

Dr Jenny Carter - Written evidence (PRT0053)

Re: Data collection and monitoring in relation to preterm birth, including variation in the recording of data.

1. The UK Preterm Clinical Network (UKPCN) is a network of doctors, midwives and scientists who are working together to prevent the problems associated with preterm birth. This work includes providing extra maternity care for women at risk so they can be offered treatments to both prevent premature labour and to reduce problems associated with preterm birth if it cannot be prevented. The UKPCN aims to improve care and pregnancy outcomes through the sharing of experience and knowledge, and the building clinical and research collaborations. The Preterm Clinical Network (PCN) Database was created to support the network in achieving these aims (www.medscinet.net/ukpcn). It provides an easy to use, web-based platform for the collection and storage of relevant information about women, the care they received and their pregnancy outcomes, such as whether or not their baby was born early, and whether they or their baby had any preterm related problems.
2. The PCN Database allows specialist preterm services to collect data specific to preterm care that is not comprehensively captured on standard electronic maternity records. They can then use this data to audit their own local practices and outcomes against regional and national standards. Third parties can apply for access to anonymised data, through the PCN Database Access Committee, for use in research exploring short, and long term, effects of specialist preterm care, monitoring and treatments, and preterm birth itself.
3. Women consent to their data being stored in the database and are also asked if they would be happy for information on their and their children's future health and wellbeing to be collected. The establishment of this longitudinal cohort of mother and child dyads

allows much longer follow up than is currently possible in individual research studies, for example, the evaluation of the long term effects preterm interventions, such as progesterone supplementation and transabdominal cerclage.

4. The PCN Database also acts as registry of potential future research participants, as women are also asked whether they would be happy to be contacted about research opportunities and for permission for their contact details to be stored.
5. The database was launched in 2016, and the number of Data Collection Centres continues to grow. Now it is financially supported through the new Tommy's National Centre for Preterm Birth Research (tommys.org), it is eligible for National Institute for Health Research (NIHR) portfolio adoption. If our application is successful, this will provide much needed Research Midwife support so that many more specialist preterm clinics will be able to contribute their data, widening its reach and diversity in terms of hospital type, geographical spread and patient demographic characteristics.

Carter, J., Tribe, R.M., Sandall, J. and Shennan, A.H., 2018. The Preterm Clinical Network (PCN) Database: a web-based systematic method of collecting data on the care of women at risk of preterm birth. *BMC pregnancy and childbirth*, 18, pp.1-9.
<https://rdcu.be/dCD3Q>

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