



# Rutland County Council

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**Meeting:** ADULTS AND HEALTH SCRUTINY PANEL

**Date and Time:** Thursday, 7 February 2019 at 7.00 pm

**Venue:** COUNCIL CHAMBER, CATMOSE

**Governance Officer:** Joanna Morley 01572 758271  
email: [governance@rutland.gov.uk](mailto:governance@rutland.gov.uk)

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**Helen Briggs**  
**Chief Executive**

## A G E N D A

**1) APOLOGIES FOR ABSENCE**

**2) RECORD OF MEETING**

To confirm the record of the meeting of the Adults & Health Scrutiny Panel held on 27 September 2018 (previously circulated).

**3) DECLARATIONS OF INTEREST**

In accordance with the Regulations, Members are invited to declare any personal or prejudicial interests they may have and the nature of those interests in respect of items on this Agenda and/or indicate if Section 106 of the Local Government Finance Act 1992 applies to them.

**4) PETITIONS, DEPUTATIONS AND QUESTIONS**

To receive any petitions, deputations and questions received from Members of the Public in accordance with the provisions of Procedure Rule 217.

The total time allowed for this item shall be 30 minutes. Petitions, declarations and questions shall be dealt with in the order in which they are received.

Questions may also be submitted at short notice by giving a written copy to the Committee Administrator 15 minutes before the start of the meeting.

The total time allowed for questions at short notice is 15 minutes out of the total time of 30 minutes. Any petitions, deputations and questions that have been submitted with prior formal notice will take precedence over questions submitted at short notice. Any questions that are not considered within the time limit shall receive a written response after the meeting and be the subject of a report to the next meeting.

**5) QUESTIONS WITH NOTICE FROM MEMBERS**

To consider any questions with notice from Members received in accordance with the provisions of Procedure Rule No 219 and No 219A.

**6) NOTICES OF MOTION FROM MEMBERS**

To consider any Notices of Motion from Members submitted in accordance with the provisions of Procedure Rule No 220.

**7) CONSIDERATION OF ANY MATTER REFERRED TO THE PANEL FOR A DECISION IN RELATION TO CALL IN OF A DECISION**

To consider any matter referred to the Panel for a decision in relation to call in of a decision in accordance with Procedure Rule 206.

**SCRUTINY**

Scrutiny provides the appropriate mechanism and forum for members to ask any questions which relate to this Scrutiny Panel's remit and items on this Agenda.

**8) EAST MIDLANDS AMBULANCE SERVICE: FUTURE VISION AND STRATEGY**

To receive a presentation from Lee Brentall, Ambulance Operations Manager, East Midlands Ambulance Service.  
(Pages 5 - 18)

**9) COMMUNITY SERVICES REDESIGN**

To receive Report No.34/2019 from Tamsin Hooton, Director lead for Community Services Redesign, West Leicestershire CCG.  
(Pages 19 - 30)

**10) LEARNING DISABILITIES MORTALITY REVIEW**

To receive Report No.30/2019 from the Strategic Director for People and a presentation from Kim Sorsky, Head of Service Prevention and Complex Care Services and James Lewis, Local Area contact, LeDeR Programme, LLR.  
(Pages 31 - 90)

**11) REPORT OF THE MENTAL HEALTH TASK AND FINISH GROUP**

To receive Report No.28/2019 from the Mental Health Task and Finish Group.  
(Pages 91 - 116)

**12) SCRUTINY PROGRAMME 2015/16 & REVIEW OF FORWARD PLAN**

To consider the current Forward Plan and identify any relevant items for inclusion in the Adults and Health Scrutiny Panel annual work plan, or to request further information.

Copies of the annual work plan and the Forward Plan will be available at the meeting. The Forward Plan can be found on the website using the following link:

<https://rutlandcounty.moderngov.co.uk/mgListPlanItems.aspx?PlanId=196&RP=133>

**13) ANY OTHER URGENT BUSINESS**

To receive any other items of urgent business which have been previously notified to the person presiding.

**14) DATE OF NEXT MEETING**

Thursday 21 March 2019.

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**TO: ELECTED MEMBERS OF THE ADULTS AND HEALTH SCRUTINY PANEL**

Mr G Conde (Chairman)

Ms R Burkitt

Mrs J Fox

Miss G Waller

Mr W Cross

Mr C Parsons

Vacancy

**OTHER MEMBERS FOR INFORMATION**

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**NHS**

**East Midlands  
Ambulance Service**

NHS Trust



# Our Future Vision and Strategy

Will Legge, Director of Strategy and Transformation



Involving you in our future, ambitions and aims

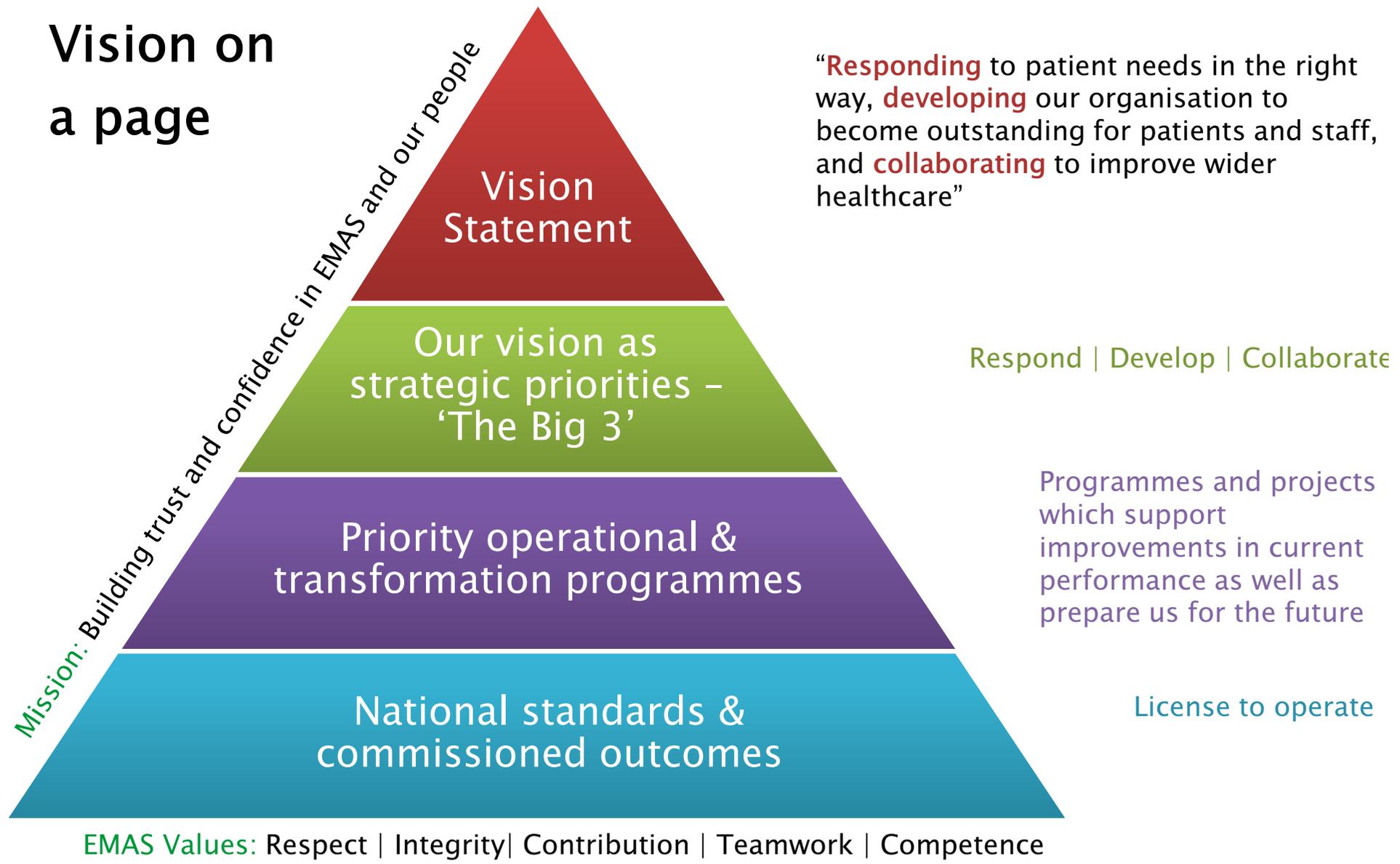
## Why we need to define a vision for EMAS

- Give EMAS a **clear sense of direction**, purpose and focus (funding)
- **Enthuse and energise staff and stakeholders** and unite everyone towards achieving a common set of goals, which can be translated easily into individual roles and objectives
- Build **trust and confidence** in EMAS and our people, and improve the organisation's reputation (as a provider and an employer)
- Demonstrate organisational **leadership at a system level**, and move away from a more inward, operational focus
- Enable us to **prioritise** and deprioritise accordingly
- **Align our strategic priorities** with those of the system, and vice versa (where appropriate)
- **Manage expectations** where we are not prioritising activities
- **Accelerate improvements** in our performance and quality of care
- **Enhance staff satisfaction** and morale

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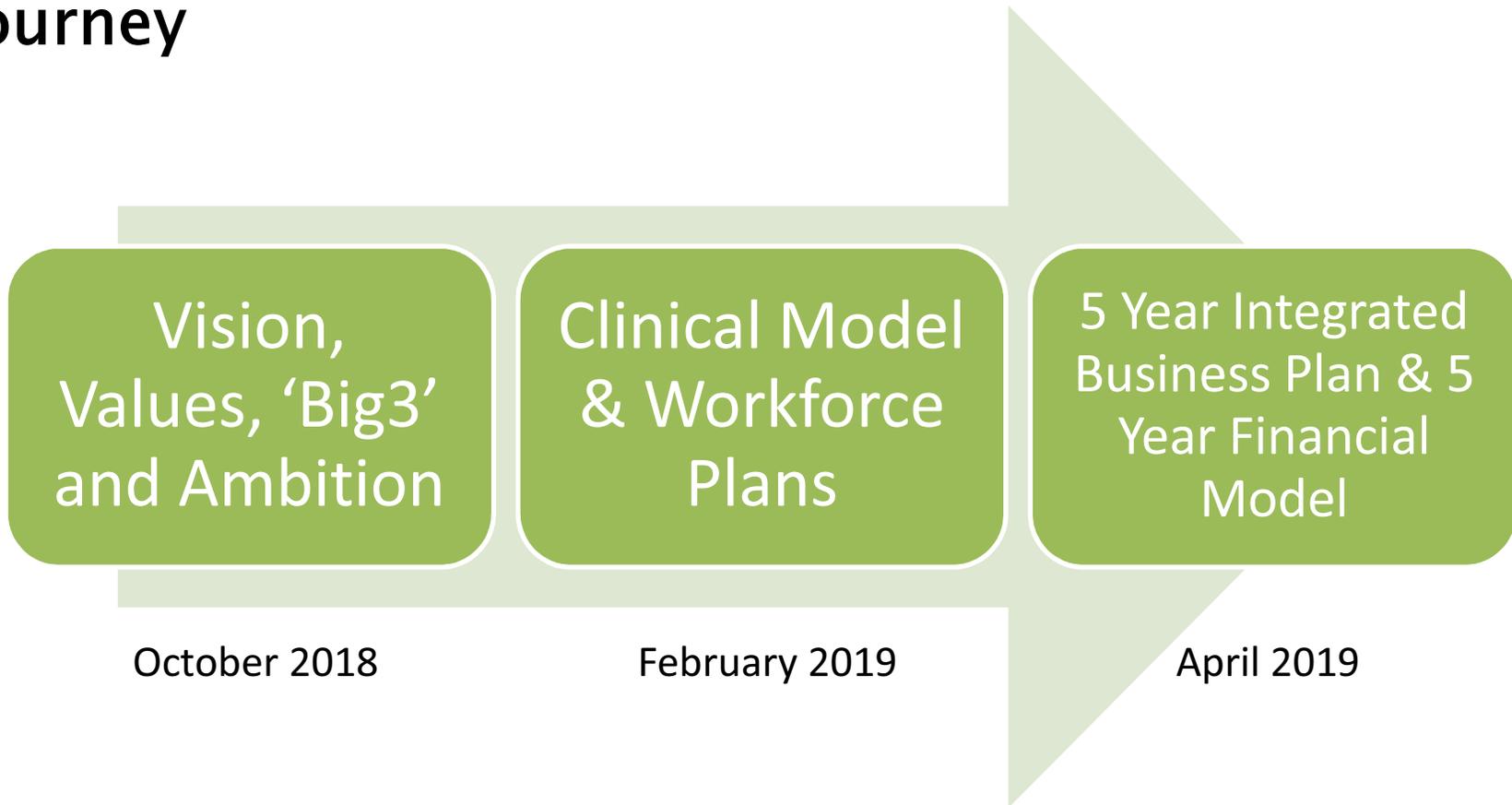
# Vision on a page

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# Our Development Journey

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## Revised vision

“**Responding** to patient needs in the right way, **developing** our organisation to become outstanding for patients and staff, and **collaborating** to improve wider healthcare”



## Revised values

Our values have been updated to reflect our commitment to encouraging innovation, team and partnership working, and looking outwards as well as inwards

EMAS has five values which underpin everything we do, including the way we deliver our services and how we all work with others. By living these values and supporting others to do the same, we will help to make sure that EMAS is an organisation we can all be proud of.

**Respect:** Respect for our patients and each other

**Integrity:** Acting with integrity by doing the right thing for the right reasons

**Contribution:** Respecting and valuing *everyone's contribution, and encouraging innovation*

**Teamwork:** Working together, supporting each other, *and collaborating with other organisations*

**Competence:** Continually developing and improving *our competence*



# The Big 3: Respond | Develop | Collaborate

**“We will respond to patient needs in the most appropriate way”**



**“We will develop our organisation to become outstanding for patients and staff”**

**“We will collaborate with partners and other organisations to reduce healthcare demand and improve wider healthcare”**



## The Big 3: Respond | Develop | Collaborate

“We will respond to patient needs in the most right way”

*We will know we have achieved this when:*

- We are making full use of the care pathways available, safely treating patients at home
- We have the right number of staff in post with the right mix of skills, knowledge and training to respond flexibly to all patient needs based on our workforce plan
- We have the right number, type and age of vehicles on the road to meet the requirements of our workforce plan
- We have access to the right equipment, ambulances and staff to meet patient demand and need

## The Big 3: Respond | Develop | Collaborate

**“We will develop our organisation to become outstanding for patients and staff”**

*We will know we have achieved this when:*

- Our patients report consistently high levels of satisfaction
- Our staff and volunteers report that they are proud to work for EMAS
- Our workforce is healthy, engaged, supported and satisfied, and everyone exemplifies the EMAS values in all that we do
- Our staff and volunteers can access opportunities, education and training to support their career development
- We have realised benefits through ensuring we operate a modern and sustainable estate
- We are consistently delivering the Ambulance System Indicators (including patient quality measures)
- We have achieved a CQC rating of ‘outstanding’ and are consistently meeting our financial targets

## The Big 3: Respond | Develop | Collaborate

**“We will collaborate with partners and other organisations to reduce healthcare demand and improve wider healthcare”**

*We will know we have achieved this when:*

- We have led and contributed to improvements in key areas of healthcare that matter most to EMAS, our patients and our partners across the area we serve. *We will insert specific areas of focus to be determined with system partners during engagement, e.g.*
  - *More patients appropriately treated at home where safe or closer to home (non-conveyance)*
  - *Closer collaboration between the two regional clinical hubs (999 and 111)*
  - *Mental health (prevention and demand management)*
  - *Public education (management and prevention)*
  - *Access to improved pathways*
  - *Further develop our relationship with 111 to ensure patients access the most appropriate care*
- Our local communities are accessing emergency and urgent care services in the most appropriate way, based on their clinical needs

# What do we want to become leaders of?

- Our use of **innovative technological solutions** to address wider healthcare issues and drive improvement
- Our proactive work on **mental health** – patients (prevention and management with partners), and staff (health and wellbeing)
- Becoming national leaders for our work on **patient safety**
- Ensuring **equality and diversity** within our workforce
- Demonstrating international best practice for our clinical outcomes for patients with **cardiac arrest**
- Developing and embedding the **paramedic skillset** in multi-disciplinary team approaches across wider healthcare (led by EMAS)
- Our proactive work with partners on **public education** (management and prevention) within our local communities
- Developing a **positive organisational culture** that means staff want to work here and have high levels of satisfaction
- Identifying and managing **sepsis** (across all geographies), building on the success of our pilot within Lincolnshire

# Next Steps

- Development of implementation plans for the new strategy, including quarterly milestones and monitoring arrangements
- Development of the EMAS Clinical Model during October – February, including the:
  - Operating Model
  - Clinical Leadership Model
  - Clinical Hub Strategy
- Re-development of the EMAS Five Year Integrated Business Plan (IBP), to be presented to Trust Board in April 2019.



## Notes

- Verbal notes on options on closer to home treatment and difference in local offers.



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## ADULTS AND HEALTH SCRUTINY PANEL

7 February 2019

### COMMUNITY SERVICES REDESIGN

Report of the Leicester, Leicestershire and Rutland CCGs

Exempt Information	No	
Relevant Portfolio:	Safeguarding-Adults, Public Health, Health Commissioning, Community Safety & Road Safety	
Contact Officer(s):	Tamsin Hooton, Director for Community Services Redesign, West Leicestershire CCG	Email: tamsin.hooton@westleicestershireccg.nhs.uk

#### DECISION RECOMMENDATIONS

That the Panel:

1. **NOTE** the progress to date in redesigning community health services and the next stage of the work

## 1 PURPOSE OF THE REPORT

- 1.1 The Community Services Redesign project (CSR) is a piece of work led by the three Clinical Commissioning Groups (CCGs) in Leicester, Leicestershire and Rutland (LLR), looking at the future model of community health. The scope of the work centres on adult community services provided by Leicestershire Partnership Trust (LPT), but also has implications for services provided in primary care, social care and other community based providers.
- 1.2 This paper provides an overview of the Community Services Redesign project. It summarises the service issues, case for change and project methodology. It also describes the work undertaken to date, in line with the methodology, to review community services including the significant engagement to support development of proposals for the future.
- 1.3 The report also outlines the principles of the proposed community health services model which is emerging from the ongoing work.

## 2 BACKGROUND AND MAIN CONSIDERATIONS

- 2.1 The Community Health Services in LLR are delivered under a block contract by LPT.

District nursing teams provide a planned nursing service, largely within people's homes, concentrating on the frail and housebound population.

- 2.2 In addition, there is an Intensive Community Support (ICS) service, which was commissioned to provide enhanced nursing care to support people at home at a time of crisis, to prevent admission or facilitate rapid discharge from hospital. It was intended to provide an alternative to staying in a hospital bed – sometimes referred to as a 'virtual ward' model. The ICS service was set up as a largely nurse-led service, with limited social care and therapies within the team and delivers rapid response nursing rather than an integrated crisis response and reablement approach, working to a 10 day length of stay, which limits reablement.
- 2.3 Community hospital beds provide a 'step down' from acute hospitals i.e. the next phase of care before people are living independently at home. There are currently 233 community hospital beds across LLR, split across 12 wards in eight community hospital sites. Patients are admitted where they have a need for continued hospital care but not in an acute setting (approximately 40%) or rehabilitation needs (60%), although these categories are not mutually exclusive and most patients have both needs to a degree.
- 2.4 In addition to community hospital beds, 'Pathway 3' reablement beds provide 24/7 bed-based care in a residential or nursing home setting with in-reach therapy for patients who are not yet well enough to be cared for at home.

### **WHY ARE WE LOOKING AT COMMUNITY HEALTH SERVICES?**

- 2.5 In 2018 we celebrated 70 years of the NHS. Things have changed a lot in that time with perhaps the greatest success of the NHS being the dramatic change in life expectancy. In 1948 the average male died at 66 - it's now 77.
- 2.6 However, people are living with more than one health condition and their needs are more complex. There are more of us, we are older and as we age we pick up illnesses that stay with us including heart disease, respiratory disease and diabetes.
- 2.7 With advancements in technology and knowledge, the NHS can do more than it ever could before. But people don't want to be ill. They tell us they don't want to have to go to hospital and have long stays in an acute or community hospital bed. They want support to stay healthy, be discharged quickly and many prefer to receive more of their care at home.
- 2.8 Clinical evidence also shows that patients achieve their maximum potential and/or recover fastest when they are in the right setting for their needs. The evidence shows that this should be the least acute setting possible and at home where appropriate.
- 2.9 In addition to this, to deliver more joined-up care for patients to aid both their outcomes and experience, greater integration is required between health and social care services. This has been the clear national and local direction for some time and significant progress has been made through close partnership working under the LLR Better Care Together (BCT) Strategic Transformation Partnership to deliver a range of improvements across a number of services.
- 2.10 Community health services in LLR however, have not been reviewed or redesigned for a number of years. The current model does not support some of the key strategic

changes within the LLR Better Care Together Strategic Transformation Partnership which aim to deliver improved care through a model which sees as much care as possible provided at home or close to home. Nor does the current model deliver the kind of care people tell us they want and which evidence shows is best for them.

- 2.11 Within the BCT plan a number of work streams were attempting to deliver more integrated community based services, most importantly the Integrated Locality Teams (ILT) work and the Home First programme. Both of these work streams have significant implications for core community health services and without a clear commissioning strategy in relation to the services provided by LPT, they have not been able to achieve the desired progress towards better integrated care models.
- 2.12 The original STP plan published in November 2016 did not have a clearly articulated community health model, which would meet current and projected demand, support the strategic shift towards more care delivered close to home, and address the issue of bed capacity requirements both within community hospitals and acute settings.
- 2.13 Staff are working really hard to deliver good care, however the current service is not configured in a way which enables it to deliver the best support to patients at home. The CCGs have therefore been working for some time to consider the improvements that are needed for reconfiguring services currently provided to people by LPT.
- 2.14 To address all of the issues described, CCGs, working with our partners, need to change the way we do things to redesign services for our needs in the 21<sup>st</sup> century, invest in the right services and provide them in the right place to match needs and improve care for local people.

## **CURRENT SERVICE ISSUES**

- 2.15 Patients tell us that they want to be cared for at home where it is suitable for them. Clinical evidence shows this is better for them. Over time however, capacity within the district nursing service to deliver care at home has been reduced. A review of community nursing establishment in late 2017 demonstrated vacancy gaps. As a result, the community nursing service 'offer' is limited and district nursing teams do not have the capacity to respond fully to the needs of patients. The ICS service has absorbed much of the day to day unplanned or urgent care needs referred by GP practices, rather than delivering a 'virtual ward' model to acutely unwell patients who would otherwise be in a hospital bed. This reduces continuity of care and means that neighbourhood community nursing teams do not have the capacity to deliver the preventative and joined up care that we aspire to deliver in ILTs.
- 2.16 Reviews of the current ICS service show that it does not fulfil its intended function and is not integrated with social care crisis response and reablement services. While there are examples of excellent close working between the ICS service and social care intermediate care services, such as Intensive Crisis Response service in Leicester City, the core ICS service does not support the Home First blueprint agreed within BCT.
- 2.17 People tell us that to be as mobile as they can be is essential. Being active is important and it also supports emotional wellbeing. However, benchmarking data indicates that LLR has roughly half the number of community physio and occupational therapists compared to the national average. This leads to long waits and limitations to the input people receive at home.

- 2.18 The medical cover within the ICS service is both limited and unclear. When it was set up, the ICS service was commissioned to take clinical responsibility for patients admitted to it but does not have any dedicated medical staffing. This has led to lack of confidence in the service from acute consultants and lack of clarity and variability within GP practices about the nature of their responsibility for care when patients are being looked after.
- 2.19 An ICS service case note review (September 2017) and subsequent ICS clinical audit (November 2018) reinforce the necessity to redesign the ICS model. The audit showed that over 50% of ICS activity was actually delivering a same day core community nursing function.
- 2.20 There is significant reliance in LLR on community hospital beds to provide 'step down' from acute hospital i.e. the next phase of care before people are living independently at home. This differs from the model in other areas of the country, where there are more discharges directly home or into intermediate care services.
- 2.21 Community Hospitals are currently used as part of an LLR wide bed base with patients placed in available beds that are not always near to where they live, dependent on patient choice and system demand. For example 2017/18 data shows 45% of Leicester City patients in community hospital beds are in community hospitals outside of the city, and 32% of patients in City beds live in East and West CCG areas.
- 2.22 Community hospitals have an average 88% occupancy rate. However a number of local audits have demonstrated that patients in these settings are not in the most appropriate place.
- 2.23 In July 2017 an extensive bed audit covering 86% of UHL beds and all community hospital beds showed that 31% of UHL patients and 55% of LPT community hospital bed patients were not in the best setting of care for their needs.
- 2.24 A review of the discharge pathways in LLR has shown that we could improve access to 'Pathway 3' reablement beds (which provide 24/7 bed based care in a residential or nursing home setting with in-reach therapy for patients who are not yet well enough to be cared for at home). This would help to prevent admission and provide step down care from community hospitals.
- 2.25 The service issues described support the case for improving community health services by redesigning them to better suit patient needs, aligning them with aspirations to provide more continuity of care within locally based services, and providing better joined up crisis response services with social care (Home First).

### **CSR project and methodology**

- 2.26 The CSR project was initiated by the CCGs in LLR in April 2018, in order to address the identified issues with core community health services and to ensure services are configured to deliver the best possible care for patients in community settings.
- The objectives of the CSR are to: Develop better integrated services with better patient outcomes
  - Support integrated locality services which manage the majority of patient care
  - Deliver a 'Home First' approach through integrated step-up and step-down services

- Reduce use of non-elective services
- Address the future model and number of community hospital beds which could be needed in future.

The scope of the redesign work includes the following LPT services:

- District nursing services – which provide home-based patients with ongoing nursing care for long-term conditions or end-of-life care, with treatments such as wound care and continence care
- ICS service – a ‘virtual ward’ providing healthcare services in a patient’s own home
- Community hospital beds (including stroke beds)
- Community physiotherapy services (not including MSK physiotherapy)
- Community stroke rehabilitation service
- Primary care co-ordinators – who work in hospitals to support staff to help get patients home as quickly as possible once they are ready to leave hospital
- Single Point of Access

The terms of reference for the redesign recognise that, in attempting to move towards better integrated services, there will be implications for other services, particularly primary care and social care, as well as acute hospital services.

2.27 The CSR work has reported into the Integrated Communities Board (ICB), one of the BCT work streams. The ICB is a system-wide group with executive membership from each of the adult social care departments, which steers the development of integrated care across LLR, through ICB members’ roles linking back to their own organisations. The ICB also has representation from Healthwatch and the BCT Public and Patient Involvement group. The project has been led by the CCGs working on a co-design basis with LPT staff and other stakeholders.

2.28 Due to the complexity of the work, achieving significant change is being seen as a two to three year transformation programme, following a systematic process to a set methodology and has included to date:

- A review of best practice models and the evidence base for integrated community services, undertaken in July 2018
- Co-design workshops with key stakeholder and BCT work streams in June to August 2018, involving staff from social care, primary care and provider trusts among others
- Clinical Reference Group which has generated options for a clinical model, meeting August 2018 onwards
- A high level model set out in September to support further discussion and engagement with stakeholders on the clinical model
- Demand and capacity modelling supported by Deloitte UK in November 2018
- Audits of current pathways – both in 2017 and Autumn 2018
- Initial costing of potential impact for CCGs, December 2018
- Engagement to support development of the proposals, which is detailed in the next section, and which includes:
  - Review of existing engagement insights
  - In-depth structured interviews with patients, carers and staff

- Online survey
- Further public events to present insights and seek views are planned for early 2019
- 
- Initial consideration of proposals by the CCGs' Collaborative Commissioning Board in December 2018, and decision making on next steps

### **Engagement to support development of proposals**

- 2.29 Engagement was undertaken with patients, carers and staff between August and October 2018. We identified the journey of care by asking evidenced based questions and now have the stories of people experiencing community services and those providing community services. The key question we were answering was: *“How will a new integrated model of community care change the experiences of staff, family carers, patients and people who use the services.”*
- 2.30 We captured the experiences and feelings of the following groups, in relation to ten emotional touchpoints and identified what matters most to people about their care. 160 in-depth one-to-one or small group interviews were undertaken with:
- People receiving community services in their own home, in community and acute hospitals, in the ICS service and other settings
  - GPs
  - Acute staff referring into community services
  - Social care staff
  - Domiciliary care workers
  - Family carers
  - Care home staff
- 2.31 An online survey designed for patients, family carers and front line staff also ran between 25 September and 21 October 2018 with 66 responses in total.
- 2.32 An independent report analysing the findings from the interviews and survey was commissioned from Arden GEM Commissioning Support Unit.
- 2.33 In addition, we examined 22 existing reports relating to community services. This review of an existing knowledge base, using research undertaken by various organisations (NHS, Healthwatch, LGBT etc.) represented feedback from 4,300 people.

### **A summary of themes highlighted by people in a place they call home**

- 2.34 In general the picture relayed by patients in their own home is mixed. Patients would prefer to stay in their own home, but their level of confidence is dependent on support from family and external agencies which can vary.
- 2.35 Relationships with services, including their GP, are important. The inability to get timely appointments and to see the same GP is a frustration. Also services not arriving on time and the lack of communication are all mentioned as issues. However, people feel that an improved relationship with health and care services would give them more confidence.

- 2.36 Falls and deteriorating health are frequently mentioned as a cause of crisis. Issues highlighted which could be improved to help service users to manage in their own home include assistive technology and home adaptations, and timely communications from services, improved relationships with staff and a better language/cultural understanding. A range of other services including better support out of hours and in rural locations are also mentioned.
- 2.37 Patients can be left feeling stressed and social isolation is experienced by this group of people. They would like to do the things they were once able to do or at least have the best mobility it is possible to have. Socialising and involvement in external agencies are important. Mobility is everything and having support to enable people to keep busy and as physically active as they can are seen as important to improve both physical wellbeing and reduce the emotional impact on their condition. Physiotherapy and occupational therapies are seen as particularly important.

### **A summary of themes highlighted by people in community beds**

- 2.38 The importance of good communication throughout all stages of the patient journey resounds throughout the insights. It is essential for patients to feel confident, cared for and supported.
- 2.39 The need to feel supported is also essential to recovery and wellbeing and discharge is seen as a really low point. People demonstrated their reliance on support not only while in hospital to aid successful recovery, particularly from physiotherapists and occupational therapists, other hospital staff, friends and relatives, but also when they return home. Community hospitals are seen as an important part of patients' treatment closer to home, although some patients were unsure why they were in a community hospital and what treatment they could expect.

### **A summary of themes highlighted by family carers**

- 2.40 Family carers want services which are reliable and appropriate to their situation and allow them to support their loved one. However, they report difficulties in getting the help they need and frustration around the processes, including decision making and discharge. Getting further help at times of crisis was a particular challenge for some. They report that providing care at home as simply waiting for the next crisis to happen.
- 2.41 Family carers reported mixed relationships with services and staff. They did not always receive consistent information and were not involved and kept informed.
- 2.42 The caring role resulted in emotional stress for carers, such that they sometimes did not feel that they could take holidays or have breaks.
- 2.43 Particular areas of concern were falls, getting help when their loved ones' health deteriorates and administering painkillers.

### **A summary of themes highlighted by frontline staff**

- 2.44 Building good relations and working together with patients and families are important aspects of the role of frontline staff. They try to involve patients in their care, but this can be challenging where patients and family disagree or do not understand the care available. Staff tell us that time and workload pressures reduce their ability to develop a good relationship with patients and families. Providing emotional support can be a very rewarding aspect of the work but more guidance, training and time is needed.

- 2.45 Equally, relationships with other services significantly impact on the care given. Good working relationships with other teams are important - where teams work well together and trust each other to do their job the outcomes for patients are improved. Currently, the quality of these relationships varies but is improved where individuals know each other. There can be issues between services, particularly connections between NHS and social care around poor communication, lack of awareness and understanding of services and processes, or where referral criteria are not clear or understood.
- 2.46 Staff feedback that good IT can support closer working between services, e.g. how the community clinical IT system, SystemOne, can improve the referral process. Job satisfaction is important to staff, they want to feel that their work is valued and they have made a difference to patients and their family. However, they report feeling stressed and tired, in particular where they are short staffed and there is a high caseload. The job is made easier by supportive colleagues and leaders who work well together and good relationships with other teams.

### **A summary of themes highlighted by care home and domiciliary staff**

- 2.47 It is apparent that staff feel very passionate about the care they deliver and the resources and support they subsequently require. Particular low points in the care pathway are around relationships with other health and social care staff and involving the person in decisions about their care.
- 2.48 In addition, co-ordination and providing physical and emotional support is an area of concern. Time pressures sometimes prevent these being considered equally.
- 2.49 Staff also find it difficult to look after their own health, wellbeing and personal resilience.
- 2.50 The importance of having integrated services, good communication and involvement and team working is widely reported.

### **Proposals for the future of Community Health Services**

- 2.51 The work undertaken by the CSR project to date, including the insights from patients, carers, staff, clinicians and stakeholders, has enabled the CCGs to:
- Set out a potential model for the future model of community based health services.
  - Make some proposals for initial changes to how community services provided by LPT are organised to improve care for patients.
  - Recommend some next steps to further develop the model.
- 2.52 The proposed new model is based around the following main services:

**Neighbourhood community nursing** as part of integrated locality teams, which would manage the majority of care of patients in the community, working closely with social care and primary care neighbourhoods (groups of GP practices with between 30,00 – 50,000 patients).

**‘Home First’ services** - integrated health and social care crisis response and reablement services, which would deliver intensive, short term care for up to six weeks. Home First services would be accessed via Locality Decision Units, with

health and social care services working on the basis of trusted assessment and delivering co-ordinated packages of care. Within Rutland, this equates to the REACH service.

**Community bed based care** - delivered either in community hospitals for patients requiring medical rehabilitation needing significant 24/7 nursing care and on-site therapies, and in 'Pathway 3' re-ablement beds for patients with lower medical needs requiring re-ablement and a degree of 24/7 support.

2.53 Key features of the model include improvements in: Co-ordinated Care

- Integrated team working
- Preventative care, support for self-care
- Pro-active approach to identifying patients who need co-ordinated care
- Focus on the frail and 'multi-morbid' patients
- Trusted assessment – where agencies trust the assessments made by those outside their organisation reducing duplication in assessment
- 'Discharge to Assess' – ensuring people leave hospital when medically fit
- Delivery of the 'Home First' principles
- Capacity in community nursing and development of a sustainable workforce

2.54 It is important to note, that the evidence review suggests if the community model described were further developed, and had sufficient capacity in the home based teams and reablement beds, there could be reduced utilisation of community hospital inpatient beds in future. This could create a shift towards using community hospital beds predominantly for patients who on discharge from an acute hospital and continue to need 24 hour care with on-site therapies.

### **CCG discussions to date**

2.55 In December 2018, a summary report outlining the work done to date, and considering the benefits and implications of moving towards the future potential model was considered by the CCGs' Collaborative Commissioning Board (CCB).

2.56 The CCB supported in principle a move towards the model outlined in this paper, but recognised that to fully deliver the vision of improved services, further work needed to be done, including:

- Continued and wider engagement with the public and partners on the potential future community health model and its implications to further develop test and strengthen plans
- Testing some initial operational changes to provide proof of concept for future changes including a move towards more integrated services and the potential to support more patients to be cared for at home. Also a more a robust process to explore the costs and activity implications of the future model.

2.57 This work will commence in January 2019 with ongoing engagement with partners and a series of public engagement events across LLR planned from February.

2.58 In the meantime, to deliver the improvements in ICS services for the benefit of

patients, carers, staff and clinicians, the CCB also supported the reorganisation of the current LPT nursing teams and specifically redeploying the capacity in the ICS service into enlarged community nursing teams at a locality level.

- 2.59 This reorganisation means the treatment delivered by the ICS service will continue to be delivered, with care still provided to patients at home in the way that it is now. There are however anticipated improvements in patient outcomes and experience through improved effectiveness and efficiency and greater capacity in locally based teams to deliver continuity of care. The CCGs will work with LPT to enact this change in the course of 2019/20.
- 2.60 To support these initial improvements to ICS services, the CCB also gave approval in principle to:
- providing dedicated medical support to patients being looked after by Home First services, conditional on approval of further work on costs and proposals for how the medical cover would be organised and employed
  - the creation of care co-ordinator posts in West Leicestershire CCG, in line with the agreed model for ILTs, again conditional on approval of the costs and employment arrangements in January/February.
- 2.61 The CCGs believe the changes proposed to the way in which ICS services are organised will have benefits for patients, carers, staff and clinicians. It is important to note, that once enacted, the changes would not preclude or prevent changes to proposals for the future configuration of community health services following further engagement.

### **Next steps**

- 2.62 Due to the complexity of the work, achieving significant change to community health services is being seen as a two to three year transformation programme, following a systematic process.
- 2.63 In recognition of the importance of the work, and the possible implications for the wider provision of care in community settings, as well as the implications on utilisation of other health services, including inpatient beds, the CCGs will embark on a second phase of work towards a full business case to redesign community health services. This work will include:
- Further engagement with local people on the future vision and options for community health based services
  - Further engagement with clinicians, staff and partners on the proposals for the future
  - Further work to define how community health services could work with social care crisis response and reablement services to deliver Home First
  - Testing the impact of more redesigned community health services and more integrated care model on patient outcomes and demand for care in different settings
  - Generation of options for further changes to community health services, including assessing the impact of increasing capacity in home based care and re-ablement

beds, which could increase the number of people who can be cared for in their own home

- Depending on the options being put forward, the CCGs will consider their legal duties in respect of formal consultation on future services changes, particularly if there are proposals to make any significant changes to the community hospital configuration. It should be noted that in any case there will be ongoing co-design with the public on the proposals.

### **3 ORGANISATIONAL IMPLICATIONS**

- 3.1 The CCGs are working with local authorities and Adult Social Care departments to discuss how they wish to be further engaged in the development and implementation of the overall model. In parallel with this, the CCGs will continue to work with social care teams and other stakeholders to develop the model of integrated care taking into account the recent publication of the NHS 10 Year plan as we do so. This will include work via the project team engaging with lead council members, leadership teams and, where appropriate Council Cabinets/ Executive Teams and scrutiny functions.
- 3.2 Further work will be undertaken to set out the milestones and governance processes for future decision making. This will be done in discussion with Adult Social Care teams and with the System Leadership Team of BCT.
- 3.3 The CCGs will continue to engage with the Joint Health Overview and Scrutiny Committee and an update will be brought in due course.

### **4 CONCLUSION AND SUMMARY OF REASONS FOR THE RECOMMENDATIONS**

- 4.1 The Health Scrutiny Committee is asked to:

**NOTE** the progress to date in redesigning community health services and the next stage of the work.

### **5 BACKGROUND PAPERS**

- 5.1 There are no additional background papers to the report.

### **6 APPENDICES**

There are no appendices to the report.

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## ADULTS AND HEALTH SCRUTINY PANEL

7 February 2019

### LEARNING DISABILITIES MORTALITY REVIEW (LEDER)

#### Report of the Strategic Director for People

Strategic Aim:	Reaching our Full Potential	
Exempt Information	No	
Cabinet Member(s) Responsible:	Mr A Walters, Portfolio Holder for Safeguarding - Adults, Public Health, Health, Commissioning , Community Safety including Road Safety	
Contact Officer(s):	Kim Sorsky, Head of Service Prevention and Complex Care Services	01572 758352 ksorsky@rutland.gov.uk
	James Lewis, Local Area Contact, LeDeR programme, LLR	01164 544839 James.Lewis@leicester.gov.uk

#### DECISION RECOMMENDATIONS

That the Panel;

1. Comments on the joint working across LLR and CCG's which has been established to improve the standard and quality of care for people with learning disabilities.

## 1 PURPOSE OF THE REPORT

- 1.1 To seek comments from the Adults and Health Scrutiny Panel on the initial work and learning from the work completed to date.
- 1.2 To request that the LeDeR programme return to Adults and Health Scrutiny Panel later this year (2019) to present local learning, recommendations and actions plans as to how health and social care services can be improved in Rutland.

## 2 BACKGROUND AND MAIN CONSIDERATIONS

- 2.1 The LeDeR Disabilities Mortality Review (LeDeR) programme was established in response to the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD). CIPOLD (the Executive Summary of which is attached as Appendix A) reviewed the deaths of 247 people with learning disabilities over a two-year period across five Primary Care Trusts in the South West. It found that:

- Men with learning disabilities died, on average, 13 years sooner than men in the general population; women with learning disabilities 20 years sooner
- For every person in the general population who dies from a cause of death relating to the quality of their care, three people with learning disabilities will do so.

The last of the report's eighteen recommendations was that 'A National Learning Disability Review Body to be established'. LeDeR, led by the University of Bristol and NHS England, was commissioned by the Health Equality Improvement Partnership to be this body.

2.2 The aims of the LeDeR programme are:

- 'To support improvements in the quality of health and social service delivery for people with learning disabilities'
- 'To help reduce premature mortality and health inequalities'

2.3 To achieve this aims each LeDeR Steering Group footprint is responsible for reviewing the deaths of all people over four years old with a diagnosed learning disability.

2.4 The reviews will focus on avoidable factors that may have contributed to a person's death, identifying differences in health and social care delivery across England and ways to improve services and prevent death and lastly develop plans of actions to guide necessary changes in health and social care services to reduce premature deaths.

2.5 The learnings from these reviews will form an evidence base for change for Leicester, Leicestershire and Rutland health and social care services. It is anticipated that the first local report will be available spring / summer 2019.

### **3 CONSULTATION**

3.1 Consultation not required as no whole scale changes to services are expected.

### **4 FINANCIAL IMPLICATIONS**

4.1 No financial implications. Current staffing resources are used across health and social care to complete reviews.

### **5 LEGAL AND GOVERNANCE CONSIDERATIONS**

5.1 N/A

### **6 DATA PROTECTION IMPLICATIONS**

6.1 A Data Protection Impact Assessments (DPIA) has not been completed because data governance has been overseen by the national LeDeR programme board.

## **7 EQUALITY IMPACT ASSESSMENT**

- 7.1 An Equality Impact Assessment (EqIA) has not been completed because there are no service, policy or organisational changes being proposed.

## **8 CONCLUSION AND SUMMARY OF REASONS FOR THE RECOMMENDATIONS**

- 8.1 The LeDeR programme has the potential to greatly improve the quality of services delivered for people with learning disabilities. To do so it relies upon the support of all key local stakeholders. The support that Rutland County Council have provided has contributed greatly to the programme's implementation and delivery.
- 8.2 From a local perspective we are expecting to deliver the first LLR LeDeR report in spring / early summer 2019. Once that report has been developed it is requested that the LeDeR programme can return to scrutiny to share our learnings and actions plans for comment.
- 8.3 From a national perspective the local LeDeR Steering Group is awaiting information from the programme board and NHS England as to the future of the programme beyond April 2019. That being, the Minister for Health has outlined his commitment to the programme in the recently published NHS Forward View.

## **9 BACKGROUND PAPERS**

- 9.1 There are no additional background papers to the report

## **10 APPENDICES**

- 10.1 Appendix 1 – Confidential Inquiry into the Premature Deaths of those with a Learning Disability
- Appendix 2 – LLR LeDeR Information Pack
- Appendix 3 – LeDeR Annual Report (2018)

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# Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)

## Executive summary

Pauline Heslop  
Peter Blair  
Peter Fleming  
Matt Houghton  
Anna Marriott  
Lesley Russ



## Background

Mencap's report *Death by Indifference* described the circumstances surrounding the deaths of six people with learning disabilities who died while they were in the care of the NHS, exposing 'institutional discrimination'. An Independent Inquiry chaired by Sir Jonathan Michael followed, which recommended the establishment of the learning disabilities Public Health Observatory, and a time-limited Confidential Inquiry into premature deaths of people with learning disabilities.

The Confidential Inquiry into the deaths of people with learning disabilities (CIPOLD) was tasked with investigating the avoidable or premature deaths of people with learning disabilities through a series of retrospective reviews of deaths. The aim was to review the patterns of care that people received in the period leading up to their deaths, to identify errors or omissions contributing to these deaths, to illustrate evidence of good practice, and to provide improved evidence on avoiding premature death.

## Methodology

CIPOLD investigated the sequence of events leading to all known deaths of people with disabilities (aged 4 years and older) over a 2-year period in 5 Primary Care Trust (PCT) areas of South-West England; the area had a mixture of urban and rural communities and a population of 1.7m.

In order to identify whether findings were specific to people with learning disabilities, the study included 58 comparator cases of adults without learning disabilities who died in the study area. They were selected so they were comparable to people with learning disabilities included in CIPOLD, weighted for i) month of death, ii) cause of death, iii) age, and iv) gender.

## The CIPOLD cohort

CIPOLD reviewed the deaths of 247 people with learning disabilities over the 2-year period in 2010–2012, approximately 2½ times the number expected. This apparent difference may reflect the under-recognition of people with mild learning disabilities in the community and that two-fifths (42%) had previously lived in local long-stay institutions and then settled nearby. Most (96%) were of white UK ethnicity.

The median age of death for people with learning disabilities (65 years for men; 63 years for women) was significantly less than for the UK population of 78 years for men and 83 years for women. Thus men with learning disabilities died, on average, 13 years sooner than men in the general population, and women with learning disabilities died 20 years sooner than women in the general population. Overall, 22% were under the age of 50 when they died.

Of the 247 people with learning disabilities, 40% had mild, 31% moderate, 21% severe, and 8% had profound and multiple learning disabilities. Of the 233 aged 18 or over, most (92%) were identified as being on a GP register of people with learning disabilities.

## Causes and certification of deaths of people with learning disabilities

As with the general population, the most common underlying causes of death were heart and circulatory disorders (22%) and cancer (20%), although both were less prevalent than in the general population (29% and 30% respectively). The final event leading to death was most frequently a respiratory infection in the people with learning disabilities. That a person had learning disabilities was mentioned on few (23%) cause of death certificates.

Fewer deaths of people with learning disabilities (38%) were reported to the coroner compared with the general population (46%). When deaths were reported to the coroner, people with learning disabilities were more likely to have a post-mortem and were as likely to have an inquest opened. Of note is that the CIPOLD Overview Panel identified some additional deaths that they thought should have been reported to the coroner, and expressed concerns about some coroners' reviews of deaths.

## Unexpected and premature deaths

Using the same definition as is used in the child death review process,<sup>1</sup> 43% of the deaths of people with learning disabilities were unexpected. Using ICD-10<sup>2</sup> data on conditions that are commonly known to be unexpected (e.g. myocardial infarction, pulmonary embolus, cerebrovascular disease), there was no significant difference between people with learning disabilities and the general population.

In the CIPOLD study, a death was considered as premature if, '*without a specific event that formed part of the "pathway" that led to death, it was probable that the person would have continued to live for at least one more year*'. This allowed the Overview Panel to take account of both lifestyle and co-morbidity in assessing the potential significance of events or omissions in the care of the person concerned, regardless of their age. Of the 238 deaths of people with learning disabilities for which agreement was reached by the Overview Panel, 42% were assessed as being premature. The most common reasons for deaths being assessed as premature were: delays or problems with diagnosis or treatment; and problems with identifying needs and providing appropriate care in response to changing needs.

## Health and social care needs of people with learning disabilities

When considering the health and social care needs of the people with learning disabilities, it was apparent that they were a very vulnerable group. Significantly more (17%) were underweight than the general population (2%), even after excluding those who had lost weight in their final illness. Two-thirds lacked independent mobility, half had problems with vision, a quarter had problems with hearing, over a fifth (21%) had problems with both vision and hearing, 30% had limited verbal communication, and 22% did not communicate verbally at all.

Almost all (97%) had one or more long-term or treatable health condition, including 43% with epilepsy (31% had had a seizure in the previous 5 years), 39% with cardiovascular disease, 22% with hypertension, 14% with dementia and 13% with osteoporosis.

Of people known to be on GP learning disability registers, 71% had received an annual health check in the year before death, but 12% had never had an annual health check. More than a third were reported as having difficulty in communicating their pain, but a pain assessment tool such as DisDAT<sup>3</sup> had been used with only 4 people. Engagement in the bowel cancer screening programme was problematic.

At the time of their deaths 64% lived in residential care homes, most with 24-hour paid carer support. For 20% of the people with learning disabilities, safeguarding concerns had previously been raised; for a further 8% safeguarding concerns were raised to the CIPOLD review retrospectively – these had not been reported or investigated at any time previously.

## Factors contributing to vulnerability and premature deaths of people with learning disabilities

While the great majority (86%) of the illnesses that led to the deaths of people with learning disabilities were promptly recognised and reported to health professionals, for 29% there was significant difficulty or delay in diagnosis, further investigation or specialist referral, and for 30% there were problems with their treatment. The lack of reasonable adjustments to facilitate healthcare of people with learning disabilities, particularly attendance at clinic appointments and investigations, was a contributory factor in a number of deaths. GP referrals commonly did not mention learning disabilities, and hospital 'flagging' systems to identify people with learning disabilities who needed reasonable adjustments were limited.

People with learning disabilities had a considerable burden of ill-health at the time of their death. Key issues that appeared to be problematic were the lack of coordination of care across and between the different disease pathways and service providers, and the episodic nature of care provision.

In addition, professionals in both health and social care commonly showed a lack of adherence to and understanding of the Mental Capacity Act 2005, in particular regarding assessments of capacity, the processes of making ‘best interest’ decisions and when an Independent Mental Capacity Advocate should be appointed. Many instances were identified of inappropriate or poorly documented DNACPR<sup>4</sup> orders.

Record keeping was commonly deficient – particularly in relation to fluid intake, nutrition, weight and seizures, and little attention was given to predicting potential problems, e.g. when a person was fearful of contact with medical professionals.

A lack of recognition of the approaching end of life commonly led to problems in coordinating end-of-life care and providing support to the person and their family. Difficulties in obtaining Continuing Healthcare funding were also reported.

## The comparator cases: similarities and differences

The ages and broad causes of death were similar between the subset of 58 adults with learning disabilities and the 58 comparators without learning disabilities. The proportion of premature and unexpected deaths was no different between the two groups, but more of the comparators died of conditions that were potentially preventable by public health measures (e.g. reducing smoking) and more of the people with learning disabilities died from causes that were potentially amenable to change by good-quality healthcare.

Similar proportions in the two groups presented promptly for healthcare, but significantly more people with learning disabilities experienced difficulties in the diagnosis and treatment of their illness than did the comparator group. All aspects of care provision, planning, coordination and documentation were significantly less good for people with learning disabilities than for the comparators.

Dependence on others for mobility and feeding was significantly more prevalent among those with learning disabilities, while lifestyle factors (e.g. smoking and alcohol) were significantly more prevalent among the comparators. Families of people with learning disabilities more commonly felt that professionals did not listen to them.

## Conclusions and recommendations

The quality and effectiveness of health and social care given to people with learning disabilities has been shown to be deficient in a number of ways. Despite numerous previous investigations and reports, many professionals are either not aware of, or do not include in their usual practice, approaches that adapt services to meet the needs of people with learning disabilities. The CIPOLD study has shown the continuing need to identify people with learning disabilities in healthcare settings, and to record, implement and audit the provision of ‘reasonable adjustments’ to avoid their serious disadvantage.

The people with learning disabilities included in CIPOLD had a range of impairments and multiple health conditions, and there was considerable evidence of fragmented care. Communications within and between agencies must be improved, and we recommend a named health professional to coordinate the care of those with multiple health conditions, aided by the routine use of patient- or carer-held health records and the continuing involvement of specialist healthcare staff, who are required not to work on a short-term or one-off assessment basis.

Proactive use of annual health checks to develop and implement health action plans, planning for the future and adapting care as needs change rather than in a crisis, and the identification of effective advocates to help people with learning disabilities to access healthcare services are all effective, low-cost measures to address this issue.

Professionals must recognise their responsibilities to provide the same level of care to people with learning disabilities as to others, and not to make rapid assumptions about quality of life or the appropriateness of medical or social care interventions. The weakest link in the chain related to problems with the diagnosis and treatment of people with learning disabilities. People having problems using recognised care pathways must be referred to specialist expertise.

Adherence to the Mental Capacity Act was generally poor. Health and social care providers must ensure that all professionals understand and act in accordance with the Act, and we recommend further work at national and local levels to support conformity to its requirements. We also recommend that guidelines for DNACPR orders be revised to separately address emergency and non-emergency situations.

Finally, we recommend the routine collection and review of data that provides intelligence about the mortality of people with learning disabilities and the establishment of a National Learning Disability Mortality Review Body to take forward the reviews of deaths of people with learning disabilities, in order to learn from experience and continue to provide a driver to reduce inequalities in care for this vulnerable population.

## Notes

- 1 A death which was not anticipated as a significant possibility 24 hours before the death or where there was a similarly unexpected collapse leading to or predicating the events which led to death
- 2 The International Classification of Diseases and Related Health Problems codes diseases, signs and symptoms, abnormal physical findings and causes of injury. ICD-10 is the 10th revision of this classification system
- 3 Disability Distress Assessment Tool (DisDAT)
- 4 Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)
- 5 National Institute for Health and Clinical Excellence

## The key recommendations from the CIPOLD review of deaths

- 1 Clear identification of people with learning disabilities on the NHS central registration system and in all healthcare record systems.
- 2 Reasonable Adjustments required by, and provided to, individuals, to be audited annually and examples of best practice to be shared across agencies and organisations.
- 3 NICE<sup>5</sup> Guidelines to take into account multi-morbidity.
- 4 A named healthcare coordinator to be allocated to people with complex or multiple health needs, or two or more long-term conditions.
- 5 Patient-held health records to be introduced and given to all patients with learning disabilities who have multiple health conditions.
- 6 Standardisation of Annual Health Checks and a clear pathway between Annual Health Checks and Health Action Plans.
- 7 People with learning disabilities to have access to the same investigations and treatments as anyone else, but acknowledging and accommodating that they may need to be delivered differently to achieve the same outcome.
- 8 Barriers in individuals' access to healthcare to be addressed by proactive referral to specialist learning disability services.
- 9 Adults with learning disabilities to be considered a high-risk group for deaths from respiratory problems.
- 10 Mental Capacity Act advice to be easily available 24 hours a day.
- 11 The definition of Serious Medical Treatment and what this means in practice to be clarified.
- 12 Mental Capacity Act training and regular updates to be mandatory for staff involved in the delivery of health or social care.
- 13 Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Guidelines to be more clearly defined and standardised across England.
- 14 Advanced health and care planning to be prioritised. Commissioning processes to take this into account, and to be flexible and responsive to change.
- 15 All decisions that a person with learning disabilities is to receive palliative care only to be supported by the framework of the Mental Capacity Act and the person referred to a specialist palliative care team.
- 16 Improved systems to be put in place nationally for the collection of standardised mortality data about people with learning disabilities.
- 17 Systems to be put in place to ensure that local learning disability mortality data is analysed and published on population profiles and Joint Strategic Needs Assessments.
- 18 A National Learning Disability Mortality Review Body to be established.

The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)

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A full copy of the report, an easy read version, and an easy read short summary are available on the CIPOLD website [www.bristol.ac.uk/cipold](http://www.bristol.ac.uk/cipold)

Should you require a hard copy, please contact the CIPOLD Team at the address above.

Prepared by the CIPOLD Team, March 2013.

Designed by Thingswedo.

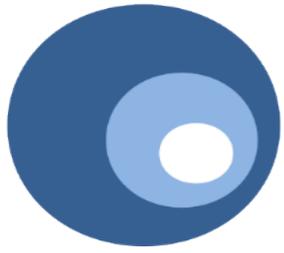
Published by Norah Fry Research Centre.

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This is the Executive Summary of the CIPOLD report into premature deaths of people with learning disabilities.

The Confidential Inquiry into the deaths of people with learning disabilities (CIPOLD) took place from 2010 to 2013 and reviewed the deaths of 247 people with learning disabilities within 5 Primary Care Trusts in the South-West of England. It also reviewed the deaths of 58 people without learning disabilities, to place the findings in context.

The study reveals that the quality and effectiveness of health and social care given to people with learning disabilities was deficient in a number of ways. Key recommendations are made which, were they individually and collectively implemented, would lessen the risk of premature death in people with learning disabilities.



# Learning Disabilities Mortality Review (LeDeR) Programme

## Information pack for Rutland County Council Adults and Health Scrutiny Panel

**February 7<sup>th</sup> 2019**

Local Area Contact for Leicester, Leicestershire and Rutland; Learning Disability Mortality Review  
James Lewis  
[james.lewis@leicester.gov.uk](mailto:james.lewis@leicester.gov.uk)  
01164 544839 / 07956 563368



# Learning Disabilities Mortality Review (LeDeR) Programme

## Introduction

### From the LeDeR Annual Report (2017)

The persistence of health inequalities between different population groups has been well documented, including the inequalities faced by people with learning disabilities (LD). Today, people with learning disabilities die, on average, 15-20 years sooner than people in the general population, with some of those deaths identified as being potentially amenable to good quality healthcare.

The Learning Disabilities Mortality Review (LeDeR) programme was established to support local areas to review the deaths of people with learning disabilities, identify learning from those deaths, and take forward the learning into service improvement initiatives. It is being implemented at the time of considerable spotlight on the deaths of patients in the NHS, and the introduction of the national Learning from Deaths framework in England in 2017. The programme is led by the University of Bristol, and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England.

### From Mencap to Southern Health – LeDeR’s origins

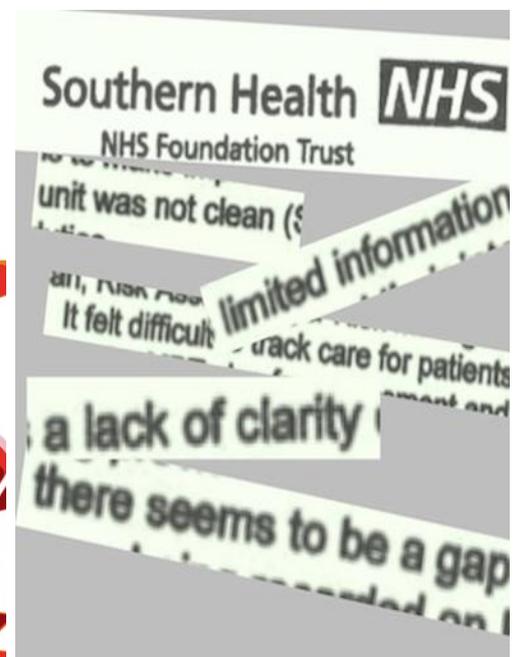
For over 10 years there have been a series of investigations, reports and scrutiny placed on health and social care services delivered for people with learning disabilities. LeDeR aims to address the inequalities, inconsistencies, and what has been determined ‘institutional discrimination’ that these reviews and reflections have brought to national attention.



Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)

Final report

Pauline Henkop  
Peter Blair  
Peter Fleming  
Matt Hoghton  
Anno Marriott  
Lesley Russ



James Lewis

Local Area Contact for Leicester, Leicestershire and Rutland; Learning Disability Mortality Review

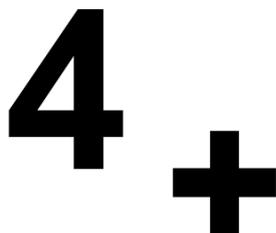
[james.lewis@leicester.gov.uk](mailto:james.lewis@leicester.gov.uk)

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# Learning Disabilities Mortality Review (LeDeR) Programme

## The LeDeR Process



Anybody over the age of 4 years old with a diagnosed learning disability is required to have a review of their health and social care services after their death

A referral to the LeDeR programme is made either online or over the phone. Details can be found at <http://www.bristol.ac.uk/sps/leder/>

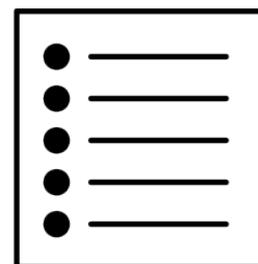
Referrals are then sent to the LLR local area contact for allocation to an available LeDeR reviewer.



For LLR LeDeR reviewers are usually Nurses from the two NHS Trusts or Social Workers from the three local authorities. They are specially trained in conducting LeDeR reviews.

The allocated LeDeR reviewer will discuss the person – their life, aspirations, what they enjoyed doing – with their family, friends, carers and involved professionals.

They will also review case records from all major organisations involved. This includes hospital records and local authority assessments and support plans.



They will use this evidence as the basis for their LeDeR review. This includes a pen portrait of the person and a timeline of their care leading up to death.

The review ends with a score of the person's care and an outline of any identified learning. If there were significant concerns a further multi-disciplinary review could be convened.

Once approved the reviews and recommendations are then passed to the LLR LeDeR Steering Group for discussion. This could lead to the development and implementation of Action Plans to improve services.

James Lewis  
Local Area Contact for Leicester, Leicestershire and Rutland; Learning Disability Mortality Review

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# Learning Disabilities Mortality Review (LeDeR) Programme

Leicester, Leicestershire and Rutland (LLR) LeDeR

<b>Approximately 15,500</b>	Estimated number of people with a learning disability across LLR*
<b>October 1<sup>st</sup> 2017</b>	LeDeR programme goes live across LLR
<b>50</b>	Indicative projection for LD deaths across LLR each year
<b>49</b>	Actual number of deaths reported to LLR LeDeR during the first year (October 1 <sup>st</sup> 2017 – September 30 <sup>th</sup> 2018)
<b>84</b>	Total LLR LeDeR referrals to date
<b>28</b>	Trained / in training LeDeR reviewers
<b>38 (45%)</b>	Referrals allocated / in process of allocation to a LeDeR reviewer
<b>36 (32%)</b>	Referrals awaiting allocation
<b>2 (3%)</b>	Reviews going through Quality Assurance process
<b>8 (10%)</b>	Completed reviews

\*Pansi data as cited by East Leicestershire and Rutland CCG 'LLR Transforming Care Plan'

<https://eastleicestershireandrutlandccg.nhs.uk/wp-content/uploads/2013/01/LLR-Transforming-Care-Plan-April-2016-2.pdf>

## Data Protection & Information Sharing

The LeDeR programme has undergone extensive work to ensure the people's data is protected in line with stipulations of contemporary legislation (including GDPR). In recognition of this work the LeDeR programme has obtained on a national level Section 251 approval from the Secretary of State to handle personal data without consent to conduct mortality reviews; on a local level an information sharing agreement signed by health and social care partners to this end. For more information visit <http://www.bristol.ac.uk/sps/leder/> or contact James Lewis.

Information Sharing Agreement

Between

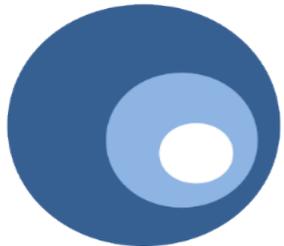
Learning Disabilities Mortality Review (LeDeR) Programme

and

Partners from Health and Social Care organisations within

Leicester, Leicestershire and Rutland Region

James Lewis  
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# Learning Disabilities Mortality Review (LeDeR) Programme

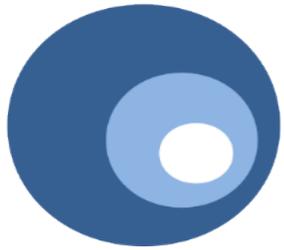
Some initial findings...	LeDeR Annual Report (01.01.17 – 31.12.17)		Leicester, Leicestershire & Rutland to 11/18	
<b>Age at death</b> 	Mild	63	Mild	64
	Moderate	63	Moderate	64
	Pro/Sev*	41	Pro/Sev*	49
	All LD	58	All LD	56
<b>Deaths under age of 50</b> 	28%		22%	
<b>Most common cause</b> 		41% of deaths reported as pneumonia		40% of deaths reported as pneumonia
<b>Place of death</b> 	Hospital	60%	Hospital	58%
	Residence	34%	Residence	38%
	Other	5%	Other	4%
<b>Usual residence</b> 	Residential	n/a	Residential	44%
	Supported Living	n/a	Supported Living	38%
	Independent	n/a	Independent	18%
<b>Lived alone</b> 	9%		10%	
<b>Ethnicity</b> 		93%		90%
		7%		10%

James Lewis

Local Area Contact for Leicester, Leicestershire and Rutland; Learning Disability Mortality Review

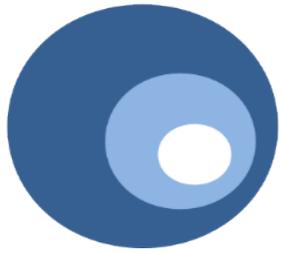
[james.lewis@leicester.gov.uk](mailto:james.lewis@leicester.gov.uk)

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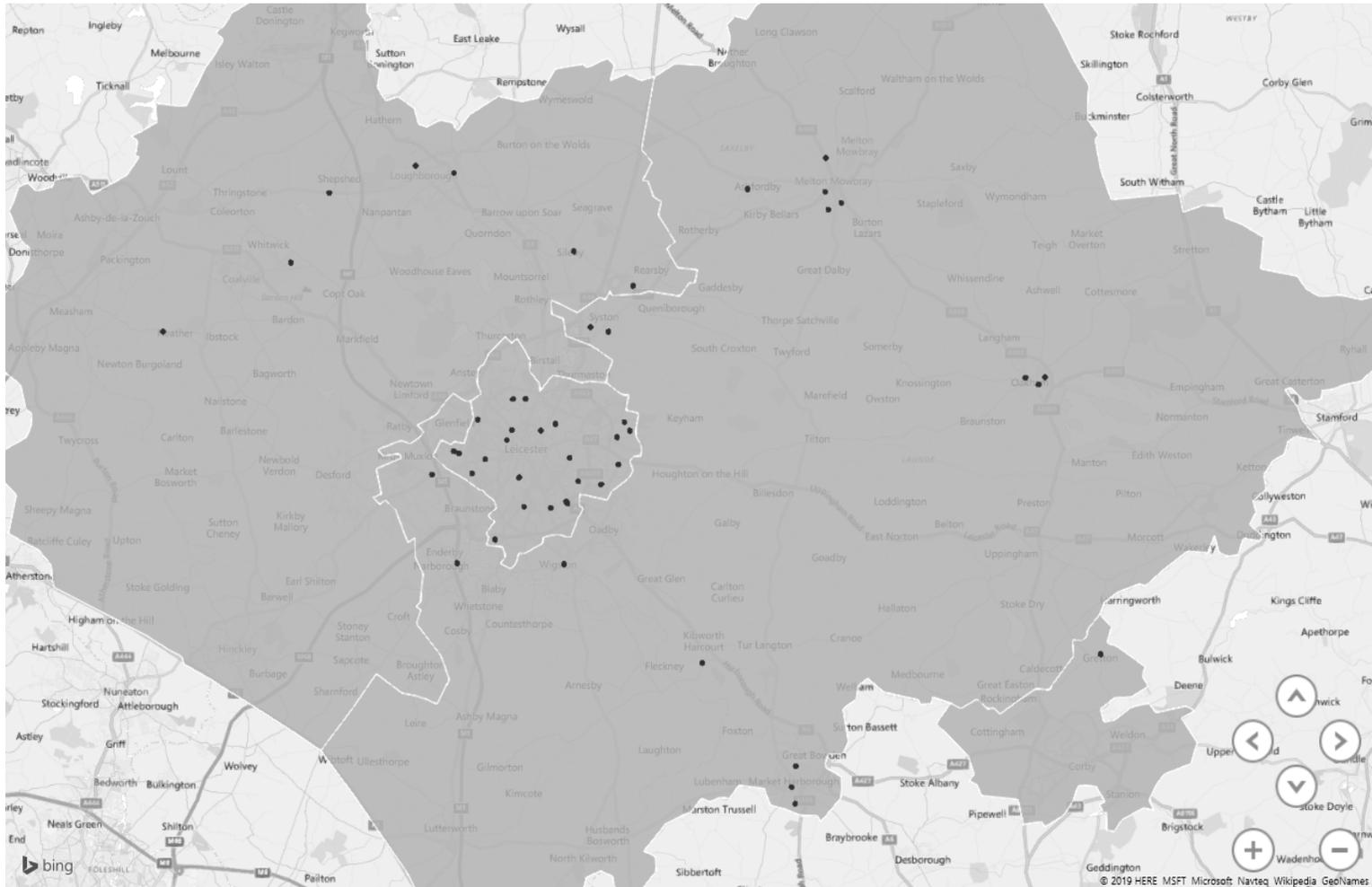
# Learning Disabilities Mortality Review (LeDeR) Programme

\*Profound and severe learning disabilities



# Learning Disabilities Mortality Review (LeDeR) Programme

Map of LeDeR referrals to date by the person's address (23.01.19)



49

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# Learning Disabilities Mortality Review (LeDeR) Programme

## Leicester, Leicestershire & Rutland LeDeR's priorities

- Recruit further LeDeR reviewers
- Continue to raise awareness of the programme with stakeholders. Presentations have been delivered to health and social care professionals, the voluntary and community sector and service user participation groups; LeDeR correspondence sent to health and social care providers across Leicester, Leicestershire and Rutland.
- Begin to formulate Action Plans based upon the findings of completed LeDeR reviews
- Integrate LeDeR into LLR's programme of work to improve services for people with learning disabilities

## How you can contribute to the LeDeR programme

- Refer the deaths of anyone over the age of 4 with a diagnosed Learning Disability to the programme (<http://www.bristol.ac.uk/sps/leder/notify-a-death/> or 0300 777 4774)
- Provide information to a LeDeR reviewer if asked for it. All key health and social care organisations have signed up to the local information sharing agreement for the purposes of the programme.
- Become a LeDeR reviewer. We are in particular looking for those whom have experience in working with people with learning disabilities in a health or social care setting. For more information please contact James Lewis.



The Learning Disabilities Mortality Review  
(LeDeR) Programme

University of  
Bristol Norah  
Fry Centre for  
Disability Studies



This information can be made available in formats such as easy read or large print, and may be available in alternative languages, upon request

# Annual Report

## December 2017

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## Executive summary

## Introduction

The persistence of health inequalities between different population groups has been well documented, including the inequalities faced by people with learning disabilities. Today, people with learning disabilities die, on average, 15-20 years sooner than people in the general population, with some of those deaths identified as being potentially amenable to good quality healthcare.

The Learning Disabilities Mortality Review (LeDeR) programme was established to support local areas to review the deaths of people with learning disabilities, identify learning from those deaths, and take forward the learning into service improvement initiatives. It is being implemented at the time of considerable spotlight on the deaths of patients in the NHS, and the introduction of the national Learning from Deaths framework in England in 2017. The programme is led by the University of Bristol, and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England.

The programme has developed a review process for the deaths of people with learning disabilities. All deaths receive an initial review; those where there are any areas of concern in relation to the care of the person who has died, or if it is felt that further learning could be gained, receive a full multi-agency review of the death. Deaths subject to the current priority review themes (aged 18-24 years or from a Black or minority ethnic background) receive multi-agency review and expert panel scrutiny. At the completion of the review, an action planning process identifies any service improvements that may be indicated.

By the end of November 2017, all but two of the 39 LeDeR Steering Groups were operational. Key processes to deliver mortality reviews of people with learning disabilities have been established, and over 1,000 local reviewers have been trained in the LeDeR methodology. The LeDeR methodology itself has been refined with routine updates twice a year, matched with amendments to training and associated materials and the LeDeR IT systems.

The programme has developed a robust quality assurance process to ensure that training is of the highest standard, is fit for purpose and ultimately delivers high quality reviews. The programme team produces targeted reports for those involved with delivering the LeDeR programme, including NHS England leads, Steering Groups, Local Area Contacts and Regional Coordinators. These reports summarise notification data, and review progress and the learning and recommendations identified in completed reviews.

The most significant challenge to programme delivery has been the timeliness with which mortality reviews have been completed, largely driven by four key factors: a) large numbers of deaths being notified before full capacity was in place locally to review them b) the low proportion of people trained in LeDeR methodology who have gone on to complete a mortality review c) trained reviewers having sufficient time away from their other duties to be able to complete a mortality review and d) the process not being formally mandated.

The programme team has been resolving these challenges in a number of ways, including the use of Key Performance Indicators; the appointment of Regional Coordinators to work with local Steering Groups; additional funding from NHS England to support local recovery plans; and the commissioning of NHS Sustainable Improvement to help address and support a reduction in the number of un-reviewed deaths, and develop a more streamlined process for the delivery of mortality reviews.

## Deaths notified to the LeDeR programme

From 1st July 2016 to 30<sup>th</sup> November 2017, 1,311 deaths were notified to the LeDeR programme. The most frequent role of those notifying a death was Learning Disability Nurse (25%), most commonly working in a Community Learning Disabilities Team.

Key information about the people with learning disabilities whose deaths were notified to the LeDeR programme includes:

- Just over half (57%) of the deaths were of males
- Most people (96%) were single
- Most people (93%) were of White ethnic background
- Just over a quarter (27%) had mild learning disabilities; 33% had moderate learning disabilities; 29% severe learning disabilities; and 11% profound or multiple learning disabilities.
- Approximately one in ten (9%) usually lived alone
- Approximately one in ten (9%) had been in an out-of-area placement.

The proportion of people with learning disabilities who died in hospital was greater (64%) than the proportion of hospital deaths in the general population (47%). Younger people with learning disabilities were more likely to die in hospital than were older people (76% of those under 24 years of age compared with 63% of those aged 65 and over); those with profound or multiple learning disabilities were more likely to die in hospital (71%) than other people with learning disabilities (59%).

The median age at death<sup>1</sup> of people with learning disabilities (aged four years and over) was 58 years (range 4-97 years). For males it was 59; for females 56. More than a quarter (28%) of deaths were of people aged under 50 years. People with profound or multiple disabilities had a median age at death of 41 years; those with mild or moderate learning disabilities had a median age at death of 63 years.

<sup>1</sup> The median age at death is the age at which exactly half the deaths were of people above that age and half were of people below that age

Less than half (44%; n=576) of deaths notified to the LeDeR programme stated a cause of death. For the remainder of the deaths notified, the exact cause of death will be confirmed to the LeDeR programme during the mortality review process itself. It is also the case that some of the preliminary causes of death given at notification, could subsequently change if, for example, a post-mortem indicates a different cause.

Almost a third of the deaths (31%) had an underlying cause related to diseases of the respiratory system. These were distributed across all age groups from aged 18 years onwards, but were more commonly given as the underlying cause of death in people between ages 25-44. The second most common category of deaths was of diseases of the circulatory system (16%). These were also distributed across all age groups but were more common in the oldest. Men were slightly more likely than women to die from circulatory disorders (18% vs. 14%).

Analysis of the individual ICD-10<sup>2</sup> codes of reported underlying causes of death indicates a significant proportion of deaths from pneumonia (16%) and aspiration pneumonia (9%).

Analysis of any conditions cited in Part I of the Medical Certificate of Cause of Deaths (MCCD) suggests causes of death broadly similar to underlying causes of death, plus sepsis (11%). People aged 25-34 were more likely to have aspiration pneumonia listed in Part I of their MCCD than were other age groups (37% vs. 24%).

<sup>2</sup> ICD-10 codes are based on the International Classification of Diseases version 10. The codes in ICD-10 classify all medical diagnoses, symptoms and procedures.

## Completed reviews of deaths of people with learning disabilities

By 30 November 2017, 103 reviews had been completed and approved by the LeDeR quality assurance process. Reviewers indicated that in 13 (13%) the person'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. For example:

- A person was discharged home with a catheter, although the care staff had never received any training about catheter care. The person was later readmitted to hospital with possible urinary sepsis.
- For one person there was evidence of several delays in their hospital care and treatment. The patient was not monitored in terms of Modified Early Warning System (MEWS) measurements. Blood tests were not taken during their brief stay in hospital. It was also noted that there was no justification or explanation in the medical or nursing records about the course of treatment the patient received.
- For one person who could not speak up for himself, there was no professional co-ordination in relation to his long term conditions. Treatment for the patient's weight loss took months; the identification of kidney stones also took months with limited pain relief being given. Identification of a urinary infection and treatment for it with antibiotics towards the end of the patient's life could and should have been sooner; and there was no recognition before he died of pyelonephritis which was the cause of death.

The deaths of 13 people received a full multi-agency review. Three of these met the criteria for Priority Themed Review.

## Learning points and recommendations from completed reviews

From the 103 completed reviews, there were 189 learning points or recommendations identified. In each review that identified one or more learning points, the average number of learning points and/or recommendations was 2.8. Thirty-six reviews (35%) did not identify any learning.

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

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

Most of the learning to-date echoes that of previous reports of deaths of people with learning disabilities, and the importance of addressing this cannot be over-estimated. We have a responsibility to families and others to ensure that any learning points at individual level are taken forward into relevant service improvements as appropriate.

As a result of the reviews completed, some actions have already been taken to improve service provision for people with learning disabilities. These have included, for example, strengthening discharge planning processes, and the provision of reasonable adjustments for people with learning disabilities.

National recommendations made based on completed local reviews of deaths in 2016-2017 are as follows:

1. Strengthen collaboration and information sharing, and effective communication, between different care providers or agencies.
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.
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 Mental Capacity Act decision-making process).
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 health care coordinator.
5. Providers should clearly identify people requiring the provision of reasonable adjustments, record the adjustments that are required, and regularly audit their provision.
6. Mandatory learning disability awareness training should be provided to all staff, and be delivered in conjunction with people with learning disabilities and their families.
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.
8. Local services must strengthen their governance in relation to adherence to the Mental Capacity Act, 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.
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.

The future focus of the LeDeR programme will be to move beyond 'learning' into 'action' to support improved service provision for meeting the health and care needs of people with learning disabilities and their families.



Chapter 1:  
**Introduction**

## Health inequalities in relation to people with learning disabilities

The persistence of health inequalities between different population groups has been receiving renewed attention recently. Focusing on trends in population mortality and life expectancy, Marmot (2017) has reported that not only have improvements in life expectancy at population level stalled, but that inequalities within and between local authorities, and between areas with different deprivation indices have persisted.

In addition, each of the six domains that are key contributors to health inequalities as identified in the Marmot Review (2010) (early child development; education; employment and working conditions; minimum income for healthy living; healthy and sustainable places to live and work; and taking a social determinants approach to prevention) are described as raising cause for concern in 2017 (Institute of Health Equity, 2017).

Health inequalities faced by people with learning disabilities have also been highlighted in recent years. Emerson and his colleagues in 2016 reported markedly poorer health for people with learning disabilities than their non-disabled peers, whilst in 2017 Osugu and colleagues concluded that in addition to having a high prevalence of diagnosed health problems, adults with learning disabilities also have a four-fold disparity in signs and symptoms that are medically unexplained.

## Inequalities in mortality of people with learning disabilities

The higher mortality rate in England for people with learning disabilities is both an outcome of health inequalities, and a health inequality itself. An overview of key reports relating to mortality of people with learning disabilities was presented in Appendix 1 of our 2015-2016 annual report (<http://www.bristol.ac.uk/sps/leder/resources/annual-reports/>). It is more than 10 years since Mencap published *Death by Indifference* (2007) highlighting 'institutional discrimination' leading to the deaths of six people with learning disabilities whilst in the care of the

NHS. In 2018 it is a decade since Sir Jonathan Michael's (2008) report 'Healthcare for all' in which he expressed shock at the 'disturbing' findings of the inquiry, and concern that the experiences of the families described in Mencap's report were by no means isolated.

Over the past few years, statistical evidence about inequalities in mortality of people with learning disabilities has been accumulating. Using data from the Clinical Practice Research Datalink database for April 2010 to March 2014 (CPRD GOLD, September 2015), Glover and colleagues at Public Health England, with the LeDeR programme, reported an all-cause standardised mortality ratio of 3.18 for people with learning disabilities (Glover et al., 2017). Their life expectancy at birth was 19.7 years lower than for people without learning disabilities. Drawing on data from the same source, Hosking et al. (2016) reported that more than a third of deaths of people with learning disabilities were potentially amenable to health care interventions. A summary of the key issues over time that have been associated with premature mortality in people with learning disabilities is presented on p.3-4 of our 2015-2016 annual report (<http://www.bristol.ac.uk/sps/leder/resources/annual-reports/>).

## National policy in relation to learning from deaths

National policy in relation to learning from deaths has been strengthened following publication of the Care Quality Commission (CQC) report 'Learning Candour and Accountability' in 2016. The report describes what the CQC found when it reviewed how NHS Trusts identify, investigate and learn from the deaths of people under their care. The report authors indicated that there was a 'common' level of acceptance and sense of inevitability when people with learning disabilities or mental illness died, and that the lack of a single framework for NHS Trusts that sets out what they need to do to maximise the learning from deaths that may be the result of problems in care was problematic. The report concluded that learning from deaths was not being given enough consideration in the NHS and

opportunities to improve care for future patients were being missed.

National Guidance on Learning from Deaths was published by the National Quality Board in March 2017. It provides a framework for NHS Trusts and NHS Foundation Trusts in England for identifying, reporting, investigating and learning from deaths of people in their care. The guidance emphasises the importance of learning from reviews of the care provided to patients who die, and that this should be integral to a provider's clinical governance and quality improvement work. It requires providers to have a clear policy for engagement with bereaved families and carers, and an updated policy on how they respond to, and learn from, deaths of patients who die. From April 2017, Trusts have been required to collect and publish on a quarterly basis specified information on deaths.

A driver for the CQC report in 2016 was the death of Connor Sparrowhawk, a young man with learning disabilities, who was under the care of Southern Health NHS Foundation Trust. A review into the circumstances at the Trust where he died revealed a very low number of investigations or reviews of deaths at the Trust (Mazars, 2015). The deaths of people with learning disabilities were therefore a particular focus of the CQC report, which is also reflected in the national guidance on Learning from Deaths. Here, it is acknowledged that the lives of people with learning disabilities often involve a complex array of service provision with multiple care and support staff. A single agency review of their death would likely fail to identify the complex interplay of circumstances leading to a person's

death, and the wide range of potentially avoidable contributory factors to their death. A cross-sector approach to reviewing deaths of people with learning disabilities is underpinned in the Learning from Deaths guidance, which states that all deaths of people with learning disabilities aged four years and older should be subject to review using LeDeR methodology.



Chapter 2:  
**The LeDeR programme**

## About the LeDeR programme

The LeDeR programme is delivered by the University of Bristol, and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. Work on the LeDeR programme commenced in June 2015 for an initial three-year period. The overall aims of the LeDeR programme are to support improvements in the quality of health and social care service delivery for people with learning disabilities and to help reduce premature mortality and health inequalities.

A key part of the LeDeR programme is to support local areas in England to review the deaths of people with learning disabilities aged four years and over. The programme has developed and rolled out a review process for the deaths of people with learning disabilities. By the end of 2017, the LeDeR programme was fully rolled out across England, with local Steering Groups in place, and the deaths of people with learning disabilities being reviewed in all regions.

The LeDeR programme also collates and shares anonymised information about the deaths of people with learning disabilities nationally, so that common themes, learning points and recommendations can be identified and taken forward into policy and practice improvements. These are reported in the following chapters of this report.

## Core principles and values of the programme

- We value the on-going contribution of people with learning disabilities and their families to all aspects of our work.
- We take a holistic perspective looking at the circumstances leading to deaths of people with learning disabilities and don't prioritise any one source of information over any other.
- We aim to ensure that reviews of deaths lead to reflective learning which will result in improved health and social care service delivery.
- Our aim is to embed reviews of deaths of people with learning disabilities into local structures to ensure their continuation.

## LeDeR methodology

The LeDeR methodology is described in a flowchart in Appendix 1, a brief summary in Appendix 2, and on the LeDeR website at [www.bristol.ac.uk/sps/leder/](http://www.bristol.ac.uk/sps/leder/)

## Delivery of the LeDeR programme

In our Annual Report 2015-2016, we reported on the progress made in establishing the programme in its first year, between 1st June 2015 to 31st May 2016. This covered details about the 'set up' activities for the programme and the ways in which we worked through the challenges faced in establishing a process for local reviews of deaths. We will not repeat this information here; rather we will provide an update from June 2016 about further developments in the programme delivery.

In June 2016, a NHS England National Operational Steering Group was established, and each NHS region appointed an NHS England Regional Coordinator to guide the roll out of the LeDeR programme, across their geographical region. Each of the four NHS England regions of England established a pilot site for the LeDeR programme in 2016. The pilot sites were as follows:

- NHS England North: Cumbria and the North East
- NHS England Midlands and the East: Leicestershire, Leicester City and Rutland
- NHS England South: Wessex, Gloucester and Oxford
- NHS England London: Lambeth, Richmond, Kingston, Camden, Islington and Tower Hamlets

The lessons learnt from the pilot sites were shared at regional 'learning and sharing' events prior to the development of regional plans to deliver the wider roll-out of the programme.

By the end of November 2017, all but two of the 39 Steering Groups were operational. Key processes to deliver mortality reviews of people with learning disabilities have been established, and over 1,000 local reviewers have been trained in using the LeDeR methodology. The LeDeR methodology

itself has been refined with routine updates twice a year, matched with amendments to training and associated materials and the LeDeR IT systems. The programme has developed a robust quality assurance process to ensure that training is of the highest standard, is fit for purpose and ultimately delivers high quality reviews. The programme team produces targeted reports for those involved with delivering the LeDeR programme, including NHS England leads, Steering Groups, Local Area Contacts and Regional Coordinators. These reports summarise notification data, the progress of reviews, and the learning and recommendations identified in completed reviews.

It is to be expected that a programme of this size and complexity, requiring the input and support from a range of stakeholders, would face challenges to its delivery. The most significant challenge has been the timeliness with which mortality reviews have been completed, largely driven by four key factors:

- large numbers of deaths being notified before full capacity was in place locally to review them
- the low proportion of people trained in LeDeR methodology who have gone on to complete a mortality review
- trained reviewers having sufficient time away from their other duties to be able to complete a mortality review and
- the process not being formally mandated.

Some participating NHS and social care organisations have made it clear that, because of their present overstretched budgets and the

pressures on staff time, contributing to LeDeR could not be prioritised as we would all like. Nevertheless, NHS Trust level participation is expected and quarterly dashboards will be published as described in the National Guidance on Learning from Deaths - the implementation of which is overseen by NHS Improvement.

The programme team has been assessing progress in resolving these challenges with four key performance indicators, as follows:

1. The proportion of those receiving training who then collect their password to the LeDeR IT system (indicating that they are likely to be conducting a review of a death).
2. The proportion of notifications of death that are awaiting allocation from the Local Area Contact to a reviewer.
3. The proportion of deaths which have been in the LeDeR review process longer than six months.
4. The proportion of trained reviewers not aligned to a Steering Group.

Additional measures taken have been the appointment of Regional Coordinators to work with local Steering Groups; additional funding from NHS England to support local recovery plans; and NHS Sustainable Improvement has been formally commissioned to help address and support a reduction in the number of un-reviewed deaths, and develop a more streamlined process for the delivery of mortality reviews.



Chapter 3:

# Demographic characteristics and information about the deaths of people with learning disabilities

This chapter describes the demographic characteristics of the people with learning disabilities whose deaths were reviewed as part of the LeDeR programme from 1st July 2016 – 30th November 2017. It also describes information relating to their deaths.

## DEATHS NOTIFIED TO THE LeDeR PROGRAMME

### Number of deaths notified to the LeDeR programme

From 1st July 2016 to 30th November 2017, 1,311 deaths were notified to the LeDeR programme. Just under half of these (48%) were from the North of England, unsurprisingly so as the LeDeR programme was first introduced in the North. Table 3.1 presents the number of notifications of deaths of people with learning disabilities by NHS England region. Figure 1 (over-page) shows that the number of deaths notified to the programme has generally been increasing each month.

**Table 3.1: Number of notifications of deaths of people with learning disabilities by NHS England region**

Region	Number	%
North	631	48
Midlands and East	241	18
South	261	20
London	178	14
Total notifications	1311	100

### Those notifying deaths

To-date, 668 different people have notified deaths to the LeDeR programme. The most frequent role of those notifying a death was Learning Disability Nurse (25%; n=168). Only three-quarters (78%; n=523) of those notifying a death included details of their employing organisation. Of these, the largest proportions worked in a Community Learning Disability Team or Community NHS Trust (38%; n=199), or in secondary or acute care (26%; n=136).

**Figure 3.1: The number of deaths notified to the LeDeR programme each month**

### Demographic characteristics and information about the deaths of people with learning disabilities

The rest of this chapter describes the demographic characteristics of the people with learning disabilities whose deaths were reviewed as part of the LeDeR programme. It also describes information relating to their deaths.

### Gender

Of the people with learning disabilities whose deaths were notified to the LeDeR programme, over half (57%; n=741<sup>3</sup>) were men.

<sup>3</sup> The gender of six people was not recorded at the time of notification.

## Marital status

Marital status was reported for 1,073 people. Of these, most people who died were single (96%). Women were more likely to have been married, divorced, widowed or separated than were men (6% vs. 2%).

## Ethnicity

The person's ethnic background was reported for 1,145 deaths notified. Almost all of these (93%) were from a White ethnic background, 4% were from an Asian background, and 4% were from other backgrounds. The proportion of people whose ethnic group was described as 'White' was higher than the 86% recorded for England and Wales as a whole (ONS, 2011).

## Severity of learning disabilities

At the point of notifying a death, the severity of a person's learning disabilities was reported for 828 people. Just over a quarter (27%) of these were known to have had mild learning disabilities; 33% had moderate learning disabilities; 29% severe learning disabilities; and 11% profound or multiple learning disabilities.

## Living alone, or away from home

Of the 1,158 people for whom the information was available at the notification of their death, 9% usually lived alone. Information about out-of-area placements was available for 1,107 deaths: of these 101 people (9%) had been in an out-of-area placement.

## Place of death

In England in 2016, 47% of deaths of the general population occurred in hospital (National End of Life Intelligence Network, 2017). Table 3.2 shows the place of death, where known at the point of

notification, for deaths notified to LeDeR. As can be seen, the proportion of people with learning disabilities who died in hospital (64%; n=801) was considerably greater than that of the general population. Younger people with learning disabilities were more likely to die in hospital than were older people, with 76% of those aged 24 and under dying in hospital (n=86) compared to 63% (n=260) of those aged 65 and older.

**Table 3.2: The place of death of people with learning disabilities**

Place of death	Number	%
Hospital	801	64
Usual place of residence <sup>1</sup>	373	30
Hospice / palliative care unit	27	2
Other <sup>2</sup>	43	3
Total	1244	100%

<sup>1</sup> Includes own or family home, and residential or nursing home that was the person's usual address

<sup>2</sup> Includes home of relative or friend, and residential or nursing home that was not usual address

Of the 828 people for whom the severity of their learning disability was recorded at notification, those with profound or multiple learning disabilities were more likely to die in hospital (71%; n=61) than other people with learning disabilities (59%; n=412), and less likely to die at their usual place of residence (23%; n=20) compared to other people with learning disabilities (35%; n=249).

## Age at death

Of the 958 people (aged four years and over ) whose death was notified to the LeDeR programme after 1st April 2017, the median age at death was 58 years (range 4-97 years).

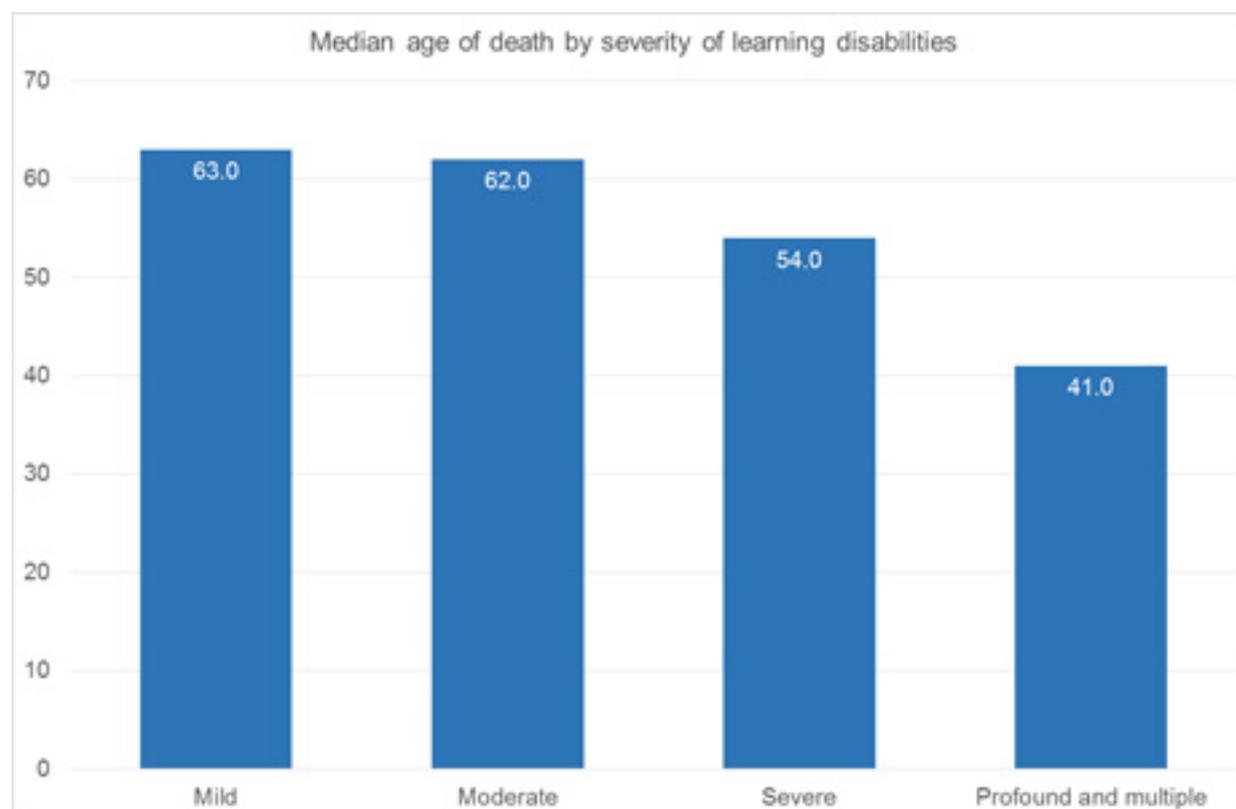
The median age at death for males aged four years and over notified to the LeDeR programme since 1st April 2017 was 59 years (range 4-92); for females it was 56 years (range 4-97).

In the general population of England and Wales in 2010, the median age at death (for all deaths including those aged 1-3 years) was 81.8 years for males and 85.3 years for females (ONS 2012 ). The difference in age at death between people with learning disabilities (aged four years and over) whose deaths were notified to LeDeR, and the general population of England and Wales (all ages, 2010 data) is therefore 22.8 years for males and 29.3 years for females.

Over a quarter (28%) of deaths notified since 1st April 2017 were of people aged under 50 years – this compares with 22% of deaths aged four years and over as reported in CIPOLD (Heslop et al. 2014), and 5% of the general population of England and Wales aged four years and over who died in 2016 (ONS 2016).

The median age at death decreased with increasing severity of a person's learning disabilities (Figure 3.2). People with profound or multiple disabilities had a median age at death of 41 years; those with mild or moderate learning disabilities had a median age at death of 63 years. However, the median age at death for people with mild learning disabilities was still considerably less than that of people in the general population.

**Figure 3.2: Median age at death by severity of learning disabilities**



## Cause of death

Less than a half (44%; n=576) of deaths notified to the LeDeR programme stated a cause of death at the time of notification. For the remainder of the deaths notified, the exact cause of death would be confirmed during the mortality review process itself. However, it is also the case that some of the causes of death given at notification, and presented in this section, may be preliminary causes which could subsequently change if, for example, a post-mortem indicated a different cause.

Medical certificates of cause of death (MCCD) are divided into two sections, Parts I and II. Contained in Part I is the immediate cause of death, tracking the sequence of causes back to any underlying cause or causes. The World Health Organisation (WHO, 1967) defines the underlying cause of death as the disease or injury which initiated the train of events leading directly to death, or the circumstances of the accident or violence which produced a fatal injury. Part II of the MCCD is used to list other significant conditions, diseases or injuries that contributed to the death, but were not part of the direct sequence leading to death<sup>4</sup>.

<sup>4</sup> The information from the MCCD is coded using the latest International Classification of Disease (ICD) codes, to form national statistics on the causes of death of a population. The LeDeR programme has applied to NHS Digital for the ICD-10 codes of all causes of death in Parts I and II of the MCCD for those whose deaths have been notified to LeDeR. This will provide a richer, and more accurate source of information about the deaths of people with learning disabilities over time.

## Underlying cause of death

Table 3.3 presents the underlying cause of death, as categorised by ICD-10 chapters. Almost a third of the deaths (31%; n=177) had an underlying cause related to diseases of the respiratory system. The second most common ICD-10 chapter was that of diseases of the circulatory system (16%; n=95).

**Table 3.3: Underlying cause of death by ICD-10 chapter**

Underlying cause of death	Number	% <sup>1</sup>
Diseases of the respiratory system	177	31
Diseases of the circulatory system	95	16
Neoplasms	55	10
Nervous system	46	8
Diseases of the digestive system	38	7
Mental and behavioural disorders	38	7
Congenital malformations, deformations and chromosomal abnormalities	33	6
Diseases of the genitourinary system	30	5
Other underlying causes	64	11
Total	576	100

<sup>1</sup> Percentages add to more than 100% due to rounding

Figure 3.3 shows that diseases of the respiratory system were distributed across all age groups from aged 18 years onwards, but were more commonly given as the underlying cause of death in people between ages 25-44. Diseases of the circulatory system were also distributed across all age groups, most commonly amongst the older age groups, but also amongst those aged 35 - 44.

Figure 3.3: Broad category of underlying cause of death by age group

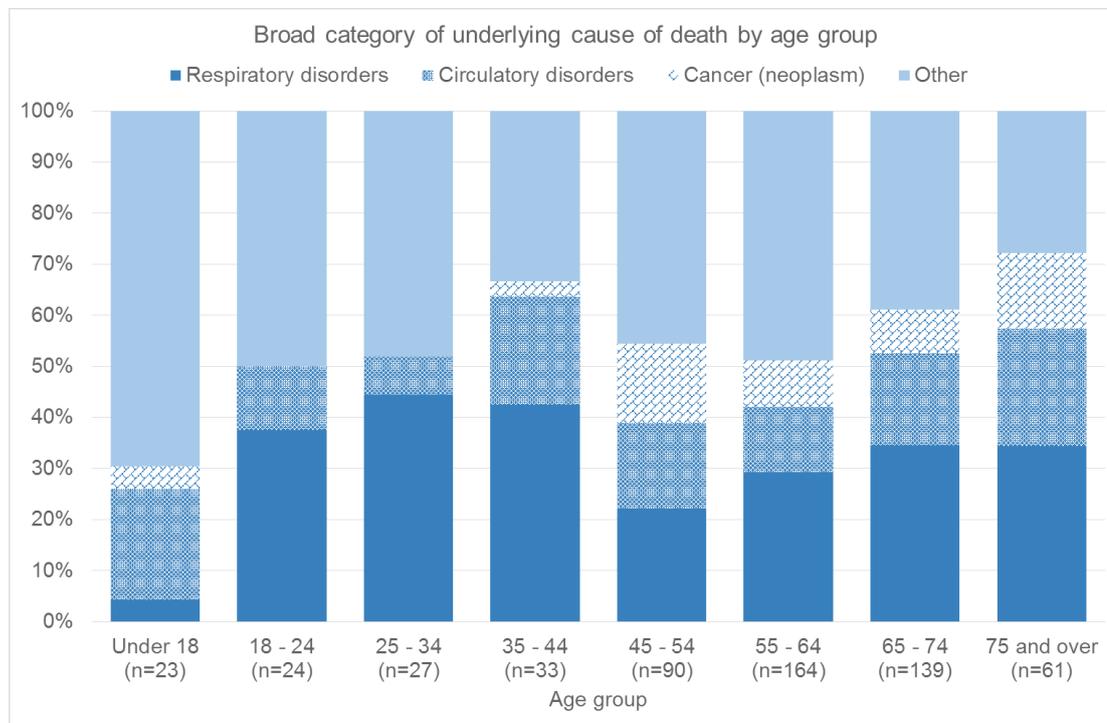


Figure 3.4 shows underlying cause of death by gender. Men were slightly more likely than women to die from circulatory disorders (18% vs. 14%), while women were slightly more likely to die from cancer (11% vs. 9%).

Figure 3.4: Underlying cause of death by gender

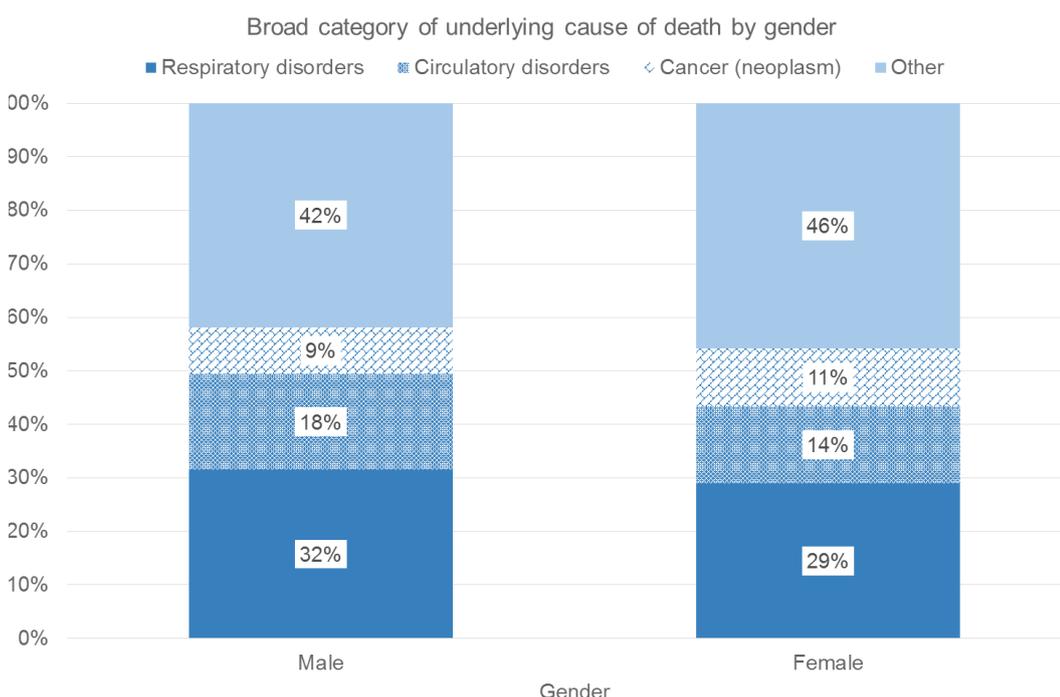


Table 3.4 provides analysis of the individual ICD-10 codes for the most commonly reported underlying causes of death. It indicates a significant proportion of deaths from pneumonia (16%; n=93) and aspiration pneumonia (9%; n=51).

**Table 3.4: Most common individual underlying causes of death by ICD-10 code**

Underlying cause of death	No.	%
Pneumonia – unspecified	93	16
Aspiration pneumonia	51	9
Epilepsy	25	4
Dementia	24	4
Down syndrome <sup>1</sup>	23	4
Total (where cause of death is reported at notification)	576	n/a

## Other causes of death recorded in Part I of the MCCD

Although the underlying cause of death is the most commonly reported and used in vital statistics, it is instructive to also consider other conditions identified in the sequence from the immediate cause of death tracking back to the underlying cause of death. In part, this is because it is important to bring to light those conditions for which service improvement initiatives may be indicated, but which are not described as the underlying cause of death. In part, it is also because there is a growing body of evidence to suggest that inconsistencies and inaccuracies frequently occur in recording the cause of death of people with learning disabilities on the MCCD (Tyrer and McGrother, 2009; Glover and Ayub, 2010; Landes and Peak, 2013; Hosking et al., 2016; Trollor et al., 2017).

The conditions most frequently cited in Part I of the MCCDs of people notified to the LeDeR programme are shown in Table 3.5. While they were broadly similar to underlying causes of death (Table 3.4), the fact that sepsis is mentioned on 11% (n=66) of MCCDs is of note, given the current NHS England national sepsis action plan<sup>5</sup>.

<sup>5</sup> <https://www.england.nhs.uk/wp-content/uploads/2017/09/second-sepsis-action-plan.pdf>

**Table 3.5: Most common conditions identified as causes of death anywhere on Part 1 of MCCD**

Most frequent causes of death	No.	%
Pneumonia – unspecified	140	24
Aspiration pneumonia	96	17
Sepsis	66	11
Dementia	34	6
Epilepsy	28	5
Down syndrome	25	4
Cardiac arrest	24	4
Respiratory infection	22	4
Total (where cause of death is reported at notification)	576	n/a

There were no significant differences between males and females in the conditions mentioned on Part 1 of the MCCD. However, people aged 25–34 were more likely to have pneumonia listed in Part I of their MCCD than were other age groups (37% vs. 24%). Other than dementia occurring in older age groups, there were no other differences in conditions listed by age group.

## COMPLETED REVIEWS OF DEATHS OF PEOPLE WITH LEARNING DISABILITIES

By 30th November 2017, 103 reviews had been completed and approved by the LeDeR quality assurance process. This section outlines some of the key findings from completed reviews.

### Involvement of someone who knew the person well

All but five reviews were completed with the assistance of someone who knew the person who had died well. Over half (56%; n=58) obtained information from staff at the home where the person lived; over a third (38%; n=39) from a family member; and a fifth from a member of a community

learning disability team (19%; n=20). Other sources of information included GP practices (17%; n=18) and social services staff (15%; n=15).

## Other investigations taking place

Reviewers reported that post-mortems were carried out on 12% (n=12) of the deaths that had completed the review process, and there was to be a Coroner's inquest into 5% (n=5) of the deaths. A further 19% (n=19) were to be subject to another investigation or review, most commonly an internal (NHS Trust) mortality review.

## Reviewers' overall assessment of the care received by the person

At the end of the review, having considered all of the information available to them, reviewers are asked to provide an overall assessment of the care provided to the individual. As Table 3.6 shows, in the majority of completed mortality reviews (79%; n=81) the care was assessed as either Grade 1 (excellent) or Grade 2 (good). A further 12% (n=12) were assessed as 'satisfactory' (Grade 3). The care received by five people (5%) was assessed as Grade 5 (falling short of best practice with the potential for learning from a fuller review of the death). The care received by one person was assessed as Grade 6 (having the potential for, or actual, adverse impact on the person).

## Aspects of care or service provision considered to have demonstrated the provision of excellent care

Almost a half (44%) of reviewers (Table 3.6) assessed the care provided to the person who had died as being 'excellent'. 'Excellent' care is described as being better than the good quality care that any patient should expect to receive. Reviewers were asked to detail any aspects of care or service provision that they considered to have demonstrated

the provision of excellent care. Generally, however, there was a lack of detail about why care was considered excellent, rather than of a good quality. For example, one reviewer commented that excellent care had been provided because 'there were numerous experts involved' in the person's care, without specifying exactly what it was that made this excellent care. Another commented that the sister of the person who had died described her care as 'exemplary' and that it had supported her sister to have 'a dignified and happy end of life', but had not explained what it was that made the care 'exemplary'.

Similarly, other examples of excellent care were related to the provision of reasonable adjustments that health services have a duty to provide under the Equality Act 2010. One reviewer described excellent care as being related to the support provided to the brother and sister-in-law of a person who died, noting that both were partially sighted and were encouraged to stay in hospital with their relative in her final weeks; the relatives had told the reviewer that they had felt well supported during and after their relative's death. Another reviewer described excellent care as being provided by the hospital learning disability liaison nurse, reporting that 'when Gerald<sup>6</sup> was not able to be safely supported at home, they worked with him to find out what was most important to him (his wife and football on TV) and ensured he had both of these with him on the ward. Gerald found this very reassuring and it greatly improved his experience'.

Additionally, a few reviewers described excellent care in relation to the home environment in which the person had lived, one reviewer noting that 'the care home went above caring', and describing it as a 'family' where the person appeared to be 'loved as well as cared for.'

Moving forward, we are hopeful that reviewers will be able to identify more tangible examples of excellent care that can be shared with all agencies, and adopted and implemented as appropriate.

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<sup>6</sup> All names have been changed to protect confidentiality

## Aspects of care or service provision which may have adversely affected the person

Reviewers indicated that 13 (13%) 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. For example, in relation to one person the reviewer noted:

Discharged home with a catheter and the care staff had never had any training on catheter care. Nick 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.

Another reviewer noted:

*'There was evidence to indicate several omissions occurred within the hospital, which caused delays in care and treatment provided to Marlon. He was not monitored in terms of Modified Early Warning System (MEWS) measurements, and no blood tests were taken*

**Table 3.6: Reviewers' overall assessment of the care received by the person**

	Overall assessment	No.	%
1	This was excellent care and met current best practice	45	44
2	This was good care, which fell short of current best practice in only one minor area	36	35
3	This was satisfactory care, falling short of current best practice in two or more minor areas, but no significant learning would result from a fuller review of the death	12	12
4	Care fell short of current best practice in one or more significant areas, but this is not considered to have had the potential for adverse impact on the person and no significant learning could result from a fuller review of the death	1	1
5	Care fell short of current best practice in one or more significant areas, although this is not considered to have had the potential for adverse impact on the person, some learning could result from a fuller review of the death	5	5
6	Care fell short of current best practice in one or more significant areas resulting in the potential for, or actual, adverse impact on the person	1	1
	No grading given	3	3
	Total	103	100%

during his brief stay in hospital - there was no documentation in the medical or nursing records to justify these courses of action.

Marlon was extremely distressed due to his skin condition and the pain associated with this. He was given analgesia and subsequently slept for long periods of time, during which he was not disturbed to be offered diet and fluids. It is likely the staff thought they were acting in his best interest by not disturbing him. While it was unlikely that even with optimal management this death could have been prevented, it should be noted that i) the omission of one dose of [medicine] is unlikely to have prevented the fatal pulmonary embolism, although it may have done so and ii) sepsis or dehydration could have contributed to the development of a pulmonary embolism in this patient. A lack of investigations performed on admission meant that these conditions, if present, were not diagnosed or treated.'

In relation to another death, the reviewer commented:

*'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 co-ordination 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.'*

## Progression to multi-agency review

If there are areas of concern identified about the death, or if it is felt that a fuller review could lead to improved practice, a more in-depth or multi-agency review takes place. This involves the range of agencies that have been supporting the person who has died, (e.g. health and social care staff). Multi-agency reviews are also undertaken when people who died meet the Priority Themed Review criteria (Appendix 2).

The deaths of 13 people received a full multi-agency review: three of these met the criteria for Priority Themed Review.

Actions taken in relation to learning and recommendations from completed reviews are described in the following chapter.



Chapter 4:

# Learning and recommendations from completed reviews

The LeDeR programme's success will be determined by the ability of commissioners and providers of services to convert learning and recommendations from completed reviews into service improvements. As such, at the end of the initial and multi-agency review forms there is space for reviewers to identify learning and recommendations (from initial reviews) and action points (from multi-agency reviews). These are collated by the LeDeR team, and reported back to Steering Groups, Regional Coordinators and Regional Leads via the routine reporting systems of the programme.

## Overall themes identified as learning points or recommendations

Of the 103 completed reviews, 67 identified a total of 189 learning points<sup>7</sup>. Thirty-six reviews (35%) did not explicitly identify any learning, the remainder identified between 1-21. Overall, the average was 2.8 learning points in each review.

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)

It should be noted that two learning points referred to evidence of good practice and the opportunity for others to learn from positive experiences, both in relation to inter-agency communication.

## Inter-agency collaboration, including communication

The largest category of learnings or recommendations related to collaboration and communication between agencies and, while some elements of good practice were identified,

concerns about a lack of coordination and sharing of information between care providers were apparent.

Good practice identified included one reviewer reporting<sup>8</sup>:

'The family actively participated in discussions with the multidisciplinary team and in planning Jenny's end of life care. This was facilitated by a high level of communication between the many acute, critical care, palliative care and community professionals involved in her care as well as by a clear and organised plan for managing her transfer back to the care home and her management there.'

Another reviewer commented:

*'There was excellent use of the traffic light assessment tool and full involvement of the LD Liaison Nurses, to ensure Frank's needs were met. All referrals within the hospital were accepted promptly and all the teams within the hospital appeared to work well together to provide consistent and timely care for him.'*

Reviews of other deaths, however, identified considerable scope for improvements in inter-agency collaboration and communication, particularly in relation to communication involving residential or care homes and health professionals.

For example, one reviewer commented:

*'A shortfall was liaison between the GP, community teams, and the residential home staff. None of the care home staff were involved in Best Interest decision meetings, so there were delays in getting the right information and sharing expertise.'*

Another reviewer reported that although the person with learning disabilities relied on those who knew his individual and communication patterns well in order identify his needs, they had no way of sharing this key knowledge with others supporting and caring for him.

A range of recommendations was made in relation to improving interagency collaboration and communication. These included:

<sup>7</sup> For simplicity, 'learnings' and 'learning points' are used in this chapter to cover learning points, recommendations and action plans.

<sup>8</sup> Learning and recommendations have been edited from the originals submitted by reviewers.

- Ensuring that a health passport is created if a person with learning disabilities does not already have one when admitted to hospital.
- A&E department to improve signage about expected waiting times and what to do if condition deteriorates whilst waiting to be seen.
- Poor or unsafe discharges from hospital to be addressed at quality review group meetings.
- Address the need for good healthcare co-ordination for people with learning disabilities.
- GP practices to follow-up the reason for non-attendance at Annual Health Checks, and inform the Community Learning Disabilities Team about those known to the service and not responding to invitations.

## Awareness of the needs of people with learning disabilities among health and social care providers

The second largest category of the learning and recommendations related to raising awareness about the 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. Several reviewers commented on the importance of health care staff being aware of behaviour as a means of communication, for example:<sup>9</sup>

*'Acute services need to be supported in recognising the needs of patients with learning disabilities in their care, particularly people with communication difficulties who may present with certain behaviours as a mechanism to communicate.'*

<sup>9</sup> Learning and recommendations have been edited from the originals submitted by reviewers.

Another reviewer notes the need to:

*'Ensure that front line practitioners are aware that changes in behaviour and mood can be a sign of an underlying medical condition.'*

Reviews of deaths also identified the need for a greater awareness of the health needs of people with learning disabilities to be embedded within the healthcare system, with one reviewer commenting:

*'GPs may benefit from a reminder of the system within Community Learning Disability Teams which identifies people who have Down's Syndrome and their need to be assessed for early onset dementia.'*

Another reviewer noted that:

*'There is still a need for GP practices and clinical leads to be made aware of the importance of full annual health checks for people with learning disabilities.'*

Raising the awareness of paid care staff about supporting people receiving palliative care was also identified as a learning point, with one reviewer recommending a discussion with the local contract monitoring team about supporting end of life awareness training in residential and supported living services.

Some of the lack of awareness of the needs of people with learning disabilities was underpinned by staff not being able to easily access a record of their specific needs. One reviewer noted that the person with learning disabilities had had anxieties about accessing services where there were stairs, and as a consequence attendance at appointments was not consistent. They felt that had this been recorded, reasonable adjustments could have been made.

Another reviewer recommended that

*'If a patient who is flagged on a register does not attend their appointments, they should be followed up to establish if reasonable adjustments are required, and not discharged first.'*

## Better understanding and application of the Mental Capacity Act

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. For example, in relation to one person, the reviewer noted:

*'Several references to lack of capacity in hospital records but no evidence of a capacity assessment in records. A consent form for the procedure did indicate a lack of capacity through a tick system but was not backed up with a full capacity assessment - a capacity assessment form was on file but not completed.'*

*'Additionally, there is evidence of close and continuous supervision at times during Ashley's admission to hospital whilst awaiting the procedure, but no evidence of a consideration for DOLs authorisation, despite a number of entries in the notes identifying that she did not have capacity. Without a formal assessment it is difficult to identify what the statement 'lacks capacity' relates to.'*

The learning and recommendations from the review related to the need for improved training about all aspects of the Mental Capacity Act and DOLS.

In the review of another death, the reviewer noted concerns about the validity of a tenancy agreement for a person's supported living accommodation as the person had not had a capacity assessment and was thought unlikely to have understood the terms of the agreement. A recommendation was made for social care annual reviews to consider the validity of tenancy agreements as part of a check on adherence to the MCA.

## From 'learning' to action

The importance of addressing the learning from individual deaths cannot be over-estimated. This is a crucial aspect of the service improvement cycle, and we have a responsibility to families and others to ensure that any learning points at individual level are taken forward into relevant service improvements as appropriate.

Several examples of actions resulting from the reviews of deaths of people with learning disabilities have been given.

For example, a couple of reviews reported concerns about unsafe discharges of people with learning disabilities. Actions taken include one hospital trust reviewing safeguarding procedures in relation to discharge planning for patients with learning disabilities, and another hospital adding a 'catheter prompt' on their discharge planning forms to ensure that any changes to the level of support that may be required for a person are identified early, and carers properly trained in any new aspects of the person's care.

In relation to the provision of reasonable adjustments for people with learning disabilities in hospital, one trust has now raised this with ward staff to ensure that 'reasonable adjustment care plans' are in place for all patients with learning disabilities.

To address poor inter-agency communication, one area has been discussing with the Clinical Commissioning Group the need to fund specialist support for people with learning disabilities when admitted to hospital in an emergency. In relation to another death that highlighted concerns about inter-agency communication, a multiagency meeting was held to review joint working arrangements.

More general learning disability awareness training has also been delivered to a range of professionals following the findings of the LeDeR review. In addition, one reviewer recorded that a hospital had now identified two members of staff to be learning disability, autism and 'hidden' disability champions, and that a folder containing advice and support about caring for people with learning disabilities is kept at the nursing station on the ward.

## The need for further action

There is, at present, a raft of initiatives in place to raise awareness of the needs of people with learning disabilities, and improve the delivery of health and care services. Some of these are:

- NHS Improvement is developing Improvement Standards for Learning Disability. The four key standards relate to improving the workforce, improving the provision of reasonable adjustments, improving specialist learning disability NHS services, and improving inclusion and engagement with people using services and their family carers.
- NHS Digital is developing a nationally available flag to be placed on a person's Summary Care Record that will indicate if the person has been identified by a care provider as being potentially eligible for reasonable adjustments, and what reasonable adjustments in care should be considered.
- The NHS England Transforming Care programme is working to improve health and care services so that people with learning disabilities can live in the community, with the right support, close to home.
- The Royal College of General Practitioners has developed a toolkit to help GPs and practice nurses carry out learning disability annual health checks to a high standard.
- NHS England is developing practice guidance for supporting people with learning disabilities who have poor outcomes in some long-term conditions, including diabetes, epilepsy, heart disease and dysphagia. The diabetes guidance is now available at <https://www.england.nhs.uk/rightcare/products/pathways/diabetes-pathway>
- NHS England is supporting the STOMP project to stop the over-use of psychotropic medicines. Resources to support this are available at <https://www.england.nhs.uk/learning-disabilities/stomp/>

However, most of the learning from mortality reviews presented in this annual report echoes

that of previous reports of deaths of people with learning disabilities, with the same issues repeatedly identified as problematic over the past decade or so. For example:

- Mencap's Death by Indifference (2007) reported that many healthcare professionals 'do not understand much about learning disability' (p.19), and 'do not understand the law around capacity and consent to treatment' (p.21).
- In 2008, Sir Jonathan Michael concluded that 'the evidence shows a significant gap between policy, the law and the delivery of effective health services for people with learning disabilities' (Michael 2008, p.53), and recommended 'improve[d] data, communication and cross-boundary partnership working' (p.54).
- In 2013, CIPOLD recommended 'Clear identification of people with learning disabilities on the NHS central registration system and in all healthcare record systems'; 'Reasonable adjustments required by, and provided to, individuals, to be audited annually'; and 'Mental Capacity Act training and regular updates to be mandatory for staff involved in the delivery of health or social care' (Heslop et al. p.108).

These same issues are being raised as problematic in LeDeR reviews some 10 years after coming to public attention in Death by Indifference.

A model that can be helpful when thinking about the development of expertise in supporting people with learning disabilities is that of 'Conscious Competence', developed in the 1970s. According to the model, we move through four stages as we develop expertise (see Figure 4.1):

- Unconsciously incompetent – we don't know that we don't have this expertise, or that we need to learn it.
- Consciously incompetent – we know that we don't have this expertise.
- Consciously competent – we know that we have this expertise.
- Unconsciously competent – we don't know that we have this expertise (it just comes naturally).

People do not usually make an effortless, smooth transition from one stage to another: different strategies are needed in the move between stages, and in making recommendations from the completed LeDeR reviews we need to bear this in mind. For example, delivering training about the requirements of the Mental Capacity Act may be necessary for those who are ‘unconsciously incompetent’, but other professionals may benefit more from the opportunity to apply the learning to their work setting, and develop their skills and expertise through joint working and reflecting on their practice.

## **Recommendations for action**

Based on the evidence from completed LeDeR mortality reviews, we make a number of important and key recommendations. These are summarised in Table 4.1 and more fully explained below.

## **Inter-agency collaboration and communication**

Evidence suggests that in general, interagency collaboration is perceived by professionals, those using services and their families, as having a beneficial impact and outcome (Cooper et al., 2016). Facilitative factors for interagency collaboration and communication are:

- ✓ Good working relationships, including a commitment from all staff to work together, trust and mutual respect across agencies, and shared understandings
- ✓ Transparent and constant communication between agencies
- ✓ Adequate funding, staffing and time, and the presence of a key worker or care co-ordinator
- ✓ Strong leadership and clear lines of accountability.(Atkinson et al. 2007).

**Table 4.1: Summary of recommendations**

	<b>Recommendation</b>	<b>Responsible agency</b>
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 Mental Capacity Act 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 health care 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 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

Our first recommendation is therefore to **strengthen collaboration and information sharing, and effective communication, between different care providers or agencies**. There may be a number of ways of addressing this, but one approach could be for health and social care agencies to appoint a person with leadership responsibility for interagency collaboration and communication. As a matter of priority, this role-holder should develop, monitor and audit the effectiveness of their policy and procedures for interagency collaboration and communication; and train all staff members about good practice in interagency communication.

Our second recommendation is to **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**. People with learning disabilities are often in touch with several health and care providers, but the records are usually siloed in different systems, or in multiple sets of paper records. We suggest that NHS England work with NHS Digital and the Professional Records Standards Body to develop information standards relating to the multi-agency care of people with learning disabilities, and others, that will enable professionals

to share high quality digital care records and promote their widespread use in health and social care systems.

Our third recommendation is that **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 Mental Capacity Act decision-making process)**. The learning disabilities annual health check scheme is a voluntary reward programme for primary medical services. Under the scheme for 2017-18, GP practices are encouraged to produce a register of all patients aged 14 years or over with learning disabilities; offer all the patients on this register an annual health check and perform the health check where the patient agrees to this; and offer all the patients on the register a Health Action Plan and produce the Health Action Plan where the patient agrees to this. A National Electronic Health Check clinical template for people with learning disabilities is currently under development (see: <https://www.england.nhs.uk/wp-content/uploads/2017/05/nat-elec-health-check-ld-clinical-template.pdf>); we feel that a strong steer is required from NHS England for this to be shared (with patient consent) across relevant health and social care agencies involved in supporting the person.

Our fourth recommendation is that **all people with learning disabilities with two or more long-term conditions (related to either physical or mental health) should have a local, named health care coordinator**. The National Institute for Clinical Excellence (NICE) quality standard (QS142) for people with learning disabilities and a serious mental illness, is that they should have a key worker to improve care coordination and help services to communicate clearly with people with learning disabilities and their family members and carers. Current NHS England recommendations are that commissioners should extend the offer of a named local care coordinator to all people with learning disabilities and/or autism who have a mental health condition or behaviour that challenges

(LGA, ADASS, NHSE, 2015; Public Health England, 2017). In the light of the extent to which potentially avoidable contributory factors leading to death are related to poor inter-agency collaboration and communication, we do not believe that this is sufficient. Rather, we suggest that parity is upheld between the impact of physical and mental health conditions, and that any person with learning disabilities with two or more long-term conditions, of whatever nature, is supported in managing their overall healthcare needs with a local, named health care coordinator.

### **Awareness of the needs of people with learning disabilities**

Our fifth, sixth and seventh recommendations focus on improving an awareness about the needs of people with learning disabilities. As already mentioned above, there is already positive work in progress to raise awareness of the needs of people with learning disabilities, and improve the delivery of health and care services; when fully introduced and implemented, these will make a positive contribution.

Our **fifth recommendation is that providers clearly identify people requiring the provision of reasonable adjustments, record the adjustments that are required, and regularly audit their provision**. The mortality reviews provided patchy evidence about the provision of reasonable adjustments for people with learning disabilities, although this is a statutory requirement for health and care services.

**Our sixth recommendation is that mandatory learning disability awareness training should be provided to all staff, delivered in conjunction with people with learning disabilities and their families**. Evidence from the mortality reviews suggested that the influence of all staff, not just 'front line' staff providing health or social care, was important and could make a difference to the outcomes for people with learning disabilities. Office secretaries, outpatient booking clerks, cleaners and meal attendants could all be influential, and it is equally important that they receive learning disability awareness training.

**Our seventh recommendation is for a national focus on pneumonia and sepsis in people with learning disabilities, to raise awareness about their prevention, identification and early treatment.** The issue of the high rate of deaths potentially amenable to good quality care also deserves attention. Here, bacterial pneumonia, aspiration pneumonia and sepsis are key contributors. Identifying the early signs of illness is essential, and carers must be alert to how these diseases may present, take all preventative measures, and be proactive in seeking timely medical attention.

### **The understanding and application of the Mental Capacity Act (MCA)**

Our eighth recommendation is that **local services 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.** The findings from the LeDeR mortality reviews echo the House of Lords post-legislative scrutiny of the Mental Capacity Act conclusion that there is a lack of awareness and understanding about the MCA, principally within the health and social care sectors. They commented:

*‘For many who are expected to comply with the Act it appears to be an optional add-on, far from being central to their working lives...the prevailing cultures of paternalism (in health) and risk-aversion (in social care) have prevented the Act from becoming widely known or embedded....The duties imposed by the Act are not widely followed.’ (p.6).*

### **The process of undertaking mortality reviews**

Our ninth recommendation is that **a strategic approach is taken nationally for training 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.** This supports, but extends, the Department of Health and Social Care (DHSC) mandate to Health Education England (HEE) which states the requirement for HEE to work with the Healthcare Safety Investigation Branch and providers to develop approaches to ensuring that ‘staff have the capability and capacity to carry out good investigations of deaths and write good reports, with a focus on these leading to improvements in care.’ (DHSC p.16).

### **The future focus of the LeDeR programme**

The focus of the LeDeR programme over the coming year will be to follow-up on the actions that are proposed in mortality reviews. We need to ensure that we move beyond ‘learning’ into a more proactive approach to meeting the health needs of people with learning disabilities, which requires targeted action and commitment to improve service delivery where required.

A model for how this could be realised was shared by Emily Lauer, the lead for mortality reviews of people with learning disabilities at Massachusetts USA. She spoke at a series of workshops for LeDeR Steering Group members in England in June 2017, to share some of the actions that have been implemented in various States in the USA and how their effectiveness is being monitored. Her presentations can be viewed at: <https://www.youtube.com/watch?v=lw-coxPOI> and <https://www.youtube.com/watch?v=nBnjwi-5sEk>



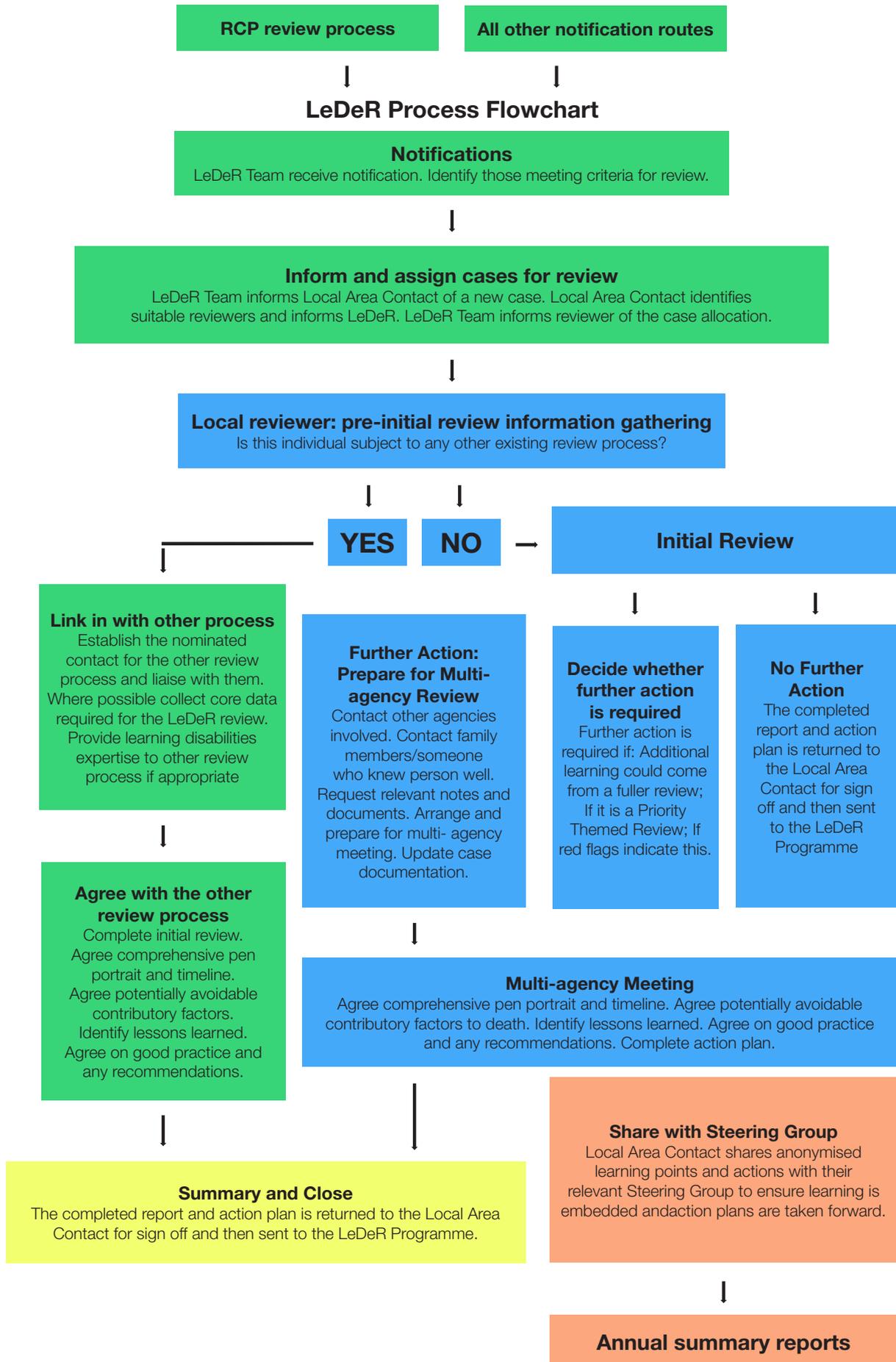
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# Appendices

# Appendix 1: LeDeR process flowchart



## Appendix 2: LeDeR methodology

### Notification of a death

The person reporting the death is asked to provide relevant core information. The information provided is checked by the LeDeR team to ensure that the death meets the inclusion criteria for the LeDeR programme. Once confirmed, the death is allocated to a reviewer under the guidance of the Local Area Contact.

### Initial review

An initial review is completed for all deaths of people with learning disabilities that meet the inclusion criteria. The purpose of the initial review is to provide sufficient information to determine if there are any areas of concern in relation to the care of the person who has died, or if any further learning could be gained from a multi-agency review of the death that would contribute to improving practice.

### Multi-agency Review of a death

A multi-agency review of a death involves the range of agencies that had been supporting the individual who had died. It considers:

- Any good practice that has been identified in relation to the person's death
- Any potentially avoidable contributory factors to the death.
- If there were any aspects of care and support that may have changed the outcome, had they been identified and addressed.
- If there have been any lessons learned, as a result of the review of the death.
- If there should be any changes made to local practices, as a result of the findings of the review.
- If there are any wider recommendations that should be made.

### Action planning process

At the end of the initial and multi-agency review forms there is space for reviewers to identify learning and recommendations (from initial reviews) and action points (from multi-agency reviews). Copies of completed reports are sent to the local LeDeR Steering Group, which agrees relevant actions, and oversees their implementation in conjunction with relevant partners and health and social care agencies in their area.

### Priority Theme Reviews

The Priority Theme Review aspect of the LeDeR programme examines the deaths of a subset of people with learning disabilities in more detail. Two themes are currently under scrutiny:

- Deaths of people aged 18 to 24 years
- Deaths of adults and children from a Black or Minority Ethnic group.

Deaths subject to Priority Themed Review receive an initial and full multi-agency review. The review documentation is anonymised by the LeDeR team, and then sent to Priority Themed Review panel members for further comment. Comments from the panels are collated by the LeDeR team and incorporated into the completed review documentation.

### The LeDeR quality assurance process

The Quality Assurance process involves a small panel of LeDeR team members looking at recently submitted reviews, to work to ensure national consistency in the quality of mortality reviews. Quality assurance enables the LeDeR team to give constructive feedback to reviewers to enrich their future reviews. It also gives the LeDeR team invaluable insight into training needs: themes picked up in quality assurance are incorporated into training improvements on an ongoing basis.

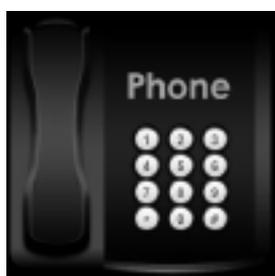
## Appendix 3: Acknowledgements

There are many people whom we would like to thank for their support and help with implementing the LeDeR programme. In particular, we would like to thank:

- NHS England, particularly Dr Dominic Slowie, Matthew Fagg, Crispin Hebron, John Trevains and Kevin Elliott
- HQIP
- The Regional Coordinators: Maria Foster, Emily Handley, Robert Tunmore, and Louisa Whit
- Members of the Independent Advisory Group chaired by Dr Dominic Slowie
- Members of the LeDeR Programme Steering Group chaired by Professor Peter Fleming
- Members of the LeDeR Programme Advisory Groups
- The National Valuing Families Forum
- All of the family members and people with learning disabilities who have attended any of the LeDeR consultation events
- Those working to implement the LeDeR programme as Steering Group members, Local Area Contacts, and reviewers

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# Thank-you for reading this report.



For more information about the LeDeR programme, please contact us:

Phone: **0117 3310686**

Email: **leder-team@bristol.ac.uk**



Or visit our website at

**[www.bristol.ac.uk/sps/leder](http://www.bristol.ac.uk/sps/leder)**



**Norah Fry Centre for Disability Studies, 8 Priory Road, Clifton, Bristol, BS8 1TZ**

You can find more information at  
**[bristol.ac.uk](http://bristol.ac.uk)**

**ADULTS AND HEALTH SCRUTINY PANEL**

7 February 2019

**MENTAL HEALTH TASK AND FINISH GROUP REPORT**

**Report of the Mental Health Task and Finish Group**

Strategic Aim:	Supporting the health & well-being needs of our community	
Exempt Information	No	
Relevant portfolio:	Safeguarding - Adults, Public Health, Health, Commissioning , Community Safety including Road Safety	
Contact Officer(s):	Karen Kibblewhite, Head of Commissioning	01572 758127 kkibblewhite@rutland.gov.uk
	Jo Morley, Governance Officer	01572 758271 jomorley@rutland.gov.uk
Ward Councillors	All	

**DECISION RECOMMENDATIONS**

That the Panel:

1. Notes the work of the Mental Health Task and Finish Group and endorses recommendations 1-8 as outlined in their report.
2. Recommends the findings of the Mental Health Task and Finish Group report to Cabinet for approval.

**1 PURPOSE OF THE REPORT**

- 1.1 To present the findings of the Mental Health Task and Finish Group to the Adults and Health Scrutiny Panel.

**2 BACKGROUND**

- 2.1 The Mental Health Task and Finish Group was set up in February 2018 as a result of mental health being a frequent topic of discussion at both the Adults and Health and the Children and Young People Scrutiny Panels. Additionally mental health had become a focus at both a national and a local level.

2.2 The purpose of the group was to review access to mental health services and to make recommendations in order to improve support for those with mental health issues.

2.3 The Mental Health Task and Finish Group met on a regular basis and their findings and recommendations can be found in the attached report.

### **3 CONSULTATION**

3.1 The Group, in the course of their work, consulted with key stakeholders including primary and secondary schools, Police, Armed Forces, Citizen's Advice, Public Health officers, and RCC officers working in HR, Adult Social Care, Children's Services and Communications.

### **4 ALTERNATIVE OPTIONS**

4.1 Not applicable.

### **5 FINANCIAL IMPLICATIONS**

5.1 There were no direct financial implications of undertaking the Task and Finish Group.

5.2 The following recommendations may have financial implications:

5.2.1 Recommendations 2 and 3 which reflect opportunities to support awareness and promotional campaigns may have costs attached. These will need to be considered as potential campaigns are identified. Where possible, officers will seek to undertake promotional work at nil cost other than staff time.

5.2.2 Recommendation 6 notes that there is some identified non-recurrent Public Health funding which might be used to support this recommendation should it be required.

5.3 The remaining recommendations have no direct financial implications.

### **6 LEGAL AND GOVERNANCE CONSIDERATIONS**

6.1 The terms of reference were approved by the Adults and Health Scrutiny Panel on 8 February 2018.

6.2 Subject to approval by the Adults and Health Scrutiny Panel this report will be sent to Cabinet in accordance with procedure rule 202: Consideration of scrutiny reports by Cabinet.

### **7 CONCLUSION AND SUMMARY OF REASONS FOR THE RECOMMENDATIONS**

7.1 It is recommended that the Panel notes the contents of the Task and Finish Group's report and recommends it to Cabinet in order that the Group's findings and recommendations can be further considered and implemented.

## **8 BACKGROUND PAPERS**

8.1 There are no additional background papers to the report.

## **9 APPENDICES**

9.1 Appendix A: Report of the Mental Health Task and Finish Group

**A Large Print or Braille Version of this Report is available upon request – Contact 01572 722577.**

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**Rutland**  
County Council

## **ADULTS & HEALTH AND CHILDREN & YOUNG PEOPLE SCRUTINY PANELS**

A report on Mental Health from the Joint Task and  
Finish Group

February 2019

## **CONTENTS**

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## 1. INTRODUCTION

Following a presentation on mental health care in Rutland at its meeting on 14 September 2017, the Adults and Health Scrutiny Panel recommended that a combined Task and Finish Group with the Children's and Young People's Scrutiny Panel be established to look at the provision of mental health service in Rutland.

The Scrutiny Commission agreed that this Task and Finish Group should be set up at the beginning of 2018 and last for a period of approximately 12 months with a final report with recommendations to be presented back to the Committee on completion.

The Adults and Health Scrutiny Panel agreed the terms of reference at a meeting in February 2018 and nominations for the group were sought.

The Joint Task and Finish Group was comprised of the following Members:

Councillor Gary Conde (Chairman)

Councillor Rachel Burkitt

Councillor William Cross

Councillor June Fox

Councillor Gale Waller

Until July 2018: Councillor Lucy Stephenson  
(departure due to appointment as a Cabinet Member)

Until February 2018: Councillor Nick Begy  
(departure due to appointment as a Cabinet Member)

Officers supporting the Task and Finish Group were:

John Morley	Deputy Director - Adult Services
Karen Kibblewhite	Head of Commissioning
Joanna Morley	Governance Officer

### **Chairman's Foreword**

On behalf of the Task and Finish Group, I would like to take this opportunity to thank all those who have contributed to this review; those working in education, healthcare, front line services and local charities, who kindly gave up their time to be interviewed and share their views, and Council officers who provided information and gave their considered views.

## TERMS OF REFERENCE

### 1.1 Objectives

- 1.1.1 To review access to mental health services in order to identify ways in which the patient experience may be improved in terms of early identification; timely and appropriate treatment; success of outcomes; costs and availability of information.
- 1.1.2 To make recommendations to appropriate organisations and partners in order to improve support for those with mental health conditions.

### 1.2 Background

Adults and Health and Children's Scrutiny panels have noted that mental health has become a focus at both a national and a local level. It has frequently been a topic of discussion for both our panels and as a result of this it was decided to form a task and finish group to explore access to mental health services.

The 2017 Primary Care Survey report carried out by Healthwatch Rutland made the following conclusion in relation to Mental Health Services in Rutland *"A theme of considerable concern on the part of those experiencing the service runs through replies to questions about mental health services. These concerns need to be addressed."*

### 1.3 Scope/Purpose

- 1.3.1 Review of the existing provision of Mental Health Services in Rutland, access to these services and outcomes for users including:
  - Demand for mental health services
  - Availability of information
  - Thresholds for service
  - Waiting times
  - Assessment
  - Length of time for treatment to start
  - Success of treatment in each service
  - Rutland specific needs assessments
- 1.3.2 Consultation with commissioners; providers; relevant organisations and service users in order to collate relevant evidence;
- 1.3.3 To collate a body of research evidence and data to inform the outcomes of the review. This will be facilitated by the provisions of Regulation 26 Local Authority

(Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 requiring ‘responsible persons’ to provide a local authority with such information about the planning, provision and operation of health services in the area of the authority as it may reasonably require to discharge its health scrutiny functions.

- 1.3.4 Investigation into models which may be effective in prevention, timely identification and early intervention;
- 1.3.5 Evaluation of costs in relation to outcomes; and
- 1.3.6 Monitoring provision of service for those patients that choose to go outside of the Rutland area for geographical reasons.

#### **1.4 Roles and Responsibilities**

- 1.4.1 The membership of the Task and Finish Group will be Councillors Lucy Stephenson, Nick Begy, June Fox, Rachel Burkitt, Gary Conde, William Cross and Gale Waller. *\*During the process Councillors Stephenson and Begy both resigned from the group when they took up Cabinet positions*
- 1.4.2 The Chair of the Task and Finish Group will be Councillor Lucy Stephenson\* (Chair of Adults and Health Scrutiny Panel). *\* Councillor Gary Conde took over from Councillor Stephenson following her appointment as a Cabinet Member*
- 1.4.3 The Governance team will provide administration support when required.
- 1.4.4 Mark Andrews (Director for People) will be kept informed on the process of the Group’s progress and will coordinate with the Chair the officer support and information the Group will require.

#### **1.5 Key Milestones**

<b>Activity</b>	<b>Provisional Dates</b>
Agreement of Terms of Reference	8 February 2018 (Adults and Health Scrutiny Panel)
Information gathering	February to September 2018
Development of Recommendations	September – December 2018
Report to Scrutiny	February 2019
Report to Council (If applicable)	February 2019

## **2. PROCESS AND METHODOLOGY USED FOR THE INVESTIGATION**

### **2.1 Methodology**

- Questioning of key stakeholders
- Desktop research – national and local.
- Schools questionnaire
- Information requested and questions posed of relevant officers/ Public Health / CCG / NHS England
- Advice and guidance from RCC Officers

The following items were provided:

- Children and Young People’s Mental Health and Emotional Wellbeing Services: “The Rutland Offer” – August 2018
- Mental Health STP Chapter - November 2017
- Presentation on Creating a Local Mental Health Strategy
- Mental Health Services: Referrers Information
- Public Health answers to questions on the School Nurse service
- Mental Health First Aid Training Options and Grant Considerations
- The Education and Health Select Committee report on the Government’s green paper on transforming children and young people’s mental health
- NSPCC website article on school referrals for mental health
- CCG Response to Feedback from the Rutland Mental Health Forum to the Board of Healthwatch Rutland regarding Public Opinion on Rutland Mental Health Services
- Material on the Heads Together charity
- Children & Young People’s Emotional, Mental Health & Wellbeing Transformation Plan 2018-2020

### **2.2 Process**

The timetable of events leading to the production of the report are set out below:

Meeting date	Items discussed/ Guests Attending
11 Dec 2017	Scoping meeting and agreement of terms of reference
28 Feb 2018	Review of Mental Health Strategy provided by the CCG
15 March 2018	Review of information provided by the Leicestershire Partnership NHS Trust. Identification of potential stakeholders
1 May 2018	Interviewing of Key Stakeholders. Participants included representatives from: Catmose College Kendrew Barracks Whissendine Primary Rutland Disabled Youth Forum Healthwatch Rutland Catmose Primary Neighbourhood Policing Sergeant Rutland Citizens Advice Public Health Resilient Rutland
15 May 2018	Discussion of the four key themes that arose from stakeholders that warranted further investigation; Community, Schools, Communication and Commissioning. School Survey to be sent out.
27 June 2018	Feedback and updates on research
8 Aug 2018	Confirmation of new Chairman. Discussion of potential report recommendations
12 Sep 2018	Meeting with representatives from the Oakham Medical Practice.
17 Oct 2018	Review of evidence and information supplied.
15 Nov 2018	Meeting with the Communications Manager to discuss a coordinated promotion campaign.
18 Dec 2018	Review of feedback from Communications and HR departments. Agreed actions
8 Jan 2019	Presentation and Q & A session with Resilient Rutland

It became clear to the Task and Finish Group members as they heard evidence that, although the initial scope included the provision of specialist services, thresholds and access to clinical treatment, the issues of identification of mental health issues and accessibility to early support were key. Consequently, the review refocused to explore in more detail prevention and early identification of support and services. It is recognized that addressing these will still have an impact on access to, and need for, more specialist treatment services.

### 3. BACKGROUND

It is widely acknowledged that nationally there is an ever increasing demand for mental health services both from adults and children and young people, and that existing services are hugely oversubscribed. Pressing issues include the need for early intervention services, improved education about mental health and wellbeing in schools, and reduced waiting times for services.

In the Government's report No Health Without Mental Health, which looked at achieving parity of esteem between mental and physical health, good mental health is recognised as central to an individual's quality of life and as having a knock-on effect on society affecting education, employment and economic success. The report notes the following statistics:

- At least one 1 in 4 people will experience a mental health problem at some point in their lives
- One in six adults has a mental health problem at any given time
- One in 10 children aged 5-15 has a mental health problem and half of all people with lifelong mental health problems have developed them by the age of 14.

Since this first report, increased and sustained focus on Mental Health by charities such as Mind and Heads Together along with endorsement by high profile figures such as Princes William and Harry to highlight the issue have meant that the Government, NHS and other national service providers have been reviewing existing provision and processes and currently undergoing great change to try and meet demand.

In addition to service providers, other organisations such as schools and businesses are trying to lessen the perceived stigma of having a mental health issue and therefore seeking help by educating their staff and students

Within organisations, research carried out by the mental health Charity Mind showed that only two in five women (38%) felt that the culture in their organisation made it possible to speak openly about their mental ill health and nearly one in three men said the same (31%). The research also showed that 24% of people felt less alone after hearing people in the public eye discuss mental health. By extension more people talking about mental health within an organisation would go a long way to normalising the issue and people therefore seeking help.

Talking about mental health issues in schools is, on one level, even more pressing as, as was quoted earlier, one in 10 children aged 5-15 has a mental health problem and half of all people with lifelong mental health problems have developed them by the age of 14. It is evident that children and young people today face an unparalleled level of scrutiny because of the ever increasing, pervasive reach and use of social media. A doctor interviewed by the group felt that excessive use of sites such as Facebook and Instagram had led to 'destructive expectation' and that there was a direct correlation with the overuse of social media and an increase in mental health issues in the young.

Against this national backdrop of a growing crisis in mental health, a reluctance by all age groups to talk about personal mental health and seek help whether it be because of an organisation/school culture, or a knowledge of where to go to for help, and the emergence of a multitude and often confusing array of new services and service providers, the Task and Finish group undertook their investigation in Rutland. This report summarises our findings and outlines our subsequent recommendations.

## **4. FINDINGS AND CONCLUSIONS**

In the course of their investigation, the Task and Finish Group spoke to different individuals and organisations about their experiences of mental health issues and how they accessed or referred to mental health services.

Generally it was recognised that for all ages there was a stigma about talking about mental health issues and confusion over where to go to get help. All sectors felt that there needed to be better co-ordination of the provision of services for low level issues and better signposting to them.

### **SCHOOLS**

Overwhelmingly, schools and those involved with children who were interviewed spoke about an increase in lower level issues such as anxiety and depression, regularly perceived as a consequence of the increased use of social media and the social pressure it brought about. There seemed to be a constant fear of being left out, not included in things, or of not measuring up. There was frustration that there were not enough resource to help address these issues and prevent them escalating into a more significant mental health problem.

Responses to the group's Schools Survey highlighted the issue of students who did not meet the thresholds for a CAMHS appointment and so were pushed back to the community or school arena. Even when a successful referral to CAMHS was made, there were waiting lists of 6 months or more which added to the difficulties of a young person already in a fragile state due to mental health problems. Additionally it seemed to schools that parents of these children had little support to help them cope with their child's situation/illness and teachers did not know where to signpost them to.

Primary schools reported that their pupils could be in need of help and support because of low self-esteem or because they had been affected by a house move or a new baby as well as bigger issues such as parents splitting up or a bereavement that triggers a crisis. Discussions with parents took place and they were advised to seek support through their GP but if problems escalated then staff made referrals to the School Nursing Service. Schools reported that regular training for named members of staff to provide a support network within school was essential.

Schools were driving their own internal initiatives to deal with issues and develop resilience in their pupils by, for example, holding mental health weeks in school and by measuring progress and success with dealing with a mental health issue by using action plans and provision maps.

## **SCHOOL NURSING SERVICE**

Schools, both primary and secondary, registered their concern with the delays and reductions in the number of school nurse appointments which led to many children needing to be directed to and referred elsewhere. The School Nursing Service previously sat with the CCG but in 2016, under the 0-19 Healthy Child programme, it came over to the Council under the transfer of Public Health responsibilities and is now funded by the Public Health Grant. The remit of the service is set by national guidelines. It should be noted that the shortage of school nurses and ongoing recruitment issues are a national issue and not specific to Rutland.

The School Nursing Service is no longer a visible daily presence in schools which can monitor and observe changes in children's behaviour. Instead, school nurses have set times doing weekly clinics in schools. The changes to the School Nursing Service mean that they now offer services such as preventative work to promote resilience, a text messaging chat service for secondary school pupils, contributions to PHSE lessons and Health and Wellbeing reviews in years 7, 9 and 11. Students needed to engage with and use these services more to increase their impact.

## **KEY STAKEHOLDERS**

In the wider Rutland community, outside of the school arena, the group heard from representatives from the Police, GPs, Armed Forces, Citizen's Advice Rutland, the Rutland Youth Forum and RCC's Public Health Team. These key stakeholders provided the group with information on how their organisations dealt with mental health issues, the approaches they took and the problems they experienced. A summary of this is outlined in the sections below.

### *Armed Forces*

The Group heard from armed forces personnel who felt that as an institution, the armed forces had been behind the curve in dealing with mental health issues but that the situation had got much better recently with more staff being instructed about mental health and how to identify it. Once a mental health issue was identified there was a referral to their own mental health services and an individual was seen immediately. After leaving the service or retiring, veterans' welfare was available so that if a mental health issue developed later on services could be accessed through them. However because of the perceived stigma of mental health, many veterans would not always declare that they were a veteran.

### *GP Surgeries*

GP surgeries, the first port of call for many, felt the pressure of not only the increasing demand of those with a mental health issue but also the fact that appointments for

these patients by their very nature, tended to be time consuming and often led to clinic backlogs and therefore pressures in other areas.

Feedback from the Rutland Mental Health Forum to Healthwatch showed that GP referrals to mental health services were lower than expected but there was conflicting advice about access routes. Some surgeries felt that self-referral was a better option because it meant patients took ownership of their problems and attended follow up appointments whereas others felt that there were those who really struggled and needed support throughout. Doctors reported that they felt that there were too many smaller services on offer that could be overwhelming to children or adults looking for help. The amount of services offered meant that there was too much opportunity for duplication and confusion and also often the initiatives in place were short-lived so just at the point where GPs were used to and actively referring to a scheme, it then finished.

### *Citizen's Advice*

Citizen's Advice Rutland were interviewed as lead provider for the Community Wellbeing Service and reported that there was not enough resource to deal with mental health issues, both in terms of the amount of advisers that Citizen's Advice had and the resources of other agencies, particularly to deal with low level issues. One of the main issues they dealt with was debt and they recognised that there was a high correlation between debt and mental health issues but there was debate about which came first, the debt or the stress and anxiety. More resource was also needed to support community involvement in preventing mental health issues, such as Good Neighbourhood Schemes, to reduce loneliness and depression.

They echoed the findings of the Rutland Health and Wellbeing Board whose previous investigations into mental health had found that there needed to be better coordination of the provision around low level issues and much better collaboration between services.

### *Police*

The Police were another organisation that gave evidence to the group. Police officers now all received training on how to identify mental health issues. Previously a black and white approach was taken and it was just a question of whether a crime had been committed without consideration of an individual's mental state, whereas now the attitudes and the approach taken was much more developed, with a mental health triage system in place. In addition there was a mental health car comprising of one specialist police officer and a mental health nurse which worked the hours 10pm -3am and covered the whole of the LLR area. They were based at a station in Leicester and could triage incidents as they came in. They did not always attend the incident but could advise on a course of action.

The use of Section 136 powers which meant that individuals could be detained under suspicion that they were mentally unstable and posed a threat to themselves or others, had declined dramatically. Section 136s used to be in double figures every week whereas in the last year for LLR it just reached double figures for the whole year. Using a Section 136 was a very ineffective use of police time as police officers would have to stay with the individual while they had the assessment which could take up hours of their time.

New officers coming through were now well equipped to deal with mental health issues and had access to mental health first aid training. It was expected that the training levels of PCSOs in Rutland would also be raised to include mental health awareness training so that they could contact and signpost people to available services. If officers felt that someone had mental health issues which posed a safeguarding threat then a report would be submitted to the adult and children safeguarding teams.

### *Disabled Youth Forum*

The Task and Finish Group also heard evidence from a member of the Rutland Disabled Youth Forum who felt that young disabled people were unaware of the services available and if they did know of them, wary of how they could access them in terms of what to expect and potential physical access problems. Online services were preferable to phone line services as it was a lot less threatening to type rather than to speak. Also people with hearing problems didn't want to use the phone as when they did so they often used the loudspeaker function and in this instance they wouldn't want others to hear their issues. Ideally the Disabled Youth Forum would like to see much more use of social media to enable them to find out about services, and interaction by text would be welcomed.

### *Public Health*

Public Health spoke about collaboration, highlighting that there was a mental health stream in the Better Care Together programme to try and address the issues of fragmentation and co-ordination of services. Additionally, the Prevention Concordat was a call to arms to all services to register what work they were doing.

The most common mental health problems recorded within Public Health data were anxiety and depression and the vast majority of interventions took place in primary care with either medication (in Rutland the second most widely prescribed medication was an anti-depressant) or Cognitive Behavioural Therapy being offered. If individuals felt they needed something more, then patients could be referred to the IAPT (Improving Access to Psychological Therapies) programme. IAPT was previously GP referral only, but there was a big attrition rate, and it was now found that those who made their own appointments were more likely to attend.

Public Health estimate that between 15 and 20% of patients would have some sort of psychological problem and would need to access treatment. This was not being

achieved in Leicester, Leicestershire and Rutland (LLR) at the moment and additional funding had been put in place to increase self-referral rates, make sure that GPs were referring to the right place and to increase the overall percentage of patients in treatment to 20%.

Public Health's emphasis and perspective was on prevention: noting that the five elements to psychological well-being: Socializing and connectivity; Exercise and activity; Mindfulness; Learning; and Volunteering and Giving; should be considered when planning services. This would result in more preventative work such as social prescribing (non-medical intervention such as exercise or debt management) and greater rethinking of day services and youth services so that there was more social interaction, particularly as Rutland was a rural, relatively isolated county.

### *RCC Officers*

The Council's Human Resources Department provided information on staff absenteeism due to mental health issues and reported that in the last quarter 199 sickness days had been taken which accounted for 20% of the total and was the second biggest reason for absence, after surgery at 23%. In the previous quarter the figure had been higher at 29% of the total and was by far the biggest cause of absence. This rate was similar to other organisations but as a snapshot, showed the impact of mental health issues such as stress, anxiety and depression. In surveying staff through its Workplace Health Staff survey, the Council found that 82% of RCC employees had trouble sleeping and that it was this factor that was their biggest concern linked to mental health. Tackling the issue of lack of sleep or sleep quality could therefore help to reduce stress and potentially absence rates and prove to be an effective preventative measure.

Recently the Government have announced many new national measures to tackle mental health. These include as part of the NHS 10 year plan, new waiting time targets for mental health treatment and stronger support for young adults with difficulties, as well as an extra £2.3 billion to pay for talking therapies for an additional 350,000 young people and 380,000 adults over the next five years. In Rutland there are also many new initiatives and programmes that are taking place which will help to address some of the problems outlined in the previous paragraphs and these include:

- The introduction of a children and young people's Improving Access to Psychological Therapies (CYP IAPT) wellbeing practitioner.
- A self-assessment tool that pulls together Public Health England's best practice and themes in order to ensure a whole school ethos that builds on the good practice already in schools and highlights future areas of development.
- Suicide and self-harm training for school and Council staff.
- Introduction to Cognitive Behavioural Therapy with children and adolescents workshop.

- An emotional and wellbeing nurse employed by the Council who supports those young children who have emotional needs, but who don't meet the CAMHS thresholds.
- A mapping of all mental health services available in Rutland by Adult Social Care officers working in partnership with GPs.
- The Children and Young People Emotional, Mental Health and Wellbeing Transformation Plan 2018-2020 for LLR which states that CAMHS will develop and commission a Triage and Navigation Service with partners, which will improve children & young people's access to services by getting them to the right service to meet their needs much quicker. It is anticipated that this service will free up clinician time so that their attention can remain focussed on delivering the right care and the specialist interventions needed.

### *Resilient Rutland*

The Resilient Rutland project work will start this year. Rutland First CiC have set up the Resilient Rutland project to respond to need expressed by Rutland young people for help in early intervention addressing mental health and wellbeing in schools. Rutland First bid for, and received, funding from the Big Lottery Fund of £484,700 to spend over the next three years in Rutland schools. The funding will provide for 1:1 sessions with practitioners (equivalent to a Band 6 Mental Health Nurse) who will also act as a triage service and signpost to other services. The practitioners will be part time and initially be in each of the four secondary schools. They will be available to all pupils who attend Rutland schools, not just those who live in Rutland, and will be accompanied by supporting work on resilience, mindfulness, young people's peer support, mapping and signposting of services, and work with parents. The project group are liaising with Council officers to ensure their work is in conjunction with local health services and the project complements and does not duplicate other initiatives. The Joint Task and Finish Group would like to see this tie-in with the Council extended throughout the lifespan of the project as sustainability of the work after the lottery funding ceases in 2022 is a concern. Sharing of data that the project group collects on the prevalence of mental health issues in Rutland schools and the impact of the work being done will lead to greater collaboration on this issue.

In summary, prevention and early intervention were key themes running through the information supplied by stakeholders. All felt these could be achieved by better co-ordination of services, more awareness and therefore identification of mental health issues, and better signposting and promotion of services. This is consistent with the Primary Care Survey conducted by East Leicestershire and Rutland CCG and Healthwatch in 2017 which had also identified these themes reporting that people felt that within mental health services, in addition to recruiting more staff, communication could be improved, more mental health training should be provided for GPs and other

healthcare professionals, improvements could be made to create more joined up working between practitioners and as we have found, more emphasis should be placed on prevention and early intervention for mental health issues.

## RECOMMENDATIONS

Throughout the meetings there were a number of recurring and interlinked themes:

- Prevention – both of poor mental health and to reduce risk of poor mental health escalating
- Stigma attached to poor mental health and asking for help
- The need for better awareness of services, coordination and collaboration, in particular for children and young people
- The need to support communities and individuals to improve their own mental health.

The Group have made the following recommendations, which it feels may support in addressing these.

### Recommendation 1

**Work is undertaken to make available a map of the referral routes and access criteria for mental health services available to adults and children in Rutland.**

Both professionals and the public would then be able to access clear information on where they can seek help. Better signposting and promotion of services would lead to earlier interventions, a main concern identified by residents and survey responders. This is key to ensure that individuals seeking help are not simply signposted between services. The mapping once completed should be available in a clear easy to follow format, with separate maps for children and young people's services and for adults' services.

### Recommendation 2

**The Council raises awareness of the mental health services available in Rutland by supporting campaigns that promote the existing provision of mental health services.**

This awareness raising should be approached in partnership with local health partners as part of a behaviour change campaign and Rutland County Council's Communications Team should engage with the communications leads from local health partners to help to tailor their campaigns to Rutland's needs. Once partner plans have been identified, the Council's Communications Team should seek to support this campaign activity and promote information on how to gain support locally. Such campaigns will raise awareness and thereby reduce the stigma of poor mental health.

### Recommendation 3

#### **Public Health promote the Leicester, Leicestershire and Rutland ‘Start A Conversation’ suicide campaign in Rutland.**

This campaign raises awareness of suicide and suicide prevention and is linked to a national Samaritans campaign. By working with Adult Social Care, the Community Safety Team, and partners such as GPs, awareness can be raised across Rutland and would signpost those in need to help and support. The Council’s Communications Team should support the distribution of promotional material across Rutland, enabling better promotion of this campaign in well-sited areas such as shops, pubs, the back of toilet doors etc.

### Recommendation 4

#### **Mental health awareness training be a requirement for all Council staff.**

There are experienced council staff who could provide mental health awareness training for staff. It is envisaged that courses would be organised through Human Resources with staff being booked onto courses in much the same way as they currently are for corporate training sessions.

Training of all staff would not only positively affect the Council work environment but also help to identify colleagues, friends and family in the wider community who may be struggling with mental health issues and so lead to earlier interventions. This links back to Recommendation 1 ensuring that services are mapped so that individuals know how and where to seek support.

### Recommendation 5

#### **The RCC Staff Health and Wellbeing Group should focus efforts and resources on addressing the issue of poor sleep because of its effect on mental health.**

A recent staff survey identified that poor sleep was a clear driver to poorer mental health. As part of a ‘Fit for February’ campaign to carry on January lifestyle resolutions, the Council would encourage employees to sign up for a ‘Sleep Week’ which would involve activities such as exercise, routine and cutting down on caffeine and screen time to promote better sleep. Again, it is anticipated that this would not only positively affect Council staff but the learning could be shared with family and friends in the wider community, and if successful the scheme could be promoted to other organisations as an effective preventative measure.

### Recommendation 6

**All schools in Rutland are encouraged to have a nominated trained Mental Health First Aider.**

Should schools need financial support to achieve this, one-off monies in the Public Health reserves are currently available which could be used towards the training of more staff (including support staff as well as teachers) to reduce the risk of gaps in provision caused when staff move on. This would support the earlier identification of poor mental health and support children and young people to access *appropriate* services. RCC could assist in promoting the value of this training within schools.

### Recommendation 7

**Rutland First's Resilient Rutland Team be asked to report to a future meeting of the Children and Young People Scrutiny Panel, to which the Adults and Health Scrutiny Panel Members would be invited.**

The Resilient Rutland project will collate a large amount of data within their work on the extent of mental health issues in Rutland schools compared with national levels and on the impact that their project has. Sharing data with partners will support the continued development of services and also identify potential gaps which need to be addressed.

### Recommendation 8

**RCC Officers be asked to report in a year's time to the Adults and Health Scrutiny Panel (to which the members of the Children's Scrutiny panel are invited) on the state of mental health in Rutland, reflecting on the recommendations in this report.**

## 5. LIST OF BACKGROUND PAPERS USED DURING THE INVESTIGATION

- The Education and Health Select Committee report on the Government's green paper on transforming children and young people's mental health  
<https://www.parliament.uk/business/committees/committees-a-z/commons-select/health-and-social-care-committee/news/green-paper-on-mental-health-report-published-17-19/>
- Government response to the report of the Education and Health and Social Care committees on the green paper 'Transforming children and young people's mental health provision'  
[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/728902/HESC\\_Print\\_3.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/728902/HESC_Print_3.pdf)
- Government Report : No Health Without Mental Health 2011  
[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213761/dh\\_124058.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213761/dh_124058.pdf)
- Government press release: Prime Minister unveils plans to transform mental health support 9 January 2017  
<https://www.gov.uk/government/news/prime-minister-unveils-plans-to-transform-mental-health-support>
- Public Health England: Prevention Concordat for Better Mental Health  
<https://www.gov.uk/government/collections/prevention-concordat-for-better-mental-health>
- CYP emotional, mental health and wellbeing transformation Plan 2018-2020  
<http://www.healthandcareleicestershire.co.uk/wp-content/uploads/2018/11/Future-in-Mind-LLR-CYPs-emotional-mental-health-and-wellbeing-transformation-plan-2018-20.pdf>

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