Necrotising Enterocolitis (NEC): Neonatology 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 focuses on the care provided during the 48-hour period preceding the first documented suspicion of NEC, and during the 24-hour period following the first documented suspicion of NEC, or until transfer out of this hospital if this occurs within the 24-hour period.

The questionnaire should be completed by the neonatologist responsible for the patient during this period.

If care was not provided to this patient in this unit during this period, please return this questionnaire to your Local Reporter (hand your assignment back) who will notify NCEPOD.

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

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

Definitions
To be update 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

1. 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

2. Gestational age at the time of the first documentation of suspected NEC
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

3. Sex

- ◯ Male
- ◯ Female
- ◯ Unknown

4. 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...

5. Did the mother receive any antenatal steroids?

- ◯ Yes
- ◯ No
- ◯ Unknown

6a. Did the baby have any congenital anomalies at birth?

- ◯ Yes
- ◯ No
- ◯ Unknown

6b. If answered "Yes" to [6a] then:
If YES, what were these? (Please tick all that apply)

- ☐ Cardiac
- ☐ Gastrointestinal
- ☐ Respiratory
- ☐ Neurological
- ☐ Metabolic

Please specify any additional options here...

7a. Prior to the diagnosis of NEC, had the baby undergone any surgery?

- ◯ Yes
- ◯ No
- ◯ Unknown

7b. If answered "Yes" to [7a] then:
If YES, what surgery had been undertaken?

C. Clinician details

1. Grade of clinician completing the questionnaire

- ◯ Consultant
- ◯ Resident with CCT
- ◯ ST1 or ST2 resident doctor (or CT equivalent)
- ◯ Neonatal nurse – Qualified in Specialty
- ◯ Specialty and associate specialist (SAS)
- ◯ ST3+ resident doctor (or equivalent)
- ◯ Advanced clinical practitioner
- ◯ Neonatal nurse – not Qualified in Specialty

If not listed above, please specify here...

2. Specialty of clinician completing the questionnaire

- ◯ Neonatologist
- ◯ Paediatric surgeon
- ◯ Paediatrician
- ◯ Paediatric critical care medicine

If not listed above, please specify here...

3. 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. Hospital details

1. Which units are available at this hospital? (Please tick all that apply)
Please see definitions

- ☐ Special Care Unit (SCU)
- ☐ Neonatal Intensive Care unit (NICU)
- ☐ None of the above
- ☐ Local Neonatal Unit (LNU)
- ☐ Paediatric Intensive Care unit (PICU)
- ☐ Unknown

2. Is there access to paediatric surgery on-site?

- ◯ Yes
- ◯ No
- ◯ Unknown

3. Is surgery for NEC undertaken on babies in this hospital?

- ◯ Yes
- ◯ No
- ◯ Unknown

E. Transfers (for babies transferred into this neonatal unit from another hospital)

1. Was the baby transferred from another hospital to this unit during the 48-hour period preceding the first documented suspicion of NEC? (either within this Trust/Health Board or from another Trust/Health Board)

◯ Yes ◯ No ◯ Unknown

If YES

2. If answered "Yes" to [1] then:
If YES, please give the name of the Trust/Health Board they were transferred from?

3. If answered "Yes" to [1] then:
Why was the baby transferred? (Please tick all that apply)

☐ Increase in level of care required ☐ Surgical assessment required
☐ Capacity issues ☐ Unknown

Please specify any additional options here...

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. Escalation of care

Please answer the questions in this section based on the care provided during the 48-hour period preceding the first documented suspicion of NEC

1a. Date of admission to this unit

☐ Unknown

1b. Time of admission to this unit

☐ Unknown

2a. What type of unit was the baby on 48 hours prior to the first documented suspicion of NEC?

- ◯ Postnatal ward
- ◯ Local Neonatal Unit (LNU)
- ◯ Paediatric Intensive Care unit (PICU)
- ◯ Special Care Unit (SCU)
- ◯ Neonatal Intensive Care unit (NICU)
- ◯ Unknown

If not listed above, please specify here...

2b. What level of care was baby receiving 48 hours prior to the first documented suspicion of NEC?

- ◯ Intensive care
- ◯ High dependency care
- ◯ Special care
- ◯ Standard postnatal care
- ◯ Unknown

If not listed above, please specify here...

3a. Had there been any changes in feed during the 48-hour period preceding the first documented suspicion of NEC? (not including the initiation of parenteral nutrition)

- ◯ Yes
- ◯ No
- ◯ Unknown

3b. If answered "Yes" to [3a] then:
If YES, please give further details

4a. Did the baby require additional support with feeding during the 48-hour period preceding the first documented suspicion of NEC? (e.g. the initiation of parenteral nutrition)

- ◯ Yes
- ◯ No
- ◯ Unknown

4b. If answered "Yes" to [4a] then:
If YES, please give further details

5a. Did the baby require additional support with respiratory function during the 48-hour period preceding the first documented suspicion of NEC?

◯ Yes ◯ No ◯ Unknown

5b. If answered "Yes" to [5a] then:
If YES, please give further details

6a. Did the baby require additional support with cardiovascular function during the 48-hour period preceding the first documented suspicion of NEC?

◯ Yes ◯ No ◯ Unknown

6b. If answered "Yes" to [6a] then:
If YES, please give further details

7a. Were additional medications started?

◯ Yes ◯ No ◯ Unknown

7b. If answered "Yes" to [7a] then:
If YES, please give further details

8a. Did the baby have any blood test results that were outside the normal parameters for their gestational age, during the 48-hour period preceding the first documented suspicion of NEC?

◯ Yes ◯ No ◯ Unknown

8b. If answered "Yes" to [8a] then:
If YES, what did the blood tests show: (please tick all that apply)

☐ Low haemoglobin ☐ High white cell count ☐ High C-reactive protein
☐ High lactate ☐ Low platelets ☐ None of the above
☐ Unknown

Please specify any additional options here...

9a. Did the baby's parent/carer flag any specific concerns or unusual symptoms during the 48-hour period preceding the first documented suspicion of NEC?

◯ Yes ◯ No ◯ Unknown

9b. If answered "Yes" to [9a] then:
If YES, please give further details

10a. Was there a documented discussion with parent/carers about the worsening symptoms during the 48-hour period preceding the first documented suspicion of NEC?

◯ Yes ◯ No ◯ Unknown

10b. If answered "Yes" to [10a] then:
If YES, please give further details

11a. With the benefit of hindsight, were there any delays in the escalation of care in the 48 hours prior to the first documented suspicion of NEC?

◯ Yes ◯ No ◯ Unknown

11b. If answered "Yes" to [11a] then:
If YES, please give further details

G. Diagnosis

1. 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

Please specify any additional options here...

2. What radiographical features of NEC were present? (Please tick all that apply)

- [ ] Pneumatosis
- [ ] Pneumoperitoneum
- [ ] Unknown
- [ ] Hepato-biliary gas
- [ ] No radiographical features present

H. Immediate treatment

Please answer the questions in this section based on the care provided during the 24-hour period following the first documented suspicion of NEC, or until transfer out of this hospital if this occurs within the 24-hour period

1. Which specialties reviewed the baby within 24 hours of the first documented suspicion of NEC? (Please tick all that apply)

- ☐ Neonatologist
- ☐ Paediatrician
- ☐ Paediatric surgeon
- ☐ Paediatric urologist
- ☐ Anaesthetist with regular paediatric sessions
- ☐ Neonatal nurse/Advanced neonatal nurse practitioner
- ☐ Dietitian
- ☐ Pharmacist
- ☐ Palliative care
- ☐ Unknown

Please specify any additional options here...

2a. Was there a multiprofessional discussion about this baby within 24 hours of the first documented suspicion of NEC? ?

◯ Yes ◯ No ◯ Unknown

2b. If answered "Yes" to [2a] then:
If YES, who was involved in that discussion?

- ☐ Neonatologist
- ☐ Paediatrician
- ☐ Paediatric surgeon
- ☐ Anaesthetist with regular paediatric sessions
- ☐ Neonatal nurse/Advanced neonatal nurse practitioner
- ☐ Dietitian/specialist feeding
- ☐ Pharmacist
- ☐ Palliative care
- ☐ Unknown

Please specify any additional options here...

3a. Were the feeds stopped within 24 hours of the first documented suspicion of NEC? ?

- ◯ Yes
- ◯ No
- ◯ Unknown
- ◯ NA - feeds already stopped during the 48-hour period preceding the first documented suspicion of NEC

3b. If answered "Yes" to [3a] then:
If YES, date made nil by mouth

☐ Unknown

3c. If answered "Yes" to [3a] then:
If YES, time made nil by mouth

☐ Unknown

4a. Did the baby receive fluid resuscitation within 24 hours of the first documented suspicion of NEC? ?

- ◯ Yes
- ◯ No
- ◯ Unknown

4b. If answered "Yes" to [4a] then:
If YES, how much?

- ◯ 10mls/kg
- ◯ 20mls/kg
- ◯ 30mls/kg
- ◯ 40mls/kg
- ◯ 50mls/kg
- ◯ >50mls/kg
- ◯ Unknown

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5. Were maintenance fluids started within 24 hours of the first documented suspicion of NEC? ?

- ◯ Yes
- ◯ No
- ◯ Unknown
- ◯ NA - already receiving maintenance fluids

6a. Was there any other escalation in support within 24 hours of the first documented suspicion of NEC? ?

- ◯ Yes
- ◯ No
- ◯ Unknown

6b. If answered "Yes" to [6a] then:
If YES, what support was given? (Please tick all that apply)

- ☐ An increase in respiratory support
- ☐ Additional medications given (not including antibiotics)
- ☐ Antibiotics for NEC commenced or changed
- ☐ Additional line access sited
- ☐ Parenteral nutrition (PN) started
- ☐ Peritoneal drain inserted by a neonatologist (questions regarding referrals for surgical peritoneal drain
- ☐ Unknown

Please specify any additional options here...

I. Surgical assessment

1a. Was the baby referred for surgical assessment for suspected NEC during this admission? (either within this Trust/Health Board or to another Trust/Health Board)

- ◯ Yes
- ◯ No
- ◯ Unknown

1b. If answered "No" to [1a] then:
If NO, why not?

- ◯ Surgery not required
- ◯ Baby too sick for surgery
- ◯ Baby died prior to referral
- ◯ Unknown

If not listed above, please specify here...

1c. If answered "No" to [1a] then:
If NO, please give further information

2. If answered "Yes" to [1a] then:
If YES, was the referral accepted

- ◯ Yes - first referral for surgical assessment accepted
- ◯ Yes - first referral for surgical assessment NOT accepted, but subsequent referral accepted
- ◯ No
- ◯ Unknown

3. If answered "Yes" to [1a] and "Yes - first referral for surgical assessment NOT accepted, but subsequent referral accepted" to [2] then:
If first referral for surgical assessment not accepted, why not?

- ◯ Surgery not required at this time
- ◯ Baby too sick for surgery
- ◯ Baby died prior to acceptance
- ◯ Unknown

If not listed above, please specify here...

4a. If answered "Yes" to [1a] and "No" to [2] then:
If NO, why not:

- ◯ Surgery not required
- ◯ Baby too sick for surgery
- ◯ Baby died prior to acceptance
- ◯ Unknown

If not listed above, please specify here...

4b. If answered "Yes" to [1a] and "No" to [2] then:
If NO, please give further information

5a. If answered "Yes" to [1a] and "Yes - first referral for surgical assessment accepted" or "Yes - first referral for surgical assessment NOT accepted, but subsequent referral accepted" to [2] then:
Where was baby referred to?

- ◯ A surgical unit/team in this hospital
- ◯ A surgical unit/team in another hospital
- ◯ Unknown

5b. If answered "Yes" to [1a] and "Yes - first referral for surgical assessment accepted" or "Yes - first referral for surgical assessment NOT accepted, but subsequent referral accepted" to [2] and "A surgical unit/team in another hospital" to [5a] then:
If A SURGICAL UNIT/TEAM IN ANOTHER HOSPITAL, please give the name of the trust/health board they were referred to?
Please do not give any clinician names

5c. If answered "Yes" to [1a] and "Yes - first referral for surgical assessment accepted" or "Yes - first referral for surgical assessment NOT accepted, but subsequent referral accepted" to [2] then:
Following referral, was the baby transferred for surgery?
Either to the surgical unit in this hospital or to a surgical unit in another hospital

- ◯ Yes
- ◯ No
- ◯ Unknown

5d. If answered "Yes" to [1a] and "Yes - first referral for surgical assessment accepted" or "Yes - first referral for surgical assessment NOT accepted, but subsequent referral accepted" to [2] and "No" to [5c] then:
If NO, why not?

- ◯ Baby died prior to transfer
- ◯ Unknown

If not listed above, please specify here...

J. Ongoing care

1. If not already inserted within 24 hours of the first documented suspicion of NEC, did a neonatologist insert a peritoneal drain whilst the baby was in this unit?

- ◯ Yes
- ◯ No - required but not inserted
- ◯ No - not required, baby needed surgery
- ◯ No - not required, baby managed conservatively
- ◯ Unknown
- ◯ Not applicable - already inserted within 24 hours of the first documented suspicion of NEC

2. Is there documentation of discussion with parent/carer throughout the episode of NEC?

◯ Yes ◯ No ◯ Unknown

3a. Was ongoing advice provided from other units?

◯ Yes ◯ No ◯ Unknown

3b. If answered "Yes" to [3a] then:
If YES, from who? (Please tick all that apply)

- ☐ Neonatal colleagues in other units
- ☐ Surgical input from other units
- ☐ Transport team
- ☐ Nutritional advice
- ☐ Pharmaceutical advice
- ☐ Unknown

Please specify any additional options here...

4a. Following this episode of NEC, did the baby have any subsequent diagnoses of NEC?

◯ Yes ◯ No ◯ Unknown

4b. If answered "Yes" to [4a] then:
If YES, how many?

☐ Unknown

4c. If answered "Yes" to [4a] then:
Please give any further information

K. Outcome

1. What was the outcome of this admission?

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

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

- ◯ Another hospital for surgical assessment
- ◯ Another hospital for increased medical care
- ◯ Another hospital due to capacity issues
- ◯ Another hospital for repatriation/step-down care
- ◯ Home
- ◯ Unknown

If not listed above, please specify here...

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3. If answered "Baby discharged/transferred alive from this hospital" to [1] and "Another hospital for surgical assessment", "Another hospital for increased medical care", "Another hospital due to capacity issues" or "Another hospital for repatriation/step-down care" to [2] then:
Was there a conversation with the parent/carer regarding the reasons for transfer?

- ◯ Yes
- ◯ No
- ◯ Unknown

4a. If answered "Baby discharged/transferred alive from this hospital" to [1] and "Another hospital for surgical assessment", "Another hospital for increased medical care", "Another hospital due to capacity issues" or "Another hospital for repatriation/step-down care" to [2] then:
Was the transfer

- ◯ Within network
- ◯ Outside of network
- ◯ Unknown

4b. If answered "Baby discharged/transferred alive from this hospital" to [1] and "Another hospital for surgical assessment", "Another hospital for increased medical care", "Another hospital due to capacity issues" or "Another hospital for repatriation/step-down care" to [2] 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...

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5. If answered "Baby discharged/transferred alive from this hospital" to [1] and "Another hospital for surgical assessment", "Another hospital for increased medical care", "Another hospital due to capacity issues" or "Another hospital for repatriation/step-down care" to [2] then:
How many units had to be contacted to find a cot?

☐ Unknown

L. 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 any 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