Protocol

Caring for babies with palliative care needs and/or multiple complex health needs with an uncertain future in England and Wales 2015-2020

Principal Investigator: Cheryl Battersby
Co-investigators: Sabita Uthaya, Neena Modi
Clinical Research Fellow: Fergus Harnden

Background

It is well recognised that a proportion of babies have palliative care needs in the neonatal period (1). In 2010 the British Association of Perinatal Medicine (BAPM) drew up a framework for palliative care. It suggested five categories of babies who may be considered for perinatal palliative care based on the presence of life-limiting conditions, birth at the margin of viability, and the presence of conditions associated with severely impaired quality of life or unbearable suffering (2).

This study aims to quantify palliative care needs among babies admitted to neonatal units in England and Wales between 2015 and 2020 using data held in the National Neonatal Research Database (NNRD). Work with a group of expert stakeholders has already taken place to determine which variables can be used to identify babies likely to have palliative care needs within each of the five BAPM categories. The outputs of this project will help inform service planning and allocation of resources to support babies and families.

Aims

To use NNRD variables to determine the number and proportion of babies admitted to neonatal units in England and Wales 2015-20 likely to have fulfilled the BAPM categories for perinatal palliative care.

Patient inclusion criteria

Babies who were born and admitted to neonatal units in England and Wales between 1 January 2015 and 31 December 2020.

Patient exclusion criteria

Babies who were born or cared for in neonatal units in Scotland.

Study outcome measures

- Number and proportion of babies who fulfil the BAPM criteria for palliative care:
    i. Overall
    ii. By BAPM category
- Number and proportion who died before discharge
- Number and proportion discharged home or to a hospice, to another hospital or ward
- Average length of stay on neonatal unit
- Average postnatal and postmenstrual age at discharge

Outcomes will be reported over time and by geography, network, gestational age, and unit levels of care.

Study design

This is a retrospective descriptive study that will use data extracted from the NNRD for babies born and cared for in England and Wales.

Ethics approval

No patient identifiable information will be used in this study and only existing anonymised data held in the NNRD will be used. The Neonatal Data Analysis Unit (NDAU) holds UK Research Ethics Committee approval, IRAS Project ID: 291589 REC reference: 21/LO/0024.

References:

1. Cochrane H, Liynage S, Nantanmbi R. Palliative Care Statistics for Children and Young Adults: Health and Care Partnerships Analysis: Department of Health; 2007 [Available from: https://webarchive.nationalarchives.gov.uk/20130221194339/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_074701.

2. BAPM. Palliative Care- A Framework for Clinical Practice in Perinatal Medicine 2010 [Available from: https://www.bapm.org/resources/30-palliative-care-a-framework-for-clinical-practice-in-perinatal-medicine-2010.