

Ethical oversight needed for social network health research

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Participant-led research, such as studies conducted via social networks, are increasingly common and have several advantages over more standard research but there are some concerns about their ethical oversight, according to experts writing in this week's *PLOS Medicine*.

Effy Vayena from the University of Zurich in Switzerland and John Tasioulas from University College London argue that the distinctive nature of such participant-led research means that the standards of ethical oversight should be adapted to strike a balance between protecting the interests of research participants and achieving the promised benefits of this new type of research.

The authors say: "Participant led research is not only potentially an exercise of [personal autonomy](#) and [empowerment](#) on the part of those involved, it is also an avenue for pursuing research into topics that are overlooked or sidelined by the scientific establishment."

They continue: "Yet, given how [group dynamics](#) may develop, a concern that arises here is the inappropriate use of peer-pressure to promote participation in a research project."

The authors argue that the ethical oversight should depend on the type of participant led research and propose three categories, in which category one has increased risk to participants and category three has minimal risk.

They say: "We believe that this scheme merits further discussion as one way of striking an appropriate balance between protecting the interests of research participants and realizing the distinctive benefits of participant led research."

The authors continue: "In this way, we might prevent ethics review becoming a strait-jacket on participant led research inspired innovation, stifling individual liberty, and serving as a disincentive to

non-experts who might otherwise make valuable contributions to [medical knowledge](#)."

Vayena and Tasioulas conclude: "Failure to adequately address this issue, and to generate consensus on best practice, poses a threat of harm to participants, risks undermining the credibility of participant led research, and may eventually provoke a backlash of over-regulation that deprives us of its potential benefits."

More information: Vayena E, Tasioulas J (2013) Adapting Standards: Ethical Oversight of Participant-Led Health Research. *PLoS Med* 10(3): e1001402. [doi:10.1371/journal.pmed.1001402](https://doi.org/10.1371/journal.pmed.1001402)

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