



Guide to data release: trends in leading causes and place of death, England 2005 to 2014

This guide is designed to support the National End of Life Intelligence Network (NEoLCIN) interactive excel based tool '[Trends in leading causes and place of death, England 2005 to 2014](#)'.

This excel based tool provides stakeholders with some of the greater detail they have requested about cause of death trends and place of death¹. It will enable people to look at variation in leading causes of death across Strategic Clinical Networks (SCNs). Providers and commissioners of end of life care services in a range of organisations such as clinical commissioning groups (CCGs), social care and public health can use this excel based tool to inform planning, development and reconfiguration of services. This will support service planning for health and social care professionals in England and across SCNs. The reporting format is intended to facilitate working between charitable, voluntary, patient/carer-led and professional networks and across organisational boundaries.

Data is presented by age, sex and leading cause of death group, as absolute numbers and proportions from 2005 to 2014. Four worksheets are provided:

1. **Trend Chart**; an interactive worksheet allows the user to compare the national average proportion of deaths in hospital by SCN, age group and leading cause of death.
2. **SCN Snapshot Report 2014**; a snapshot of the latest available annual data, with numbers and proportions of deaths, including by place of death.
3. **SCN Trends in numbers of deaths (last ten years)**; 2005 to 2014.
4. **SCN Trends in percentage of hospital deaths (last ten years)**; 2005 to 2014.

This tool is presented as a macro-enabled excel file (*.xlsm), which you can download to your own computer. Once the file opens, you may need to select 'Enable content' when prompted. Guidance on how to navigate the tool is available on the first page of the spreadsheet. The tool allows you to select your area and then generate a range of data tables and charts. These can be copied and pasted into your own documentation (please reference 'National End of Life Care Intelligence Network (NEoLCIN), Public Health England').

Leading cause of death

Causes of death were defined using the International Classification of Diseases (ICD), Tenth Revision (ICD-10). Office for National Statistics (ONS) leading cause of death groups, on which NEoLCIN groups are based, are defined on a list developed by the WHO, modified for use in England and Wales. There have been incremental changes and developments in the way that leading causes of death are defined^{2 3 4 5}.

NEoLCIN leading cause of death groups are based on the leading cause of death groups used by ONS in their February 2015 publication⁴, but these have been further developed to allow application over the time trend 2005 to 2014 by taking account of changes in:

- annual reclassifications of ICD ten classifications of disease by the WHO between 2005 and 2014
- UK local codes for 'Homicide and probable homicide', and 'Suicide and injury/poisoning of undetermined intent' in 2006

The NEoLCIN leading cause of death group applied to the data release was determined by the underlying cause of death code and year of death registration as shown in the supporting excel based tool and **Table 1** (page 4).

Place of death

Definitions for each of the five categories of place of death are provided below:

Place of death	Definition
Hospital	Includes: NHS or non-NHS Hospitals Acute, or community hospitals Not psychiatric hospital/units.
Home	Usual place of residence where this is not a communal establishment. Some deaths at home may have involved an element of hospice outreach care. ONS mortality data does not identify these.
Care home	Communal establishments which may be: <ul style="list-style-type: none"> • local authority residential homes • private residential homes • NHS nursing homes • private nursing homes <p>Some deaths in care homes may have involved an element of hospice outreach care. ONS mortality data does not identify these.</p> <p>Some people who die in care homes are temporary residents. They may have been admitted to the care home in which they died from a variety of other locations. The proportion of these temporary care home residents varies according to factors such as cause of death, comorbidities, access to carers and support, social care and other funding streams and local commissioning arrangements. This report does not show how outcomes vary according to temporary/permanent care home residence.</p>
Hospice	Free standing hospices. Many hospices are 'free standing' but some are found within NHS hospitals. At present ONS classifies the place of death as hospice only when the event occurred in a free standing hospice premises. This data will therefore under-report deaths in hospice as some will be recorded as deaths in hospital. Hospice care is also not indicated where this has been delivered as outreach in other locations such as care homes and other residences.
Other places	Includes: <ul style="list-style-type: none"> • other communal establishments • private addresses other than the usual place of residence • outdoor locations • psychiatric hospitals

Note: for more information on categorising place of death see, 'Classification of place of death: A technical bulletin' from the [National End of Life Care Intelligence Network](#) ⁶ .

Table 1: relationship between ONS leading cause of death classification (2013 data) and NEoLCIN classification for 2004 to 2006 and 2007 to 2014

Displayed cause label	ICD10 code group label			Underlying cause of death
	2004 to 2006 (NEoLCIN)	2007 to 2014 (NEoLCIN)	2013 (Visual ONS)	
Accidental drowning/submersion	W65-W74	W65-W74	W65-W74	Accidental drowning and submersion
Accidental falls	W00-W19	W00-W19	W00-W19	Accidental falls
Accidental poisoning	X40-X49	X40-X49	X40-X49	Accidental poisoning
Accidental threats to breathing	W75-W84	W75-W84	W75-W84	Accidental threats to breathing
Acute respiratory diseases (excluding flu/pneumonia)	J00-J06,J20-J22	J00-J06,J20-J22	J00-J06,J20-J22	Acute respiratory diseases other than influenza and pneumonia
Aortic aneurysm/dissection	I71	I71	I71	Aortic aneurysm and dissection
Benign tumour (in situ and uncertain behaviour)	D00-D48	D00-D48	D00-D48	Benign neoplasms, in situ and uncertain behaviour
Bladder cancer	C67	C67	C67	Malignant neoplasm of bladder
Bone cancer	C40-C41	C40-C41	C40-C41	Malignant neoplasms of bone and articular cartilage
Bowel cancer	C18-C21	C18-C21	C18-C21	Malignant neoplasm of colon, sigmoid, rectum and anus
Brain cancer	C71	C71	C71	Malignant neoplasm of brain
Breast cancer	C50	C50	C50	Malignant neoplasms of breast
Cardiac arrhythmias	I47-I49	I47-I49	I47-I49	Cardiac arrhythmias
Cardiomyopathy	I42	I42	I42	Cardiomyopathy
Cerebral palsy & other paralytic syndromes	G80-G83	G80-G83	G80-G83	Cerebral palsy and other paralytic syndromes
Cerebrovascular diseases	I60-I69	I60-I69	I60-I69	Cerebrovascular diseases
Conditions in the perinatal period	P00-P96	P00-P96	P00-P96	Certain conditions originating in the perinatal period
Congenital defects	Q00-Q99	Q00-Q99	Q00-Q99	Congenital malformations, deformations and chromosomal abnormalities
Dementia and Alzheimer's	F01,F03,G30	F01,F03,G30	F01,F03,G30	Dementia and Alzheimer's disease
Emphysema/bronchitis	J40-J47	J40-J47	J40-J47	Chronic lower respiratory diseases
Epilepsy	G40,G41	G40,G41	G40,G41	Epilepsy and status epilepticus
Flu/pneumonia	J09-J18	J09-J18	J09-J18	Influenza and pneumonia
Heart disease	I20-I25	I20-I25	I20-I25	Ischaemic heart diseases
Heart failure	I50-I51	I50-I51	I50-I51	Heart failure and complications and ill-defined heart disease
High blood pressure	I10-I15	I10-I15	I10-I15	Hypertensive diseases
Homicide	X85-Y09, incl Y33.9, excl U50.9	X85-Y09, excl Y33.9, incl U50.9	X85-Y09,Y33.9	Homicide and probable homicide
Kidney cancer	C64	C64	C64	Malignant neoplasm of kidney, except renal pelvis
Liver cancer	C22	C22	C22	Malignant neoplasm of liver and intrahepatic bile ducts
Liver disease	K70-K77	K70-K77	K70-K77	Cirrhosis and other diseases of liver
Lung cancer	C33,C34	C33,C34	C33,C34	Malignant neoplasm of trachea, bronchus and lung
Lymphoid cancer	C81-C96	C81-C96	C81-C96	Malignant neoplasms of lymphoid, haematopoietic and related tissue
Meningitis	A39,A87,G00-G03	A39,A87,G00-G03	A39,A87,G00-G03	Meningitis
Mental and behavioural (psychoactive substance)	F10-F19	F10-F19	F10-F19	Mental and behavioural disorders due to psychoactive substance use
Musculoskeletal diseases	M00-M99	M00-M99	M00-M99	Diseases of the musculoskeletal system and connective tissue
Neonatal	Not applicable	Not applicable	Not applicable	Neonatal
Nonrheumatic valve disorders	I34-I38	I34-I38	I34-I38	Nonrheumatic valve disorders
Ovarian cancer	C56	C56	C56	Malignant neoplasm of ovary
Pancreatic cancer	C25	C25	C25	Malignant neoplasm of pancreas
Parkinson's disease	G20	G20	G20	Parkinson's disease
Pregnancy related conditions	O00-O99	O00-O99	O00-O99	Pregnancy, childbirth and the puerperium
Prostate cancer	C61	C61	C61	Malignant neoplasm of prostate
Pulmonary oedema	J80-J84	J80-J84	J80-J84	Pulmonary oedema and other intestinal pulmonary diseases
Septicaemia	A40-A41	A40-A41	A40-A41	Septicaemia
Skin cancer	C43,C44	C43,C44	C43,C44	Melanoma and other malignant neoplasms of skin
Suicide	X60-X84,Y10-Y34, excl. Y33.9	X60-X84, Y10-Y34,inc. Y33.9	X60-X84,Y10-Y34	Suicide and injury/poisoning of undetermined intent
Systemic atrophies (central nervous system)	G10-G13	G10-G13	G10-G13	Systemic atrophies primarily affecting the central nervous system
Throat cancer	C15	C15	C15	Malignant neoplasm of oesophagus
Transport accidents (land)	V01-V89	V01-V89	V01-V89	Land transport accidents
Urinary disease	N00-N39	N00-N39	N00-N39	Diseases of the urinary system
Womb cancer	C53-C55	C53-C55	C53-C55	Malignant neoplasm of uterus

The remainder of codes (which are not leading causes of death), were labelled 'other', except when neonatal

Note: in England and Wales, verdicts of suicides cannot be returned for children under the age of ten years. This report includes deaths from children aged ten and over. From the ages ten to 14 the cause of death would be Intentional self-harm and for those aged 15 and over it would be Intentional self-harm and event of undetermined intent.

Important changes which affect trends in mortality coding

Trends in mortality are affected by many factors, one of which is coding practice. Four key elements are known to affect the coding of mortality data between 2005 and 2014. There have been at least two major specific changes in coding practice in England (in 2010 and 2014)^{7, 8, 9}. In addition, death certification reforms since 2008 have brought about some procedural changes, which are known to affect the detail and quality of death certification data in some areas of England^{10, 11, 12}. Delays in death registration also have an impact on annual mortality data¹³. Each of these factors is described in more detail below, and it is very important to take them into account when considering how the data changes over time.

1. Changes to coding in 2010: new ICD-10 software

Since January 2001, cause of death in England has been coded using the WHO Tenth Revision of the International Classification of Diseases (ICD-10). Between January 2001 and December 2010, the Mortality Medical Data System (MMDS) ICD-10 version 2001.2 software provided by the United States National Centre for Health Statistics (NCHS) was used to code cause of death. In January 2011, this was updated to version 2010, which incorporated most of the WHO amendments authorised up to 2009.

ONS identified the following key findings⁷:

- there has been a 32% increase in the number of deaths with an underlying cause coded to 'Mental and Behavioural Disorders'; large proportion of this increase is caused by a correction to the coding of vascular dementia which was assigned the underlying cause cerebrovascular disease (I67.9) in ICD-10 v2001.2, but is corrected to vascular dementia (F01) in ICD-10 v2010
- the number of deaths with an underlying cause coded to 'Diseases of the Circulatory System' has decreased by 5% – this decrease is caused by selection rule changes to cardiomyopathy (I42), heart failure (I50) and cerebrovascular diseases (I60–I69)
- the number of deaths assigned to 'Diseases of the Genitourinary System' has decreased by 21% – this decrease is mainly caused by a change to the modification tables allowing a death certificate recording urinary tract infection (N39.0) and dementia (F01 and F03) to assign dementia as the underlying cause
- 'Diseases of the Respiratory System' have shown an increase of 2% – within this group, deaths coded with an underlying cause of pneumonia (J18) increased by 8% due to selection rule changes spread across the other groups

2. Changes to coding in 2014: New IRIS software

On 1 January 2014, ONS changed the software used to code cause of death to a package called IRIS (version 2013). The development of IRIS was supported by Eurostat, the statistical office of the European Union, and is now managed by the IRIS Institute hosted by the German Institute of Medical Documentation and Information in Cologne. IRIS software version 2013 incorporates all official updates to ICD-10 approved by WHO, which were timetabled for implementation before 2014.

ONS published guidance on the impact of these changes^{8, 9} with the following key findings

- dual coding of 38,718 deaths registered in 2012 in England and Wales showed statistically significant percentage increases in the deaths allocated to an underlying cause in seven ICD-10 chapters, and significant decreases for five chapters when coded in ICD-10 v2013 (IRIS), however, 95 % of deaths remained in the same chapter
- a change in the coding of chest infections contributed to a reduction of 2.5% in deaths allocated an underlying cause of respiratory disease and an increase of 7.0% in those allocated to the mental and behavioural disorders chapter, which includes dementia
- deaths given an underlying cause of dementia were also increased by a rule change to count aspiration pneumonia as being a consequence of one of a number of other conditions – the total percentage change in deaths attributed to an underlying cause of dementia was 7.1%
- deaths allocated to certain infectious and parasitic diseases as an underlying cause increased by 4.9% following the transfer of deaths involving sepsis/septicaemia from other chapters
- a rule change to count diabetes as the underlying cause of certain types of renal disease led to an increase of 5.7% in the chapter on endocrine, nutritional and metabolic diseases – deaths with an underlying cause of diabetes rose by 6.8%

In addition, particular attention was paid to the impact on dementia and heart disease:

- some of the rise in dementia since 2001 is due to an update to the coding framework used for cause of death and a better understanding of dementia; a consequence of the latter is likely to be increased reporting of dementia on death certificates
- the number of deaths attributable to heart disease and dementia (two leading causes of death) differs significantly for men and women – for every 100 women who died of heart diseases, 150 men died, but, for every 100 women dying from dementia and Alzheimer disease, 50 men died
- studies suggest biological and behavioural reasons for the higher number of male deaths from heart diseases, such as a higher percentage of men who smoke and drink – in addition, men are less likely than women to visit the doctor, leading to later diagnosis and treatment; studies have also linked oestrogen in pre-menopausal women to the lower incidence of heart disease in women
- the likelihood of developing dementia and Alzheimer's disease increases with age – as female life expectancy is greater than male life expectancy, women are more likely to survive to older ages, where they are at increased risk of developing dementia and Alzheimer disease; scientists have shown, however, that even when correcting for age, women are at greater risk from dementia and Alzheimer disease – it is not yet clear why

3. Potential impact of changes due to death certification reforms.

Harold Shipman (GP) certified the deaths of 250 victims without challenge. An inquiry¹⁰ into Shipman's crimes in 2004 recommended that:

- all deaths that do not require investigation by a coroner will undergo the independent scrutiny of a locally appointed Medical Examiner
- independent and proportionate scrutiny of relevant health records, examining the deceased person's body (in most cases) and in all cases discussing the death with a relative or other appropriate person

Death certification reform pilots commenced in 2008. ONS carried out a case study investigating records from five of the six pilot areas. This analysed the cause(s) of death proposed initially by the certifying medical practitioner and also the confirmed cause(s) of death following medical examiner scrutiny of the deceased's medical history and hospital notes. Key findings were that:

- medical examiners were more likely to add supplementary information to the death certificate

- this often led to more conditions being mentioned and to the order in which they were presented on the cause of death certificate being altered
- as a result there was a change to the underlying cause of death in 22% of cases

Impacts on cause of death were:

- 1% more death certificates with an underlying cause of cancer
- 6% increase in the proportion of deaths that were attributed to diseases of the circulatory system
- 7% decrease in deaths attributed to a respiratory disease
- in general, more conditions were mentioned on the death certificate as a result of scrutiny by medical examiners

There have been delays in the subsequent reform timetable¹¹. An open consultation regarding death certification reforms closed on 15 June 2016¹².

4. Registration delays

Some death registrations may be delayed for a variety of reasons. ONS published a document discussing the potential impact of registration delays in 2011¹³ and found that the vast majority of deaths are registered within the required five day registration period, with 94% being registered within one month of death. Consequently, statistics based on death registrations should provide an accurate reflection of all death occurrences. This is true for statistics aggregating all deaths and statistics based on specific causes of death which are not influenced by registration delays.

Interpreting statistics from specific causes of death which typically show long registration delays should be interpreted more carefully. In particular, data on deaths from external causes are more likely to reflect a proportion of delayed as well as recent occurrences of deaths. Therefore, analysing trends in deaths where there are few registration delays, such as most types of cancers, will provide an accurate reflection of occurrences. In contrast, analysing trends in external causes of death can reflect the confounding influence of delayed registrations. Data will reflect instances of death registration delays which occurred some time ago, and not include deaths which have occurred and are currently unregistered.

References/bibliography:

¹ Developing data and intelligence for end of life care – Outcomes from workshops held with Strategic Clinical Networks and the National End of Life Care Intelligence Network (October 2015).

www.endoflifecare-intelligence.org.uk/resources/publications/scnstakeholder

Definition of leading causes of death:

² Leading causes of death in England and Wales – How should we group causes? (Claire Griffiths, Cleo Rooney, Anita Brock; Health Statistics Quarterly 28, Winter 2005)

www.ons.gov.uk/ons/rel/hsq/health-statistics-quarterly/no--28--winter-2005/index.html

³ Leading Causes of Death infographic (Part of ONS Deaths Registered in England and Wales (Series DR), 2012) Release December 2013)

www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--series-dr-/2012/info-causes-of-death.html

⁴ What are the top causes of death by age and gender? (Part of ONS Deaths Registered in England and Wales (Series DR), 2013 Release (Beta), February 2015)

<http://visual.ons.gov.uk/what-are-the-top-causes-of-death-by-age-and-gender/>

⁵ What do we die from? (Part of Mortality Statistics: Deaths Registered in England and Wales (Series DR), 2014 Release, December 2015)

www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--series-dr-/2014/sty-what-do-we-die-from.html

Definition of leading causes of death:

⁶ Classification of place of death: A technical bulletin, NEoLCIN, June 2013

www.endoflifecare-intelligence.org.uk/resources/publications/classification_of_place_of_death

⁷ Statistical bulletin: results of the ICD-10 v2010 bridge coding study, England and Wales, 2009.

www.ons.gov.uk/ons/rel/subnational-health3/results-of-the-icd-10-v2010-bridge-coding-study--england-and-wales--2009/2009/index.html

Implementation of new IRIS software (2014)

⁸ Statistical bulletin: impact of the Implementation of IRIS Software for ICD-10 Cause of Death Coding on Mortality Statistics, England and Wales:

www.ons.gov.uk/ons/rel/subnational-health3/impact-of-the-implementation-of-iris-software-for-icd-10-cause-of-death-coding-on-mortality-statistics/england-and-wales/index.html

⁹ ONS Guidance and methodology: changes to cause-of-death coding in England and Wales in 2014

www.ons.gov.uk/ons/guide-method/user-guidance/health-and-life-events/Changes-to-cause-of-death-coding-in-England-and-Wales/index.html

Death certification reforms since 2008

¹⁰ The Shipman Inquiry

<http://webarchive.nationalarchives.gov.uk/20090808154959/http://www.the-shipman-inquiry.org.uk/reports.asp>

¹¹ Reported potential impact of delays in death certification reforms
www.bbc.co.uk/news/uk-30909270

¹² Open consultation: death certification reforms (closing 15 June 2016 11:45pm)
www.gov.uk/government/consultations/death-certification-reforms

Registration delays

¹³ Impact of registration delays on mortality statistics, 2011
www.ons.gov.uk/ons/guide-method/user-guidance/health-and-life-events/impact-of-registration-delays-on-mortality-statistics/index.html

Other resources from PHE NEoLCIN

- a) End of Life Care Profiles
<http://fingertips.phe.org.uk/profile/end-of-life>
- b) PHE's National End of life Intelligence Network Website
www.endoflifecare-intelligence.org.uk/home
- c) End of life care ambitions
<http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/A-Presentation-of-the-Ambitions-for-Palliative-and-End-of-Life-Care1.pdf>

External resources

- d) World Health Organisation - International Classification of Diseases (ICD) webpages
www.who.int/classifications/icd/en/

First published: June 2016

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