Improving breastfeeding services for neonates with Congenital Heart Defect using the Experience-Based Co-Design approach

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Rationale: Previous studies have shown that breastfeeding benefits infants with Congenital Heart Defect (CHD). This thesis studies the trajectory families undergo to breastfeed their infants. It aims to understand the challenges families and health professionals experience to deliver high quality breastfeeding services, alongside the improvements required to make the breastfeeding journey successful. Additionally, this project also aims to understand if the Experience-Based Co-Design (EBCD) methodology was a suitable approach to sustain quality improvement developments within the paediatric setting.

Methodology: The study was performed using the EBCD methodology. Fieldwork involved 25 filmed interviews of families and staff members. During the course of the project three events were organised where participants gave feedback on their experiences. Necessary improvements to the breastfeeding services provided were also discussed by participants. The project setting was at The Royal Brompton Hospital (RBH), a Paediatric cardiac unit in London, England.

Results: The experiences reported confirm that breastfeeding a cardiac infant is challenging and tailored support is required. “Education for staff”, “Family support & well-being” alongside “Communication” are the main themes needed to improve breastfeeding journeys at the RBH. Furthermore, respondents described EBCD as a successful and sustainable method of improving the individual family experience and the overall quality of the health service.

Conclusion: A policy/guideline for breastfeeding cardiac infants needs to be developed for high quality care to be attained. For this document to be developed improvements, primordially around efficient education and investment in human resources, in cardiac units is required. Regarding the EBCD methodology, the primary strength noted was the improvements immediately reflected on the unit. Nevertheless, time constrains and lack of human resources to adequately develop the methodology can portray a challenge.