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Young people's views about consenting to data linkage: Findings from the PEARL qualitative study

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Objectives

Electronic administrative data exist in several domains which, if linked, are potentially useful for research. However, benefits from data linkage should be considered alongside risks such as the threat to privacy. Avon Longitudinal Study of Parents and Children (ALSPAC) is a birth cohort study. The Project to Enhance ALSPAC through Record Linkage (PEARL) was established to enrich the ALSPAC resource through linkage between ALSPAC participants and routine sources of health and social data. Qualitative research was incorporated in the PEARL study to examine participants' views about data linkage and inform approaches to information. This paper focusses on issues of consent.

Approach

Electronic administrative data exist in several domains which, if linked, are potentially useful for research. However, benefits from data linkage should be considered alongside risks such as the threat to privacy. Avon Longitudinal Study of Parents and Children (ALSPAC) is a birth cohort study. The Project to Enhance ALSPAC through Record Linkage (PEARL) was established to enrich the ALSPAC resource through linkage between ALSPAC participants and routine sources of health and social data. Qualitative research was incorporated in the PEARL study to examine participants' views about data linkage and inform approaches to information. This paper focusses on issues of consent.

Results

Electronic administrative data exist in several domains which, if linked, are potentially useful for research. However, benefits from data linkage should be considered alongside risks such

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Conclusion

Findings from this study question the validity of 'informed consent' as a cornerstone of good governance, and the extent to which potential research participants understand different types of consent and what they are consenting, or not consenting, to. Pragmatic, imaginative and flexible approaches are needed if research using data linkage is to successfully realise its potential for public good without undermining public trust in the research process.

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