The Quantified Patient in the Doctor's Office

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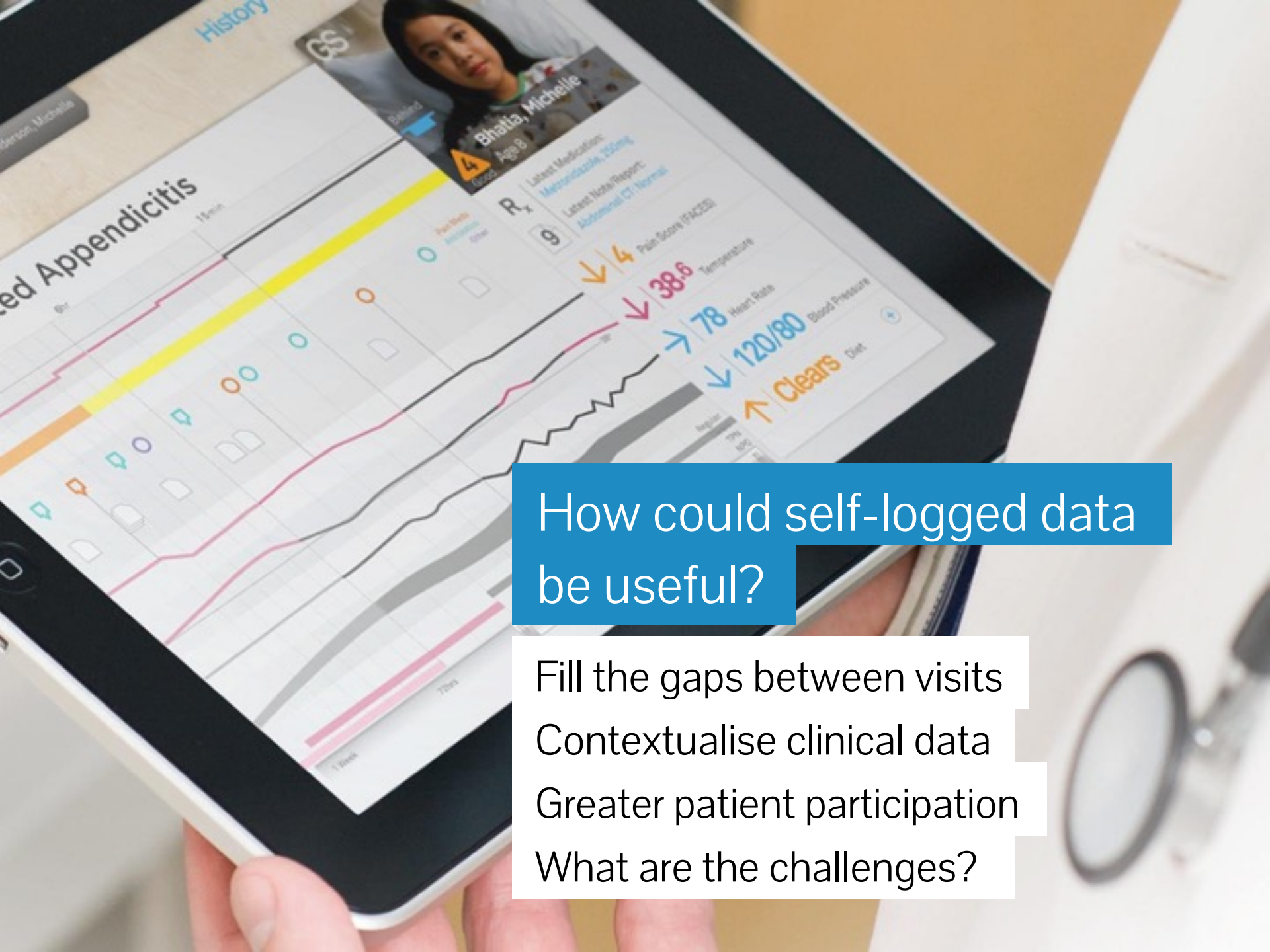
Photo: Shinya Suzuki

We are quantified patients.

High quality sensors, pervasive,
easy to self-log.

Photo: iFixIt HTC One M9



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:

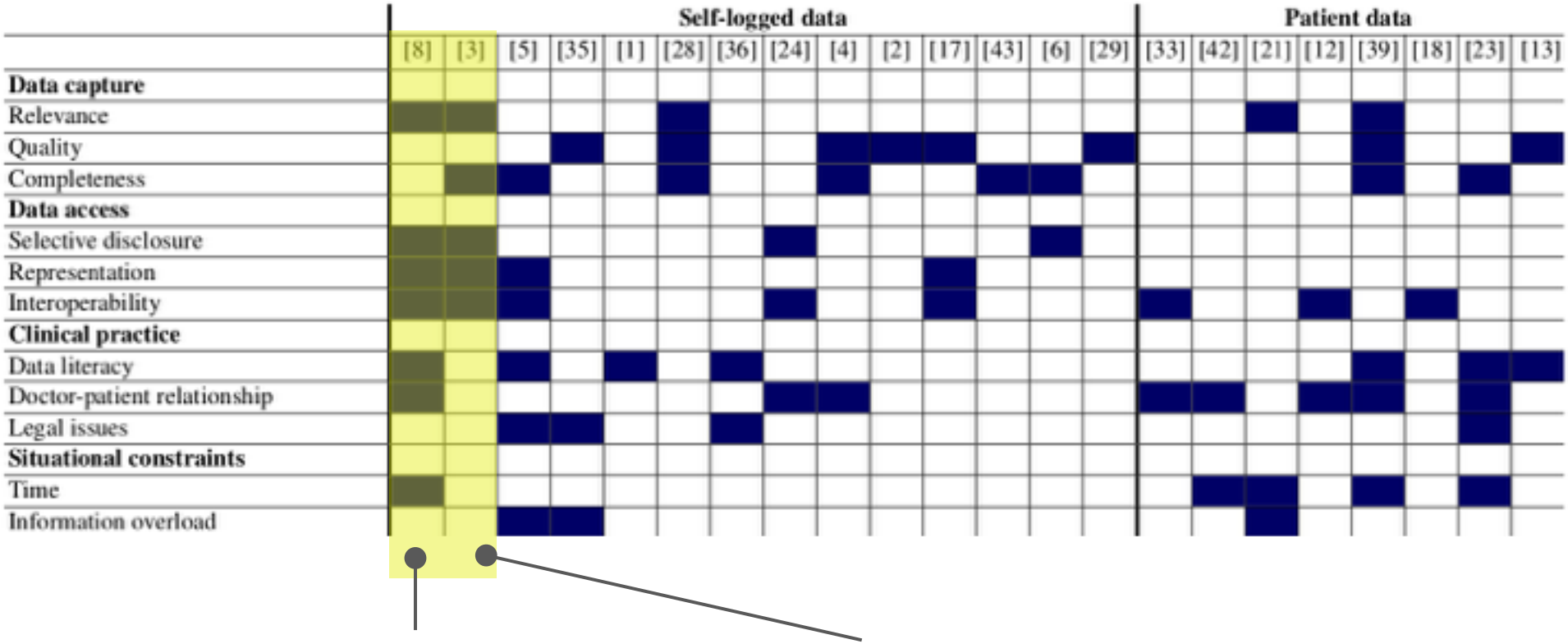
Data capture: relevance, quality, completeness

Data access: selective disclosure, representation, interoperability

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

Situational constraints: time, information overload

Pre-study: Literature review



Chung et al (2015). More Than Telemonitoring: Health Provider Use and Nonuse of Life-Log Data in Irritable Bowel Syndrome and Weight Management

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.

#5: Well I think she must be a little obsessed.

#4. And then you'll be seeing her in front of you and you can get an idea of what you think just based on what she looks like when she's in the office.

#5: And does she have coffee in her hands when she walks in. It seems a little obsessive [referring to chart], most people would not do this.

R: Right

#2: Then again, I would agree, I mean, I don't, in terms of normal caffeine intake and to the best of my knowledge, high intake of caffeine still doesn't cause... I mean you gotta have astronomical amounts to uhh have significant effects on you so I don't know if this qualifies as being at the levels where you can have real effects or not, I'd have to look that up.

#5: There's probably an app for that.

#1: The other thing is, that it's typical that patients like this that come in and they give you, you get this whole story, and then they want you to focus on this it and it takes your attention away, or they're going to tell you this is the reason why all of this is going on, and then you have to say well ok but let's just put that there.

#3: I agree with #1 because I think, you know, I don't know about you fair amount of my patient have comorbid psychiatric disorders t (some laughter), I mean it polite, ..

#5: Even with this patient? [sigh]

#1: We have renal deliver people absolutely… just kidding

#3: Well it's the priorities that count, uhm, anyway, so I'm thinkin thinking more about this then someone hands me a chart, they'r tell me something, like they're trying to indirectly tell me that they' that they're overdosing on caffeine, or taking too much caffeine be their studies, do their job, work and keep up, and they're have t what that means to me. now, I may be looking into it too much, a

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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)

ID	Level of care	Gender	Country	Speciality
GP1	Primary	Male	UK	–
GP2	Primary	Female	UK	–
GP3	Primary	Male	UK	–
Sp1	Secondary	Male	USA	Nephrology
Sp2	Secondary	Male	USA	Rheumatology
Sp3	Secondary	Male	USA	Pulmonology
Sp4	Secondary	Male	USA	Hepatology
Sp5	Secondary	Male	USA	Cardiology
Sp6	Secondary	Female	USA	Nephrology
Sp7	Secondary	Female	USA	Pulmonology

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:

The Man Who Wobbled

The middle-aged man clicked his way through the multiple reruns of late-late-night television. He should have been in bed hours ago, but lately he hadn't been able to get to sleep. Suddenly his legs took on a life of their own. Stretched out halfway to the center of the room, they began to shake and twitch and jump around. The man watched helplessly as his legs disobeyed his mental orders to stop moving. He had no control over them. He felt nauseous, sweaty and out of breath, as if he had been running some kind of race. The next day he visited his GP.

By the time the man arrived at the GP surgery, the twitching in his legs had subsided and his breathing had returned to normal.

The patient considered himself pretty healthy, but the past year or so had been tough. In 2011, at the age of 54, he had had a mild stroke. Not long after his stroke, his wife encouraged him to become a vegetarian. He has given up eating all meat products, and has restricted consumption of dairy products (including no eggs) to skim milk in coffee—which amounts to about a cup of milk per week.

He had no medical problems that put him at risk for stroke — no high blood pressure, no high cholesterol, no diabetes. A work-up at that time showed that he had a hole in his heart that allowed a tiny clot from somewhere in his body to travel to the brain and cause the stroke. He was discharged on a couple of blood thinners to keep his blood from making more clots. He hadn't really felt completely well, though, ever since. His balance seemed a little off, and he was subject to these weird panic attacks, in which his heart would pound and he would feel short of breath whenever he got too stressed. Mostly he could manage them by just walking away and focusing on his breathing. Still, he never felt as if he was the kind of guy to panic.

And he had always been quick on his feet. The first half of his career he had been in the steel business — building huge metal trusses and supports. He and his team put together 60-plus tons of steel structures every day. For the past decade he had been machining car parts. After his stroke, work seemed to get a lot harder.

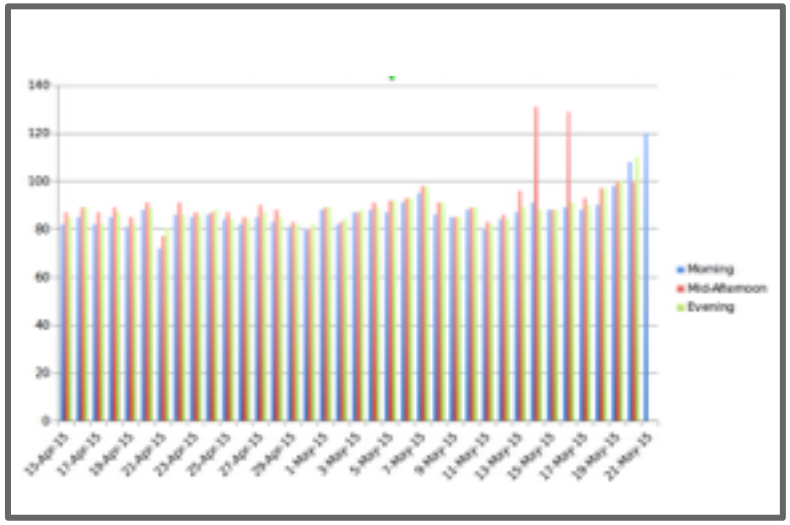
Concerned about his heart rate during panic attacks, he bought a heart monitor and has brought the attached resting pulse rates with him to the GP consultation. These readings were taken in the morning, mid-afternoon, and around 10:00PM in the evening.

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:

A Case of the Dizzy Student

A few snowflakes had made their way to the ground when the 21-year-old third year student awoke. She hadn't been feeling well for the past few days. Taking it easy hadn't helped. She was still tired. Still sore. And the pounding behind her forehead that dogged her for the past few weeks was still lurking just behind her eyes. She had just gotten over a cold when she came home for Christmas break three weeks earlier. Was it coming back?

Getting out of bed she felt even worse — lightheaded and off balance, weak and tired and kind of queasy. She took a few tentative steps. There was a rushing sound in her ears and soft grey fuzz appeared at the edge of her vision. Black and grey dots like an untuned TV set darkened the room. A couple more steps and the black and gray rushed in. The next thing she knew, she was falling to the floor.

She might have blacked out but wasn't really sure. She got up slowly and, holding on to the wall for support, made it to the bathroom. The young woman stood at the sink, looking in the mirror. All the color was gone from her face. Even her lips had a greyish tint. Suddenly the rushing noise started again. The gray softness approached and she felt like she might faint again. She sat on the toilet and put her head down.

Her body felt strangely heavy, as if she had been working out all morning rather than sleeping. She eased her way back to her room, back to the soft safety of her bed.

Then she called her doctor. The soonest she could get an appointment was late in the afternoon. She took the appointment, hoping that she would feel better before then.

When she arrived at the surgery, she was almost too dizzy to walk. she told her GP and then recounted the events of the morning and the days before. Did she have any other medical problems? the doctor asked. Eighteen months earlier she had had surgery on her back. Twice. Once to fix a pinched nerve, and once to cut out the infection that somehow took root there afterward. She had been on antibiotics for months after that. And then, just a few months earlier, someone ran a red light, smashing into her car, and she had had headaches from the whiplash ever since. She also had a little asthma and a little scoliosis.
Other than that she was a just your regular hard-working university student.

She didn't smoke, she didn't use drugs. She had a glass of wine every now and then. She worked very hard at university, and drank copious amounts of coffee to keep her awake. She was worried about her caffeine intake, so she downloaded a caffeine intake app on her iPhone, and tapped in whatever she ordered at Starbucks, Costa, or Cafe Nero. She was surprised to see her daily consumption of caffeine was way above the 400mg/day target she set for herself. She brought along her caffeine consumption over a two week period.

She took a birth control pill every day and inhaled Advair for her asthma. Other than these, she was on no other medications.

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

Theme 1: Diagnostic workflow

Chopping down the decision tree, eliminating hypotheses systematically

"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

Need to gather data to support hypothesis

Theme 2: Representation

“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

Theme 2: Representation

"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

Need to reorganise information according to clinical training

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.

Theme 3: Confidence in the measurements

"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

Patient's motives questioned because self-logging is an unusual thing to do.

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 "

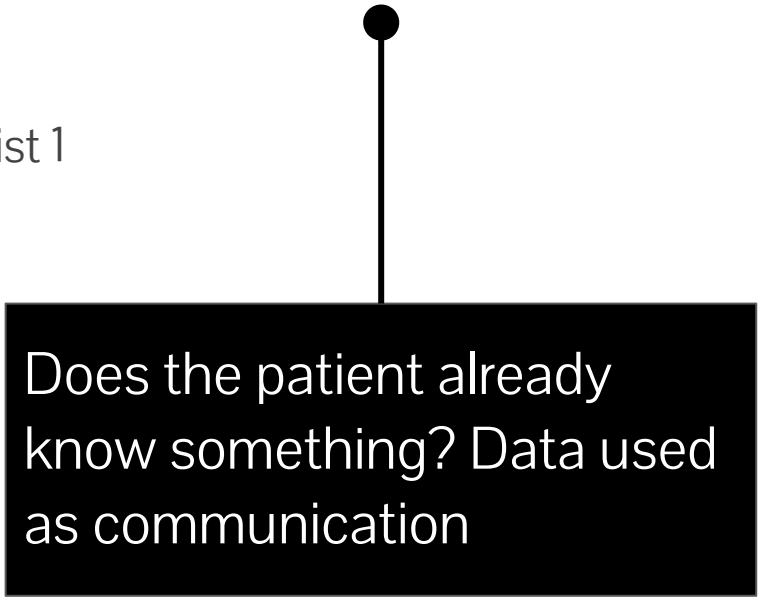
Specialist 3

Certain groups may be inclined to bring in self-logged data

Theme 4: Patient Motivation

"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



Theme 4: Patient Motivation

“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

Questioning underlying psychological reasons

Theme 5: Constraints

“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

Theme 6: Expertise

"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

Challenges & Design Implications

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.

Universitetssykehuset Nord-Norge

Challenge 1: Can the data be admitted?

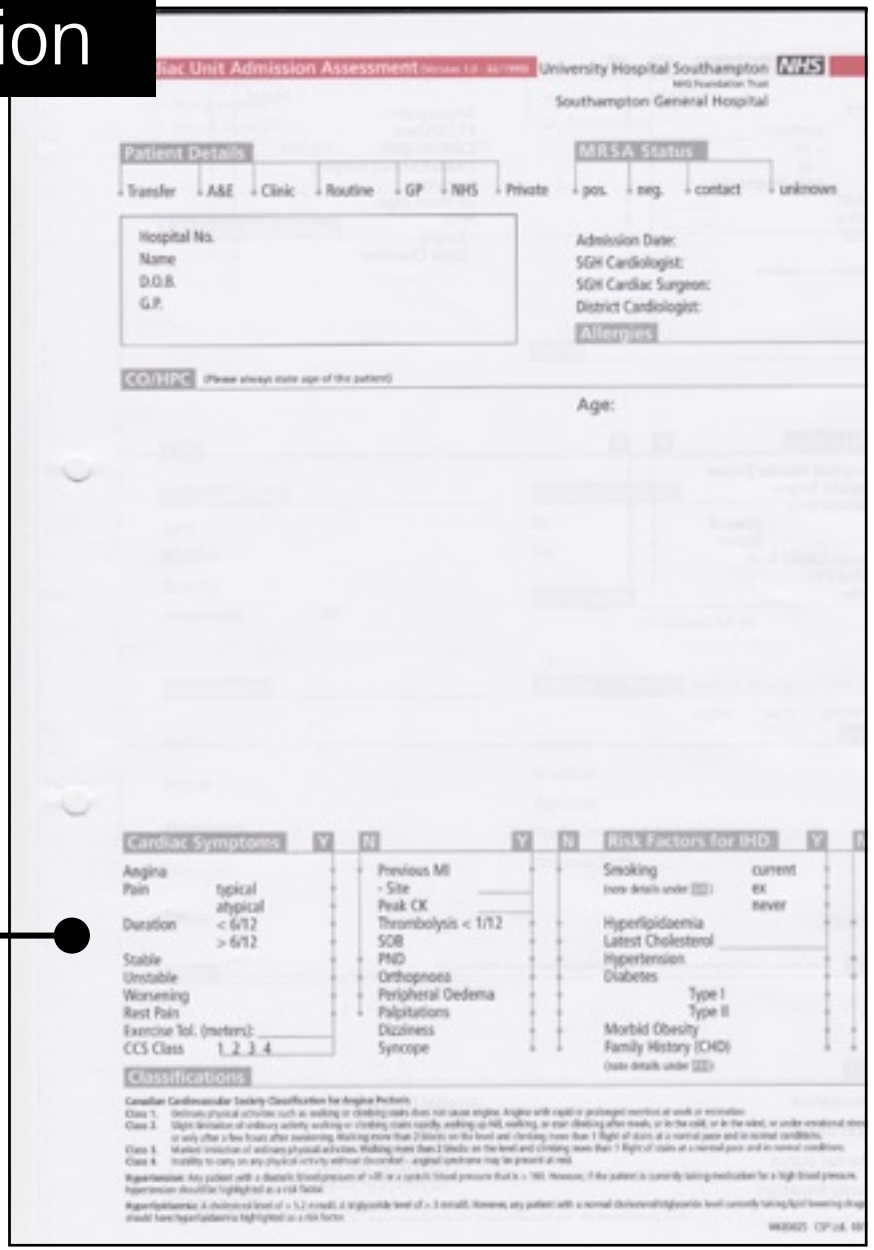
Provide metadata about device parameters, firmware, medical compliance

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.

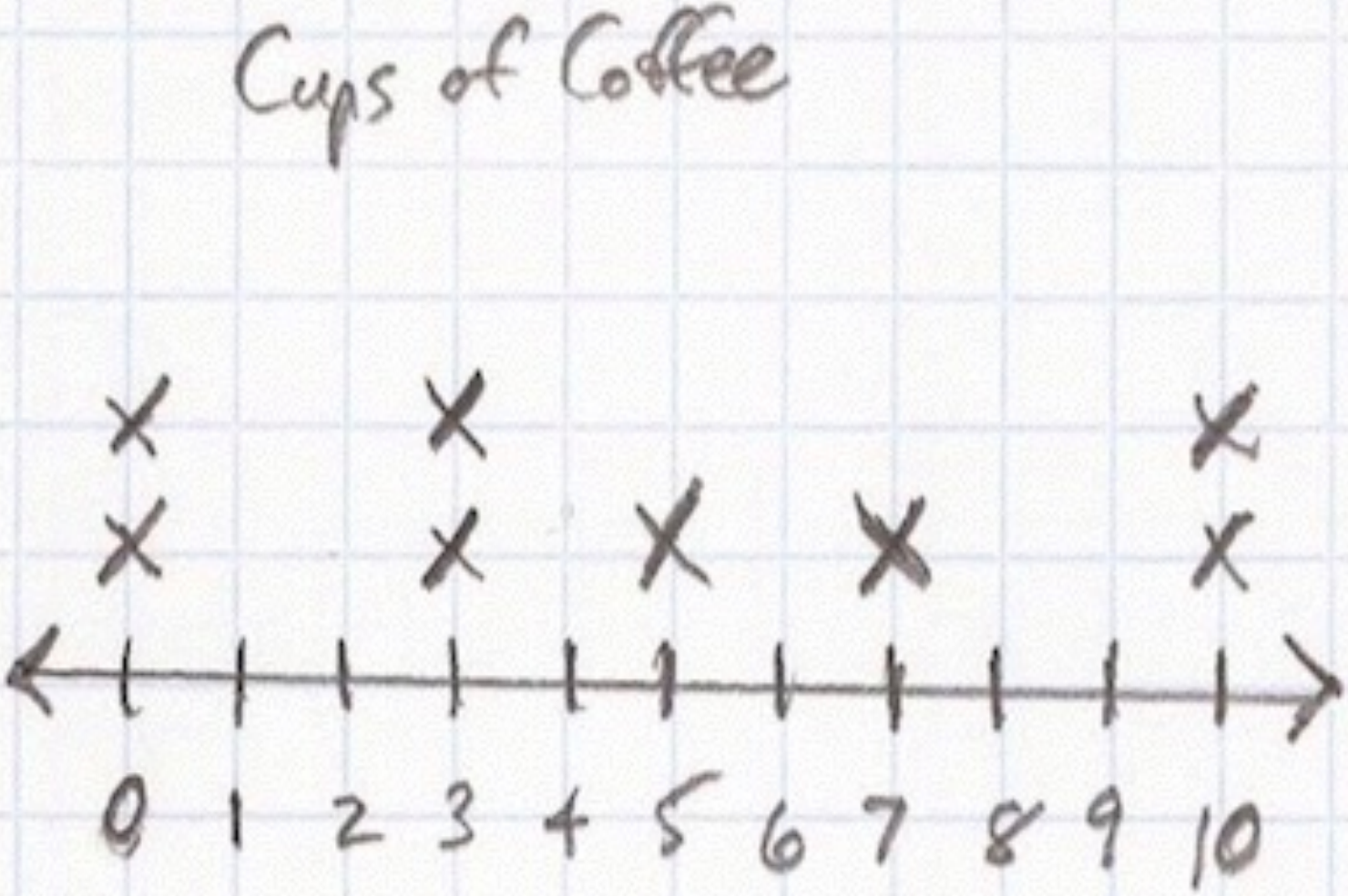
Challenge 2: Representation

Use standardized formats to reduce need to rearrange information

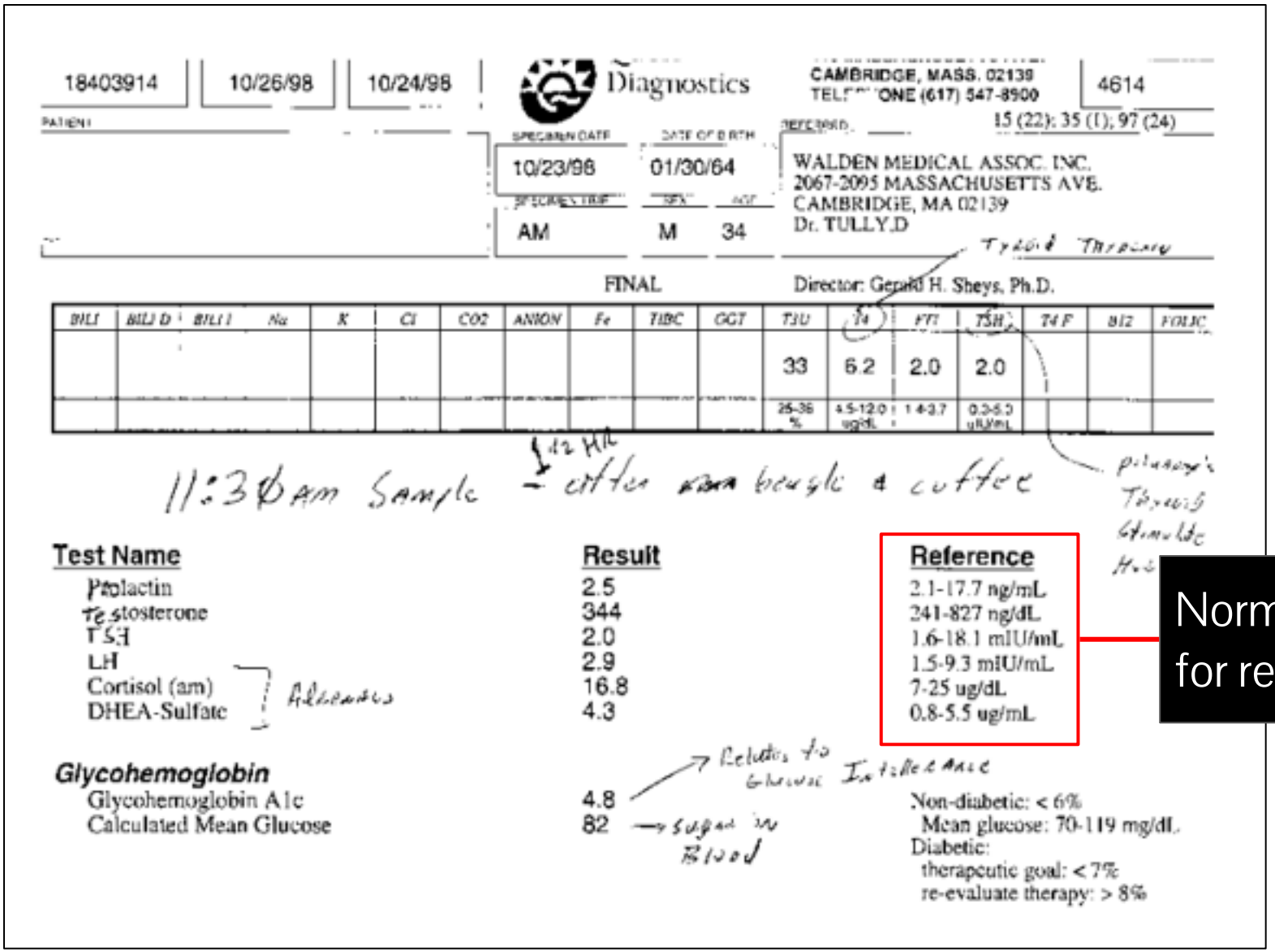
Admissions forms are succinct and quick to interpret



Challenge 2: Representation



Challenge 2: Representation



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15 (22); 35 (1); 97 (24)

PATIENT

SPECIMEN DATE: 10/23/98 | DATE OF BIRTH: 01/30/64

SPECIMEN TIME: AM | SEX: M | AGE: 34

WALDEN MEDICAL ASSOC. INC.
2067-2095 MASSACHUSETTS AVE.
CAMBRIDGE, MA 02139
Dr. TULLY,D

Thyroid Therapy

FINAL

Director: Gerald H. Sheys, Ph.D.

BILI	BILI D	BILI I	Na	K	Cl	CO2	ANION	Fe	TIBC	GGT	T3U	T4	FTI	TSH	T4 F	B12	FOLIC
											33	6.2	2.0	2.0			
											25-35 %	4.5-12.0 ug/dL	1.4-3.7	0.3-5.0 uIU/mL			

12 Hr

11:30 am Sample – after bagel & coffee

Pituitary's Thyroid Stimulating Hormone

Test Name	Result	Reference
Prolactin	2.5	2.1-17.7 ng/mL
Testosterone	344	241-827 ng/dL
TSH	2.0	1.6-18.1 mIU/mL
LH	2.9	1.5-9.3 mIU/mL
Cortisol (am)	16.8	7-25 ug/dL
DHEA-Sulfate	4.3	0.8-5.5 ug/mL

Adrenals

Glycohemoglobin

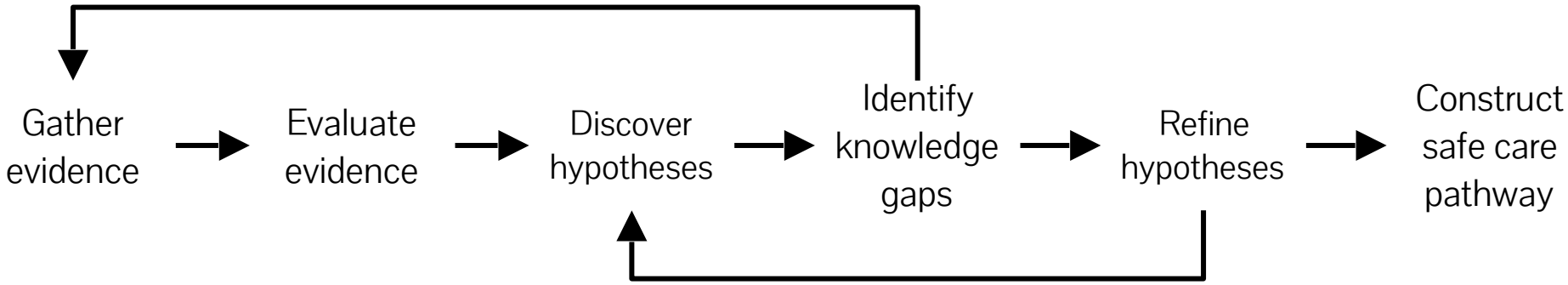
Glycohemoglobin A1c	4.8	Non-diabetic: < 6%
Calculated Mean Glucose	82	Mean glucose: 70-119 mg/dL
		Diabetic:
		therapeutic goal: < 7%
		re-evaluate therapy: > 8%

Relates to Glucose Intolerance

Sugar in Blood

Normal levels for reference

Challenge 3: Design for the diagnostic process



Supporting diagnostic workflow is important

Not an area explored by Quantified Self

Summary

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.

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Photo: Hine on Flickr