

# 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 March 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

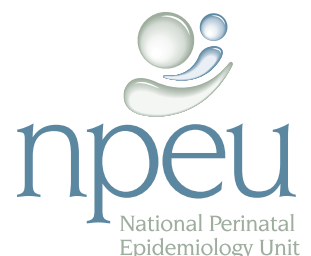
2. **Spontaneous Intestinal Perforation (SIP) :** Infants who satisfy the definition of Necrotising Enterocolitis above but are found to have a single perforation at surgery or post-mortem

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<sup>1\*</sup>**
- 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"/> |



	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 suspected NEC) and at the time of decision for surgery?**

	At presentation	At the time of decision for surgery
Infant on inotropes	Yes <input type="checkbox"/> No <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/>
Infant ventilated	Yes <input type="checkbox"/> No <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/>
Infant on antacids	Yes <input type="checkbox"/> No <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/>
Infant on antibiotics	Yes <input type="checkbox"/> No <input type="checkbox"/>	Yes <input type="checkbox"/> No <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 within the 2 weeks before NEC was first suspected?**

Yes  No

If Yes, give dates of all transfusions received

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

Stoma formation

with resection  without resection

Clip and drop

with resection  without resection

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 to the stoma?**

cm

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

cm

**5.10 Was any part of 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/treatment)

6.1 Did the infant develop any complications of the surgery/drain insertion 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/drain insertion?

Yes  No

If Yes, please specify

Date of surgery	Details of further surgical procedure
<input type="text" value="DD"/> / <input type="text" value="MM"/> / <input type="text" value="YY"/>	
<input type="text" value="DD"/> / <input type="text" value="MM"/> / <input type="text" value="YY"/>	
<input type="text" value="DD"/> / <input type="text" value="MM"/> / <input type="text" value="YY"/>	

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/treatment

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



## 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