

Reporting Patient Deaths Post-Autologous Stem Cell Transplant Programme

Introduction and Who this Standard Operating Procedure applies to

This CYPICS network standard operating procedure (SOP) 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 SOP 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

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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Accreditation Implications	Supports compliance with FACT-JACIE standards
Target Audience	CYPICS consultants and Quality Manager
Lead Manager	Dr Sophie Wilne
Authorised by: (Programme Director or Quality Manager)	Name: Dr Sophie Wilne Signature: SHW Role: Programme Director Date: 21.12.2020

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Contents

1. Introduction	4
2. Purpose and Objectives	4
3. Responsibilities	5
4. Procedure	5
4.1 Death before day +100 post-transplant (see appendix 1)	5
4.2 Death after day +100 post-transplant (see appendix 1)	6
4.3 Death following autologous stem cell harvest (cells remain in storage)	6
5. Limitations	6
6. References/ Further Information	6
Appendix 1: Flow chart for reporting deaths post-transplant	8

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 Transfusion (NHSBT) Cellular and Molecular Therapies 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.
- 3.2 The EMCYPICS quality manager is responsible for emailing the SCFT transplant team with the patient details, date and category of death of a child or young person post-HSCT within 7 working days.
- 3.3 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.
- 3.4 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.

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 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 Within 7 working days of the patient's death, the 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 Clinical Quality Manager: 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.

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 Clinical Quality Manager: Sharon.Barrott@nhs.net
SCFT Data Manager: Ellie.nash@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 consultant must ensure that M&M discussion is conducted at the relevant MDT within 6 weeks of the patient's death.

4.3.2 The quality manager must provide a summary of death and/or verified outcome summary from the MDT M&M discussion within 6 weeks of death to:

SCFT Consultant Oncologist: Dan.Yeomanson@nhs.net

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

SCFT Clinical Quality Manager: Sharon.Barrott@nhs.net

SCFT Data Manager: Ellie.nash@nhs.net

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.pdf](#)

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](#)

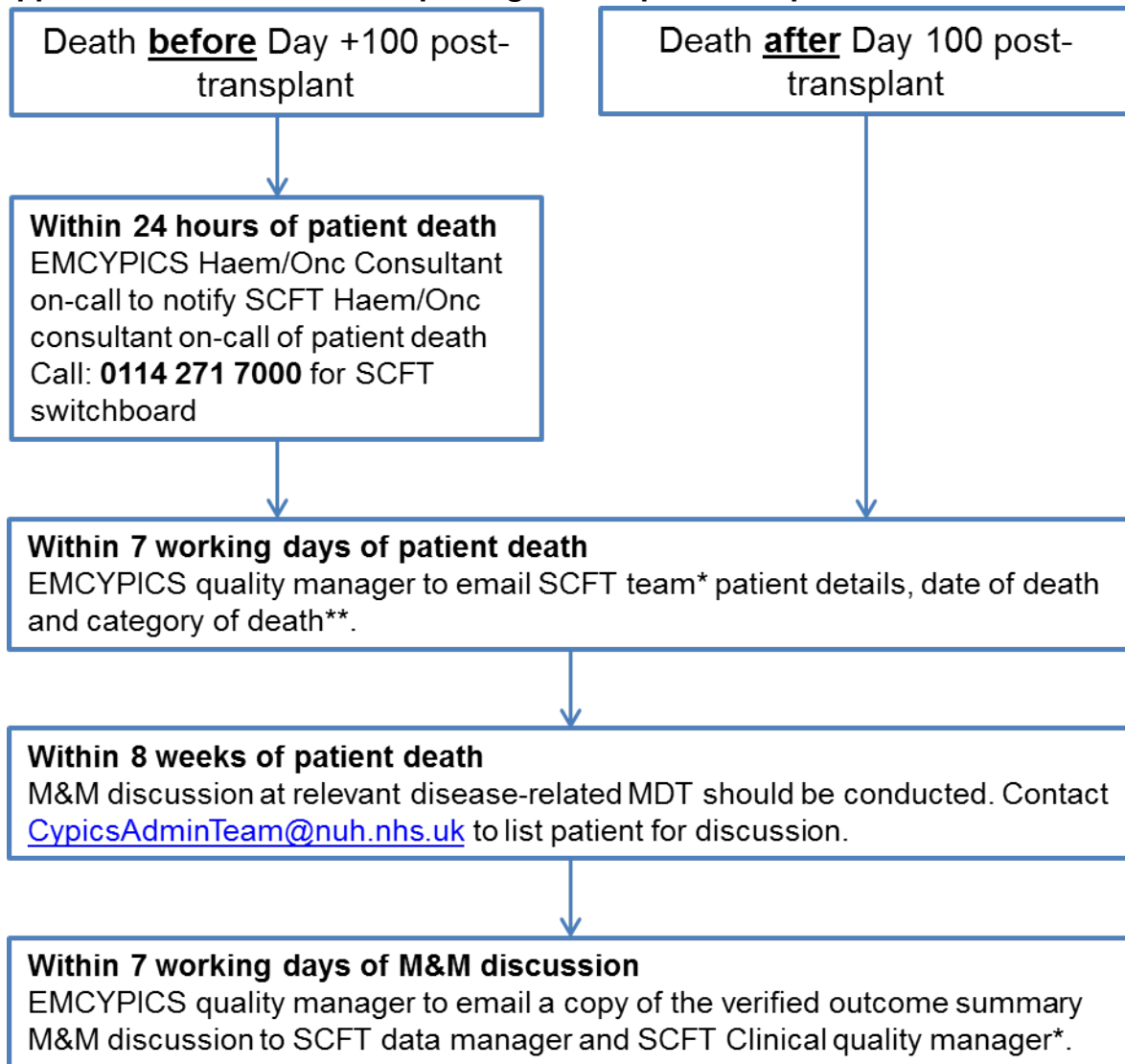
Child Death and CDOP Process (0-18 years) UHL Childrens Hospital
Guideline

Rainbows Referral UHL Childrens Hospital Guideline

Last Offices Care of the Deceased UHL Policy

ReSPECT Leicester Leicestershire Rutland Policy

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 Clinical Quality Manager:
Sharon.barrott@nuh.nhs.uk
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

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None

Key Words

Children, CYPICS, Haemopoietic Stem Cell Transplant (HSCT), Haematology, Oncology
Young People:

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	
SOP Lead (Name and Title) Emma Ross; Consultant Paediatric Oncologist	Executive Lead Chief Medical Officer
Details of Changes made during review: New SOP	