Making Consent Clearer

Improving Training on Informed Consent in Health Data Trials

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TOPCAT — Towards Optimising Practice: Courses for Health Systems Data in Trials

HDR UK — Health Data Research UK

Background

Trials using health system data (like GP or hospital records) can answer research questions more efficiently, but explaining how patient records are used makes consent complex[1]. Multimedia tools such as videos or animations can make this clearer and more accessible — and are recommended by the Health Research Authority[2].

Purpose

- Worked on the TOPCAT programme (Transforming Data for Trials: Consent, Access and Training) to create a training video for researchers on informed consent in health data trials[3].
- Reviewed guidance and research, and attended events to learn from experts.
- Ran a session with the Public Advisory Group (PAG); their feedback shaped the final video.

Timeline

Exploring Consent

Started broad: reviewed guidance and research on informed consent in health data trials.

Narrowing Focus

Identified key themes: multimedia tools, underrepresented groups, and digital exclusion.

Learning from Experts

Attended a digital health festival, a primary care research conference, and a talk on equality in clinical research.

Spoke with researchers to gather insights.

Working with the Public Advisory Group (PAG)

- Helped plan and run a session with the TOPCAT PAG — designing slides, preparing prompts, and presenting multimedia consent ideas.
- Members were enthusiastic about the potential to make consent clearer and more engaging.
- They also highlighted the importance of cultural relevance, raised cautions about digital exclusion, and stressed the need for two-way dialogue.
- Their input directly shaped my final script and training video.

Final Output

Produced a training video for researchers, co-designed with public input, which will be published on the HDR UK Futures training platform as part of the TOPCAT programme.

Outcomes, Impact and Key findings

- Produced a training video for researchers, co-designed with public input, to support better consent practice.
- The video will be shared on HDR UK Futures with other training resources for health data trials.
- Public involvement made the resource more inclusive, highlighting accessibility, cultural relevance, and digital exclusion.
- The project strengthened my skills in organisation and accessible communication, and confirmed my interest in a career in research.

References

1. HRA & MHRA. Joint statement on seeking and documenting consent using electronic methods (eConsent). Health Research Authority, 2018.
2. HRA. Participant Information Design and Review Principles. Health Research Authority, 2023.
3. Bhattacherjee A, Wickramasinghe N, et al. Self-directed multimedia process for delivering participant informed consent. BMJ Open. 2020.

Read more here:

https://www.cardiff.ac.uk/centre-for-trials-research/research/studies-and-trials/view/top-cat