PremPath: Improving the optimisation and stabilisation of the preterm infant

We would like to thank all the parents who took part in interviews for the PremPath study. We are grateful to everyone who generously shared their experiences and views to help improve care for families in the future. The interviews provide new insights and moving testimony that inform the recommendations coming from this research.

Nici, Julie, Janet and the PremPath team

About the research

We looked at a pathway of care for premature babies, born before 37 weeks of pregnancy, in England. The pathway has 7 different interventions, designed to give premature babies the best chance of survival, and of being healthy in the long term. Some interventions take place before birth and others after. We looked at how the pathway works in practice, and how to improve it.

We studied how teams work together and how care is coordinated within and between hospitals. We also looked at how decisions are made and how parents are involved. To do this we:

- Interviewed network and clinical leads across regions in England;
- Observed care in 4 NHS Trusts in England;
- Interviewed 29 healthcare staff;
- Interviewed 41 parents of preterm babies.

We worked with key partners to make sense of the information we collected, including Bliss, a charity that supports parents and families of premature or sick babies, a panel of parents of preterm babies, and an expert advisory board of academics and clinicians.

The research has produced a series of recommendations around data management, coordination of care, equity and respectful care. We will be sharing the findings of the study widely over the coming months. Alongside policy makers, professional bodies, and charities, we will work together to influence change.

This document is a summary of the findings from interviews with 41 parents. We heard from 2 fathers and 39 mothers of preterm babies born at a variety of gestations. The majority of parents interviewed were White British (66%). Parents lived across England.

Summary of findings from interviews with parents

Parents had very different journeys. For some their baby had been born suddenly and unexpectedly. Some had a long journey where preterm labour seemed likely. Preterm birth can have ongoing impact on parents' mental health and wellbeing. Parents wanted staff to see them as individuals shaped by their experiences.

Parents were mostly unaware of the pathway. Most parents knew about individual elements such as steroids or cord management. Expressing colostrum or early breast milk is one element of the pathway. It is a very personal decision to express or not. Some women felt strongly that they wanted to express but support varied by unit and on different days. Other women felt pressured to express or judged for their decision not to express.

Mothers found it very difficult to be separated from their babies. This was made worse by poor communication and lack of staff support. For example, mothers in recovery were not always updated about their baby. Mothers recovering from birth were not supported by staff to go to the neonatal unit. Inflexible hospital routines meant mothers sometimes missed meals and medication. Long stays in the neonatal unit are expensive for families.

Parents valued reassurance and guidance about how to touch their baby in the neonatal unit. Shortage of staff to support this sometimes limited physical contact. Families valued being involved in their babies' care.

Most parents were unprepared for preterm birth and had little prior knowledge. Parents valued clear information, tailored to their situation and delivered with compassion. Emergencies could mean conversations were rushed. Sometimes conversations happened when women were distressed or in pain. It was hard to take this information in or be involved in decisions. Opportunities were sometimes missed to counsel families at more appropriate times, even when pregnant people were in hospitals for days or weeks before they gave birth.

Key implications of the research

We have 17 recommendations in total to improve care for preterm infants and their families. We have also suggested some areas for further research. Some key actions are:

1. To improve **coordination between neonatal units, recovery areas and postnatal wards**
2. To think about how birth parents' **decisions about early breast milk are recorded and shared** with staff to make sure birth parents are supported and their decisions are respected
3. To make sure families know how to access **help with costs** and highlighting where they may be entitled to Neonatal Care Leave and Pay
4. To establish **who is responsible for talking to parents about preterm birth and the best timing** for these conversations
5. To do more research about how **shared decision-making** can be done well in different situations relating to preterm birth

Find out more

If you would like to hear about the study in more detail

Listen to the PremPath team talking about the study on the NIHR Greater Manchester Patient Safety Research Collaboration (PSRC) podcast for Patient Safety week.

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