

Protecting and improving the nation's health

This presentation includes:

- Slides presented during the webinar
- Notes on each slide
- Summary of Q & A session



Protecting and improving the nation's health

Webinar: introducing a factsheet for place of death

National End of Life Care Intelligence Network

September 2021

Empowering to deliver together

Webinar overview

- The work of the National End of Life Care Intelligence Network (Andy Pring)
- The new place of death factsheet (Reza Indrakusuma)
- Questions

National End of Life Care Intelligence Network (NEoLCIN)

Information and resources for health and social care professionals to improve the quality of services and reduce inequalities in care.

- Originally within the NHS formed following 2008 End of Life Care Strategy published by Department of Health
- Part of Public Health England since 2013
- Transitioning on 1st October 2021 to a new Office for Health Improvement and Disparities (OHID) within the Department of Health and Social Care

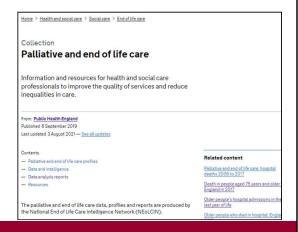
Webinar: Introducing NEoLCIN's factsheet Place of death

Until recently the team had been working in the COVID response. The national end of life care intelligence network was originally set up following the publication of the End of Life Care Strategy in 2008, and our part in this was to improve the availability and use of data for health and social care professionals to improve the quality of palliative and end of life care services and reduce inequalities in care.

We became part of PHE when it was formed in 2013, and in just a few days, as PHE ceases to exist we are transitioning to the new Office for Health Improvement and Disparities (OHID) within the Department of Health and Social Care.

NEOLCIN - Where to find us GOV.UK website

https://www.gov.uk/government/collections/palliative-and-end-of-life-care



Webinar: Introducing NEoLCIN's factsheet Place of death

Where to find our work, first the GOV.uk website which hosts our reports and bulletins together with useful links elsewhere

NEOLCIN - Where to find us Palliative and End of Life Care Profiles

https://fingertips.phe.org.uk/profile/end-of-life



Webinar: Introducing NEoLCIN's factsheet Place of death

And second the Health profiles, or Fingertips website. This hosts many of the regular statistics that are produced by PHE, including the Palliative and End of Life Care profile, where the new place of death factsheets can be found.



Protecting and improving the nation's health

Place of death factsheet

Place of death factsheet

- · Why a factsheet?
- · Contents of factsheet
- Guided tour through the images and the table
- Live demonstration on Fingertips and
- Answers to some key questions

Why a factsheet?

To present the most recent data available

- · Place of death factsheet uses provisional monthly data from ONS
- Factsheets will be updated monthly next scheduled update 5th October 2021
- · Currently available at CCG Level
- · The content and geographies will be reviewed regularly

To improve timeliness of data available on the Palliative and End of Life Care Profiles

- Mortality indicators are produced using finalised ONS data indicators are only updated annually and do not include recent data
- · Stakeholders have frequently requested that more timely updates would be made available

Webinar: Introducing NEoLCIN's factsheet Place of death

Why did we create a factsheet? We wanted to have a data product that presents the most recent data available. Now for the place of death factsheet, we use provisional mortality data from ONS which is provided to us on a monthly basis. This means that we can and we will update our factsheet every month too. The next update is actually scheduled to go live next week.

Currently we present the factsheet at the most recent CCG level to provide local intelligence, but we will periodically review the content and geographies to see if the factsheet is meeting stakeholders' needs.

The factsheet is also a way of improving on the timeliness of data available on our current Palliative and End of Life Care Profiles, especially for our mortality indicators which have historically been produced using the finalised ONS data that were released to us annually and therefore never had recent data. Timeliness of the data was also probably the most frequently received feedback from stakeholders on our profiles.

Contents of the factsheet

- Introduction
- Summary of data
- Methodology
- · Local considerations and additional resources

Webinar: Introducing NEoLCIN's factsheet Place of death

We produce factsheets for the most recent CCG configuration; and there are currently have 106 factsheets. Each factsheet follows the same structure: the introduction on place of death, the methodology and the resources are shared between each factsheet and the summary of data is tailored to the individual CCG level. These will be describe in the preceding slides.

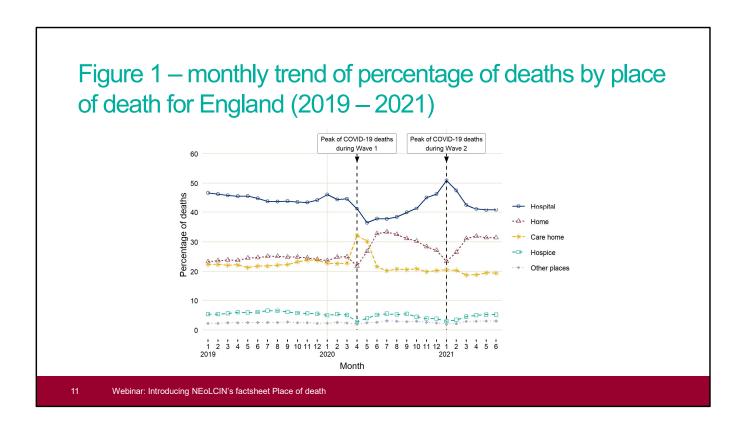


Figure 1 show the beginning of January 2019 and ends currently, in June 2021. On the x axis you will find the individual months, whilst the y axis shows the percentage of deaths. There are 5 trend lines, one for each place of death: hospital, home, care home, hospice and other places. In addition, we have included 2 vertical reference lines to indicate the peak of COVID-19 deaths for respectively wave 1 and wave 2

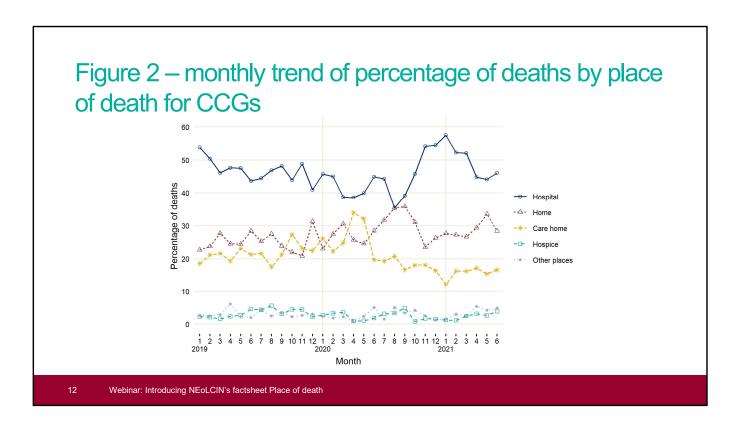


Figure 2 is essentially figure 1 but configured at the individual CCG level. It follows the same structure: the months are presented on the x axis, the percentage of death is presented at the y axis and there are 5 trend lines for each place of death. One thing to note is that CCGs can vary significantly in size and therefore in the number of deaths that they experience Since we present the trend by month, some of the trend lines can show a much noisier trend line, where it goes up and down by month compared to the England level figure.

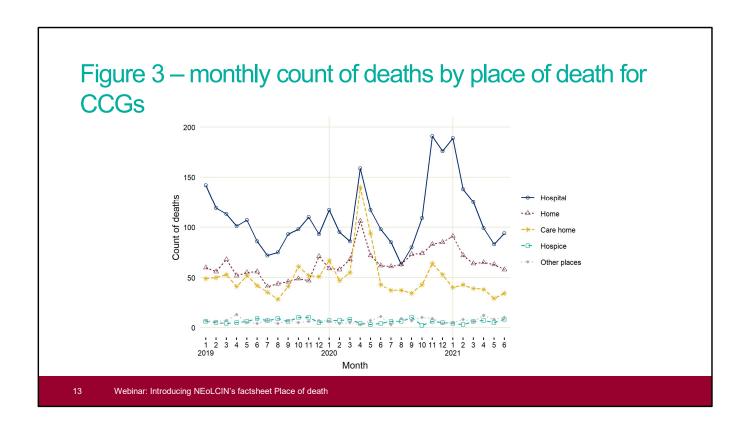


Figure 3 follows the same presentation format as Figure 2, but this time the y axis shows the count of deaths, instead of the percentage while the other figure elements remain the same. This figure is included because the absolute numbers provide a better sense of how many deaths there are per month for each place of death and in total. For the same reasons as for figure 2, these trend lines can be quite noisy due to the monthly fluctuation.

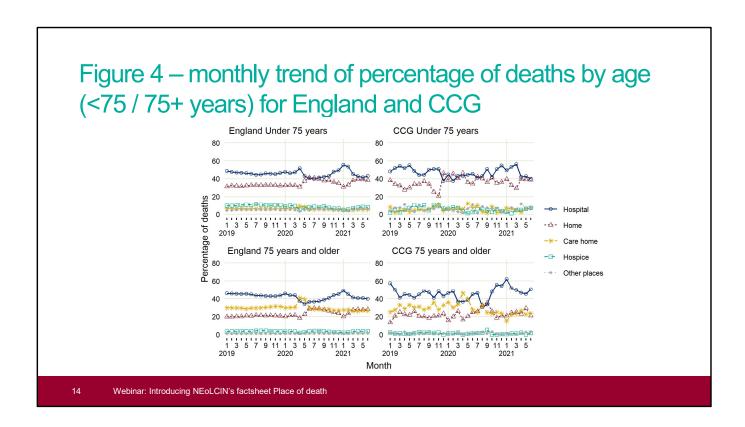


Figure 4 is slightly different compared to the previous figures, as it is actually a grid of 4 figures for the monthly percentage of deaths, arranged in 2 columns and 2 rows. The left column shows the visualisations for England and the right column shows the individual CCG, while the top row is for people under 75 years, and the bottom row is for 75 and older. Each visualisation however follows the same format, with the same 5 trend lines for each place of death. Because of the grid structure the trend lines can be compared between the individual CCG and England within each age group.

Table 1

Presents the total counts of deaths for each place of death by year

Includes a statistical comparison between 2019 and 2020, 2021

Includes sub-tables broken down by age group:

- All ages
- <65
- 65-74
- 75-84
- 85+

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In addition to monthly trend lines, the factsheet includes a table to provide the total counts of deaths for each place of death by year, so for 2019, 2020 and 2021.

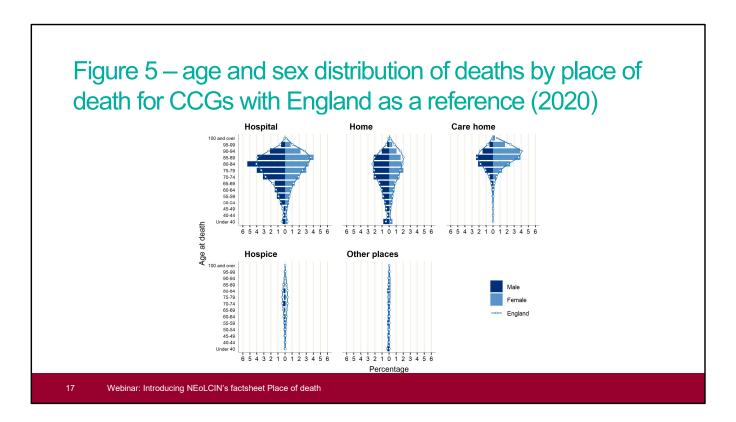
The table also includes a statistical comparison between 2019 - which is considered a reference year for this factsheet – and 2020 and 2021. The table could actually be considered a collection of subtables, as we have a table for all ages and then another 4 tables for the different age groups: for people under 65 years old, those 65 to 74 years old, 75 to 84 years old and those 85 and over.

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All ages Under 65 year	rs 65 to 74 years	75 to 84 y	ears 85 year	s and older	
2019 Measure	Hospital	Home	Care home	Hospice	Other places
Number of deaths	1,209	645	555	82	78
Percentage of deaths	47.1	25.1	21.6	3.2	3.0
2020 (provisional)					
Measure	Hospital	Home	Care home	Hospice	Other places
Number of deaths	1,376	864	714	68	78
Percentage of deaths	44.4	27.9	23.0	2.2	2.5
Comparison with 2019	Lower	Higher	Similar	Lower	Similar
2021 (provisional, incomple	te)				
Measure	Hospital	Home	Care home	Hospice	Other places
Number of deaths	728	413	223	33	49
Percentage of deaths	50.3	28.6	15.4	2.3	3.4
Comparison with 2019	Higher	Higher	Lower	Similar	Similar

This slide is a screenshot of the table as it appears in the factsheet and shows the data for all ages. The top rows are presenting the 2019 data, the middle rows are for 2020 and the bottom rows are for 2021.

For each year, the table presents the years total number and percentage of death for each place of death.



The last figure is a collection of 5 figures, one for each place of death and produced with 2020 data only.

Each y axis presents the age groups, starting with under 40 and ending with 100 and over. The x axis presents the percentage of death for males and females separately; where the males are shown on the left side with the dark blue columns and the females are shown on the right side with the light blue columns. The height of the horizontal columns represents the percentage of deaths for each age group by sex.

This figures also includes a line graph that represents the England value for each age group by sex and can be considered a reference for the individual CCG values.

Live demonstration on Fingertips

https://fingertips.phe.org.uk/profile/end-of-life

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The link leads to the main landing page of the Fingertips website, where you can find a link to the Palliative and end of life care profiles. This opens the landing page for our data that describes what our profiles include. On the right hand side you will find the recent updates column that includes a link to the currently live factsheet. Following this link will take you directly to the factsheet. To navigate to the factsheets yourself, follow the link to the data, and you will arrive in the Fingertips data view. You can see 3 menus at the top: Data view, Geography and Topic. Each of which can be opened with the 3 dots icon. We have a broad collection of indicators for different geographies and different topics, so it is important to select the correct geography for the data you wish to see. For the place of death factsheet, we need to change the data view to "reports". Currently we produce the factsheets for the most recent CCG level, which currently is the CCG configuration since April 2021. You can select this under the area type, which will then default to the first factsheet in alphabetical order. If you want to view a different CCG, you can select this in the geography panel under area. This will open a drop down menu for all CCGs available. Clicking on them will bring you to their factsheet.

In order to open the actual factsheet you can click on the blue link with the CCG name and it will open the factsheet in another tab.

Scroll through the factsheet to quickly access sections and visualisations. We have the general introduction, the tailored summary of data with the visualisations and the table. The table can be opened for each age group, by clicking on the age groups at the top. The factsheet ends with our methodology and resources section, the latter which includes a few hopefully useful links to other PHE tools.

Questions

Please post any questions via:

- Chat in Microsoft Teams
- Email NEOLCIN@PHE.GOV.UK

Public Health England – National End of Life Care Intelligence Network (NEoLCIN)

Contact us: neolcin@phe.gov.uk

https://www.gov.uk/government/collections/palliative-and-end-of-life-care

https://fingertips.phe.org.uk/profile/end-of-life

1. When does the provisional data (e.g. for 2020) become confirmed data?

The 2020 provisional data was published as confirmed data on 5th October 2021. We anticipate that 2021 data will become confirmed data in October 2022.

2. Is the underlying data available to anyone via ONS? Is there significant processing between the data received from ONS and this fact sheet, or is it primarily collation/presentation? (This is answered in the methodology so do not worry if it is not answered during this)

The methodology section in the factsheet provides a high-level summary of the data and methods used to produce this factsheet. Please find a reprint of this section below.

Methodology

- this factsheet includes statistics for deaths registered in 2019 and 2020 and provisional data for deaths registered in 2021
- the latest data includes deaths registered in July 2021
- the date reported for each death is determined by the date of registration. There can be a delay
 between the date a death occurred and the date a death was registered. This is explained by the Office
 of National Statistics in Impact of registration delays on mortality statistics
- for further information on the methods used for all place of death indicators as classified by Office for National Statistics (ONS) death certificate data, please see PHE's National End of Life Care Intelligence Network publication: Classification of Place of Death: A technical bulletin

- in Table 1 the comparison between data for different years is calculated using either a Chi-squared test or a Fisher's exact test with the value labelled higher or lower when the test reports a *P* value less than 0.05. The Chi-squared test is used except when any of the expected numbers of deaths for the measures are less than 5, in which case a Fisher's exact test is preferred
- the PHE held Mortality & Births Information System (MBIS) data used for 2021 was deduplicated using MBISID as a unique person identifier
- individual deaths are assigned to a CCG according to the deceased's place of residence
- the reported CCG is not necessarily the CCG where a death occurred, particularly where the place of occurrence is not "home" i.e. hospital, care home, hospice, or other places

3. For CCGs where there are 'no reports available' are these in progress?

Two CCGs were excluded from the September 2021 publication release because of initial concern about data disclosure of small area statistics. However, after consultation and agreement from ONS these can now be released, and they were published on October 5 2021.

4. Is this all deaths or only patients on palliative care registers in primary care? If it is all deaths, are there any plans to source / link it to the palliative care registers from Practice systems?

The factsheet reports on all deaths. Please see the answer to Q2 above where the methodology section for the factsheet is also provided.

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5. When will data be available by ICS? I think it's not yet available? I appreciate that the boundaries have only recently been decided by Government!

We do not have an exact publication date for ICS geographies, but we plan to publish these when they are made available to us.

6. Can we select multiple CCGs? Aggregated CCG data would give us ICS info

You can currently select multiple CCGs using the geography tab on the Fingertips tool. You cannot use the tool to produce aggregate statistics.

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7. Do you have a visual representation of dementia deaths in individual CCG's

We do not currently provide data about dementia , however, our colleagues in OHID produce two dementia specific factsheets:

 $\frac{\text{https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia/data\#page/13/gid/1938133052/pat/15/par/E92000001/ati/166/are/E38000004/iid/91/age/27/sex/4/cat/-1/ctp/-1/cid/4/tbm/1$

 $\underline{https://www.gov.uk/government/statistics/dementia-profile-updates/statistical-commentary-dementia-profile-march-2021-update}$

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8. What does 'other places' mean in the categories of place of death?

Other places include all places not classified as 'own residence', 'hospital', 'care home' or 'hospice' and includes psychiatric hospitals, schools, convents and monasteries, university and college halls of residence, young offender institutions, secure training centres, detention centres, prisons, and remand homes. It also includes places such as someone else's home, a workplace, public place, or not in a building, for example on a road. This category also includes people pronounced dead on arrival at hospital.

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