Developing routinely recorded clinical data from electronic patient records as a national resource to improve neonatal health care: the Medicines for Neonates research programme

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Plain English summary

The Medicines for Neonates research programme

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Plain English summary

Increasingly, health-care professionals record data in electronic patient records (EPRs) rather than traditional paper case notes. EPRs are a rich source of data with great potential to improve patient care, services and outcomes. We aimed to develop the use of EPRs to support neonatal specialised care, a high-cost NHS service for approximately 80,000 newborn infants each year.

We carried out six inter-related workstreams. We pooled data from newborn EPRs across all 200 NHS neonatal units and developed their use as a national resource. We tested the use of EPR data in research and health service evaluations. We assessed the reliability of EPR data for evaluating development in preterm babies at the age of 2 years. We compared EPR data against the same data recorded as part of a clinical research trial, and determined if we could link EPR data successfully with NHS administrative data. In a specific workstream, we obtained parent views on using routine clinical EPR data in research.

We show that it is possible for a clearly defined extract of EPR data to be stored in a National Neonatal Research Database as a resource for multiple purposes. We found that data from EPRs do not provide a reliable assessment of development at the age of 2 years in children who were born very preterm. Routine EPR clinical data show reasonable agreement with the same data recorded as part of a clinical research trial, and the data are higher in quality than similar data recorded for administrative purposes. We were able to link around two-thirds of EPR data with NHS administrative data. We found that in general there is strong parent support for sharing routine health data for research purposes.

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