



National end of life care
INTELLIGENCE NETWORK



National End of Life
Care Programme
Improving end of life care



Predicting Death

Estimating the proportion of deaths that
are 'unexpected'



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1. Background

A key workstream within the National End of Life Care Strategyⁱ is the identification by health professionals of individuals who are in the last year of life so that they can be offered Advanced Care Planning. End of Life Care Registers are being developed to support this by holding information on these patients. This information will be readily available to health and social care professionals who may be involved in planned or emergency care for these individuals. There is conflicting information on the proportion of the population for whom this may be possible.

There is also a desire to understand the extent to which death is predictable in order to plan care and to estimate costs specifically of end of life care.

This paper summarises data from a number of sources to try to estimate the proportion of registered deaths which may be unexpected and therefore unlikely to be included on an End of Life Care Register.

In some cases an unexpected death has been defined as “any death not due to terminal illness; or a death the family was not expecting”ⁱⁱ. However, patients with chronic or terminal diseases also die unexpectedly and this definition as will be seen in this report may be too stringent.

2. Data sources

It should be noted that the Ministry of Justice report provides data for England and Wales; and the ONS mortality data has been extracted for England.

2.1 Ministry of Justice Coronial Service Statistics

Ministry of Justice Coronial Service Statistics have been examinedⁱⁱⁱ for the purpose of this report as in England and Wales if any of the following criteria defining an unexpected death are met the case is referred by the clinician to the coronerⁱⁱ.

Criteria for an unexpected death include:

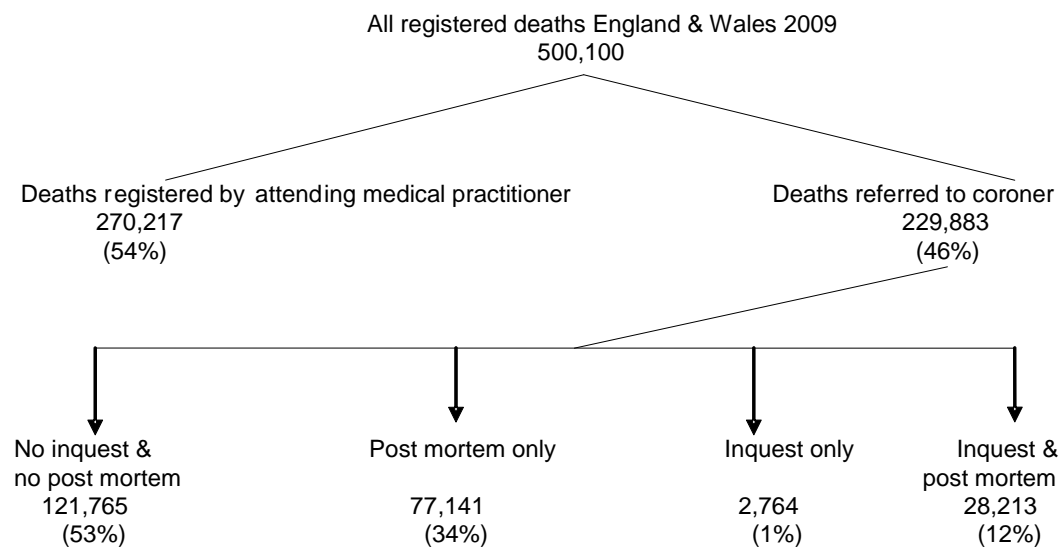
- documented evidence is not available to show that a visiting medical practitioner has stated death is predictable or expected as a result of a prolonged illness or long term condition;
- death is the result of an accident/untoward incident;
- death is from a suspected industrial disease*;
- suicide is suspected;
- overdose (including accidental) is suspected;
- death is related to surgery/anaesthetic;
- cause of death is unknown;
- concern exists regarding clinician/carer neglect/competence;
- death is within 24 hours of admission to hospitalⁱⁱ;
- there are unusual/disturbing features surrounding the death;
- a medical practitioner had not visited the patient in the 14 days preceding death^{ii, iv}

* Despite industrial disease being included in the criteria for referral to the coronial service these deaths should not be included when quantifying unexpected deaths as they are likely to be anticipated deaths (of the verdicts returned from the coronial service for England and Wales 2009, 9% were classified as deaths from suspected industrial disease).

When cases are referred to the coronial service the following actions are taken: 1) a discussion takes place between the Coroner and referring clinician when it is felt that neither a post mortem nor an inquest are required; 2) a post mortem occurs; 3) an inquest occurs; or 4) both a post mortem and an inquest occursⁱⁱⁱ.

Figure 1 shows the processing by the coronial service of all registered deaths in 2009, using Ministry of Justice statisticsⁱⁱⁱ.

Figure 1: Flow chart showing processing of all deaths in England and Wales, 2009



Source: Ministry of Justice Statistics bulletinⁱⁱⁱ

Using the data in Figure 1 it can be stated that 46% (229,883 / 500,100) of all registered deaths from 2009 were referred to the coroner. Using the definitions above, it could be suggested that this proportion of all registered deaths in 2009 were unexpected. However, sometimes deaths are referred to the coroner simply because the doctor who knows and has seen the patient in the last 14 days prior to death is not available to sign the death certificate.

Analysing the data in Figure 1 further, it could be assumed, however, that referrals to the coronial service where no inquest and no post mortem were required were in fact not unexpected deaths because a death certificate could be issued following a discussion between the clinician and coroner only, in which case 22% (229,883-121,765/500,100) of all registered deaths in 2009 could be classified as unexpected.

It should be noted that the Ministry of Justice statistics do not identify process taken by the coronial service (for example post-mortem) by final verdict. It is therefore not possible to identify those deaths from suspected industrial disease in Figure 1.

It should be noted that the percentage of all registered deaths referred to the coroner have, until the last few years, been increasing, furthermore that this increase could be due to more cautious practices being implemented as a result of the Harold Shipman case; and also increased use of GP deputising services. The increase in deaths reported to coroners is reported as approximately 180,000 per annum in 1990 to 229,900 per annum in 2009ⁱⁱⁱ.

2.2 Office for National Statistics (ONS) mortality data

ONS mortality data has been extracted for this report in order to ascertain the proportion of all registered deaths in England which were unexpected by assessing cause of death on the death certificate.

The underlying cause of death is defined by the World Health Organisation as ‘the disease or injury that initiated the train of events directly linked to death; or the circumstances of the accident or violence that produced the fatal injury’ and is the cause of death data recorded on a death certificate.

In order to identify unexpected deaths using this dataset, certain underlying causes of death on death certificates can be assumed to cause an unexpected death. The underlying causes of death extracted for this purpose are shown in Table 1 below.

Table 1: Causes of death deemed to be the cause of unexpected death

Description	ICD-10 Codes
Acute myocardial infarction	I21*, I22*
Pulmonary embolism	I26*
Pulmonary aneurysm	I281
Sudden cardiac death	I461
Cerebrovascular disease	I60-I69
Aortic aneurysm	I71*
Acute Respiratory disease <i>includes influenza, pneumonia</i>	J10-J29, J85-J86, J91-J96
Injury, poisoning, other consequences of external causes	S00-T98
External causes	V01-Y98

The data extracted is shown in tables 2 and 3. Table 2 shows an average of 472,270 deaths were registered in England each year between 2006 and 2008 of which unexpected deaths accounted for 116,717 (i.e. a quarter of all deaths). Table 3 shows this unexpected deaths value represented as a percentage (24.7%).

Table 2: Average annual number of deaths in England (deaths registered 2006-2008) and deaths where underlying cause is unexpected as defined in this report

	All deaths	Acute Myocardial infarction	Pulmonary embolism	Pulmonary aneurysm	Aortic aneurysm	Sudden cardiac death	Cerebro-vascular disease	Acute respiratory disease	Injury, poisoning and other external causes	Any unexpected cause
All Deaths	472,270	29,053	2,882	2	7,172	40	44,055	29,068	4,445	116,717
Sex										
Male	225,564	16,479	1,132	1	4,306	27	16,943	11,717	3,194	53,798
Female	246,706	12,574	1,750	1	2,867	13	27,112	17,351	1,251	62,919
Age										
0-64	81,775	4,331	444	1	572	37	3,025	1,770	3,432	13,613
65-84	226,366	15,756	1,485	0	4,517	3	19,780	10,300	769	52,610
85+	164,129	8,965	953	1	2,083	0	21,250	16,998	244	50,494
Deprivation										
Most Deprived	100,691	6,675	615	0	1,361	7	8,262	5,979	1,104	24,003
2	98,289	6,118	594	1	1,497	10	8,857	6,157	963	24,196
3	97,890	5,984	620	0	1,523	9	9,297	6,066	874	24,373
4	94,133	5,567	575	0	1,497	8	9,374	5,850	806	23,679
Least Deprived	81,267	4,709	478	1	1,294	6	8,265	5,016	697	20,467

Table 3: Average annual number of deaths as percentage of category total, England (deaths registered 2006-2008) and deaths where underlying cause is unexpected as defined in this report

	All deaths	Acute Myocardial infarction	Pulmonary embolism	Pulmonary aneurysm	Aortic aneurysm	Sudden cardiac death	Cerebro-vascular disease	Acute respiratory disease	Injury, poisoning and other external causes	Any unexpected cause
All Deaths	100	6.2	0.6	0	1.5	0	9.3	6.2	0.9	24.7
Sex										
Male	100	7.3	0.5	0	1.9	0	7.5	5.2	1.4	23.9
Female	100	5.1	0.7	0	1.2	0	11	7	0.5	25.5
Age										
0-64	100	5.3	0.5	0	0.7	0	3.7	2.2	4.2	16.6
65-84	100	7	0.7	0	2	0	8.7	4.6	0.3	23.2
85+	100	5.5	0.6	0	1.3	0	12.9	10.4	0.1	30.8
Deprivation										
Most Deprived	100	6.6	0.6	0	1.4	0	8.2	5.9	1.1	23.8
2	100	6.2	0.6	0	1.5	0	9	6.3	1	24.6
3	100	6.1	0.6	0	1.6	0	9.5	6.2	0.9	24.9
4	100	5.9	0.6	0	1.6	0	10	6.2	0.9	25.2
Least Deprived	100	5.8	0.6	0	1.6	0	10.2	6.2	0.9	25.2

It is interesting to note that the proportion of deaths from unexpected causes increases with age from 16.6% in patients under the age of 65 to 30.8% in adults aged 85 or over.

2.3 National Audit Office

Data from a National Audit Office document focusing on place of death for end of life care in Sheffield^v has also been sourced for the purpose of this report. The National Audit Office document summarises results from a retrospective study of 348 deaths surveyed out of a total of 420 registered deaths (73% coverage) in Sheffield PCT during one month (October 2007). The figure quoted in the report for the proportion of unexpected deaths is 8%.

2.4 Omega report

'Omega' the National Association for End of Life Care have produced a report on 'End of Life care in primary care'^{vi} and this is further data sourced for the purpose of this report. The Omega report 'End of Life care in primary care' summarises the results of an online After Death Analysis tool to provide information on all deaths of the registered practice populations of 502 general practices from February 2009 – March 2009 (a total of 4487 people). The results of this study states that of the 4,487 deaths assessed, 42% could be defined as sudden or unexpected.

3. Limitations of data sources

The focus of the National Audit office report with Sheffield PCT^v is on place of death and therefore detailed data supporting statements on unexpected deaths in the report are not presented. It also appears that there is conflicting data presented on the number of unexpected deaths in the population – one figure (2.3) states 8% of the deaths surveyed (28 out of 348 deaths) were unexpected; yet another figure (5.1) presents numbers of deaths which were 'not expected' as being approximately 32% (this is approximated as numbers are given in graphical format). We therefore assume in this report that the conclusion of 8% is an under-estimate of the proportion of registered deaths in England and Wales that could be defined as unpredictable.

The Omega report identifies 42% of deaths as being 'sudden' or 'unpredictable' which is higher than the results of the Ministry of Justice statistics and ONS mortality data findings.

This is based on the clinical opinion of general practitioners who have access to case notes and will include patients with chronic disease who deteriorated suddenly and other diagnoses which we have not included in our selection of 'unexpected' causes of death.

4. Conclusions

Based on the data and limitations outlined above, this report concludes that at least 25% of all deaths in England and Wales are unexpected deaths from sudden causes. Of course, many patients with chronic disease may also die unexpectedly and this would increase the proportion of 'unexpected' deaths and would account for some of the discrepancy with the 42% of deaths described as 'sudden' or 'unpredictable' in the Omega report.

This statement is supported by recent research on end-of-life care in hospital^{vii} which has shown a range of only 20% to 33% of patients who died in hospital could have been looked after at home. Patient choice must also be considered if policy is to be set regarding place of death.

References

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- iii Ministry of Justice (2010) *Statistics Bulletin: Statistics on deaths reported to coroners England and Wales, 2009*
- iv NHS Kirklees (2008) *Policy and Procedure for the Verification of an Expected Death by Registered Nurses*
- v Sheffield Primary Care Trust and the National Audit Office (2008) *Identifying alternatives to hospital for people at the end of life: report of findings*
- vi Omega (2009) *End of life care in primary care 2009 national snapshot*
- vii Abel J, Rich A, Griffin T, Purdy S (2009) „End-of-life care in hospital: a descriptive study of all inpatient deaths in 1 year“ *Palliative Medicine* 00:1-7

About the South West Public Health Observatory

The South West Public Health Observatory (SWPHO) is part of a network of regional public health observatories in the UK and Ireland. These were established in 2000 as outlined in the Government White Paper *Saving lives: our healthier nation*. Key tasks include: monitoring health and disease trends; identifying gaps in health information; advising on methods for health and health impact assessment; drawing together information from different sources; and carrying out projects on particular health issues.

The SWPHO incorporates the National Drug Treatment Monitoring System South West (NDTMS-SW), and in April 2005 merged with the South West Cancer Intelligence Service (SWCIS). The SWPHO works in partnership with a wide range of agencies, networks and organisations regionally and nationally to provide 'a seamless public health intelligence service' for the South West.

For more information about the SWPHO and its partners, please visit www.swpho.nhs.uk.



SWPHO is part of the UK & Ireland Association of Public Health Observatories.

About the National End of Life Care Intelligence Network

The Department of Health's National End of Life Care Strategy, published in 2008, pledged to commission a National End of Life Care Intelligence Network (NEoLCIN). The Network was launched in May 2010. It is tasked with collating existing data and information on end of life care for adults in England. This is with the aim of helping the NHS and its partners commission and deliver high quality end of life care, in a way that makes the most efficient use of resources and responds to the wishes of dying people and their families.

Key partners include the National Cancer Intelligence Network (NCIN), which will work closely with the Network to improve end of life care intelligence; and the South West Public Health Observatory, lead public health observatory for end of life care, which hosts the NEoLCIN website. The SWPHO has been commissioned to produce key outputs and analyses for the Network, including the national End of Life Care Profiles.

See www.endoflifecare-intelligence.org.uk for more information about the Network and its partners.

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