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Health data on public trial: To what extent should patients control access to patient records?

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Objectives

The secondary use of health data for public and private good raises complex questions of privacy and governance. Such questions are ill-suited to opinion polling where citizens must choose quickly with little information between multiple choice answers. This project aims to extend our knowledge about what control informed citizens would seek over health records after participating in a deliberative process.

Approach

Two citizens' juries, of 17 citizens each, were convened; each jury was chosen to reflect national demographics, from a pool of almost 400 volunteers. Juries met separately over three days, to address the charge "To what extent should patients control access to patient records for secondary use?" Citizens heard from and questioned five expert witnesses (chosen either to inform the jury, or to air arguments for and against the secondary use of data), interspersed with opportunities to deliberate amongst themselves, using a range of tools including facilitated discussion and guided role-play. Jurors voted on a series of questions associated with the jury charge, giving their rationale. Individual views were polled at the beginning and end of the process against the jury charge.

Results

Thirty-three out of 34 jurors voted in support of the secondary use of data, with 24 wanting individuals to be able to opt-out and 6 favouring opt-in. Many jurors changed their opinion about who should get access to these records, with more people supporting wider information sharing by the end of day 3. When considering who should get access to data, the two juries had very similar rationales. Both thought that public benefit was

a key justification for access. Jury 1 was more strongly supportive of sharing patient records for public benefit, whilst jury 2 was more cautious and sought to give patients more control. The questionnaire results suggest that over the course of three days a few people moved towards more patient control over patient records, but overall more people moved towards enabling greater sharing of health data for public benefit. Despite our endeavours to ensure otherwise, bias was reported by a few jurors, particularly regarding the impartiality of information from expert witnesses.

Conclusion

These findings illustrate that citizens often change their minds about complex policy questions when they become more informed about a public policy problem. It may also suggest that many, but not all, people become less sceptical about health data sharing as they become better informed of its benefits and risks.

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