Data Sharing in a Pandemic Citizens' Juries

Results from Group Work in 5 July Post-Juries' Online Workshop

There was 25 minutes of group work followed by 10 minutes plenary feedback during the workshop. There were 8 breakout groups led by 8 facilitators who recorded the results below. Each group tackled one of 4 questions about action to take in response to the citizens' juries and their results.

Question 1: information for better transparency

For Groups	Group Facilitator
1	John Carvel
2	Nicky Cullum

Question 1:
In the draft NHSX Data Strategy just launched, the government has asked for our views on how to increase transparency. Learning from the juries, in the future what *type of information* should the government be providing about new data initiatives such as the Data Store and Platform, and the Summary Care Record Additional Information?". **Identify up to three important types of information.**

Group 1 results:
- The types of information should be balanced: people mistrust attempts to be transparent that focus only on the benefits (whereas the media often focus on the risks.) By all means be clear about the benefits, but be honest. And be accessible in the way information is presented.
- People want to know what actually happens to their data, with some real-life examples tailored to particular audiences. What does the data look like that passes, for example from the GP to NHS Digital? And what is the security?
- Don't ask what information should be provided TO people: find out what people want to know and provide that. Stop talking about "ordinary people." Who are they? The aim should be to satisfy the information needs of diverse groups of extraordinary people.
- With whom is the data being shared? Public or private sector? Who is funding this data sharing and who has oversight of it? Who's in charge? Does whoever it is have the right priorities? If the Data Store is "owned" by the NHS, does that help social care to get attention for its priorities?
- Information sharing must be dynamic, not static, with ongoing engagement.
- A group member with experience of running focus groups on explaining algorithms to the public, said people want all the information to be available at a high level, backed up by more detailed information on request about specifics, e.g. data privacy/risks.

The group also wanted to talk about actions to improve transparency, which was outside our brief. However, it's worth mentioning enthusiasm for using popular techniques, such as the "grab a jab" campaign to persuade the 18+ age group to get vaccinated. One ingenious idea was to represent data as a cartoon character and follow its journey, stopping off wherever it could be useful. This brought to mind the character Data in Star Trek, going boldly where no data had gone before. However, the dangers of data scraping by the Klingons suggested caution.

Group 2 results:

There was consensus within the group that the following information should be clearly communicated:

- NHS needs to ascertain what transparency means for different stakeholders (NHS, NDG, patients, public)
- What can be learned from OpenSafely (which people trust)?
- A shared understanding of what data access arrangements exist NOW and what will change as a result of the new initiative; what is the purpose of the new initiative and how will things be different as a result?
- The balance of risks and benefits. How can risks be mitigated and what choices do they have?
- How will data be safeguarded? What are the data governance safeguards and what are the rules for changing them in the future?

The group also discussed the draft data strategy. It was seen as an example of "*How not to consult on strategy*"; draft strategy not an easy read; difficult to find; one month is absolutely not long enough for a consultation, especially at this time of year. There was a feeling that the consultation was disingenuous and not a real consultation. There was consensus on the above and also that people need time to think about the strategy, discuss it with friends and family. There was also a feeling that the draft strategy doesn't say much beyond the obvious about improving patient care by streamlining access in the health and care system.

Question 2: action for better transparency

For Groups	Group Facilitator
3	Elisa Jones
4	Reema Patel

Question 3:
In the draft NHSX data strategy just launched, the government has asked for our views on how to increase transparency. Learning form the juries, in the future what things should be done by government to make people aware of data initiatives such as Data Store and Platform, and the Summary Care Record Additional Information? **Identify up to 3 important next steps**.

Group 3 results:
- It was felt that they need a stronger commitment to sharing information more widely. Needs to be more active communication. The media tend to scaremonger and not tell the full story. More imaginative ways of communicating are required. It was suggested that this would need a multipronged campaign (not just letters/a blog) to ensure that different groups of people are reached. This would require different ways for reaching different people. This all needs more time, effort, resource and money to be successful.
- It is important to identify trusted voices – either through looking at previous research that has been carried out on this, or by carrying out new research. Find out from who and where people are getting their information and use this information to help shape future communications.
- Ask patient/public, GPs and Health care professionals to co-produce/co-design the communication and engagement strategy with communication professionals. Working together to decide both what types of information they would like; the wording that is used to communicate and the method by which this is communicated (e.g. adverts; letters; text messages from GP etc). This should not be a consultation, but more active involvement.

The group felt it is important that patients/public feel in control and respected. Being more in control might be achieved through allowing patients to see what information is in their health records more easily. Make it more understandable what information is kept on them and why. How can you trust when you don't know what data is held about you, and is about to be shared.

Group 4 results:
- Being clear, GP initiative + Care.Data - unclear about what is happening, these issues aren't front of mind, people are busy
- Write to every named patient, pay the GPs to send the letter, what's said in letter should be true. NHSX telling different things to different groups, not writing to patients, can publish a copy of, and demonstrable effort to actually reach every patient
- Data usage reports, open a channel from institutions to individuals, tells you how your data has been used, impact it has had etc - open a channel from a 21st century NHS
- Transparency - NHSX publish a privacy notice, doesn't give full information - needs to be a direct channel between individual, government and NHSX - not always high level government publications, messages need to be relevant to where the data has been used - from own GP. Perception of OpenSAFELY - how transparent they are!
- We may forget data literacy - we overestimate how much people know about their data, individualised, communicated, diversity of engagement
- 'Mixing' of uses has been and is a consistent issue in public trust; one can educate people about this, exclude the most 'toxic' ones (trickier than it may seem), and/or give people more 'granular', meaningful choices. And respect them.
- We need to surface success stories as well as alarmist narratives - what are those?
- Funding and resourcing engagement exercises are important - should there be a funded engagement approach - require different conversations with lots of different people.

Question 3: Summary Care Record Additional Information action

For Groups	Group Facilitator
5	Malcolm Oswald
6	Sarah Atwood

Question 3:
A majority of jurors wanted the Summary Care Record Additional Information initiative to continue as long as it is valuable, but they wanted decisions about the future of the Summary Care Record to be made outside NHS Digital (e.g. by an independent advisory group of experts and lay people). What should happen next? **Identify up to 3 important next steps**.

Group 5 results:
- Redefine purpose of Summary Care Record (SCR) / SCR Additional Information if it changed during the pandemic with the COPI Notice regulations and that purpose is to continue
- Seek advice from the SCR independent advisory group on the future of SCR Additional Information
- Improve transparency to explain what has happened although it is recognised effective communication to millions of people is difficult and costly. If communicating, explain the context of the SCR in relation to other direct care uses, and be clear about the distinction between direct care/secondary uses which is not well understood.

Group 6 results:
- **Organise independent oversight and scrutiny**
  Determine whether this will be a one-off activity to decide about the future of the SCR additional information or a more continuous activity that becomes part of a wider structure for oversight of data sharing more generally.
- **Develop criteria for deciding if/until when the SCR additional information can be considered valuable**

The benefits that contribute to the 'value' of the SCR additional information need to allow weighing against risks and disadvantages. The criteria will help the independent oversight group in their decision making, and will help to give an indication of how long the initiative is expected to continue.

- **Improve communication and increase transparency**
  To improve communication of new health data sharing initiatives in future time-sensitive events (e.g. a next pandemic), NHSD/the SCR should have communication strategies ready to respond quickly in informing the public. A good communication strategy would engage the public to read information about how their data is being shared. This information should be easy to access and understand, which will contribute to increased transparency of *what* has been decided. In addition, the public should also be aware of and engaged in *how* these decisions have been made.

- **Publicise more widely that people can opt out and make opting out easier**
  The juries accepted that the model changed from opt-in to opt-out during the pandemic and that there wasn't much time at the time to publicise this more widely. But now that we are moving from an emergency situation back to 'normal' practice, NHSD/the SCR should make an effort to increase the public's awareness that they can opt out, and make this option more easily accessible for those who don't wish the additional information to be shared as part of their SCR.

Question 4: Data Store and Data Platform action

For Groups	Group Facilitator
7	Louise Laverty
8	Kyle Bozentko

Question 4:
A majority of jurors wanted the Covid 19 NHS Data Store and Data Platform initiative to continue as long as it is valuable, but they wanted decisions about the future of the Data Store and Platform to be made outside NHSX and NHS England (e.g. by an independent advisory group of experts and lay people). What should happen next ? **Identify up to 3 important next steps**.

Group 7 results:
- Best practice examples of independent advisory groups that influence policy should be explored looking at other areas and/or learning from international work.
- Engagement with the public should not be risk-averse to gain public trust. For example, the government should accept that the public will say no to some initiatives, and this should not deter engagement and consultation on a topic.
- There should be ongoing conversations with the public about data that make the most of up-to-date tangible real-world examples to illustrate how data may be used to build trust over time. This recognises that trust isn't measured in discrete time and is not linear but may change.
- There is an opportunity within the wider system with the draft data strategy and a change of leadership to use the citizens' juries' findings for impact.

Group 8 results:
- It must be acknowledged that final decisions about the future of the COVID-19 Data Store & Platform are within the realm of Parliament, MPs and Ministers per the Constitution
- Given this, it would be worthwhile to explore what current types of bodies and Independent Advisory group/council/etc., arrangements exist and whether or not these could be adapted or reconfigured to provide insights and continually feedback to decision-making bodies regarding key issues and decisions on the use and sharing of health data.
- It would also be worthwhile to determine if new models of engagement might be developed

and implemented to provide insight to Parliament per the Juries' recommendations. One option could be an ongoing citizens' jury that is continually refreshed and drawn together to engage on new decisions or sharing initiatives, uses, etc.

- There may be opportunities to combine effective data platforms and other models of data sharing initiatives with ongoing engagement in ways that are more closely in line with this recommendation – noting that if an initiative or model is more local it is more likely to be relevant and responsive to local needs and realities. The Health Data Hubs model could be combined or aligned more meaningfully with ongoing engagement. The Trusted Research Environment approach could be applied as comprehensively and efficiently as possible.