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Building a birth cohort of births and their outcome in England and Wales using linkage of administrative data

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Background / rationale

When a baby is born in England and Wales, the event is recorded in several separate systems, each of which contains different data items. Data recorded at birth registration are mainly socio-demographic, while some different data items are recorded when the birth is notified to the NHS. The data recorded in hospital systems in England and in Wales about the majority of babies who are born in NHS maternity units are largely clinical.

Over a ten year period, a series of three collaborative projects have linked data about 7,013,804 births registered in 2005–14 to establish a birth cohort for use in research and national statistics and to quality assure the linkage. Data about outcomes of birth in terms of death and subsequent readmissions to hospital have also been linked in. The linked data are held in the Secure Research Service at the Office for National Statistics.

The data have been used for analyses of pattern of births by time of day, day of the week and season and in relation to obstetric intervention in labour and birth. They are now being used by other researchers.

not subject to NHS Digital's opt-out policy. Data access policies should reflect the higher public trust in research uses of NHS data compared to commercial uses.

Challenges encountered

There were major problems in accessing NHS data for England, compounded by intermittent availability of funding.

Lessons learned

Despite the many challenges, it proved feasible to construct a linked birth cohort which has increased the scope and range of national maternity data for England and Wales. NHS Digital's opt-outs are causing gaps in national data and could invalidate linkage.

Recommendations

The cohort should be updated with data for more recent years. Linkage should be undertaken within ONS by teams who are

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