

## From subject to fellow researcher: reconceptualising research relationships to safeguard potentially vulnerable survey participants

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## **From Subject to Fellow Researcher: Reconceptualising Research Relationships to Safeguard Potentially Vulnerable Survey Participants**

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In this open peer commentary, we suggest that the dilemma encountered by Levinson et al. arises as a consequence of conceptual and practical decisions, which collectively, inappropriately dilute authority and accountability for survey data. We argue that it may be possible to reduce the ethical dilemmas encountered by Levinson et al., (2020) if not eliminate them entirely, by reconceptualising the inherent value of survey participants, their status and role in research. We suggest that when designing surveys, researchers should frame potential respondents as active collaborators and contributors of data, rather than merely as passive “subjects”. This shift in positioning delivers a conceptual foundation to proactively establish norms and expectations which respect participant privacy and anonymity, while safeguarding public safety.

### *Establishing a Dilemma Context: Sources of Concern*

The ethical dilemma encountered by Levinson et al. derives from the tension between the need to preserve participant anonymity, and to react to unexpected survey data highlighting an unanticipated health risk (Yildiz et al. 2019). While responding to such considerations will not always generate conflict, in this case certain factors in the recruitment and consent process established a context in which the dilemma encountered was unfortunate but almost inevitable. These factors include;

- 1) Devolving the consent process to administrators of surveyed schools, some of whom interpreted omission by guardians to decline their child’s participation as legitimate consent to participate.

- 2) Seeking consent from parents of those surveyed, rather than the respondents themselves.
- 3) Framing respondents as “subjects” rather than “participants.”
- 4) Emphasising that surveillance, unlike research, typically does not entail responsibilities to the respondents or duties to report findings to “subjects.”
- 5) Guaranteeing complete anonymity to respondents, which subsequently could not be maintained.
- 6) Neglecting to communicate the limits of confidentiality to respondents.
- 7) Deferring responsibility for circulating findings to the gatekeepers, who could exercise discretion over whether they would share findings with participants.

Some of these factors are, to an extent, justified; given that those surveyed were high school children, it is appropriate to assume that parents be approached to give consent (Taylor et al. 2018). Similarly, as noted in the Target Article, anonymity is typically expected in both research and surveillance studies. Collectively, however, these factors created a research context in which the young people surveyed were effectively moved to the periphery of the research process before participation, while their interests and wellbeing demoted in favour of other concerns. Consequently, systems were not in place to effectively respond to unexpected data which revealed a significantly higher level of mental ill-health in one cohort of the surveyed population.

### *Centring Survey Respondents*

Our contention here is twofold; first, that respondents should occupy a prominent position at the very centre of the research process, rather than being relegated to its periphery. Second, researchers should be motivated by this to establish robust protocols in advance of recruitment to address unanticipated clinically relevant findings thereby safeguarding respondents' welfare. These suggestions are grounded in recent literature on the role and status of research participants (the “every participant is a PI” or “EPPI”

approach) (Buyx et al. 2017), and on the importance of solidarity between researchers and research participants (Pratt, Cheah, and Marsh 2020). This literature recommends a much flatter hierarchy in the research context to empower participants, improve recruitment and the quality of participation, reduce attrition, and deliver better, more just research (Buyx et al. 2017; Pratt, Cheah, and Marsh 2020). The emphasis on the creation of a more egalitarian relationship between researchers and participants can also be found in the community-based participatory research (CBPR) model, which was rejected by the authors of the Target Article.

It is not our intent, however, to suggest that researchers must always fulfil the demands of CBPR, since we agree with the authors that this may in some circumstances be overly demanding, and impractical for survey research. Rather, we would encourage investigators to acknowledge and respond to the reasons why the CBPR or EPPI approaches are often appropriate – and that those surveyed do contribute to research, and may reveal significant vulnerability in doing so. Therefore, we suggest researchers should view those who are surveyed as active participants to whom responsibilities are owed, rather than passive subjects whose interests are often overlooked in the development of research protocols. Viewing potential survey respondents as quasi-collaborators, they are centred and empowered in the design of the research process, while researchers are confronted with a duty of care for their contributors, and their accompanying vulnerabilities.

### *Practical Steps*

Framing potential respondents in this way, at the start of the research design process, can ensure research design which embeds practices which guard against the kind of dilemmas encountered by Levinson et al. Critically, recruitment and the consent process should be structured to empower and protect potential respondents. Practically, this could involve; first, both parental consent, and participant *assent* to take part in research. Second, providing advance notice to participants of the themes of the survey questions, the potential that they may cause distress, and cautioning that they

are free to respond to, or ignore, any questions that they wish. Third, identifying local sources of support, such as mental health organisations, drug and/or alcohol rehabilitation programmes, or support for victims of sexual violence that are available to them (Sharkey, Reed, and Felix 2017). Fourth, emphasising that participants are making an important contribution to public health, and that their answers may help others. Fifth, offering an option to receive a summary of local results in an appropriate format, with explanation of relevant data, which emphasises local sources of support of particular relevance to these findings (in the survey discussed in the Target Article for instance, organisations offering mental health support may be most relevant).

Crucially, each of these steps is focussed on providing support and guidance to participants directly (and potentially also to parents or guardians), rather than indirectly, through school administrators or others in gatekeeping roles. It is the participants who provide the data upon which the survey results rely, and whose vulnerabilities and risks are brought to light through surveillance. Emphasis on providing relevant information and welfare services to research participants, and on communicating the value of their contributions is intended to safeguard participants, and acknowledge their vital role as contributors of data. While gatekeepers have a role to play in facilitating the production of data, their access to it should never be prioritised over and above participants, simply put, because it is not theirs. Further, as noted by Levinson et al., doing so engenders a conflict of interest; young people who are at risk with an entitlement to information which could help to lessen or alleviate their vulnerability may be denied access because of gatekeepers' motives.

### *Conclusion*

The dilemma encountered by Levinson et al. is challenging, and we recognise that attempts to resolve it will be demanding. Our goal in this commentary has been to suggest that pre-empting similar scenarios in the future begins by acknowledging survey respondents as active participants in research, not

passive subjects of surveillance (even where “mere” surveillance is the goal of researchers). Recruitment and consent procedures should therefore be aligned with this fundamental conceptual principle. This will inevitably entail proactively constructing processes to value and include respondents in the research process, to the extent that their vulnerabilities are prioritised over gatekeeper interests. This can be achieved by ensuring participants are automatically provided with guidance on relevant welfare services, and can opt to receive summaries of relevant findings. This may be costly, but not doing so fails to value the contributions made by respondents, ignores the risks and vulnerabilities that may be triggered through participation, and codifies them as mere sources of data, rather than persons whose needs, vulnerabilities, and autonomy should be respected and actively enacted and empowered (Williams 2008).

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