



Short Interim Report

February 2011

‘To raise awareness in the health service of the risk of premature avoidable death, and to promote sustainable good practice in local assessment, management and evaluation of services, the Department of Health should establish a learning disabilities Public Health Observatory. This should be supplemented by a time-limited Confidential Inquiry into premature deaths in people with learning difficulties to provide evidence for clinical and professional staff of the extent of the problem and guidance on prevention’ (Sir Jonathan Michaels, 2008)

The information contained in this report is based on a small number of deaths. Please do not quote any statistics from this report, as they may not reflect those when the study is complete.

1. Introduction

Over a decade ago, McCuigan et al. (1995) reported that people with learning disabilities were much more likely to die before the age of 50 than the general population. This was highlighted in the learning disability White Paper Valuing People (2001) which stated that *'evidence of available illness and premature death amongst people with a learning disability is a major cause of concern for the Government'* (p.62). The situation was affirmed in the recent public health strategy for England (DH, 2010) which stated that people with learning disabilities have significantly poorer life expectancy than would be expected based on their socioeconomic status alone.

A number of reports followed, which highlighted the circumstances for people with learning disabilities when accessing appropriate health care (Mencap, 2004, 2007, 2010; DRC 2006, 2007; MacArthur J. & Brown M. 2008). In 2007, Sir Jonathan Michael was asked by Patricia Hewitt, the then Secretary of State for Health, to chair an inquiry that would identify the action needed to ensure adults and children with learning disabilities receive appropriate medical treatment in the NHS. The Inquiry reported in 2008 that it had found convincing evidence that people with learning disabilities had higher levels of unmet need and received less effective treatment than others, despite the fact that the Disability Discrimination Act and Mental Capacity Act set out a clear legal framework for the delivery of equal treatment. One of the key recommendations from this report was for the Government to set up a time-limited Confidential Inquiry into the premature deaths of people with learning disabilities.

Following the Michael Report in 2008, the Secretary of State for Health invited tenders for a learning disabilities Public Health Observatory (PHO) and a confidential Inquiry into the deaths of people with learning disabilities. A team based at the Norah Fry Research Centre, University of Bristol, was subsequently asked to undertake the Confidential Inquiry (CI). The Secretary of State requested an interim report about its progress in February 2011. The CI team will be presenting this to Paul Burstow.

This is a summary of the full Interim Report submitted to the Secretary of State in February 2011. We have omitted from this summary report any early findings that may influence how investigators or nurses conduct their investigations, or what they focus on within those investigations. This is because we do not want to steer investigations in any particular direction, as to do so would risk the CI becoming biased. Please do not quote any statistics from this report, as they may not reflect those when the study is complete.

2. Setting the scene

The aims of the Confidential Inquiry

The principal aim of the CI is to establish the extent to which people with learning disabilities die prematurely. The objectives are:

- To detect potentially modifiable contributory factors in the care of a person with learning disabilities who has subsequently died
- To identify inadequate pathways of care or gaps in the treatment of people with learning disabilities within health and care services and develop recommendations to rectify these
- To identify good practice in the treatment of people with learning disabilities within health and care services and to contribute to the evidence base for best clinical and professional practice for meeting their needs
- To provide information to guide the commissioning of services to meet the needs of people with learning disabilities
- To establish a usable system for reporting the deaths of people with learning disabilities that can be replicated across different geographical areas
- To improve the standard and quality of care for people with learning disabilities and ultimately their health outcomes.

These aims accord with some of the key priorities for the NHS which Andrew Lansley, Secretary of State for Health set out in his speech on 2nd July 2010. The CI will directly contribute to:

- keeping the emphasis on patients being at the heart of everything

- ensuring that the NHS focuses on achieving continuously improving outcomes for patients
- supporting work on prevention and on public health in order to improve overall health outcomes
- providing information to support commissioners and providers of services.

The aims of the CI also match the concerns of the White Paper *Equity and Excellence: Liberating the NHS* (DH, 2010), particularly those relating to:

- Domain 1: Preventing people from dying prematurely
- Domain 4: Ensuring people have a positive experience of care
- Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm.

In the social care arena too, the CI is helping to deliver on some of the strategic aims of Coalition Government policy. The proposals outlined in the consultation document '*Transparency in Outcomes: a framework for adult social care*' (DH, 2010) stress the importance of improving outcomes for those with care and support needs, and improving the quality of care services, both of which the CI will contribute to. '*A vision for Adult Social care: capable communities and active citizens*' (DH, 2010) reiterates the commitment of the Coalition Government to ensuring that people with learning disabilities, their families and carers have greater control over their health and care, and are well supported in this by health and care professionals.

The process of the Confidential Inquiry

The step-by-step process taken to investigate the deaths of people with learning disabilities is outlined below and summarised in Appendix 1.

1. A communication network reports the death of a person with learning disabilities.
2. The core team logs the death, verifies that the person meets the inclusion criteria, and requests core standardised information regarding the person who has died from those that have been in contact with them.
3. An investigator and nurse are allocated to the case. The investigator reviews case notes and records pertaining to the person who has died, interviews the different professionals involved in their care and undertakes a Root Cause

Analysis of the death. The CI team nurse visits the family of the person who has died, with their consent¹, to offer bereavement support and advice, and to talk with them about the life and death of the person.

4. All of the investigation evidence is collated into a standardised format and prepared for a multidisciplinary Local Review Panel. The focus of the Local Review Panel meeting is to identify what learning can be taken from the death of the person, what evidence of good practice can be shared, and if there are any recommendations that can be made. A summary report of the meeting is distributed to everyone who has contributed to the CI process and the Local Review Panel meeting.
5. Documentation from each case is fully anonymised in preparation for the Overview Panel stage. The Overview Panel consists of a group of experienced people from a multidisciplinary background who meet regularly throughout the course of the CI. Each Overview Panel meeting reviews the conclusions of the Local Review Panel meetings for several deaths, provides an external perspective in relation to each case, and identifies overall patterns and themes that are arising from a number of cases.
6. The Overview Panels produce aggregated updates which will summarise evidence for clinical and professional practice and provide information for PCTs and local authorities to guide the commissioning of local services. Summary data from the Overview Panels is collated and reported to the Department of Health.

3. The scope of the Confidential Inquiry

From the outset, the CI team has worked closely with the newly established learning disabilities Public Health Observatory (PHO) to agree a suitable definition of 'learning disability'. Guidance on the practical steps that can be taken to identify a child or adult with learning disabilities is available from the Public Health Observatory² and Confidential Inquiry websites³.

¹ The CI nurses are able to offer bereavement support to all families but because of the Ethics Committee restriction on making direct unsolicited contact with families, they are only permitted to do so if the family request this once they have received information about the CI.

² <http://www.improvinghealthandlives.org.uk/about/definition>

³ <http://www.bris.ac.uk/cipold/how-you-can-help-us/notify-the-team/learning-disability-criteria.pdf>

The CI reviews the deaths of all people with learning disabilities from the age of four onwards.

In the first year of the CI it covers Gloucestershire and the (former) Avon area (Bristol; North Somerset; South Gloucestershire; Bath and North East Somerset). These areas have a mix of urban and rural areas that are very close to the national average, although are under-represented with regards to Black and Minority Ethnic (BME) groups. It is essential that in the second year of the CI, consideration is given to maximising the number of people from BME groups, as existing data suggests that there is an increased prevalence of people with moderate or severe learning disabilities in Pakistani and Bangladeshi communities in particular (Emerson et al., 2010).

A focus of the CI is to determine whether or not the deaths of people with learning disabilities are premature. To put the findings into perspective, both within this particular group and in the context of the wider society, the CI will include two comparator groups. One comparator group is of people with learning disabilities whose death has been investigated and not been considered to be premature. Recruitment to this comparator group is already taking place. The second comparator group will be of people without learning disabilities who are broadly matched to a person with learning disabilities who has died, on the basis of age, gender, cause of death (categorised), and geographical area. Recruitment to this comparator group will take place in Years 2 and 3 of the CI. The use of comparator groups is particularly important as it will help put the findings in context and identify modifiable factors specific to people with learning disabilities.

4. The progress of the Confidential Inquiry

To the end of December 2010, the CI had been informed of the deaths of 69 people with learning disabilities eligible to be included in the Confidential Inquiry.

The CI is supported by a core team (team manager, secretary, project workers, lead investigator, lead nurse, chair of the Overview Panel and statistician), supported by a

'pool' of 11 learning disability nurses and 20 investigators working on a case by case basis.

All of the nurses and investigators have honorary contracts with the University of Bristol to ensure that contractual agreements (such as those regarding confidentiality) are upheld, the quality of the work is monitored and insurance arrangements are in place.

5. Working with the Learning Disabilities Public Health Observatory

The CI fits well alongside and within the work of the PHO. Joint work has been undertaken with the PHO relating to:

- reasonable adjustments for people with learning disabilities in relation to the Disability Discrimination Act
- using death certificates as a source of information about cause of death in people with learning disabilities
- understanding population patterns relating to people with learning disabilities who have moved from institutional to community care
- reviewing demographic data at Primary Care Trust level to determine which areas the CI could usefully cover
- reviewing expected numbers of deaths of people with learning disabilities at a local level
- presenting information about the CI and the PHO to key local, national and international audiences. A summary of how the Inquiry's work is being shared with commissioners, health and social care providers, and people with learning disabilities and their families/carers is included in Appendix 2.

6. Preliminary Findings

In the first six months of receiving notifications of deaths (June to November 2010 inclusive) the CI team opened investigations into the deaths of 55 people with learning disabilities. A further 14 deaths have been reported in December 2010.

- 17 of the investigations have been completed and have been reviewed by the Overview Panel
- 9 cases have been investigated and are awaiting review by the Overview Panel
- 43 cases are currently being investigated/awaiting investigation.

The data analysis that follows is based on analysis of the 55 cases reported to the CI in the six months from the beginning of June (three of the deaths occurred in May 2010) to the end of November 2010.

The proportion of cases from each of the geographical areas in the CI is shown in Table 1. Not surprisingly a larger number of the deaths came from Bristol and Gloucestershire which include the larger conurbations.

Table 1: The proportion of cases from each of the geographical areas in the CI

Area	Number	Proportion*
Bristol	22/55	40%
Gloucestershire	19/55	35%
Bath & NE Somerset	6/55	11%
North Somerset	5/55	9%
South Gloucestershire	3/55	6%

*proportions may not total 100% due to rounding

Notification and length of investigation

The median time from a death occurring to the CI team being notified was one day [Inter-quartile range: 0-3 days]; five of the 55 deaths were reported late (between three and seven weeks) although there has been a noticeable improvement in notification times as the study has progressed.

The median time from death to Local Review Panel (for the 23 cases that have so far been to Panel) was 16 weeks [Inter-quartile range: 9-19 weeks].

The median time from death to the Overview Panel (for the 17 cases that have so far been to Panel) was 21 weeks [Inter-quartile range: 15-23 weeks].

The process from a person's death to the completion of the investigation (including data input) has taken 24-26 weeks. This is approximately three months shorter than the equivalent processes in the Child Death Review process with which some CI team members have been involved.

Those interviewed

The number of professionals, family members and friends providing information for the CI about each death has ranged from 2 to 12, with a median of 6 different interviews conducted with key informants per death. Table 2 (over-page) provides an overview of the range of people interviewed by investigators.

At 13 of the 17 Local Panel Review meetings, all of the key health professionals involved in the case (e.g. hospital staff/GP/specialist/ community learning disability team) attended. In the four occasions on which all professionals did not attend, there was more difficulty both in the investigation and in feedback to the relevant agencies.

Table 2: The range of people interviewed by investigators

Person	Number	Proportion
Current GP	54	98%
Home manager	43	78%
Hospital Specialist	34	62%
Relative	24	44%
CLDT* Doctor	23	42%
CLDT* Nurse	23	42%
Nurse Specialist	15	27%
CLDT* Social worker	13	24%
CLDT* Occupational Therapist	12	22%
Attending hospital doctor at time of death	10	18%
Previous GP	7	13%
Day Service	6	11%
Advocacy Service	≤5	≤10%
Social Services Case Manager	≤5	≤10%
Paid Carer	≤5	≤10%
Friends	≤5	≤10%
Voluntary Agency	≤5	≤10%
Community Matron	≤5	≤10%

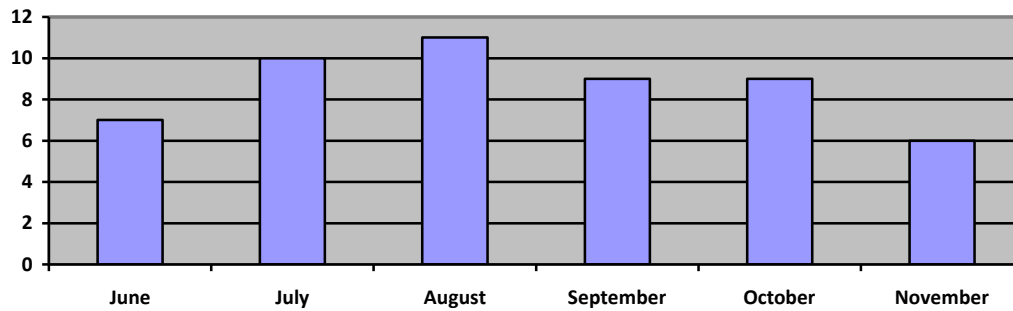
* Community Learning Disability Team

Demographic information

Number of deaths

Figure 1 (over-page) shows the number of deaths reported by month of year.

Figure 1: Number of deaths by month of year



Using data drawn from an analysis of Cause of Death certificates by the PHO (Glover and Ayub, 2010), the number of deaths of people with learning disabilities in the CI study area from 2006-8 was estimated to be 143, suggesting around 48 deaths a year. This equates to a crude death rate of 2.9 per 100,000 of the population. However the projected yearly total in our study area based on the first six months of data suggests around 110 cases a year with a crude death rate of 6.6 per 100,000 of the population, two to three times higher than expected.

We have a number of hypotheses about why there is a discrepancy between our original estimate and our current number of cases:

- We know that there were a number of long-stay institutions in the (former) Avon and Gloucestershire areas which were closed during the 1970s, 1980s and 1990s. Many of the residents of these long-stay institutions moved into community homes in the local area. We have analysed data about long-stay institution migration and the adjustments made in resource allocations which took account of the numbers of people with learning disabilities who were resettled in CI study areas. This suggests that the current study area has an over-representation of people with learning disabilities and institutional histories compared to the national 'average'.
- We know that there has been some migration into the (former) Avon and Gloucestershire areas, with decisions made to relocate some people with learning disabilities to areas where there are existing facilities and perceived attractive surroundings. This would contribute to the over-representation of people with learning disabilities in these areas compared to the national 'average'.

- As well as the over-representation of people with learning disabilities, we may also be capturing a higher death rate in these populations than might be expected. Many of the former residents of the long-stay institutions are now reaching their middle to old age, and we may be seeing a bulge in the death rate associated with aging in a population whose early life experience in long-stay institutions may have left them more vulnerable.
- Another reason for the higher death rate in people with learning disabilities than might be expected may be an excess of deaths related to socio-economic deprivation. The (former) Avon and Gloucestershire areas have pockets of entrenched rural poverty and urban deprivation – both of which are factors that contribute to premature deaths.
- It is also likely that the death certificate data on which our original estimates were based may have under-reported that a person had learning disabilities.
- Our original estimate was that we would be notified of the deaths of 70% of deaths in the (former) Avon and Gloucestershire areas, but we suspect that the CI is being notified of a larger proportion of deaths than this.

The CI investigators now obtain information about the histories of those whose deaths are being investigated to determine whether institutionalisation has been a feature, and to provide evidence about patterns of migration. When sufficient cases have been completed, their distribution will be mapped onto patterns of poverty and deprivation in the geographical areas being covered. Once a whole year's data has been collected (which takes into account seasonal differences in the number of deaths), the mortality rates in the CI areas can be recalculated based on actual rather than expected figures, thus providing commissioners and service providers with more accurate data on which to make decisions.

Cause and mode of death

The cause of death has been established for 49 of the deaths and broadly categorised into four groups (Table 3). The majority of these deaths (55%) have been from cardio-respiratory causes; none of the deaths have been from accidental or non-accidental trauma.

The mode of death has so far been identified for 25 of the deaths (also Table 3). Just over a third of the cases were receiving planned palliative care and a similar proportion died after a failed resuscitation attempt.

In all, 64% of the 25 deaths for which the mode of death was reported were identified by the Overview Panel as being unexpected. The death was reported to a coroner for 12 cases; a post-mortem examination was conducted for 11; and an inquest was held into two.

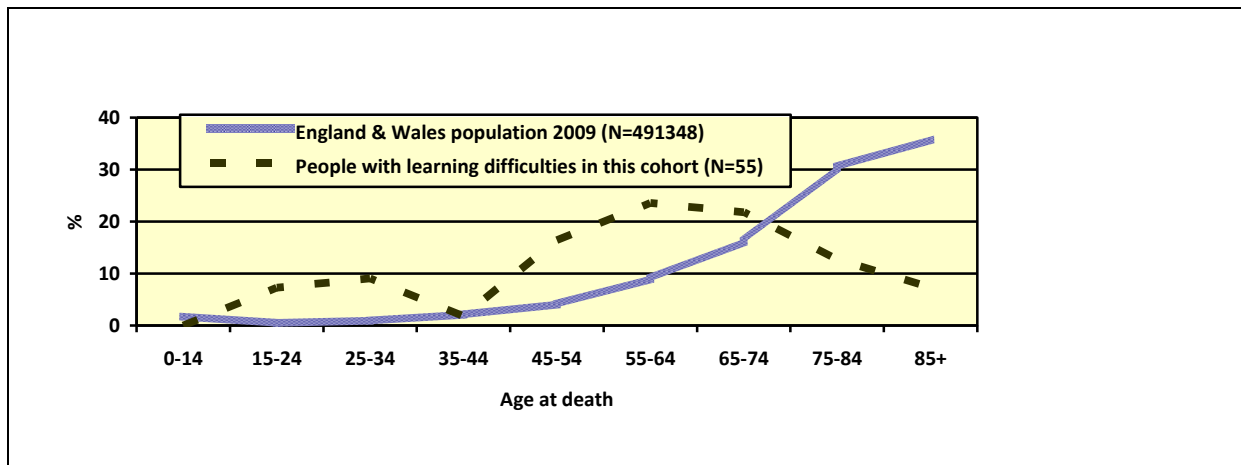
Table 3: Cause and mode of death

Cause	Number	Proportion
Cardio-Respiratory	27/49	55%
Malignancy	10/49	20%
Trauma, accidental & non-accidental	0/49	0%
Other*	12/49	24%
Mode	Number	Proportion
Planned palliative care	9/25	36%
Failed CPR	9/25	36%
Witnessed event	6/25	24%
Found dead	1/25	4%
* including abdominal haemorrhage, bowel obstruction, epileptic seizure, sudden unexpected death and Alzheimer's disease		

Age at death

The median age of death for the 55 cases was 62 years (interquartile range: 48 to 69 years) ranging from 18 to 94 years. This distribution is in sharp contrast with age at death for the general population in England & Wales in 2009, where the median age of death fell into the 75-84 year age bracket (Figure 2). The pattern of age at death in the CI shows a striking bi-modal distribution, with peaks in early adulthood, possibly reflecting the transition from children's to adults' services, and between the ages of 45-65. Over a third (35%) of people with learning disabilities in the CI were under the age of 50 when they died, compared with approximately 9% of the general population.

Figure 2: Age at death in the Confidential Inquiry (2010) compared with national data for the general population in England and Wales (2009)

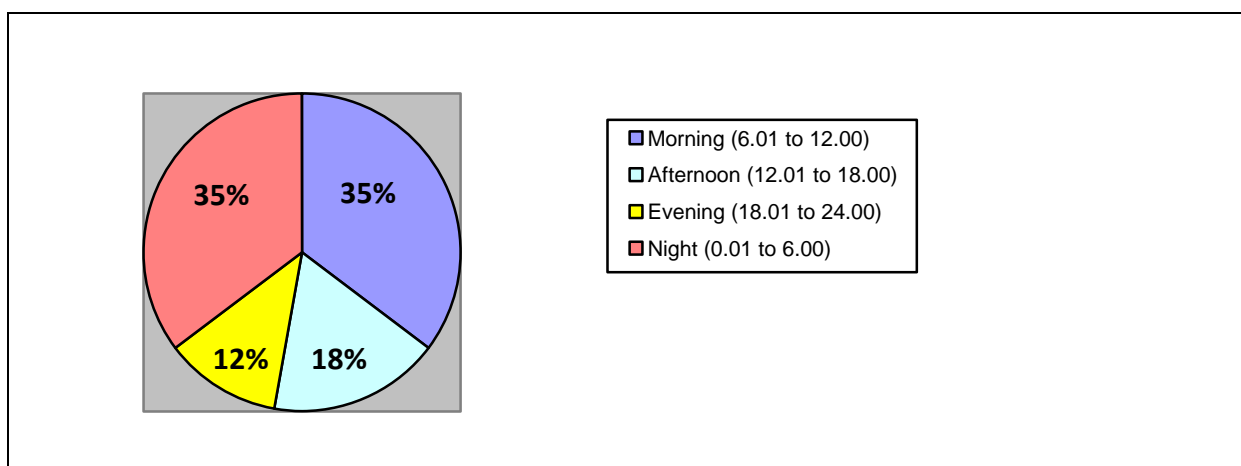


Source of national data: ONS website

Day and time of death

There was no particular day of the week that had an increased prevalence of death; sixteen of the 55 deaths occurred at the weekend (29%) - the proportion one would expect assuming a uniform distribution. Figure 3 shows the time of day the deaths occurred. The majority occurred during the night (from midnight to 6am) or in the morning (after 6am to noon), which is very much in line with what is known about the timing of deaths generally – both for adults and children.

Figure 3: The time of day that people with learning disabilities died



Characteristics of those who had died

Table 4 (over-page) details some of the characteristics of the people with learning disabilities included in the Inquiry.

Table 4: Characteristics of people with learning disabilities included in the CI

Characteristic	Category	n/N	%*
Gender	Male	35/55	64%
	Female	20/55	36%
Ethnicity	White (British)	46/47	98%
	White (Other)	1/47	2%
Body Mass Index (BMI)	Underweight (BMI <18.5)	8/39	21%
	Normal (BMI 18.5 to <25)	14/39	36%
	Overweight (BMI 25 to < 30)	8/39	21%
	Obese (BMI 30+)	9/39	23%
Type of accommodation	Residential home	24/48	50%
	Nursing home	9/48	19%
	Parental home	6/48	13%
	Own home	6/48	13%
	Other private residence	3/48	6%
Living with	Other residents	32/48	67%
	Other family members	6/48	13%
	Alone	5/48	10%
	Parents	4/48	8%
	Live-in carer	1/48	2%
Support provider	Paid carer	38/46	83%
	Parents	5/46	11%
	Family members	3/46	7%
History of long-term institution	No	20/30	67%
	Yes	10/30	33%
Smoker	No	20/28	71%
	Yes	8/28	29%

*proportions may not total 100% due to rounding. Given the small numbers involved, percentages should be used with caution, and not without confidence intervals

As Table 4 shows, there were more males than females. All of the cases to-date are of white ethnicity, which is a higher proportion than would be expected: the proportion of people from BME backgrounds in the study area is 10% and, assuming

uniform distribution of risk factors amongst people with learning disability from different ethnic groups, we would have expected 3-6 deaths of people from BME groups over a six month period. It is possible that some people (particularly people living with their extended family) might not have been reported as having learning disability, had their death occurred. It is also possible that the age profile of people from BME backgrounds, including those with learning disability, differs from that of the majority white population in the study areas, with a higher proportion of the BME population being in the younger age groups.

A larger proportion of people with learning disabilities who had died were either underweight or overweight/obese than would be expected in the general population. Just under a third of those who died lived privately in the parental home or their own home; the majority lived in residential or nursing homes. Few lived alone, some lived with family, but, reflecting the type of accommodation arrangements, the majority lived with other residents. A third of the people who died had lived in a long-term institution in the past, usually for many years (19 to 40 years). The proportion of smokers was 29%. Just one person had been in paid employment and one person had been engaged in voluntary work.

Severity of learning disabilities and its impact

Table 5 (over-page) shows the severity of the person's learning disability and the impact on daily living this had. Of the 35 cases for which information was available, just under a half had severe or severe/profound learning disabilities, and a third had mild or mild/moderate learning disabilities.

Of the completed cases, approximately a third of the people with learning disabilities needed total support to get around, were inactive, unable to communicate verbally and may not have had the capacity to make day-to-day decisions for themselves. More than half required total support in managing their own personal care (washing, dressing, personal hygiene etc) and three-quarters required total support with their daily living (cooking, cleaning etc). In terms of overall support, the majority (85%) received support 24 hours a day provided by a paid carer (83%) or family member(s) (17%).

Table 5: Severity of learning disability and its impact on daily living

Characteristic	Category	n/N	%*
Severity of learning disabilities	Mild	10/35	29%
	Mild to Moderate	1/35	3%
	Moderate	6/35	17%
	Moderate to Severe	3/35	9%
	Severe	6/35	17%
	Severe to Profound	9/35	26%
Mobility	Independently mobile	10/35	29%
	Needs some support	14/35	40%
	Needs total support	11/35	31%
Activity	Generally active	5/30	17%
	Light exercise only	14/30	47%
	Inactive	11/30	37%
Personal Health	Manages own personal health	7/34	21%
	Requires some support	9/34	27%
	Requires total support	18/34	53%
Daily living skills	Manages independently	1/32	3%
	Requires some support	8/32	25%
	Requires total support	23/32	72%
Verbal communication	Good	18/33	55%
	Limited	3/33	9%
	Unable to communicate verbally	12/33	36%
Decision-making	Able to understand and make most decisions	9/27	33%
	Able to make day-to-day decisions	6/27	22%
	Needs support to make day-to-day decisions	4/27	15%
	May not have capacity to make day-to-day decisions	8/27	30%
Provision of support	24 hours a day	35/41	85%
	Daily	4/41	10%
	Every other day	2/41	5%

*proportions may not total 100% due to rounding. NB. Given the small numbers involved, percentages should be used with caution, and not without confidence intervals

Premature deaths

There are two main ways of defining a premature death. One is to consider the typical life expectancy at birth of the general population and to regard a premature death as one which occurs before a standardised age, indicating a measure of global life expectancy. Whilst this may be an appropriate measure of prematurity in a general population, for a population of people with learning disabilities who may have associated life-limiting conditions, such a definition would skew the proportion of deaths thought to be premature. The second main way of defining a premature death is to consider potential life-expectancy. Here, a death is considered premature if, without a specific event that formed part of the 'pathway' that led to death, it was probable (i.e. more likely than not) that the person would have continued to live for at least a few more years. This is the approach taken in the CI. Whilst accepting that there is the potential for judgements being made, rather than descriptions of circumstances, the CI asks both the Local Review Panel and the Overview Panel to assess (separately) whether they consider each death to be premature using the above definition.

Agreement between Local Review Panel and Overview Panel

Of the 17 completed cases reviewed by the Overview Panel, agreement of whether a death should be considered premature or not was generally poor. In only eight cases (47%) was there agreement. In seven cases the Overview Panel considered the death premature whilst the Local Review Panel either did not or was unsure; for the remaining two cases the Local Review Panel thought the cases were premature but the Overview Panel was unsure of one and thought the other was not. This perhaps underlines the importance of the Overview Panel. Local Review Panel meetings are attended by those who have been closely involved in supporting the individual who has died, and their degree of objectivity may be different from that of the Overview Panel members who are expert professionals from a range of backgrounds and who have had no involvement with the individual case.

Age was not found to be a factor in whether the death was considered to be premature or not. The median age of the premature deaths was 62 years, and it was

65 years amongst the non-premature deaths. This provides some support for the rationale taken by the CI as to the definition of premature death. Three of the twelve (25%) premature deaths were in people over the age of 70, compared with one in five (20%) of the non-premature deaths.

7. The difference that the CI is making

To-date, more than 150 professionals have contributed to the investigations into the deaths of people with learning disabilities. Some professionals have been involved in the investigations of more than one person who has died. For most of these professionals, the CI has afforded them a valuable opportunity to reflect on their practice and consider their own role as part of a team supporting an individual. Anecdotal comments made during interviews or at Local Review Panel meetings suggest that professionals have, in the main, benefited from this aspect of the CI. The CI team now offers a Certificate of Completion for professionals that they can provide as evidence for their own professional development.

Six - ten weeks after each Local Review Panel meeting, each professional who has been involved with the case is sent a Feedback Questionnaire on which to record their reflections on participating in the CI, any changes that they may have made to their practice as a result, and any suggestions that they may have regarding the conduct of the CI. To-date, only a small number of forms have been returned, but these indicate that individually and collectively, changes are being made. One professional, for example, wrote a long report back to the CI team detailing the discussion that took place at a meeting of four hospital consultants and a specialist nurse. They are now making a number of changes in relation to all of their patients, as well as some changes specific to patients with learning disabilities regarding communication, record-keeping and the presentation of information.

Following each interview with a family member, the CI nurse asks the person to provide feedback to the CI team about their reactions to the interview. A form and Freepost envelope are left with the family member for them to return their comments anonymously. To-date, the comments that have been received have been very

positive about the value of the CI in supporting bereaved families. One family member, for instance, commented:

'Talking with the interviewer helped me come to terms with the circumstances surrounding my sister's death'.

Another said:

'In a way, it brought him back to us for a while...It was the first time we had spoken in depth about our recent bereavement...Our interviewer was very sympathetic to our recent loss and it was really good to talk about him so openly and with feeling. The tears were good tears'.

Other family members have stressed that although losing their family member was a painful experience, they hope to help others by engaging with the CI, and ultimately contributing to the joint working with the PHO as a mechanism for sharing the findings with commissioners, health and social care providers, and people with learning disabilities and their families/carers.

8. The way forward

The CI is providing new and important evidence regarding premature deaths in people with learning disabilities. In order for a robust study, the CI now needs to extend, in Years 2 and 3, to:

- over-sample populations of people from BME backgrounds in order to determine if the deaths of people with learning disabilities from these communities share similar or different characteristics
- add a comparator group of people without learning disabilities who die prematurely, in order to determine whether the circumstances of the deaths of people with learning disabilities are the same or different to those of the general population
- and ideally, add a new geographical area to the study, in order to determine if the findings from the existing study area are common to other parts of the country.

The CI team appreciates that we are operating in a stringent financial environment and that we need to contribute to cost savings wherever possible. We are also clear

about what would constitute 'good science' for the CI and are dedicated to delivering a scientifically robust study about premature deaths in people with learning disabilities that will identify significant and potentially modifiable contributory factors to provide clear evidence on which future commissioning decisions and practice improvements can be made. Such evidence will also have the potential to empower people with learning disabilities and their families/carers to influence effectively the way in which local services are provided for them.

References

DH (2010) White Paper *Equity and Excellence: Liberating the NHS*. Department of Health, 2010.

DH (2010) *Transparency in Outcomes: A framework for adult social care*. Department of Health, 2010.

DH (2010) *Health Lives, Healthy People: Our strategy for public health in England*. Department of Health, 2010.

DH (2010) *A vision for adult social care: capable communities and active citizens'* Department of Health, 2010.

Emerson, E., Hatton, C., Robertson, J., Roberts, H., Baines, S. & Glover, G. (2010) *People with Learning Disabilities in England 2010*. Learning Disabilities Public Health Observatory: Lancaster.

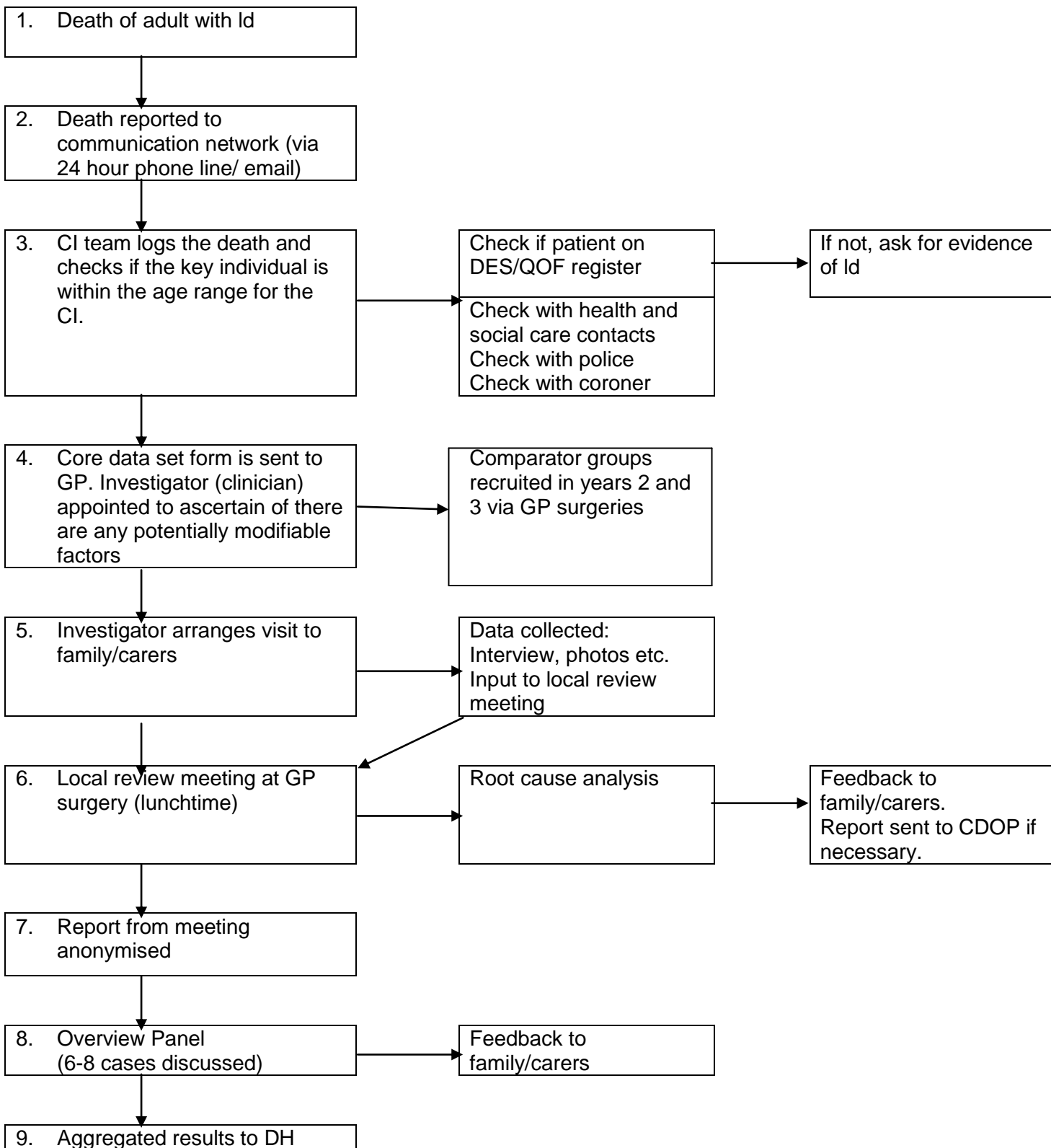
Emerson E. and Baines S. (2010) Health inequalities and people with learning disabilities in the UK: 2010. Improving health and lives: Learning Disabilities Public Health Observatory: Lancaster.

Glover, G. & Ayub, M. (2010) How people with learning disabilities die. IHAL: Learning Disabilities Observatory.

Lansley, A. (2010) 'A shared ambition to improve outcomes'
http://www.dh.gov.uk/en/MediaCentre/Speeches/DH_117103

McGuigan SM., Hollins S. & Attard M. (1995) Age specific standardized mortality rates in people with learning disability. *Journal of Intellectual Disability Research* 39: 527–31

Appendix 1: The step-by-step process for the CI



**Appendix 2: Formal dissemination events
at which the work of the CI has been presented or represented**

May 2010

- Bristol LD Health Work Group from the Partnership Board
- Bristol LD Providers Forum
- Bridge Conference, an international conference held in Bristol, focusing on the health of people with learning disabilities
- South West LD Nurses Conference

June 2010

- Commissioning team in Gloucestershire
- Bristol LD Partnership Board meeting
- National A2A meeting
- LD county wide social workers meeting
- Gloucestershire LD Partnership Board meeting
- Gloucestershire LD Providers meeting

July 2010

- CLDT Locality Managers meeting, Bristol
- Bristol and South Gloucestershire Carers Forum
- South Gloucestershire LD Partnership Board meeting
- Death and Dying Conference – a national conference (no formal presentation given, but a member of CI team provided information about the CI)
- National LD Nursing Conference in York

August 2010

- Stroud CLDT meeting
- Gloucester CLDT meeting

September 2010

- South West LD Commissioners Forum
- LD Nurses CPD event, Gloucester

October 2010

- Black Members People First Group conference
- North Somerset Providers meeting

- International Association for the Scientific Study of Intellectual Disabilities' European Conference in Rome
- North Somerset CLDT meeting

November 2010

- National Network for Palliative Care for People with Learning Disabilities annual conference on "People with learning disabilities, Dementia and End of Life" (no formal presentation given, but a member of CI team provided information about the CI)
- PHO event for Learning Disability Health Commissioners, Birmingham

December 2010

- PHO event for Learning Disability Health Commissioners, Bristol,
- LD Today (joint presentation with PHO), London

January 2011

- London Wide Health Network Meeting
- PHO event for Learning Disability Health Commissioners in Burnley
- Practice Managers' meeting in Bristol.



Prepared by the CI team, February 2011

**The Confidential Inquiry Team
Norah Fry Research Centre, University of Bristol
3 Priory Road
Clifton
Bristol BS8 1TX**

**Tel: 0117 3310980
Fax: 0117 3310978**

email: ci-team@bristol.ac.uk

website: www.bristol.ac.uk/cipold