

British Association of Paediatric Surgeons Congenital Anomalies Surveillance System (BAPS-CASS)

Necrotising Enterocolitis

Data Collection Form

Infants diagnosed on or after 1st March 2013 and before 1st April 2014

Include:

- i. All infants with suspected NEC where a decision for surgery was made, irrespective of whether surgery was performed.
- ii. All infants subsequently found to have SIP.

Exclude:

All infants where the final diagnosis is **NOT** NEC or SIP, eg volvulus

Case Definition:

1. **Necrotising Enterocolitis (NEC):** NEC is defined using the following criteria diagnosed at surgery, at postmortem examination or clinically and radiographically:

At least **one** of the following clinical signs present:

- Billious gastric aspirate or emesis
- Abdominal distension
- Occult or gross blood in stool (no fissure)

AND

At least **one** of the following radiographic findings present:

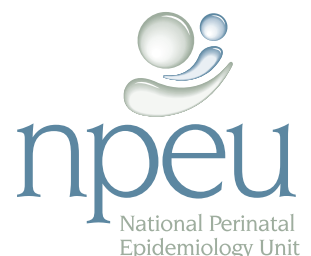
- Pneumatosis intestinalis
- Hepato-biliary gas
- Pneumoperitoneum

OR

2. **Spontaneous Intestinal Perforation (SIP) :** Infants who satisfy the definition of Necrotizing Enterocolitis above but are found to have a single perforation at surgery or post-mortem

Please return the completed form to:

BAPS-CASS
National Perinatal Epidemiology Unit
University of Oxford
Old Road Campus
Oxford
OX3 7LF
Fax: 01865 617775
Phone: 01865 289714



Case reported in: _____

Instructions

1. Please do not enter any personally identifiable information (e.g. name, address or hospital number) on this form.
2. Please record the ID number from the front of this form against the infant's name on the Clinician's Section of the blue card retained in the BAPS folder.
3. Fill in the form using the information available in the infant's case notes.
4. If codes or examples are required, some lists (not exhaustive) are included on the back page of the form.
5. Tick the boxes as appropriate. If you require any additional space to answer a question please use the space provided in section 8.
6. Please complete all dates in the format DD/MM/YY, and all times using the 24hr clock e.g. 18:37
- 7. If you do not know the answers to some questions, please indicate this in section 8.**
8. If you encounter any problems with completing the form please contact the Study Administrator or use the space in section 8 to describe the problem.

Section 1: Antenatal / Birth Data

- 1.1 What was the mother's year of birth?**
- 1.2 Please give the first alphabetical part of mother's postcode**
(e.g. OX for Oxfordshire, EH for Edinburgh, L for Liverpool)
- 1.3 Ethnic group^{1*}**
- 1.4 Gestational age at birth (completed weeks)**
- 1.5 Gender** male female indeterminate
- 1.6 Birthweight** g
- 1.7 Was this infant from a multiple birth?** Yes No
If Yes, specify number of fetuses?
- 1.8 Was the infant delivered by caesarean section?** Yes No

Section 2: Risk Factors

Maternal Risk Factors:

- 2.1 Were any of the following MATERNAL risk factors present during THIS pregnancy?**

Abruption	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Not known	<input type="checkbox"/>
Polyhydramnios	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Not known	<input type="checkbox"/>
Oligohydramnios	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Not known	<input type="checkbox"/>
Pre-eclampsia	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Not known	<input type="checkbox"/>
Chorioamnionitis	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Not known	<input type="checkbox"/>
Maternal HIV	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Not known	<input type="checkbox"/>
Hepatitis B	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Not known	<input type="checkbox"/>
Maternal use of indomethacin	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Not known	<input type="checkbox"/>
Maternal diabetes	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Not known	<input type="checkbox"/>
Thromboembolic event	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Not known	<input type="checkbox"/>

- 2.2 Were antenatal steroids given?** Yes No Not known
- 2.3 Was there premature rupture of membranes?** Yes No Not known
 If Yes, did this occur more than 48 hours before delivery? Yes No
- 2.4 Was an antenatal doppler study performed?** Yes No Not known
 If Yes, what were the findings? (*tick one only*)
- Reversed end-diastolic flow
- Absent end-diastolic flow
- Normal

Neonatal Risk Factors:

- 2.5 Were any of the following NEONATAL risk factors present?**
- Apgars <5 @10minutes Yes No Not known
- Respiratory distress syndrome Yes No Not known
- Indomethocin for closure of PDA Yes No Not known
- Intraventricular haemorrhage (grade III or above) Yes No Not known
- Umbilical catheter ever used Yes No Not known

Section 3: Initial presentation and investigations for NEC

- 3.1 Age at first presentation to your hospital with NEC** days
- 3.2 What was the date and time NEC was first suspected?** / /
- 3.3 Was the infant transferred from another hospital?** Yes No
 If Yes, please specify hospital where the infant was born _____
- 3.4 Was the infant discharged home after birth and before diagnosis?** Yes No
- 3.5 Did the infant have a PDA?** Yes No
 If Yes, Was PDA ligation performed? Yes No
- 3.6 Did the infant have any other cardiac surgery?** Yes No
- 3.7 Did the infant have any other congenital anomalies?** Yes No
 If Yes, please specify _____
- 3.8 What features were apparent at presentation and at the time of decision for surgery? (*tick all that apply*)**

	At presentation	At the time of decision for surgery
Bilious gastric aspirate or emesis	<input type="checkbox"/>	<input type="checkbox"/>
Blood stained aspirates	<input type="checkbox"/>	<input type="checkbox"/>
Abdominal distension	<input type="checkbox"/>	<input type="checkbox"/>
Occult or gross blood in stool (no fissure)	<input type="checkbox"/>	<input type="checkbox"/>
Abdominal wall erythema	<input type="checkbox"/>	<input type="checkbox"/>

	At presentation	At the time of decision for surgery
Abdominal wall discolouration	<input type="checkbox"/>	<input type="checkbox"/>
Other feature	<input type="checkbox"/>	<input type="checkbox"/>

If Other, please specify feature noted: _____

3.9 Were any of these managements being used at presentation (before diagnosis of NEC) and at the time of decision for surgery? (tick all that apply)

	At presentation	At the time of decision for surgery
Infant on inotropes	<input type="checkbox"/>	<input type="checkbox"/>
Infant ventilated	<input type="checkbox"/>	<input type="checkbox"/>
Infant on antacids	<input type="checkbox"/>	<input type="checkbox"/>
Infant on antibiotics	<input type="checkbox"/>	<input type="checkbox"/>

3.10 Was an X-ray performed? Yes No

If Yes, what features were noted? (tick all that apply)

- Pneumatosis intestinalis
- Hepato-biliary gas
- Pneumoperitoneum
- Ascites
- Gasless abdomen
- Distended bowel loops
- Other

If Other, please specify _____

Section 4: Initial Management

4.1 Was the infant on enteral feeds at the time NEC was first suspected? Yes No

If Yes, what date were they started? / /

What types of enteral feeds were being given? (tick all that apply)

- Mother's milk
- Bank human milk
- Hydrolyzed preterm formula
- Standard formula

4.2 Had enteral feeds been stopped before NEC was first suspected? Yes No

If Yes, what date were they stopped? / /

4.3 Was the infant receiving TPN at the time NEC was first suspected? Yes No

If Yes, what date was TPN started? / /

If No, was TPN started after NEC was first suspected? Yes No

If Yes, what date was TPN started? / /

4.4 Did the infant have a blood transfusion

Yes No

If Yes, gives dates of all transfusions received within the 2 weeks before NEC was first suspected.

Transfusion 1 / /

Transfusion 2 / /

Transfusion 3 / /

(If more than 3 transfusions in the 2 weeks before diagnosis, please continue in section 8.4)

Section 5: Surgery

5.1 What date and time was the decision to operate (insertion of drain and/or laparotomy) made?

/ / : 24hr

5.2 What was the indication for surgery? (tick all that apply)

- Failed medical treatment
- Perforation
- Fixed loop
- Mass
- Stricture
- Suspected necrotic bowel
- Other

If Other, please specify _____

5.3 Was a drain inserted before surgery?

Yes No

If Yes, what was the date and time of insertion?

/ / : 24hr

5.4 Was a laparotomy performed?

Yes No

If No, Why was a laparotomy not performed?

Infant too ill Infant recovered

If no laparotomy performed, please go to Section 6

5.5 What was the date and time of laparotomy?

/ / : 24hr

5.6 What surgical procedure was performed? (tick one only)

- Resection and primary anastomosis
- Resection and stoma formation
- Clip and drop
- Open and close (NEC totalis)
- Negative laparotomy

5.7 Was the ileocecal valve resected during the procedure?

Yes No

5.8 Following surgery, what was the remaining length of small bowel from DJ flexure? cm

5.9 Following surgery, what was the total small bowel length remaining? cm

5.10 Was the colon spared during the procedure?

Yes No

If Yes, which parts were spared (tick all that apply)

- Ascending
- Transverse
- Descending
- Sigmoid
- Rectum

5.11 Was there an intra-operative liver bleed?

Yes No

5.12 Was the abdomen left open after the first laparotomy?

Yes No

5.13 Was this SIP (spontaneous intestinal perforation)?

Yes No

Section 6: Early Morbidity (28 days post initial surgery)

6.1 Did the infant develop any complications of the surgery within the first 28 days?

Yes No

If Yes, please tick all that apply

Wound sepsis

Intra-abdominal collection

Stoma related complications

Other

If Other, please specify _____

6.2 Were any further surgical procedures required in the first 28 days post surgery?

Yes No

If Yes, please specify

Date of surgery	Details of further surgical procedure
<input type="text" value="D"/> <input type="text" value="D"/> / <input type="text" value="M"/> <input type="text" value="M"/> / <input type="text" value="Y"/> <input type="text" value="Y"/>	
<input type="text" value="D"/> <input type="text" value="D"/> <input type="text" value="M"/> <input type="text" value="M"/> <input type="text" value="Y"/> <input type="text" value="Y"/>	
<input type="text" value="D"/> <input type="text" value="D"/> <input type="text" value="M"/> <input type="text" value="M"/> <input type="text" value="Y"/> <input type="text" value="Y"/>	

6.3 Did the infant have any other morbidity?

Yes No

If Yes, please give details _____

Section 7: Feeding during the 28 days after surgery

7.1 Was the infant on TPN at 28 days?

Yes No

If No, please give date TPN stopped

 / /

7.2 Were enteral feeds started in the first 28 days?

Yes No

If Yes, please give date started

 / /

What types of enteral feeds were being given (tick all that apply)

Mother's milk

Bank human milk

Hydrolyzed preterm formula

Standard formula

Section 8: Outcomes/Other information

8.1 Has the infant been discharged home?

Yes No

If Yes, specify date of discharge

/ /

8.2 Has the infant been discharged to another hospital?

Yes No

If Yes, please give name of hospital _____

Name of responsible consultant _____

Date of transfer

/ /

8.3 Did this infant die?

Yes No

If Yes, please give date of death

/ /

Cause of death as stated on the death certificate *(please state if not known)*

Was a post-mortem performed?

Yes No

If Yes, was the diagnosis of NEC confirmed?

Yes No

8.4 Please add other relevant information below

Section 9:

Name of person completing the form _____

Designation _____

Today's date

/ /

You may find it useful in the case of queries to keep a copy of this form.

Definitions

1. UK Census Coding for ethnic group

WHITE

01. British
02. Irish
03. Any other white background

MIXED

04. White and black Caribbean
05. White and black African
06. White and Asian
07. Any other mixed background

ASIAN OR ASIAN BRITISH

08. Indian
09. Pakistani
10. Bangladeshi
11. Any other Asian background

BLACK OR BLACK BRITISH

12. Caribbean
13. African
14. Any other black background

CHINESE OR OTHER ETHNIC GROUP

15. Chinese
16. Any other ethnic group