The Quantified Patient in the Doctor’s Office

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Photo: Shinya Suzuki
We are quantified patients.

High quality sensors, pervasive, easy to self-log.
How could self-logged data be useful?

Fill the gaps between visits
Contextualise clinical data
Greater patient participation

What are the challenges?
Pre-study: Literature review

Number of results: 2340 → 429 → 22

Themes:

Data capture: relevance, quality, completeness

Data access: selective disclosure, representation, interoperability

Clinical practice: data literacy, doctor-patient relationship, legal issues

Situational constraints: time, information overload
Pre-study: Literature review


Ancker et al (2015). The Invisible Work of Personal Health Information Management Among People With Multiple Chronic Conditions: Qualitative Interview Study Among Patients and Providers
Many parts of the care pathway

Focused on differential diagnosis.
Key questions

How would doctors judge patient-supplied data?

Would doctors use patient-supplied data?

How does patient-supplied data align with current workflows and work practices?
Method: Role-play interviews

Patient narratives, drawn from real cases in the “Think Like A Doctor” column of The New York Times

Modified to describe patient self-logging.

Supplied self-logged data.
Data collection and analysis

Think-aloud protocol

Transcribed

Thematic analysis
10 Participants

3 General Practitioners in the UK
7 Hospital Specialists in the US (various specialities)

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<tr>
<th>ID</th>
<th>Level of care</th>
<th>Gender</th>
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</table>

Table 2. Level of care, gender, and country of practice for participants, and speciality for participants in secondary care. Participants comprised of general practitioners (GP) and specialists (Sp).
Narrative 1:

Male, middle aged. Legs won’t stop moving, sleepy, out of breath.

On anticoagulants due to stroke.

Plots pulse three times a day, normally 85bpm, spikes 130bpm.

Cause: Vitamin B12 deficiency
Narrative 2:

Female university student. Blueish lips, headaches, blurry vision, fainting.

Had infection after back surgery.

Worried about caffeine intake. Logs it daily, occasionally exceeds 1000mg.

Cause: Postural Tachycardia Syndrome (POTS)
6 main themes
Theme 1: Diagnostic workflow

“What's the worst possible thing the person could have and work backwards from there.”

Specialist 5

Rule out high-risk conditions first, patient safety is key.
“I've chopped, chopped, chopped, and we come to here. And now I think, ‘we've pruned off all of that, now I've got the bare tree.’ [...]”

“And it's very easy to see, this is my path now. It's your heart, mate. And I need to do just one or two tests to show. Otherwise the trunk of this tree becomes thicker, and I will go that way. That's how I think.”

General practitioner 1
“Right! This could be a coffee headache. Well if you stop drinking coffee you get a headache. If you start drinking coffee you get a headache. Daily consumption - wow - above 400mg, 150mg per cup. Yeah, so this could be a coffee withdrawal headache.”

General practitioner 1

Need for unit conversion, adding cognitive load
"I couldn't help but read it, and then reorganise information in a way that we are all sort of classically trained, history, present illness, past medical, and surgical medications, social and so forth."

Specialist 2
Theme 3: Confidence in the measurements

“I want to use my machine, which has been pre-calibrated, not off the shelf, because I don't know about this machine's calibration.

“Can I trust all the data? No.

“Can I assume all the data is correct? No.”

General practitioner 1

Uncertainty about the quality of the measurements leads to a lack of trust.
“He's having episodes where his heart rate is abnormal, or at least abnormal depending on what he's doing - that's the bit I would want to know more about - what happened on those dates when his heart rate spiked, what symptoms was he having?”

Specialist 2

Need to understand what the patient was doing or experiencing at the time.
Theme 4: Patient Motivation

“I would ask a bit more about this caffeine chart and why she's done this anyway, just to have an understanding of the reasons. Because not everyone charts their caffeine.”

General practitioner 3
Theme 4: Patient Motivation

“Usually you can predict what kind of job they have, people who do they would **typically be an engineer**… Engineers always bring in stuff like this ”

Specialist 3

Certain groups may be inclined to bring in self-logged data
“It's typical that patients like this come in and they give you stuff, you get this whole story, and then they want you to focus on it.”

Specialist 1

Does the patient already know something? Data used as communication
“They're faking it!

“If someone brought this chart to me, there's a red flag that this guy's got psych issues.”

Specialist 4
“The layers of information, data assessment - it's ramping up and up, and all of these devices are certainly adding, or will add, yet more of this. [...]”

“At some point you have to ask yourself, what is efficient here and what is not?”

Specialist 1

Questioning if it’s efficient to use data within time constraints
“Well one thing that struck me is how little variability there was in the heart rate during the time of the day.

“I would need to ask a cardiologist, but I thought there was greater variability in heart rate.”

Specialist 2
Challenge 1: Can the data be admitted?

Doctors need confidence in data for higher-risk decisions.

Make it easier for doctors to have confidence in the data.

Reduce need for additional, potentially invasive, tests.
Challenge 1: Can the data be admitted?

Provide metadata about device parameters, firmware, medical compliance

Record contextual data, such as how the measurement was taken (e.g. body placement and device orientation), time of day, location and recent activity of patient.
Challenge 2: Representation

Use standardized formats to reduce need to rearrange information

Admissions forms are succinct and quick to interpret
Challenge 2: Representation

Cups of Coffee

0 1 2 3 4 5 6 7 8 9 10
Challenge 2: Representation

Normal levels for reference
Challenge 3: Design for the diagnostic process

Gather evidence → Evaluate evidence → Discover hypotheses → Identify knowledge gaps → Refine hypotheses → Construct safe care pathway

Supporting diagnostic workflow is important

Not an area explored by Quantified Self
We wanted to identify challenges & opportunities in the use of self-logged data in differential diagnosis.

Challenges we found pertained to: confidence in data quality, clinical workflow, data representation, motivations for self logging, use constraints, and expertise.

Addressing these challenges may start to make self-logged data admissible & useful to clinicians.

Requires a joint exploration of the design space with designers, doctors, & patients.