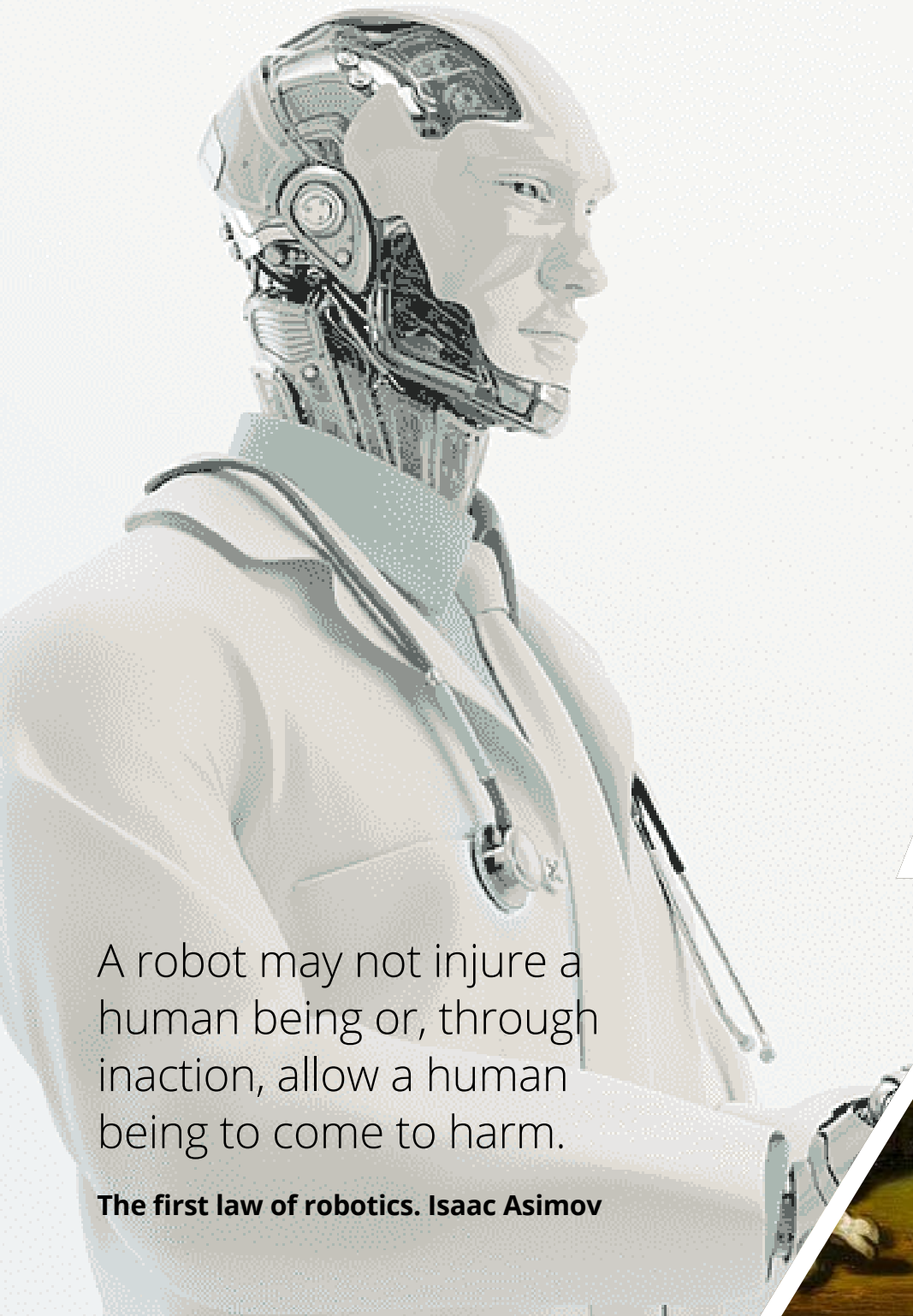# Mostly about the people

What we know about people's experiences of digital healthcare, and how we can fill gaps in our knowledge.

Patient Experience Library

October 2023

First, do no harm.

Hippocrates

A robot may not injure a human being or, through inaction, allow a human being to come to harm.

The first law of robotics. Isaac Asimov

1. Boot up

Digital healthcare is not just about clever technology. It is also about people and as with other aspects of healthcare, it needs to be patient-centred.

Digital "solutions" that are not patient-friendly run the risk of making healthcare worse. An obvious risk is an increase in digital exclusion. Further risks come from artificial intelligence, where bias and prejudices built into machine learning could increase health inequalities. "Big data" approaches to epidemiology and population health could founder if people mistrust the tech companies behind them, and opt out of data-sharing.

So we need a good evidence base for people's experiences of, and attitudes towards, digital healthcare.

This report describes our attempt to do the first ever mapping of the evidence base for patient experience in digital healthcare. We shine a spotlight on areas of saturation, we expose the gaps and we make suggestions for how research funders and national NHS bodies could steer the research to get better value and better learning. And if you want to explore the evidence base for yourself, you can skip straight to our interactive map to see what it looks like.

2. I'm sorry Dave,

I'm afraid I can't do that.[1]
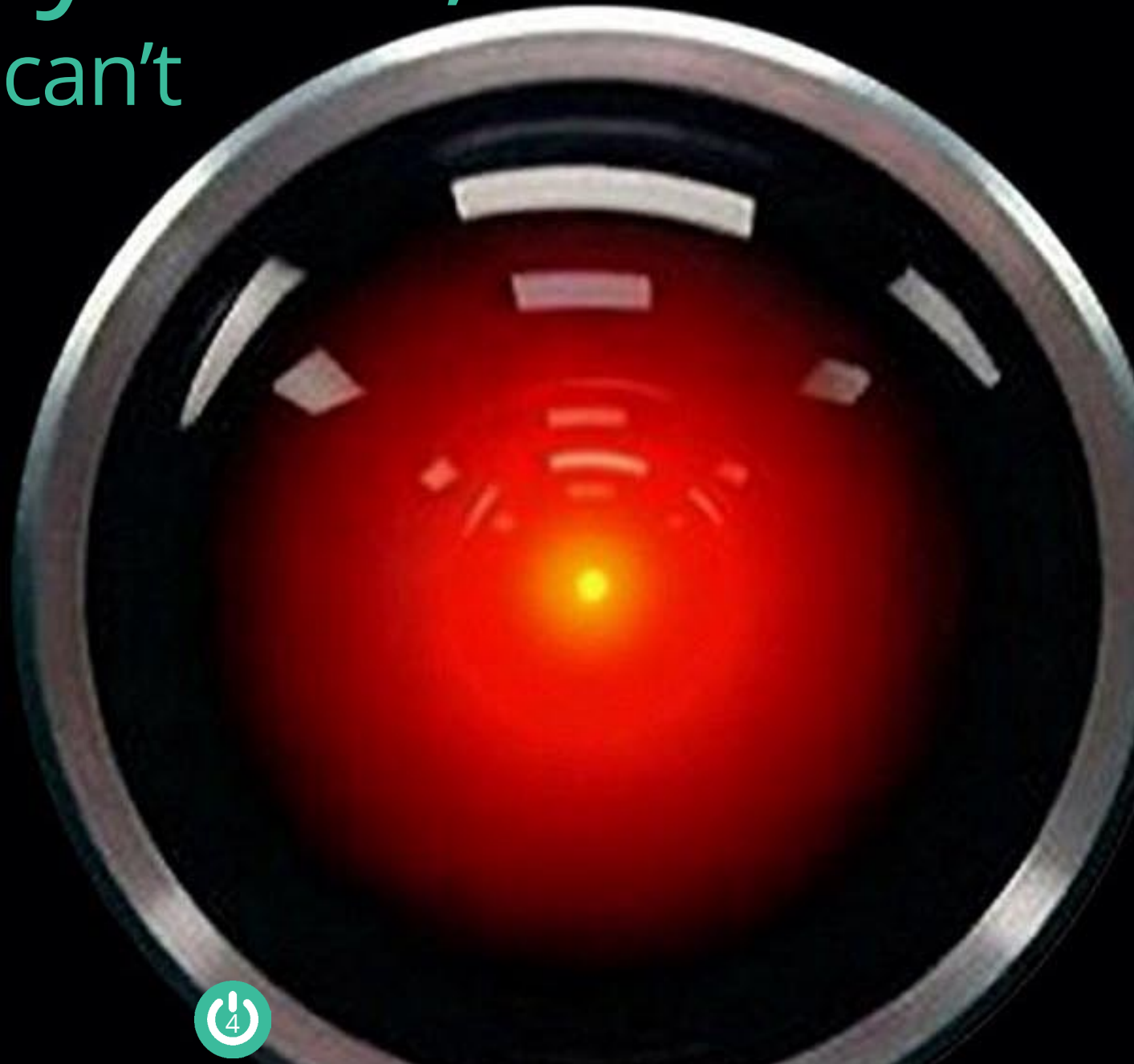
HAL9000 onboard computer.
2001: A Space Odyssey. MGM, 1968

People first

Digital healthcare has been talked about for a long time. As far back as 2008, the King's Fund was saying that digital healthcare could "provide information and help monitor patient health, aid access to services and help shape personal behaviour". At the same time, it was warning that "Each of these areas is significantly under-developed"[2].

In 2016, the Wachter Review[3] took up the challenge, with a high-level analysis of how and why the NHS should digitise. Importantly, its first recommendation was "Carry Out a Thoughtful Long-Term National Engagement Strategy".

This was based on the observation that "Getting it right requires a new approach, one that may appear paradoxical yet is ultimately obvious: digitising effectively is not simply about the technology, it is mostly about the people".

Cyberblunder

There has been little sign of the "thoughtful long term national engagement strategy" that Wachter called for. Instead, we have seen major failures in public engagement.

In 2016, the same year as the Wachter review, the government attempted to launch Care.data, a system to extract and link large amounts of data collected as part of NHS care. Following public concerns over confidentiality, the scheme was first suspended, then closed.

A year later, the Wannacry ransomware attack forced the cancellation of 19,000 appointments and landed the NHS with a £92 million repair and recovery bill[4]. None of the 80 NHS Trusts affected by the attack had applied an advised Microsoft patch update[5]. In a subsequent survey, 53% of respondents said their confidence in the ability of the NHS to handle data was negatively affected[6].

In 2021, the government attempted another large-scale healthcare data collection, this time called General Practice Data for Planning and Research (GPDPR). Again there was widespread concern over confidentiality and data security, and again the scheme had to be put on hold.
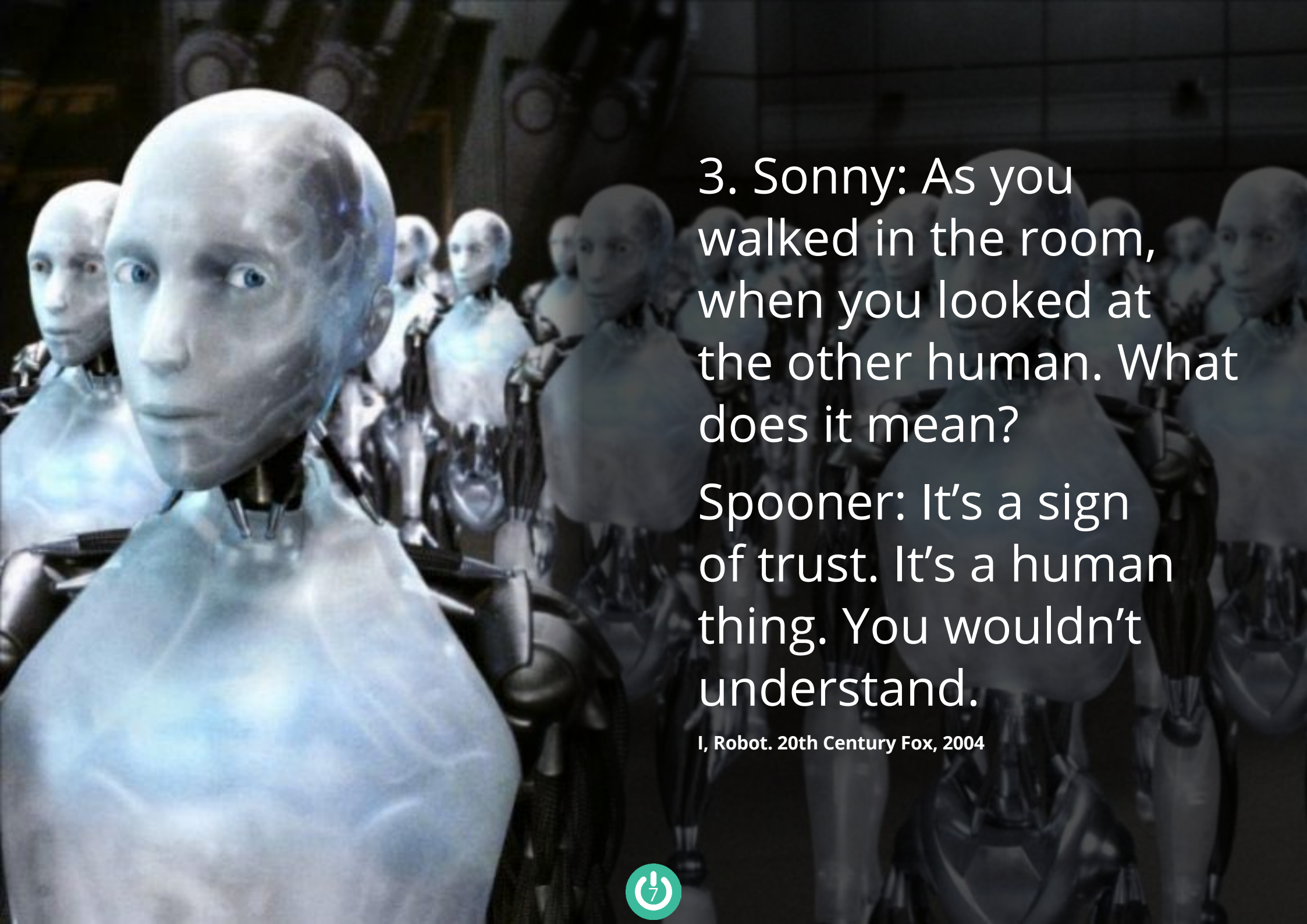
Build trust

If the NHS can get digitisation right, it might find a warm welcome among patients.

- During the crisis period of the Covid pandemic, "use of telemedicine soared and use of patient portals increased rapidly"[7].

- The 2022 national GP patient survey showed that over half of patients (55%) had used an online general practice service in the past 12 months – up from 44% in 2021[8].

- Patient groups are increasingly organising online, offering information, education and peer support to one another, and becoming expert advocates in their own causes[9].

Perhaps because of these trends, government continues to take an interest in digitisation, and six years on from the Wachter Review, the 2022 Goldacre Review took another look at the question of better use of NHS data for analysis and research. Its first recommendation? "Build trust"[10].

3. Sonny: As you walked in the room, when you looked at the other human. What does it mean?

Spooner: It's a sign of trust. It's a human thing. You wouldn't understand.

I, Robot. 20th Century Fox, 2004

Flying blind

To build trust in digital healthcare, we have to understand public attitudes to it. What do people want? What don't they want? What might they be anxious about, or suspicious of?

To find answers, we need to understand what public engagement has taken place in recent years. Which parts of the community have been invited to share their views? What topics have been explored? And where have the findings been published?

But herein lies a difficulty.

National NHS bodies have never acted on Wachter's vision of a "thoughtful long term national engagement strategy", so any engagement that has taken place has been piecemeal and unco-ordinated. It is hard to know what we know, and what we don't know

Exploring the evidence

We wondered if it might be possible to map the evidence base on public experiences of, and attitudes towards, digital healthcare.

We ran a series of searches in our own Patient Experience Library[11], which acts as the national evidence base for patient experience and involvement. We found 174 documents in total, from sources including government bodies, patient voice organisations, health charities and academic institutions.

The biggest single source was the Healthwatch network, with 111 reports. The smallest was open access peer-reviewed journals, where we found only 7 papers.

The Covid effect

The timing of the research is intriguing. Between 2010 and 2019, we found 45 documents on patient and public views and experiences of digital healthcare.

In 2020, the year the Covid pandemic hit, 44 studies and reports were published: as many in one year as in the whole of the previous decade. At the point where "use of telemedicine soared"[12], research into people's experiences of telemedicine also soared.

2021 was even busier, with 60 reports published. By 2022, things were calming down a little, but there were still 25 reports – more than in any single year prior to Covid.

Saturation

We looked at the main topics covered by the 174 reports. The single biggest topic was "service access and experience", accounting for 38% of the topics covered.

Given the sudden shift to online access to health services during the pandemic, it is perhaps unsurprising that researchers wanted to understand how people were experiencing that shift. But with over a third of the literature examining that topic, it is possible that – for now, at least – we have enough understanding of service access in digital healthcare.

The second most researched topic is people's experiences of provider websites. This is a very popular subject with local Healthwatch, which is the source of 36 out of the 38 reports mostly covering GP websites. Here, there might be value in local Healthwatches continuing to examine the websites of providers local to their area. But for a general overview of what matters to website users, it may be that the evidence base is strong enough for now.

Gaps

Given the collapse of public trust in the Care.data and the General Practice Data for Planning and Research schemes, we might expect to see a significant literature on public attitudes towards data sharing. So we were surprised to find only 6 reports (less than 3% of the total) with a specific focus on this issue.

Similarly, there has been a big push from government for take-up of the NHS App. Are researchers investigating patient experiences of the App? Apparently not – or at least not at any great scale. Here, there are just 5 reports.

For patients, a key issue for years has been access to electronic health records. But here too, the evidence base is thin, with just 6 reports looking at attitudes and experiences from the patients' point of view.

Artificial Intelligence (AI) is big news, and NHS England has an AI Lab, looking to "use AI safely and ethically at scale"[13]. But we found only 3 reports dealing with public experiences and views on AI in healthcare.

4. Implications

For this exercise in mapping the evidence base on patient experience of digital healthcare, our searches were exclusively within the Patient Experience Library. The Library only collects open access literature, so it is possible that further evidence lies behind paywalls put up by journals and other research databases. Even so, there are some useful learning points:

1. **A growing evidence base on digital healthcare from the point of view of patients and public is now in plain sight.**

Researchers, policymakers and campaigners: Use our interactive map to see what the evidence base looks like, and explore it for yourselves.

2. **We now have the basis for better prioritisation.**

National Institute for Health Research and NHS England: Use our findings to move future research away from duplication, and towards gap-filling.

3. **We can now focus on the people.**

Department for Health and Social Care: The number one recommendations of the Wachter and Goldacre Reviews were "Carry Out a Thoughtful Long-Term National Engagement Strategy" and "Build trust".

It is interesting to see that the general public are being invited to help shape future use of health data by the NHS.[14] This is starting to resemble a long term engagement – but it could go much further. DHSC could use our mapping to develop deeper public engagement and to build a comprehensive evidence base on all aspects of digital healthcare from the point of view of patients.

Finally...

This report is part of a wider evidence mapping project for patient experience and engagement.

While medical research has rigorous prioritisation processes, evidence gathering on patient experience is, essentially, a free-for-all. One consequence is extensive duplication and waste. Another is big gaps in the evidence base. These are very often in relation to so-called "hard to reach" communities – the very people whose voices really need to be heard.

With funding from the Health Foundation's Q Community, we have undertaken the first ever exercise in mapping key areas of the evidence base on patient experience. Our results are being disseminated via a series of reports like this one, and through a set of interactive online evidence maps.

We are laying the foundations for better research prioritisation in patient experience – to steer time and money more effectively, and to help the NHS ensure that its promises of patient-centred care are soundly evidence-based.

Our evidence maps can help research funders to see how to get better value for money, help researchers to see how to avoid time-wasting and duplication, and help patient advocates to see who is – and is not – getting heard in patient experience evidence-gathering.

For more on the project, visit the evidence maps page on our website. And if you want to partner with us to produce more maps, please get in touch: info@patientlibrary.net

Acknowledgements

We would like to thank:

Dr Sebastian Stevens and Apollo Health Innovations for research assistance.

The Health Foundation's Q Community for funding via the Q Exchange programme.

Q Community members for backing this project, and supporting our vision.

Endnotes

1   https://www.youtube.com/watch?v=ARJ8cAGm6JE

2   King's Fund, 2008. Engaging patients in their health: How the NHS needs to change. Report from the Sir Roger Bannister Health Summit, Leeds Castle, 17–18 May 2007. Page 8.

3   National Advisory Group on Health Information Technology in England, 2016. Making IT Work: Harnessing the Power of Health Information Technology to Improve Care in England. Page 6

4   https://www.nationalhealthexecutive.com/articles/wannacry-cyber-attack-cost-nhs-ps92m-after-19000-appointments-were-cancelled

5   Department of Health and Social Care 2018. Lessons learned review of the WannaCry Ransomware Cyber Attack. Page 8.

6   Understanding Patient Data, 2018. Public attitudes to patient data use. A summary of existing research.

7   Hägglund M et al, 2022. Patient empowerment through online access to health records. BMJ 2022;378:e071531 http://dx.doi.org/10.1136/bmj-2022-071531

8   Ipsos Mori, NHS. GP Patient Survey, national report – 2022 survey.

9   Richards T, 2023. Networked patients set the pace. BMJ 2023;380:p758 http://dx.doi.org/10.1136/bmj.p758

10   Department of Health and Social Care, 2022. Better, Broader, Safer, Using Health Data for Research and Analysis. Page 10.

11   www.patientlibrary.net

12   Hägglund M et al, 2022. Patient empowerment through online access to health records. BMJ 2022;378:e071531 http://dx.doi.org/10.1136/bmj-2022-071531

13   https://transform.england.nhs.uk/ai-lab/

14. https://www.england.nhs.uk/2023/09/public-asked-to-shape-future-use-of-health-data-by-the-nhs/

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