

HOPES

People hope that in the future data will be used to improve their lives without controlling their lives.

They hope that in the future citizens will have real power at every stage of research; that communities decide the priority areas of research, they get involved in clinical trials, and they stay informed about new discoveries and new choices [4,7]. They do want medical research to keep moving forwards [2] but they also want lots more attention given to the ways 'social determinants' (like housing, education, income, and inequality) [3] affect our health. All of this data can be used to have clear, well-informed conversations with real people about our choices [1].

Outside of the hospital, people hope data will work in the background to help us to stay healthy and safe. This will mean different things to different people. For some of us, like people who have dementia, this might mean tracking your location [5] so you can keep going out by yourself, knowing that if you get lost or confused someone can help. For other people being tracked is unnecessary and inappropriate. For some carers a well designed data platform will help them manage information for both them and the person they care for [6]. Some people will want to see all the details of their medical data [8], some people will only want notifications when they have important decisions [7] and for some others, it's ok to just know their family's data is safe [9].

If you were given a say, what health problem or social care question would you want to be researched? How should we choose whose questions are answered first?

The last time you made a choice to improve your health or your life, what information did you use? Was there any other information you would have liked to have? Or that would have helped you?

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TESTING THE TEST

When we talk about 'health data' we usually mean information about the physical or mental health of groups of people or individuals. But how do we know that information is correct if we don't also have data about the trustworthiness of the people and organisations who will own and use that health data?

People want to know that the frontline staff filling out forms, managers setting targets, and executives buying new data technologies, will use that data honestly and fairly.

If they call out prejudice or discrimination, if they think there's a mistake in a record or decision, or if they ask for a second opinion, will they be supported and listened to? Or will they be ignored or bullied, and maybe get worse treatment as a result? Can they be sure information will be used and shared properly even if it reveals targets were missed, mistakes were made, or senior staff misbehaved?

Because if we can't trust the people then we can't trust the data, or the decisions and discoveries that we got from the data.

In the future, data could help build this trust. Artificial intelligence could analyse thousands of treatment decisions [3], and where it finds inequalities, evidence of prejudice, or problems in the data [4], it could make alerts public so they can't be brushed aside. Complaints procedures could be transparent [6], and people could share worries and warnings anonymously [7] so they don't need to worry about retaliation. Organisations will face microscopic scrutiny [8] of data-sharing deals, security, and privacy, from experts and from ordinary people who can explain how problems might affect them. People will have all the information they need about treatment and care options [1], and when they discuss those options with staff they will be able to give feedback [2], so the whole service invests in giving staff the training, time and tools they need to have productive conversations.

Would you like to see data about whether your local GP or hospital makes diagnoses or prescribes treatments fairly across different groups of people? Why or why not?

If you complained about a GP practice or a hospital would you worry that they would treat you differently in the future?

Some people worry that publishing data about both complaints and feedback could be used to harass staff. How could we make sure this doesn't happen?



TRUST & TRAUMA

When people have had bad experiences of health or care data being shared, they can be unwilling to share it in future. If data sharing is going to work for everyone the health & care services need to listen to what went wrong, make real changes, and earn back their trust.

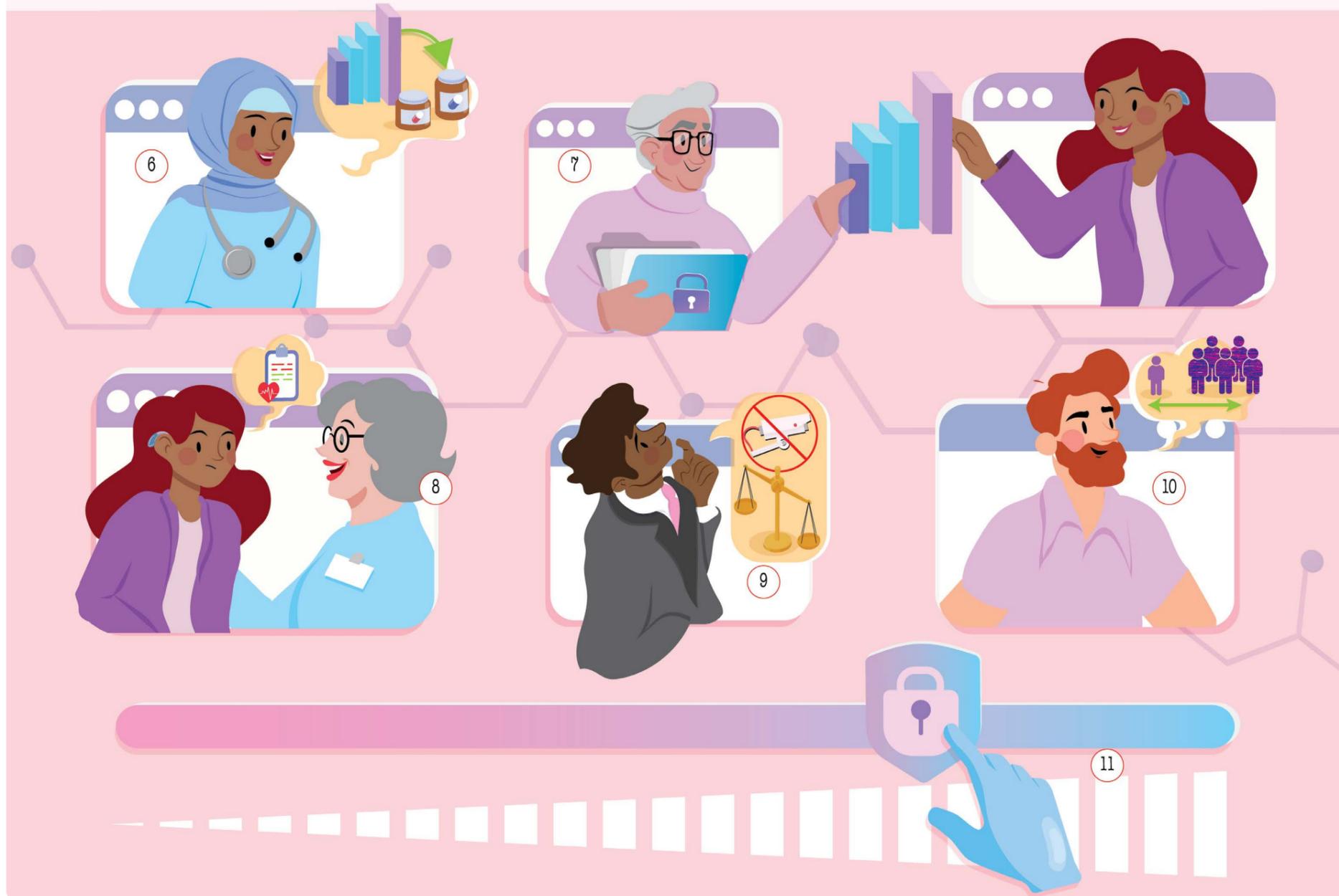
Data from social media, and CCTV cameras in supermarkets and streets, is used in deciding people's eligibility for benefits and social care. People who claim benefits can feel like they are watched and judged everywhere they go [1] and that the data never helps them - it is only used to 'prove' them wrong.

Trust can be harmed in many ways. Perhaps from serious errors in data sharing which nearly kill you [2]. Or being told all your problems are due to being overweight [3]. Maybe records of a mental health problem in your teens will be used ten years later to 'prove' something new is 'all in your head' [4]. When 'data' is used not to find answers, but to 'prove' you are wrong or lying you might feel you have no voice or choice [5].

People who have been harmed by these mistakes have some ideas about how we can rebuild trust:

- Give examples [6] of how data could help them or the people they care about.
- Make it simple to see and understand the data that is collected about them [7] and explain how sharing works [10].
- Listen to people's worries [8], and put proper legal protections in place [9] to stop problems happening again.

Trust can be earned and lost. In the future, flexible systems might let people choose the ways their data is shared and used, and allow new choices as systems improve [11].



Have you ever been harmed or ignored by an organisation that had power over you, like your employer, or your school, or a healthcare provider? If so, what kind of protections would you need to see put in place, for you to feel sure it wouldn't happen again?

Do you think people should be able to choose not to share their health data, even if it makes it more expensive and difficult to run healthcare services or do research?