Learning Disabilities Mortality Review (LeDeR) Programme

Cambridgeshire and Peterborough
Clinical Commissioning Group

Learning Disability Mortality Review (LeDeR)

Cambridgeshire and Peterborough Annual Review

April 2018 – March 2019

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.

Publication date: July 2020

1. Background

It is sadly all too well known that people who have a learning disability experience health inequalities. One of the most shocking and saddening statistics is that people who have a learning disability die younger than people who do not have a learning disability. The difference in median age of death between people with a learning disability (who are aged four and over) and the general population is 23 years for men, and 27 years for women (University of Bristol Norah Fry Centre for Disability Studies, 2019).

It is also known that some of these deaths are preventable. This has been highlighted in many reports, but particularly in the Confidential Inquiry of People with a Learning Disability (CIPOLD; Heslop et al, 2013), carried out in 2013. This found evidence that the quality and effectiveness of health and social care given to people with learning disabilities is deficient in a number of ways, and that premature deaths could be avoided by improving the quality of the healthcare they receive.

The Learning Disabilities Mortality Review (LeDeR) programme was developed in response to the conclusions identified in CIPOLD.

2. The LeDeR Programme

2.1 Values and principles

LeDeR was established to support local areas to review the deaths of any person with a learning disability over the age of four, to identify learning from the experiences and circumstances for each person who died, and to take this into service improvement initiatives. The programme is led by the University of Bristol and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England.

The core principles and values of the programme are:

- Valuing the contribution of people with learning disabilities and their families to all aspects of our work.
- Taking a holistic perspective, looking at the circumstances leading to deaths of people with learning disabilities, and not prioritising one source of information over another.
- Aiming to ensure that reviews of deaths lead to reflective learning, which will result in improved health and social care service delivery.
- To embed reviews of deaths of people with learning disabilities into local structures to ensure the continuation of the learning taken from the reviews.

2.2 Partners involved in the LeDeR programme

NHS England funds and manages the LeDeR programme. It makes sure LeDeR is helping to improve the quality of health and social care for people with learning disabilities.

Healthcare Quality Improvement Partnership (HQIP) manages the contract between the University of Bristol and NHS England.

Clinical Commissioning Groups (CCGs) work in every area of England to make sure that LeDeR reviews are carried out in a timely way. CCGs also monitor the quality of reviews.

North of England Commissioning Support Unit (NECS) has been commissioned by NHS England to carry out some of the LeDeR reviews on behalf of CCGs.

2.3 Accountability

Whilst the programme is managed by Bristol University on behalf of NHS England, NHSE has aligned LeDeR to the national Transforming Care Programme (TCP). The ongoing development and progress of LeDeR locally is monitored through the Cambridgeshire and Peterborough TCP Board.

2.4 Key roles within LeDeR

Local Reviewers are responsible for undertaking robust and high-quality reviews of the deaths of people with learning disabilities. These are typically professionals who work in the region, and are familiar with the needs of people who have a learning disability, and with the services that are provided to this population.

Local Area Contacts are the link between the local steering group and local reviewers. They quality assure the reviews, provide ongoing advice, support and training for local reviewers as necessary, and work with the local steering group to take appropriate actions in relation to the findings from reviews of deaths.

Local Steering Groups are responsible for the implementation of the LeDeR Programme in that area and ensuring that any learning, recommendations and actions arising from reviews are considered and taken forward, as appropriate, using locally agreed governance structures.

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 2018-2019.

During the time period considered in this report, C&P LeDeR has experienced a number of challenges that have had a significant impact on the region's ability to carry out reviews in a timely manner. The capacity of the established pool of reviewers to progress reviews alongside their usual workloads has been limited, and staffing challenges have meant that it has not been possible to have a dedicated Local Area Contact to oversee the programme.

3.2 Population demographics

According to the ONS 2011 Census, the population of Cambridgeshire was 648,237 and the population of Peterborough was 198,914. In 2018, the Quality and Outcomes Framework (QOF) Register, the

prevalence of people who have a diagnosed learning disability across Cambridgeshire and Peterborough was recorded at 0.4%, which is slightly below the national average of 0.5%.

In Peterborough, around 1100 people registered with GP surgeries are recorded as having a learning disability, and just under 3400 people in Cambridgeshire. Of those, in the adult population, approximately 500 in Peterborough are receiving support from the local authority, with just over 1600 receiving such support in Cambridgeshire.

In Peterborough there are approximately 1600 children and young people who are a registered as having a learning disability, and just under 3000 children and young people in Cambridgeshire.

3.3 Notifications: Overview

Between April 2018 – March 2019 Cambridgeshire and Peterborough LeDeR received notification of 48 deaths. Of these, only one death occurred outside of the reported time period.

The majority of deaths were reported by community learning disability nurses; health liaison nurses (based in acute settings), and care providers. A small number of other professionals, including speech and language therapists, GP practice managers, physiotherapists and consultant psychiatrists, have also informed LeDeR when a person has passed away.

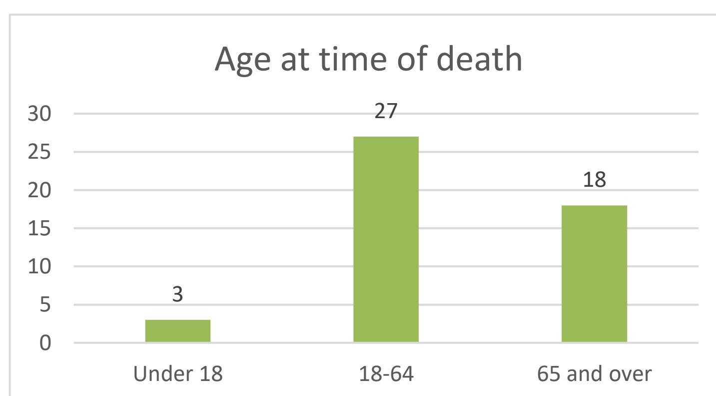
Of the death notifications received, three reviews have been carried out. From the remaining number, 30 will be reviewed by a NECS reviewer on behalf of Cambridgeshire and Peterborough, and 15 will be completed by local reviewers.

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.

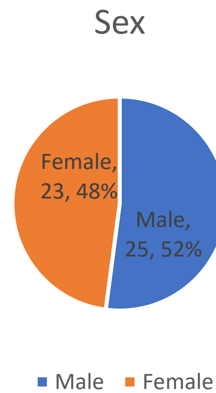
The median age of death was 58 years. This is comparable to national data for people with learning disabilities, which also calculates the median age as 58 years. This is considerably lower than that of the general population median age of death, of 81 years.



The age range of deaths reported was 9 years – 89 years.

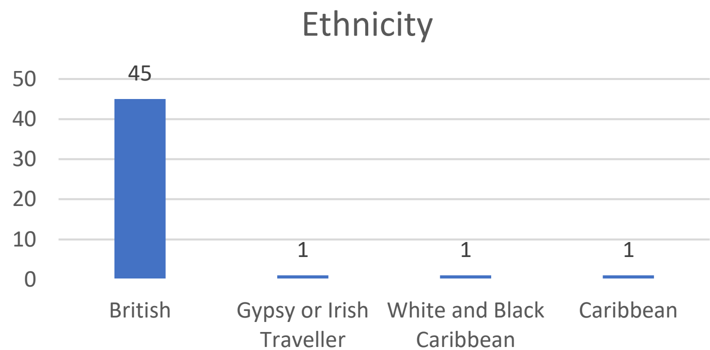
3.4.2 Sex

The numbers of males and females who passed away, was relatively comparable (48% female, 52% male).



3.4.3 Ethnicity

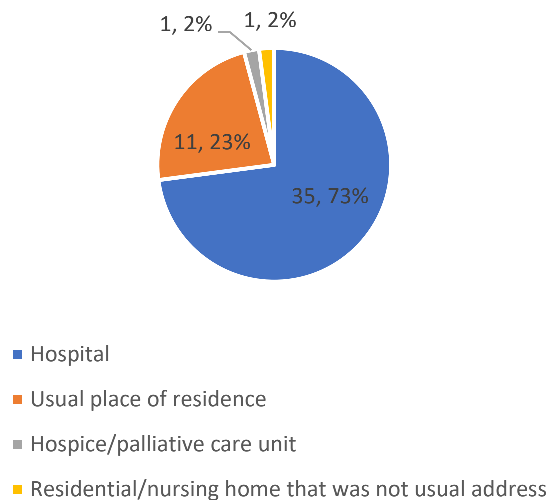
94% of the deaths notified to the LeDeR programme were of people identified as White British. It is known nationally that fewer people from ethnic minority groups tend to access services than their majority ethnic counterparts, so it is important to view this figure with caution, as this may be an underrepresentation of the deaths that have actually occurred locally.



3.4.4 Location at time of death

The majority of deaths (73%) occurred when people were in hospital. This is higher than the national LeDeR figure of 62%, and significantly higher than for people who do not have a learning disability (46%, University of Bristol, 2018).

23% deaths occurred in the person's usual place residence.



3.3.5 Cause of death

As only three of the 48 death notifications received have been formally reviewed, there is limited data upon which to report. For those where information is available, the cause of death was sepsis, neuroendocrine carcinoma, and empyema (a condition that affects the space between the outermost layer of the lungs and the pleural space).

3.3.6 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, in a future report, to ensure that the most meaningful commentary can be given.

4. Health Inequalities

4.1 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 1.

Table 1: Number of deaths per district, across Cambridgeshire and Peterborough (data based on the person's registered address at their time of death).

District	Number
North Hertfordshire*	2
Huntingdonshire	8
Fenland	12
South Cambridgeshire	10
Peterborough	10
Cambridge	3
East Cambridgeshire	3
TOTAL	*48*

**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 is particularly helpful, as it can be used to access data in indices 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). Nationally available data (Public Health England, accessed 2020) 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.
- 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 1 shows the graphical depictions of these relationships. Analysis reveals 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[1].

4.2 Deprivation and learning disability prevalence

GP practices in the UK are also ranked in terms of deprivation using the Index of Multiple Deprivation Score. Considering this in relation to people who have a learning disability, it is possible to correlate this against two different sources of information; the percentage of patients who have a learning disability (as recorded on practice registers), and the percentage of all respondents who indicated "learning disability" in response to the GP patient survey question: "Which, if any, of the following long-term conditions do you have?".

Analysis reveals that there is no statistically significant relationship (correlation) between GP deprivation scores, and these two measures of learning disability prevalence (see Appendix 2). Whilst limited conclusions can be drawn from this single data source, and will by no means reflect individual circumstances, this is a useful contextual information.

[1] *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. These findings should therefore be considered with caution.*

5. Next Steps

Despite the difficulties in sufficiently resourcing LeDeR locally, there has been significant energy and dedication behind the programme. This has enabled the CCG to secure funding for a Senior Lead and Local Area Contact post (0.4 FTE), an administrator (0.4 FTE), and a reviewer (0.8 FTE). The former two post holders joined the CCG in early 2020, and the latter is due to join the team in later on in the same year.

Furthermore, interest and commitment to LeDeR has been seen across health (acute and community) and social services, and the Steering Group has been able to meet quarterly, with membership from learning disability liaison, safeguarding, commissioning, primary care, and adult social care. It is likely this is a significant factor in ensuring that the central programme have been notified of deaths, even without a high rate of reviews being completed.

The commitment to improving the activity and progress of Cambridgeshire and Peterborough reviews can be seen in a number of activities that are being progressed:

A. Extensive stakeholder mapping and liaison, with a clear commitment to developing new and strengthening existing relationships. This includes:
    - Enhanced working relationships with Safeguarding Leads across Children's and Adult's Services (health and social care).
    - Establishing links with Coroner's Office.
    - Building on existing relationships with the Child Death Overview Panel, to ensure learning from any deaths of children and young people under the age of 18, are included in LeDeR reporting.

B. Establishing a suite of responses to addressing the outstanding reviews:
    - Recruiting a substantive reviewer post within the LeDeR team (as described above).
    - Commitment to a group review methodology, to support reviewers with sharing knowledge and expertise, and to support multiple reviews being completed at one time.
    - Bringing on a number of additional reviewers from the local professional network.
    - Agreeing approximately one third of notifications that have not yet been reviewed, to be allocated to the North East Commissioning Support team, for review.
    - Working towards comprehensive requests and collation of all patient notes, to enable reviewers to begin their reviews in a timely manner.

C. Additional mechanisms to support quality assurance:
    - Development of a service user engagement strategy for LeDeR, to include family carers and people who have a learning disability.
    - Development of a Quality Assurance Group with skilled and knowledgeable local membership, to have oversight of the reviews to be taken forward into the steering group.
    - Securing independent chairing of the Steering Group for another twelve months.

6. Closing Statement

It is regrettable that at this time, it has not been possible to report in greater detail on the deaths of people with a learning disability in Cambridgeshire and Peterborough in 2018-2019. However, this LeDeR programme and Steering Group are committed to LeDeR; to progressing reviews, to learning from these reviews, and to monitoring the effectiveness of this implementation, and are confident that steps are underway to secure this for the future.

7. References

Heslop, P., Blair, P. Fleming, P., Houghton, M., Marriott, A., Russ, L. (2013). *Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD).* Retrieved from: http://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf. Accessed: 1st March 2020.

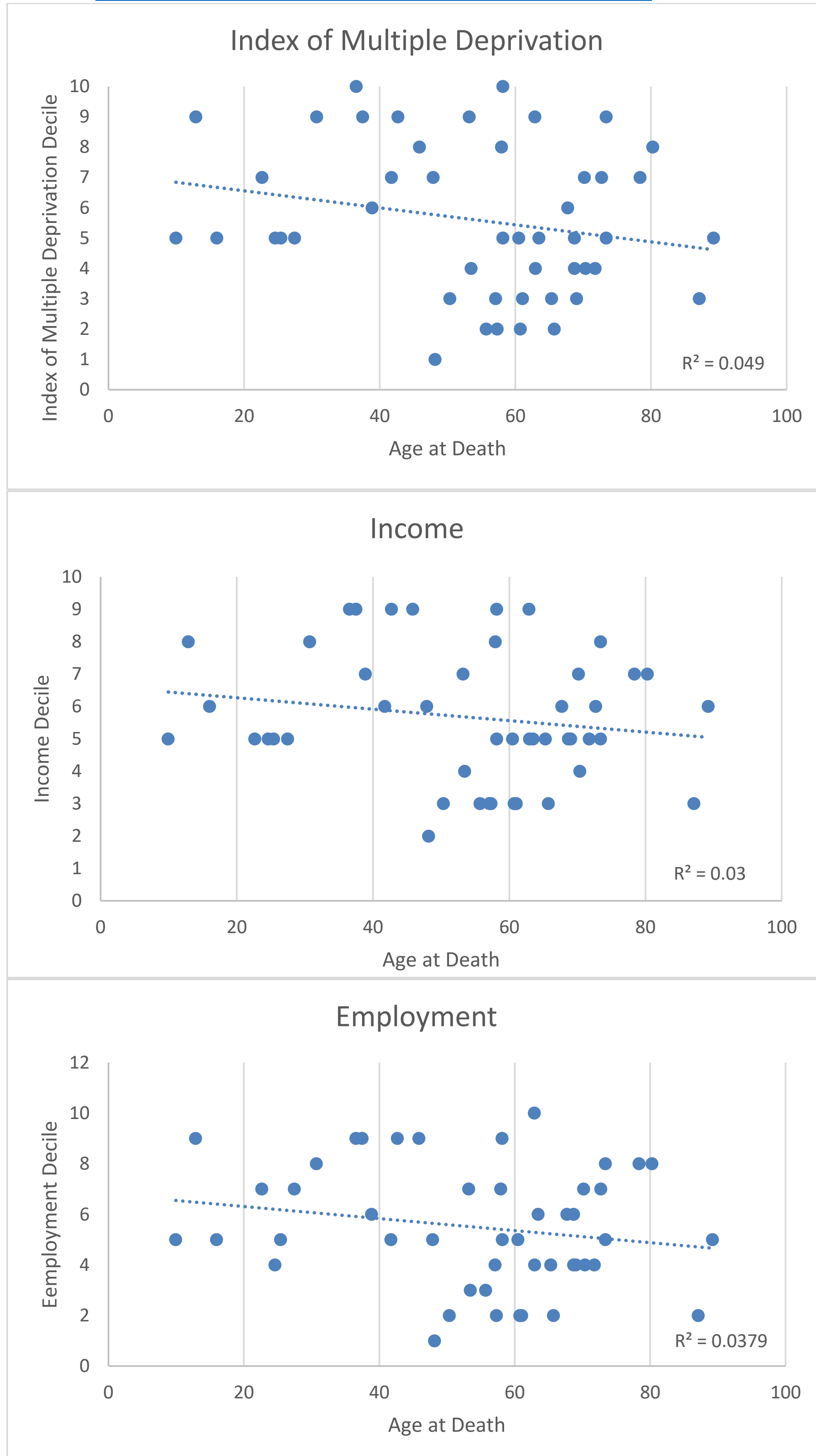
Poverty and Social Exclusion (2016). *Deprivation and Poverty*. Retrieved from: https://www.poverty.ac.uk/definitions-poverty/deprivation-and-poverty. Accessed 7th July 2020.

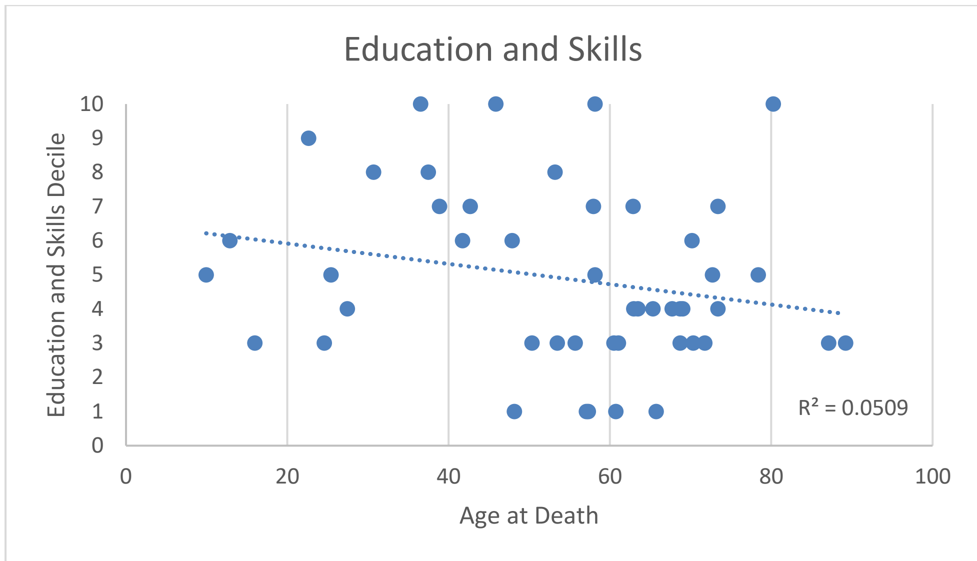
Public Health England (2020). *Index of Multiple Deprivation.* Retrieved from: http://imd-by-postcode.opendatacommunities.org/imd/2019. Accessed 20th September 2020.

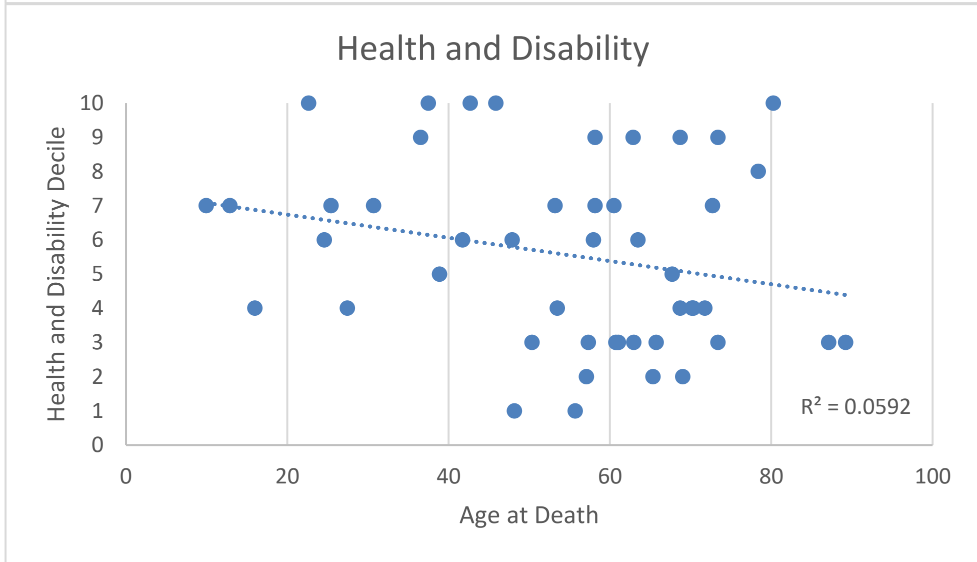
University of Bristol Norah Fry Centre for Disability Studies (2018). *The Learning Disability Mortality Review 2018 Annual Report.* Retrieved from: https://www.hqip.org.uk/resource/the-learning-disabilities-mortality-review-annual-report-2018/#.XuEAW-RYZAl. Accessed: 1st March 2020.

Appendix 1: Graphs to show Indices of deprivation in relation to age at death in Cambridgeshire and Peterborough

Source: http://imd-by-postcode.opendatacommunities.org




Education and Skills
Education and Skills Decile
10
9
8
7
6
5
4
3
2
1
0
0
20
40
60
80
100
Age at Death
R² = 0.0509


Health and Disability
Health and Disability Decile
10
9
8
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2
1
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0
20
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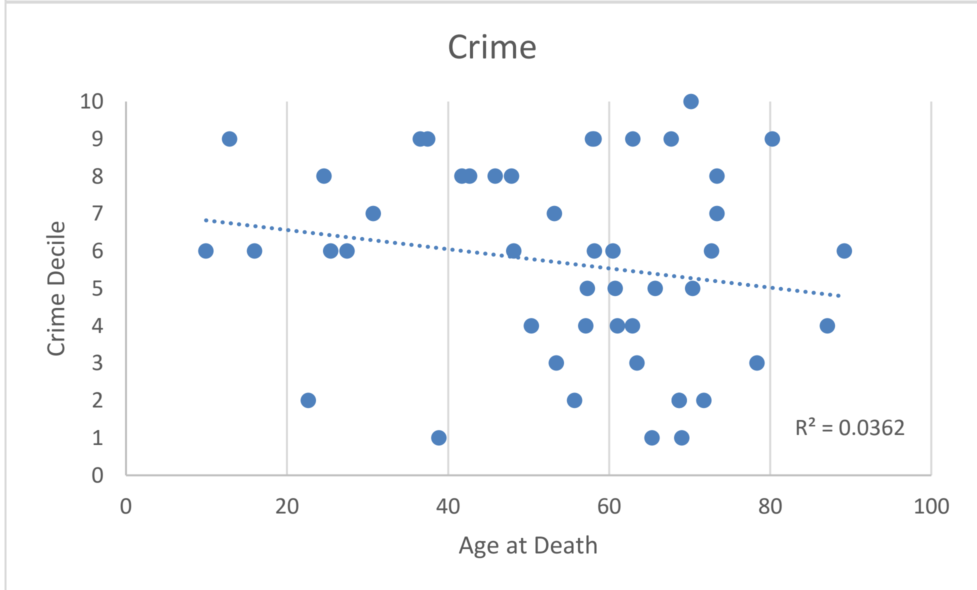
80
100
Age at Death
R² = 0.0592


Crime
Crime Decile
10
9
8
7
6
5
4
3
2
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0
20
40
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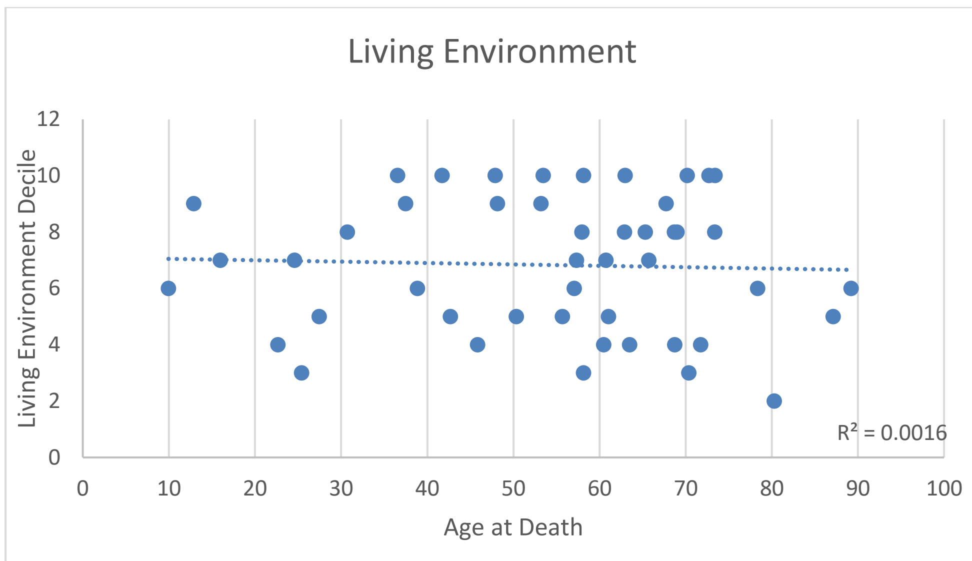
80
100
Age at Death
R² = 0.0362


Living Environment
Living Environment Decile
12
10
8
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30
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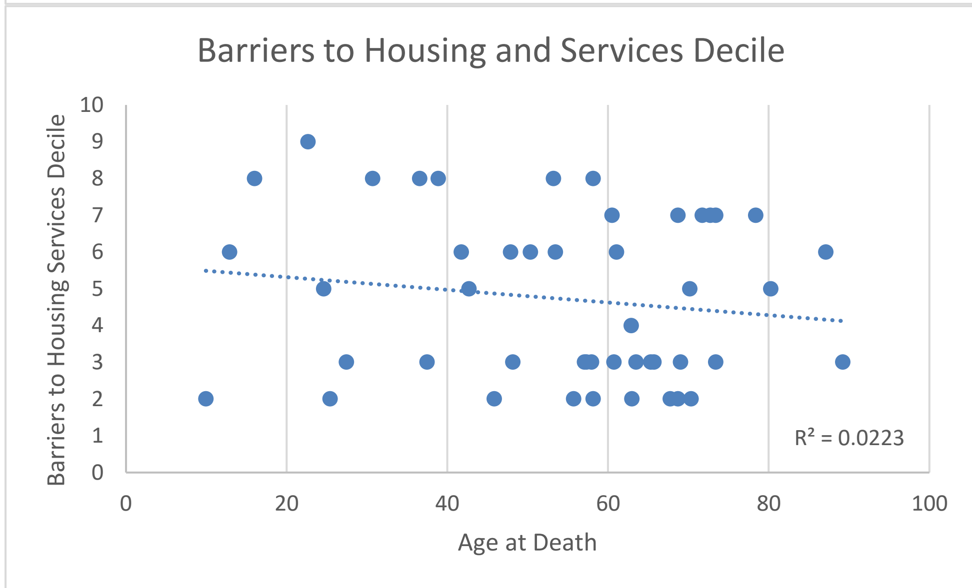
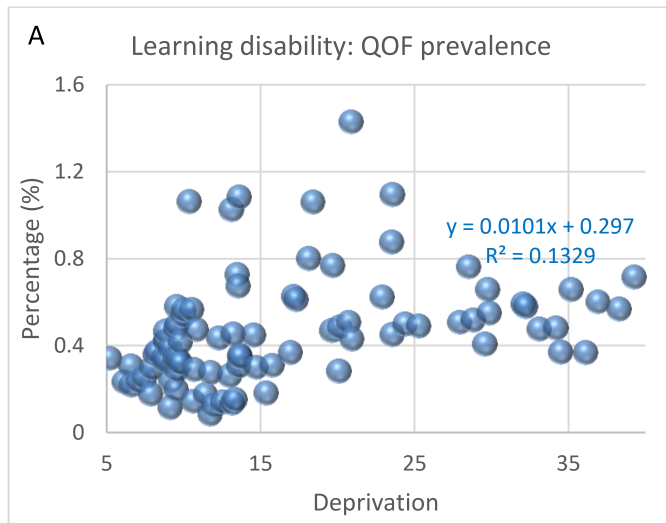
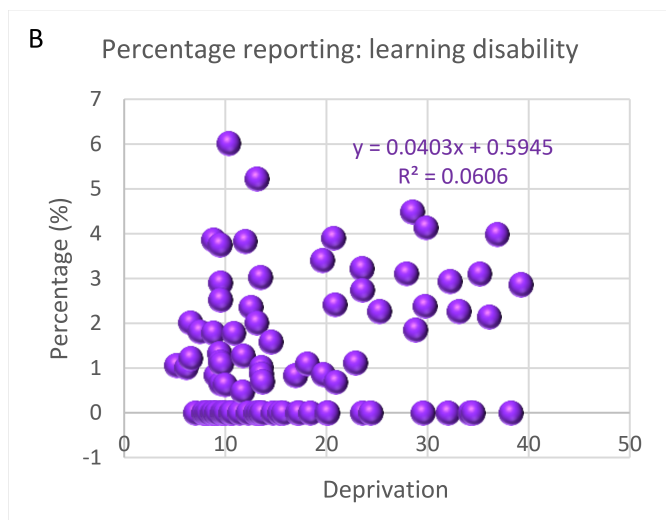
90
100
Age at Death
R² = 0.0016


Barriers to Housing and Services Decile
Barriers to Housing Services Decile
10
9
8
7
6
5
4
3
2
1
0
0
20
40
60
80
100
Age at Death
R² = 0.0223

Appendix 2: Deprivation and learning disability prevalence in Cambridgeshire and Peterborough

Source: fingertips.phe.org.uk





Key:

- X axis: GP deprivation score using the Index of Multiple Deprivation 2019 (lower value, less deprived; higher value, more deprived).
- Y axis: (A) Learning disability prevalence, (B) and percentage of self-reporting a learning disability in response to the GP patient survey question: "Which, if any, of the following long-term conditions do you have?".
- Each sphere represents a GP practice with Cambridgeshire and Peterborough.

A linear trendline (best fit) was calculated (with equation and coefficient of determination, or R^2) to examine whether there was a directly proportional correlation between the value of the above indicators, and deprivation. The R^2 value does not reach statistical significance on either analysis (A: $R^2 = 0.13$, B: $R^2 = 0.06$). As the R^2 for both is below 0.15, the linear (dotted) trendline is not shown