LeDeR Training Handbook

Version 1, May 2021

This guide complements the LeDeR training for reviewers and LACs. The guide should be read alongside the LeDeR policy which gives more detailed information about the core aims, values and governance of LeDeR. The policy also serves as a guide to professionals working in all parts of the health and social care system on their roles in delivering LeDeR.

LeDeR training

Anyone who needs access to the LeDeR web-based platform will need to undertake the online LeDeR training before using it. The online training can be accessed via the LeDeR web-based platform.

All users complete the same training regardless of their role and attend refresher training on an annual basis.

If a user has been inactive for six months or over, they will need to redo the training to ensure that they are confident in using the LeDeR system.

Advice for completing the LeDeR online training:

- Set aside a full day to complete the eLearning.
- You don’t have to complete it in a single day, you can complete the course over seven days, the system will log what you have completed. If you take longer than seven days, the training will expire and you will need to start again.
- Have a quiet place, so you can participate in the programme with minimal distraction.
- Use the next button to progress through the screens. The next button will appear when you have completed a section.
- Use the back button or content list to revisit any section.
- Be sure to use accompanying documents such as the case studies, reference materials, knowledge review and assessment sections.

Information governance

The Legal basis for sharing personal information for the LeDeR programme is explained in some detail from page 39 onwards in the LeDeR policy 2021. The policy covers:

- The definition of confidential patient information
- Approval for data to be shared for the purposes of LeDeR under Section 251 of the NHS Act 2006.
- The need to apply the principles of the UK General Data Protection Regulation (GDPR) to personal information about living individuals including family members involved in LeDeR reviews and what this means.
- The need to apply the common law duty of confidentiality for people who have died.
- The need for organisations who are processing patient data to maintain an up to date Data Security and Protection (DSP) Toolkit
- An introduction to the national data opt out (there is further information below)
- A draft data sharing agreement that can be used by ICSs

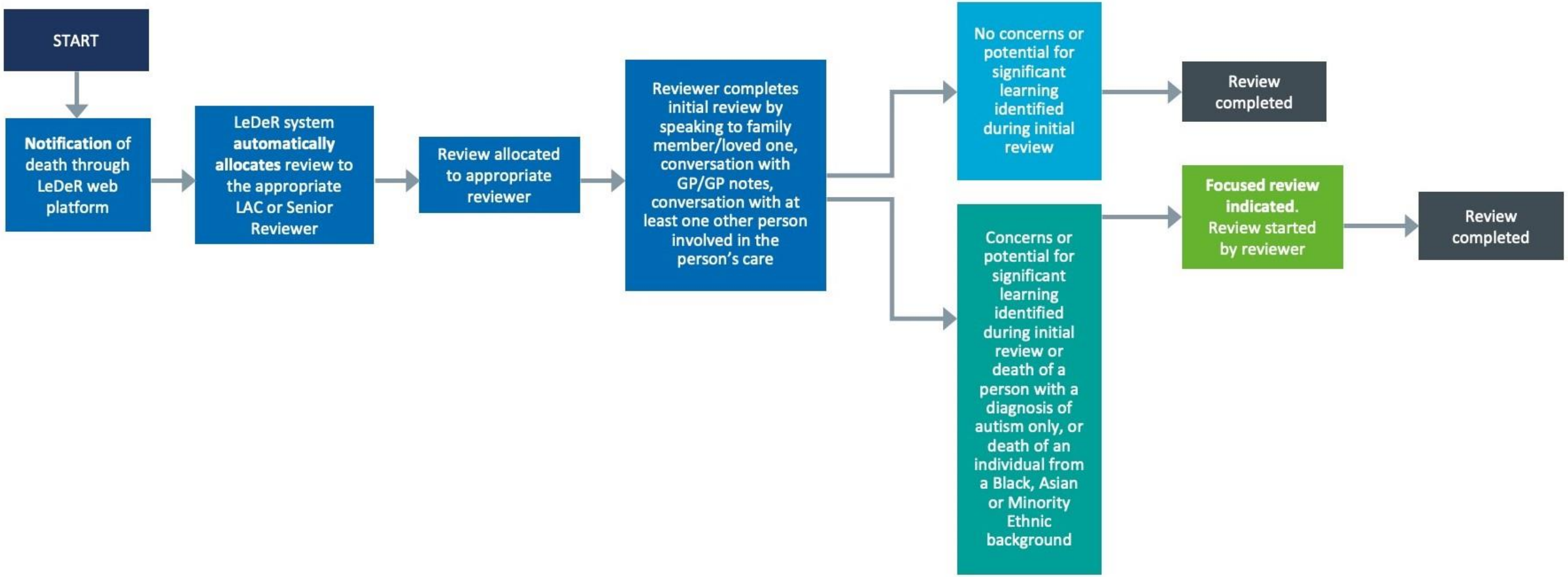
Confidentiality Advisory Group (CAG) Approval

The LeDeR policy 2021 gives the details of LeDeR's CAG approval to share patient information.

LeDeR's CAG Section 251 approval covers information sharing by health service bodies and relevant social care bodies. A relevant social care body is a local authority, or any other body or person engaged in the provision of social care on behalf of a local authority.

It is worth noting that at the time of writing (May 2021) the CAG approval for LeDeR applies only to data about people with a learning disability who have died. We are in the process of applying to have the approval extended to cover autistic adults. This will need to be in place before reviews for autistic people who do not have a learning disability begin in late 2021.

Overview of review process



Notifying a death

To notify LeDeR of a death:

- Click the ‘report a death’ button on the LeDeR website.
- Ensure the person is over four years old and click ‘start now’.
- Complete the form with relevant information. If you miss a mandatory field, the system will prompt you to complete it. Click on the problem line(s) to complete any missed field.
- When families notify a death, there are fewer mandatory fields.
- Click the ‘accept and send’ button, when you’ve completed and checked the form.
- The system will generate a reference number for the notification.
- There is an option to take a short survey which helps build the service and ensure it remains fit for purpose.

The notification form will require the following information

  - Your relationship to the person who has died.
  - Personal details of the person e.g. name, date of birth, date of death, age and sex.
  - Address of the person and where they died.
  - Ethnicity, religion and marital status of the person who died.
  - NHS number and GP details of the person. These are optional for a family member.
  - Next of kin details, do they know about the reporting?
  - Your (notifier) details
- Other questions include:
  - Has their death been registered?
  - Was it COVID-19 related?
  - What is the belief about the cause of death?
  - Has anyone else been notified about the death?
  - Do you have any concerns about the death?

Allocating a review

Once a death has been notified, it is automatically linked to a CCG & local region and appears on the local area contact (LAC) screen, ready for allocation to a senior reviewer. There is information on how to allocate a review in the LeDeR training.

When allocating a review the local area contact and/or senior reviewer should assess the notification form and likely complexity of a review to determine what skills and experience the review might need. They should also consider what the process should look like, whether additional support and resources are required and what form these should take.

Data opt out

If someone chose not to have information shared for use beyond patient care before their death, then that should be respected by LeDeR so that a review is not carried out. Organisations being asked to provide information in support of a LeDeR review should check whether an opt out was in place.

The LeDeR policy 2021 explains that LeDeR adheres to the National Data Opt-Out policy. This means that reviewers must be confident that the individual did not opt out of having their personal information used for research and planning purposes before their death. Any national data opt-out that has been set by a person with parental responsibility for a child under the age of 13 will remain in place unless and until it is proactively changed.

Review teams will need to ensure that records are not requested for those individuals who have opted out and a LeDeR review does not take place.

To check a list of notifications against the individuals' opt out status using their NHS numbers, review teams will need to implement NHS Digital's technical solution. The technical solution uses the messaging exchange for social care and health (MESH) to enable you to submit lists of NHS numbers and receive lists back with the NHS numbers removed for those patients that have opted out.

To help GP practices become compliant with the national data opt-out, the main GP IT systems are being updated with new functionality. This means that reviewers may also be able to identify individuals who have opted out through their GP practice.

Further information on the national data opt-out policy and how to comply can be found on NHS Digital's website here: https://digital.nhs.uk/services/national-data-opt-out/compliance-with-the-national-data-opt-out/check-for-national-data-opt-outs-service

Preparing for a review

In the initial review, the aim is to have a conversation with the person's GP (or review their GP notes) and at least one person who knew the individual well but ensure that this is proportionate to the number of people in their life and organisations involved in their care and support. So, if someone had many significant family members and others in their life or had multiple agencies involved in their care or at the end of their life, it would be appropriate to ensure a conversation with more than just one person as part of the initial review.

Before starting the review is it important to map the key people you will need to speak to. Reviewing the notification page will provide information which will help you decide who to talk to and will highlight where information is missing.

Before talking to the people on your list it is useful to do the following:

1. Review the initial review questions. Key questions include:

- Demographic data
- Cause of death
- Summary of discussion with family/ carer or someone who knew the person well
- Summary of discussion with the GP/ and or clinician involved in the care of the person who died
- Pen portrait
- Any long-term conditions linked to the cause of death
- Whether or not the person had a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) in place, with paperwork correctly completed

More on preparing for a review

Preparing for a review

2. Review the questions in the LeDeR 21 form and cross reference them with the information you already have. Consider mapping the questions where you will need to gather data and information, against the organisations that were involved in the person's care and support. This will help inform the request you send to each, including the questions you will want to ask.
   For example, if someone has a history of dysphagia, the questions in the focused review support your engagement with speech and language therapy.

3. Use a standard letter asking for data and information. Clearly define your requests and cover common questions likely to come up, for example data sharing, as well as a realistic timeline for response.

4. Make contact with people in key roles in relevant organisations, such as GP Practice Managers, social workers and care home managers.

5. Use smartcards for accessing GP records as an alternative to requesting copies of the notes.

6. Is there someone in a team coordinator role you can work with who focuses on data and information gathering, building relationships across their local area?

- Consider safeguarding issues or other investigations in place before contacting families – who is the person who knew the person best.
- Key prompts when speaking to families and others.

Accessing information

To complete LeDeR reviews, reviewers need to be able to access health and social care records and other information in a timely way about the person who has died. Not being able to access information relevant to the person, can delay a review.

Here are a few points to consider when preparing to gather the data for the review:

- Is the person's family engaged and aware of the review? An example letter template is available.
- Who was involved in the person's day to day care and support?
- Were other organisations involved in their last episode of care?
- The timeframe that data and information covers.

Sharing Health and Social Care Records with LeDeR

LeDeR GP leaflet

Historically there has been some resistance to sharing health and social care records with LeDeR, particularly from a small number of GPs. This should be reduced by the roll-out of smart cards for LeDeR reviewers (see next page for information about smart cards), however, in areas where this has not been possible, or where there is still concern, the GP leaflet can be shared with all providers of health services (including GP practices) as reassurance that LeDeR's CAG approval permits information to be shared.

More on accessing information

Using NHS smartcards for LeDeR

NHS smartcards are similar to chip and PIN bank cards and enable healthcare professionals to access clinical and personal information appropriate to their role.

A smartcard used in conjunction with a passcode, known only to the smartcard holder, gives secure and auditable access to national and local Spine enabled health record systems.

To use an NHS smartcard the staff member will need access to a smartcard reader.

The LeDeR policy 2021 recommends giving LeDeR reviewers NHS smartcards to enable them to access health records directly.

Each ICS will use a Registration Authority service in their area who manage smart card access rights and reviewers should contact their Registration Authority (usually via their CCGs IT support) to request smartcard access.

Further information on NHS smartcards, including contact details for local registration authorities can be found on NHS Digital's website here: https://digital.nhs.uk/services/registration-authorities-and-smartcards#smartcards

More on accessing information

Obtaining primary care records from Primary Care Support England (PCSE)

After a person has died, their paper primary care records will be transferred to Primary Care Services England (PCSE) for storage. This usually take some time and should not affect LeDeR reviews completed within the six month period expected.

PCSE cannot be a data controller for records relating to de-registered patients until they are physically transferred into their possession. Therefore, if a practice retains an electronic copy of the record on EMIS / SystmOne the practice continues to be legally responsible for that information and should provide you with the information when you ask for it. If paper records have already been transferred when notes are requested for LeDeR (for example, where notification to LeDeR has been delayed), LeDeR reviewers will need to complete a 'subject access request form' and send it to PCSE via email (pcse.accessrequests@nhs.net) to request access to the person's paper notes.

The subject access request form can be downloaded from PCSE's website here: https://pcse.england.nhs.uk/services/medical-records/accessing-medical-records/

Reviewers will need to include details of the Section 251 agreement for LeDeR on the subject access request form to ensure that the PCSE employee reviewing the request for access has sufficient detail to ensure that their decision on disclosure is accurate and appropriate.

As practices retain legal responsibility for electronic records, they can be asked to provide these after paper records have been transferred to PCSE (or they can be accessed by reviewers via NHS smartcards).

Contacting families

The example introductory letter template may help with your initial approach to the family. There is also an example post-review letter template which should be used after the review is completed.

The prompt sheets contain helpful tips for speaking to families and others.

Before you visit a family, you need to know the name of the person who has died, the family members' names and the circumstances. Check what other processes are ongoing such as safeguarding, serious incident or coroners. If other processes are ongoing, the needs of the family and carers should be given careful consideration so as to avoid duplication of questioning and unnecessary upset.

Knowing the basic facts allows you to build an initial rapport and shows respect to the individual who has died. For example, the name of the person who died and how to refer to them. Sometimes names are shortened. or people are known by their middle names or nicknames. Please be mindful of anniversaries and birthdays wherever possible.

More on contacting families

Contacting families

When talking to families reviewers should:

- Explain the LeDeR process as well as the benefits of families being involved. There is a family leaflet which may help with this.
- Make it clear this is a review, not an investigation. The aim is to learn what needs to change and not to incriminate individuals. It is essential to explain to families the purpose of LeDeR reviews and how they fit with other complaints and investigation processes. This can be confusing for families, and understandably, they may be expecting more from the LeDeR review than can be delivered. You will need to be clear and patient in your descriptions, available and willing to answer questions.
- Signpost to other processes where they are more appropriate
- Ensure that you leave contact details so the family can get back to the reviewer with any other questions they may have.
- Show warmth and kindness throughout the review. Individualise the family's experience and never treat this as a ‘box ticking’ procedure. It is not.
- Build in breaks if families are distressed. This can help to make conversations more manageable.
- Accurately reflect the concerns and questions the family has, to identify any issues where learning could help to improve services.
- Recognize the person who has died as an individual. The pen portrait is a good starting point for this.
- Inform families where they can access advocacy and other support services (do not offer bereavement support yourself or refer them to other bereaved families).
- Ask the family if they would like to provide feedback on the process

Contacting professionals

The initial review process involves either reviewing the person's GP records or having a **meaningful** conversation with their GP. The reviewer should also speak to at least one other person who was involved in the care of the person, this might be their social worker, a member of care staff, a member of the community learning disability team, a member of hospital staff, the person who has undertaken a Structured Judgement Review of the person's death, another family member, partner, friend or someone else who knew the person well.

If the pathway to the person's death was complex and involved many different organisations and parties, then are you are likely to need to speak to more than other person. The number of people you speak to should be proportionate.

The prompt sheets contain helpful tips for speaking to professionals.

Working with other processes

When undertaking a review, reviewers may have to either refer to or be involved in other sorts of reviews. These may include safeguarding, serious incidents or coroners' investigations.

During the initial review

If at any point whilst undertaking the initial review and gathering information, a reviewer is concerned about the care or treatment that the person had received they should stop and think about safeguarding and serious incidents.

If the reviewer has safeguarding concerns:

- The reviewer should stop the review and have a discussion with the senior reviewer or LAC about their concerns.
- The senior reviewer or LAC will then speak with the local safeguarding lead.
- The senior reviewer or LAC can decide in conjunction with the safeguarding lead, how to proceed.
- It is important to ensure the terms of reference for the Safeguarding Adult Review (SAR) includes the LeDeR review outcomes, and that someone represents the LeDeR programme on the subgroup.

If the reviewer thinks that a serious incident should be considered:

- The LeDeR reviewer should stop the review and speak with the senior reviewer or LAC in order to raise the incident with the organisation involved (this could be the patient safety lead or manager within a private provider).
- The information from the completed serious incident, can inform the LeDeR review.

More on working with other processes

Multiple processes

It is important to ensure that you avoid duplication. Reviewers need to be clear where and how the LeDeR process links with other review or investigation processes.

Where another review or investigation is indicated or underway, the reviewer should, in the first instance, discuss this with the senior reviewer or LAC. It is important that clear lines of communication between the review team or LAC and the lead/key contact of the other investigation or review process are established. On a case-by-case basis, the extent of each investigation or review, and a plan for the collection of core data for each review process, will need to be developed.

Once a Safeguarding Adults Review (SAR) or Serious Incident (SI) review is completed, the information from the review can be inputted into the LeDeR review.

If a number of other investigatory or statutory processes are undertaken looking into the death of an individual a decision not to undertake a focused review may be made other than where the person was from a minority ethnic community.

Talking to Families about complaints, investigations and inquests

If other processes are ongoing, the needs of the family and carers should be given careful consideration so as to avoid duplication of questioning and unnecessary upset.

It’s essential to explain to families the purpose of LeDeR reviews and how they fit with other complaints and investigation processes. This can be confusing for families, and understandably, they may be expecting more from the LeDeR Review than can be delivered. You will need to be clear and patient in your descriptions, available and willing to answer questions.

Health inequalities

When completing a LeDeR review it is important to remember that health inequalities are not caused by one single issue, but by a mix of environmental and social factors which play out in a local area or place such as race, ethnicity, education, poverty, health literacy and housing.

It is important for reviewers to understand the nature of the local population and consider any relevant aspects where health inequalities may need to be addressed.

People with a learning disability from minority ethnic communities face additional health inequalities and it is important that reviews consider factors in the person's care and support relating to race, ethnicity and culture. LeDeR is committed to identifying and addressing these additional inequalities.

Every LeDeR steering group has been asked to identify a named lead who will ensure that the challenges faced by people from minority ethnic communities in their local area are considered and addressed as part of the LeDeR programme.

NHS England and NHS Improvement's definitions of health inequalities.

Completing a Review

The LeDeR initial review and focused review forms follow a ‘skip logic model’. This means that for each case reviewers will only see the relevant questions. For example, if a reviewer indicates that a Do Not Attempt Cardiopulmonary Resuscitation (DNA CPR) decision was in place for the person then the questions on DNA CPR will automatically appear for completion.

Review the initial review questions to ensure that you capture all information that is required, key questions include:

- Demographic data
- Cause of death
- Summary discussion with family/ carer or someone who knew the person well
- Summary of discussion with the GP/ and or clinician involved in the care of the person who died
- Pen portrait
- Any long-term conditions linked to the cause of death.
- Whether or not the person had DNACPR in place, with paperwork correctly completed

The focused review builds onto the initial review. Data from the initial review will automatically populate the focused review form. The focused review asks for the reviewer to confirm if the person had any known medical conditions. For each condition that the person was affected by, a sub form will automatically appear containing further questions about the condition and applicable medication. The focused review also asks relevant questions regarding the social care and support the person received.

Completing the timeline

The timeline in the LeDeR21 form should provide an overview of important dates in relation to health and social care events.

Generally, you would expect to see a comprehensive overview of the person’s care for the last six months of their life.

However, there may be occasions where older information is required to provide a fuller picture.

More on completing a review

Completing a pen portrait

A pen portrait is a concise summary of the person, including their personality, how they communicated, their health and care needs and social activities. It is best practice to include the following in the pen portrait:

- Information about how the person communicated their needs or feelings, health and care needs, as well as service contact.
- The person's lifestyle, sense of belonging to the local community, family and other contact, significant life events, and social activities.
- Short summary of the person’s health in general, significant episodes of previous illness, hospital admissions, and if they were waiting for any health-related treatments.
- Important events in the person’s life that may have had an impact on their health.
- The pen portrait should be relevant and concise. The text is limited to 750 words so you may want to plan your portrait using a few words against key headings.

The purpose is to present a clear picture of the person, their health and care needs, and the extent to which those needs have or have not been met by health or care services.

Sources of information for the pen portrait include family, friends, support workers or other people who knew the person well.

When you’re writing the pen portrait, consider how it will be received by the audience, including bereaved families. Use the same language as friends and family used to describe the person and avoid using jargon.

Grading care

Reviewers will be asked to grade the care the person received at the end of a focused review (cases which only receive an initial review will not be graded).

Care is graded on two elements of the health and social care the person received:

1. Quality of care the person received
2. Availability and effectiveness of services the person

Care is graded on a scale of 1-6 where 1 represents poor care and 6 represents excellent care. The scales on which care is graded can be found on the next page. **Please note that this is different to how LeDeR previously graded care.**

The system may suggest a grade for a review based on the answers a reviewer has given to previous questions (for example, where the reviewer has indicated that there were gaps in service provision or NICE guidance was not followed the system will suggest that the review is graded as a 3). The reviewer can change the suggested grade and add an explanation as to why they have changed it.

When a review is graded 1 or 2, it is important for the reviewer to think about potential safeguarding and serious incidents and speak with the local area contact.

More on grading care

Grading care

Grade	Quality of care	Availability and effectiveness of services
6	This was excellent care (it exceeded expected good practice). Please identify in learning and recommendations what features of care made it excellent and consider how current practice could learn from this.	Availability and effectiveness of services was excellent and exceeded the expected standard
5	This was good care (it met expected good practice). Please identify in the review learning and recommendations any features of care that current practice could learn from.	Availability and effectiveness of services was good and met the expected standard
4	This was satisfactory care (it fell short of expected good practice in some areas but this did not significantly impact on the person's wellbeing). Please address these issues in your recommendations for service improvement, and identify in learning and recommendations any features of care that current practice could learn from	Availability and effectiveness of services fell short of the expected standard in some areas but this did not significantly impact on the person's wellbeing.
3	Care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to the cause of death. Please address these issues in your recommendations for service improvement, and identify any features of care that current practice could learn from.	Availability and effectiveness of services fell short of the expected standard and this did impact on the person's wellbeing but did not contribute to the cause of death.
2	Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.	Availability and effectiveness of services fell short of the expected standard and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.
1	Care fell far short of expected good practice and this contributed to the cause of death.	Availability and effectiveness of services fell far short of the expected standard and this contributed to the cause of death.

Quality

There are a number of mechanisms built into the LeDeR process to ensure that reviews conducted are of a good quality:

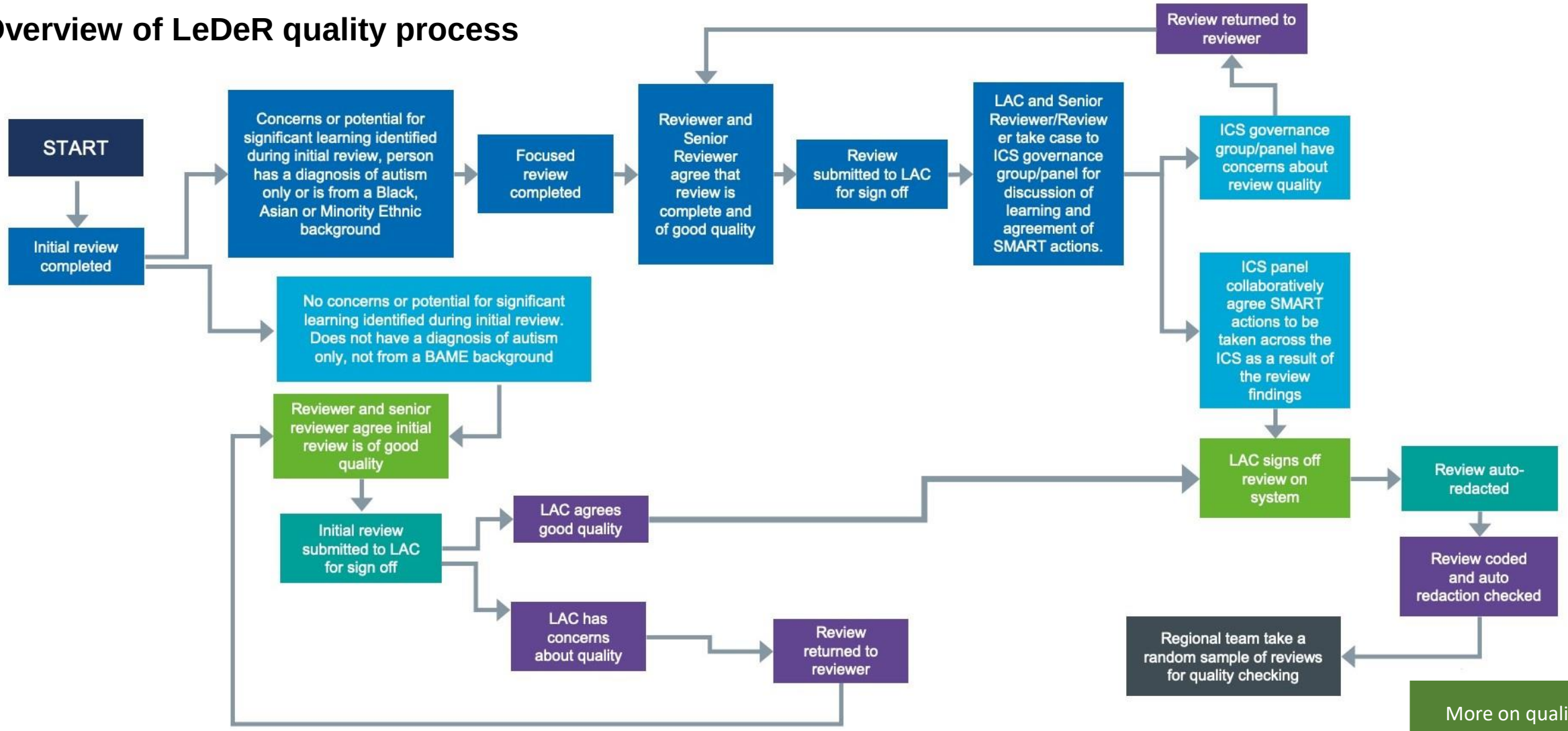
- Reviewers must complete the LeDeR training before conducting their first review and refresh their training annually.
- Reviewers must be employed on at least a 0.5 wte basis to ensure that they are well practised in completing reviews and can do so in a timely way.
- Reviewers are part of multidisciplinary team and can access peer support and professional supervision.
- Regional teams will quality check a random sample of reviews in their region.

Once a review has been completed by a reviewer, there is a quality process to check that the review meets quality standards. An overview of the quality process can be found on the next page.

1. The first step in the quality process is for the reviewer to agree with their senior reviewer that the review is of good quality. The quality checklist may help with this.
2. The review is then submitted to the LAC.
3. The next step differs according to whether the review is an initial review or a focused review:
    a) If the review is an initial review the LAC will review for quality, sign it off if they agree that it meets quality standards or return to reviewer for further work if it does not.
    b) If the review is a focused review then the reviewer or senior reviewer and the LAC take the review to the governance group to agree SMART actions and to sign off in terms of quality. If the panel agrees that the review meets quality standards then the LAC will formally sign it off on the system, otherwise it will be returned to the reviewer for further work.

More on quality

Overview of LeDeR quality process



More on quality

Quality

	Quality Checklist
Structure	Accurate and concise, and written in a way that is clear, jargon free and not repetitive.
	Where used, complex medical and organisational terms are explained simply.
	Fact based timeline describing the events leading up to the death of the person.
	Comprehensive and proportionate pen portrait.
	Highlighted relevant issues which are supported by evidence.
	Clear reasons for any missing information, or information not made available to the reviewer.
	Logical progression in the reasoning, and conclusions supported by facts.
Gathering and analysing information	Evidence of appropriate involvement of families at the relevant stages of the review process, or an explanation of why family has not been involved.
	Appropriate evidence available and used e.g. case records from agencies involved.
	Relevant parties involved in the review process.
	Appropriate focus upon identifying potential contributory facts and learning from the circumstances leading to the person's death.
	Observations on care and treatment are valid and supported by evidence.
	Focus is upon improvement.
	Actions as a result of learning are SMART and are cognisant of, and feed into, the strategic plan for the local area.

Delivery of actions from reviews

At the end of a review the reviewer will need to identify issues, concerns or potential problems with care and reflect these in the findings. They will also need to identify any good practice that could benefit others.

Generally reviewers will not set actions or give recommendations.

The actions that are set as a result of the learning from LeDeR reviews should be set by local governance panels/ groups and must be SMART. SMART stands for:

- specific,
- measurable
- achievable
- relevant
- time-bound

Very occasionally, in some infrequent cases, **in initial reviews**, 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. The reviewer and senior reviewer will agree these and the LAC will approve when the review is submitted. The CCG/ICS will need to ensure that they have oversight of the delivery of these actions.

In both cases, actions will be added to the CCG or ICS's action plan and delivery of the actions will be monitored by the ICS with oversight from the governance group. LACs must ensure that action owners are aware of what is expected of them.

Finalising a review

Once an initial review has been signed off by the LAC or a focused review has been approved by the governance group the LAC will sign it off on the system and it will be sent for coding and redaction by South Central and West CSU.

When the review has been redacted it should be shared with **everyone who was involved in the person's care** including their family, their GP and all health and care providers. The post-review letter for families template can be used as a covering letter.

Useful information

LeDeR Information, Systems and Support

South, Central and West LeDeR Technical support email address: support.leder@nhs.net

NHS England and NHS Improvement LeDeR national team email address: england.lederprogramme@nhs.net

Link to LeDeR policy: https://www.england.nhs.uk/publication/learning-from-lives-and-deaths-people-with-a-learning-disability-and-autistic-people-leder-policy-2021/

Legal basis for sharing information with LeDeR

Details of the CAG S251 approval (ref: 20/CAG/0067 (previously 16/CAG/0056)) 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/

The General Medical Council's (GMC) Confidentiality Guidance advises that doctors should disclose relevant information about a patient who has died where disclosure is authorised under section 251 of the NHS Act 2006. Paragraph 137 of the General Medical Council (GMC) guidance: https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/confidentiality/managing-and-protecting-personal-information#paragraph-137

Other Information

Inclusion tool for Learning Disability: https://www.learningdisabilityservice-leeds.nhs.uk/get-checked-out/resources/gps-and-practice-staff/