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Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) policy 2021

Version 1, 23 March 2021

Contents

An easy read version of this document is available on the NHS England and NHS Improvement website.

1. Introduction

This policy sets out for the first time for the NHS, the core aims and values of the LeDeR programme and the expectations of different parts of the health and social care system in delivering the programme from June 2021. It will serve as a guide to professionals working in all parts of the health and social care system on their roles in delivering LeDeR.

This policy introduces the inclusion of autism into the programme for the first time, from late 2021.

Learning from lives and deaths – People with a learning disability and autistic people, or LeDeR (formerly known as the Learning from Deaths Review Programme) started in April 2017. It grew out of the Confidential Inquiry into Premature Deaths of People with a Learning Disability (CIPOLD)[1] and was piloted in parts of the country in 2016. A commitment to continuing the LeDeR programme was made in the NHS Long Term Plan 2019:

> "3.31 We will continue to fund the LeDeR [Programme], the first national programme aiming to make improvements to the lives of people with a learning disability".[2]

In developing this policy, we have engaged with a wide range of partners and stakeholders including co-producing elements of the policy with people with lived experience. In total, we have engaged with over 400 people in developing this policy including people with a learning disability and their carers, bereaved families, commissioners, health and care providers, members of the LeDeR workforce, social care providers and voluntary sector organisations, LeDeR experts (academics and policy experts). We also commissioned IPSOS Mori to undertake independent research into views of stakeholders about how to improve the LeDeR programme to make it fit for the future.

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[1] http://www.bristol.ac.uk/cipold/reports/

[2] NHS Long Term Plan, 2019

1.1 What is the purpose of LeDeR?

LeDeR is a service improvement programme which aims to improve care, reduce health inequalities and prevent premature mortality of people with a learning disability and autistic people by reviewing information about the health and social care support people received. It does this by:

- Delivering local service improvement, learning from LeDeR reviews about good quality care and areas requiring improvement.
- Driving local service improvements based on themes emerging from LeDeR reviews at a regional and national level.
- Influencing national service improvements via actions that respond to themes commonly arising from analysis of LeDeR reviews.

Responsibility for ensuring the delivery of LeDeR reviews currently lies with clinical commissioning groups (CCGs). As we move into new arrangements in the NHS through 2021 and into 2022, local integrated care systems (ICSs) will become responsible for ensuring that LeDeR reviews are completed for their local area and also, and very importantly, **that actions are implemented** to improve the quality of services for people with a learning disability and autistic people to reduce health inequalities and premature mortality.

ICSs will be responsible for ensuring that LeDeR reviews are completed of the health and social care received by people with a learning disability and autistic people (aged four years and over) who have died, using the standardised review process. This enables the ICS to identify good practice and what has worked well, as well as where improvements in the provision of care could be made. Local actions are taken to address the issues identified in reviews. Recurrent themes and significant issues are identified and addressed at a more systematic level, regionally and nationally.

A LeDeR review is not a mortality review. It does not restrict itself to the last episode of care before the person’s death. Instead, it looks at key episodes of health and social care the person received that may have been relevant to their overall health outcomes. LeDeR reviews take account of any mortality review that may have taken place following a person’s death.

LeDeR reviews are not investigations or part of a complaints process, and any serious concerns about the quality of care provided should be raised with the provider of that service directly or with the Care Quality Commission (CQC) via their online system.

1.2 The case for change

The LeDeR Programme was initially led by the University of Bristol including policy, overall responsibility for the direction of the reviews, the operation of the web platform and the analysis of the data; with CCGs conducting reviews. The end of NHS England and NHS Improvement's contract with the University of Bristol in May 2021 meant a timely opportunity to reflect on what has gone well with LeDeR to date and to identify areas of the programme that need to improve.

Since LeDeR was established, CCGs and their local authority partners have reviewed the health and social care received by over 8,500 people who had a learning disability, and a huge amount has been learned about how best to conduct reviews and the impact of local actions based on learning from reviews. Feedback from the engagement has shown that there is strong agreement and recognition of the importance of LeDeR and its aims.

However, there was also acknowledgement that the main focus so far has been on the completion of reviews. We have not systematically captured evidence that, where recommendations are being made, they are being acted upon or that changes are having the desired impact. Therefore, it has not always been clear how health and care services are using the learning from LeDeR reviews to improve services.

ICSs **must** systematically act upon findings in LeDeR reviews and improve the care provided by all services (not just learning disability specific services) to stop people dying prematurely and provide better quality services. NHS England and NHS Improvement will hold ICSs to account for the delivery of the actions identified in reviews as part of their assurance processes so that ICSs improve the ways that local health and care services meet the needs of people with a learning disability and autistic people.

Historically, LeDeR reviews have been time and resource intensive with reviewers struggling to access records and care notes. In our new approach, we are improving the review process including the development of a new web-based platform which will help streamline reviews and improve reviewer training. By putting reviews in the hands of the ICS, access to clinical records becomes a collective capability.

We are recommending that reviewers are provided with smart card access to clinical records to speed up access to the right notes at the right time, and reduce the burden on clinical teams, especially primary care. Reviewers should be able to access the data they need when they need it to complete a review in an efficient but effective way. This will mean that reviews should be completed, and action taken, sooner. All of this will enable the completion of high quality, objective reviews which identify learning and drive change.

There has previously been significant variation in the quality of reviews, and this has stemmed in part from the limited number of reviews some reviewers complete, and the training and support that reviewers have received.

Reviewer training will be improved and include annual refresher sessions, meaning that reviewers are equipped and supported to consistently deliver high-quality reviews in a timely manner, and to influence the development of actions to drive improvement.

In future, reviewers will work in larger teams, with regular supervision and support including administrative support which will promote consistency in the quality of reviews. Reviewers will be close enough to ICSs to understand how the integrated care system operates, (for example who the providers of services are and the commissioner landscape) but reviews will be completed in such a way that they are still independent from the providers within the integrated care systems in which the reviewers operate.

Creation of the NHS England and NHS Improvement Autism Programme has focused attention on the need for reliable data on the health inequalities faced by autistic people. The changes to the LeDeR programme have provided an opportunity to address this: reviews of the health and social care received by autistic people who have died will now be included within LeDeR’s remit for the first time.

2. Policy context

2.1 Audience for this policy

This policy is aimed at all health and social care professionals with a role in delivering LeDeR. This includes:

- Staff in ICSs
- LeDeR workforce (reviewers, local area contacts, administrative staff)
- Local authority commissioners of care for people with a learning disability and autistic people
- CCG commissioners and directors of quality
- Acute care staff involved in quality improvement.
- Mental health trust staff involved in quality improvement.
- GPs and practice managers in primary care
- Primary care networks (PCNs)
- NHS primary, community and secondary care staff involved in the care of people with a learning disability and autistic people
- Social care services including care providers
- NHS England and NHS Improvement staff, including regional staff
- Community and voluntary sector organisations supporting the LeDeR programme
- Members of child death review panels.

2.2 Core principles and values

The core principles and values of the LeDeR programme are:

1. LeDeR is a service improvement programme aimed at improving local services for people with a learning disability and autistic people, and reducing premature mortality.
2. We value the on-going contribution of people with a learning disability and autistic people and their families to all aspects of our work, and see this as central to the development and delivery of everything we do.

3. LeDeR reviews will be conducted by dedicated reviewers working in multi-disciplinary teams with appropriate supervision and administrative support.
4. Reviews will be completed in as timely a way as possible so that where good practice is identified, or issues identified these can be shared and addressed as soon as possible.
5. We take a holistic perspective, looking at a person's life as well as their death.
6. The key principles of communication, cooperation and independence will be upheld when working alongside other investigation or review processes.
7. The programme overall strives to ensure that reviews lead to reflective learning which will result in improved health and social care service delivery.
8. LeDeR reviews are not investigations.

2.3 Timescales and transition arrangements

This policy outlines a number of changes to existing LeDeR processes. Some of these changes, such as the new review process, will need to be implemented by ICSs in line with the changes to the web-based platform which will go live on **1 June 2021**. Other changes, such as staffing models and local governance arrangements will need to change in line with the development of ICSs and relevant human resources processes. It will be the responsibility of ICSs to ensure that appropriate communications are in place for these in collaboration with their regional colleagues.

From 2021, adults who have a diagnosis of autism without a learning disability will also be eligible for a LeDeR review; further advice will be published in coming months.

By **1 April 2022** all changes within this policy must be implemented by ICSs, subject to legislative changes relating to ICSs being passed in coming months.

2.4 Definitions and scope

2.4.1 Scope of the LeDeR programme

Everyone with a learning disability aged four and above who dies and every adult (aged 18 and over) with a diagnosis of autism[3] is eligible for a LeDeR review.

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[3] Diagnosis must be recorded in the person's clinical record.

The child death review (CDR) process reviews the deaths of all children who are aged 4-17.[4] This will be the primary review process for children with learning disabilities and autistic children; the results are then shared with the LeDeR Programme. We are aware that how the two processes work together are different in different parts of the country and further guidance will be shared from both review programmes about this in coming months.

We are working with the CDR process to see how we can access more of the data they have about children and young people's deaths. This will allow us to do more analysis and comparison, and understand in greater depth the deaths of children with a learning disability and autistic children.

The LeDeR programme uses the following definition of a learning disability:

Individuals with a learning disability (internationally referred to as individuals with an intellectual disability) are those who have:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence)

with:

- a significantly reduced ability to cope independently (impaired adaptive and/or social functioning)

and:

- which is apparent before adulthood is reached and has a lasting effect on development.

Learning disability is different from a specific learning difficulty (such as dyslexia), or autism or a mental health condition. Some people have all of these and also have a learning disability. A person does not necessarily need to have been on a locally held learning disability register (also sometimes called a GP quality outcomes framework [QoF] register) to be eligible for a LeDeR review.

For an autistic person to be eligible for a LeDeR review, they must have had a confirmed diagnosis of autism[5] recorded in their clinical records prior to their death.

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[4] Before the age of 4 years it can be difficult to ascertain if a child has a learning disability, unless they have a specific syndrome always associated with a learning disability. The LeDeR programme therefore starts reviewing deaths of people with a learning disability from age 4 years onwards.

[5] Further information on autism can be found at https://www.nhs.uk/conditions/autism/

2.4.2 Notification of deaths to LeDeR

Notification of the deaths of people with a learning disability or autistic people to the LeDeR programme is not mandated. However, there is a strong expectation – supported by CQC – that providers of health and social care services, including GPs, will do so.

Notification of a death can be made by anyone via the LeDeR website. This includes health and social care staff, administrative staff, family members and others who knew the person. If a death is notified more than once, the LeDeR system will identify this from the details provided and generate a single review for the individual.

Deaths of autistic people will not be able to be notified to the system until later in 2021.

2.5 Outcomes

We will know that the LeDeR programme is effective when local areas identify:

- a reduction in the repetition of recurrent themes found in LeDeR reviews
- reduced levels of concern and areas for improvement in reviews
- reduced frequency of deaths that were potentially avoidable or amenable to good quality healthcare.
- evidence of service improvement actions as a result of learning from reviews. This can often be quite simple changes put in place by health and social care providers like ensuring proper communication between family members and carers or between carers and hospital staff, making sure that people's care plans are followed, or that postural support is provided or that annual health check health plans are followed.

We expect the LeDeR programme to deliver:

- a positive experience of the LeDeR process for bereaved families
- decreasing numbers of preventable deaths
- greater use of reasonable adjustments in health and care services for people with a learning disability and autistic people
- better outcomes for people as a result of local service improvement projects

- increased awareness of the main causes of death for people with a learning disability and autistic people among health and social care professionals both locally and nationally
- improved data about the lives and deaths of autistic people.

ICSs are expected to measure the impact of their work to demonstrate improvements in services. NHS England and NHS Improvement’s Impact Framework may help local areas to think through how they will evaluate and measure the impact of their work.

ICSs are expected to complete 100% of all their reviews within six months of them being notified on the LeDeR web platform unless statutory processes prevent that being possible or family members of those bereaved have asked for the review to be delayed.

3. The review process

3.1 Changes to the LeDeR review process from 1 June 2021

A revised LeDeR review process will be put in place from 1 June 2021 and will be supported by the new web-based platform and new training for the LeDeR workforce. ICSs will need to implement the changes to the review process from this date. The review process for autistic people will be implemented later in 2021. The University of Bristol platform will not be available after 1 June 2021. Data held currently on the University of Bristol platform will be transferred over to the new web-based platform.

The main changes to the review process are highlighted below and expanded on in more detail further in the policy:

- Notification of deaths will be through the LeDeR website only.
- Members of the LeDeR workforce will need to complete the initial training and then undertake refresher training on an annual basis.
- Every person with a learning disability whose death is notified to LeDeR will have an initial review of the health and social care they received prior to their death.
- Using their professional judgement and the evidence available to them, the reviewer will determine where a focused review is required. The person's family has the right to request a focused review. Focused reviews will also be completed for every person from a Black, Asian or Minority Ethnic background.[6]

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[6] We know that there is significant under reporting to LeDeR from Black, Asian and Minority Ethnic communities and that premature mortality in Black, Asian and Minority Ethnic communities is significantly increased therefore it is important that we review each of these deaths to understand better the health inequalities faced by each of these different groups and to help tackle inequalities identified.

- The policy includes autistic people within the scope of LeDeR for the first time.
- Reviewers will no longer make recommendations for each review, instead they will present areas of learning, good practice and areas of concern to the local governance group/panel.
- ICSs will need to establish a local governance group/panel, which as well as signing off the quality of focused reviews will, in discussion with the reviewer, agree SMART (specific, measurable, achievable, realistic and timebound) actions which feed in to, and are cognisant of the strategic plan for the local area.
- The local governance group/panel will consist of people from across the ICS who have responsibility for the quality of services and can take action to improve services.
- The governance group/panel must include people with lived experience.[7]
- LeDeR governance must not sit separate to and remote from wider ICS quality governance.
- NHS England and NHS Improvement regional teams will hold ICSs to account assuring that the actions are robust, address the issues identified and will achieve the objectives required.
- NHS England and NHS Improvement regional teams will ensure that ICSs report quarterly on performance against the actions agreed for all reviews completed.

3.2 How the new LeDeR review process will work

Notifications to the programme

Anyone can notify a death to the LeDeR programme via the website.

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[7] This includes people with a learning disability, autistic people and family carers. The proportion of people with a learning disability and autistic people without a learning disability should be proportionate to the number of reviews being completed for each.

Assigning a review to a reviewer

Once a LeDeR review is notified to the web platform, the local area contact (LAC) will receive a notification and will assign it to the senior reviewer. In the transition period while review teams are being established, the LAC will allocate the reviews to reviewers themselves but over time, this will become the responsibility of the senior reviewer who will have oversight of review team capacity. ICSs should develop these teams and the senior reviewer role as a priority within the LeDeR programme.

Initial review

The reviewer will carry out an initial review using the new web platform to guide them through the process. This initial review will include:

- a guided conversation with the family member or someone close to the person who died, this might also be someone they lived with or a carer who they were particularly close to.
- a detailed conversation with the GP or a review of the GP records which will be accessed via a Smart Card where possible giving direct access to the GP system.
- a conversation with at least one other person involved in the care of the individual who died – this might be for example the person who carried out the mortality review in the hospital (if they died in an acute trust), or simply another family member who wants to speak to the reviewer about the care their loved one received.

Outcome of initial review

From the information gathered the reviewer will use their professional judgement to decide whether a focused review is required. The LAC will review the justification for this and confirm that they are content that this should remain as an initial review or move to a focused review.

In some infrequent cases, even though the reviewer and LAC agree that a focused review is not required, they may agree that there are one or two **immediate** SMART actions for a specific individual or team within the ICS which need to be implemented.

Focused review

Situations where a focused review will be carried out are:

1. If the individual is from a Black, Asian or Minority Ethnic background, a focused review will automatically be completed due to significant under reporting and increased health inequalities in these communities. (This may include, for example, and not be limited to, Romany Gypsy, Irish traveller or Jewish communities).[8]

2. If in the professional judgement of the reviewer that there is significant learning likely for the ICS from carrying out a LeDeR review.

3. If there are concerns about the quality of care provided to the person by one or more providers, or there is evidence of lack of integrated or co-ordinated care.

4. A family member can always ask for a focused review to be completed. If such as request is made, a conversation should take place between the family and the reviewer about the expected outcome of a LeDeR review. LeDeR is a service improvement approach and cannot satisfy performance issues for a whole organisation or individual staff members, for which there are other processes, including within organisations themselves and via the CQC. Families should be informed by the reviewer about the options which exist to raise issues they have about the care received by their loved one.

5. In the years 2021-2023, all deaths of adults who have a diagnosis of autism but who do not have a learning disability will have a focused review.

A focused review will be completed using the LeDeR web platform to guide the review process.

Where a reviewer comes to a view that a review they are working on is complex, they will work with their senior reviewer and use the expertise of the wider multi-disciplinary team of reviewers to support them. In rare cases with very complex and unique circumstances, senior reviewers may carry out reviews – particularly when they are very complex and require significant expertise. We expect these very complex cases to be rare.

Reviewers will need to consider whether any other process, such as referral to safeguarding, provider complaints process or a serious incident investigation,

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[8] https://www.citizensadvice.org.uk/law-and-courts/discrimination/protected-characteristics/race-discrimination/

should be conducted alongside or in place of a LeDeR review. LeDeR is a service improvement programme therefore, where appropriate, the LeDeR review may arrive at differing learning and recommendations to other reviews or investigatory processes.

Medical examiner offices are being established in acute trusts in England, to provide independent scrutiny of all non-coronial deaths. Medical examiners can play a unique role, enabling greater scrutiny and clarity of the reasons for a person's death, and also as a contact point for the bereaved; providing an opportunity for families and carers to raise any concerns, such as unsatisfactory interactions with health services. These sensitivities need to be understood and addressed with compassion following a death.

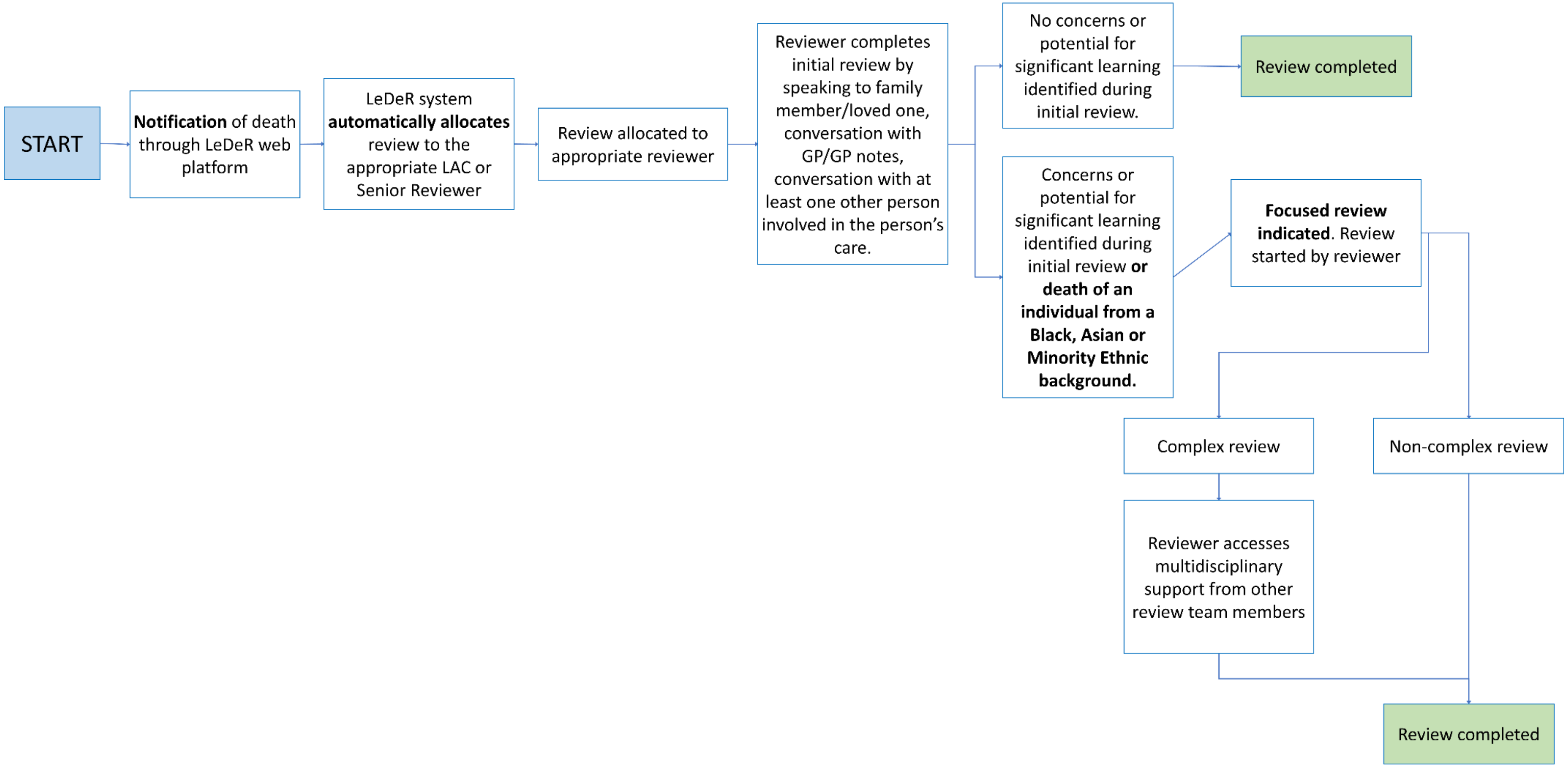
It is important that LeDeR review teams and medical examiners form strong links, clarify processes for referrals, and share information about the causes of death and quality of care provided. By working together, we can make progress to address the disproportionate number of avoidable deaths of people with a learning disability and autistic people.

In coming months, further advice will be produced for medical examiners and the LeDeR workforce on working together. It is expected that all organisations undertaking separate processes relating to the same person will establish good working relationships to ensure appropriate information is shared and that the response is co-ordinated between agencies (where required) with careful consideration given to the needs of families and others affected.

Where the purpose and terms of reference of processes are the same, organisations may wish to choose to work together as part of a combined effort to avoid duplication.

Communication with the family or others affected by the loss should be co-ordinated, timely, thoughtful, honest and sensitive.

Figure 1: LeDeR review process overview



3.3 Quality assurance

ICSs should have a clear plan in place by 30 September 2021 for the new quality assurance structures and processes which will be implemented for LeDeR and fully operational from 1 April 2022. In the meantime, ICSs will need to agree with their regional teams how they will assure quality during this transition phase.

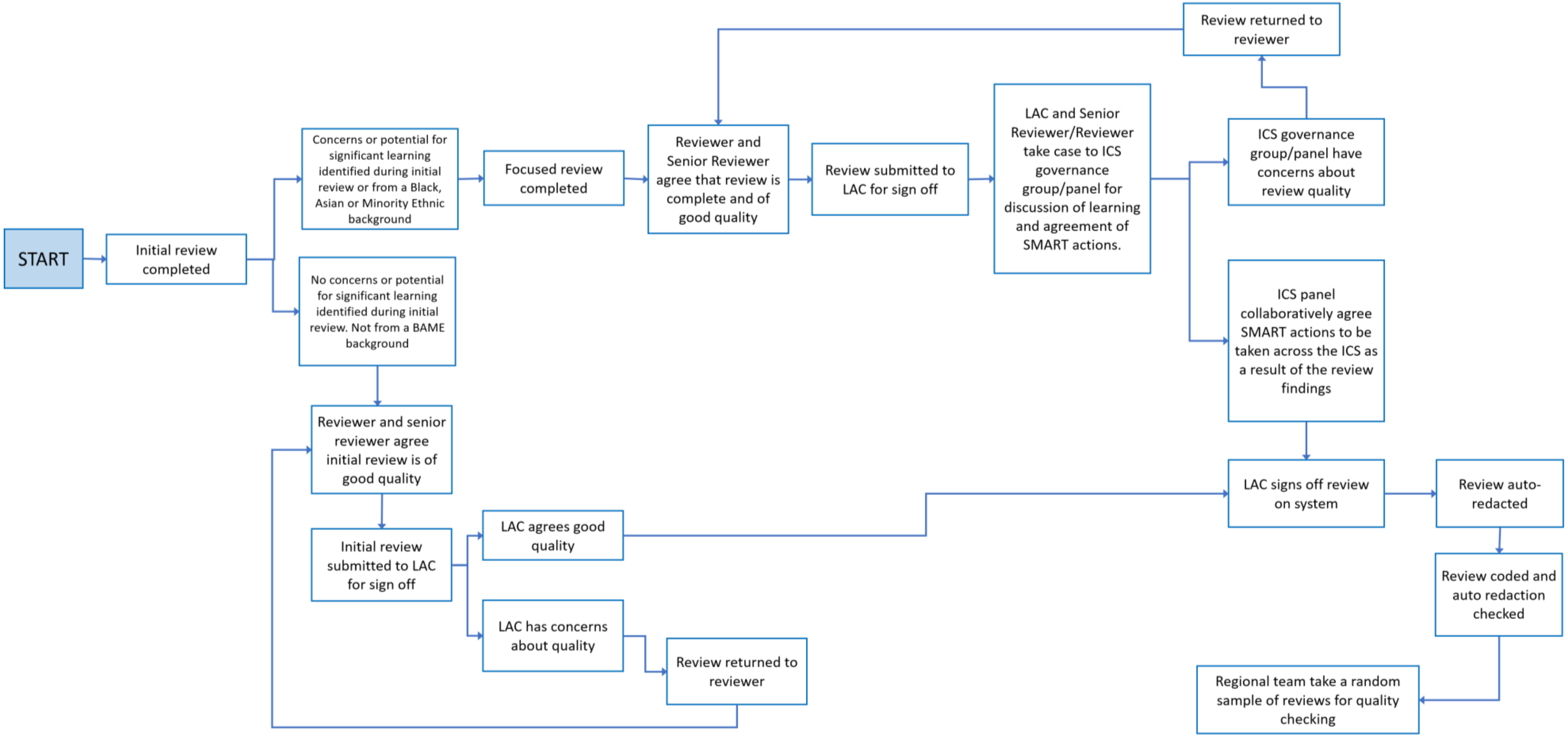
Nationally, the LeDeR programme team will support by offering:

- New improved and more consistent training on ‘what good reviews look like’ to help ensure better quality reviews.
- The ‘template’ for reviews on the new web-based platform will help to ensure consistency in terms of quality.
- Additional guidance in the form of frequently asked questions updated on a regular basis.

Over time:

- Reviewers will work in conjunction with senior reviewers who will also check their work to ensure good quality reviews.
- Local LeDeR governance groups/panels will have oversight of the quality of reviews.
- NHS England and NHS Improvement regional learning disability and autism teams will carry out some sampling to assure quality of reviews.

Figure 2: LeDeR quality process overview



4. Involving families in reviews

Bereaved family members or someone who knew the person well should be meaningfully involved throughout the LeDeR process. Families are often well placed to contribute rich information about high quality care and areas for improvement that can significantly enhance the learning to improve services for other people.

As a minimum, families should be informed that the review is taking place, invited to contribute information about the person that has died and offered the opportunity to receive a copy of the completed review. Family members should be given an opportunity to comment on a draft review/pen portrait if they would like to do so.

All bereaved families are different and should be consulted to determine how much involvement they would like in the LeDeR review, this may include contributing to determining actions coming out of the review. All communication with families should be timely, sensitive and authentic, ensuring that families understand the purpose and limits of LeDeR reviews and know how to raise any additional questions or concerns they may have, including any that should be addressed outside of the LeDeR process.

Further advice on engaging with families will be provided to reviewers as part of the LeDeR training.

ICSs should be prepared to signpost families to bereavement support should this be considered helpful.

A review should still be undertaken if a family indicates that they do not wish to participate. The reviewer should be mindful of this.

5. Governance

The LeDeR programme is a local service improvement programme. As such, local ICSs and their constituent organisations need to ensure local governance is robust enough to use the learning from the reviews of deaths of people with a learning disability and autistic people to bring about improvements in health and social care services for other people with a learning disability and autistic people, reducing health inequalities and premature mortality.

Local governance arrangements should feed into local quality surveillance groups and, for local authorities, health and wellbeing boards, to ensure the people who can affect the necessary improvements understand the issues that need to be addressed.

Collaborations between partners across health, care services, public health and the community and voluntary sector will be key to help to address health inequalities, improve outcomes and deliver joined up, efficient services for people with a learning disability and autistic people.

Responsibility for ensuring the delivery of LeDeR currently (2020/21) lies with CCGs. As the systems evolve over the next year, responsibility and accountability for LeDeR will change to rest with ICSs. Each ICS will be expected to develop an implementation plan by 30 September 2021 and implement new governance arrangements by 1 April 2022.

LeDeR reviews, development of actions and delivery of those actions needs to continue throughout this transition period.

LeDeR **must** be incorporated into the routine quality reporting arrangements of the ICS and not sit separately from it. Local differences will mean different quality and governance arrangements in each ICS, so it will be the responsibility of individual ICSs to determine how LeDeR can best be governed within its own evolving structures. Local governance arrangements are expected to achieve the outcomes listed in Appendix A.

In some parts of the country, LeDeR has been seen to be the responsibility of commissioners. This policy makes it clear that providers will take a much more active role in driving forward the delivery of actions to reduce premature mortality and improve services for those with a learning disability. ICSs will be held to account by NHS England and NHS Improvement's regional teams through regional oversight arrangements.

Local authorities are expected to contribute to and be part of ICSs, and have a role to play in reducing health inequalities and premature mortality of people with a learning disability and autistic people.[9]

Local governance arrangements **must** promote meaningful co-production with people with lived experience.

Specific governance roles are outlined below in Section 6, roles and responsibilities.

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[9] Under the Health and Social Care Act 2012 each local authority must take steps appropriate for improving the health of its local population and all public bodies have a duty to have due regard to the need to eliminate discrimination and advance equality of opportunity for groups with protected characteristics such as a disability.

6. Roles and responsibilities

The following section briefly describes the role of each part of the health and social care system in delivering LeDeR. It is recognised that these roles will not be fully embedded until 1 April 2022, but ICSs must be working towards this approach throughout 2021/22.

6.1 Integrated care systems (including local area contacts)

The roles expected of the LAC will sit within the ICS. This is a different role to the current LAC role and there will be greater independence between the review team and the LAC in future.

In order to deliver the expectations set out above, ICSs will need to:

Governance	Identify an executive lead to be the senior responsible officer for the delivery and assurance of the LeDeR programme within the ICS.
	Ensure LeDeR governance is an integral part of ICS governance and quality reporting arrangements and is not stand-alone.
	Convene a local governance group/panel to meet on a frequency determined by the number of reviews anticipated for your area. (It is suggested that ICSs use data from numbers of notifications in 2019 to support this). This will be a group comprised of senior people from across local health providers and commissioners and social care partners all of whom should have the authority to affect change. The membership of the group will be dictated by the ICS's own local geography, governance and quality assurance arrangements and by the issues that are important for health inequalities in that area. (For example, if the majority of reviews in a local area highlighted an issue with screening services, the area may wish to ensure that the governance group includes a representative from the screening team.) The group will have final

	sign-off on reviews completed for the ICS and determine the actions to be taken as a result of reviews as well as developing and monitoring the ICS LeDeR local action plan. See Appendix D for further details on potential membership of the local governance panel.
	Noting that there is significant under reporting to the LeDeR programme of deaths from Black, Asian and Minority Ethnic communities, and that where these deaths are notified there are significant inequalities in the age of death with demonstrable premature mortality, each ICS will appoint a named individual who will ensure that the challenges faced by people from Black, Asian and Minority Ethnic communities within that ICS are considered and addressed as part of the LeDeR programme including increasing notification of deaths from Black, Asian and Minority Ethnic communities proportionate to the local communities within the ICS. Local public health engagement in this work will be crucial.
	Ensure sufficient resources are available to complete LeDeR reviews for the ICS in line with this LeDeR policy including that sufficient dedicated staffing is identified to complete reviews[10] staff may be either employed by an NHS or local authority partner within the ICS or commissioned from a member of the NHS family or a local authority. (See below).
Programme management and co-ordination	Identify at least one LAC with sufficient time, knowledge, skills and capacity to: • complete the relevant LeDeR training initially and then the refresher training on an annual basis • act as the point of contact for the NHS England and NHS Improvement regional coordinator • promote LeDeR at a local level across health and social care • liaise with review team • ensure that the appropriate data sharing agreements are in place within the ICS to enable timely access to notes and work within the ICS to facilitate access to health and care notes for reviewers, for example through Smart Cards • assure quality of initial reviews, assure justification of initial reviews and sign off initial reviews on behalf of the ICS • co-ordinate focused reviews to go to local governance panels to agree actions

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[10] Local systems will know from their 2019 data the number of deaths notified to them in that year and therefore what we expect the workload to be in a usual given year to support workforce modelling now that all their historical cases have been reviewed.

	- agree with reviewers any actions coming out of initial reviews (these should be infrequent), including confirming ownership of those actions and ensuring the actions are added to the LeDeR action plan for the ICS and are followed up over time - add the actions from initial reviews to the LeDeR web platform (these should not be numerous or frequent) - upload SMART actions onto the web-based platform once agreed at panel/ governance meetings - raise concerns and ensure that any issues are raised at ICS quality governance meetings - analyse the data coming from reviews to develop and co-ordinate a three-year strategic plan and annual report on behalf of the ICS and escalate any concerns and establish good working relationships with statutory processes to ensure that information is shared, and the response is co-ordinated between agencies; eg safeguarding adult reviews, serious case reviews, mental health homicide reviews, child death reviews, domestic homicide reviews - LACs should be independent of reviewers in all cases.
	Advise reviewers on routes other than/as well as a LeDeR review which may be appropriate in a specific review and support the reviewer to signpost families and those who are bereaved to suitable services to support them in their loss such as bereavement services if these are needed.
	Escalate any case/process/system issues which fall outside of the scope of the local area to the regional co-ordinator.
	Monitor and report on local performance against LeDeR key performance indicators (KPIs) quarterly to NHS England and NHS Improvement regional team.
Staffing	Determine and ensure that staffing arrangements are in place through commissioning or employment of a dedicated, independent, larger, multi-disciplinary team of reviewers supervised by a senior reviewer and supported by administrative staff. The team of reviewers will be supported through training, peer support and professional supervision. At present, the national team are recommending that reviewers are employed on at least a 0.5 whole time equivalent basis to ensure activity levels and maintain timeliness of reviews. ICS should ensure that reviewers are representative of their local population and should ensure that they understand the local communities they work within including ensuring an

	appropriate understanding of culture, and belief, bereavement and death and learning disability and autism in those communities. This should be monitored and reviewed over time.
Access to clinical; records	Ensure appropriate information sharing protocols are in place to facilitate effective data sharing from the purpose of LeDeR across the ICS. Provide access for reviewers and their administrative staff to clinical records as required across health and social care systems to complete LeDeR reviews in a timely manner including providing Smart Card access to GP records to complete LeDeR reviews within the six-month time limit or as soon as completion of statutory processes allows.
Partnership working	Encourage health and care partners across the ICS to notify all deaths of people with a learning disability and adults with a diagnosis of autism to LeDeR and co-operate fully with both the completion of reviews and the governance around and delivery of actions using contracting as a lever where appropriate. Work with social care commissioners and providers to support their co-operation and participation in the LeDeR review process including support to release records in a timely manner.
Action from learning	Consider the issues, concerns and areas of good practice and learning identified in LeDeR reviews at local governance groups/ panels and agree, considering all the recent reviews, a set of SMART actions to address those issues including both strategic and practical activity that will reduce premature mortality and improve quality of services. Then deliver those actions within local provider organisations, reporting on the delivery of the actions to provide assurance.
	Analyse and address themes from completed reviews.
	Follow up on the implementation of local actions across the ICS.
	Record and monitor timely delivery and impact of recommendations. Report to region on a quarterly basis.
	Collate evidence of local actions taken to improve care and address the health inequalities faced by people with a learning disability and autistic people.
	Identify good practice locally and share this nationally via NHS England and NHS Improvement regional teams.

	Publish on the website each year a copy of the annual ICS LeDeR report, which has been taken to a public meeting of the board, and to the health and wellbeing board, and preferably to the local safeguarding adult board as well. This should also be available in easy read.
	Put processes in place to ensure that redacted reviews are shared by the review team with all who were involved in the care of the individuals, including the person's family or other loved ones, their GP, relevant health and care providers.

6.2 LeDeR review teams

The key responsibilities set out below are not aimed at, and will not in any way replace a robust role description and person specification for the roles.

However, they are aimed at providing the system with an overview of the type of function each of the roles will deliver and how they differ from one another.

Reviewers and senior reviewers are likely to be clinical or from a social care background, but this is not a requirement.

Reviewers and senior reviewers need to be independent from providers of services, so should sit within commissioning arms of ICSs, or be commissioned from a separate body within the NHS family or local authorities.

ICSs should move towards teams of reviewers with senior reviewer and administration support roles as quickly as they are able. This should be a priority for LeDeR programmes within ICSs, to ensure robust quality reviews that use resources as effectively as possible.

Reviewers, senior reviewers and their administrative support will either be NHS or local authority employees (using appropriate IT equipment supplied for this purpose and encrypted to suitable standards).

6.2.1 Senior reviewers

Line management of the senior reviewer will be a local decision, based on the employment/commissioning arrangements for the review team. The senior reviewer must however, remain independent of and separate to the LAC role.

The key responsibilities of senior reviewers will be:

Training	Complete the relevant LeDeR training initially then the refresher training on an annual basis.
Team management	Lead a multidisciplinary team of reviewers providing line management support and professional/clinical supervision and ensuring that the team works cooperatively together to deliver all the reviews within their remit.
	Oversee and ensure that peer support is in place to help prevent isolation of reviewers and ensure that reviewer skills are best used.
Governance	Attend local governance meetings as required
	Report on performance to the LAC and regional team.
Review process	Act at all times in a professional, compassionate, and caring way, treating bereaved family members and loved ones with utmost respect and with courtesy. Consider the best evidence available including the conversation with the family or loved one, conversation with the GP or GP records and other health and care data sources and using the best professional judgement and experience determine and agree with regional co-ordinator (RC) support if required, whether a review proceeds to a focused review (where they are themselves carrying out a focused review of a particularly complex case). Any conversation with the family member must explain the parameters of the LeDeR review, signpost to other processes such as complaints processes, and discuss with the family their expected outcome of any LeDeR review setting realistic expectations at the start.
	Provide oversight and quality control for reviews completed by members of the reviewing team.
	Liaise with the LAC for the ICSs covered by the team to allocate reviews appropriately. The senior reviewer is responsible for allocating reviews to individual reviewers within the team however, until the senior reviewer role is in place the LAC will undertake this allocation role.

	Help reviewers to determine whether a review receives an initial review or a focused review using their professional judgement to advise and guide the reviewer where necessary. Other review team members may be included in this discussion for professional input in case of dispute.
	Act as an arbiter where there is any conflict about whether or not a focused review should be completed escalating any issues which cannot be resolved to the RC. This includes considering matters and supporting conversations with a family if there is a difference of view about whether a focused review should be completed.
	Where they have carried out a complex focused review, present review findings at governance panels and support the panel to define SMART actions offering professional challenge to ensure that the actions that are developed will achieve the needs of the findings of the review
	Escalate any technical issues with the LeDeR web-based platform through to the RC.
	Act on any concerns about a review that has been started as soon as this is brought to their attention, in discussion with the LAC and then the RC who will take advice from the national team, if needed.
	Link with, escalate and refer concerns to other processes where necessary and advise families where another process (for example a trust complaints process) would be more appropriate.
	Agree with reviewers any actions coming out of initial reviews and act as arbiter in case of dispute with the LAC about those actions, escalating to the RC as needed.
Completing reviews	Senior reviewers will be experienced in completing reviews and will be allocated those rare but very complex cases to review. This should not be the bulk of their work.
	Complete LeDeR reviews according to the standardised review process to the highest standards focusing on service improvement and adhering the to eight key principles of the LeDeR programme.

6.2.2 Reviewers

Reviewers will be employed specifically to carry out LeDeR reviews at least 0.5 whole time equivalent. Reviewers will therefore always have dedicated time to complete reviews in a timely manner. Key responsibilities will be:

Training	Complete the relevant LeDeR training initially and then the refresher training on an annual basis.
Team working	To work collegiately and provide peer support to other reviewers, particularly around their own area of expertise.

Governance	Attend local governance meetings to update on the status of reviews, present areas of good practice and concern from each review and contribute to the discussion on determining actions to be taken.
Review process	Act at all times in a professional, compassionate, and caring way, treating bereaved family members and loved ones with utmost respect and with courtesy. Consider the best evidence available including the conversation with the family or loved one, conversation with the GP or GP records and other health and care data sources and using the best professional judgement and experience determine and agree with senior reviewer, whether a review proceeds to a focused review. Any conversation with the family member must explain the parameters of the LeDeR review, signpost to other processes such as complaints processes, and discuss with the family their expected outcome of any LeDeR review setting realistic expectations at the start. Raise any concerns about the review process with the senior reviewer as soon as they are aware of them.
	Present review findings at governance panels and support the panel to define SMART actions offering professional challenge to ensure that the actions that are developed will achieve the needs of the findings of the review.
	Link with, escalate and refer concerns to other processes where necessary and advise families where another process (for example a Trust complaints process) would be more appropriate.
	Agree with LACs (and senior reviewers where necessary) any actions coming out of initial reviews (these will be limited and infrequent)
Completing reviews	Complete LeDeR reviews according to the standardised review process to the highest standards focusing on service improvement and adhering the to eight key principles of the LeDeR programme.

6.2.3 Administrative staff

Administrative staff will be employed as part of the review team and will support the LeDeR review process as below. We do not envisage that administrative support for LACs with ICS governance group/panel meetings is included in this role and see this as separately resourced if required.

The key responsibilities of LeDeR Administrators will be as follows:

Training	Complete the relevant LeDeR training initially and then the refresher training on an annual basis.
Communication	Ensure that communication with families is sent out in line with the recommendations set out in the standard operating procedure.

	Ensure that redacted reviews are shared with all of those who were involved in the care of the individual who has died after sign off including the person's family or other loved ones, their GP, relevant health and social care providers and specified system partners such as the CQC.
	Liaise with statutory processes such as safeguarding, medical examiners and the coroner's office to ensure effective sharing of information.
Team administration	Arrange team meetings, case discussion meetings and supervision as necessary.
Access to case notes	Support reviewers to access health and social care notes as appropriate.
	Take responsibility for uploading notes to the system where appropriate.

6.3 Regional learning disability and autism programme teams (including regional co-ordinators)

Across each of the regions, the regional learning disability and autism programme team provides oversight of the LeDeR programme. Key responsibilities include:

Programme management and co-ordination	Complete the relevant LeDeR training initially and then the refresher training on an annual basis.
	Provide operational support for local area contacts and reviewer teams and act as a point of escalation where issues cannot be resolved locally.
	Support to tackle unwarranted variation in the delivery of the LeDeR programme.
	Act as a critical friend to ICS in relation to LeDeR as appropriate.
	Ensure the effective flow of LeDeR related information across the region including national advice, reports and requests and co-ordinate ICS responses, including cascading information from the national team where appropriate.

	Provide a regional single point of contact for issues affecting the web-based platform and communication with the contract holder for this regarding review related issues.
	Act as the point of contact and liaise with other regional co-ordinators around any case or process issues which arise.
Communication and engagement	Promote the LeDeR programme at a regional level and across ICS where there are challenges with engagement.
Governance	Provide assurance to the national team around local ICS LeDeR processes.
	Report to the national team on performance of ICSs as required.
	Hold local areas to account for their performance against the expectations set out in this policy.
	Intervene in cases of dispute between ICS and reviewer team in relation to reviews including in the process whether a focused review or other process should be undertaken.
Policy and process	Contribute to the development of the national LeDeR policy other supporting documents.
Quality assurance	Ensure there are systems in place to assure quality of reviews and check that ICSs are producing stretching and challenging actions to reduce variation and ensure consistent quality.
	Work within regional quality oversight arrangements to address any system quality and safety issues impacting on the performance of the regional LeDeR programme.
	‘Call in’ a random sample of reviews to quality assure reviews including both initial and focused reviews.
	Monitor the percentage of reviews that translate from initial to focused reviews, co-ordinating with NHS England and NHS Improvement national team and colleagues across the country to ensure equity and parity.
Action from learning	Support greater collaboration between regional partners in health, care, public health and voluntary partners to promote and support action as a result of learning from LeDeR findings.

	Ensure that any relevant regional and national priorities are communicated and addressed at a local level
	Collate and share examples of good practice and improvement from across the region to inform the annual national Action from Learning report.
	Ensure that the findings of LeDeR reviews inform the learning disability and autism health inequalities workstream and wider health Inequalities workstream at a regional level.
	Identify and share regional themes arising from LeDeR reviews.
	Ensure that the findings of LeDeR reviews are communicated within regional quality oversight arrangements to address any system quality and safety issues.
	Request and review quarterly reports on action from learning from ICSs to assure that timely, impactful actions are implemented in response to learning from LeDeR and that service improvement is demonstrated.

6.4 National LeDeR programme team

The national LeDeR team leads the LeDeR programme at a national level. Key responsibilities of the national team are:

Training	Ensure that the available training meets the needs of the system. Complete the relevant LeDeR training initially and then the refresher training on an annual basis.
Policy and process	Continue to coproduce LeDeR policy and other relevant documentation as required and as understood as needed from the system.
	Continued engagement with end users to ensure LeDeR meet their needs and achieves end benefits.
Support and escalation	Act as a point of escalation where issues cannot be dealt with locally/regionally or where a national approach is required.

	Support regional colleagues to address performance issues, regarding review completion and/or Action from Learning, within ICSs when required.
Communication and engagement	Promote the LeDeR programme at a national level.
	Engage with national partners to LeDeR.
	Providing national communications about the programme.
Data	Ensure the availability of appropriate data and reporting tools for ICSs, regions and programme partners.
Action from learning	Liaise with other teams and programmes within NHS England and NHS Improvement and external partners to highlight relevant findings from LeDeR and agree appropriate action at a national level.
	Manage a repository of learning and good practice on the LeDeR website which will allow ICSs to learn from others.
	Manage national contracts relating to the running of LeDeR (including the LeDeR web-based platform, website, training and academic support) and other related work such as the annual report.
Resources	Manage and oversee the national budget for the LeDeR programme.
Governance	Hold regional teams to account for their region’s performance under LeDeR.
	Ensure the involvement of people with lived experience in all decision-making processes at a national level in respect of LeDeR.
Quality assurance	Reviewing the percentage of reviews being completed across the country at initial and focused review stages and work with regions to agree parameters within which acceptable proportions of reviews will fall

7. Delivery expectations

7.1 Local delivery expectations

CCGs and then ICSs will be expected to deliver the following in relation to LeDeR:

No.	Statement	Deliverables	Method of Measurement	Frequency of collection	Date of Delivery
1.	*A robust plan will be in place to ensure that reviews are completed within six months of the notification of death.	Target: 100% of reviews (both initial and focused) are completed within six months of notification.	Monthly dataset shows ICS completion of eligible reviews within six months of notification. Evidence of robust plans in place to achieve 100% where performance is below this figure.	Monthly	30 June 2021
2.	Each quarter all actions from LeDeR reviews will be considered and progress on delivery will be reported to the NHS England and NHS Improvement regional team	ICS will demonstrate each quarter that there is progress against delivery of LeDeR actions which will be monitored using a RAG rating	Quarterly reports to NHS England and NHS Improvement regional teams	Quarterly	30 September 2021
3.	*An annual LeDeR report demonstrating how the ICS is delivering on local actions addressing those areas identified in LeDeR reviews. The annual report will be published in June each year and will be taken to a public meeting of CCG/ICS/ HWB. It will demonstrate effective delivery of actions from learning from LeDeR reviews.	Annual report agreed at public meeting of CCG/ ICS and local Health and Wellbeing Board by end of Q1 each year. Annual report, including an accessible version published in June each year via the ICS website.	Documents approved within CCG / ICS governance and available as stated and shared with NHS England and NHS Improvement regional teams	Annually	30 June 2021

4.	*A three-year LeDeR strategy demonstrating how the ICS will act strategically to tackle those areas identified in aggregated and systematic analysis of LeDeR reviews and national findings including how the ICS will reduce the health inequalities faced by people from Black, Asian and Minority Ethnic communities who live locally who have a learning disability	Three-year strategy shared with NHS England and NHS Improvement's Regional Team and updated annually in June each year. Strategy contains section on issues faced by people with learning disability from Black, Asian and Minority Ethnic backgrounds who have a learning disability.	Documents approved within ICS governance and available as stated and shared with NHS England and NHS Improvement regional teams	Annually	30 June 2021
5	ICSs will demonstrate how they are narrowing the gap in health inequalities and premature mortality for those who have a learning disability in their local area	Locally determined targets agreed with NHS England and NHS Improvement regional teams to include measures around: • A reduction in the repetition of recurrent themes found in LeDeR reviews in a local area. • Reduced levels of concern and areas for improvement • Reduced frequency of deaths that were potentially avoidable or amenable to good quality healthcare.	Agreed with NHS England and NHS Improvement regional teams. Through LeDeR reporting and analysis of reports	Annually	30 June 2021
6.	Clear and effective governance in place which includes LeDeR governance within mainstream ICS quality surveillance and governance arrangements.	LeDeR actions reported on as part of routine quality assurance of the ICS and to the NHS England and NHS Improvement regional team.	Minutes of quarterly meeting of ICS governance meeting.	Annually	Plan in place 30 September 2021, Operational 1 April 2022
7	A named executive lead as SRO with accountability for LeDeR from across the ICS	Named executive lead as SRO for LeDeR within the ICS by June 2021.	Minutes of quarterly meeting of ICS governance meeting.	Annually	30 June 2021

8	*A named lead with responsibility for Black, Asian and Minority Ethnic inequalities	a) Named Black, Asian and Minority Ethnic lead within governance group by April 2021. b) Increased reporting of deaths from people from relevant Black, Asian and Minority Ethnic communities within the ICS proportionate and relative to the communities living within that geography	a) Minutes of quarterly meeting of ICS governance meeting. b) Baseline data April 2022	Annually Annually	a) 1 April 2021 b) 1 April 2022
9	Clear strategy for meaningful involvement of people with lived experience in LeDeR governance	Evidence of meaningful engagement of people with lived experience in local governance group by September 2021 which engages autistic people who have a learning disability proportionately to the number of notifications received locally for each group	Minutes of meetings Membership of meeting Report to NHS England and NHS Improvement regional team on approach	Annually	30 September 2021
10.	Senior ICS leaders, including local authority partners are involved in governance meetings where issues found in local reviews are discussed and actions agreed collaboratively, to support joined-up actions to improve services, reduce health inequalities and reduce premature mortality.	Clear accountability and ownership of actions with consideration of effective partnership working to support the success of the programme. Local needs will the direct partners within local governance structures by 1 April 2022.	Terms of reference for governance group submitted to NHS England and NHS Improvement regional team	Annually	1 April 2022

*existing deliverable

8. The use of data in LeDeR

8.1 Legal basis for processing personal information.

The LeDeR programme submitted a request under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 to process confidential patient information without consent. This received approval from the Secretary of State for Health and Social Care. Section 251 of the NHS Act 2006 (ref: 20/CAG/0067 (previously 16/CAG/0056)) is the legal basis that allows identifiable information about deceased people with a learning disability and autistic people to be shared with the LeDeR programme.

The current status of the Confidentiality Advisory Group (CAG) Section 251 approval can be located at: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/confidentiality-advisory-group-registers/ (April 2013 onward approved non-research applications).

Confidential patient information is information about either a living or deceased person that meets the following three requirements:

- Identifiable or likely identifiable eg from other data likely to be in the possession of the data recipient

and

- Given in circumstances where the individual is owed an obligation of confidence

and

- Conveys some information about physical or mental health or condition of an individual, a diagnosis of their condition; and/or their care or treatment.

The UK General Data Protection Regulation (GDPR) definition of personal data relates to any information relating to living individuals, this applies to personal information processed about family members and next of kin. Confidential patient information regarding deceased individuals is subject to the common law duty of confidentiality. The common law of duty of confidentiality requires that information that has been provided in confidence may be disclosed only for the purposes the subject has been informed about and has consented to, unless there is a statutory or court order requirement otherwise.

A CAG amendment will be required for reviews of autistic people's deaths and the information will be updated on the NHS England and NHS Improvement website before those reviews commence.

8.2 Compliance

UK GDPR and Data Protection Act 2018 are applicable in relation to records of deceased patients next of kin/family members. LeDeR must be able to demonstrate compliance with the six data protection principles which are summarised below:

1. **Personal data shall be processed lawfully, fairly and in a transparent manner in relation to individuals**

Under Articles 6(1)(e) and 9(2)(h) of the GDPR personal data must be processed in line with statutory duties - that of improving health and care service provision. LeDeR will be clear to agencies from whom we are requesting information about the purposes of the LeDeR Programme. LeDeR will not mislead people as to why we are collecting the information, and we will only collect information from those from whom it is relevant to collect it.

2. **Personal data shall be collected for specified, explicit and legitimate purposes and not further processed in a manner that is incompatible with those purposes**

Data collected for the LeDeR Programme will only be used for that purpose. However, if during the local reviews, safeguarding issues are raised that are putting any other person in danger, we have a duty under the Care Act 2014 to report it to the relevant safeguarding authority.

3. **Personal data processed must be adequate, relevant and limited to what is necessary in relation to the purposes for which they are processed**

Only the minimum information that is necessary for the purpose for the LeDeR Programme will be obtained.

4. **Personal data shall be accurate and, where necessary, kept up to date**

Personal data will be accurate and will not be misleading to any matter of fact. The source of information will always be included on records.

5. **Personal data shall be kept in a form which permits identification of data subjects for no longer than is necessary for the purposes for which the personal data are processed**

Information that is identifiable will only be held until the completion of the case review. After this, it will be pseudonymised. Pseudonymised data will be held for the retention time of 10 years.

6. **Personal data shall be processed in a manner that ensures appropriate security of the personal data, including protection against unauthorised or unlawful processing and against accidental loss, destruction or damage, using appropriate technical or organisational measures**

Organisations involved in the processing of data to support the LeDeR programme must be compliant with NHS Digital Data Security and Protection (DSP) Toolkit.

8.3 Data security and protection requirements

The Data Security and Protection Toolkit (DSP Toolkit) https://www.dsptoolkit.nhs.uk/ forms part of a framework for assuring that organisations are implementing the ten data security standards and meeting their statutory obligations on data protection and data security recommended in the government's response to the National Data Guardian for Health and Care's Review of Data Security, Consent and Opt-Outs and the Care Quality Commission's Review 'Safe Data, Safe Care'.

All organisations that have access to NHS patient data and systems **must** use the DSP Toolkit to provide assurance they are practicing good data security and that personal information is handled correctly. When completing a DSP Toolkit an organisation **must** meet the data security standards (see Appendix B).

All organisations involved in the LeDeR programme and processing patient data must maintain an up-to-date DSP Toolkit.

8.4 National data opt-out

The national data opt-out allows patients to opt out of their confidential patient information being used for research and planning. It applies to the disclosure of confidential patient information for purposes beyond individual care across the health and adult social care system in England.

National data opt-out continues to be maintained and applies for an individual after they have died. Upholding patient objections is a standard condition of CAG approval under section 251 of the NHS Act 2006.

The LeDeR Programme adheres to the National Data Opt-Out.

Appendix A: Outcomes of good local governance for LeDeR

It is the responsibility of individual ICSs to determine how LeDeR is best governed within its own quality and governance arrangements however, the governance of LeDeR must sit within the quality mainstream assurance and surveillance of the ICS and not isolated from it.

Local governance arrangements are expected to achieve, as a minimum, the outcomes listed below:

- Clear and robust reporting mechanisms including ownership by local quality governance systems as well as the Learning Disability (and Autism) System Programme Board.
- Clear ownership and accountability for completing reviews and for the delivery of actions.
- Involvement of people with lived experience in the decision making about what actions should be taken and in recruitment of reviewers and local area contacts and regional co-ordinators with autistic people and people who have a learning disability represented proportionately to the numbers of notifications received.
- Clarity regarding roles and responsibilities at all levels of the system including national, regional and system roles.
- Ensure that the appropriate workforce is in place across the system including recruitment of high-quality reviewers, training & refresher training including in relation to local circumstance and community, support is in place for reviewers, clinical/professional oversight and support is in place.
- Embedded as part of quality assurance/mortality/safeguarding work, primary care development/ownership, commissioning intentions, contract delivery to ensure service change is written into contracts.
- Oversight and engagement from all system partners including NHS, local authorities and elected members, provider trusts (specialist and acute), general practice, etc.
- Partnership working to support the success of the programme and make sure that no single interest will undermine the programme.

- All risks are assessed and managed well, putting in place actions and contingency plans for all high impact risk.

Appendix B: Data security

When completing a DSP Toolkit an organisation must meet the data security standards below:

People: Ensure staff are equipped to handle information respectfully and safely, according to the Caldicott Principles	
Data Security Standard 1	All staff ensure that personal confidential data is handled, stored and transmitted securely, whether in electronic or paper form. Personal confidential data is shared for only lawful and appropriate purposes.
Data Security Standard 2	All staff understand their responsibilities under the National Data Guardian's Data Security Standards, including their obligation to handle information responsibly and their personal accountability for deliberate or avoidable breaches.
Data Security Standard 3	All staff complete appropriate annual data security training and pass a mandatory test, provided linked to the revised DSP Toolkit.

Process: Ensure the organisation proactively prevents data security breaches and responds appropriately to incidents or near misses	
Data Security Standard 4	Personal confidential data is only accessible to staff who need it for their current role and access is removed as soon as it is no longer required. All access to personal confidential data on IT systems can be attributed to individuals.
Data Security Standard 5	Processes are reviewed at least annually to identify and improve processes which have caused breaches or near misses, or which force staff to use workarounds which compromise data security.
Data Security Standard 6	Cyber-attacks against services are identified and resisted and security advice is responded to. Action is taken immediately following a data breach or a near miss, with a report made to senior management within 12 hours of detection.
Data Security Standard 7	A continuity plan is in place to respond to threats to data security, including significant data breaches or near misses, and it is tested once a year as a minimum, with a report to senior management.

Technology: Ensure technology is secure and up to date.	
Data Security Standard 8	No unsupported operating systems, software or internet browsers are used within the IT estate.
Data Security Standard 9	A strategy is in place for protecting IT systems from cyber threats which is based on a proven cyber security framework such as Cyber Essentials. This is reviewed at least annually.
Data Security Standard 10	IT suppliers are held accountable via contracts for protecting the personal confidential data they process and meeting the National Data Guardian’s Data Security Standards.

Appendix C: How the LeDeR policy responds to the Oliver McGowan review recommendations

	Recommendation	Action to be taken by:	Does the new LeDeR policy address this issue
1	Reporting a person's death to the LeDeR programme should be mandatory, with the responsibility placed on clinical commissioning groups (CCGs) to ensure this happens in their locality.	Department of Health and Social Care	This is a recommendation for the Department of Health and Social Care (DHSC)
2	Clear guidance should be produced to enable CCGs to effectively 'triage' individual deaths, to ensure that the most appropriate governance methodology is used to review them (based on circumstances and complexity).	National LeDeR programme team	An improved LeDeR review process is outlined as part of this policy. A new training programme will equip reviewers to use the new process. Training and review documentation will also emphasise to reviewers to consider whether referral to statutory or complaints processes etc may be appropriate. **Section 3**
3	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.	CCG	This policy introduces multi-disciplinary LeDeR review teams led by Senior Reviewers to enable more effective professional and peer support for reviewers as well as buddying where appropriate. **Section 2.3**
4	There should be clear guidance on the roles of buddy and second reviewers.	National LeDeR programme team	This policy introduces the LeDeR review teams. Reviewers will not work alone but in multidisciplinary teams supported by a senior reviewer and administrative support. **Section 2.3**

Recommendation		Action to be taken by:	Does the new LeDeR policy address this issue
5	Dedicated time and administrative support must be given to reviewers and LACs to undertake complex LeDeRs.	CCG	This policy introduces the LeDeR review teams highlighting the role of administrative support and the expectation that reviewers will be NHS or local authority employees whose role it is to conduct LeDeR reviews. **Section 2.3**
6	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.	CCG	This policy outlines a series of expectations for the clear and robust governance of LeDeR within ICS systems. **Section 4**
7	Governance of LeDeR should be appropriately embedded into emerging new structures, such as sustainability and transformation partnerships (STPs) and integrated care systems (ICSs), from the onset.	NHS England and NHS Improvement	
8	Additional guidance should be produced that supports and advises LeDeR reviewers and LACs in situations where there are local disputes regarding the process or outcome of a LeDeR. This must include an independent escalation procedure to be used where there is a difficulty or impasse that cannot be resolved locally.	National LeDeR programme team	In this policy we are clear that LeDeR is not an investigatory process but a service improvement process. This should reduce the potential conflicts about any review however, the new LeDeR process has an enhanced role for regional teams to engage where there are disputes between ICSs and reviewers. **Section 5.3**
9	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 team responsibility to complete the process to the required standards, rather than it falling to an individual (the lead reviewer, in this case).	LACs and Lead Reviewers	The new review team structure will support team responsibility for completion of reviews. Reviewers will be supported by the senior reviewer and can access multi-disciplinary input from other team members. **Section 2.3**

	Recommendation	Action to be taken by:	Does the new LeDeR policy address this issue
10	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.	CCGs	This will be an expectation under the LeDeR delivery expectations outlined in this policy. **Section 6.1**
11	Experienced reviewers should be used when circumstances are intricate or challenging. The national LeDeR team should hold a national database of such reviewers to aid this process.	National LeDeR programme team	Each new review team will be led by a senior reviewer who will have the capability to take on intricate or challenging reviews and support reviewers to undertake challenging reviews. **Section 3.2**
12	The CCG executive lead for LeDeR will ensure that LeDeRs 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.	CCGs	These expectations are included in this policy under the roles and responsibilities of ICSs. **Section 5.1**
13	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.	LeDeR reviewers and LACs	LeDeR reviews will no longer include a MAR process. Instead, reviewers will access multidisciplinary support from within the review team. **Section 3.2**
14	One of the requirements for a MAR is determined by an initial scoring system of 1–6, with a score of 6 indicating that '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'. Currently, this scoring is not carried forward into the main report. It is recommended that there is a review of this scoring process and that the initial score is retained as a record in the main report.	National LeDeR programme team	This is being addressed in the way the new web platform is being developed.

	Recommendation	Action to be taken by:	Does the new LeDeR policy address this issue
15	In regard to the MAR meeting itself, it is recommended that there is action taken to: • ensure that families are central to the process, are offered full sight of all documents, and are invited to attend all or part of the meeting as they wish	CCG	Families will receive copies of redacted reviews going forward.
			Conversations between reviewers and families will be improved through better training and support for reviewers. Families will always receive a redacted copy of the review on completion. **New LeDeR Training (to be launched Spring 2021)**
	• review the purpose of the MAR with specific reference to the function of Question 8 (now Question 9 in version R05) and should this question be retained, provide clear guidance for MAR participants; also, to think through whether this question should be asked in confidence if it is a particularly difficult situation	National LeDeR programme team	Not applicable as MARs are no longer carried out in the same way. We have reviewed the approach to reviews in detail and in future reviewers will work in multi-agency teams in order to support one another professionally and ensure that all reviews benefit from multi-agency input where needed. Reviewers will have training on Mental Capacity Act and Best Interest Decision Making as part of ongoing training.
	• provide specific guidance and training for MAR chairs delivered by the national LeDeR team and families to include key topics such as the Mental Health Act, Mental Capacity Act and best interest decision making	National LeDeR programme team	
	• maintain a national list of experienced, trained people who could be called on to chair complex or contentious MARs.	National LeDeR programme team	Every team will have a senior reviewer who will be able to complete more complex reviews where these are necessary recognising that LeDeR reviews are service improvement reviews and not investigations or complaints processes.
16	There should be a review of the LeDeR methodology against similar processes, such as child death reviews, in order to garner the learning and include any improvements as appropriate.	National LeDeR programme team	In the production of this policy the National LeDeR team has engaged with a wide range of stakeholders including representatives from statutory processes, mortality reviews and similar processes.

	Recommendation	Action to be taken by:	Does the new LeDeR policy address this issue
17	A system process chart should be developed to enable reviewers to ensure they are undertaking the review correctly. This should include standard templates and a self-assessment tool that reviewers can use, to ensure consistency across the country.	National LeDeR programme team	A LeDeR process chart is included in this policy in **section 3.2** A new web-based platform will be launched in Spring 2021 to support the new LeDeR Review process. The new platform will make it easier for reviewers to follow the review process and this will be supported by the new training **New LeDeR web-based platform (to be launched Spring 2021)** **New LeDeR Training (to be launched Spring 2021)**
18	There should be an assurance process with regards to providing regular, appropriately documented supervision for individual LeDeR reviewers	CCGs	This policy introduces multi-disciplinary LeDeR review teams led by Senior Reviewers to enable more effective professional and peer support for reviewers as well as buddying where appropriate. **Section 2.3,**
19	The LeDeR guidance must make explicit (to all parties) that it is completely acceptable for LeDeR reviews, where appropriate, to arrive at differing conclusions to other reviews or inquests. This is on condition that they have the evidence to support this determination and that the LeDeR itself was subject to correct governance processes.	National LeDeR programme team	This policy highlights the requirement for the LeDeR reviews to co-ordinate with other review processes. LeDeR is a service improvement programme and as such identifies learning and recommendations to help provide better services to reduce health inequalities and reduce premature mortality and these may differ from the outcomes of other reviews, as LeDeR is not an investigatory process. **Section 3.2**
20	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.	CCGs	This policy introduces a new process for deciding actions from LeDeR reviews so that ICS leaders are engaged in the process of deciding actions and take responsibility for their monitoring and delivery. **Section 3.1,**

	Recommendation	Action to be taken by:	Does the new LeDeR policy address this issue
21	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.	CCGs and ICSs	This new national policy re writes the way LeDeR reviews are to be undertaken including governance, production of recommendations and monitoring of actions. Responsibility for LeDeR is moving from CCGs to ICS as part of this policy and we do not therefore believe that this is necessary for CCGs and ICS at this time.
	This review and the accompanying action plan must be submitted to, and monitored by, the local integrated care system (ICS), giving feedback to the national LeDeR team around progress. The panel wishes for a senior, single point of contact from NHS England and NHS Improvement to ensure all actions are taken and progress monitored.	NHS England and NHS Improvement	The national LeDeR team will monitor performance of ICSs in delivery of the new policy through its usual assurance routes supported by its regional teams.

Appendix D: Membership of local governance groups

While the national team cannot and will not dictate the membership of local governance groups generally, local ICSs will want to ensure that they have suitable membership of those groups to ensure that LeDeR governance is both robust and ‘mainstreamed’.

This is so that action planning around reviews of deaths of people with a learning disability and autistic people is not marginalised and is part of the quality assurance of mainstream services, which is where the majority of people with a learning disability die.

Membership should therefore consist of:

- family members who are carers (ICSs may want to specifically include a family member who is bereaved).
- people who have a learning disability (appropriately supported)

and senior leaders from:

- each of the main acute providers in an ICS
- the mental health and community learning disability team providers
- commissioning of acute (including ambulance providers), community mental health and learning disability and autism services (including those within provider collaboratives)
- PCN representatives across the ICS
- social care commissioning
- the provider arm of social care (where social care is delivered by the local authority)
- screening services (unless access to screening is demonstrated not to be an issue locally).

ICSs may wish to refine their membership by drilling down into their local data. For example, if an ICS finds they have significant numbers of people dying from poor care delivered in emergency care settings, the ICS may wish to ensure that the person responsible for quality in the emergency department is invited to the governance meeting where deaths of people with a learning disability and autistic people are discussed.

The ultimate aim of this work is to ensure that those who can take decision and action are present when actions are agreed and then hold themselves and others accountable and that the deaths of people with a learning disability and autistic people are seen as important as the deaths of others.

Appendix E: Draft data sharing agreement

Every ICS needs to have in place a robust data sharing agreement which enables appropriate data to be shared across the ICS to facilitate and enable LeDeR reviews to be completed in a timely manner. This draft agreement is shared here as an example only and each ICS will need to check the details with their own information governance advisors to satisfy their own processes.

This Data Sharing Agreement is made on [Insert date]	
1	Between: [*List the parties*]
2	Purpose, objectives of the information sharing: The Learning Disabilities Mortality Review (LeDeR) has Section 251 (of the NHS Act 2006) approval for the use of patient identifiable information in order that reviews can be undertaken of the deaths of people with learning disabilities. This approval provides assurance that the work of LeDeR has been scrutinized by the Confidentiality Advisory Group (CAG). The CAG is appointed by the Health Research Authority to provide expert advice on uses of data as set out in the legislation and advises the Secretary of State for Health whether applications to process confidential patient information without consent should or should not be approved. The key purpose of the CAG is to protect and promote the interests of patients and the public while at the same time facilitating appropriate use of confidential patient information for purposes beyond direct patient care. More information about Section 251 approval is available at: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/confidentiality-advisory-group-registers/ This aim of this agreement is to formalise information sharing arrangements between xxxxxxxxxxx and xxxxxxxxxxxx for the purpose of s251 approved reviewing deaths of people with disabilities and making practice improvements based on the outcomes of such reviews. Data Protection legislation only applies to living individuals. However, the eight Caldicott Principles always should be adhered to: 1. Justify the purpose(s) for using confidential information 2. Use confidential information only when it is necessary 3. Use the minimum necessary confidential information 4. Access to confidential information should be on a strict need-to -know basis 5. Everyone with access to confidential information should be aware of their responsibilities 6. Comply with the law 7. The duty to share information can be as important as the duty to protect patient confidentiality 8. Inform patients and service users about how their confidential information used.

3	Controller/s *[List here all organisations which are controllers as part of this agreement and for which purposes]*	
4	Processor/s [*List here all organisations acting as processors and sub-processors as part of the agreement (and to which purpose they relate to) and state which controller(s) they report to,* *or* N/A] [If no organisations acting as processors mark as N/A]	
5	Data items to be processed (add more lines if required) (These are the data items that will be shared subject to this agreement for each person who dies and whose death is covered by the LeDeR process)	
	Detail Item	**Justification**
	Name of the next of kin/relative of the deceased	Data protection legislation will only apply to the personal identifiable information collected about the next of kin/relative (name, address, telephone number and / or email). This is the minimum necessary to enable the deceased person's relatives / next of kin to be contacted to inform the review of the death. The legal basis for access to contact information is the s251 support. CAG s251 approval 16 CAG 0067 (previously 16 CAG 0056)
	Address of the next of kin/relative of the deceased	
	Telephone number of the next of kin/relative of the deceased	
	Email address of the next of kin/relative of the deceased	

	Name of the deceased	Data Protection Legislation does not apply to deceased persons information. For individual deaths to be reviewed, reviewers require access to the deceased's sensitive and patient identifiable information in order to trace the deceased person's pathways of care, obtain the views of agencies and family members regarding the circumstances leading up to the death, and obtain documentation from agencies who have supported the individual prior to their death. It is inevitable that the identity of the person who has died will need to be known to those contributing to the review. The legal basis for processing this information is the s251 support. CAG s251 approval 16 CAG 0067 (previously 16 CAG 0056)
	Date of birth of the deceased	
	Date of death of the deceased	
	NHS number of the deceased	
	First two digits of post code of the deceased	
	Gender of the deceased	
	Ethnicity of the deceased	
	Information about the circumstances leading to the death of the individual, including the person's medical history, details of diagnoses and treatments, contacts with services, the care and support that they have received prior to death	
6	Article 6 Condition – Personal Data Data protection legislation will only apply to the personal identifiable information collected about the next of kin/relative (name, address, telephone number and / or email). This is the minimum necessary to enable the deceased person's relatives / next of kin to be contacted to inform the review of the death. The legal basis for access to contact information of family members/next of kin is the s251 approval.	

	Legal Basis (One of these must apply whenever you process personal data)	**Tick which one you are using**
	(a) Consent: the individual has given clear consent for you to process their personal data for a specific purpose.	
	(b) Contract: the processing is necessary for a contract you have with the individual, or because they have asked you to take specific steps before entering into a contract.	
	(c) Legal obligation: the processing is necessary for you to comply with the law (not including contractual obligations).	
	(d) Vital interests: the processing is necessary to protect someone's life.	
	(e) Public task: the processing is necessary for you to perform a task in the public interest or for your official functions, and the task or function has a clear basis in law.	✓
	(f) Legitimate interests: the processing is necessary for your legitimate interests or the legitimate interests of a third party, unless there is a good reason to protect the individual's personal data which overrides those legitimate interests. (This cannot apply if you are a public authority processing data to perform your official tasks.)	
7	**Article 9 condition – Special Categories of Personal Data**	
	Conditions for processing special category data	**Tick which one you are using**
	(a) Explicit consent: (the data subject has given explicit consent)	
	(c) Vital interests: (to protect the vital interests of the data subject, who cannot give consent (life or death situations)	
	(f) Legal claims or judicial acts: (the establishment, exercise or defence of legal claims or whenever courts are acting in their judicial capacity)	
	(g) Reasons of substantial public interest (with a basis in law): (which shall be proportionate to the purpose and, respect the essence of the right to data protection)	

	(h) Health or social care (with a basis in law): (preventive or occupational medicine, for the assessment of the working capacity of the employee, medical diagnosis, the provision of health or social care or treatment or the management of health or social care systems and services)	
	(i) Public health (with a basis in law): (protecting against serious internal or cross-border threats to health or ensuring high standards of quality and safety of health care and of medicinal products or medical devices)	
	(g) Archiving, research and statistics (with a basis in law): (archiving purposes in the public interest, scientific or historical research purposes or statistical purposes	
	Other:	
	Please state (and indicate) below if you are processing data based on Schedule 1, Part 1, Data Protection Act 2018:	
8	**Individual rights and preferences**	
	Individual right	**Indicate how the right will be managed or why it is not applicable**
	The right to be informed	When families/next of kin are first involved/notified they will be invited to take part in the review. Full information will be provided and they will be asked to contribute information about the deceased to the review. The legal basis for processing their name, address and relationship to the deceased is a part of the s.251 agreement. Upon initial contact family members can agree to participate in the review or not. They are informed they can withdraw from the review at any time. This will be done via initial contact letter. The processing of personal information of people who have died is supported by S251 approval. Personal data about families is used to identify them as a contributor of information about a person who has died.

	The right of access	For living individuals this will be via existing Subject Access Request procedures. Requests access to deceased records will be via existing Access to health Records Act procedures.
	The right to rectification	For living individuals this will be done in accordance with existing procedures.
	The right to erasure	For living individuals this will be done in accordance with existing procedures.
	The right to restrict processing	For living individuals this will be done in accordance with existing procedures.
	The right to portability	Not applicable
	The right to object	For living individuals this will be done in accordance with existing procedures.
	Rights in relation to automated decision-making profiling	Not applicable.
	Please state below how you will manage any complaints raised regarding the proposed data sharing: (Insert here each organisations own IG process) **Does the National Data Opt-out apply to proposed purpose/s for data sharing? Y** **If yes, please state how these will be managed:** Organisations being asked to provide information in support of the review will check whether an opt out was in place and ensure that data is not unlawfully processed.	
9	**Compliance with duty of confidentiality / right to privacy** The LeDeR programme holds approval from the Confidentiality Advisory Group (CAG) of the Heath Research Authority under Section 251, for information to be shared for the purpose of the LeDeR programme without consent – ref 20/CAG/0067 (previously 16/CAG/0056). Details of the CAG S251 approval can be found on the Health Research Authority's website https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/confidentiality-advisory-group-registers/ . Where safeguarding concerns are identified in the course of a review data may be shared with appropriate safeguarding bodies. Details of relatives of the deceased will be used only to enable reviewers to contact them to discuss details of their relative’s death. **Is there any interference with Human Rights Article 8?** Not applicable	

10	**Transparency** The cohort are deceased therefore it is impossible to notify directly those affected. An ongoing communication plan is in place to raise awareness of the LeDeR across a broad cross section of stakeholders including but not limited to people with a learning disability, autistic people, families of people with a learning disability, families of autistic people, carer organisations, independent and voluntary sector organisations and health and social care statutory agencies.
11	**How will the data sharing be carried out?** • Data shared either by NHSmail-NHSmail (or using the NHSmail '[secure]' facility) or uploaded directly onto the secure web-based platform designed specifically for the LeDeR programme. • Data is not being transferred outside of the UK.
12	**Accuracy of the data being shared** Families that have contributed to the review will be given the opportunity to check that their views have been reported accurately. Access and Rights Request Procedure exists covering all data subject rights. For deceased patients the records cannot be changed.
13	**Rectification of data that has been shared** Families that have contributed to the review will be given the opportunity to check that their views have been reported accurately. Any identified inaccuracies will be rectified and standard operating procedures are in place for all to follow.
14	**Retention and disposal requirements for the information to be shared - including details of the return of information to the source organisations (if applicable)** Patient data is only retained until a review of a death is complete.
15	**Breach management** Managed in accordance with each organisations incident management policies and, in the case of reportable incidents, in accordance with NHS Digital's Guide to the Notification of Data Security and Protection Incidents and UK GDPR/Data Protection Act 2018.

16	**Specify any particular obligation on <u>any</u> party to this agreement** Each party agrees that they will put into effect the requirements below in order that the following points are complied with: • Each party maintain an up to date NHS Data Security and Protection Toolkit (DSP Toolkit) • Access to personal data must be used solely for the purpose of the LeDeR programme. • Appropriate information security protocols are followed to protect personal data. • Laptop computers or other portable electronic storage devices or removable media used by staff working or contributing to the LeDeR Programme are encrypted to protect any personal data processed on such devices. • Staff accessing the LeDeR web based platform system are appropriately trained for that use. • Confidentiality agreements are included in the contracts of all staff working in or contributing to the LeDeR Programme. • All signatories to this agreement accept responsibility for ensuring that all appropriate security arrangements are complied with. Any issues concerning compliance with security measures will form part of the annual review of this agreement.
17	**Contacts – Information Governance and Caldicott Guardian** [*List here the IG contacts for each organisation*]
18	**Commencement of agreement** [*Specify the date the Agreement will come into force*]
19	**Review of agreement** [*Specify if, and when, and by whom (specify job role) the agreement will be reviewed*]
20	**Review period** [*Specify, if applicable, how long any review period will be*]
21	**Variation** [*Specify here if the parties, or any party, can vary the terms of this agreement. If so, detail how this is done*]
22	**Ending the agreement** [*Specify how a party ends their participation in the Agreement, and how data will be managed by the exiting party*]
23	**End date** [*Specify the date the agreement ends*]
24	**Signatories** [*Each organisation signs here, detailing the name and position of the signatory based on the sharing required. ie DPO/SIRO/CG/CEO/Head of service*]

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