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Including seldom-heard voices in a novel, circular and reflective data learning model: the Citizen Panel at UK Longitudinal Linkage Collaboration (UK LLC)

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Background

The UK LLC Citizen Panel is a research and public engagement project which is the first proof of concept of an innovative model of learning in data research governance, proposed by Understanding Patient Data (UPD).

Methods

The Citizen Panel was designed in two stages, co-designed by a Steering Group and comprising of 15 members, with 50% participants from LPS collaborating with UK LLC and 50% public members from seldom-heard voices in longitudinal research. The Panel operated in two rounds, held six online meetings and two hybrid workshops.

Results

The Citizen Panel conducted an end-to-end assessment (audit) of the UK LLC application process and provided two sets of innovative recommendations to UK LLC. This model enhanced scrutiny and audit of the UK LLC data access process, evolved the UPD data learning model for research governance and shifted the UPD idea towards a circular and reflective model of work, built on multiple feedback loops and embedded in co-design, mutual learning, dialogue and deliberation with public members from minoritized groups often under-represented in longitudinal research.

Conclusions

The UK LLC Citizen Panel provided novel and important insights on the UK LLC data access process and decision making. The Panel could expand its impact beyond UK LLC to improve the UK's data infrastructure landscape and a model for national and international research organisations. The UK LLC Citizen Panel model is fundamental to good ethical practice and building trust with publics, inclusion of underserved and underrepresented groups and for broader dialogue between citizens and science.

