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Peer Review

Review of: "Trust and Trade: Patient Perspectives on the Ethics of Real-World Data Monetisation"

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The manuscript provides a nice overview and discussion of current models/the current thinking about patient trust in the secondary use concept.

I also agree with the outlined safeguards; however, their discussion is a little too shallow to fully understand how exactly the author imagines the implementation of some of these to look like. The discussion of the practical feasibility of these guardrails also happens in a vacuum, assuming that implementations like the EHDS will happen from “scratch” and are not already well on their way. The (unfortunate) reality is that current implementation plans seem to move in directions that de-emphasize the role of patients as the primary data holders. This does not mean that we should stop pushing towards more patient trust, but a discussion of the current reality is required to derive productive suggestions on how to move forward on these issues.

One more fundamental aspect that I was missing is the topic of digital health literacy. Trust is always based on understanding. For most citizens (and frankly even for most experts, me included), the practical impact of data leaks and mishandling of health data is not well understood, making it impossible to do a tangible risk-benefit analysis for the sharing of medical data. This makes actual “consent” impossible (as the risk of sharing your data cannot be evaluated). Putting guardrails for patient consent in place without finding ways to improve digital health literacy makes consent forms just the next cookie banner and writing consent forms a marketing exercise with the sole goal of making patients click the “consent” button.

I don't have any concrete suggestions for improvements besides these broader points, which I understand are difficult to implement (as they are difficult topics in general). I still hope these comments can serve as nudges to the author to further expand the manuscript.

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More voices emphasizing trust and patient involvement in data-sharing processes are a good thing, in my opinion, and works like this can hopefully be the basis to form practical suggestions and ultimately influence legislation.

Declarations

Potential competing interests: No potential competing interests to declare.

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