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PhD Title: Public involvement of seldom heard voices in managing and organising big data research
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Brief summary

The recent digitalisation of information allowed the creation and linkage of large, multi-source health data sets to provide novel healthcare applications. These are often called 'big data' and can be used for various purposes, including research. The social benefits are to deliver better, more efficient healthcare and to improve health inequalities of seldom heard voices. The public mostly supports the usage of big data, but it also concerned with how data is shared and who can access it. This presents researchers with not only legal but also ethical issues. The case of care.data in the UK showed that public needs to support data so researchers have to engage with population and be transparent about their work, otherwise risk failure of the project (as it happened with care-data). Improving relationship, understanding and transparency between researchers and the public can be achieved by public involvement. People can contribute to the development of transparent and accountable governing policies-advising researchers on how big data can be organised and maintained. A particular focus of public involvement should be to include seldom heard voices- sometimes also called 'socially excluded' or 'hard-to-reach' groups. Not incorporating them can make findings ungeneralisable to all parts of society and miss nuance specific to those groups.

The summary of research plan:
Year 1: Literature review on public involvement in big data research
Year 2: Qualitative study with a seldom heard group to co-produce involvement mechanisms
Year 2/3: Produce implementation strategies and ways of assessing the impact of involvement for public and community involvement and engagement in the creation and running of large health data sets.