NHS
Somerset
Clinical Commissioning Group

Report to the NHS Somerset Clinical Commissioning Group on 22 July 2021

Title: ANNUAL REPORT 2020/21 "Somerset Learning from life and death reviews (LeDeR)"	**Enclosure H**

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Summary and Purpose of Paper

This is the third Learning Disability Mortality Review (LeDeR) Annual Report that has been produced by NHS Somerset CCG. The report covers the period from 1 April 2020 to 31 March 2021 and provides an overview against the notifications received in Somerset during this period.

The purpose of the report is to provide Somerset CCG and key partners with an update on the key priorities for the LeDeR programme, an overview of the cases reviewed, and our local Somerset performance against NHS England measures.

Recommendations and next steps

To approve the report; the learning points for development and the local LeDeR Improvement Priorities set for 2021-2022

Impact Assessments – key issues identified	
Equality	The work of the review programme will positively impact on the quality of health and care services provided for people with a learning disability.
Quality	All activities in the action plan are aimed at improving quality and safety for people with a learning disability. It is likely there will be a wider positive impact for other vulnerable people as consequence of LD improvement activities.
Privacy	No impact on privacy
Engagement	The involvement of families and people who knew the person well is central to conduct of the mortality reviews. Improvement work includes both people with learning disabilities and their family/carers. The LeDeR Steering Group membership included an Expect by Experience.
Financial / Resource	The LeDeR team and programme is currently funded as part of Somerset CCG business as usual activity. This also includes funding streams to support improvement activities, which needs to be a balance between adaptation of business as usual services and activity which supports service change, development and improvement.

<table>
<tr><td></td><td colspan="4">The need to focus on putting the learning from LeDeR reviews into action may create future funding issues for the Quality and Safety team, but will need to be considered as part of the wider ICS framework.</td></tr>
<tr><td>Governance or Legal</td><td colspan="4">It is a statutory duty of the CCG to ensure it promotes equality of service provision for those people with protected characteristics which includes people with a learning disability.</td></tr>
<tr><td>Risk Description</td><td colspan="4">There is one risk within the CCG risk register relating to the LeDeR Programme. This is currently rated as a moderate risk (amber). This amber scoring relates to making LeDeR 'business as usual' as part of the wider ICS framework, coupled to the current delays moving to a new national LeDeR policy and platform.</td></tr>
<tr><td rowspan="2">Risk Rating</td><td>Consequence</td><td>Likelihood</td><td>RAG Rating</td><td>GBAF Ref</td></tr>
<tr><td>3</td><td>3</td><td>9</td><td>362</td></tr>
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Learning Disabilities Mortality Review (LeDeR) Programme

NHS Somerset Clinical Commissioning Group

SOMERSET LEARNING FROM LIFE AND DEATH REVIEWS (LeDeR)

ANNUAL REPORT 2020/21

NHS England

The Learning Disabilities Mortality Review (LeDeR) Programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP), on behalf of NHS England.

Working Together to Improve Health and Wellbeing

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Acknowledgements

We would like to thank family members, carers, service providers, reviewers, steering group members who have contributed to the review of deaths of people with a Learning Disability in Somerset and worked to put service improvements in place.

Further resources:

For more information on LeDeR or to report a death to the programme please visit this website: *https://www.leder.nhs.uk/*

To view the national LeDeR policy in full please follow this link: *https://www.england.nhs.uk/wpcontent/uploads/2021/03/B0428-LeDeR-policy-2021.pdf*

EXECUTIVE SUMMARY

This is the third Learning Disability Mortality Review (LeDeR) annual report that has been produced by NHS Somerset CCG. The report covers the period from 1st April 2020 to 31st March 2021 and provides an overview against the 54 notifications received in Somerset during this period, noting that five notifications where for individuals who died in 2019/2020.

The purpose of the report is to provide Somerset CCG and key partners with an update on the key priorities for the LeDeR programme, an overview of the cases reviewed, and our local Somerset performance against NHS England measures.

The Somerset LeDeR Programme has responded to the challenges of the COVID-19 pandemic experienced throughout the 2020/21 period in a number of ways; by reviewing its resources and processes, implementing a range of measures to improve performance and quality, and made changes across our community that will benefit Somerset residents with a Learning Disability. Much of this has been achievable through effective partnership working both locally and nationally.

Nationally, there have been a number of changes for the LeDeR programme with changes to the provision of the national platform on which our reviews are undertaken, as well as the launch of a new national policy for the LeDeR programme **Learning from Lives and Deaths - People with a Learning Disability and Autistic People LeDeR Policy 2021**.

In Somerset **86** reviews were completed between April 2020 and April 2021 (this included outstanding reviews carried forward from previous years for completion).

54 deaths were notified to LeDeR for Somerset for the period 1/4/2020 – 31/3/2021 Of these **49** reviews have been completed; **15** were female and **39** were male. Of those not yet completed, **1** notification was out of scope (the person did not have a learning disability) so no review was undertaken. **3** are for children/young people – these cannot be completed until the Child Death Overview Process (CDOP) which is a statutory review concludes.**1** review was notified too late to be completed before the cut-off date for 2020 to enable the new LeDeR system to be launched from 1st June 2021.

Somerset has a very low diversity with a Minority Ethnic (ME) population of 3.1% (ONS 2016). There has been **1** notifiable review for individuals with a ME background in Somerset for 2020/21.

INTRODUCTION

The overall aim of the National Learning from Life and Death Review (LeDeR) programme is to drive improvement in the quality of health and social care service delivery and to help reduce premature mortality and health inequalities.

This framework is relevant to all commissioners and operational frontline health and social care staff within Somerset.

From June 2021 and with the introduction of the new NHS England policy, reviews may also include those adults with Autism who do not have the diagnosis of a Learning Disability. The programme aims to help:

- Identify what works well to support people with Learning Disabilities/Autism to live long and healthy lives;
- Identify factors which may have contributed to deaths of people with Learning Disabilities/Autism so that changes can be made to reduce the impact of these factors;
- Develop action plans to make any necessary changes to health and social care services for people with Learning Disabilities/Autism;

The LeDeR programme collates and shares the anonymised information about the deaths of people with Learning Disabilities/Autism so that common themes, learning points and recommendations can be identified and taken forward into policy and practice improvements.

In March 2021, the programme launched a new policy: Learning from Lives and Deaths - People with a Learning Disability and Autistic People, which states that LeDeR will also review the lived lives and deaths of those with Autism. The date from which we will commence reviews for individuals with autism is yet to be determined by NHS England.

Going forward all notifications of a person's death will receive an initial review including talking to their family or people who knew them well, talking to their GP or looking at the GP records, and talking to at least one other person involved in the person's care. If the reviewer feels a more detailed review is needed, a focused review will follow. Families can say if they think a focused review is needed.

All people from Minority Ethnic (ME) communities will have a focused review because the evidence so far shows that the health inequalities experienced by people from these communities are very significant, and there is also significant under-reporting of deaths from these communities.

All reviews of people who are autistic without a learning disability will be focused reviews initially; as this is a new area of learning it is important that we are able to learn as much as possible from every one of these reviews to support a base line.

The LeDeR programme is **not** an investigation. If, during or after a review of a death, the Local Area Contact (LAC) or deputy has concerns which have not or cannot be addressed within the scope of the LeDeR review process, the LAC or deputy will recommend to the appropriate organisations/bodies the need for a fuller investigation (e.g. Adult Safeguarding Review).

The LeDeR programme works closely with other existing mortality review processes. Notifications of deaths submitted to the LeDeR Team are received by Somerset through the LeDeR platform system. These are then allocated to the LeDeR reviewer for an initial review. If the initial review indicates that further learning may be gained, or if there are concerns raised, a focused review will take place.

OUR QUALITY ASSURANCE AND GOVERNANCE PROCESS

Our LeDeR Steering Group was originally established in August 2017 to have strategic oversight of the programme locally. The terms of reference for the group are being strengthened as an interim transition measure to move the Somerset programme arrangements closer to the newly launched national policy in 2021. Building on previous arrangements the LeDeR Steering Group continues to work in partnership to assist the Somerset Clinical Commissioning Group in its implementation of the LeDeR programme so that it can efficiently and effectively deliver on the following key outcomes:

- Undertake the necessary quality reviews in Somerset;
- Agree themes of the learning and recommendations drawn from the reviews of lived lives and deaths of individuals with a Learning Disability;
- Translate learning into action and system change that will improve the lived lives, experiences and outcomes for those living in Somerset;

To satisfy this role the Steering Group maintains an oversight of the programme activity, performance and work with the following assurance:

- That the programme is operationalised subject to compliance with the Oliver McGowan Report and information governance compliance;

Lastly the Steering Group acts to review and advise on:

- Thematic information submitted from local reviews, including areas of good practice in preventing premature mortality, and areas where improvements in practice could be made;
- Provide expert professional and local knowledge in the interpretation of learning from reviews;

Steering Group and Quality Assurance Panel Membership

Representatives from:

Somerset CCG

Somerset County Council

Somerset Primary Care

Taunton & Somerset NHS FT

Somerset Partnership NHS FT

Yeovil District Hospital NHS FT

NHS England

Safeguarding Board (Adults & Children)

Expert by Experience (Lay Family Member)

Healthwatch

- Nominate and support access to senior colleagues to chair multi-agency reviews as required;
- Agree and mobilise system contacts and resources, which may include working groups, quality improvement groups and others, to support and enable meaningful system change against local action plans;
- Support recommendations to the CCG senior leadership team where these are essential to support the delivery of the programme;
- Identify when the sharing of publicised anonymised case information is appropriate.

The administration of the Somerset LeDeR Quality Assurance Panels and Somerset LeDeR Steering Group and the role of the Local Area Contact are hosted by Somerset CCG. The Quality Assurance Panel is chaired by the Local Area Contact or deputy whilst the CCG Clinical Lead for Learning Disabilities chairs the Steering Group. Members for both include representatives from across Somerset systems to maintain a multi-agency approach in supporting the quality of reviews and the implementation of actions from review recommendations.

The Somerset governance structure has been updated as part of the development of our local operational policy and has delivered regular reports on programme activity and performance to the CCG's:

- Patient Safety and Quality Committee;
- The Somerset Learning Disability and Autism Programme Partnership Board;
- Somerset Quality Surveillance Group;
- NHS England Regional Lead;
- Somerset CCG Governing Body (Annual Report plus any exceptions);
- Somerset Safeguarding Boards (Annual Report).

Where mandatory review processes or investigations (Safeguarding, Child Death Overview Process, Coroner / Police) are required, these take precedence. The CCG LeDeR team and the allocated reviewer work to ensure a co-ordinated approach is taken to these reviews in order to minimise duplication and maximise expertise and learning.

Nationally all LeDeR programmes will move to a different arrangement with the implementation of the new LeDeR national platform following the shutdown of the existing platform at the end of April 2021.

OUR STRATEGIC VISION STATEMENT

Our strategic vision for Somerset (in line with the NHS Long Term Plan) is to support people with learning disabilities and/or autism to look after their health and lead healthier lives. We see the LeDeR programme as a key enabler to shaping our emergent strategy and to inform local commissioning, planning, learning and continuous improvement; it is not a standalone process.

Our strategic aims ensure people receive timely and appropriate health checks and have better access to health services whilst improving the level of awareness and understanding across the NHS of how we can best support each individual.

We want people with learning disabilities and/or autism to be able to say that:

- I will have a fulfilling life as a Somerset citizen, including having equal opportunities and choice of where to work, study, enjoy leisure and social activities as well as have meaningful relationships and friendships;
- I will be able to have and/or remain in my own home;
- I will have access to good quality mainstream services when needed;
- I will have timely access to good quality and safe specialist services as close to home as possible;
- I will have access to specialist bed provision when needed and this would be for the shortest possible time required.

Our ambition in delivering on these key priorities will mean that more people with learning disabilities and/or autism who live in Somerset are able to live their lives in the way that they choose.

Sharing and Communicating Local Learning

In 2018 Somerset launched its first LeDeR newsletter. Our Somerset LeDeR newsletter aims to raise awareness amongst the public and other organisations in key areas from the learning coming out of the reviews. It also showcases examples of best practice and good work being done in Somerset, as well as sharing useful resources covering areas such as “reasonable adjustments” and “healthy lifestyle choices”. In 2020/21 we have so far focused our newsletters on two key areas: ‘COVID-19’ and ‘Dysphagia’ (which is a condition with difficulty in swallowing food or liquid).

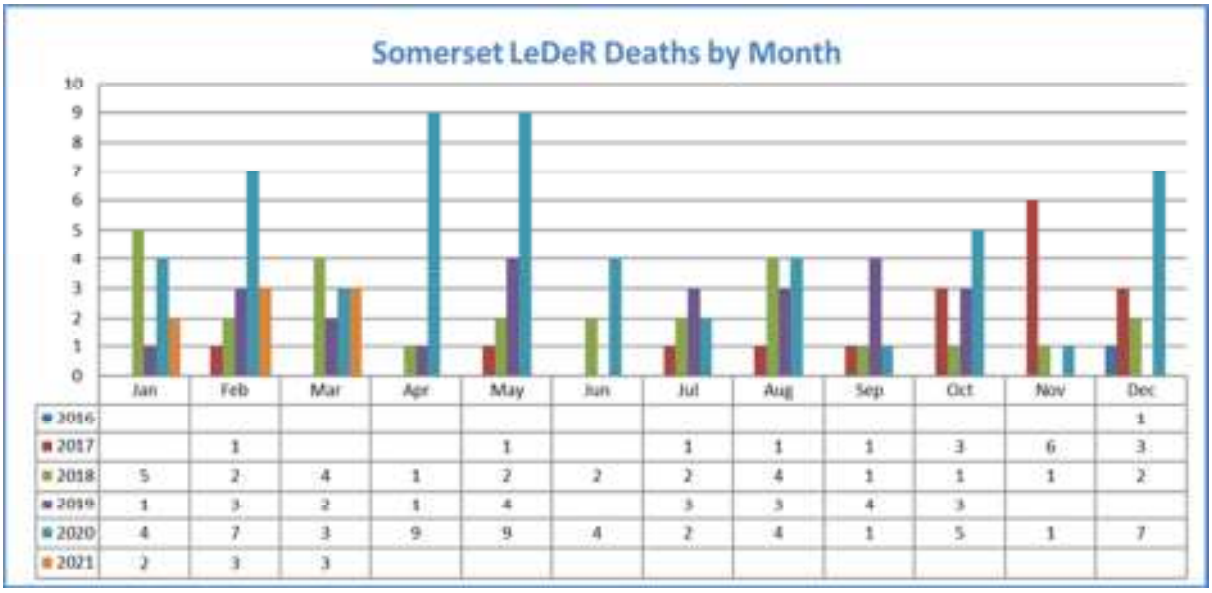
Feedback has been positive and the newsletters have been well received as one of the number of methods used for sharing key learning locally from LeDeR reviews in Somerset.

Context of this year's Annual Report

With the challenges faced across the health and social care system due to the COVID-19 pandemic, Somerset, despite many of the LeDeR team being redeployed and taking on additional roles, have still achieved solid progress against a number of key LeDeR priorities. The Somerset system remains committed and passionate in driving improvements forward for our people with a learning disability; this is evident in our continued approach to system learning and continuous improvement.

This report defines key areas of focus for the forthcoming year 2021/22. We also launch from June a number of significant changes to the LeDeR process. In anticipation of these changes, Somerset has made good progress in reviewing its systems, processes and resources necessary to mobilise effectively this new approach, which is described in greater detail later in the report.

We start this year's report by reflecting sensitively on the number of deaths recorded from April 2020 to the end of March 2021. We also compare this position to previous years of the LeDeR programme. Our data sadly indicates a significant rise in deaths, particularly in April and May 2020 and the impact of COVID-19.

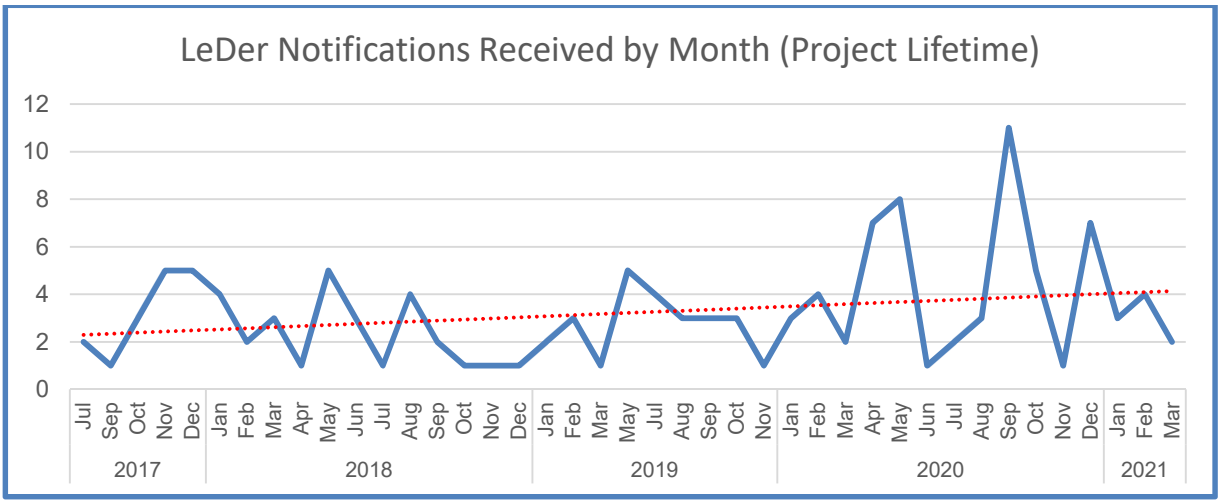


	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
2016												1
2017		1			1		1	1	1	3	6	3
2018	5	2	4	1	2	2	2	4	1	1	1	2
2019	1	3	2	1	4		3	3	4	3		
2020	4	7	3	9	9	4	2	4	1	5	1	7
2021	2	3	3									

(Dates of death between April 2020 and the end of March 2021 are shown in the table below alongside all deaths since the LeDeR programme began in 2017)

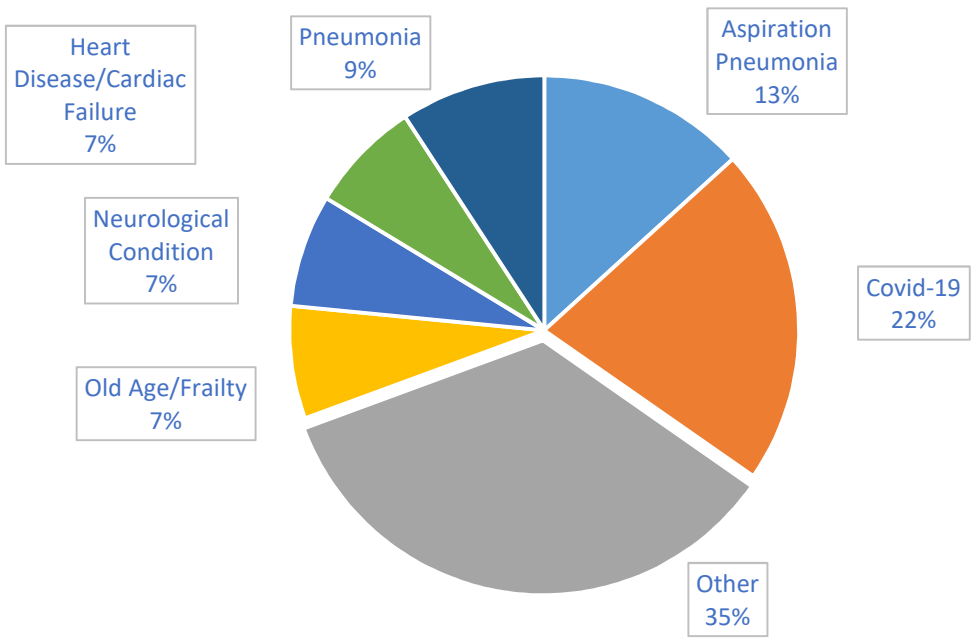
NOTIFICATIONS - Deaths notified to the LeDeR programme

In 2020/21 a total of 54 notifications were received by LeDeR relating to people with a Learning Disability within Somerset. It's important to note this represents a significant increase of 98.86% when comparing to the number of 'Notifications' received in 2019/20 where 28 cases were reported. The number of LeDeR deaths reported corresponded to the COVID-19 pandemic waves and peaked in April / May 2020, and again in December 2020.



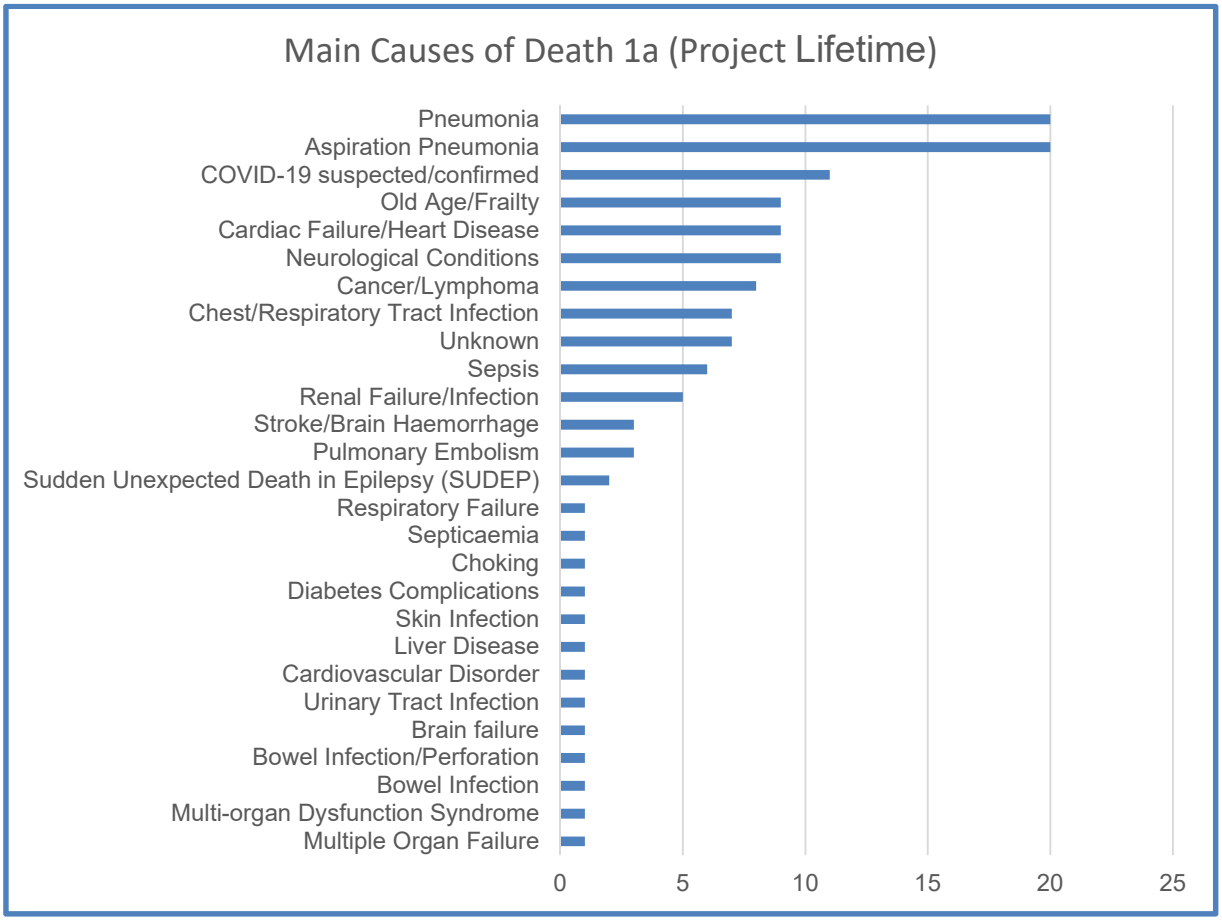
(The above graph provides a summary of the number of Notifications received on a monthly basis from July 2017 to March 2021. The graph also includes a 'Linear Red Trendline', which demonstrates a steady increase in the number of Notifications received within this period.)

The main causes of death in Somerset for individuals with a learning disability where a 'notification' was received in 2020/21 are illustrated in the chart below:

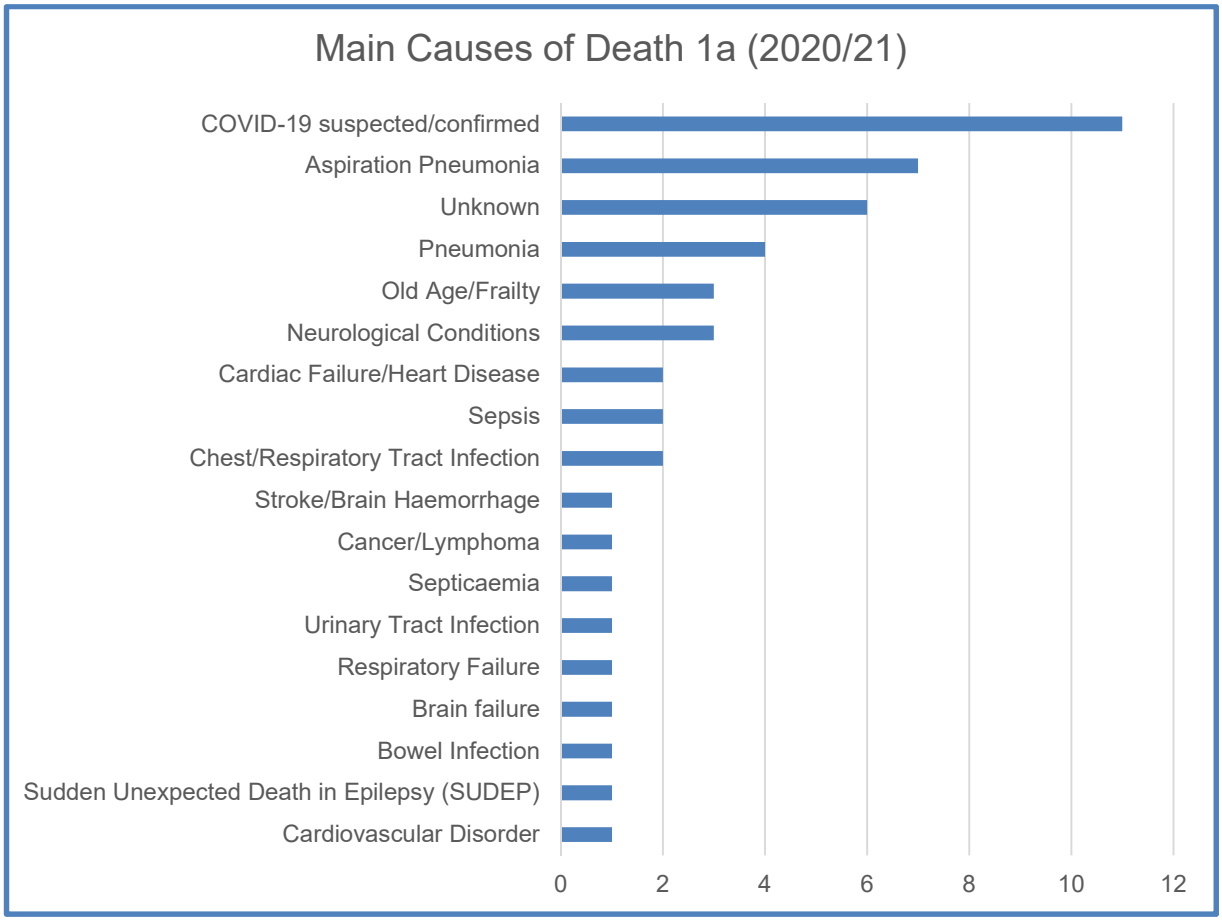


Of the 132 individuals that have died since the commencement of the project in 2017 we have observed the following 5 main causes of death (COD). The graph below lists all COD. The unknown COD in this list were not known at the time of data capture and cannot be understood retrospectively:

- Pneumonia (15.15%)
- Aspiration pneumonia (15.15%)
- COVID-19 suspected/confirmed (8.33%)
- Old age/frailty (6.82%)
- Cardiac failure / heart disease (6.82%)

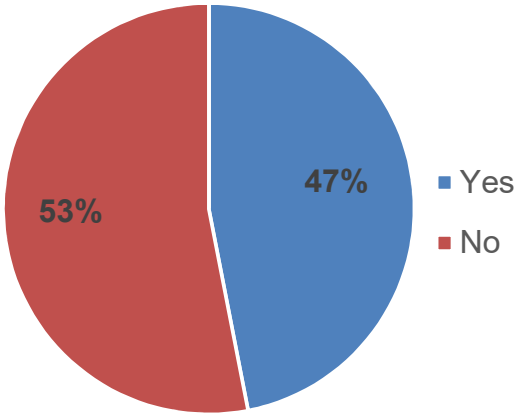


We have repeated the analysis for 2020/21 to determine the main causes of death in that period only.



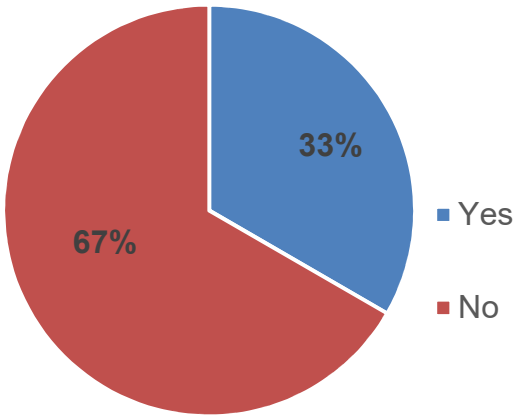
Co-Morbidity (2020-2021)

The following chart provides a summary of the 49 deaths recorded in 2020/21, where upon 23 of those individuals also had additional health issues that contributed to, but did not directly cause death (1b & 1c). Chart 1b



Co-Morbidity (2017-2021)

The following chart provides a summary of the 132 deaths recorded since the project commenced in 2017, where upon 44 of those individuals also had additional health issues that contributed to, but did not directly cause death (1b & 1c). Chart 1c



Detailed breakdown of Cause of Death 2017-2021

CONDITION	CASES	CONDITION	CASES
COVID-19	11	Bowel infection	1
Aspiration Pneumonia	7	Bowel obstruction	1
Pneumonia	5	Brain failure	1
Heart Disease / Cardiac failure	4	Cardiovascular disorder	1
Neurological Conditions	4	Respiratory failure	1
Old Age / Frailty	4	Septicaemia	1
Cancer / Lymphoma	2	Stroke	1
Chest / Respiratory Tract infection	2	Sudden Unexpected Death	1
Dementia	2	Suspected Heart Attack	1
Sepsis	2	Urinary Tract infection	1

COVID-19 and LeDeR 2020-2021

The pandemic created challenges for Somerset in its delivery of the LeDeR programme. The impact of COVID-19 is wide, diverse and difficult to appreciate fully still at this stage. In support of future understanding the LeDeR review content changed to reflect enquiry into areas that might be impacted by COVID-19 to enable learning to emerge.

As a consequence of COVID-19 a mini review project was initiated to appreciate secondary indirect impacts on 19 deaths of people in Somerset with a Learning Disability between March and June 2020.

Findings were difficult to quantify but soft themes did emerge around the need for effective communication, delays in accessing services as well as the significant upset and distress caused by local changes and the COVID-19 pandemic effect.

The CCG participated in the South West NHSE/I Rapid Mortality Review which aimed to identify rapidly learning or practice to improve local support for people with Learning Disability and enable the escalation of concerns to prevent further deaths in the context of COVID 19.

We know that sadly the impact of COVID 19 on Minority Ethnic (ME) is disproportionate to the rest of the population. Somerset has a very low diversity with a ME population of 3.1% (ONS 2016). There has been one notifiable review for individuals with a ME background in Somerset for 2020/21.

We also know that the pressure of working in the pandemic impacted colleagues in the health and care system who were not able on occasion to submit notifications in a timely way. These were subsequently picked up and reviews undertaken retrospectively. Key colleagues in critical roles including senior reviewer, local area contact and deputy local area contact were redeployed to support critical work in our health and social care system. Volunteer and bank reviewers could no longer contribute the time that they had previously to support LeDeR as they too had to prioritise work as part of the pandemic efforts.

The CCG, Somerset care system and its providers were focused rightly on prioritising safe care and as such this significantly interrupted our ability to undertake reviews for at least six months of the year and as a consequence reviews began to build up as a backlog.

In November 2020 and as staff returned from redeployment, internal support was directed towards LeDeR to help re-energise the programme and bring performance back in line. The national team of reviewers were instrumental in helping this effort undertaking many of our reviews in the later part of the year.

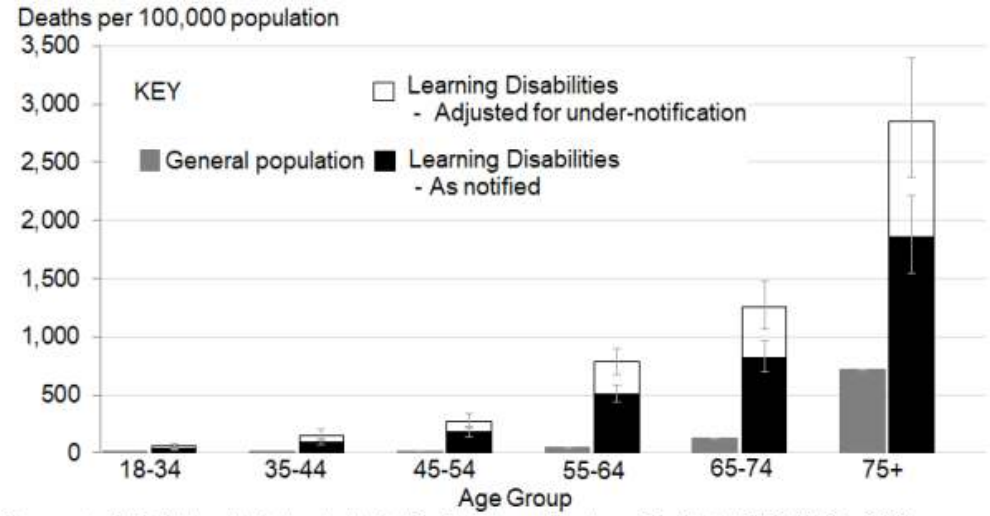
Historically LeDeR reviewers in Somerset have been mostly voluntary and drawn from professionals in our health and social care system. This has created challenges for staff to commit the hours alongside their existing roles, and this model was not suitable for the growing numbers of reviews awaiting allocation.

In recognition of this and to align ourselves more closely to the new national policy requirements, Somerset CCG has supported funding to secure staffing resource across all areas of the LeDeR programme, including administration, review staff and a local area contact for 2021/22. In addition we retain our most experienced reviewer as a substantive colleague and new team leader to keep up with the increasing number of notifications received and retain the talent and expertise to support new reviewers.

Somerset continues to reach out for ME representation in our programme but this is challenged by a very low diversity in Somerset. In the interim our Equalities Officer supports our governance requirements.

LeDeR and Public Health England Reports

The PHE report shows a national death rate from COVID-19 at least 4.1 times higher than the general population (up to 692 per 100,000 as compared to 109 per 100,000); for the 18-34 age group is was 30 times higher. The graph below shows age-specific rates, per 100,000 adults, to 5 June 2020 for reports of COVID-19 deaths to LeDeR and for COVID-19 deaths in the general population. Grey and black bars show rates using data as notified. Outlined white bars show estimated COVID-19 death rates for people with Learning Disabilities allowing under-notification.



Sources: LeDeR (1) (unadjusted and adjusted for likely level of under-notification), LDHC 2018 to 2019 (10), QOF 2018 to 2019 (9), ONS provisional death records 2020, ONS Mid-year estimates of population 2019.

Source: Public Health England report
https://www.gov.uk/government/publications/COVID-19-deaths-of-people-with-learning-disabilities

Our local analysis of COVID-19 data shows a striking difference in age for COVID-19 deaths, with about half occurring in those aged 50 – 69 (general population half over 85).

Somerset Foundation Trust who provide services for people with a learning disability continues to work closely with the CCG to identify those individuals who are vulnerable to COVID-19, additional data has been gathered, and this confirms an increase in the main cause of death recorded as a respiratory issue such as pneumonia in the table below:

Main Cause of Death (LeDeR)	2020 (Jan-Oct)	2019
Aspiration Pneumonia	18%	12%
Pneumonia	12%	20%
Chest / Respiratory Infection	4%	0%
COVID-19 Suspected/Confirmed	8%	0%
Total %	42%	32%

Respiratory-related deaths	2020 (Jan-Oct)	2019
Main cause (1a)	22	10
Contributing (1b,c)	4	1

Referrals to the Learning Disability Specialist Health Team continue to be of great benefit by improving outcomes for patients who need additional care and support.

There is also a Learning Disability Register Inclusion tool to support GPs in identifying a person in this vulnerable group.

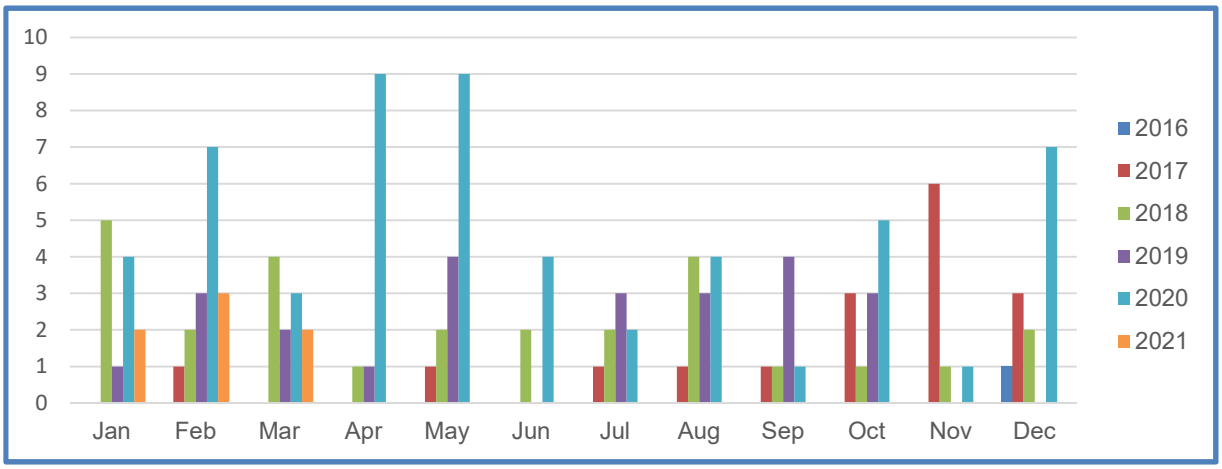
Our analysis also highlights the main long-term health conditions for those people who died from COVID-19.We have taken this important learning to ensure preventative measures are implemented where necessary.

- Mobility impairment 74%
- Respiratory conditions 72%
- Epilepsy 48%
- Cardiovascular disease 34%
- Hypertension 33%
- Obesity 33%
- Down's syndrome 20% (now on extremely clinically vulnerable list and shielding measures were taken)

BREAKDOWN OF SOMERSET LeDeR DEATHS

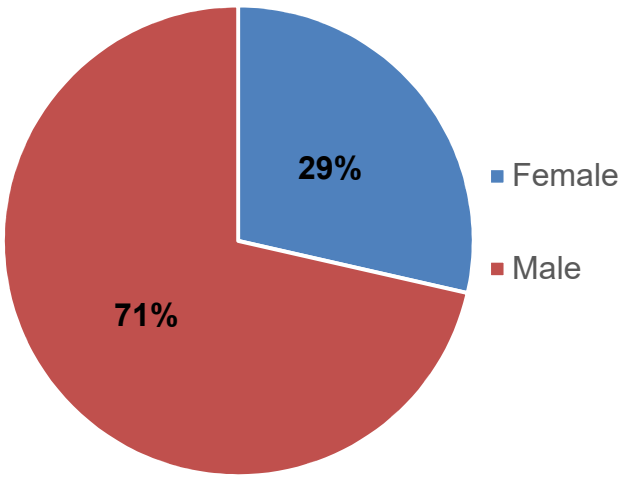
The following graphs provide a breakdown by gender, location and age of recorded LeDeR deaths across Somerset. This, along with a wider analysis of data collected across all national and local LeDeR key performance indicators (KPIs) has enabled the development of future actions and priorities to improve the care delivered across Somerset to people with a learning disability.

Since the commencement of the project in 2017, 132 deaths have been recorded relating to an individual with a learning disability in Somerset.



Somerset LeDeR Deaths by Gender (2020/21)

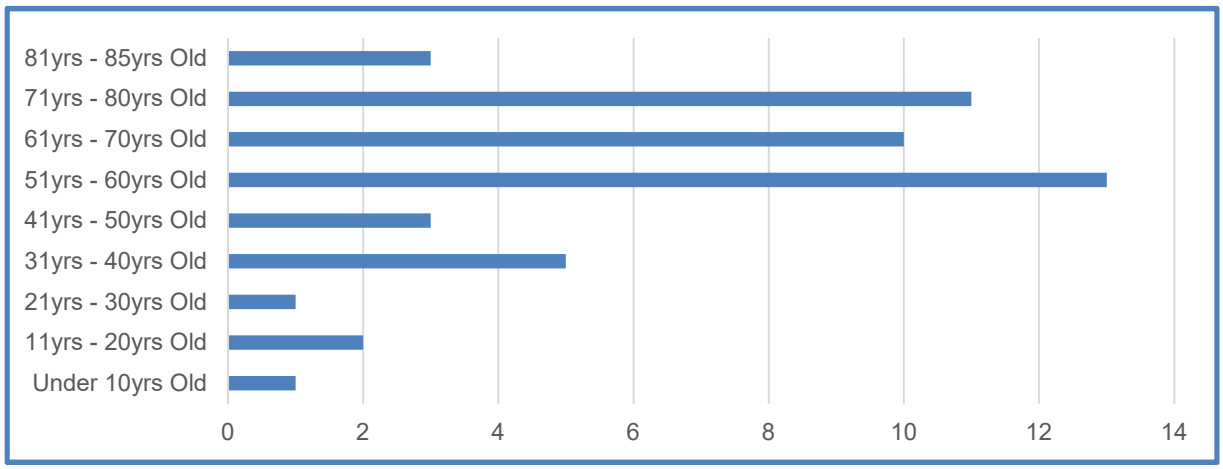
The chart below provides a breakdown of the 49 LD recorded deaths in 2020/21 by 'Gender'.



Of the 132 LD recorded deaths since the commencement of the project in 2017 by 'Gender' we can see that 37% are male and 63% female a significant difference that we will explore further to understand what is driving this difference.

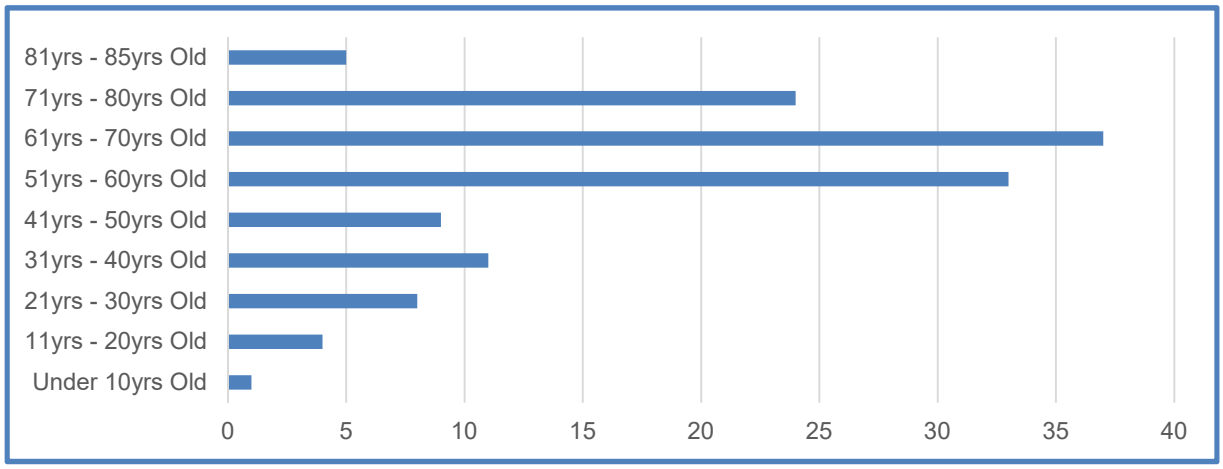
Somerset LeDeR Deaths by Age (2020-2021)

The below graph provides a summary of the age of the 49 individuals when they died in 2020/21. It is worth noting that the median age is 59 years old.



Somerset LeDeR Deaths by Age (Project Lifetime)

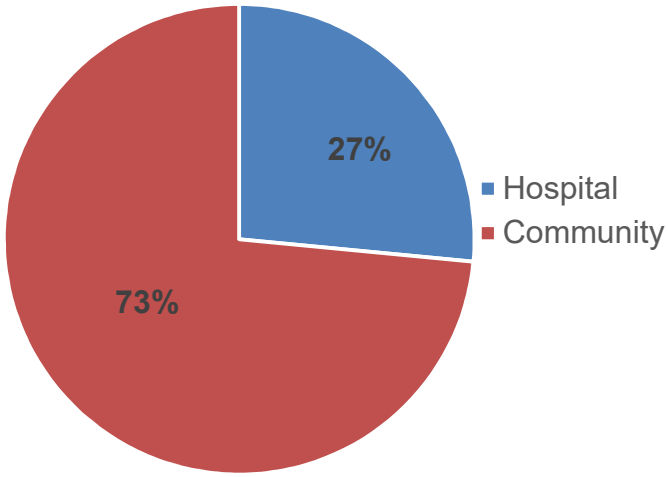
The below graph provides a summary of the age of the 132 individuals when they passed away in since the commencement of the project. It is worth noting that the median age is 56 years old.



Somerset LeDeR Deaths by Location (2020/21)

Of the 49 individuals that died in 2020/21, 36 did so whilst in a community setting and 13 in an acute hospital setting.

Of the 132 individuals that died since the project commenced, 72 did so whilst in a community setting and 60 in an acute hospital setting (see over).


27%
73%
Hospital
Community

ACTION LEARNING INTO PRACTICE

Progress during 2020-2021

The Somerset LeDeR team have, despite the many challenges of the past year continued to drive change through evidence-based learning collated from previous LeDeR review analysis. We have successfully implemented and achieved the following outcomes to date:

- Annual Health Check (AHC) themed project groups have embraced integrated system working and learning into action from LeDeR reviews. This includes supporting practices in delivering AHCs, support/ training for care staff, advance care planning, gathering views of people with Learning Disabilities to inform improvements required.

- Development of a suite of resources for GP practices to use in delivery of Annual Health Checks supplemented by calls to individual practices.

- Report circulated to GP practices drawing on the national PHE report and the LeDeR report of learning from the first 50 deaths due to COVID-19 and emphasising the importance of Annual Health Checks.

- Informal mini-review project into deaths of a number of people in Somerset during the pandemic reported through LeDeR, looking particularly at any soft signs and the impact of COVID-19 which may have impacted on quality of health care (e.g. reluctance to engage with services and possible delays in treatment).

- Close working with the Somerset Primary Care Board to draw on local best practice and developing “champion” practices in Primary Care Networks, providing local support, troubleshooting and solutions.

- List of practice and Primary Care Network Learning Disability leads developed to enable information and resources about Annual Health Checks and other relevant topics to reach the right people within practices.

- Communication with a wide range of agencies – including in easy read formats - regarding COVID-19 and vaccinations for people with a Learning Disability.

- Local and South West-wide groups/webinars attended by Quality Team where information is shared on a range of factors relating to Learning Disability, including Annual Health Checks, reasonable adjustments and good practice examples.

- LeDeR reviews during COVID-19 required to include information on a range of issues, including the person’s ability to follow guidance on staying safe and distancing measures care homes had put in place, access to Personal Protective Equipment (PPE), risk factors and reasonable adjustments made.

- Somerset has been successful in recruiting three part-time substantive LeDeR reviewers on a 12 months fixed contract and a part substantive administrator. At the time of writing this report we are also interviewing for a part time substantive LAC position.

Identified Best Practice from LeDeR Reviews During 2020/21

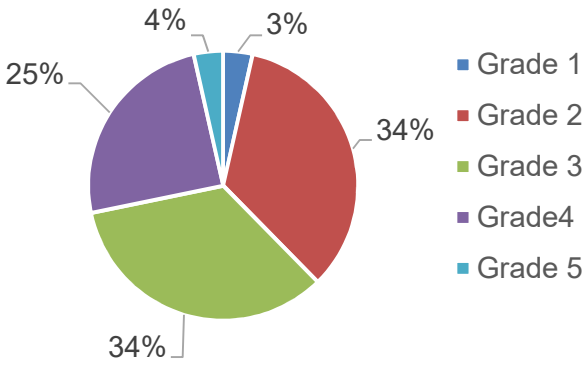
The following section provides a summary of key learning points that have emerged from LeDeR reviews undertaken in Somerset over the 2020/21 period. Each review is given a rating defining the "Quality of Care" received by the person with learning disability.

The following table provides a summary of the 'Quality of Care' Grades:

Overall Assessment of Quality of Care	
Grade 1	This was excellent care (it exceeded expected good practice).
Grade 2	This was good care (it met expected good practice).
Grade 3	This was good care, which fell short of current best practice in only one minor area.
Grade 4	Care fell short of expected good practice but did not contribute to cause of death.
Grade 5	Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.
Grade 6	Care fell far short of expected good practice and this contributed to the cause of death.

The following chart illustrates a summary of the 'Quality of Care' received by each individual reviewed in 2020/21.

The quality of care grading's received by an individual reviewed throughout the lifetime of the LeDeR project to date are illustrated here and it is positive to note over half of the reviews demonstrate a good level of care received.



Many of the 49 completed LeDeR reviews have shown examples of best practice including:

- Easy Read usage as a reasonable adjustment supporting the person;
- Person-centred approach by services;
    - Example: ‘Carers informed hospital staff about X's favourite 'superhero' and they committed to put pictures of the hero in X’s room’;
- LD Liaison Nurses within acute trusts improved understanding and communication;
- Primary Care support during COVID-19;
    - Example: ‘Contact with family was maintained through the use of Skype in lieu of face to face visits due to limitations of contact options’;
- Examples where family or carers were able to support the person in hospital despite COVID-19 restrictions;
- Support to die at home / with family in preferred environment at end of life, supported by people they know well;
    - Example: Nursing home accepted X home to die in familiar surroundings, which also meant his sister could visit, even though he was COVID-19 positive;
- Support from Community Learning Disability professionals;
- Care settings going above and beyond;
    - Example: supported living setting created a personal lounge in a spare room with TV, music and a sofa as X increasingly struggled in a larger group due to dementia;

Learning Points for Development 2021-2022

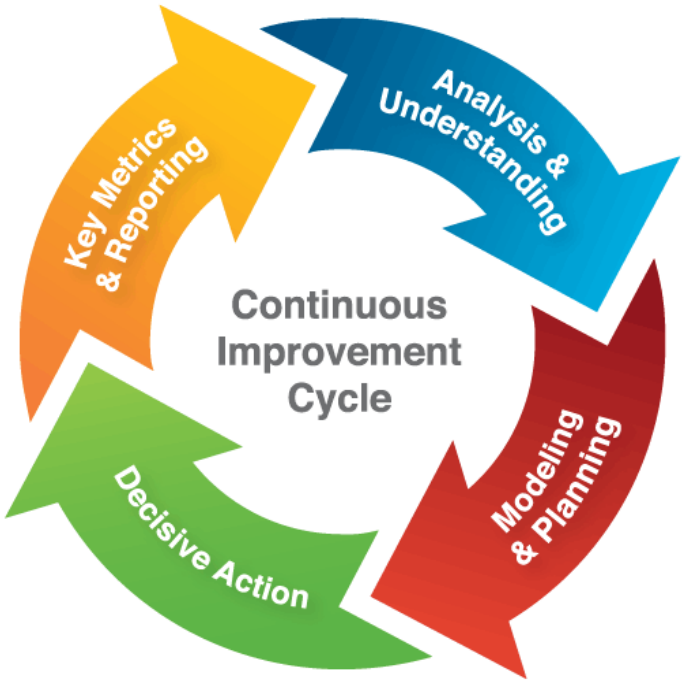
From our individual LeDeR reviews it is evident that our health and social care system has a number of key learning opportunities that require specific focus, some of which include areas being worked upon as part of a wider quality improvement initiative for the whole Somerset population.

Our emphasis regarding the importance of Annual Health Checks has never been more relevant looking at our recent learning from COVID-19, along with key recommendations based on local learning from LeDeR reviews highlighting the following which also mirror national learning:

- Annual health check needs to note all health issues and their management and be linked to a health action plan.

- Ensure that GP practices use correct coding for patients with Learning Disabilities to ensure they are on the practice LD register and can be easily identified.
- GP practices across England to use their clinical judgement to determine who, on their GP register, should be considered at a higher risk of serious illness from COVID-19 and to take appropriate action to advise those individuals and their carers (as appropriate) of the need to take additional precautions.
- Risk of diagnostic overshadowing is highlighted, as the presentation of people with a learning disability with COVID-19, or another condition which causes health to deteriorate rapidly may be different to the general population. Considering this will help ensure opportunities are not missed in provision of appropriate and timely health care.
- Use more local population demographic data to compare trends within the population of people with learning disabilities.
- Continue working with health and social care stakeholders to identify where notifications are not being made, particularly for Minority Ethnic (ME) groups.
- Look closer at any implications of gender inequality for women within reviews and the impact of support to make healthier lifestyle choices and access care and treatment this may have, in particular for conditions such as pulmonary embolism or deep vein thrombosis.
- Care and support of people with dementia in relation to deterioration due to co-morbidities.
- Actively promote the importance of reasonable adjustments across the whole workforce at all levels, particularly with use of best practice examples. Continue to develop a greater understanding of how these should be provided across the system, in both primary care and acute settings.
- Collaboration between the LeDeR programme and STOMP working group (a programme of work to reduce overuse of medication in people with a learning disability) to ensure that the learning from reviews where individuals were on one or more anti-psychotics at the time of their death informs local process.
- Treatment Escalation Plans (TEPs)/ End of Life plans – these are not always completed in primary care to best meet someone's needs and are often left for hospital admission to trigger, which can lead to unwarranted hospital admissions. Not always completed in line with Mental Capacity Act requirements.
- Mental Capacity Act - increased knowledge around consent and decision-making processes would be beneficial for all health staff.
- Learning disability and autism training for acute hospital staff.
- Annual health checks – areas of focus include
    - age and gender-specific screening
    - greater recognition of obesity as a risk factor
    - consideration of end of life needs and Advanced Care Planning undertaken
    - ensure Health Action Plans are produced. *(see **appendix 1** for summary of key improvements achieved to date)*

- Commissioning particularly within Adult Social Care – focus needs to be on care packages designed to meet increasing and diverse needs. Care providers need to be equipped with the necessary skills and resources to meet those needs, e.g. relevant skills and knowledge to safely support someone if they have dementia and physical health needs, to help prevent further accommodation moves in coming years.



Overarching Local LeDeR Improvement Priorities for 2021-2022

Based on the identified learning points above we have established **three key themes** for focus in 2021-2022 (incorporating feedback from NHSE we have incorporated these into our three year Learning Disabilities & Autism roadmap/strategic direction):

1. **Annual Health Checks - improve the quality and uptake**
2. **Mental Capacity Act – includes (Do Not Attempt Cardiopulmonary Resuscitation/Treatment Escalation Plan/Deprivation of Liberty Safeguards)**
3. **Holistic Commissioning for people with Learning Disabilities and Autism**

Improvement Priority 1: The Annual Health Check (AHC) Programme

Key Aim: Increase the uptake and quality of Annual Health Checks in Somerset. Linking to primary care / care providers / Children and young people (CYP), Special Educational Needs and Disability (SEND) / Advanced Care Planning (ACP) / Co-production

Outcomes:
Increase number of AHCs
Ensure consistency in quality of AHCs
Increase in the number of Health Action Plans created
Improve health inequalities
Improve screening offer

Enable healthy living conversations (diet and weight management)
Improve Mental Health provision
Enable conversations around death and dying (ACP**)** (March 2022)

Improvement Priority 2: Mental Capacity Act (MCA)

Key Aim: Ensure effective understanding and interpretation of the MCA and its application for people with a Learning Disability and Autism (Do Not Attempt Cardiopulmonary Resuscitation/Treatment Escalation Plan/Deprivation of Liberty Safeguards) (March 2022)

Outcome: Ensuring legal compliance and improving informed decision-making

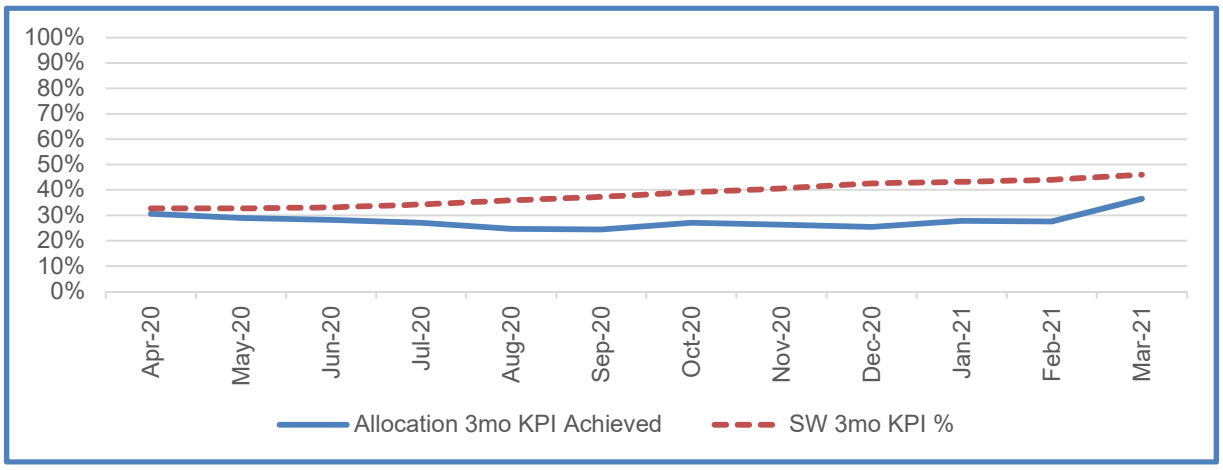
Improvement Priority 3: Effective Joint Commissioning

Key Aim: Developing a joint health and social care approach to commissioning and quality contract management that supports holistic care to individuals (epilepsy / dementia / mental health etc.)

Outcome: Agreement of joint shared commissioning principles and approach for future commissioning and quality contract management enabling the person-centred provision of holistic care and support for people with learning disabilities and autism.

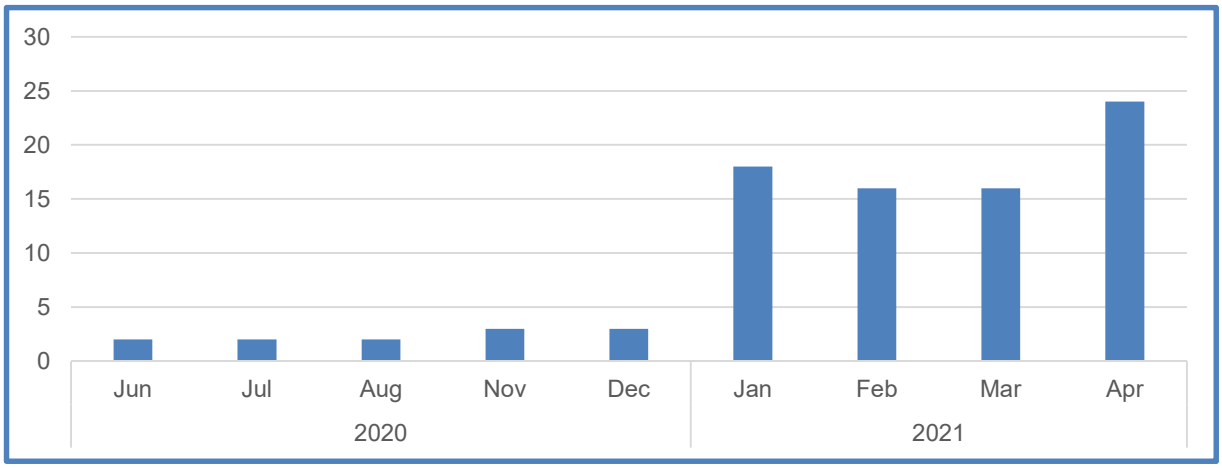
Somerset LeDeR Performance 2020-2021

The three month allocation key performance indicators (KPI) graph below demonstrates that initially, when notifications were low, allocations were being made within the three month timescale. As the number of notifications increased, the number of notifications that were allocated within the three month timescale decreased steadily until it was in-line with the South West three month KPI average.



LeDeR Reviews Completed by Month (2020/21)

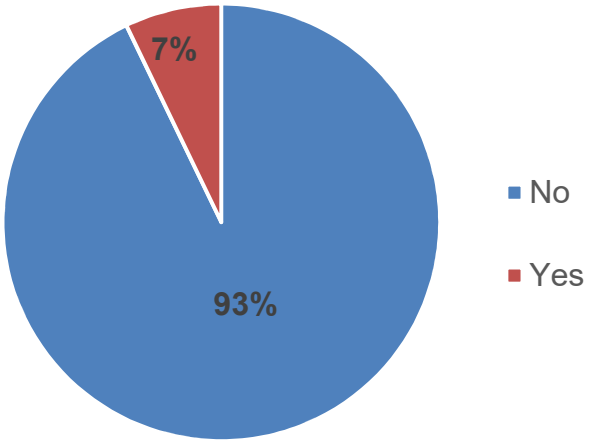
The following graph provides a summary of the number of LeDeR Reviews (86) completed on a monthly basis in 2020/21. Please note, this graph also captures those reviews completed in April 2021, this is due to the project extension.



Multi Agency Reviews

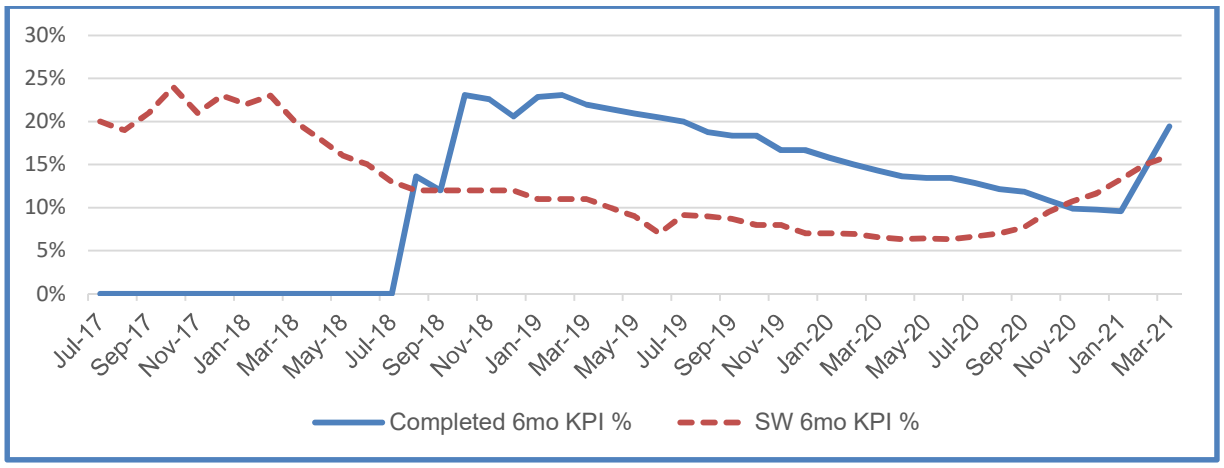
It is worth noting that of the 126 Reviews completed since 2017 only nine have resulted in a Multi-Agency Review (MARs). Of the nine MARs, Notifications for the related individuals were received in the following years:

- 2017 – x6 Notifications;
- 2018 – x2 Notifications;
- 2019 – x1 Notification;



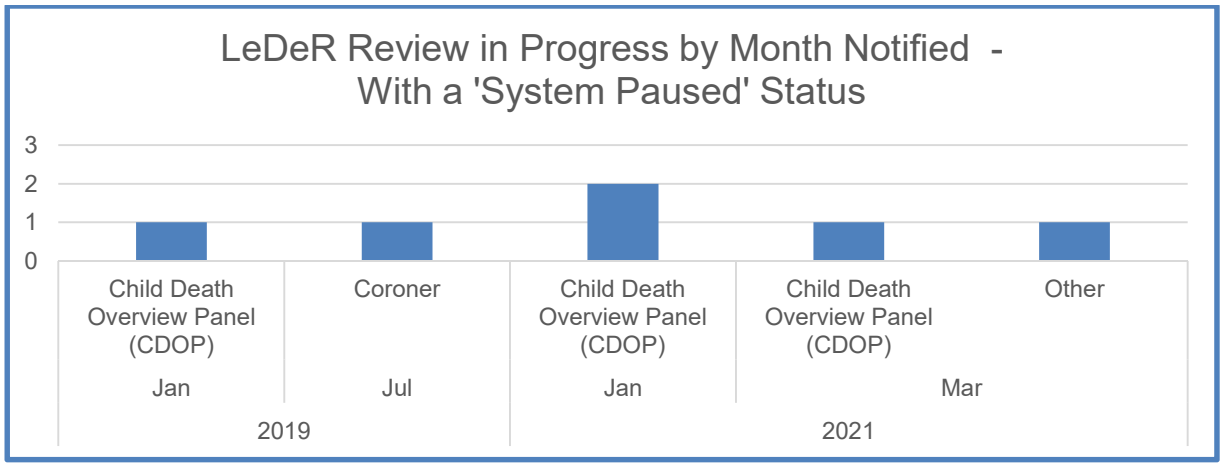
Six Month Completion KPI Performance %

The six month completion KPI demonstrates that until August 2018, notifications were taking longer than six months to complete. After this time, there were a substantial number that were completed within six months, however as notifications continued to be received, the six month completion performance steadily reduced to be in line with the SW KPI Performance.



Reviews remaining 'In Progress' as at 30th April 2021

The following graph provides a summary of those reviews remaining 'in progress' as at 30th April 2021. It is worth nothing that three of the reviews are for children/young people, which have been delayed due to a pause locally in convening the Child Death Overview panel. Two of the review notifications were received in 2019, with the remaining four being received in 2021.



LeDeR 'Closing Activity Snapshot'

This final table provides a closing activity snapshot of NHS Somerset's LeDeR Project for 2020/21.

Total no. of Notifications received in 2020/21	Total Reviews completed in 2020/21	Total Reviews in progress with 'Active' Status	Total Reviews in progress with 'System Paused' Status
54 (*)	86 (**)	0	6

** of the 54 Notifications received in 2020/21, 5 individuals actually passed away in 2019/20*

*** of the 86 Reviews completed in 2020/21, 1 was recorded as 'Out of Scope' and 19 were completed in April 2021, as part of the project extension*

APPENDICES

APPENDIX 1 - FOCUS ON ANNUAL HEALTH CHECKS IN SOMERSET

The CCG have worked closely over the past year with the Primary Care Board to put additional support measures in place to assist practices in achievement of robust Annual Health checks. This has been particularly important to address the Health inequalities for people with learning disabilities, with the vulnerability of this group in relation to COVID-19 evidenced at national and local level. Quality Annual Health Checks provide an opportunity to identify health issues and improve overall patient health outcomes.

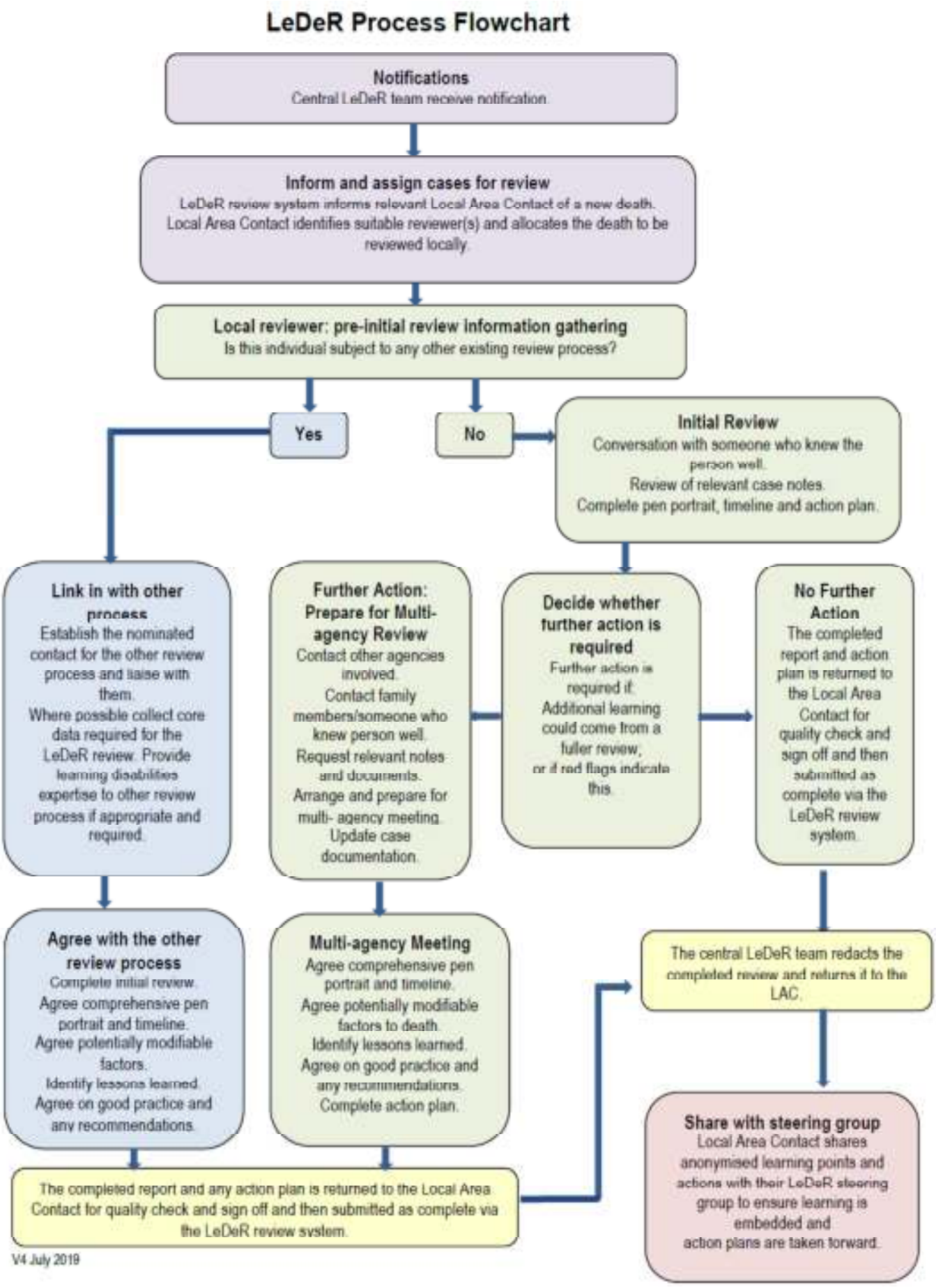
Our learning into action from LeDeR has embraced a co-production approach. This is predominately undertaken through a ***'mend the gap'*** initiative, promoting knowledge which derives from people's experiences to inform what gaps exist between people receiving services and those supporting and delivering services. (Thereby also addressing the powerlessness some feel as 'silent' recipients of a service).This initiative has been developed by working in collaboration with 'Our Voice' (Somerset LeDeR Peer Support Group) and in partnership with The Open University.)

The group has co-created 10 'principles of expectations' when they go for their Annual Health Check (AHC). One of the main aspects of feedback has been that the AHC only focuses on physical health and overlooks mental health & well-being. Our Voice will produce a video in June 2021 based on these principles.

This co-production has been possible due to a successful bid to NHSE/I for funding to support LeDeR locally. In addition to the "Mend the Gap" initiative during 2020 the CCG circulated a suite of practical documents including a guide for practices on Annual Health Checks.

APPENDIX 2 – NATIONAL LeDeR REVIEW PROCESS

(NB this process applies only to 2020/21)



APPENDIX 3 – LOCAL LEDER REVIEW SUPPORT PROCESS