their care (Nundy et al., 2014), which was seen to improve patient compliance and well-being (Bellicha et al., 2017).

### 5.3.6 Overcoming Recall Biases

Data collected via self-tracking technologies was often perceived to be more reliable than a patient's recall of events. A study in diabetes management (where clinicians normally relied on patients recalling events) found clinicians were more trusting of self-tracked data because they were not subject to recall bias (Nundy et al., 2014). Similarly, in weight management, Kim et al. (2017) found that self-tracked data provided information about a patient's eating habits more reliably than recall. When relying on a patient's recall of eating habits, clinicians stated that recall errors cause a patient to present only partial information. Self-tracking ensured that information was complete, enabling a better understanding of whether patients were maintaining regular diets (Kim et al., 2017).

### 5.3.7 Collecting Ecologically Valid Measurements

Self-tracked data were sometimes perceived to be more ecologically valid than clinically collected equivalents because self-tracking takes place in the patients' day-to-day settings, rather than in clinical environments. In sleep centres, patients are typically fitted with observation equipment which can create a disruptive environment for sleep (Ravichandran et al., 2017). In a study of sleep self-tracking, clinicians perceived self-tracked data as more reflective of sleep behaviours because patients slept in their natural sleep environment (Ravichandran et al., 2017). Similarly, in itching management, using self-tracking tools in the home environment meant clinicians could observe the patients' normal behaviours, in turn leading to better diagnoses and treatments (Lee et al., 2017). With more ecologically valid data, clinicians proposed that self-tracked data could help better understand a patients' lifestyle and tailor treatment plans (Ravichandran et al., 2017).

## 5.4 BARRIERS TO USING SELF-TRACKED DATA

The review revealed twelve barriers to using self-tracked data within these clinical settings: unfamiliar data representations, misaligned motivations, insufficient time, unclear accuracy and reliability, fear of consequences of sharing data, poor interoperability, lacking contextual information, information overload, data are often incomplete, misalignment with clinical training, patient lacks access to technology, and insufficient clinical validation of tool. These are shown in Table 13 with respect to the studies they were identified within. Each barrier is described in detail below.

### 5.4.1 Unfamiliar Data Representations

Chung et al. (2015) state that standardised representations help clinicians efficiently and accurately interpret data, even when such data are multivariate and voluminous. Self-tracking tools, however, were found to rarely use or derive representations based on these standards (Bellicha et al., 2017). A suggested reason for this is that most self-tracking tools are developed by technology companies inexperienced in clinical informatics (Bellicha et al., 2017). Moreover, health apps

**Table 13.** Occurrence of barrier themes in each study.

Reference	Unfamiliar Data Representations	Misaligned Motivations	Insufficient Time	Unclear Accuracy and Reliability	Fear of Consequences of Sharing Data	Poor Interoperability	Lacking Contextual Information	Information Overload	Data are Often Incomplete	Misalignment with Clinical Training	Patient Lacks Access to Technology	Insufficient Clinical Validation of Tool
Ancker et al. (2015a)	✓	✓				✓	✓		✓			✓
Ancker et al. (2015b)		✓		✓						✓		
Baos et al. (2005)*												
Bauer et al. (2018)										✓		
Bellricha et al. (2017)	✓	✓	✓	✓	✓	✓		✓				✓
Cheng et al. (2015)	✓	✓			✓	✓						
Chung et al. (2015)	✓	✓	✓	✓			✓	✓				
Chung et al. (2016)	✓	✓	✓	✓								
Cohen et al. (2016)	✓	✓	✓	✓		✓			✓	✓		
Feller et al. (2018)	✓	✓	✓	✓						✓		
Gabriels and Moerenhout (2018)		✓	✓	✓	✓	✓		✓	✓	✓		✓
Giunti et al. (2018)				✓	✓	✓						
Hong et al. (2018)		✓							✓			
Huba and Zhang (2012)*												
Kelley et al. (2017)	✓		✓	✓	✓							
Kim et al. (2016)			✓	✓	✓	✓	✓		✓	✓		
Kim et al. (2017)	✓	✓	✓	✓		✓		✓		✓		✓
Lee and Hong (2017)										✓		
Lee et al. (2017) *												
Lindroth et al. (2018)					✓							
Malu and Findlater (2017)		✓	✓	✓					✓			
Mamykina et al. (2016)	✓							✓				
Mentis et al. (2017)*												
Nundy et al. (2014)		✓	✓	✓	✓	✓					✓	
Orlowski et al. (2018)		✓	✓	✓			✓				✓	
Piras and Miele (2017)		✓	✓	✓		✓						
Raj et al. (2017)	✓	✓	✓	✓					✓			
Ravichandran et al. (2017)	✓	✓			✓							
Schroeder et al. (2017)	✓	✓		✓								
Schroeder et al. (2018)	✓	✓	✓									
Vandenbergh and Geerts (2015)	✓						✓	✓				
Wallace et al. (2017)*												
West et al. (2016)	✓	✓	✓	✓	✓			✓	✓		✓	
Zhu et al. (2016)	✓	✓	✓	✓	✓	✓	✓	✓	✓			
Zhu et al. (2017)			✓				✓					
<b>Total studies</b>	17	16	15	12	8	7	7	7	6	6	5	4

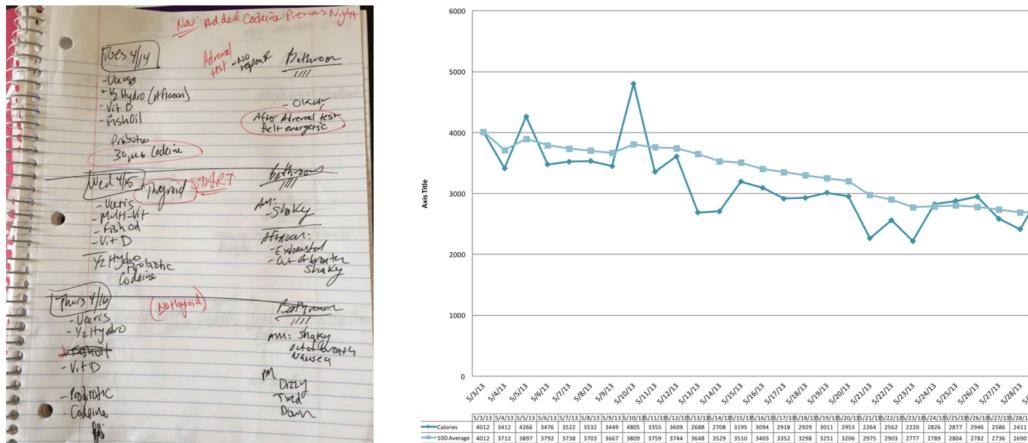
\* While Baos et al. (2005), Huba and Zhang (2012), Lee et al. (2017), Mentis et al. (2017), and Wallace et al. (2017) fulfilled the inclusion criteria, they did not report on clinician's perceived barriers to self-tracked data in their papers, hence these rows is empty.

and wearables are typically created for consumers, not for clinical purposes (Bellicha et al., 2017). Other plausible reasons are that these apps are designed to be easy-to-use and avoid technical representations to appeal to non-specialist individuals (Chung et al., 2015). Such non-standard representations made clinicians' interpretation of data more difficult (Schroeder et al., 2017).

In one study, clinicians in chronic condition management questioned how a 'step count' from activity trackers maps onto the duration and intensity of physical activity they were more familiar with (Bellicha et al., 2017). In a sleep management study, doctors could not discern what 'sleep quality values' meant because they were computed by a proprietary algorithm which had not been publicly disclosed (Ravichandran et al., 2017). Similarly, Chung et al. (2015) found that apps for IBS management frequently reduce a patient's self-tracked data to a factor unhelpful for clinicians. Beyond being unlike clinical representations, there appears to be significant variation across different self-tracking tools, whether wearable sensors (Cohen et al., 2016) or electronic self-tracking apps (Chung et al., 2015). Such variations extended beyond the specific visual representations used to present and summarise the data, to variations of data granularity, aggregation methods, to units of measure.

When patients used more traditional methods, such as hand-written notes, word processors, or spreadsheets, data representations were varied for different reasons. Patients naturally structured data in ways most intuitive to them, which was often idiosyncratic to their preferences and goals. Figure 21 shows two such visualisations used by patients when tracking symptoms, well-being, and weight (Chung et al., 2016). Variations and disparities of representation were seen as a direct obstacle to quick, safe and effective use of self-tracked data (West et al., 2016). Similarly, self-tracked heart rate data presented to hospital clinicians prompted varying interpretations because they were presented in a non-standard form decided by the patient (West et al., 2016). However, having patients prepare data in a form that made sense to them was often seen as an important goal to self-management (West et al., 2016). If clinicians represented data in a clinical format, patients may become overwhelmed or confused (Raj et al., 2017).

The relative importance of using specific representations depended on who was reviewing the data. Primary care physicians and nurses were often more flexible at "piecing together" disparate evidence, based on heterogeneous, varied information sources, including data from self-tracking tools and recounted personal experience (Cohen et al., 2016). Hospital specialists, however, more often expressed the need to re-organise, re-order, and sometimes re-structure information into standardised forms (such as the clinical admissions form) before being able to effectively evaluate it (West et al., 2016). In a study of sleep management, clinicians wanted raw data so they could rearrange them into familiar forms (Vandenbergh and Geerts, 2015). Chronologically ordering events into a timeline appeared to be important within hospital (West et al., 2016) and chronic care settings (Schroeder et al., 2018) to understand the relationship between events.



**Figure 21.** Patients in Chung et al. (2016) used multiple formats for logging their health. Left: a paper diary used to record symptoms and medications. Right: a graph of weight and calorie consumption. The diversity of formats illustrates that a clinician may need to interpret information atypical of clinical settings.

Doctors in IBS management stated that simply adding normal ranges for values (perhaps derived from population levels) could be helpful (Schroeder et al., 2017). Sleep management clinicians said device manufacturers should adopt clinical standards (Vandenbergh and Geerts, 2015), while chronic care management doctors wanted a summary of the patient's activity data which highlights abnormalities (Kim et al., 2017). Similarly, West et al. (2016) found hospital doctors simply wanting a way to summarise data so they could use them effectively in the limited time they have with the patient.

#### 5.4.2 Misaligned Motivations

A prominent barrier amongst the studies was the misalignment of the clinician's and patient's objectives. Misaligned objectives led to patients tracking aspects of their health unrelated to their problems (Zhu et al., 2016) and having unrealistic expectations of the benefits of self-tracking (Chung et al., 2015). Consequently, doctors were often curious about why patients engaged in self-tracking and what they hoped to achieve (West et al., 2016). Many clinicians acknowledged that patients have legitimate reasons to self-track, such as to help manage their long-term conditions or identify symptom triggers (Ancker et al., 2015b). The presentation of self-tracked data was often seen as an artefact of the fact that self-tracking was on the rise and patients felt such data would be useful for clinicians during the consultation (Chung et al., 2015; West et al., 2016). However, clinicians suggested three alternative motives that may cause patients to bring self-tracked data to consultations: coercion, obsession, and worried well.

##### 5.4.2.1 Coercion

Of greatest concern to clinicians were patients who brought self-tracked data to consultations to coerce the clinician into making a certain decision. West et al. (2016) described doctors stating they were under increasing pressure by patients to prescribe medications and that patients may be motivated to present self-tracked data to coerce the doctor into writing a prescription. This may not always be de-

liberate coercion; one doctor presumed a patient faked their self-tracked caffeine charts to get a prescription, but an underlying psychological condition motivated them to do this (West et al., 2016). However, a study of multiple chronic conditions observed a more surprising example where a mother tried to have her daughter's insulin therapy delayed by providing a faked blood glucose log, possibly to avoid raised insurance premiums (Ancker et al., 2015b). Indeed, doctors have concerns that the fear of insurance premiums has led to patients providing misleading or incomplete information (Ancker et al., 2015a; Bellicha et al., 2017). Alternatively, patients may deny some aspect of their health and try to provide information to convince the clinicians they do not have a certain condition (Ancker et al., 2015a).

#### **5.4.2.2 Obsession**

Several studies observed clinicians concerned that patients 'obsessed' over some aspect of their health (West et al., 2016; Gabriels and Moerenhout, 2018; Ancker et al., 2015b; Bellicha et al., 2017). In multiple chronic condition management, some doctors perceived self-tracking to be obsessive and compulsive, especially where the data had little clinical relevance to the current consultation (Ancker et al., 2015b). Bellicha et al. (2017) saw diabetes clinicians concerned that patients were becoming addicted to self-tracking using electronic activity monitors, which caused a negative impact on their well-being. West et al. (2016) found that hospital doctors considered a patient's obsession with an aspect of their health could suggest an underlying psychological disorder, such as depression or being overwhelmed by work.

#### **5.4.2.3 Worried Well**

The 'worried well' refers to patients who are healthy but concerned about their health. Clinicians in a cardiology study found those who engaged in self-initiated self-tracking were almost always already healthy, creating a widening health disparity between the healthy and the sick (Gabriels and Moerenhout, 2018). This reflects concerns raised in Chapter 2 that normativity in consumer self-tracking products sees them designed primarily for those who are already fit (Spiel et al., 2018). Gabriels and Moerenhout (2018) suggests this is creating an overabundance of medically unnecessary data suitable for the realm of fitness, not medicine: "the already healthy population might become even 'healthier,' whereas the ones who would benefit most from self-monitoring are harder to reach" (Gabriels and Moerenhout, 2018).

#### **5.4.3 Insufficient Time**

In several studies, clinicians said there was insufficient time to use self-tracked data. West et al. (2016) found that hospital doctors and general practitioners were wary that they already work with lots of data in the limited time they have with patients, and there would be insufficient time to use self-tracked data. In IBS management, Chung et al. (2015) found that clinicians would not normally have time outside of consultations to look at self-tracked data. Instead, clinicians were constrained to the 15 to 20 minute consultations with patients where other matters

may be more pressing. Within this time constraint, doctors did not have time to meaningfully explain what the data meant (Chung et al., 2015). Bellicha et al. (2017) found that doctors who manage long-term illnesses rarely have sufficient time to interpret self-tracked data. However, doctors in this study were willing to use data as an artefact for discussion. In one study of physical therapy, time constraints led to tensions as patients tried to use self-tracked data to maximise their time with clinicians (Zhu et al., 2016). In mental health, Kelley et al. (2017) found that clinicians tried to mitigate the tensions by negotiating the discussions around only the data relevant to the consultation topics.

Data presentation could be an important factor in ensuring that relevant data can be interpreted quickly and efficiently. The nature and kinds of relationships sought in the data often shaped the representations that were seen to be the most efficient (Kim et al., 2016). In one study, clinicians said temporal relationships were the most important, as they can quickly establish causal relationships between potential triggers and symptoms (Feller et al., 2018). Time-efficient representation of information could mean more time is spent communicating with the patient, which clinicians in diabetes management saw as crucial (Feller et al., 2018).

#### 5.4.4 Unclear Accuracy and Reliability

A prominent barrier to using self-tracked data was the *accuracy* of data, which describes the ability of a self-tracking technique to measure the phenomenon correctly and confidently (Batini et al., 2009). Clinicians perceived accuracy to be an important quality of self-tracked data because accurate data allowed causal connections to be identified with symptoms or an underlying cause (Kim et al., 2016; Zhu et al., 2016; Ancker et al., 2015b). However, while evaluating the quality of self-tracked data, clinicians in the studies often found it was unclear how accurate the data were. In cardiology, clinicians had difficulty in establishing the quality of self-tracking devices and apps and were therefore critical of the reliability of patients' measurements (Gabriels and Moerenhout, 2018). Admitting data with poor accuracy, poor reliability, or insufficient precision was perceived to increase the risk of medical errors (West et al., 2016), hence clinicians usually trusted clinically gathered information above self-tracked data (Ancker et al., 2015b; Kim et al., 2016). Doctors sometimes wished to re-take measurements using their own clinically calibrated tools (West et al., 2016).

Patients may misjudge measurements when recording data. In a mental health study of students, clinicians were concerned that students may misjudge the time they spend studying. In a study of diabetes and primary care, Nundy et al. (2014) found that doctors needed more sensitive information than was available from self-tracked data. While self-tracked data may report that a patient complied with their medication, conversation with the patient may reveal the patient skipped some medications but reported high compliance (Nundy et al., 2014). In a study of multiple chronic conditions, self-tracked data were perceived to carry emotional valence, creating ambiguity in their meaning (Ancker et al., 2015b).

#### 5.4.5 Fear of Consequences of Sharing Data

Clinicians are increasingly aware of the privacy concerns of patients and the importance of keeping data secure. Such requirements for security add a barrier to using self-tracked data in clinical settings. In several studies, clinicians were concerned about who might gain access to patients' self-tracked data. Bellicha et al. (2017) found that doctors were concerned that private insurers could use activity data of patients to penalise patients who do not meet a set amount of activity. In multiple sclerosis management, Giunti et al. (2018) echoed this, with clinicians expressing unease with handling self-tracked data because pharmaceutical or insurance companies could use the data to market medications or decide insurance premiums. Assurances of privacy and security of information were therefore seen to be paramount when considering accepting self-tracked data. In one study, primary care physicians worried that legal responsibility would fall to them to ensure data were held securely and in compliance with the US Health Insurance Portability and Accountability Act (HIPAA), adding to the burden of using self-tracked data (Cohen et al., 2016). One clinician in physical therapy believed that unless self-tracked data were stored in a secured server, it would violate HIPAA and could therefore not be admitted into their practice (Zhu et al., 2016).

Clinicians in some studies suggested that having access to self-tracked data could lead to additional liability of the clinician. If a clinician did not act upon data presented by a patient and the patient's health was to subsequently decline, the clinician may be held responsible (Cheng et al., 2015). Conversely, if the clinician never received the data, he or she could not be held responsible (Gabriels and Moerenhout, 2018). Clinicians also worried that accepting self-tracked data could lead to mistakes in diagnoses and treatment. In one study of high-risk infant care, the system used to track infant health wrongly sent out post-partum depression alerts to clinicians and parents, which, in a non-study environment, could have led to unnecessary interventions or medical errors (Cheng et al., 2015). In the study environment, the incorrect alerts caused the parents to worry and left clinicians liable for the erroneous alerts (Cheng et al., 2015). In sleep and chronic illness management, doctors suggested there should remain oversight by experts or designated nurses over data analysis to prevent mistakes (Kim et al., 2017).

A final topic of legal concern was the legality of using self-tracking tools. Specifically, Kim et al. (2016) observed diet management in South Korea where remote medical examinations of patients are illegal; there was concern amongst clinicians that self-tracking could constitute medical examinations and therefore be illegal.

#### 5.4.6 Poor Interoperability

The lack of interoperability with healthcare information systems was a barrier to using self-tracked data, with many consumer devices using proprietary or undocumented formats. In two studies, doctors struggled to export data from the self-tracking tools: Chung et al. (2015) found IBS doctors unable to export data from self-tracking apps without using a complex API and Zhu et al. (2017) found

that commercial sleep tracking technology did not support exporting data in any form. In both studies, clinicians consequently preferred that patients use paper diaries so they could be photographed and entered into their healthcare information systems. In diet management, Kim et al. (2016) found the inability to export food tracking data prevented them from cross-referencing with the patient's record.

Even where data could be exported, healthcare information systems rarely provided ways to interoperate with such formats (Ancker et al., 2015a; Kim et al., 2016; Chung et al., 2015). While some electronic patient ports allow data to be transferred between health organisations, this was seldom seen within the studies, with one study mentioning this was only possible for one patient (Ancker et al., 2015a). Thus, clinicians were pragmatic in how data could be retrieved, with any data being better than none (Ancker et al., 2015a). In sleep centres, clinicians were observed transferring data via USB drives because the software they used was not permitted on the hospital network (Vandenbergh and Geerts, 2015). Even when data could successfully be viewed on IT systems, EMRs rarely provided a way to store data in non-standard formats, limiting the use of the self-tracked data to the consultation they were presented in (Zhu et al., 2016). Non-standard formats were found to be particularly problematic in mental health contexts, causing doctors to rely on patients to keep track of information as they moved between different healthcare organisations (Orlowski et al., 2018).

In many studies, doctors were vocal about needing changes to information systems to improve sharing capabilities. In multiple chronic condition management, doctors predicted that effective sharing through personal health records could reduce the burden of managing information which patients currently must deal with (Ancker et al., 2015b). However, clinicians knew this would require significant changes to their IT infrastructure (Zhu et al., 2016).

#### 5.4.7 Lacking Contextual Information

Self-tracking tools rarely collect contextual information, such as where a measurement was taken, ambient temperature, and posture. These kinds of information help clinicians judge the data's validity (Schroeder et al., 2017), identify the cause and effect of events (West et al., 2016), and contribute a better understanding of the patient (Chung et al., 2015). A study of IBS management documented clinicians' difficulties in using patient diaries because clinicians needed "to know more about the context of the data in order to trust it, citing possible confounds including emotional and physical health, hydration, and exercise" (Schroeder et al., 2017). In cardiology, doctors were unsure if readings were of the patient or another person who had used the device, leading to fears that a medical error could result from incorrect assumptions about the context of the information (Gabriels and Moerenhout, 2018).

Single data streams on their own may provide insufficient context about a patient's recordings for clinicians to make suitable judgements from them. Thus, the availability of context was often seen as crucial to deciding whether to admit self-tracked data as evidence (Schroeder et al., 2017). Contextual information could

comprise other data available in a patient's health record or through self-tracking other kinds of information (Schroeder et al., 2017). In sleep centres, cameras and microphones are used to monitor the patient during the night to help contextualise sleep measurements and identify overlapping problems (Vandenbergh and Geerts, 2015). However, this kind of information is typically unavailable in home environments where the patient is self-tracking (Vandenbergh and Geerts, 2015). Sometimes, collaboration enabled clinicians to make greater sense of the context of self-tracked data, such as by asking patients what happened during certain times (Schroeder et al., 2017). However, memory effects during recall are likely to result in poor quality data (Nundy et al., 2014).

#### 5.4.8 Information Overload

A concern amongst clinicians in the studies was that self-tracked data could create a situation where there is too much information to effectively use or it becomes overwhelming. In cardiology, *information overload* was a significant risk if a patient presented self-tracked data (Gabriels and Moerenhout, 2018). A concern raised by doctors in diabetes management was that information may be automatically transferred to the doctor, meaning doctors would have no choice but to look at the data, in turn causing information overload (Bellicha et al., 2017). West et al. (2016) found concern amongst secondary care specialists that there can be too much data to effectively utilise, as well as the potential for irrelevant data to create a distraction.

A possible mitigation to the problem of overload is to ensure data are appropriately represented. In physical therapy, raw self-tracked data were seen to be overwhelming and appropriate visualisation could help prevent this (Zhu et al., 2016). Raj et al. (2017) found specialists in paediatric diabetes wanting a data representation which allowed them to explore self-tracked data. Without this, the data can be overwhelming (Raj et al., 2017). In sleep management, doctors proposed a hierarchical view of sleep and activity information to help effective exploration of data (Kim et al., 2017). In mobility impairment management, doctors expressed the importance of keeping information concise to prevent information overload (Malu and Findlater, 2017). Cardiology doctors suggested overload could be mitigated by having specialist nurses analysing self-tracked data while clinicians focused on solving discovered problems (Gabriels and Moerenhout, 2018).

#### 5.4.9 Data are Often Incomplete

Completeness refers to the state of having all sufficient information necessary (i.e., with nothing missing) for the task at hand (Wang and Strong, 1996). Many clinicians within the studies perceived self-tracked data to be often incomplete. These data only had limited value in clinical decisions or were seen to increase the risk of medical errors (Ancker et al., 2015a). For example, if a patient recorded their blood pressure three times a day, every day, but missed several measurements prior to a spike in blood pressure, valuable information may be missing to describe the events leading up to the spike (Gabriels and Moerenhout, 2018). One study found

the drop-out rate amongst patients who self-tracked was high which led to incomplete data (Gabriels and Moerenhout, 2018) and another found that patients rarely tracked with sufficient frequency (Chung et al., 2015). Insufficient detail or incomplete information was sometimes attributed to patients finding data collection arduous, such as recording food intake (Kim et al., 2016). Doctors were concerned that asking patients to record more consistently might make self-tracking too arduous, in turn causing them to abandon self-tracking altogether (Kim et al., 2016).

Gaps in data created ambiguities in what happened in those periods (Hong et al., 2018). In paediatric oncology, clinicians perceived verbal communication to be insufficient for understanding what happened in these gaps due to recall bias (Hong et al., 2018). Therefore, to ensure completeness, it was important that data collection was sustained over a long period (Kim et al., 2016) and for the collection technique to be detailed and granular (Chung et al., 2015). Self-tracking devices, such as wearable sensors, provide a means of capturing data at high-resolution and granularity with little or no effort to end-users, supporting the creation of time series datasets with high completeness (Chung et al., 2015). However, even automatic data collection, such as through Fitbit, would likely result in gaps because their users will take them off at certain times or forget to wear them. Moreover, clinicians reported that some patients are motivated to selectively report their information (Ancker et al., 2015a). In IBS management, patients sometimes concealed information which they did not realise was relevant or reflected poorly on their management adherence (Ancker et al., 2015a). Chung et al. (2016) suggests that highlighting missing data could help clinicians identify causes and patterns of such gaps in the data, in turn encouraging patients to improve their self-tracking adherence.

#### 5.4.10 Misalignment with Clinical Training

A barrier reported in some studies was that clinicians were not trained to use the data from self-tracking tools. The variation of tools and the consumer-oriented design of them led to large variations in data granularity, aggregation methods, and units of measure. The diversity of types and structures of self-tracked information illustrates that a clinician may need to be skilled in interpreting information in forms atypical of clinical settings. When interviewing hospital doctors about using patient self-tracked heart rate and caffeine intake data, West et al. (2016) found that clinicians had difficulties interpreting the information in the format they were presented in. Heart rate data were presented in a chart unfamiliar to clinicians, and the caffeine chart (measured in cups of coffee) did not indicate normal levels, so clinicians were left unsure what a normal level of caffeine was (West et al., 2016). The clinicians explained that, in the absence of sufficient training on interpreting specific kinds of information, it would be necessary to contact an expert to interpret the information. Similarly, in diabetes management, many doctors have limited training in mathematics and statistics and find it difficult to interpret self-tracked data when they are not presented in a standard clinical form (Feller et al., 2018). To use these data effectively, the clinicians explained they would require

hours of training to gain proficiency in using visual analytic tools for interpreting self-tracked data (Feller et al., 2018). Doctors in dietary management suggested automation will be necessary for analysing self-tracked data to overcome skill shortages (Kim et al., 2016). In West et al. (2016), a hospital doctor posited that younger doctors are more willing to engage in learning to use self-tracking tools and stated doctors are averse to change: “you’ve been doing something for ten, fifteen years the same way, you’re going to carry on doing it”.

#### **5.4.11 Patient Lacks Access to Technology**

A barrier discussed in a few studies was that patients may not have access to self-tracking technologies. This was seen to be an important barrier in mental health settings, where patients may not have the capacity to use some self-tracking tools (Orlowski et al., 2018). Some clinicians found patients who self-tracked to be unforthcoming about their mental health issues because self-tracking tools were typically designed for the least impaired members of society and did not consider the needs of those with severe mental health issues (Lee and Hong, 2017; Bauer et al., 2018). Moreover, certain populations did not have access to technologies. In diabetes and primary care, Nundy et al. (2014) found doctors concerned about the unavailability of patient self-tracking tools amongst racial minorities and elderly patients. Doctors who managed multiple chronic conditions found elderly and less affluent patients often could not access self-tracking technologies, despite those groups being most at risk of multiple chronic conditions (Ancker et al., 2015b).

#### **5.4.12 Insufficient Clinical Validation of Tool**

In some studies, clinicians considered the suitability of self-tracking tools before admitting the data they generate as evidence. The most common tools were consumer products, such as heart rate trackers and sleep trackers, which usually lacked any clinical evaluation or evidence of their efficacy, meaning it was unclear whether the devices were clinically calibrated and whether they used sensing approaches analogous to those used by clinical instruments (Bellicha et al., 2017). In managing obesity and Type-2 diabetes, clinicians reported having difficulty keeping up with the increasing number of consumer self-tracking devices and cautioned that these devices tend to be validated only after launching to market (Bellicha et al., 2017). In a study in cardiology, clinicians were observed comparing the information from the patient’s devices and information from clinical devices to find deviations; deviations were common, prompting doubts over the devices’ reliability (Gabriels and Moerenhout, 2018). Other clinicians in this study only wanted to accept data from devices approved by medical organisations but could not find organisations who issued such approvals (Gabriels and Moerenhout, 2018). Kim et al. (2017) report that doctors in sleep and chronic illness management were unsatisfied with the lack of evidence correlating self-tracking with outcomes. While there is limited evidence of the effectiveness for some uses of self-tracking, much of this evidence either is subject to biases or is not reflective of the gen-

eral population. For example, participant selection is commonly biased toward computer-literate people in affluent areas (Ancker et al., 2015a).

### 5.5 CHAPTER SUMMARY

This study involved a systematic review of literature around self-tracked data to identify current opportunities and barriers to using such data in clinical practice. A total of 35 relevant studies were identified amongst scholarly literature, most of which were published in the past three years (2016, 2017, and 2018), highlighting the rapid growth of the field of self-tracking. Several important opportunities for self-tracked data were raised within the studies, including using data to understand a patient's condition between consultations, empowering patients to take greater responsibility in their care, and enhancing doctor-patient collaboration. Several barriers were also raised within the studies, including concerns about the quality of self-tracked data, that data formats are likely to be unfamiliar, and that there is insufficient time to interpret these data.

## 6 CLINICAL WORKFLOWS FOR USING SELF-TRACKED DATA

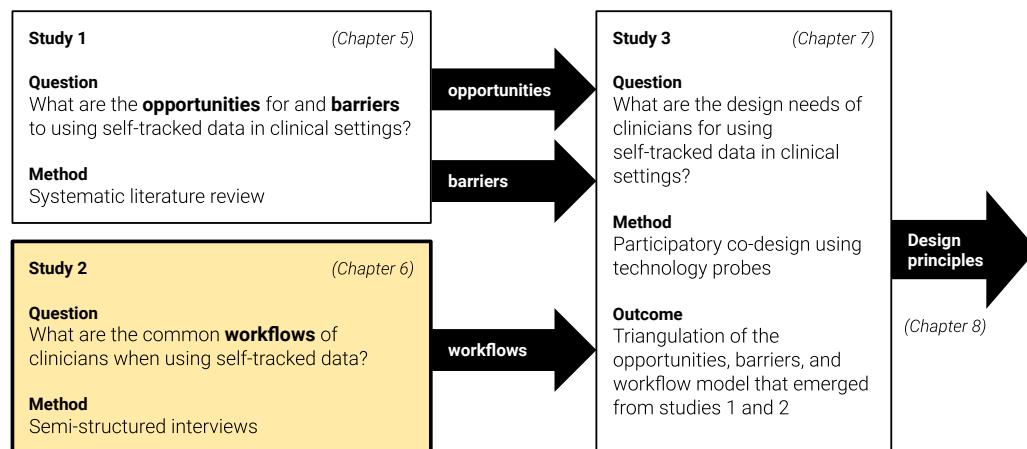
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This study aimed to analyse how self-tracked data are used within the clinical settings, thereby uncovering common work practices which clinicians work in when using self-tracked data. As shown in Figure 22, this chapter aims to answer the second research question: *what are the common workflows of clinicians when using self-tracked data?* This chapter describes an interview study conducted with 13 clinicians, the findings of which are then reported as a six-stage common workflow which emerged during analysis.

The findings from this chapter have been published and presented at the 2018 Conference on Human Factors in Computing Systems (West et al., 2018). This chapter extends this publication by providing greater depth on the methodology, findings, and discussion. Page limits had prevented this in the publication.

### 6.1 METHOD: SEMI-STRUCTURED INTERVIEWS

To generate an understanding of the workflows of clinicians using self-tracking data, this study opted to use interviews as a research method. By interviewing clinicians directly, the findings would reflect the clinicians' lived experiences and perceptions, which was crucial for understanding how self-tracked data would realistically be used in real clinical settings (Manen, 1990). Clinicians of various roles were interviewed about their experiences and potential uses for self-tracked data within their workflows. The diversity of the participant's background and experiences precluded the development of a structured interview script, hence the interviews were semi-structured. Semi-structured interviews permitted the interviewer and participant to go off-script to explore themes which had not been anticipated. These rationales have been used in a previous semi-structured interview study which had a similarly diverse clinical sample group (Louise Barriball and While, 1994). The recruitment process and procedure are described below.



**Figure 22.** Study 2 focused on identifying the workflows for using self-tracked data in clinical settings.

### 6.1.1 Recruitment

Thirteen clinicians of diverse roles took part in this research. The participants were sampled according to the following inclusion criteria:

1. *The sample should maximise the variety of clinical roles.* The usage scenarios of self-tracked data are likely to be different between different clinical roles, such as, for example, cardiac nurses who work with patients of specific chronic conditions, and general practitioners who work with a variety of patients with a diversity of chronic and non-chronic conditions (MacLeod et al., 2013). Therefore, it was desirable to ensure that as participants were sampled, the final sample would represent a variety of clinical roles. This is known as *maximum variation sampling* (Palinkas et al., 2015).
2. *Participants regularly work with patients.* This research is focused on the use of self-tracked data for making decisions about individual patients (not, for example, ‘big data’ uses), so only clinicians who work directly with patients were included.
3. *Participants have used, or are interested in using, self-tracked data.* This ensures the clinicians included were willing to use self-tracked data and would not reject them based on an unwillingness to use technology (Ancker et al., 2015b) or fear of litigation (Sullivan, 2014). Though their concerns of self-tracked data are important, these concerns have been the subject of prior work (see Chapter 2), and those who reject self-tracked data for these reasons are unlikely to reflect on issues pertaining to how they could be used.

Identifying clinicians who met the inclusion criteria presented two difficulties: first, a mass survey to identify potential participants would be an unwelcome workload in a clinician’s already busy schedule (Zeldes and Baum, 2011), and second, such a survey would need to be circulated to multiple clinical workplaces to ensure diversity of clinical roles and settings. However, through prior acquaintance with several clinicians, a convenience sample (Etikan et al., 2016) of clinicians could be formed. Although these acquaintances encompassed a variety of clinical roles, a concern remained that merely including acquaintances might introduce a sampling bias (in particular, a bias towards recent graduates whom I attended University with). Indeed, a prominent criticism of convenience sampling is that the sample may not be representative of the entire population (Johnston and Sabin, 2010). The implication is that findings from this study should not be taken to be representative of the population. With this limitation acknowledged, convenience sampling was utilised because it was a practical way to access a difficult-to-reach population (Etikan et al., 2016).

To expand the sample pool, *snowball sampling* was used, in which the participants in the initial seed sample helped to recruit further participants to a final larger sample (Babbie, 2012, p. 191–192). Critically, snowball sampling provides access to clinicians who may not have been accessible via convenience sampling alone (Atkinson and Flint, 2001). This sampling technique was used in a similar inter-

view study about self-tracking in chronic illness management to ensure a greater diversity of clinical roles (MacLeod et al., 2013). The outcome of this recruitment procedure is described in Section 6.2.1 of this chapter.

### 6.1.2 Interview Procedure

Interviews lasted 30 minutes to an hour and were carried out face-to-face or by phone. Audio was recorded using a Dictaphone and then transcribed. An interview schedule was constructed to elicit insights into the kinds of clinical settings in which self-tracked data may be useful and how they might be used. Interviews were semi-structured, permitting participants to take the conversation in directions they considered important. The interview schedule was as follows:

1. *What is your clinical role and how do you work with patients?* This question aimed to understand the roles and relationships the participant has with patients to identify opportunities for self-tracked data and whether barriers pertained to specific roles or clinical settings.
2. *Do you see the same patients regularly or typically only new patients?* This was useful to understand whether the participant has ongoing relationships with patients, potentially impacting how they may use self-tracked data.
3. *Have you had patients bringing in their own kinds of data?* This probed the participant's current use of self-tracking and set up the interview to ask about types of information which may be routine in the participant's practice.
4. *What kinds of information would be helpful to you which could be collected by the patient?* This explored how self-tracked data may be useful for 'bridging the gaps' between consultations and whether barriers were prevalent with specific kinds of data.
5. *How would you want self-tracked data to be structured or displayed?* This explored any ideas they had about suitable data representations for self-tracked data, possibly influenced by clinical systems they use. This was important for understanding whether clinicians might expect, for example, paper notes, paper charts, or data visualisations within mobile apps.
6. *How would you evaluate self-tracked data?* This explored the clinician's process of appraising evidence. To explore this deeper, questions were asked about how the participant might judge data if it was obvious that it had been selectively presented (missing data points) or if the patient was obsessed that they had a particular condition.
7. *What actions would you take based on self-tracked data?* This explored the process of clinical decision-making with evidence and how they would weigh self-tracked data against other medical evidence. Questions were asked about the choices they might make, such as if they would approve a surgical procedure based on self-tracked data.

8. *Is it important to have the patient in the room while looking at self-tracked data?*  
This explored the importance of self-tracked data for clinician-patient communication and the patient's role for contextualising the data.
9. *How would your decisions change in different circumstances?* This question was tailored to each participant. For example, a cardiologist was asked about a patient who frequently visits hospital with palpitations, versus a stable patient who only needs infrequent check-ups. This explored the unique opportunities for self-tracked data in different clinical scenarios.
10. *What do you think the future holds for self-tracking in clinical practice?* This was an open question to allow the participant to express any general ideas they have about self-tracking.

#### 6.1.3 Data Analysis

Analysis of the transcripts comprised four stages. First, transcripts were iteratively open-coded using NVivo 12, whereby quotes from the transcripts were arranged into salient themes around how self-tracked data gets used (e.g. checking data accuracy). To ensure inter-rater reliability, coding was conducted by three researchers: myself, Richard Giordano and Max Van Kleek. Second, the themes were inductively categorised into particular work practices and activities (e.g. ensuring data quality). It emerged that clinicians expressed that the use of self-tracked data was part of several distinct activities of a workflow. Thus, the third stage drew on the workflow elements model (Unertl et al., 2010) to consider the actors performing actions (clinician and patient), the artefacts used (e.g. patient self-tracked data), the actions taken, the characteristics of these actions, and the outcomes of these actions. The workflow activities were ordered to form a generalised workflow for using self-tracked data in clinical settings. Finally, these themes were compared to identify generalisable opportunities, barriers, and workflows across different clinical settings. Observing the differences and similarities between the behaviour of clinicians of different roles revealed the more generalisable uses of self-tracked data.

## 6.2 OVERVIEW OF INTERVIEW RESULTS

### 6.2.1 Participants

Thirteen clinicians of a variety of roles and experience took part. Table 14 lists the participants by their years in practice and clinical role. As previously described, recruitment comprised snowballing an initial seed sample of acquaintances into a larger and more diverse sample. An initial set of fourteen acquaintances were approached for participation in the study, of which twelve agreed to take part. As the study proceeded, participants were asked if they knew others who would be interested in taking part, resulting in the nomination of nine potential participants. Unfortunately, most of the nominated potential participants could not participate or did not respond to invitations. As shown in Figure 23, only one participant in the final sample resulted from snowballing. Of the 23 clinicians contacted, thirteen took part, representing a 57 per cent participation rate.

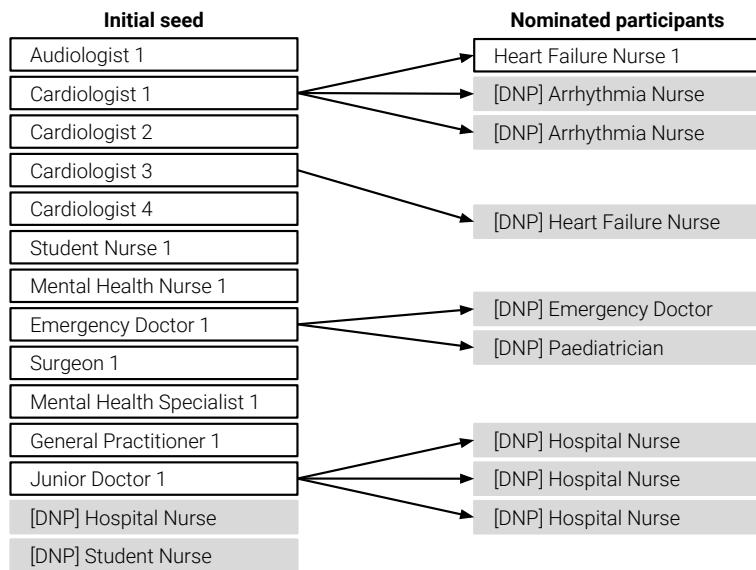
Despite the snowball process being relatively unsuccessful at growing the sample, the final sample spanned a broad range of clinical roles, including cardiologists, mental health nurses, surgeons, student nurses, and general practitioners. Experience ranged from a few years to a few decades in practice. It was expected that junior clinicians in the sample may exhibit different behaviours to more senior clinicians because they may be less dependent on the heuristic thinking which results from years of practice (Kahneman, 2012). Indeed, junior clinicians tended to reflect more on how they had been trained to deal with data, whereas more senior clinicians tended to talk about their subconscious workflows they had developed over time.

Another anticipated difference between junior and senior clinicians was how they engaged with technology. Junior clinicians appeared to have a greater engage-

**Table 14.** Participants of interviews by clinical role, and years in practice.

Participant	Years in practice	Prior use of self-tracked data	Involvement in development of self-tracking tech.
Cardiologist 1	20+ years	Yes	Yes
Cardiologist 3	20+ years	Yes	No
Cardiologist 2	20+ years	Yes	No
Cardiologist 4	20+ years	No	No
Heart Failure Nurse 1	20+ years	Yes	No
Mental Health	6-10 years	Yes	No
Specialist 1			
Mental Health Nurse 1	0-5 years	Yes	No
Student Nurse 1	0 years*	No	No
Junior Doctor 1	0-5 years	Yes	No
Emergency Doctor 1	0-5 years	Yes	No
Surgeon 1	0-5 years	No	No
GP 1	20+ years	Yes	No
Audiologist 1	0-5 years	No	No

\* This participant was still in training.



**Figure 23.** Thirteen participants took part in the interviews. This tree illustrates how the snowball sample was built. Each arrow signifies a referral from one participant to another. DNP indicates an individual who was contacted but did not participate ( $n=10$ ).

ment with technology and talked about specific products they owned and used, such as the Fitbit wearable tracker. Their insights were particularly relevant to clinical practice in the context of self-tracked data, with this generation “having grown up with technology at school and at home, they are infinitely more comfortable with it than their parents are” (Alch, 2000). Capturing the views of junior clinicians was therefore important because they represent the next generation of clinicians and are therefore likelier to encounter forms of self-tracked data in their practice. Capturing the views of senior clinicians was important to understand how training can become subconscious workflows over years of practice.

### 6.2.2 Topics Discussed

The semi-structured nature of the interviews allowed exploration of unique challenges that clinicians face within their specific roles. For example, three cardiologists discussed atrial fibrillation (AF), a chronic heart condition common amongst their patients. The condition causes an irregular heart rhythm and affects approximately two per cent of people at age 65, increasing with age (Go et al., 2001). Appropriate management of AF is necessary to reduce the risk of stroke (Wolf et al., 1991). Within the interviews, it became clear that AF management is influenced by a variety of factors unique to each patient, including caffeine, diet, and alcohol and drug use, so the cardiologists were asked about how relevant self-tracked data could form part of their workflow. Three cardiologists spoke specifically about the use of an app, named AFinity<sup>1</sup>, for tracking atrial fibrillation and how they anticipated using data from the app. It was helpful to ask questions about these specific tools to understand the affordances which make them useful and drill down on specific characteristics of self-tracking which they found effective.

<sup>1</sup>AFinity app for atrial fibrillation patients - <http://lifecour.se/> [Accessed on 18 Aug 2018]

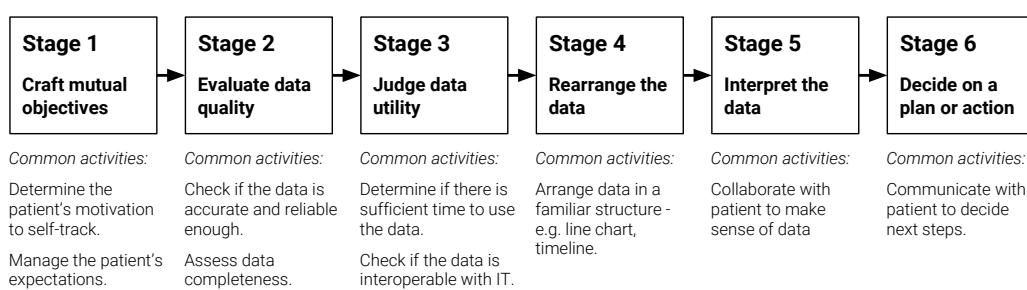
While participants expressed unique scenarios and potentials for self-tracked data amongst the settings they work in, there were commonalities in how these data were perceived to fit within clinicians' workflows. The next section describes a six-stage workflow model which encompasses these commonalities.

### 6.3 A COMMON WORKFLOW FOR USING SELF-TRACKED DATA

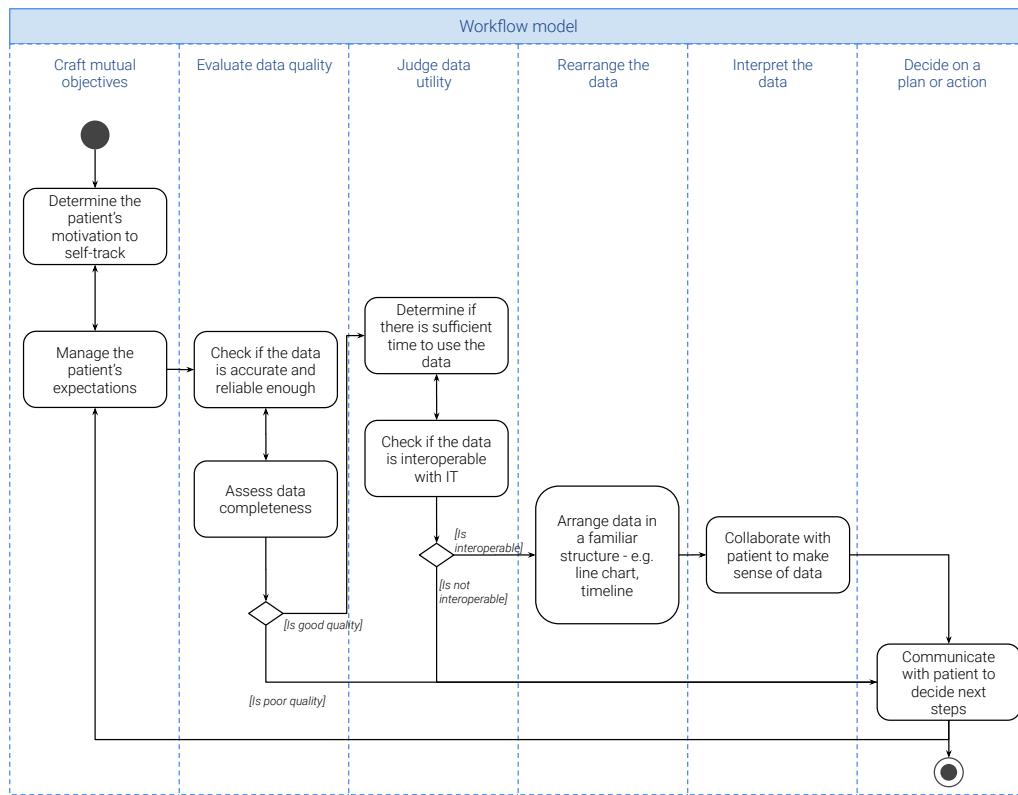
Analysis of the literature and interviews revealed six common stages to using self-tracked data in clinical settings. These stages have been formalised in a workflow model, shown in Figure 24. First, the patient's and clinician's objectives must be aligned to ensure they both are working towards the same goal. Second, the quality of information is assimilated, taking into account the data's completeness and reliability. Third, a judgement is made about how the data can be utilised. Fourth, the data are rearranged into a form the clinician can understand. Fifth, the clinician and patient collaborate on a shared interpretation of the data, thereby building a mutual understanding of the patient's condition. Finally, a plan or action is decided using the self-tracked data as evidence. While each stage takes place in chronological order, they are not necessarily discrete; activities may take place multiple times within different stages. Moreover, while these stages appeared to be common across the clinical settings represented by the population sample, there may be differences in how the workflow appears in other clinical settings.

Using the Workflow Elements Model (Unertl et al., 2010), a graphical model of workflow stages, actors, artefacts, and activities was developed. Figure 25 presents this model as a UML swimlane diagram. The diagram illustrates several discrete activities within each workflow stage. The model has been idealised for illustration, and in practice the workflow would change considerably across individual work contexts.

This section describes the activities within each stage, and how these stages may differ across clinical settings.



**Figure 24.** Common workflow model for using self-tracked data in clinical settings, comprising six stages, each of which describes common activities to using self-tracked data by their approximate chronological order.



**Figure 25.** The workflow modelled as a swimlane UML diagram, idealised for illustration. The diagram illustrates the discrete activities within each workflow stage swimlane UML diagram. In practice, the workflow would change considerably across individual work contexts.

### 6.3.1 Crafting Mutual Objectives

The first workflow stage involves aligning patient and clinician objectives within the clinical consultation. When a patient presents self-tracked data to a clinician, one of the first questions clinicians ask themselves is why the patient engaged in self-tracking; what are the patient's objectives? Understanding the patient's objectives has been long discussed as a key challenge in effectively addressing patient concerns and delivering appropriate care (Krahn et al., 2003). Investigating patient motivation gives clinicians an understanding of what the patient hopes to achieve and what they should expect from the consultation, as well as their underlying reasons for self-tracking. Having aligned, or *mutual*, objectives was seen to facilitate the ability for clinicians and patients to collaborate on the management of a patient's condition and engender mutual trust. As described by *Cardiologist 1*:

Trust of the data would be determined by what the patient's expectations were and drivers for using self-tracking. – *Cardiologist 1*

While participants typically perceived a patient's self-tracking objective as a willingness to engage in their health, some worried that patients may obsess over aspects of their health or have hidden motivations for presenting the data. *Heart Failure Nurse 1* said “some patients can go a little bit over the top and collect everything,” while *Emergency Doctor 1* said patients may obsess over aspects of their health which are much less important than the patient believes:

You do get patients who fixate on it a bit too much. That can be a hindrance, because they say look at all this effort I've put in, and then you glance at it, and say "actually that's not that relevant to what's brought you in today." With blood pressure, it's sometimes a lack of understanding of what blood pressure is and how it's regulated. – *Emergency Doctor 1*

In the context of a patient unnecessarily bringing in a urine volume chart, *Heart Failure Nurse 1* explained that a patient's objective may be to emulate their observed practices of clinicians:

I think they'd seen people do it in their hospital and then thought it would be a good idea at home. But when patients become more stable you don't need that kind of information. – *Heart Failure Nurse 1*

Yet, other clinicians said that a patient's self-tracking objective simply demonstrates good compliance with their treatment plan. Hence, self-tracked data provided clinicians with some assurances that the patient had been taking care of their health:

Self-tracking tells you that the patient is going to be looking at their blood sugars regularly and monitoring themselves, and you know that then you can base your clinical decision on that. You know that if something goes wrong, then they come back and see you, because you know that they take care of themselves and look after their health. – *Emergency Doctor 1*

Understanding a patient's self-tracking objectives was sometimes seen to reveal the underlying characteristics of a patient's condition. For example, *Mental Health Specialist 1* said some conditions and behaviours may motivate a patient to provide false or embellished information:

If you ask about their data, you do start spotting body language changes when you say, "you said this, is that the case?" You see a certain shiftiness or a quick response which is maybe tinged with a bit of irritation or anger, tell-tale signs that something isn't stacking up. – *Mental Health Specialist 1*

In contrast, *Mental Health Nurse 1* said her patients were unlikely to lie about their health:

I don't think people would lie because the kinds of people I work with are generally quite mild anyway. There is a certain complex mental health problem where people might want to manipulate it a bit and feed you a bit more, but I don't get that impression from people generally with what we do. – *Mental Health Nurse 1*

This suggests that approaches to crafting mutual objectives may depend on the clinical role and context of the situation. Indeed, long-term care professionals saw one objective of self-tracking as the patient wanting to contribute towards health decisions, whereas clinicians in acute settings found this conflicted with their objective of focusing on the patient's immediate problems:

In the acute setting it's difficult, because you want to deal with the problem that they've got there and then – why they've been brought in – rather than looking at their general health or doing health promotion. – *Emergency Doctor 1*

More generally, clinicians asserted that self-tracking may lead patients to have unrealistic expectations of their care, such as a patient expecting a correlation within captured information to be sufficient for identifying problems and treatments.

Clinicians described a process of “managing the patient’s expectations” (*Cardiologist 1*) to provide a way for the clinician and patient to agree on the objectives of the consultation and inform the patient of what can reasonably be expected given the patient’s condition.

We manage their expectations by saying, “are you sure your symptoms are likely to be due to this? When we put you on that tablet, we look back at your data there was a drop in your number of episodes by 50 percent, and yet your general well-being was still not good. Do you think it’s possible that your heart condition is not the main reason?” That’s helpful for them because people feel a real release in saying “so what you’re saying is my heart condition probably isn’t as bad as I thought it was”. Bingo! – *Cardiologist 3*

*Cardiologist 1* explained that a lack of patient understanding of their condition stands as the greatest challenge to patient participation in long-term condition management. Self-tracking was perceived to overcome this challenge by enabling data-augmented communication, which improves both the clinician and patient’s understanding and expectations of the patient’s health. As described by *Junior Doctor 1*, self-tracked data could encourage a patient to better understand their condition and therefore empower them in their care:

If a patient can understand their condition better then they understand how to manage their condition better, and if they can manage their condition better then you’re more likely to empower them to take responsibility for their condition. It’s a joint effort. You have to work in partnership with the patient to achieve that. It’s not just the patient’s sole responsibility, but if the patient understands their condition better they’re more likely to trust you as a doctor or nurse. And then doing that, they’re more likely to help themselves and be aware of issues that could happen by interpreting the data. – *Junior Doctor 1*

Crafting mutual objectives was thus seen to be a bidirectional process; the clinician must understand the patient’s objectives and the patient must understand the clinician’s objectives. Objectives can conflict, such as a clinician wanting to find a diagnosis and a patient wanting a drug prescription. To resolve such conflicts, clinicians try to negotiate a mutual understanding of treatments, symptoms, and prognoses. By crafting a mutual understanding of each other’s objectives, the clinician and patient can work towards crafting mutually agreeable objectives for the consultation and eventual purposes of the patient’s self-tracked data.

### 6.3.2 Evaluating Data Quality

A second workflow stage common across clinical settings comprised judging whether data were of sufficient quality to be admitted as clinical evidence. *Quality* entailed several properties of the data, including their accuracy, precision, and reliability. For example, in the context of self-tracking blood pressure, *Surgeon 1* described needing to know how precise the self-tracking equipment was and whether the patient was using it correctly:

There is a question about how precise their equipment is and are they doing it right. But if they bring in the equipment and show you it, you can see that it’s fairly accurate. But I don’t often take things at face value. – *Surgeon 1*

Self-tracked data typically do not explain how the data were produced, the accuracy of the collection tool, or how the patient used the tool, which limited potential use-cases for the data. *GP 1* described a consequence of not knowing the reliability of data as a lack of objectivity:

It's not gone through some objective or analysis of assessment. It won't stand up to that kind of scientific approach. It would be more a commentary, it assists the subjective kind of discussion, the subjective embellishment of what they are feeling. I couldn't use it in any objective way. – *GP 1*

In the absence of reliable information about quality, clinicians' judgements of quality often involved assumptions about the likeliness that the patient followed a rigorous procedure for data collection:

You can usually be fairly confident that what they're doing is right because you've given them a whole education process. Patients that are likely to not be particularly good at that are the ones that aren't actually weighing themselves and bringing you the data anyway. So I'm generally confident if they bring reams of weights on the same scales and the same time I can be fairly confident that its accurate. – *Heart Failure Nurse 1*

The completeness of the data was also considered by clinicians to be an important quality of self-tracked data. Missing data leaves ambiguity around the patient's condition and activities during those periods of time. When discussing potential gaps in a patient's self-tracked heart rate data, *Cardiologist 4* said:

Is it because they were unwell and therefore didn't make the reading, because they were in bed or sitting in a chair at home? Or is it because they were out partying and having so much fun that they didn't bother to make the reading? Unfortunately, missing data is very ambiguous. It could be because people were seriously ill – the condition that you're interested in – or they might have even been away clubbing or on holiday if it was a long gap. – *Cardiologist 4*

Similarly, *Mental Health Specialist 1* was asked about a patient who filled in their mood every morning, afternoon, and evening for a week, but who omitted the occasional measurement:

You've diligently filled in a form, morning, afternoon and evening on Monday, but other days are gaps. So, Sunday morning, you either forgot or you didn't fill it out or didn't see the need to fill it out. – *Mental Health Specialist 1*

*Mental Health Specialist 1* raised the possibility that gaps could be caused by a patient forgetting to take a measurement, and that automatic self-tracking devices could mitigate this. Gaps in automatically collected data would, however, raise questions:

With a Fitbit, there's consistency from start to finish. There wouldn't be the same gaps in recording that there would be in the other charts because the patient might forget. My impression of a Fitbit would be "why is there gaps?" And I can obviously see the spikes in their data. That would be worthy of asking questions. – *Mental Health Specialist 1*

Other clinicians were more confident about the meaning of gaps in the data. In the context of a patient with a heart condition who recorded their general well-being on a scale of 1 to 5, *Cardiologist 1* said that a gap in data collection simply meant the patient was well enough that they didn't feel the need to collect data:

Gaps make me think that they can't be highly symptomatic because they aren't so bothered as to record it. It's an act of omission, and omission means they're fine. – *Cardiologist 1*

Although completeness was a commonly raised quality issue of self-tracked data, clinicians perceived the importance of completeness differently across different clinical settings. In some settings, incomplete data was not a significant concern but instead was seen as an indicator either of wellness or that patients experienced only transient or mild symptoms that did not concern them. Patients would be more likely to keep track of things when they were of most concern to them. Yet, in other settings, missing data was more troubling, provoking questions about the patient's well-being during those times.

One final barrier relating to quality was the need for clinicians to understand what the patient was doing during the time of data collection. Such contextual information is crucial for establishing the reliability of self-tracked data. For example, in the context of blood pressure measurements, *Emergency Doctor 1* said high blood pressure may not indicate a medical problem, but can instead mean “you were excited, you’re angry, or there was something that was bringing your blood pressure up.” In the context of a patient’s chart of their heart rate, *Cardiologist 4* said:

The thing that's missing is what were people doing. Had they had any medication? Had they had a beta blocker? Is this somebody who's got high blood pressure, or some dysrhythmic palpitations? Was this at rest or post-exercise? And it would be good to know the age of the person because, say, 140bpm would not be particularly high for a child, whereas it would be for an 80-year-old. So there's a lot of context to me that's missing for me to make better sense of that. – *Cardiologist 4*

*Surgeon 1* also raised the importance of knowing what the patient was doing when they made a measurement:

It's helpful to have them with you to go “so when you pressed the button here what were you doing?” I suppose it depends on the data and whether it needs contextualising. – *Surgeon 1*

The need to evaluate data quality was crucial for clinicians to admit data as evidence in their decision-making. Understanding how the data were generated and the patient’s self-tracking habits underpinned their judgement of data quality.

### 6.3.3 Judging Data Utility

The third stage of using self-tracked data comprised deciding whether the data could or should be used in the clinical setting. Participants across all clinical roles described barriers to what could be considered *utilisable*<sup>2</sup> data for their clinical settings. Factors which influences the perceived utility of self-tracked data included the time available, the potential for it to be distracting, and the data’s interoperability with health information systems.

Most participants said they are increasingly time constrained in their practice, with pressures to see more patients in shorter windows of time:

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<sup>2</sup>This thesis distinguishes between *utility*, which is the suitability of a product to a given task, and *usability*, which is the ability of a product to be used with ease and intuition (Nielsen, 2012).

We work to really tight, increasingly tighter timetables. In terms of seeing, assessing and producing management plans for patients, our workload does not get lighter, it gets heavier. – *GP 1*

Yet, for clinicians specialising in chronic condition management, putting the time in to utilise a patient's self-tracked data may be necessary to ensure the patient perceives their efforts as worthwhile:

If we're asking patients to go away and adopt self-care behaviours, if they go ahead and do that and present you with something and then you don't spend the time looking at it with them, it kind of devalues the effort that they're putting into it. – *Heart Failure Nurse 1*

*Emergency Doctor 1* explained that self-tracked data will not always apply to the problem needing immediate attention, and it would take time to judge whether the data apply to the current clinical setting. Determining the relevance of self-tracked data may come down to building a better picture of the patient and their circumstances:

Everyone is different. It's all about them and it's what they need and every patient is going to need something different, so the relevance of the data would really depend. – *Student Nurse 1*

*Junior Doctor 1* suggested that the burdens of identifying the relevance and usefulness of self-tracked data could be a source of distraction:

The more information you have, sometimes it might detract away from analysing the root cause of the problem. – *Junior Doctor 1*

Another common concern raised amongst participants was the data's interoperability with health information systems. There appeared to be a common concern that self-tracking devices and their data would simply be too difficult to incorporate into a patient's records. *GP 1* found this particularly hindering:

It's a case of finding devices that interface with the IT system. The devices are of extremely limited value if they are just another part of a conversation. If they integrate with the IT systems so that the data can then be integrated and summarised in a very smart, quick to see format, then it becomes a useful tool. – *GP 1*

Despite time constraints, the potential for distraction, and lack of interoperability, participants seemed to perceive self-tracked data as valuable evidence which can support clinical judgements:

I always think if you've got the evidence there, then it would be quite useful to have it to support your clinical judgement or your reasoning for doing something. – *Junior Doctor 1*

*Cardiologist 1* described patient self-tracked data as 'the only way we have of judging the success of a procedure.' Clinicians described several kinds of information which are not currently available through clinical means but could be made available through self-tracking: quality of life (e.g., the burden of symptoms on the patient's general well-being), symptom frequency and severity (e.g., palpitations or chest pain), and major life events (e.g., death of a family member). Thus, parti-

cipants were optimistic that self-tracked data were utilisable as reliable indicators of a patient's condition where relevant data are otherwise unavailable.

#### 6.3.4 Rearranging the Data

The fourth workflow stage comprises the rearranging of self-tracked data into useful and familiar forms. When asked about prior experiences with self-tracked data, clinicians described patients bringing in data in forms unconducive to their clinical settings, such as handwritten diaries or data from a Fitbit. *Heart Failure Nurse 1* explained that, in the management of heart failure, she would often receive data about weight, blood pressure, and heart rate, but the format of these data differ. 'Tech-savvy' patients are likely to present data on a device or as paper charts, whereas elderly patients are likely to present information jotted down on pen and paper. *Cardiologist 4* suggested that the format of data is often most congruent with the capture, rather than the display, of data:

It's dominated by a format in which you might want to capture the data. It's tempting to say you might want to graph that data but... that would certainly help to indicate when it was going above normal threshold. – *Cardiologist 4*

When participants were asked about how they would expect to see data presented, answers varied between structures familiar to the clinician and structures familiar to the patient. Clinicians described wanting to rearrange information into a form they were familiar with to ensure trends and correlations in the data are made clear. In the context of a patient who provided heart rate measurements over time, *Student Nurse 1* described wanting to draw a line graph to identify trends in their heart rate. Rearranging information was also seen to ensure the efficient use of time. As described by *Audiologist 1*:

It would have to be very simply displayed, not overbearing, or too much information, but so you can see what's going on and go from there, just in terms of time efficiency. – *Audiologist 1*

*Cardiologist 2* described the importance of reducing large quantities of data down to visual or numerical information:

I wouldn't want reams of paper to then have to make my own mind up as to what it is. I want some objective evidence and that could just be visually displayed, graphically displayed, or numerically displayed. – *Cardiologist 2*

Similarly, *GP 1* said he would enter data into the patient's record to form aggregates:

I will get them to leave me a hard copy and then I enter the data into their notes. It becomes useful within the scope of the system, because then it kind of aggregates with the data that we are recording and you can start to see if there is an obvious difference between home data and clinical data. – *GP 1*

Participants' depictions of conducive structures for self-tracked data often placed events in chronological order, resembling a 'patient history'. A patient history is a familiar format to clinicians which comprises a chronological story of medical details leading up to the patient's current condition. This chronological represent-

ation of the patient's health is the basis of medical records (NHS England, 2016) and gives clinicians a view of significant events in the past (Huba and Zhang, 2012). *Student Nurse 1* described filtering down the data to find the most significant parts for contributing to a patient history:

You would read through the data when they get admitted. Anything of concern you would write down for future reference. You wouldn't really use it after that because you've written down everything that you are concerned about. – *Student Nurse 1*

The process of forming a patient history often involves asking the patient about events that took place at certain times. For example, in the context of dementia, *Mental Health Specialist 1* described collaborating with the patient to form a medical history of their life prior to the onset of dementia:

I would do some life history work with them, to understand more about them as individual people prior to becoming mentally unwell. I wouldn't have a baseline of what that person was like before having a diagnosis, so having a written record, or some sort of information about that person's life history, really assists me. – *Mental Health Specialist 1*

Rearranging data was not always seen to be a necessary step in using self-tracked data. *Heart Failure Nurse 1* described a patient who brought in weight graphs that were in a form already helpful for understanding the patient's heart failure:

One guy I was talking to has his weight on nice little graphs that he shows me on his smartphone. He's got it month by month, so he can look back at trends. That's quite helpful for me because I've usually got a trend of what his renal function is doing as well so you can see some kind of correlation. – *Heart Failure Nurse 1*

### 6.3.5 Interpreting the Data

The penultimate workflow stage involves the clinician reading and making sense of the self-tracked data. Much of this stage focused on clarifying ambiguities in the data, such as subjective data. For example, when discussing a diary of a patient's well-being over time, encoded as numbers between 1 (feeling terrible) and 5 (feeling great), *Mental Health Specialist 1* wanted to know what the patient meant by each of these values:

What is the patient's definition of 'terrible'? Because 1 being terrible, 5 being great, what exactly does 2 mean? What is 3? I would want to ask what the difference is between a 2 and a 3. – *Mental Health Specialist 1*

Where self-tracked data were perceived to be subjective, there was ambiguity in the meaning of individual measurements. An exception to this was patients' perceptions of their experiences, of which the subjective nature was considered important. *Cardiologist 1* said:

It's their perception of their quality of life and symptoms that they've had over a long time-frame well documented with drug adherence, correlated with other things that have been going on in their lifestyles that allow us to get a much better understanding of what's going on... There is such a difference in perception of symptoms between and within patients at different times. – *Cardiologist 1*

Cardiologists often deal with heart-related symptoms (such as palpitations) which are distressing to patients but not necessarily life-threatening. In the management

of atrial fibrillation, a procedure in which part of the heart is destroyed (atrioventricular node ablation) can reduce a patient's symptoms (Camm et al., 2010). This procedure carries risks, does not improve prognosis, and the improvement is often temporary, so the decision to undertake it will usually be based on the severity of the patient's experiences (Camm et al., 2010). *Cardiologist 2* argued that a patient's subjective experience provides clinicians with the necessary information about patient experience to determine whether such a procedure is appropriate:

Most of the procedures we do for atrial fibrillation are generally for symptomatic gain. So it's the patient's perception of symptoms that's more important than actually what they're objectively getting. – *Cardiologist 2*

*Cardiologist 3* placed a high degree of confidence in patients' subjective information:

There's an argument that the data can't be wrong because it's what the patient is receiving. People who are anxious often exaggerate a situation – we're all used to that – but one thing that's quite interesting is the concept that it could be wrong. I mean, they're describing their perception of what's happening to their body so in some ways it's difficult to say it could be wrong. – *Cardiologist 3*

Another source of ambiguity was missing data, which often led to different interpretations by different participants. For example, *Cardiologist 1* assumed missing heart rate recordings would indicate the patient is well, while *Mental Health Specialist 1* assumed missing recordings would indicate the patient was unwell. It is possible such ambiguities present a danger where incorrect assumptions are made about the meaning of data (or lack thereof). For example, it may be assumed missing data indicates the patient was too unwell to take the measurements, while they were, in fact, just not adhering well to data collection, which could in turn lead to unnecessary procedures. To overcome such ambiguities, clinicians often rely on patients recalling past events to 'fill in the blanks' in their data. In the interviews, several clinicians described the importance of talking with patients to find out what happened during ambiguous periods in the data:

There are conditions where people die, so it's important to know if they're at risk. You can show them how few diary entries they've made and say "you haven't been filling in the diary. Is that because you feel okay?" – *Cardiologist 3*

Similarly, *Mental Health Nurse 1* described engaging in conversation with patients to understand more about what has been recorded.

A diary can be a bit vague with what you can find out from it. You can't get people to write absolutely everything down, but you might notice that at certain times of the day things are worse. You go through it with them and you see if they notice any patterns, and then I might pick up on something that they haven't picked upon. – *Mental Health Nurse 1*

However, as *Cardiologist 1* explained, recall can be unreliable.

Brains aren't wired to precisely relate what we were doing at specific times. A patient may remember going to a football game on Saturday, and had bad palpitations during it, because they can link it to an event. But in the great majority of consultations, it's a very rough judgement. – *Cardiologist 1*

Despite the potential flaws of self-recall, clinicians stated that, whilst in a consultation with a patient, self-tracked data would trigger questions about salient events in their data, thereby facilitating more effective communication. *Cardiologist 3* said, “a diary would be a really useful way of them being able to show you what’s happened to them because we can talk about it by reminding themselves what they’ve written down”. Moreover, it was mentioned that self-tracking tools may provide more accurate data than patient recall because of the proximity to events which are happening. *Cardiologist 2* explained:

Patients say, “I may get one episode a week,” or something like that, which doesn’t really give you a proper time-frame. I don’t think when people think back on it they actually get an accurate reflection of what it is. So having it diarised on a daily basis, I think, is a much better and accurate way of evaluating that data. – *Cardiologist 2*

Thus, a patient’s presence during data interpretation, although not considered essential, was perceived to deepen a clinician’s understanding of the patient’s condition.

#### 6.3.6 Deciding on a Plan or Action

The final workflow stage involves the clinician taking an action as a result of using the self-tracked data. When working with patients with long-term conditions, such as diabetes, clinicians tended to propose using self-tracked data as a basis for treatment planning and interventions. For example, if a diabetic patient provided data showing consistent low blood sugar, *Emergency Doctor 1* said he would immediately change their insulin dose. Similarly, *Cardiologists 1, 2, and 3* described using such data to justify surgical interventions for long-term heart conditions. Conversely, *Junior Doctor 1* suggested that self-tracked data alone are not normally sufficient to deliver an intervention. Instead, it helps to decide whether to pursue further investigation, such as medical tests, examination, and consultations with other clinical specialists.

The actions that clinicians were prepared to take based on self-tracked data varied by clinical setting and reflected their distinct clinical training. Clinicians in chronic care settings seemed more willing to use self-tracked data in deciding on possible interventions. There were two contributing factors to this decision-making process. First, self-tracked data were often seen to be the only form of evidence available to describe the patient’s health condition over a long period and between consultations. Information about symptoms, the patient’s subjective experience, and medication compliance were deemed to be important when deciding on chronic conditions. Second, taking actions as a result of self-tracking was seen to engage patients in their care and ensure patients know the risks of interventions:

It allows you to sit down with the patient and say, “if we look at a scale of symptoms, you rank low compared to others. Therefore, your potential gain from this procedure is less than for others. But if you accept that, and understand the risks, then that’s fine.” It gives you a stronger way of counselling the patient. – *Cardiologist 2*

This collaboration reflects classical models of shared decision-making: patient and clinician are present; they share information; they build a consensus about preferred treatments; and, an agreement is reached on which treatment to implement (Charles et al., 1997). Self-tracking was therefore seen by *Junior Doctor 1* to enable a move away from paternalistic decision-making, toward more collaborative decision-making:

We're moving away from a paternalistic model of medicine where the doctor tells the patient what to do, towards a partnership approach of empowering the patient to be more responsible for their condition. Involving data and trying to get patients to understand it will help them understand their condition better, and minimise risks with their condition. – *Junior Doctor 1*

Self-tracked data were seen to open the potential for greater co-construction and co-evaluation of patients' treatment plans. For example, *Cardiologist 3* wanted patients to take greater overall responsibility in the management of heart conditions:

Most patients want to take control of their own care. If we give them the tools, they will. But it's not our job to police them. People don't understand that. I can recommend someone who's just had a heart attack and nearly died to stop smoking. It's not my job to stop them smoking, it's my job to give them the information. If they enjoy smoking so much that they're prepared to die of it, I fully support their decision. If they're getting AF and don't want to monitor it, that's their choice. But we give them the tool to do it if they want to. – *Cardiologist 3*

Moreover, the rising demand on health services and the increasingly automated consumption of self-tracked data may make use of such data a more typical and necessary part of a clinical workflow:

We'll see much more automated care based on data the patients capture delivered by algorithms and decision support tools. It's an essential part of the future of the health service. Without it, the health service is not really sustainable because we don't have enough clinicians to keep a safe eye on all the patients who have complex long term conditions. – *Cardiologist 4*

Participants usually described the process of deciding a plan or action as involving the patient, and since these interviews did not involve observing a doctor and patient interacting, it is difficult to know how these interactions take place. This workflow therefore considers the stages up to the deciding an action or plan, and to understand steps thereafter would require observation of doctors and patients interacting, which was out of scope for this research.

#### 6.4 MAIN FINDINGS

Three main findings emerged from this study. First, there appeared to be common tasks across different clinical settings for working with self-tracked data. These tasks pertained to assimilating data quality and safely interpreting information. Second, clinicians expressed a need to include patients as collaborators in interpreting self-tracked data to contextualise information and come to a mutual understanding around the patient's condition. Third, use of self-tracked data parallels with a shift in practice from paternalistic care, where the patient is a receiver of care, to participatory care, where the patient is a stakeholder in their care.

These findings are explored further in the next study, where clinicians co-designed a tool for using self-tracked data which highlighted the importance of patient participation and designing for unique clinical workflows.

### 6.5 CHAPTER SUMMARY

This study involved interviews with 13 clinicians of several clinical roles to elicit their experiences with self-tracked data to identify common workflows amongst diverse clinical settings. In the first workflow stage, *crafting mutual objectives*, clinicians aimed to craft mutual objectives for the consultation by having a discussion about self-tracking. In the second workflow stage, *evaluating data quality*, clinicians aimed to identify if the patient's self-tracked data were of sufficient accuracy and completeness to be used. In the third workflow stage, *judging data utility*, clinicians determined how they could use the information, which depended on their time constraints and the data's interoperability with healthcare IT systems. In the fourth workflow stage, *rearranging the data*, clinicians tried to arrange self-tracked data into more familiar forms. In the fifth workflow stage, *interpreting the data*, clinicians aimed to collaborate with patients to form an understanding of the meaning of the data. In the final workflow stage, *deciding on a plan or action*, clinicians determined the appropriate action to take based on the data.

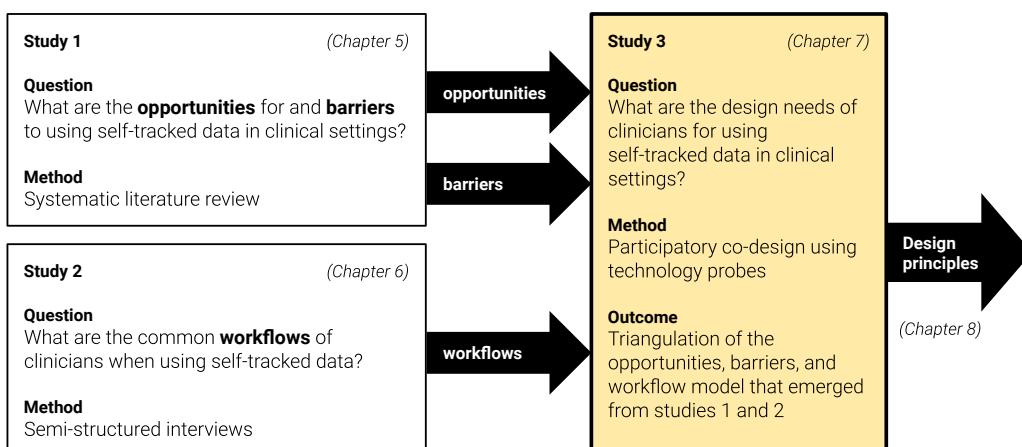


This chapter details the findings of a participatory design approach to investigating the third and final research question: *what are the design needs of clinicians for using self-tracked data in clinical settings?* As illustrated in Figure 26, the principle behind the participatory approach was to collaborate with clinicians on designing a tool for using self-tracked data in the management of chronic heart conditions. This chapter begins by describing the participatory design method used, followed by the findings from the mockup workshops and technology probe interviews.

### 7.1 METHOD: PARTICIPATORY DESIGN

As described in Chapter 4, the intention was to use a participatory design approach to achieve a mutual understanding between the researcher (me) and the users (clinicians). Three related approaches helped guide the design of this methodology: user-centred design, scenario-based design, and participatory action research. Each approach has merits and limitations for this research, as listed in Table 15.

User-centred design pre-dates participatory design and focuses on how the technology being designed will meet the user's needs (Sanders, 2003). An important concept within user-centred design is that a researcher acts as a communicator between the designer and the user, thereby offering measurable interpretations of usability, such as effectiveness, efficiency, safety, and utility (Abras et al., 2004). Users are iteratively shown prototypes of the product throughout the design cycle, and feedback is relayed to designers to make adjustments (Abras et al., 2004). In this process, the user is not part of the team, but rather the researcher takes on responsibilities of communicating between user and designer, reducing the burden on both (Sanders, 2003). This is in contrast to participatory design, where the roles



**Figure 26.** Study 3 focused on the participatory design of a clinical tool for using self-tracked data.

**Table 15.** Five potential participatory approaches are displayed in this table. The merits and limitations applicable to this research are presented for each, synthesised from the discussion in Chapter 4.

Approach	Merits	Limitations
User-centred design	Sets usability goals for design; researcher maintains research autonomy; design process is typically fast; can focus on the usability goals of the many.	Testing with users may be difficult if they have not been involved in the design process.
Scenario-based design	Considers usability of software based on scenarios; design process is typically fast; can focus on the usability goals of the many.	Does not directly involve stakeholders; scenarios may not consider the needs of sub-populations.
Participatory design	Involves stakeholders in design; prompts deep discussions about problems and design solutions.	Happens over a long period of time, so participant attrition is a problem; focuses on the few, rather than the many.
Participatory action research	Involves participants in research interpreting research data	Happens over a long period of time, so participant attrition is a problem; focuses on the few, rather than the many.

of the designer and researcher are merged, and the user is the part of the team, which gives them an empowered role within the design process (Sanders, 2003).

The second approach, scenario-based design, uses narratives of envisioned usage scenarios to guide designers in the development process (Rosson and Carroll, 2009). Like user-centred design, scenario-based design focuses on understanding how users will use the system within their work practices and settings (Carroll, 2000). However, it differs to user-centred design by using scenarios – stories comprising a sequence of actions and an outcome – to enable rapid communication and mutual understanding between designers and users, often using sketches and storyboards (Rosson and Carroll, 2009). This is distinct from a typical design approach, where users may be overwhelmed by technical jargon (Wood, 1997) and where designers may not have enough information to evoke reflection of users' needs (Carroll, 2000). While participatory design aims to achieve this mutual understanding by facilitating discussion between users and designers within workshops, there is no strict regimen of using scenarios (Kensing and Blomberg, 1998).

The third approach, participatory action research, bases its approach on a partnership with the community to identify problems and inequalities, in turn enabling action for improvement to the practices and settings within the community (Kemmis et al., 2013). Participatory action research comprises iterative reflection cycles, in which data are collected and analysed for the purpose of achieving action (Baum et al., 2006). Like participatory design, this approach focuses on addressing how the interests of the powerful (in this case, the researcher) can often influence or overwhelm the users' interests (Baum et al., 2006). Participatory action research

therefore advocates for power to be shared such that the roles of the researchers and the researched become blurred (Kemmis et al., 2013). A fundamental difference with participatory design is that, while participatory design seeks to change the world by delivering meaningful innovation (Björgvinsson et al., 2010), participatory action research takes this a step further by using this innovation as a research tool for better understanding communities (Baum et al., 2006).

While participatory design gives users greater empowerment within the design process by involving them directly in design workshops (Schuler and Namioka, 1993), the researcher's academic role within user-centred design provides a way to gain an understanding of usability. Therefore, within this research, the researcher and the designer, who are one and the same, emphasises applying academic rigour to analysing usability within discussions with the users. This strikes a balance between empowering the users in the design process while the researcher maintained control over the direction of the research. The need for a participatory approach which engaged users in cooperative design (co-design) whilst maintaining researcher autonomy led to the decision to use the MUST method (a Danish acronym for "theories of and methods for design activities"). MUST focuses on analysing the needs of users in the generation of a co-designed technology product in an organisational setting (Kensing et al., 1998) and defines six principles:

1. *Participation*: participation of users enables mutual learning between the designer and users to ensure the tool corresponds with the user's needs.
2. *Close links to project management*: participatory design requires quality control and dealing with conflicting goals.
3. *Design as a communication process*: at the outset, designers have knowledge of technological approaches and users have knowledge of their work practices. Communication between these actors is essential to ensure mutual understanding of work practices and technological solutions.
4. *Combining ethnography and intervention*: while ethnographers avoid changing the phenomena they study, interventionists aim to elicit reactions by changing the organisation. Participatory design should use a combination of both: ethnography (through, for example, interviews) to measure the needs of users and intervention to observe users' perceptions of changes (through, for example, workshops). Interviews and workshops are used in this study to capture both perceptions.
5. *Co-development of IT, work organisation, and users' skills*: participatory design should consider the resources available within the work domains and the individual skills of users so that systems are designed to be usable. For example, it may be important for a tool for using self-tracked data to interoperate with existing clinical information systems.
6. *Sustainability*: there should be a balance between the utilisation of technology and protecting existing work practices. Consequences of the technology in the workplace should be considered and balanced against the potential for negative impacts to how users currently work; for example, if a system

is difficult to use, workers' work practices may become more difficult or stressful.

The MUST principles delineate a process of forming a mutual understanding between the designer and the users while ensuring existing work practices are respected. These are important properties for this research because it could uncover to what extent self-tracked data could be useful with respect the common workflow model described in Study 2.

The participatory design method used in this research built on these principles by splitting the process into two stages. First, mockup workshops were used to engage clinicians in a creative process while eliciting their perspectives on self-tracked data. The second stage involved the development and deployment of a technology probe (Hutchinson et al., 2003) amongst clinicians to find out to what extent the probe met their needs. Below, the participants are first described, followed by a description of both stages of the participatory design.

### 7.1.1 Study Context and Participants

Unlike studies 1 and 2, which focused on several clinical settings, Study 3 focused specifically on cardiology. This was deemed to be beneficial because it allowed deeper analysis of the needs of an individual setting rather than the generalised needs across multiple settings. As found in Study 2, there are differences in how clinicians work across different settings. For example, in the long-term care setting of atrial fibrillation, if a patient rated their symptom severity by some arbitrary score which defined their subjective experience of that symptom, it could help a cardiologist determine whether they should receive a particular treatment. However, such subjective scores were deemed to be less useful in, for example, emergency care. This presented a challenge for investigating several clinical settings at once, motivating the selection of a single clinical setting as the study context.

Cardiology offered the largest selection of participants from Study 2, so was chosen to be the focus of this study. Four cardiologists, one mental health specialist with stroke management expertise, and one student cardiac nurse were therefore invited to participate in this study. Each participant took part in both a mockup workshop and an interview, except *Mental Health Specialist 1* who only took part in the workshop and *Cardiologist 1* who only participated in the interview. The attendance of participants throughout this study is listed in Table 16.

**Table 16.** Participant attendance throughout the participatory design stages. Interview participants within the field of cardiology were selected for participation co-design workshops and feedback interviews.

<b>Participant</b>	<b>Study 2</b>		<b>Study 3</b>	
	<b>Interview</b>	<b>Co-design workshop</b>	<b>Feedback interview</b>	
Cardiologist 1	✓			✓
Cardiologist 3	✓	✓		✓
Cardiologist 2	✓	✓		✓
Cardiologist 4	✓	✓		✓
Heart Failure Nurse 1	✓			
Mental Health Specialist 1	✓	✓		
Mental Health Nurse 1	✓			
Student Nurse 1	✓	✓		✓
Junior Doctor 1	✓			
Emergency Doctor 1	✓			
Surgeon 1	✓			
GP 1	✓			
Audiologist 1	✓			
<b>Total</b>	13	5		5

### 7.1.2 Procedure Overview

The procedure comprised two stages:

1. *Mockup workshops*: clinicians co-designed tools for using self-tracked data in clinical settings. This stage resulted in several ‘feature artefacts’ which exhibited several possible methods of presenting self-tracked data.
2. *Technology probe*: a functional software prototype was built from the feature artefacts. Clinicians were invited back to be asked what they thought of the software prototype and if it fulfilled their needs.

Both stages were audio recorded and transcribed. The procedure and findings for each stage are reported in depth in the next sections of this chapter.

### 7.1.3 Data Analysis

Like the previous studies, thematic coding was applied to the transcripts to pick out important points of discussion. Themes were checked with another researcher and agreement rates were calculated. Disagreements were resolved with discussion.

In the Stage I, the themes were grouped into three topics pertaining to the main objectives that clinicians aimed to achieve through the tool and how these objectives could enable opportunities, overcome barriers, and fit within the workflow model identified within the prior stages. The three main topics which emerged in Stage I served to structure the analysis in the subsequent technology probe stage. These topics were: *data representation*, which included matters pertaining to how data were made available or visualised; *collaborative investigation*, which pertained to how the clinician could collaborate with a patient towards investigating a clin-

ical problem; and, *audit trail* which concerned the provision of information which could facilitate auditing the data trustworthiness.

#### 7.1.4 Procedure Critique

The participatory design procedure was initially designed to engage groups of participants in workshops, but due to time constraints of participants each workshop only involved one participant and one researcher. This could have limited the insights from doctors having discussions with each other, in turn reducing the opportunity for serendipitous discussion. However, one-on-one workshops enabled the researcher to have greater control over the proceedings, meant that feedback was not dominated by just a few of the most vocal participants (Bradbury-Jones et al., 2009), and afforded a deeper understanding of the perspectives of each individual doctor.

The participatory design process was exploratory in nature and did not aim to result in a usable tool for clinical use of self-tracked data. Instead, the process aimed to engage participants in a creative process to understand their lived experiences and needs of such a tool. This is why the design process begins with sketches which participants were encouraged to modify towards their needs. Existing tools were alluded to (described below as *vignettes*) when sketching these mockups, which highlighted how participants' ideas were grounded in the merits and pitfalls of existing technology (Fischer, 2017).

The presence of a designer in the workshop enabled rapid prototyping of the participants' ideas. The need for rapid prototyping meant that the designs had usability problems which would normally be resolved through careful design and iteration (Abras et al., 2004). For example, the technology probe introduced in Section 7.3 lacks Y-axes which could have made charts more readable. However, the designs aimed to reflect ideas which were *useful* for clinicians in their workflows, not necessarily *usable* (Fischer, 2017).

## 7.2 STAGE I: MOCKUP WORKSHOPS

### 7.2.1 Procedure

Before the mockup workshops began, several initial mockups were developed based on the findings from Studies 1 and 2. These ‘feature artefacts’ were hand drawn or computer-generated and served to initiate discussions in the workshops. For example, findings from Study 2 suggested certain data would be best displayed as a line chart, so a line chart was sketched for the purpose of discussion. The artefacts were not designed to be concrete solutions to previously identified problems, but rather served as stimuli for cooperation which could be iterated on, improved, or rejected. Each feature artefact is described later in this section.

Mockup workshops were then conducted in which clinicians designed tools for using self-tracked data in the management of heart conditions. Workshops were selected as a method because they allow open discussion between designer and participant and empowered both to participate equally (Kensing and Blomberg, 1998). There was no script or set order of discussions. Instead, participants could take discussions in directions which they considered important. Democratising design in this way was considered an important aspect of participatory design because the designer was not a domain expert and the participants were the potential users of the tool (Abras et al., 2004).

The participants took part in one mockup workshop each (with exception of *Cardiologist 1* who could not participate) which aimed to collaboratively sketch, critique, and iterate on feature artefacts. Each workshop began by the designer presenting the feature artefacts, after which participants could provide their interpretations, opinions, and reflections on the strengths and weaknesses of the artefacts. Participants could interact with the artefacts, and some arranged the artefacts to suit their needs using pen and paper or highlight how parts of the design could function.

### 7.2.2 Overview of Results

The workshops facilitated important discussions of potential challenges and opportunities for using self-tracked data. Focusing on the single work domain of cardiology helped drill-down on these important and often bespoke concepts, which would have been much more difficult or overgeneralised by including many work domains.

Thematic analysis was applied to the transcripts as per Section 7.1.3. Three overall topics emerged, under which 18 individual themes were identified. The workshops initially centred on applying clinical data representations to self-tracked data (topic 1). As the workshops progressed, mockups also addressed the need for collaborative investigation (topic 2) and providing an audit trail (topic 3). Each topic comprised *vignettes*, which were digressions specific to a particular problem, and *mockups*, which were collaboratively designed solutions to problems. In this section, vignettes and mockups are collectively referred to as *artefacts* and serve as the subjects of discussion and analysis. Figure 27 illustrates the order in which

the artefacts emerged, and how the workshops digressed into different the three different topics.

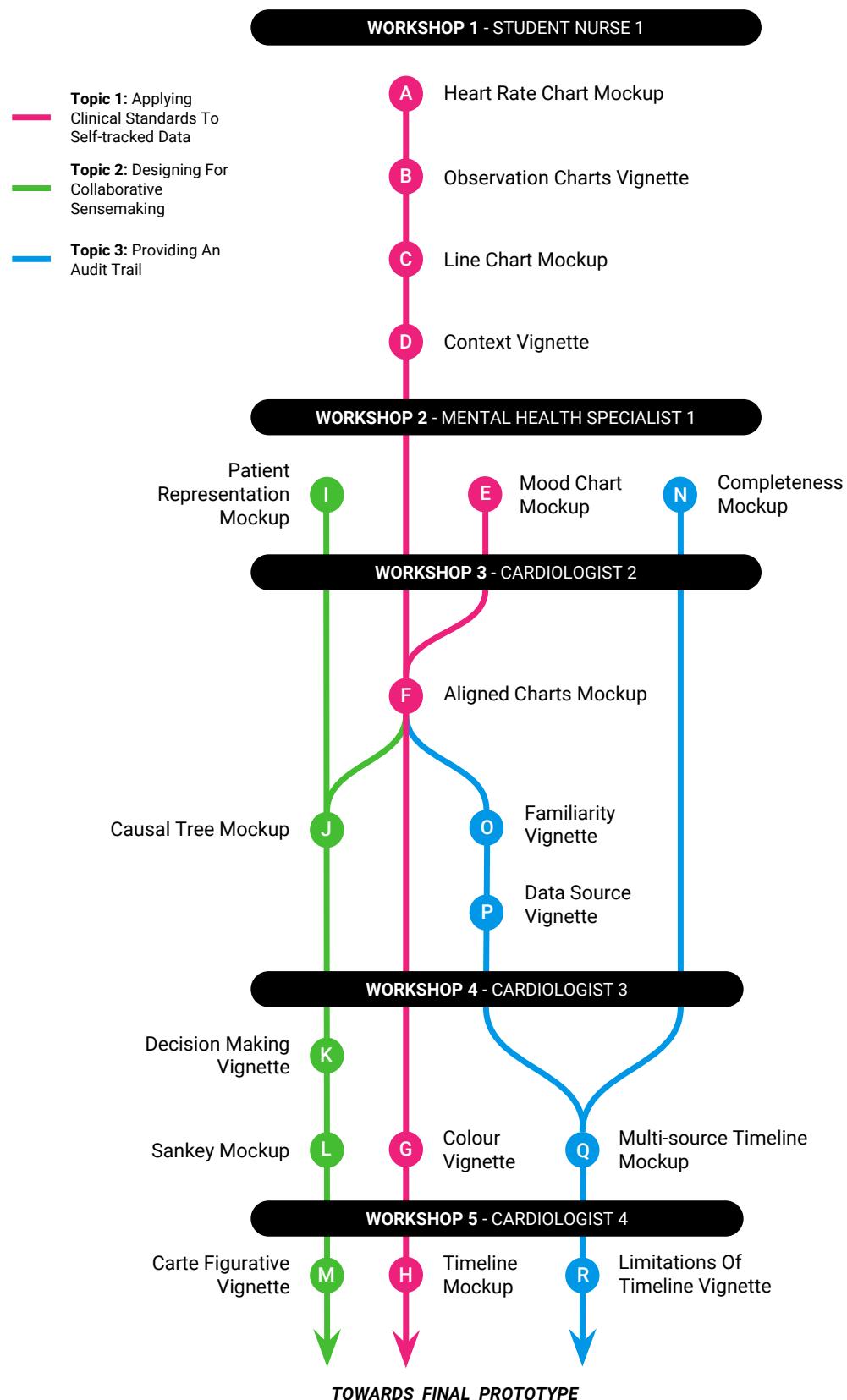
The themes were checked by a second researcher, finding full agreement with three top-level themes, but some disagreement with three of the identified artefacts. This represented an 86 per cent agreement rate of total themes, which comprised the three topics and 18 artefacts. The three disagreements are outlined below.

For *Artefact B: Observation Chart Vignette*, the reviewer suggested separating out discussion around digital observation charts into a separate theme. However, since there was very little discussion with the participant around digital observation charts, we resolved to not create a separate vignette.

For *Artefact J: Causal Tree Mockup*, the reviewer suggested that the chart was unclear and could have misled the participant into finding causal relationships between events where they did not necessarily exists. We resolved to keep the theme because this was the artefact shown to the participant and therefore was important to contextualise the findings. However, in the later stage of this chapter, the eventual pitfalls of the designed technology probe are discussed with regards to the potential influence on participant's responses.

Finally, for *Artefact K. Decision Making Vignette*, the reviewer initially disagreed with this theme because it derived from discussions with a participant around the TV show *House M.D.* which has inaccurate portrayals of medical practice. We resolved to keep the theme because it was a participant's observation and therefore a reflection of their perceptions.

The remainder of this chapter discusses each topic, presenting and analysing the artefacts within each.



**Figure 27.** Three topics emerged during the five workshop sessions. This diagram shows how the artefacts (represented by letters in the circles) iterated on previous artefacts discussed within each topic. Each topic is denoted by a different colour.

### 7.2.3 Topic 1: Data Representation

Initial input from participants in the mockup workshops centred on using clinical standards for displaying data. This included discussions about charts which clinicians were familiar with, the meaning of colour, and the representation of context. Eight artefacts emerged within this topic, with each described below.

#### 7.2.3.1 Artefact A: Heart Rate Chart Mockup

The first artefact was prepared by me prior to the mockup workshops. As shown in Figure 28, this artefact comprised a scatter plot of a patient's heart rate over a period of a week roughly sketched on paper. It included two notable qualities designed to provoke discussion: it was hand-drawn, with obvious inaccuracies in the axis; and the frequency of the heart rate data was inconsistent. *Student Nurse 1* was the first participant to see this mockup and commented that the chart's usefulness would depend on the circumstances:

It depends on how accurate data need to be in that ward and what the patient is coming in for. If they are coming in with just a high heart rate, they probably wouldn't be coming in just for that because they wouldn't be bedded just for that. If they were coming in for chemotherapy, we need to monitor heart rate because if they spiked during chemotherapy, then you would be more concerned because you don't know if it's the chemotherapy that is causing this or something which would be a very big concern, or if it's just something else that they have had all along. – *Student Nurse 1*

The student nurse went on to explain that the chart mockup was similar to standard 'observation charts' used within his practice.

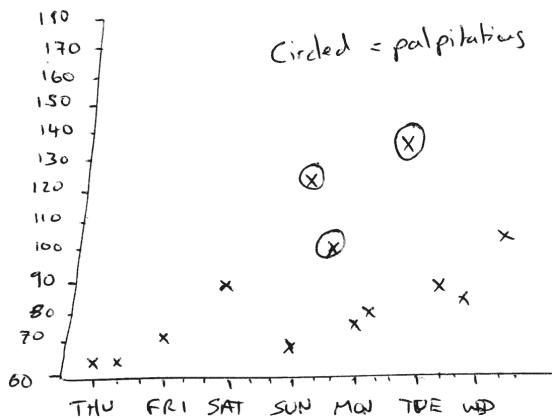
#### 7.2.3.2 Artefact B: Observation Charts Vignette

Observation charts were perceived by *Student Nurse 1* to be crucial to nursing practice, particularly when done digitally via tablet computers:

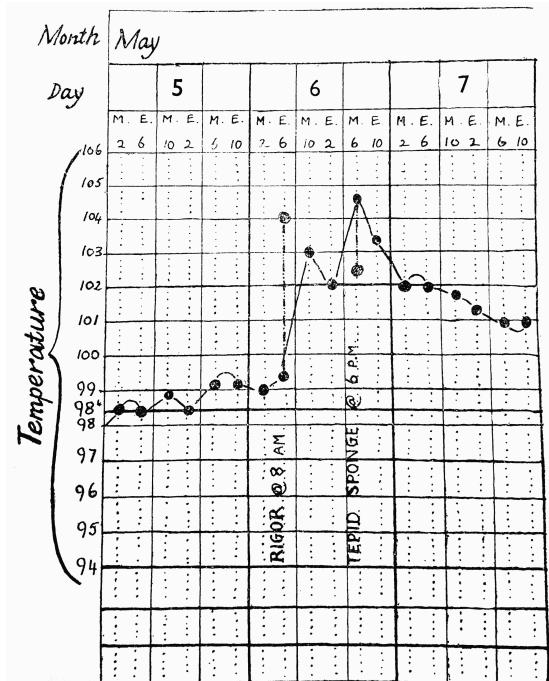
You do everything in observation charts. You enter it in to the tablet, and then you get everything in charts. The chart you showed me [Artefact A] could be put as a graph any way you want. It's much better than the hand notes. – *Student Nurse 1*

He explained that tablets were only used in one hospital he had worked at and paper observation charts were more common.

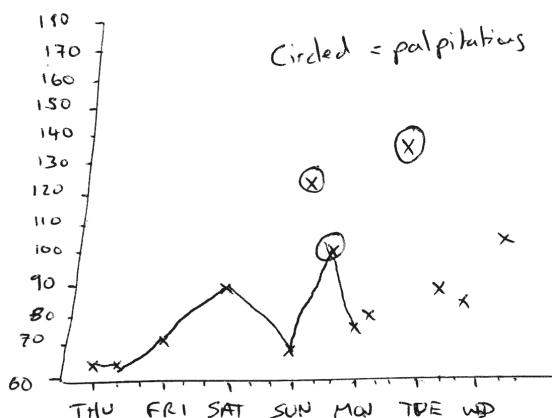
Paper observation charts are often found on a clipboard at the end of a patient's bed and have been described as "the mainstay of detecting patient deterioration" (Chatterjee et al., 2005). Indeed, a 1956 book on the practice of nursing describes the importance of recording a patient's temperature, blood pressure, and heart rate for the purpose of observing changes over time (Gration and Holland, 1956). Figure 29 shows a temperature chart presented by Gration and Holland, which uses lines to highlight trends. This practice of recording and plotting temperature remains in common use today, though, in practice, observation charts vary between clinical setting. In a review of observation charts used in a hospital in London, Chatterjee et al. (2005) found several common features: body temperature plotted as a line chart, blood pressure plotted as a line chart, heart rate plotted as a line chart and written as a number below, respiratory rate written as a number, and oxygen saturation plotted as a line chart.



**Figure 28.** Artefact A: chart of a patient's heart rates every day over a week, sketched by the designer. Each instance of palpitations is circled.



**Figure 29.** Artefact B: temperature chart with trend lines from Gration and Holland (1956), depicting a typical ‘observation chart’.



**Figure 30.** Artefact C: *student nurse 1* drew a line on the HR chart to identify trends and spikes. The line is incomplete and skips a data point.



**Figure 31.** Artefact D: Fitbit was raised as an example of demonstrating context. The app shows what a person was doing during high heart rate.

Observation charts have been iterated over decades and have adopted characteristics which ensure patient safety. For example, Chatterjee et al. (2005) found plotted values on observation charts are better detected than written values, thereby preventing misinterpretation and subsequent medical errors. On using a line chart over other forms, *Student Nurse 1* explained that time constraints limit a nurse's ability to, for example, plot a bar chart. Line charts are quick to draw, yet informative enough to identify trends and patterns.

The handy thing about observation charts is that you see an X and you can just mark it off. Remember, you are doing, say, 36 patients every 4 hours, so it's quite demanding, plus you are doing everything else. – *Student Nurse 1*

To ensure safe and efficient interpretation of information, line charts became the typical visualisation for representing numeric measurements over time in subsequent mockups.

#### *7.2.3.3 Artefact C: Line Chart Mockup*

The digression around observation charts led *Student Nurse 1* to modify Artefact A by sketching a line over the data points, as shown in Figure 30. Immediately this enabled a quicker analysis of the data:

You join the dots and you see a trend. You link it up to see if it spikes. That one [pointing to highest heart rate measurement on the line] is really unusual because usually our patients are lying in bed all day, so you are expecting to see just a steady heart rate, or maybe a slight up down and up down. But not dramatic, because they are just lying in bed all day. If you saw dramatic spikes like that you would be concerned. – *Student Nurse 1*

Instances of high heart rate were not necessarily cause for concern. Rather, instances of high heart rate drew concern if they were 'spikes' outside of the patient's normal range. Adding a line to the chart enabled identification of spikes because it indicated the rate of change of the patient's heart rate. The line drawn by *Student Nurse 1* is incomplete and skips a data point, possibly because the misshapen axes on the original sketch caused confusion.

#### *7.2.3.4 Artefact D: Context Vignette*

While discussing Artefact C, *Student Nurse 1* highlighted the need to understand the context of measurements, such as whether the patient had been running prior to a spike in heart rate:

You don't know what they were doing. If they just went for a run their heart rate would be higher. Or this could be their resting heart rate. – *Student Nurse 1*

He raised Fitbit as an example of a product which may provide context by showing what a person was doing during high heart rate:

Would a Fitbit tell you what you were doing at the time? It would say the time of a measurement, but would it say you were running at the time? If you were running and your heart rate was high, that would be normal. If you were resting, that wouldn't be normal. – *Student Nurse 1*

As shown in the screenshots of the Fitbit app in Figure 31, Fitbit provides information about a user's physical activity which could contextualise heart rate data. In

the screenshots, the user is shown to have a moderately high heart rate but is also seen to have completed a 2.1-mile run, suggesting a higher heart rate would be expected. The screenshots also describe the user's physical activity over time as steps walked; these could further contextualise the user's heart rate.

*Student Nurse 1* explained that if contextual information were available, such as a patient's physical activity, then he could understand whether a particular heart rate value would be normal or unusual:

If someone came in with that chart, you could ask "what were you doing at the time?", because I can tell you right now, if I went for a run and you checked it, that would be pretty normal for me straight after. But if they were resting and they had done nothing all day then I would be very concerned and I am sure they would feel quite ill. – *Student Nurse 1*

*Student Nurse 1* also raised the importance of understanding who the patient is, including their medical history:

Activity data might lead you to be concerned about a spike, but it would also depend on the patient. If it was a 55-year-old man who had high heart rate for no reason, then you would be concerned. If he is in hospital, we can check if he had a change in medication. But outside the hospital, you wouldn't be able to. You'd have to ask if he went to the doctor and did he change your medication in the last week. – *Student Nurse 1*

Presenting contextual information thus became a pertinent problem in the next few mockups. This concluded the first workshop.

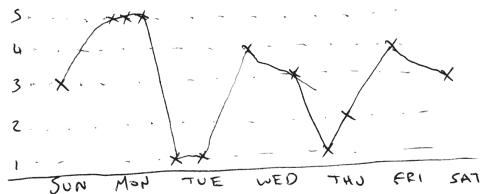
#### 7.2.3.5 *Artefact E: Mood Chart Mockup*

In the second workshop, *Mental Health Specialist 1* was presented with a hand-drawn chart of a patient's mood – rated between 1 (very unhappy) and 5 (very happy) – over time, shown in Figure 32. Similar to *Student Nurse 1*, *Mental Health Specialist 1* explained that without understanding the events which happened around the patient's recordings, the data's meaning was unclear:

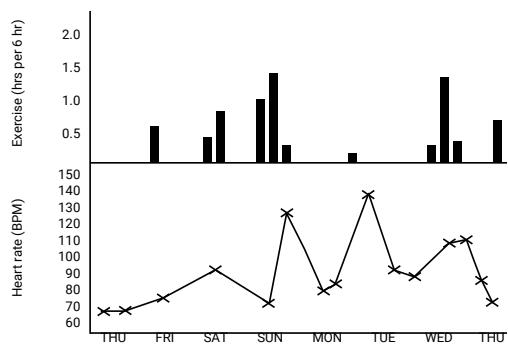
What were they doing at that particular point? What sorts of things were going on in their life at that point? Was it the fact that this was a physiological precursor to the stroke occurring or had someone just given them bad news? Has your best mate from the Navy has just died? Well, that would be upsetting, so that's what the physiological data would record, which we would completely understand. So we have to be able tell the difference between distressing life events and precursors to stroke. – *Mental Health Specialist 1*

Discussions in both workshops thus far indicated a need to understand diverse aspects of a patient's life to establish context and enable understanding of the meaning of a patient's self-tracked data. Two examples were established within these workshops: physical activity and patient history for understanding heart rate information, and life events for understanding self-reported mood.

The need for context was raised as a barrier to using self-tracked data in the first study. Chung et al. (2015) found that the availability of contextual information (such as what the patient was doing and where they were during a measurement) contributes a better understanding of the patient (Chung et al., 2015). Thus, the next artefact explores potential ways of representing such contextual information.



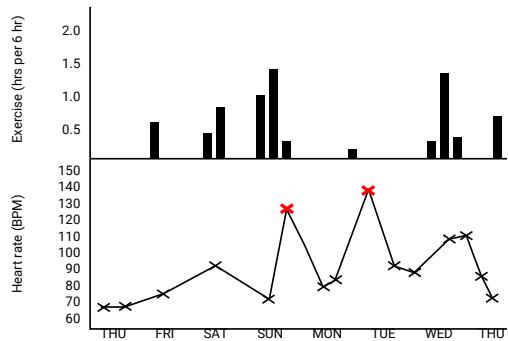
**Figure 32.** Artefact E: sketched line chart of how a patient felt over time. Clinicians pointed out that the chart demonstrated the subjectivity of the scale of one to five, and could use this as a basis to discover what a patient means by each score. The lines could potentially cause erroneous interpolation of values between the data points.



**Figure 33.** Artefact F: multiple computer-generated charts on a shared axis to show context of measurements.

HbA1c mmol/mol (new units)	HbA1c % (old units)	Estimated average glucose mmol/L
42	6	6.9
53	7	8.5
64	8	10.2
75	9	11.8
86	10	13.3
97	11	14.9
108	12	16.5
119	13	18.1

**Figure 34.** Artefact G: advice by Edinburgh Centre for Endocrinology and Diabetes (2016) for patients with diabetes includes a table of normal, high, and very high values for blood sugar (clinically known as *estimated average glucose*, the rightmost column). Green, amber, and red illustrate the relative safety of those values, reflecting the ubiquitous use of traffic light colours in clinical practice (Christ et al., 2010).



**Figure 35.** Artefact H: colours integrated into charts; high heart rate is displayed in red.

### 7.2.3.6 Artefact F: Aligned Charts for Context Mockup

As found in the first study, contextual information may consist of other data sources available in a patient's health record or through self-tracking other kinds of information (Schroeder et al., 2017). For example, the Fitbit app shown in Artefact D contextualised a heart rate measurement by adjacently displaying a person's physical activity. Building on this concept, a new computer-generated mockup (Figure 33) was rendered by the designer which displayed two charts on the same axis: heart rate and time spent exercising. It was hoped that seeing time spent exercising would allow contextualising heart rate measurements.

*Cardiologist 2* was the first participant to see Artefact F, commenting that displaying multiple data types on a single scale enabled asking deeper questions of the data:

Immediately, I can ask "is it that it's palpitations with a high heart rate and activity, or is it a complete mix of things?". So that sort of data presented in a meaningful way would be quite important. This is what I was meaning in terms of being able to look at and get a feel for a lot of data with a single screen that you're not having to go through lots of different screens. – *Cardiologist 2*

*Cardiologist 2* went on to suggest several scenarios where additional data types could enable answering clinical questions tailored to individual patients:

People's perceptions of symptoms are often dependent on the ambient temperature. And equally with some individuals you find there's a specific day of the week. Often, for working people with heart failure, after a weekend where they've drunk a little more, their fluid balance status will change on Monday. If those sorts of trends can be picked out, it would be interesting. – *Cardiologist 2*

Later mockups would include more data types on the same axis to allow identifying such trends.

### 7.2.3.7 Artefact G: Colour Vignette

*Cardiologist 2* suggested using colour to indicate the severity or urgency of values:

In medicine we use the traffic light system all the time. It's standard. Green you ignore, orange might be a factor, red is something to be highlighted and is clinically important. – *Cardiologist 2*

This reflects a response in the interviews in the previous stage about colour:

I would expect to see a table and a graph. A blood sugar between 5 and 7 is good glycaemic control, so they've got good control of their diabetes. Less than 5, or 4, then they're hypoglycaemic, so not enough sugar, and that needs to be corrected quite soon. Above 7, above 11, that sort of range, then these are a bit too high. Above 15 and 20, then we get into the danger zone. Imagine a graph where they've got a different line delineating their blood sugar level, a red line for 4, a green line for 7, and amber... like a traffic light as the values go up. That would be quite useful. – *Emergency Doctor 1*

This description of an 'ideal presentation' of data draws from the doctor's expertise in working with diabetic patients. The normal and dangerous values are familiar, and the colours – green, amber, and red – are routinely used in emergency clinical practice (Christ et al., 2010). Advice by Edinburgh Centre for Endocrinology and Diabetes (2016) for patients with diabetes includes a table (Figure 34) with similar

qualities to those described by *Emergency Doctor 1*: the normal, high, and very high values align to what *Emergency Doctor 1* described, and the colours green, amber, and red are used to illustrate this. Doctors in acute settings draw heavily on their expertise to interpret data ‘at a glance’ in a short amount of time and they work most effectively when the data presented to them is familiar.

#### **7.2.3.8 Artefact H: Aligned Colour Charts Mockup**

To address *Cardiologist 2*’s suggestion of using traffic light colours, Artefact F (aligned charts mockup) was modified to highlight spikes in the patient’s heart rate in red, as shown in Figure 35. Earlier comments by *Student Nurse 1* suggested that seeing spikes in heart rate is more important than periods of high heart rate, so only points which are relatively high compared to their surrounded data points are highlighted.

This artefact was shown in the final workshop. *Cardiologist 4* was able to see an association between high heart rate and palpitations, but wished to see the data over a longer time-span:

There’s quite a lot you could read into this data. For example, there were two days during this week when somebody had palpitations. And there was a blank day in between when they didn’t have it. The next question is: what’s the pattern before and afterwards? This is probably inadequate to really get a feel for what the level of concern might be with that patient, but it does seem that their palpitations are related to a rapid heart rate. – *Cardiologist 4*

This was alluded to in Huba and Zhang (2012), where timelines were considered important for interpreting personal health records. Hence, at this stage, the mockup was described as a ‘timeline’.

#### **7.2.4 Topic 2: Collaborative Investigation**

The second topic within the mockup workshops centred on designing for collaborative investigation, which included helping patients understand their symptoms and helping clinicians understand the patient’s history. Six artefacts emerged within this topic.

##### **7.2.4.1 Artefact I: Patient Representation Mockup**

*Mental Health Specialist 1* was presented with a table of a patient’s heart rate for the morning, afternoon, and evening of every day over a week, sketched by the designer (Figure 36). Any instance of palpitations was indicated with an asterisk. The mental health specialist was immediately open to using the data representation because it made sense to the patient when they recorded it, and therefore fostered to greater potential for collaboration:

Immediately it facilitates a discussion between me and the other person. I’m pleased that they have taken the time to write it in their own language. They have produced this themselves which means its usable to them, rather than me, as a clinician, telling them that this is possibly a different way of how to record their daily thoughts and feelings. – *Mental Health Specialist 1*

The mental health specialist wished to ask the patient (who we assumed to have recently had a stroke) about the meaning of individual recordings:

	MORN	AFT	EVE
SUN		3	
MON	5	5	5
TUE	1	1	
WED	4		3
THU	1	2	
FRI		4	
SAT			3

**Figure 36.** Artefact I: A table sketched by the designer which documents how a patient has felt on each morning, afternoon, and evening of the week. The scale is from one (terrible) to five (great).

Is this completely based on stroke, or are there other factors which led you to feeling terrible? On Monday evening you felt great. Was this because the grandkids came along and you got taken out for the evening and you enjoyed a few of your favourite whiskies? On Tuesday morning you felt dreadful. Was that because you forgot to take your medication because you had too many whiskies the night before? I would be asking about the chart, and would be genuinely pleased if they presented me with something like this because it would give me an opportunity to talk to them about it. – *Mental Health Specialist 1*

However, the patient's own choice of representation was not always conducive to making sense of the data. *Cardiologist 4* had difficulty interpreting the table:

A table of numbers is difficult to read. In this case it's slightly curious. What this is asking me to do is to compare the numbers of the mornings, the afternoons and the evenings, and I'm not sure why it's been grouped in that way. If it was blood sugars in a diabetic, it makes more sense because its relevant to meal times and so on. but the choice of the columns is curious. But this is the way you might format a data capture form but why format it in this way, I'm not sure. – *Cardiologist 4*

#### 7.2.4.2 Artefact J: Causal Tree Mockup

*Cardiologist 2* was concerned that the quantity of information was difficult to handle, so there would need to be a way to focus in on the relevant parts:

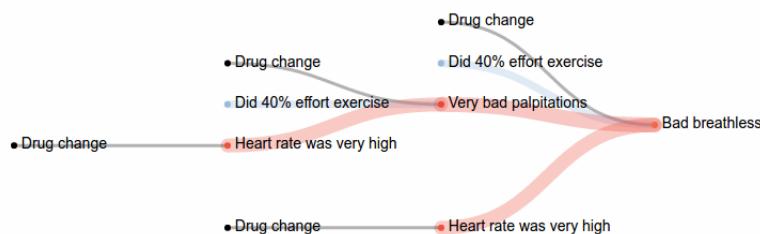
There's a huge amount of data that you've then got to go through with each patient. You don't want to be spend 40-minutes looking at all of this to try and understand what's going on. [...] There needs to be an ability to focus in on what the real issue is, because that's what we do in clinics. The patient walks in and we say "how are you doing?", and they say "great, perfect three months, no problems at all." and we'll just go through some specifics there. Then someone comes in and the last three months have been awful, and I say "what's been going on?"; "well, cat died, moved house, and I've been not feeling so well". And then you've got to then start drilling in on that. – *Cardiologist 2*

*Cardiologist 2* described wanting to work with patients to identify the relationship between events. Doing so could help identify triggers or patient behaviours which led to worsening patient condition:

The linkage between events is important. You associate high activity with a high heart rate and then you would be looking at modifying their drugs to deal with fast heart rate with activity. That would lead to a specific intervention. – *Cardiologist 2*



(a) The directed graph shows a major event on the right, “felt very ill” (with 1 indicating the wellness score between 1 and 5), and the two known events which may have caused this: medium effort (40%) exercise, and a very high heart rate. The thicker line indicates a stronger relationship; the high heart rate may have a larger significance to feeling ill than exercise perhaps because of the patient’s specific condition or the high heart rate event was closer to when the patient felt unwell.



(b) A more complex directed graph showing the potential relationship between several events which a patient self-tracked. Like (a), the relationships indicate potential causes of events, in this case leading up to an incident of bad breathlessness. Several factors may have led up to this, including a drug change, exercise, palpitations, and high heart rate. These causes may have, in turn, been caused by several earlier events, including an earlier drug change, exercise, high heart rate, and before that, another drug change. This may indicate a need to investigate how certain drugs are affecting the patient, or discuss lifestyle changes with the patient.

**Figure 37.** Artefact J: weighted flowcharts showing the possible relationship between self-tracked events. Clinicians said these were useful for helping patients understand how habits (e.g. exercise) can lead to symptoms (e.g. feeling unwell) and for collaborating on health management options. The relationships in these flowcharts were not determined using a scientifically validated algorithm but provoked discussing with clinicians within the workshops.

As a consequence of these discussions, *Cardiologist 2* and I mocked up the directed graphs shown in Figure 37 to indicate the potential causal relationships between events. The nodes represent events (such as high heart rate), and the width of the lines connecting them represent the strength of the relationship between them.

*Cardiologist 3* commented that these made it easier to take a high-level view of the data:

Let’s say something like their husband died, or they got fired at work. Suddenly you got a cluster of really bad events. That would be really useful for this kind of thing because life events are a very big reason why someone’s health, which is precarious, has then gone off the edge. – *Cardiologist 3*

*Cardiologist 3* suggested it would be a powerful tool for helping patients understand their conditions and triggers:

You would use it with patients and say “what was it about that period of time do you think that set all this off when you were feeling so bad?”. Then you click on compliance and suddenly you see that they haven’t been taking the tablets regularly for the few days before. Because not everyone who gets ill is a genius, and it’s surprising sometimes that they literally haven’t understood that because they were on holiday and they didn’t bother taking their tablets with them. So the [directed graph] would show really big thick contribution which is “you haven’t complied, you berk!” – *Cardiologist 3*

*Cardiologist 3* also suggested this could be used for determining triggers of asthma:

This would be perfect for a young person with asthma! Because there are lots of factors to can set off an asthma attack. Sometimes your asthma is so good and sometimes you go through periods of time in a year where it's so bad you nearly died from it, and it's a mystery to us. But with this tool, every time you've had really bad asthma, we can trace that you made a visit to your granny's house which has these trees that you're allergic to. – *Cardiologist 3*

#### 7.2.4.3 Artefact K: Decision-Making Vignette

*Cardiologist 3* compared using the directed graph with the differential diagnosis approach used by the fictional physician, Dr House. In the TV show *House MD*, Dr House raises possible causes of a patient's condition and writes them on a whiteboard (see Figure 38). As evidence is gathered, House can dismiss possible causes, crossing them off, until one remains.

It's like an episode of House. He says "you better go break into their house because there's this really rare... molybdenum poisoning". And no doctor has ever heard of molybdenum poisoning, except a few people in the world. But because House is House he thinks "ah this is manganese oxide poisoning - you only get that in a certain type of paint. Break into their house and see if they've got that paint". And sure enough, under the sink is a bucket of that paint. This is this [pointing to Artefact J]. Because House's brain is working backwards and somewhere around here there's molybdenum poisoning. And he followed that strand back. That's what we're often doing in medicine. – *Cardiologist 3*

He described the use of the directed graph as like solving a crime:

Trying to work out why someone has developed a deterioration in their condition is like solving a crime. There's a lot to that because it's based on a timeline. This [Artefact J] is a way of thinking. You're presenting people with a facility that allows them to think in a certain way, and you can follow thought backwards or forwards. You can ask "how did all of those go into that line?" – *Cardiologist 3*

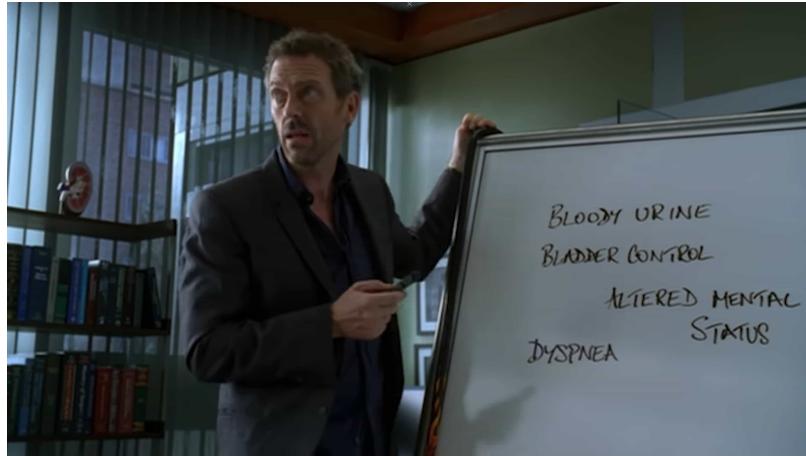
#### 7.2.4.4 Artefact L: Sankey Mockup

Discussion with *Cardiologist 3* about the direct graph mockup led to him suggesting Sankey plots.

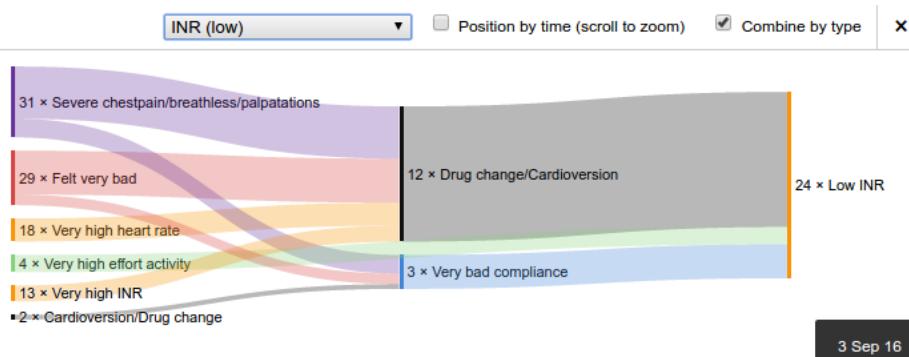
What are those energy things called... Sankey? The weights on a Sankey would be really strong for this because you can ask "was the drug change a week ago more important than the feeling very ill a day ago?" – *Cardiologist 3*

*Cardiologist 3* and the designer mocked up a Sankey chart for visualising the causal relationship between events (Figure 39). For the purpose of the mockup, the widths of the lines on the Sankey chart – which were indented to indicate the strength of relationships between events – were random.

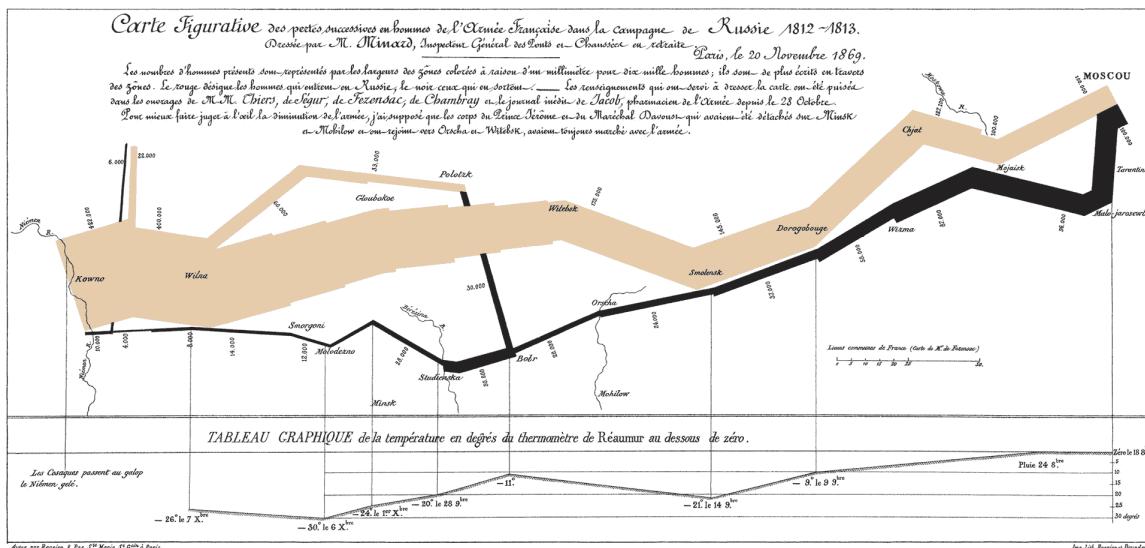
Where this would be fantastic would be something like a hospitalisation for heart failure. Heart failure is a terrible thing to have because the prognosis is bad. So the whole game is about making people last as long as you can, and making them feel as good as you can while they're lasting. Was it the change in diuretic? Did that contribute more than the fact that they started getting palpitations? So I wouldn't discard you being able to use the Sankey type thickness of the contribution both ways. So we started hospitalisation - what was the biggest contributor? it's very strong. – *Cardiologist 3*



**Figure 38.** Artefact K: in the TV show *House MD*, Dr House raises and dismisses potential diagnoses based on available evidence.



**Figure 39.** Artefact L: Cardiologist 3 and the designer mocked up a Sankey chart for visualising causal relationships between events. In a real-world scenario, the width of the lines would indicate the strength of the relationship between the events (but for the purpose of the co-design were random). The Sankey could help identify the cause of frequent events (e.g. palpitations).



**Figure 40.** Artefact M: Charles Joseph Minard's diagram of the French Invasion of Russia 1812, *Carte Figurative*, illustrates the divergences and sharp decline of Napoleon's army on their route to and from Russia. This information design informed the Sankey diagram for illustrating the causal relationship between health events mocked up with participants.

#### **7.2.4.5 Artefact M: Carte Figurative Vignette**

Cardiologist 4 argued the need for a scale on the Sankey, raising the example of Carte Figurative (Figure 40), Charles Joseph Minard's diagram of the French Invasion of Russia 1812. The diagram illustrates the divergences and sharp decline of Napoleon's army on their route to and from Russia.

It reminds me of the classic diagram of Napoleon's troops on the campaign to Russia that Edward Tufte always quotes, and there's this incredible loss when they cross over rivers. And then there's this return journey, this is the group that broke off to go a different place, and then they came back, and this is the temperature if I remember, getting lower and lower below zero. – Cardiologist 4

However, Cardiologist 4 cautioned about the learning curve of such diagrams:

One of the big questions I always have when people talk about data visualisation is “what are you trying to visualise? What task are you trying to help people with? And what are the risks associated with that task that you don't want to gloss over?” [...] It is quite complicated, and I suppose according to the task you may have to chart different data in a different order. There's a learning curve with them, but there may be some presentation of the data which the learning curve is shorter and which allow people to pick up the problems earlier. – Cardiologist 4

#### **7.2.5 Topic 3: Audit Trails**

The third topic within the mockup workshops centred on providing an audit trail. Five artefacts emerged within this topic.

##### **7.2.5.1 Artefact N: Completeness Mockup**

Artefact N (Figure 41) comprised a table sketched by the designer documenting a patient's heart rate each morning, afternoon, and evening of the week. Clinicians saw obvious omissions within the data and could use this as a basis for eliciting information about those missing data from the patients. Mental Health Specialist 1 needed to know why a person did not fill in certain days. As previously raised in the interviews, gaps in the data can be a cause of ambiguity to what was happening in that time:

Is it because they were unwell and therefore didn't make the reading, because they were in bed or sitting in a chair at home? Or is it because they were out partying and having so much fun that they didn't bother to make the reading? Unfortunately, missing data is very ambiguous. It could be because people were seriously ill – the condition that you're interested in – or they might have even been away clubbing or on holiday if it was a long gap. – Cardiologist 4

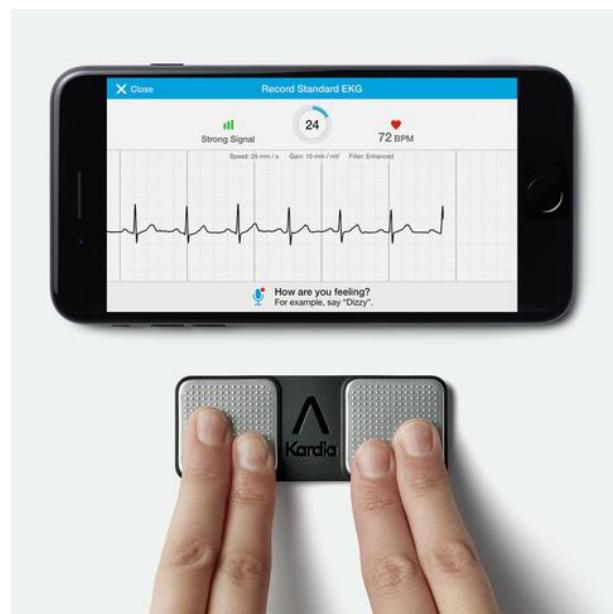
##### **7.2.5.2 Artefact O: Familiarity Vignette**

One way clinicians were able to overcome issues of ambiguity within data was by using devices known to them. Cardiologist 2 raised the AFinity app (Figure 43), which he had been involved in the development of. He therefore knew how well it had been calibrated and how to effectively retrieve data from it:

Patient comes in with AFinity and there's a PDF or summary sheet that shows their symptoms, and so you can look at their symptoms on a single screenshot in the last six months and that will help inform you in terms of that counselling process. AFinity should be in a format where we can see this a little bit clearer and it's very clear. You could quickly flick through the last 6 months and get a real feel for what symptoms that patient is experiencing. – Cardiologist 2

	MORN	AFTERN	EVE
THU	68	68	
FRI		74	
SAT			90
SUN	69	122*	100*
MON	75	80	
TUE	140*	92	89
WED		100	

\* = palpitations



**Figure 41.** Artefact N: table of a patient's heart rate for morning, afternoon, and evening for every day of a week, sketched by the designer. Instances of palpitations were indicated with asterisks. Clinicians saw obvious omissions within the data and said this would provoke eliciting information about those missing data from the patients.

**Figure 42.** Artefact P: the app *AliveCor* shows the algorithm used to generate values.



**Figure 43.** Artefact O: Cardiologist 2 raised the AFinity app (Figure 43), which he had been involved in the development of. He therefore knew how well it had been calibrated and how to effectively retrieve data from it.

### 7.2.5.3 Artefact P: Data Source Vignette

Cardiologist 2 wanted to know how self-tracked data were recorded and if those tools had been validated.

How is the physical activity measured? That's based on their recording of it? The most important thing is the validation of this, because it's meaningless unless we know that there is value to it. And so we really need to understand how that affects the decision-making process. And that's a difficult one to prove, because the only real way of doing that is with a clinical study. And so you manage a group of patients with this and without it and see whether there's any specific differences in their outcome. So that's a big thing to do. – Cardiologist 2

One app which Cardiologist 2 was familiar with – AliveCor (Figure 42) – had been clinically validated. This tool presented the algorithm used to generate the ECG trace displayed in the app.

This is where you would really start to have to have validated data. Because if you had an app triggering people to go to their GP and the GP says “well why are you coming to see me?” “Well my app told me to do so.” Then the GP would have to have confidence that there's value in the that. – Cardiologist 2

### 7.2.5.4 Artefact Q: Multi-source Timeline Mockup

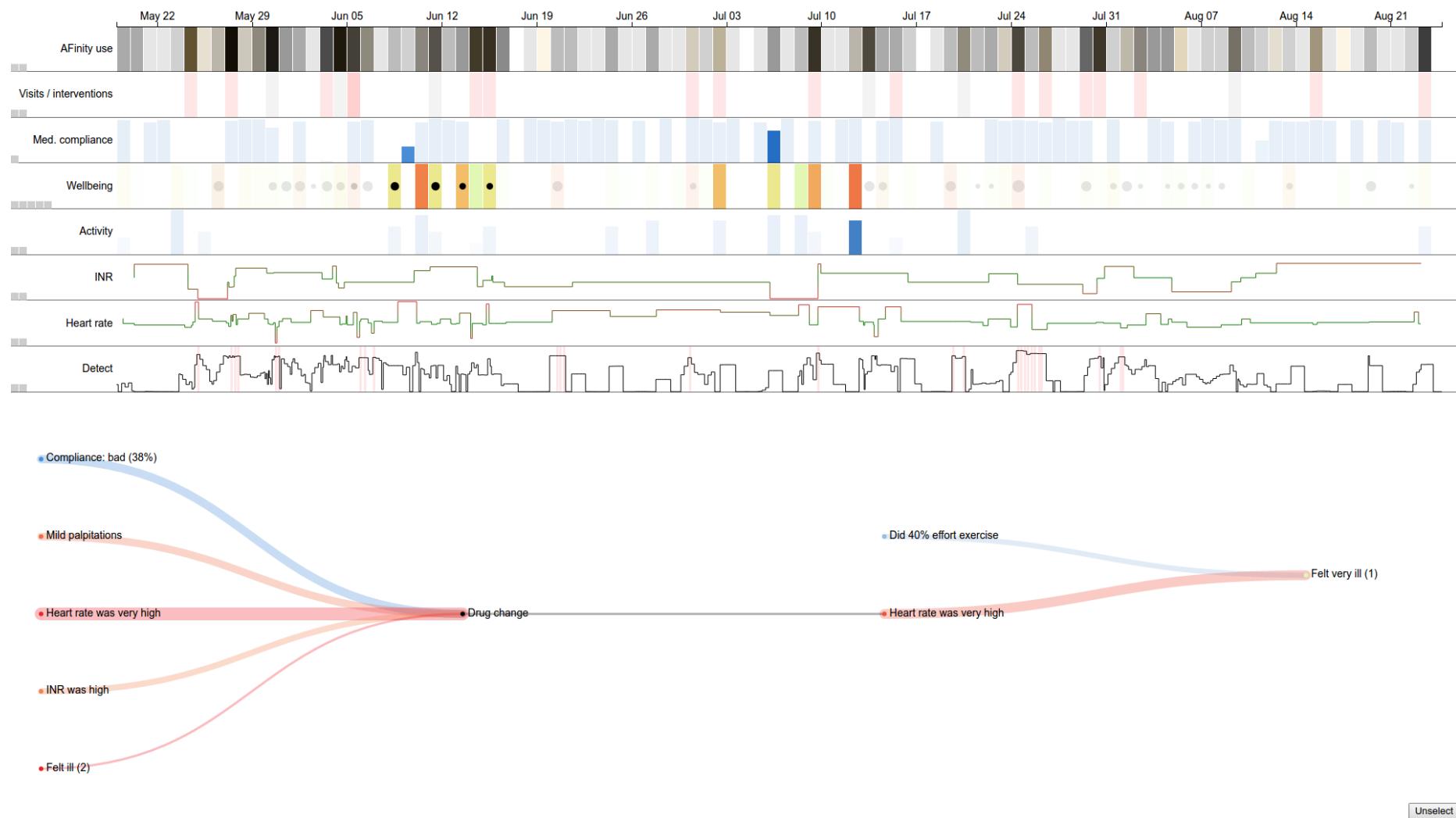
Building on the artefacts of the other two topics, the timeline was modified to better explain the source of information. In Artefact Q (Figure 44), a row at the top is named “AFinity use”; AFinity is a cardiology app that Cardiologist 2 was familiar with (he was involved with its development). By describing the source of the information as the app he was familiar with, his confidence in the data improved.

When Cardiologist 3 looked at the artefact, he explained it would be useful for gaining an understanding of trends and patterns:

It will be a very clear thing, as you showed in one of your first examples, in changing the medication and someone are getting a lot better or a lot worse. Because sometimes you might be able to do it in reverse and say well what was it in that period of time that maybe was much better. It might show they did more exercise before. They did significantly more exercise in the few days leading up to that week there they felt really good... And then in a place where they felt really terrible, they hadn't done any exercise for the few days before. It might be that you could look at both feeling good and feeling bad. It's a really good idea. – Cardiologist 3

He also suggested the tool has value in research:

As a piece of research, if you ever got permission, you had access to a lot of these things, it would be very powerful way of doing research because if you see in large numbers of people whether the number of episodes of atrial fibrillation precipitates more admissions to hospital... Or did the fact that someone had high heart rate lead to a higher instance of stroke. So you'll be able to ask a lot of interesting questions if you had a whole lot of these. – Cardiologist 3



**Figure 44.** Artefact Q: multi-source timeline mockup. The top half shows several charts sharing the same axes. AFinity use refers to how many times the patient has opened the aforementioned AFinity app each day. The darker the colour, the more times the app has been opened. Below, the directed graph from earlier workshops is shown.

### 7.2.5.5 Artefact R: Limitations of the Timeline Vignette

Returning to an original artefact (Figure 44), we reviewed how the mockups had evolved. Interestingly, *Cardiologist 4* raised that the line chart, which now formed part of the timeline in Artefact Q, could lead to erroneous interpolation of values between the data points:

You're not really entitled to draw a line between there and there because you don't know what the heart rate was doing in the middle of this gap. So probably it should be a bar chart, and maybe there should be a threshold. It's not that easy to interpret, the writing is terribly small. What might be useful is you could have open bars where there were palpitations for example. And what might be useful is an indication of the normal heart rate for that individual. – *Cardiologist 4*

The cardiologist also described conversing with patients to understand more about the context, or what the patient was doing during measurements, of the data:

It's important to talk to the patient, because I can say: "I see your blood pressure was this last Thursday, can you remember what you were doing? Had you just been exercising? Did you feel faint?". Had they had any medication? Had they had a beta blocker? I could spend half an hour discussion. – *Cardiologist 4*

The cardiologist suggested this artefact should prompt investigation towards its effectiveness:

The best thing would probably be an empirical investigation using data in this format versus a number of other formats and giving it to clinicians and finding out how well they pick up important patterns or findings. so it's quite limited. – *Cardiologist 4*

## 7.3 STAGE II: INTERVIEWS WITH TECHNOLOGY PROBE

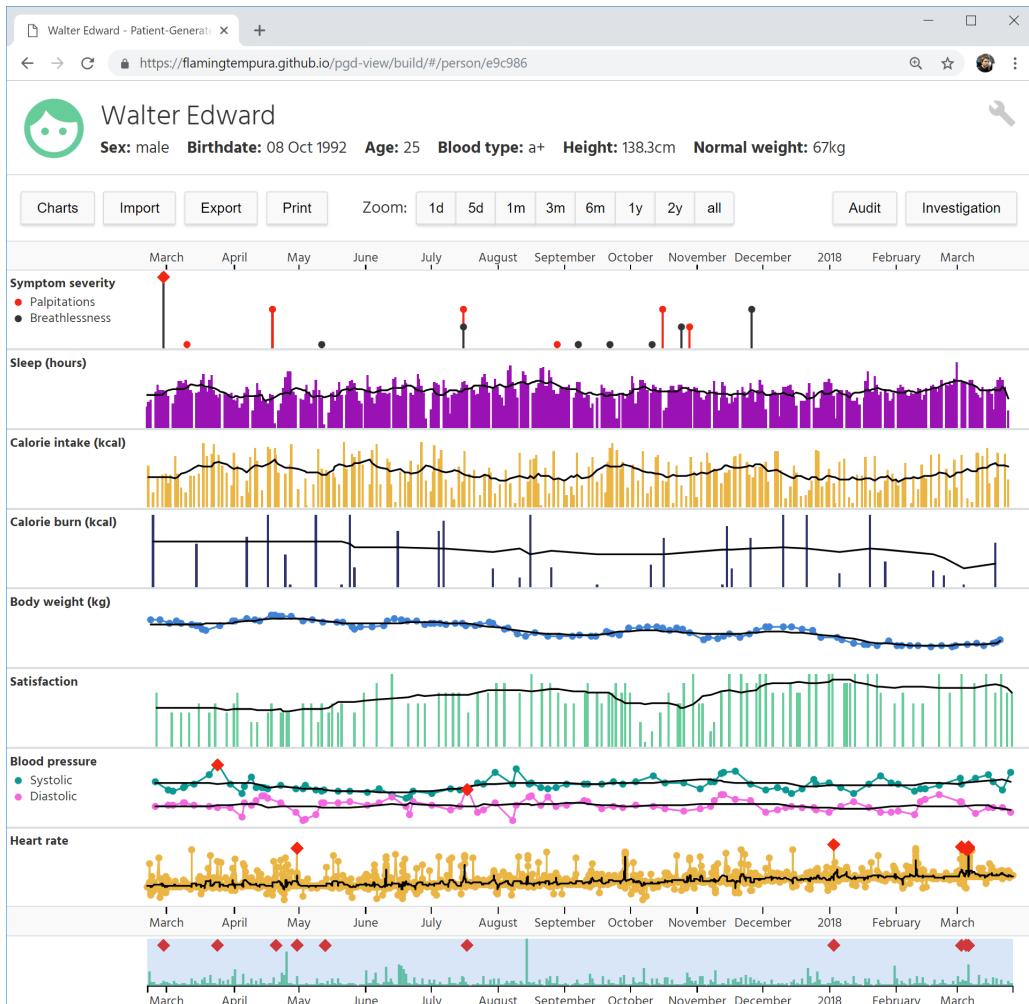
The findings from the mockup revealed three important topics: data representation, collaborative investigation, and audit trails. This stage takes forward each topic as a technology probe.

A technology probe is a technology introduced into a setting to collect data about its use and how it changes behaviours (Hutchinson et al., 2003). Similar to a cultural probe (Gaver and Dunne, 1999), a technology probe aims to elicit participants' reflections on their everyday activities by introducing a thought-provoking technology into workplaces or daily routines (Huang et al., 2014). A technology probe builds on cultural probes by embedding itself for multiple activities, rather than just one, to stress the technology and explore its capabilities and limitations (Hutchinson et al., 2003).

Technology probes conventionally involve deployment into real-world settings, such as a real clinical consultation (Huang et al., 2014). However, deploying technology to a clinical environment without clinical validation would risk patient safety. Thus, for this study the technology probe was deployed to participants in interviews to elicit their feedback across a variety of use-cases.

### 7.3.1 Development of the Technology Probe

The co-designed mockups were collated into a single interactive technology probe for viewing and analysing self-tracked data. As I (the researcher/designer) have a background in computer science, I was able to create the technology probe, which



**Figure 45.** The technology probe features a “timeline” view of self-tracked data, where each type of self-tracked data is displayed as a chart on a shared time axis.

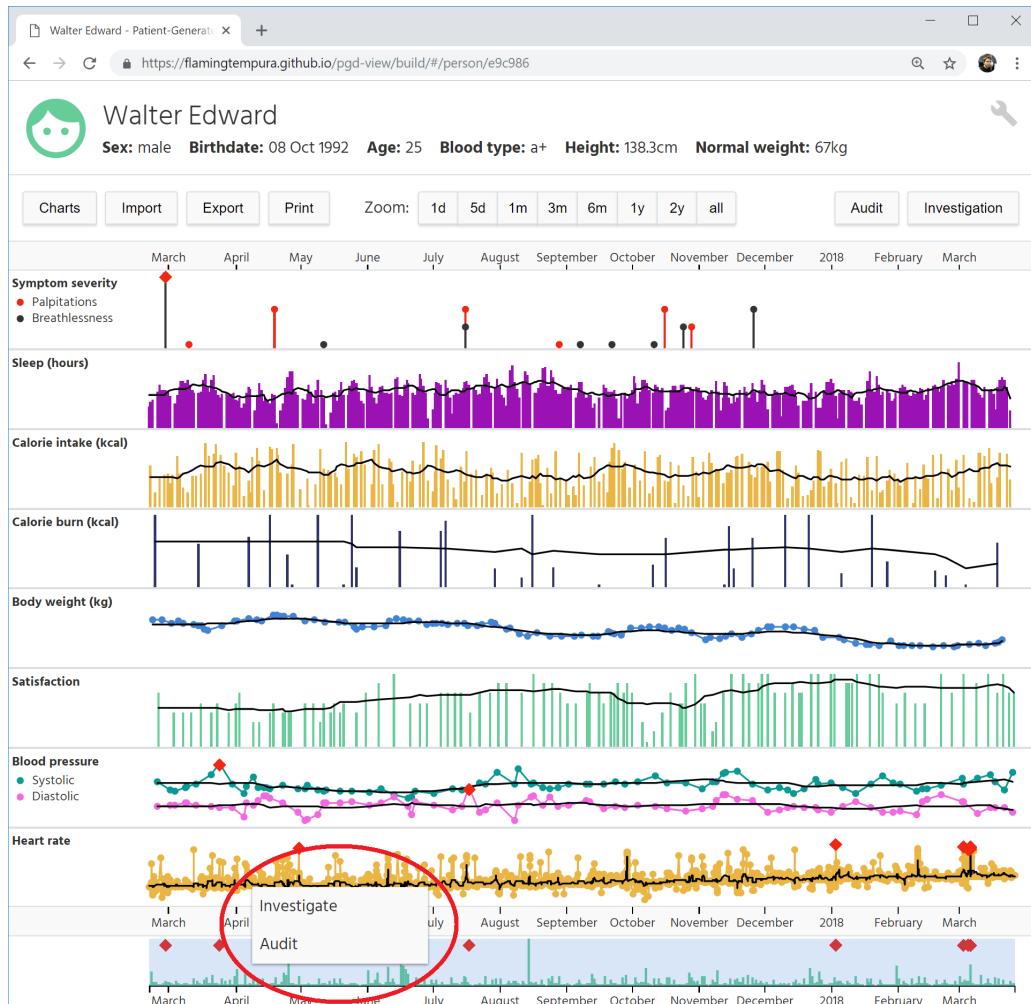
comprised a web application (a computer program accessible via web browsers) written in the *JavaScript* programming language. An interactive demonstration of the technology probe can be found online<sup>1</sup> and the source code is available open source<sup>2</sup>. *D3*, a powerful framework for rendering charts and visualisations, was used to visually display self-tracked data.

Initial development of the technology probe centred on creating data representations which might be familiar to clinicians. In Study 1, unfamiliar structure was seen to be a significant barrier to using self-tracked data within prior empirical studies. Within the interviews, clinicians suggested data would need to be rearranged into a more familiar form before they could be used. The mockup workshops helped to unpack how clinicians might want to rearrange these data, thus hinting at suitable representations for such data.

Observation charts, which are the mainstay of nursing practice in hospitals, served as a good example during the workshops of clinical standards for displaying

<sup>1</sup>Interactive demonstration of the technology probe – <https://flamingtempura.github.io/pgd-view>

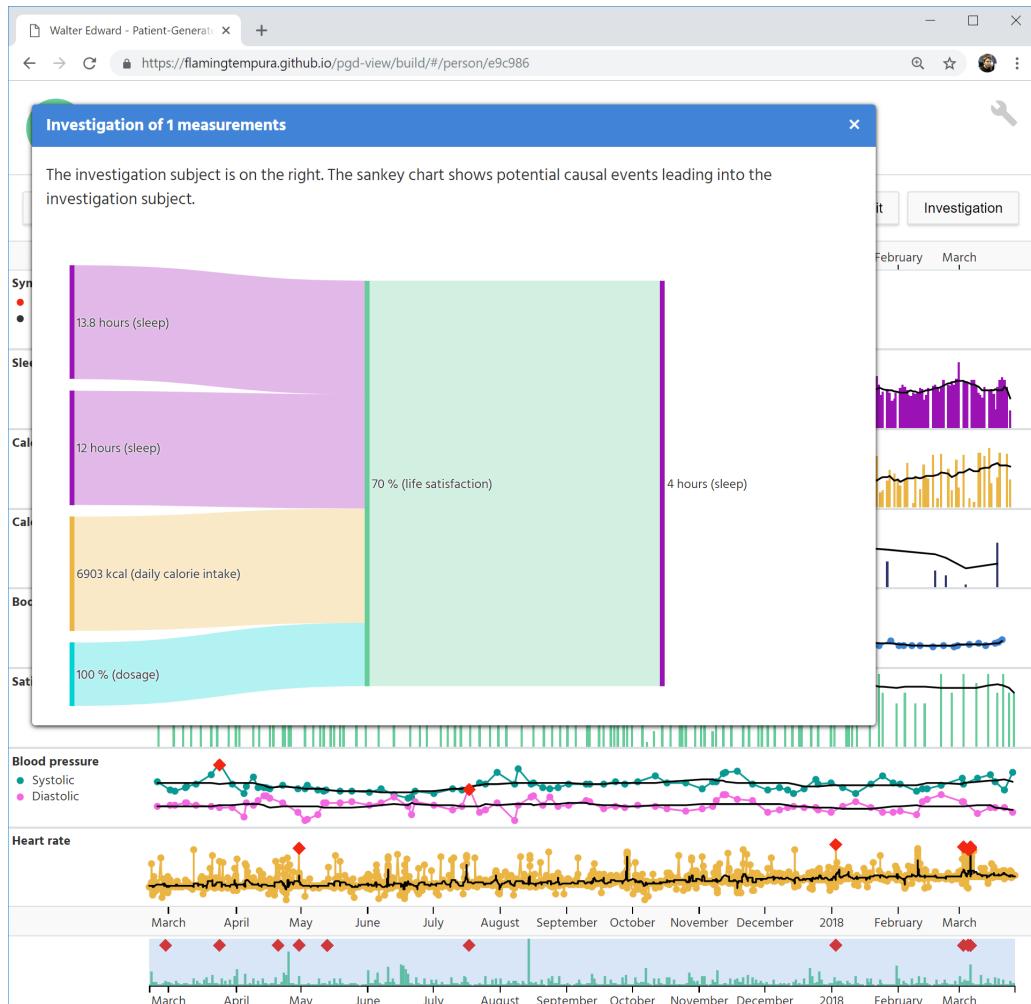
<sup>2</sup>Source code for the technology probe on GitHub – <https://github.com/FlamingTempura/pgd-view>



**Figure 46.** Any data point on the timeline can be clicked on to bring up a menu with additional actions.

information. These charts have been in use for decades and comprise line charts on a shared axis which are quick to draw and reliable to interpret. Observation charts served as a key inspiration for data visualisations in the technology probe. The first stage in developing the technology probe was to implement a tool which rendered self-tracked data as line charts on a shared axis, drawing heavily on the design of observation charts. As shown in Figure 45, the technology probe features a “timeline” of self-tracked data, which comprises several charts of self-tracked data, each sharing the same time axis. This primarily considered quantitative self-tracked data which could be charted and were relevant to cardiology. Data types such as blood pressure and heart rate are displayed as line charts. For non-continuous data types, such as hours of sleep, histograms were used.

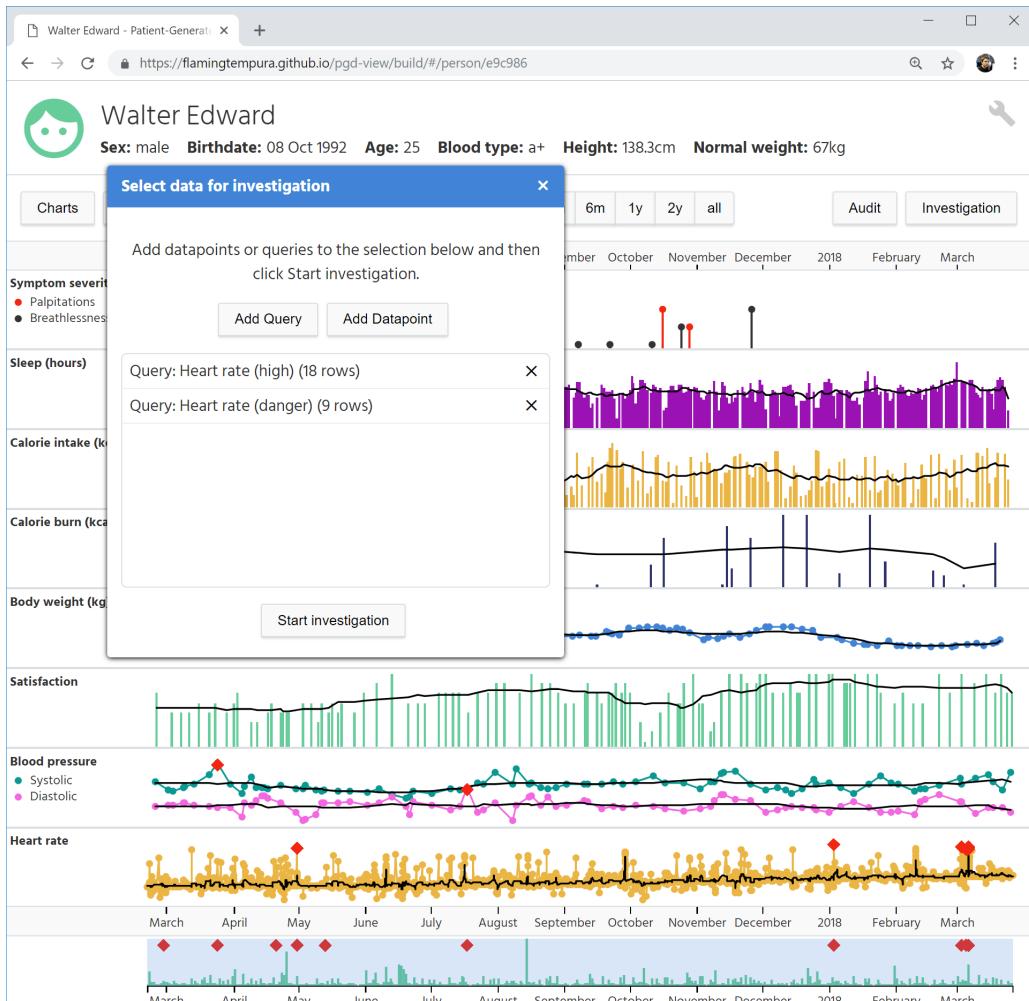
The timeline is interactive. Moving the mouse cursor over any data point reveals its date, time, and value. In Figure 46, a heart rate measurement was clicked on to reveal the menu (circled, bottom left). Two actions are available when clicking on a data point:



**Figure 47.** The investigation view lets a user inspect a data point's relationship with preceding data points.

- The *Investigate* action will launch a Sankey chart which would show the possible relationship between this data point and prior data points. This is designed to enable collaborative investigation of the patient's condition.
- The *Audit* action will launch a data sheet which would provide details about the value, provenance, and context of the data point. This is designed to provide an audit trail of the self-tracked data.

The mockup workshops revealed important considerations for investigating self-tracked data in collaboration with the patient. The collaborative investigation tool (Figure 47) aimed to help identify possible causal relationships between events to help with collaborative investigation. A Sankey chart – developed within the mockup workshops – is used to illustrate potential causal relationships between events. In the above example, the user has launched an investigation into a sleep measurement, seen on the right of the Sankey. The patient had only four hours of sleep that night, so the purpose of this investigation is to find out possible reasons why the patient experienced less sleep than usual. The most recent event is on the right, with preceding events on the left.



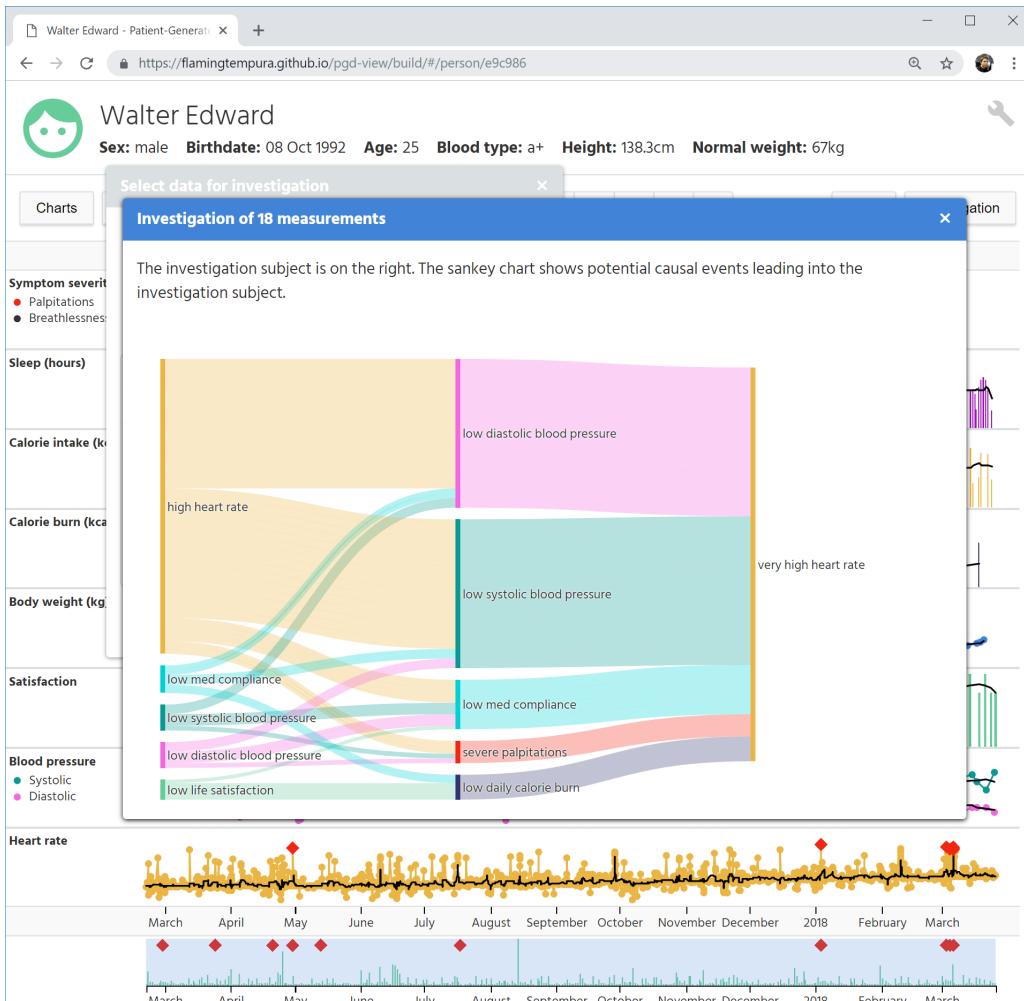
**Figure 48.** The query planner is used to select data points to collectively investigate.

The width of the lines indicates the strength of the relationship between events. In this instance, the algorithm identified a strong possibility that the patient's life satisfaction – recently self-reported as 70 per cent (they were relatively unhappy) – led to the patient having less sleep. Preceding that, the algorithm identified the patient's excessive sleep, high caloric intake, and medication adherence as possibly leading to the patient's reduced life satisfaction.

Note that the algorithm used to determine the relationship between events is not validated and is not appropriate for use in clinical settings. Rather, this technology probe served to demonstrate a possible way to visualise the relationship between events. In a real clinical scenario, the algorithm would need to be replaced with a clinically validated algorithm.

In the example in Figure 48, the query planner has been used to select all heart rate measurements which are higher than normal or considered 'dangerous' (outside certain safe thresholds). When "Start investigation" is clicked, the investigation tool will launch, allowing the user to identify possible causes of all high or dangerous heart rates.

The query planner is designed to be flexible in which types of data can be investigated. Other possible scenarios include:



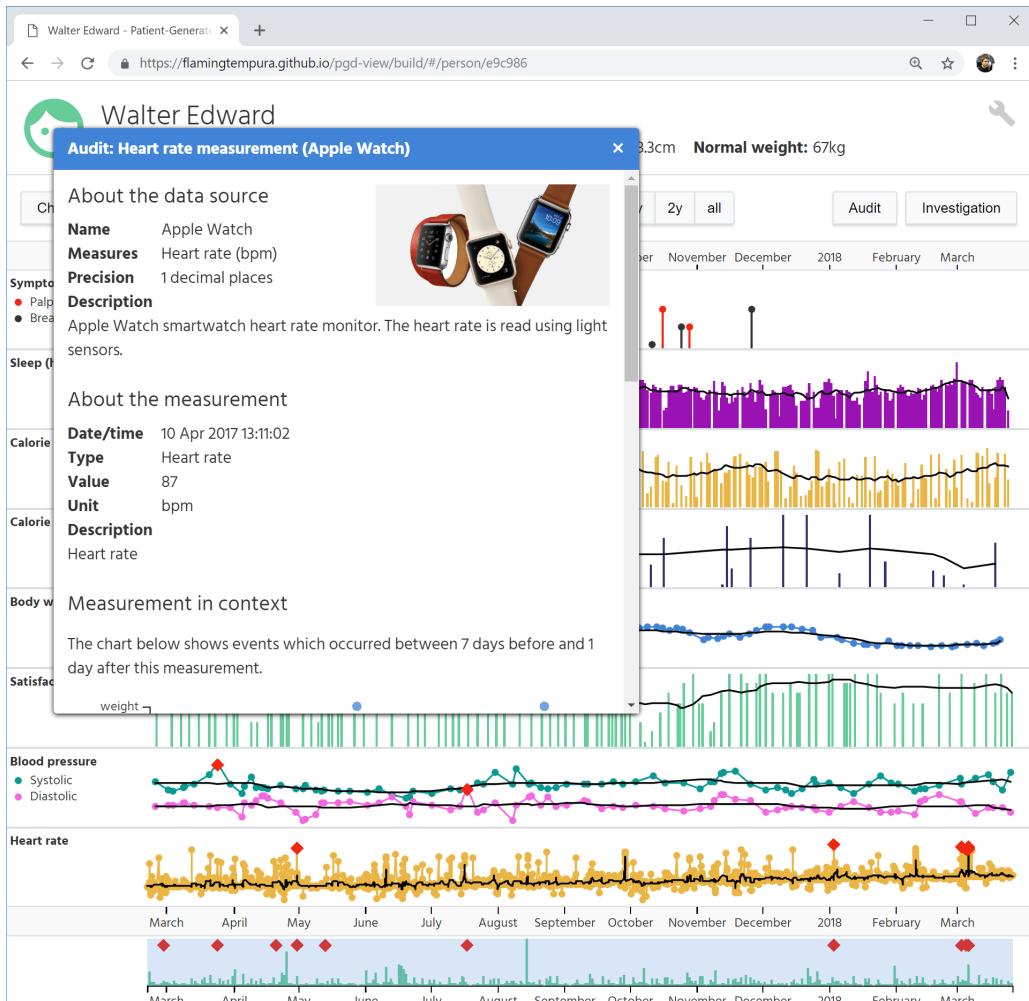
**Figure 49.** The investigation view is shown after selecting data in the query planner.

- identifying environmental triggers of asthma attacks
- identifying events which precede a patient's hospital re-admissions
- identifying foods which trigger episodes of irritable bowel syndrome

Figure 49 shows the investigation which resulted from the query (high heart rate measurements). There were 18 instances of high heart rate measurements. The algorithm identified the potential causes of each and consolidated them. The resulting Sankey chart shows the most likely events which caused the patient's high heart rates.

In this instance, low blood pressure appears to be the most significant contributor towards high heart rate. Low medication compliance, severe palpitations, and less physical exercise are also possible contributors. Preceding these events, high heart rate appears to be a significant contributor to low blood pressure. Since the algorithm to derive these relationships is not clinically validated, the causes presented in this example may not represent a good clinical judgement.

The purpose of this tool was to demonstrate a possible way to visualise self-tracked data in a way which allows collaborative investigation between the clinician and patient.



**Figure 50.** Each data point can be audited using the audit tool.

The audit tool (Figure 50) was designed to provide the user with information about the provenance and reliability of self-tracked data. In the example above, the audit tool is displaying the following information about a heart rate measurement:

- the measurement was made using an Apple Watch (which is also pictured)
- heart rate is measured in beats per minute (BPM)
- the device is precise to one decimal place
- the device uses a light sensor to measure heart rate
- the measurement was made on 10 April 2018 at 1:11 PM
- the value is 87 BPM

When this view is scrolled down (Figure 51), a plot shows where this measurement (in red) is relative to other recent measurements (blue). For example, it can be seen that this heart rate measurement is the only one made on the 10 April. The intention of this plot is to summarise how complete the data are. In this instance, there is missing data about the patient's heart rate before and after this measurement.

Below this, a list of reviews of this device is presented. These result from a PubMed search for the device name. The intention behind this is to provide clinicians with a quick way to verify the validity of measurements from the device.



**Figure 51.** The audit tool also allows identifying the measurement in the context of others, and any published reviews of the device.

### 7.3.2 Synthetic Patient Data

The technology probe was populated with synthetic, but realistic, patient self-tracked data to demonstrate the technology probe. While it would have been desirable to use real self-tracked data, there are very few publicly available datasets from self-tracking tools. Therefore, an algorithm<sup>3</sup> was constructed to generate synthetic data of the following facets of health: heart rate, blood pressure, caloric intake, hours of sleep, mood, weight, clinic visits, medical interventions, diagnoses, symptoms, medication dosages, and physical activity. The algorithm begins with a patient story encoded in JSON<sup>4</sup>, then the frequencies and values of self-tracked data points are determined based on the story's progression, relationships with other temporally co-located events, and a random number generator. Three personas were created, each with a unique set of circumstances:

1. Melissa Howes: female, 57 years old, 87kg, smoker, recent increase in palpitations and breathlessness. Has previously been diagnosed with atrial

<sup>3</sup>Random data algorithm on GitHub – <https://github.com/FlamingTempura/mhealthgen>

<sup>4</sup>JSON (which stands for JavaScript Object Notation) is a digital standard for structuring data in a human-readable form – <http://json.org> [Accessed on 20 Sep 2018]

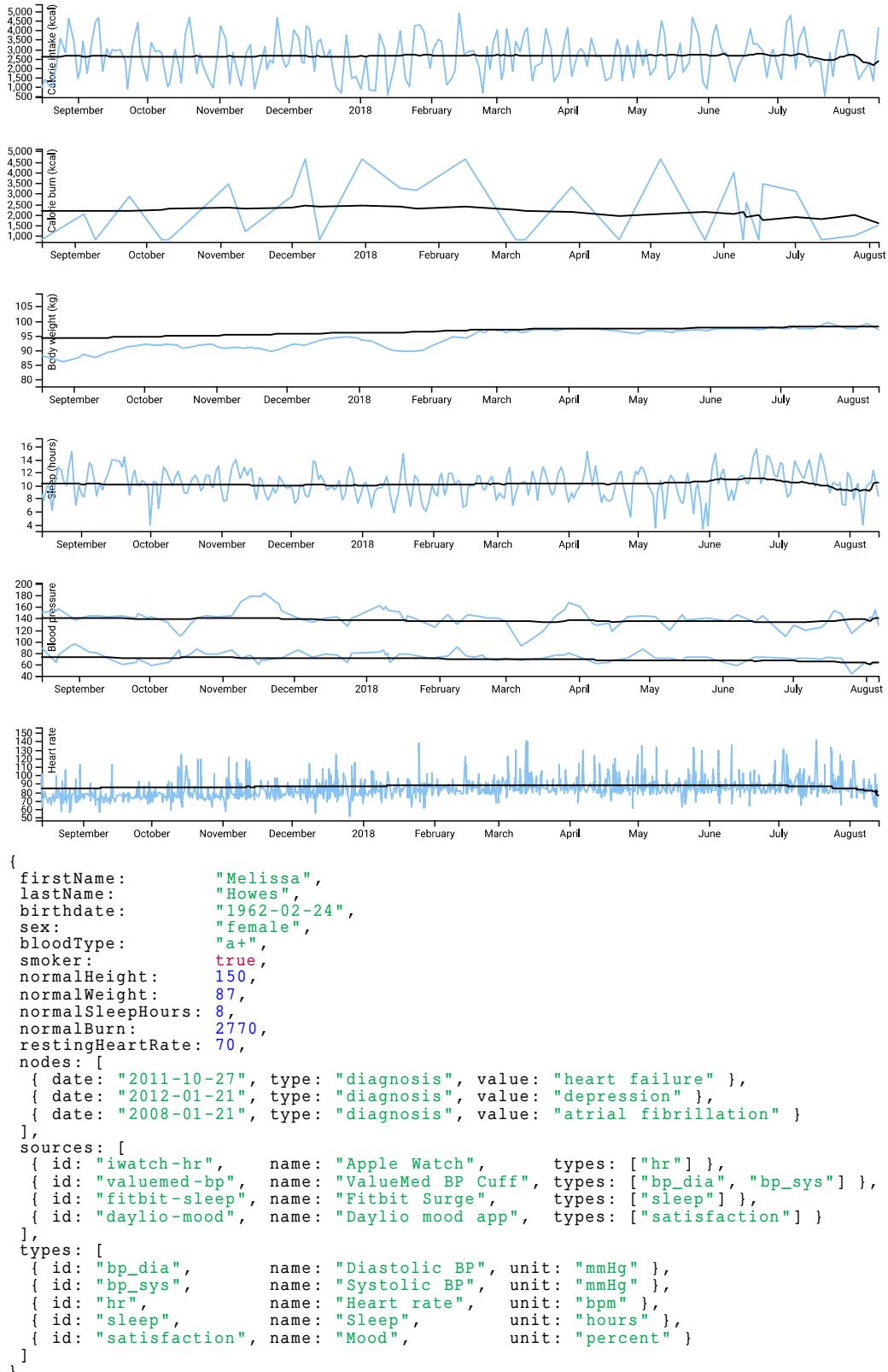
fibrillation and has been prescribed Warfarin to prevent stroke, but is not particularly compliant with taking it daily. Recently diagnosed with heart failure and depression.

2. Thomas Wheaton: male, 60 years old, 72kg, occasional but severe palpitations, fairly normal sleep patterns. Heart rate has dropped very low on several occasions and he has had unexplained weight loss over the past year. Despite several recent clinic visits, he has no specific diagnoses.
3. Walter Edward: male, 26 years old, 67kg. Generally healthy but occasional breathlessness and palpitations. High compliance with medications and generally physically active. Recovering from depression after the loss of a family member. Sleep is sporadic and varies between 4 and 14 hours a night.

A detailed example of how the random generator works is as follows: Melissa Howes (the first above persona) has recently started tracking her blood pressure using consumer devices. She suffers from depression and atrial fibrillation, two common co-morbidities within heart failure patients (Rutledge et al., 2006; Laugsand et al., 2014), so she tracks her mood and heart rate. A person's sleep habits are typically affected by their mood (Dinges et al., 1997), so the algorithm lowers the patient's reported mood where their sleep is poor and raises the patient's reported mood when their sleep is good. The converse is also true: the person's mood is affected by their sleep (Morin et al., 2003), so the algorithm will use the patient's sleep to determine their mood. These associations could cause a feedback loop in the algorithm: the patient's sleep is poor so their mood gets poorer, and in turn their sleep gets poorer, et cetera, meaning that neither sleep nor mood would ever improve. Realistically, there are likely to be other factors which influence the patient's sleep and mood (for example, a break from work to improve mood or earplugs for better sleeping), so the algorithm introduces random noise to simulate these stimuli. Specifically, simplex noise was computed because it generates smooth gradients such that changes in, for example, weight changes are gradual, not sudden. The resulting dataset describes the physiological and psychological conditions of the fictitious patient over a long period, therefore simulating the kinds of data which may be possible with current and future self-tracking technologies. The encoding and charts of this patient's fictional data are shown in Figure 52.

### 7.3.3 Interview Procedure

Participants were invited to attend interviews to provide feedback on the technology probe. The interviews aimed to understand how clinicians could work with self-tracked data by evaluating the technology probe tool. This stage was originally planned to use workshops to bring participants together to stimulate ideas and experiences as a group (Lindlof and Taylor, 2002, p. 182). However, because of the busy schedules and geographical dispersion of the participants, it was not possible to arrange a time that suited multiple participants. Instead, this stage was run as interviews with individual participants.



**Figure 52.** Above: A year of synthetic self-tracked data, generated using the random data algorithm. The charts comprised calorie intake, calorie burn, weight, life satisfaction, hours of sleep, and blood pressure. An association between calorie burn and body weight is visible: calorie burn has decreased and caused an increase in weight. Below: The story of this person is encoded in JSON format.

Each interview began with a demonstration of each feature of the technology probe on a laptop. The participants were encouraged to interact with the technology probe, which displayed synthetic data from the three aforementioned personas. Participants were told the interview's purpose was to understand how the technology probe fulfilled the needs of clinicians in their workflows and whether the technology probe's features could overcome barriers identified in earlier in this research. The interviews served a secondary purpose of identifying how self-tracking tools could be better designed to fit within clinical workflows.

Interviews were semi-structured and lasted between 30-minutes and an hour. Questions around three topics were asked, each pertaining to the app's main features: timeline, investigation, and audit. The questions formed an evaluative framework for the technology probe, inspired by Nielsen's heuristic framework for evaluating user interfaces (Nielsen, 1993). While Nielsen's heuristic framework serves as a check-list for software, the evaluation framework for this study comprised open questions designed to encourage discussion. The questions were as follows:

### **Topic 1: Data Representation**

These questions pertained to the timeline feature described in Section 7.3.1.

- *Can you tell how complete the data are?* This question aimed to identify if the tool overcame barriers relating to assimilating data completeness.
- *Does this let you focus on relevant information?* This question aimed to identify how effectively the tool allows filtering data to relevant information.
- *Is filtering data helpful? (If so, why?)* This question aimed to understand if filtering data overcame barriers relating to time constraints and information overload, or if it was helpful for other unforeseen reasons.

### **Topic 2: Collaborative Investigation**

These questions pertained to the investigation feature described in Section 7.3.1.

- *How could the investigation tool help when using patient data?* This question explored whether the investigation tool could be used for its intended purposes (improving the collaboration with patients) or other purposes.
- *Does the investigation tool show relationships between events effectively?* This question aimed to identify whether the tool was intuitive and understandable.
- *Is it important to understand the relationship between events? (If so, why?)* This question aimed to understand if understanding the relationship between events overcame barriers, such as insufficient time.
- *[For a given example] what is the relationship between these events?* For this question, a random data point was picked for investigation and the clinician was asked to interpret its relationship with surrounding events. The question aimed to see if the visualisations were being correctly interpreted.

### **Topic 3: Audit Trails**

These questions pertained to the audit feature described in Section 7.3.1.

- Does the audit tool make the accuracy and reliability of data easy to judge? This question aimed to evaluate whether the audit tool overcame barriers relating to assimilating data quality.
- Does the audit tool give sufficient context to the data? This question aimed to understand if the technology probe overcame barriers relating to lack of data context, such as what the patient was doing when they took a blood pressure reading.
- Does the audit tool allow you to judge the clinical validity of the data? This question aimed to investigate whether the technology probe overcame barriers pertaining to the clinical validity of self-tracking tools.
- How could the audit tool be important to your practice? The question aimed to encourage clinicians to voice their own interpretations of how the audit tool could be used.

Participants were observed using the technology probe and their feedback was audio recorded using a Dictaphone. Recordings were transcribed and coded using NVivo 12, with codes corresponding to the three aforementioned topics.

#### 7.3.4 Interview Findings

Five clinicians were interviewed: four from the previous stage, and one additional cardiologist from Study 2. Thematic coding of the interviews was conducted using the three topics from Stage I as a base set of themes: data representation, collaboration investigation, and audit trails. The coding was checked by another researcher yielding a 100 per cent agreement rate (the reviewer agreed with all codings).

##### 7.3.4.1 Topic 1: Data Representation

The timeline view was designed to use standard representations for data, such as a line graph for heart rate. *Cardiologist 2* stated that many of the charts were familiar:

This is not an unusual appearance to how we're presented with data. It is the sort of format that we are presented with on a regular basis from our implantable cardioverter defibrillators. Things like the number of shocks, episodes of arrhythmia, atrial fibrillation, ventricular rate, patient activity, transthoracic impedance, heart rate variability. So it is a format we're used to seeing. – *Cardiologist 2*

*Cardiologist 3* said it was familiar to a system he regularly used:

From a distance I would say that looks very similar to MetaVision. And you can scroll back, forward, zoom in and zoom out, click on a bit. So this is looking very similar to that. – *Cardiologist 3*

This suggests the timeline view can leverage clinicians' existing training for interpreting information. However, *Student Nurse 1* stressed that the timeline must be customisable for different roles. In his case, as a nurse, he expected fewer charts:

This is similar to what you do in the hospital. You've got heart rate, which you can see has gone over 153. But well-being... what exactly is that? Oh so felt bad, felt good, breathless... I get what you mean. It's good to monitor your symptom and all that stuff. But what we need on ours is blood pressure, all that stuff. Doctors have their own tablet [referring to the technology probe] each and they go around and they have a lot more on it. – *Student Nurse 1*

During the interviews in Study 2, clinicians worried that the volume of information could become overwhelming. The timeline aimed to address this by charting the data in familiar ways. *Cardiologist 2* stated that, despite the volume of information, using standard representations meant it was not overwhelming:

Your concern is that there's too much data being presented here in one go. But in my field I don't think we would balk at seeing this. It's not overwhelming, and, certainly within our area, it's not unusual for this to be the sort of appearance that we would get on our patients. – *Cardiologist 2*

*Cardiologist 3* described it as crucial that multiple charts were displayed, showing that the timeline could be agnostic to data types:

It's standard to give people a lot of monitoring. Some people are off and on inotropes, which are drugs to keep their blood pressure up and keep their heart pumping hard enough. Levels which are very often adjusted, blood pressure, medication data, and urine output, should be on the same chart. So that's the importance of a multi-channel display of all their observations. – *Cardiologist 3*

Some clinicians said the volume of information stressed the importance of providing ways to filter the data to the more relevant parts:

It does let you focus on relevant information, as long as it's customisable: scale, completeness of data, and then being able to decrease which of the important variables you want to look at for a specific patient. Because some of the things are more important for specific patients. – *Cardiologist 1*

All of the data you've got there is relevant, but with time there will be things on there that are not relevant. Say you had 50 charts then that would start to become a problem. But there would be clearly, properly, predefined filters that you press to say "I'd like to look at symptoms". Condition denoted filters so that it got rid of some symptoms; headaches, some sort of blood assessments, blood sugar. – *Cardiologist 2*

*Cardiologist 1* suggested one method towards filtering information could be to condense less relevant information into daily or weekly summaries:

There are some things where you don't want to have daily reports. Maybe weekly would be good enough, and you could impute for a week. It would be worthwhile having a display mechanism that from time to time anchors huge amounts of data in very, very solid data points so as to inform further what this all means. Do you see what I mean? Imagine that you gave biannual or quarterly life questionnaires to back up the satisfaction score, then you could have a dot there so you could take your cursor onto the dot and it would give you the quality of life questionnaire, or the data, more robust data. A fiducial point. – *Cardiologist 1*

*Cardiologist 2* suggested that the increasing volume of information which clinicians will need to filter through highlights a need for automation to identify and represent the more relevant information:

If you are presented with all of the data, then it's up to you to determine what's relevant to the clinical question that you're asking. That relies on your clinical knowledge to determine what bits you look at. But there is a huge amount of data there, and you are just not going to get that. If you wanted to restrict it then you would have some sort of automated process to say, I want to look at this patient's haemodynamic status, and so then you would start to restrict it to the factors that are relevant to that. – *Cardiologist 2*

*Cardiologist 1* suggested that some types of data will need to be looked at by domain specialists. Data pertaining to the patient's life experience (the mockup showed this as varying between 'very bad' to 'very good') would be more meaningful to a cardiologist after being interpreted by a quality of life professional:

I don't have a sense as to what that means in terms of the worseness when I'm speaking to the patient face-to-face. Is there a scoring mechanism that is intuitive? You've said where the bars are highest, but what does that actually mean in terms of a severity assessment? Because there are a whole variety of quality of life professionals out there. So should this be validated by intermittent quality of life professionals? – *Cardiologist 1*

Two main shortcomings of the timeline were raised. First, while there was a clear X-axis on the timeline showing time, the timeline charts lacked Y-axes. Because of space constraints, Y-axes were omitted. However, *Cardiologist 1* stated that Y-axes are needed to quickly identify the value of data points (this is currently facilitated by moving the mouse cursor over individual data points):

I wonder whether the readings need to be contextualised. Most people would expect to see some sort of bar that tells you, you know, 5 kilometres – *Cardiologist 1*

The second shortcoming pertained to zero values on bar charts. When a value is zero, the bar chart is not visible, which could be confused with no data being available for that time:

When there is a 0 entry would one be inclined to compute values? Or will you assume that a 0 entry means 'I've taken no drugs'? As it stands at the moment I think it's not helpful clinically. It should be, but I don't know how to interpret it. – *Cardiologist 1*

Like the mockup stage, this raised ambiguity about whether missing data could mean the patient is well enough to not feel the need to record data, or that they are so ill that they were unable to:

If there is absent data, it may be there is nothing filled in because they haven't taken their drugs at all and that means compliance is terrible. But maybe every time there's a gap all the drugs are taken and compliance is excellent. So it doesn't give you the meaningful information for that. – *Cardiologist 1*

*Cardiologist 3* said the high compliance of reporting calorie intake suggested high compliance of reporting symptoms:

You can't tell that they're filling their symptom in accurately because it completely depends whether they had any and didn't declare them. So the answer to your question is I can't tell for sure, but based on the calorie intake [which is filled in for most days] it looks like they are filling in some information about five days over six I should think. – *Cardiologist 3*

*Student Nurse 1* was unsure if a missing data point of medication compliance meant they hadn't taken the medication or hadn't reported that they had:

I'd say that they didn't take the medication... Actually no, I'd say they didn't bother to record it... You can't assume. – *Student Nurse 1*

*Cardiologist 3* explained that the compliance levels represented in the timeline examples would be unrealistic:

I happen to think that's very unlikely that you would get a result like that in real life. Because either they won't fill it in because they're not compliant, or they'll just say they're taking it, which is what patients do – *Cardiologist 3*

#### 7.3.4.2 Topic 2: Collaborative Investigation

On showing the Investigation tool, *Cardiologist 1* reflected that the Sankey chart helped identify the relationship between events:

I can see how events interplay with one another. This is important because all things are multi-factorial. Nothing happens by itself. So understanding the relationship with one parameter changing with another is indicative of what the clinical circumstances leading to a deterioration are, and what you need to reverse to improve well-being. – *Cardiologist 1*

*Cardiologist 1* stated that showing such relationships is important because the correlation between events rarely obvious on conventional charts:

All the clinic visits the patient has made and these measurements taken at times when things were relatively quiet, there's no obvious correlation between clinical events. I guess as time goes on that would be an interesting thing to observe. The relationship is to healthcare uptake, or these sorts of things where the burden of clinical care exists, as compared to a report on patients' well-being, and then the other thing I'm not clear about. – *Cardiologist 1*

*Cardiologist 3* stated this could help demonstrate the effect of a patient's behaviours on their health:

It's very nice, because if you set it to say what's the relationship between the blood pressure and their compliance with the tablets for example, there's nowhere to hide with that. – *Cardiologist 3*

However, *Cardiologist 3* stated that the given scenario of identifying causes of blood pressure was not the best example. A more useful application may be to identify links between glucose and insulin dose:

I mean it's not the best example. Heart rate is associated with blood pressure but it won't be causing the blood pressure. Whereas a change in medication definitely would. But if you see the link between glucose monitoring and insulin given, this type of chart could be really useful. – *Cardiologist 3*

*Cardiologist 1* also suggested the investigation tool could be helpful for identifying links to blood glucose, but the time-frame for related events would be different to, for example, heart failure:

What you really want to know is the information over a time-frame before that, and how long that time-frame is dependent on the clinical condition that you're looking at. So some things happen slowly, some things happen quickly, and then the granularity of the information will vary. So this needs to be customisable for the particular clinical circumstances of any given patient. It will change comparing a diabetic with someone with heart failure, and comparing somebody with inflammatory bowel disease. – *Cardiologist 1*

In the technology probe, links between events were deduced using a series of rules described in Section 7.3.1. *Cardiologist 2* suggested that creating rules for relating events could be challenging. *Cardiologist 1* suggested that algorithms would need to be capable of learning the patterns in data of individual patients. *Cardiologist 2* said this presents an opportunity for AI:

It's creating the rules that's the challenge in all of this isn't it? But I guess that is something that AI is about and it builds up the rules and gets better as time goes on, and it gets it more personalised to that individual so it recognises patterns. When this individual became breathless before, or there was this sequence of events, and it's recognising those sequences of events again. – *Cardiologist 2*

Three main shortcomings of the investigation tool were raised. The most prominent shortcoming was that it was not immediately clear how the investigation tool should be used:

I'm trying to work out what this vertical size means. It's an intriguing way of putting it. So there's a high heart rate, very high effort activity... and that's the same thing on the same day. For some reason it's added into that one. Why is that? And then what's this funny fold thing which looks like a bit of that very high activity effort has contributed to this thing up here. High heart rate. Yeah, as well as the drug change a few days before. It's fascinating how you've managed to visualise this. – *Cardiologist 4*

*Cardiologist 1* and *Cardiologist 2* suggested these shortcomings could be overcome with sufficient training:

So it's come up with these two factors as being something that may have triggered the thing that you wanted to investigate. There will need to be some education required for that. – *Cardiologist 2*

So that's the importance of the training then; to understand what it's actually showing you. – *Cardiologist 1*

The second shortcoming was the lack of an X-axis showing time. This contributed to the first shortcoming by making it unclear which direction the chart should be interpreted and the temporal relationship between events:

I'm slightly confused by the chart the way it is now because you've got three different heart rates, I don't know when they were derived from. I don't understand why the three threads then go into a comment about dosage. So I can't completely understand the way it's presented. But if you had an X-axis with time and you were able to, for example, show that the patient had stopped taking a couple of their tablets, and that led to their blood pressure going up – that would be useful. – *Cardiologist 3*

Part of this confusion arose from the Sankey chart using a different time-scale to the timeline:

So the time scale here is different? I don't know how many days this is, but you've got a non-linear time-scale working up to today Is it still that timeline there? No, it's not. – *Cardiologist 4*

The thing that would be useful on that particular view is an X axis, because you can't tell what time period that is made over. So that would be useful. – *Cardiologist 3*

The third shortcoming was that the colours used in the investigation tool were misleading:

I'm assuming that green is okay and pink is bad. – *Cardiologist 1*

I don't understand the colours. And why do those three lines run into that blue one? I don't quite get that. – *Cardiologist 3*

Participants' need for axes and familiar use of colours is further evidence of clinicians' need for data representations standardised within their practices.

#### 7.3.4.3 Topic 3: Audit Trails

The context chart of the Audit tool was seen to be particularly useful for understanding the relevance of particular data points:

I think understanding the context of it with all the other data collection leading up to that, so we can see that it's sort of isolated, and we've got more data leading up to that beforehand. The chart puts the data point into context. – *Cardiologist 2*

The context chart provided a way of effectively judging the data's completeness:

Just eye-balling that, very clearly you can see that there's concentrated data around sleep hours and heart rate, and you've got a more paucity of data regarding calorie burn and compliance. So I think that that very clearly and visually indicates the density of data. I don't think you could be much clearer than that. It doesn't tell us about accuracy, but it tells us more about the compliance. – *Cardiologist 2*

The colours of the context chart were perceived by *Cardiologist 1* to be 'simple' enough to understand, so could be helpful for improving the colours of the Investigation tool.

PubMed results were seen to be a useful feature for checking if data collection tools had been validated:

I think the PubMed results are useful for a clinician, not for a patient. I think it will be useful because it gives you an immediate way of being able to look at the literature. But the problem with this is there likely to be some data sources that lack descriptions. – *Cardiologist 1*

*Cardiologist 2* described the device summary and PubMed results as useful for determining the trustworthiness of unknown devices:

There's going to be increasing numbers of data creation tools that, as a clinician, you don't know what the value is. I don't know what a Fitbit Surge is, but if you're saying that the sleep accuracy is to 0.2 hours then I would take that as pretty accurate in terms of understanding the sleep pattern. If it said that it was only 1 hour, then it started to become less accurate. Equally if an individual is measuring their blood pressure and it comes from a non-consumer device as opposed to a consumer model that is less accurate, I'd want to know how heavily I can rely on that data. So bringing that up to reflect that I think is very helpful and will become increasingly helpful. – *Cardiologist 2*

However, the audit tool was not always seen to provide sufficient information to overcome concerns about the accuracy and reliability of data, other than describing whether the data was manually or automatically recorded:

Why would it make the reliability and the accuracy easier to judge? Because all I can see is that it came from an Apple Watch? Well it's definitely useful, as we were talking about before, to know whether the patient inputted it themselves, or whether it's automatically acquired. But it can't tell you about the accuracy can it? You would need to know what the accuracy of the Apple Watch's heart rate monitor was. So I don't think it would be useful to know where the information came from. – *Cardiologist 3*

*Cardiologist 1* suggests that a scoring mechanism for data sources may be helpful for evaluating data accuracy and reliability:

This audit tool needs to have some further refinement. Bring a scoring mechanism to the quality of data, for example. It currently tells you the data source, it doesn't tell you how good that is. Just because you know it's a Fitbit, you don't know about the accuracy and reliability of it. It doesn't give me a qualitative assessment, or even a quantitative assessment of the data that that source is generating. I want to know what the quality of the data source is and the sensitivity of the value of data acquisition value. – *Cardiologist 1*

### 7.3.5 Technology Probe Critique

Using a technology probe engaged clinicians in discussion around a tool for viewing and analysing self-tracked data. The discussion resulted in an improved understanding of how doctors use self-tracked data and assess their quality. However, the discussions also revealed problems with the tool which reduced the usability and usefulness of the tool.

Possibly the most prominent problem raised by clinicians was the use of colour in data visualisations. In clinical practice, green is typically used to indicate acceptable or normal values, and red used to indicate dangerous values (Christ et al., 2010). However, in the technology probe these colours were used to indicate different data types. The line chart of systolic blood pressure, for example, shows the line in green regardless of if the value is high or low, possibly leading to the erroneous interpretation that the value is acceptable.

A second problem raised was the lack of Y-axes on charts, which were omitted to reduce clutter on the screen. Without the Y-axes, clinicians had difficulty quickly interpreting values on the charts. Instead, clinicians needed to hover the mouse cursor over individual points to read values. Future designs could follow information design rules for clinical data representation, particularly around clinical records and observation charts (Wright et al., 1998).

Finally, the structure and navigation of the technology probe were not always clear to participants. The query tool was seen to be particularly complex, and a barrier to accessing information about how different events related to each other. This was an experimental display, and future research could focus on making the query tool more intuitive to use.

Whilst these design problems limited the usability of the probe tool, the technology probe was not designed to be used in real life scenarios. Rather, it was designed to provoke discussion and elicit a better understanding of clinicians use of such tools. These findings therefore can therefore help in the future design of tools for using self-tracked data.

A final point of critique pertains to the data used to populate the technology probe. The data were generated based on synthetic patient histories and random noise. The personas consider possible future scenarios where technology are capable of collecting thorough and diverse health data. Generating synthetic data ensured that there were sufficient data to demonstrate the prototype in such a scenario. However, the data were, in places, unrealistic. For example, one patient's body weight was seen to fluctuate by 10kg in one day. Real patient data may have enabled more realistic usage of the tool, so a future avenue for research may be applying this technology probe with real patient data. This presents a challenge for

collecting real patient data; the tool requires data sufficiently diverse and detailed, which is challenging using today's available technologies. Event passive sensors, such as Fitbit, must be taken off to charge their batteries, so gaps in data would be expected.

#### 7.4 MAIN FINDINGS

This co-design study revealed two main findings. First, clinicians prioritised seeing self-tracked data in forms they were familiar with, such as observation charts. Clinicians described the need to quickly interpret data, so using data representations that compliment their training, as well as highlighting salient information, was seen to be important. Second, clinicians expressed a need to 'zoom-in' on regions of data, such that they can explore the relationship between events and contextualise measurements. The next chapter synthesises these findings into generalised recommendations for design and research practitioners.

#### 7.5 CHAPTER SUMMARY

This study involved clinicians collaboratively designing a software-based tool for using self-tracked data in cardiology settings, which encouraged clinicians to speak openly about the problems they have and creatively engage in devising solutions to those problems. Applying clinical standards to self-tracked data was considered important, with clinicians discussing and sketching potential graphical displays for self-tracked data inspired by representations they were already familiar with. Clinicians brought up the need to support collaborative investigation with the patient, reflecting the findings from the Study 2 on the workflows for using self-tracked data to enhance collaboration. This prompted designs that enable the doctor and patient to discuss and co-interpret the patient's self-tracked data. Clinicians also wished to audit self-tracked data by seeing information about the device used, how the patient used it, and how the data were manipulated.



## 8 DISCUSSION

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This chapter discusses the findings from this research in two topics. First, the findings are distilled into recommendations for design, software, and research practitioners working with self-tracked data. Second, the significance of this research is argued with respect to existing work.

### 8.1 RECOMMENDATIONS FOR PRACTITIONERS

#### 8.1.1 Recommendation 1: Analyse Information Quality Needs

Barriers to using self-tracked data in clinical settings often arise because of problems with *information quality*. For example, the interviews in Study 2 revealed clinicians were unclear on the accuracy and completeness of self-tracked data. Similarly, the systematic review found that data from self-tracking technologies are typically perceived to be poor quality and incomplete as a consequence of self-tracking technologies seldom having clinical verification. The usefulness of self-tracked data depends on the perceived quality of information. It is therefore necessary to understand which aspects of information quality are likely to be important for the target users and clinical settings when designing information systems for using self-tracked data.

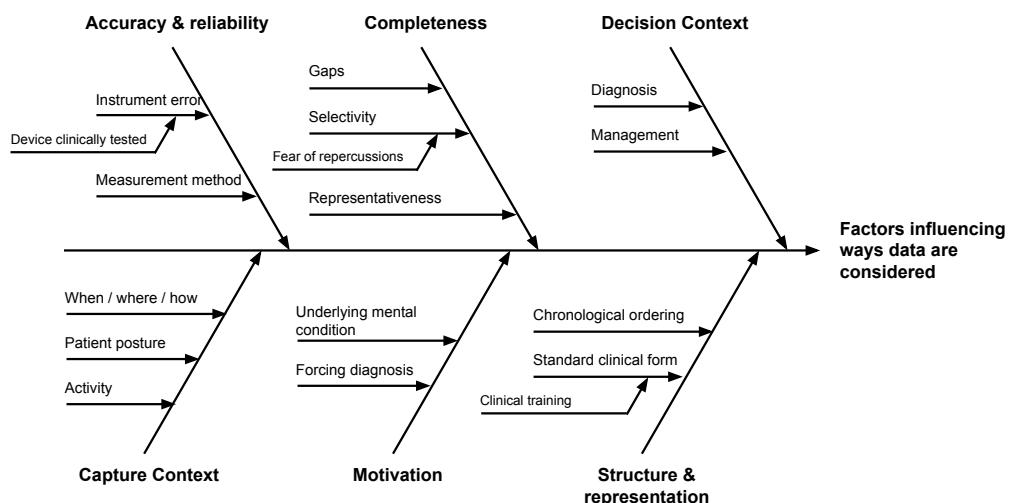
To help understand information quality needs, a model of information quality has been synthesised from the findings to illustrate how different aspects of information quality become important during the journey from the patient's collection of data to the use of their data in clinical settings. Figure 53 shows this model, comprising a fishbone model with causal relationships between events (Ishikawa, 1968). The fishbone model shows several issues of self-tracked data quality, shown roughly in order, from capture context, to decision context<sup>1</sup>.

The model begins at the data's inception – the **capture context** – such as when a patient records their weight or when a wearable sensor generates a heart rate reading. The context in which these data were collected has three important components for information quality: when, where, and how. It is important *when* a measurement was taken because it may be affected by events which take place around the same time. For example, if a person is taking a blood pressure reading, it will naturally be higher if they have just exercised. Knowing *where* a measurement was taken helps contextualise a measurement; if the patient was at home when they took their blood pressure reading, they are likely to be more relaxed leading to a more reliable reading. It is important to know *how* a person made the reading, particularly if they used the correct procedure. For example, if a blood pressure reading is taken when standing, it is likely to be high.

Shortly following the capture context, the focus shifts to the device's **accuracy and reliability**. Clinicians had several concerns around device accuracy and reli-

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<sup>1</sup>The fishbone model has been published in the *Frontiers Journal of Public Health* (West et al., 2017)



**Figure 53.** A fishbone model of information quality issues influencing how self-tracked data are evaluated by clinicians. The issues are ordered chronologically, with issues on the left pertaining to data capture and issues on the right pertaining to use of data.

ability, including instrument error and incorrect use of the device. Part of these concerns stemmed from the lack of information about most self-tracking tools, including whether they had been the subject of clinical trials. Without such information, there was no assurance that information created by the self-tracking devices would be sufficiently accurate to use in clinical judgements.

**Motivation** was also considered a factor influencing information quality. Prior work by Choe et al. (2014) observed that motivations to self-track are diverse, including self-reflection or simply curiosity. However, the systematic review revealed that there are profound consequences of a patient's motivation to self-track. Several studies raised examples of patients providing irrelevant or manipulated information, potentially because they wanted to receive or avoid particular diagnoses. Understanding the patient's motivations for self-tracking therefore became an important issue for evaluating information quality, particularly during the interview study where it was a prominent area of discussion. Specifically, clinicians wished to deduce if a patient recorded certain information to 'force a diagnosis', or if there may be an underlying condition which could cause the patient to obsess over some aspects of their health.

**Completeness** was considered an important factor of information quality. The fishbone model breaks this down into several causes: *gaps* in the data because of low adherence to self-tracking or technology constraints (e.g., taking a wearable tracker off during battery recharge), *selective reporting* (e.g., to conceal habits that a patient worries might reflect negatively on them), and *poor representativeness*, where a sample is insufficiently detailed to represent the patient's condition.

Approaching the end of the model, **structure and representation** becomes an important factor of information quality. The literature clarified that patient self-tracked data are most useful to clinicians when presented in forms comparable to clinical systems. However, self-tracking tools rarely make data available in such forms because designers assume the tools' users will be non-specialists.

Finally, the **decision context**, in which self-tracked data are used, was an important factor for determining the needs for information quality. For example, the decision contexts of differential diagnosis and chronic condition management had different information quality needs. For diagnosis, self-tracked data served as supporting evidence for establishing plans of care, so accuracy was considered an essential quality. Conversely, in chronic condition management, self-tracked data were primarily perceived to indicate the patient's subjective experience (e.g. quality of life), so accuracy was seen to be of less importance.

This fishbone model can be used to 'walk-through' self-tracking scenarios to better understand information quality needs. For example, a patient, Rupert, suffers chest pain while climbing stairs and subsequently makes a note of his blood pressure and heart rate. The fishbone model can help understand the possible information quality issues that may arise in the recording and use of Rupert's recording. Rupert had no prior chest pain, so presents to a GP. After initial assessment by the GP, the patient shows the note he took, comprising a hand-written blood pressure reading and heart rate. The GP could have some immediate questions about this data: How were these data collected? Was Rupert sitting down when measuring his blood pressure? Does Rupert remember the details of the event, such as where he was and what he was doing?

The GP may want to enquire about the accuracy and reliability of the data. What device did Rupert use to collect the data? Did this device come from a reputable manufacturer? Is the reading likely to be accurate based on Rupert's recollection of how he had taken the measurement? Understanding Rupert's motivation to see the GP may also fall into question. Is the data consistent with Rupert's recollection and medical history? Does it stack up? Rupert felt a fairly urgent need to see the GP, so does make Rupert's data more trustworthy? Questions about the completeness of data may be asked. Is the data complete enough to make a diagnosis? What gaps need to be filled by collecting new data, such as running tests? The structure and representation is also questioned. It is written on paper; is it legible? Are the readings using standard units of measurement? The responses to these questions could help the GP determine whether the data are sufficient for making a diagnosis. Perhaps the GP decides there is not enough evidence for making a diagnosis, glances at the data out of courtesy to the patient, sets it aside, and plans for tests to support a diagnosis.

Consider another scenario, where Rupert had previously been diagnosed with angina and had been educated on correct use of a blood pressure cuff. Rupert experiences chest pain, records his blood pressure and heart rate, and presents to the GP. The patient having prior education on using a blood pressure cuff gives the GP confidence in the accuracy and reliability of the data. While the data might not rule out another possible condition, it may be of high enough quality to document his condition.

While the data provided to the GP is the same in each scenario – both in content and structure – the decision contexts of each influence the information qual-

ity needs. In the former, a lack of prior diagnosis or history of chest pain meant the GP had many possible hypotheses, with the patient's self-tracked data proving insufficient to safely narrow down these hypotheses. In the latter, the data could be placed in context of a prior diagnosis of angina, and formed part of treatment monitoring. The fishbone model helps explore these diverse cases to understand potential information needs for using self-tracked data.

### 8.1.2 Recommendation 2: Provenance for Self-Tracking

The fishbone model illustrates that information quality problems are temporal, manifesting at multiple points from when the data are first collected, to when they are used in a decision context. For example, accuracy depends on how data are collected, while representing information pertains to when the data are being used. Thus, when thinking about potential ways to overcome information quality challenges, it is important to consider how the quality of information changes over time as it is collected, manipulated, and presented. These changes over time are encapsulated in the term *provenance*, that is, the history of an artefact for use as "a guide to authenticity or quality" (Oxford English Dictionary, 2008).

Establishing confidence in an artefact's authenticity has historically been a challenge in fine art. Significant resources are applied to identifying the derivation of works of art from their original sources to deduce, for example, the chain of ownership and any restorations which have taken place. Moreau et al. (2008) assert that provenance is of growing importance to electronic data so people can reason about the data's origins, how they have been retrieved, analysed, and manipulated, when these actions took place, and by whom. Moreau et al. state that this information is crucial for people to decide whether they should trust electronic data and encourage designers to make data systems 'provenance-aware'. Provenance-aware systems document how data were recorded, transformations it has undergone, and who has manipulated it (Bachour et al., 2015).

Moreau et al. (2008) argues that provenance could be of particular importance to healthcare, with the example given for its use in organ donation:

By making organ transplant management provenance-aware, powerful queries that were not possible before can be supported, such as: find all doctors involved in a decision, find the blood test results that were involved in a donation decision, find all data that led to a decision to be taken. Such functionality can be made available not only to the medical profession but also to regulators or families. – Moreau et al. (2008)

This case study presents interesting parallels for use of self-tracked data. If self-tracking systems were made to be provenance-aware, then information becomes available about when and how the data were recorded, how the data have been manipulated and for what reason, and how these data have been used in decision-making processes. Providing methods to query this information could help overcome many of the barriers to using self-tracked data which have been identified in this research. For example, if a clinician was concerned about the accuracy of heart rate readings, they could query the provenance documentation for what device was used to make the readings and how these data were manipulated. As seen in the

prototype's audit tool in Study 3, providing such information can help clinicians form a more confident judgement of the information quality.

However, self-tracked data rarely contain provenance documentation so there is a need to consider how it could be captured. Freire et al. (2008) define two key parts to data provenance: capture and representation. Provenance documentation is itself data, and thus can be created and represented computationally. While it can be captured manually (such as through notes), computationally collecting information reduces user burden and can increase the quality of provenance documentation. One key effort to represent data provenance has been W3C's PROV, an open standard for representing provenance as a graph (Bachour et al., 2015). It focuses on representation and is agnostic to the capture approaches. PROV is a highly technical approach, comprising detailed technical specifications, including the storage of low-level metrics like CPU usage. Freire et al. (2008) note that using such techniques creates vast quantities of provenance documentation and representing it directly may lead to information overload. Thus, it would be crucial to present such documentation at multiple levels, allowing higher-level abstractions which can be "zoomed in" to understand lower-level details.

While there are significant design challenges for implementing provenance-aware self-tracking technologies, such provenance promises to provide clinicians with a technique for more confidently determining the quality of information, and thus their suitability for clinical decisions.

### 8.1.3 Recommendation 3: Support Collaboration Sensemaking

Self-tracked data were seen to be important for collaborative sensemaking purposes so patients and doctors could reach mutual understanding and agree on management goals and treatment plans (West et al., 2016). This collaboration can support hypothesis generation by providing a basis for prioritising symptoms (Chung et al., 2015), especially for poorly understood conditions where little other information is available (Lee et al., 2017). Furthermore, collaboration around self-tracked data could support the personalisation of treatment plans and consequently lead to a prevention of medical errors (Chung et al., 2015).

This research has revealed two main opportunities for supporting doctor-patient collaboration sensemaking around self-tracked data. First, engaging the patient in discussion about their data could help trigger questions about salient events in their data and facilitate a better understanding of the patient's condition. While a patient's presence during data interpretation was not always considered essential, it was perceived to deepen a clinician's understanding of the patient's condition:

A diary would be a really useful way of them being able to show you what's happened to them because we can talk about it by reminding themselves what they've written down – *Cardiologist 3*

Second, a patient's presentation of data about their health encourages clinicians to involve the patient in understanding their health and potential interventions.

Self-tracking could therefore help patients better understand their own health and facilitate a mutual understanding:

If a patient can understand their condition better then they understand how to manage their condition better, and if they can manage their condition better then you're more likely to empower them to take responsibility for their condition. It's a joint effort. You have to work in partnership with the patient to achieve that. – *Junior Doctor 1*

The eagerness of some clinicians to engage patients in using their self-tracked data illustrates that using self-tracked data is not one way (patient-to-doctor), but rather a collaborative exercise in which clinician and patient work towards forming a mutual understanding of the data. This process lets the doctor better understand the patient's condition and helps the patient understand how their actions affect their health and quality of life and, as described by *Junior Doctor 1*, empowers them to take "greater responsibility for their condition".

A prior empirical study by Chung et al. (2016) of self-tracked data being used by doctors and IBS patients uncovered that self-tracked data acts as a *boundary object* (Star and Griesemer, 1989), where clinicians and patients organise, present, and collaboratively interpret relevant data to reach mutual goals and shared understanding of the patient's condition. Defining boundary objects, Huvila et al. (2014) states:

Boundary objects are abstract or physical artefacts that reside in the interfaces between organisations or groups of people. They have the capacity to bridge perceptual and practical differences among communities and facilitate cooperation by emerging mutual understanding. They negotiate meaning between groups of people and provide means to explain how and where communities, cultures and information infrastructures are connected and disconnected. – *Huvila et al. (2014)*

Boundary artefacts encourage discussion and collaboration, where actors (in this case, clinicians and patients) organise and present data, along with other relevant data sources, to reach mutual goals and shared understanding of the patient's condition (Star and Griesemer, 1989). For example, a clinician may seek a diagnosis, whereas a patient may want a particular prescription. But by collaborating around data about the patient's health, clinicians and patients alike share knowledge and information to negotiate a mutual agreement and shared expectations about treatments, symptoms, and prognoses. Clinicians consider this important because it empowers patients to take steps to improve their clinical outcomes or quality of life.

The collaborative process of using self-tracked could help overcome barriers pertaining to information quality. For example, if a clinician cannot determine the accuracy of blood pressure readings, they can ask the patient about the source of the data, what device it came from, and gain a better understanding of accuracy. Facilitating collaborative sensemaking could therefore be an important step towards maximising the value of self-tracked data. For supporting collaboration, data should be understandable by both patient and clinician (Patel et al., 2012). For example, overlaying other data sources can help clinicians and patients reflect on co-occurrences of symptoms and events (Patel et al., 2012). User interface design is

also a crucial factor; Frankel et al. (2005) observed that electronic health records had a negative impact on patient-clinician communication in consultations (in particular relating to reduced eye-contact) but mitigated this problem by making the user interface simpler and easier to use. However, facilitating collaboration may not be addressable through design alone and may require shifting practice from paternalistic care towards participatory care (Ballegaard et al., 2008):

We emphasise a need to revise this traditional clinical perspective. With a growing number of chronic patients and elderly and through the invention of novel healthcare technology, the treatment is no longer confined to the hospital, but also involves and impacts the citizens' everyday life in their home, at work, in public places, and when traveling. Thus, there is an everyday life to attend to as well as the health problems – and the clinical perspective of patients and clinical experts does not support or recognize this. – (Ballegaard et al., 2008)

#### 8.1.4 Recommendation 4: Include Stakeholders in Design

During the studies, several clinicians in the study raised the problems they have with technology, expressing frustration with the lack of technological progress made in the healthcare setting. One emergency doctor described his difficulties with information systems in his practice:

How long should it take you to request an X-ray – something as simple that – in the acute setting? It can take anywhere from 5 to 10 minutes because I'm waiting for the computer to load. Then I have to click on the investigation I want, write why I want that investigation, and then I have to go through these tick box exercises... It's just ridiculous. I'm sitting there in front of the patient and I'm like "oh yeah just give me a couple of minutes while I request this X-ray." A couple of minutes. Surely it shouldn't take this long. It's just a waste of time. – *Emergency Doctor 1*

There is a divide between what clinicians need and what they get from technology, reflecting a lack of involvement of stakeholders, such as clinicians, researchers, and clerks, in technology design (Orlikowski, 1992). As suggested by Wyatt and Wright (1998), inclusion of stakeholders can be crucial to effective information design. While information designers could guess what might overcome barriers to using self-tracked data, clinicians' insights will be important as they are the decision makers when it comes to using such data.

Past literature has focused on the practice of participatory design to overcoming the power inequality between designers and the stakeholders. Cornwall and Jewkes (1995) described this as "creating spaces in which people can be 'empowered' to engage in a process through which they can identify and confront their problems." This was the intention of participatory design in this research; to empower clinicians in the research process, enabling them to raise the problems they experience in their work practices and relate those to the self-tracking practices of patients. Indeed, participants in participatory design study were thankful for the opportunity to express their own thoughts on information technology, and it became clear technology deficiencies are abundant within their current workflows. These problems were diverse – affecting various tasks and interactions – and pervasive – affecting everyday workflows. Common complaints included personal health records not being available promptly, slow computers, and confusing user inter-

faces. The interview stage of this research helped to identify these problems and validated the need for clinician participation in healthcare IT design.

Clinicians are the front-line stakeholders to healthcare delivery, so including them within in the design of systems to facilitate using self-tracked data can help understand their workflows, opinions, and concerns. A participatory design approach enables collaboratively exploring with clinicians potential ways in which workflows can be improved to overcome barriers to using self-tracked data and pick out the problems which could be solved by future research.

## 8.2 SIGNIFICANCE OF THIS RESEARCH

This research contributes an understanding of commonalities and differences in how self-tracked data are used across different clinical settings. For example, the workflows for chronic care management are typically very different to paediatric care. Consider management of IBS, a chronic gastrointestinal disease which affects approximately 10% of the UK population (National Health Service, 2017). IBS has no known cure, and treatment takes place over a patient's lifetime to improve symptoms through dietary changes, medications, and counselling (Chung et al., 2015). Treatment plans are most effective when tailored towards a patient's own routines and habits, particularly regarding their diet. Self-tracking technologies have been deployed to enable patients to record their diet, in turn providing clinicians with information that helps tailor management plans (Chung et al., 2015). Conversely, in paediatric care, clinicians are less likely to prioritise empowering patients because, in many cases, patients will be too young to manage their own care (Piras and Miele, 2017). However, self-tracked data may still serve to bridge the gaps between consultations (Piras and Miele, 2017). Understanding these commonalities and differences in workflows across different clinical settings will be crucial to ensuring effective use of self-tracked data.

There are several reasons why self-tracked data are handled in such diverse ways across clinical settings. Clinicians in acute settings described self-tracked data as clues to warrant further investigation and did not see self-tracked data as concrete evidence to support a diagnosis or intervention. Prior work suggests this limited use of self-tracked data is typical in acute settings, where clinicians need to work quickly while ensuring patient safety (West et al., 2016). Conversely, in the management of chronic conditions, such as heart conditions, self-tracked data about symptoms, patient's subjective experience, and medication compliance, are deemed important when deciding on what actions should be taken. By having patients engage in self-tracking, they are seen to be more engaged in their care and could therefore form a larger part of the decision-making process. This may reflect a more collaborative nature of long-term health management typical in chronic care settings, where clinicians aim to engage patients in their care (Chung et al., 2015). This may also draw from self-tracked data being the only information clinicians have available to describe the patient's health condition over a long period and between consultations (Ancker et al., 2015b).

Time pressures may also contribute to self-tracked data use, with prior work finding primary care practitioners having limited time to analyse self-tracked data between consultations (Chung et al., 2015). The interviews confirmed this, with clinicians explaining that time limitations may make it unrealistic to make use of self-tracked data. However self-tracked data were seen to still provide opportunities for investigating difficult to communicate problems. Migraine, for example, is often under-treated, in part because patients have difficulty communicating their symptoms and clinicians underestimate migraine severity (Schroeder et al., 2018). Self-tracked data could improve patient-clinician communication and increase patient satisfaction by acting as an artefact for mutual discussion (Schroeder et al., 2018). Such data may enable primary care doctors to better assess pain intensity and potential triggers, in turn contributing to improved treatment plans (Baos et al., 2005).

The propensity for self-tracked data to be incomplete, often with missing periods of information, led interviewed clinicians to consider relying on the patient's recall to 'fill in the blanks'. In heart failure management, interviewed cardiologists said they often rely on patients recalling events – including general well-being, symptoms, medication adherence, and exercise – in their daily practice. They were, however, aware of the perils of self-recall as being prone to various retrospective memory effects, including memory biases, selective recall, and framing effects. Indeed, for other clinical scenarios, such as dieting (Zia et al., 2016), recall was seen to result in information not detailed enough for making informed decisions. It is likely that acceptability of recalled data depends on the decision context, including the kind of condition which is being monitored and the likeliness of patients to have recall errors or embellish to truth.

The difference in actions taken based on self-tracked data could be explained by different work patterns across these clinical settings. For example, in acute contexts, where decisions must be made quickly, practice may reflect a paternalistic model of medicine, where the clinician is in charge and is primarily responsible for making decisions about the patient's health, including the collection of information (Charles et al., 1997). This is in contrast to the more collaborative nature of managing long-term conditions, where clinicians aim to engage patients in their healthcare decision-making. Scenarios with the greatest opportunities for self-tracking are likely to be those where it is important to understand habits and routines (Kim et al., 2016). For poorly understood conditions, self-tracked data may be the only factor for deciding how to manage their condition.

The collaboration between clinician and patient around self-tracked data is consistent with prior work on boundary objects. As stated by Chung et al. (2016), these sources of information "sometimes conflict with each other or are unclear for medical decision-making, and therefore require that providers and patients collaboratively interpret the data". This reflects classical models of shared decision-making: patient and clinician are present; they share information; they build a consensus about preferred treatments; and, an agreement is reached on which

treatment to implement (Charles et al., 1997). Other work has found contrasting use of self-tracked data, with such data seen to undermine trust and weaken clinician-patient relationships (Ancker et al., 2015a). This suggests that the nature of self-tracked data as a boundary object may depend on the decision making context. Prior work has argued that traditional clinical practice must be revised to a more participatory healthcare to address the collaboration problems in doctor-patient use of IT systems (Unruh et al., 2010; Ballegaard et al., 2008). Self-tracking may therefore rely on a shift toward more collaborative decision-making, which is increasingly considered important for chronic condition management (Holmström and Röing, 2010).

A related concern was that a patient's motivation for recording self-tracked data can be unclear, potentially indicating an underlying condition. In contrast to chronic care management, where self-tracking is often part of an agreed management plan with the clinician, doctors in primary care are often surprised when a patient presents data, and occasionally concluded that a patient may be 'obsessed' with some aspect of their health. Clinicians spoke about the importance of understanding why a patient engaged in self-tracking so that their objectives can be understood. This is consistent with prior work; Zhu et al. (2016) found that avid self-tracking was sometimes seen as an indicator of obsession, compulsiveness, or significant concern about particular symptoms. Another study found that the act of presenting data to clinicians indicated a patient's desire to confirm or "beg for" a diagnosis (West et al., 2016). On the other hand, prior work has suggested that the act of a patient providing self-tracked data may simply be an artefact of the fact that self-tracking is on the rise and that patients think such data would be useful for clinicians during the consultation (Chung et al., 2015; West et al., 2016). Moreover, people who self-track are often inspired by a desire to improve one's own health and well-being, and, thus, attention to collecting this information indicated that the patient could be trusted to look after their health (MacLeod et al., 2013). Again, the importance of patient motivation differed depending on clinical context.

This research strengthens the understanding of self-tracked data quality. As prior work found, self-tracked data are sometimes perceived to be too unreliable to make a safe clinical decision based upon them (West et al., 2016). The importance of perceived quality depended on the circumstances: in diagnostic decisions highly reliable data may be critical (Chung et al., 2015), whereas in the long-term management, clinicians may be more pragmatic and accept data where it is available (Ancker et al., 2015a; Kim et al., 2016). One study described clinicians as having little confidence in self-tracked data due to "perceived lack of diligence, moral valence of the data (with patients unwilling to 'admit' undesirable numbers), and fear of consequences" (Ancker et al., 2015b). The most common approach to overcoming this barrier was to run additional clinical measurements, which was done routinely to support hypotheses whenever it was practical (Ancker et al., 2015a; West et al., 2016). For example, in differential diagnosis, prognostic decisions based

on self-tracked data were made only after considering substantial additional supporting evidence, which was systematically sought (Ancker et al., 2015a).

However, this research identified that quality is not always perceived to be crucial. Clinicians often lack complete or accurate information about patients with chronic conditions leading to poor care coordination and medical errors, so data of any form were seen to be preferable to none. Moreover, when data are examined cooperatively with patients, such as for reflection or to facilitate self-recall, notions of data quality may be less important than the personal significance and communicative roles served by the data. Data artefacts may not necessarily be seen as accurate and representative evidence, but rather communications tools created by the patient to communicate aspects of his or her understanding of their health. In contrast to prior work where objectivity of data was considered essential (Ancker et al., 2015b), the interview participants identified *subjectivity* as an important quality. These findings suggest that attitudes toward self-logged data vary depending on the type of clinical setting. Thus, a clinical tool for representing self-tracked data may have greater opportunity by focusing on long-term improvement of general well-being over short-term improvement of prognosis.

Prior work found that the design of data representation plays a crucial part in time-effective use of data. Summaries and tailored visualisations can make information more easily retrievable in time constraints (Mishra et al., 2016; Chung et al., 2016; Kim et al., 2016). While complex visualisations can help in greater exploration of the data (Schroeder et al., 2017), clinicians in the interviews feared that excessive information could lead to information overload. In ambulatory care, for example, doctors are used to working with charts in clinical standard representations which enable fast and effective decision-making (West et al., 2016). In the co-design workshops, this led clinicians to focus on designing data representations which were familiar to them. These mockups were iterated into a ‘timeline’ view of data which shares similar design goals to other prior work, such as LifeLines (Plaisant et al., 1995). Timelines have been seen as a natural way to represent patient records because they enable causal and temporal relationships to be identified between potential triggers and symptoms (Plaisant et al., 1995; Huba and Zhang, 2012). Chung et al. (2015) describes the identification of trends or correlations as an important aspect of investigating a patient’s condition: “if their goal is to identify specific triggers for symptoms, they look for correlations between factors, whereas if providers are monitoring a symptom or outcome, they try to identify trends and outliers in the data.” Findings from this research are consistent with these prior studies; clinicians needed data to be arranged in familiar ways which make irregularities and relationships obvious.

As discussed in Chapter 2, past works have formulated design principles for medical information systems. Leveson and Turner (1993) provided several safety-critical design principles lessons-learned from Therac-25 radiation therapy disaster. These principles focused on ensuring that systems are engineered with patient safety as a top priority; for example, “do not design a system where a single error

can be catastrophic". Similarly, Konschak et al. (2013) presented several design principles for designing electronic medical records, focusing the safety and usability of such technologies; for example, "to ensure data are easily, accurately, and reliably retrievable". While these design principles provide an important barricade against engineering dangerous or unusable medical systems, they do not specifically consider the specific needs of clinicians when using self-tracked data. This thesis presents several new design recommendations specific to using self-tracked data.

## 9 CONCLUSIONS

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This thesis presented an investigation of three research questions to understand the potential role of patient self-tracked data in clinical settings. This chapter summarises the findings and concludes with potential future directions for research.

### 9.1 SUMMARY OF RESULTS

Chapter 1 stated three research questions on the topics of opportunities and barriers for using self-tracked data, clinical workflows for using such data, and design principles for self-tracking technologies. These questions were investigated using a systematic review, interviews, and participatory design. The findings of each are summarised below.

#### **What are the opportunities for and barriers to using self-tracked data in clinical settings?**

This question aimed to identify how self-tracked data could improve healthcare and challenges to their use. A systematic review of literature around self-tracked data subsequently revealed there is currently very limited use of self-tracked data in clinical settings. However, several opportunities became clear. First, self-tracked data can provide information about a patient's health between consultations. Second, self-tracked data can facilitate collaboration in consultations. Finally, patients who self-track may become empowered in healthcare decisions by taking management of their own health information. These opportunities may be particularly important for chronic illnesses where patients may benefit from self-tracking by becoming more engaged in and knowledgeable about their care.

Despite these opportunities, the review identified several barriers to using self-tracked data within clinical settings. With a vast array of consumer devices and differences in patient self-tracking practices, clinicians often lack confidence in the reliability of self-tracked data. Contextual information – such as what the patient was doing while they took a measurement – could be crucial here. Knowing how a patient made measurements, what they were doing at the time, and the device they used could help clinicians appraise the data. With clinicians only having limited time in their work practices, efficient presentation of self-tracked data is also critical to the clinical use of such data.

#### **What are the common workflows of clinicians when using self-tracked data?**

This question aimed to discover sequences of processes that clinicians follow when a patient presents self-tracked data. Thirteen clinicians of various roles were interviewed about their experiences with self-tracked data and how they could use such data. Their workflows for using self-tracked data differed between clinical settings, but some activities were common across these settings. These activities were constructed into a six-stage workflow model to describe how clinicians may typically

work with self-tracked data. The model comprises stages relating to data capture, quality, utility, structure, interpretation, and finally application in a plan or action. The model affords an understanding of the potential broader uses of self-tracked data and presents an important model for identifying ways to overcome barriers to using such data.

#### **What are the design needs of clinicians for using self-tracked data in clinical settings?**

This question aimed to construct design principles for enabling the opportunities for self-tracking, overcoming the barriers to their use, and operating within clinical workflows. A co-design process was undertaken with five cardiologists to understand their needs for using self-tracked data. The process comprised mockup workshops<sup>K</sup> and technology probe interviews, implementation of a software prototype, and feedback interviews. Several design recommendations around three areas were constructed from the findings of this co-design study. First, designers should aim to apply clinical standards to self-tracked data where possible. This ensures clinicians can interpret information efficiently and accurately. Second, designers should aim to enable collaborative investigation with patients. This includes, for example, ensuring that data representations can be useful for both clinicians and patients. Finally, designers should provide an audit trail of self-tracked data so clinicians can assimilate the data's accuracy and reliability. These design principles provide future designers with a check-list for design self-tracking technologies to be safe and useful for clinical purposes.

#### **9.2 STRENGTHS AND LIMITATIONS OF THIS RESEARCH**

This research used a participatory design approach to engage clinicians in creative tasks, and was thus able to elicit deep insights into clinicians lived experiences when working with self-tracked data. Moreover, the use of interviews and a technology probe enabled a deeper understanding of each individual clinician which may have been missed with a quantitative approach. However, this research has several limitations which limit the generalisability of the findings. First, only clinicians were interviewed, not patients. Findings around patient's perspectives of workflows were derived only from prior literature. As scoped out in Chapter 1, clinicians were intentionally the focus of this research because it was deemed important to understand the workflows of clinicians. However, patient perspectives will be important to understand when designing for collaborative workflows. Second, the workflows only consider the interactions between one clinicians and one patient. Many consultations will include other actors, such as carers and other health professionals, whom this workflow does not model the interactions with. Third, while it was considered important to interview a diverse range of clinicians, the sheer number of different roles meant that only a small subset of common roles were covered. Within these covered roles, only between one and four members were interviewed, limiting insights to a small sample of each role. Fourth, the sampling methods (convenience and snowball) means that the sample is not

representative of the entire population, limiting the generalisability of the findings (Atkinson and Flint, 2001). Finally, the interviews were all conducted within the UK, so findings may be affected by the standardised practices and workflows of the NHS. There may be considerable variation in practices and workflows between different countries, hence the workflow model and design recommendations may not be generalisable across different countries.

### 9.3 FUTURE DIRECTIONS FOR RESEARCH

While this research has identified several commonalities between clinicians' work practices across different clinical settings, it became clear that each clinical setting and clinical role had work practices unique to them. This has an important effect on the role of self-tracked data in clinical settings. For example, in mental health settings, it was sometimes important just to see if a patient had engaged in self-tracking, not necessarily *what* they self-tracked, as an indicator of the patient's condition. This use of self-tracked data was distinct to their use in emergency medicine, where a doctor was looking for familiar tabulated or graphed data, such as blood pressure or glucose levels. While clinicians in both situations went through common stages of asking patients about the data and checking data quality, these differences warrant investigations into specific clinical settings. The design needs of clinicians across different settings may be different. Thus, one obvious future direction for research would be to gather empirical data about the design needs of specific clinical settings.

The findings from the literature synthesis and interviews revealed that the use of self-tracked data is a collaborative process, so a second important direction for future research is the broadening of the research to include patients. Eliciting patients' experiences of self-tracking could reveal deeper knowledge about the opportunities for and barriers to using self-tracked data in clinical settings. Observing doctors and patients collaborating with such data as they might in real-world consultations would help understand the extent to which the common workflow model identified in this research is collaborative. This has implications for how self-tracking may empower patients and personalise care, two important milestones for tackling growing worldwide health epidemics.

The third avenue for research would be to consider other countries. This research has considered clinicians in the NHS, and so the findings may be affected by the standardised practices and workflows of the NHS (Department of Health, 2012). Only a few studies have so far investigated self-tracking in developing countries, where work practices are likely to be very different and where remote monitoring and mHealth technologies have become crucial to remote communities (Konschak et al., 2013). Including clinicians from other countries would help understand the greater role of self-tracked data worldwide.

Finally, the workflow model and design recommendations put forward in this research has relevance to the design of personal health records. Such records are designed to incorporate patient-collected information, so there may be overlap

in the design needs for self-tracked data. PHRs empower patients to participate in their care and medical decision making, and present new opportunities for personalized medicine (Pearson et al., 2011). However, PHRs are not currently well suited for patients due to poor usability, complex vocabulary and limited functionality (Ancker et al., 2015a). Future research could focus on validating the workflow model and recommendations made in this research in the context of PHRs to help overcome their current design challenges.

#### 9.4 CONCLUDING REMARKS

Devices for quantifying one's own health, such as Fitbit and Apple Health, have become fashionable and ubiquitous, galvanising a new well-being economy. They have empowered patients to become quantifiers of their own health, promising to enable a democratised and collaborative medicine. The data from these devices could describe a patient's health over a long time while helping to motivate patients to take a greater role in their care. A cross-discipline interest has therefore grown in understanding how self-tracked data can contribute to better health and care. The manuscripts published as part of this research have, as of October 2019, amassed 85 citations<sup>1</sup> spanning Health Science and Computer Science journals.

Despite the clear opportunities for self-tracked data, this thesis has identified that clinicians are hampered in engaging with such data in their workflows. Clinicians are unsure of data quality, unfamiliar with data structures, and concerned with patients' motivations to self-track. Without sufficient inclusion of clinicians in the design of self-tracking tools, these barriers are likely to remain. By immersing clinicians in a participatory design exercise, this research developed a new understanding of clinicians' needs when using self-tracked data. The resulting design principles could help shape future self-tracking tools to be useful and reliable in clinical settings.

Where does this leave the role of self-tracking in medicine? Clearly, self-tracking has important roles to play; it could help doctors manage chronic illnesses and help patients take charge of their health. As more people engage in self-tracking, further opportunities for self-tracking are likely to become apparent. For example, healthcare research is increasingly looking to AI to reduce the workload of clinicians and improve the precision of medicine towards individual patients. Self-tracking could provide the necessary information fuel these AI systems. But healthcare remains dominated by fax and paper forms, so it is unclear how modern pervasive self-tracking technologies could work alongside such antiquated technologies. Moreover, clinicians are demanding evidence that self-tracking technologies are reliable and accurate. The tech industry will need to work with health providers towards clinical validation of these devices. Regulators may need to step in to ensure that these devices are safe. Coordination between the device designers, healthcare industry, and regulators will thus be crucial to solving these

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<sup>1</sup>Google Scholar reports 85 citations <https://scholar.google.co.uk/citations?user=2-YEd24AAAAJ> [Accessed 2 Oct 2019]

problems. If these problems are solved, self-tracking promises to pave the way towards greater patient engagement and more personalised medicine.



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## A PARTICIPANT INFORMATION SHEET

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*Version 3.0, 19th January 2017*

**Study Title:** Co-design of a clinical tool for using patient-logged data in long-term care management

**Researcher:** Peter West

**Ethics number:** 22500

**Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.**

### **What is the research about?**

This study is part of my PhD research into self-tracking devices, like the Fitbit and Apple Watch. In the future, it is likely that data from these devices will be contributed to health records. The UK government, for example, has published the Health and Care 2020 framework, which proposes that patients will be able to contribute their own data to health records. The primary aim of this study is to understand of how health professionals might, in future, interpret and use patients' self-tracked data to learn about patients' health. With the participation of health professionals, I am aiming to develop a prototype of a clinical tool for representing self-tracked data in clinical settings. From this, we can learn how tools for looking at self-tracked data can be made safe, and how the tools can fit into clinical workflow.

### **Why have I been chosen?**

Health professionals will often work with patients who have long-term illness, so will be able to give valuable insights into the kinds of self-logged information which may be useful in clinical decisions.

### **What will happen to me if I take part?**

You will be asked via email if you wish to participate in a series of interviews and workshops for understanding how health professionals interpret self-logged data relating to a patient's health. If you wish to participate, you will be able to decide a time and location of your choosing for an initial interview. In this interview, you will be presented with tools for self-logging, such as mobile apps. You will then be asked the kinds of information you would consider important in care management, and what you would consider the most effective ways to view this information. Over the following months, you will be asked to attend two workshops in which you will be presented with a prototype for viewing self-logged data. In these workshops, you will be able to discuss with other participants the interface. During both the interview and workshops, you will be recorded using an audio recorder or smartphone. Video recording will take place during the workshops, but the camera will be pointed at the desk on which the activities will take place. Following the last session, you will be kept informed about the results and any publications that follow this study. If you are unable to meet on Highfield campus, we will meet you elsewhere where possible.

### **Are there any benefits in my taking part?**

You will be contributing to a new understanding of patient-logged data in clinical settings. In turn, this will inform the design of clinical information systems which can take advantage of such data. This may help doctors care for their patients, improve the lives of patients, and help empower patients in their care.

### **Are there any risks involved?**

We have taken measures to ensure research data (such as audio recordings) are held securely. We do ask that you avoid revealing personally identifiable information while you are being recorded during interviews and workshops.

**Will my participation be confidential?**

During the study, data will be collected pseudonymously – you will only be identified by a unique number. Personally identifiable information, such as name and address, will not be collected. Occupation (for example, senior cardiologist) will be collected. Only the researchers listed at the top of this document will have access to the collected data. The data will only be publicly available in an aggregate form. You can request to view data relevant to themselves, at which point the researchers will make reasonable efforts to make this data available within a reasonable timeframe (24 hours). The point of contact should be the primary investigator, *[contact details removed]*.

**What happens if I change my mind?**

At any stage, you may request to withdraw and/or have their data to be removed, at which point we will, within a reasonable timeframe (two weeks), delete information associated with them. However, the aggregate data, once published, will no longer be able to be changed.

**What happens if something goes wrong?**

In the unlikely case of concern or complaint, contact the Research Governance Manager *[contact details removed]*.

**Where can I get more information?**

If you have any questions, please contact the primary investigator *[contact details removed]*.

## B PARTICIPANT CONSENT FORM

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*Version 3.0, 19th January 2017*

**Study title:** Co-design of a clinical tool for using patient- logged data in long-term care management

**Researcher name:** Peter West

**Ethics reference:** 22500

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (19 th January 2017, Version 3.0 of participant information sheet) and have had the opportunity to ask questions about the study.

(initials)

I agree to take part in this research project and agree for my data to be used for the purpose of this study.

(initials)

I agree that my participation will involve audio and video recording devices. These recordings will only be seen by the researchers Peter West, Max Van Kleek, and Richard Giordano.

(initials)

I understand my participation is voluntary and I may withdraw **at any time** without my legal rights being affected.

(initials)

### Data Protection

*I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous.*

Name of participant (print name).....

Signature of participant.....

Date.....