Necrotising Enterocolitis (NEC): Surgical Questionnaire

A. Introduction

What is this study about?
The aim of this study is to improve the quality of acute care provided to babies born before 32 weeks gestation who develop NEC

Inclusions
Babies born at <32 weeks gestation who develop NEC at <40 weeks of gestation and were discharged/died between 1st January 2024 – 31st December 2025.

Who should complete this questionnaire?
This questionnaire should be completed for all patients assessed for surgery, including those who did not undergo a procedure.

The questionnaire should be completed by the surgeon responsible for the care of this patient at the time of assessment and/or surgery.

Please do not include any patient identifiers in the free text boxes.

If the patient had multiple episodes of NEC, please answer in relation to the patient's first episode.

Definitions
To be updated with link

Questions or help
If you have any queries about this study or this questionnaire, please contact: nec@ncepod.org.uk or telephone 020 7251 9060.

CPD accreditation
Consultants who complete NCEPOD questionnaires make a valuable contribution to the investigation of patient care. Completion of questionnaires also provides an opportunity for consultants to review their clinical management and undertake a period of personal reflection. These activities have a continuing medical and professional development value for individual consultants. Consequently, NCEPOD recommends that consultants who complete NCEPOD questionnaires keep a record of this activity which can be included as evidence of internal/self directed Continuous Professional Development in their appraisal portfolio.

About NCEPOD
The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) reviews healthcare practice by undertaking confidential studies, and makes recommendations to improve the quality of the delivery of care, for healthcare professionals and policymakers to implement. Data to inform the studies are collected from NHS hospitals and Independent sector hospitals across England, Wales, Northern Ireland and the Offshore Islands. NCEPOD are supported by a wide range of bodies and the Steering Group consists of members from the Medical Royal Colleges and Specialist Associations, as well as observers from The Coroners Society of England and Wales, and the Healthcare Quality Improvement Partnership (HQIP).

Impact of NCEPOD
Recommendations from NCEPOD reports have had an impact on many areas of healthcare including:
Development of the NICE ‘Acutely ill patients in hospital guideline’ (CG50) – ‘An Acute Problem’ (2005).
Appointment of a National Clinical Director for Trauma Care – ‘Trauma: Who Cares?’ (2007).
Development of NICE Clinical Guidelines for Acute Kidney Injury, published 2013 – ‘Adding Insult to Injury’ (2009).
Development of ICS Standards for the care of adult patients with a temporary Tracheostomy, published 2014 – ‘On the right trach?’ (2014).
Development of guidelines from the British Society of Gastroenterology: diagnosis and management of acute lower gastrointestinal bleeding, published 2019 – ‘Time to Get Control’ (2015).
Development of the British Thoracic Society’s Quality Standards for NIV, published 2018 – ‘Inspiring Change’ (2017).
Development of NHSE Children and young people's cancer service specification - 'On the Right Course?' (2018)
Update to NICE 'Transition from children’s to adults’ services' Quality Standard (QS140) – 'The Inbetweeners' (2023)

Update to NICE 'Endometriosis: diagnosis and management' guideline (CG73) – 'A long and painful road' (2024)
Development of the GIRFT Children and Young People: Testicular torsion pathway – 'Twist and Shout' (2024)
Development of the GIRFT Paediatric Rheumatology national specialty report - 'Joint Care?' (2025)

This study was commissioned by The Healthcare Quality Improvement Partnership (HQIP) as part of the Clinical Outcome Review Programme into Child Health.

B. Baby's details

1a. What gestation was the baby born at?

Please state in weeks and days

If the baby was born at or after 32 weeks gestation, please return this questionnaire to your Local Reporter (hand your assignment back) who will notify NCEPOD

1b. Gestational age at the time of NEC diagnosis

Please state in weeks and days

If the baby developed NEC at >40 weeks of gestation, please return this questionnaire to your Local Reporter (hand your assignment back) who will notify NCEPOD

2. Sex

- ◯ Male
- ◯ Female
- ◯ Unknown

3. Baby's ethnicity

- ◯ White British/White - other
- ◯ Black/African/Caribbean/Black British
- ◯ Asian/Asian British (Indian, Pakistani, Bangladeshi, Chinese, other Asian)
- ◯ Mixed/Multiple ethnic groups
- ◯ Unknown

If not listed above, please specify here...

C. Clinician details

1. Did this baby undergo a surgical assessment for NEC?

◯ Yes ◯ No ◯ Unknown

If NO or UNKNOWN, please return this questionnaire to your Local Reporter (hand your assignment back) who will notify NCEPOD

2a. Did the baby undergo surgery for NEC?

◯ Yes ◯ No ◯ Unknown

2b. If answered "Yes" to [2a] then:
If YES, what procedure was undertaken?

☐ Laparotomy ☐ Peritoneal drain insertion ☐ Unknown

Please specify any additional options here...

If LAPAROTOMY ONLY, please complete the questionnaire BASED ON THIS PROCEDURE

If PERITONEAL DRAIN INSERTION ONLY, please complete the questionnaire BASED ON THIS PROCEDURE

If LAPAROTOMY & PERITONEAL DRAIN INSERTION, please complete the questionnaire BASED ON THE LAPAROTOMY PROCEDURE

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3. Grade of clinician completing the questionnaire

◯ Consultant
◯ Specialty and associate specialist (SAS)
◯ Resident with CCT
◯ ST3+ resident doctor (or equivalent)

If not listed above, please specify here...

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4. Specialty of clinician completing the questionnaire

◯ Paediatric surgeon ◯ Paediatric urologist ◯ Neonatologist

If not listed above, please specify here...

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5. Please use the box below to provide a brief summary of this case, adding any additional comments or information you feel relevant. You should be assured that this information is confidential. NCEPOD attaches great importance to this summary. Please give as much information as possible about the care of this baby.

D. Unit details

1a. Date of admission to this unit

☐ Unknown

1b. Time of admission to this unit

☐ Unknown

2. What type of neonatal unit was this baby admitted to?
Please see definitions

- ○ A Neonatal Intensive Care unit (NICU)
- ○ A Paediatric Intensive Care unit (PICU)
- ○ Unknown

If not listed above, please specify here...

E. Transfers

1. Was the baby transferred from another hospital to this unit?

◯ Yes ◯ No ◯ Unknown

If YES

2a. If answered "Yes" to [1] then:
Was the baby transferred from a hospital where surgery couldn't be undertaken?

◯ Yes ◯ No ◯ Unknown

2b. If answered "Yes" to [1] and "Yes" to [2a] then:
If YES, why was the baby transferred for this episode of NEC? (Please tick all that apply)

- ☐ Increase in level of care required/need for surgery
- ☐ No surgeon competent to undertake the required procedure at the referring site
- ☐ No anaesthetist competent to anaesthetise the baby at the referring site
- ☐ Capacity issues
- ☐ No paediatric surgical services at the referring site
- ☐ Unknown

Please specify any additional options here...

3a. If answered "Yes" to [1] then:
Was there a documented discussion with the parent/carer regarding the reasons for transfer upon arrival?

◯ Yes ◯ No ◯ Unknown

3b. If answered "Yes" to [1] and "Yes" to [3a] then:
If YES, please provide further information

4a. If answered "Yes" to [1] then:
Was the transfer

◯ Within network ◯ Outside of network ◯ Unknown

4b. If answered "Yes" to [1] and "Outside of network" to [4a] then:
If outside of network, why was this? (Please tick all that apply)

- ☐ No capacity
- ☐ Parental request
- ☐ Need for subspecialty input
- ☐ Unknown

Please specify any additional options here...

4c. If answered "Yes" to [1] and "Outside of network" to [4a] then:
If out of network, did the transfer follow an established referral pathway?

◯ Yes ◯ No ◯ Unknown

F. Diagnosis

1a. What clinical features of NEC were present? (Please tick all that apply)

- ☐ Bilious gastric aspirate or emesis
- ☐ Occult or gross blood in stool
- ☐ Unknown
- ☐ Abdominal distension
- ☐ No clinical features present

1b. What radiographical features of NEC were present?

- ☐ Pneumatosis
- ☐ Pneumoperitoneum
- ☐ Unknown
- ☐ Hepato-biliary gas
- ☐ No radiographical features present

2a. In your opinion, were there any delays in the diagnosis of NEC?

- ◯ Yes
- ◯ No
- ◯ Unknown

2b. If answered "Yes" to [2a] then:
Please give further details

G. Surgical review

1a. Date of first surgical review (ST3 or above)

☐ Unknown

1b. Time of first surgical review (ST3 or above)

☐ Unknown

2a. Was the baby reviewed by a consultant surgeon?
This may the same clinician who undertook the first surgical review (ST3+)

◯ Yes ◯ No ◯ Unknown

2b. If answered "Yes" to [2a] then:
If YES, date of first consultant surgical review

☐ Unknown

2c. If answered "Yes" to [2a] then:
If YES, time of first consultant surgical review

☐ Unknown

2d. If answered "No" to [2a] then:
If NO, was there a discussion with a consultant surgeon?

◯ Yes ◯ No ◯ Unknown

3a. Was a decision made to operate?

◯ Yes - following the first surgical review ◯ Yes - following a subsequent surgical review
◯ No - a decision was made not to operate ◯ Unknown

3b. If answered "Yes - following a subsequent surgical review" to [1] then:
If the decision to operate was made following a subsequent surgical review, what was the reason for the initial decision not to operate?

◯ Surgery not required at this time ◯ Baby too sick for surgery
◯ Unknown

If not listed above, please specify here...

3c. If answered "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
Date of decision to operate

☐ Unknown

3d. If answered "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
Time of decision to operate

☐ Unknown

H. Pre-operative care

To be completed for all patients where a decision was made to undertake surgery for NEC
This question is repeated at the start of sections I and J. It is acting as a filter to bring up the relevant questions in each section based on whether a decision was made to operate or not. If you change the answer to this question at any point, your answers in the other section will be lost and you will need to go back and recomplete them before the questionnaire can be submitted.

1. Was a decision made to operate?

- ◯ Yes - following the first surgical review
- ◯ Yes - following a subsequent surgical review
- ◯ No - a decision was made not to operate
- ◯ Unknown

If the decision was made not to operate, please move to section K

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2. If answered "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
Did waiting for crossmatched blood cause a delay in getting to theatre?

- ◯ Yes
- ◯ No
- ◯ Unknown

3a. If answered "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
Was there an multiprofessional discussion about this baby prior to surgery?

- ◯ Yes
- ◯ No
- ◯ Unknown

3b. If answered "Yes" to [3a] and "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
If YES, who was involved in that discussion? (Please tick all that apply)

- ☐ Neonatologist
- ☐ Paediatrician
- ☐ Paediatric surgeon
- ☐ Paediatric urologist
- ☐ Anaesthetist with regular paediatric sessions
- ☐ Neonatal nurse
- ☐ Dietitian
- ☐ Pharmacist
- ☐ Palliative care team representative
- ☐ Unknown

Please specify any additional options here...

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4. If answered "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
Was there a documented discussion with the parent/carer about the prognosis prior to surgery?

- ◯ Yes
- ◯ No
- ◯ Unknown

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5. If answered "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
Was there documented discussion with the parent/carer about the risks prior to surgery?

- ◯ Yes
- ◯ No
- ◯ Unknown

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6. If answered "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
Was a consent form completed? (Please tick all that apply)

- ☐ Yes - by the surgical team
- ☐ Yes - by the anaesthetic team
- ☐ Yes - by the parent/carer
- ☐ No
- ☐ Unknown

I. Surgery

To be completed for all patients where a decision was made to undertake surgery for NEC
This question is repeated at the start of sections I and J. It is acting as a filter to bring up the relevant questions in each section based on whether a decision was made to operate or not. If you change the answer to this question at any point, your answers in the other section will be lost and you will need to go back and recomplete them before the questionnaire can be submitted.

1. Was a decision made to operate?

- ◯ Yes - following the first surgical review
- ◯ Yes - following a subsequent surgical review
- ◯ No - a decision was made not to operate
- ◯ Unknown

If the decision was made not to operate, please move to section K

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2. If answered "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
Was surgery for NEC undertaken?

- ◯ Yes
- ◯ No
- ◯ Unknown

If no surgery was undertaken

3a. If answered "No" to [2] and "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
If NO, why not?

- ◯ Baby died prior to surgery
- ◯ Baby's condition improved
- ◯ Unknown

If not listed above, please specify here...

3b. If answered "No" to [2] and "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
If NO, please give further information

If surgery was undertaken

4a. If answered "Yes" to [2] and "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
Date of surgery

☐ Unknown

4b. If answered "Yes" to [2] and "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
Time of surgery

☐ Unknown

5a. If answered "Yes" to [2] and "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
Grade of most senior clinician undertaking the operation:

- ◯ Consultant
- ◯ Specialty and associate specialist grade (SAS)
- ◯ Senior Clinical Fellow
- ◯ Resident doctor/specialist trainee (ST6-8 or equivalent)
- ◯ Resident doctor/specialist trainee (ST3-5 or equivalent)
- ◯ Unknown

5b. If answered "Yes" to [2] and "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
Principal specialty of most senior clinician undertaking the operation:

- ◯ Paediatric surgeon
- ◯ Paediatric urologist
- ◯ Neonatologist
- ◯ Unknown

If not listed above, please specify here...

6a. If answered "Yes" to [2] and "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
Where was the surgery undertaken?

- ◯ Paediatric theatre
- ◯ Other theatre
- ◯ Neonatal intensive care unit
- ◯ Paediatric intensive care unit
- ◯ Unknown

If not listed above, please specify here...

6b. If answered "Yes" to [2] and "Neonatal intensive care unit" or "Paediatric intensive care unit" to [6a] and "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
If in NICU or PICU, was it undertaken in a dedicated area for the surgery?

- ◯ Yes
- ◯ No
- ◯ Unknown

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7. If answered "Yes" to [2] and "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
What operation did the baby undergo?

- ◯ Diagnostic laparotomy/washout only
- ◯ Resection and primary anastomosis
- ◯ Resection and stoma formation
- ◯ Stoma formation, no resection
- ◯ End stoma and Hartmann's pouch
- ◯ Clip and drop
- ◯ Intra-abdominal drain insertion only
- ◯ Open and close palliative
- ◯ Unknown

If not listed above, please specify here...

8a. If answered "Yes" to [2] and "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
Category of urgency
Please see definitions

- ◯ Immediate (Immediate life, limb or organ-saving intervention – resuscitation simultaneous with interve
- ◯ Urgent (Intervention for acute onset or clinical deterioration of potentially life-threatening conditions, f
- ◯ Expedited (Patient requiring early treatment where the condition is not an immediate threat to life, lim
- ◯ Unknown

If not listed above, please specify here...

8b. If answered "Yes" to [2] and "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
In your opinion, was surgery undertaken under the correct category of urgency?

◯ Yes ◯ No ◯ Unknown

8c. If answered "Yes" to [2] and "No" to [8b] and "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
If NO, what should have been the category of urgency?
Please see definitions

◯ Immediate (Immediate life, limb or organ-saving intervention – resuscitation simultaneous with interve
◯ Urgent (Intervention for acute onset or clinical deterioration of potentially life-threatening conditions, f
◯ Expedited (Patient requiring early treatment where the condition is not an immediate threat to life, lim
◯ Unknown

If not listed above, please specify here...

9. If answered "Yes" to [2] and "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
What were the findings at operation? (Please tick all that apply)

☐ Pneumatosis in a single area of small bowel
☐ Pneumatosis in multiple areas of small bowel
☐ Pneumatosis in >50% of the small bowel
☐ Pneumatosis in a single area of large bowel
☐ Pneumatosis in multiple areas of large bowel
☐ Pneumatosis in >50% of the large bowel
☐ Ischaemia in a single area of small bowel
☐ Ischaemia in multiple areas of small bowel
☐ Ischaemia in >50% of the small bowel
☐ Ischaemia in a single area of large bowel
☐ Ischaemia in multiple areas of large bowel
☐ Ischaemia in >50% of the large bowel
☐ Single perforation without gross faecal contamination
☐ Single perforation with gross faecal contamination
☐ Multiple perforations without gross faecal contamination
☐ Multiple perforations with gross faecal contamination
☐ Unknown

10a. If answered "Yes" to [2] and "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
Was there a delay in undertaking the procedure?

◯ Yes ◯ No ◯ Unknown

10b. If answered "Yes" to [2] and "Yes" to [10a] and "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
If YES, please give further details

11a. If answered "Yes" to [2] and "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
Did the baby require further surgery related to NEC?

◯ Yes ◯ No ◯ Unknown

11b. If answered "Yes" to [2] and "Yes" to [11a] and "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
If YES, was this:

◯ A planned procedure ◯ An unplanned procedure ◯ Unknown

11c. If answered "Yes" to [2] and "Yes" to [11a] and "Yes - following the first surgical review" or "Yes - following a subsequent surgical review" to [1] then:
If YES, please give further details regarding further surgery

J. Outcome

1a. What was the outcome of this admission

- ◯ Baby discharged/transferred alive from this hospital
- ◯ Baby died in this hospital
- ◯ Unknown

1b. If answered "Baby discharged/transferred alive from this hospital" to [1a] then: If discharged/transferred alive where was the baby discharged/transferred to?

- ◯ Another hospital for ongoing medical care (stepped-down in care)
- ◯ Another hospital due to capacity issues
- ◯ Home
- ◯ Unknown

If not listed above, please specify here...

K. Overall

1a. In your opinion, could the care during this baby's episode of NEC have been improved in any way?

◯ Yes ◯ No ◯ Unknown

1b. If answered "Yes" to [1a] then:
Please give further details

2a. In your opinion, were there any potential barriers to delivering care in this case (including delays in delivering care)?

◯ Yes ◯ No ◯ Unknown

2b. If answered "Yes" to [2a] then:
Please give further details

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE

By doing so you have contributed to the dataset that will form the report and recommendations due for release in late 2027