REPORT TO THE TRUST BOARD IN PUBLIC
27 January 2022

Title	Learning from Excess Mortality During Waves 1 and 2 of the COVID-19 Pandemic
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Purpose of the report

This paper reports on analysis of ELFT data on deaths of people in contact with ELFT services during the first two waves of the COVID-19 pandemic. It is intended to enable the Trust to understand the scale of impact of the pandemic on the people we serve, and to help identify opportunities to reduce risks for our service user populations in future. The Board is asked to discuss the findings.

Committees/meetings where this item has been considered

Date	Committee/Meeting
10/01/21	Quality Assurance Committee

Key messages

ELFT service users are particularly vulnerable to the direct and indirect effects of the COVID-19 pandemic. There were an estimated 1,144 excess deaths among ELFT service users during the first two waves of pandemic combined. Deaths were 2.6 times above expected numbers during the first wave and 1.5 times above expected numbers during the second wave.

Preventative approaches to population health are an important way to reduce population health risks and must remain a core part of ELFT's strategy. This paper recommends continuation of both short and long-term preventative action, including:

1. Support for people to achieve a healthy standard of living and prioritisation of prevention and early detection of illness in disadvantaged groups through our population health strategy
2. Promoting vaccination uptake among staff and service users
3. Maintaining infection prevention and control procedures in line with current UKHSA guidance
4. Retaining a focus on the underlying drivers of inequalities in health and health outcomes and ELFT's role in addressing these
5. Improving data collection to enable more sophisticated assessment of health inequalities within and between population groups

Strategic priorities this paper supports

Improved population health outcomes	☒	Lessons learnt from this report should help in reducing risks to population health directly and indirectly attributable to COVID-19.
Improved experience of care	☒	The aim of this paper is to support provision of improved care for service users.

Improved staff experience	☐	
Improved value	☒	Through full understanding of our population and the risks they face, we aim to improve the quality of care we provide through earlier, preventative intervention which improves efficiency and value for money for the NHS.

Implications

Equality Analysis	This report considers inequalities in excess mortality between different groups of service users including between different groups of services, geographical regions, ethnic groups, and learning disability status. Highlighting where inequalities in outcomes exist may help the Trust to identify ways to reduce these inequalities in future.
Risk and Assurance	This paper gives assurance that the Trust continues to learn from the ongoing pandemic and will take robust action to reduce excess mortality among service users.
Service User/ Carer/Staff	The paper estimates the extent of increases in risk of death for service users during the first two waves of the COVID-19 pandemic and makes recommendations for ongoing vigilance in infection prevention and control. These will affect patient and staff experience and outcomes.
Financial	No financial implications identified.
Quality	The report makes recommendations for improvements to services to increase focus on prevention, and for changes to the collection of safety monitoring data to enable deeper analysis in future.

1.0   Background

1.1   This paper examines excess deaths among people in contact with ELFT services over the course of the first two waves of the COVID-19 pandemic between January 2020 and May 2021. Excess deaths are deaths above the number which would be expected to occur over a given time period.

1.2   The pandemic has led to declining life expectancy driven by increased mortality in countries around the world.[1] During the first wave, a disproportionate number of deaths were reported to have occurred in health and care settings, particularly among care home residents).[2,3] There was, and remains, considerable interest in the lessons that health and care providers could learn from patterns of excess deaths.

1.3   Analysis by ELFT's public health team at the end of the first wave (reviewing data from January 2020 to June 2020) identified a similar or slightly higher increase in excess deaths among ELFT service users than in the regional populations served by the Trust. This paper extends that analysis and uses deaths in 2019 as a comparator to estimate excess deaths during both of the first two waves of the pandemic. The longer time period and comparator to 2019 deaths, gives us more data to be able to fully reflect on the pandemic and review our findings and learning.

1.4   Reviewing and learning from deaths is a key responsibility of NHS Trusts. ELFT continues to review individual deaths through Structured Judgement Reviews and Serious Incident Reviews. This paper complements those reviews through analysis of wider population data on excess deaths across the Trust.

2.0   Methods

2.1   ELFT records all reported deaths among people in contact with its services via Datix. These Datix records are the primary source for this analysis. Data were extracted covering all incidents occurring from 1 January 2019 to 31 May 2021 in which the Person Harm field recorded a death.

2.2   This analysis includes all deaths, not only COVID-19 deaths. Inconsistencies in the rates of COVID-19 testing at different stages in the pandemic mean that exclusion of deaths which were not attributed to COVID-19 would lead to an incomplete assessment of the pandemic's direct impact. It would also be unable to capture the indirect effects of the pandemic on overall mortality. Monitoring of weekly excess deaths has been proposed as an effective way to understand the total impact of the pandemic on mortality.[5] This paper is based on that approach.

2.3   Weekly excess deaths are deaths occurring above the expected number for that week of the year. This report defines the expected number of deaths as the number of deaths among ELFT service users recorded in Datix in a model based on the corresponding week in 2019. Excess deaths for any given week of 2020 or 2021 are calculated as the difference between these expected deaths and the actual (observed) number of deaths. No adjustments have been made to account for changes in the population of people in contact with ELFT services. In order to understand differences between subgroups in the scale of excess deaths, both absolute differences (numbers) and ratios (observed / expected deaths) were calculated.

2.4   For this analysis, wave 1 is dated from Monday 23 March 2020 to Sunday 31 May 2020 and wave 2 from Monday 7 September 2020 to Sunday 25 April 2021. These dates are the nearest whole weeks corresponding to the pandemic waves identified in national analysis by the Office for National Statistics, though there is some uncertainty, as the virus

is thought to have been circulating prior to the date identified as the beginning of the first wave.[6]

2.5   An additional analysis compares the total number of deaths by each cause recorded in Datix during the calendar years 2019 and 2020.

2.6   Statistical tests were carried out to assess the strength of evidence of differences between wave 1 and wave 2, and between some different demographic groups.

2.7   Peer review of this paper was invited from members of ELFT's Quality Improvement, Safety and Public Health teams and from relevant clinical and nursing leaders within the Trust.

3.0   Findings and interpretation

3.1   Deaths between January 2019 and May 2021

3.1.1   Figure 1 (below) shows the total number of deaths reported among ELFT service users in each week from the first week of January 2020 to the final week of May 2021, and the number of deaths in the equivalent week in 2019. The peak of wave 1 can be seen in the week commencing 6 April 2020 (week 15), when there were 158 deaths. The peak of wave 2 can be seen in the week commencing 4 January 2021 (week 1), when there were 103 deaths.

Figure 1: weekly number of deaths reported among ELFT service users (n = 6106 from 1 January 2019 to 31 May 2021)
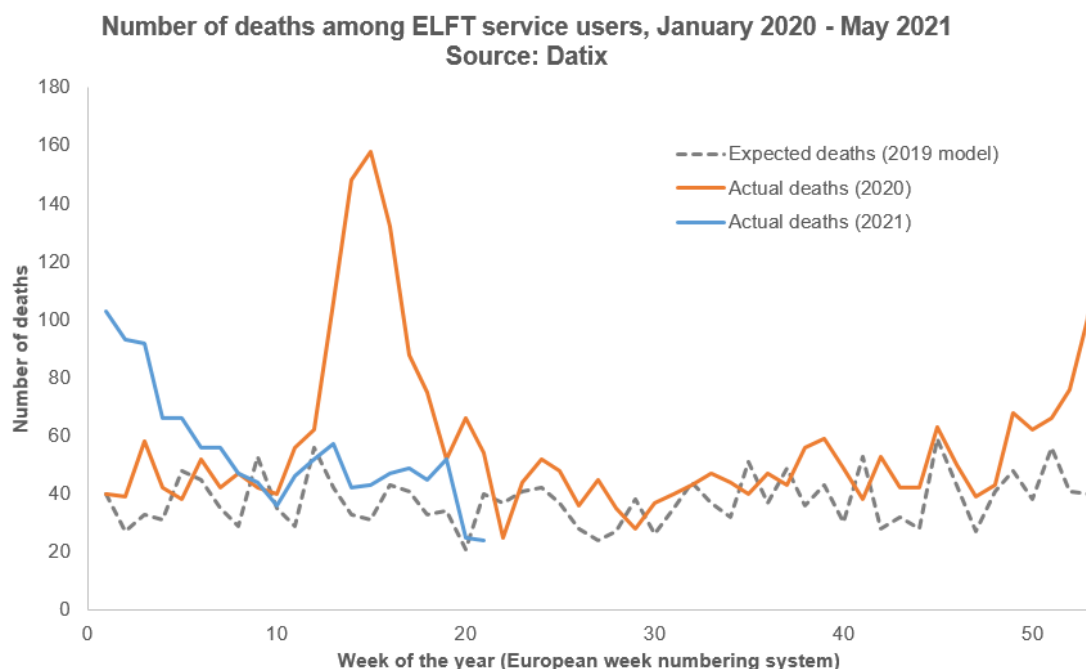
3.2   Total excess deaths in the first two waves of the pandemic

3.2.1   The estimated total number of excess deaths from all causes among ELFT service users during the first two waves of the pandemic was 1,144. During the first wave, an average of 90.4 ELFT service users died per week, 2.6 times as many as expected based on the number of deaths in 2019, a total of 549 excess deaths. During the second wave, an average of 50.5 ELFT service users died per week, 1.5 times as many as expected. The peak in mortality was statistically significantly lower in the second wave. However, this

wave had a longer duration, so the estimated absolute total number of excess deaths during this wave was higher, at 595.

3.2.2   National and regional excess mortality data for East of England and London also shows peaks in April 2020 and in January 2021. Experimental data analysis from the Office of Health Improvement & Disparities (formerly Public Health England) suggests that deaths during the first wave were 2.0 times expected numbers in London and 1.6 times expected numbers in East of England. During the second wave, deaths were 1.2 times expected numbers in London and 1.1 times expected numbers in East of England.[7] These ratios appear lower than those reported for ELFT service users. However, it is important to note that they are not directly comparable, as they were calculated using a different methodology and based on the general population and not a healthcare population which would be at higher risk of mortality,

3.2.3   Excess deaths in the second wave are highly likely to have been reduced by the vaccination programme, which began on 8 December 2020, as well as by the application of infection prevention and control measures and learning from wave one on shielding vulnerable populations. Vaccination is at least 90% effective in preventing COVID-19 hospitalisation and death, and the majority of people aged over 70 had received a first dose by the end of January 2021.[8]

3.2.4   Nevertheless, the high ratio of observed to expected deaths in both waves suggests that the ELFT service user population is highly vulnerable to the combined direct and indirect effects of the pandemic. High overall excess mortality among ELFT service users suggests that the Trust should look for both short-term and long-term opportunities to reduce modifiable mortality risk factors. Deaths from COVID-19 are associated with risk factors including older age; male sex; obesity; mixed, South Asian or Black ethnicity; or pre-existing medical conditions including diabetes, chronic respiratory disease and chronic cardiac disease.[9] Most risk factors for COVID-19 death are also associated with risk of death from other causes, suggesting that COVID-19 largely multiplies existing risks and exacerbates existing inequalites.[10]

3.3   Excess deaths by service type and location

3.3.1   Community Health services had higher absolute numbers of deaths than Mental Health services in both London and Bedfordshire / Luton in both waves of the pandemic (table 1). Bedfordshire / Luton Community Health services had the highest relative increase in deaths compared to expected numbers during both waves, with 3.7 times as many deaths as expected during the first wave, and 2.4 times as many deaths as expected during the second wave. Statistical tests showed significantly higher excess deaths in Community Health services than Mental Health services during wave 1; and significantly higher excess deaths in Bedfordshire & Luton than London during wave 2. High excess mortality ratios in in Bedfordshire / Luton Community Health Services may be related to the population served; if there is an older demographic, this would lead to a greater increase in risk.

Table 1: Observed, expected and excess deaths among ELFT service users in Community Health and Mental Health in Beds/Luton and London during the first two waves of the pandemic

	Wave 1 (WC 23/03/20 to WC 25/05/20)				Wave 2 (WC 07/09/20 to WC 19/04/21)				Total
	Expected deaths (n)	Observed deaths (n)	Excess deaths (n)	Average deaths per week (n)	Expected deaths (n)	Observed deaths (n)	Excess deaths (n)	Average deaths per week (n)	**Excess deaths (n)**
Beds / Luton - Community Health	57	213	156	21	207	502	295	15	**451**
Beds / Luton - Mental Health	65	109	44	11	194	263	69	8	**113**
London - Community Health	183	433	250	43	699	828	130	25	**380**
London - Mental Health	50	149	99	15	203	304	101	9	**200**
Total	**355**	**904**	**549**	**90**	**1302**	**1897**	**595**	**57**	**1144**

3.3.2 The reduction in the ratio of observed to expected deaths between the first and second waves of the pandemic was greater in London than in Bedfordshire and Luton. London saw a high burden of cases and deaths during the first wave.[11] This may be related to the timing of preventative policy measures (lockdowns), which were implemented simultaneously around the country on 23 March, at a time when London was at a more advanced stage of the epidemic than other parts of the country.

Figure 2: ratio of observed to expected deaths among ELFT service users by location and service type during the first two waves of the COVID-19 pandemic
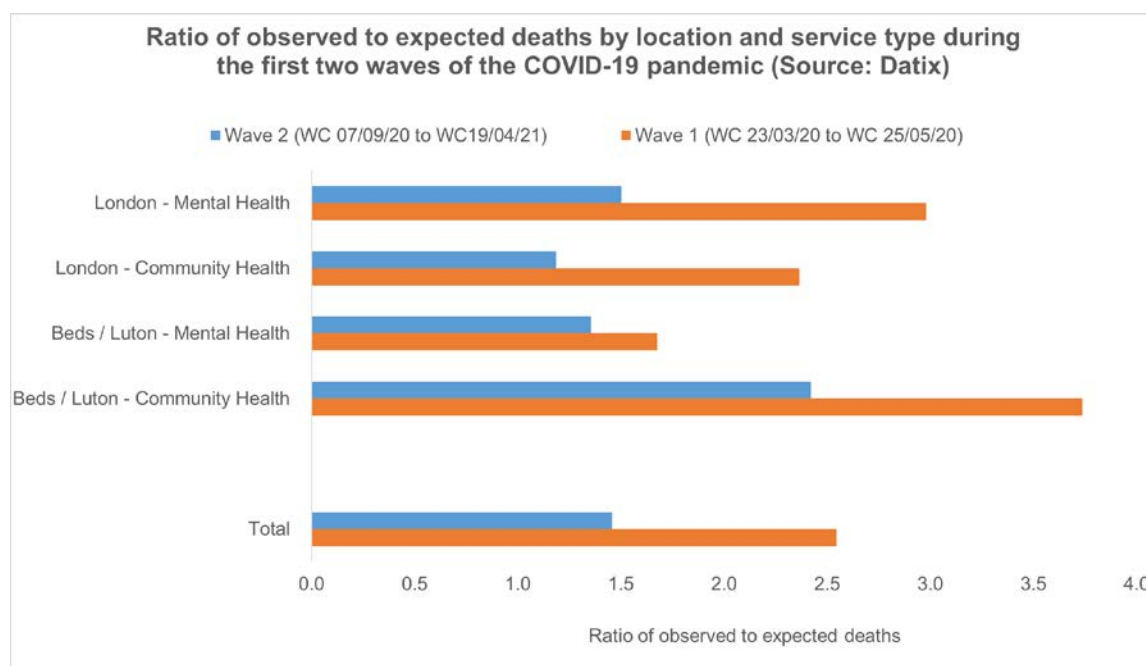
3.4 Excess deaths by ethnicity

3.4.1 Formal statistical tests found no significant difference in increased risk of death for ELFT service users from Black, Asian and minority ethnic backgrounds compared to those from White backgrounds. The only reported significant difference between ethnic groups was higher risk for White people during Wave 2.

3.4.2 This finding is different to data from the general population, which showed an increased risk of hospitalisation and death for some Black and Asian ethnic groups.[7,12]Ethnic differences in risks from COVID-19 could be linked to differences in occupation, household composition, population density, housing conditions, public transport use and wider social disadvantage.[13]

3.4.3 ELFT data are not directly comparable to the national data due to different methods of data analysis and differences in population risk. In particular, the analysis of ELFT data could not control for age, which is a leading risk factor for deaths from COVID-19. This would make the risk for White British service users appear unusually high if they are older on average than service users from other ethnic backgrounds. It also includes deaths from all causes rather than only from COVID-19; people of Black and Asian ethnicity are at greater risk of COVID-19 death than people of White ethnicity, but lower risk of death from other causes.[10] It is also possible that ethnic differences in underlying risk factors such as obesity or pre-existing health conditions are narrower among ELFT service users than the wider population, which could explain the narrower variation in excess deaths. Improvements to data collection and management would enable more sophisticated analysis to investigate questions like this in future.

Table 2: observed, expected and excess deaths among ELFT service users, by ethnicity, during the first two waves of the pandemic

	Wave 1 (WC 23/03/20 to WC 25/05/20)				Wave 2 (WC 07/09/20 to WC 19/04/21)				**Total**
	Expected deaths (n)	Observed deaths (n)	Excess deaths (n)	Average deaths per week (n)	Expected deaths (n)	Observed deaths (n)	Excess deaths (n)	Average deaths per week (n)	**Excess deaths (n)**
Mixed or Other	10	19	9	2	33	38	5	1	**14**
Not stated	40	78	38	8	175	226	51	7	**89**
Asian / Asian British	58	142	84	14	202	315	113	10	**197**
White / White British	210	561	351	56	737	1128	392	34	**743**
Black / Black British	37	104	67	10	156	190	34	6	**101**
Total	**355**	**904**	**549**	**90**	**1302**	**1897**	**595**	**57**	**1144**

Figure 3: ratio of observed to expected deaths among ELFT service users by ethnicity and wave of the pandemic
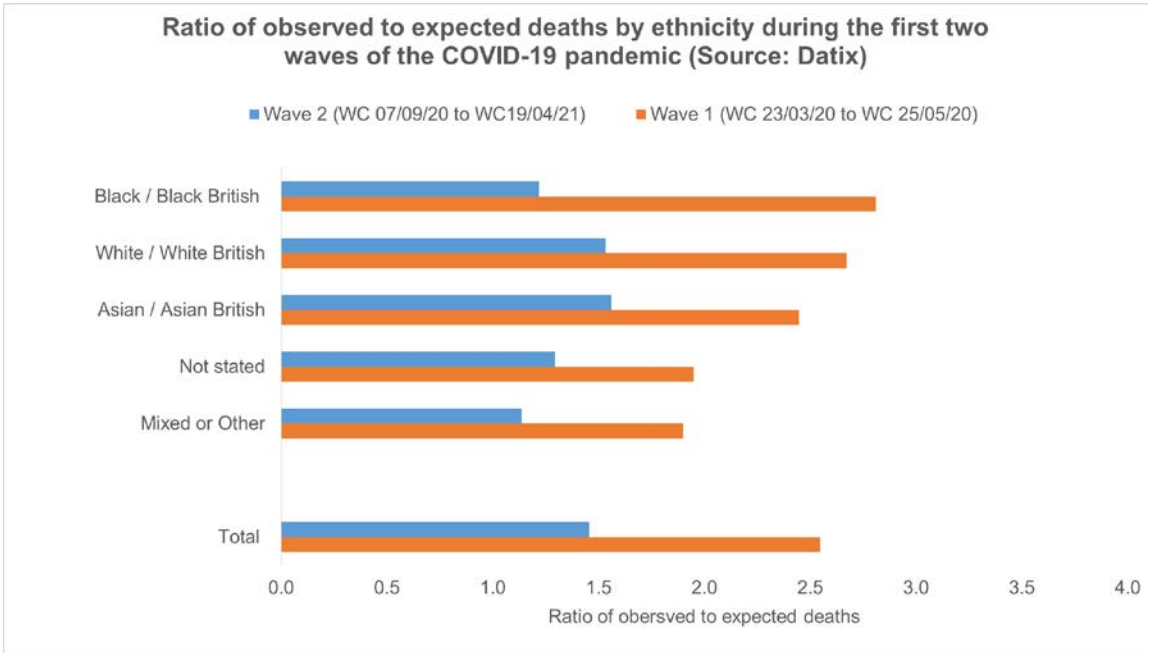
3.5   Excess deaths by learning disability status

3.5.1   There were an estimated total of 37 excess deaths among ELFT service users with learning disabilities during the first two waves of the pandemic, including 22 in the first wave and 15 in the second wave (table 3). Among people with learning disabilities, there were three times the expected number of deaths during the first wave and 1.6 times expected number during the second wave (figure 4).

3.5.2   Differences in excess death ratios between people with and without learning disabilities are shown in figure 4. These were not found to be statistically significant in either wave. Small numbers can reduce the precision of statistical tests so it is possible that the differences were not found to be significant for this reason. Analysis of national data found a higher rate of mortality among people with learning disability than the general population, with a greater disparity in younger adult age groups, people with more severe learning disability and those in residential care.[14] This highlights the importance of vaccination and of high quality health care for people with learning disabilities.

3.5.3   There were also specific considerations affecting risk among people with learning disabilities in the population ELFT serves. Historically there was a long stay institution for people who had a learning disability just outside Bedford, and this has led to high levels of private provision in the area. There is a significantly greater provider population in B&L than in London, and so a higher number of the deaths of people who had a learning disability in this area were attributable to outbreaks in care homes. Mechanisms for sharing information and support between partners was strengthened between the first and second waves in 2020 and early 2021, with an increasing awareness of the vulnerability of this population. This led to outbreaks being managed more effectively, and increased scrutiny of the use and application of DNACPR when people with a learning disability were admitted to hospital.

Table 3: observed, expected and excess deaths among ELFT service users, by learning disability status and wave of the pandemic

	Wave 1 (WC 23/03/20 to WC 25/05/20)				Wave 2 (WC 07/09/20 to WC 19/04/21)				**Total**
	Expected deaths (n)	Observed deaths (n)	Excess deaths (n)	Average deaths per week (n)	Expected deaths (n)	Observed deaths (n)	Excess deaths (n)	Average deaths per week (n)	**Excess deaths (n)**
No recorded learning disability	344	871	527	87	1277	1856	579	56	**1106**
Recorded learning disability	11	33	22	3	26	41	15	1	**37**
Total	**355**	**904**	**549**	**90**	**1302**	**1897**	**595**	**57**	**1144**

Note: the discrepancy in the total estimated number of excess deaths in this table is due to rounding

Figure 4: ratio of observed to expected deaths among ELFT service users by learning disability status and wave of the pandemic
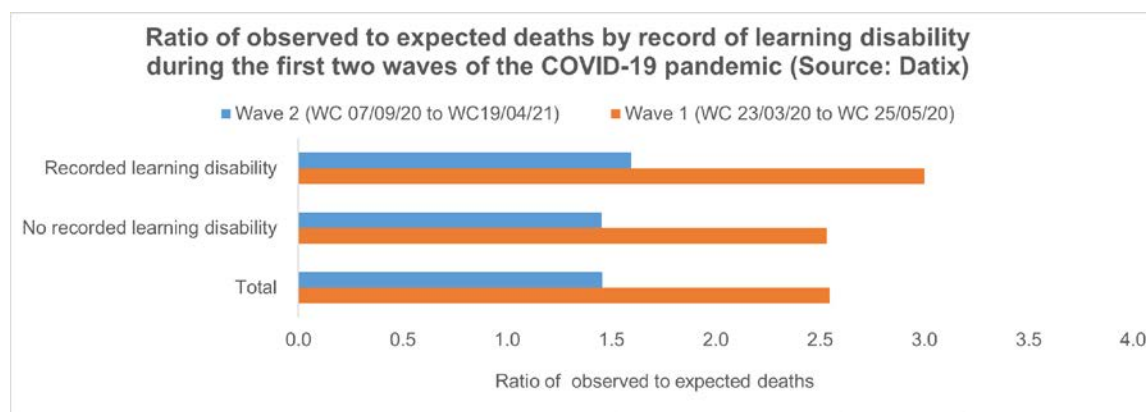
3.6   Causes of death

3.6.1 Although Datix contains limited information about causes of death, it does record whether
       they are expected or unexpected, and whether they are attributable to a known cause, an
       unknown cause, suspected suicide or COVID-19. In addition to the deaths which were
       directly attributed to COVID-19, there was also an increase between 2019 and 2020 in
       other causes of death, particularly expected deaths and unexpected deaths with an
       unknown cause (figure 5).

**Figure 5: number of deaths attributed to each cause among ELFT service users in 2019
and 2020**
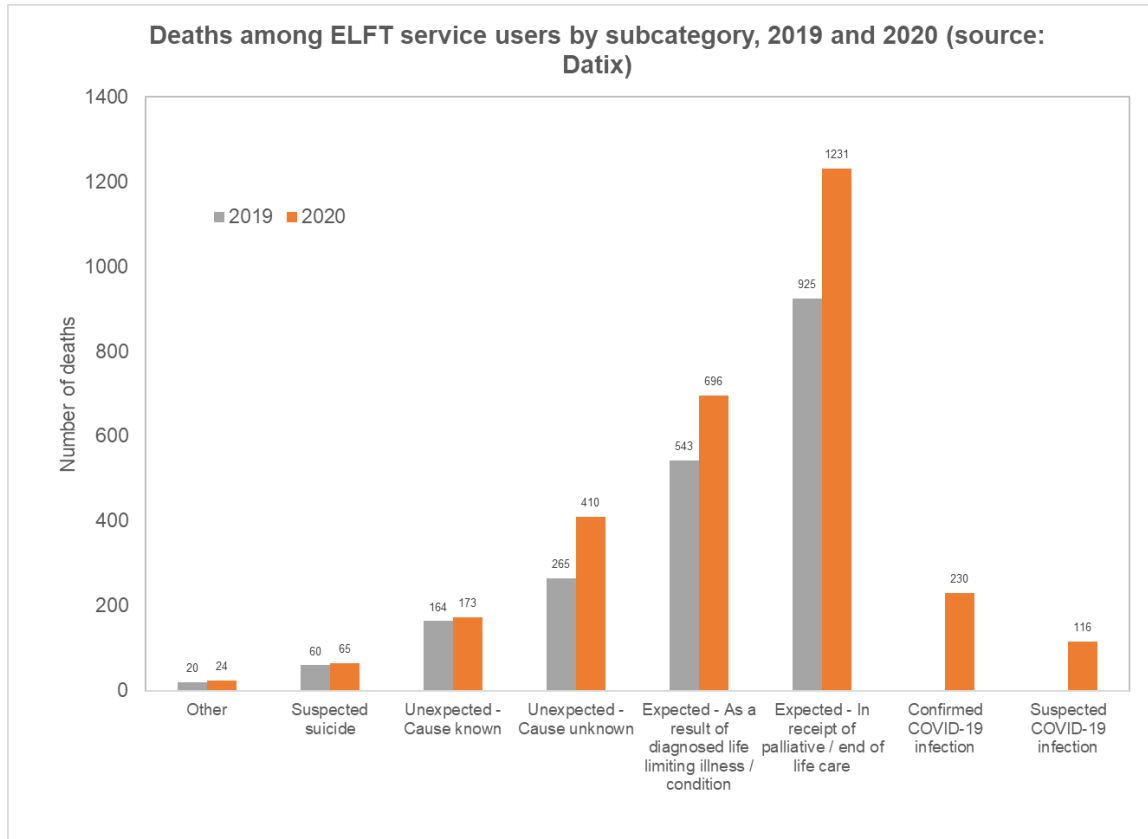
3.7   There are several possible interpretations of the finding of an increase in expected deaths,
       all of which are related to the pandemic. First, it is possible that deaths which were
       suspected to be caused by COVID-19 early in the pandemic were categorised as
       "expected." No deaths were attributed to COVID-19 prior to 1 April 2020. Second, it is
       possible that some deaths among people with life-limiting conditions or receiving palliative
       care may have been caused by unrecognised COVID-19 early in the pandemic. Thirdly, it
       is possible that some deaths occurred from delayed or limited access to treatment for
       other conditions from health services with limited capacity during the peak of the
       pandemic.

3.8   Unexpected deaths with an unknown cause may have increased directly due to
       unrecognised or unconfirmed COVID-19 or from other causes arising from displacement
       of other health and care services. It is also possible that this increase could be partially
       explained by recording differences arising from limited staff capacity during 2020.

4.0   Strengths and limitations of this analysis

4.1   The use of a comparator based on expected deaths at the same time of year, and the extension of the analysis to include the second wave of the pandemic are strengths of this report.

4.2   Nevertheless, a number of important limitations remain, and all findings should be interpreted with caution. First, the dataset does not include deaths beyond May 2021. This means that the full impact of the vaccination programme and of the relaxation of social distancing requirements on deaths among our service users are not apparent.

4.3   Second, the use of 2019 as a comparator introduces a potential source of bias. If there were changes in the service user population or in the quality and consistency of recording of deaths between 2019 and 2020, this could lead to a biased estimation of excess deaths. If fewer people were using ELFT services in 2020, or if recording of deaths was poorer, this would lead to an underestimation of the extent of excess mortality.

4.4   Third, there are some limitations to the statistical analysis. In particular, no adjustments were made to take account of differences in age or other potential confounding factors. In addition, no statistical tests were carried out to examine differences between 2019 and 2020 in causes of death because categories changed part way through the year in 2020, which would have rendered this comparison difficult to interpret (section 3.5). Additionally, a lack of statistically significant evidence of differences between subgroups should not always be interpreted as evidence of a lack of differences. This is particularly the case where numbers are small and confidence intervals are wide, as is the case for excess mortality estimates among people with learning disability in this analysis.

4.5   Finally, improvements to data collection systems would enable more comprehensive analysis of specific causes and circumstances of death in our service users as a whole and among specific demographic groups.

5.0   Summary

5.1   This report has summarised data analysis estimating that there were 1,144 more deaths among ELFT service users during the first two waves of the pandemic than during the equivalent time period in 2019. ELFT service users may have been at higher risk than the overall population in East of England or London, as expected from a healthcare population. There was higher rate of excess deaths in community services in Bedfordshire and Luton during both waves of the pandemic. The rate of excess mortality and the size of differences between different demographic groups appears to have been lower in the second wave, but absolute numbers remain high.

6.0   Recommendations

6.1   People who use ELFT services may be particularly vulnerable to both the direct and indirect effects of COVID-19. Both long-term and short-term preventative action are needed to reduce inequalities in outcomes between ELFT service users and the general population.

6.2   Short-term action includes maximisation of vaccination uptake among both staff and service users, including of boosters. High standards in infection prevention and control should also be maintained, including PPE use; cleaning; and testing and isolation of possible cases in line with current national and international guidance from the UK Health Security Agency. A focus on reducing inequalities should be maintained throughout this work.

6.3   Longer-term action should include primary, secondary and tertiary prevention delivered through our strategic approach to population health. This work should aim to maintain and

improve the health and wellbeing of our service users, reducing their vulnerability to COVID-19, other infections, and non-communicable diseases. This would help to reduce inequalities across our population. This should include focusing on the structural factors which lie behind differences in behavioural risks such as smoking, alcohol and substance misuse, physical inactivity and poor diets.

6.4   Improvements are also needed to the Datix system to enable more reliable and comprehensive analysis factors contributing to the risk of death among ELFT service users. This could include reviewing data entry and retrieval systems; developing clear definitions of core data required for safety, assurance and improvement purposes; and linkage to patient records to enable more sophisticated analysis.

7.0   Action being requested

7.1   The Board is asked to RECEIVE and DISCUSS the findings of the report

References

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