

Engagement and Co-Design: Routes to Lawful Research?

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Background

The 'deficit' model of engagement, which educates the public about research, has been subject to increasing criticism, as if people's attitudes arise from ignorance which should be corrected. Nevertheless, a number of attempts to understand public views on the use of Administrative Data for research have used informative models.

This can be problematic from a legal perspective, as the law is concerned with data subjects' 'reasonable expectations', not their hypothetical expectations had they received more information. Recent controversies around reasonable expectations have included Google DeepMind and Royal Free, as well as Cambridge Analytica.

Objectives

This paper considers how public engagement can help administrative data controllers meet their legal obligations when data are processed for research, and how to avoid confusion by placing too much reliance on the views of informed participants as a means of gauging wider public opinion.

Methods

We refer to the findings of an exploratory study of individual attitudes towards Administrative Data Research, which indicate that views and norms around ADR are incipient and ambivalent, especially when compared to perceptions of 'conventional' medical research. We consider the legal obligations administrative data controllers have to shape reasonable expectations in light of this uncertainty.

Findings

Engagement which informs the public about research does have value. It indicates what the attitudes of the public might be, were certain facts about research more commonly known, and thus underscores the importance of public information campaigns. However, this work cannot provide an accurate representation of public opinion as a whole in the absence of wider dissemination of information across society.

Conclusions

There will inevitably be a number of facets to public engagement: information, representation and transparency. Each of these will correlate differently with data controllers' legal obligations, and it is essential to understand these connections.

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