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National end of life care INTELLIGENCE NETWORK

NHS
National End of Life Care Programme
Improving end of life care

Deaths from Renal Diseases in England, 2001 to 2008

NEoLCIN Bulletin

1 Introduction

The South West Public Health Observatory (SWPHO) is currently undertaking analyses of a variety of sources of information to help inform and support the implementation of the National End of Life Care Strategy. This first phase of the analysis on end of life care for people with a renal disease uses mortality data compiled by the Office for National Statistics (ONS), based on death registrations. In this document, the analyses are based on deaths in people who were usually resident in England and who died 'from', or 'with' specified renal diseases between 1st January 2001 and 31st December 2008. Full details are listed in the 'Methods' section below.

1.1 Definitions and caveats

'Underlying cause of death' as defined by the World Health Organisation is:

i) the disease or injury that initiated the train of events directly linked to death; or

ii) the circumstances of the accident or violence that produced the fatal injury.

'Mentions' are citations on a person's death certificate of diseases or conditions where they are recorded as:

i) the underlying cause of death; or

ii) as part of the causal sequence of events leading to death; or

iii) they contribute to the death but are not part of the causal sequence.

Each of the tables and charts in this document shows the source of the information as the Office for National Statistics, which reflects the original data source. All analyses, tables and charts have been produced by the South West Public Health Observatory.

It is worth noting that, according to the 'rules' concerning the recording of deaths, people who die from a completely unrelated disease, for example, a road accident, will not have a renal disease recorded as either an underlying or mentioned cause of death. Consequently, the numbers of deaths referred to in this document are not a true measure of the numbers of people 'who die and who have' a renal disease, nor are the numbers shown a measure of either incidence (numbers of people newly diagnosed with a renal disease) or prevalence (numbers of people living with a renal disease). However, the inclusion of mentions of renal diseases gives a clear indication of the numbers of people dying where these diseases are a direct or important factor in those deaths.

2 Methods

In this report analyses are based on deaths of people who were usually resident in England and who died 'from', or 'with' various renal diseases between 1st January 2001 and 31st December 2008. Renal diseases and groups of diseases were selected using the International Statistical Classification of Diseases and Related Health Problems (ICD 10 codes) as mentioned in the death certification shown in the Table below.

Cause of death	**ICD 10 codes**
Chronic renal failure (includes end stage renal disease)	N18 (any 4th digit)
Acute renal failure	N17 (any 4th digit)
Renal carcinoma	C64 (any 4th digit)
Renal ischaemia and infarction	N28 (any 4th digit)
Hypertensive renal disease (includes hypertensive renal and heart disease)	I12 (any 4th digit) I13 (any 4th digit)

Mortality records were included where:

- one or more of the diagnosis codes listed above were mentioned in any of the causes of death fields (i.e. the underlying cause of death field or any of the 15 secondary cause of death fields); and
- the usual place of residence of the deceased was in England, identified using the Government Office Region (place of residence) codes 'A','B','D','E','F','G','H','J','K'; and
- the calendar year of death was between 2001 and 2008.

3 Results

3.1 Overview

In the years 2001 to 2008, there were 175,917 deaths for which one or more of the selected renal diseases were mentioned on death certificates. This represents approximately 5% of all deaths (3,865,264) recorded in England over the same period. Of the 175,917 people who died with a mention of one of the renal diseases, 43,884 (25%) people had one of these diseases recorded as being the **'underlying cause'**. For the remainder of people, 132,033 (75%) the disease was recorded as being either part of the causal sequence of events leading to death, or a contributing factor to the death but not part of the causal sequence – described here as **'mentions'**. 19,326 (11%) people had more than one renal disease recorded as implicated in their death. This highlights how important it is to search the whole death certificate for mentions of renal diseases to get a clearer picture of how many people may be dying with them as they may contribute to specific needs for care at the end of their life.

3.2 Renal diseases as the underlying cause of death

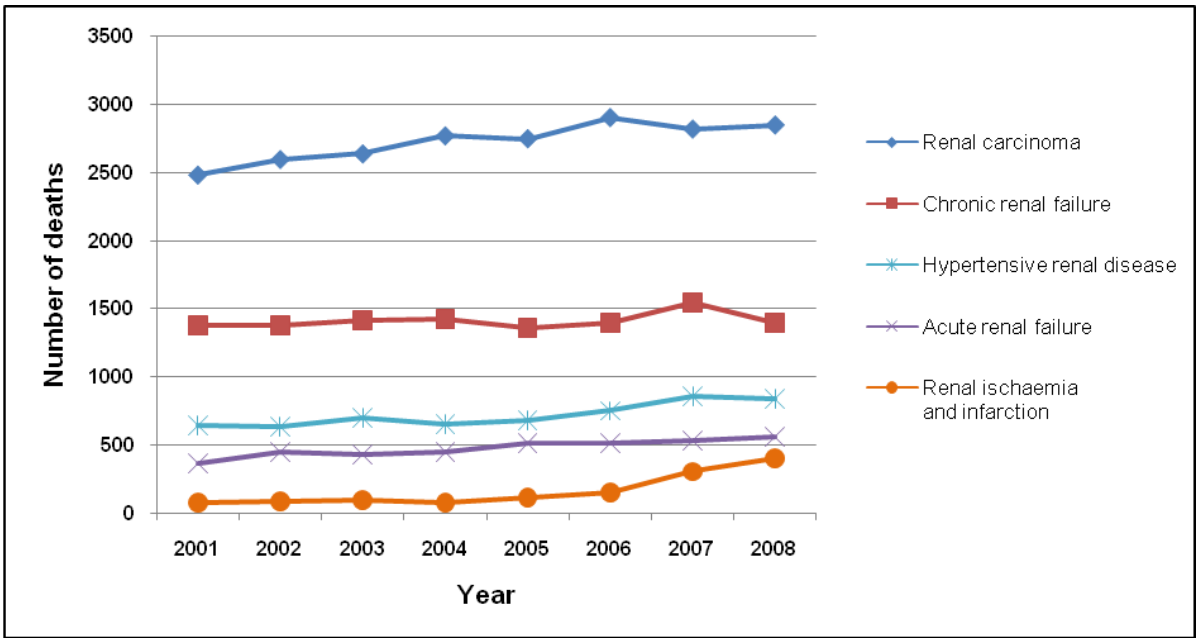
Table 1 and Figure 1 show how often a renal disease was recorded as the underlying cause of death. Of the 175,917 people who died with a mention of one or more renal diseases between 2001 and 2008, 43,884 (25%) had a renal disease coded as the underlying cause of death compared with 132,033 people who died during the period 2001 to 2008 with a renal disease mentioned as being connected to the death, but where it was not the underlying cause. There are therefore three times as many deaths where renal diseases are mentioned but not attributed as the underlying cause to those where the renal disease is the underlying cause of death. People dying with renal diseases recorded as the underlying cause of death are likely to have specific end of life care needs related to these conditions.

Table 1: Underlying causes of death from selected renal diseases, England, 2001 to 2008

	2001	2002	2003	2004	2005	2006	2007	2008	Total
Renal carcinoma	2,478	2,593	2,634	2,767	2,746	2,902	2,817	2,847	**21,784**
Chronic renal failure	1,378	1,382	1,414	1,422	1,359	1,395	1,546	1,397	**11,293**
Hypertensive renal disease	643	633	697	651	679	751	857	835	**5,746**
Acute renal failure	360	446	429	445	510	508	528	559	**3,785**
Renal ischaemia and infarction	75	82	90	73	109	148	301	398	**1,276**
Total	**4,934**	**5,136**	**5,264**	**5,358**	**5,403**	**5,704**	**6,049**	**6,036**	**43,884**

Source: Office for National Statistics, annual mortality extracts

Figure 1: Trends in underlying causes of selected renal diseases at death, England, 2001 to 2008



Source: Office for National Statistics, annual mortality extracts

3.3 Mentions of renal diseases at death

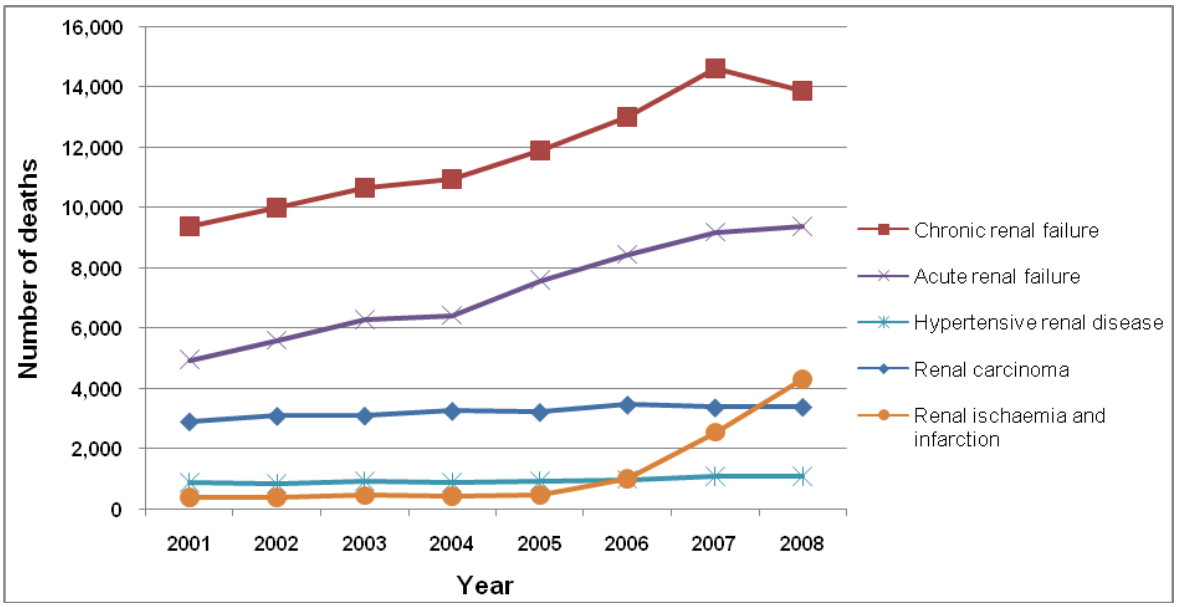
Table 2 and Figure 2 show how many times a renal disease was mentioned for the 175,917 people who died with one of these diseases between 2001 and 2008. There were 196,210 mentions of a renal disease at death for the whole period. In some instances, a person might have more than one renal disease recorded as being implicated in their death.

Table 2: Mentions of selected renal diseases at death, England, 2001 to 2008

	2001	2002	2003	2004	2005	2006	2007	2008	Total
Chronic renal failure	9,394	10,020	10,688	10,966	11,898	13,026	14,633	13,895	**94,520**
Acute renal failure	4,952	5,602	6,295	6,438	7,607	8,468	9,212	9,404	**57,978**
Renal carcinoma	2,915	3,101	3,108	3,266	3,228	3,475	3,383	3,401	**25,877**
Hypertensive renal disease	891	856	943	910	951	1,002	1,109	1,098	**7,760**
Renal ischaemia and infarction	410	391	466	433	473	1,012	2,564	4,326	**10,075**
Total	**18,562**	**19,970**	**21,500**	**22,013**	**24,157**	**26,983**	**30,901**	**32,124**	**196,210**

Source: Office for National Statistics, annual mortality extracts

Figure 2: Trends in mentions of selected renal diseases at death, England, 2001 to 2008



Source: Office for National Statistics, annual mortality extracts

- The renal disease most frequently mentioned in mortality records was chronic renal failure, accounting for almost half (48%) of all deaths in which one of the selected renal diseases was mentioned.
- The numbers of people dying with a mention of chronic renal failure and acute renal failure increased steadily from 2001 to 2007.
- The numbers of people dying with a mention of renal ischaemia and infarction remained steady between 2001 and 2005, but increased rapidly from 2006 to 2008.

Table 3 shows that the numbers of underlying cause deaths as a proportion of total death mentions varied considerably across the individual causes of death, ranging from 7% for acute renal failure up to 84% for renal carcinoma.

Table 3: The proportion of deaths which mention a renal disease and record it as the underlying cause, England 2001 to 2008

	%
Renal carcinoma	84
Hypertensive renal disease	74
Chronic renal failure	12
Renal ischaemia and infarction	13
Acute renal failure	7

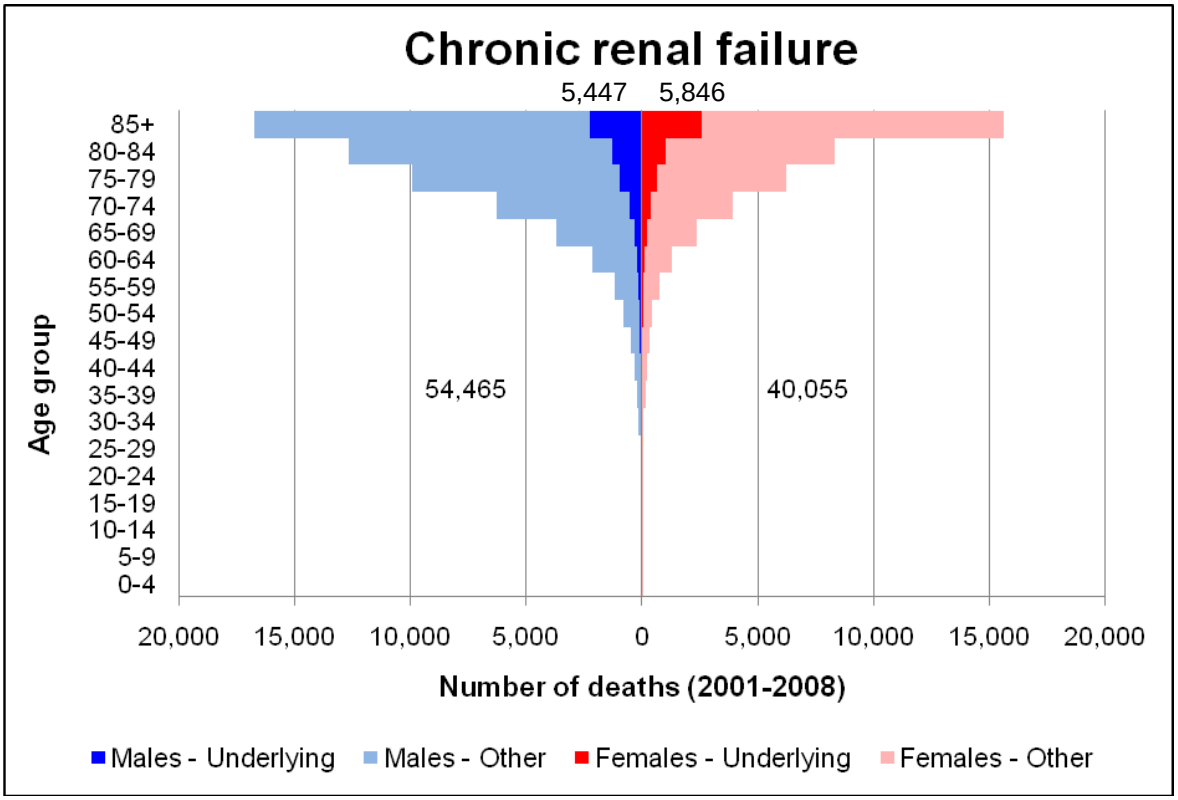
Source: Office for National Statistics, annual mortality extracts

3.4 Age and sex distributions of underlying cause and mentions of renal diseases

Figures 3 to 7 show the age-sex distributions of underlying cause and mentions of renal diseases. Total numbers for males and females are also shown. Detailed tabulations by age and sex are presented in Appendix 1.

3.4.1 Chronic renal failure underlying cause and mentions by age and sex

Figure 3: Age and sex distribution of people who died with chronic renal failure recorded as either the underlying cause or a mention, England, 2001 to 2008



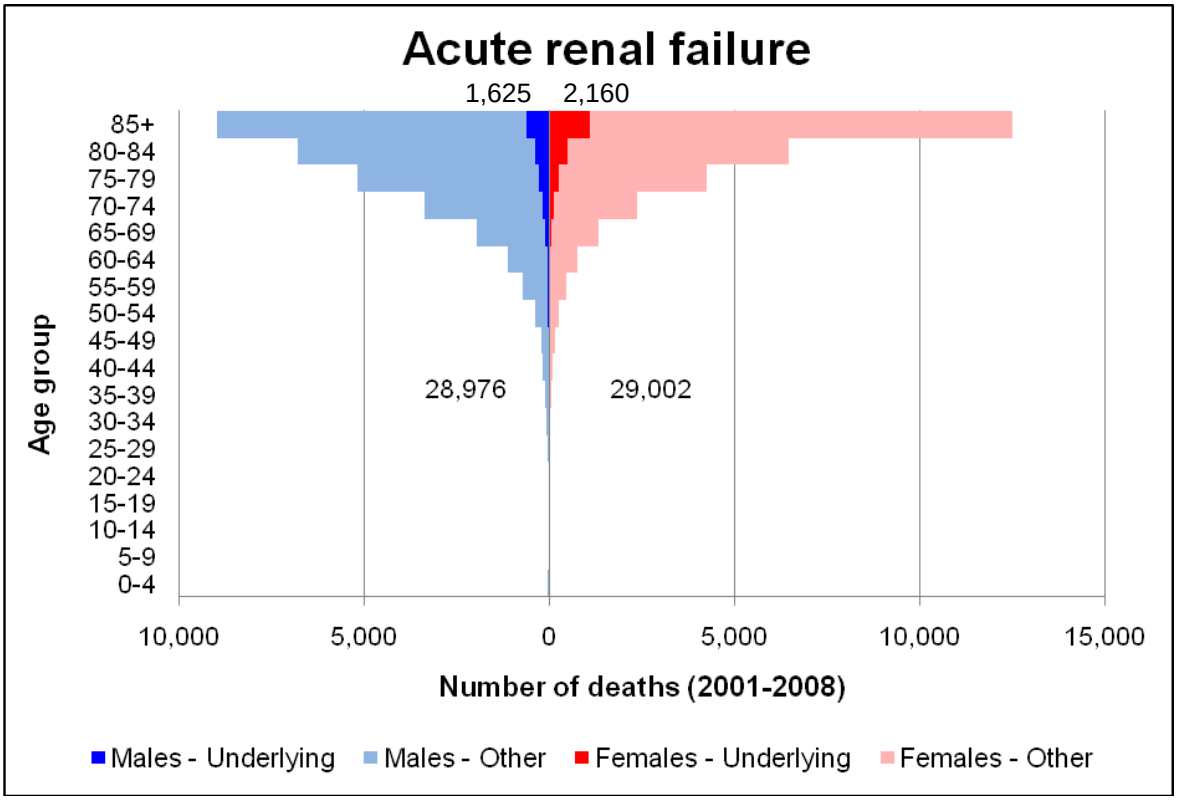
Source: Office for National Statistics, annual mortality extracts

- 11,293 people died with chronic renal failure recorded as the underlying cause between 2001 and 2008.
- 94,520 people died with a mention of chronic renal failure between 2001 and 2008.

- More males (54,465) than females (40,055) had chronic renal failure mentioned on their death certificate. Slightly more females (5,846) than males (5,447) had chronic renal failure recorded as the underlying cause of death.
- 85,691 (91%) of deaths occurred amongst those who were 65 years and older when they died.
- The largest group in whom chronic renal failure was recorded as an underlying cause of death was women aged 85 and over (2,619).

3.4.2 Acute renal failure underlying cause and mentions by age and sex

Figure 4: Age and sex distribution of people who died with acute renal failure recorded as either the underlying cause or a mention, England, 2001 to 2008

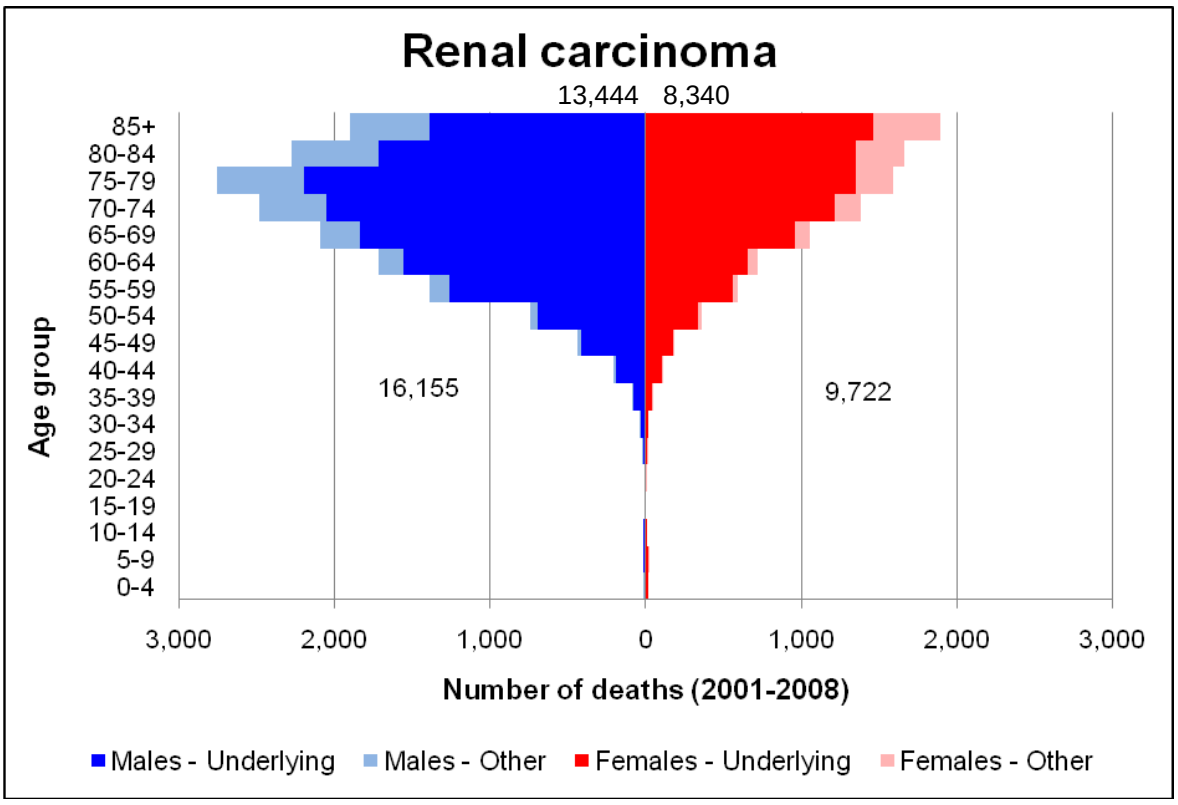


Source: Office for National Statistics, annual mortality extracts

- 3,785 people died with acute renal failure recorded as the underlying cause between 2001 and 2008.
- 57,978 people died with a mention of acute renal failure between 2001 and 2008.
- Similar numbers of males (28,976) and females (29,002) had acute renal failure mentioned in their death. More females (2,160) than males (1,625) had acute renal failure recorded as the underlying cause of death.
- 53,214 (92%) of deaths occurred amongst those who were 65 years and older when they died.
- Women aged 85 and over had the largest numbers of acute renal failure deaths recorded as both underlying cause (1,104) and mentions (12,512).

3.4.3 Renal carcinoma underlying cause and mentions by age and sex

Figure 5: Age and sex distribution of people who died with renal carcinoma recorded as either the underlying cause or a mention, England, 2001 to 2008

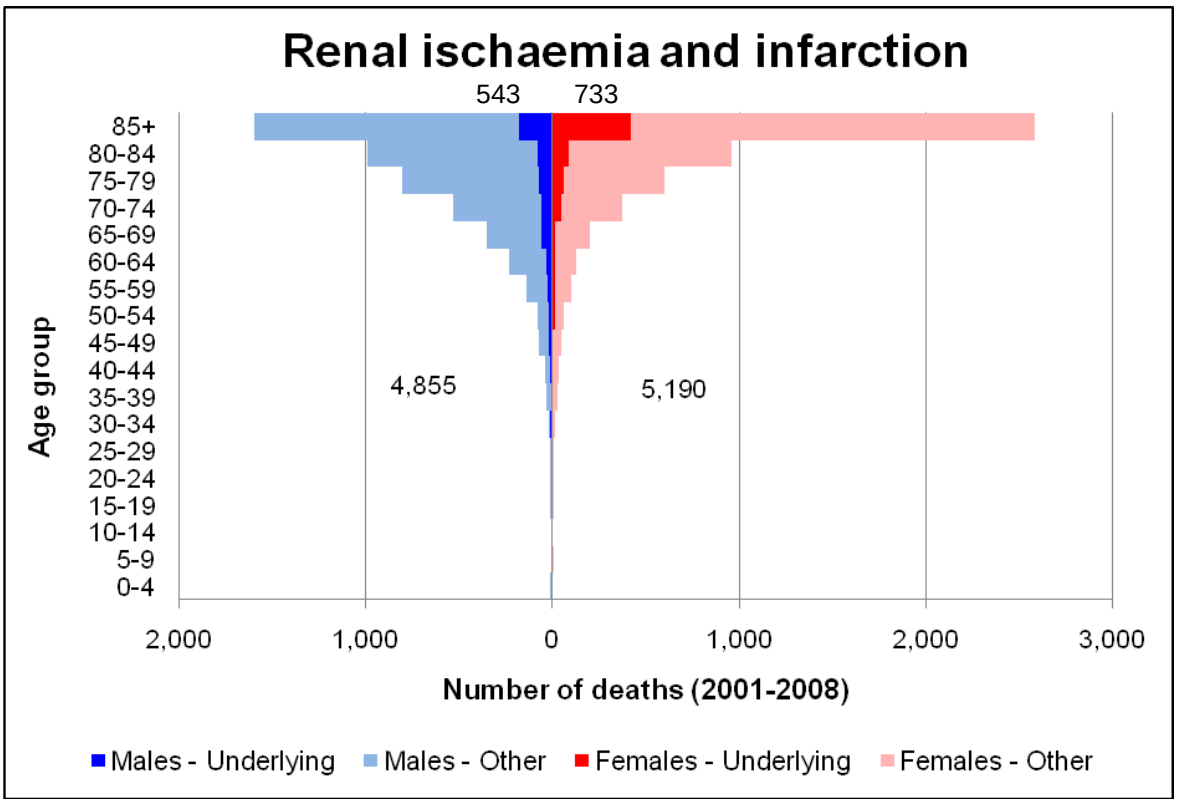


Source: Office for National Statistics, annual mortality extracts

- 21,784 people died with renal carcinoma recorded as the underlying cause between 2001 and 2008.
- 25,877 people died with a mention of renal carcinoma between 2001 and 2008.
- Considerably more males (16,155) than females (9,722) had renal carcinoma mentioned on their death certificate. Deaths coded as underlying causes were also more common in males (13,444) than females (8,340).
- 19,098 (74%) of deaths occurred amongst those who were 65 years and older when they died.
- 82 (0.4%) deaths were recorded as the underlying cause in children aged under 15.

3.4.4 Renal ischaemia and infarction underlying cause and mentions by age and sex

Figure 6: Age and sex distribution of people who died with renal ischaemia and infarction recorded as either the underlying cause or a mention, England, 2001 to 2008

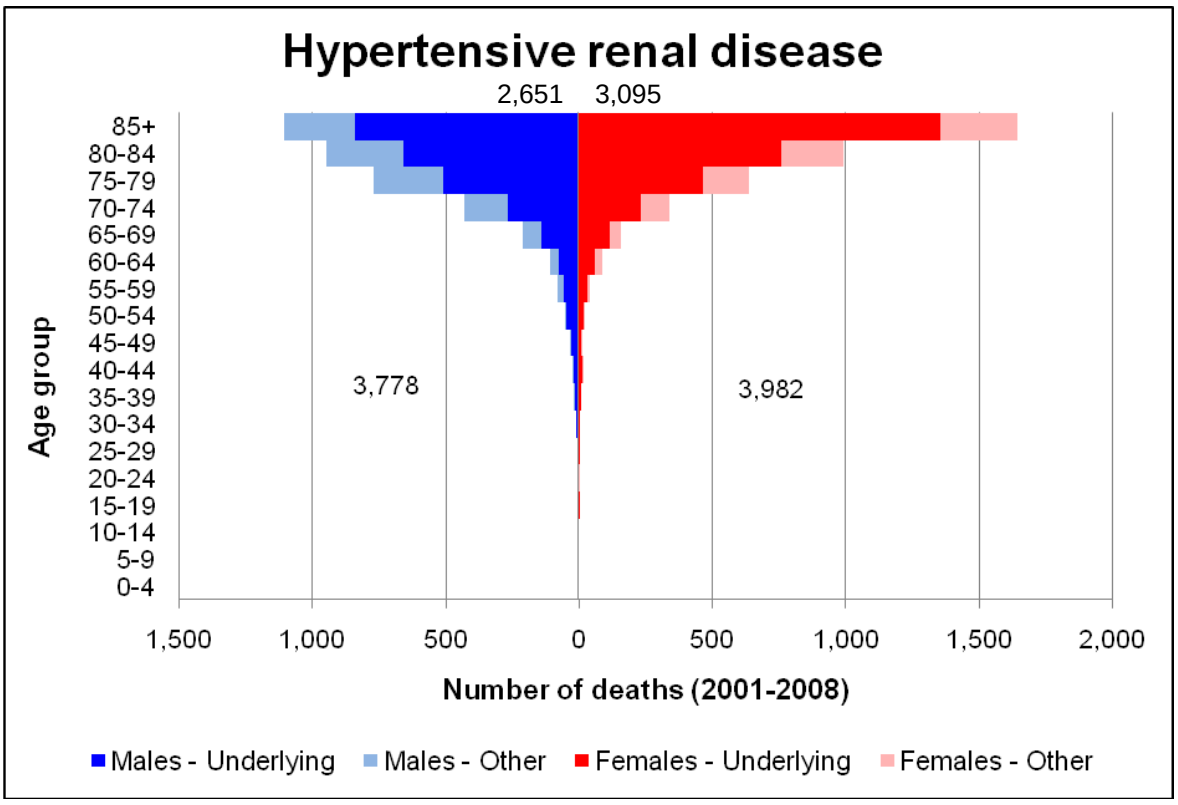


Source: Office for National Statistics, annual mortality extracts

- 1,276 people died with renal ischaemia and infarction recorded as the underlying cause between 2001 and 2008.
- 10,075 people died with a mention of renal ischaemia and infarction between 2001 and 2008.
- Slightly more females (5,190) than males (4,885) had renal ischaemia and infarction mentioned in their death. Deaths coded as underlying causes were also more common in females (733) than males (543).
- 8,999 (89%) of deaths occurred amongst those who were 65 years and older when they died.
- Women aged 85 and over had the largest numbers of renal ischaemia and infarction deaths recorded as both underlying cause (425) and mentions (2,159).

3.4.5 Hypertensive renal disease underlying cause and mentions by age and sex

Figure 7: Age and sex distribution of people who died with hypertensive renal disease recorded as either the underlying cause or a mention, England, 2001 to 2008



Source: Office for National Statistics, annual mortality extracts

- 5,746 people died with hypertensive renal disease recorded as the underlying cause between 2001 and 2008.
- 7,760 people died with a mention of hypertensive renal disease between 2001 and 2008.
- Slightly more females (3,982) than males (3,778) had hypertensive renal disease mentioned in their death. Deaths coded as underlying causes were also more common in females (3,095) than males (2,651).
- 7,233 (93%) of deaths occurred amongst those who were 65 years and older when they died.
- Women aged 85 and over had the largest numbers of hypertensive renal disease deaths recorded as both underlying cause (1,358) and mentions (1,647).

3.5 Place of occurrence of renal disease deaths

Place of death is an important determinant of the quality of a person's death. The place where someone dies is influenced by the nature of their final condition and its complications, their age and usual place of residence (e.g. own residence, nursing home or old people's home). Data have been presented by males and females combined as there is little variation by gender.

3.5.1 Renal diseases as the underlying cause of death

Table 4 shows the places of occurrence of death for those people who died with a renal disease as the underlying cause of death between 2001 and 2008.

Table 4: Underlying causes of death from renal diseases by place of death, England, 2001 to 2008

	Hospital		Hospice		Nursing home		Ole people's home		Own residence		Elsewhere		Total	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Renal carcinoma	9,332	43	4,550	21	1,422	7	604	3	5,586	26	290	1	**21,784**	100
Chronic renal failure	7,769	69	124	1	1,113	10	934	8	1,271	11	82	1	**11,293**	100
Hypertensive renal disease	3,993	69	116	2	396	7	317	6	873	15	51	1	**5,746**	100
Acute renal failure	3,455	91	6	0	121	3	106	3	89	2	8	0	**3,785**	100
Renal ischaemia and infarction	737	58	6	0	141	11	196	15	186	15	10	1	**1,276**	100
Total	**25,286**	**58**	**4,802**	**11**	**3,193**	**7**	**2,157**	**5**	**8,005**	**18**	**441**	**1**	**43,884**	100

Source: Office for National Statistics, annual mortality extracts

- Slightly over half of deaths (58%) where renal diseases are the underlying cause of death occur in hospitals.
- The proportions dying in hospital vary considerably across the selected renal diseases, ranging from 43% for deaths from renal carcinoma to 69% of deaths in which chronic renal failure and hypertensive renal disease are recorded as the underlying cause and 91% for acute renal failure.
- Overall, people dying from renal diseases as underlying causes are more likely to die outside of hospital than people who die with a mention of renal disease. This is because deaths with renal disease as the underlying cause are dominated by renal carcinoma, from which patients are more likely to die in a hospice or their own residence.
- Almost half of all people dying with renal carcinoma recorded as the underlying cause die in hospices (21%) or at home (26%), reflecting the particular end of life care needs of people with cancer.
- 9% of males and 16% of females die with a renal disease as an underlying cause of death in a residential or nursing home and if own residence deaths are added to this, the proportions rise to 29% and 32% respectively (data not shown).

3.5.2 Mentions of renal diseases at death

Table 5 shows the places of occurrence of death for those people who died with a mention of renal disease between 2001 and 2008.

Table 5: Mentions of death from renal diseases by place of death, England, 2001 to 2008

	Hospital		Hospice		Nursing home		Ole people's home		Own residence		Elsewhere		Total	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Chronic renal failure	76,702	81	1,101	1	4,637	5	3,414	4	8,191	9	475	1	**94,520**	100
Acute renal failure	55,318	95	322	1	708	1	526	1	1,008	2	96	0	**57,978**	100
Renal carcinoma	11,747	45	4,835	19	1,639	6	748	3	6,534	25	374	1	**25,877**	100
Renal ischaemia and infarction	6,304	63	103	1	919	9	921	9	1,743	17	85	1	**10,075**	100
Hypertensive renal disease	5,646	73	148	2	438	6	357	5	1,105	14	66	1	**7,760**	100
Total	**155,717**	**79**	**6,509**	**3**	**8,341**	**4**	**5,966**	**3**	**18,581**	**9**	**1,096**	**1**	**196,210**	100

Source: Office for National Statistics, annual mortality extracts

- Overall, the large majority of deaths (79%) where renal diseases are mentioned occur in hospitals.
- The proportions dying in hospital vary considerably across the selected renal diseases, ranging from 45% for deaths with a mention of renal carcinoma up to 95% for deaths with a mention of acute renal failure.
- Significant proportions of people dying with a mention of renal carcinoma die in hospices (19%) or at home (25%), reflecting the particular end of life care needs of people with cancer.
- 5% of males and 9% of females die with a renal disease as an underlying cause of death in a residential or nursing home and if home deaths are added to this the proportions rise to 16% and 17% respectively (data not shown).

4 Summary and next steps

This report is the first to provide a high level overview of deaths from renal diseases in England. It shows the absolute numbers of deaths, where these are mentioned as the underlying cause of death, and where these are listed as mentions on the death certificate and therefore contributed to the death. This highlights how important it is to search for mentions of these conditions to get a clearer picture of how many people may be dying with these conditions, where they contribute to the specific needs of people at the end of their life.

However, it is important to note that recent studies from Northern Ireland have shown that advanced kidney disease is very significantly under-recorded on death certificates. For example, among patients dying whilst receiving renal replacement therapy, only 17% had a primary cause of death code for renal disease, 66% had a secondary code and 17% had no renal coding on the death certificate. In patients with a glomerular filtration rate of less than 15ml/min/1.73m^2, renal disease was mentioned as the primary cause of death in only 8.5% and as a secondary cause in only a further 35%.

The report also, through the use of population pyramids, illustrates the different age profiles of people dying with renal diseases. These differences in age profiles are important as they will determine the needs of the individuals affected, along with their families and carers, and also determine where people are likely to receive end of life care at the time of their final illness.

This report is the first in a series to be produced for the National End of Life Care Intelligence Network. Subsequent analyses will further examine:

- in more depth, the influence of underlying cause of death on place of death for each of the main renal diseases, comparing, for example, place of death for those who die of a renal disease as the underlying cause with those who die of some other underlying cause where a renal disease is cited elsewhere on the death certificate.
- The underlying causes of death where renal disease appears only as a mention on the death certificate as this is important to the understanding of the role these conditions play as co-morbidity.
- the pattern of admissions and type of care received in hospital during the last year of life for those dying in and out of hospital.

Discussions are also already in progress with the UK Renal Registry to undertake joint more detailed studies of end of life care and renal disease. Proposed linkage between the Renal Registry and the National Cancer Intelligence Network's (NCIN) Urological Cancer Hub (www.swpho.nhs.uk/urologicalcancerhub) would also allow more in-depth evaluation of end of life issues in urological cancers.

Appendix 1

Table A1: Numbers of underlying causes of death from selected renal diseases by age and sex, England, 2001 to 2008

	Chronic renal failure		Acute renal failure		Renal carcinoma		Renal ischaemia and infarction		Hypertensive renal disease	
	Males	Females	Males	Females	Males	Females	Males	Females	Males	Females
0-4	2	1	3	2	10	18	1	0	0	0
5-9	1	1	0	0	13	22	1	1	0	0
10-14	0	1	0	0	8	11	1	0	0	0
15-19	5	5	0	1	4	7	1	1	2	1
20-24	9	5	1	1	7	5	2	1	2	2
25-29	13	9	4	0	19	9	2	3	3	3
30-34	16	12	1	1	32	21	7	5	10	2
35-39	31	28	4	4	74	45	4	7	15	8
40-44	44	48	9	3	190	107	7	4	16	14
45-49	67	41	6	6	408	181	13	6	25	10
50-54	93	65	21	13	695	338	14	14	45	18
55-59	120	98	29	27	1,260	560	23	19	57	35
60-64	192	157	49	31	1,552	660	31	20	72	62
65-69	317	239	102	68	1,830	966	56	16	140	118
70-74	530	396	179	133	2,051	1,216	59	53	264	234
75-79	932	662	257	265	2,190	1,351	72	67	506	468
80-84	1,272	1,060	367	501	1,713	1,353	75	91	658	762
85+	2,202	2,619	593	1,104	1,388	1,470	174	425	836	1,358
Total	**5,846**	**5,447**	**1,625**	**2,160**	**13,444**	**8,340**	**543**	**733**	**2,651**	**3,095**

Source: Office for National Statistics, annual mortality extracts

Table A2: Numbers of mentions of selected renal diseases by age and sex, England, 2001 to 2008

	Chronic renal failure		Acute renal failure		Renal carcinoma		Renal ischaemia and infarction		Hypertensive renal disease	
	Males	Females	Males	Females	Males	Females	Males	Females	Males	Females
0-4	24	12	46	27	12	18	7	3	2	0
5-9	9	3	8	9	13	23	1	2	0	0
10-14	8	5	5	3	8	11	1	1	0	0
15-19	17	13	10	11	4	7	7	3	2	1
20-24	37	28	10	9	7	6	9	4	2	3
25-29	52	64	30	23	22	10	9	10	3	3
30-34	115	97	52	35	34	21	19	15	10	2
35-39	198	165	84	61	80	48	26	32	19	8
40-44	307	255	157	107	200	112	36	38	22	16
45-49	440	334	209	154	434	190	67	48	32	11
50-54	772	483	378	280	740	361	73	65	49	22
55-59	1,180	796	701	483	1,386	595	135	106	77	44
60-64	2,118	1,297	1,094	778	1,715	722	229	130	108	91
65-69	3,660	2,388	1,943	1,355	2,091	1,060	352	207	208	161
70-74	6,273	3,929	3,345	2,395	2,483	1,383	526	374	427	339
75-79	9,894	6,235	5,183	4,274	2,755	1,597	800	604	770	640
80-84	12,620	8,325	6,776	6,486	2,271	1,662	991	964	944	994
85+	16,741	15,626	8,945	12,512	1,900	1,896	1,597	2,584	1,103	1,647
Total	**54,465**	**40,055**	**28,976**	**29,002**	**16,155**	**9,722**	**4,885**	**5,190**	**3,778**	**3,982**

Source: Office for National Statistics, annual mortality extracts

Further information

This bulletin is available online at:
www.endoflifecare-intelligence.org.uk

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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.