LEARNING FROM DEATHS POLICY

Summary

Learning from a review of the care provided to patients who die is integral to a provider’s clinical governance and quality improvement work. To fulfil the standards and new reporting set out for acute, mental health and community NHS Trusts and Foundation Trusts, Trusts now need to ensure their governance arrangements and processes include, facilitate and give due focus to the review, investigation and reporting of deaths, including those deaths that are determined more likely than not to have resulted from problems in care. Trusts should also ensure that they share and act upon any learning derived from these processes.

This policy outlines how The Royal Marsden NHS Foundation Trust (the Trust) responds to, and learns from, deaths of inpatients who die under its management and care, including:

i. How inpatient deaths in the Trust are reviewed and reported
ii. Categories and selection of deaths in scope for case record review using the structure judgement review
iii. The Trust’s approach to undertaking case records reviews using the structure judgement review
iv. How the Trust’s processes respond to the death of an individual with a learning disability or mental health needs, an infant, child, or maternal death
v. Approach to the issue of potentially avoidable mortality and the Trust’s mortality governance processes.

Also outlined in this document is a clear policy for engagement with bereaved families and carers, including giving them the opportunity to raise questions or share concerns in relation to the quality of care received by their loved one.

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1. INTRODUCTION

1.1 In March 2017, the National Quality Board issued a framework for NHS trusts on identifying, reporting, investigating and learning from deaths in care called “National Guidance on Learning from Deaths”\(^1\). In accordance with this document, this policy was developed.

Deaths within The Royal Marsden NHS Foundation Trust are an inevitable consequence despite the complex treatment and care delivered to patients with advanced cancer. The quality of care patients experience before those deaths and bereaved relatives experience afterwards must be reviewed in order to learn from any mistakes that may have occurred. This scrutiny is overseen both within Clinical Units but also at Trust wide level with direct report to the Board.

2. DEFINITIONS

2.1 The following definitions apply for the purposes of this policy:

(i) **Case record review** (as defined by the National Quality Board): The application of a case record review to determine whether there were any problems in the care provided to the patient who died in order to learn from what happened. The template used is the *Structured Judgement Review* recommended by the Royal College of Physicians 2017 (Appendix A).

(ii) **Investigation**: The act or process of investigating; a systematic analysis of what happened, how it happened and why. This draws on evidence, including physical evidence, witness accounts, policies, procedures, guidance, good practice and observation - in order to identify the problems in care or service delivery that preceded an incident to understand how and why it occurred. The process aims to identify what may need to change in service provision in order to reduce the risk of future occurrence of similar events.

(iii) **Death due to a problem in care**: A death that has been clinically assessed using a recognised methodology of case record/note review and determined more likely than not to have resulted from problems in healthcare and therefore to have been potentially avoidable.

(iv) **Case note review/Review of deaths**: Each clinical team in the Trust will review a patient’s death in a variety of ways. This review is often presented at morbidity and mortality meetings or at multidisciplinary team meetings. In addition the Hospital Mortality Review Group reviews all deaths as detailed in section 3 below.

(v) **Reasonably Expected Death**: A death that is reasonably expected is one which given the overall clinical condition, the patient is unexpected to survive. All attempts at treating reversible conditions will have been attempted and the death is due to irreversible progressive disease.
2.2 **FLOWCHART OF REVIEW OF DEATHS IN THE TRUST**

Clinical teams review any deaths at mortality and morbidity meetings or at MDT meetings.

In addition Child deaths (up until 18th birthday) follow the ‘Child death review process’. (See section 10)

In addition Head of Safeguarding ensures where a death involves a person (aged 4-74) with learning disabilities follow the LeDeR process. (See section 8)

In addition for maternal deaths report to NCEPOD for inclusion in maternal mortality audit and complete a case record review/structured judgement review. (See section 11)

Report any deaths that meet criteria for Serious Incident investigation to Risk Management team. (See section 5)

Hospital Mortality Review Group each quarter reviews all hospital inpatient deaths. (see section 3)

HMRG identify deaths that meet criteria for ‘Care record review/Structured judgement review’. (see section 3)

Palliative Medicine Consultant and Consultant in Critical Care Medicine conduct ‘Case record review/Structured judgement review’. (see section 5)

HMRG report findings quarterly to IGRM, QAR and the Trust Public Board meeting.

Medical Director reports to NHS Improvement/NHS England as requested.

3. **HOW INPATIENT DEATHS ARE REVIEWED AND REPORTED BY THE HOSPITAL MORTALITY REVIEW GROUP**

3.1 Patient lists of inpatient deaths every quarter are obtained by the Trust's Quality Improvement Auditor and the Clinical Auditor.

3.2 Relevant electronic patient records are then reviewed and data summarised in an Excel spreadsheet.

3.3 Data collected by the Quality Improvement Auditor and Clinical Auditor include hospital site, ward, admissions date, date of death, length of hospital stay prior to death, cancer diagnosis and stage, admission reason, elective/emergency, palliative care referral date, palliative care review date, summary of admission notes, evidence of metastatic disease, prognosis, preferred place of death, place of death, cause of death, reason for death at The Royal Marsden, information on whether the death was reasonably expected considering overall patient clinical condition, information on whether the patient was expected to die at The Royal Marsden, whether the patient had a learning disability, whether the patient had any
mental health issues, whether the patient was an infant or child, maternal death, number and outcomes structured case reviews undertaken, any failures of care identified, letters of condolences written, any queries/concerns highlighted from family or carers.

3.4 All deaths whether reasonably expected or not are reviewed and if the deaths raise any concerns as described in section 4.2, then a case record review is undertaken and learning from this is shared.

3.5 Review of all inpatient deaths undertaken by Consultant in Critical Care Medicine; Palliative Medicine Consultant; and Head of Adult Safeguarding, where required.

3.6 Consultant in Critical Care Medicine; Palliative Medicine Consultant; Head of Adult Safeguarding; Head of Quality Assurance; Quality Improvement Auditor; Clinical Auditor (Hospital Mortality Review Group) and PALs and Bereavement Lead meet quarterly to discuss the cases.

3.7 Data summarised against the following standards for care:

- **Standard 1**: 100% of in-hospital deaths should either be expected given the patient’s overall clinical condition, or should have a clear identifiable irreversible reason for death that could not have been prevented by clinical intervention.

- **Standard 2**: 100% of patients who died in hospital with a documented preferred place of death that was not “hospital” should have a clear, identifiable reason outside the control of RM as to why their preferred place of death was not achievable. (Clear, identifiable reasons could include: patient too unwell to move elsewhere, hospice bed not available or family/care home unable to facilitate home death).

- **Standard 3**: A discussion with the Symptom Control and Palliative Care team takes place in 80% of the admissions which resulted in patient death in hospital, where the death was reasonably expected as per Standard 1.

- **Standard 4**: 100% of patients for whom the Structured Judgement Review is undertaken have no failures of care identified.

3.8 Findings are reported quarterly to the Trust’s Integrated Governance and Risk Management Committee, Quality, Assurance and Risk committee and the Trust Board.

Finding and conclusions are rated:

- If Standards 1 and 4 are red then overall is red.
- If Standards 1 and 4 are green and at least one of Standards 2 & 3 is green, then green.
- All else, amber.
### Report Standards

| Standard 1 | 100% of in-hospital deaths should either be expected given the patient’s overall clinical condition, or should have a clear identifiable irreversible reason for death that could not have been prevented by clinical intervention. |
| Standard 2 | 100% of patients who died in hospital with a documented preferred place of death that was not “hospital” should have a clear identifiable reason outside the control of The Royal Marsden as to why their preferred place of death was not achievable. |
| Standard 3 | A discussion with the Symptom Control and Palliative Care team takes place in 80% of the admissions which resulted in patient death in hospital, where the death was reasonably expected as per standard 1. |
| Standard 4 | 100% of patients for whom the Structured Judgement Review is undertaken have no failures of care identified. |

### Ratings

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<tr>
<td>GREEN</td>
<td>100% for Standards 1, 2 and 4 or &gt;80% for Standard 3</td>
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<tr>
<td>AMBER</td>
<td>80-99% for Standards 1, 2 and 4 or 65-79% for Standard 3</td>
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<td>RED</td>
<td>&lt;79% for Standards 1, 2 and 4 and &lt;64% for Standard 3</td>
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### 4. Categories and Selection of Deaths in Scope for Case Record Review Using the Structured Judgement Review

#### 4.1 Case note review takes place routinely across the Trust within department mortality and morbidity meetings. All deaths are reviewed in a multidisciplinary forum with discussion on circumstances leading up to the death and review of any learning from the death.

#### 4.2 For case record review within the Hospital Mortality Review Group, the group will specifically focus reviews on inpatient deaths within the following categories:

- a. Inpatients with learning disabilities
- b. Inpatients with mental health needs (those detained under the Mental health Act, those detained in a prison)
- c. Inpatients who are under an urgent or standard authorisation of Deprivation of Liberty Safeguards (DOLs)
- d. In infants and children where death was unexpected, preventable or treatment related
- e. In maternal deaths
- f. In a service specialty, particular diagnosis or treatment group where an alarm has been raised to the provider through whatever means (e.g. Summary of Hospital level Mortality indictors, concerns raised by audit work, mortality and morbidity meetings, CQC or another regulator)
- g. Inpatients where patients were not expected to die, i.e. did not fulfil Standard 1
h. Inpatients where concerns have been raised by families or carers either during admission or after death
i. Inpatients who have raised concerns regarding their care during admission prior to death.
j. Inpatients who have an ecoli bacteraemia identified during their final admission

4.3 Findings from the case record reviews undertaken within the Hospital Mortality Review Group are reported quarterly to the Trust’s Integrated Governance and Risk Management Committee, the Quality, Assurance and Risk committee and the Trust Board. Actions will be taken if any failures of care identified.

5. APPROACH TO UNDERTAKING REVIEW OF DEATHS

5.1 There are three levels of scrutiny that the Trust applies to the care provided to someone who dies; (i) death certification; (ii) case record review; and (iii) investigation. They do not need to be initiated sequentially and an investigation may be initiated at any point, whether or not a case record review has been undertaken.

- **Death Certification:** In the existing system of death certification in England, deaths by natural causes are certified by the attending doctor. Doctors are encouraged to report any death to the coroner that they cannot readily certify as being due to natural causes.

- **Case Record Review using the Structured Judgement Review:** Some deaths should be subject to further review as outlined above, looking at the care provided to the deceased as recorded in their case records in order to identify any learning.

- **Investigation:** The Trust may decide that some deaths warrant an investigation and should be guided by the circumstances for investigation in the Serious Incident Framework. When a death meets Serious Incident criteria there is no need to delay the onset of investigation until case record review has been undertaken. Refer to the Trust policy ‘Accident/Incident and Patient Safety Incident Reporting Policy Including Serious Incidents Requiring Investigation’.

- Some deaths will be investigated by other agents, notably the coroner. While care should be taken not to compromise such investigations, equally waiting until other investigations are completed may cause unacceptable delay.

5.2 The purpose of the case record review is to provide information from which teams or the organisation can learn. Explicit judgement commentaries serve two main purposes. First, they allow the reviewer to concisely describe how and why they assess the safety and quality of care provided. Second, they provide a commentary that other health professionals can readily understand if they subsequently look at the completed review.

5.3 There are two stages to the case record review process. In the first stage review, the Consultant in Palliative Medicine and Consultant in Critical Care Medicine review the case notes to identify patients who require second stage review based on the categories outlined in 4.2. The second-stage review is undertaken by two reviewers. A Consultant Reviewer from the same speciality and either the Consultant in Critical Care Medicine or the Consultant in Palliative Medicine.
5.4 The format of the second stage case note review is based on the Structured Judgement Review method recommended by the Royal College of Physicians (Appendix A).

5.5 It is recognised that case record reviews are a fine balance and subject to significant inter-reviewer variation. It does not support comparison between organisations and should not be used to make external judgements about the quality of care provided.

5.6 To ensure objectivity, case record reviews should wherever possible be conducted by clinicians other than those directly involved in the care of the deceased. If the specific clinical expertise required only resides with those who were involved in the care of the deceased, the review process should still involve clinicians who were not involved in order to provide peer challenge. Objectivity of reviews should be a component of clinical governance processes.

5.7 Where case record review identifies a problem in care that meets the definition of a patient safety incident (any unintended or unexpected incident which could have or did lead to harm to one or more patients receiving NHS care) then this should be reported to the Trust Risk Management Team.

5.8 All patient safety incidents reported as resulting in death or severe harm to a patient that meet the criteria for Serious Incident (SI) reporting will be clinically reviewed by the National Patient Safety Team at NHS Improvement to determine if there are implications for national learning and if a response is appropriate. Any deaths that are identified via case record review as due to problems in healthcare would meet the criteria for SI reporting which includes reporting to the NRRL. More information on the national process is available at https://improvement.nhs.uk/resources/patient-safety-alerts. The Risk Management Team coordinates the internal and external SI reporting processes.

6. FORUMS WERE INPATIENT DEATHS ARE REVIEWED IN THE TRUST

6.1 Forums where inpatient deaths are reviewed within the Trust and may be considered as part of the first stage case notes review.

6.1.1 30 day post Systemic Anti-cancer Therapy
The list of all deaths that occur inside and outside the Trust in the 30 days following systemic anti-cancer therapy is sent every quarter to the Consultant Medical Oncologist (GI) in Sutton and the Consultant Medical Oncologist (Lung/AOS) and the Consultant Medical Oncologist (Breast/AOS) in Chelsea. These deaths are formally reported quarterly to the Trust’s Integrated Governance and Risk Management Committee in the quarterly Integrated Governance Monitoring Report. The mortality data and learning from deaths are shared at the Chemotherapy mortality meetings (solid tumour only) which are chaired by the Consultant Medical Oncologist (GI) and at the Medical Oncology Consultants meetings which take place three times a year and are chaired by the Consultant Medical Oncologist (Lung).
6.1.2 Haematology
All haematology deaths both inside and outside the Trust are reviewed at a quarterly mortality and morbidity meeting, chaired by the Consultant Haematology. The multidisciplinary team reviews the circumstances leading up to the death and are formally reported quarterly to the Trust’s Integrated Governance and Risk Management Committee in the quarterly Integrated Governance Monitoring Report.

6.1.3 Paediatrics
The paediatric department have a quarterly clinical quality forum (CQF), chaired by a Paediatric Oncologist or Paediatric Palliative Care Consultant. All deaths on treatment which include inpatient paediatric deaths are discussed. A summary of the case is presented and learning from the deaths is discussed.

6.1.4 Critical Care Unit
Deaths in critical care are reviewed quarterly as part of the morbidity and mortality review group, chaired by a CCU Consultant and presented at the Critical Care Unit multidisciplinary team meetings, chaired by the Clinical Lead of Critical Care. Case mix adjusted standardised mortality ratios are reported externally to the Intensive Care National Audit and Research Centre and benchmarked against other critical care units.

6.1.5 Palliative Care
The hospital specialist palliative care team reviews all inpatient deaths weekly at the palliative care multidisciplinary team meetings, chaired by a Palliative Care Consultant/Nurse Consultant on each site. The review of death is recorded and learning shared with the team. All deaths are reviewed as a rolling audit of compliance with the principles of care document.

6.1.6 Surgery
Peri-operative deaths are discussed at the two-monthly joint Surgical and Anaesthetic Audit Meetings. All peri-operative deaths within 30 days of surgery are reported to the coroner. The minutes of this report are circulated to the Senior Surgeons and Anaesthetics group, chaired by the Chief of Surgery and the Trust’s Integrated Governance and Risk Management Committee in the quarterly Integrated Governance Monitoring Report.

6.1.7 Safeguarding Adults
The safeguarding adult’s team should be notified of any death where a patient with care and support needs dies as a result of suspected or known abuse or neglect and there is a concern that partner agencies could have worked more effectively to protect the adult. The safeguarding adult’s team will then review and consider referral to the relevant Safeguarding Adults Board for consideration of a safeguarding adults review (SAR) under Section 44 of the Care Act 2014.

6.2 Should any of these forums highlight any concerns about care during the first stage review, the case should be referred to the Risk Management Team and the Hospital Mortality Review Group for second stage review using the Structured Judgement Review.
7. **GOVERNANCE STRUCTURE**

7.1 Mortality governance is a key priority for The Royal Marsden Trust Board. Executives and non-executive directors must have the capability and capacity to understand the issues affecting mortality in their Trust and provide necessary challenge.

7.2 The Executive Director for mortality review is the Medical Director. There is also an appointed Non-Executive director. The Executive Director for End of Life Care is the Chief Nurse. Their roles are to ensure that:

i. Robust systems are in place for recognising, reporting, reviewing or investigating deaths and learning from avoidable deaths that are contributed to by lapses in care.

ii. The Trust is learning from problems in healthcare identified through reviewing or investigating deaths by ensuring that the processes their organisation have in place are robust, focus on learning and can withstand external scrutiny, by providing challenge and support; quality improvement becomes and remains the purpose of the exercise, by championing and supporting learning, leading to meaningful and effective actions that improve patient safety and experience, and supporting cultural change; and the information the provider publishes is a fair and accurate reflection of its achievements and challenges.

iii. Case record reviews and investigations are carried out to a high quality, acknowledging the primary role of system factors within or beyond the organisation rather than individual errors in the problems that generally occur.

iv. Mortality reporting in relation to deaths, reviews, investigations and learning is regularly provided to the Board in order that the executives remain aware and non-executives can provide appropriate challenge.

v. That learning from reviews and investigations is acted on to sustainably change clinical and organisational practice and improve care, and reported in annual Quality Accounts.

7.3 The systematic approach outlined in this document enables the issue of potentially avoidable mortality to be identified and facilitates a robust mortality governance processes. This allows the Trust to identify any areas of failure of clinical care and ensure the delivery of safe care. This includes a Hospital Mortality Review Group with multidisciplinary and multi-professional membership which includes a Consultant Anaesthetist; Palliative Care Consultant; Head of Adult Safeguarding; Head of Quality Assurance; Quality Improvement Auditor; Clinical Auditor, and quarterly mortality reporting to the Integrated Governance and Risk Management Committee, the Quality, Assurance and Risk committee and the Trust Board, outputs of the mortality governance process including investigations of deaths being communicated to frontline clinical staff.

7.4 Information on deaths are reported quarterly to the Trust’s Integrated Governance and Risk Management Committee and includes the total number of the Trust’s inpatient deaths, those deaths that the Trust has subjected to case notes review and whether the set standards have been met (standards 1-4). A summary will be published in the Trust’s Annual Quality Account.
7.5 Failings of standards or failings of care identified during case notes review must be investigated in a timely manner with actions and learning disseminated to staff. Feedback to bereaved families and carers is also an important part of this process.

8. **DEATHS OF PATIENTS WITH LEARNING DISABILITIES**

8.1 The Learning Disabilities Mortality Review (LeDeR) programme was established in response to the recommendations of the Confidential Inquiry into the premature deaths of People with learning disabilities (CIPOLD) and was commissioned by NHS England and is managed by the Healthcare Quality Improvement Partnership (HQIP).

8.2 Recommendation 7 of the report states: Provider organisations and commissioners must work together to review and improve their local approach following the death of people receiving care from their services. Provider boards should ensure that national guidance is implemented at a local level, so that deaths are identified, screened and investigated, when appropriate and that learning from deaths is shared and acted on.

8.3 The LeDeR programme uses White Paper ‘Valuing People’ (2001) definition of learning disabilities which is;
- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with
- a reduced ability to cope independently (impaired social functioning)
- which started before adulthood, with lasting effect on development

8.4 As a result, the Trust must report all deaths of people with learning disabilities aged between 4-74 years old and registered with a GP in England to the LeDeR programme. This includes the deaths of both children and adults with learning disabilities.

8.5 All deaths must first be reviewed to determine whether there are potential safeguarding concerns and whether it meets the criteria for a serious incident and further discussion held at local levels about how this will relate to the LeDeR review process.

8.6 The purpose of the LeDeR review is to;
- Identify any potential avoidable factors that may have contributed to the persons death and
- Develop plans of action that individually or in combination, will guide necessary changes in health and social care services in order to reduce premature deaths of people with learning disabilities

8.7 To report a death of a person with learning disabilities, the Trust safeguarding team should be notified and they will take the lead responsibility to complete the Notification of Death to the programme via the programme’s secure web portal or via telephone (0300 7774 774). A decision will then be made by the LeDeR programme about whether this meets the criteria and whether a LeDeR review is required.
8.8 Learning from LeDeR reviews will be agreed by local LeDeR steering groups and shared internally within the Trust’s mortality audit committee and Trust Safeguarding Adults and Children’s Boards and other relevant groups within the Trust. Externally, the learning will be shared with the relevant Safeguarding Adults and Children’s Partnership Boards.

9. DEATHS OF PATIENTS WITH MENTAL HEALTH NEEDS

9.1 Physical and mental health are closely linked. People with severe and prolonged mental illness are at risk of dying on average 15 to 20 years earlier than other people. In addition, people with long term physical illnesses suffer more complications if they also develop mental health problems.

9.2 Reporting and reviewing of any death of a patient with mental health problems should consider these factors i.e. premature death of those with a mental disorder and the increased risk of complications for those with physical and mental health difficulties.

9.3 Inpatients detained under Mental Health Act: Regulations 17 require mental health providers to ensure that any death of a patient detained under the Mental Health Act (1983) is reported to the Care Quality Commission without delay. In 2015, the Care Quality Commission reported concern that providers were failing to make this notification in 45% of cases. The Commission has since updated its notifications protocols to ensure that providers ensure they report in a timely way.

9.4 Under the Coroners and Justice Act 2009, coroners must conduct an inquest into a death that has taken place in state detention, and this includes deaths of people subject to the Mental Health Act. Providers are also required to ensure that there is an appropriate investigation into the death of a patient in state detention under the Mental Health Act (1983).

9.5 In circumstances where there is reason to believe the death may have been due, or in part due to, to problems in care - including suspected self-inflicted death - then the death must be reported to the provider’s commissioner(s) as a serious incident and investigated appropriately. Consideration should also be given to commissioning an independent investigation as detailed in the Serious Incident Framework.

9.6 Points 9.3 to 9.5 are satisfied within existing Royal Marsden Hospital systems. Death of a Royal Marsden inpatient detained under the MHA is an extremely rare occurrence. The Trust Safeguarding lead and Consultant Liaison Psychiatrist must ensure the CQC are informed without delay. The Trust Legal Team must inform the Coroner. An inpatient suicide, or problem in care contributing to the death, would be reported via Datix and investigated as a Serious Incident and a case notes review should be undertaken by the Hospital Mortality Review Committee in conjunction with the Liaison Psychiatry team. The findings should be reported to the Trust’s Integrated Governance and Risk Management Committee. Consideration should also be given to commissioning an independent investigation (e.g. drawing on the expertise of a London Mental Health Trust other than the one that provides the Liaison Psychiatry and MHA support to The Royal Marsden).
10. DEATHS OF INFANTS AND CHILDREN

10.1 The Royal Marsden Hospital is a specialist tertiary cancer service for children and young people aged 1-19 years. The Paediatric Palliative care team (PATCH service) provides a dual model of care working in parallel with the Paediatric Oncology service to provide high quality holistic care and services to children with cancer.

10.2 Definitions:
‘Palliative care deaths’- death from progressing or relapsing disease.
‘Treatment-related deaths’- death related to the treatment, management or sequelae of the cancer.
‘A preventable death’- defined as a death in which ‘modifiable factors may have contributed to the death and which, by means of nationally or locally achievable interventions, could be modified to reduce the risk of future deaths.’
‘Unexpected death’- the death of a child which was not anticipated as a significant possibility 24 hours before the death.
‘Expected death’- the death of a child which was anticipated as a significant possibility in the preceding 24 hours before the death.

10.3 The Paediatric Palliative care policy outlines the process of care for a child during palliation, death, care of their body and bereavement support for their family. It also defines key points of communication and provides information regarding the role of CDOP (CDOP is now the Child death review process carried out by child death review partners), completion of form A to notify child death review partners of the death of a child via the local administrator and completion of form B, the process of tissue and organ donation and communication of the child's death with involved professionals.

10.4 The Child Death review partners are an external independent body which is responsible for reviewing all child deaths (from birth up until 18th birthday) in a local authority or area. Currently at the child’s death, it is determined if the death is ‘expected’ or ‘unexpected’. If the child’s death is unexpected then a Multi Professional Child Death Review Meeting is convened. This is a coordinated response to accurately investigate the circumstances regarding the child’s death and ensure the family is supported. For all ‘expected’ child deaths a form A and B are completed and all cases are reviewed by the Child Death review partners and preventable and/or contributing aspects leading to the death are collated. CDOP provides individual case feedback as part of their review process to services where indicated. All families have an assigned CDOP keyworker who supports the family through the CDOP process. New guidance on this was published in August 2018.
10.5 Review process for the death of a child

Population:
Any child, aged 1-18 years, whilst under the care of Royal Marsden Hospital Paediatric Oncologist or Paediatric Palliative Care Consultant with a cancer diagnosis whether their death occurred within the Trust, community, shared care or intensive care.

Clinical concern or safeguarding:
Any health professional with concerns can raise a clinical incident form around any aspect of the child’s care at any time and this will then follow the appropriate Trust policy for clinical incidence. If the concern raised relates to child protection or safeguarding then the Named Lead for Children must be informed.

At the death of the child:
   a. Communication on the death of a child:
The organisation where the child dies is responsible for informing of the death to all professionals involved in the child’s care including health (GP, shared care hospital, hospice and community services, education and social services.
   b. CDOP: Child Death Review
   Professionals present or involved directly at the point of death complete the Child Death Review 'form A' document. If the death is considered 'unexpected' then a Multi Professional Child Death Review Meeting is initiated by the Child Death Review Partners.

Case review:
All cases are reported at the Clinical quality forum. The Clinical quality forum (CQF) is a quarterly Paediatric MDT meeting attended by the Paediatric clinical unit. The forum is a platform for presentations and discussions on clinical audits, new or updated guidance and policies, morbidity and mortality meeting and feedback of clinical incident investigations. An overview and context of all deaths are reviewed each quarter with monthly and quarterly trends over the preceding 5 year period reviewed.

Treatment-related deaths:
All 'treatment' related deaths are formally presented. Involved professionals from outside the Royal Marsden Paediatric MDT are invited for specific clinical cases where a child died from a 'treatment related' cause outside RM; providing a single overarching review of the child’s death. Summary of the case, discussion and outcome or learning points are recorded and placed in the electronic patient record for the patient and shared with local services where appropriate. Learning points with action points are taken forward by clinical quality forum lead.

Deaths at St George’s Hospital:
All deaths within PICU and St George’s are reviewed at the Morbidity and Mortality review meeting at St George’s Hospital. The Royal Marsden Oncology MDT team including the Paediatric Oncology Consultant attends this meeting when an oncology patient is presented.
Palliative care deaths:
All palliative care deaths, wherever the death occurs, have a death summary issued by the PATCH team to all involved professionals and sent to the CDOP Child Death Review. The death summary includes: name, age, gender, diagnosis, date of birth and death, place of death, presence of advance care plans, involved services, summary of clinical care, palliation and end of life, medication at end of life, admissions during palliation and bereavement support. The death summaries have been updated to include the presence of known learning disability and serious mental health conditions.

All palliative care deaths are reported at the quarterly Clinical quality forum. If considered appropriate the case is formally presented and reviewed.

A professional debrief and case discussion is offered to involved professionals at a place local to the death of the child. This is led by the PATCH team.

10.6 Bereavement support following the death of a child
Bereavement support is outlined in the Paediatric Palliative care policy.

In summary:
- A representative from RM will attend the funeral where appropriate.
- Consultant Oncologist will offer a follow up with family 6-8 weeks after the death of the child.
- All deaths are discussed at the monthly Paediatric Palliative care (PPC) MDT and a bereavement proforma of the bereavement support is completed.
- All children who were under the care of the RM despite their place of death have a bereavement keyworker assigned at the first PPC MDT after the death of a child.
- The bereavement support is reviewed at 6 weeks, 6 months and 12 months post the child’s death at the MDT.
- CLIC Sargent service provides ongoing bereavement support groups and activities for parents and siblings. This includes a closed bereaved parents group.
- Psychology services provide ongoing individual support to family members or sign post to local services.
- The Paediatric palliative care team holds a biannual bereaved parents forum where patient/parent information, guidelines and processes around service delivery and support to children receiving palliative care is reviewed.

11. MATERNAL DEATHS

11.1 The Trust occasionally cares for pregnant and breast feeding mothers. A maternal death is defined as a death of a woman during or up to six weeks (42 days) after the end of pregnancy (whether the pregnancy ended by termination, miscarriage or birth).

11.2 If deaths occur within this patient group, a full case record review using the Structured Judgement Review should take place by the treating clinical unit and the report shared with the Hospital Mortality Review Group.

11.3 These deaths would be reported to NCEPOD for inclusion in the maternal mortality.
11.4 All maternal deaths must be included in the Trust’s Integrated Governance and Risk Management Committee Report.

12. **STAFF TRAINING AND SUPPORT**

12.1 Staff reviewing and reporting deaths must have appropriate skills through specialist training and protected time under their contracted hours to review and investigate deaths to a high standard. This may involve attendance of relevant external and internal courses.

12.2 If staff are affected by the death of a patient they should seek support from line managers in the usual way and through Staff Support/ Occupational Health services. Further guidance is also available in the policy for supporting staff involved in potentially traumatic or stressful incidents, complaints, claim or attendance at an inquest or employment tribunal [2039].

12.3 Skills for Health and NHS Health Education England have made available an e-learning resource for staff entitled ‘Learning from deaths’ this will be available on the trust’s Learning Hub for staff to access.

13. **BEREAVED RELATIVES AND CARERS**

13.1 The Trust should engage meaningfully and compassionately with bereaved families and carers in relation to all stages of responding to a death. The staff member conveying the news of a death should be able to give as much information as they can about the circumstances of the death and if appropriate and answer any questions raised by the relatives or carers.

13.2 The principles of openness, honesty and transparency as set out in the Duty of Candour should always be applied when dealing with bereaved relatives.

13.3 All wards should give relatives or friends of the deceased the leaflet ‘My relative or friend has died in hospital: What do I need to do?’ This gives practical information about registering a death and arranging an appointment with the bereavement service.

13.4 All relatives or friends of the deceased will be invited to a bereavement meeting. The purpose of these meetings is twofold: to talk through the necessary administrative processes when a person dies including reviewing the death certificate; and providing support which includes signposting to appropriate bereavement support services and listening to their experience. The PALS/bereavement advisors will also enquire if there are any concerns the relatives/friends wish to discuss about the care or medical management of the deceased, as part of the meeting. Any issues that can’t be resolved informally at the meeting will be referred to the lead clinician/case review process as detailed below.

13.5 At the meeting they will also be given further information ‘Information for families following a bereavement’ which gives more detailed information should the family wish to raise a concern (add in link once leaflet is on intranet). If concerns are raised, this should lead to an automatic case record review using the structured judgement review undertaken within the Hospital Mortality Review Group.
13.6 If a risk management investigation takes place as per Trust policy following the death of a patient in the Trust, bereaved relatives and carers should receive timely, responsive contact and support in all aspects of the investigation.

13.7 Bereaved relatives should have a single point of contact and liaison with the Trust which is the nominated person within the PALS/ Bereavement team or the risk management team.

13.8 Bereaved relatives should have an opportunity to respond to the investigation and report findings and be made aware of the processes that have changed following the investigation.

14. LINKED DOCUMENTS
This policy should be read alongside the following policies.

- Care of Dying and Deceased Patients in Hospital Policy: 115
- Concerns and Complaints Policy and Procedure: 160
- Being Open and Duty of Candour Policy: 1760
- Accident/Incident and Patient Safety Incident Reporting Policy Including Serious Incidents Requiring Investigation: 0482
- Children/Young People’s Palliative Care Operational Policy: 0457
- Child Protection and Safeguarding Children Policy: 0140
- Safeguarding Adults Policy and Procedures: 1623
- Policy for supporting staff involved in potentially traumatic or stressful incidents, complaints, claim or attendance at an inquest or employment tribunal: 2039

15. REFERENCES
2. Learning disabilities mortality review (LeDeR) programme - www.bristol.ac.uk/sps/leder


10. University of Bristol and NHS England; Guidance for the conduct of reviews of the deaths of people with learning disabilities (2017) [http://www.bristol.ac.uk/medialibrary/sites/sps/leder/Guidance%20for%20the%20conduct%20of%20reviews%20%20FINALv2.2.pdf](http://www.bristol.ac.uk/medialibrary/sites/sps/leder/Guidance%20for%20the%20conduct%20of%20reviews%20%20FINALv2.2.pdf)


12. Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children 2018 Department for Education
Appendix A: Template for Structured Judgement Review

### 1. Baseline information - Patient Hospital Number

Name of Reviewer:  
Date of Review:

Age at death (years):  
Gender: M/F  
First 3/4 digits of the patient’s postcode:  
Day of admission/attendance:  
Day of death:  
Number of days between arrival and death:  
Specialty team at time of death:  
Specific location of death:  
Type of admission:  
Cause of death:

### 2. Phase of care: Admission and initial management (first 24 hours)

Please record your explicit judgements about the quality of care the patient received and whether it was in accordance with current good practice (for example, your professional standards or your professional perspective). If there is any other information that you think is important or relevant that you wish to comment on then please do so.

Please rate the care received by the patient during this phase.  
1 = very poor care  2 = poor care  3 = adequate care  4 = good care  5 = Excellent care  
Please circle only one score.
2. Phase of care: Ongoing care

Please record your explicit judgements about the quality of care the patient received and whether it was in accordance with current good practice (for example, your professional standards or your professional perspective). If there is any other information that you think is important or relevant that you wish to comment on then please do so.

<table>
<thead>
<tr>
<th>Please rate the care received by the patient during this phase.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 = very poor care 2 = poor care 3 = adequate care 4 = good care 5 = Excellent care</td>
</tr>
<tr>
<td>Please circle only one score.</td>
</tr>
</tbody>
</table>

3. Phase of care: Care during Procedure or Peri-operative care

Please record your explicit judgements about the quality of care the patient received and whether it was in accordance with current good practice (for example, your professional standards or your professional perspective). If there is any other information that you think is important or relevant that you wish to comment on then please do so.
4. Phase of care: End of life care

Please rate the care received by the patient during this phase.
1 = very poor care 2 = poor care 3 = adequate care 4 = good care 5 = Excellent care
Please circle only one score.
5. Phase of care: Overall care

Please rate the care received by the patient during this phase.
1 = very poor care 2 = poor care 3 = adequate care 4 = good care 5 = Excellent care
Please circle only one score.

6. Assessment of problems in healthcare

In this section, the reviewer is asked to comment on whether one or more specific types of problem(s) were identified and, if so, to indicate whether any led to harm.

6.1 Were there any problems with the care of the patient? (Please circle)
No       Yes

6.2 If you did identify problems, please identify which problem type(s) from the selection below and indicate whether it led to any harm. Please circle all that relate to the case.

Problem types:

a. Problem in assessment, investigation or diagnosis (including assessment of pressure ulcer risk, venous thromboembolism (VTE) risk, history of falls)
No       Yes
Did the problem lead to harm? No / Probably / Yes

b. Problem with medication / IV fluids / electrolytes / oxygen (other than anaesthetic)
No       Yes
Did the problem lead to harm? No / Probably / Yes

c. Problem related to treatment and management plan (including prevention of pressure ulcers, falls, VTE)
No       Yes
Did the problem lead to harm? No / Probably / Yes
d. Problem with infection management
No   Yes
Did the problem lead to harm? No / Probably / Yes

e. Problem related to operation / invasive procedure (other than infection control)
No   Yes
Did the problem lead to harm? No / Probably / Yes

f. Problem in clinical monitoring (including failure to plan, to undertake, or to recognise and respond to changes)
No   Yes
Did the problem lead to harm? No / Probably / Yes

g. Problem in resuscitation following a cardiac or respiratory arrest (including cardiopulmonary resuscitation (CPR))
No   Yes
Did the problem lead to harm? No / Probably / Yes

h. Problem of any other type not fitting the categories above
No   Yes
Did the problem lead to harm? No / Probably / Yes

7. Your view on avoidability of death. Please choose one of the following (circle):

Score 1 Definitely avoidable
Score 2 Strong evidence of avoidability
Score 3 Probably avoidable (more than 50:50)
Score 4 Possibly avoidable but not very likely (less than 50:50)
Score 5 Slight evidence of avoidability
Score 6 Definitely not avoidable

Please explain your reasons for your judgement of the level of avoidability of death in this case, including anything particular that you have identified.