

Response to commentaries on 'Should free-text data in electronic medical records be shared for research? A citizens' jury study in the UK'

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Response to commentaries on “Should free-text data in electronic medical records be shared for research? A citizens’ jury study in the UK”.

Elizabeth Ford and Malcolm Oswald.

Many thanks to commentators for these erudite, insightful, and challenging commentaries on our paper *“Should free text data in electronic medical records be shared for research? A citizen’s jury study in the United Kingdom”*.

We note a range of interesting and challenging points which take forward the discourse around the ethics of sharing patient data. Of most note are: criticisms of our jury recruitment and methods; questioning how we can engender trust and support from the wider, uninformed public when we only have the view of a small informed public; asking what work needs to be done to ethically transfer data from a clinical care setting to that of research; suggesting that dynamic consent with opt-outs could be an avenue for allowing patients more control over the use of their medical data for research; and asking how we bridge from “is” (a description of public views) to “ought” (what should policy be?).

The first criticisms to be addressed focus on the recruitment and methods of our jury, raised by Carter {carter ref}. She suggests that the selection of participants, using a population distribution of responses to a data-sharing question, resulted in a jury too positively oriented to data-sharing at the outset. Further, that we counted individual votes rather than allowing the jury to come to a collective position, that jurors were not asked to prioritise the common good, that we present a lack of data from the jury’s deliberations, and as a result, there is a difficulty with evaluating the reasoning and authenticity of deliberation. Regarding recruitment of our jury, our stated aim, which we acknowledge is not shared by all juries, was to achieve a sample which broadly matched what we would expect if we sampled representatively across the population. If we had not done this, there was a risk that the group selected might by chance be either disproportionately in favour or disproportionately against data sharing. We chose to recruit our jurors to reflect the results of a national survey of 1524 UK adults who ranged on a Likert scale from “Very willing” to “very unwilling” to allow their medical records to be used for medical research [1]. We wanted our small group of jurors to be a microcosm of the English population, to give us the first flavour of public thought on this unexplored topic. Of course we recognise that the views of 18 members of the public cannot be extended to represent the whole population. Had funding allowed, we would have run multiple juries. Further research, with bigger samples, and necessarily using different methods, will be needed to establish the range and balance of views held in the population.

Regarding the voting and deliberation, it is a valid criticism that we did not collect data (such as audio recordings or note-taking) of the deliberation sessions. Several previous juries have done this [2,3] but others have not [4-6]. We acknowledge that recordings would have provided insight into the different juror journeys to their final decision and given more context to why some people became more and some became less supportive, as well as enabling us to see the depth of the discussions and the varied positions articulated in the process. We chose anonymous voting because we did not want an emphatically stated minority view to dominate the jury’s collective decision making. With anonymous voting, each juror could give the response that matched their values and their conscience without worrying about the reactions of their jury peers.

Carter {carter ref} states that jurors were not asked to prioritise the common good. Individual goods and public good were both at stake in this jury. We know that many jurors came to understand more about the public good of data sharing throughout the process (and this is reflected in their reasoning). We argue that it would be inappropriate to deliberately prioritise the public good or the individual goods: this ultimately was what we were asking the jurors to weigh.

Whether public policy can be based on a small, well-informed public when it must be acceptable to and trusted by a wider, uninformed public is an excellent question posed by Largent {Largent ref}. Public policy makers do have to listen to the wider public, and we would argue more empirical research should be conducted on public views for sharing of medical free text. Policy should take account of the views of the wider public, the more informed but small microcosm of the public that is represented in a citizens' jury, and experts, in reaching their policy conclusions, and make their reasoning and sources transparent when explaining policy [7]. It is possible to invite the public in to watch deliberative engagements like citizens' assemblies, and when on important issues of public interest like climate change, they are often covered by the media [8]. This is a way of engaging the public in deliberative democracy and public policy decision-making. Indeed, the current Covid-19 pandemic may inadvertently provide an opportunity to discuss with the public how patient data can be repurposed for health research for the public good and elicit further views on this topic.

Morrison asks what work needs to be done to ethically transfer data from a clinical care setting to that of research, without transgressing the original tacit agreement about data collection in the clinic, and suggests that dynamic consent may be the answer {Morrison ref}. As discussed in Ford et al., 2019 [9], the transfer of confidential medical data out of the healthcare clinic and into the university, or controversially, a tech company, for research and analysis, needs to be founded on core principles of inclusivity and transparency. How to achieve these core tenets, however, is currently not clear, and is the subject of much discussion in health data research networks. Although our jurors proposed that an opt-out mechanism for consent would be most acceptable to them, opt-outs garner criticism that those who are most marginalised in society are least likely to have the information needed to set their preference. This may be true of dynamic consent models also, which risk skewing included samples to the highly educated and engaged (in an opt-in model) or leaving the digitally marginalised with little capability to action their choice (in an opt-out model).

Finally, how do we bridge from "is" to "ought"? Unlike Carter, we would argue that the public, like ethicists, are capable of more than "moral intuitions" and "hopes and concerns". Through processes like citizens' juries, they too can reach moral conclusions by examining empirical evidence and applying their own reasoning and normative judgement. Their recommendations are not simply insights that rely upon a researcher's normative bridge. We argue that public policymakers *ought to* take account of the values and recommendations of an informed public. Philosophical ethicists' forensic examinations of competing arguments are potentially valuable, but rarely lead to any kind of consensus that could be used by policymakers. As Jonathan Wolff observes:

"Philosophers become famous for arguing for a view that is highly surprising even to the point of being irritating, but is also resistant to easy refutation. The more paradoxical, or further from common sense, the better. Philosophy thrives on disagreement, and there is no pressure to come to an agreement. Indeed, agreement is unhelpful as it cuts discussion short. In public policy, however, a report must be written, or a recommendation made, or a law or policy drafted, just as in science and social science a practical outcome is sought." [10]

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