



I have told you a thousand times...

A review of the learning from the national mortality review programmes

How many times do we have to be told?

The nationally commissioned mortality review programmes and confidential enquiries usually report annually. In some cases programmes will themselves commission discrete pieces of work to understand specific areas of concern. Common to all programmes is the publication of recommendations and learning points that emerge from their reviews.

All healthcare is represented both by these programmes and within the reviews written, and all healthcare organisations, and healthcare workers within those organisations, potentially have access to the reports. However, despite the ability to disseminate the findings widely, there is a view from the programmes that the implementation of actions required by organisations to correct the issues identified is less successful. It is possible that this perception arises due to the quantity of information that is disseminated, which is, paradoxically, too much to easily assimilate.

This review has been written to attempt to summarise the issues that are seen in multiple reports both in time and across the boundaries of patient groups. It is an attempt to identify those themes shared by all such reports and programmes as well as reinforcing the unique aspects of the specific programme recommendations.

The commissioned programmes are:

1. The Learning Disabilities Mortality Review (LeDeR) Programme
2. The National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH)
3. The Medical and Surgical Clinical Outcome Review and the Child Health Clinical Outcome Programmes (NCEPOD)
4. The National Mortality Case Record Review Programme (NMCRR)
5. The Maternal, Newborn and Infant Clinical Outcome Review Programme (MBRRACE-UK)

A more comprehensive account is given under each programme link later in this review. These programmes collate the endeavours of many healthcare workers, and although they are at differing points in maturity, often articulate common issues.



In partnership with



What common themes have emerged?

Reviewing the contemporaneous recommendations and learning points from all the active programmes reveals a small number of generic issues that continue to affect healthcare across all sectors. These can be summarised in four relatively simple messages:

1. Improvements in recognition and management of sepsis are needed to prevent premature mortality in all client and patient groups.
2. Early detection of, and then appropriate escalation of, patients who are deteriorating or exhibit 'red flags' at presentation will further prevent premature mortality.
3. Patients across all healthcare organisations sometimes continue to be denied life-saving therapies on the grounds of being older, pregnant or having a learning disability.
4. Better communication both within organisations, and between organisations and healthcare agencies will help avoid premature deaths.

None of these four key descriptors, which are relatively simple in concept, will come as a surprise to any healthcare worker. The issue is not one of awareness or ignorance of the matter but one of positive action to correct it. We all have the potential to play a positive role in making these improvements. It is also evident that many of these themes have recurred over time and this in itself is a 'common theme'.

Specific mortality programmes also have unique areas of learning

Not surprisingly, and probably as a measure of the differing types of mortality review, the various programmes have also identified unique learning points. These unique learning points can be found in the programme links.



The challenge

Very few readers of this review will be ignorant of its simple messages.

Indeed, as the title suggests, you may feel that you have been told these things a 'thousand times'.

The programme leaders therefore offer you the following challenge:



Programme links

1. The Learning Disabilities Mortality Review (LeDeR) programme
www.bristol.ac.uk/sps/leder
2. The National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH)
<https://sites.manchester.ac.uk/ncish>
3. The Medical and Surgical Clinical Outcome Review and the Child Health Clinical Outcome Programmes (NCEPOD)
www.ncepod.org.uk/index.html
4. The National Mortality Case Record Review Programme (NMCRR)
www.rcplondon.ac.uk/projects/national-mortality-case-record-review-programme
5. The Maternal, Newborn and Infant Clinical Outcome Review Programme (MBRRACE-UK)
www.npeu.ox.ac.uk/mbrance-uk

The Learning Disabilities Mortality Review (LeDeR) programme

Pauline Heslop, programme lead, University of Bristol

Louisa Whait, regional coordinator, Midlands and the East, NHS England

The Learning Disabilities Mortality Review (LeDeR) programme was established in 2015 in response to several reports, case studies and inquiries that have consistently highlighted that in England people with learning disabilities die younger than people without learning disabilities. The Confidential Inquiry into premature deaths of people with learning disabilities¹ (CIPOLD) reported that for every one person in the general population who died from a cause of death potentially amenable to change by good quality care, three people with learning disabilities would do so. More recent analysis of data from the Primary Care Research Database suggested that the all-cause standardised mortality ratio for people with learning disabilities was 3.18, and that people with learning disabilities had a life expectancy 19.7 years lower than people without learning disabilities.²

The LeDeR programme was established to contribute to improvements in the quality of health and social care for people with learning disabilities in England. It does this by supporting local areas to carry out reviews of the deaths of people with learning disabilities aged 4 years and over, following the established LeDeR programme methodology. The emphasis of the programme is on service improvements; all reviews conclude with the reviewer(s) identifying learning that has come from the review and any recommendations that might improve the provision of services for people with learning disabilities and their families.

The most recent annual report for the LeDeR programme (2016/17, published in May 2018) is based on the completed reviews of 103 deaths. It highlights an apparently widening gap between the age at death of people with learning disabilities when compared with the general population, and a different pattern of causes of death. More people with learning disabilities died in hospital than people in the general population; fewer than expected had postmortem examinations and fewer than expected had inquests opened into their death. Reviewers indicated that 13% of people's health had been

adversely affected by one or more of the following: delays in care or treatment; gaps in service provision; organisational dysfunction; or neglect or abuse. Such a picture of inequities in health access and outcomes is not new, but it is a stark reminder about the continuing inequalities faced by people with learning disabilities and their families, and the need for determined service improvements to ameliorate this.

The most commonly reported learning and recommendations were made in relation to the need for:

- a) Inter-agency collaboration, including communication
- b) Awareness of the needs of people with learning disabilities
- c) The understanding and application of the Mental Capacity Act (MCA)

The greatest number of learning or recommendations identified in the completed reviews related to the scope for improvements in collaboration and communication within and between agencies, particularly in relation to communication involving residential or care homes and health professionals. Proposals to improve this included the greater use of 'health passports', poor or unsafe discharges from hospital to be addressed at quality review group meetings, and GPs proactively following up people with learning disabilities who fail to attend planned appointments.

The second largest category of the learning and recommendations related to raising awareness about the specific needs of people with learning disabilities. Training needs across a spectrum of roles were noted, including those working in A&E, the local authority, acute services, care providers and primary care. Recommendations for training included general awareness about the health needs of people with learning disabilities and how they may indicate pain or discomfort, as well as their needs for reasonably adjusted care.

The third largest category of the learning and recommendations related to the need for a better understanding and application of the Mental Capacity Act (MCA). Reviewers identified problems with the level of knowledge about the MCA by a range of professionals, and concerns about capacity assessments not being undertaken, the Best Interests process not being followed, and Deprivation of Liberty Safeguards (DOLS) not being applied.

The need for improved training about all aspects of the MCA and DOLS, and its application was recommended.

Based on the evidence from completed LeDeR mortality reviews, we made a number of important and key recommendations.

These are summarised below.

Recommendation	Responsible agency
1. Strengthen collaboration and information sharing, and effective communication, between different care providers or agencies.	Commissioners
2. Push forward the electronic integration (with appropriate security controls) of health and social care records to ensure that agencies can communicate effectively and share relevant information in a timely way.	NHS England
3. Health Action Plans developed as part of the Learning Disabilities Annual Health Check should be shared with relevant health and social care agencies involved in supporting the person (either with consent or following the appropriate MCA decision-making process).	NHS England Commissioners Providers
4. All people with learning disabilities with two or more long-term conditions (related to either physical or mental health) should have a local, named healthcare coordinator.	Commissioners
5. Providers should clearly identify people requiring the provision of reasonable adjustments, record the adjustments that are required, and regularly audit their provision.	Providers
6. Mandatory learning disability awareness training should be provided to all staff, delivered in conjunction with people with learning disabilities and their families.	Commissioners Providers
7. There should be a national focus on pneumonia and sepsis in people with learning disabilities, to raise awareness about their prevention, identification and early treatment.	NHS England
8. Local services should strengthen their governance in relation to adherence to the MCA and provide training and audit of compliance 'on the ground' so that professionals fully appreciate the requirements of the Act in relation to their own role.	Commissioners Providers
9. A strategic approach is required nationally for the training of those conducting mortality reviews or investigations, with a core module about the principles of undertaking reviews or investigations, and additional tailored modules for the different mortality review or investigation methodologies.	NHS England

A national joint 'Learning into Action' group has now been established to address some of the key issues relating to early deaths of people with learning disabilities. Specific work on early detection of symptoms of sepsis, early warning signs recognition, dysphagia, pneumonia, constipation, epilepsy and the effective use of the Mental Capacity Act in urgent care settings is underway. The group coordinates and signposts a coalition of health and care agencies, provider trusts and other

stakeholders to produce packages of best practice measures and urgent health interventions across health and social care for people with learning disabilities. Learning into Action briefings are shared by the LeDeR team on a bimonthly basis, and local actions tracked against recommendations on a quarterly basis. A formal response from the Department of Health and Social Care was published at the beginning of September 2018.

The following two examples illustrate the importance of understanding early deaths of people with learning disabilities from a holistic perspective.

Example one

‘ This was a gentleman who could not advocate for himself. He was under the care of a urologist when a child, this stopped at age 18. For 8 years he had no follow-up care and during this time he developed a large kidney stone which was the main cause of his death. There was no professional coordination in relation to his long-term conditions; the treatment of his weight loss took months; the identification of his kidney stones took months; limited pain relief was given, the identification of urinary infection and commencement on antibiotics towards the end of his life could have been done sooner; and there was no recognition of pyelonephritis, which was the cause of death.’

Example two

‘ Nick was discharged home with a catheter and the care staff had never had any training on catheter care. He was later readmitted to hospital with possible urinary sepsis. The failure to liaise with carers about their knowledge and skills in catheter care contributed to an unsafe discharge, readmission and rapid decline in health.’

References

1. Heslop P, Blair P, Fleming P, Hoghton M, Marriott A, Russ L. *The Confidential Inquiry into premature deaths of people with learning disabilities. Final Report*. Bristol: The Norah Fry Research Centre, 2013. www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf
2. Glover G, Williams R, Heslop P, Oyinola J and Grey J M. *Mortality of people with intellectual disabilities in England*. *Journal of Intellectual Disability Research* 2017;61(1):62–74.

A review or an investigation?

(i) Review: A review is usually a proactive process, often without a ‘problem’, complaint or significant event. It is often undertaken to consider systems, policies and processes. A review is a broad overview of a sequence of events or processes. It can draw on the perceptions of a range of individuals and a range of sources. The resulting report does not make findings of fact, but it summarises the available information and makes general comments. A review may identify some areas of concern that require investigation eg if there is some evidence of poor practice, in which case the appropriate recommendation for an investigation should be made.

(ii) Investigation: An investigation generally occurs in response to a ‘problem’, complaint or significant event. An investigation is often initiated in relation to specific actions, activities or questions of conduct. It is a systematic analysis of what happened, how it happened and why. An investigation 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 the event to understand how and why it occurred and to reduce the risk of future occurrence of similar events.

The National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH)

Dr Pauline Turnbull, project manager

The National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH) (formerly the National Confidential Inquiry into Suicide and Homicide by People with Mental Illness) is an internationally unique project. Our study has collected in-depth information on all suicides in the UK since 1996.¹ Our evidence is cited in national policies and clinical guidance and regulation in all UK countries. We have shown that implementing NCISH recommendations in health services is associated with a reduction in suicide rates within that service.^{2,3} There has been a decrease in suicides in specific high-risk settings that our recommendations targeted, including inpatients, crisis teams, and the post-discharge period. This work has contributed to an overall decrease in suicide nationally (estimated 250–300 fewer deaths per year).

The economic cost of each suicide death is around £1.7 million.⁴ Based on these figures, 300 fewer suicide deaths in England and Wales represent a potential cost saving of £510 million annually.

We formulated 20 years of NCISH recommendations into a self-audit toolkit of 10 clinical standards which are associated with suicide reduction – our ‘10 ways to improve safety’. These elements of safer care are presented here as quality and safety statements about clinical and organisational aspects of care. They are intended to be used as the basis for self-assessment by specialist mental healthcare providers, and responses should ideally be based on recent local audit data or equivalent evidence.

Suicide prevention: the evidence



Safer wards

We advise that services review their inpatient safety, and remove ligature points (including low-lying ligature points) from wards. Observation is a skilled intervention to be carried out by experienced staff – this should be recognised in the observation policy. Services should consider measures to prevent patients from leaving the ward without staff agreement; this might be through better monitoring of ward entry and exit points and by improving the inpatient experience through recreation, privacy and comfort. Care planning for agreed leave is important.

Early follow-up on discharge

Patients discharged from psychiatric inpatient care to be followed up by the service within 2–3 days of going home. A care plan covering crises and life stresses should be in place at the time of discharge.

No out-of-area admissions

Very ill patients to be accommodated in a local inpatient unit. Being admitted locally means that patients stay close to home and the support of their friends and family and are less likely to feel isolated or to experience delayed recovery. We would expect local admissions to result in simpler discharge care planning.

24 hour crisis resolution/home treatment teams

Community mental health services to include a 24-hour crisis resolution/home treatment team (CRHT) with sufficiently experienced staff and staffing levels. CRHTs provide intensive support in the community to patients who are experiencing crisis, as an alternative to inpatient care. CRHT teams should be monitored to ensure that they are being used safely: (1) contact time and staffing to reflect the need and risk associated with the service, (2) appropriate placement to be checked; one-third of patients under CRHT who died by suicide had been using the service for less than a week.

Family involvement

Consultation with families from first contact, throughout the care pathway and when preparing plans for hospital discharge and crisis plans could improve service safety. Staff could also make it easier for families to pass on concerns about suicide risk and be prepared to share their own concerns. This could help to ensure there is a better understanding of the patient's history and what is important to them in terms of their recovery, and may support better compliance with treatment. A post-incident multidisciplinary review should occur following all suicide deaths; involving input from and sharing information with families is a reflection of a learning culture.

Guidance on depression

A local trust policy based on NICE (or equivalent) guidelines for depression and self-harm, including clear recommendations on comprehensive assessment, and delivery of interventions.

Personalised risk management

All patients' management plans to be based on the assessment of individual risk and not on the completion of a checklist. Patients should have the opportunity to discuss with their mental health team the signs that they will need additional support, such as specific stresses in their life.

Outreach teams

Community mental health teams to include an outreach service that provides intensive support to patients who are difficult to engage or who may lose contact with traditional services. This might be patients who don't regularly take their prescribed medication or who are missing appointments.

Low staff turnover

There should be a system in place to monitor and respond to staff turnover rates. The NICE Quality Standard for service user experience in adult mental health services emphasises the need for continuity of care, which inspires trust and confidence.

Services for dual diagnoses

We recommend there be drug and alcohol services available that work closely with mental health services for patients with mental illness and alcohol and drug misuse. Services to ensure specialist skills in substance misuse are available for patients with mental illness and substance misuse; this might be through joint working with drug and alcohol teams, and also through the training of mental health staff.

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3. Kapur N, Ibrahim S, While D et al. Mental health service changes, organisational factors, and patient suicide in England in 1997 and 2012: a before-and-after study. *The Lancet Psychiatry* 2016;3:526–34.
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The Medical and Surgical Clinical Outcome Review and the Child Health Clinical Outcome Review Programmes

Marisa Mason, National Confidential Enquiry into Patient Outcome and Death

The aim of the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) is to undertake confidential enquiries and make recommendations for clinicians and service providers. NCEPOD uses a peer review process, along with questionnaires completed by clinicians involved in a patient's care, to assess the quality of care provided. Multidisciplinary groups of healthcare professionals review cases relevant to their specialty. This method ensures that the recommendations made are clinically robust.

NCEPOD undertakes the Medical and Surgical Clinical Outcome Review and the Child Health Clinical Outcome Review Programmes, commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England, the Welsh Government, the Department of Health in Northern Ireland, the Scottish Government and the States of Jersey, Guernsey, and the Isle of Man. NCEPOD as an organisation was established in 1988. At that time NCEPOD reviewed in-hospital perioperative deaths. In 2003 its remit was extended to review the quality of medical care and the method was also changed so that anyone could suggest an idea for a topic for review and the topics and reviews became more focused. Death is still used as an outcome for inclusion, but other outcomes such as discharge, or admission to critical care may also be used.

Each study undertaken explores a specific topic in detail. However, a number of common themes have emerged that are relevant to the care of all patients admitted to hospital. These include:

1. More timely consultant review
2. Continued supervision of trainee doctors
3. Better multidisciplinary review
4. Improved accuracy of documentation in case notes
5. More frequent patient monitoring and use of early warning scores
6. Improved morbidity and mortality review attendance and occurrence
7. Better use of networks of care
8. Greater existence, and audit, of policies, protocols, proformas and guidelines

National Mortality Case Record Review Programme

Clare Wade, NMCRR Programme manager

The National Mortality Case Record Review (NMCRR) Programme aims to improve understanding and learning about problems and processes in healthcare associated with mortality, and also to share best practice.

It will also help healthcare professionals to identify themes and address deficiencies in processes and patient care. Once the standardised review process is implemented within governance and quality improvement structures, hospitals, staff, patients and families will benefit from better care, outcomes and confidence in an open and honest culture.

NMCRR programme and clinical governance

The aim of the programme is to introduce a standardised methodology for reviewing case records of adult patients who have died in acute general hospitals in England and Scotland. The primary goal is to improve healthcare quality through qualitative analysis of mortality data using a standardised, validated approach linked to quality improvement activity. The work will not cover deaths that occur in other settings.

Around 50% of all deaths occur in hospital and most of these are inevitable, but around 3–5% of acute hospital deaths are thought to be potentially preventable. The Structured Judgement Review (SJR) review methodology has been validated and used in practice within a large NHS region. It is based upon the principle that trained clinicians use explicit statements to comment on the quality of healthcare in a way that allows a judgement to be made that is reproducible.

The Maternal Newborn and Infant Clinical Outcome Review Programme

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Elizabeth Draper, Perinatal Programme lead, University of Leicester

The Mothers and Babies: Reducing Risks through Audits and Confidential Enquiries in the UK (MBRRACE-UK) collaboration is responsible for conducting surveillance of maternal deaths up to 1 year after pregnancy, stillbirths and neonatal deaths up to 28 days of age and confidential enquiries into maternal deaths and selected maternal morbidities as well as selected perinatal deaths and morbidities. One of the most striking observations of both programmes is that repeated recommendations, that is, those that are clearly the most difficult to implement, are those which cross the boundaries between obstetrics and other areas of medicine. There appears to be an increasing tendency to work solely within different medical silos and consideration of pre-pregnancy and pregnancy care is not necessarily seen as a wider responsibility.

Most recently the perinatal programme has conducted enquiries into congenital diaphragmatic hernia, antepartum stillbirths and intrapartum-related stillbirths and neonatal deaths. Of particular relevance to this theme when examining the care of women whose babies are subsequently stillborn or die in the neonatal period is the observation concerning the use of joint clinics for women with diabetes and other medical conditions in pregnancy; ongoing care for women with diabetes appeared not to be in a joint clinic for half of the women with the condition.¹

The maternal programme continues the long-running Confidential Enquiry into Maternal Death which began in England and Wales in 1952 and has thus been in operation for more than 60 years, over which time maternal death rates have fallen ten-fold. When these enquiries were first begun, more than two-thirds of maternal deaths were due to direct obstetric causes such as haemorrhage and only one-third due to medical and mental health complications. This pattern has now completely reversed, with only one-third of deaths due to obstetric causes and two-thirds due to medical and mental health conditions, the largest group of which are deaths due to cardiac disease.

It is striking that across these disparate complications and among both women who died and those who survive but have severe morbidity, one recurring dominant theme emerges. There remain multiple opportunities to reduce women's risk of complications in pregnancy through early and forward planning of the care of women with known pre-existing medical and mental health problems by all the specialty teams involved in their care. Provision of appropriate advice and optimisation of medication prior to pregnancy, referral early in pregnancy for the appropriate specialist advice and planning of antenatal, intrapartum and postnatal care and effective postnatal provision of advice concerning risks and planning for future pregnancies are the key improvements needed to prevent women dying or having severe complications in the future.

The following are key recurring recommendations from recent reports.^{2,3,4,5}

- > Women with pre-existing medical conditions should have pre-pregnancy counselling by doctors with experience in managing their disorder in pregnancy. This should include open access to appropriate contraceptive advice.
- > Women should not be denied relevant investigations or treatments for life-threatening conditions, simply because they are pregnant or breastfeeding.
- > Pregnant and postpartum women presenting to the emergency or acute medical departments with medical problems should be discussed with a member of the maternity medical team.
- > Repeated presentation with pain and/or pain requiring opiates should be considered a 'red flag' and warrant a thorough assessment of the woman to establish the cause.
- > The postnatal care plan for women with complex and multiple problems should include the timing of follow-up appointments, which should be arranged with the appropriate services before the woman is discharged and not left to the GP to arrange.

The following two contrasting vignettes illustrate the challenges in caring for women with medical disorders in pregnancy and how good care can make a real difference.

Example one

“A multiparous woman had known severe lung disease. Prior to her current pregnancy, she had been seen regularly by her respiratory physician who had noted a significant decline in her respiratory function, but had put this down to a concurrent chest infection. Despite a previous complicated pregnancy, there is no evidence from her records that the possibility of further pregnancy was ever considered by her physician and associated risks discussed. She asked for transfer to a different physician as she felt she was not being listened to. She presented repeatedly during her pregnancy and at every stage her deteriorating lung function was underestimated with no clear coordination of care. She was delivered in the third trimester due to deteriorating lung function but deteriorated again in the postnatal period and died.”

Example two

“A woman with known juvenile myoclonic epilepsy had seizures which were well controlled outside pregnancy but had shown deterioration in a previous pregnancy. She was correctly identified as high risk. There was very good communication between all members of her neurology, GP, midwifery and obstetric teams throughout pregnancy. There was a joint epilepsy anti-epileptic clinic in place. All appropriate advice and risk discussions happened. Her antiepileptic drugs were manipulated properly leading to improved seizure control. She received appropriate advice to reduce the dosages after delivery. Exemplary care led to a good pregnancy outcome for both her and her baby.”

References

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