

# SICKLE CELL AND THALASSAEMIA STUDY

National Confidential Enquiry into Patient Outcome and Death (NCEPOD)

## QUESTIONNAIRE

**CONFIDENTIAL**

**Hospital number of patient** 

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**Name of healthcare professional completing questionnaire** \_\_\_\_\_

**What is this study about?**  
 NCEPOD will be collecting data on all haemoglobinopathy patients that die between 1<sup>st</sup> January 2005 and 31<sup>st</sup> December 2006. The primary aim of the study is to collect information on the care received by haemoglobinopathy patients who die in order to identify remediable factors in the care of these patients. Data will be collected from sites across England, Wales, Northern Ireland, Isle of Man, Guernsey, Defence Secondary Care Agency Hospitals and the Independent Sector.

**Inclusion criteria for this study**  
 All patients for whom sickle cell disease (ICD-10 D57) or thalassaemia (ICD-10 D56) appears in any part of the diagnosis or cause of death. The study includes both adults and children. Data will be collected on hospital and community-based deaths.

**CPD accreditation for completing NCEPOD Questionnaires**  
 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.

**Please do not keep a copy of this questionnaire in the patient notes for legal reasons.**

**Questions or help**  
 If you have any queries about the study or this questionnaire, please contact NCEPOD at sicklecell@ncepod.org.uk or Tel: 020 7631 3444

**Thank you for taking the time to complete this questionnaire. The findings of this study will be published in May 2008.**

**Who should complete this questionnaire?**  
 This questionnaire should be completed by the healthcare professional responsible for the patient's haemoglobinopathy management at the last unit they attended. The unit may be a hospital, a specialist centre or a GP surgery.

If the patient did not die at the unit at which they were regularly managed, a questionnaire will also be sent to the healthcare professional responsible for the regular management of the patient.

Please return completed questionnaires in the stamped addressed envelope provided.

**How to complete this questionnaire**  
 This form will be electronically scanned. Please use a black or blue pen. Please complete all sections either in block capitals or a bold cross inside the box provided e.g.

Did the patient receive transfusions?  
 Yes       No       Unknown

If you make a mistake, please "black-out" the box and re-enter the correct information e.g.

Did the patient receive transfusions?  
 Yes       No       Unknown

**Unless indicated, please cross only one box per question.** Free space is provided on page 15 for your comments.

Incomplete questionnaires may be followed up.

**Definitions:** Where <sup>(def)</sup> is indicated, a definition is provided on the back of the questionnaire.

## WHICH PART TO COMPLETE?

- If you were responsible for the patient's **regular management and the patient died at your unit** <sup>(def)</sup> → please complete **parts 1, 2 & 3**
- If you were responsible for the patient's **regular management** but they died elsewhere → please complete **part 1**
- If you were responsible for the patient's care **at the time of death** but not their regular management → please complete **parts 2 & 3**
- **All complete section A**

## A – THE PATIENT

1. Age at death                            2. Sex     Male                       Female
3. Date of death
- d d                      m m                      y y

## PART 1 – THE PATIENT'S REGULAR MANAGEMENT

## B – THE PATIENT'S HAEMOGLOBINOPATHY DETAILS

4. Which haemoglobinopathy did the patient have?

- |                                                             |                                                        |
|-------------------------------------------------------------|--------------------------------------------------------|
| 1 <input type="checkbox"/> Sickle cell anaemia (HbSS)       | 5 <input type="checkbox"/> β-thalassaemia major        |
| 2 <input type="checkbox"/> Sickle haemoglobin C (HbSC)      | 6 <input type="checkbox"/> β-thalassaemia intermedia   |
| 3 <input type="checkbox"/> Sickle haemoglobin D (HbSD)      | 7 <input type="checkbox"/> Other, please specify _____ |
| 4 <input type="checkbox"/> Sickle β-thalassaemia (HbSβThal) | 8 <input type="checkbox"/> Unknown                     |

5. At what age was the patient first diagnosed as having a haemoglobinopathy?

- 1  At birth
- 2  Aged 0-10 years
- 3  Aged 11-20 years
- 4  Aged 20+ years
- 5  Unknown

6. What were the patient's usual haematological values <sup>(def)</sup>?

- |                          |                                                                  |                                    |                                  |
|--------------------------|------------------------------------------------------------------|------------------------------------|----------------------------------|
| a HbS                    | <input type="text"/> <input type="text"/> . <input type="text"/> | %                                  | <input type="checkbox"/> Unknown |
| b HbF                    | <input type="text"/> <input type="text"/> . <input type="text"/> | %                                  | <input type="checkbox"/> Unknown |
| c HbA                    | <input type="text"/> <input type="text"/> . <input type="text"/> | %                                  | <input type="checkbox"/> Unknown |
| d HbA2                   | <input type="text"/> <input type="text"/> . <input type="text"/> | %                                  | <input type="checkbox"/> Unknown |
| e Total Hb               | <input type="text"/> <input type="text"/> . <input type="text"/> | g.dl <sup>-1</sup>                 | <input type="checkbox"/> Unknown |
| f Haematocrit            | <input type="text"/> <input type="text"/> . <input type="text"/> | %                                  | <input type="checkbox"/> Unknown |
| g White blood cell count | <input type="text"/> <input type="text"/> . <input type="text"/> | × 10 <sup>9</sup> .l <sup>-1</sup> | <input type="checkbox"/> Unknown |
| h Mean cell volume (MCV) | <input type="text"/> <input type="text"/> <input type="text"/>   | fI                                 | <input type="checkbox"/> Unknown |

7. What were the patient's last three ferritin values?

a	<input type="text"/> <i>d d</i>	<input type="text"/> <i>m m</i>	<input type="text"/> <i>y y</i>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	$\mu\text{g.l}^{-1}$	<input type="checkbox"/> Unknown
b	<input type="text"/> <i>d d</i>	<input type="text"/> <i>m m</i>	<input type="text"/> <i>y y</i>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	$\mu\text{g.l}^{-1}$	<input type="checkbox"/> Unknown
c	<input type="text"/> <i>d d</i>	<input type="text"/> <i>m m</i>	<input type="text"/> <i>y y</i>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	$\mu\text{g.l}^{-1}$	<input type="checkbox"/> Unknown

### C – REGULAR MANAGEMENT

8. a Did the patient receive transfusions?  Yes  No  Unknown

b If **YES**, please give details. Specifically: What type of transfusion did the patient receive? Were there any recognised allo-antibodies? If known, how many units were transfused to the patient over the last 10 years/their lifetime? Was the patient on chelation therapy? Was the patient on a chronic transfusion regimen?

9. a Was the patient taking regular pain medication between crises?

Yes  No  Unknown

b If **YES**, what regular pain medication was the patient taking? *(Please cross ALL that apply)*

Opioids <sup>1</sup>  Please specify \_\_\_\_\_  
Frequency and dose (per day) \_\_\_\_\_

NSAIDS <sup>2</sup>  Please specify \_\_\_\_\_  
Frequency and dose (per day) \_\_\_\_\_

Paracetamol <sup>3</sup>  Frequency and dose (per day) \_\_\_\_\_

Other <sup>4</sup>  Please specify \_\_\_\_\_  
Frequency and dose (per day) \_\_\_\_\_

Unknown <sup>5</sup>

10. Was the patient taking folic acid?  Yes  No  Unknown

11. a Was the patient taking prophylactic antibiotics?  Yes  No  Unknown

b If YES,

i Please specify antibiotics taken \_\_\_\_\_  Unknown

ii How long had the patient been taking antibiotics for?

y y

m m

Unknown

12. a Was the patient taking hydroxyurea?  Yes  No  Unknown

b If YES,

i What was the daily dosage?  mg/day  Unknown

ii How long had the patient been taking hydroxyurea?

y y

m m

Unknown

13. a Was the patient taking any other medication?

Yes

No

Unknown

b If YES, please specify \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

14. Had the patient received the following vaccinations?

a Pneumococcal vaccine  Yes  No  Unknown

b Haemophilus influenza type b vaccine  Yes  No  Unknown

c Meningococcal vaccine  Yes  No  Unknown

d Annual influenza vaccine  Yes  No  Unknown

## D – ORGANISATION OF REGULAR CARE

15. Where was the patient regularly managed?

(Please cross ALL that apply)

1  GP surgery

2  Specialist centre <sup>(def)</sup>

3  Non-specialist hospital unit

Please specify names of units <sup>(def)</sup> \_\_\_\_\_  
\_\_\_\_\_

16. a Did the patient attend a haemoglobinopathy outpatient clinic?

Yes

No

Unknown

b If YES, how regularly?

1  Weekly

2  Monthly

3  Bi-monthly

4  Quarterly +

5  Irregularly

6  Unknown

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17. In the last year, how many visits did the patient make to the GP surgery, specialist centre or non-specialist hospital unit for haemoglobinopathy-related reasons?

GP surgery

Visits

Unknown

Specialist centre

Visits

Unknown

Non-specialist  
hospital unit

visits

Unknown

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18. Please provide a commentary on the care of the patient. Including: the patient's compliance with their treatment regimen.

**PART 2 – FINAL CLINICAL EPISODE**

**E\* - EXPERIENCE IN MANAGING HAEMOGLOBINOPATHIES**

*(Hospital deaths only)*

19. a What consultant speciality was the patient admitted under?

- 1  Haematology *Please go to question 20*  
2  Other, please specify \_\_\_\_\_  
3  Unknown

b If the patient was **not admitted under a consultant haematologist** was the patient referred to, or was advice sought from, a consultant haematologist?

- 1  Yes, a consultant haematologist within this hospital  
2  Yes, a consultant haematologist from another hospital/specialist centre <sup>(def)</sup>  
3  No  
4  Unknown

20. What was the grade of the most senior doctor to see the patient in their final episode?

- |                            |                      |                            |              |
|----------------------------|----------------------|----------------------------|--------------|
| 1 <input type="checkbox"/> | Consultant           | 5 <input type="checkbox"/> | SpR year 1/2 |
| 2 <input type="checkbox"/> | Associate specialist | 6 <input type="checkbox"/> | SHO          |
| 3 <input type="checkbox"/> | Staff Grade          | 7 <input type="checkbox"/> | Other        |
| 4 <input type="checkbox"/> | SpR year 3+          | 8 <input type="checkbox"/> | Unknown      |

21. a Does the most senior doctor involved in the patient's management have a special interest in haemoglobinopathies?

- Yes  No  Unknown

b If **YES**, is the most senior doctor a member of the UK Forum on Haemoglobin Disorders?

- Yes  No  Unknown

22. How many haemoglobinopathy patients has the most senior doctor involved in the patient's care managed in the last 12 months?

- |                                                                |                              |                                  |
|----------------------------------------------------------------|------------------------------|----------------------------------|
| <input type="text"/> <input type="text"/> <input type="text"/> | Sickle cell disease patients | <input type="checkbox"/> Unknown |
| <input type="text"/> <input type="text"/> <input type="text"/> | Thalassaemia patients        | <input type="checkbox"/> Unknown |

23. How many years has the most senior doctor involved in the patient's care been involved in the management of haemoglobinopathy patients?

- Years  Unknown

24. In your opinion, are there any issues relating to the training of the medical team/junior doctors in the management of haemoglobinopathies:

a In this case?

Yes

No

Unknown

i If YES, please specify

b In general?

Yes

No

Unknown

i If YES, please specify

## F – SEQUENCE OF PATIENT EVENTS BEFORE DEATH

25. Please provide a commentary on the sequence of events leading up to the death of this patient. Including: presentation, initial diagnosis, initial investigations, initial management (including pain relief), continuing care and surgical interventions (if appropriate).

*(See also section H or I if the case is a perioperative<sup>(def)</sup> or maternal death.)*

*(Please continue on additional sheets if required)*

26. a Did the patient develop acute chest syndrome?

Yes

No

Unknown

b If **YES**, please give details of management. Including: hydration, antibiotics, timing of transfusion and ICU involvement.

27. a Were there any factors in the patient care during this episode that could have affected outcome?

Yes

No

Unknown

b If **YES**, please specify

## G – CLINICAL PATHOLOGY

28. What was the patient's cause of death as given on the death certificate?

1.a \_\_\_\_\_

1.b \_\_\_\_\_

1.c \_\_\_\_\_

2 \_\_\_\_\_

29. a Was an autopsy performed?

Yes

No

Unknown

b If **YES**, was the autopsy consented or medico-legal (coronial)?

<sup>1</sup>  Consented

<sup>2</sup>  Medico-legal

<sup>3</sup>  Unknown

**PLEASE SEND NCEPOD A COPY OF THE AUTOPSY REPORT ON RETURN OF THIS QUESTIONNAIRE**



30. Did the patient undergo surgery in the final clinical episode?  Yes  No  Unknown

If YES, please go to section H.

If NO, please go to section I.

**H\* – MORTALITY ASSOCIATED WITH SURGERY**

*(Hospital deaths only)*

31. What was the operation for and what procedure was undertaken?

32. a Were the patient's HbS and total Hb values measured pre-operatively?  Yes  No  Unknown

b If YES, please specify

i HbS   .  %  Unknown

ii Total Hb   .  g.dl<sup>-1</sup>  Unknown

33. a Did the patient receive any haemoglobinopathy-specific pre-operative preparation?  Yes  No  Unknown

b If YES, please provide details. Including: exchange or top up transfusion, intravenous fluids, supplemental oxygen, treatment of infection and advice from a haematologist/haemoglobinopathy team.

34. What was the grade of the most senior anaesthetist involved in the patient's management?

- 1  Consultant
- 2  Associate Specialist
- 3  Staff Grade
- 4  SpR year 3+
- 5  SpR year 1/2
- 6  SHO
- 7  Other
- 8  Unknown

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35. How many haemoglobinopathy patients has the most senior anaesthetist involved in the patient's care managed in the last 12 months?

- |                      |                      |                      |                              |                          |         |
|----------------------|----------------------|----------------------|------------------------------|--------------------------|---------|
| <input type="text"/> | <input type="text"/> | <input type="text"/> | Sickle cell disease patients | <input type="checkbox"/> | Unknown |
| <input type="text"/> | <input type="text"/> | <input type="text"/> | Thalassaemia patients        | <input type="checkbox"/> | Unknown |

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36. What was the grade of the most senior surgeon involved in the patient's management?

- 1  Consultant
- 2  Associate Specialist
- 3  Staff Grade
- 4  SpR year 3+
- 5  SpR year 1/2
- 6  SHO
- 7  Other
- 8  Unknown

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37. How many haemoglobinopathy patients has the most senior surgeon involved in the patient's care managed in the last 12 months?

- |                      |                      |                      |                              |                          |         |
|----------------------|----------------------|----------------------|------------------------------|--------------------------|---------|
| <input type="text"/> | <input type="text"/> | <input type="text"/> | Sickle cell disease patients | <input type="checkbox"/> | Unknown |
| <input type="text"/> | <input type="text"/> | <input type="text"/> | Thalassaemia patients        | <input type="checkbox"/> | Unknown |

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38. Was incentive spirometry used post-operatively?

- Yes
- No
- Unknown

39. Did the patient experience any of the following during the perioperative<sup>(def)</sup> period?

*(Please cross ALL that apply)*

- 1  Fever
- 2  Hypovolaemia
- 3  Hypoxia
- 4  Hypercarbia
- 5  Acidosis
- 6  Low flow state (including use of tourniquet)
- 7  Hypothermia
- 8  Acute chest syndrome
- 9  Sepsis – If **YES**, which organ(s)?

10  Other significant complications  
Please specify

40. a Are there local protocols for the anaesthetic management of haemoglobinopathy patients?

Yes       No       Unknown

b If **YES**, were these protocols followed?

Yes       No       Unknown

**PLEASE SEND NCEPOD A COPY OF ANY PROTOCOLS ON RETURN OF THIS QUESTIONNAIRE**

**I \* – MATERNAL DEATH**

*(Hospital deaths only)*

41. Please describe the patient's sequence of events leading up to the patient's death. Including: last menstrual period (LMP), expected delivery date (EDD) for gestation; if > 24 weeks was fetus born alive? Intrauterine growth restriction (IUGR)? Hypertension, cardiac or pulmonary problems in pregnancy?

*(Please continue on additional sheets if required)*

42. What was the grade of the most senior obstetrician involved in the patient's management?

- 1  Consultant
- 2  Associate Specialist
- 3  Staff Grade
- 4  SpR year 3+
- 5  SpR year 1/2
- 6  SHO
- 7  Other, please specify \_\_\_\_\_
- 8  Unknown

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43. How many haemoglobinopathy patients has the most senior obstetrician involved in the patient's care managed in the last 12 months?

<input type="text"/>	<input type="text"/>	<input type="text"/>	Sickle cell disease patients	<input type="checkbox"/>	Unknown
<input type="text"/>	<input type="text"/>	<input type="text"/>	Thalassaemia patients	<input type="checkbox"/>	Unknown

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44. How was the baby delivered?

- 1  Vaginal delivery
- 2  Caesarean section
- 3  Unknown

---

45. a Was the patient's HbS value measured during pregnancy?  Yes  No  Unknown

b If YES, please specify  .  %

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46. a Did the patient receive any change in haemoglobinopathy-specific therapy during pregnancy?  Yes  No  Unknown

b If YES, please provide details. Including: exchange or top up transfusion, intravenous fluids, supplemental oxygen, treatment of infection, advice from a haematologist/haemoglobinopathy team.

## PART 3 – ORGANISATION OF CARE

### J – GUIDELINES

47. Does the unit <sup>(def)</sup> have locally available guidelines for the management of haemoglobinopathy patients with the following? *(Please cross ALL that apply)*

- |    |                          |                             |
|----|--------------------------|-----------------------------|
| 1  | <input type="checkbox"/> | Pain                        |
| 2  | <input type="checkbox"/> | Pregnancy                   |
| 3  | <input type="checkbox"/> | Sequestration crisis        |
| 4  | <input type="checkbox"/> | Priapism                    |
| 5  | <input type="checkbox"/> | Acute anaemia               |
| 6  | <input type="checkbox"/> | Acute chest syndrome        |
| 7  | <input type="checkbox"/> | Chronic renal failure       |
| 8  | <input type="checkbox"/> | General anaesthesia         |
| 9  | <input type="checkbox"/> | Iron-chelation therapy      |
| 10 | <input type="checkbox"/> | Blood transfusion           |
| 11 | <input type="checkbox"/> | Other, please specify _____ |
| 12 | <input type="checkbox"/> | None                        |

48. Does the unit have separate guidelines for children and adults?

Yes       No       Unknown

**PLEASE SEND NCEPOD A COPY OF ANY GUIDELINES ON RETURN OF THIS QUESTIONNAIRE**

### K – PROVISION OF CARE

49. How many haemoglobinopathy patients were cared for at this unit in the year April 2003 – March 2004?

<input type="text"/>	<input type="text"/>	<input type="text"/>
----------------------	----------------------	----------------------

Sickle cell disease patients

Unknown

<input type="text"/>	<input type="text"/>	<input type="text"/>
----------------------	----------------------	----------------------

Thalassaemia patients

Unknown

50. Is there a dedicated haemoglobinopathy team at the unit?

- |   |                          |                                                |
|---|--------------------------|------------------------------------------------|
| 1 | <input type="checkbox"/> | Yes, sickle cell disease and thalassaemia team |
| 2 | <input type="checkbox"/> | Yes, sickle cell disease team only             |
| 3 | <input type="checkbox"/> | Yes, thalassaemia team only                    |
| 4 | <input type="checkbox"/> | No <i>If NO, please go to question 57</i>      |
| 5 | <input type="checkbox"/> | Unknown                                        |

<b>51.</b>	<b>a</b>	Does the team include, or is there regular access to, a haematologist?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
	<b>b</b>	If <b>YES</b> ,			
	i	How many haematologists are there at the unit?	<input type="text"/> <input type="text"/>	Haematologists	<input type="checkbox"/> Unknown
	ii	What is the total programmed activities <sup>(def)</sup> in his/her/their job plan for haemoglobinopathies?	<input type="text"/> <input type="text"/>	Programmed activities	<input type="checkbox"/> Unknown
<hr/>					
<b>52.</b>	<b>a</b>	Does the team include, or is there regular access to, a nurse practitioner?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
	<b>b</b>	If <b>YES</b> ,			
	i	How many nurse practitioners are there at the unit?	<input type="text"/> <input type="text"/>	Nurse practitioners	<input type="checkbox"/> Unknown
	ii	How many hours a week in total are allocated to haemoglobinopathies?	<input type="text"/> <input type="text"/> <input type="text"/>	Hours	<input type="checkbox"/> Unknown
<hr/>					
<b>53.</b>	<b>a</b>	Does the team include, or is there regular access to, a pain specialist <sup>(def)</sup> ?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
	<b>b</b>	If <b>YES</b> ,			
	i	Is the named pain specialist a doctor or a nurse?	1 <input type="checkbox"/>	Doctor	
			2 <input type="checkbox"/>	Nurse	
			3 <input type="checkbox"/>	Other, please specify _____	
			4 <input type="checkbox"/>	Unknown	
	ii	How many sickle cell disease patients has the named pain specialist managed in the last 12 months?	<input type="text"/> <input type="text"/> <input type="text"/>	Patients	<input type="checkbox"/> Unknown
	iii	How many years has the named pain specialist been involved in managing patients with sickle cell disease?	<input type="text"/> <input type="text"/>	Years	<input type="checkbox"/> Unknown
<hr/>					
<b>54.</b>		Does the team include, or is there regular access to, an anaesthetic specialist?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
<hr/>					
<b>55.</b>		Does the team include, or is there regular access to, a psychologist?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
<hr/>					
<b>56.</b>	<b>a</b>	Does the team include, or is there regular access to, any other services (including ophthalmic, neurology, osteoarticular and renal)?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
	<b>b</b>	If <b>YES</b> , please specify _____			

57. Do you have agreed policies with other hospitals for the transfer of haemoglobinopathy patients?

Yes

No

Unknown

***PLEASE SEND NCEPOD A COPY OF ANY POLICIES ON RETURN OF THIS QUESTIONNAIRE***

58. Do you have a care pathway for haemoglobinopathy patients at the unit?

Yes

No

Unknown

***PLEASE SEND NCEPOD A COPY OF ANY CARE PATHWAYS ON RETURN OF THIS QUESTIONNAIRE***

59. Please write clearly any additional observations you wish to report about the management of this patient

***Thank you for taking the time to complete this questionnaire***

**On return of this questionnaire, please send photocopies of the following:**

- **The patient's last six months medical records: GP/specialist centre records and hospital case notes (GP referral letter, medical notes, nursing notes, fluid balance charts and TPR charts)**
- **Autopsy report (if available)**

***Only the information requested above should be returned to NCEPOD***

## Definitions

TERM	DEFINITION
<b>Perioperative</b>	The time before, during and after the operative procedure.
<b>Programmed activity</b>	A scheduled period, nominally equivalent to four hours, during which a consultant undertakes contractual and consequential services.
<b>Specialist</b>	A healthcare professional with experience in managing haemoglobinopathies.
<b>Specialist centre</b>	A centre with a dedicated team specialising in the management of haemoglobinopathies.
<b>Unit</b>	A hospital, GP surgery or specialist centre.
<b>Usual haematological values</b>	The usual 'steady-state' haematological values of the patient. The values given on the patient's haemoglobinopathy card, if available.

NCEPOD  
 Epworth House  
 25 City Road  
 London  
 EC1Y 1AA

<b>FOR NCEPOD USE ONLY</b>										
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