

Infant deaths in the UK community following successful cardiac surgery: building the evidence base for optimal surveillance, a mixed-methods study

Katherine L Brown,^{1*} Jo Wray,¹ Rachel L Knowles,² Sonya Crowe,³ Jenifer Tregay,¹ Deborah Ridout,² David J Barron,⁴ David Cunningham,⁵ Roger Parslow,⁶ Rodney Franklin,⁷ Nick Barnes,⁸ Sally Hull⁹ and Catherine Bull¹

¹Cardiac Unit, Great Ormond Street Hospital NHS Foundation Trust, London, UK

²Population Policy and Practice Programme, University College London Institute of Child Health, London, UK

³Clinical Operational Research Unit, University College London, London, UK

⁴Cardiac Surgery Department, Birmingham Children's Hospital NHS Foundation Trust, Birmingham, UK

⁵National Institute for Cardiovascular Outcomes Research, University College London, London, UK

⁶Faculty of Medicine and Health, University of Leeds, Leeds, UK

⁷Paediatric Cardiac Unit, Royal Brompton and Harefield Hospitals NHS Trust, London, UK

⁸Department of Paediatrics, Northampton General Hospital NHS Trust, Northampton, UK

⁹Primary Care Department, Queen Mary University of London, London, UK

*Corresponding author

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Plain English summary

Infant deaths after cardiac surgery

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In recent years the outcomes of children's heart surgery have greatly improved, largely because of better management in hospital. However, after hospital discharge some babies die unexpectedly or require emergency readmission to intensive care. The Infant Heart Study aimed to explore risk factors for poor outcomes after hospital discharge for infants undergoing heart surgery, to understand how the health system works for them after discharge and to propose interventions to improve outcomes. We used a range of different methods to collect data: we identified relevant published literature, analysed national audit data routinely collected about UK babies undergoing heart surgery or admitted to intensive care and conducted interviews with parents of children who had died or been readmitted unexpectedly after hospital discharge, health professionals who work with these babies in hospitals or the community, and charity helpline staff. A group of people from different backgrounds was convened to suggest effective interventions. Results indicate the need for improved discharge planning and communication between professionals in specialist hospital, local hospital and community settings that care for infants discharged after heart surgery; for infants identified as being at high risk to be discharged from the specialist hospital to their local hospital before going home; for a home-monitoring programme for infants at high risk; for clear guidance to families and health professionals about spotting early warning signs in a baby who has had heart surgery; for standardised training and information for families prior to discharge; and for the opportunity for families to seek peer support from other families through charity-based groups or social media.

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Editorial contact: nihredit@southampton.ac.uk

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