

REPORT TO THE TRUST BOARD: PUBLIC
23 JULY 2020

Title	Learning from Covid-19 Excess Deaths
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Purpose of the report

This report reviews the excess deaths of people that were in contact with East London NHS Foundation Trust over the period of the Covid-19 pandemic period. The aim of the report is to summarise the characteristics of these deaths; to identify any variation in patterns of deaths or unexpected deaths.

Summary of key issues

Background: Covid-19 has caused a substantial increase in deaths in the UK during the first half of 2020 (1). A disproportionate amount of these deaths are known to have occurred in healthcare settings, particularly care homes and other residential care settings (2). There is currently active discussion about what lessons can be taken from the deaths that have occurred to those in receipt of health and/or care services (3).

Methods: Datix reports were used as the primary source for this analysis. All Datix-reported deaths are included, not only those where COVID-19 was a factor.

Findings: Trends in Datix-reported deaths show a clear ‘pandemic’ period when the number of deaths exceeded previous trends. This ‘pandemic’ period in London covers a period of five weeks, beginning w/c 22/3/20, and in Beds & Luton covers seven weeks beginning w/c 29/3/20. Overall during these ‘pandemic’ periods there were the equivalent of over 350 estimated excess deaths to ELFT service users, over what would have been expected based on pre-pandemic rates. The increase in death rates was greater in London, in care homes, in service users of BAME ethnic groups, and to service users with a learning disability. These differentials mirror those in the wider UK population.

Conclusion: The excess mortality experienced by ELFT’s service-users during the Covid-19 pandemic occurred during relatively narrow ‘pandemic’ windows, the timing of which suggest that most people who died may were likely to have been infected prior to rigorous infection prevention and control measures being implemented nationally.

The Board is asked to:

Note the contents of this report
Consider the recommendations set out under section 4.4

Strategic priorities this paper supports

Improved population health outcomes	<input checked="" type="checkbox"/>	This paper reviews the deaths of services users during the first spike of the COVID pandemic. The lessons learnt from this will assist us in putting in place appropriate mitigation if there is another spike; and to
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		inform preparations for protection against other infectious diseases; to reduce disproportionate poor outcomes in specific populations.
Improved experience of care	<input checked="" type="checkbox"/>	The aim of this paper is to provide improved care for service users.
Improved staff experience	<input checked="" type="checkbox"/>	The purpose of this report is to update the Board on patterns among service users' deaths - and lessons learnt by staff to improve their working experience.
Improved value	<input checked="" type="checkbox"/>	Through full investigation of these incidents we aim to improve the quality of care we provide including improving efficiencies and providing value for money.

Committees/meetings where this item has been considered

Date	Committee/Meeting
	N/A

Implications

Equality Analysis	The report does not include a formal equality analysis. Inequalities in excess death rates between various service user groups are presented.
Risk and Assurance	Monitoring and understanding excess deaths during the first spike of the pandemic provides assurance that there is a robust approach to mortality if there is a further spike.
Service User/Carer/Staff	The process for analysing and investigating deaths ensures that learning and improvement takes place, positively impacting on service users, carers and families.
Financial	There are financial implications associated with mortality reviews. NHS Quality Board national guidance requires case note review of mortality to be routinely undertaken.
Quality	The themes arising from serious incidents and the work being done to address them have clear quality implications and act as drivers for improvement.

Supporting documents and research material

See reference list at end of document

1.0 Background/Introduction

- 1.1 Covid-19 has caused a substantial increase in deaths in the UK during the first half of 2020 (1). A disproportionate amount of these deaths are known to have occurred in healthcare settings, particularly care homes and other residential care settings (2). There is currently active discussion about what lessons can be taken from the deaths that have occurred to those in receipt of health and/or care services (3).
- 1.2 This report reviews the excess deaths of people that were in contact with East London NHS Foundation Trust over the period of the Covid-19 pandemic period. The aim of the report is to summarise the characteristics of these deaths; to identify any variation in patterns of deaths or unexpected deaths.
- 1.3 Excess deaths is defined as “the difference between deaths in a given time period and the number usually expected (for example, based on historic trends)” (1). The paper looks at a range of variables including age, gender, service/place of death and ethnicity to help ELFT begin to understand the impact of the pandemic from an organisational perspective.
- 1.4 Reviewing and learning from deaths is a responsibility of NHS Trusts, as per national Guidance published in 2017 (4). ELFT’s approach to learning from deaths includes undertaking Structured Judgement Reviews for a proportion of expected deaths. Outcomes from these SJRs are reviewed elsewhere in the main Q4 Learning from Deaths report.
- 1.5 Covid-19 in the UK is known to have had unequal impacts, with men, older people, people with pre-existing health conditions, people from BAME ethnic groups and those living in residential settings including care homes particularly likely to have been hospitalised or died with Covid-19 infection (5). Furthermore Covid-19’s spread has been geographically uneven within the UK: during April and May 2020, London had the highest age-standardised mortality rate (85.7 deaths per 100,000 persons involving Covid-19) (6), which was twice as high as the next UK Region. Newham, Hackney and Tower Hamlets had then 2nd, 3rd and 9th highest age-standardised Covid mortality rate between March and May of any UK Local Authority area (6).¹
- 1.6 Understanding the scale of the excess mortality among ELFT’s service users – and whether it fell particularly on certain groups of service-users – is important in enabling ELFT to mitigate against any future risk of Covid-19 deaths and for any other communicable disease, including seasonal influenza.

¹ Note – Newham was the LA area with the highest Covid-19 death rates for the shorter period of March 1st -April 19th. For the full three months (March-May), Brent had the highest Covid-19 age-standardised mortality rate.

- 1.7 When thinking about the learning from excess deaths may be helpful to think about the immediate increased risk vulnerability to Covid-19, for example underlying health conditions, age and ethnicity but also the longer term social risk factors for poor health and wellbeing such unemployment, poor housing and financial instability, which are known to drive health inequalities including in Covid-19 deaths.

2.0 Methods

- 2.1 Where any ELFT service user dies, a Datix report is raised; these Datix reports were used as the primary source for this analysis. All Datix reports where the Type, Category or Sub-Category mentioned death, and where the date of death was listed between 1/1/20 and 17/6/20 were extracted. Analysis were limited to those Datix's where the person affected by the incident was a service user. Raw data were used – these were not further verified; there may therefore be some minor inconsistencies. Please note all deaths were reviewed not just those where COVID-19 was a factor.
- 2.2 For comparing pre-Covid, Covid and post-Covid period, 'pandemic' periods were identified separately for London and for Beds/Luton, based on trends in Datix-reported deaths in each region. Weekly average deaths were calculated, for several sub-groups, and are presented below. Based on visual inspection of charts of deaths by time, the following periods were identified:

	Dates included (London)	Dates included (Beds/Luton)
Pre-pandemic	1/1/20 to 21/3/20	1/1/20 to 28/3/20
Pandemic	22/3/20 to 24/4/20	29/3/20 to 16/5/20
Post-pandemic	25/4/20 to 18/6/20	17/5/20 to 18/6/20

- 2.3 Calculation of excess weekly deaths: the increase in deaths experienced during pandemic phase is the relative increase in weekly deaths during the pandemic phase as compared to the pre-pandemic baseline. The pandemic period lasted for different lengths and covers different dates in London (5 weeks where excess deaths observed) and Beds/Luton (7 weeks); therefore, for overall increases in weekly deaths, a weighted average across the two areas is taken.

3.0 Findings

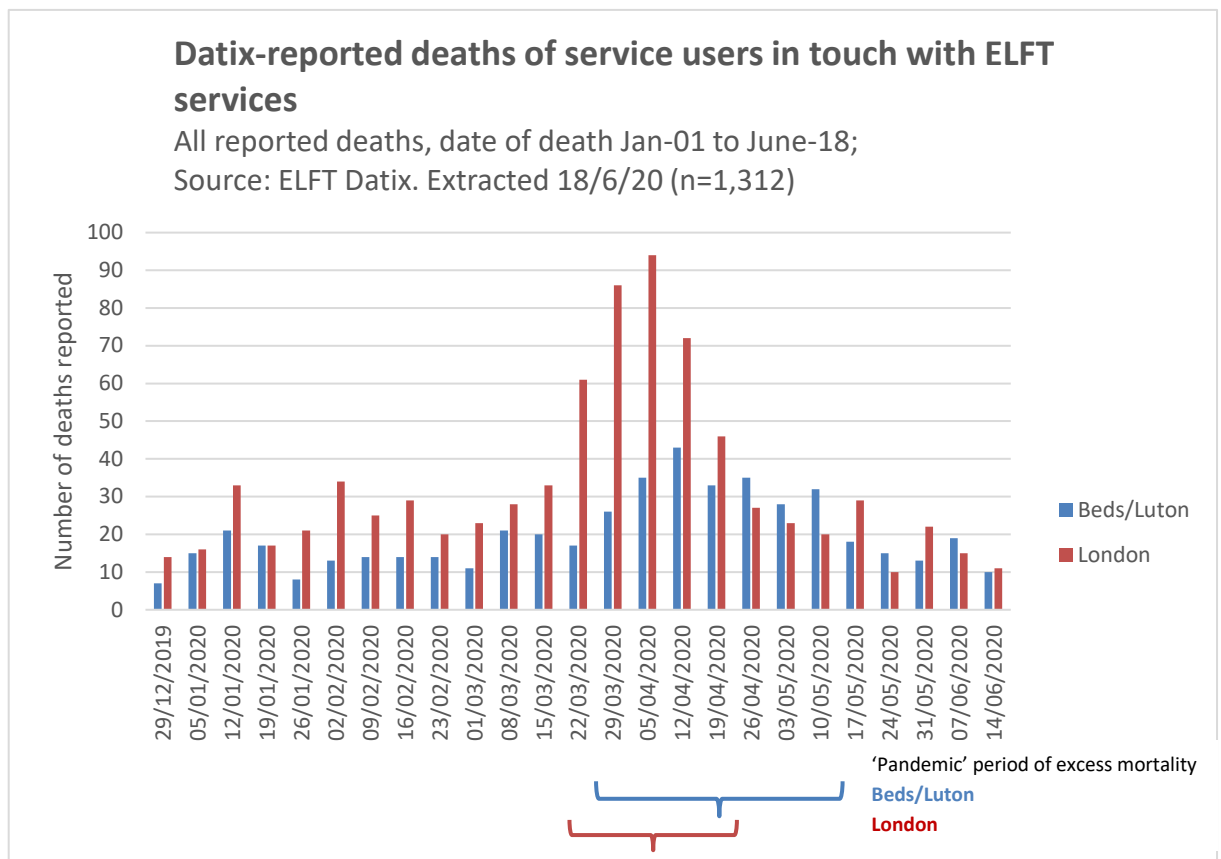
3.1 Excess deaths during Covid-pandemic period

- 3.1.1 Due to testing issues, many people who died, particularly outside of hospital, were not tested for Covid. This means counting deaths where Covid was diagnosed (or listed on Datix) would not give an accurate picture of the excess

deaths related to Covid. Instead we can look at when an excess of deaths occurred, compared to previous trends for all causes.

3.1.2 Chart 1 below shows the summary of Datix-reported deaths by date of death, from 1st January 2020 to 18th June 2020. The chart shows a clear ‘pandemic’ period when the number of deaths exceeded previous trends. This ‘pandemic’ period in London covers a period of five weeks, beginning w/c 22/3/20, and in Beds & Luton covers seven weeks beginning w/c 29/3/20. This is in line with the national experience: that the impact of Covid was earlier and more severe in London than elsewhere (1,6).

3.1.3 Chart 1: Datix reported deaths 1.1.2020 to 18.6.2020



3.1.4 **Interpretation:** The average time from infection to death for Covid-19 is around 23 days, though this varies widely (5 days from infection to symptoms, 18 days from symptoms to death in those who die). Based on this average period, most ELFT service users who died during the London ‘pandemic’ phase may have been infected between late February and late March; while those who died in Beds/Luton may have been infected between early March and mid-April.

This suggests many of the excess deaths among ELFT’s service users may have been people who had been infected before control measures, such as community social distancing and/or routine PPE within healthcare settings, were in place. Social isolation measures for symptomatic individuals in the community (without

travel history) began to be implemented from mid-March. Testing prior to 27th March was limited to hospital inpatients; this was expanded to cover symptomatic care home residents from 15th April. Throughout march there were logistical problems across health and social care in accessing sufficient PPE: a cross-governmental plan to ensure PPE was delivered to NHS and social care staff was published on 10th April (7). National Guidance for care homes on receiving discharges from acute settings was published on 2nd April (8).

3.1.5 The table below shows that the average number of weekly Datix-reported deaths across ELFT rose by 47.4 (London) and 18.4 (Beds/Luton) during the ‘Pandemic’ phase.

3.1.6 During the five-week ‘Pandemic’ period in London, weekly deaths were 194% higher than pre-pandemic. During the fortnight commencing 29/03/20, the average weekly London deaths reported in Datix was 269% higher than pre-pandemic.

3.1.7 During Beds/Luton’s 7-week pandemic period, weekly deaths rose to 124% higher than pre-pandemic; with a peak rise of 157% during the fortnight commencing 12/04/20.

3.1.8 *Table 1: Overview of weekly deaths during the pandemic period*

	Average weekly deaths			Weeks of pandemic phase (C)	Total estimated excess deaths ((B-A)*C)
	Pre-pandemic phase (A)	Pandemic phase (B)	Excess deaths during pandemic phase (B-A)		
London	24.4	71.8	47.4	5	237
Beds & Luton	14.8	33.1	18.4	7	129
Trust-wide Total					366

3.1.9 **Interpretation:** Table 1 shows that there were an equivalent of 350 estimated excess deaths to ELFT service users, over what would have been expected based on pre-pandemic rates. These rises in weekly deaths during the peak of pandemic are similar to the increase in excess deaths in the UK overall. For example:

- in London overall there was a 240% increase in deaths during the pandemic’s

peak week (1). This is similar to the 269% increase in deaths among ELFT's London service-users.

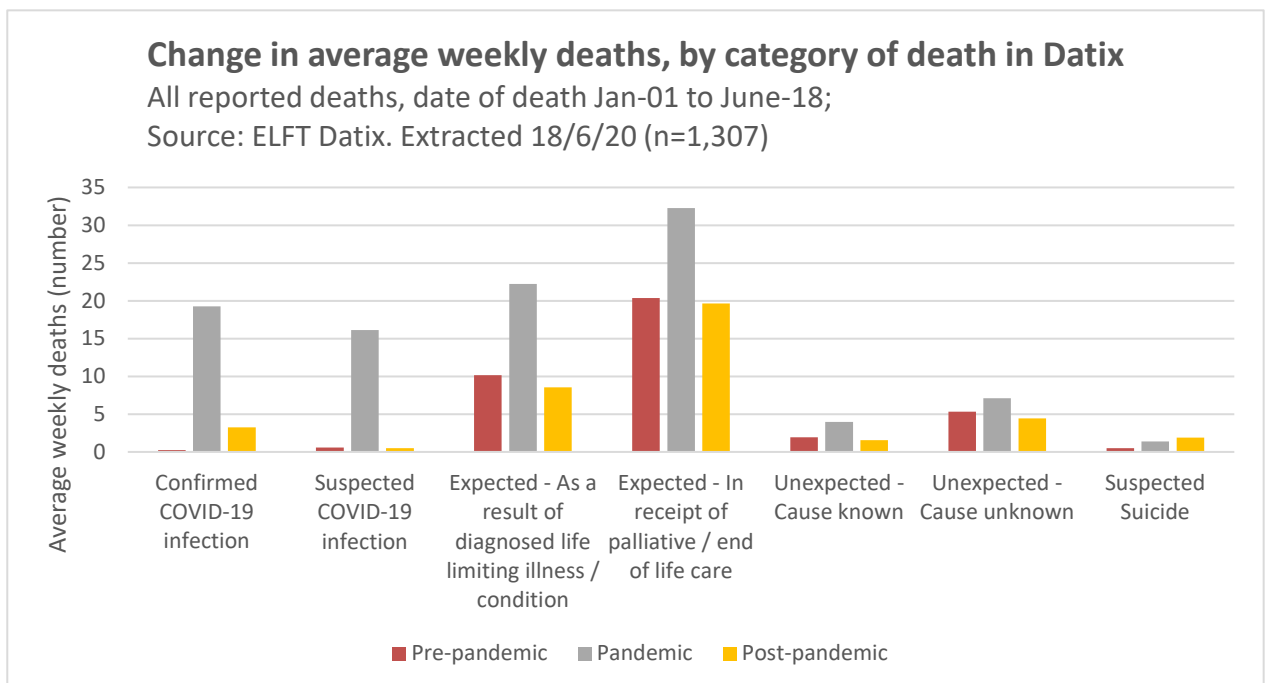
- In East of England overall there was a 115% increase in deaths during the peak week (1). This is similar but slightly lower than the 157% increased among ELFT's Bedfordshire and Luton service users (but note the non-comparable geographies).

The increases noted among ELFT's service users may be slightly higher than the rise in the overall population due to the increased vulnerabilities of ELFT's service users, or due to ELFT covering more deprived sub-geographies within London and East of England, respectively.

3.2 Cause/categorisation of death

3.2.1 Chart 2 below shows the average weekly deaths by category of death listed in Datix. As expected, there were large increases in weekly deaths categorised in Datix as Covid-19 (confirmed or suspected). However, other Expected and Unexpected deaths (not categorised as Covid-19) also increased during this period. Weekly expected deaths increased by 59% (end of life) and 118% (diagnosed life limiting condition). Weekly Unexpected deaths increased by 106% (cause known) and 33% (cause unknown) during the pandemic period.

3.2.2 Chart 2: Change in weekly deaths by cause Jan – June 2020.



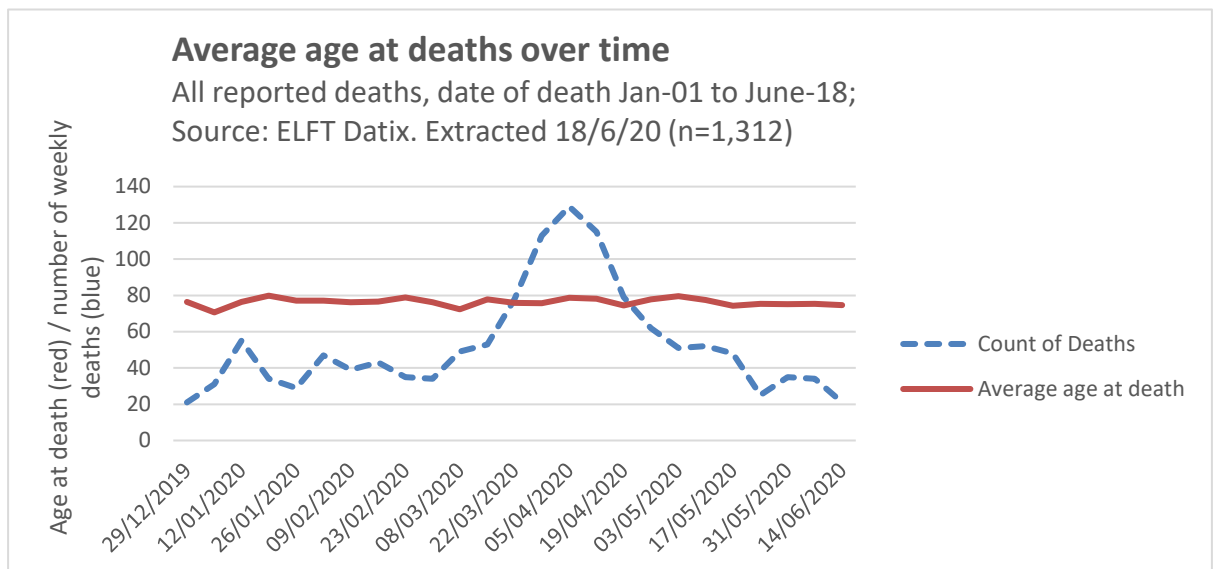
3.2.3 All but two categories of death saw return to pre-pandemic levels following the pandemic (the exceptions being Confirmed Covid-19, and Suspected Suicide. Suspected suicides rose from 0.5 average per week during pre-pandemic, to 1.4 during pandemic phase and continued rising to 1.9 average per week during post-pandemic (total 11 deaths during post pandemic). Small numbers of suspected suicides mean this warrants continued attention going forward.

3.2.4 Interpretation: There are several possible interpretations for the increase in deaths reported in Datix as 'Expected' during the pandemic phase. Firstly, this may be a data/coding issue: deaths where Covid-19 was diagnosed/suspected may in some cases have been entered in Datix as 'Expected' and in others as Covid-19. Secondly, it may be that many Covid deaths were not diagnosed/identified as such (and thus not clinically managed as a Covid case) – for example if people with life-limiting / End of Life conditions were discharged to ELFT care with Covid infection during this time but this was unknown to clinical care teams. Thirdly, it may be that people with non-Covid conditions may have been more likely to die during the pandemic weeks than pre-pandemic, for example this could be due to stretched NHS services unable to provide care for other conditions or delayed access to care. The numbers for ELFT are relatively small but the reasons for increased 'Expected' deaths will undoubtedly be part of a national review of the impact of the pandemic and lockdown.

3.3 Age at death

3.3.1 Chart 3 below shows average age of death during the Covid period. As can be seen, despite substantial increase in total numbers of deaths per week (from baseline of around 40 per week, to over 100 per week in the peak of pandemic), the average age at death remained very consistent.

3.3.2 Chart 3: Average age at death.

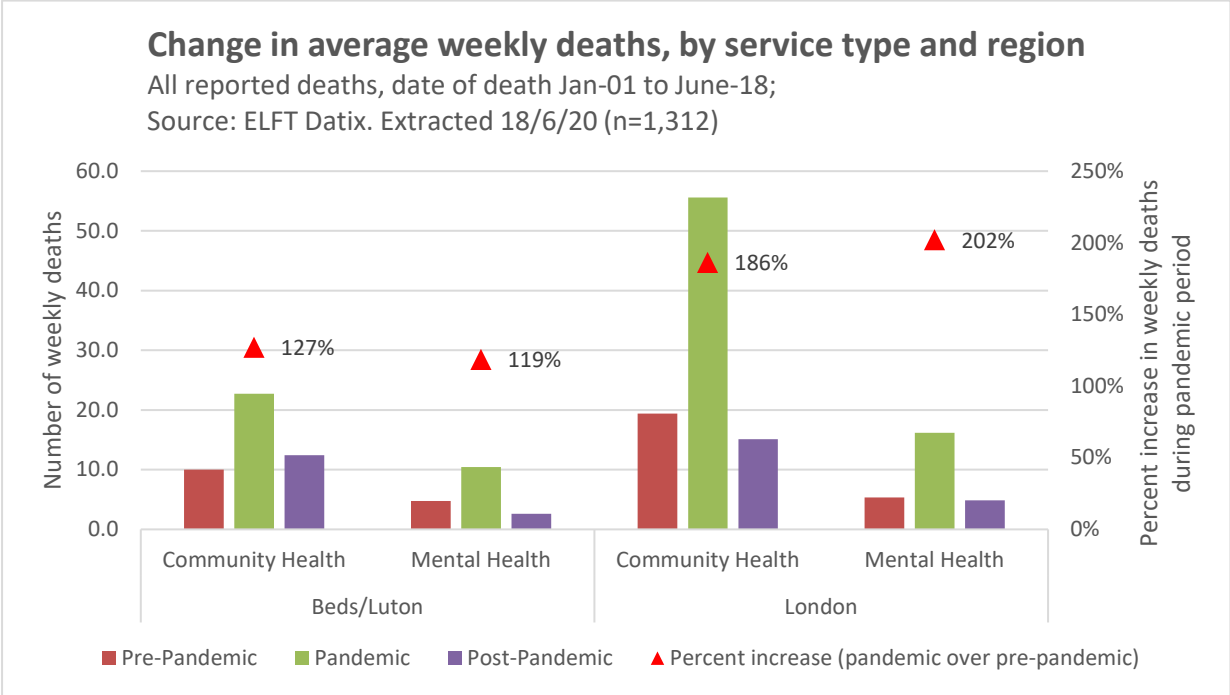


3.3.3 Interpretation: This fits with wider evidence which is that the age pattern of death from Covid and other health conditions, mirrors that among the general population and increases with age.(5,6) Thus, although a much larger number of people died during the pandemic weeks, their breakdown by age is similar to the breakdown of deaths pre-Covid.

3.4 **Service and setting:**

3.4.1 Chart 4 below shows the average number of deaths reported weekly to Datix; separated by pre-pandemic, pandemic, or post-pandemic period. As can be seen, the increases in weekly death rates were consistent across Community Health and Mental Health services and were slightly higher in London (around 200% increase) than Beds/Luton (around 120% increase) – reflecting the shorter, more intense pandemic period in London.²

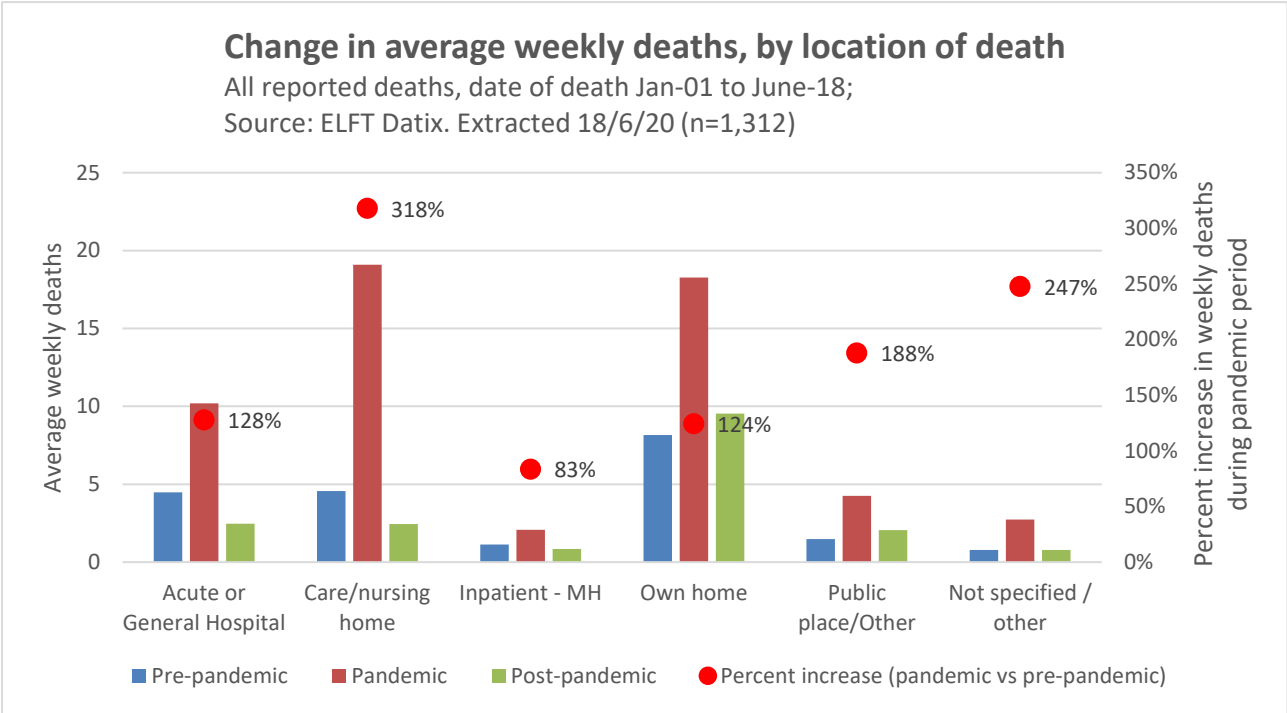
3.4.2 Chart 4: Average weekly deaths, by service type and region.



3.4.3 Chart 5 below then presents the changes in weekly deaths by location of deaths (as reported on Datix). As can be seen, deaths in care homes saw the greatest increase, at over 300% increase in numbers of deaths comparing the pandemic period to pre-pandemic. The increase in inpatient MH settings (83% increase) was lower than that in acute / general hospital settings (128%). There was an over 2-fold increase in the number of deaths occurring in the service users’ own home or in a public place.

² Note: % increases depict the proportionate increase over what was the case in the pre-pandemic period. Thus a 100% increase indicates that twice as many deaths occurred during the pandemic period than pre-pandemic.

3.4.4 Chart 5: Weekly deaths by location



3.4.5 Interpretation: The increase in deaths within care homes, compared to pre-pandemic levels of deaths, is substantial and tragic. By the week of 17th April in the UK as a whole, the number of deaths in care homes had increased by 240% over the national average (9,10). Several factors contribute to explaining why people in care homes saw a greater increase in numbers of weekly deaths during the pandemic. Existing frailty, underlying conditions, and older age of people within care homes puts them at increased risk of Covid-19 and many other communicable and non-communicable diseases.

ELFT’s increase in rate of excess deaths during this pandemic period is slightly larger (318%) than that in the general population (240%) which may be due to (a) random variation; (b) recording issues in Datix (such as location of deaths during pre-pandemic or pandemic period); (c) ELFT’s care homes being predominantly in London which was hit harder than elsewhere in the country; (d) ELFT’s care home residents being more vulnerable to Covid either due to their age, gender, ethnic profile; or due to features of the home.

National data show that Dementia and Alzheimer’s disease was the most common main pre-existing condition found among deaths involving Covid-19 and was involved in 25.6% of all deaths involving Covid-19) in March to May 2020.

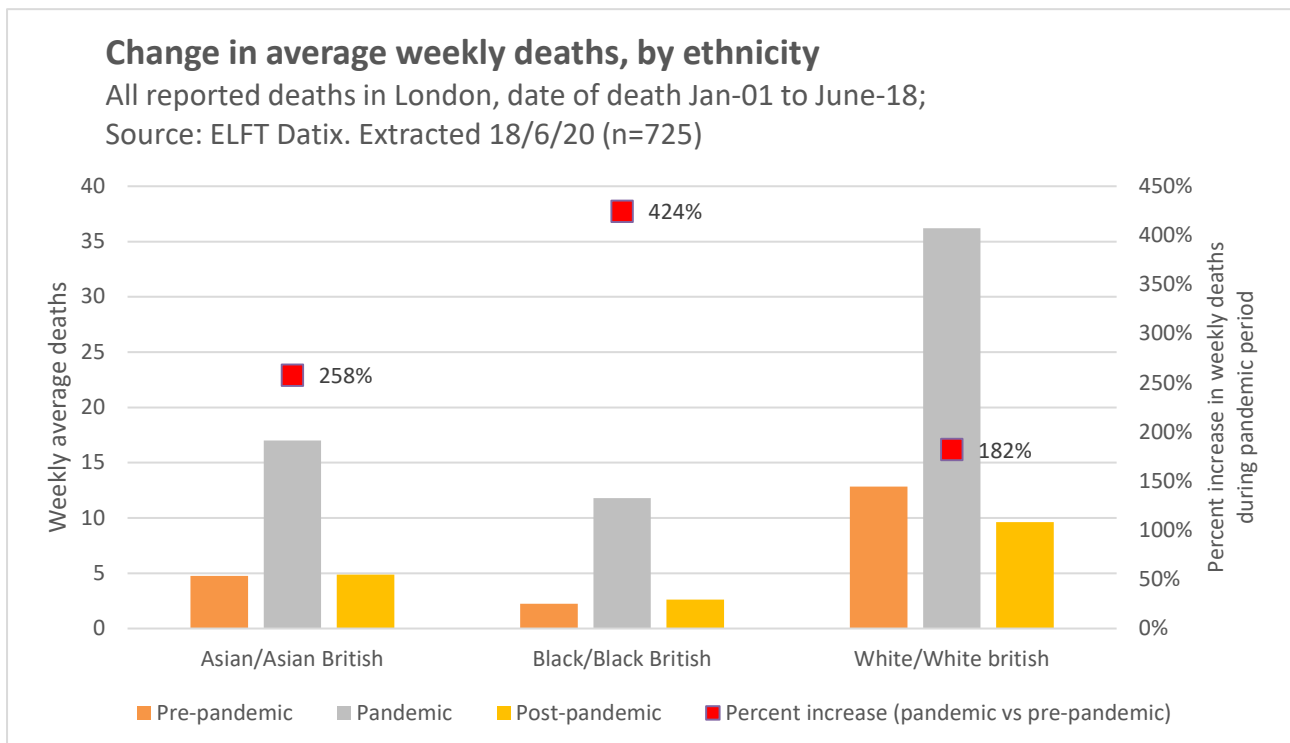
Furthermore throughout March, Acute Trusts continued to discharge patients to

care homes – large numbers of discharges were made before the publication on 2nd April of guidance for care homes regarding new admissions (8). This may have meant many infected people were discharged into care homes having become infected within acute hospitals (or elsewhere).

3.5 Ethnicity

3.5.1 Chart 6 below shows the changes in weekly deaths across pre-, during- and post-pandemic periods, by ethnicity of service user (as reported on Datix). Due to the low numbers of non-white service users outside of London, this is limited to London service users. The average absolute number of weekly deaths (bars) is higher for people of white ethnicity at all periods, reflecting the larger number of ELFT service users who are white (these figures are absolute numbers, not rates). During the pandemic period, the weekly deaths for Asian/Asian British people was 250% times higher than pre-pandemic; while the weekly deaths for Black/Black British people were over 400% higher. These increases were substantially larger than for White people, whose weekly deaths rose by 180% during the pandemic period.

3.5.2 Chart 6: Weekly deaths by ethnicity



3.5.3 Investigation of average age at death shows no significant trends by ethnicity among deaths reported to ELFT’s Datix. The average age at death 77.7 during ‘pandemic’ phase; very slightly higher than 76.5 during pre-pandemic. Black and

Asian groups saw slightly larger increases in the average age at death during the Pandemic phase than people in White ethnic group.

3.5.4 Table 2: Average age of death ELFT service users.

Average age at death		
	Covid phase	
Ethnic group	Pre-pandemic	Pandemic
Asian/Asian British	71.0	73.2
Black/Black British	70.7	76.0
Mixed or Other	76.2	56.3
White/White British	78.1	79.6
Total	76.5	77.7

3.5.5 **Interpretation:** The additional risk of excess deaths for service users from BAME background is in-line with what national epidemiological data, which have shown large increase in deaths for people from black, and from Asian backgrounds compared to white. Nationally, mortality rates in the pandemic period were 4 times higher than expected (based on previous years) among Black males, almost 3 times higher in Asian males and almost 2 times higher in White males. The greater increased risk experienced by ELFT’s service users is likely due to increased age and greater rate of diagnosed conditions compared to in the general population.

3.6 **Learning Disability**

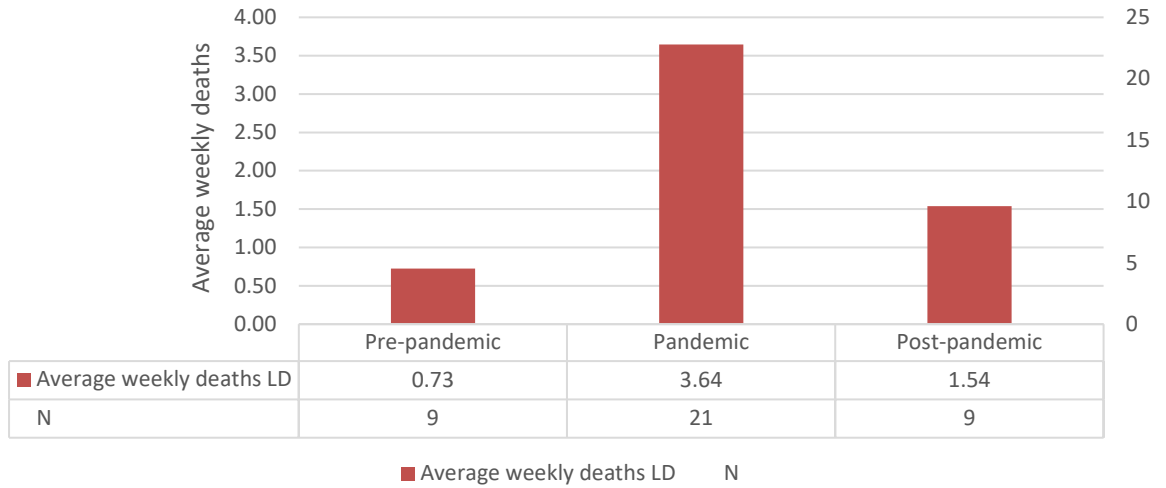
3.6.1 Reported deaths where the service-user had a learning disability are flagged routinely within Datix. Pre-pandemic during 2020 there were 9 deaths to service users with LD, whereas during the pandemic period there were 21 deaths to service users with learning disability. This represents a 400% increase in the average weekly deaths (from 0.7 pre-pandemic to 3.6 during pandemic). This is a much larger increase than the increase for service-users without LD.

3.6.2 Chart 7: weekly deaths where the service user has a learning disability.

Change in average weekly deaths, by learning disability

All reported deaths with service-user marked as having a learning disability, date of death Jan-01 to June-18;

Source: ELFT Datix. Extracted 18/6/20 (n=29)



3.6.3 Interpretation: There were 27 deaths of people who have a learning disability that ELFT were made aware of during the period 1.3.2020 until 19.5.2020. Of those 27, not all were currently in receipt of services but had historically been in contact with ELFT services or in the case of one person, settled in an out of area care home placement. For more information see Appendix.

Across North East London, all LD patients who died had one or more underlying health conditions such as respiratory conditions (chronic obstructive pulmonary disease (COPD), asthma, and recurring chest infections), heart conditions and chronic kidney disease and at risk of contracting Covid19. Most patients attended the hospital with hospital passports. Excellent care was recorded on all palliative care patients. The majority of our learning disability service users live in supported living accommodation. It was evident that we had more deaths recorded on service users with moderate learning disability compared to mild, severe and profound.

A particular issue facing people with a Learning Disability was the fact that individuals with LD were not immediately advised to Shield. Not everyone who has a learning disability has physical health co-morbidities so a blanket shielding letter would be inappropriate; however greater consideration should be given to this group to decide who should be shielding in the event of a second wave.

3.7 Data limitations

3.7.1 Datix records do not allow for easy extraction of other service user information: service user's sex/gender; postcode (to allow for investigation of inequalities by

deprivation of residence); experiencing homelessness or rough sleeping; existing diagnoses (mental or physical health – especially underlying health conditions such as diabetes, CVD, obesity)

4.0 Conclusion and Recommendations

4.1 There is clearly learning to be taken from the management of Covid-19 at a national and organisational level. The increase in mortality and morbidity from the direct and indirect impacts of Covid-19 have been and will continue to be seen for many months and years ahead.

4.2 The excess mortality experienced by ELFT's service-users during the Covid-19 pandemic occurred during relatively narrow 'pandemic' windows, the timing of which suggest that most people who died may were likely to have been infected prior to rigorous infection prevention and control measures being implemented nationally.

4.3 Potential inequalities explored in this report show that excess Deaths of ELFT service users mirror national patterns of excess deaths by age, ethnicity etc. ELFT's data and learning from excess deaths should be seen in the context of national patterns of impact. Covid-19 disproportionately impacted older people, males, people from BAME communities, deprived communities and some frontline occupations.

4.4 Key areas for further discussion and investigation:

4.4.1 Reducing the impact of future communicable diseases and Covid-19 for ELFT at risk populations.

- Access to appropriate PPE, infection control and social distancing should remain in place. This is especially important for older service users, particularly those with Alzheimer's and dementia; those in care homes and people with learning disabilities. A continued, renewed focus on improving the management of underlying health conditions could be an area of focus.
- Continued testing and working with clinical and care teams on infection prevention and control (IPC) measures should be a priority. IPC measures in residential settings should be a priority for QI projects in the near future. Safe discharge policy and practice into Care Homes should continue to be a priority, with discharges from acute hospitals or other settings remaining isolated for appropriate periods upon arrival at a care home.
- ELFT should continue to consider all available IPC guidance, including that from WHO, alongside UK guidance. In this instance, WHO Guidance recommended more stringent IPC before equivalent recommendations were made by UK government.
- People with learning disabilities were particularly vulnerable to Covid-19, but experience reduced life expectancy generally for a wide range of factors. A focus on this group and lessons learned around how to improve their health and wellbeing; as well as reduce the risk of death could be a valuable pieces of work. This is already taking place through the Shaping Our Future work programme.

4.4.2 Improving data and recording

- To better understand the impact of COVID-19 and other deaths it would be helpful to review the way that service user information is recorded and stored in Datix. For example having a link to Rio could allow better understanding of underlying health conditions; diagnoses; postcode (which would allow investigation of inequalities by area-level deprivation) and particular at-risk statuses (such as homelessness) would be helpful to understand patterns of death.

5.0 Action Being Requested

The Board is asked to:

- 5.1 Note the contents of this report
- 5.2 Consider the recommendations set out under section 4.4 above

Appendix: COVID19 Related Learning Disability Deaths Summary - March to 19.5.2020

There were 27 deaths of people who have a learning disability that ELFT were made aware of during the period 1.3.2020 until 19.5.2020. Of those 27, not all were currently in receipt of services but had historically been in contact with ELFT services or in the case of one person, settled in an out of area care home placement.

A brief review of the deaths that have been reported shows the following information –

- People with all levels of learning disability from mild to severe have died due to COVID19 – there may have been an assumption that people with moderate to severe learning disability were at greater risk but this has not necessarily been evident in this group
- 14 females and 9 males have died
- The rate continues to rise in London but has flattened in Bedfordshire and Luton
- The range of ages of those who died were from 19-83
- Of the 27 deaths the mean age of death was **54.5** years of age
- 5 people with a diagnosis of Downs Syndrome died – their mean age of death was **31.4**, with the majority of these deaths in Newham
- Only two of those who died did not have underlying health conditions.
- The incidence of Diabetes, Epilepsy and Kidney Failure was high with some people having more than one of these conditions (8 Diabetics, 8 Epilepsy, 5 Kidney failure)
- Two people were receiving palliative care when they contracted COVID19
- Only two people died at home, with 25 dying in hospital
- We are only aware of one person having a shielding letter

One of the key issues to consider is how people with multiple conditions are coded in Primary Care records – for example, if Learning Disability is the primary code, it's possible that additional conditions such as Diabetes and a neurological condition such as Epilepsy could be missed when considering who should be shielding.

Not everyone who has a learning disability has physical health co-morbidities so a blanket shielding letter would be inappropriate however, greater consideration should be given to this group to decide who should be shielding in the event of a second wave.

19.5.2020

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