Mortality Surveillance and Learning from Deaths

- responding to deaths

UCLH policy

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<tr>
<th>Policy number</th>
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<td>Issue date</td>
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<td>Senior Directors Team</td>
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<td>Responsible Director</td>
<td>Corporate Medical Director</td>
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<td>Policy Author</td>
<td>Head of Quality</td>
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<td>Patient Safety Committee</td>
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**List of reviewers & contributors**
*Include here whether Counter Fraud; Infection Control Team or Interserve Facilities Management (IFM) were asked to review the policy and if comments were received*

| Mortality Surveillance Steering Group (including the corporate medical director and the divisional clinical director for surgical specialties) |
| Non-Executive Director for Mortality Surveillance |
| Executive Director for Mortality Surveillance |
| Director for Quality and Safety |
| Consultants Cancer services, Acute medicine, Intensive Care and Emergency services |
| Divisional Risk Manager for Women’s Health |
| Divisional Directors Women’s health and Paediatrics |
| Clinical coding department |
| Performance and Partnerships team |
| Transforming End of Life Care team |
| Bereavement team |
| Coagulation team |

**Summary of main points from consultation**
NA – new policy

| Review body | Patient Safety Committee |
| Date of meeting when policy reviewed and endorsed: July 2017 |
| Date of meeting when policy reviewed by PASG | 12/09/17 |

**Review amendment log**

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UCLH - 2017

Issue date: (29/08/17)
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# Appendices

1. **Structured Judgement Review template** - Guidance is available [here](#)
2. **Learning from deaths of patients with severe mental illness**
3. **Learning from deaths of patients with a learning difficulty**
4. **Learning from expected deaths and at the End of Life - listening to and learning from bereaved relatives and carers**
5. **Learning from maternal deaths**
6. **Learning when stillbirths occur or neonatal deaths occur**
7. **Learning from deaths of children and young people**
8. **UCLH investigation and learning from in hospital cardiac arrests framework**
**Mortality review process for learning at UCLH**

**Additional categories of deaths to be reviewed**
- Severe mental illness*/deaths whilst detained under the MHA
- Elective access pathway
- CQC mortality outlier notification
- All deaths where bereaved families and carers, have raised a significant concern about the quality of care provision* (other than a formal complaint)
- Death in the community within 30 days of discharge* /attendance at ED (except for the terminally ill who die in a hospice or if preferred place of death was home)
- Deaths where the patient was not under UCLH care at the time of death but where another organisation suggests that the trust should review the care provided to the patient in the past
- Sampling e.g. sepsis, diabetes, AKI, cardiac arrests, deaths out of hours

**Existing death review processes**
- Maternal death (CIRG review)
- Stillbirth (CIRG & MBRRACE reviews)
- Neonatal death (CIRG review)
- Child death* (Child Death panel)
- Learning disability* (LeDeR programme)
- Complaints*
- Inquest / Prevention of future death ruling*
- Serious incident* (via Datix)
- Cardiac arrests rapid review
- SACT- 30-day mortality after systemic anticancer treatment study
- Hospital acquired thrombosis

*Mandated by national policy

**Figure 1**

1. Structured judgement review
2. Deaths judged more likely than not to have been due to problems in care
3. Findings input to DATIX mortality review platform *(when available)*
5. Report for QSC, senior directors and public part of the board
6. Annual review for the Board
1. **Summary**

UCLH is required by NHS England to have in place a policy on how we respond to, and learn from, deaths of patients who die under our management and care, which includes:

1) How our processes respond to the death of an individual with a learning disability or mental health needs, an infant or child death and a stillbirth or maternal death.

2) An evidence-based methodology for reviewing the quality of care provided to those patients who die. UCLH has chosen to use the methodology recommended for acute trusts - **The Structured Judgement Review (SJR)**.

3) The categories and selection of deaths in scope for case record review. These are outlined in **Figure 1**. The policy also describes the arrangements in place at UCLH to meet the NHS England requirement to collect and publish on a quarterly basis specified information on deaths. This will be via a paper and an agenda item to a public board meeting in each quarter. This data will include the total number of in-patient deaths at UCLH (and Emergency Department deaths), and deaths within 30 days of discharge, and those deaths that UCLH has subjected to a further investigation including the SJR. Of these deaths subjected to review, we will provide estimates of how many deaths were judged more likely than not to have been due to problems in care.

The pathway for deaths reviews is laid out in figure 1 on page one. The right hand box includes our existing processes for review of deaths. The box in the left hand side includes the deaths that will be identified for review via coding. They may or may not have been reviewed through existing mortality and morbidity processes.

1.1 In summary, the process for mortality review is as follows:

- All deaths are identified and screened for the triggers. This is to identify additional categories of deaths to be reviewed as outlined in figure 1, by the performance team.

- Deaths that meet the screening criteria as per figure 1 will be notified monthly to the quality and safety team. These include those deaths where the family have raised concerns about the care of their loved one via the bereavement team or as a result of receiving the end of life care survey and contacting the trust.

- Selected deaths via coding (left hand side box) are to be allocated to appropriate reviewers who use the methodology of the RCP SJR with a deadline for completion of the structured judgment review within 30 days.

- SJR reviewers will be asked to rate the care at various stages as per the methodology (see **appendix 1** for the structure of the review) and an overall rating.
• For other death reviews (right hand side box) the investigator/SJR reviewer will be asked to rate the overall care as per the definition of death due to a problem in care

• The findings of the SJR reviews will be entered on to the Datix mortality module once this is available

• The findings for the other death reviews will be noted according to the type of review (e.g. serious incident summary, complaint summary)

• All the findings and learning will be collated into a report for the public part of the board of directors.

1.2 Learning

Learning will be shared as follows:

At the end of each quarter a report including learning will be presented to the senior director team and the public part of the board of directors.

This will also be distributed to medical directors, divisional clinical directors, managers and chief nurse team for local sharing in clinical teams and for presentation to specialty mortality and morbidity meetings where relevant.

It will also be shared with the commissioners through the Clinical Quality Review Group

Current processes for learning will continue:

Publication in appropriate trust wide publications such as the quality and safety monthly bulletin, the monthly summary of learning from serious incidents ‘Look and Learn’ and the Safer Use of Medicines - SUMtips newsletter and the Claims and Inquests reports produced for the divisions.

1.3 Action

Policies, clinical guidelines and care pathways may require reviewing and updating as appropriate, according to the learning gained.

Assurance that learning is acted upon and that change has occurred and is embedded is important and where learning has been identified and an action plan put in place assurance will be sought that the actions have been completed and are embedded and monitored as appropriate.

There will be changes to the quality accounts regulations that will require that the data we publish to be summarised in our quality account from June 2018, including evidence of learning and action as a result of this information and an assessment of the impact of actions that UCLH has taken.
2. Equality Impact Statement

The author of this policy has undertaken an Equality Impact Assessment (EIA) and has concluded that there is no negative impact on any of the protected equalities groups. The completed EIA form is available from the policy compliance officer.

3. Definitions

3.1 Structured Judgement Review  The application of a case record/note review produced by the Royal College of Physicians, to determine whether there were any problems in the care provided to the patient who died in order to learn from what happened.

3.2 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.

3.3 Death due to a problem in care A death that has been clinically assessed using a recognised methodology of SJR and determined more likely than not to have resulted from problems in healthcare from which we can derive learning.

The judgement of whether a problem may have contributed to a death requires careful review of the care that was provided against the care that would have been expected at the time of death. Research has shown that when case record review identifies a death that may have been caused by problems in care, that death tends to be due to a series of problems none of which would be likely to have caused the death in isolation but which in combination can contribute to the death of a patient. Some of these elements of care are likely to have occurred prior to the admission and UCLH will support other organisations, for example in primary care, to understand and act on areas where care could be improved, by informing them.

3.4 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. The coroner referral criteria is available in the ‘Provision of care and respect after death policy’ on Insight.

3.5 Family or relevant person The person nominated as next of kin by the patient (who may or may not be a family member) or where there are no relatives, a friend or carer. Throughout the policy the term ‘family’ means relatives or relevant person.

Currently, clinical teams and the bereavement service ensure relatives are given a chance to express any concerns about the cause of death and clinical teams will as a result of this refer any deaths to the Coroner, where these appear to involve
serious lapses in clinical governance or patient safety, and it is thought these may have or could have contributed to the death. Where significant concerns are raised by relative’s e.g. by the bereavement service, these will be forwarded to the head of quality for consideration in the death screening process.

3.6 End of Life Care Governance Data form A Green form completed by the doctor who completes the Medical Certificate for the Cause of Death which provides information around the patient’s end of life care, including whether the patient’s care was supported using ‘Excellent care in the last days of life’ documentation.

3.7 End of Life Care Survey A questionnaire given to every bereaved family by the Bereavement team inviting feedback on the quality of care received at UCLH in the last days of life and after death.

4. Introduction
From April 2017, all trusts are required to collect and publish information on deaths and serious incidents, including evidence of learning and improvements being made as a result of that information.

This is part of a systematic, NHS-wide approach to reviewing and learning from deaths, being led by the Department of Health, NHS Improvement (NHSI) and the Care Quality Commission (CQC). Guidance has been provided to ensure a consistent approach to identifying and reporting, investigating and learning from deaths, and where appropriate, sharing information with other services and organisations. The trust board will ensure that the guidance is implemented at a local level, and that learning from deaths is shared and acted on using the reporting dashboard.

UCLH will ensure that we have robust governance arrangements in place for review of deaths – that meetings are being scheduled to look at deaths, that deaths are being looked at and that there is local learning, shared centrally to enable trust wide learning.

5. Objectives
1) To make learning from deaths, and the valuable opportunities for improvement from that, a priority for UCLH.
2) To engage families and carers and recognise their insights as a vital source of learning in the investigation of deaths identified for review.

6. Scope
The policy applies to all UCLH patients. It applies to all clinical teams at UCLH except pathology where the patients they provide services to would be expected to have their deaths investigated by the clinical team in charge of their care.

6.1 Categories and selection of deaths in scope for case record review
AS a minimum, UCLH will focus reviews on patient deaths in line with the criteria specified by NHS England:
1. All deaths where bereaved families and carers, or staff, have raised a significant concern to include where a formal complaint about the quality of care provision is made.
2. All inpatient deaths of those with severe mental illness as outlined in appendix 2.
3. All inpatient deaths of those with learning disabilities will be reviewed under the LeDeR review process outlined in appendix 3.
4. All deaths where people are not expected to die, such as when undergoing elective procedures.

We will also consider:

5. Deaths where learning will inform UCLH’s existing or planned improvement work such as due to sepsis, acute kidney injury (AKI), unrecognised deterioration and hospital acquired venous thromboembolism. To maximise learning, such deaths may be reviewed thematically.
6. A further sample of other deaths that do not fit the identified categories 1-5 so that UCLH can take an overview of where learning and improvement is needed most overall. A practical sampling strategy will be used and may be targeted on areas where there is a concern or indicators such as an increasing SHMI or number of cardiac arrests.
7. The above minimum requirements are additional to existing requirements for UCLH to undertake specific routes of reporting, review or investigations for defined groups of patients, such as deaths of perinatal women, neonates or children (see appendices 5-7).
8. We will continue to investigate deaths where there is an inquest and where there is an issue of a “Regulation 28 Report on Action to Prevent Future Deaths” (PFD) in order to examine the effectiveness of our own review process.
9. UCLH will review cases of people who had been an inpatient, or were seen in our emergency department but had died within 30 days of leaving hospital unless (except for the terminally ill who die in a hospice or if preferred place of death was home.)
10. Deaths where the patient was not under UCLH care at the time of death but where another organisation suggests that the trust should review the care provided to the patient in the past.

6. Duties and responsibilities

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<tr>
<td>Corporate Medical Director</td>
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<tr>
<td>Non-executive director (Chair of QSC)</td>
<td>Oversight of progress with the implementation of this policy and of providing assurance to the public part of the board on a quarterly basis.</td>
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<tr>
<td>Director for Quality and Safety team</td>
<td>• Responsible for implementing and monitoring compliance with the policy and providing reports to</td>
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### Role of groups/boards/committees

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| the QSC for assurance                                           | - Complaint team responsible for identifying and flagging complaints about the care of patients who have died  
- Patient safety team responsible for identifying and flagging serious incidents where the patient has died  
- Claims and Inquest team responsible for flagging learning from inquests or Prevention of Future Death (PFD) orders |
| Medical directors of each clinical board                        | Have overall responsibility within their Boards to ensure that the response to patient deaths is conducted in line with the principles and procedures laid out in this policy. Ensuring that there is a sufficient pool of trained investigators in divisions with supplementary professional activity sessions (SPAs) funded for death reviews to enable rapid and thorough reviews of deaths, by peers. |
| Divisional clinical directors (DCDs)                           | Responsible for ensuring their clinical teams are aware of this policy and that it is followed. Responsible for ensuring that staff are given access to training and SPAs are allocated for death reviews. |
| Bereavement team and Transforming End of Life Care team         | Responsible for providing the End of Life survey to all bereaved relatives and flagging to Quality and Safety when families raise concerns about the care of their relative. |
| Consultant medical staff                                       | Responsible for ensuring the staff in their clinical teams are aware of this policy and that it is followed. Participate in the review of deaths as per the policy |
| Clinical teams                                                 | Responsible for being aware of this policy and for ensuring that when a death review is initiated that they cooperate fully with the investigator to ensure that learning is maximised. |
| Performance and Partnership team                                | - Responsible for identifying deaths for review using the UCLH screening tool as laid down in figure 1. (Additional categories of deaths to be reviewed).  
- Information team to provide monthly list of deaths within 30 days of discharge or attendance at ED to Director of Quality and Safety team (those who die in a hospice or their chosen place of death will be excluded).  
- Responsible for providing data to the Director for Quality and Safety team in order to report to the QSC, executive board and the board of directors. |
| Clinical coding                                                | Responsible for coding and identifying relevant diagnostic codes |
| Consultant haematologist (and Chair of the Trust HAT committee) | Responsible for providing data to the Quality and Safety team on patients who die as a result of a thrombotic event |

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### Board of Directors
To receive a quarterly report from the Quality and Safety committee (QSC) on deaths, deaths reviewed and learning. Executive medical director and non-executive director to support the review programme.

### The Quality and Safety Committee
Responsible for receiving the quarterly report for discussion and comment prior to submission to the board.

### The Mortality Surveillance steering group (MSG)
Responsible for monitoring the implementation of this policy and its regular review.

### Clinical boards
Responsible for nominated leads to support the implementation of this policy. Responsible for monitoring compliance with the policy and for ensuring that learning gained from death reviews is widely shared and acted upon.

### Divisional management / quality and safety / governance meetings
DCDs are responsible for ensuring that divisional management / quality and safety / governance meetings discuss outcomes and activity to include learning gained from death reviews. DCDs are responsible for ensuring that learning is acted upon.

### 7. Specific details to explain the policy

#### 7.1 Governance of processes- fit with existing procedures
The death screening process will take into account the existing processes in place at UCLH for reporting and investigating incidents and complaints, for investigating child and maternal deaths and those of patients with a learning disability (see appendix. It will also integrate with other systems for review of deaths as follows.

#### 7.1.1 Deaths of patients with cancer, hospital acquired thrombosis, or on the intensive care unit.

- Deaths of patients with cancer within 30 days of receiving chemotherapy are reported to the Systemic Anti-Cancer Therapy national study (SACT).

- The radiology department flag hospital-acquired thrombosis (HAT) identified by scanning to the coagulation team. The coagulation team log the HAT and provide the patients clinical team with a root cause analysis template. When this completed the coagulation team send this to the quality and safety team to commence the serious incident investigation process. If death has resulted from a HAT whilst inpatient or within 30 days of discharge an SJR will be conducted by a member of the coagulation team.

- Deaths on the intensive care unit are reviewed by the designated lead for mortality. Specific deaths that trigger the structured judgement process will also be reviewed using the SJR.
7.1.2 Refer to the UCLH ‘Provision of care and respect after death (including maternal death) policy’ for immediate actions to be taken when there is death on a ward.

7.2 Informing other organisations who may have an interest (including the deceased person’s GP)

The discharge summary should be completed within 24 hours of a patient’s death and sent to the GP.

When deaths within 30 days of discharge occur in the community the reviewer will contact the patient’s GP to confirm the cause of death, determine if an investigation is being carried out in the community and if so, who they should liaise with. The quality and safety team will also inform the clinical commissioning group that we are liaising with the GP and if we require any assistance with that liaison.

7.3. Serious incidents

Where a death is being investigated within the serious incident (SI) framework we will not duplicate the current rigorous system in place of investigating such cases, including the early (72 hour) review, by conducting an SJR. The SI investigation process at UCLH identifies any lapses in care or services and the action plan includes how such learning should be shared and acted upon. Families and carers are engaged where appropriate and asked if they have anything they wish to contribute to the investigation, or anything they wish included in the investigation.

Where an SJR 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) this is to be reported via Datix. In the instance of a death where an SJR is being conducted and the reviewer believes it may also meet the SI criteria, the reviewer will notify the Quality and Safety team. The SJR review will be completed by the reviewer.

8. Cross-system reviews and investigations

Where a death being investigated involves other providers, such as primary care, we will, on a case by case basis, liaise appropriately with these providers. We will build up a knowledge base over time of the best process and key contacts.

9. Engagement with families and carers to recognise their insights as a vital source of learning in the investigation of deaths identified for review

9.1 Bereavement Support

Dealing respectfully, sensitively and compassionately with families and carers of dying or deceased patients is crucially important. The principles of openness, honesty, and transparency that we expect at UCLH are laid out in the UCLH Being Open policy and the UCLH Duty of Candour policy.

Provision of quality care for patients in the last days of their life, and bereavement support for their families and carers, is the responsibility of all staff they come into contact with.
contact with during this time. Specific services for bereavement are available through the Bereavement Service at UCLH who provide the following:

- Arrange completion of all documentation, including the Medical Certificate of the Cause of Death (MCCD) and information about registering a death at the Registrar's office.
- Inform the family at the initial family meeting, of services and support available to them.
- Facilitate collection of personal belongings where necessary (either at the bereavement office or from the wards).
- Facilitate visits to the chapel of rest and accompany the family, with support as needed.
- Facilitate discussion of concerns from the family, with the clinical teams and refer to Quality and Safety any serious concerns for mortality review (if this is not already in process with the clinical team).
- Give advice on coroner referral
- Liaise with funeral directors, police, social services, and housing.
- Provide emotional support, including counselling assessment (for all age groups) and follow up if appropriate, signpost and facilitate referral to specialist services e.g. mental health, post-traumatic stress disorder (PTSD). The bereavement team training collectively includes for example: registered specialist psychotherapist, mental health practitioner, training in trauma, children and family support, and a British speech and language speaker.
- Provide information and advice on other services e.g. funeral directors and costs, Department for Social Security (DSS) support, advocacy and transport.

Other support services and opportunities for feedback include the following:

- Hospital post mortem advice is provided by the clinical team under guidance of the Human Tissue Authority Designated individual (consultant histo-pathologist), facilitated at point of referral.
- Coroner post mortem advice is provided by the St Pancras and Westminster Coroner’s office.
- Language needs: Interpreter services are arranged through the ward, prior to relatives/next of kin visiting the bereavement office. Information is available about services providing counselling and support in other languages.
- The Transforming End of Life Care team collates feedback on quality of care in the last days of life from bereaved relatives via the End of Life Care survey (issued by the bereavement service). Learning is reported through the End of Life Care board and actions taken.
- The Transforming End of Life Care team offers training to all staff around care for patients who may be in the last days of life, with a focus on compassionate care and conversations.
- The Specialist Palliative Care Team offers support to dying patients, those close to them and the staff caring for them.
- The Transforming End of Life Care team runs ‘Difficult Conversations' study days with input from the bereavement service, which provide staff training on conversations around end of life care.
• Staff training for new starters is provided routinely and bespoke on request for all ward staff is provided by the bereavement service, mortuary team and chaplaincy.

9.2 Raising concerns
Bereaved families and carers will be asked if they have any concerns about the quality of care received by the deceased to inform decisions about the need to undertake a case record review or investigation. When a patient dies the bereavement team offer the family the UCLH End of Life Care Survey which asks them about their loved one’s care at the end of their life. The questionnaire and covering letter offer the family the opportunity to provide us with their contact details if they wish to discuss any significant concerns about the care of the deceased. Further detail is provided in appendix 4. Refer also to section 3.5 Family or relevant person

Depending on the nature of the death, it may be necessary for several organisations to make contact with those affected. This should be discussed with the bereaved families and carers and a co-ordinated approach should be agreed with them and the organisations involved. If other patients and service users are involved or affected by the death they should be offered the appropriate level of support and involvement.

We will ensure that the deceased person’s General Practitioner is informed of the death and provided with details of the death as stated in the medical certificate at the same time as the family or carers.

10. Data collection and reporting
We will collect data on all deaths on a quarterly basis, including an assessment of those that are more likely than not to be due to problems in care, and evidence of learning and action that is happening as a consequence of this information. This will cover the total number of in-patient deaths, deaths of patients who were seen in our emergency department at UCLH and those deaths we are aware of within 30 days of discharge.

The report will include the subset of deaths that we have subjected to case review following application of the SJR methodology, and those that have been subjected to the alternative methods of review described in figure one and an estimate of how many deaths were thought more likely than not to have been related to problems in care. We will record the outcome of our decision whether or not to review or investigate the deaths, which will have been informed by the views of bereaved families and carers.

A quarterly report of this information will be provided to the public meeting of the board of directors. An annual review of progress with the mortality governance framework will be reported to the board of directors.
11. Training requirements

UCLH has reviewed the skills and training required to support this policy. The Royal College of Physicians is training regional trainers in the structured judgement review process who will cascade training in case record review skills training to NHS acute providers. There is however guidance on undertaking structured judgement reviews which will be made available to reviewers who have not yet undertaken the training.

12. Implementation

12.1 UCLH Standards

- Clinical activity, outcomes, complications and deaths will be discussed in relevant divisions and specialties for a minimum of an average of one hour per week
- Every division will have a system in place for learning from their death reviews
- Clinicians undertaking structured judgement reviews will be provided with training.
- Deaths will normally be identified through coding and the criteria applied within six weeks of the death—deaths outside the trust are likely to take longer.
- All deaths identified from the routine screening that the performance team perform will be reviewed within 30 days

12.2 Dissemination and communication

- The policy will be circulated via email to all divisional directors and managers, all consultant medical, nursing and midwifery staff
- The policy will be disseminated as an attachment to the quarterly quality and safety bulletin which has wide distribution across UCLH. It will be publicised on the UCLH intranet to engage staff who may not access email
- The policy will be launched at a UCLH Leadership forum, attended by leaders from across the trust
- Awareness will be raised amongst clinical staff on the availability of training and by protected time being built into job plans to conduct the SJRs
- Awareness will be further raised by regular discussion of the findings of death reviews and the learning from them at divisional governance meetings

13. Monitoring and audit

<table>
<thead>
<tr>
<th>What in the policy is going to be monitored?</th>
<th>Monitoring method</th>
<th>Who will lead the monitoring?</th>
<th>How often?</th>
<th>Where will it be reported?</th>
</tr>
</thead>
<tbody>
<tr>
<td>The number of Structured Judgement reviews</td>
<td>Reports from the quality and safety team</td>
<td>Quality and safety team</td>
<td>Quarterly</td>
<td>Within the MSG report to the QSC and the board</td>
</tr>
<tr>
<td>Other deaths</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
14. References

Using the structured judgement review method
Data collection form
(England version)
National Mortality Case Record Review Programme: Structured case note review data collection

Please enter the following.

Age at death (years):

Sex: M/F

First 3/4 digits of the patient’s postcode:

Day of admission:

Time of admission:

Day of death:

Time of death:

Number of days between admission and death:

Month cluster during which the patient died:
Dec/Jan/Feb  Mar/Apr/May  Jun/Jul/Aug  Sept/Oct/Nov

Specialty team at time of death: 1 – Surgical, 2 – Medical

Type of admission: 1 – Emergency, 2 – Elective, 3 – Day case

Recorded cause of death:

Risk factors

Did the patient have a learning disability?

1. No indication of a learning disability – proceed with this review.

2. Yes – clear or possible indications from the case records of a learning disability. Action: after your review, please refer the case to the hospital’s clinical governance group to link with the Learning Disability Mortality Review Programme.
Structured case note review data collection

Phase of care: **Admission and initial management (approximately the 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.
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.

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.
Phase of care: **Care during a procedure (excluding IV cannulation)**

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>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>very poor care</td>
</tr>
<tr>
<td>2</td>
<td>poor care</td>
</tr>
<tr>
<td>3</td>
<td>adequate care</td>
</tr>
<tr>
<td>4</td>
<td>good care</td>
</tr>
<tr>
<td>5</td>
<td>Excellent care</td>
</tr>
</tbody>
</table>

Please rate the care received by the patient during this phase.

Please circle only one score.
Phase of care: **Perioperative 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.

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.

Phase of care: **End-of-life 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.

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.

**Implicit structured case note review data collection sheet**

Phase of care: **Overall assessment**

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.

Please rate the quality of the patient record.
1 = very poor care 2 = poor care 3 = adequate care 4 = good care 5 = Excellent care

Please circle only one score.

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.

Were there any problems with the care of the patient? (Please tick)
No ☐ (please stop here) Yes ☐ (Please continue below)

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

**Problem types**

1. **Problem in assessment, investigation of diagnosis** *(including assessment of pressure ulcer risk, venous thromboembolism (VTE) risk, history of falls)*
   - Yes ☐
   - Did the problem lead to harm? No ☐ Probable ☐ Yes ☐

2. **Problem with medication/IV fluids/electrolytes/oxygen** *(other than anaesthetic)*
   - Yes ☐
   - Did the problem lead to harm? No ☐ Probable ☐ Yes ☐

3. **Problem related to treatment and management plan** *(including prevention of pressure ulcers, falls, VTE)*
   - Yes ☐
   - Did the problem lead to harm? No ☐ Probable ☐ Yes ☐

4. **Problem with infection control**
   - Yes ☐
   - Did the problem lead to harm? No ☐ Probable ☐ Yes ☐

5. **Problem related to operation/invasive procedure** *(other than infection control)*
   - Yes ☐
   - Did the problem lead to harm? No ☐ Probable ☐ Yes ☐

6. **Problem in clinical monitoring** *(including failure to plan, to undertake, or to recognise and respond to changes)*
   - Yes ☐
   - Did the problem lead to harm? No ☐ Probable ☐ Yes ☐

7. **Problem in resuscitation following a cardiac or respiratory arrest** *(including cardiopulmonary resuscitation (CPR)*
   - Yes ☐
   - Did the problem lead to harm? No ☐ Probable ☐ Yes ☐

8. **Problem of any other type not fitting the categories above**
   - Yes ☐
   - Did the problem lead to harm? No ☐ Probable ☐ Yes ☐


Avoidability of death judgement score (only at second-stage reviews)
We are interested in your view on the avoidability of death in this case. Please choose from the following scale.

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Definitely avoidable</td>
</tr>
<tr>
<td>2</td>
<td>Strong evidence of avoidability</td>
</tr>
<tr>
<td>3</td>
<td>Probably avoidable (more than 50:50)</td>
</tr>
<tr>
<td>4</td>
<td>Possibly avoidable but not very likely (less than 50:50)</td>
</tr>
<tr>
<td>5</td>
<td>Slight evidence of avoidability</td>
</tr>
<tr>
<td>6</td>
<td>Definitely not avoidable</td>
</tr>
</tbody>
</table>

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

Please note that this data collection sheet is subject to change following conclusion of the pilot phase of the programme.
Appendix 2

Learning from deaths of patients with severe mental illness (SMI)

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.

SMI does not have a set definition – it could have a very broad and inclusive meaning or, more often, refer to mental illnesses with psychotic features (schizophrenia, schizoaffective disorder and bipolar affective disorder). The NHS England document “Improving the physical health of people with serious mental illness” uses the term SMI to refer to psychotic disorders.

Based on this we will screen patients coded for F200 to F319 who die for potential review.

In reviewing the death of a patient with mental health problems we consider whether death has been premature or there has been increased risk of complications for those with physical and mental health difficulties.


Inpatients detained under Mental Health Act (1983).

We routinely refer the death of patients subject to the Mental Health Act to the coroner in compliance with the Coroners and Justice Act 2009. 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 is reported to the our commissioners as a serious incident and investigated appropriately. Consideration is also given to commissioning an independent investigation as detailed in the serious incident framework.
At UCLH patients with LD who die are reported to the LD clinical nurse specialist / safeguarding team via a weekly alert from performance team. This LeDeR flow chart explains how to report a death and the process thereafter for review.

[Diagram of Learning Disability Mortality Review Process for Adults (February 17)]
Appendix 4

Learning from expected deaths and at the end of life - listening to and learning from bereaved relative and carers

1. Expected deaths

In July 2014 the Leadership Alliance for Dying People published “One Chance to Get it Right”, an important document which details an approach to caring for dying people to be adopted by all health and care organisations. The approach focuses on provision of individualised, patient-centred care based around five Priorities of Care:

1. Recognise that the patient may be dying, and communicate this clearly
2. Communicate sensitively with the patient and those important to them.
3. Involve the dying person and those important to them in decisions,
4. Support to ensure that the needs of patients and those close to them are explored, respected and met
5. Plan and do; agree, coordinate and compassionately deliver and individual plan of care.

In response, UCLH and Central North West London (Camden) NHS Foundation Trusts developed and implemented ‘Excellent care in the last days of life’, documents which promote and support staff to deliver top-quality, individualised end of life care, based on the five Priorities and centred around the patient.

Communication includes informing the family if we intend to review or investigate the care provided to the patient.

Evidence* suggests older patients who die, or those where death may be expected, are no less likely to have experienced problems in healthcare than patients who die unexpectedly. Therefore, we do not exclude such deaths from consideration for a structured judgment review. Whether or not a death is expected is captured by the End of Life Care Governance Data (green) form completed by the doctor completing the death certificate.

Initial contact with families is usually managed by the clinicians responsible for the care of the patient. Given that we offer families/carers the opportunity to express concerns about the care given to patients who have died, then the involvement of clinicians who cared for the patient may be considered a barrier to raising concerns. All families at UCLH are offered an End of Life Care survey by the bereavement team when their relative/friend dies. The questionnaire invites families to comment on the quality of care received at UCLH during the last days of life and after death. The survey document also asks families to provide their contact details if they wish to raise significant concerns about the care of their relative in our hospitals. When we contact families about their concerns we determine the extent to which they wish to be involved.

If their concerns trigger a serious incident investigation or the duty of candour because moderate or severe harm was experienced we let the family know that they will be contacted/involved in line with those processes.

2. The complaints and legal processes

The UCLH complaints team will flag any contacts or complaints received from families that contain concerns about the care of their relative or friend who have died, or who are expected to die in our hospitals.
We offer guidance, where appropriate, on obtaining legal advice for families, carers or staff.

Appendix 5

Learning from maternal deaths

The full investigation process for when a maternal death occurs is laid down in the maternal death guideline (add link when published). This appendix outlines how the Women’s health team liaise with families when a mother dies and how the trust learns from that death.

1. Family liaison

Contact will be made with the family / nominated next of kin (NNOK) as soon as possible if not already present.

- A link staff member will be allocated to the family/NNOK to provide a link between the hospital and family during the period immediately following the death to provide support and information and to answer any queries the family has. This is commonly either a matron or a member of the bereavement team (depending on the day of the week and/or those involved).

- Duty of Candour (DOC) will be commenced by the lead consultant and/or matron present for deaths occurring within the hospital. For deaths occurring outside the hospital the Women’s health safety team (WHST) will make contact with the NNOK and commence the candour process in conjunction with the will make contact with the NNOK and commence the candour process in conjunction with the divisional governance lead consultant. governance lead. The candour process will encourage the nominated NNOK to identify any areas of concern which the family would like to be included into the terms of reference of the review and investigation. The NNOK will be given information regarding the information process and sharing of the findings of the investigation in line with the DOC policy.

- Once approved, the NNOK will be contacted, the findings of the review/investigation shared and an offer made to meet with the family to answer any outstanding questions as well as to provide a copy of the completed investigation report.

2. Learning

The final report, investigation findings and lessons to be learned will be presented and discussed in umbrella and local governance meeting(s) and the senior team meeting.

The report / findings will be reported to MBRRACE, the clinical commissioning group and NHS England to ensure lessons are learned and shared at a regional and national level.

Additionally lessons to be learned will be shared via:

- Women’s Health safety team weekly newsletter
- Individual feedback offered to those directly involved in care, with an opportunity to meet and discuss events, the investigation process and the report findings
- Final report shared with clinical area(s) involved in care provision, with an opportunity to meet and discuss events, the investigation process and the report findings
- Outcomes / lessons learned shared with the clinical practice facilitator team lead for maternity services to inform the mandatory education process
- After Action Review and debriefs

Feedback will be offered to the mother’s NNOK with an offer to meet and discuss events, the investigation process and the report findings.
Learning from when stillbirths or neonatal deaths occur

Appendix 6

The process for review and investigation (if required) in response to a stillbirth or neonatal death occurs is laid down in the Women’s Health Risk Management Strategy (under review). This appendix outlines how the Women’s health team liaise with families when a stillbirth or neonatal death occurs and how the trust learns from that death.

1. Family Liaison
   - Contact will be made with the parents/nominated next of kin (NNOK) as soon as possible, to offer an apology/express condolences and inform them of the review process.
   - A link staff member will be allocated to the parents/NNOK to provide a link between the hospital and family during the period immediately following the death to provide support and information and to answer any queries the family has. This is usually a member of the bereavement team.
   - Duty of Candour (DOC) will be commenced by the lead consultant and/or matron present if the timing is considered appropriate. Where a DOC conversation has not been appropriate or possible before discharge home, the Women’s Health safety team (WHST) will make contact with the parents/NNOK and commence the candour process in conjunction with the governance lead. The candour process will encourage the parents/NNOK to identify any areas of concern which the family would like to be included into the terms of reference of the review. The parents/NNOK will be given information regarding the information process and sharing of the findings of the investigation in line with the DOC policy.
   - The case will be subject to review within 72 hours of the death by the WHST and the governance leads from the neonatal unit to determine whether there are clear, contributory cares or service delivery problems (CSDPs). If so the case will be declared as an investigation by the WHST and the parents told about the investigation and asked to nominate any concerns regarding care provision to inform the terms of reference of the investigation.
   - If there are no clear contributory CSDPs, no investigation will be formally launched. The parents/NNOK will be informed of the date for review to enable them to identify any queries regarding care provision in advance of the review and to inform the CIRG review process.
   - Once the report is finally approved, the parents/NNOK will be contacted, the findings of the review/investigation shared and an offer made to meet with the family to answer any outstanding questions as well as to provide a copy of the completed investigation report (if relevant).

2. Learning
   The final report, investigation findings and lessons to be learned should be presented and discussed in umbrella and local governance meeting(s) and the senior team meeting. The report / findings will be reported to MBRRACE and the CCG to ensure lessons are learned and shared at a regional and national level.

   Additionally lessons to be learned will be shared via:
   - Women’s Health Safety Team weekly newsletter
   - Individual feedback offered to those directly involved in care, with an opportunity to meet and discuss events, the investigation process and the report findings
   - Final report shared with clinical area(s) involved in care provision, with an opportunity to meet and discuss events, the investigation process and the report findings
   - Clinical practice facilitator team lead for maternity services
   - After action review and debriefs

   Feedback will be offered to the woman’s NNOK with an offer to meet and discuss events, the investigation process and the report findings.
Learning when a child or young person dies  

Appendix 7

The ‘Child Death Reporting- Responsibilities in relation to Child Death Overview Panel reporting procedures’ and process for rapid response to the unexpected death of a child-UCLH procedure’ describes in detail the procedures required after the death of a child, regardless of whether the death was expected or not, from live births up to the age of eighteen. The specific points in the child death review process that address the objectives of the Responding to Deaths policy are:

**Objective one: To make learning from deaths, and the valuable opportunities for improvement from that, a learning a priority for UCLH.**

1. **ULCH ongoing involvement with child death review process**

The chair of the Child Death Overview Panel (CDoP) will ask the consultant paediatrician to complete a more detailed proforma (usually referred to as form B)

- An initial case discussion meeting will usually take place within a week. The lead paediatric consultant and other relevant ULCH staff will be invited to attend and share all relevant information by the chair of the CDoP.
- This meeting will include representatives from police and social care together with any other professionals involved with the family.
- It will be decided at the meeting what actions and further meetings will be required. This will include ensuring appropriate bereavement services are offered to the family.
- The coroner’s officer will talk to the parents before the post-mortem is done and within a few days after the post-mortem is done about the preliminary results.
- The pathologist will report to the Coroner and the police but not to the paediatric consultant.
- The final pathologist’s report should be ready within between one and three months. One factor is whether neuro-pathological investigation needs to be done.
- The result will not come to the consultant paediatrician who will need to get it by contacting the relevant coroner’s officer.
- It is very unlikely that the result will lead to a need for a further strategy discussion but there may be a final multi agency meeting to ensure all actions are completed and to think about any learning from the events and how this can be shared.
- The paediatric consultant should offer to meet with the parents to discuss the final post-mortem result.

**Objective two: To engage families and carers and recognise their insights as a vital source of learning in the investigation of deaths identified for review**

- An initial case discussion meeting will usually take place within a week. It will be decided at the meeting what actions and further meetings will be required. This will include ensuring appropriate bereavement services are offered to the family.
- A bereavement letter is sent to the bereaved parents to ask them if they would like the opportunity to meet with the paediatrician to discuss any questions they may still have surrounding the circumstances of their child’s death.

In all cases enquiries should seek to understand the reasons for the child’s death and consider any lessons to be learnt about how best to safeguard and promote children’s welfare in the future.

2. **Learning and sharing**

Learning from unexpected deaths of children is shared routinely at UCLH via the child safeguarding committee, and in staff training. Learning is also shared with appropriate groups in local meetings as needed. Expected deaths are also reported to the child death review panel but at UCLH these are in the main premature babies or adolescents with cancer and these are all part of national research programmes which identify treatment and pathway learning.
Investigation and learning from in-house cardiac arrest deaths

The Patient Emergency Response and Resuscitation team (PERRT) record all cardiac arrests (CAs) on the incident reporting system Datix. Regular meetings occur, in most cases weekly, between the Quality and Safety department and the PERRT senior nurse, to discuss in-hospital CAs across the trust and any investigations. The 72 hour review form used for serious incidents has been adapted to include a second template designed to capture the specific questions related to cardiac arrests. This is called the PERRT analysis tool and is completed along with the adapted 72 hour review template for most unexpected in-hospital cardiac arrests (exclusions include patients with a DNACPR order). This process has had the benefit of standardising the process of investigation, ensuring all relevant information such as immediate actions and consideration of whether escalation to serious incident (SI) status is required.

As the 72 hour review process is already familiar within the clinical teams, it is a good way of discussing the in-hospital cardiac arrests with the team involved present, with copies of the medical notes and key questions raised in the PERRT Analysis tool included as part of the investigation. This way, the discussion and learning is also documented, even if the incident does not meet SI criteria.

Having this process in place has also enabled identification of common themes.

(NB. Still under consultation and may change)