National Learning Disability Review Development Project

Stage 1 – Options Development Report

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Executive summary

Background
For almost two decades, there has been evidence showing a higher prevalence of early mortality and significant health inequalities among people with a learning disability (LD). In response to the most recent report on this issue by the Confidential Inquiry into the premature deaths of people with learning disabilities (CIPOLD), a national mortality review function for people with learning disabilities is now being established.

What did we do?
The National Confidential Inquiry into Suicide and Homicide by People with Mental Illness (NCISH) was commissioned by the Healthcare Quality Improvement Partnership (HQIP) to develop an options appraisal report to inform the specification for a national mortality review function for people with learning disabilities. The questions we were asked to address were:

1. How can learning disability mortality cases be identified? Where this is not possible, what remedial action needs to be taken?
2. What degree of learning disability should be included in a National Learning Disability Mortality Review Function i.e. mild, moderate or severe?
3. What data linkages already exist, are likely to be created and which are needed to allow for a comprehensive register of all people with a learning disability?
4. Which deaths would be reviewed (all or a random selection)?
5. Should only cases of death be reviewed or should case note review around a particular topic area e.g. choking or management of diabetes where the individual has not died (serious morbidity cases) be considered for review also?
6. What will be the process for reviewing deaths and who would be involved on the reviewing team/panel?
7. What are the governance issues in obtaining clinical and patient information and how can we streamline this process?
8. How would learning from each case review be communicated and spread across the NHS/health and social care system?
We therefore carried out a review of relevant literature, engaged with experts in the field of LD, including people with LD, their families and carers, and national charities and representative organisations. In particular, we sought the views of members of NHS England's project oversight group.

**What should a national mortality review consist of?**

We suggest that the national mortality review function should be developed in line with a number of principles and that whatever decisions are made about the final shape of the mortality review function, it should conform to these. The specific answers to the questions above are presented in Box 1 below.

1. The national mortality review function should be a long-term initiative, reflecting the importance of the topic but also the time it will take to develop a comprehensive national review process. However, this should not delay the setting up of the optimum feasible review function in the immediate future, with a pragmatic focus on deaths and on people known to services, i.e. predominantly adults with severe LD or syndromic causes.

2. The aim of the mortality review function should not simply be to demonstrate higher mortality in people with LD - that is already well established. It should aim to drive improvement in services, by clarifying the contribution of various causes, and measuring variation (e.g. between areas) and impact of service change.

3. The overall review function should consist of local and national components. Exactly where the balance should lie between local and national, and what the relationship between them should be, are features of the options that we are presenting. However, a strong local process is a feature of all options - there are already a number of excellent local initiatives.

4. The overall mortality review function should be based on "graded" data collection in which there is a trade-off between the number of deaths and the amount of information collected nationally on each. This would mean that (i) the national collection of detailed information from intensive case review would be limited to a selected sample of deaths, (ii) a short standardised dataset would be developed for all reviewed cases and (iii) a small amount of information would be collected on all deaths.

5. All stages of the mortality review, but particularly examining cases and drawing up recommendations, should include people with LD, their families or carers, and representative organisations.

6. In addition to the mortality review itself, there are additional pieces of work that need to take place to strengthen the process in the future. These are on subjects such as death certification,
reasonable adjustments and data linkage and they will mean joint working with other organisations. We have presented these separately to the options for mortality review.

7. The review function should work alongside other key initiatives on learning disability, in particular the Improving Health and Lives Learning Disabilities Observatory (LDO) project within Public Health England. The LDO would be able to provide population-level data that would support a fully functioning national mortality review. More broadly, governance arrangements should encourage a closer relationship to bodies that can provide intelligence or help disseminate findings, e.g. the Care Quality Commission (CQC).

Topics that a national mortality review function should address

Most people we spoke to supported a rolling programme of thematic priorities for the mortality review to investigate. Suggested topics were:

1. Differences in services and social conditions between areas with apparent high and low rates of mortality.
2. Deaths from specific clinical causes, namely epilepsy and aspiration pneumonia.
3. Deaths in specific demographic groups, namely children and ethnic minorities.
4. Deaths in specific conditions, namely Down’s syndrome, diabetes and obesity.

Options for a national learning disability mortality review function

Key features of three options are presented below. They are presented as distinct although it would be possible to mix certain features or change the emphasis from one option to another over time. More detailed descriptions are presented in section 9.2.

Option 1: a balance of local and national processes

Key features of option 1 are:

- The national review function will be built on a robust model of local case review carried out by a multi-agency panel, to include people with LD and carers. Local services, led by local authorities (LAs) and Clinical Commissioning Groups (CCGs), will identify people with LD who have died; all cases will be reviewed, leading to lessons for local services. Sources of data will include case notes, reports from professionals and, if possible but not a requirement, interviews with families.
- The national team will aim to build up the number of participating areas, identifying local leadership and providing advice on standardised methods including a core data tool.
- The national team will receive core data on all cases, recording these on a central database.
• The national team will develop a web-based national review function for selected cases according to an agreed rolling programme of thematic priorities (see above) - this could also be a means of quality assurance of local reviews.

• As the number of participating areas increases, the national team will be able to examine variation between local areas - for example, areas that appear to have high v. low numbers of deaths or, over time, that appear to be showing substantial v. little improvement.

Advantages of this option are that it would explicitly set out to expand and strengthen local review and local learning, linking this to a more selective system of national review. There is already a mechanism for collaboration between local agencies, the Joint Health and Social Care Self-Assessment Framework (SAF). Central data collection will allow less common causes of death to be studied and will help to transfer learning between areas.

Disadvantages are that participation will be voluntary and locally-resourced. Only half of local LD partnership boards were able to contribute complete mortality data to the SAF. A national panel of reviewers will have to be recruited and supported.

An important feature of this option will be the intention to develop an alternative and more comprehensive method of identifying individuals with LD who have died, from primary care LD registers - for example, using the General Practice Extraction Service (GPES), linked to Office for National Statistic (ONS) mortality data. This would allow the national team to support LAs by notifying them of deaths in their areas eligible for review. However, this would be a complex process and is relatively untested at present.

Option 2: a predominantly local process

Option 2 is similar to option 1 but with a reduced national component:

• The national team will have no case review role.

• It will however develop and standardise reviews in local areas, receive and analyse core data on all cases and disseminate recommendations.

Advantages are in avoiding the time and cost of setting up a secure website and expert panel to support a national review function; and in ensuring local involvement in reviews of national thematic priorities. Disadvantages are greater reliance on participation of local services and the quality of local reviews, and reduced capacity for national learning.
Option 3: a predominantly national process

Option 3 is similar to option 1 but with a greater role for national case review:

- In addition to reviewing cases corresponding to thematic priorities, the national team will review a sample of cases in general.
- Sampling will be based on cases identified through GPES and ONS mortality data (see option 1).

Advantages will be greater reliability, with the national team carrying out more reviews, and less dependence on the quality of local review. Disadvantages will be that the national-local collaboration will be weaker. National sampling will require a high proportion of local areas to participate. The use of GPES in this way is new (see option 1). An alternative primary care database, the Clinical Practice Research Dataset (CPRD), may be used for related projects but does not allow identification of individuals.

Additional projects

As well as the options for the mortality review function itself, a number of projects should be carried out alongside this, in collaboration with other organisations:
1. A national mapping and typology of reasonable adjustments.
2. Improving death certification in LD.
3. Use of GP registers and data linkage in support of case identification and sampling (see options 1 and 3).

Costing

We estimate the costs of options 1 to be £775,000, including GPES. Costings for option 3 are similar and for option 2 are substantially less because there is no national-level case review. Excluding GPES or using an alternative extraction system would reduce the costs of any option. Additional projects will cost in the region of £50,000 each per year.

Conclusion

We believe that option 1 should be the preferred option, with the additional projects, and following the principles outlined above. We have outlined the key components of a service specification in Box 2. We have not addressed every detail - it will be up to groups bidding for this work to fill in the remaining gaps.
Box 1: Answers to the questions we were asked to address.

How can LD mortality cases be identified?
Mortality data alone cannot identify people with LD who have died because LD is poorly recorded on death certificates. However, GP LD registers, which GPs are paid through the Quality Outcomes Framework (QOF) to maintain, could be linked to ONS mortality data in order to measure a national LD mortality indicator. At the moment however, we are not confident that this system can be relied on - further work will be needed to test it. The pragmatic alternative is to ask all local services to identify deaths of local people with LD, i.e. known to LD services. (see section 6.1)

What degree of LD should be included in a national mortality review function?
It will be necessary to identify people with LD through service contact and initially that will mean limiting the review, at least in adults, to predominantly severe LD. Recording of LD in primary care is said to be improving and over time, it will be possible to include more people with mild-moderate LD. (see sections 7.2 and 7.5)

What data linkages already exist, are likely to be created, or are needed to allow for a comprehensive register of all people with a LD?
The GPES is the only national extraction service for obtaining patient data from GP IT systems across England. Data linkage between ONS mortality data, GP data and Hospital Episode Statistics (HES) data would be possible via a GPES extraction (once information governance procedures were completed). However, it is unclear whether GPES will be fully functional in the near future and further development work is suggested (see sections 7.5 and 9.3). The CPRD is an anonymised clinical dataset of participating GP practices with an established link to ONS mortality and HES data. However, the CPRD is currently based on around 9% of practices nationally and, being anonymised, is unable to provide a sampling frame for case review.

Should all deaths be reviewed or a random selection?
Even with the current restriction to more severe LD, there are over 3,000 eligible deaths nationally - too many for national-level review. However, we are proposing that all deaths, including child deaths, should be reviewed locally (20 per LA on average), with main findings feeding into a core national dataset, while the national review function concentrates on thematic priorities. In our predominantly national option, a random sample of local deaths would also be reviewed. (see section 6.2)

Should only cases of death be reviewed or should case note review around a particular topic area where the individual has not died (serious morbidity cases) also be considered for review?
It will be a major task to set up a review function focused on mortality; any expansion to serious morbidity should wait until this is fully functioning.

What will be the process for reviewing deaths and who would be involved on the reviewing panel?
Local review should be multi-agency and should include people with LD and families or carers. The local review process should submit core data, key findings and recommendations to the national team for aggregation. Cases reviews by the national team should be uploaded to a secure, web-based case note viewing system. An expert panel of assessors should be recruited, again multi-agency with people with LD, carers/families and representative organisations. (see sections 6.2)

What are the governance issues in obtaining clinical and patient information and how can the process be streamlined?
Obtaining patient data will be dependent on obtaining Section 251 approval or on receiving Direction status, in addition to adhering to the thorough information governance procedures of the Health and Social Care Information Centre (HSCIC) who manage GPES. Data sharing agreements will be required to access data from local authorities, such as Child Death Overview Panel (CDOP) reports. (see sections 7.5 and 7.7)
Box 1 continued.

How would learning from each case review be communicated and spread across the NHS and health and social care system?

The national review team would publish findings and recommendations from thematic reviews and collated from local reviews. We suggest an annual report, including an easy read version. We are also proposing versions of any report targeted at different audiences and closer working with organisations that can drive service improvement, such as CQC. (see section 8)

Box 2: Essential elements of a service specification

(i) To identify local services that will conduct multi-agency case review into deaths of people with learning disability
(ii) To prepare a process and timetable by which all services will set up local review
(iii) To develop a standardised methodology for case review, including input from people with LD and families/carers, and a core dataset
(iv) To establish a central database for aggregating core local data
(v) To establish a process for the identification of thematic priorities, i.e. topics for detailed study
(vi) To create a secure website for national-level review and recruit a national panel of reviewers
(vii) To draw up a proposal for the development of more comprehensive identification of deaths of people with LD, based on linkage of current databases
(viii) To draw up project plans and timetable for related work: developing a national map of reasonable adjustments and a process to improve death certification in LD
(ix) To develop a proposal that will ensure the national mortality review function will work alongside other key initiatives in learning disability.
1. **Background**

There are approximately 1.14 million people in England with a learning disability (2% of the general population) of whom one fifth are children.\(^1\) Furthermore, projections of future need suggest the number of people requiring LD services will increase by at least 1% per annum over the next two decades.\(^2\)

The higher prevalence of early mortality in people with LD compared to the general population has been known for almost two decades.\(^3,4\) Evidence of health inequalities for people with LD have been reported since the publication of the government report Valuing People, in 2001\(^5\) (see Box 3). Mencap’s report Death by Indifference,\(^6\) the subsequent Michaels Report Healthcare for All\(^7\) and the Parliamentary and Health Service Ombudsman’s report Six Lives\(^8\) all documented the failures of health and social care services to comply with equalities legislation and highlighted widespread poor healthcare provision for people with LD leading to compromised patient safety.\(^9\) The Michael’s report\(^7\) recommended the establishment of the Learning Disabilities Public Health Observatory and a Confidential Inquiry tasked with examining the premature deaths of people with LD ‘to provide evidence for clinical and professional staff of the extent of the problem and guidance on prevention’.

The Confidential Inquiry into the premature deaths of people with learning disabilities (CIPOLD)\(^10\) subsequently investigated the deaths of 247 people with LD (aged 4+) in five Primary Care Trusts (PCTs) in South West England between 2010 and 2012. Thirty-seven per cent of deaths were judged to have been avoidable due to failings in the healthcare system; this was compared to 13% of the general population. Individuals with a LD died on average 16 years earlier than individuals without a LD.\(^11\) Extrapolating these figures to the English population, Glover and Emerson\(^12\) calculate approximately 3.5 deaths of people with LD per day could be avoided through good quality healthcare, equating to 25 deaths per week.

Eighteen key recommendations were identified by the CIPOLD study that if implemented, would reduce the risk of premature death in people with LD, of which one was to establish a national learning disability mortality review body. In the US, Connecticut’s state-wide LD mortality review is well established and has led to changes in practice.\(^13\) In the UK, although a national LD mortality review function has not yet been established, some local areas have developed a review function for people with LD who die in their catchment area. For example, the North East and Cumbria LD Clinical Network are working with the LDO to develop systems to identify avoidable and premature deaths of people with LD in their area (see section 8.11).\(^14\)
Since the publication of the CIPOLD report, the government has set out a range of actions across the 18 CIPOLD recommendations to improve the experience and outcomes of people with LD and their family carers, with an update on progress 12 months later. Mencap have, however, been critical of the government’s response one year on from CIPOLD stating there has been an ‘unacceptable lack of progress in stopping avoidable deaths’.

2. Aims and objectives

The National Confidential Inquiry into Suicide and Homicide by People with Mental Illness (NCISH) was commissioned by the Healthcare Quality Improvement Partnership (HQIP), on behalf of NHS England, to produce an options appraisal report providing a number of options, for the NHS England Project Oversight Group to consider, on how a national project on mortality in people with learning disability could be taken forward. The aim of the options appraisal project was to answer the following questions:

- How can learning disability mortality cases be identified?
- What degree of learning disability should be included in a national learning disability mortality review function i.e. mild, moderate, severe, profound?
- What data linkages already exist, are likely to be created, or are needed to allow for a comprehensive register of all people with a learning disability?
- Should all deaths be reviewed or a random selection?
- Should only cases of death be reviewed or should case note review around a particular topic area e.g. choking or management of diabetes where the individual has not died (serious morbidity cases) also be considered for review?
- What will be the process for reviewing deaths and who would be involved on the reviewing panel?
- What are the governance issues in obtaining clinical and patient information and how can the process be streamlined?
- How would learning from each case review be communicated and spread across the NHS and health and social care system?

The objectives of the options appraisal project were to:

- examine the topic of mortality in people with learning disabilities in detail, drawing on existing literature and data, in order to understand the extent of premature and/or avoidable death in people with learning disabilities, and the general standard of care that they receive;
Box 3: Key reports

**Valuing People (2001)** the first government report for 30 years outlining a strategy for LD services.\(^5\)

**Treat Me Right (2004)** showed that ‘urgent action is needed to improve the health of people with a learning disability’.\(^7\)

**Equal Treatment: Closing the gap (2006)** a formal investigation of the physical health inequalities experienced by people with LD and/or mental health problems showing people with LD were 4 times as likely to die of preventable causes as the general population.\(^18\)

**Death by Indifference (2007)** a review of the deaths of six people with LD, which publically exposed the unequal healthcare that people with LD receive while in the care of the NHS.\(^6\)

**Healthcare for all (2008)** an independent inquiry into access to healthcare for people with LD established, concurrently to the Ombudsman investigation,\(^8\) by the Department for Health (DH) and in response to Death by Indifference\(^6\). It highlighted the need for systems to be developed in primary and secondary care so that the journey of people with LD is traceable.

**The NHS Operating Framework for 2009/10 (2008)**\(^19\) directed PCTs to make ‘reasonable adjustments’ for people with LD as set out in Healthcare for all\(^7\) and subsequent updates seek to reduce deaths and to address inequalities in healthcare provision.

**Six Lives: The provision of public services to people with learning disabilities (2009)**\(^8\) an Ombudsman investigation of the six deaths in Death by Indifference\(^6\) that found ‘maladministration, service failure and unremedied injustice’ in a number of the NHS bodies and local councils involved.

**Valuing People Now (2009)** set out a strategy to improve support, opportunities and services for people with LD.\(^20\)

**How people with learning disabilities die (2010)**\(^21\) found half of people with LD and no physical condition reported as a cause died 15 years younger than people without LD.

**Six Lives Progress Report (2010)**\(^22\) assessed any improvements to healthcare and treatment for people with LD since the initial Six Lives\(^8\) report.

**Death by Indifference: 74 deaths and counting (2012)** reviewed progress since Healthcare for all\(^7\) and concluded that ‘not enough progress has yet made in addressing the health inequalities experienced by people with a learning disability’.\(^23\)

**CIPOLD (2013)** found that people with LD continue to have poor experience and outcomes compared to people without LD.\(^10\)

**Government response to CIPOLD (2013)** in relation to recommendation 18 the ‘DH and NHS England agree that better information is needed to enable an accurate assessment of the causes of death of people with learning disabilities’.\(^14\)

**Premature deaths of people with learning disabilities: progress update (2014)** an update summarising action taken or underway against each of CIPOLD’s recommendations which identified that ‘more detailed scoping work is required to define the detail of how a mortality review function would work, before a review can be procured’.\(^15\)

**CIPOLD one year update report (2014)** Mencap’s ratings of progress against the 18 CIPOLD recommendations show: (i) progress in three; (ii) some progress in nine; and (iii) unacceptable progress in six recommendations.\(^16\)
• engage with experts in learning disability, including people with LD, national charities and organisations representing people with a learning disability, Patient Safety Leads at NHS England, the HSCIC, and the National Clinical Directors for Children and Learning Disability;
• identify the role of existing data sources in supporting a national mortality review function; and
• propose a number of options for a learning disability review function, highlighting advantages and disadvantages associated with each option.

3. Methods
Three approaches were used to meet the project’s aims and objectives. Firstly, stakeholders, people with LD and their family carers, and potential providers of the review function (via email, text message, telephone calls, and meetings) were consulted on the (a) main questions that the review function should address, and (b) relevant sources of data. Secondly, a literature review of existing research on the mortality of people with LD was conducted, including the findings of the CIPOLD report. Thirdly, relevant sources of data that would allow for the most effective design for the future monitoring of deaths of people with LD, including data linkage, and how these could be applied to establish a LD review function within a set budget were considered.

4. Themes raised by stakeholders
The following key themes arose from consultation with stakeholders, people with LD and family carers on the main questions to be addressed by the review function, other opinions are also dispersed throughout the report.

Identifying and defining people with all spectrums of LD
➢ The review should be fully inclusive of all severities of LD, mild/moderate LD being under-recorded currently in health and social care systems, and should include Autistic Spectrum Disorder (ASD) where there is also LD.
➢ There is no way of identifying mild LD in the short term; in the mortality review LD will have to be defined by health or social care service contact and this will continue to exclude people with mild LD.
➢ The review should capture all deaths of people with learning disabilities, including children (from the age of 4) and offenders.
➢ The review should include all people with LD regardless of their residential status at the time of death (i.e. should not just include hospital deaths).

Mortality and morbidity
The review should address the most common health conditions and co-morbidities associated with preventable mortality in people with learning disabilities are and whether access to better quality care (i.e. screening, flu vaccinations and annual health checks) could improve future outcomes.

The most common health conditions that were mentioned were: epilepsy, congenital heart disease, respiratory diseases, aspiration pneumonia, diabetes, obesity and incontinence.

The response to the death of a person with LD, including post-mortem or inquest.

**Access to good quality healthcare**

Continued focus on poorer access to healthcare than the general population and how this could be improved - for example, hospital passports and the provision of a 24 hour learning disability liaison nurse function, improving the provision of and access to annual health checks and associated health action plans and screening, better training in LD for all healthcare professionals specifically in reasonable adjustments and the Mental Capacity Act (MCA), the use of easy read literature, the use of jargon free language during appointments, and longer appointment times.

Better understanding, recognition and staff training in working with people with LD with limited or no communication.

Recognition of the impact a regularly changing workforce and the use of bank staff can have on a person with LD’s feeling of safety, particularly in a residential care setting.

Continued focus on poorer health outcomes for people with learning disabilities and whether a poor health outcome (i.e. premature, avoidable death) is correlated with poor care provision (i.e. the lack of a learning disability liaison nurse, lack of access to screening/an annual health check), personal characteristics (especially those that come under the 2010 Equality Act), and/or living conditions.

The extent to which reasonable adjustments are in place, and how well they are personalised to the individual, and whether the individual is ‘flagged’ as having a LD when referred to secondary or specialist care from primary care.

How well the MCA is enacted and understood among clinicians, families and carers, and whether there was a proportional response to the MCA if needed (i.e. was urgent treatment undertaken when required rather than waiting for all the relevant professionals to be consulted and thereby delaying a potentially lifesaving procedure?)

How to avoid diagnostic overshadowing, and pejorative attitudes such as how people with LD may not be seen as having ‘worthwhile lives’ (i.e. the use of Do Not Attempt Cardiopulmonary resuscitation) or as unable to cope with intrusive medical procedures.
 Whether the Equalities Act is applied in practice during health related activities.
 Whether people with LD and their family and carers have appropriate input into their health and social care?

_Evidence of improvement_
 Whether any of the deaths could have been avoided through better healthcare and if the number of avoidable deaths decreases year on year as evidence of the implementation and measurement of key recommendations.
 The identification of lessons to be learnt and how they could change practice across the NHS.
 Whether rates of mortality (including preventable mortality or mortality amenable to better healthcare) are changing over time (and by personal characteristics and living conditions).

_Geographical variation_
 The extent to which rates of mortality among people with LD vary by geography.
 The review needs to examine geographical variations in care over time in order to be better able to identify deficits in care.

_The wider social and health care context_
 What was the wider social or health care context in which people with LD were being supported, and whether there were gaps in their care throughout their lifespan that could have prevented the outcome?
 What the background was to a person’s death and whether there were any circumstances, such as regular hospital admissions, availability and access to advocacy, change in/lack of care-coordinator, which could have contributed to the death (or prevented the death if the circumstances were different)?
 Was the person receiving the support they needed prior to their death, for example in getting health checks, health action plans and access to screening?
 What is the impact of deprivation and wider determinants of health (including employment, income, housing, diet, Body Mass Index (BMI), smoking status) on the rates of mortality in people with LD?
5. **Lessons from NCISH**

In setting up and modifying the methods of NCISH, we have had to address many of the questions now facing the LD mortality review function. In particular, there are four aspects of NCISH methodology that could be applied.

5.1. **Balance of national and local data collection**

When NCISH was relocated to the University of Manchester in 1996, information on people who died by suicide or who received an open verdict at coroner’s inquest were forwarded regularly to NCISH by the Directors of Public Health (DPH) in what were then 104 health authority districts in England and Wales. All health authorities agreed to take part, and some used the system as a basis for local case review. Over time we replaced this system with national identification of cases, but the facility for local services to use standardised national methods locally has remained. In particular, national data collection is based on a standardised questionnaire that can also be used for local audit.

5.2. **"Graded" data collection**

NCISH collects three levels of detailed data. On all suicides and homicides, there is a limited dataset covering basic demography and geographical area. On all mental health patients, there is a standardised dataset covering key aspects of health and social care. On selected patient groups there is more detailed information, usually obtained by additional projects.

5.3. **A rolling programme of priority topics**

Every year an open call for new study topics is made by NCISH. Initial assessment of topics for feasibility and cost is made by the NCISH team and final selection of topics is made by an independent advisory group. This allows more intensive study of deaths that are causing particular concern to stakeholders.

5.4. **Assessing the impact of service change**

At NCISH we have examined the uptake and implementation of our main recommendations by services, and compared suicide rates pre- and post-implementation in those NHS Trusts that had implemented each recommendation. Over the study period the number of recommendations implemented increased and lower patient suicide rates were found among those services implementing a higher number of recommendations. Specific service changes were associated with large falls in suicide in the patient groups they were intended to target. This methodology could be applied to changing services and reasonable adjustments and their impact on LD mortality.
6. Case review

In this section we consider the features of case review and questions that would have to be addressed in establishing a national mortality review function.

6.1 Local case review

Local case review after a death is a widely used method of investigation and it was the basis of the CIPOLD method. Applied to deaths of people with LD, it should be multi-agency and should include families or carers and people with LD themselves. The individuals who take part need to be independent of the services that are being examined. The gold standard for case review includes interviews with the families of the individual who has died as well as case-note review; this is a rich source of locally-relevant information. However, making this a requirement might deter LAs from taking part at all - it can add considerably to costs, families need support if they are to contribute, and there is potential confusion with complaint-handling or independent inquiries. Therefore, we see it as desirable, to be done where possible.

On the other hand, case-notes alone may be insufficient. Their strength as a source of information is that they are a contemporary record, written before a death has occurred and therefore uninfluenced by knowledge of outcome. They can be lacking in relevant detail and will need to be supplemented by reports from key staff members, written after the death.

Case review can lead to immediate changes in local practice, especially if a formal component of “reflective learning” is included, but it does also carry general disadvantages. It is resource-intensive and largely unstandardized, being based on the views of individuals. It can be unfocused unless well-led and conclusions may be general rather than specific and therefore difficult to put into practice. The information from a series of reviews can be hard to aggregate. Local case review relies on a system of case identification; in the deaths of people with LD, this will be limited to people who are known to services, identified either through local records or an electronic tool such as MiQuest (see box 4).

Assuming that there are over 3000 identifiable deaths per year, a comprehensive review function system based on local case review would expect an average-sized local authority to review over 20 cases per year. Some LAs will have much larger numbers and sampling will be needed – another potential source of bias. There is a local collaborative mechanism – the LD Partnership Boards (see Box 5) Self-assessment framework – that could be built on. At the moment, around half report...
complete mortality data – the first step in a case review process. A local multi-agency system of case review (CDOP) already exists for children (see section 7.7).

Our proposals therefore place considerable emphasis on the importance of local case review but recognise that it is of variable depth and quality – and may not be done at all in some areas. It is not possible simply to expand the more intensive CIPOLD method to all parts of the country. We believe the role of a national review function should include improving the quality of local review, incorporating a desirable standard of interviewing families and other people involved in the individual’s death, encouraging all LAs to conduct a review of sufficient depth to provide core data, and providing a platform for dissemination of findings.

<table>
<thead>
<tr>
<th>Box 4: NHS MiQuest system</th>
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</thead>
<tbody>
<tr>
<td>• MiQuest is a direct query tool used by commissioning organisations that enables them (subject to consent) to execute queries and extract data from different types of GP practice information systems (of which there are six) using a common query language i.e. Read codes.</td>
</tr>
<tr>
<td>• Once the MiQuest query is run a table of data is returned through NHSnet.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Box 5: Learning Disability Partnership Boards</th>
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</thead>
<tbody>
<tr>
<td>• Partnership Boards were established following Valuing People, and they ensure that the government proposals in Valuing People and Valuing People Now happen in their area.</td>
</tr>
<tr>
<td>• There are 152 Partnership Boards in England, although coverage varies (see appendix 2).</td>
</tr>
<tr>
<td>• Partnership Boards are accountable to Health and Wellbeing Boards</td>
</tr>
<tr>
<td>• They are most often geographically arranged around upper-tier local authorities; with the exception of Lancashire who define themselves based on former PCT boundaries.</td>
</tr>
<tr>
<td>• Partnership Board members include representatives from: (i) patients and their families; (ii) health services; (iii) advocacy services and voluntary organisations; (iv) employment services; (v) education; and (vi) council services.</td>
</tr>
<tr>
<td>• Partnership Boards do not have a clear place within LA decision-making processes and have limited authority.</td>
</tr>
</tbody>
</table>

6.2 National case review

A case review function at national level will have similar advantages and drawbacks to those already described for local review. However, it will be based more on case notes, supplemented by reports from professionals. It will be able to assess a sample of deaths, selected randomly or by cause of death, demographic group, local area characteristics, etc. National-level review will rely on a national panel (or regional panels) and is likely to be more reliable than local review because all
reviewers are drawn from a limited group and can be trained and supported in the same way. It can be difficult to manage logistically: a web-based review facility, presenting case-notes and other reports, could help address this.

Additional features of national review are outlined below.

6.2.1 A graded system of data collection
A graded system of national data collection is a sliding scale in which there is a trade-off between the number of cases and the amount of information collected on each. In the LD mortality review function, this would mean: (i) demographic data on all deaths in England of people with LD in contact with services; (ii) the collection of core standardised data on all people whose deaths have subject to local review; (iii) intensive case review on a sample of cases driven by different priority questions.

6.2.2 Rolling set of priority topics
One way of sampling at national level is by cause of death, with a rolling set of priority causes selected after consultation. Topics suggested to us for thematic review were: (i) differences in services and social conditions between areas with apparent high and low rates of mortality; (ii) deaths from specific clinical causes namely epilepsy and aspiration pneumonia; (iii) deaths in specific demographic groups namely children and ethnic minorities; and (iv) deaths in specific conditions, namely Down's Syndrome, and people with diabetes or obesity. This would be similar to the programme of work of the Child Health Review-UK (see section 8.7) who last year published their findings on a themed case review of morbidity and mortality in children and young people with epilepsy, and to NCISH’s programme of work (see section 5.3).

6.2.3 Ensuring geographical spread
Geographical variations in service configuration, e.g. the degree of development of community rather than residential care, and the impact of local deprivation on the mortality of people with LD have been highlighted in our consultations. These factors may affect the basis of sampling or, as with NCISH, allow analysis of service predictors of higher or lower mortality. The sampling of cases will also need to consider the residential status of individuals prior to death, e.g. living away from home in residential care or in hospital. There is also evidence that residential homes are concentrated in less affluent areas or in areas where property prices are less expensive. Geographical variation in the mortality of people with LD may be influenced by historical patterns of institutional settings with ex-residents from the old institutional homes settling in the local area. It is also likely that different
areas prioritise different services, with some areas focusing on community living and others on residential care.

6.2.4 "Very serious error cases"
One disadvantage to case sampling is that it can omit individual cases that are of substantial importance. This may be because they illustrate fundamental problems in care that may be less clear in other cases, or because they illustrate a rare or new failure of care. It may also be that they are serious enough to achieve a national profile – one such case is the death of Connor Sparrowhawk by drowning on an LD assessment unit.

6.2.5 Judging the standard of care
Judging the standard of care after a death has occurred is problematic; retrospective bias is hard to avoid. Where possible the review process could adopt objective standards of care against which services could be assessed in an individual case. Objective standards would ideally be based on National Institute for Clinical Excellence (NICE) clinical guidelines or quality standards, or similar published sources. In addition, care should be assessed for reasonable adjustments and a method of doing this in a way that is comparable across care settings should be developed.

6.2.6 Approximate costs of a case note review
Using examples from other Clinical Outcome Review Programmes (CORP), the cost of case note review per year would be approximately £175,000. This would include costs associated with locating, accessing, receiving, scanning and redacting medical records; some data costs; panel, training or chapter-writing meetings; and the maintenance of a secure, web-based case note viewing system (including costs for programmers for the secure system, but excluding the initial costs for procuring this). This estimate excludes the majority of staffing costs i.e. mid-grade and senior-grade research staff and high-level staffing costs. We anticipate, as with existing CORP programmes, that local assessors will not be paid for their time.
The use of register data

7.1 Definitions of LD

Definitions used to describe people with learning disabilities vary across countries, studies, and over time (see Box 6). In the UK, three definitions are most commonly used, the definition in Valuing People5 (e.g. see 7,32-34), the definition in the current version of the World Health Organisation’s (WHO) International Classification of Disease (ICD-10)35 (e.g. see 3,4), and the definition of the LDO36 (e.g. see 10,11).

A further factor in defining a person with LD is whether or not they have comorbid autism. The definitions of LD described above include autism as long as the person also has a LD,5,34 but do not include people with a higher level ASD who may be of average or above average intelligence.5 The WHO definition35 specifies that autism if present with LD should be coded independently as a pervasive developmental disorder.

7.2 Severity

Typically LD is divided into 4 degrees of severity: (i) mild; (ii) moderate; (iii) severe, and (iv) complex or profound. The WHO ICD-10 classification35 provides a description of each of these degrees of LD severity (see Box 6). The review function should encompass people with all severities of LD, whilst acknowledging that there is likely to be an under-estimation of people with mild LD, as will be discussed in more detail below.

7.3 Age

The CIPOLD study included children from the age of 4 in their reviews.10 The review function should also adopt this lower age limit. At 4 years a child enters the school system and could potentially be referred to a SEN register, and thus identified as having LD. However, this will exclude children who are born with severe disabilities who die (predominantly in hospital) before they acquire a LD label. In terms of an upper age cut off, the review function should be bought into line with the NHS Outcomes Framework Indicator 1.7 ‘Excess under 60 mortality in people with LD’ or with the ongoing work of the North East and Cumbria LD Clinical Network (particularly if the age range for indicator 1.7 is extended) who propose establishing an upper age limit of 75 - the average life expectancy in the general population.

7.4 Identification and prevalence of people with LD

There is no definitive record of the number of people with LD. Best estimates are derived from a combination of research, population predictions and data on the number of people with LD using
Box 5: Definitions of learning (or intellectual) disability

**American Association on Intellectual and Developmental Disabilities (AAIDD)**

Intellectual disability is characterised by significant limitations in both:
- intellectual functioning, measured by an IQ test score of around 70 or under, and;
- adaptive behaviour, problems with the collection of conceptual, social, and practical skills that people use in their everyday lives, which;
- originates before the age of 18.

**Valuing People**: Learning disability includes the presence of:
- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with:
- a reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development.

**WHO ICD-10 classification**: Mental retardation (F70-79) is a condition of arrested or incomplete development of the mind, characterised by impairment of skills (cognitive, language, motor, and social abilities) manifested during the developmental period. Degrees of mental retardation are estimated by IQ tests and supplemented by scales assessing social adaption.
- **Mild** – IQ range of 50 to 69, some learning difficulties in school, many adults will be able to work, maintain good social relationships and contribute to society
- **Moderate** – IQ range of 35 to 49, marked developmental delays in childhood, some degree of independence and adequate communication and academic skills
- **Severe** – IQ range of 20 to 34, require continuous need of support
- **Profound** – IQ under 20, severe limitation in self-care, continence, communication and mobility.

**A working definition of LD**: Consider an adult or child to have a LD if any of a number of conditions are met:
- have been identified within education services as having a Special Educational Need (SEN) associated with moderate, severe or profound multiple learning difficulty
- have an IQ score of less than 70
- have been identified as having LD on locally held disability registers (including registers held by GP practices or PCTs) or by relevant Read codes in health information systems
- they attended a special school or unit for children with moderate, severe or profound multiple learning difficulty
- they report having significant difficulties in literacy and numeracy and there is evidence to suggest they have had these difficulties since childhood.
health and social care services.\textsuperscript{1} For most adults with LD this is unknown not only to their GP but to any health or social care service,\textsuperscript{37,38} especially given the drop in the reported prevalence of LD from 3\% among children to less than 0.5\% among adults.\textsuperscript{39} In particular, information on people with mild LD is poorly recorded and so little is known about this population.\textsuperscript{1}

7.5 GP registers

Since 2006 GP practices have been rewarded, through the QOF, for maintaining a register of adults with LD on their practice lists (in addition to other relevant indicators such as epilepsy, diabetes, obesity, and seasonal influenza vaccination uptake). In order to benefit from this performance related scheme and receive payment for identifying patients with LD, GP practices have to support external automated queries that operate through NHSnet to annually extract this information through pre-determined computer codes or Read codes. Effective from April 2014 the age restrictions for the QOF LD indicator were removed so the LD register GPs are paid to maintain under QOF now include people with a LD of any age.\textsuperscript{40} Approximately 5 in every 1000 adults with LD are currently identified on GP practice lists (see Table 1), roughly equivalent to the number identified in LA adult social care, but only one sixth of the number known to schools.\textsuperscript{37} The number of people identified on GP LD registers is however increasing (92\% of the CIPOLD sample were on their GP’s LD register\textsuperscript{10}; see Table 1).

\begin{table}[h]
\centering
\begin{tabular}{|l|c|c|c|c|c|c|}
\hline
\hline
Total number of people (>18) on GP LD registers & 144,909 & 160,165 & 179,064 & 188,819 & 198,877 & 206,132 \\
Rate per 1,000 adults & 3.40 & 3.80 & 4.20 & 4.33 & 4.53 & 4.66 \\
\hline
\end{tabular}
\caption{Prevalence Data from GP LD Registers for England (age 18 and over)\textsuperscript{1,41}}
\end{table}

Although GP data is the best available standardised source of data on the number of people with LD in the general population there are a number of limitations:

(i) GP registers do not capture all people with LD. Evidence shows, for example, that the number of adults identified by their GPs as having LD is approximately half that who are receiving Disability Living Allowance\textsuperscript{1};

(ii) current data on the number of children with LD on GP LD registers and whether the expansion of QOF has impacted on the recording of LD in children is not yet available (the QOF does not provide age standardised data, but this could be estimated by comparing with data from previous years). It is expected, however, that the expansion of the QOF to an all age register will improve the identification of children with LD on GP registers and allow them to be tracked into adulthood;
(iii) for the majority of adults with mild or moderate LD with no apparent syndromic cause this is unlikely to be identified or recorded by their GP (and may not be wanted by patients themselves), a significant number of people with Down’s syndrome are also not included on GP LD registers as they have mild LD;
(iv) people with mild LD are less likely to be known to social services and hence will be missing from any GP LD registers that are populated by LA notifications of people using social care services. GP LD registers that are populated only by LA notifications will also have many more patients with severe than mild LD.
(v) There is an age-specific decline in the prevalence of LD at the point of transition to adult health or social care services because children with a LD in education may not be eligible for adult LD services and are therefore unlikely to be identified as having a LD on GP registers (referred to as the transition cliff). However, it is anticipated that the new Education, Health and Care Plans (EHCP), introduced in September 2014, may improve the transition cliff. EHCPs are statutory plans which replace the Statement of SEN (which ceased when a young person left school) and are designed to coordinate the support available to families across their child’s education, health and social care from birth to 25 years. An EHCP can therefore be taken from school into further education and training.

How GP LD registers could be used as a data source for identifying people with LD who have died

GP data extraction systems extract information from the main GP IT systems, either nationally (GPES), locally (MiQuest, PRIMIS) or in anonymised samples of participating GP practices (the CPRD, The Health Improvement Network, IBM Information Management System and QResearch). The GPES allows for the extraction of Read coded patient data from GP IT systems across England. Other datasets, like the CPRD, extract Read coded data from an anonymised sample of GP practices across the UK.

GPES

GPES is a centrally managed process through which extracts can be obtained of information from computerised notes systems in all GP practices in England. It is the only national extraction service for obtaining patient data from GP IT systems across England. It is managed for the NHS by the HSCIC and involves thorough information governance procedures. GPES extracts Read coded data from GP IT systems. Other elements of the patient record that are not Read coded (i.e. free text, diagnostic images, scanned letters) are out of the scope of GPES. Data extracted from GP systems are returned to the HSCIC and passed on to the customer; the HSCIC’s copy of the data is then deleted.
Linking ONS mortality data with GP data via an annual GPES extraction would enable the development of a comprehensive national database on the causes of premature mortality in people with LD. Further linkage with other health data systems (i.e. HES, the Mental Health and Learning Disability Data Set (MHLDD) and cancer registries), LA processes for reviewing child deaths and social care data (although this would only be possible at an aggregate upper-tier LA level) would allow the collection of further information on the individual’s care and their circumstances prior to their death. Obtaining patient-identifiable information for case review could also be achieved by specifying in a data extraction request to GPES that a patient identifiable data extract is required. GPES supports the extraction of both patient-level and aggregate data, and the HSCIC works with each prospective customer to understand and refine the details of the data extraction request with each request undergoing an information governance assessment.

**Advantages**

GPES is the only national process for extracting aggregate and patient-level data from GP patient records, covering all GP information systems in England and thus providing Read coded data on the most complete population of people with LD that there is available, as well as the basis for a sampling frame.

**Disadvantages**

It is currently taking GPES in the region of 40 weeks from initial enquiry to data provision. HSCIC is, however, looking to streamline this process. The demand for data extractions using GPES also exceeds current capacity so HSCIC is working through a backlog of GPES extraction requests. NHS England, the DH and the HSCIC, however, recognise the importance of LD work and the HSCIC is currently undertaking prioritisation work that balances high priority areas such as LD with wider data extraction commitments. Work is also underway with HSCIC to seek clarity about the timeframe for delivery and the capacity of GPES to deliver data extractions. However, GPES may not be operational in a timescale suitable for the review function.

GPES requires GP practices to ‘opt-in’ to new studies requesting GPES data extractions (as set out in the GPES Information Governance principles). Extractions of data using GPES would therefore be reflective of the number of GP practices that opted into the study. There is also a mechanism within GPES that captures ‘a patient’s preference to be excluded from disclosures of patient identifiable data by GPs for secondary uses’.\(^2\) It is the responsibility of any GP practice that opts in to the study
to make patients aware of how their data are used for research purposes and to give them the opportunity to opt out of their data being used in this way. Therefore no patient data will be extracted by GPES if the GP has recorded a patient’s objection to disclosure for secondary uses. However, the Confidentiality Advisory Group (CAG) can provide a legal justification to set aside the common law duty of patient confidentiality for defined medical purposes. The CAG’s advice to the Secretary of State can also provide GPs with a legal basis to disclose patient identifiable data without consent (section 251). If HSCIC were to receive Direction Status (see Box 7) from NHS England (or the DH) this would override the need to go to CAG. HSCIC would thereby have to be the informatics provider for the review function. However, the issuing of Directions does not override the requirement of GP practices to opt in or the patient’s right to opt out of their data being used for secondary purposes. The advice on whether HSCIC could be given Direction status to ‘override’ these confidentiality issues varies, and such data governance issues (including the sharing of identifiable information on individual cases) would need to be addressed and clarified in the first year of the national review function.

**Box 7: Directions**

- Directions are a written instruction that is drawn up by lawyers, to an organisation (i.e. the HSCIC) to facilitate data collection or to process certain information.
- Directions do not automatically address issues including capacity, confidentiality or practice/patient consent, but they can provide a legal basis for the collection of patient identifiable data without consent that would otherwise require another statutory basis (Section 251 of the NHS Act 2006).
- There are powers in various Acts of Parliament for the Secretary of State (or in some cases NHS England) to make Directions.
- In the case of the review function, NHS England would need to tell the DH to Direct HSCIC to extract data using GPES.

**The CPRD and contracting individual IT systems via HSCIC to procure GP data**

The CPRD was established in 1987 and currently covers a sample of almost 9% of GP practices in the UK. It captures all the data pertaining to a patient’s interface with their GP (i.e. demographic data, medical diagnoses, referrals, medication, immunisations, screening, and lifestyle information). Data is extracted using Read codes. Keywords can also be used to navigate through the free text. In addition, the CPRD has established linkages to a number of other datasets (ONS mortality, HES and cancer registry data). However linkage to these datasets is only available for approximately 70% of CRPD practices in England who have consented to participate, equating to 375 practices.
There are private commercial companies (i.e. GP Systems of Choice - GPSoC) who can be contracted to extract Read coded GP data from the main GP IT systems. For example, on behalf of the national Chronic Obstructive Pulmonary Disease (COPD) audit programme the HSCIC is contracting the main GP IT providers to extract, via GPSoc, patient identifiable data on patients with COPD. This extracted patient identifiable data will then be pseudonymised at HSCIC using a persistent study identification number before being passed onto the COPD audit, theoretically this could then be de-anonymised if the additional relevant Section 251 approvals were in place; allowing for a patient-identifiable sampling frame. The COPD audit has to recruit GP practices to opt into the audit and anticipate a 50% sign up rate (covering a sample of approximately 400,000 patients with COPD). The COPD audit is a three year programme. In year one, the HSCIC will extract GP data on living patients linked to HES data. In year two, HSCIC will also link GP and ONS mortality data to allow for the identification of COPD patients who have died. A similar approach could be adopted for the review function given the delays with GPES and the limitations of using the CPRD.

**Advantages**

Seventy percent of English GP practices on the CPRD (who have consented to linkage) are already linked to ONS and HES data. Unlike GPES, the CPRD has the capability to navigate through free text in addition to providing Read coded data. However, this is a laborious process, and will not always yield useful information. Read codes to extract data on patients with LD from the CPRD have already been identified (see Appendix 1). Data quality is also ensured as GP practices have to produce data up to a certain standard in order to remain a CPRD practice.

**Disadvantages**

The CPRD would not identify individual patients or GP practices to users and therefore cannot be used as a sampling frame. The CPRD only covers a sample of approximately 9% of all GP practices, who can opt in and out of the CPRD overtime, and cannot therefore be used for the national surveillance of mortality. The domains of data available from the CPRD differ markedly in their consistency and quality. For example, prescribed medication is 100% complete and accurate, whereas socio-demographic and lifestyle information is poorly recorded and incomplete. The CPRD is also difficult to work with and would require a CPRD expert. Finally, there is no systematic way for stratifying severity – there is a hierarchy of Read codes but these aren’t necessarily used by GPs and if codes are stratified this is likely to be ad hoc (however would apply to any process extracting Read coded data from GP systems, including the GPES).
7.6 Local LD registers

Local LD registers collect and maintain information on the numbers, characteristics and needs of people (mainly adults) with LD within a defined area. The individuals who have been referred to these registers (and consented to having their details shared) are typically current users of specialised health and/or social care services for people with LD. Local LD registers are used to locally support and plan the delivery of health and social care services for people with LD in the area. In addition, data held by the LD registers in Leicestershire and Sheffield (see Box 8) have contributed to a number of research publications, including on the mortality of people with LD in a given area.1,33,34 Recent policy and funding changes have however resulted in the discontinuance of some registers (Croydon, Kingston and Surrey LD register), whilst placing others at risk (Lambeth LD register). Established registers report prevalence rates of LD of between 0.3-0.5% of the adult population.44 However, local LD registers are also limited in identifying people with LD as:

(i) they under-represent people with mild LD who are less likely to use specialist services and are thereby less likely to be referred to the register33,34;
(ii) they do not capture all people with LD and only include those who are known to health and/or social care services and who have opted into being included on the register;
(iii) there are inconsistencies between different local LD registers in terms of methods of identification, whether they include children and adults, and the information that they collect.

How local LD registers could be used as a data source for identifying people with LD who have died

Local LD registers have previously provided sampling frames for research projects, and previous projects have also combined information across different registers. However, pooling data across different registers would not achieve a national sample of people with LD in the same way that accessing GP LD registers would. Furthermore, a link with ONS mortality data would be required to reliably identify those who had died and the associated governance issues related to achieving this.

7.7 Local authority records

Adults

People with LD can be identified through their use of specific LA services for people with learning disabilities. All LAs have case management systems with details of the adults they provide social care support to that are aggregated and provided to the HSCIC and used to identify people with LD who may be eligible for an annual health check. The number of adults with LD identified from adult social
care is equivalent to the number identified from GP LD registers (approximately 5 in every 1000 adults). The limitations of using LA records, however, for identifying people with LD are:

(i) the definition of LD in this sense is based on the eligibility for a service rather than on a diagnosis. Furthermore, social care services eligibility criteria have tightened so that people who may have been considered eligible for a service 10 years ago won’t be now and would therefore be omitted from an eligibility-based definition of LD.

(ii) people with mild LD who are less likely to need support from social care services will be missing from LA records of people with LD.

(iii) adult social care performance data is only provided to the HSCIC at an aggregate level, it would therefore only be possible to link social care data with GP data on an aggregate (upper tier LA), not at an individual level.

(iv) The impact of the transition cliff.

Children

In the education system

Children with LD are easier to identify than adults as they are within the education system where health and disability surveillance is easier to maintain. The Department for Education (DfE), for example, collects information on the number of children with special educational needs associated
with LD in the National Pupil Database, which is populated with data from the school census. The census collects data on approximately 97% of children of school age and records the child’s primary and secondary (if relevant) SEN. There are three types of SEN associated with LD: moderate; severe and profound multiple learning difficulty. Research has typically identified children within the education system as having a SEN associated with LD if they are at the School Action Plus stage of assessment (extra or different help is provided and advice or support is received from outside specialists) or have a statement of SEN (replaced in September 2014 with EHCPs). Using this data approximately 3% (236,000) of children attending mainstream schools have a LD. However, although the school census currently has better coverage of children of school age with LD than GP registers, there has been a decline in the number of children identified as having a SEN associated with LD when the number of children on school rolls has increased. There is also the question of whether this data could be linked to mortality data to obtain a dataset of children with LD who die.

LA Child Disability Registers.
Since the Children’s Act 1986 it has been a statutory requirement for all LAs to hold a disability register for children residing in their area. The information on the register assists LAs with identifying the needs of children in their area. Children eligible for the register typically have physical and/or cognitive impairments which have a substantial and long-term effect on their ability to carry out day-to-day activities. Such registers are parent-led and it is the parent’s responsibility to consent to having their child’s details on the register. In 2012 almost 24,000 children (0.21% of the child population) were identified as being in need (referred to the LA as being in need of services) and to have a disability associated with learning. Aggregate information on the number of children in need is published by the DfE. Individual-level data, if obtainable, would depend on Section 251 approval and a data sharing agreement with each LA being in place, before any question of the feasibility of linkage to mortality data could be considered.

Child Death Overview Panels.
CDOPs are legally responsible for collecting information and reviewing the deaths of all children aged up to 18 in their area, on behalf of their respective Local Safeguarding Children’s Board (LSCB). The panel, which includes representatives from a range of agencies such as social care and the police, uses the evidence available to decide whether there were factors which may have contributed to the vulnerability or death of the child. However, there is currently no national consistency in the methodology of the 87 CDOPs in England and Wales. HQIP have invited relevant stakeholders to submit tenders for a contract to develop a CDOP Information System and Database Development Project, which will rationalise the CDOP process. This 18 month project will result in a national information system that will facilitate the collection, analysis and interpretation of CDOP
Consultation has revealed that LD will be included in the design for this database. Collaboration between the review function and the CDOP process would provide the review function with (a) data on children with LD who die, and (b) in depth information on the circumstances and background to their death from all the agencies involved, thereby negating the need for an intensive case review by the review function. Although this would, again, be dependent on Section 251 approval and a data sharing agreement with each LA being in place.

7.8 Secondary care

In secondary care, the learning disability census, which provides data on people with learning disabilities and/or ASD occupying CQC-registered inpatient beds (excluding outpatients or people receiving community-based services), shows 3,250 people with LD were in receipt of inpatient services in 2013. In terms of hospital outpatient activity, HES data for 2011/12 show there were 104,709 attended outpatient appointments with clinical specialists who have a primary expertise in learning disabilities. However, these sources do not provide information on people with LD who may be using out-patient or A&E services more widely. Furthermore, the majority of inpatient deaths of people with LD are likely to occur in physical healthcare.

How secondary care data could be used as a data source for identifying people with LD who have died

(i) Hospital Episode Statistics (HES)

HES provide data on all admissions, outpatient appointments and A&E attendances at NHS hospitals in England. In addition, the HSCIC link ONS mortality data to HES on a monthly basis allowing a dataset which captures deaths of people who have attended or been admitted or treated in hospital. However, HES does not have a reliable way of identifying people with LD who use secondary care services. A connection between linked HES-ONS mortality data and GP LD registers would allow a comprehensive register of mortality in people with LD known to their GP that includes information about the care process and circumstances prior to an individual’s death (see Figure 1). HES data on A&E admissions for ambulatory conditions could also be used as a systemic marker for how well primary and secondary care services are working with acute care services (serious morbidity cases). The CPRD has established linkages to HES and linkage of GP data to this dataset would be possible for approximately 70% of CPRD contributing practices in England. Alternatively, a connection between HES and GPES data could be sought.

(ii) The Mental Health and Learning Disability Data Set (MHLDDS)

The MHLDDS (renamed from the Mental Health Minimum Data Set, MHMDS) contains record-level data about the care of adults using secondary services in the community, as well as hospital and
outpatient care. From September 2014 the MHMDS was expanded to include LD and ASD patients. The MHLDDS is a mandated data return for all NHS providers of specialist mental health and LD services. Linkage with the MHLDDS would give the review function additional community data, supplementary to linkage with HES.

Figure 1: Suggested data sources to be linked to create a comprehensive register of people with LD who died prematurely.

7.9 Mortality and morbidity
There is currently no comprehensive system for identifying individuals with LD, living or deceased. The review function should help to drive better recording of LD through work with coroners, GPs and LAs.

7.9.1 The identification and incidence of premature death in people with LD

Problems with death certificates

Estimates from death certificates report approximately 1000 deaths per year in England in people with LD.\textsuperscript{1,21} This is based on the number of people whose death certificate either stated directly that the deceased had LD or included a medical diagnoses making LD highly likely (i.e. Downs Syndrome), but is less than a quarter the number expected from estimates of the number of adults with LD from GP LD registers.\textsuperscript{21} This is because LD is incompletely and inconsistently recorded on death certificates. Incompletely because only around 25-40% of death certificates record that the person had a LD or had a condition that causes LD.\textsuperscript{10,21} Inconsistently because, for example, some conditions (i.e. Downs Syndrome) are better identified than others (i.e. Fragile-X syndrome, ASD).\textsuperscript{4,21,33} Medical certificates of cause of death only ask certifying doctors to record conditions that they consider to have directly or indirectly contributed to the death, therefore when people die of illnesses not
known to be associated with any kind of LD, the fact that a person has a LD is not recorded because it is not regarded as a background condition. It has been suggested that Section 2 of death certificates needs to be re-examined and altered to improve the identification of people with a LD who die.

The ‘voluntary reporting’ of LD deaths

CIPOLD’s methodology for reporting the deaths of people with LD, by means of a voluntary local notification network, found 247 deaths in the study period equating to over 120 deaths per year or around 25 deaths per year per PCT.\footnote{Glover and Emerson\footnote{12} propose that on the basis of extrapolating whole-population age-specific rates, the CIPOLD findings suggest there would be a total of 3,830 deaths per year in people with LD in England as a whole. They further suggest that using the number of patients on GP LD registers under QOF, the annual number of deaths in people with LD would be 3,356. Given that there are just under 8,000 (7,962) GP practices in England,\footnote{46} this would equate to around 1 death per GP practice every 2 years, or to 22 deaths per LA per year (given that there are 152 upper-tier LAs in England).}

Data sources for identifying premature mortality in people with LD

(i) ONS mortality data
Records of all deaths in England are available from ONS. ONS mortality data gives the sex, dates of birth and death, age at death, up to eight causes for the death and where the individual normally lived. However, as death certificates inconsistently record the presence of a LD, ONS mortality data could only be used for the review function if linked with primary care data via a GP extraction system such as GPES or the CPRD as discussed above.

(ii) Primary Care Mortality Database (PCMD)
The PCMD was introduced post Harold Shipman to examine the mortality rates of GP practices. It is linked with ONS mortality data, and includes information on the GP practice the individual is registered with and the NHS numbers for all the deceased individuals recorded (although this information is not released). However, it does not identify people with LD and is a very resource-intensive dataset. As additional linkage to GP LD registers would still be required, similar to Gyles Glover’s Section 254 direction for an annual extraction of information from GP systems linked to other data systems, this dataset has been ruled out for the review function.

7.9.2 Age at death
Patterns of mortality are different in people with LD compared to the general population. Their life expectancy is lower and they have an increased risk of early death compared to the general
population (see figure 2). The median age of death of people with LD ranges from 16 to 24 years earlier than the general population, with shorter life expectancies for young adults and women compared to men. Recent research indicates there has been a reduction in the mortality rate and an increase in life expectancy for people with LD over the last 3 decades that mirrors the general population, but that the absolute gap between the two has remained constant (776 excess deaths per 100,000 people with LD).

Figure 2: Age at the time of death of people with LD in the CIPOLD cohort compared to the general population (Source: CIPOLD Final Report)

Life expectancy also decreases as the severity of LD increases (see figure 3), with the life expectancy of people with mild LD reported as approaching that of the general population. A negative association between life expectancy and specific genetic conditions causing LD (such as Downs Syndrome, or cerebral palsy) is also reported. This is, however, likely to be a reflection of the presence of coexisting congenital abnormalities and the increased risk for other health conditions such as hypothyroidism, obesity, epilepsy, sensory defects, and the early onset of dementia.
7.9.3 Causes of death

The most common causes of death in people with learning disabilities are broadly consistent across the international literature. Respiratory disease (especially pneumonia), heart or circulatory diseases (almost half of people with Down’s syndrome have congenital heart malformations), nervous system diseases (including epilepsy), and infectious and parasitic diseases (especially septicaemia) have all been found to be more commonly associated with death in people with learning disabilities than in the general population. Whilst cancers are less common in people with LD than in the general population, with the exception of gastrointestinal cancer and leukaemia (in children with Downs Syndrome). Two causes of death have been found to stand out as being particularly preventable in people with LD who die – aspiration pneumonia and epilepsy or convulsions. Forty-two percent of deaths in the CIPOLD cohort were considered to be premature, mainly because of delays or problems with treatment or because of problems with investigating or assessing the cause of illness. Furthermore, over a quarter of the deaths reviewed were amenable to better quality healthcare, with people with more severe LD or deaths related to the nervous system, congenital and chromosomal abnormalities and the respiratory system being more likely to be avoidable through good quality healthcare. Extrapolating on the basis of whole-population age-specific rate, further research suggests that on the basis of the CIPOLD findings 37% of deaths of people with LD per year could be amenable to the best quality healthcare.

There is little research examining suicidal behaviour in people with LD. The scarcity of research may be due to the belief that people with LD do not have the capacity or capability for suicide. However, an as yet unpublished, review of the literature shows that in the limited studies examining suicidal behaviour in people with LD, intent to die was shown, including amongst those with severe LD.
(Myfanwy Maple, personal correspondence). Data collected by NCISH also reveal that approximately 3 people a year with either a primary or comorbid diagnosis of LD die by suicide (Isabelle Hunt, personal correspondence).

7.9.4 Morbidity

Compared to the general population, there are higher rates of asthma, Type 1 and Type 2 diabetes, epilepsy, and sensory and physical impairments reported among adults and children with LD. In addition, carer estimates of the overall general health of the person they care for are reported as being worse than for people without LD. There is also evidence that the lifestyle of people with LD can lead to poorer health outcomes - poor diet, lack of exercise, and obesity have all been reported as being more common. Difficulties with urinary and bowel incontinence in people with LD are also reported to lead to additional health risks if not effectively managed. In addition, people with LD, especially mild LD, have been found to be more likely to be exposed to a number of social and environmental risk factors that could act as determinants for poorer health (including poverty, poor housing, unemployment, social exclusion, violence, abuse, and contact with the criminal justice system) in turn increasing their risk for a shorter life expectancy. However, risk factors for poorer health and mortality in the general population such as smoking, alcohol and drug use are much lower in people with LD.

The treatment, diagnoses and prevention of disease and ill-health are judged against systemically developed recommendations to guide best practice set out in NICE guidance. However, we are aware of only twelve NICE guidelines that specifically refer to the assessment and treatment of people with LD. Furthermore, NICE guidelines are predominantly based on single conditions and do not currently account for the multi-morbidity found in people with LD, although new guidelines are in progress (see section 8.10).

7.10 Access to good quality healthcare

7.10.1 Reasonable adjustments

It is a legal requirement for all public sector services to provide reasonable adjustments (see Box 9) for people with LD. This means making their services for people with LD as accessible and as effective as they would be for people without disabilities. There is evidence, however, that NHS and primary care services are not making the full range of reasonable adjustments to address inequalities in healthcare provision for people with LD. A national survey of NHS Trusts showed although there were examples of good practice by some Trusts in the provision of reasonable adjustments, overall there was not always robust evidence to support those Trusts who stated reasonable adjustments had been implemented. A similar survey of 6 NHS acute hospitals showed
the implementation of reasonable adjustments was not consistently replicated. There is an overall lack of effective flagging systems in NHS hospitals to identify patients with LD and a reluctance of staff to flag LD when the system is available to do so, thus creating a barrier to better hospital care. It is suggested patients referred to hospital should be asked short simple questions to screen for LD, as it is likely they will not have been flagged as having LD in their referral.

7.10.2 Health checks

GP annual health checks were introduced as a reasonable adjustment to care in 2008 following recommendations by the DRC and were incentivised to GPs under the Directed Enhanced Service (DES) in 2009 whereby GPs are rewarded financially for offering comprehensive health checks to eligible adults with LD (LD has to be known to both the GP and their LA social services department). In April 2014 the DES was extended to young people with learning disabilities and GPs are now also paid for offering health checks to young people aged 14-17. Data on health checks offered and completed in this age group will be available next year. However, only around half of the adults eligible for health checks under the DES currently receive them. This is despite evidence that health checks are effective in increasing the detection of many of the unmet and potentially treatable health problems of people with LD, and in increasing the identification of people with LD on GP registers. Furthermore, there is evidence that where health checks are routinely offered there is no linkage with a health action plan. This is despite the requirement for health action plans to be part of the annual health check since April 2014.

7.10.3 Screening

There is a low uptake of health screening among people with LD, including assessments for sensory screening – this lack of access to timely screening could be a reason for the early mortality of people with LD. The SAF provides the first national data about the coverage of cancer screening for people with LD and the findings suggest it is 40% as complete as for the general population.

7.11 Evidence on interventions/of improvements

That there has been progress in the provision of services for people with LD in recent years is best evidenced by an increase in life expectancy, particularly for people with Down’s syndrome. However, there remains a gap in life expectancy between people with LD and the general population. There are examples of local good practice in terms of the provision and evidence for reasonable adjustments and for the action that has been taken or is underway since the publication of the CIPOLD report. However, the overall provision of good quality care for people with learning disabilities remains piecemeal, and good examples are noticed because they are the exception rather than the rule.
Box 9: Commonly recommended reasonable adjustments

The LDO database of reasonable adjustments is made up of examples from NHS Trusts sent into the LDO in their 2010 Reasonable Adjustment Survey. There are currently over 200 examples of local good practice in the provision of reasonable adjustments listed. The LDO have also produced guidance for commissioners and providers of healthcare on what reasonable adjustments should be made to ensure equity of access, which draws on the research findings of the national survey. 

A recent report from the LDO has also listed the most commonly recommended systemic reasonable adjustments within primary care services and acute hospitals:

i) Clear identification of people with LD in all healthcare record systems (i.e. the flagging system between primary and secondary care at Derriford Hospital, Plymouth).

ii) Patient-held records for all people with LD with multiple health conditions (i.e. the Complex Health Intervention Pack in Sussex; NHS England are also looking into developing a national standard)

iii) Named healthcare coordinator for people with complex or multiple health needs

iv) Universally available, accessible information for people with LD and carers (easy read forms and leaflets, and jargon free language in face to face communications)

v) Accessible processes for people with LD to make appointments (i.e. some local systems, such as in Cornwall, divert patients with LD using the Choose and Book system to a LD liaison nurse to assist with securing an appointment time and date)

vi) Longer appointment times, such as double appointments, and planned appointments at beginning/end of day (i.e. South Gloucestershire).

vii) Working in partnership with families and paid carers, especially in provision of information including during appointments, inclusion in decision-making, adjusted visiting hours, facilities for overnight stay

viii) Access to LD liaison specialist staff to remove barriers and facilitate access to effective health services (there has been an increase in the provision of LD liaison nurses and the LDO’s interactive map showing the provision of acute liaison nurses across NHS Trusts in England shows there are currently LD acute liaison nurses at 56 sites across England, including in every NHS Trust in the North East).

ix) Comprehensive annual health check (there has been an increase in the number of annual health checks and the LDO’s map of the percentage of people with LD who have had an annual health check shows that in West Berkshire LA over 90% of eligible people have had an annual health check).

x) Clear health action plan following from annual health check (i.e. Coventry and Warwickshire Partnership NHS Trust)

xi) Risk assessment and associated linked reasonable adjustments action plan for people with LD entering acute care

xii) Advocacy for people with LD

xiii) Annual audits of scale, type and effectiveness of reasonable adjustments

xiv) Training for all staff to promote effective reasonable adjustments for people with LD
In September 2014, the DH published their one year progress report on the CIPOLD recommendations. This report concluded that ‘encouraging progress had been made’, but that there now needed to be a ‘concerted national effort to see more equal access and outcomes for people with learning disabilities’.

Mencap, however, believe many of the recommendations have not been adequately addressed with ‘unacceptable progress’ in at least 6 of the 18 recommendations, including the standardisation of annual health checks and the introduction of patient-held records to all patients with learning disabilities with multiple conditions. Mencap believe an important outcome of the mortality review function would be a set of good practice guidelines that could be adopted by all Trusts. The implementation of such guidelines, and indeed of the CIPOLD recommendations, across all health services could be evaluated by comparing progress in areas where they have been adopted to progress in areas where they have not (similar to the process described in section 5.4).
8. Setting the review function in the context of wider work on LD

The review function should work alongside other key initiatives on learning disability, including:

8.1 The Improving Health and Lives: Learning Disabilities Observatory (LDO)

The LDO was established in April 2010, following a recommendation in Healthcare for all. It is a collaboration between Public Health England, the Centre for Disability Research at the University of Lancaster and the National Development Team for Inclusion (NDTi). It brings together a wealth of information on the number of people with LD and the services for them. Their projects include: an annual report of LD in England; ways of monitoring need locally; what reasonable adjustments are being made by health services; the use of annual health checks; and health inequalities for people with LD. The LDO also collates and validates responses from the 152 Learning Disability Partnership Boards (see Box 5) for the SAF, an annual local self-review process of the provision of health and social care for people with LD.

8.2 Winterbourne View Joint Improvement Programme (JIP)

The JIP is led by the Local Government Association and NHS England and is funded by the DH. It was established in response to the abuse uncovered at Winterbourne View. The aim of the JIP is to support local area partners to work together to develop safe, appropriate and high quality services that allow people with LD and/or autism who have mental health conditions or behaviour that challenges to get the support they need to live locally in community-based settings and thereby reduce reliance on inpatient care.

A key part of the JIP’s work activity is the provision of a range of support options for local areas, across both health and social care systems, which bring together local partners, including people who use services and their families, and encourage collaborative working and problem-solving. Its programme of work has been built around an in-depth understanding of the issues and challenges from across the partnership, beginning with a detailed stocktake of local authorities and CCGs. The JIP has also developed a programme of workshops, including ten commissioning workshops for local (CCG and local authority) commissioners and NHS England specialised commissioners, which aim to support local area partners to develop clear pathways between services commissioned by specialised NHS commissioners and those commissioned by local commissioners. Workshops are also planned or underway which cover key issues including housing, advocacy and lifelong planning.

8.3 The Improving Lives Team (ILT), NHS England

The ILT was established as part of NHS England’s response to the abuse uncovered at Winterbourne View. The work of the ILT focuses on reviewing the current care of the 48 former residents of
Winterbourne View; however, the team also review the care of people currently residing within inpatient learning disability settings who are referred from a number of sources, including commissioners, families or by lobbying groups. The team are reviewing people within both NHS and independent sector services (children are not in the remit of the ILT review process).

The ILT is made up of professionals from clinicians, social care and third sector and include 'experts by experience' who are family carers or people with LD. Each review lasts around 2 days, during which the ILT will visit the person’s place of residence and will individually speak with the person in question and their family, initially, and then with the different professionals involved in their care. A panel meeting follows the review which is then followed with a report outlining the findings of the review and any recommendations for improvements in care. The report is given to the service provider, all the people involved in the person’s care and to the person’s family. A follow up review is then conducted to ensure that these recommendations have been acted upon. The ILT supports the work of the JIP and works closely with the CQC.

8.4 The NHS Outcomes Framework

The NHS Outcomes Framework was established in December 2010 and provides an overview of how well the NHS is performing. It is updated every year to ensure the most appropriate indicators are included. The indicators are grouped around five domains, which focus on improving health and reducing health inequalities by: (i) preventing people from dying prematurely; (ii) enhancing quality of life for people with long term conditions; (iii) helping people to recover from episodes of ill health or following injury; (iv) ensuring that people have a positive experience of care; and (v) treating and caring for people in a safe environment and protecting them from avoidable harm. Links with domains 1 and 5 would be of particular value to the review function. Domain 1 – Indicator 1.7 specifically relates to reducing premature mortality in adults with LD. Domain 5c – deaths in hospital from problems in care (avoidable deaths) went live in April 2014. The methodology behind this indicator is retrospective case record review by clinical experts who assess the quality and safety of the care provided to patients who died in hospital, and this could be particularly complimentary to the review function.

8.5 The Adult Social Care and Public Health Outcomes Framework (ASCOF)

The ASCOF indicators measure how well social services are performing in delivering better care and outcomes for adults with support needs. It is updated annually in partnership with local government. Disaggregation for client groups with LD (all ages) is available for the following domains:

(i) Enhancing quality of life for people with care and support needs
(ii) Ensuring that people have a positive experience of care and support
Safeguarding adults whose circumstances make them vulnerable and protecting them from avoidable harm

8.6 The Harris Review - deaths in custody independent review
This review has been established by the Ministry of Justice to examine the self-inflicted deaths of 18-24 year olds in custody. The review is led by Lord Harris and will focus on a number of issues including: vulnerability; safety; staff education and training; and staff prisoner relationships. The Independent Advisory Panel have set out a number of questions which are relevant to the review and which may be examined, including how vulnerability in terms of having a LD can be better identified in custody.

8.7 Child Health Reviews – UK (CHR-UK); a Clinical Outcome Review Programme
The CHR-UK is a UK wide review examining mortality and morbidity in children and young people (1-18 years). It links ONS mortality data with longitudinal hospital admissions to provide more accurate and clinically relevant causes of death classifications. Learning disabilities are included in their grouping of chronic conditions grouped according to the clinical pathway likely to be taken to manage the condition (mental health/behavioural conditions). However, there are also groupings of other chronic conditions which are potentially relevant to children and young people with LD, such as respiratory conditions and neurological/sensory conditions (i.e. epilepsy, cerebral palsy). Their most recent thematic review of children and young people with epilepsy included a detailed case note review of those with epilepsy as a sole diagnosis, and epilepsy with concurrent LD. Over half of the children with epilepsy identified had a LD.

8.8 The Care Quality Commission
The CQC monitors, inspects and regulates health and adult social care services to ensure that they meet standards of quality and safety. In July 2014 changes to the way hospitals are inspected were announced, including the implementation of the following four questions: (i) do you have anyone with an LD in hospital at present? (ii) what reasonable adjustments do you make for people with LD? (iii) do you have a specialist nurse for LD? (iv) do you audit the care given to patients with LD? Professor Chris Hatton will be analysing the new model hospital inspections data and examining reports from a pilot sample of inspections carried out in acute settings to see what they say on LD services and to find out if CQC need to further alter their inspection reports or their reporting of LD. CQC also conduct themed inspections which look at specific standards, sectors or types of care. Previous themed reviews have included a review of LD services, and currently include end of life care which will examine the experiences of people with dementia, mental health needs, and LD. The
findings of the review function could help CQC better refine the questions they ask in their inspections and assist them with developing a more robust surveillance model.

8.9 **NHS Benchmarking Network**
The NHS Benchmarking Network (a membership group of NHS organisations) has recently completed two pilot studies examining LD services nationally: (i) Commissioning LD Services project (involving CCGs and LA partners); and (ii) Providing LD Services project (involving Mental Health, Community and Acute NHS Trusts). The objective of the projects was to collect a dataset of LD service commissioning and provision that could be used in benchmarking LD across a wide range of metrics, including turnover and WTE staff employed (provider project), and the number of people registered with GPs as having a LD, LD services commissioned, LD service availability, health checks, inpatient beds, and community services. In the future, it is planned that this data will be collected annually. Outputs will be available to NHS Benchmarking Network members as a written report and an interactive online tool.

8.10 **National Institute for Health and Clinical Excellence**
NICE guidelines should take into account multi-morbidity commonly found in people with LD, and develop guidance about the most common co-morbidities for any single condition and the management of patients with multi-morbidity. There are now 3 guidelines in progress relating to improving the long term outcomes for people with LD: (i) Challenging behaviour and learning disabilities: prevention and interventions for people with LD whose behaviour challenges (publication date May 2015); (ii) Mental health problems in people with LD: management of mental health problems in people with LD (anticipated publication date September 2016); (iii) care and support of older people with LD (development of guidance to begin in 2015/16).

8.11 **The North East and Cumbria Learning Disability Clinical Network (LD Network)**
In response to CIPOLD, the LD Network has begun devising the framework for a local pilot that would review mortality among people with LD. They are currently developing their inclusion criteria but anticipate the following: all deaths of people with LD; a lower age limit of 4 and an upper age limit of 75; and all severities of LD. The LD Network are currently establishing how they would identify their cases and suggest that an ideal model would be data linkage between GP, social care, hospital and mortality data using the NHS number. However, establishing such a link is problematic and to begin piloting the local review function (which they hope to begin doing in the New Year) they suggest using the LD flagging system, which as a region is very well used. For example, any person with LD who died in hospital (approximately 46% of all people with LD) should have been flagged as having a LD when they were referred from primary to secondary care services.
They propose a specially appointed individual with an administrative role would pull together data on all the notified individuals from GP, LD Services, acute Trusts and social care. The data could include: demographics; death data (including cause of death, and whether the death was avoidable); and individual needs (such as any long-term health conditions, medication, impairments, smoking, BMI). This data would be reviewed by a consultant (with dedicated time), who would then determine the cases that should be included in the next audit meeting. They propose a review panel would meet on a scheduled basis and have a standard membership, which would be multi-disciplinary, predominantly clinical, but would also include social care and potentially an advocacy voice. The panel would not include individuals with direct knowledge of the cases for practical reasons, but should have access to the case’s medical records. Aspects of the review will include examining: the pre-hospital pathway such as social isolation, unmet physical health needs, access to health screening and immunisations, health checks and if they had a health action plan, if they had a hospital passport; whether the person was flagged as having a LD and whether reasonable adjustments were in place to reflect this; whether there was appropriate co-ordination of care; whether there were delays in care; the person’s capacity; the quality of record keeping and whether there was any evidence of forward planning. The review panel would establish lessons to be learnt.

8.12 Serious case reviews (SCR)

a) Vulnerable adults (aged 18+ who receives or may need community care services because of a disability, age or illness, and who are unable to live independently or protect themselves from significant harm)

The Care Act 2014 made SCRs (see Box 10) mandatory in adult safeguarding if a vulnerable adult dies and abuse or neglect is known or suspected to be a factor in their death.

b) Children

A LSCB must undertake a SCR when a child dies and abuse or neglect is known or suspected or where there is cause for concern as to the way professionals acted together to safeguard the child. Final reports of SCRs are published anonymously on the relevant LSCB website and are also submitted to the NSPCC’s electronic library of SCRs.
Box 10: SCR process

- Month 0: The Local Safeguarding Board (LSB) for the area where the individual is normally resident is notified of an incident of harm/abuse/neglect.
- Months 0-1: The LSB must decide whether the incident meets the criteria for a SCR.
- Months 1-6: The LSB appoints one or more individuals to lead the SCR, they are independent of the case under review, the LSB and any of the organisations involved in the case.
- Months 1-6: The LSB ensures there is appropriate representation in the review process of professionals and organisations involved with the individual and their family. The LSB may request each relevant organisation to provide written information of their involvement with the individual concerned.
- Month 6: The LSB should aim to complete a SCR within 6 months of the initial notification. The multi-agency review will establish whether there are any lessons to be learnt that could prevent future deaths.
- Month 6+: Upon completion the SCR will be published on the LSB’s website. The decision to share a SCR prior to it being made publically available sits with the LSB.
9. Options for taking the review function forward

9.1 Features of a national mortality review function

Based on the views of those consulted, we suggest that the national mortality review function should be developed in line with a number of fundamental principles. These should underlie whichever option is selected for the national mortality review function.

1. The national mortality review function should be a long-term initiative, reflecting the importance of the topic but also the time it will take to develop a comprehensive national review process. However, this should not delay the setting up of the optimum feasible review function in the immediate future, with a pragmatic focus on deaths and on people known to services, i.e. with severe LD.

2. The aim of the mortality review function should not simply be to demonstrate higher mortality in people with LD - that is already well established. It should aim to drive improvement in services, by measuring variation (e.g. between areas) and the impact of service change and to provide clear evidence of where practice is good and how to improve on that.

3. The overall review function should consist of local and national components. Exactly where the balance should lie between local and national, and what the relationship between them should be, are features of the options that we are presenting. However, a strong local process is a feature of all options - there are already a number of excellent local initiatives.

4. The overall mortality review function should be based on "graded" data collection in which there is a trade-off between the number of deaths and the amount of information collected nationally on each. This would mean that mean that (i) the national collection of detailed information from intensive case review would be limited to a selected sample of deaths, (ii) a short standardised dataset would be developed for all reviewed cases and (iii) a small amount of information would be collected on all deaths.

5. All stages of the mortality review, but particularly examining cases and drawing up recommendations, should include people with LD, their families or carers, and representative organisations.

6. In addition to the mortality review itself, there are additional pieces of work that need to take place to strengthen the process in the future. These are on subjects such as death certification, reasonable adjustments and data linkage and they will mean joint working with other organisations. We have presented these separately to the options for mortality review.

7. The review function should work alongside other key initiatives on learning disability, in particular the LDO project within Public Health England. The LDO would be able to provide population-level data that would support a fully functioning national mortality review. More
broadly, governance arrangements should encourage a closer relationship to bodies that can provide intelligence or help disseminate findings, e.g. the Care Quality Commission.

9.2 Options for a national LD mortality review function

Taking into account all of the issues discussed throughout this report we propose the following options for taking forward a national LD mortality review function. We provide details of costing, insofar as we are able, for each option. Table 3 compares the estimated costs for each option in a summarised format. Our preference is option 1; options 2 and 3 offer a different emphasis on local and national processes.

Option 1: a balance of local and national processes

Key features of option 1 are:

- The national review function will be built on a robust model of local case review carried out by a multi-agency panel, to include people with LD and carers. Local services, led by local authorities and CCGs, will identify people with LD who have died; all cases will be reviewed, leading to lessons for local services.
- The national team will aim to build up the number of participating areas, identifying local leadership and providing advice on standardised methods including a core data tool.
- The national team will receive core data on all cases, recording these on a central database.
- The national team will develop a web-based national review function for selected cases according to an agreed rolling programme of thematic priorities (see section 6.2.2) - this could also be a means of quality assurance of local reviews.
- As the number of participating areas increases, the national team will be able to examine variation between local areas - for example, areas that appear to have high v. low numbers of deaths or, over time, that appear to be showing substantial v. little improvement.

In this option, we propose that the national review function is built on a robust model of local multi-agency case review (see figure 4). Lead representatives from local authorities and CCGs will be approached by the national team coordinating the review function to work with their LD Partnership Boards and Quality Surveillance Groups to put in place a process that would identify and collect service records on the deaths of people with LD in their area, and review the care that each individual received. Data will be collated from GP systems through locally submitted queries.
(MiQuest, PRIMIS) or by direct liaison with GP practices, and also from LA case management and NHS Trust’s hospital patient record systems.

Local case review of all deaths will be carried out by a multi-agency panel of professionals, including people with LD and carer representatives – local reviews are not necessarily limited to case notes and may take information directly from staff or families. The outputs from the reviews will be expected to lead to local learning. In addition, the local review will provide information on each case to a core dataset designed and managed by the national team.

Concurrently, the national team will develop a secure, web-based case-note viewing system to which selected cases will be uploaded according to an agreed rolling programme of thematic priorities (see section 6.2.2), thus allowing for a more selective system of nationally coordinated case review. Nationally recruited reviewers will assess notes prior to a multi-disciplinary panel meeting that would then make recommendations and identify lessons to be learnt on the basis of the information that they had reviewed and discussed. The same method could be used as a means of quality assurance for local reviews.

It will be the responsibility of the national team to build up the number of participating areas, identify local leadership and provide advice on standardised methods of data collection including the core data tool. It is anticipated that as the number of participating areas increases, the national team will be able to examine variation between local areas - for example, areas that appear to have high v. low numbers of deaths or, over time, that appear to be showing substantial v. little improvement.

An important feature of this option will be the intention to establish over time an alternative and more comprehensive method of identifying individuals with LD who have died, from primary care LD registers, using the GPES to extract cases and linking the extract to ONS mortality data, with additional linkage to HES data. This would allow the national team to support CCGs and LAs by notifying them of deaths in their areas that were eligible for review, and asking them to collate data from the full range of services that each individual may have been in contact with - GP practices, LD Services, acute Trusts and social care. In other words, comprehensive national case identification would support and not replace local case review. However, using GPES extractions of GP data would also provide the national team with a core dataset of key Read coded data items relevant to the individual’s care without the reliance on local post-review submission. However, this combination of linkage and individual identification would be a complex process and is relatively untested at present.
– for this reason we have not relied on it in Option 1, though we do see it as a priority for development.

Figure 4: Methodology for option 1.

Advantages of this option are that it would explicitly set out to expand and strengthen local review and local learning, linking this to a more selective system of national review. There is already a mechanism for collaboration between local agencies, i.e. the SAF. One role of the national team would then be co-ordination – standardising methods and receiving local outputs that can become the basis of national lessons and dissemination. Case review at national level will focus on national priority topics and will allow less common causes of death to be studied.

Disadvantages are that participation will be voluntary, locally-resourced and conducted by a standardised method. Only half of Partnership Boards were able to provide complete data on the mortality of people with LD resident in their areas for the most recent SAF. Initially at least, this option will not provide a comprehensive national sample of all deaths of people with LD known to services. Participation is likely to improve once reports are published showing non-participants but it will also depend on local pressure and regional and national leadership. A national panel of reviewers will have to be recruited and supported. A secure, web-based case note viewing system will have to be sourced and procured, and programmers skilled in developing and maintaining the system will have to be recruited as part of the national team. There may be problem over bias – the areas with the best services will be most likely to participate. Variation in the size of local authorities will mean that some will have far more cases to review, and this may lead to local sampling by methods that are unclear. Smaller CCGs and LAs may have to work together, or in a geography that
suits their circumstances. Governance will have to be carefully considered – in addition to Section 251 approval, data-sharing agreements will be required with each CCG and LA.

Costings

The local notification of LD deaths, the provision of core data to the national team and the process of local case note review will have to be incorporated into the routine work of local agencies. Costs would therefore relate to national case note review, which would be in the region of £175,000 (see section 6.2.6) and the operational costs of the national team, which would be in the region of £400,000 (on the basis of a team comprising 3 clerical assistants, 3 research associates, 1 research fellow/project manager, 1 clinical lead at professional level working 3 days/week and associated overheads). Once GPES has been tested as a process by which to identify people with LD who die – the cost of a GPES extraction will have to be incorporated. The owners of GPES are not in a position to quote estimates in advance. However, they have provided a cautious estimate for guidance only of £200,000. Separately from GPES, data linkage services would incur additional costs. The total cost for option 1 (including a GPES extraction) would therefore be in the region of £775,000.

Option 2: a predominately local process

Option 2 is similar to Option 1 but with a reduced national component and a stronger reliance on the local services. The national team will have no case note review role. The role of the national team will be to receive and analyse core data and reports, to examine variation and progress within local areas, and to collate and disseminate local recommendations to all areas. In addition, it will aim to improve standardisation of the review process. As in Option 1, local services will be asked to identify deaths of local people with LD and to conduct multi-agency reviews on all cases – this will include the thematic priorities. There will be no national quality assurance, the national team essentially receiving local reports and recording their findings in a way that allows national aggregation.

Advantages are in a greater focus on local service improvement including local leadership on national thematic priorities. Option 2 avoids the time and cost of setting up a secure, web-based case note viewing system and an expert panel to support a national review function. The main disadvantage is the greater reliance on the participation of local services and the quality of local reviews and a reduced capacity for national learning.

Costings
Costs will relate to the coordinating function of the national team and their role in receiving and analysing data and disseminating recommendations – on the basis of a small team as detailed above this will total in the region of £400,000 (see Option 1). Potentially this will make it easier to fund the additional project work outlined below (see section 9.3).

**Option 3: a predominantly national process**

Option 3 is similar to Option 1 but with a larger role for national case review and potentially greater use of national databases. In this option, the national team will be responsible for reviewing cases corresponding to thematic priorities, as with Option 1, but in addition will review a geographically representative sample of cases to explore variation and progress in different areas. Sampling will be based on cases identified through a patient-level GPES extraction linked with ONS mortality data (see Option 1). The GPES extract will also provide the core dataset based on key Read coded data items available from the individual’s GP record (i.e. long-term health conditions, medication, access to screening, health checks etc).

It will be the responsibility of the national team to obtain case notes so that these can be assessed by a multi-disciplinary team of reviewers via a secure, web-based case note viewing system. Local case review will continue but will be more independent. There is also the potential to use the CPRD to explore aspects of care for people with LD: 70% of GP practices on the CPRD are already linked with ONS mortality, HES and cancer registry data. Studies using the CPRD will be on anonymised data so there would be no link to individual case review.

Advantages will be greater reliability, with the national team carrying out the majority of reviews, and less dependence on the quality of local review. Disadvantages will be that the national-local collaboration will be weaker – in particular the self-assessment component of case review will be separate from the national lessons. National sampling will require a high proportion of local areas to participate. The use of GPES as a sampling frame is new and relatively untested (see option 1). The CPRD currently covers a sample of 9% of all GP practices and cannot be used as a sampling frame.

**Costings**

The cost of a GPES extraction, case note review and the operational costs of a national team have already been described in Option 1, but will total in the region of £775,000.

The rates for accessing CPRD data are based on the number of patients (see Table 2). A dataset will also incur researcher costs, which are normally between £3,000 and £5,000. Additional linkage to
HES data would be in the region of £7,500 to £8,500 for a sample size of 101 to 10,000 subjects. Consequently, if the review function were anticipating a sample of approximately 3,000 people the total cost for CPRD data would be in the region of £31,000. However, given that a number of rolling priority topics would be likely to be conducted using the CPRD, an annual licence for online access to the CPRD database (with or without HES data) may be more cost effective. The price of online access to the database and training for two users is covered by an annual licence fee of £127,500.

Table 2: Fees for the CPRD*

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<tr>
<th>Number of patients</th>
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<td>Less than 1,000 subjects</td>
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<td>1,000 to 50,000 subjects</td>
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<td>Over 300,000 subjects</td>
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*These rates are only applicable if the funding source for the purchase of data is academic, NIHR grant or charitable. Funding from other sources will be double that quoted above.

We have only been able to obtain a very rough estimation for the cost of contracting individual GP IT providers to extract data on people with LD from GP registers with additional linkage to HES and ONS mortality data. This would be in the region of £50,000-£150,000 for data extraction alone.

9.3 Additional projects in support of national case review

In addition to the mortality review itself, there are additional pieces of work that need to take place to strengthen the process in the future. These will mean joint working with other organisations.

1. The review function should help to drive better recording and identification of LD on death certificates and more accurate recording of cause of death, including contributory causes, in people with LD. This work could be undertaken as a joint project with coroners, GPs, and hospital doctors (just under half of people with LD die in hospital\textsuperscript{10}), possibly in collaboration with the Royal Colleges of General Practitioners and Physicians.

2. A project that nationally maps how and when local health and social care services provided commonly recommended reasonable adjustments, for which a new typology would be needed. This would be in collaboration with NHS Benchmarking and the LDO. Other systemic markers for how well local services are providing and commissioning services could include the number of
hospital admissions for ambulatory conditions, and rates of missed or incomplete appointments (although both would depend on how well hospitals flag LD in their patient systems or on linkage with HES).

3. In section 7 we have set out the potential use of registers to identify people with LD who have died and to sample deaths nationally for individual projects. The likeliest mechanism for this is GPES but there are uncertainties over whether it is ready for such an ambitious use within a matter of months. We are therefore suggesting a ‘testing phase’ to examine the ability of GPES: to provide the core Read coded data on the key data items of interest, including a complete extraction of all people with LD on GP registers; to link with other datasets primarily ONS mortality data, but also HES data; and to extract patient-identifiable data that would allow a sampling frame for case note review.

9.4 Overall estimated costs

We estimate the costs of options 1 to be £775,000, including GPES (see Table 3). Costings for option 3 are similar and for option 2 are substantially less because there is no national-level case review. Excluding GPES or using an alternative extraction system would reduce the costs of any option. Additional projects will cost in the region of £50,000 each per year.

Table 3: Estimated overall cost structure

<table>
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<tr>
<th>Methodology</th>
<th>Estimated data costs</th>
<th>Case note review cost</th>
<th>National team costs (staffing, overheads, non-salary costs)</th>
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<td>Local notification Incorporating into the routine</td>
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<td>GPES</td>
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<td>£400,000</td>
<td>£625,000-£725,000</td>
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¹ Does not cover staffing costs (with the exception of programmer costs for the secure, web-based case-note viewing system)
A team comprising 3 clerical assistants, 3 research associates, 1 research fellow/project manager, 1 clinical lead at professional level working 3 days/week

An annual licence will allow CPRD data users to access CPRD data at markedly reduced costs (see section 9)
References


Accessed 16 October 2014.
## Appendix 1 – Read codes

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1 = definite, 2 = almost certain
Appendix 2 – Map of LD Partnership Boards