Qeios

Peer Review

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

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The author describes a persistent problem in the realm of patient data in the scope of real-world evidence. He outlines the importance of the need for transparent and clear communication to patients regarding the use and monetisation of their data. He proposes safeguards that he acknowledges are challenging to fulfil.

While the topic has been raised by patient organisations for decades, it is always welcome to see a spotlight on these important questions of transparency, data ownership, and consent.

Speaking from an EU perspective, the author has not addressed that patients are represented on the steering group of EMA's DARWIN project and that this project is regularly presented to the representative patient and healthcare professional groups at EMA for their input and discussion. The data from DARWIN is not sold but made available for further analysis and research.

One question would be regarding one of the safeguards of 'benefit sharing'. Given the difficulty for charities and patient organisations to raise funds for their survival, I am not entirely certain how the author intends to re-invest the funds raised to organisations, as they are often dispersed and data can be gathered from multiple geographic locations, in particular if the condition being investigated is a rare disease.

I would recommend this commentary for publication.

Declarations

Potential competing interests: No potential competing interests to declare.

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