The importance of listening and changing

I believe that when it comes to listening to the public, we should do so with an open mind and an appreciation that part of good listening means having a genuine readiness to change your actions in response to what you are told.

The concept of active listening has been on my mind a lot this week, prompted by a discussion I took part in about the citizens' juries public deliberation project we co-commissioned with the National Institute for Health Research Applied Research Collaboration Greater Manchester and NHSX earlier this year.

The project's focus was data sharing in a pandemic.

Three citizens' juries spent 36 hours each learning about and discussing three data sharing initiatives introduced nationally to support the response to COVID-19. The jurors were asked to consider how much they supported each initiative, and what more could be done to ensure these projects were trustworthy.

At the citizens' jury report launch earlier this week, I was asked to speak about why involving the public in questions of sharing health and social care data matters. It's one of those questions that on the surface feels so obvious that it doesn't need much thinking about. But it proved an important question for me to return to, because understanding why people need to be involved informs how they are involved.

If the purpose of involving people is purely to make sure that they know what's happening, or what's changing, then it's a matter of 'transmit communications'. For example, showing people what data is held about them and raising awareness about how it's used.

However, in some instances, more than just awareness raising is needed. Research and system planning requires accurate, complete and representative data about different groups of people's experience of health and illness. And as the individuals whose data is essential to this work, we need to feel confident that we can trust the way confidential information about us will be used before we share it.

Talking with health and care professionals is equally important. They need to feel confident that proposed uses of data are in keeping with their professional duties and values, not least that of ensuring that the care of their patient is their first concern. This confidence is supported by knowing that there is active support for those data uses from patients, the public and professionals alike.

I don't think it's possible for any system, initiative or organisation to achieve support, or 'social license', for its data use purely through being on 'transmit'. And neither did the members of the public who participated in

our jury. One of the key findings was that members of the public should not just be informed about, but also involved in, decisions about data sharing, in partnership with data experts. This was far preferable to the jurors than those decisions being taken by the organisations using the data or by politicians.

Another public dialogue that we held last year about [how to make sure that health and care data is used in ways that benefit people and society](#) had a similar finding: that people from a cross-section of society should be involved in assessing how data is used, to decide whether there is a public benefit to it or not.

Both of these dialogues deliver a clear message about what authentic engagement looks like. It must be a two-way process, which involves listening, and that those listening must be prepared to change course on the basis of what they have heard.

A data system can be designed behind closed doors, by experts, without public involvement. I know from experience that these well-meaning experts operate with a lot of personal integrity and work incredibly hard to do the right thing for patients and the public. But the closed-door approach risks underpinning a project's ambitions with untested assumptions about what matters most to its users. It is easy for unconscious bias, potential vested interests (professional if not commercial) and group think to compromise solutions, as with any closed human system, in health and care or otherwise.

Public involvement not only helps to demonstrate trustworthiness by opening up the system to scrutiny by the people whose data it will use. It also improves the integrity and strength of the system itself. It reminds system designers that it's important not just to believe in their project but also, as with any scientific endeavour, to keep doubting, to ensure that the evidence is constantly and openly tested. A two-way process also improves understanding about what conditions need to be met in order to win the public's support for data use. The public trust that the health and care system needs to create is not a blind trust, but a trust that is informed, strong and sustained.

By making conscious and continual efforts to engage a wide range of people, public involvement can also help build in the strength that diversity of experience and perspective will bring to decisions about data. This citizens' jury work demonstrated the opposite of group think, with participants looking at data use from a number of different angles and perspectives: teasing out and exploring the boundaries and contours of problems and proposing potential solutions. The jurors came up with excellent insights, questions and challenges that would not have occurred to me and may not have occurred to those designing the systems either.

At the launch event, we were fortunate enough to hear from some of the jurors. They described how interesting and satisfying it had been to learn more about how data is used. They were enthusiastic about what could be done with data collected during the pandemic, both immediately and in the future. But their support for this data use came with clear caveats, all of which are

described in the report. We hope that the insights from this public deliberation will prove useful learning and play a part in strengthening data system design and decision making in future.

Engaging the public in these important conversations isn't always an easy thing to do, but it's the right thing to do. Going beyond transmit mode means investing time and resources to enable members of the public to engage in a way that can lead to meaningful change. It means being ready to listen. And it means accepting that the outcome of the conversation might mean changing your plan or your perspective.