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Citizen’s Juries on health and social care data sharing in a pandemic

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Citizen's Juries as public engagement

- Developed by the Jefferson Center (Minnesota, US) and similar to Citizens' Assemblies (e.g. used in Ireland)
- Aim to give the public a role in democratic decision making.
- Premise is that given the time, opportunity, support, and resources people will make considered, informed judgments about complex matters

Usually consist of 12-20- randomly selected and demographically representative paid members of the public.

Jury charged with one or more policy question

Citizen’s Juries 2021 – data sharing during a pandemic

Why was this of interest?

- The UK government issued Control of Patient Information (COPI) notices in April 2020 to make data sharing easier
- The COPI notices were temporary legal powers introduced to tackle the pandemic
- Many data sharing initiatives were introduced under the COPI notices that may have value beyond the pandemic
- What should be the future of these initiatives? And who should make these decisions?

Setting up the juries

- ARC GM funded 2 juries, with NDG and NHSX co-funding a 3rd jury
- Citizens' juries c.i.c. and the Jefferson Centre and cross ARCs
- March to May 2021

- Three juries of 18 people covering 3 geographical regions: GM, (rural) Sussex, England
- Jurors paid £60 per day, recruited from range of job recruitment websites, representative of English population in terms of: gender, age, ethnicity, educational attainment, employment status and prior views on data sharing

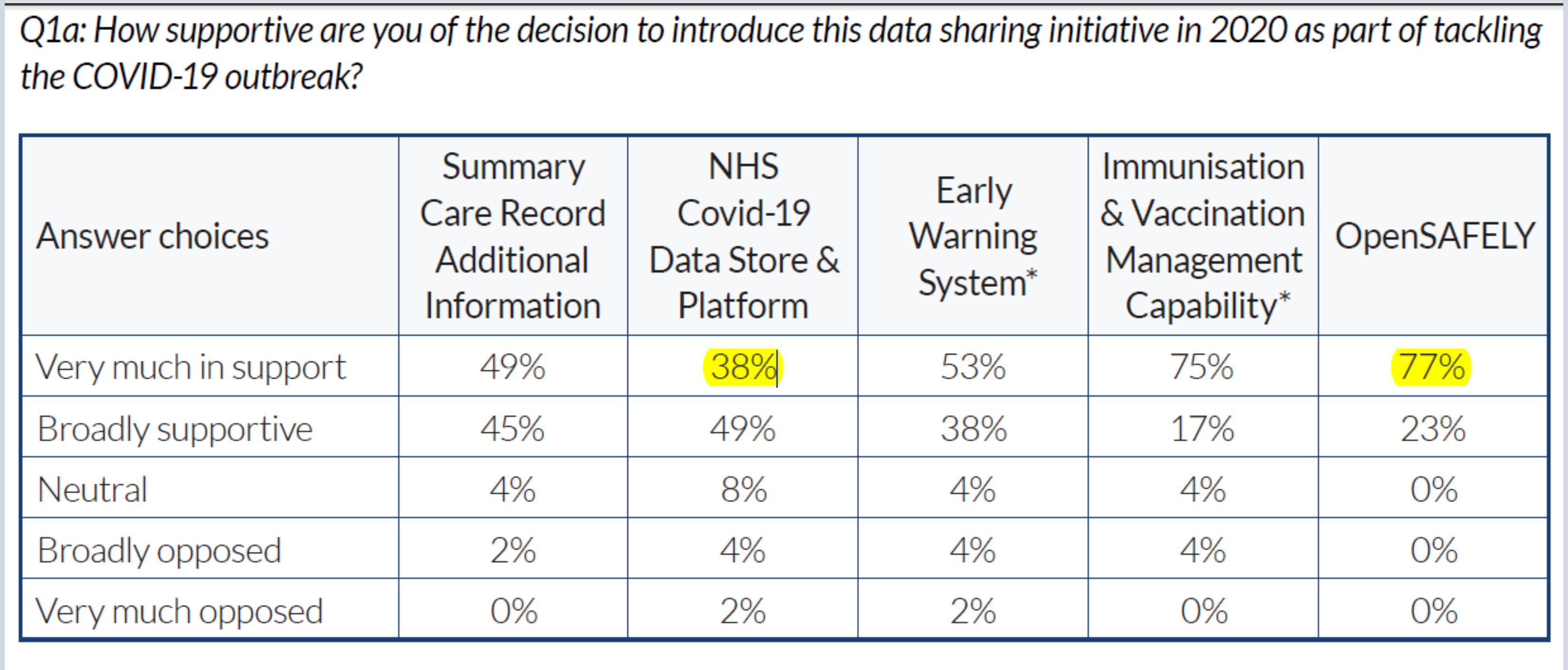
- Data sharing initiatives: Summary Care Record, OpenSAFELY, NHS Covid-19 Data Store

Jury programme

- Presentations by impartial and partial expert witness to inform the juries and stimulate discussion about rules for data sharing in general, what changed as a result of the pandemic, and about the data sharing initiatives.
- Attendees also given the opportunity to put questions to expert witnesses after they have heard their presentations.
- Small- and large-group discussions about the acceptability and appropriateness of data sharing practices during a pandemic
- Electronic voting on some issues before-after the jury

Results of the juries

- Full results are in the report online (https://arc-gm.nihr.ac.uk/)
- Whilst supportive, many jurors were concerned that there was a lack of transparency



Q1a: How supportive are you of the decision to introduce this data sharing initiative in 2020 as part of tackling the COVID-19 outbreak?

Answer choices	Summary Care Record Additional Information	NHS Covid-19 Data Store & Platform	Early Warning System*	Immunisation & Vaccination Management Capability*	OpenSAFELY
Very much in support	49%	38%	53%	75%	77%
Broadly supportive	45%	49%	38%	17%	23%
Neutral	4%	8%	4%	4%	0%
Broadly opposed	2%	4%	4%	4%	0%
Very much opposed	0%	2%	2%	0%	0%

Key recommendations from the juries

- Supporting the decisions to introduce the initiatives in 2020
- Most supportive of OpenSAFELY and least supportive of the NHS Data Store and Platform
- The Summary Care Record Additional Information and NHS Data Store and Platform should be more transparent
- OpenSAFELY considered the most transparent, trustworthy, and secure of the three data sharing initiatives
- Most jurors wanted the data initiatives to continue for as long as valuable but for decisions to be made *outside the responsible organisations* by experts and lay people

Qualitative work with CJ attendees

- What do people think about health data sharing during a pandemic once they become informed about the topic? Did this change?
- Audio-recordings of large plenary group discussions and observations of small group discussions. Materials from the group activities (post-it notes, flipcharts) recorded.
- Whilst jurors were asked to do their voting on behalf of the public, the discussions gave space for jurors to reflect on their own beliefs and thoughts.

Qualitative findings

- Jurors felt there was an assumption that the public would be willing to compromise on some changes to data-sharing rules due to the importance of responding to the pandemic.
- What we found was that many jurors explicitly stated that they believed rules around data sharing should not have been changed because of the pandemic.

Qualitative findings

1. Speed and health data sharing during the pandemic

- the *slow* Government's response to pandemic
- the *speed* of COPI's introduction and initiatives
- Uncertainty about COPI *duration* and/if *reversible*

2. Political and economic concerns coming to the foreground

- Political uses and abuses of data for political/financial gain
- Mistrust/misinformation culture and parliament

3. Nuances between ownership and authorship of health data records

- Lack of clarity about ownership of records and rights once data has been pseudonymised/anonymised
- What is being produced by authors of records (bias etc) - *Effectively it's a book about me written by people who don't really know me*

Impact of the CJs

- Online workshop (5th July 2021) including jurors, NHS representatives, the National Data Guardian for Health and Social Care and academics, and we collectively considered the results of the juries and made recommendations for action. .
- The Citizens' Juries were extensively cited by Goldacre and Morley in their April 2022 review, Better, Broader, Safer: Using Health Data for Research and Analysis, commissioned by the Secretary of State for Health and Social Care.
- The Summary Care Record Independent Advisory Board have used the jury findings to recommend changes to the Summary Care Record's communication and public engagement strategies.
- The Juries called for more transparency and meaningful public engagement in health data sharing, which has been reinforced by references to these jury findings by the National Data Guardian and in the Goldacre report.
- The Unlocking Data partners considered the juries a best practice example for public engagement and planned to use it as a model for their own plans for engaging the public in their regional data integration projects.

Further information

Research team:

- Sabine van der Veer (PI), Niels Peek, Louise Laverty, at the University of Manchester.
- Elisa Jones, supervised by Lucy Frith, at the University of Liverpool.
- Malcolm Oswald, Citizen's Juries c.i.c
- Wider project team includes Caroline Sanders and Nicky Cullum, University of Manchester and the Jefferson Centre.

Questions?