Cancer in Children, Teens and Young Adults

National Confidential Enquiry into Patient Outcome and Death (NCEPOD)

Clinician Questionnaire A

To be completed by the doctor who prescribed the most recent protocol of SACT

CONFIDENTIAL

DETAILS OF THE CLINICIAN COMPLETING THIS QUESTIONNAIRE

Grade: _____ **Specialty:** _____

What is this study about?

To identify and explore avoidable and remediable factors in the process of care of children, teens and young adults aged 25 and younger who died/ or had an unplanned admission to ICU (Level 3) within 60 days of receiving systemic anti-cancer therapy (SACT)

Inclusions:

Patients:

- Up to and including the age of 25 years

- Who have a cancer diagnosis (ICD10 codes C00-D10; D37-D48)

- Who have received systemic anti cancer therapy (SACT) - intravenous, oral, subcutaneous, intrathecal, or intraperitoneal chemotherapy, monoclonal antibodies or cytokines; and

- Who have died or been admitted to PICU/ICU within 60 days of receving SACT

For the purpose of this questionnaire the most recent procotol/cycle refers to the most recent date within the study time period (1st March 2014 - 31st May 2016)

Exclusions:

- Planned admissions to ICU (e.g. post surgery)
- Incidental deaths (e.g. trauma-related)

CPD accreditation:

Consultants who complete NCEPOD questionnaires make a valuable contribution to the investigation of patient care. It 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.

Questions or help?

If you have any queries about this study or this questionnaire, please contact:

cictya@ncepod.org.uk

Or telephone: 020 7251 9060

Thank you for taking the time to complete this questionnaire. The findings of the study will be published in December 2017.

This questionnaire should be completed by the named consultant in the accompanying letter who prescribed the protocol of SACT, but can be completed by one of their trainees if signed off by the named consultant.

NOTE OF CONFIDENTIALITY: **Your responses are strictly confidential and will only be used as part of this aggregated data set and will not be shared with any third parties.**

If you (the clinician completing the questionnaire) would like email confirmation of the completion of this questionnaire for your records, please clearly supply your email address below:

NCEPOD number: | | | | | | |

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CODES FOR SPECIALTY

SURGICAL SPECIALTIES

100 = General Surgery	110 = Trauma & Orthopaedics	161 = Burns Care
101 = Urology	120 = Ear, Nose & Throat (ENT)	170 = Cardiothoracic Surgery
103 = Breast Surgery	130 = Ophthalmology	172 = Cardiac Surgery
104 = Colorectal Surgery	140 = Oral Surgery	173 = Thoracic Surgery
105 = Hepatobiliary & Pancreatic Surgery	145 = Oral & Maxillo-Facial Surgery	180 = Accident & Emergency
106 = Upper GI Surgery	150 = Neurosurgery	190 = Anaesthetics
107 = Vascular Surgery	160 = Plastic Surgery	192 = Critical/Intensive Care Medicine

MEDICAL SPECIALTIES

300 = General Medicine	314 = Rehabilitation	350 = Infectious Diseases	500 = Obstetrics & Gynaecology
301 = Gastroenterology	315 = Palliative Medicine	360 = Genito-Urinary Medicine	502 = Gynaecology
302 = Endocrinology	320 = Cardiology	361 = Nephrology	800 = Clinical Oncology
303 = Clinical Haematology	326 = Acute internal medicine	370 = Medical Oncology	810 = Radiology
306 = Hepatology	330 = Dermatology	400 = Neurology	820 = General Pathology
307 = Diabetic Medicine	340 = Respiratory Medicine	410 = Rheumatology	823 = Haematology
		430 = Geriatric Medicine	

PAEDIATRIC SPECIALTIES

171 - Surgery	219 - Plastic Surgery	253 - Clinical haematology	262 - Rheumatology
211 - Urology	220 - Burns Care	254 - Audiological Medicine	263 - Diabetic Medicine
212 - Transplantation Surgery	221 - Cardiac Surgery	255 - Clinical Immunology	264 - Cystic Fibrosis
213 - Gastrointestinal Surgery	222 - Thoracic Surgery	and Allergy Service	280 - Interventional Radiology
214 - Trauma and Orthopaedics	223 - Epilepsy	256 - Infectious diseases	290 - Community Paediatrics
215 - Ear, Nose & Throat (ENT)	241 - Pain management	257 - Dermatology	291 - Neuro-disability
216 - Ophthamology	242 - Intensive Care	258 - Respiratory Medicine	321 - Cardiology
217 - Maxillo-Facial Surgery	251 - Gastroenterology	259 - Nephrology	421 - Neurology
218 - Neurosurgery	252 - Endocrinology	260 - Medical Oncology	420 - Paediatrics
		261 - Metabolic Disease	

DEFINITIONS

Cycle:	Chemotherapy is typically given in cycles, which is a treatment followed by a period of rest. A cycle can last one or more days, but is usually one, two, three, or four weeks long.
CV access:	Central Venous Access - a long thin and hollow plastic tube called a 'catheter' or 'line' is placed in a vein and this provides a way of administering regular invasive medication.
Febrile neutropenia	Febrile neutropenia is the development of fever, often with other signs of infection, in a patient with neutropenia, an abnormally low number of neutrophil granulocytes (a type of white blood cell) in the blood which can lead to neutropaenic sepsis, a potentially fatal complication of anticancer treatment (particulary chemotherapy)
Levels of care	Level 3 (PICU/PCCU)
Paediatrics:	A unit delivering Level 2 and Level 3 paediatric critical care (and Level 1 if required). This unit may also be called a Paediatric Intensive Care Unit (PICU).
Adult/general:	Level 3: (ICU) - Patients requiring advanced respiratory support alone or basic respiratory support together with support of at least two organs. This level includes all complex patients requiring support for multi-organ failure. (NB: basic respiratory and basic cardiovascular do not count as two organs if they occur simutaneously but will count as level 3 if another organ is supported at the same time)
Performance score (Lansky/ Karnofsky):	Lansky/Karnofsky performance score is used to determine the functional status of a patient. The Lansky score has been designed for patients aged less than 16 years old and the Karnofsky score is designed for patients aged 16 years and older (see page 14 for Lansky/Karnofsky scale)
Paediatric oncology shared care unit (POSCU)	A designated hospital that shares the care of paediatric oncology patients with a Principal Treatment Centre
Principal treatment centre (PTC)	The specialist paediatric oncology unit that is coordinating the patient's care
Protocol/ regimen/ line:	A protocol of chemotherapy is the number of cycles of chemotherapy that consistute a complete chemotherapy treatment. Typically 4-6 cycles of chemotherapy constitute a protocol (or line) of chemotherapy.
Systemic anti cancer therapy (SACT)	To include all "traditional" cytotoxins - intravenous, oral, subcutaneous, intravesical, intrathecal, or intraperitoneal chemotherapy, monoclonal antibodies or cytokines, but excluding vaccines, gene therapy and hormonal agents
Teenage/young adult designated hospital	Teenage and Young Adult specialist haematology and oncology unit that coordinates the patient's care

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A. CASE SUMMARY

TIMEFRAME - QUESTIONNAIRES SHOULD BE COMPLETED FOR PATIENTS WHO WERE TREATED WITH SACT BETWEEN 1ST MARCH 2014 - 31ST MAY 2016 - for patients admitted with multiple treatments this refers to the last treatment within the study period.

1. Please use the box below to provide a brief summary of this case, adding any additional comments or information you feel relevant. Please write clearly for the benefit of the case reviewers. You may also write or type on a separate sheet.

NCEPOD attaches great importance to this summary. Please give as much information as possible about the care of this patient.

B. PATIENT DETAILS

2. Age (date the patient died/was admitted to PICU/ICU*) ☐☐☐ years

3. Gender ☐ Male ☐ Female

*Please see definitions on p.2

4a. Were there any difficulties in communication with the patient/ patient's family (e.g. learning difficulities/ language barriers)? ☐ Yes ☐ No

4b. If YES to 4a, please provide details:

5. For solid tumours and lymphomas:

a. Please state primary site of tumour or type of haematological malignancy:

i) Head and neck

ii) CNS

iii) Thorax

iv) Abdomen

v) Other (please state):

☐ Unknown

C. PAST MEDICAL HISTORY

6. What was the date of the first diagnosis of cancer? ☐☐ ☐☐ ☐☐ dd/mm/yy

7. Please list any significant past medical history not relating to the cancer:

	Condition	Date first diagnosed
a.		☐☐ ☐☐ ☐☐ dd/mm/yy
b.		☐☐ ☐☐ ☐☐ dd/mm/yy
c.		☐☐ ☐☐ ☐☐ dd/mm/yy

8a. Has this patient recently been transitioned between services? ☐ Yes ☐ No

8b. If YES to 8a, was this:

i) Paediatric to adolescent services ☐ Yes ☐ No Date: ☐☐ ☐☐ ☐☐ dd/mm/yy

ii) Paediatric to adult services ☐ Yes ☐ No Date: ☐☐ ☐☐ ☐☐ dd/mm/yy

8c. If YES to 8a, in your opinion, were there any problems associated with the transition of care? ☐ Yes ☐ No

8d. If YES to 8c, please provide details:

9a. Has this patient undergone surgery as part of their treatment of this malignancy? ☐ Yes ☐ No

9b. If YES to 9a, please provide details:

Date: ☐☐ ☐☐ ☐☐ (d d m m y y)

Surgery:

10a. Has this patient received radiotherapy as part of their treatment of this malignancy? ☐ Yes ☐ No

10b. If YES to 10a, please specify the following:

i) Date of first fraction: ☐☐ ☐☐ ☐☐ (d d m m y y) ☐ Unknown

ii) Site: ☐ Unknown

iii) Dose in Gy: ☐☐☐☐ ☐ Unknown

iv) Number of fractions: ☐☐☐☐ ☐ Unknown

v) Duration (days): ☐☐☐☐ ☐ Unknown

11. Was radiotherapy given concurrently with this most recent protocol* of SACT*? ☐ Yes ☐ No ☐ Unknown

***Please see definitions on p.2**

12a. Has this patient had previous protocols of SACT for the current or other cancer? ☐ Yes ☐ No ☐ Unknown

*Please see definitions on p.2

12b. If YES to 12a, please supply details of the most recent four protocols given in this table, making clear the number of cycles completed for each one, the response to treatment and intent:

Protocol/ regimen* (not including the most recent):	Start of protocol date: d d m m y y	No. of cycles* completed	Patient responding to treatment (Y/N)	Intent of treatment: curative/ pallative
	☐☐ ☐☐ ☐☐	☐☐☐	☐ Y ☐ N	☐ C ☐ P
	☐☐ ☐☐ ☐☐	☐☐☐	☐ Y ☐ N	☐ C ☐ P
	☐☐ ☐☐ ☐☐	☐☐☐	☐ Y ☐ N	☐ C ☐ P
	☐☐ ☐☐ ☐☐	☐☐☐	☐ Y ☐ N	☐ C ☐ P

D. MEDICAL CONDITION AT TIME MOST RECENT PROTOCOL OF SACT WAS PRESCRIBED

13. Please select the known site(s) of disease when this protocol of SACT was started (select all that apply):

☐ No macroscopic disease ☐ Lymph nodes ☐ Metastases

☐ Primary site (specify sites):

☐ Other (specify sites):

☐ Unknown

14a. For haematological malignancies please state if this was:

☐ Acute lymphoblastic leukaemia ☐ Acute myeloid leukaemia

14b. At the time the most recent protocol was prescribed was the patient in remission? ☐ Yes ☐ No

14c. If YES to 14b , what was the recorded date of remission: ☐☐ ☐☐ ☐☐ dd/mm/yy

14d. Had the patient relapsed? ☐ Yes ☐ No

14e. If YES to 14d, please state date(s) and site(s) of relapse(s):

Date:	Site:
☐☐ ☐☐ ☐☐ (d d m m y y)	
☐☐ ☐☐ ☐☐ (d d m m y y)	
☐☐ ☐☐ ☐☐ (d d m m y y)	
☐☐ ☐☐ ☐☐ (d d m m y y)	

15a. Was a performance score taken to describe the fitness of the patient immediately prior to when the most recent protocol of SACT was initiated? ☐ Yes ☐ No

15b. If YES to 15a, please state which one was used and the performance score recorded*:

☐ LANSKY (1-100)* ☐ KARNOFSKY(1-100)* ☐ Other score

*Please see definitions on p.14

☐☐☐ ☐ Unknown ☐☐☐ ☐ Unknown

15c. If NO to 15a (no score was recorded) how was the fitness for treatment recorded?

16. Compared to the previous protocol of SACT, if this is not the first protocol what was the clinical status of the patient?

☐ Patient responding to treatment ☐ Patient not responding to treatment (no deterioration)

☐ Patient not responding to treatment (deterioration in condition) ☐ N/A (first protocol)

☐ Other (please state):

17. Please state any comorbidities present at the time of prescription of the most recent protocol of SACT?

☐ Cardiac ☐ Respiratory ☐ Psychiatric ☐ Sepsis

☐ Renal ☐ Haematological ☐ Gastrointestinal ☐ Endocrine

☐ Vascular ☐ Musculoskeletal ☐ Genetic abnormality or syndrome ☐ Neurological

☐ Other (please state): ☐ Unknown

18. Please state any medical complications of cancer present at time of protocol prescription:

☐ Renal failure ☐ Liver failure ☐ Pleural effusion ☐ Ascites

☐ Neurological dysfunction (specify)

☐ Other (specify)

☐ Unknown

E. MANAGEMENT PLAN

19. Please provide details of the most recent planned protocol of SACT:

i) Protocol/regimen

ii) Drugs

iii) Method of calculation: target doses mg/m2 or AUC ☐ Unknown

v) Which service oversaw prescription of SACT: ☐ Adult haematology ☐ Adult solid tumour

☐ Other (please state): ☐ Paediatric chemotherapy service

20a. Was this protocol of SACT agreed at an MDT meeting? ☐ Yes ☐ No

20b. If YES to 20a, which specialities were in attendance at this MDT meeting?

☐☐☐ ☐☐☐ ☐☐☐ ☐☐☐ ☐☐☐ ☐☐☐ **Specialty codes on p.2**

21. What was the grade of doctor who initated/ prescribed the protocol of SACT? **Please mark one only**

☐ Consultant ☐ Associate Specialist ☐ Clinical Fellow ☐ Staff Grade

☐ F1/F2 ☐ ST 1/2 ☐ ST3 and above ☐ Not documented

☐ Other (please state): ☐

22. Please state the specialty of doctor who initiated/ prescribed this protocol of SACT?

☐☐☐ **Specialty codes on p.2**

23. Is there a local written clinical care pathway for the management of this malignancy? ☐ Yes ☐ No ☐ Unknown

24a. Was this protocol of SACT given as part of a research study? ☐ Yes ☐ No ☐ Unknown

24b. If YES to 24a, was this:

☐ A single-centre trial ☐ A multi-centre trial

☐ An industry sponsored trial ☐ A national cancer research network approved trial

☐ Unknown

24c. If YES to 24a, which phase of the study was it?

☐ Phase 1 ☐ Phase 2 ☐ Phase 3

25a. Was consent for therapy documented in the case notes? ☐ Yes ☐ No ☐ Unknown

25b. If YES to 25a, who took consent?

☐ Consultant ☐ Associate Specialist ☐ Clinical Fellow ☐ Staff Grade

☐ F1/F2 ☐ ST 1/2 ☐ ST3 and above ☐ Not documented

☐ Other (please state): ☐

25c. If YES to 25a, please specify the specialty of the clinician who took consent ☐☐☐ **Specialty codes on p.2**

26. Were discussions around consent recorded in the notes other than on the consent form? ☐ Yes ☐ No

27a. If YES to 25a, did the child/ teenager/young adult give assent? ☐ Yes ☐ No

27b. If YES to 27a, did the child/ teenager/young adult give consent? ☐ Yes ☐ No

28. Did you feel that any potential side effects were fully understood by:

i) The patient ☐ Yes ☐ No ☐ N/A ☐ Unknown

ii) The parent(s)/ carer/ relatives ☐ Yes ☐ No ☐ N/A ☐ Unknown

29. Was the intent of treatment recorded in the notes? ☐ Yes ☐ No ☐ Unknown

30. Please mark the box that best describes the SACT treatment intent:

☐ Potentially curative ☐ Palliative ☐ Intent unclear from notes ☐ Unknown

31. What was your estimated chance of cure in this patient:

i) At the time the protocol was first prescribed?

☐ >50% ☐ >20 - 50% ☐ >5 - 20% ☐ <5% ☐ Unknown

ii) At the time the final cycle was first prescribed?

☐ >50% ☐ >20 - 50% ☐ >5 - 20% ☐ <5% ☐ Unknown

32. Did you feel that the chance of cure were fully understood by:

i) The patient: ☐ Yes ☐ No ☐ N/A ☐ Unknown

ii) The parent(s)/ carer/ relatives: ☐ Yes ☐ No ☐ N/A ☐ Unknown

33a. In your opinion, was there any pressure on the prescribing clinician to prescribe SACT at the time this protocol was prescribed?

☐ Yes ☐ No ☐ Unknown

33b. If YES to 33a, was this pressure from:

i) The patient ☐ Yes ☐ No ii) The parent(s) /carer/ relatives ☐ Yes ☐ No

iii) Both the patient and their parent(s) ☐ Yes ☐ No iv) Other (please state): ☐ Yes ☐ No

34. Was written information regarding the following aspects of care given to the patient/ parent(s)/ carer/ relatives:

	i) Patient	ii) Parent(s)/ carer/ relatives
a. The chance of success/ potential side effects	☐ Yes ☐ No ☐ Unknown	☐ Yes ☐ No ☐ Unknown
b. Advice given regarding what to do in the event of:		
i) Fever	☐ Yes ☐ No ☐ Unknown	☐ Yes ☐ No ☐ Unknown
ii) Bleeding	☐ Yes ☐ No ☐ Unknown	☐ Yes ☐ No ☐ Unknown
iii) Vomiting	☐ Yes ☐ No ☐ Unknown	☐ Yes ☐ No ☐ Unknown
iv) Other symptoms/signs	☐ Yes ☐ No ☐ Unknown	☐ Yes ☐ No ☐ Unknown

35. Did the patient/ carer/ relative(s) receive training regarding: ***Please see definitions on p.2**

a. How to recognise febrile neutropenia*/ neutropaenic sepsis? ☐ Yes ☐ No

b. What to do in the event of febrile neutropenia/ neutropaenic sepsis? ☐ Yes ☐ No

c. If YES to 35a or b (patient/carer/relative received training in how to recognise and what to do in the event of febrile neutropenia/ neutropaenic sepsis) please provide details:

36. Were there any difficulties in communication relating to:

a. Language ☐ Yes ☐ No

b. Understanding of medical terminology ☐ Yes ☐ No

c. Acceptance of the situation ☐ Yes ☐ No

d. Other issues of communication (please state): ☐ Yes ☐ No

e. If YES to any of the above (36a-d) please provide details:

37a. Were there any previous problems with compliance? ☐ Yes ☐ No

37b. If YES to 37a, please provide details:

37c. If YES to 37a, were these concerns regarding:

☐ The patient ☐ The parent(s)/ carers/ relatives

☐ Other (please state):

38a. Did any palliative care discussions/ ceilings of treatment discussions take place at any point in the care of this patient?

☐ Yes ☐ No ☐ Unknown

38b. If NO to 38a, in your opinion should there have been?

☐ Yes ☐ No

38c. If YES to 38a, when did the discussion(s) take place? ☐☐ ☐☐ ☐☐ dd/mm/yy ☐ Unknown

38d. If YES to 38a, what did this involve?

38e. If YES to 38a, did the palliative care/ceilings of treatment discussions involve:

i) The child/ teenager/young adult ☐ Yes ☐ No ☐ N/A

ii) The parent(s)/ carer/ relatives ☐ Yes ☐ No ☐ N/A

38f. If YES to 38c, in your opinion did they take place at the right time? ☐ Yes ☐ No

39. Was there a named key worker for this patient? ☐ Yes ☐ No

F. MOST RECENT CYCLE OF SACT (cycle immediately prior to death/ICU admission)

40a. Cycle number*: *Please see definitions on p.2 ☐☐☐ of ☐☐☐ ☐ Unknown

40b. Date of decision to treat: ☐☐ ☐☐ ☐☐ dd/mm/yy ☐ Unknown

40c. Date (day 1 of prescription): ☐☐ ☐☐ ☐☐ dd/mm/yy ☐ Unknown

40d. Date (day 1 of administration): ☐☐ ☐☐ ☐☐ dd/mm/yy ☐ Unknown

41a. Was a performance score taken to describe the fitness of the patient immediately prior to when the most recent cycle of SACT was initiated? ☐ Yes ☐ No

41b. If YES to 41a, please state which one was used and the performance score recorded*:

☐ LANSKY (1-100)* ☐ KARNOFSKY(1-100)* ☐ Other score *Please see definitions on p.14

☐☐☐ ☐ Unknown ☐☐☐ ☐ Unknown

41c. If NO to 41a (no score was recorded) how was the fitness for treatment recorded?

42. What method was used to administer SACT (select all that apply):

☐ Intravenous ☐ Subcutaneous ☐ IV Peripheral ☐ Unknown

☐ Oral ☐ Intrathecal ☐ IV through central line

43a. Did the patient have CV access?* *Please see definitions on p.2 ☐ Yes ☐ No

43b. If YES to 43a, which type?

43c. If YES to 43a, were there any immediate complications in the administration in the final cycle of SACT? ☐ Yes ☐ No

43d. If YES to 43c, please provide details:

44. Please complete the table below regarding drug dosages prescribed/administered for final cycle of SACT:

Drugs	Dose (mg/m2 or AUC)	Caculated full dose (mg)	Dose given (mg)/ % full dose
	☐☐☐☐	☐☐☐☐	☐☐☐☐
	☐☐☐☐	☐☐☐☐	☐☐☐☐
	☐☐☐☐	☐☐☐☐	☐☐☐☐
	☐☐☐☐	☐☐☐☐	☐☐☐☐

45. Was this cycle of SACT: ☐ Administered as planned

☐ Delayed (Length of delay): ☐☐☐ days ☐ Unknown

(Please state reason for delay:):

☐ Administered at a reduced dose State % dose reduction): ☐☐☐ % ☐ Unknown

(Please state reason for reduced dose):

46a. Who prescribed this cycle of SACT?

☐ Consultant ☐ Associate Specialist ☐ Clinical Fellow ☐ ST 1/2

☐ Staff Grade ☐ ST3 and above ☐ F1/F2 ☐ Unknown

☐ Other (please state): ☐ Not documented ☐ Specialist Nurse Practitioner

46b. Please specify specialty: ☐☐☐ **Specialty codes on p.2**

47a. Who reviewed the patient on the day of SACT treatment? (mark all that apply)

☐ Consultant ☐ Associate Specialist ☐ Clinical Fellow ☐ ST 1/2

☐ Staff Grade ☐ ST3 and above ☐ F1/F2 ☐ Unknown

☐ Other (please state): ☐ Not documented ☐ Specialist Nurse Practitioner

47b. Please specify specialty/ specialties of clinicians who reviewed the patient on the day of SACT?

☐☐☐ ☐☐☐ ☐☐☐ **Specialty codes on p.2**

48. Who administered the most recent cycle of SACT?

☐ Oncology/ haematology consultant ☐ Oncology/ haematology trainee ☐ F1/F2

☐ Oncology nurse ☐ Other nurse ☐ The patient

☐ Paediatric oncology/ haematology consultant ☐ Paediatric oncology/ haematology trainee ☐ Parent/ Carer

☐ Other (please specify): ☐ Paediatric nurse

49a. Where was the most recent cycle of SACT administered? (please select all that apply): ***Please see definitions on p.2**

☐ Local district general hospital <500 beds (small) ☐ Local district general hospital >500 beds (large)

☐ Principal treatment centre (PTC)* ☐ Paediatric specialist hosptial

☐ Paediatric oncology shared care unit (POSCU)* ☐ Teenage/young adults designated hospital*

☐ Specialist cancer unit ☐ University teaching hospital

49b. Please specify if the most recent cycle of SACT was administered at any of the following (please select one):

Day cases

☐ Outpatient clinic ☐ Daycare unit ☐ Designated chemotherapy unit

☐ Other location (please specify): ☐ Patient's home ☐ Unknown

Inpatients

☐ Chemotherapy ward ☐ Oncology ward ☐ Haematology ward ☐ Unknown

☐ Other (please specify):

50. At the time of the prescription of the most recent cycle of SACT, were checks made that the patient/ parent(s) were aware of:

a. How to recognise potential neutropaenic sepsis? ☐ Yes ☐ No ☐ N/A ☐ Unknown

i) Please give further details:

b. What to do in the event of neutropaenic sepsis? ☐ Yes ☐ No ☐ N/A ☐ Unknown

i) Please give further details:

51a. At the time of prescription of the most recent cycle of SACT:

i) Was the patient's height recorded? ☐ Yes ☐ No ☐ Unknown

ii) Was the patient's weight recorded? ☐ Yes ☐ No ☐ Unknown

51b. If YES to 51a(i), please state height: ☐☐☐ cm **OR** ☐☐ ft ☐☐ inches

51c. If YES to 51a(ii), please state weight: ☐☐☐ kgs **OR** ☐☐ st ☐☐ lb

52a. Is there a record of every dose of SACT the patient has received? ☐ Yes ☐ No ☐ Unknown

52b. If YES to 52a, is this:

☐ Hard copy case notes at the hospital ☐ Electronic records - accessible by secondary specialist care only

☐ Electronic records - accessible by secondary/primary/community care

G. STRUCTURED COMMENTARY

53. Please outline any organisational aspects of SACT for children, teens and young adults in your hospital that in your opinion may have had a negative effect on patient outcome:

54. With the benefit of hindsight, is there anything you believe could have been done differently regarding the management of this patient? We have highlighted some areas that you might want to consider with respect to patient outcome:

- ☐ Decision to treat with SACT
- ☐ Consent to SACT treatment
- ☐ Administration of SACT
- ☐ Patient information given regarding SACT, regarding sepsis etc
- ☐ Prescribing of SACT, dose etc

H. GENERAL COMMENTS

55. Please write clearly regarding any additional observations you wish to report

Thank you for taking the time to complete this questionnaire

LANSKY/ KARNOFSKY PERFORMANCE SCALE

LANSKY SCALE (patient aged <16)		KARNOFSKY SCALE (patient aged >16)	
Able to carry out normal activity; no special care is needed		**Able to carry out normal activity; no special care is needed**	
100	Fully active	**100**	Normal no complaints, no evidence of disease
90	Minor restriction in physically strenuous play	**90**	Able to carry on normal activity
80	Restricted in strenuous play; tires more easily; otherwise active	**80**	Normal activity with effort
Mild to moderate restriction		**Unable to work, able to live at home cares for most personal needs, a varying amount of assistance is needed**	
70	Both greater restrictions of, and less time spent in active play	**70**	Cares for self, unable to carry on normal activity or do active work
60	Ambulatory up to 50% of time, limited active play with assistance/supervision	**60**	Requires occasional assistance but is able to care for most needs
50	Considerable assistance required for any active play, fully able to engage in quit play	**50**	Requires considerable assistance and frequent medical care
Moderate to severe restriction		**Unable to care for self; requires equivalent of institutional or hospital care, disease may be progressing rapidly**	
40	Able to initiate quiet activities	**40**	Disabled, requires special care and assistance
30	Needs considerable assistance for quiet activity	**30**	Severely disabled, hospitalisation indicated, although death not imminent
20	Limited to very passive activity initiated by others (e.g. TV)	**20**	Very sick, hospitalisation necessary
10	Completely disabled, not even passive play	**10**	Moribund, fatal process progressing rapidly

This study was commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the Clinical Outcome Review Programme into Medical and Surgical Care.

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