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The Northern Ireland Baby Hearts Study: A Case-Control study using a hybrid data linkage method

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Background

The Northern Ireland (NI) Baby Hearts study aimed to investigate risk factors for congenital heart defects (CHD), and to investigate the health behaviours of a representative sample of NI pregnant women.

Methods

We performed a case-control study with hybrid data collection methods, including self-administered iPad questionnaire or postal questionnaire, information held in maternity records and linkage to prescription records. Cases (n=286) were recruited following diagnosis prenatally or postnatally, controls (n=966) were recruited during recruitment months in each maternity unit at 18-20 weeks gestation.

Findings

Refusal rates for questionnaire completion were low (7-8%). Among those recruited, consent for access and linkage to medical records was high (98%). Recruitment of both cases and controls was closely representative of the NI population in terms of age, area of residence and deprivation. There was considerable discordance between self-report questionnaires, maternity records and prescription records regarding medications taken in the first trimester, and between self-report questionnaires and maternity records regarding behaviours such as preconceptional folic acid, pregnancy planning, and smoking. However, there were no differences between cases and controls that would indicate recall bias.

Conclusions

Our results suggest that hybrid data collection approaches are a useful way forward for aetiological studies.

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