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Public understanding of, and attitudes towards, data linkage in research

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Objectives

There is an ongoing need to involve and inform the public about data linkage research. Projects at the South East Wales Trials Unit (SEWTU) and Division of Population Medicine, Cardiff University have focused on participant and public understanding of, and attitudes towards the use of routine/linked data for research purposes.

Approach

HealthWise Wales is a Welsh national cohort using prospectively collected data linked with NHS records. Face-to-face and online focus groups were conducted to explore the barriers and facilitators to signing up to this project as well as discussing the best way to communicate the technical details of the project. MINIMAL PhD conducted a focus group with care-experienced young people to gather attitudes towards the collection and linkage of child maltreatment data. The Public and Patient Involvement activities of the Building Blocks 2-6 Study included meetings with a young mothers group utilising their skills as advisors on communicating data linkage issues with study participants. These projects have been undertaken independently however comprise the same underlying questions âĂŞ Do the public understand why routine & linked data is used for research? Will this be a barrier to participating? How can we communicate study design to ensure participants are fully informed? This presentation will summarise the similarities and contrasting attitudes and beliefs emerging from these projects.

Results

We have identified similar emerging themes from both the HealthWise Wales focus groups and MINIMAL PhD focus groups. Participants found it challenging to understand the methodology of data linkage and this acted as a barrier to taking part in data linkage projects. Once participants felt fully informed of the method, their concerns around data safety and confidentiality were reduced. Participants required assurances that their data were safe, that they could not be identified, and that researchers can be trusted to access these data before considering the research project in discussion. Participants also discussed the collection of sensitive data from various sources through data linkage, consent issues, and the balance between research risk/benefit for the MINIMAL PhD focus group.

Conclusion

These qualitative studies will contribute to knowledge of how to better inform members of the public about routine / linked data, as it is clear than there remains a lack of understanding of the research conducted in this area, and the importance for researchers to utilise these data. Researchers need to get the communication right in order to be successful at recruiting and retaining participants.

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