CHILD HEALTH CLINICAL OUTCOME REVIEW PROGRAMME
HEALTHCARE IMPROVEMENT PLAN 2026 – NECROTISING ENTEROCOLITIS

1. INTRODUCTION

The Child Health Clinical Outcome Review Programme assesses the quality of healthcare provided to children and young people by using clinical peer review to undertake a deep dive into a variety of conditions, procedures and processes to determine where improvements can be made and highlight learning from examples of good practice.

This study will look at the necrotising enterocolitis (NEC). Concerns have been raised around the timing of transfer to a neonatal surgical unit, referral to a neonatal surgeon and the timing at which surgery occurs. This study will aim to improve the quality of acute care provided to babies born before 32 weeks gestation who develop NEC.

Data will be collected from England, Wales, Northern Ireland and Jersey. A summary of how data flows through the process can be found here.

2. IMPROVEMENT GOALS

The study aims to highlight variation in the provision and quality of care to stimulate improvements for future patients. Identified by the programme's topic-specific study advisory group and HQIP's independent advisory group the improvement goals will be to:

- Improve the organisation of services, access to paediatric surgery and transfer arrangements for babies with NEC by making recommendations to improve the delivery of care

Data will be collected from the organisational questionnaire, the neonatal questionnaire and reviewer assessment form

- Highlight the need for earlier recognition of NEC to improve patient care by reviewing the timeliness and frequency of clinical assessments, and the time taken to reach diagnosis.

Data will be collected from the neonatal questionnaire, the surgical questionnaire, the reviewer assessment form and the parent carer survey

- Review the timeliness and appropriateness of the escalation of care to identify opportunities to improve patient care and clinical outcomes

Data will be collected from the neonatal questionnaire, the surgical questionnaire, the reviewer assessment form and the clinician survey

- Review access to paediatric surgery for timely assessment and intervention to identify opportunities to improve patient outcomes

Data will be collected from the organisational questionnaire, the neonatal questionnaire, the surgical questionnaire, the reviewer assessment form and the clinician survey

- Evaluate staffing arrangements and multidisciplinary team working in relation to clinical decision-making and transfer processes to identify opportunities for improving coordination, communication, and patient care

Data will be collected from the organisational questionnaire, the neonatal questionnaire, the surgical questionnaire and the reviewer assessment form

- Assess the availability of information and support for parent carers, and explore their involvement in care and recognition of deterioration, to identify opportunities for improving patient outcomes

Data will be collected from the organisational questionnaire, the neonatal questionnaire, the surgical questionnaire, the reviewer assessment form, and the parent carer survey

3. IMPROVEMENT METHODS

Recommendations, agreed by consensus of all involved in the study (SAG, case reviewers and steering group, including patient/parent/carer/lay involvement) and evidenced from data in each report, will aim to improve care and reduce variation. These recommendations will be supported by quality improvement resources. In addition, the programme team will engage with opportunities for collaboration and alignment with other initiatives around the care under review to ensure longevity for both pieces of work and co-ordinate outputs for those implementing the findings to reduce duplication.

a. Local

Recommendations will be accompanied by suggested ideas for local implementation, and methods by which hospitals can monitor their own activity and the effect of any changes they make:

- A recommendation checklist - a pre-populated gap analysis tool
- A fishbone diagram - to help users determine what will lead to improved care
- A driver diagram - to help users determine what will lead to improved care
- An audit tool – a ready-made tool for local clinical audit
- A commissioner's guide – summarising what the findings mean for them
- A slide set – with a narrative for local presentations.
- Links to existing resources
- Good practice repository with contact information where possible.

In every hospital NCEPOD has a local contact based commonly in the audit/clinical governance department who acts as a liaison between us and the hospital.

The NCEPOD local reporters will likely be responsible for initiating the QI work streams when reports are released (covered in the 'national' section).

Many local reporters are supported by senior clinicians known as NCEPOD Ambassadors. Ambassadors will be expected to take report findings to executive board meetings for discussion and development of an action plan.

b. National

Recommendations will be targeted to specific groups such as NHS England/Department for Health and Social Care, Welsh Government, Department of Health in Northern Ireland and Jersey as well as royal colleges and specialist societies. Suggested areas for research where the current knowledge and evidence base is lacking will also be highlighted.

We will work closely with charities and patient-focused organisations relevant to each topic to ensure that the patient/parent/carer/lay voice is at the centre of the study from the start, and to help raise awareness of the outputs, encouraging the service users to drive change by questioning the care they receive.

As part of the study development, we will collaborate through the study advisory group (SAG), the governance and advisory bodies that will support the review:

- British Association of Perinatal Medicine
- British Association of Perinatal Medicine network representation
- Neonatal Surgical Forum
- National Neonatal Surgical Interest Group
- British Association of Paediatric Surgeons
- Royal College of Paediatrics and Child Health
- Paediatric Critical Care Society
- Association of Paediatric Anaesthetists
- Royal College of Anaesthetists
- Royal College of Surgeons
- Association of Surgeons of Great Britain and Ireland
- Royal College of Nursing
- Neonatal Nurses Association
- Association of Chief Children's Nurses
- Neonatal Transport Group
- British Association of Parenteral and Enteral Nutrition
- British Society of Paediatric Gastroenterology, Hepatology and Nutrition
- Children's Hospital Alliance
- British Dietetics Association Neonatal Specialist Sub-Group
- The British Society of Paediatric Radiology
- National Neonatal Audit Programme
- National Perinatal Epidemiology Unit
- National Child Mortality Database
- Neonatal Medicine Research Group
- National Neonatal Research Database
- NECUK
- Bliss
- Lay representation
- Parent carer representation

For this topic we will also work closely with the following stakeholders:

- GIRFT (neonatology)

The above groups, along with case reviewers and the NCEPOD steering group will identify the individuals, organisations, and system drivers that are likely to be important in using the results.

Study outputs including a report and infographic summary will be produced to maximise impact. At publication a link to these will be emailed to all local reporters/ambassadors/clinical and patient stakeholders for forwarding - this equates to approximately 2,000 initial contacts, as well as being made available on our website www.ncepod.org.uk and through social media (BlueSky, Facebook, and LinkedIn).

To help disseminate the findings we will:

- Present the study findings at national conferences and local hospital meetings.
- Use social media to stimulate discussions.
- Provide YouTube videos summarising the findings.

Details can be found in the study engagement and dissemination plan.

Stakeholder workshops

One year after a report has been released, we will undertake a stakeholder workshop with national, regional, local and patient involvement to determine what impact the report has had. From this we will share examples of good practice and issue an update on the report to all stakeholder groups. The aim of this meeting will be to understand and document what QI has been undertaken on the report recommendations and what more can be done.

c. Parent/carer and lay involvement

Parents/carers/lay representative will be included:

- By being involved in the design of the study
- By co-producing, and responding to, anonymous surveys of patients/parents/carers, along with face-to-face focus groups so that the views of service users and the public can be included
- Co-producing outputs for patients and the public including infographics or a ‘what you should expect’ leaflet to facilitate patients/parents/carers seeking care in line with expected standards.

d. Communications

There will be regular communication with all stakeholders, including parents/carers in the following ways:

- Keeping the website updated (https://www.ncepod.org.uk/nec.html)
- Parent carer leaflets on how to seek high quality care
- Using social media
- Newsletters
- Having stands at meetings/conferences
- Meeting with people to keep them updated and talk about the work
- Undertake local and national presentations
- Undertake stakeholder meetings once the report has been published
- Work with professional, sensible, health journal contacts for follow-up editorial pieces.

4. ANALYSIS PLAN

Data sources

- National data (National Neonatal Audit Programme (NNAP)) will be used to assess sample sizes.
- Patients will be identified for inclusion via the NNAP (in addition to local reporters) using data already routinely collected for them.
- An organisational questionnaire (OQ) will be sent to each participating organisation.

- Online anonymous surveys will be used to gather the views of parents/carers and views of healthcare providers.

To collate core data on a sample of patients for the study, in addition to the patients identified via NNAP, a patient identification spreadsheet will be sent to all relevant healthcare providers. For each included patient:

- A neonatal questionnaire will be sent to the clinician responsible for the baby at the time of admission to the neonatal unit where the baby was being cared for 48 hours before the diagnosis of NEC was made.
- A surgical questionnaire will be sent to the clinician responsible for the baby at the time of admission to a surgical NICU (where applicable)
- Copies of the case notes relating to the episode under review will be requested and peer reviewed by a multidisciplinary group of healthcare professionals. They will complete a reviewer assessment form (RAF).

Data preparation

- Quantitative data will be checked to ensure no erroneous data have been added, to assess missing data, and to make sure that the data are sensible. Any absent data will be classified as ‘not answered’.
- Qualitative data collected from the case reviewers’ opinions and free-text answers in the clinician questionnaires will be coded, where applicable, according to content to allow quantitative analysis.
- Descriptive data summaries will be produced supported by tables and graphs.
- Anonymised case studies will be used to illustrate the themes with examples of good and poor care.

Data analysis rules

- Small numbers will be suppressed if they risk identifying an individual. This is usually five or fewer but will vary depending on the dataset.
- Any percentage under 1% will be presented in the report as <1%.
- Percentages are not calculated if the denominator was less than 100 so as not to inflate the findings, unless to compare groups within the same analysis.
- There will be variation in the denominator for different data sources and for each individual question as it is based on the number of answers given.
- The sampling method of this enquiry, unlike an audit, means that data cannot be displayed at a hospital/trust/health board/regional level.

The findings will be reviewed three times prior to publication by the SAG, case reviewers and the NCEPOD Steering Group, which includes clinical co-ordinators, trustees, and lay representatives.

5. EVALUATION

This improvement plan will be considered at the start and end of each study to keep it updated with lessons learned through the process.

Progress against improvement goals will be reported to:

- To the programme board at each meeting – every couple of months

- The NCEPOD board of trustees and steering group – quarterly for trustees and spring and autumn for steering group
- To HQIP at contract review meetings – spring and autumn.

An impact assessment linking back to any QI objectives for each report will be undertaken every six-months to review:

- The impact at the point of publication e.g. professional responses
- Report downloads
- Social media activity
- Talks given
- Editorials written
- Report citations
- Local impact and QI undertaken, notified to us by the NCEPOD Local Reporters
- National impact through the report being used by others e.g. NICE/specialist societies
- General and case reviewer feedback
- Learning from the stakeholder workshops.