# 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:

- Bilious 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?	YYYY	
1.2	Please give the first alphabetical part of mother's post (e.g. OX for Oxfordshire, EH for Edinburgh, L for Liverpoo		
1.3	Ethnic group¹*		
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?  If Yes, specify number of fetuses?	Yes No	
1.8	Was the infant delivered by caesarean section?	Yes No	
Section 2: Risk Factors			
Mat	ternal Risk Factors:		
2.1	Were any of the following MATERNAL risk factors pre	esent during THIS pregnancy?	
	Abruption	Yes No Not known	
	Polyhydramnios	Yes No Not known	
	Oligohydramnios	Yes No Not known	
	Pre-eclampsia	Yes No Not known	
	Chorioamnionitis	Yes No Not known	
	Maternal HIV	Yes No Not known	
	Hepatitis B	Yes No Not known	
	Maternal use of indomethacin	Yes No Not known	
	Maternal diabetes	Yes No Not known	

2.2	Were antenatal steroids given?		Yes	No Not known	
2.3	Was there premature rupture of m		Yes	No Not known Yes No	
2.4	Was an antenatal doppler study p  If Yes, what were the findings? (	performed?	Yes	No Not known	
	Reversed end-diastolic flow  Absent end-diastolic flow  Normal				
Nec	onatal Risk Factors:				
2.5	Were any of the following NEONA	ATAL risk factors prese	nt?		
	Apgars <5 @10minutes	•	Yes	No Not known	
	Respiratory distress syndrome		Yes	No Not known	
	Indomethocin/Ibuprofen for closu	ure of PDA	Yes	No Not known	
	Intraventricular haemorrhage (gr	rade III or above)	Yes	No Not known	
	Umbilical catheter ever used		Yes	No Not known	
Sec. 3.1	Section 3: Initial presentation and investigations for NEC				
J. 1					
3.2	What was the date and time NFC	was first suspected?		IIVII/I Y I Y I I N I N I - I M I M I	
3.2 3.3	What was the date and time NEC Was the infant transferred from a If Yes, please specify hospital w	nother hospital?	D D / M	Yes No	
	Was the infant transferred from a	nother hospital? here the infant was born	diagnosis of	Yes No Yes No	
3.3	Was the infant transferred from a lf Yes, please specify hospital will Was the infant discharged home	nnother hospital? here the infant was born after birth and before o	diagnosis of		
3.3	Was the infant transferred from a lf Yes, please specify hospital will Was the infant discharged home suspected NEC?  Did the infant have a PDA?	nnother hospital? here the infant was born after birth and before o	diagnosis of	Yes No Yes No	
3.4 3.5	Was the infant transferred from a lf Yes, please specify hospital wide Was the infant discharged home suspected NEC?  Did the infant have a PDA?  If Yes, Was PDA ligation perform	nother hospital? here the infant was born after birth and before of ned? diac surgery?	diagnosis of	Yes No Yes No Yes No No	
3.3 3.4 3.5 3.6	Was the infant transferred from a lf Yes, please specify hospital will Was the infant discharged home suspected NEC?  Did the infant have a PDA?  If Yes, Was PDA ligation perform Did the infant have any other care Did the infant have any other core.	nother hospital? here the infant was born after birth and before of ned? diac surgery? ngenital anomalies?		Yes No	
3.3 3.4 3.5 3.6 3.7	Was the infant transferred from a lf Yes, please specify hospital will Was the infant discharged home suspected NEC?  Did the infant have a PDA?  If Yes, Was PDA ligation perform Did the infant have any other care Did the infant have any other con lf Yes, please specify  What features were apparent at p	nother hospital? here the infant was born after birth and before of ned? diac surgery? ngenital anomalies?	time of decisio	Yes No	
3.3 3.4 3.5 3.6 3.7	Was the infant transferred from a lf Yes, please specify hospital will Was the infant discharged home suspected NEC?  Did the infant have a PDA?  If Yes, Was PDA ligation perform Did the infant have any other care Did the infant have any other con lf Yes, please specify  What features were apparent at p	here the infant was born after birth and before oned?  diac surgery?  ngenital anomalies?	time of decisio	Yes No Yes	
3.3 3.4 3.5 3.6 3.7	Was the infant transferred from a lf Yes, please specify hospital will Was the infant discharged home suspected NEC?  Did the infant have a PDA?  If Yes, Was PDA ligation perform  Did the infant have any other care  Did the infant have any other con lf Yes, please specify  What features were apparent at p for surgery? (tick all that apply)	here the infant was born after birth and before oned?  diac surgery?  ngenital anomalies?	time of decisio	Yes No Yes	
3.3 3.4 3.5 3.6 3.7	Was the infant transferred from a lf Yes, please specify hospital will Was the infant discharged home suspected NEC?  Did the infant have a PDA?  If Yes, Was PDA ligation perform Did the infant have any other care Did the infant have any other care Did the infant have any other con lf Yes, please specify  What features were apparent at p for surgery? (tick all that apply)  Billious gastric aspirate or emesis	here the infant was born after birth and before oned?  diac surgery?  ngenital anomalies?	time of decisio	Yes No Yes	
3.3 3.4 3.5 3.6 3.7	Was the infant transferred from a lf Yes, please specify hospital will Was the infant discharged home suspected NEC?  Did the infant have a PDA?  If Yes, Was PDA ligation perform Did the infant have any other care Did the infant have any other condit Yes, please specify  What features were apparent at progression of the infant have apparent at progression of the surgery? (tick all that apply)  Billious gastric aspirate or emesis  Blood stained aspirates	here the infant was born after birth and before oned?  diac surgery?  ngenital anomalies?	time of decisio	Yes No Yes	

		At presentation	At the time of decision for surgery
	Abdominal wall discolouration		
	Other feature		
	If Other, please specify feature	noted:	
3.9			
		At presentation	At the time of decision for surgery
	Infant on inotropes	Yes No	Yes No No
	Infant ventilated	Yes No	Yes No
	Infant on antacids	Yes No	Yes No No
	Infant on antibiotics	Yes No	Yes No
3.10	Was an X-ray performed?		Yes No
	If Yes, what features were note	ed? (tick all that apply)	
	Pneumatosis intestinalis		
	Hepato-biliary gas		
	Pneumoperitoneum		
	Ascites		
	Gasless abdomen  Distended bowel loops  Other		
	If Other, please specify		
Sec	ction 4: Initial Managemen	t	
4.1	Was the infant on enteral feeds	at the time NEC was firs	t suspected? Yes No
	If Yes, what date were they sta	arted?	D D / M M / Y Y
	What types of enteral feeds	were being given? (tick al.	l that apply)
	Mother's milk		
	Bank human milk		
	Hydrolyzed preterm formula		
	Standard formula		
4.2	Had enteral feeds been stopped	d <mark>before</mark> NEC was first su	uspected? Yes No
	If Yes, what date were they sto		DD/MM/YY
4.3	Was the infant receiving TPN at	the time NEC was first s	suspected? Yes No
	If Yes, what date was TPN sta	rted?	DD/MM/YY
	If No, was TPN started after N	EC was first suspected?	Yes No
	If Yes, what date was TPN	started?	D D / M M / Y Y

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 DD/MM/YY
	Transfusion 2 D D / M M / Y Y
	Transfusion 3 DD/MM/YY
	(If more than 3 transfusions in the 2 weeks before diagnosis, please continue in section 8.4)
Sec	ction 5: Surgery
5.1	What date and time was the decision to operate (insertion of drain and/or laparotomy) made?
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?
5.4	Was a laparotomy performed?
	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?
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?
5.9	Following surgery, what was the total small bowel length remaining?
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 b	leed?	Yes No No
5.12	5.12 Was the abdomen left open after the first laparotomy?		Yes No
5.13	5.13 Was this SIP (spontaneous intestinal perforation)?		Yes No
	``	· ·	
Sec	tion 6: Early Morbidity (28 da	ays post initial surgery/treatme	nt)
6.1	Did the infant develop any complica within the first 28 days?	ations of the surgery/drain insertion	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 procedure surgery/drain insertion?	es required in the first 28 days post	Yes No
	If Yes, please specify		Ť
	Date of surgery	Details of further surgical p	rocedure
	DD/MM/YY		
	DD MM YY		
	DD/MMXYY		
6.3	Did the infant have any other morbi	dity?	Yes No
	If Yes, please give details		
Sec	tion 7: Feeding during the 28	3 days after surgery/treatment	
7.1	Was the infant on TPN at 28 days?		Yes No
	If No, please give date TPN stoppe	ed	DD/MM/YY
7.2	Were enteral feeds started in the fir	st 28 davs?	Yes No
	If Yes, please give date started		DD/MM/YY
	What types of enteral feeds were b	eing given <i>(tick all that apply)</i>	
	Mother's milk	· · · · · · · · · · · · · · · · ·	
	Bank human milk		
	Hydrolyzed preterm formula		
	Standard formula		

Sec	tion 8: Outcomes/Other information	
8.1	Has the infant been discharged home?  If Yes, specify date of discharge	Yes No No DD/MM/YY
8.2	Has the infant been discharged to another hospital?  If Yes, please give name of hospital  Name of responsible consultant  Date of transfer	Yes No No DD/MM/YY
8.3	Did this infant die?  If Yes, please give date of death  Cause of death as stated on the death certificate (please state if not known)	Yes No
	Was a post-mortem performed?  If Yes, was the diagnosis of NEC confirmed?	Yes No Yes No
8.4	Please add other relevant information below	
		_
		)
Sec	tion 9:	
Name of person completing the form		
Designation		
	y's date	$ \begin{array}{ c c c c c c c c c c c c c c c c c c c$
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

