

Sickle Cell and Thalassaemia Study

National Confidential Enquiry into Patient Outcome and Death (NCEPOD)

ASSESSMENT FORM

CONFIDENTIAL

Questionnaire number

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Instructions for completion

The data presented in this questionnaire have been extracted by a NCEPOD researcher from the questionnaires and casenotes provided for each patient. Please complete the sections entitled **'To be completed by Advisor'**

Please complete all questions with either block capitals or a bold cross inside the boxes provided. If you make a mistake please "black-out" the box and re-enter the correct information. Unless indicated, please mark only one box per question.

Please cross **'Insufficient data'** where the information is not available from casenotes or if the casenotes are missing. **Definitions** are provided on the back of the assessment form.

A – THE PATIENT

1 Month and year of birth

m	m	y	y	y	y

2 Sex

	Male		Female
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3 Patient's haemoglobinopathy

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

4 Age at time of death

			years
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5 Place of death

- 1 Hospital death^{def}
- 2 Community death^{def}
- 3 Died in the community following discharge from hospital^{def}

B – ADMISSION DETAILS*(This section only needs to be completed for patients who died in hospital)*

6 Date of admission

<i>d</i>	<i>d</i>		<i>m</i>	<i>m</i>		<i>y</i>	<i>y</i>

 Insufficient data

7 Time of admission

		:				<i>(24 hour clock)</i>
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 Insufficient data

8 Number of days spent in hospital

				days
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C – LONG-TERM MANAGEMENT (Specialist centre/GP management)

9 Number of visits in the 6 months prior to date of death

 GP surgery visits Insufficient data Specialist centre ^{def} visits Insufficient data Non-specialist unit visits Insufficient data**To be completed by Advisor**

10 a Did the patient refuse to accept medical advice or treatment?

 Yes No Insufficient data

b If yes, in your opinion could this have had any impact on the patient's outcome?

 Yes No Insufficient data

c If yes, please give details

11 a Did the patient show any reluctance to attend appointments/hospital?

 Yes No Insufficient data

b If yes, in your opinion could this have had any impact on the patient's outcome?

 Yes No Insufficient data

c If yes, please give details

12 a Was the patient receiving analgesia for their long term care?

Yes

No

Insufficient data

b If yes, please specify medication taken

c Was this a regular prescription?

Yes

No

Insufficient data

To be completed by Advisor

(This section only needs to be completed for patients receiving analgesia for their long-term care)

13 Is there any evidence that the patient's medication was being dispensed from multiple sources?

Yes

No

Insufficient data

14 a i In your opinion, is there any evidence that the patient was experiencing dependency issues?

Yes

No

Insufficient data

ii If yes, please give details

b i If yes, is there any evidence that the clinician explored this aspect of care?

Yes

No

Insufficient data

ii If yes, please give details

15 a Did the quantity/frequency of the patient's analgesia increase in the last 6 months?

Yes

No

Insufficient data

b i In your opinion, is there any evidence that the patient was developing a tolerance to opioids?

Yes

No

Insufficient data

ii If yes, please give reasons

D – FINAL EPISODE

16 Please indicate if any of the following complications were a feature of patient's final episode

- | | |
|---|---|
| <input type="checkbox"/> Acute chest syndrome | <input type="checkbox"/> Stroke - haemorrhage |
| <input type="checkbox"/> Pneumococcal bacteraemia | <input type="checkbox"/> Hip surgery |
| <input type="checkbox"/> Splenic sequestration | <input type="checkbox"/> Hepato-biliary surgery |
| <input type="checkbox"/> Stroke - infarction | <input type="checkbox"/> Seizures |
| <input type="checkbox"/> None | |

17 If the patient died in hospital please give details of reviews in (a) first 24 hours and (b) final 24 hours

- No evidence of patient being reviewed
- Not applicable
- Insufficient data

a First 24 hours following admission

Date (day and month)	Time (24-hour clock)	Grade of reviewer (see definitions)	Specialty of reviewer
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b Final 24 hours

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To be completed by Advisor

18 a Was the frequency of reviews acceptable for the severity of this patient's condition? Yes No Insufficient data

b If no, please give details

19 Is there evidence of combined care ^{def}? Yes No Insufficient data

20 Did the first hospital at which the patient was admitted in their final episode have a dedicated haemoglobinopathy team? Yes No Insufficient data

To be completed by Advisor

21 a Was the first hospital at which the patient was admitted suitable to manage the patient's haemoglobinopathy? Yes No Insufficient data

b If no, was the patient transferred to a more appropriate hospital? Yes No Insufficient data

c If no, in your opinion could this have had any impact on the patient's outcome? Yes No Insufficient data

d If yes, please give details

22 What consultant specialty was the patient admitted under? _____

(Please refer to Q 19 on questionnaire) Insufficient data

23 What consultant speciality was the patient under at time of death? _____

Insufficient data

To be completed by Advisor

24 a Was the specialty of the consultant that the patient was admitted under appropriate? Yes No Insufficient data

b If no, was the patient transferred to an appropriate speciality? Yes No Insufficient data

25 a Did junior doctors seek advice from senior staff as required? Yes No Insufficient data

Not applicable

b Please give details

26 a If appropriate, was advice sought from external experts? Yes No Insufficient data

Not applicable

b Please give details

27 If the patient was managed in hospital in the final episode, please list wards where the patient was managed

Date (Day and month)	Time (24-hour clock)	Type of ward	Time on ward (Days and hours)
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To be completed by Advisor

28 Was the patient managed on an appropriate ward(s)? Yes No Insufficient data

29 a Did a lack of clarity about where the patient should be managed lead to delay? Yes No Insufficient data

Not applicable

b If yes, please give details

30 a Was the patient's fluid balance management appropriate? Yes No Insufficient data

Not applicable

b If no, please give details

31 a Was the frequency of observations appropriate? Yes No Insufficient data

Not applicable

b If no, please give details

32 List all investigations requested (including haematology, biochemistry, x-ray)

To be completed by Advisor

38 Was the experience and seniority of the anaesthetist appropriate? Yes No Insufficient data

39 Was the experience and seniority of the surgeon appropriate? Yes No Insufficient data

40 Was the surgery performed:

a at an appropriate time? Yes No Insufficient data

b in an appropriate hospital? Yes No Insufficient data

c If no, please give details

41 a Did the patient receive appropriate analgesia post-operatively? Yes No Insufficient data

b If no, please give details

42 a Were there any peri-operative ^{def} complications? Yes No Insufficient data

b If yes, please give details

43 a Were any of these complications avoidable? Yes No Insufficient data

b If yes, please explain reasons

F- DEATH (Please refer to section G on questionnaire)

44 How was the cause of death recorded on the death certificate?

1 a _____

1 b _____

1 c _____

2 _____

No cause of death recorded in notes

To be completed by Advisor

45 a Was the given cause of death correct? Yes No Unsure

b If no, how should the cause of death been recorded?

1 a _____

1 b _____

1 c _____

2 _____

c Any additional comments

46 Was a consented autopsy^{def} performed? Yes No Insufficient data

47 Was the patient referred to a coroner? Yes No Insufficient data

48 a Was a coronial autopsy^{def} performed? Yes No Insufficient data

To be completed by Advisor

48 b If a coronial autopsy was not performed, should the patient have been referred to a coroner? Yes No Insufficient data
 Not applicable

c If yes, please give details

G – OVERALL ASSESSMENT OF PATIENT CARE

To be completed by Advisor

49 a Overall assessment of **ongoing management** for this patient

- 1 Good practice - a standard that you would accept for yourself, your trainees and your institution
- 2 Room for improvement – aspects of **clinical care** that could have been better
- 3 Room for improvement – aspects of **organisational care** that could have been better
- 4 Room for improvement – aspects of both **clinical** and **organisational care** that could have been better
- 5 Less than satisfactory – several aspects of **clinical** and/or **organisational care** that were well below satisfactory
- 6 Insufficient information submitted to assess the quality of care
- 7 Not applicable

b Please provide reasons for assigning this grade

50 a Overall assessment of care in the **final clinical episode** of care

- 1 Good practice - a standard that you would accept for yourself, your trainees and your institution
- 2 Room for improvement – aspects of **clinical care** that could have been better
- 3 Room for improvement – aspects of **organisational care** that could have been better
- 4 Room for improvement – aspects of both **clinical** and **organisational care** that could have been better
- 5 Less than satisfactory – several aspects of **clinical** and/or **organisational care** that were well below satisfactory
- 6 Insufficient information submitted to assess the quality of care
- 7 Not applicable

b Please provide reasons for assigning this grade

To be completed by Advisor

51 Cause for concern cases

Occasionally NCEPOD will refer cases that have been identified as 5 (Less than satisfactory) when it is felt that further feedback to the Trust concerned is warranted. This is usually due to an area of concern particular to the hospital or clinician involved, and not for issues being highlighted across the body of casenotes. In cases that are referred, the advisors have concerns that the pattern of practice fell below a standard, which indicates that the practitioner or team or Trust is likely to put future patients at risk, if not addressed. This process has been agreed by the NCEPOD Steering Group and the GMC. The Medical Director of the Trust is written to by the Chief Executive of NCEPOD explaining our concerns. This process has been in operation for two years and the responses received have always been positive in that they feel we are dealing with concerns in the most appropriate manner.

If you feel this case should be considered for such action please cross

52 a Are there any particular issues you feel should be highlighted in the main report?

 Yes No

b If yes, please give details

Advisor – please initial

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Codes

CODES FOR GRADE	
CON = Consultant	SHO = Senior House Officer
SGR = Staff grade	NUR = Nurse
ASP = Associate specialist	OTH = Other
SPR = Specialist registrar	UNK = Unknown

Definitions

TERM	DEFINITION
Combined care	All appropriate medical specialties involved in the patient's care.
Consented autopsy	A consented autopsy may be requested by the doctor managing the patient to confirm the cause of death, investigate effects of treatment and investigate any possible abnormalities in other organs which may have been involved in the disease. In order for a consented autopsy to be performed the patient's relatives must give consent. http://www.wandsworth-pct.nhs.uk/policies/ClinicalGovernance/31336.frm.doc
Coronial autopsy	Coronial autopsies are mandatory and are required by the coroner to investigate sudden and unexpected deaths, deaths where the cause is unknown and the doctor therefore cannot issue a death certificate and death where the cause of death is known or suspected to be due to causes other than natural diseases (eg accidents and industrial diseases). http://www.wandsworth-pct.nhs.uk/policies/ClinicalGovernance/31336.frm.doc
Death in hospital	The deceased was clearly under the care of a hospital at the time of death.
Death in the community	The deceased was not under the care of a hospital at the time of death. Including: patients received by accident and emergency departments who are dead on arrival; and patients who are admitted to an accident and emergency department but are not under the active and ongoing care of a hospital for more than one hour prior to death.
Death in the community following discharge from hospital	The deceased died in the community within 14 days of being discharged as an in-patient at a hospital.
Peri-operative	The time before, during and after an operative procedure. The peri-operative period starts on first contact with an anaesthetist.
Specialist centre	A centre with a dedicated team specialising in the management of patients with haemoglobinopathies.