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 surveyed 211 patients, interviewed 18 patients, and co-designed a dataset of 31 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 enmeshed 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.5.m. Information interfaces and presentation (e.g., HCI); Miscellaneous.

Introduction
In today’s health care system, the role of patients is increasing. Patients are expected to be active participants in their own care, and to manage their health data. This shift has led to the development of new technologies, such as patient-generated data (PGD), which allows patients to collect and share data about their health. However, the use of PGD in clinical decision-making is still in its early stages. There is a need for better understanding of how patients and providers interact and collaborate when using PGD.

PGD acts as a boundary object
PGD can empower patients as part of health decision making

Related Work

Chung et al (2016). Boundary negotiating artifacts in personal informatics
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.
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.
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 + Semi-Structured Interviews

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

Analysed 22 papers
## Themes

12 themes across 22 papers

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<tbody>
<tr>
<td>Structure</td>
<td>Data structure is unfamiliar or inconsistent.</td>
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<td>Completeness</td>
<td>Missing measurements or poor patient adherence.</td>
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<td>Reliability</td>
<td>Inaccuracies in data, or self-tracking practice not clinically validated.</td>
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<td>Context</td>
<td>What the patient was doing at the time of measurement is unknown.</td>
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<td>Relevance</td>
<td>Data are irrelevant to the current clinical context.</td>
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<td>Selective disclosure</td>
<td>Patients may be withholding certain information.</td>
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<td>Underlying condition</td>
<td>Self-tracking behaviour may indicate obsession or psychiatric disorder.</td>
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<td>Insufficient time</td>
<td>Clinicians do not have sufficient time to interpret and analyse data.</td>
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<td>Insufficient expertise</td>
<td>Clinicians have not received training for using such data.</td>
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<tr>
<td>Information overload</td>
<td>Too much information for the clinician to work with.</td>
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<tr>
<td>Poor interoperability</td>
<td>Data difficult to integrate into clinical systems, can go missing.</td>
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<tr>
<td>Impact to workflow</td>
<td>Negative impact to doctor-patient relationship.</td>
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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.

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

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

1. Align patient and clinician objectives
2. Evaluate data quality
3. Judge data utility
4. Rearrange the data
5. Interpret the data
6. Decide on a plan or action
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
Stage 1: Align patient and clinician 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
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

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
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
“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

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

Unfamiliar structure
“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
“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
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.”

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

<table>
<thead>
<tr>
<th>Name</th>
<th>Apple Watch</th>
</tr>
</thead>
<tbody>
<tr>
<td>Measures</td>
<td>Heart rate (bpm)</td>
</tr>
<tr>
<td>Precision</td>
<td>1 decimal places</td>
</tr>
<tr>
<td>Description</td>
<td>Apple Watch smartwatch heart rate monitor. The heart rate is read using light sensors.</td>
</tr>
</tbody>
</table>
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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References

- American Heart Association Heart Disease and Stroke Statistics 2017 At-A-Glance (Additional link to full stats on the At-A-Glance)