Leicester, Leicestershire and Rutland LeDeR Annual Report June 2021

This report covers the period from 1 April 2020 to 31 March 2021

Leicester City Council

NHS
Leicester City Clinical Commissioning Group
West Leicestershire Clinical Commissioning Group
East Leicestershire and Rutland Clinical Commissioning Group

Leicestershire County Council

NHS
Leicestershire Partnership NHS Trust

Rutland County Council

NHS
University Hospitals of Leicester NHS Trust

Contents

Executive Summary

The primary purpose of the Learning from Deaths of people with Learning Disability (LD) review programme (LeDeR) is to review the care each person has received leading up to their death and make recommendations that could help improve the care for other people and reduce premature deaths. Recommendations from each review are intended to highlight best practice and thereby support health and social care professionals and policy makers to implement positive change for people to have better experience of their care.

The core principles and values of the LeDeR programme are as follows:

- The programme overall must effect change and make an identifiable difference to the lives of people with learning disabilities and their families.
- We value the on-going contribution of people with learning disabilities and their families to all aspects of our work and see this as central to the development and delivery of everything we do.
- We take a holistic approach, looking at the circumstances leading to deaths of people with learning disabilities and don't prioritise any one source of information over any other.
- The key principles of communication, cooperation and independence will be upheld when working alongside other investigation or review processes.
- The programme overall strives to ensure that reviews of deaths lead to reflective learning which will result in improved health and social care service delivery.

This is why the LeDeR programme is so important. It represents a real opportunity to improve the lives of people with learning disabilities. Implementation in Leicester, Leicestershire and Rutland has been difficult, but much progress has been made; we are now in a position to make evidence-based recommendations as to how the quality of health and social care services for people with learning disabilities can be improved.

There are two sets of people that deserve special recognition.

- Our LeDeR reviewers. Without their expertise, experience and passion we would not be where we are.
- The families, friends, carers and health and social care professionals who have provided critical contributions to each LeDeR review. Their support has been invaluable.

We must not rest upon the contents of this report. Instead all partners across the Leicester, Leicestershire and Rutland health and social care sector must embrace the initial findings of this report, everyone has a role to play. Only then will we ensure that every person with a learning disability receives the high quality of care that they deserve. Only then will we address health inequality.

Caroline Trevithick, Chief Nurse & Executive Director, West Leicestershire CCG

Heather Pick, Assistant Director (Adults & Communities), Leicestershire County Council and former Assistant Director **Peter Davis.**

David Williams, Director of Strategy and Business Development, Leicestershire Partnership NHS Trust

Good practice checklist

We can make a real difference to people in the following ways;

Listen to people with Learning Disabilities and their families and carers	✓
Ensure everyone is fully up to date with training	✓
Everyone having a clear understanding of the difference between Learning Disability and learning difficulties	✓
Carry out Mental Capacity Assessments in every relevant case	✓
Ensure patient records are fully accurate and changes are recorded correctly	✓
Communicate more effectively, in particular • with people with LD • across providers about Care Plans • discharge planning • advocacy • decision making • end of life • DNACPR	✓
Make no assumptions, particularly about LD being related to cause of death	✓
Check procedures to ensure nothing is missed in any process	✓
Ensure Annual Healthchecks are provided for every eligible person	✓
Support people to attend appointments, especially for Annual Healthchecks and screening programmes	✓
Ensure the correct versions of documents are used and completed accurately, including death certificates	✓

Acknowledgements

Leicester, Leicestershire and Rutland Clinical Commissioning Groups would like to acknowledge the support provided to the LeDeR programme by the following organisations, groups and individuals:

NHS England and Improvement National Team (NHSE/I)

NHS England and Improvement Regional Team

All our Reviewers and Clinical Leads

All family members' contributions

Leicestershire Partnership Trust

North East Commissioning Support (NECS)

University Hospitals of Leicester

Primary Care

Insight Training and Consultancy

Leicester City Council

Leicestershire County Council

Rutland County Council

Leicester, Leicestershire and Rutland Child Death Overview Panel (CDOP)

Introduction

This is the second Annual Report for Leicester, Leicestershire and Rutland (LLR) Learning from Deaths Review Programme and describes progress from the previous year's report.

The aims of the LeDeR programme are:

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

The programme is funded by NHS England with responsibility devolved to Clinical Commissioning Groups. However the programme is delivered through local partnerships across health and social care organisations in LLR.

The LeDeR process is summarised below:

- Anyone with a diagnosed learning disability who has died over the age of 4 years old since October 1st 2017 can and should be referred to the programme. The more people who are referred the stronger an evidence base for change can be developed.
- Each LeDeR referral is allocated to a local LeDeR reviewer. In LLR these are trained health and social care professionals experienced in working with people with learning disabilities. As much as possible LeDeR reviewers are not asked to review care for individuals where their 'home' organisation was a substantial part of service delivery. This is not always possible. However, the LeDeR Steering Group is assured that where this is the case, reviewers are impartial in their consideration.
- The purpose of the 'Initial Review' is to identify key learnings and recommendations to improve local health and social care services. To do this the LeDeR reviewer will consider relevant case records and speak to family, friends and carers to form a 'pen portrait' of the individual and a coherent narrative of their care in the lead up to their death.
- Where there were significant concerns about the person's health and social care service delivery further information can be gathered through a Multi-Agency Review (MAR).
- Before each Initial Review is approved it undergoes a quality assurance process. LLR has set high standards that every review must meet.
- Learnings and recommendations from every completed LeDeR review is fed into national and local 'Learning into Action'.
- Deaths for children with a learning disability are reviewed as part of the Child Death Overview Panel (CDOP) process. In LLR this is achieved through 'themed' panels where the exclusive focus is on learning disability deaths. The learnings and recommendations are then fed into LLR LeDeR Programme and implementation of 'Learning into Action'.

Statement of Purpose

The LLR Learning Disability and Autism Partnership is committed to the ongoing delivery of the LeDeR Programme. This means:

- That LeDeR reviews are allocated and completed to a high standard within the stipulated programme timescales.
- That identified learnings and recommendations become 'Learning into Action'.
- That 'Learning into Action' improves the quality of health and social care services and reduces the health inequality faced by people with learning disabilities.
- That all stakeholders, including people with learning disabilities and their family, friends and carers, feel an equal partner in the LeDeR programme.

These ambitions sit within the broader LLR system-wide Person-Centred Leadership Framework.

Local Progress

Last year's annual report stated the intention of the LLR LeDeR programme for 2020/21 was to analyse the recommendations from the completed reviews and identify the key themes in order to undertake change and implement improvements. However, there have been a number of causal factors that have largely prevented putting learning into action and making the desired improvements.

The LLR LeDeR Programme had several unallocated reviews and reviews that had been allocated but not completed. This position was neither satisfactory nor conducive to identifying the key learning to implement changes or improvements. Consequently, the focus of LeDeR within LLR changed to eradicate the backlog of reviews by mid-December 2020 with the intention that an analysis of the recommendations could be undertaken between December and March and concentrate on putting the learning into action from April 2021.

All reviews allocated to reviewers (79.53%) were completed within the timeframe. There remained 23 reviews that could not be completed because they had been referred into a statutory process e.g. coroners reports; CDOP reports; police or safeguarding investigations and waiting for the outcomes from those. These, along with reviews referred to LeDeR between 1 March and 30 April 2021, comprised the remaining 20.47%

The pandemic outbreak of COVID-19 had a significant impact on reviewers, especially those working within the University Hospitals of Leicester NHS Trust, Leicestershire Partnership Trust and local authorities due to the redeployment of some reviewers' activity to focus on clinical roles.

The three CCGs in LLR underwent a major management of change programme resulting in significant staff changes within the LeDeR leadership team. Although two clinical leads (WTE 1.8) had been appointed to support reviewers, their contracts ceased at the end of March 2021. Permanent posts have been agreed and recruited into from June 2021. The two Local Area Contacts (LAC), one from the CCG and one from the local authority both left the programme and were replaced with staff new to the role and the programme. A third LAC, also the senior administrative support left the programme and was replaced by someone in

a seconded position. Recruitment has successfully taken place for the administrative position, commencing April 2021.

NHS England national LeDeR team announced in 2020 that there will be changes to the reporting and review processes and a new national policy describing the changes would be published in spring 2021. The announcement included the need to complete all possible open reviews by 30th April 2021 because the online reporting system would cease to operate and information on any incomplete reviews would not transfer to the new system.

The requirement to complete and close reviews by the necessary deadline restricted the planned analysis of recommendations identified in the completed reports and limited the learning into action that could be implemented.

The outcome of the Oliver McGowan report identified changes to local LeDeR processes to be put in place (see McGowan Report Recommendations). Whilst LLR has been able to implement these changes that will also support positive outcomes for people with LD in LLR, it did detract from making other improvements following the outcome of reviews.

The achievements made by the LLR LeDeR programme include The profile of the LeDeR programme being raised using effective communication tools resulting in more consistent notification of deaths and strengthening across all partners, including Primary Care, to obtain and upload patient records for reviewers to access.

The backlog of reviews was eradicated within the timeframe although there will be a small number of referrals to LeDeR whose reviews are unable to start because of the changeover of online systems. However, this is not expected to further impede reviewing the themes from the completed reviews.

All the recommendations for CCGs resulting from the Oliver McGowan review have been implemented.

LPT has reviewed and strengthened its internal governance processes regarding reviews of people who have died, which will inevitably support outcomes for people known to have a diagnosed learning disability.

UHL has carried out several reforms to improve the experience people have of their stay in hospital:

- The launch of the 'Helping me in Hospital' communication tool in March 2020 gives ward staff essential information about the patient to enable individualised plans of care to be implemented
- Carers & relatives have been allowed to continue to provide support on the wards to LD patients despite Covid visiting restrictions to advocate for the patient and aid communication
- Timely completion of the 'Home First' electronic tool helps to identify where there may be issues regarding discharge to prevent lengthy delays particularly where a care provider can no longer provide the level of care a patient need
- The development of a specific LD electronic admission checklist to be used as part of the core nursing assessments whenever a patient with a learning disability is admitted to a ward (Due to go live June 2021)
- Clarification of the process of referring adult inpatients for imaging under general anaesthetic

- Review and strengthening of the electronic assessment tool regarding the nutritional needs of patients.

Leicestershire County Council has held continuing professional development events for a range of staff within the organisation; the focus of events being the application of professional curiosity using a sample case that had also been the subject of a safeguarding investigation.

Rutland County Council has a monthly Continuing Professional Development session delivered to all our Adult Social Care (ASC) teams including therapy and housing. At least one of these sessions is scheduled annually to deliver a learning session on LeDeR as well as information shared at team meetings across ASC especially those with a high staff turnover.

Leicester City Council is establishing an internal review group to review the LeDeR learning into action in relation to care and support providers and ensuring that there is a process for supporting providers to implement learning. This will become embedded within the Quality Framework and commissioning processes. Provider Forums are used to reinforce messages from learning emerging from the LeDeR reviews.

Governance Arrangements

The LLR LeDeR Steering Group provides monthly updates to LLR Learning Disability & Autism Executive Board. Additionally periodic updates are provided for LLR Safeguarding Boards and other stakeholders. This includes reporting on behalf of local CCGs to NHSE/I.

The LLR LeDeR Programme is overseen by a Steering Group. Each LLR local authority, Clinical Commissioning Group (CCG) and NHS Trust is a member. It is chaired by the Head of LD and Mental Health, LLR CCGs.

The day to day management of the LeDeR Programme has been undertaken by the three Local Area Contacts (LACs). Each focuses on a different aspect of the programme: administration, clinical quality, and performance and business intelligence. Further support is provided by two locally funded Clinical Quality Leads who are responsible for ensuring the quality and speed of local LeDeR Reviews. Alongside the Steering Group Chair this forms the LLR LeDeR Leadership Team.

In order to ensure the LLR LeDeR programme has met its responsibilities under the Equalities Act, the Steering Group has endeavoured to engage with people with Learning Disability, their families and carers as well as voluntary groups, community and faith organisations to ensure views from a range of ages, demographic groups and cultures are captured.

Equality Impact & Demographic Data

Where demographics have been recorded in cases, these have been used to identify differences between people in various age groups, by disability, first language and ethnicity.

Age

According to mid-census statistics of June 2017 (Leicestershire Partnership Trust Demographic Profile of Leicester, Leicestershire and Rutland Local, Unitary, and District Authority Areas 2017 Mid-Year Estimates and 2011 Census), the LLR population is 1,083,226 for all ages. The age profile for male and female is similar to the national profile for England.

The most recent national data taken from the LeDeR programme (2019) states in 2018, the majority (85%) of people in the UK population died aged 65 and over. The corresponding proportion of people with learning disabilities was 37%. For deaths notified in 2019, the median (average) age at death was 61 for males and 59 for females, an increase of 1 year for males since 2018. Analysis of data from the local LeDeR system shows the median age of death for people, both male and female with LD in LLR who died in 2019-20 was 59 years. In 2020-21 this remains unchanged.

Disability

The national data reports that of people with a disability 9.3% reported that their day-to-day activities were limited a little, and a further 8.3% reported that their day-to-day activities were limited a lot. LLR data showed that the activities of 9.1% of people with a disability were only a little limited whilst a further 7.1% of people with a disability were restricted a lot.

First Language

Compared to the England benchmark, Leicester, Leicestershire, and Rutland had a lower proportion of people who spoke English as their first language. In Leicester, Leicestershire, and Rutland the most widely spoken first language was English (88.7%), followed by Gujarati (4.3%), Punjabi (1.0%), Polish (1.0%), and Urdu (0.4%). These languages covered over 95% of the population of Leicester, Leicestershire, and Rutland.

Ethnicity[1]

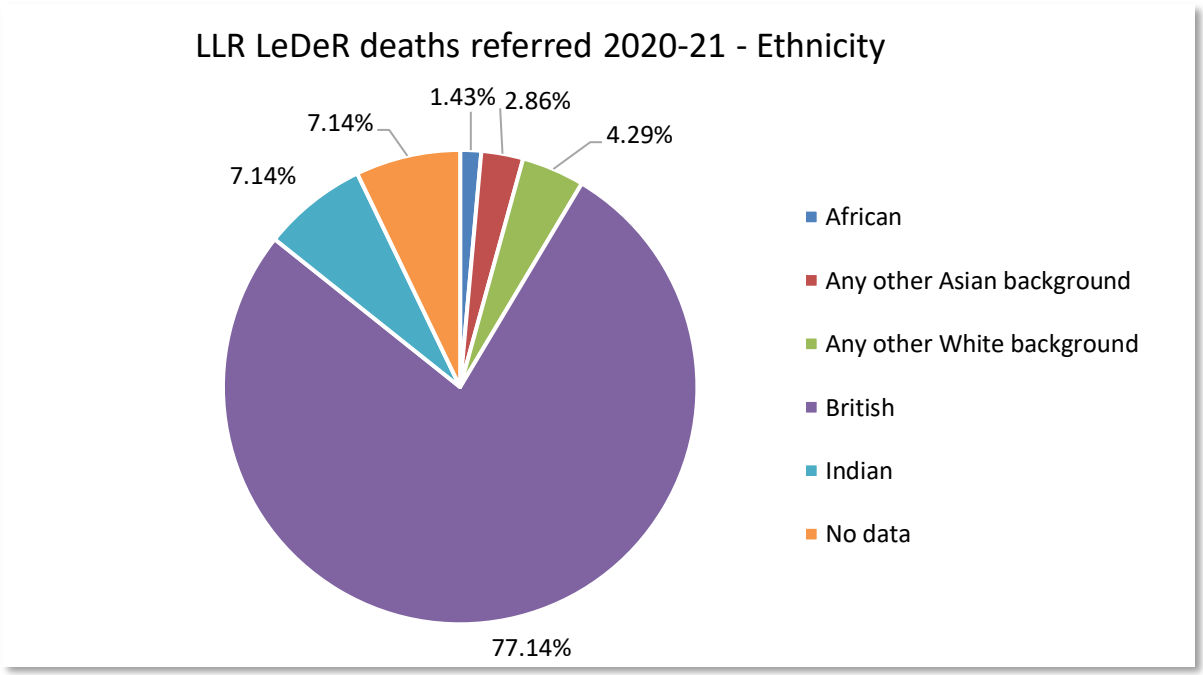
Compared to the England benchmark, LLR had a higher proportion of people from an Asian or other ethnic group background. However, this is more focused within the boundaries of Leicester city as Leicestershire and Rutland counties had a lower proportion of people from an Asian or other ethnic group than Leicester city or the England benchmark.

The LLR LeDeR programme is aware that it receives fewer notifications of death from the ethnic minority population than the local demographic suggests would be expected. We have appointed a nominated lead for ethnic minorities* who is a GP. Her role within the LeDeR programme is to raise the profile of LeDeR amongst ethnic minorities in LLR and to ensure that needs are addressed equitably across primary care and other organisations.

[1] For accuracy, it is important to note that in reports available to the LLR LeDeR team on original LeDeR online system, 'British' is listed as an ethnicity, and for these cases we assume 'White British' unless otherwise indicated.

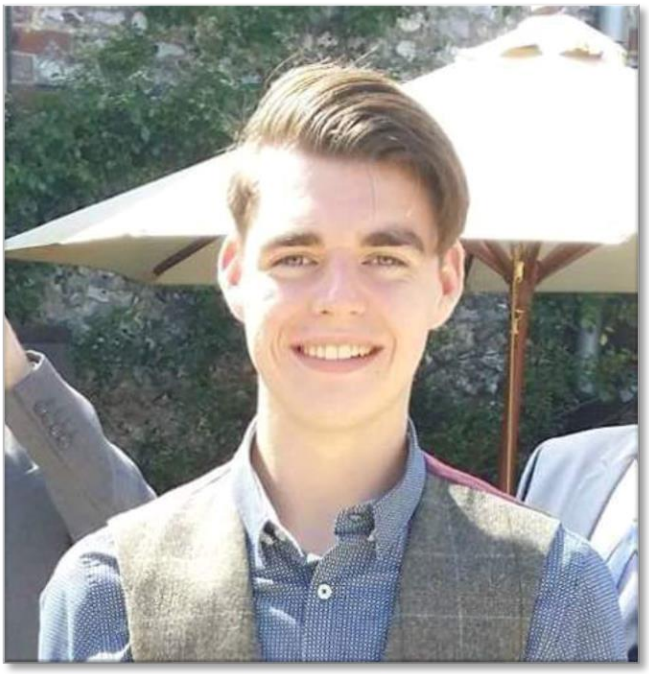
*We use ‘ethnic minorities’ to refer to all ethnic groups except the White British group. Ethnic minorities include White minorities, such as Gypsy, Roma and Irish Traveler groups[2].

Figure 1 shows that of deaths referred to LLR in 2020-21, the majority 77.14% were ‘British’ (White), 7.14% were ‘Indian’, 1.43% were ‘African’, 2.86% were ‘Any other Asian background’ and 4.29% were ‘Any other White background’. 7.14% had no ethnicity recorded. Figure 1



[2] www.gov.uk March 2021

McGowan Report Recommendations



Oliver McGowan was a teenager who had mild autism, epilepsy and learning difficulties, and was admitted to Southmead Hospital in November 2016 after having partial seizures. An independent LeDeR Review found that his death was 'potentially avoidable'.

In 2019, NHS England and Improvement commissioned an independent panel to review Thomas Oliver McGowan's previous LeDeR Review.

The rationale for the review related to what had been described as a number of inconsistencies in the local quality assurance processes for LeDeR, and specifically some of the draft reports for Oliver's LeDeR review that were sent to the family via the Freedom of Information Act in 2018.

Additionally, Oliver's family had expressed their anxiety about a perceived lack of transparency within previous reports and processes. The report forms the second part of a two-stage process – the first being to review and complete Oliver's LeDeR.

The recently published report by Fiona Ritchie OBE, Chair on behalf of Oliver's Independent Panel for NHS England and NHS Improvement made recommendations for the national, regional and local teams, particularly the governance arrangements surrounding local LeDeR programmes.[3]

One of the recommendations was *"each CCG must formally undertake and document and review its own systems and processes against the learnings and recommendations arising from Oliver's re-review".*

Appendix I provides the response undertaken by LLR for each recommendation from the review.

Cause of Death

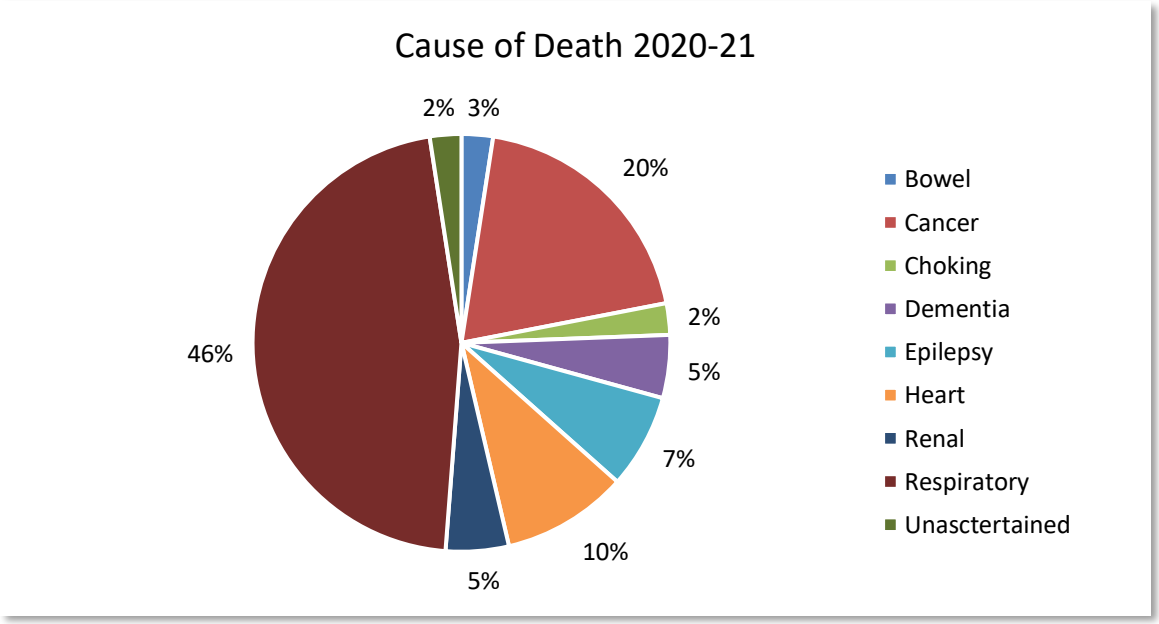
The majority (46%) of deaths were from respiratory causes

[3] https://www.england.nhs.uk/publication/independent-review-into-thomas-oliver-mcgowans-leder-process-phase-two

Data shows that the majority (46%) of deaths were from respiratory causes including the 6 Covid deaths. This is much higher than national findings (20%) presented in the most recent data. It is noted from the LLR reviews there is a lack of recognition of the deteriorating patient by carers. The LLR LeDeR system intends to work with partners to reduce the high percentage of deaths from respiratory causes by introducing a programme of education for care homes and other carers using a recognised early warning scoring system. The national LeDeR annual report in 2019 recommends using the RESTORE2 that was co-produced by West Hampshire CCG and Wessex Patient Safety Collaborative.

Figure 2 shows of the remainder, the largest group at 20% were cancers, followed by cardiac issues at 10%, 7% dying from epilepsy, dementia and renal issues each causing the deaths of 5% of cases, 3% from bowel issues and 2% from choking. In 2% of cases, cause of death was not ascertained.

Figure 2



COVID-19

At the start of the COVID-19 pandemic, LLR established the Learning Disability and Autism Sub-Cell, which reported to the COVID Health and Social Care Cell. The purpose of the meeting was to agree and implement additional support for the LD/A population, their families and carers, across LLR. LeDeR was represented on this group.

One of the first actions implemented was to identify those individuals at greater risk of harm and a register was quickly developed that identified the level of risk of hospitalisation due to the virus or the effects of services being temporarily closed or restricted, isolation and/or social distancing.

Resulting from the multi-agency reviews was the Learning Disability and Autism (LD/A) Response Service. This service utilised capacity available following the closure and restricted

use of regular mainstream services normally provided by health and social care, its aim was to prevent people with a learning disability and/or autism or their family and carers from coming to harm or requiring further, more significant health and social care intervention by providing support typical of that which would be received in day services, supported living or short breaks for a period of no longer than 72 hours by which time more permanent additional support could be delivered.

COVID-19 and age

The number of LD/A people diagnosed with COVID-19 was regularly reviewed at the meeting & cross referenced with the notifications of death. Of 73 reported deaths of all ages in 2021-22, there were 16 notified as *potentially* due to COVID-19 . 14 of these had COVID-19 listed as primary cause of death, comprising 5 females aged between 54 and 76, and nine males aged between 34 and 70. The remaining two cases listed COVID-19 as a possible secondary cause.

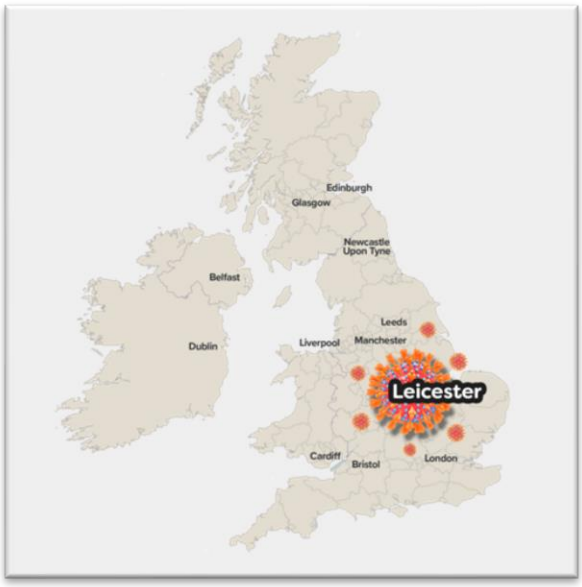
COVID-19 and ethnicity

Of all cases in which COVID-19 was a potential cause of death, ethnicity recorded was as follows

- 11 'British'
- 3 'Indian'
- 2 'Any other white background'

For reference, a table detailing the demographic breakdown of potential COVID-19 deaths has been provided in Appendix II.

N.B. in Leicester, Leicestershire and Rutland, COVID-19 lockdown was not lifted as it was across much of England, with particularly Leicester City remaining in lockdown throughout. For this reason, COVID-19 deaths have not been split by lockdown period for purposes of this report.

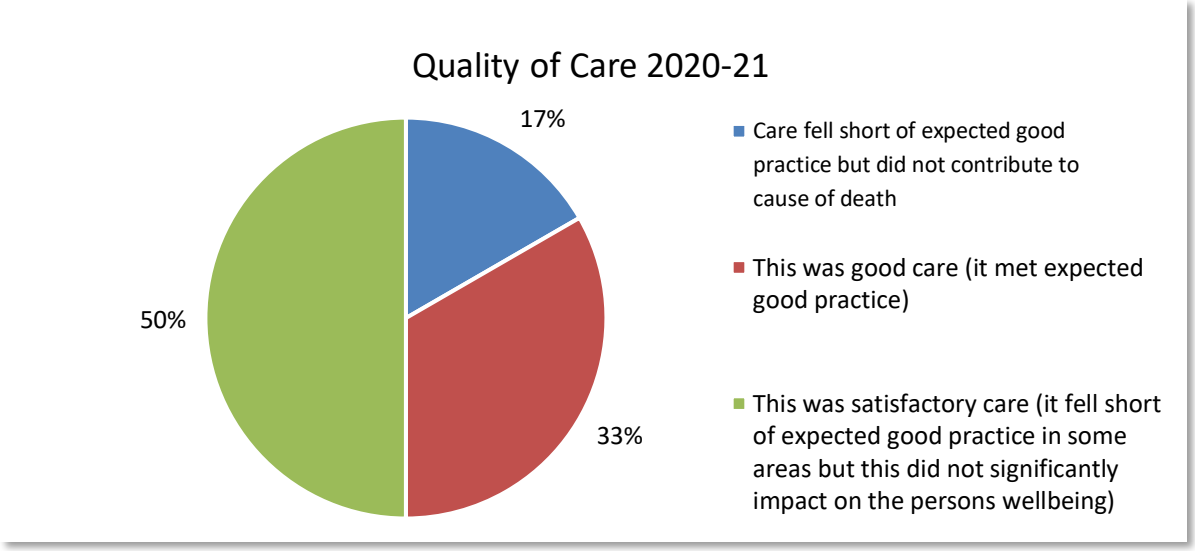


Quality of Care

33% showed good care

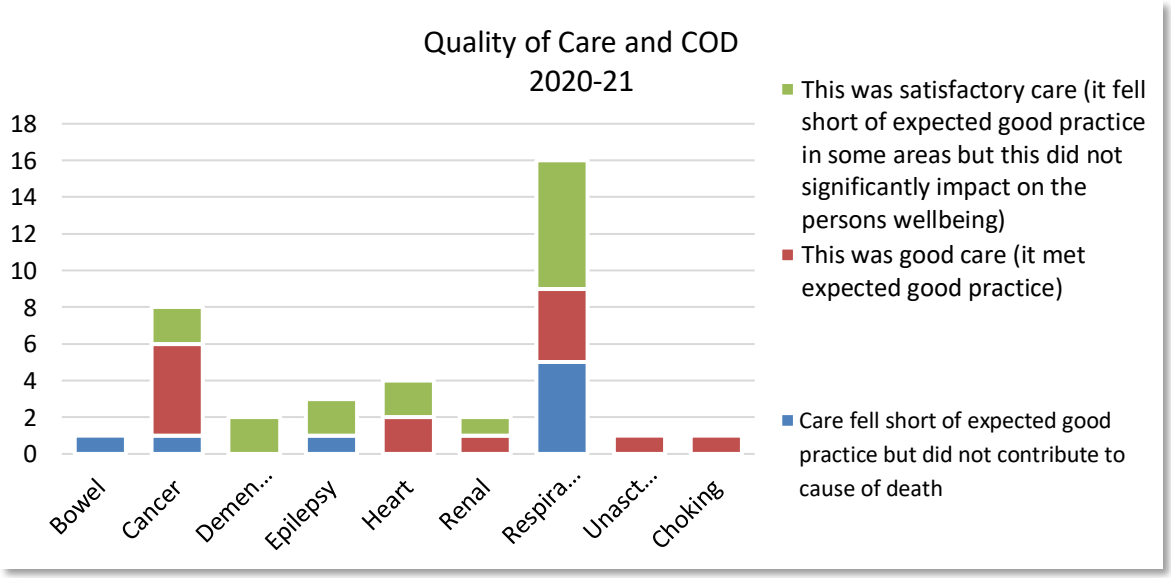
In 17% of 2020-21 cases, as shown in Figure 3, 'Care fell short of expected good practice but did not contribute to cause of death', while 33% showed 'good care' and half showed 'satisfactory care'.

Figure 3



Of the 38 reviews referred in 2020-21 that noted quality of care; these are broken down in Figure 4 by Cause of Death (COD) in 2020-21. The majority of these (16) demonstrated 'Satisfactory care' that fell short of expected good practice in some areas but did not significantly impact on the person's wellbeing. 14 cases showed 'Good care' that met expected practice and a further 8 in which 'Care fell short of expected good practice but did not contribute to cause of death'.

Figure 4



Action from Learning

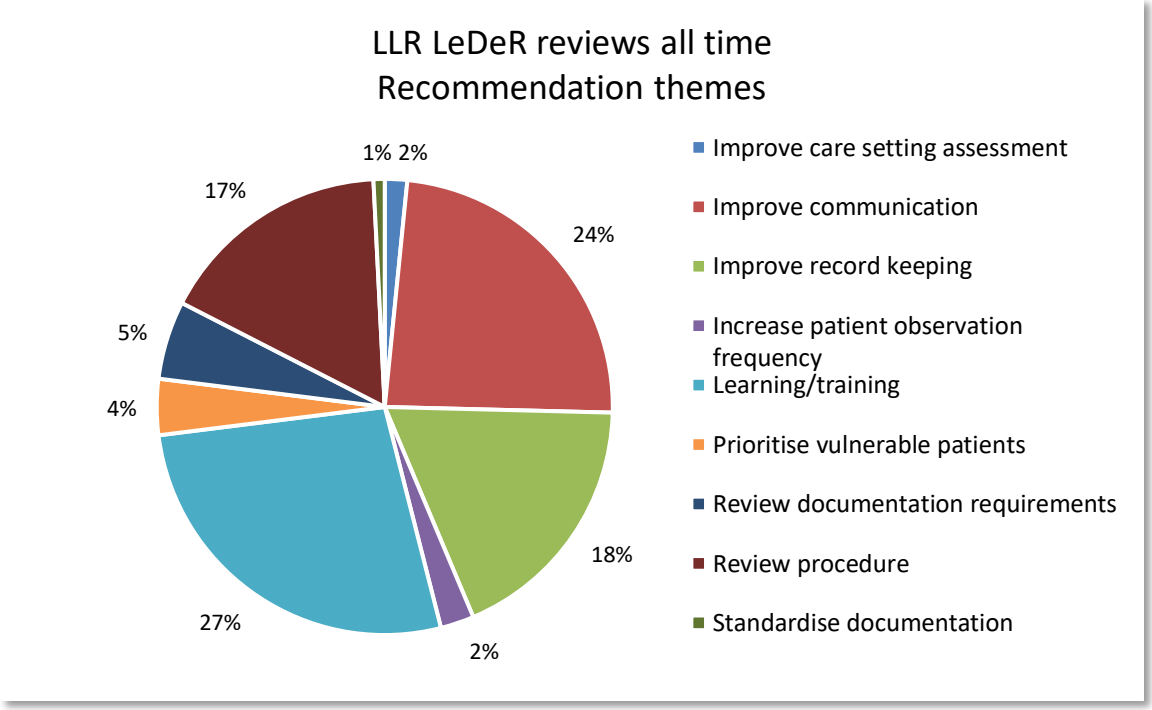
Learning and recommendations from all completed reviews (all time) were analysed to categorise them and identify how they related to organisations.

Recommendation themes

Largely mirroring national themes, analysis indicated the majority of recommendations related to four main themes, as illustrated in Figure 5.

- Learning and training (27%)
- Improving communication (24%)
- Improving record keeping (18%)
- Reviewing procedure (17%)

Figure 5



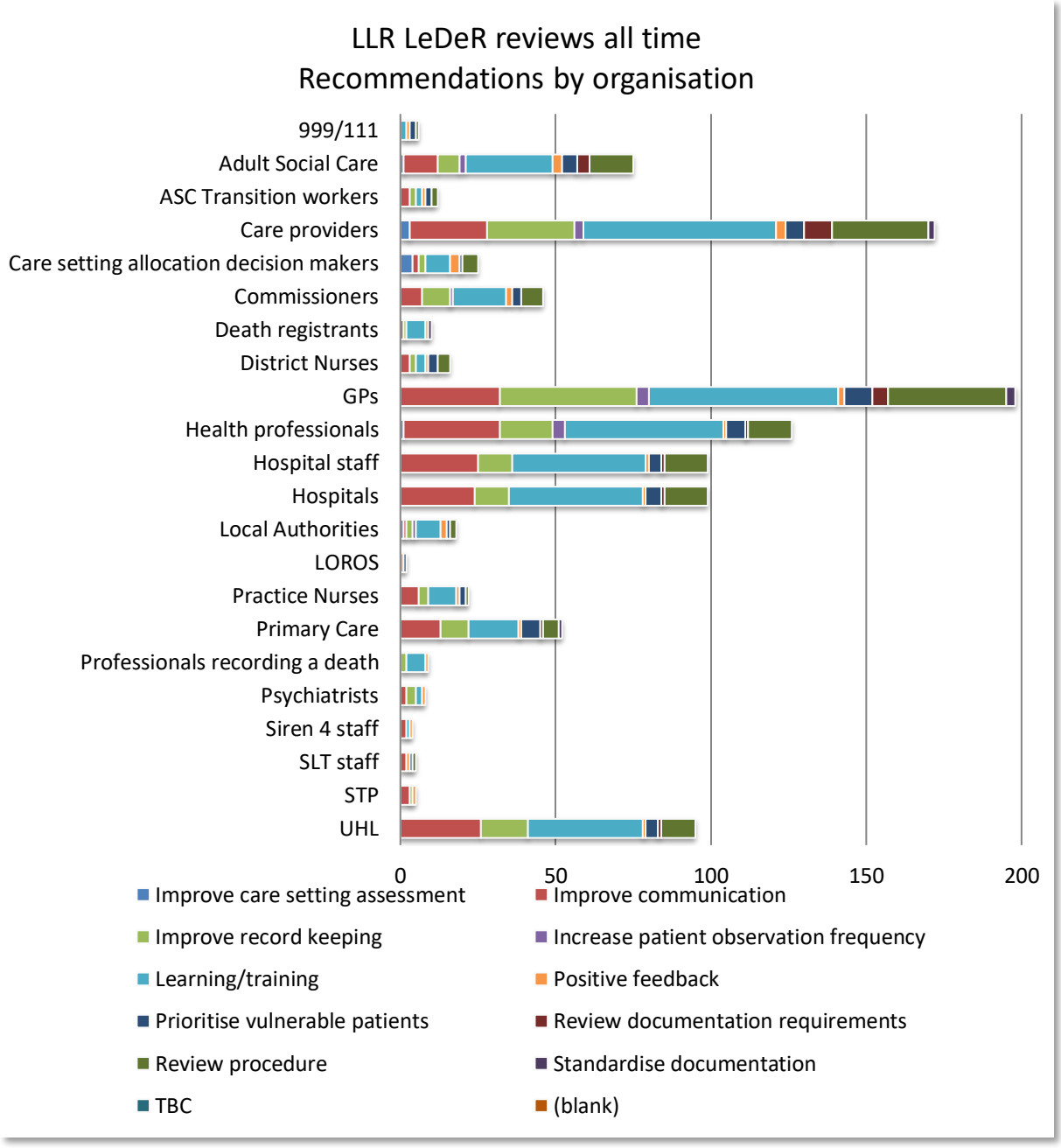
Recommendation relevance to organisations

Recommendations were also categorised by their relevance to organisations, staff groups and professions.

Figure 6 clearly shows the majority of recommendations were relevant to

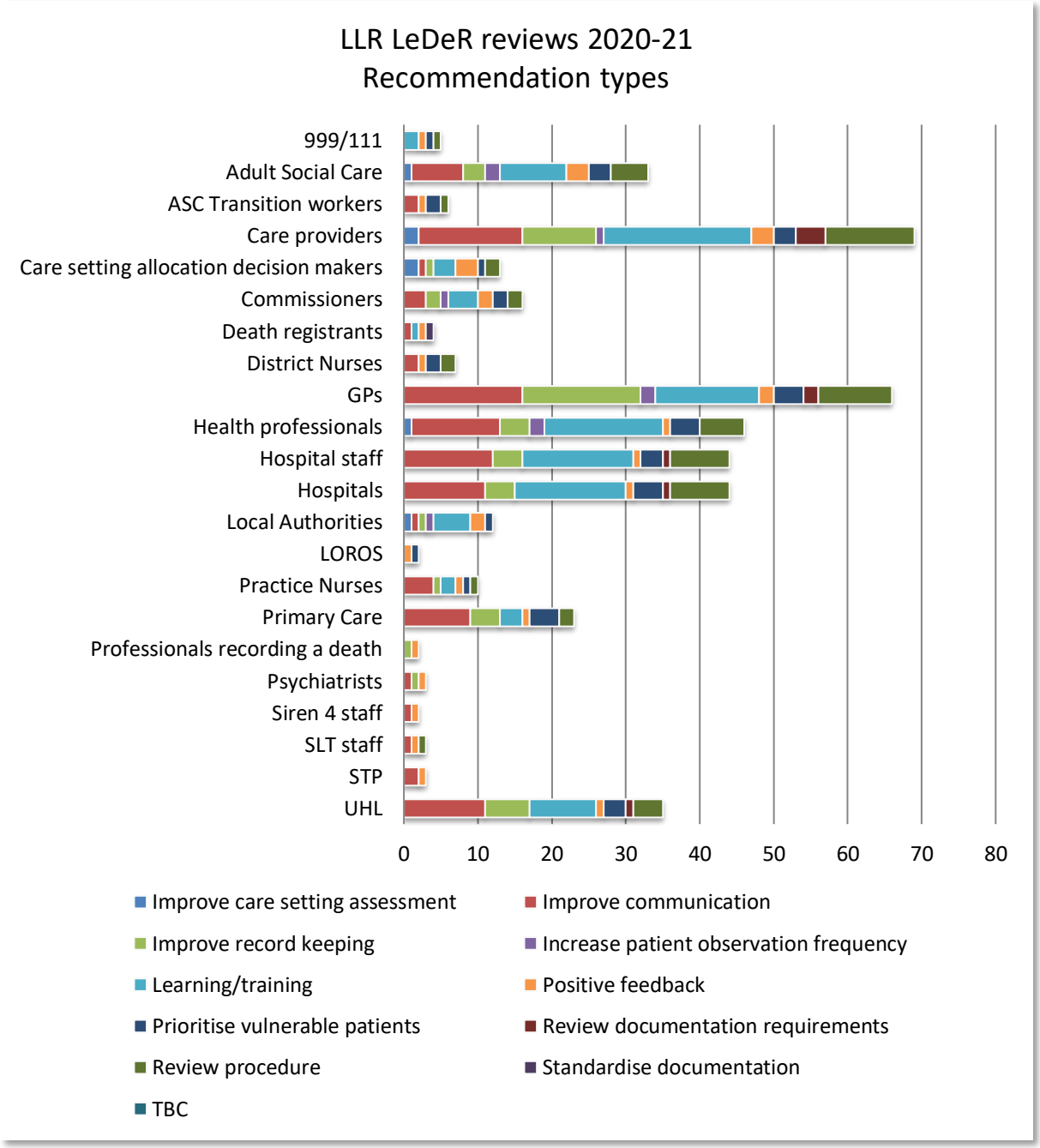
- GPs (198)
- Care providers (172)
- Health professionals (126)
- Hospitals/Hospital staff (99)

Figure 6



In cases from 2021-22, the picture was slightly different (see Figure 7), in that the greatest number of recommendations were relevant to Care Providers, followed by GPs.

Figure 7



Many actions suggested were very small, quick-fix issues that on initial discussion with providers had already been implemented as a result of their own reviews (e.g. having copies of care plans available to staff without having to ask). Informal discussions facilitated these smaller changes while others need reinforcement through improved, ongoing training, including avoidance of diagnostic overshadowing and keeping accurate records.

Learning from 2020-21 will be approached, managed and evaluated more formally and transparently by the new LeDeR Team roles, specifically regular reporting to Steering Group and sharing of improvements with all stakeholders.

Performance

LLR successfully completed a substantial backlog of reviews by December 2020

During 2020-21, in common with many systems, LLR successfully completed a substantial backlog of reviews from previous years, by the deadline of 11 December 2020. Some of the backlog was outsourced to NECS via NHSE/I, though some of those were returned to LRR for completion. In addition to this, 73 further deaths were referred in-year to LLR for review.

Performance from the start of the programme was reported weekly at TCP Improvement meetings and during routine monthly LAC calls with NHSE/I Midlands. At the end of March 2021, 76.35% of all reviews were complete, 6.4% were in progress and 4.43% were awaiting allocation, including newly-referred cases to be carried forward to the new system. By the end of April 2021, all open cases were completed (79.53%) with the remainder on hold either for statutory processes or pending launch of the new system.

To facilitate the smooth transition to a new LeDeR online system in June 2021, on 1 March 2021 the current LeDeR online system was paused so that no further referrals could be allocated to Reviewers. At the time, it was unclear how much data would be transferred from the old to the new system and advice was to complete as many open reviews as possible and submit by 30 April in order to minimise any loss of data that would require work to be repeated.

At 31 March 2021, 23 cases remained on hold pending the outcome of statutory investigations including Child Death Overview Panel, Safeguarding Adults Reviews and Coroner's Inquests. In line with policy, those cases will be reviewed within the new system, upon receipt of process outcomes. Eleven cases were under active review and completed by 30 April 2021 in order to minimise requirements for transfer of data to a new national LeDeR system.

Future Plans

A new LeDeR Policy *Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) policy 2021*[4] was published in March 2021, to be fully implemented by 31 March 2022. LLR LeDeR plans are included in the wider LLR Community

[4] https://www.england.nhs.uk/publication/learning-from-lives-and-deaths-people-with-a-learning-disability-and-autistic-people-leder-policy-2021/

Transformation 3-year plan and a further, fully detailed plan will be provided to support the programme over the next 3 years.

Ahead of the new policy, recognising the significance of LeDeR and the risks presented by the temporary nature of key roles within the programme, in January 2021 LLR agreed to strengthen its commitment and performance by introducing substantive posts to the LeDeR Team. 1.8WTE substantive Clinical Lead roles and a 1WTE Senior Assistant for administrative support were recruited to carry the programme forward with the launch of the new LeDeR system from June 2021.

The Clinical Lead roles have specific responsibility to embed learning into action

The Clinical Lead roles have specific responsibility to embed learning into action and support a cycle of learning, positive change, monitoring and evaluation throughout each year, reporting directly to the Steering Group and contributing to each annual report.

Reviewer roles will also be developed in line with the new policy, with formally contracted Reviewer roles of a minimum 0.5 WTE per role in place within the year. A significant change to LeDeR is the requirement for any deaths of people with Autism and no LD to be afforded a review. This will also inform the development of our Reviewer roles, taking into account the knowledge and experience of those reviewers and the needs of the families involved, in the same way for those with LD.

Strong focus will be on learning into action and on developing good practice for the addition of Autism cases to be included later in 2021.

Appendix I

LLR McGowan response

No.	Action for CCGs	LLR Response	Achieved
1.	All those who are new to the role of lead reviewer, or local area contact (LAC), must be allocated a 'buddy' who is experienced in the LeDeR process.	In LLR every reviewer is 'buddied' up with one of the 2 clinical leads and an admin buddy for every review. They have an initial peer support meeting to identify what records are needed and establish how best to access them. They are also provided with a 'reviewer pack' with useful contact details and local top tips. Reviewers can keep in touch with their buddies as much or as little as needed. New reviewers tend to need more support initially. The clinical lead will then check in and ask for a progress update regularly if there has been no contact and this is escalated as appropriate.	✓
2.	Dedicated time and administrative support must be given to reviewers and LACs to undertake complex LeDeR reviews.	During 2020-21, LLR had a senior administrative assistant undertaking LeDeR duties alongside other administrative roles. There was a dedicated temporary administrative support person in place. This has now ceased and has been revised to 1.0 WTE permanent and dedicated administrative support.	✓
3.	There must be a transparent process for LeDeR in each locality, with robust governance and appropriate resources to ensure that each review is properly monitored in terms of procedure and outcomes.	LLR has a leadership team for LeDeR comprising of a local area contact (LAC) from the CCG and a local authority, lead clinical reviewers and senior administrator. The team has developed a process to include allocation of reviews through to the quality assurance of reviews and final submission to the University of Bristol. Recommendations are logged and periodic thematic reviews undertaken to identify learning. A weekly quality assurance and allocation meeting is held where progress of reviews is discussed by the LeDeR leadership team and reports to the LeDeR Steering Group monthly.	✓
4.	The LAC and the lead reviewer should confirm at the onset of the LeDeR process how much support is needed and what it should look like. Guidance for reviewers should emphasise that when undertaking a LeDeR, there is an onus on a	Every review is triaged by the leadership team prior to allocation at a weekly meeting and a judgement is made as to who the best available Reviewer would be to undertake the review. We have robust processes in place for obtaining records and on the whole this works well.	✓

No.	Action for CCGs	LLR Response	Achieved
	team responsibility to complete the process to the required standards, rather than it falling to an individual (the lead reviewer, in this case).	We have a very clear timeline and when a review is allocated the 'admin buddy' sends the reviewer an email with some useful information and a date for submission. This allows enough time in the process for Quality Assurance to be undertaken by 2 people and then the review be returned for amendments before the final submission date. Both clinical leads undertake reviews and advise on all complex cases.	
5.	Each CCG must identify an executive lead to be responsible for the LeDeR programme and for ensuring that the board has full sight of progress.	The executive lead for LLR is the Head of Mental Health, Learning Disability, Autism and Dementia Services and chairs the LeDeR Steering Group reporting to the LD and Autism Board.	✓
6.	The CCG executive lead for LeDeR will ensure that LeDeR reviews are completed in a timely and correct manner and will intervene where problems are escalated, such as the inability to obtain critical information from the relevant agencies.	There is a two-way communication route with the executive lead to facilitate the sharing of concerns. This allows for any serious concerns to be escalated accordingly.	✓
7.	When a multi-agency review (MAR) is indicated, it is important that the correct process and outcomes are achieved. It is therefore expected that where the reviewer and the LAC have no previous experience of a MAR, they will seek support from a 'buddy' who does.	We have held 3 MAR's in LLR in the last 12 months. We have established clear roles and responsibilities; we have had the same experienced chair and other roles such as administration. COVID has been challenging when involving families but with the support of the clinical leads we have managed to ensure they have been fully involved throughout the entire meetings. All relevant paperwork is shared and the families have been supported to go through this with the reviewer and or the clinical lead.	✓
8.	There should be an assurance process with regard to providing regular, appropriately documented supervision for individual LeDeR reviewers.	LLR holds quarterly Peer Support Forums' with opportunity for reviewers to add any concerns or share achievements. Each forum meeting has an agenda and minutes are circulated to all reviewers.	✓
9.	Appropriate support should be available to reviewers, along with strong governance, to ensure that all LeDeR recommendations are robust and actioned in a timely manner, and that lessons learnt are shared nationally.	We have a peer support 'WhatsApp' group for reviewers to have general discussions and share top tips (this is well used) and we have quarterly peer support meetings with everyone. We are also establishing a discussion forum for the whole team on our secure TCP shared workspace on the FutureNHS platform.	✓

Appendix II

All entries in this table are exactly as entered in the LeDeR online system, spellings in context.

Age at death	Place of death	N_COD_1a	N_COD_1b	N_COD_P2	Gender	Ethnicity
59	Hospital	Aspiration pneumonia (COVID)		COVID-19 pneumonia Cornelia de Lange Syndrome	Male	British
36	Usual place of residence	COVID-19		Cerebral Palsy, pressure ulcers	Male	British
56	Usual place of residence	COVID-19	CCF and Hunter Hurler Syndrome		Male	British
34	Hospital	COVID-19 pneumonia		Right ventricular impairment, chronic renal disease	Male	British
35	Hospital	COVID-19 Pneumonia			Male	Any other White background
66	Hospital	Covid Pneumonitis		Asthma diaphragmatic hiatus hernia	Male	British
69	Hospital	COVID-19	Aspiration Pneumonia, Dementia	Trisomy 21 (Downs Syndrome)	Male	British
76	Not known	COVID-19 infection			Female	British
59	Hospital	COVID19 Pneumonia			Female	British
54	Hospital	COVID-19 pneumonia			Female	British
70	Hospital	COVID-19 Pneumonia			Female	Indian
63	Hospital	COVID-19 Pneumonia		Epilepsy, Autism	Male	British
70	Hospital	COVID-19 Pneumonia		Dementia, frailty	Male	Any other White background
61	Hospital	COVID-19 ,pneumonia.		Kyphoscolliosis	Female	Indian
74	Usual place of residence	Dementia (covid secondary)	COVID-19		Female	British
50	Usual place of residence	Probable COVID-19 Pneumonia			Male	Indian