NHS Devon

End of Life Care: A Health Needs Assessment in Devon

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1. Executive Summary

1.1 A number of national and local policies exist to guide the provision of palliative and end of life care in Devon. Compared to the rest of England, Devon has an above average need for end of life care, primarily because its population has a relatively high proportion of people aged 65 and over. Current spend on end of life care in Devon is low: hospice and nursing services and bereavement services are both funded at low levels when benchmarked against spending elsewhere in the country. Provision of inpatient specialist palliative care beds is below recommended levels. Increased investment in end of life care is needed to bring Devon in line with levels of funding elsewhere. The relationships between current levels and models of service provision and local need are unclear. Further assessment of need should be conducted on a Devon-wide basis.

2. Introduction

2.1 A health needs assessment is "a systematic method for reviewing the health needs of a particular population, leading to agreed priorities and resource allocation, which will lead to improved health and reduced health inequalities" (NICE 2005).

2.2 End of life care, as defined in the National End of Life Care Strategy (Department of Health 2008), is care that "helps all those with advanced, progressive and incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support"

2.3 The aim of this health needs assessment is to estimate levels of need and compare them to current service provision within the NHS Devon area. The needs assessment takes a population perspective and focuses on the end of life care needs of adults.

3. Background

3.1 A statement by Cicely Saunders, founder of the modern hospice movement, is often used in reference to the importance of end of life care: "How people die remains in the memory of those who live on." End of life care refers to services intended to support people with advanced, progressive, incurable illnesses to live as well as possible until they die. The term encompasses the supportive and palliative care needs of both patients and families in the last phase of life and into bereavement and includes management of pain and other symptoms as well as provision of psychological, social, spiritual and practical support. (National End of Life Care Programme 2008).

3.2 The National End of Life Care Strategy (Department of Health 2008) identified a range of necessary activities: raising the profile of end of life care and changing societal attitudes to death and dying; ensuring an integrated approach to strategic commissioning of end of life care is taken across health and social care; identifying people approaching the end of life; advanced care

planning; co-ordinating care; ensuring rapid access to care; delivering high quality services in all locations; delivering care in the last days of life and care after death; involving and supporting carers; providing education, training and continuing professional development; conducting measurement and research.

3.3 The 2011-12 NHS Operating Framework (Department of Health 2010) stated the NHS should continue to ensure implementation of the End of Life Care Strategy. Doing so includes promoting high quality care and working to offer patients the choice of where to be cared for as they approach the end of life, and where to die, regardless of their condition. It also involves ensuring staff members are adequately trained in understanding and providing end of life care.

3.4 Within Devon, the joint NHS Devon – Devon County Council "The Way Ahead" (2008) strategic framework set out several aims for end of life care. These are set out in Box 3.1. Timelines and specific indicators are more clearly set out for some of these aims than others.

Box 3.1 "The Way Ahead"

We will:

● Reduce the number of people being admitted to hospital in the last days of their life, when they would rather die at home.

● Commission care and support for people at the end of life that specifies co-ordination around the person and their family. This recognises primary care, emergency services, social care, sitting services, care homes, hospitals and specialist end of life and bereavement services all have an important part to play. We will promote dignity, choice, freedom from avoidable pain and fear, and support for families and carers as minimum standards.

● Extend evidence-based practice across all providers of end of life care in Devon, using the Gold Standard Framework and Liverpool Care pathway, accompanied by an emphasis on training and a drive for continued improvement.

● Ensure consistent access to end of life care across Devon, including the availability of core services such as out-of-hours nursing. This will be in place during 2009.

● Build on the excellent practices already underway, such as special patient messages to communicate wishes between different parts of the service, and just-in-case boxes to supply palliative care drugs. We will continue to develop arrangements for sharing good practice across the whole of the county.

● Ensure high quality end of life care is key within the new complex care teams being developed across Devon.

● Make sure vulnerable groups receive the right care and support at the end of life, for example, people with learning disabilities or neurological conditions. We will also take care to meet the needs of young people, carers, people with dementia, and people from ethnic minorities who may have particular end of life needs.

● Develop local arrangements for end of life care, linked closely to outreach support from specialist providers to bring assessment, clinics and appropriate palliative care services closer to home.

● Have end of life care as a topic for wider discussion to generate better understanding and greater support for an aspect of life that is not discussed often enough.

We will achieve:

● A halving, over a four-year period, in the number of people being admitted to acute hospitals in an emergency in the last days of their lives. We will reduce overall unplanned admissions to hospital from nursing homes in the last 12 months of life by 10% a year for the next three years.

● Evidence to demonstrate that planned place of death preferences are achieved by 2010, with action plans to make continued improvement in granting people's wishes.

● In 2009, every person in Devon clinically assessed as requiring end of life care receiving systematic evidence-based care, using the Gold Standard Framework.

● Nobody in avoidable pain, and support for every person to die with dignity. There will be sensitivity and support for families and carers. This will be measured by audits and feedback on aspects of care that are the most important at the end of life.

● Access to outreach end of life support in local centres across Devon by the end of 2009, to a point where this is available within 20 minutes' drive time of the majority of patients' homes.

4. Demography and Population Projections

4.1 Although palliative and end of life care may be needed by people of any age the need for services, on a population level, tends to be greater the older the population. We can get some idea of how Devon's population compares with populations elsewhere in the country by looking at the numbers of people aged 65 and over and the proportion of the total population which is in this age group.

4.2 The percentage of people aged 65 and over in England is 16.5%. In the South West this proportion is higher (19.6%) and in Devon it is higher still (21.7%). The highest proportion of older people, by locality, is in Southern where the proportion of people aged 65 and over is more than 33% higher than in England as a whole. Note that there may be even higher proportions of older people in areas below the locality level – notably, parts of Eastern Devon are known to have high proportions of older people. Table 4a summarises the age structures of Devon localities and other areas.

4.3 The high proportion of older people in the population is reflected in the high annual incidence of deaths (see Table 5a). This proportion influences the level of resources required to meet end of life care needs.

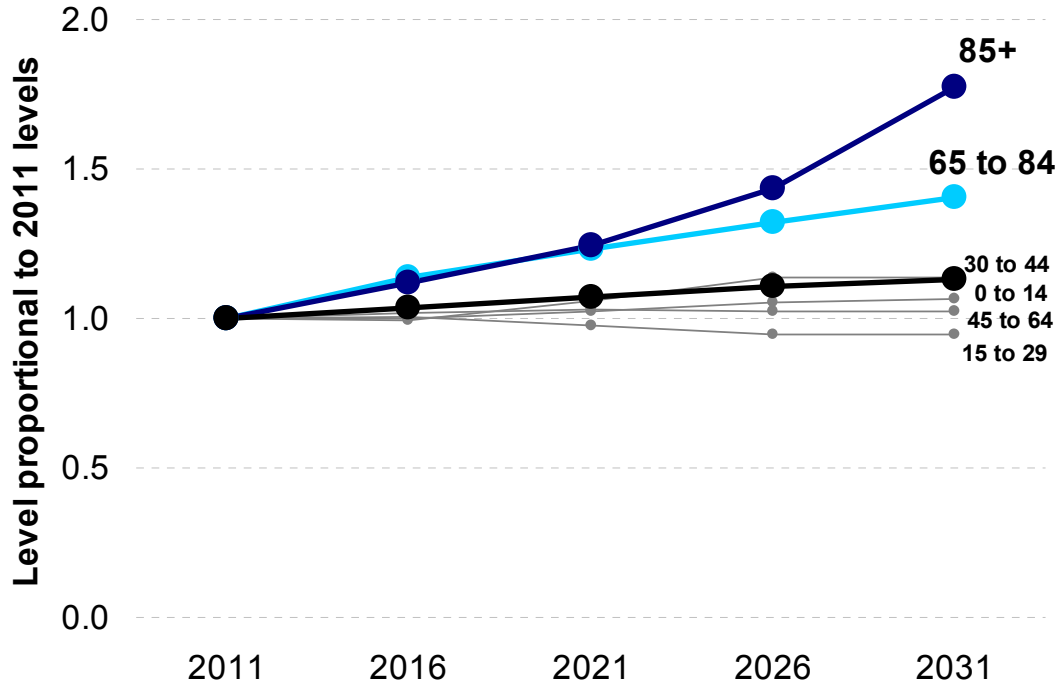
4.4 Between 2011 and 2031 the total population of Devon is expected to grow by 13% but there are marked differences in expected changes by age group. The number of Devon residents aged 15 to 29 is expected to decline by 5% but the number of residents aged 65 to 84 is expected to grow by 40% and of residents aged 85 or older to grow by 78% (see Figure 4a). Both the numbers of older people in Devon and the proportion of older people in the population are likely to grow over the next twenty years and the need for end of life care is likely to rise in line with this. The increase in numbers of older people is likely to be accompanied by an increase in the numbers of people with dementia, which will place further demands on health and social-care services for this group.

Table 4a: Population by age group (2010)

Age Group	Eastern		Northern		Southern		Devon		South West*		England	
0-4	17957	4.8%	7871	4.8%	10227	4.4%	36055	4.7%	290200	5.5%	3266900	6.3%
5-9	18068	4.8%	8072	4.9%	11161	4.8%	37301	4.8%	272400	5.2%	2902500	5.6%
10-14	20072	5.3%	9367	5.7%	13340	5.7%	42779	5.5%	298800	5.7%	2981000	5.7%
15-19	22837	6.0%	9961	6.1%	14037	6.0%	46835	6.1%	331300	6.3%	3267100	6.3%
20-24	26624	7.1%	8511	5.2%	11571	5.0%	46706	6.0%	342000	6.5%	3598200	6.9%
25-29	21691	5.7%	7813	4.8%	10400	4.5%	39904	5.2%	302900	5.8%	3585700	6.9%
30-34	20261	5.4%	7883	4.8%	10228	4.4%	38372	5.0%	276000	5.3%	3303100	6.3%
35-39	22850	6.1%	9549	5.8%	12973	5.6%	45372	5.9%	323100	6.2%	3563300	6.8%
40-44	26455	7.0%	11545	7.1%	16421	7.1%	54421	7.0%	376000	7.2%	3905000	7.5%
45-49	26802	7.1%	11941	7.3%	18046	7.8%	56789	7.3%	381200	7.3%	3820200	7.3%
50-54	24069	6.4%	11224	6.9%	16573	7.1%	51866	6.7%	341000	6.5%	3307600	6.3%
55-59	23207	6.1%	11023	6.7%	16470	7.1%	50700	6.6%	322000	6.1%	2970200	5.7%
60-64	26744	7.1%	13020	8.0%	18834	8.1%	58598	7.6%	360900	6.9%	3139300	6.0%
65-69	22003	5.8%	10730	6.6%	15017	6.5%	47750	6.2%	290800	5.5%	2433100	4.7%
70-74	18208	4.8%	8365	5.1%	11657	5.0%	38230	4.9%	237400	4.5%	2051900	3.9%
75-79	15011	4.0%	6644	4.1%	9819	4.2%	31474	4.1%	196800	3.7%	1667700	3.2%
80-84	12299	3.3%	5015	3.1%	7597	3.3%	24911	3.2%	154000	2.9%	1253000	2.4%
85-89	8159	2.2%	3254	2.0%	5307	2.3%	16720	2.2%	102800	2.0%	791700	1.5%
90+	4296	1.1%	1668	1.0%	2676	1.2%	8640	1.1%	52600	1.0%	405900	0.8%
Total	**377613**	**100.0%**	**163456**	**100.0%**	**232354**	**100.0%**	**773423**	**100.0%**	**5252300**	**100.0%**	**52213400**	**100.0%**

*Subnational Population Projections, 2010-based projections

Figure 4a: Expected growth in Devon's population, by age group



Source: Devon County Council population projections

4.5 Table 4b shows the proportion of the population who describe themselves as white is on average higher in the South West than in England as a whole, and higher in Devon than in the South West as a whole. Within Devon, the Eastern locality has a slightly higher proportion of its population who describe themselves as belonging to one of the other ethnic groups, and the 1.9% of its population who describe themselves as Asian is higher than the 1.2% in both the Northern and Southern localities – but lower than the 2.2% in the South West and 6.1% in England for this group. In relation to end of life service provision this information has consequences for provision of education and training, which should include consideration of the need to be able to provide appropriate care to members of all ethnic groups, even if such need is relatively unusual.

4.6 In relation to religion (Table 4c), compared to England as a whole, Devon has a higher proportion of people who indicated their religion is Christian or who selected the "Other" or "None" categories in the 2001 Census. Devon has a similar proportion of Buddhists to England as a whole, and a broadly similar proportion of people did not state their religion, but markedly lower proportions of people who indicated their religion was Hinduism, Judaism, Muslim, or Sikh. 0.4% of the Devon population falls into one of these groups compared to 5.4% of the population of England as a whole.

Table 4b: Ethnic group

	Eastern	Northern	Southern	Devon	South West	England
White	311500 94.9%	150500 95.9%	253500 96.3%	715400 95.6%	4920500 94.0%	45313200 87.4%
Mixed	3600 1.0%	1500 0.9%	2300 0.8%	7600 1.0%	68200 1.3%	956700 1.8%
Asian	6300 1.9%	2000 1.2%	3400 1.2%	11500 1.5%	118000 2.2%	3166800 6.1%
Black	2600 0.7%	1400 0.8%	1800 0.6%	5600 0.7%	62700 1.1%	1521400 2.9%
Other	3900 1.1%	1500 0.9%	2000 0.7%	7500 1.0%	61800 1.1%	851600 1.6%

Source: ONS Experimental Population Estimates by Ethnic Group for local authority districts and higher administrative areas in England and Wales for 2009 (published 18th May 2011). The estimates are consistent with the Mid-Year Population Estimates current at that date.

4.7 Within Devon there are slightly higher proportions of some of these minority religious groups in the Eastern locality (e.g. people who indicate they are Jewish or Muslim) but the absolute proportions are still relatively low. Again, the implication for provision of end of life services is that it is important to ensure appropriate care is available to people of all religious backgrounds, even when they are few in number. Training and education should reflect this.(Holloway 2010)

Table 4c: Religion

	Eastern	Northern	Southern	Devon	South West	England
Christian	253097 74.3%	110268 75.2%	163844 75.3%	527209 74.8%	3646488 73.9%	35251244 71.7%
Buddhist	814 0.2%	273 0.1%	612 0.2%	1699 0.2%	11245 0.2%	139046 0.2%
Hindu	208 0.0%	58 0.0%	82 0.0%	348 0.0%	8260 0.1%	546982 1.1%
Jewish	372 0.1%	85 0.0%	193 0.0%	650 0.0%	6753 0.1%	257671 0.5%
Muslim	1054 0.3%	190 0.1%	226 0.1%	1470 0.2%	23427 0.4%	1524887 3.1%
Sikh	107 0.0%	50 0.0%	13 0.0%	170 0.0%	4604 0.0%	327343 0.6%
Other	1343 0.3%	522 0.3%	932 0.4%	2797 0.3%	18169 0.3%	143811 0.2%
None	56781 16.6%	23167 15.8%	34550 15.8%	114498 16.2%	825461 16.7%	7171332 14.5%
Not stated	26865 7.8%	11858 8.0%	16901 7.7%	55624 7.8%	383851 7.7%	3776515 7.6%

Source: 2001 Census

5. Prevalence, Epidemiology and Burden of Disease

5.1 The single most important indicator of palliative care need in a population is the annual incidence of deaths. Standardised mortality ratios are not useful in this context – since it is the number of deaths that influences the need for services the most useful statistic is the ratio of deaths to population.(Tebbit 2004)

Table 5a: Average Annual Incidence of Deaths from All Causes, Cancer, All Circulatory Disease (ICD10 I00-I99), Coronary Heart Disease (ICD10 I20-I25), Stroke (ICD10 I60-I69), COPD (ICD10 J40-J44)

	Eastern	Northern	Southern	Devon	South West	England
All deaths	3823	1667	2569	8059	52149	461017
Rate per 100,000	*1012.4*	*1019.8*	*1105.6*	*1042.0*	*988.85*	*882.6*
Cancer	1082	453	675	2210	14417	129509
Rate per 100,000	*286.5*	*277.1*	*290.5*	*285.7*	*273.4*	*247.9*
Circulatory Disease	1226	577	913	2716	16798	147287
Rate per 100,000	*324.7*	*353.0*	*392.9*	*351.2*	*318.5*	*282.0*
CHD	476	236	343	1055	7040	65243
Rate per 100,000	*126.1*	*144.4*	*147.6*	*136.4*	*133.5*	*124.9*
Stroke	396	207	292	895	5178	40486
Rate per 100,000	*104.9*	*126.6*	*125.7*	*115.7*	*98.2*	*77.5*
COPD	140	88	87	315	2258	22353
Rate per 100,000	*37.1*	*53.8*	*37.4*	*40.7*	*42.8*	*42.8*

Source: Cases and crude rates from the Information Centre Mortality Files (2010)

5.2 As shown in Table 6a, the annual incidence of deaths in Devon is higher than the average rates for the South West and for England, by 5% and 18%, respectively. The annual incidence of deaths varies across Devon and the Southern locality has a rate 25% higher than the English average while the incidences in the Eastern and Northern localities are each 15% higher than the English average.

5.3 Just over a quarter of deaths in Devon (27.4%) are from cancer. The annual incidence of deaths from cancer does not vary widely across the Devon localities but in all of them the incidence is higher than both the South West and English averages.

5.4 Around one-third of deaths in Devon (33.7%) are from circulatory disease. The higher annual incidence of deaths in the Southern locality is partly attributable to high mortality rates from circulatory disease, which are higher than the other localities and at 393 per 100,000 are 24% higher than the mean South West rate of 318 per 100,000 and 39% higher than the English rate of 282 per 100,000.

Table 5b: Preferences versus reality: where people want to be cared for and where they actually die

	Preferred place of death – 2002 survey	Eastern	Northern	Southern	Devon	South West*	England*
Home	56%	796 20.8%	376 22.6%	449 17.5%	1621 20.1%	33076 21.0%	283779 20.3%
Hospice	24%	218 5.7%	90 5.4%	167 6.5%	475 5.9%	7620 4.8%	72686 5.2%
NHS Hospital	11%	1832 47.9%	822 49.3%	1214 47.3%	3868 48.0%	78401 49.7%	760445 54.5%
Care Home (resident)	4%	685 17.9%	250 15.0%	398 15.5%	1333 16.5%	35007 22.2%	248533 17.8%
Care Home (non-resident)		234 6.1%	91 5.5%	290 11.3%	615 7.6%		
Other places		58 1.5%	38 2.3%	51 2.0%	147 1.8%	3548 2.3%	30572 2.2%
Total		**3823 100.0%**	**1667 100.0%**	**2569 100.0%**	**8059 100.0%**	**157652 100.0%**	**1396015 100.0%**

*aggregated data for 2008-10

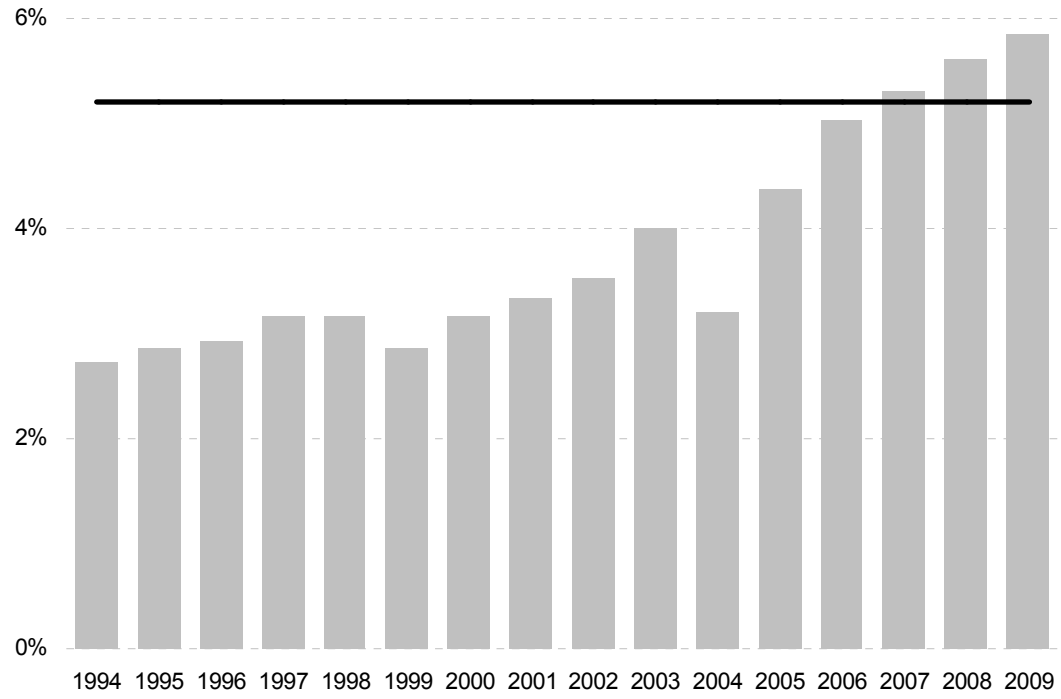
5.5 Survey results indicate the majority of people, though by no means all, say they would prefer to die at home. The National Council for Palliative Care and the Cicely Saunders Foundation (NCPC 2003) undertook a national telephone survey undertaken in 2002, and the findings of this survey in relation to place of death are shown in the first column of Table 6b. In relation to dying at home there is a marked contrast between these findings, in which 56% of people reported they would prefer to die in their own home and the most recent national and local data on place of death.

5.6 Compared to the South West and England averages, a higher proportion of deaths in Devon are in hospices and care homes, and a slightly lower proportion are in NHS hospitals. In Devon in 2010, 20.1% of people died at home, a figure close to the English average of 20.3%. Compared to England as a whole, fewer people in Devon died in a hospital: 48.0% versus 54.5%. People who died in Devon were more likely to die in a care home than in England as a whole: 15% more likely in the Northern locality, 35% in the Eastern locality, and 51% in the Southern locality. Deaths in a hospice were slightly higher in each of the Devon localities than in the South West or England overall.

5.7 Table 5c summarises recent trends in place of death in Devon. Since 2002 there has been a steady rise in the proportion of deaths in a hospice (up more than two-thirds from 3.5% in 2002 to 5.9% in 2010) and a slight drop in the proportion of deaths in NHS hospitals (down from 50.5% to 48.0%) but no change in the proportion of deaths at home, which has remained around 20%

through this period. Viewed over a longer period, the rise in deaths in hospices in Devon is more striking (see figure 6a). The start of this rise coincides with, and is likely explained by, the opening of an inpatient unit in North Devon Hospice.

Figure 5a: Proportion of deaths in Devon taking place in hospice, 1994-2009



5.8 Tables 5d to 5f summarise trends in place of death for the Eastern, Northern, and Southern localities respectively. In each of the localities there has been a rise in the proportion of deaths in hospices, most notably in the Northern locality. In general, trends in place of death in the localities are broadly similar to that in Devon as a whole.

5.9 The proportion of deaths in Devon that take place in a person's own home is substantially lower than that indicated by research into where people say they would like to die, although local figures are similar to those recorded at a national level. To meet targets regarding people's wishes about where they would like to die, and policy ambitions related to reducing the proportion of people who die in hospital, further action is needed.

5.10 There are currently no data linking individual wishes about place of death in Devon to actual place of death but these data should be available soon.

Table 5c: Trends in place of occurrence of death in Devon

	2002	2003	2004	2005	2006	2007	2008	2009	2010	South West*	England*
Hospice	302 *3.5%*	345 *4.0%*	266 *3.2%*	362 *4.4%*	406 *5.0%*	433 *5.3%*	467 *5.6%*	479 *5.9%*	475 *5.9%*	7620 *4.8%*	72686 *5.2%*
NHS hospital	4318 *50.5%*	4266 *49.7%*	4257 *51.3%*	4258 *51.5%*	4027 *49.9%*	3949 *48.6%*	4167 *50.0%*	3986 *48.8%*	3868 *48.0%*	78401 *49.7%*	760445 *54.5%*
Nursing home	992 *11.6%*	953 *11.1%*	826 *9.9%*	790 *9.6%*	874 *10.8%*	884 *10.9%*	837 *10.0%*	755 *9.3%*	773 *9.6%*	35007 *22.2%*	248533 *17.8%*
Other care home	1029 *12.0%*	1127 *13.1%*	1100 *13.2%*	993 *12.0%*	950 *11.8%*	1051 *12.9%*	1070 *12.8%*	1122 *13.8%*	1175 *14.6%*		
Home	1717 *20.1%*	1668 *19.4%*	1670 *20.1%*	1633 *19.8%*	1627 *20.2%*	1640 *20.2%*	1638 *19.7%*	1654 *20.3%*	1621 *20.1%*	33076 *21.0%*	283779 *20.3%*
Elsewhere	191 *2.2%*	224 *2.6%*	185 *2.2%*	230 *2.8%*	188 *2.3%*	167 *2.1%*	154 *1.8%*	164 *2.0%*	147 *1.8%*	3548 *2.3%*	30572 *2.2%*
Total	**8549** ***100.0%***	**8583** ***100.0%***	**8304** ***100.0%***	**8266** ***100.0%***	**8072** ***100.0%***	**8124** ***100.0%***	**8333** ***100.0%***	**8160** ***100.0%***	**8059** ***100.0%***	**157652** ***100.0%***	**1396015** ***100.0%***

*aggregated data for 2008-10

Table 5d: Trends in place of occurrence of death in Eastern Locality

	2002	2003	2004	2005	2006	2007	2008	2009	2010	South West*	England*
Hospice	198 *4.8%*	209 *5.2%*	175 *4.4%*	210 *5.2%*	186 *4.8%*	187 *4.9%*	219 *5.5%*	219 *5.6%*	218 *5.7%*	7620 *4.8%*	72686 *5.2%*
NHS hospital	2087 *50.6%*	2038 *50.6%*	2061 *51.5%*	2150 *53.0%*	2013 *52.2%*	1943 *50.8%*	2078 *52.4%*	2000 *51.4%*	1832 *47.9%*	78401 *49.7%*	760445 *54.5%*
Nursing home	366 *8.9%*	352 *8.7%*	312 *7.8%*	317 *7.8%*	353 *9.1%*	338 *8.8%*	299 *7.5%*	266 *6.8%*	321 *8.4%*	35007 *22.2%*	248533 *17.8%*
Other care home	554 *13.4%*	589 *14.6%*	596 *14.9%*	511 *12.6%*	491 *12.7%*	568 *14.9%*	540 *13.6%*	552 *14.2%*	598 *15.6%*		
Home	839 *20.3%*	729 *18.1%*	765 *19.1%*	764 *18.8%*	738 *19.1%*	720 *18.8%*	774 *19.5%*	766 *19.7%*	796 *20.8%*	33076 *21.0%*	283779 *20.3%*
Elsewhere	82 *2.0%*	111 *2.8%*	90 *2.3%*	105 *2.6%*	79 *2.0%*	67 *1.8%*	59 *1.5%*	85 *2.2%*	58 *1.5%*	3548 *2.3%*	30572 *2.2%*
Total	**4126** ***100.0%***	**4028** ***100.0%***	**3999** ***100.0%***	**4057** ***100.0%***	**3860** ***100.0%***	**3823** ***100.0%***	**3969** ***100.0%***	**3888** ***100.0%***	**3823** ***100.0%***	**157652** ***100.0%***	**1396015** ***100.0%***

*aggregated data for 2008-10

Table 5e: Trends in place of occurrence of deaths in Northern Locality

	2002	2003	2004	2005	2006	2007	2008	2009	2010	South West*	England*
Hospice	7 *0.4%*	7 *0.4%*	1 *0.1%*	32 *1.9%*	84 *4.9%*	99 *5.7%*	101 *5.6%*	112 *6.5%*	90 *5.4%*	7620 *4.8%*	72686 *5.2%*
NHS hospital	920 *51.9%*	996 *51.9%*	907 *50.7%*	874 *51.2%*	813 *47.4%*	819 *47.2%*	872 *48.6%*	822 *47.7%*	822 *49.3%*	78401 *49.7%*	760445 *54.5%*
Nursing home	231 *13.0%*	195 *10.2%*	174 *9.7%*	152 *8.9%*	185 *10.8%*	172 *9.9%*	190 *10.6%*	167 *9.7%*	153 *9.2%*	35007 *22.2%*	248533 *17.8%*
Other care home	169 *9.5%*	209 *10.9%*	193 *10.8%*	196 *11.5%*	170 *9.9%*	190 *11.0%*	184 *10.3%*	201 *11.7%*	188 *11.3%*		
Home	391 *22.1%*	456 *23.8%*	462 *25.8%*	381 *22.3%*	400 *23.3%*	403 *23.2%*	410 *22.9%*	386 *22.4%*	376 *22.6%*	33076 *21.0%*	283779 *20.3%*
Elsewhere	55 *3.1%*	56 *2.9%*	51 *2.9%*	72 *4.2%*	65 *3.8%*	52 *3.0%*	37 *2.1%*	34 *2.0%*	38 *2.3%*	3548 *2.3%*	30572 *2.2%*
Total	**1773** ***100.0%***	**1919** ***100.0%***	**1788** ***100.0%***	**1707** ***100.0%***	**1717** ***100.0%***	**1735** ***100.0%***	**1794** ***100.0%***	**1722** ***100.0%***	**1667** ***100.0%***	**157652** ***100.0%***	**1396015** ***100.0%***

*aggregated data for 2008-10

Table 5f: Trends in place of occurrence of death in Southern Locality

	2002	2003	2004	2005	2006	2007	2008	2009	2010	South West*	England*
Hospice	97 3.7%	129 4.9%	90 3.6%	120 4.8%	136 5.5%	147 5.7%	147 5.7%	148 5.8%	167 6.5%	7620 *4.8%*	72686 *5.2%*
NHS hospital	1311 49.5%	1232 46.7%	1289 51.2%	1234 49.3%	1201 48.1%	1187 46.3%	1217 47.4%	1164 45.6%	1214 47.3%	78401 *49.7%*	760445 *54.5%*
Nursing home	395 14.9%	406 15.4%	340 13.5%	321 12.8%	336 13.5%	374 14.6%	348 13.5%	322 12.6%	299 11.6%		
Other care home	306 11.5%	329 12.5%	311 12.4%	286 11.4%	289 11.6%	293 11.4%	346 13.5%	369 14.5%	389 15.1%	35007 *22.2%*	248533 *17.8%*
Home	487 18.4%	483 18.3%	443 17.6%	488 19.5%	489 19.6%	517 20.1%	454 17.7%	502 19.7%	449 17.5%	33076 *21.0%*	283779 *20.3%*
Elsewhere	54 2.0%	57 2.2%	44 1.7%	53 2.1%	44 1.8%	48 1.9%	58 2.3%	45 1.8%	51 2.0%	3548 *2.3%*	30572 *2.2%*
Total	**2650** **100.0%**	**2636** **100.0%**	**2517** **100.0%**	**2502** **100.0%**	**2495** **100.0%**	**2566** **100.0%**	**2570** **100.0%**	**2550** **100.0%**	**2569** **100.0%**	**157652** ***100.0%***	**1396015** ***100.0%***

*aggregated data for 2008-10

6. Health Inequalities

6.1 Across England both life expectancy and disability-free life expectancy vary according to socioeconomic status. For example, men aged 65 living in the most deprived Index of Multiple Deprivation (IMD 2007) quintile could expect to live another 15.4 years, 6.9 of them without disability whereas those in the least deprived quintile could expect to live another 19.4 years, 12.0 of them with disability.(Smith 2011)

6.2 Evidence indicates providing palliative and end of life care to people in deprived areas requires more resources than caring for people in more affluent areas. (Clark 1997; Higginson 1999). One London-based study suggested achieving similar levels of home death rates in deprived and affluent areas required twice the resources in the deprived areas. (Higginson 2000), Tebbit (2004) suggests deprivation is, after the annual incidence of deaths, the most important factor affecting population-level need for palliative and end of life resources.

6.3 Table 6a indicates the population in Devon tends towards the national mean, in terms of deprivation, and is on average less deprived than in England as a whole. Two points should be noted here: first, index of multiple deprivation scores may fail to capture rural deprivation adequately; second, even in relative affluent areas there can be smaller pockets of marked deprivation.

Table 6a: Deprivation

Deprivation Quintile	Eastern	Northern	Southern	Devon	South West	England
Most Deprived	5.0%	7.4%	2.8%	4.8%	9.0%	20.0%
Second Most Deprived	17.6%	29.5%	12.8%	18.6%	19.1%	20.0%
Average	33.9%	40.0%	37.6%	36.3%	26.7%	20.0%
Second Least Deprived	39.8%	23.2%	38.3%	35.9%	35.0%	20.0%
Least Deprived	3.6%	0.0%	8.5%	4.4%	10.2%	20.0%

Note: Figures relates to number of lower super output areas (LSOAs) by deprivation split by quintiles, based on Index of Multiple Deprivation 2010 (IMD2010) scores

6.4 The National End of Life Intelligence Network reported (2010) that, across England, the distribution across the quintiles of deprivation for those dying in hospices is more or less equal. Conversely, a greater proportion of people dying in hospital are from deprived quintiles: people from more deprived areas are more likely to die in hospital than those from less deprived areas. These observations are borne out in what we see locally. For example, the figures for Devon for 2006-08 indicate 42.5% of people in the most deprived quintile whose underlying cause of death was cancer died in a hospital compared to 38.4% in the least deprived quintile.

6.5 If people remain in their own homes towards the end of their lives, they need both good professional support and support from informal carers. People living alone are less likely to be able to obtain informal care and a systematic review identified key factors associated with home death in people with terminal cancer as home care and its intensity, living with relatives, and extended family support (Gomes 2006). Information about the proportion of single person households helps us understand the relative difficulty of enabling people to be cared for and die at home: Populations with higher proportions of single pensioner households are likely to need higher levels of community palliative care services.

Table 6b: Single-person and all-pensioner households (percentages refer to households)

	Eastern	Northern	Southern	Devon	South West	England
Single-person households: pensioners	24510 16.8%	9618 15.6%	15338 16.6%	49466 16.5%	322420 15.4%	2939465 14.3%
Other single-person households	18972 13.0%	7569 12.2%	10883 11.8%	37424 12.5%	295392 14.1%	3210799 15.6%
Other all-pensioner households	19203 13.1%	8004 12.9%	12421 13.4%	39628 13.2%	241707 11.5%	1908837 9.3%

Source: 2001 Census

6.6 Table 6b indicates that compared to the averages for the South West and England, Devon has a higher proportion of single-person pensioner households and a lower proportion of other single-person households. These results reflect population age structures as well as urban-rural differences. Higher proportions of other single person households are characteristic of cities and larger towns; where populations are relatively younger, and the lower figures recorded in Devon are what we would expect for a population with large rural areas.

6.7 The Eastern locality is notable in that it has higher proportions of single-person households both where the person involved is a pensioner and when they are not. In total, almost 30% of people in the Eastern locality live alone. In the Southern locality, in contrast, there are high proportions of single-person pensioner households but low proportions of other single-person households.

7. Evidence of Effectiveness

7.1 Central to end of life care is excellent quality of care: “To live well in the time left to them, patients with fatal chronic conditions need confidence that their healthcare system ensures excellent medical diagnosis and treatment, prevention of overwhelming symptoms, continuity and comprehensiveness of care, advance care planning, patient centred decisions, and support for carers.” (Lynn 2008). However, end of life care is unlike other forms of care in terms of the expected outcomes and the metrics we apply to other situations may not be applicable.

7.2 There is evidence patients who receive early palliative care have less aggressive care at the end of life but survive longer with better quality of life and fewer depressive symptoms – timely intervention is essential (Temel 2010). To improve the quality of end of life care, we need clear goals, appropriate teams, means of assessing progress and improvements, and the embedding of improved processes in practice (Lynn 2002).

7.3 Murray and Sheikh (2008) describe three functional trajectories prior to death, typically associated with cancer, with organ failure, and with physical and cognitive frailty (see Figure 7.1). Comprehensive end of life care is sometimes better provided for people dying from cancer than from other conditions and is challenging because of the differing patient trajectories associated with different conditions (short decline in the case of cancer, periodic exacerbations and sudden death in organ failure, and longer decline in the case of physical or cognitive frailty) (Murray 2008). An important aspect of end of life care is that it is organised in a sufficiently flexible way to be able to provide appropriate care for people who experience each of these trajectories.

Figure 7.1 Trajectories prior to end of life

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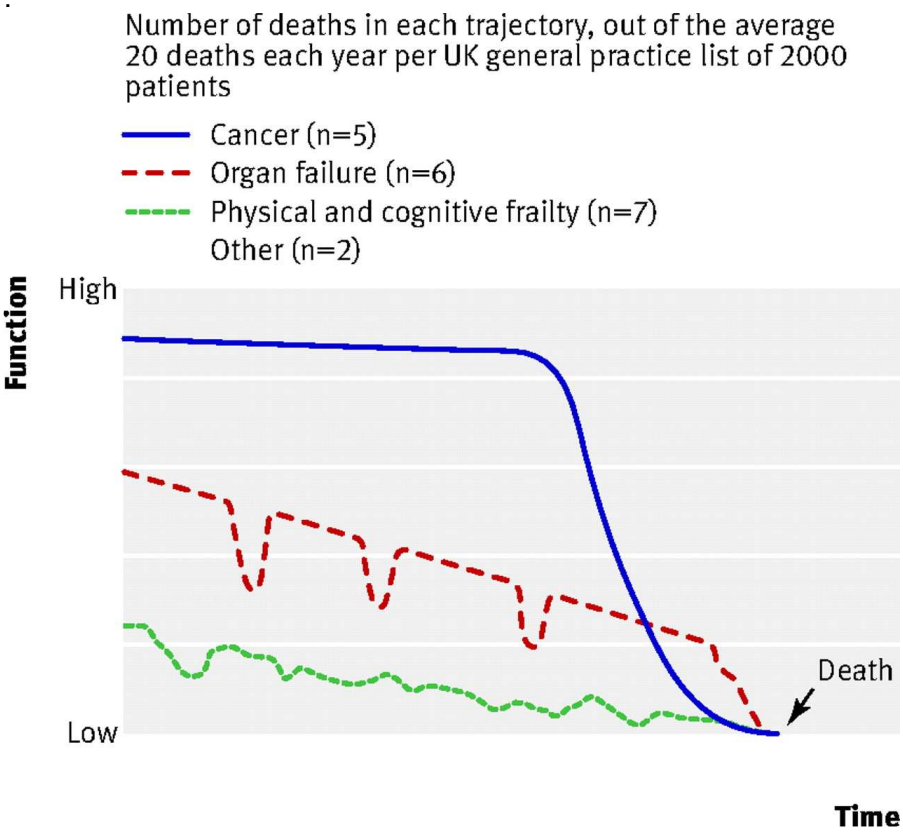

7.4 The NICE quality standard on end of life care for adults sets out 16 quality statements (NICE 2011). A local audit is needed to assess the extent to which local provision meets this standard.

7.5 Two recent documents on bereavement services have been published: a Department of Health commissioned review of evidence, and a Scottish Government consultation. The Department of Health (Arthur 2010) review on bereavement services found bereavement is associated with raised risks of

mortality, increased use of health services, and worsening mental and physical health. Information on the extent to which bereavement services change these outcomes is difficult to interpret because of differences in providers, contexts, and the range of outcomes assessed. The best evidence relates to targeted and specific intervention for people with complex grief reactions and there is no evidence to support the universal provision of intensive bereavement services. They recommended:

1. Enable universal and equitable access to first-level bereavement services.

2. Provide self-contained information about services available to all those recently bereaved, including children.

3. Do not medicalise bereavement but recognise importance of links to communities e.g. through organisations like Cruse.

4. Ensure bereavement services are not artificially separated from end of life care.

5. Provide training in grief reactions to health, education and social care staff and to voluntary sector providers.

6. Ensure greater transparency of provision, uptake and costs of bereavement services, including audit, particularly outside of hospice settings.

7.6 The Scottish Government Health Directorate Consultation Document "Shaping Bereavement Care" (2010) made recommendations relating to bereavement services at Health Board level (similar to English Primary Care Trusts in population size) proposing each should:

- nominate a board-level executive lead responsible for development and delivery of bereavement services

- identify a bereavement services co-ordinator to lead service development and promote partnership working

- review all existing services relating to end of life care and care of the deceased to assess and reduce negative impact on the bereaved

- develop a policy on care of the bereaved that ensures equity, adequate funding for services, a co-ordinated approach, and, where external services are funded, that these services are of suitable quality.

8. Current Commissioning

8.1 A independent review of palliative care funding, commissioned by the Secretary of State for Health in 2010, found the current system of funding of palliative care was confusing and called for the implementation of an NHS palliative care tariff based on need, a funding system that incentivises good outcomes for patient, and the commissioning of integrated care packages that stimulate community services (Hughes-Hallett 2011). Pilots of a new funding

system are currently taking place at seven sites (for adults) and a consortium (for children). None of the pilot sites are in the South West Peninsula.

8.2 Current commissioning for palliative and end of life care in Devon is primarily based around grants and block contracts, which are not suitable for all types of service because they give commissioners little say over volume or quality of service provided. Provision and funding, both overall and in relation to specific commissioned services, are based on historical levels rather than assessment of need.

8.3 As a consequence of these factors it is difficult to ascertain (a) what services are currently being provided in the NHS Devon area and paid for directly by NHS Devon, (b) what overlap exists between different local providers, e.g. the nursing care provided by Marie Curie Cancer Care and that provided by the hospices, (c) on what needs-related basis current levels of service provision have been established, and (d) which models of service provision are best suited to current and future patterns of local need and the relationship between these and extant models.

8.4 Inpatient provision for the NHS Devon area is currently provided by four hospices that provide a total of 56 inpatient beds (12 beds at Hospiscare in Exeter, 7 beds at North Devon Hospice, 17 beds at Rowcroft Hospice in Torquay, and 20 beds at St Luke's Hospice in Plymouth). The geographical coverage of these hospices extends beyond the NHS Devon population, however, and includes the populations of Torquay, Plymouth, and part of Cornwall.

8.5 We can benchmark local spending on end of life care by comparing local expenditure to expenditure reported elsewhere. Useful metrics for doing this include spend per death, spend per head of population, or spend per head of population aged 65 or over.

8.6 Whichever of these three metrics we look at, NHS Devon's expenditure on specialist palliative care is markedly below the national average. NHS Devon mean spend per death on specialist palliative care in 2009-10 was £453 (121st of 141 Primary Care Trusts for which data were available; mean national spend was £844 per death and interquartile range was from £556 to £1093) – see Figure 9.1. Spend per head of total population in the same year was £4.94 (103rd of 141 Primary Care Trusts; mean national spend was £7.07 per head and interquartile range was £4.62 to £10.64). Spend per head of population aged 65 or over was £22.53 (128th of 141 Primary Care Trusts; mean national spend was £43.47 per head and interquartile range was £26.58 to £74.30) – see Figure 9.2.

8.7 Bereavement services are currently commissioned in the Southern locality through an annually renewable contract with Cruse Bereavement Care. No service is commissioned elsewhere. The local hospices provide varying levels of bereavement care but this is not specified by contract.

9. Projections of Need

9.1 A number of figures have been proposed in relation to need for end of life services. Based on a systematic review, Franks and colleagues proposed a guideline figure of 40 to 50 specialist palliative care beds per million population (Franks 2000). These figures were based on studies conducted in 1990s, when different models of service may have been used, and some newer recommendations have been made. The levels of provision recommended by the National Council for Palliative Care (NCPC) are 52 beds per million population for cancer patients and 26 beds per million population for non-cancer patients. Recommendations from Sue Ryder Care as slightly lower: 41.6 beds per million population for cancer patients and 26 per million for non-cancer. Predicted levels of need for Devon using these figures for current and projected Devon populations are shown in Table 9a.

Table 9a: Projections of need for current and future Devon populations

		2011	2021*	2031*
Devon population		773423	821438	868606
Franks' estimates	Lower (40 per million)	30.9	32.9	34.7
	Upper (50 per million)	38.7	41.1	43.4
NCPC	Cancer	40.2	42.7	45.2
	Non-cancer	20.1	21.4	22.6
	Total	*60.3*	*64.1*	*67.8*
Sue Ryder Care	Cancer	32.2	34.2	36.1
	Non-cancer	20.1	36.1	22.6
	Total	*52.3*	*55.5*	*58.7*

* Devon County Council projections

9.2 In paragraph 5.2 we noted that Devon has an annual incidence of deaths 18% higher than the English average. This places it in the 20% of Primary Care Trusts with significantly higher than (>10% above) average need (de Zoete 2009) so actual levels of need are likely to be higher than those quoted.

9.3 56 inpatient specialist palliative care beds currently available locally, a figure in the middle of our estimates of need based on the NCPC and the Sue Ryder Care estimates. This does not take into account, however, (a) the fact that these beds serve a total population of over a million, not the smaller NHS Devon population, and (b) the increased level of need associated with the high local annual incidence of deaths.

9.4 These simple metrics suggest specialist palliative care beds are currently underprovided in Devon. The expected increase in Devon's population suggests even more beds will be needed in future, if a service model with similar inpatient bed usage is maintained.

10. Recommendations

10.1 Devon has an above average need for end of life care services, primarily because of the high proportion of people aged 65 or over living here. Despite this, Devon has a below average expenditure on end of life care. Local funding and commissioning of end of life care should follow, as far as possible, the recommendations of the independent review on palliative care funding, i.e. should strive to incentivise good outcomes for patients and to commission integrated care packages that stimulate community services.

10.2 The service specification for specialist palliative care needs should include not only in-patient beds but other essential services including community-based nursing, other services to enable people to live and die in their own homes, and bereavement services. It should also include consideration of the geographies to be served. Services should be commissioned equitably across Devon and in line with the guidance referred to above to ensure an integrated palliative care service is in place.

10.3 The quality of local service provision should be audited using the recently published NICE quality standard on end of life care for adults (NICE 2011).

10.4 Data linking expressed wishes about place of death and actual place of death will soon be available through the ADASTRA register. These data should be analysed and monitored to assess whether local services are providing people with what they want in relation to this aspect of end of life care, and patients and carers should be involved to ensure services meet patient expectations.

11. Acknowledgments

10.1 Members of the Devon End of Life Strategic Commissioning Group and others commented on an earlier draft of this paper and their contributions are gratefully acknowledged.

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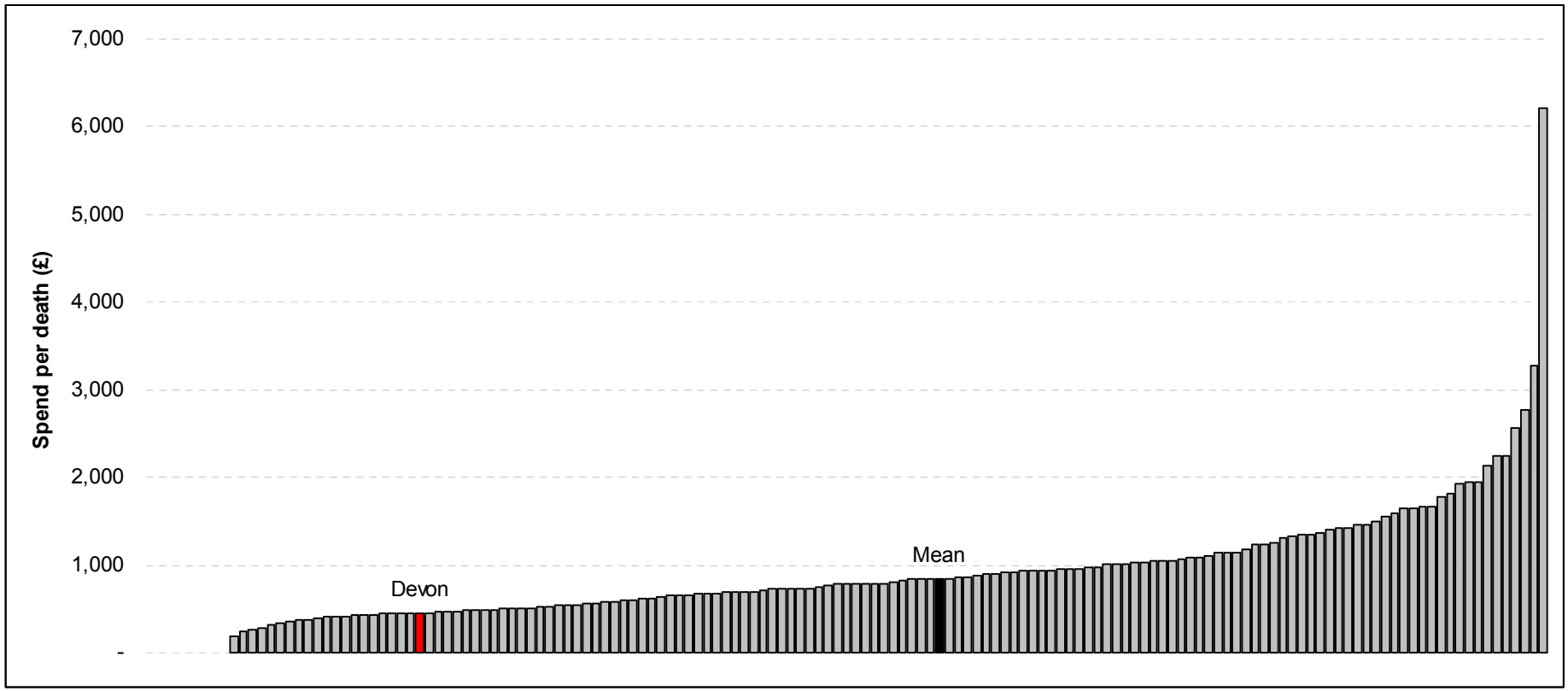
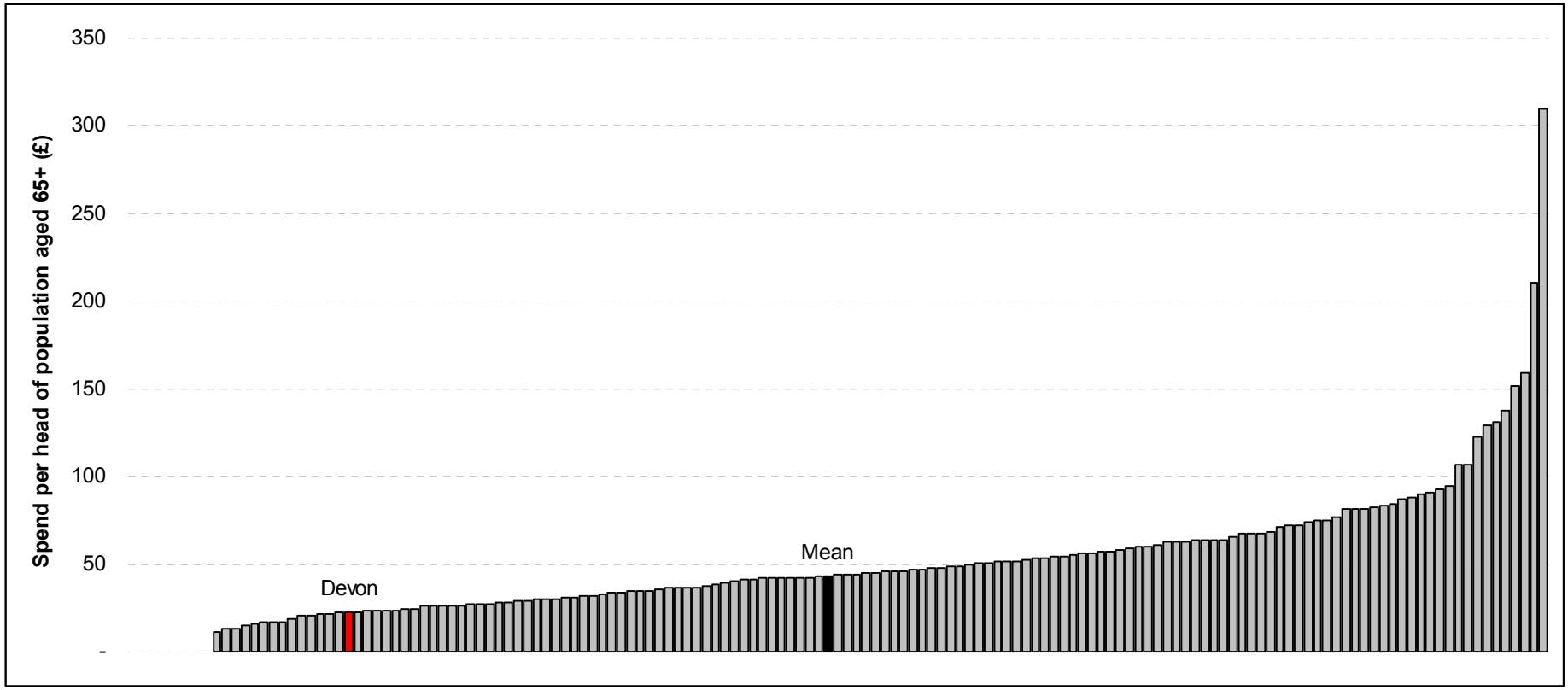
Figure 8.1 2009/10 expenditure reported by Primary Care Trusts on specialist palliative care, per death



Source: Department of Health PCT returns of Specialist Palliative Care Spend (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_130336)

Figure 8.2 2009/10 expenditure reported by Primary Care Trusts on specialist palliative care, per head of population aged 65 or over



Source: Department of Health PCT returns of Specialist Palliative Care Spend (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_130336)

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