

Reporting patient deaths post-autologous stem cell harvest and haematopoietic stem cell transplant UHL Children's Hospital Guideline

Introduction and Who this Standard Operating Procedure applies to

This CYPICS network guideline has been developed by clinicians from Nottingham Children's Oncology Unit with consultation across the network including from the Leicester Royal Infirmary and has been ratified by the Leicester Children's Hospital guideline process.

This guideline applies to all children and young people under the age of 19 years who are receiving chemotherapy for malignant disease

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NOTTINGHAM UNIVERSITY HOSPITALS NHS TRUST & UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST

Reporting Patient Deaths

CHILDREN'S HOSPITAL SOP

East Midlands Children's and Young Persons' Integrated Cancer Service Post-Autologous Stem Cell Transplant Programme

Title	Reporting patient deaths post-autologous stem cell harvest and haematopoietic stem cell transplant
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Consultation Undertaken	Dr Sophie Wilne, Consultant Paediatric Oncologist. Dr Jennifer Turnbull, Consultant Paediatric Oncologist. Margaret Parr, CYPICS Lead Nurse. Ellie Nash, Data Manager, Sheffield Children's (NHS) Foundation Trust. Sharon Barrott, Clinical Quality Manager, Sheffield Children's (NHS) Foundation Trust.
Accreditation Implications	Supports compliance with FACT-JACIE standards
Target Audience	CYPICS consultants and Quality Manager
Lead Manager	Dr Sophie Wilne



Document Control

Issue Status	Version	Issue Date	Lead Author	Description
Final	V1	21/12/20	Katie Manning	Original document
Final	V2	February 2023	Elizabeth Ralling	Amendment to names/contact details of relevant professionals Addition of 3.6. Streamlining of procedure in section 4. Addition of QM into procedure flow.

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1. Introduction

- 1.1 All patients undergoing haematopoietic stem cell transplant (HSCT) are required to be registered with the European Society for Blood and Marrow Transplantation (EBMT). Children and young people within the care of EMCYPICS that undergo HSCT will be referred to Sheffield Children's (NHS) Foundation Trust (SCFT) for their procedure. The SCFT data manager registers children and young people with EBMT and is required to report deaths post-transplant.
- 1.2 Deaths that occur post-transplant need to be reported within specified timeframes (see appendix 1) to SCFT so that the transplant team can update their local records and inform EBMT.
- 1.3 SCFT will also inform NHS Blood and Transplant (NHSBT) Cellular and Molecular Therapies (CMT) so that any stored cells from autologous harvest may be discarded. This ensures that unnecessary and additional storage costs are avoided.

2. Purpose and Objectives

- 2.1 The purpose of this SOP is to ensure that the death of a child or young person post-autologous stem cell harvest and transplant is reported to the appropriate members of the Sheffield Children's Hospital (NHS) Foundation Trust (SCFT) transplant team within the specified timeframes.
- 2.2 The death of a child or young person post-transplant must be reported to EBMT to ensure compliance with national requirements and JACIE standards.
- 2.3 Timely reporting of deaths will ensure that stored cells may be discarded to prevent unnecessary storage costs.
- 2.4 Sharing details of patient deaths across the transplant programme will ensure that all professionals working with the child and family throughout the programme are aware of the child/young persons' death to ensure appropriate communication with and support for the family and other health professionals.



3. Responsibilities

- 3.1 The hot week or on-call paediatric haematology/oncology consultant is responsible for informing the SCFT on-call haematology/oncology consultant within 24 hours of the death of any child or young person post HSCT before day +100.
- 3.2 The patient's named consultant is responsible for ensuring that the deceased child or young person is listed for M&M discussion at the relevant MDT within specified timeframes.
- 3.3 The EMCYPICS quality manager is responsible for emailing the SCFT HSCT team with the patient details, date and category of death of a child or young person post-HSCT within 7 working days.
- 3.4 The EMCYPICS quality manager is responsible for providing the summary of death and/or M&M records to the SCFT transplant team within specified timeframes.
- 3.5 The quality manager or the NUH consultant attending the SCFT quality management group meeting are responsible for ensuring that any deaths following autologous stem cell harvest or transplant are reported in the autologous deaths agenda item.
- 3.6 The EMCYPICS quality manager is responsible for ensuring an easily accessible record of patient deaths post-HSCT is kept up to date.

4. Procedure

4.1 **Death before day +100 post-transplant (see appendix 1)**

- 4.1.1 Following the death of a child or young person before day +100 post HSCT the on-call haematology/oncology consultant must inform the SCFT transplant team within 24 hours.
- 4.1.2 The **CYPICS** haematology/oncology consultant must contact the SCFT haematology/oncology consultant on-call via the SCFT switchboard on 0114 271 7000. The patient details, date and category of death should be provided.



4.1.3 Inform NUH Quality Manager on nuhnt.cypicasct@nhs.net of patient details, date and category of death. Within 7 working days of the patient's death, the NUH Quality Manager must email the patient details, date and category of death to:

SCFT Consultant Oncologist: Dan.Yeomanson@nhs.net

SCFT BMT Nurses: scn-tr.bmtnurses@nhs.net

SCFT HSCT Quality Manager: Eleanor.Leaney1@nhs.net

SCFT HSCT Quality Management Officer: Sharon.Barrott@nhs.net

SCFT Data Manager: Ellie.nash@nhs.net

4.1.4 The patient's named consultant must ensure that M&M discussion is conducted at the relevant MDT within 8 weeks of the patient's death. Contact CypicsAdminTeam@nuh.nhs.uk to list the patient for discussion and be sure to note the 8 week time frame.

4.1.5 The quality manager will email a copy of the verified outcome summary M&M discussion within 7 working days of M&M discussion to:

SCFT HSCT Quality Management Officer: Sharon.Barrott@nhs.net

SCFT Data Manager: Ellie.nash@nhs.net

SCFT HSCT Quality Manager: Eleanor.Leaney1@nhs.net

4.1.6 The quality manager or haematology/oncology consultant attending the SCFT quality management group meeting must report the death of the child or young person within the autologous deaths agenda item following local M&M discussion.

4.2 Death after day +100 post-transplant (see appendix 1)

4.2.1 Following the death of a child or young person after day 100 post HSCT the quality manager must complete steps 4.1.3 – 4.1.6

4.3 Death following autologous stem cell harvest (cells remain in storage)

4.3.1 Following the death of a child or young person where autologous stem cells have been harvested and cells remain in storage, but no transplant has been undertaken the named c, steps 4.1.3 – 4.1.6 must be completed.

5. Limitations

5.1 In the absence of the quality manager the liaison nurses will undertake the roles for reporting patient deaths to the SCFT transplant team as per ASCT/C/001 [Autologous Stem Cell Transplant Programme Recovery Plan](#)



- 5.2 This SOP should be followed in addition to any local and national guidance/policies following the death of a child or young person.

6. References/ Further Information

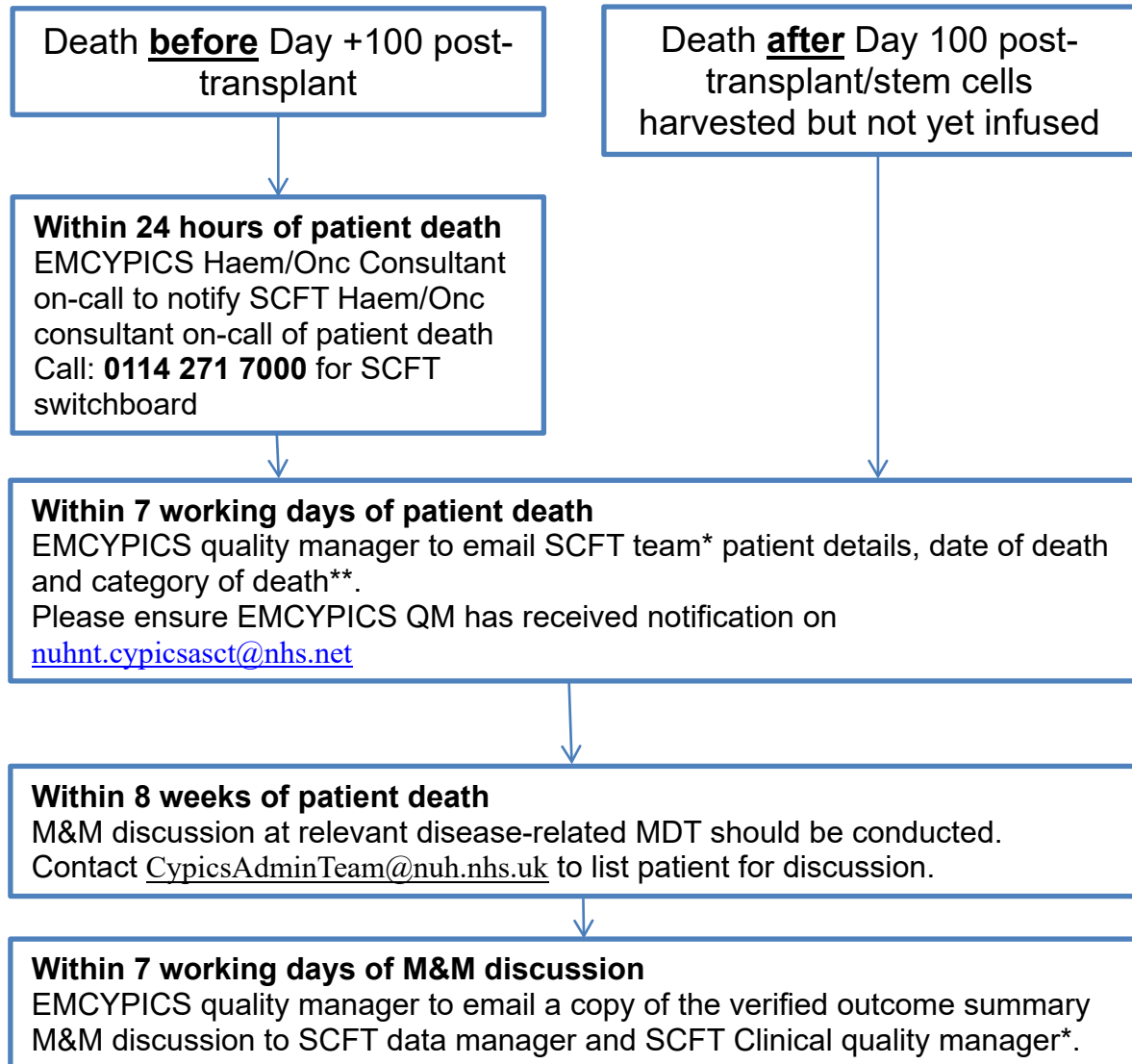
ASCT/C/001 [Autologous Stem Cell Transplant Programme Recovery Plan](#)

NUH Paediatric End of Life Resources [National and NUH Paediatric End of Life Policies and Guidance](#)

Child Death and CDOP Process (0-18 years) UHL Childrens Hospital
Guideline UHL Trust ref: D3/2021



Appendix 1: Flow chart for reporting deaths post-transplant



*Emails to be sent to:
 SCFT Consultant Oncologist:
Dan.Yeomanson@nhs.net
 SCFT BMT Nurses: scn-tr.bmtnurses@nhs.net
 SCFT HSCT Quality Manager:
Eleanor.Leaney1@nhs.net
 SCFT HSCT Quality Management Officer:
Sharon.Barrott@nhs.net
 SCFT Data Manager: Ellie.nash@nhs.net

**Category of death:

- SAEAR (serious adverse event and reaction)
- Transplant-related
- Disease Progression
- Relapse



UHL Education and Training

None

Key Words

Children's & young person's integrated cancer services (CYPICS), European Society for Blood and Marrow Transplantation (EBMT)

The Trust recognises the diversity of the local community it serves. Our aim therefore is to provide a safe environment free from discrimination and treat all individuals fairly with dignity and appropriately according to their needs. As part of its development, this policy and its impact on equality have been reviewed and no detriment was identified.

CONTACT AND REVIEW DETAILS	
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Details of Changes made during review: Document new to UHL. Network version 2, changes made listed page 3	