Learning Disabilities Mortality Review (LeDeR) Programme

NHS
Cambridgeshire and Peterborough
Clinical Commissioning Group

Learning Disability Mortality Review (LeDeR)

Cambridgeshire and Peterborough Annual Review

April 2019 – March 2020

Foreword

The aim of this report, and those like it, is to bring information together to understand local needs and to learn lessons that can inform practice.

This cannot happen unless the reader stays connected to the meaning of the events behind the data - this report is about people who have died. The people whose deaths are reported here are people who were loved, were loving, and whose loss will have had a profound impact on those around them.

Cambridgeshire and Peterborough are committed to action and practice that respects this.

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Contents

1. Background

The Learning Disabilities Mortality Review (LeDeR) programme is now established throughout England, and is in its fourth year. It has now become sadly all too well known that the difference in median age of death between people with a learning disability and the general population is significant; recently updated data shows the difference to be 22 years for men, and 27 years for women[1]. This shocking statistic is one of many that make up the reason why the LeDeR programme was established; to better understand the significant health inequalities experienced by people who have a learning disability, with the aim of creating parity of esteem for people with learning disabilities, and reducing premature morbidity.

This is the second annual report for the Cambridgeshire and Peterborough programme. It presents information about the deaths of people with learning disabilities aged four years and over, notified to the programme between 1st April 2019 – 31st March 2020.

The partners, roles and structures of the LeDeR programme have been summarised in the 2018-2020 Cambridgeshire and Peterborough report. This, along with an accessible version of the report, can be accessed at the CCG's website[2]. The LeDeR review process itself is summarised in Appendix 1, and more information on this process can be found on the University of Bristol's website[3].

Where relevant, data in the present report will be compared to the most recent (2019) national annual LeDeR report, which can be found on the University of Bristol's website[4].

2. The National LeDeR Programme

2.1 Summary

From 1st July 2016 - 31st December 2019, 7,145 deaths were notified to the LeDeR programme (Table 1). Of these, 820 were reported in the East of England.

[1] http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf
[2] www.cambridgeshireandpeterboroughccg.nhs.uk/your-health-and-services/mental-health-learning-disability-services/
[3] www.bristol.ac.uk/sps/leder
[4] www.bristol.ac.uk/sps/leder/resources/annual-reports/

Table 1: Number of "in scope" notifications of deaths of people with learning disabilities aged 4 years and over, by NHS England region.

	1st July – 31st Dec. 2016	1st Jan. – 31st Dec. 2017	1st Jan. – 31st Dec. 2018	1st Jan. – 31st Dec. 2019	Total
North West	10	236	380	436	1,062
North East & Yorkshire	46	327	392	537	1,302
Midlands	*	128	534	621	1,284
East of England	0	137	338	345	820
South East	25	132	521	477	1,155
London	*	180	312	338	834
South West	14	125	243	306	688
Total♦	100	1,265	2,720	3,060	7,145

* Number of deaths fewer than 10.

♦Notifications between 2016 and 2018 are slightly lower than reported last year, as 216 notifications have since been identified as duplicates and removed from the data.

Of the data aggregated across this four year time period, some of the key findings are reported in Table 2.

This information is documented here in order to provide useful contextual information within which Cambridgeshire and Peterborough's data sits.

Table 2: Key findings documented in the 2019 National Annual report, between 2016-2019.

The person's gender was reported for 7,127 deaths. Of these, over half (58%) were males.
The person's ethnicity was reported for 6,569 deaths. The majority (90%) were of white British ethnicity; 4% were Asian; 2% from other white ethnic groups; 2% mixed and 2% were from other ethnicities.
The median age at death for 7,145 people with learning disabilities (aged 4 years and over) was 60 years. For males it was 60 years (min 4 years; max 98 years); for females it was 59 years (min 4 years; max 104 years) (Figure 7).
Of 7,096 deaths for which date of death was reported, the peak months of deaths were October to December. There was a greater proportion of deaths of people with learning disabilities from October – December than in the general population
The level of a person's learning disabilities was reported for 3,557 deaths. Of these, 30% were known to have had mild learning disabilities; 33% had moderate learning disabilities; 27% severe learning disabilities; and 10% had profound and multiple learning disabilities.
Of the 6,931 notifications of deaths of people with learning disabilities for which the place of death was reported, 60% died in hospital.
People from minority ethnic groups died at disproportionately younger ages than white British people. Of those who died in childhood, 43% were from minority ethnic groups
Of 3,195 people with learning disabilities whose deaths have been reviewed, 3,006 (94%) had at least one long-term health condition. The mean number of long-term health conditions was three.
The five most common long-term health conditions reported in completed reviews were: • **Epilepsy (36%)** • **Cardiovascular problems (32%)** • **Dysphagia (29%)** • **Mental ill health (26%)** • **Constipation (23%)**

3. Cambridgeshire and Peterborough (C&P) LeDeR

3.1 Programme delivery

To guide expectations of the reader, it is important to note that at the time of writing, it has only been possible to provide a brief overview of the deaths reported during 2019-2020.

During the time period considered in this report, C&P LeDeR experienced a number of challenges that have had a significant impact on the region's ability to carry out reviews in a timely manner. Those familiar with the 2018-2019 report will be aware of this context: commitment to the programme between all partners was significant, but the capacity of the established pool of reviewers was limited, there was no dedicated programme lead to oversee and drive forward the programme. Whilst significant progress has been made during 2020, the gains made do not yet translate into a comprehensive analysis of completed reviews. However, plans to ameliorate this are firmly on track for 2020-2021 (see section 5).

3.2 Population demographics

The ONS 2011 Census, the population of Cambridgeshire was 648,237 and the population of Peterborough was 198,914, giving a total population of 847,151 people across these two regions.

In 2019, the Quality and Outcomes Framework (QOF) Register indicates that 4,052 adults in Cambridgeshire and Peterborough had a diagnosed learning disability. This represents 0.8% of the local population, or approximately 1 in 209 people. Fifty-nine percent were male.

From this total number (4,052 people), the number of people registered across the different GP practice areas is shown in Table 3.

***Table 3: People registered with a learning disability, by GP catchment area (*Learning Disability Register data, 2019/20)**

	Numbers (%) adults with a learning disability 2019/20
Cambridge GPs	1330
Peterborough GPs	1227
Huntingdon / Fenland GPs	1495
	Total: 4052

Of these adults, 41% (a total of 1665 people) received support through the local authority. This is broken down by age/type of support, in Table 4.

Table 4: Types of support provided to adults with the learning disability, by age, across Cambridgeshire and Peterborough.

Support type	**Number of people**
18yrs - 64yrs	**Total: 1493**
Community	1,252
Nursing	8
Residential	233
65yrs +	**Total: 172**
Community	117
Nursing	4
Residential	51

For children and young people, data is obtained from the 2020 Department for Education release (Special Educational Needs in England), which is populated using the Spring 2020 census. This indicates that there were 4,235 children and young people with a disability across Cambridgeshire and Peterborough, in 2019-20; 3,041 in Cambridgeshire (37.8% female, 62.2% male), and 1,194 in Peterborough (38.5% female, 61.5% male). The number of children with a learning disability, by region, is shown in Table 5.

Table 5: Children and young people with a learning disability, by region (DfE data).

	Numbers (%) children/young people with a learning disability 2019/20
Cambridge	351 (8%)
East Cambs	497 (11.7)
Fenland	471 (11.1%)
Huntingdonshire	922 (21.7%)
South Cambs	800 (18.9%)
Peterborough	1194 (28.1%)
	Total: 4235

3.3 Notifications – overview

Between April 2019 – March 2020, Cambridgeshire and Peterborough LeDeR received notification of a total of 34 deaths. All deaths reported during the time frame 2019/20 will be included within this report, although of these reported deaths, four deaths occurred outside of the reported time period. The services who made the notifications are outlined in Table 6.

Table 6: Notifications received, by service.

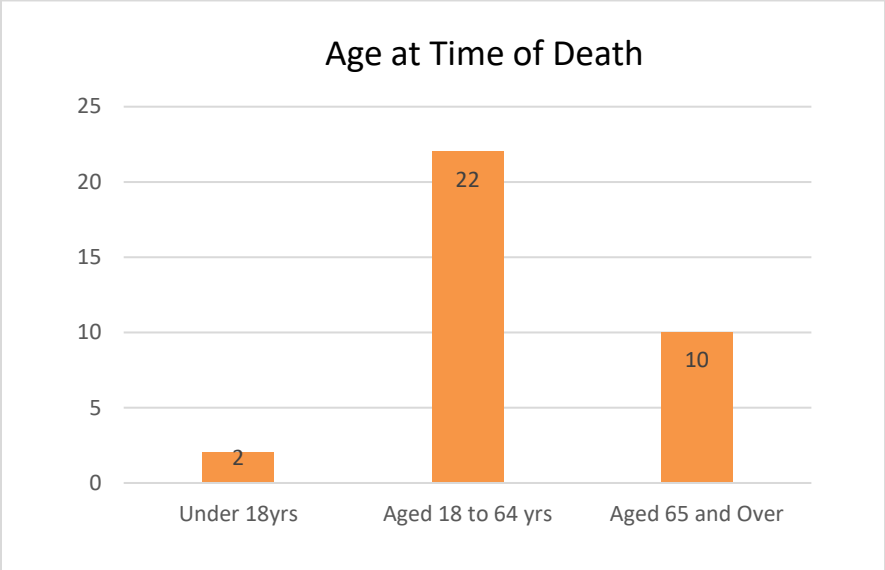
Reporting Team / Service	**No. Reports**
Acute trusts	17
Learning Disability Partnership Team/Community Teams	8
Care providers	7
Other (grouped to maintain anonymity)	2
Total	34

Of the notifications received, a total three reviews have been carried out at the time of the report.

3.4 Descriptive information: The people whose deaths were notified to LeDeR

3.4.1 Age at time of death

Information regarding the age death is of significance to the programme, given that this is a key marker of health inequality.

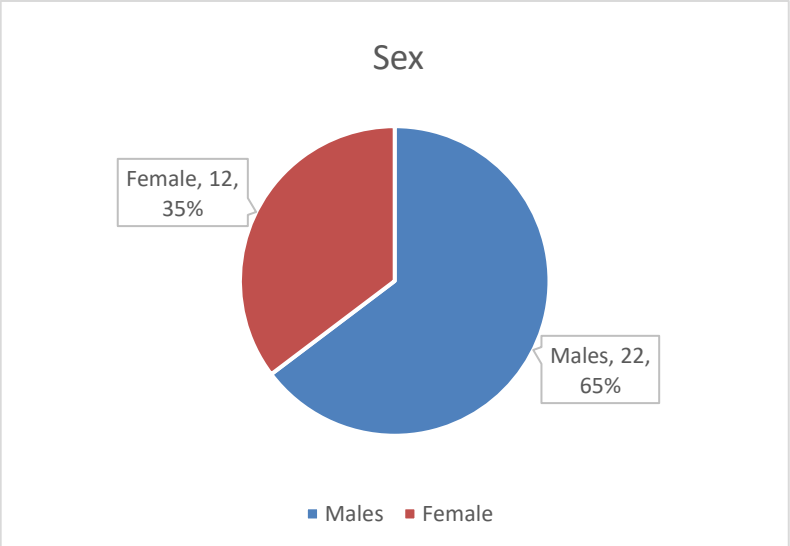


The age range of deaths reported during this period was 8 years – 82 years. The median age of death in our reported data was 53 years. This differs to the national data for people with learning disabilities in 2019, where the calculated median age was 60 years (61 for male, 59 for females). (Incidentally, examining of the scatter plots presented in Appendix 2 for the health inequalities analysis, reveals that the deaths are largely clustered around the 4-30, and 50-80 age brackets).

In the general population of England (from 2016- 2018), the median age at death (for people of all ages, including 0-4 years) was 83 years for males and 86 years for females[5]. As is sadly anticipated, these figures for people with a learning disability are considerably lower than this national average.

3.4.2 Sex

There was a significant difference between the deaths recorded for males and females. Nearly 2 out of 3 deaths were male, with a total of 22 male deaths (65%) compared to 12 female deaths (35%).

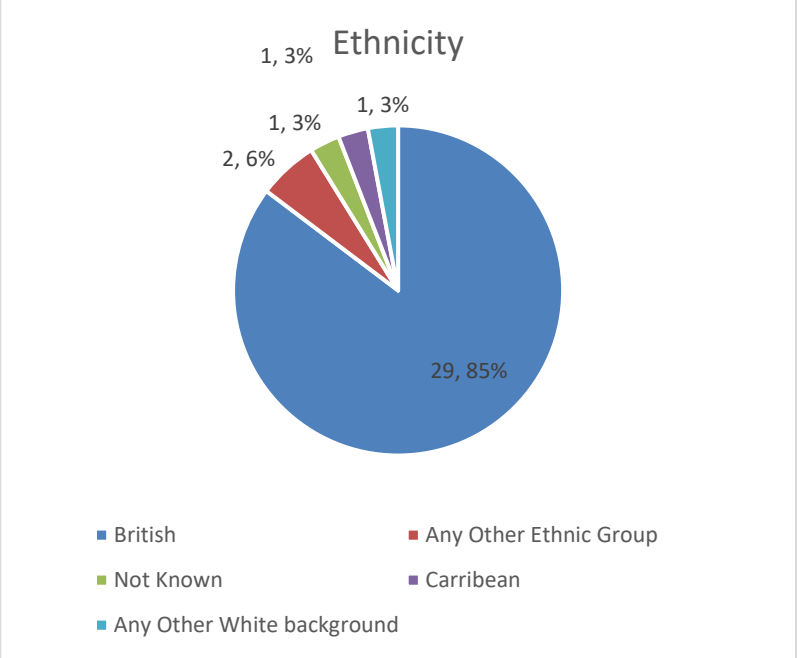


[5]https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/datasets/averageageatdeathbysexuk

3.4.3. Ethnicity

85% of the deaths notified to the LeDeR programme were of people who were identified as being of White British. ethnicity Data describing the 15% of people who were from minority ethnic backgrounds is somewhat limited by use of general categories such as “not known” and “any other ethnic group”.

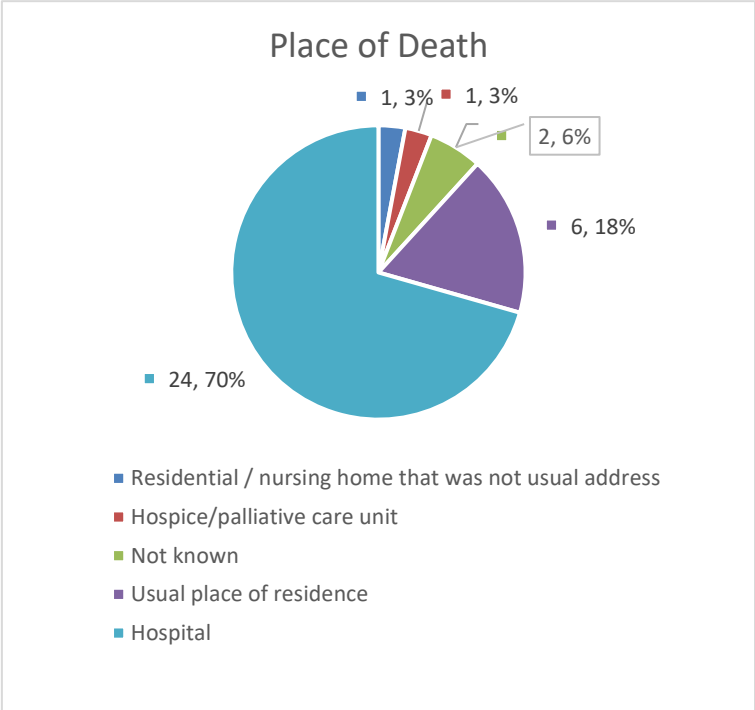
It is known nationally that fewer people from minority ethnic groups tend to access services than their majority ethnic counterparts, so it is important to view this figure with caution, as this may be an underrepresentation of the deaths that have actually occurred locally.



3.4.4 Location at time of death

The majority of deaths occurred in a hospital setting, representing 24 (70%) deaths. In comparison to the national LeDeR figures for 2019, the proportion was 60%, so these local figures are notably higher.

18% of deaths occurred in the person’s usual place of residence, with the remaining being made up of 2 (6%) residents place of death being unknown at the time of notification, 1 (3%) in a hospice and 1 (3%) within residential care but not of their normal residence.

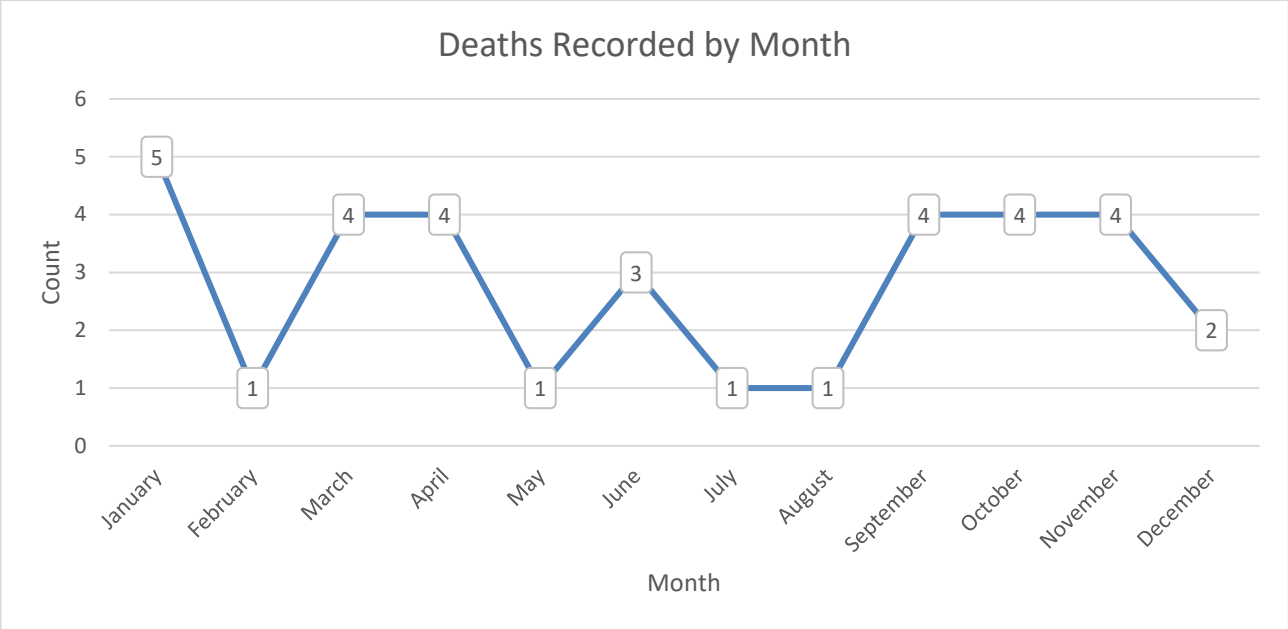


3.4.5 Cause of death

Only three of the 34 death notifications received during the time frame have been formally reviewed, so therefore the data is limited upon which to report. For those three cases where information is available, the cause of death was acute left ventricular failure, and there were two incidents of pneumonia recorded.

3.4.5 Month of death

Looking at the overall number of notifications received within this time frame, there are no significant trends to the peaks or troughs of notifications.



Larger cohorts can afford a greater ability to examine seasonal patterns. Considering all of the deaths reported *nationally* since the start of the LeDeR programme (2016-2019), the peak months of deaths were October to December. There was a greater proportion of deaths of people with learning disabilities from October – December than in the general population[6].

4. Learning and recommendations

The small number of completed reviews from this time period means there is limited amount of information that can be considered in detail. Rather than offer a commentary on this small sample, we have taken the decision to consider the themes arising from these completed reviews, together with the notifications received in 2018-2019, in the 2020-2021 report, to ensure that the most meaningful commentary can be given.

[6]https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/monthlyfigureson deathsregisteredbyareaofusualresidence

5. Health Inequalities

5.1 Indices of deprivation as a marker of health inequality

Of the deaths notified to the LeDeR programme, the district the person lived in, at the time of their death, is depicted in Table 7.

Table 7: Number of deaths per district, across Cambridgeshire and Peterborough (data based on the person's registered address at their time of death).

District	Number
Cambridge	3
East Cambridgeshire	2
Fenland	5
Huntingdonshire	3
King's Lynn and West Norfolk	1
North Hertfordshire	1
Peterborough	12
South Cambridgeshire	7
Total	34

**Individuals may live outside of Cambridgeshire/Peterborough, and are included in this overall data analysis as they are registered with a Cambridgeshire or Peterborough GP.*

This information can be used as an indicator of deprivation, to explore what health inequalities may have been experienced by the individuals concerned. This makes it possible to examine whether the people who passed away have experienced any health inequalities, in addition to the known health inequality that is sadly present as a consequence of having a learning disability.

Deprivation can be defined "the consequence of a lack of income and other resources, which cumulatively can be seen as living in poverty" (Poverty and Social Exclusion, 2016[7]). Nationally available data (Public Health England[8]) enables categorisation and ranking of every postcode within the UK, according to an index of deprivation, known as the Index of Multiple Deprivation Score. This is a single index that gives an indication of deprivation based upon information across seven domains:

- Income Deprivation Domain
    - This measures the proportion of the population in an area experiencing deprivation relating to low income. The definition of low income includes both those people that are out-of-work, and those that are in work but who have low earnings.
- Employment Deprivation Domain
    - This measures the proportion of the working-age population in an area involuntarily excluded from the labour market. This includes people who would like to work but are unable to do so due to unemployment, sickness or disability, or caring responsibilities.
- Education, Skills and Training Deprivation Domain
    - This measures the lack of attainment and skills in the local population.

[7] https://www.poverty.ac.uk/definitions-poverty/deprivation-and-poverty
[8] http://imd-by-postcode.opendatacommunities.org/imd/2019

- Health Deprivation and Disability Domain
    - This measures the risk of premature death and the impairment of quality of life through poor physical or mental health.
- Crime Domain
    - Crime is an important feature of deprivation that has major effects on individuals and communities. This domain measures the risk of personal and material victimisation at local level.
- Barriers to Housing and Services Domain
    - This measures the physical and financial accessibility of housing and local services
- Living Environment Deprivation Domain
    - This measures the quality of the local environment; both the quality of housing and the 'outdoors' living environment contains, such as air quality and road traffic accidents.

Lower scores are indicative of regions where residents experience less deprivation; higher scores indicate greater deprivation.

To explore possible health inequalities, postcode data was used to obtain a 1-10 ranking on all of the above indices, and correlated with the age of death for the individuals described in this report. Appendix 2 shows the graphical depictions of these relationships. The scatterplots showed that there was no demonstrable linear relationship between age of death and any of the variables being explored, and analysis revealed no statistically significant correlations between age of death and any of these indices. This suggests that the district the person lived in, and its associated deprivation profile, has no significant bearing on the age at which a person with a learning disability in Cambridgeshire and Peterborough, passes away[9].

6. Next Steps

In the 2018-2019 report, we described a number of steps that were being taken to bring the LeDeR programme on locally. The time frame for implementation of these changes has directly overlapped with the COVID-19 pandemic, and the all too familiar scene across geographical regions and health and social care sectors is that this has provided significant disruption to business as usual and service planning and delivery.

In spite of this, it has been possible to move forward with every single step outlined in the 2018-2019 report. This has resulted in more robust networks with partners and service providers, more reviewers, increased number of reviews being completed, and an active quality assurance process being put in place.

As we move into the next phase of the programme, the local LeDeR team are now working closely with a Quality Assurance Group to draw out key issues, learning, recommendations, and areas of positive practice from completed reviews. These are currently being aggregated, and mechanisms are

[9] *It should be noted that this analysis is substantially limited by the small sample size, lack of ability to explore any circumstances that may be indicative of any individual experience of inequality or deprivation (e.g. whether the person is in receipt of benefits), and whether the district they lived in at the time of their death was representative of their living circumstances throughout the majority of their life.*

being developed to actively take these forward to the local steering group for their review, and progression into strategic learning into action.

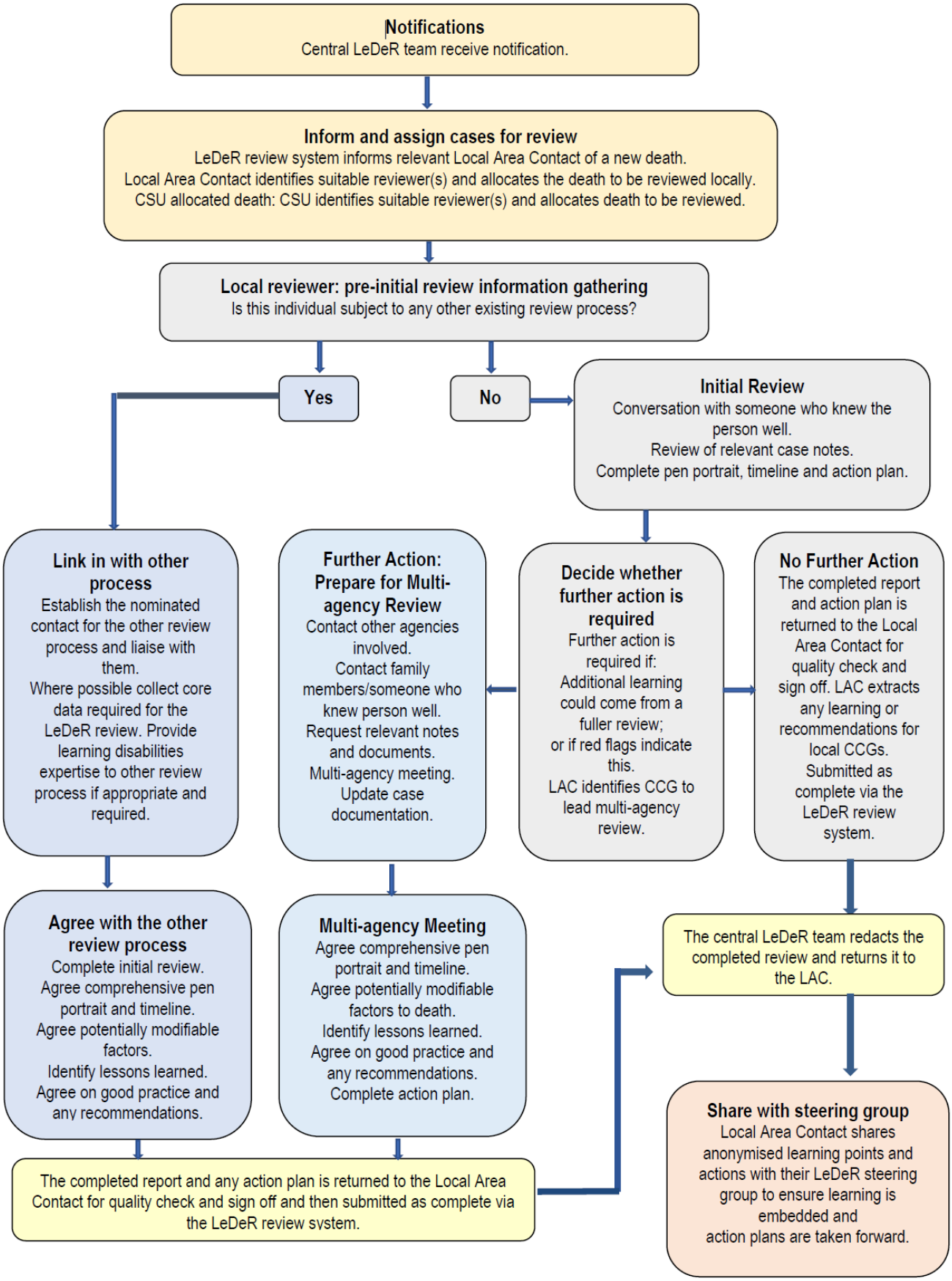
The team is also working closely with the local Safeguarding Adults Board to align processes and ways of working where cases are rated as having poor care that contributed to the person's death, and require Multi Agency Review.

Consequently, Cambridgeshire and Peterborough are on track to not only have completed the 2020-2021 reviews in timely manner, but also to use the 2020-2021 report as a vehicle for reporting on the key themes, learning and outcomes for completed reviews since the programme's local inception in 2017.

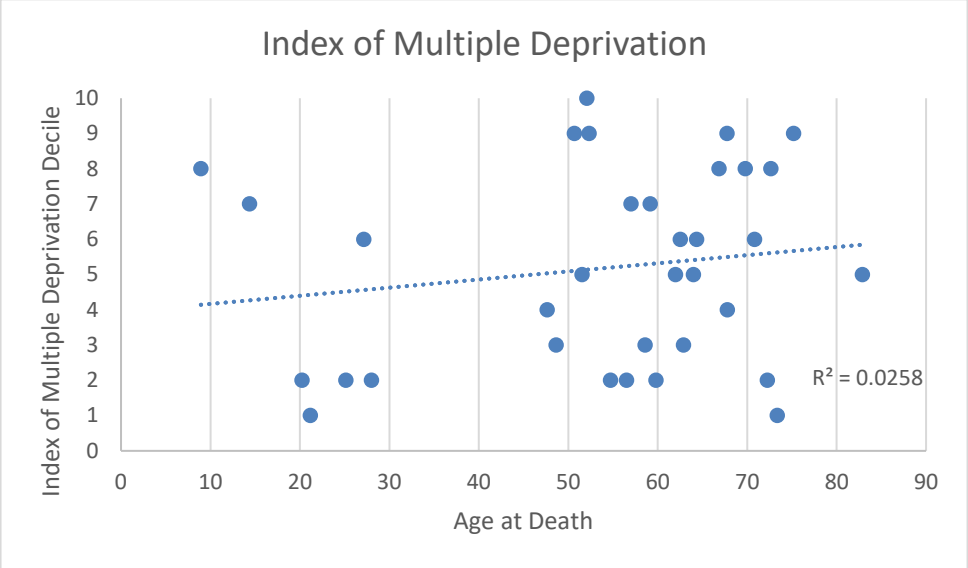
7. Closing Statement

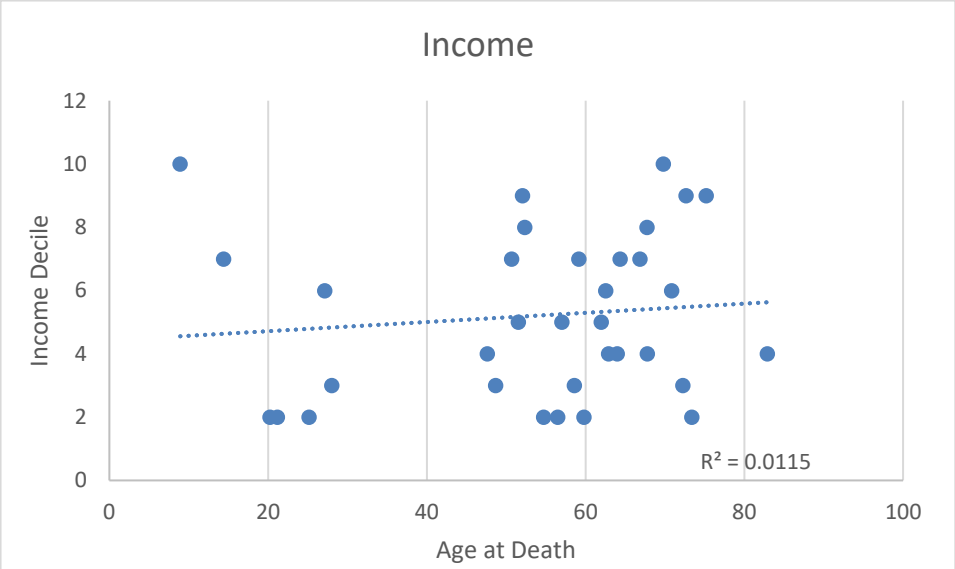
The Cambridgeshire and Peterborough LeDeR programme and Steering Group remain highly committed to LeDeR. Whilst it is regrettable that this report does not offer the level of detail and analysis, the team and steering group are confident that the work undertaken in the past few months has created a sustainable footing for the LeDeR programme locally. This work and progress will be reflected in the 2020-2021 report, and it is anticipated this will lead to demonstrable improvements in the quality of care for people with learning disabilities.

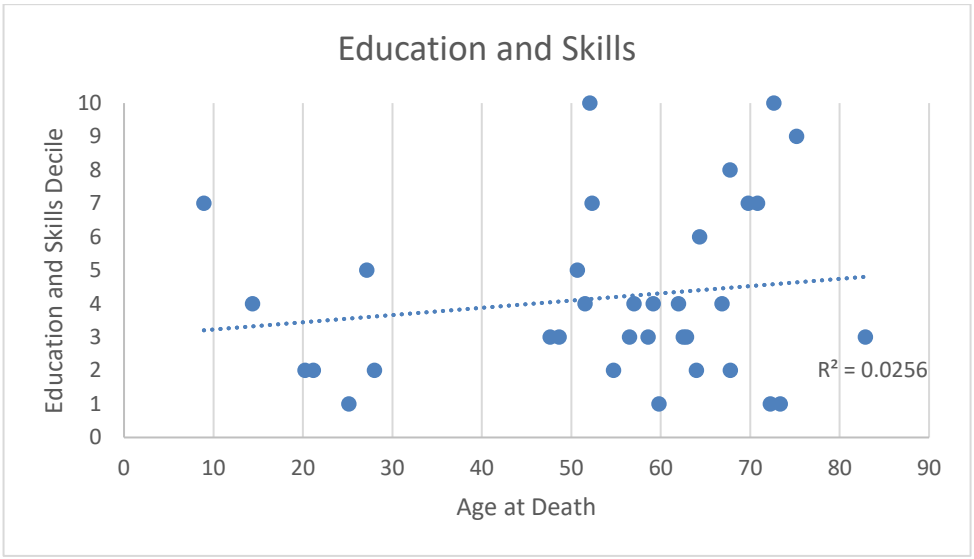
Appendix 1: The LeDeR review process (Source: 2019 Annual Report)

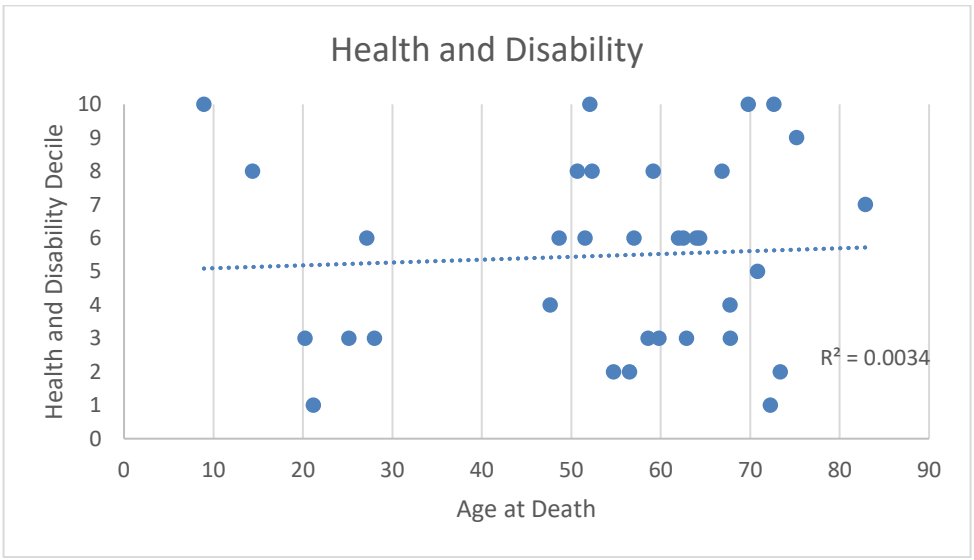


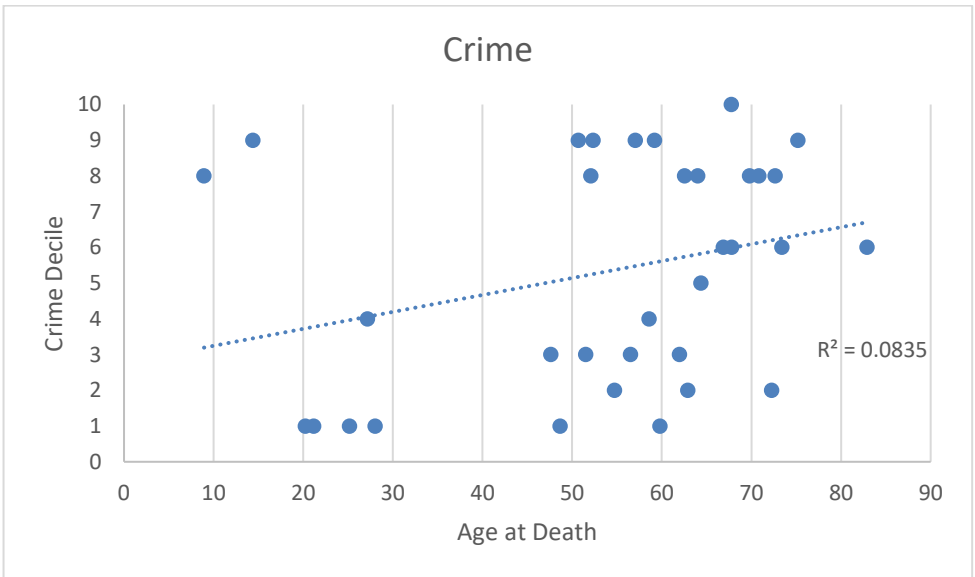
Appendix 2: Graphs to show Indices of deprivation in relation to age at death in Cambridgeshire and Peterborough

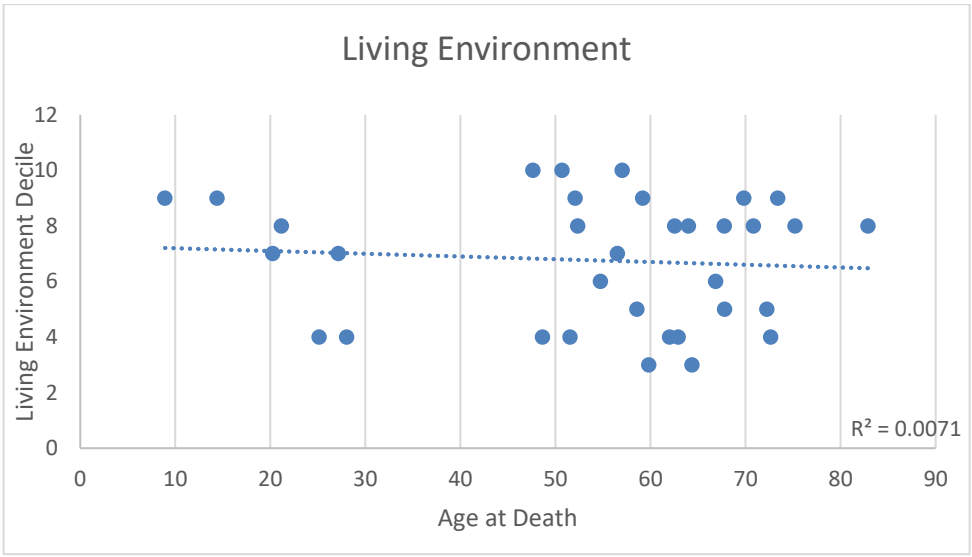


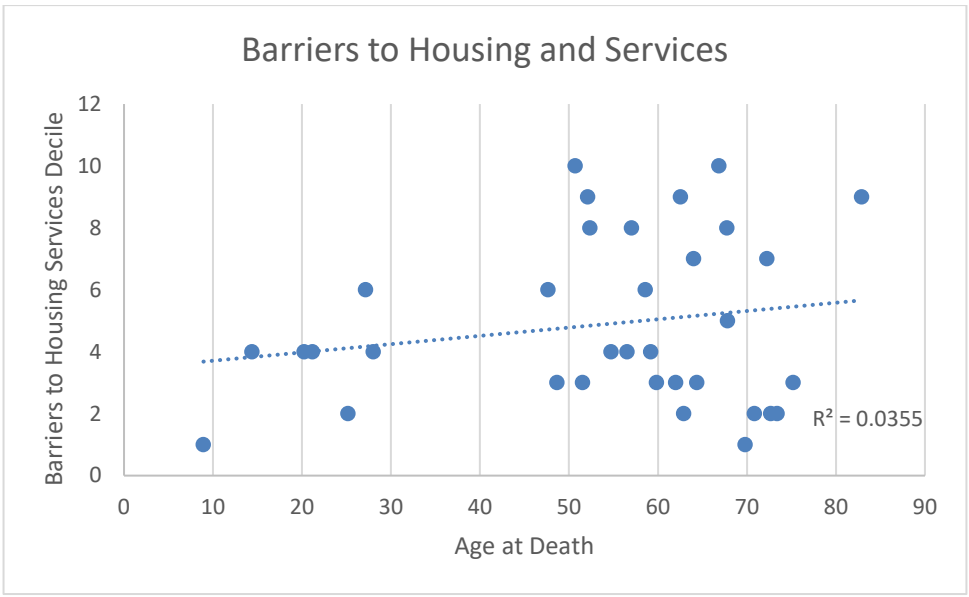



Education and Skills
Education and Skills Decile
Age at Death
R² = 0.0256


Health and Disability
Health and Disability Decile
Age at Death
R² = 0.0034


Crime
Crime Decile
Age at Death
R² = 0.0835


Living Environment
Living Environment Decile
Age at Death
R² = 0.0071
0
2
4
6
8
10
12
0
10
20
30
40
50
60
70
80
90


Barriers to Housing and Services
Barriers to Housing Services Decile
Age at Death
R² = 0.0355
0
2
4
6
8
10
12
0
10
20
30
40
50
60
70
80
90