

Common Barriers to the Use of Patient-Generated Data Across Clinical Settings

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Patient-Generated Data

Any kind of data which a patient has recorded using their own means.



Wearables

Fitbit, Apple Watch



Smartphone apps

Google Fit, Strava



Health products

Blood pressure cuffs,
weighing scales



Journals

Hand-written and
electronic

Health Self-Tracking Tools are Increasingly Popular

One third of US adults track at least one indicator of health (such as weight or symptoms) on using an app (MobiHealth News 2013)

Over **15 million Fitbits** sold in first quarter 2017 (Statista 2018)



Challenges facing healthcare

We are living longer! But, this means more chronic illness.

Diabetes

422 million worldwide
Almost 4x more than 1980

(Mathers 2006)

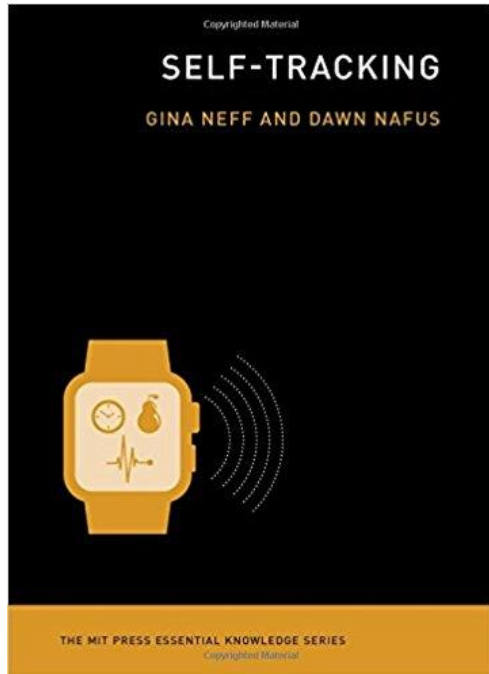
Heart failure

6.5 million in USA
Predicted to rise 46% by 2030

(American Heart Association 2017)

Doctors are facing **increasing workload** and a need for more **personalised care**.

Visions for Patient-Generated Data



Neff and Nafus (2016). *Self-Tracking*

Personalising medicine towards individual patients

Fill the gaps between visits

Early detection of health abnormalities

Boundary Negotiating Artifacts in Personal Informatics: Patient-Provider Collaboration with Patient-Generated Data

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ABSTRACT

Patient-generated data is increasingly common in chronic disease care management. Smartphone applications and wearable sensors help patients more easily collect health information. However, current commercial tools often do not effectively support patients and providers in collaboration surrounding these data. This paper examines patient expectations and current collaboration practices around patient-generated data. We survey 211 patients, interview 18 patients, and re-analyze a dataset of 21 provider interviews. We find that collaboration occurs in every stage of self-tracking and that patients and providers create boundary negotiating artifacts to support the collaboration. Building upon current practices with patient-generated data, we use these theories of patient and provider collaboration to analyze misunderstandings and privacy concerns as well as identify opportunities to better support these collaborations. We reflect on the social nature of patient-provider collaboration to suggest future development of the stage-based model of personal informatics and the theory of boundary negotiating artifacts.

Author Keywords

Personal informatics; self-tracking; patient-generated data; patient-provider collaboration; chronic disease management; boundary negotiating artifacts.

ACM Classification Keywords

H.1.5.m. Information interfaces and presentation (e.g., HCI); Miscellaneous.

INTRODUCTION

To better address individual health concerns and coordinate long-term care planning, chronic disease care is moving from clinical care to home care [18] with increased focus on, use of, and even reliance on patient-generated data [14]. The

prevalence of smartphone self-tracking applications (e.g., *MyFitnessPal*, *WeightWatchers*) and wearable sensing devices (e.g., *Fitbit*, *Apple Watch*, *Microsoft Band*) increases patient capacity for collecting health data and engaging with that data to support personal health and wellness goals.

These data have the potential to complement standard measures in the clinic with rich, everyday health behavior information. However, of the one-third of current self-trackers who share data with providers, most reported dissatisfaction with provider engagement with the data [24].

For patients with irritable bowel syndrome (IBS) or overweight and obesity, managing these conditions and achieving desired health outcomes relies upon everyday lifestyle choices and monitoring to identify individual symptom triggers or weight loss barriers. Self-management programs and lifestyle counseling are clinically effective in these two populations [25,61], and both of these approaches encourage self-tracking. However, limited time and resources inhibit providers in clinical practice from fully engaging with and reviewing data collected by patients. As a result, patients are dissatisfied with feedback received from healthcare providers on data obtained from such diaries [28]. In addition, most commercially available self-tracking tools were not designed to support sharing or collaboration within or outside of the clinic visit, which makes the collaboration even more time-consuming and infeasible [10].

This paper examines how to support providers and patients in their engagement with patient self-tracking data by answering the following questions:

- How do self-tracking tools and patient-generated data currently support patient-provider interaction?
- How do these tools and data currently support patients coordinating between self-care and care in the clinic?

We explore patient goals for sharing self-tracking data with their providers in a survey of 211 patients and more in-depth follow-up interviews with 18 patients. We also contrast patient views with provider perspectives in a re-analysis of 21 healthcare provider interviews [10]. We examine these combined datasets through the lenses of the stage-based model of personal informatics [34] and boundary negotiating artifacts [32]. Specifically, we contribute an understanding of:

- Patient expectations for sharing self-tracking data with their healthcare providers;

Related Work

Chung et al (2016). *Boundary negotiating artifacts in personal informatics*

PGD acts as a boundary object

PGD can empower patients as part of health decision making

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Crafting a View of Self-Tracking Data in the Clinical Visit

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ABSTRACT

When self-tracking encounters clinical practices, the data is reshaped by goals and expertise that exist within a healthcare framework. To uncover these shaping practices, we provided a Fitbit Zip step-count sensor to nine patients with Parkinson's disease. Each patient wore the sensor for four weeks and then returned for a clinical visit with their neurologist. Our analysis focuses on this first clinical visit after four weeks of data had been collected. Our use of conversation analysis of both talk and action makes visible the practices engaged in by both collaborative members to 'craft a view' of the data toward shared decision making. Our findings reveal the deliberate guiding of attention to specific views and interpretations of the data through both talk and actions and we explain how our systematic analysis has uncovered tools for the mutually beneficial crafting practices of the clinician and patient.

Author Keywords

Activity tracker; quantified self; self-tracking; perception.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI); Miscellaneous.

INTRODUCTION

For those with difficult-to-manage chronic conditions, aligning self-tracking data with health goals is a crucial step in sustaining healthful behavior. As self-tracking data is increasingly being integrated into electronic health record (EHR) patient portals the potential is there for bringing this data into the clinical office visit [34,36]. These new tools offer the possibility for relating the information that is generated during doctors' visits with the information from people's daily lives. In a sense, self-tracking is blurring the line between the home and clinic [9], and a challenge for the design and use of self-tracking tools is how to design

for this bridging moment. For instance, the US-based EHR provider, EPIC, is now supporting patients to upload certain self-tracking data through the patient portal. But there is no indication that clinicians nor patients know how to incorporate this data during routine clinical visits. Despite incentives under the U.S. Affordable Care Act to support more data-driven medicine, questions still remain about what practices and tools needs to be in place so self-tracking data can be integrated into patient records and used to monitor health in a patient-centered manner. Self-tracking data needs to move beyond the rhetoric of simply being there to "inform" as that will be greeted as more work by clinicians. And yet there is a lack of evidence in how to support the discussion and use of this data in order to integrate it into clinical management of chronic conditions.

This is a challenging question if you consider that when self-tracking encounters clinical practices the data is reshaped by goals and expertise that exist within a healthcare framework [34]. One can not simply fold self-tracking data into established clinical practices without some work on the part of both the patient and the clinician. For one, the data differs from what is reflected upon at home. For instance, one's multiple blood sugar readings when at home have very different implications on care trajectories when discussed during the clinical visit [32]. This is because of how the data is shaped and co-interpreted by both the clinician and patient [1,19–21,37]: an object of scrutiny may take on many different forms as a result of each of the different actors' viewpoints [31]. Data is only understood via manipulation and interpretation based on context and experience. This means that data viewed by oneself may transform and take on an entirely different meaning in a collaborative viewing full of negotiation and interpretation [1,20,37].

In our research program, we were motivated to explore the practices that emerge by both the patient and clinician in utilizing that data within a clinical visit. Although self-tracking practices as well as the integration of self-tracking data into the clinical sphere have been of great interest to the HCI community, the studies to date have not explored the talk and actions that surround the use of the data within the clinical realm [2,22,46]. Our immediate questions are not whether self-tracking data will be used in clinical healthcare settings or if it has some measurable effect on health outcomes (although this is an interest of ours in the

Related Work

Mentis et al (2017) - *Crafting a View of Self-Tracking Data in the Clinical Visit*

Using patient-generated data is a collaborative process between doctor and patient

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Our previous findings

West et al (2016) - The Quantified Patient in the Doctor's Office

PGD can form part of a diagnosis workflow

Doctors lacked confidence in measurements

There are challenges around how PGD are represented.

The Quantified Patient in the Doctor's Office: Challenges & Opportunities

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ABSTRACT

While the *Quantified Self* and *personal informatics* fields have focused on the individual's use of self-logged data about themselves, the same kinds of data could, in theory, be used to improve diagnosis and care planning. In this paper, we seek to understand both the opportunities and bottlenecks in the use of self-logged data for differential diagnosis and care planning during patient visits to both primary and secondary care. We first conducted a literature review to identify potential factors influencing the use of self-logged data in clinical settings. This informed the design of our experiment, in which we applied a vignette-based role-play approach with general practitioners and hospital specialists in the US and UK, to elicit reflections on and insights about using patient self-logged data. Our analysis reveals multiple opportunities for the use of self-logged data in the differential diagnosis workflow, identifying capture, representational, and interpretational challenges that are potentially preventing self-logged data from being effectively interpreted and applied by clinicians to derive a patient's prognosis and plan of care.

Author Keywords

Quantified self; clinical decision making; self-tracking

ACM Classification Keywords

H.5.2 Information interfaces and presentation (e.g., HCI): User-centered design; J.3 Life and medical sciences: Health

INTRODUCTION

Empowering patients to "take charge" of their health is an idea frequently championed by politicians [22, 16], technologists [27], journalists [19] and healthcare experts alike [37]. Yet, despite both government and industry-led initiatives across both Europe and North America to encourage this "patient-led healthcare revolution," widespread adoption has been slow [41].

One area, however, where individuals have been taking the lead in understanding their own health is the *Quantified Self* movement. This primarily comprises of non-expert ordinary

people who use technological tools to record and interrogate the minutiae of their physical and mental states over time [37]. As the population of those interested in self-logging has grown, industry has responded with a vast collection of wearable and embeddable sensors which enable people to keep an accurate record of their health with low effort and high fidelity. For these reasons, it has been proposed that the Quantified Self movement can contribute to health care, helping clinicians diagnose and treat illnesses [36]. However, some clinicians outright reject the use of self-logged data, citing concerns about data quality, time constraints, and insufficient resources [35].

What are the barriers to the use of self-logged data in critical clinical decision making settings? This is a delicate question to approach for several reasons: first, during the course of a single patient visit, there are many kinds of decisions made by a different clinicians in different roles in different settings. Paramedics in an ambulance, triage nurses within an emergency room, specialists in acute care units or hospital wards, to general practitioners (GPs) in their offices, all make decisions regarding patients under distinct situational and informational constraints [11]. Second, even if focus is centred around a single setting by a single class of medical professionals, such as GPs, there are many significant differences in day-to-day work practices between individuals. For example, there can be variation in the degree to which GPs use electronic medical records (EMRs) to organise patient data, how particular tests or treatments are prescribed, and the mechanisms that they use to maintain good patient relationships [34].

We focused on two clinical roles: primary care physicians on the "frontline" of the medical service, and secondary care specialists who work in hospitals. Filling a gap in empirical research, we sought to understand the nature of evaluation and use of "self-logged" data voluntarily recorded by the patient without advice from clinicians, particularly of the most common types facilitated by consumer health monitoring tools. We wished to identify factors behind the under-use of self-logged data by clinical professionals, including *what* was captured, *how* they were captured, the *representation* made available during a patient consultation, and other, yet unidentified, issues. From this, we wished to extrapolate how such problems might be addressed through HCI research, such as by re-thinking tools people use to monitor themselves, the kinds of data they capture, or the ways that

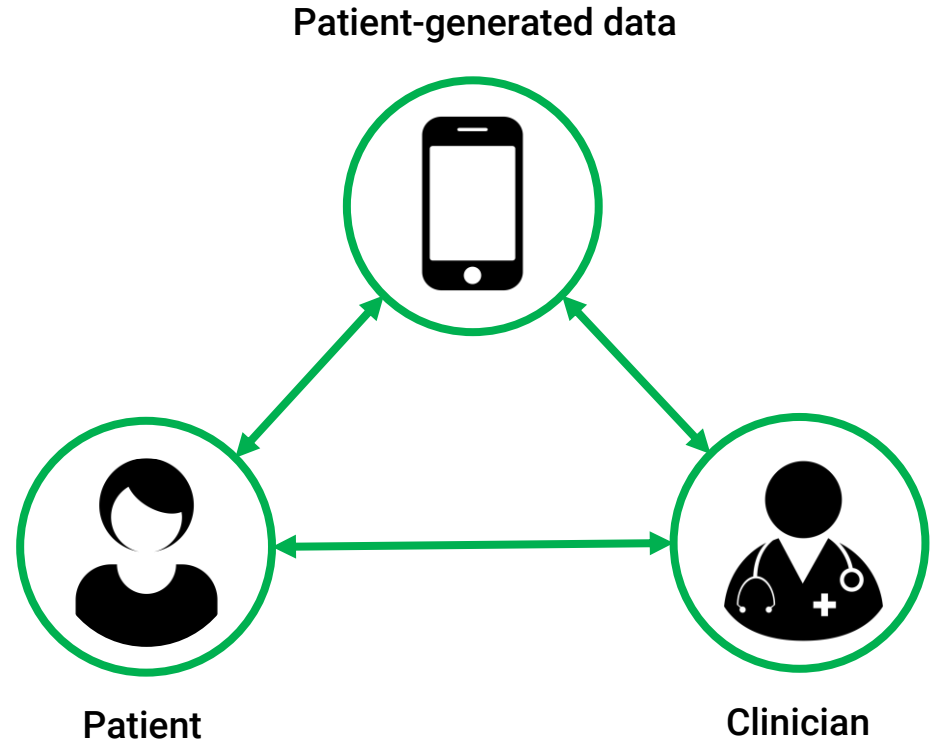
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Research Question

What are the common barriers to using patient-generated data in clinical workflows?

Workflows

1. The **order** in which work is conducted
2. How the actors **interact**



Method

Literature Review

To identify barriers across different clinical settings found in prior work.



Semi-Structured Interviews

To understand how these barriers manifest within clinician workflows.

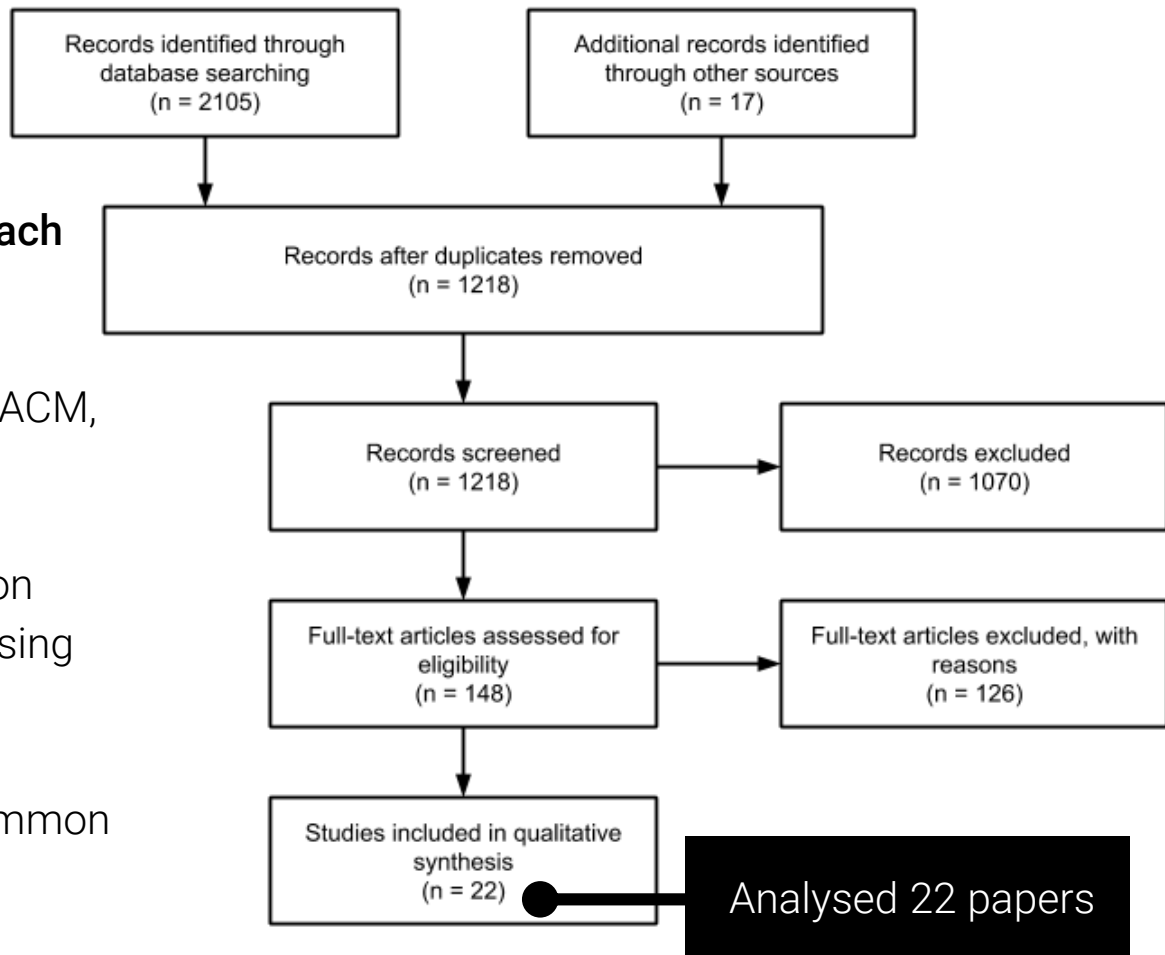
Literature review

We followed a **systematic approach** using PRISMA.

Searched **7 databases** including ACM, Web of Science, and PubMed.

Included papers which reported on clinician's **lived experiences** of using patient-generated data.

Thematic analysis to identify common themes.



Themes

12 themes across 22 papers

Themes

12 themes across 22 papers

Barrier	Description	General [23, 26, 54]	Irritable bowel syndrome [13, 14]	Sleep [44, 50]	Chronic illness [30]	Diagnosis [51]	Multiple chronic conditions [2, 3]	Weight loss [11]	Itching [29]	Hospitalisation [33]	Parkinson's [32]	Diabetes [39, 42]	Breast cancer [24, 40]	Disease prevention [15, 26]	Mental health [25]
Structure	Data structure is unfamiliar or inconsistent.														
Completeness	Missing measurements or poor patient adherence.														
Reliability	Inaccuracies in data, or self-tracking practice not clinically validated.														
Context	What the patient was doing at the time of measurement is unknown.														
Relevance	Data are irrelevant to the current clinical context.														
Selective disclosure	Patients may be withholding certain information.														
Underlying condition	Self-tracking behaviour may indicate obsession or psychiatric disorder.														
Insufficient time	Clinicians do not have sufficient time to interpret and analyse data.														
Insufficient expertise	Clinicians have not received training for using such data.														
Information overload	Too much information for the clinician to work with.														
Poor interoperability	Data difficult to integrate into clinical systems, can go missing.														
Impact to workflow	Negative impact to doctor-patient relationship.														

Table 2. Barriers to using patient-generated data identified within the literature review, listed with the clinical contexts in which they were observed.

Interviews: Participants

13 clinicians were selected using the following criteria:

- I. They were a certified healthcare professional
- II. They regularly worked with patients
- III. The sample reflected a variety of specialisms

Table 1. Participants of interviews by clinical role, and years in practice.

Clinical role	Participants	Years in practice
Cardiologist	P1, P2, P3, P4	All 20+ years
Mental health specialist	P5, P6	10 years, 5 years
Emergency doctor	P7	5 years
Junior surgeon	P8	5 years
Hospital doctor	P9	4 years
General practitioner	P10	20+ years
Heart failure nurse	P11	20+ years
Oncology nurse	P12	2 years
Audiologist	P13	3 years

All were practicing in the UK

Interviews: Semi-Structured Approach

Our aim was to elicit perspectives on patient-generated data, so we asked questions pertaining to:

- their clinical background and relevant contexts,
- their typical encounters with patient-generated data,
- how they would evaluate and use such data,
- how such data might impact their work.

Using semi-structured interviews allowed discussions of concepts which we had not been anticipated.

Analysis

We coded interview transcripts and consolidated with literature review themes. Several **chronological stages** of using patient-generated data become evident.

We used the **Workflow Elements Model** (Unertl et al 2010) to develop a workflow based on these stages.

We consider the actors, the artefacts used, the actions taken, the characteristics of these actions, and the outcomes of these actions.

We then analysed the **barriers** we had identified by the workflow stages they appeared in.

Results



A workflow of six stages

**Align patient and
clinician objectives**

1

Evaluate data quality

2

Judge data utility

3

**Decide on a plan
or action**

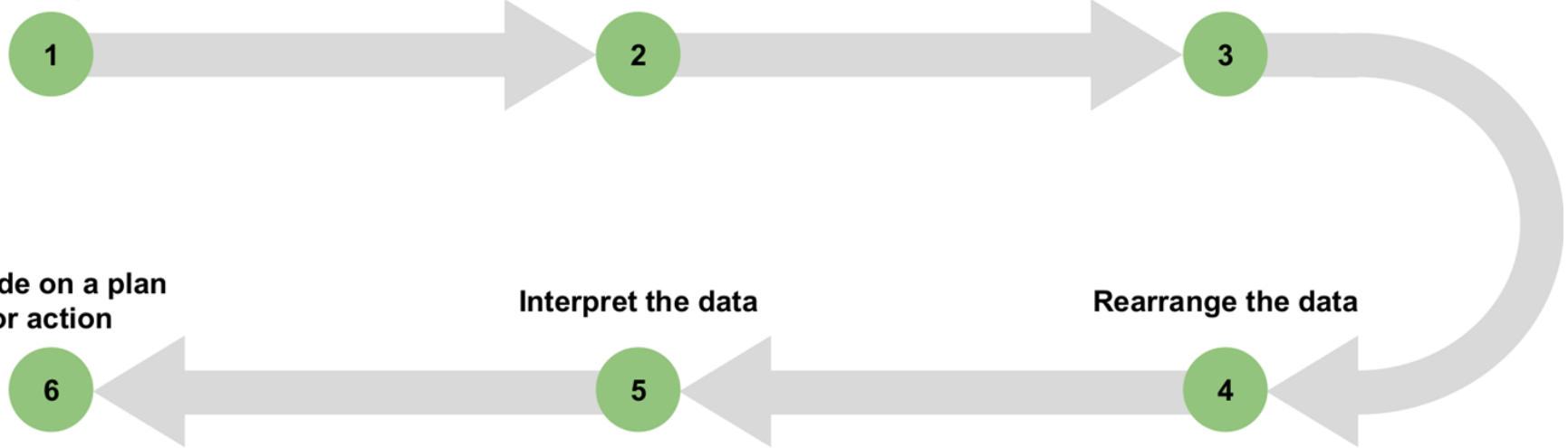
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Interpret the data

5

Rearrange the data


4



Stage 1: Align patient and clinician objectives

“If you ask about their data, you might see shiftiness tinged with a bit of irritation or anger, tell-tale signs that **something isn't stacking up.**”

P5, mental health specialist



Patient motivation is
not always obvious

Stage 1: Align patient and clinician objectives

Misaligned objectives

“You do get patients who **fixate on self-tracking 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 brought you in today**.’”

P7, emergency doctor

Crafting mutual objectives for the consultation.

Stage 2: Evaluate data quality

Data quality is often unclear



“There is a question about **how precise their equipment is and if they are doing it right**. But if they bring in the equipment and show you it, you can see that it's fairly accurate.”

P8, junior surgeon

Stage 2: Evaluate data quality

Data is often incomplete

Did they skip recording because they were **unwell** and they were in bed at home?

"Or is it because they were out partying so they didn't bother to make the reading?"

P4, cardiologist


HEART RATE

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

* = palpitations

Stage 3: Judge data utility

Patient-generated data
may not be relevant



“This data is **not necessarily relevant** to what's brought you in today. It is of some use, but in the acute setting it's difficult because you want to deal with the problem that they've got there and then.”

P7, emergency doctor

Stage 4: Rearrange the data

Value of information
prepared in a way
which makes sense to
the patient.

“They have produced this themselves, which means **it's usable to them, rather than me**, as a clinician, telling them how to record their daily thoughts and feelings.”


P5, mental health specialist

Unfamiliar structure

Stage 5: Interpret the data

“Most procedures we do for atrial fibrillation are for symptomatic gain, so **the patient's perception of symptoms is more important than what they're objectively getting.**”

P3, cardiologist



Subjectivity can be an important quality

Stage 5: Interpret the data

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

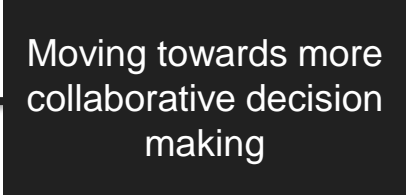
“What is the patient's definition of ‘terrible’? Because if one is ‘terrible’, and five is ‘great’, what exactly does two mean? What is three? **What is the difference between two and three?**”

P5, mental health specialist

Ambiguity in
subjective data

Stage 6: Decide on a plan or action

“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.”



Moving towards more
collaborative decision
making

P9, hospital doctor

There are barriers in each workflow stage

Align patient and clinician objectives

1

B1.1: Patient motivation is not always obvious
B1.2: Misaligned objectives

Evaluate data quality

2

B2.1: Unclear accuracy and reliability
B2.2: Data is often incomplete
B2.3: Data often lacks context

Judge data utility

3

B3.1: Insufficient time
B3.2: Data can be irrelevant
B3.3: Data can be distracting
B3.4: Poor interoperability

Decide on a plan or action

6

B6.1: Patient-generated data not considered concrete evidence
B6.2: Data use limited by practice or training

Interpret the data

5

B5.1: Ambiguity in subjective data
B5.2: Unclear meaning of missing data
B5.3: Reliance on patient recall

Rearrange the data

4

B4.1: Unfamiliar structure
B4.2: Unhelpful structure

Design Challenges and Implications



Data Collection Tools and Practices

How can we improve compliance of data collection?

We could aim to **automate data collection** to reduce burden and improve compliance.

But not all forms of data collection can be automated.

Goal setting?



Data Collection Tools and Practices

Collect context and provenance information:

- What was used to collect the data?
- How has it been manipulated?
- Has the device been clinically evaluated?

About the data source

Name	Apple Watch
Measures	Heart rate (bpm)
Precision	1 decimal places
Description	

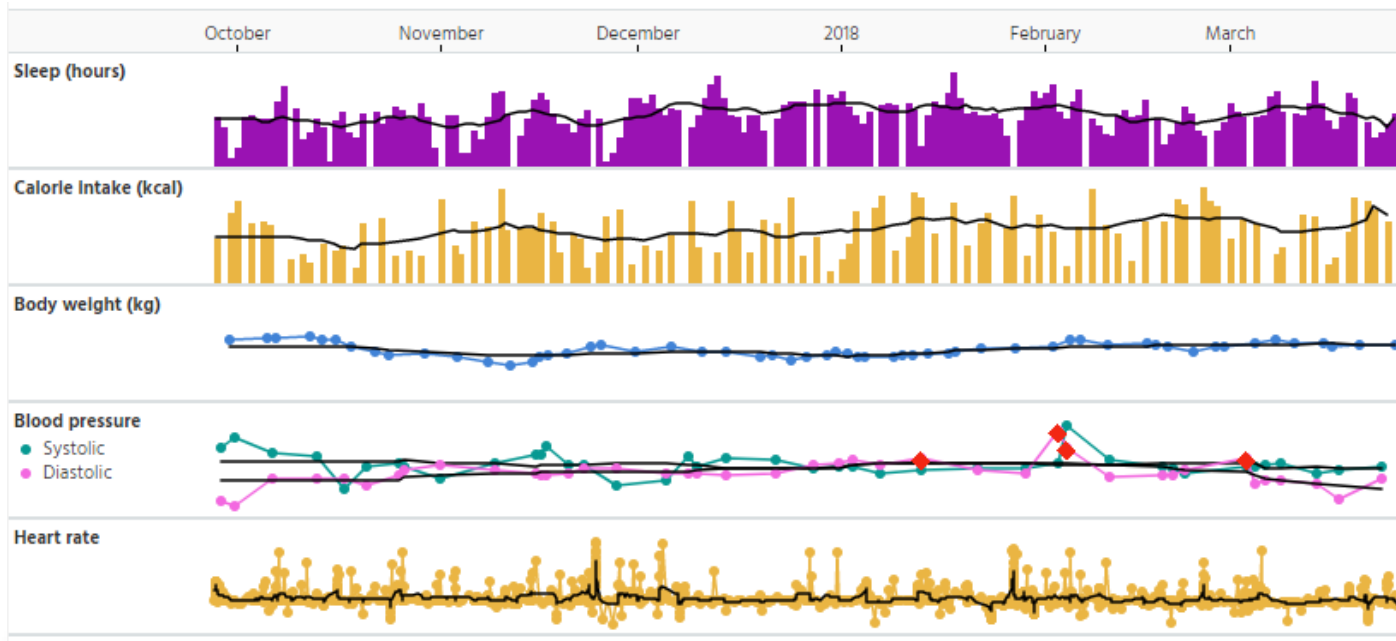
Apple Watch smartwatch heart rate monitor. The heart rate is read using light sensors.



Tools for Use and Interpretation

Draw on clinical standards for displaying information.

Filter data to only show relevant information.



Clinical Practice and Training

Increase collaboration with patient so they understand reasons for self-tracking, addressing problems of misaligned objectives, ambiguity in the data, and improving patients' awareness of what to track.

“If a patient can understand their condition better then they understand how to manage their condition better, and 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.”

P9, hospital doctor

Limitations of this work

We interviewed clinicians only (not patients)

This is one side of the study, and complements CHI work on patient data interaction

We interviewed a sample of clinical roles

There's are many other roles in healthcare, so our work is not representative of every role. These are representative of the roles we interviewed

All our participants are clinicians in the UK

We would like to extend this to other countries.

Summary

We aimed to identify barriers to using patient-generated data in different clinical settings.

We found that doctors often follow a **workflow** for utilising patient-generated data.

Understanding this workflow could help address **barriers** through design and HCI research.



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