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METHODOLOGICAL CHALLENGES IN DELIBERATIVE EMPIRICAL ETHICS

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The empirical turn in bioethics and the deliberative turn in democracy theory occurred at around the same time, one at the intersection of bioethics and social science,(1, 2) the other at the intersection of political philosophy and political science.(3-5) Empirical bioethics and deliberative democratic approaches both engage with immediate problems in policy and practice with normative intent, so it was perhaps inevitable that they would eventually find one another,(6-8) and that deliberative research would become more common in bioethics.(9)

This commentary responds to a paper by Ford et.al., who ran a single jury of 18 people in Brighton in the UK in June 2018.(10) The jury were asked to consider whether secondary research use of non-structured, free text data from medical records should be permitted. I will consider three issues: the effort required in deliberative work, the challenge of sampling and selection of jurors, and the basis for drawing normative conclusions from deliberative research.

First: this report makes clear the effort involved in running a jury. These researchers contracted an external agency experienced in the method, established an oversight committee of policymakers with power to act, developed expert witness briefs, selected witnesses and coordinated their testimony, and created a questionnaire to measure participants' views, activities to support their understanding, and a scenario for consideration. Doing deliberative work takes significant time and resources, and this report evidences substantial commitment from the team.

Second: to the always-challenging question of juror selection. The deliberative democratic literature returns repeatedly to this problem: how do the participants in a deliberative process stand in relation to the broader public from which they are drawn? This matters because mini-publics are taken to be doing democratic—which is to say political—work: enacting *a better form of democracy*, one which is inclusive, deliberative, and involves active citizenship.(4)

So: how to recruit and select an inclusive jury, or at least a jury where there is equality of opportunity to participate, or no systematic exclusion of affected publics?(4) The strategy used by Ford et al. is in line with accepted practices for recruiting a group demographically reflective of a population.(11) Stratifying a sample to match a population with respect to gender, age, ethnicity and educational attainment is expensive, time consuming and difficult; the fact that the authors have achieved this goal is a mark of their concern for quality in design. But deliberative theorists debate whether such a design can ensure legitimacy. Parkinson, for example, argued instead for *equal representation* of all relevant differences in deliberation, to ensure that no one position can dominate by sheer force of numbers.(5) Dryzek and Neimeyer argued from rationality, ontology and ethics for representing all relevant *discourses* in deliberative processes.(12)

Although proportional demographic representation is not unusual in deliberative research, I have particular concerns about the use of a survey question to select these jurors. The researchers asked prospective jurors the Ipsos Mori 2016 survey question "*How willing or unwilling would you be to allow your medical records to be used in a medical research study? The information given to researchers would not include your name, date of birth, address or any contact details.*" Jurors were recruited *proportionally* using this question. That is, to reflect the prevalence of attitudes in the population, the researchers constructed a jury of 15 people who were willing to share, and 3 people

who were unwilling to share, then asked these people whether data should be shared. It is not clear how participants' attitudes on sharing intersected with other characteristics (e.g. whether those unwilling to share may have also been from groups, such as people of colour, younger people or women, who may feel less able to participate actively).

In my view, this proportional sampling on attitudes potentially undermines the democratic legitimacy of the process. Presumably this jury was convened because the researchers thought the normative question "should free-text data be used for research?" was open, that is, that a good case could be made on either side. The final answer—yes it should—would be more convincing if the jury had not been stacked in favour of secondary use at the outset. As a deliberative researcher, I see this as a cautionary tale about the potentially significant effect of the accretion of small methodological choices on the final outcome.

This also relates to my final observation, regarding how deliberative researchers can cross the bridge from is to ought, a bridge that empirical bioethics researchers have been reinforcing and redecorating for the last decade. Like Jackie Leach Scully, I hold that bioethics researchers should use empirical social science methods to understand people's moral intuitions and judgements, but that researchers should make their own arguments for any normative implications that may follow.⁽¹³⁾ Deliberative processes, however, are different to the interpretive methods more common in empirical bioethics. Deliberative methods arise from political theory, enact an ideal form of democracy, and are intended to have direct and indirect *consequences* in governance.⁽¹⁴⁾ That is, juries are—at least in their ideal form—convened for the purpose of delivering legitimate normative recommendations to decision makers, from participants, on behalf of their fellow citizens.

To have such normative force juries are generally expected to have certain characteristics, and in my view some of these were lacking here. Many deliberative researchers conduct multiple processes in diverse locations, rather than making recommendations based on a single jury. These jurors were not asked to prioritise the common good (and the scenario encouraged thinking about an individual patient), researchers counted the votes of individual jurors rather than encouraging the jurors to come to a collective position, lack of data from the deliberations makes it more difficult to evaluate reasoning and the authenticity of deliberation, and it's hard to interpret the extensive concerns and suggestions expressed in light of the final votes. I would especially like to know whether support for data use was conditional on these issues being addressed.

Given my concerns about sampling and interpretation, this process may be better understood, in Parkinson's terms, as an information-gathering rather than a decision-making exercise.⁽⁵⁾ The process certainly provides insight into the hopes and concerns of well-informed publics on secondary data use of this kind. The normative work of bridging these findings to policy action, however, is still to be done.

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