

**The level of need for palliative
care in the Highland Council area:
Update of the previous 2008
assessment**

September 2017

About the Epidemiology & Health Science Team

As part of the NHS Highland Directorate of Public Health, the Epidemiology & Health Science team provide specialist skills in the areas of:

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1.0 Background

The previous work related to numbers of persons in their last year of life during the five year period 2003 to 2007. Projections of future numbers were based on 2004- based population projections to 2025 and the rates of need assessed during the five year period 2003 to 2007. The identification of potential palliative care need was based on particular diagnostic groups in the death records and further refined by published estimates of the rate of symptoms relevant to requiring palliative care associated with these diagnostic groups. The methods used were those described by Higginson, 1997¹ in her epidemiologically-based needs assessment. The geographical areas that were reported on were the Local Health Partnerships.

To provide the opportunity to all people in their last year of life to die where they would wish to is an important aspiration in the overall delivery of palliative care. Therefore, the place of death was also mapped across the council area as an indicator of variation that may reflect accessibility to palliative care services.

The Palliative End of Life Care Leadership group in Highland Health & Social Care Partnership (HHSCP) has requested this work with the purpose of informing the service providers (Hospice, NHS Highland hospitals, Macmillan and Marie Curie nursing) in terms of current and future numbers so as to plan and prioritise their services.

The National Institute for Clinical Excellence (NICE)² has described end of life care need as the care of those who are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and coexisting conditions that mean they are expected to die within 12 month
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events.

Therefore, any palliative care provided within the last 12 months of life is regarded as end of life care. In addition to managing physical symptoms such as pain, breathlessness, nausea and increasing fatigue, this will also include helping with anxiety, depression, social and spiritual difficulties.

The numbers in our population who may benefit from end of life care is not easy to estimate as indeed is counting the number of people who actually receive it. The latter is mostly due to the relevant data not being practically retrievable as a consequence of the wide range in types of staff or organisations delivering end of life care and in the range of settings it is delivered in for example, various clinical and social care staff delivering in a person's own home, hospital, hospice, care homes. A literature search revealed that most estimations of the number who could benefit from this care are based on a person's last year of life (those dying) and the underlying cause of their death. These together with where a person normally resides, their place of death, age, gender and the type of condition they had, will demonstrate any patterns and variations that may exist across the Health Board. Variations for example in the proportion dying at home may be an indicator of differences in the availability of services that could have enabled a person to die in their own home if they so wished.

It has been reported that the majority of people (56-74%) in their last year of life express home as their preferred place of death³. During the course of their illness, this preference may change. For example, it has been found that for those with terminal cancer, the percentage preferring home as their place of death decreased from 90% to 50% and the percentage preferring hospice, increased from 10% to 40%³. A recent published review⁴ also suggests caution around the belief that the majority of patients prefer home as their place of death. The researchers found that this applies when

responses are analysed from those who actually provided a preference but it fails to be when data from those who did not give a preference or who possibly were not asked (i.e. missing data) are included. Therefore good quality care must take into account that a preference for a place of death may change during the course of illness and that those who previously had not expressed a preference, may actually have a preference.

2.0 Methods for estimating the likely number in Highland Health & Social Care Partnership area (H HSCP) requiring end of life care

The following stages with their rationale are described below:

1. A literature search to identify any more recent needs assessments to Higginson, 1997¹. The purpose of this is to retrieve any more recent methodologies that may be an alternative to that previously used.
2. Analysis of mortality data extracted for the period of time 2009 to 2015 by area of residence and underlying cause of death. Mortality data also be extracted from the previous time period of 2003 to 2008 to identify any trends on the basis of the more recent geographical areas (9 x Community Partnerships).
3. Where relevant the results are presented by each Community Partnership area and locality in Argyll & Bute HSCP
4. Future need estimated on the basis of 2014-based population projections up to 2036.

3.0 Results

3.1 The literature search for methods of quantifying palliative care need

Search strategy

Keywords: Prevalence; end of life care; palliative care; conditions

Limits: 1998 onwards; English language

Resources: OVIDMedline; Scottish Public Health Observatory (ScotPHO); Public Health England (PHE) – Public Health Observatories; NHS England; Google/Google Scholar

Results:

Murtagh F., et al (2014) How many people need palliative care? A study developing and comparing estimates for population-based estimates. *Palliative Medicine* 28(1):49-58

<http://journals.sagepub.com/doi/pdf/10.1177/0269216313489367>

Rosenwax L., et al (2005) Estimating the size of a potential palliative care population. *Palliative Medicine* 19(7):556-562

<http://journals.sagepub.com/doi/abs/10.1191/0269216305pm1067oa>

Gomez-Batiste X., et al. (2014) Prevalence and characteristics of patients with advanced chronic conditions in need of palliative care in the general population: A cross-sectional study. *Palliative Medicine*, Vol. 28(4) 302–311 <http://journals.sagepub.com/doi/pdf/10.1177/0269216313518266>

Hughes-Hallett T., et al (2011) Funding the right care and support for everyone; creating a fair and transparent funding system; the final report of the palliative care funding review (Chapter 6 – How many people need palliative care and how many are not getting it?) https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215107/dh_133105.pdf

Calanzani N., Higginson I.J., Gomes B. (2013) Current and future needs for hospice care: an evidence-based report. Commission into the Future of Hospice Care http://cdn.basw.co.uk/upload/basw_103716-5.pdf

Kane P.M., et al. (2015) The Need for Palliative Care in Ireland: A Population-Based Estimate of Palliative Care Using Routine Mortality Data, Inclusive of Non-malignant Conditions. *Journal of Pain and Symptom Management*, Vol. 49 (4) 726-733 <http://www.sciencedirect.com.proxy.knowledgeservices.org/science/article/pii/S088539241400548X?np=y&npKey=0f21e612d5fe09e71b4ade722d0f8bb01ce85587a430f9f381d169bacd6c2610>

National End of Life Care Intelligence Network (website) <http://www.endoflifecare-intelligence.org.uk/home>

Out of these, the most relevant and most directly applicable in relation to the availability of data was the first one i.e. Murtagh F et al. This described refinements of existing methods and resulted in a specified list of underlying conditions that could be applied to mortality data. This list differed from the previous one used in 2004 as per Higginson 1997 and has the advantage of providing direct numbers without the application of estimated symptom rates. The list and specification of the included conditions are presented in table 1.

3.2 Analysis of mortality data

3.2.1 Trends in numbers potentially with end of life (EoL) care needs

The numbers arising from the extraction of mortality data based on the causes of death as specified in table 1, for the year 1980 to the most recent year for which data was available (2015), are depicted graphically (figure 1). As seen, there have been increasing trends in deaths from cancer and pre-senile & senile conditions and decreasing numbers with circulatory conditions although there has been a rise in the latter over the last two years.

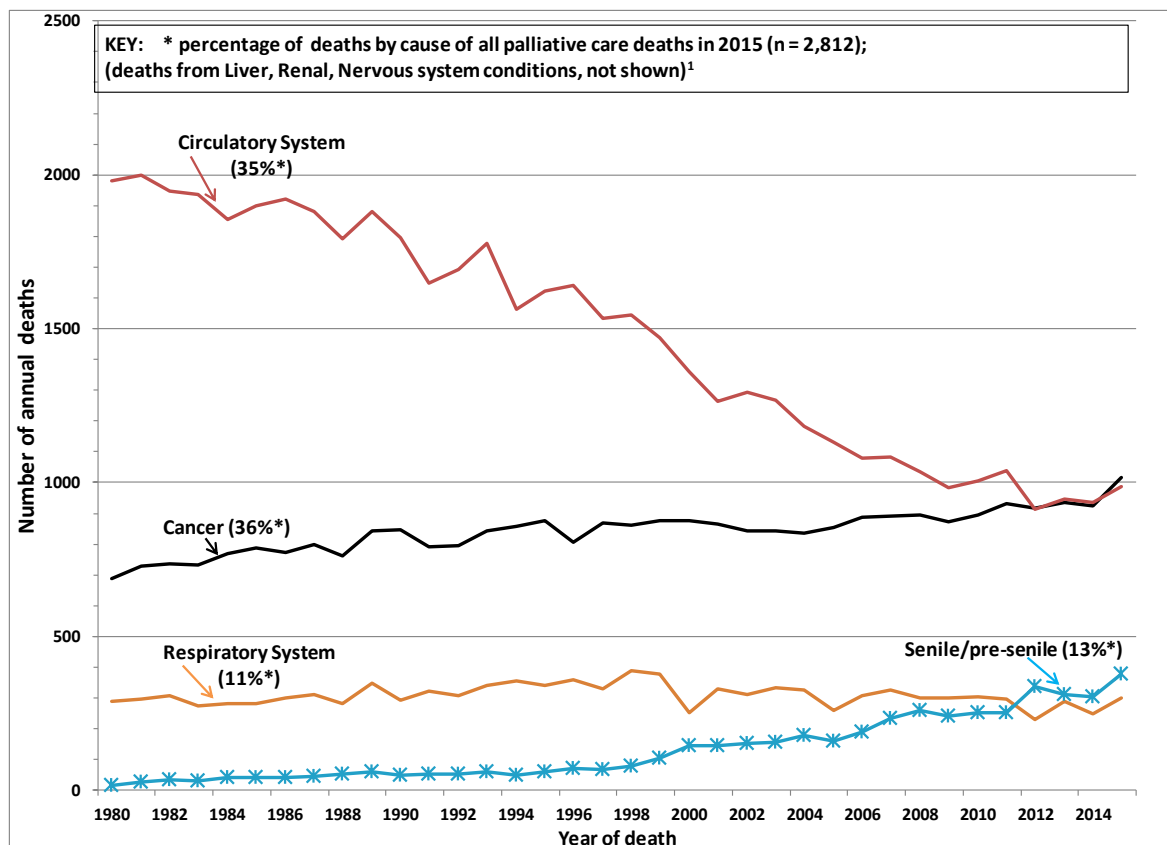
The total numbers of the potential end of life care population remained fairly constant over the last fifteen years making up around three quarters (77%) of all cause deaths (2,620 versus 3,419 average annual during 2011-2015, see figure 2). This percentage is within but at the higher end of the range previously estimated for high income countries of 69% - 82%⁵. The age composition of the potential end of life care five yearly cohorts had lower proportions of those aged under 65 years than that of the equivalent all deaths cohorts (figure 2). This reflects the higher prevalence of longer term conditions in older people as opposed to the more sudden causes of death e.g. from accidents in younger people. Both cohorts reflected the same increasing trend in the proportion of the oldest age group (85 years & over) during the last fifteen years increasing from 29-30% to 35-36% which reflects the ageing population (figure 2).

Table 1: Sub-groups & individual conditions (all ages excluding neonatal deaths)

	Category no.	ICD9 (inclusive)	ICD10 (inclusive)
Cancers			
Lung, Trachea, Bronchus	C1	162	C33-C34
Lip; oral; Pharynx; Larynx	C2	140-149; 161	C00-C14; C32
Digestive; peritoneal	C3	150-159	C15-C26
Female breast	C4	174	C50
Genitourinary	C5	179-189	C51-C68
Lymphatic & Hemopoietic	C6	200-208	C81-C96
Other unspecified	C7	190-199	C76-C80
Multiple primary sites	C8	N/K	C97
Circulatory			
Ischaemic Heart Disease	H1	410-414	I20-I25
Stroke	H2	430-468	I60-I69
Cardiac Failure	H3	428	I50
Hypertensive Disease	H4	401-405	I10-I11
Coronary Heart Disease	H5	393-398	I00-I09; I20-I52
Respiratory			
Pneumonia	R1	480-486	J12-J18
Influenza	R2	487	J10-J11
COPD	R3	490-496	J40-J47
Selected others: Laryngopharyngitis, bronchiolitis; bronchitis; URI	R4	4650;4658;4659;4660; 46611;46619;51851; 51853;51881;51883; 51884	J06-09; J20-22; J96
Nervous S. & Sensory organs			
Motor Neurone	N1	3352	G122
Multiple Sclerosis	N2	340	G35
Parkinsons	N3	332	G20
Huntingtons	N4	3334	G10
Multiple system degeneration	N5	3330	G903
Senile & Pre-senile conditions			
Alzheimers Dementia	S1	3310	G30
Vascular dementia	S2	2904	F01
Unspecified Dementia	S3	2900; 2901;2902	F03
Senility	S4	797	R54
Liver disease			
Chronic Liver disease		571-572	K70-K77
Alcoholic liver disease	L1	5710-5713	K70
Others not selected above	L2	Others NS	K71-K77
HIV AIDS	V	042-044	B20-B24
Renal disease			
Acute renal failure	G1	584	N17
Chronic kidney disease	G2	585-586	N18
Other disorders of kidney and ureter, not elsewhere	G3	593	N28
Hypertensive renal disease	G4	4031; 4039	I12
Hypertensive heart & renal disease	G5	4040; 4041	I13

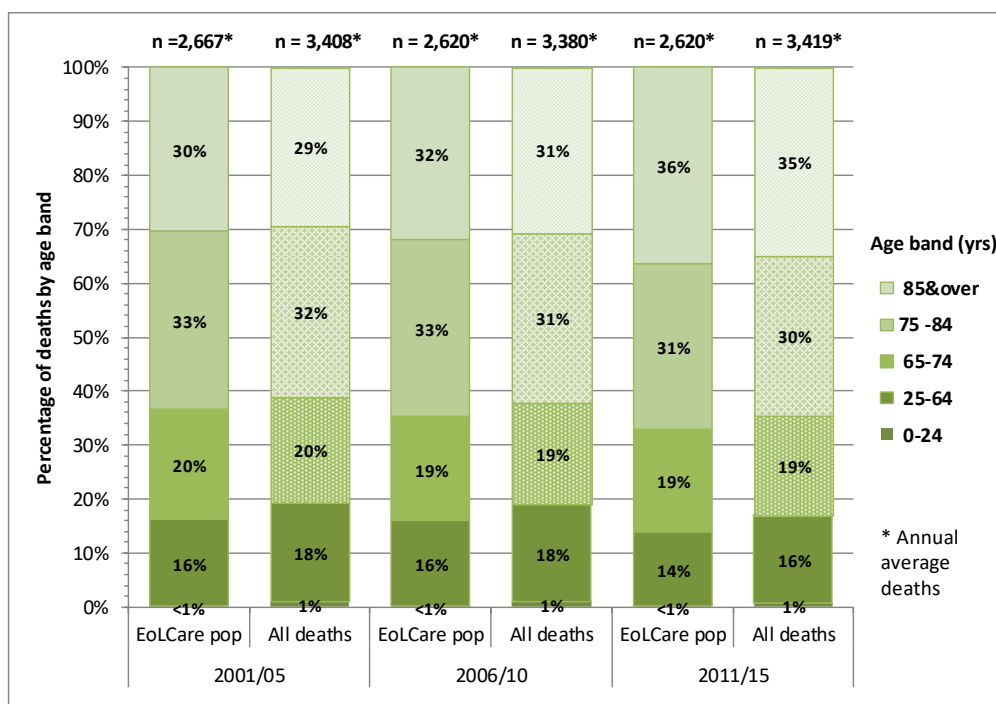
Source: Based on Murtagh FEM et al 2014 and adapted for pre- 2000 coding of deaths

Figure 1: Deaths from underlying causes relevant to the need for palliative care: NHS Highland residents from 1980 to 2015



Analysis of Mortality data (NRS) using codes for underlying cause relevant to palliative/end of life care as per table 1
¹ Proportions of all deaths were: Nervous system, 2%; Liver; 2%; Renal, <1%

Figure 2: Age composition of five year death cohorts: deaths from potential End of Life (EoL) Care causes compared to deaths from all causes: 2001 to 2015, NHS Highland residents

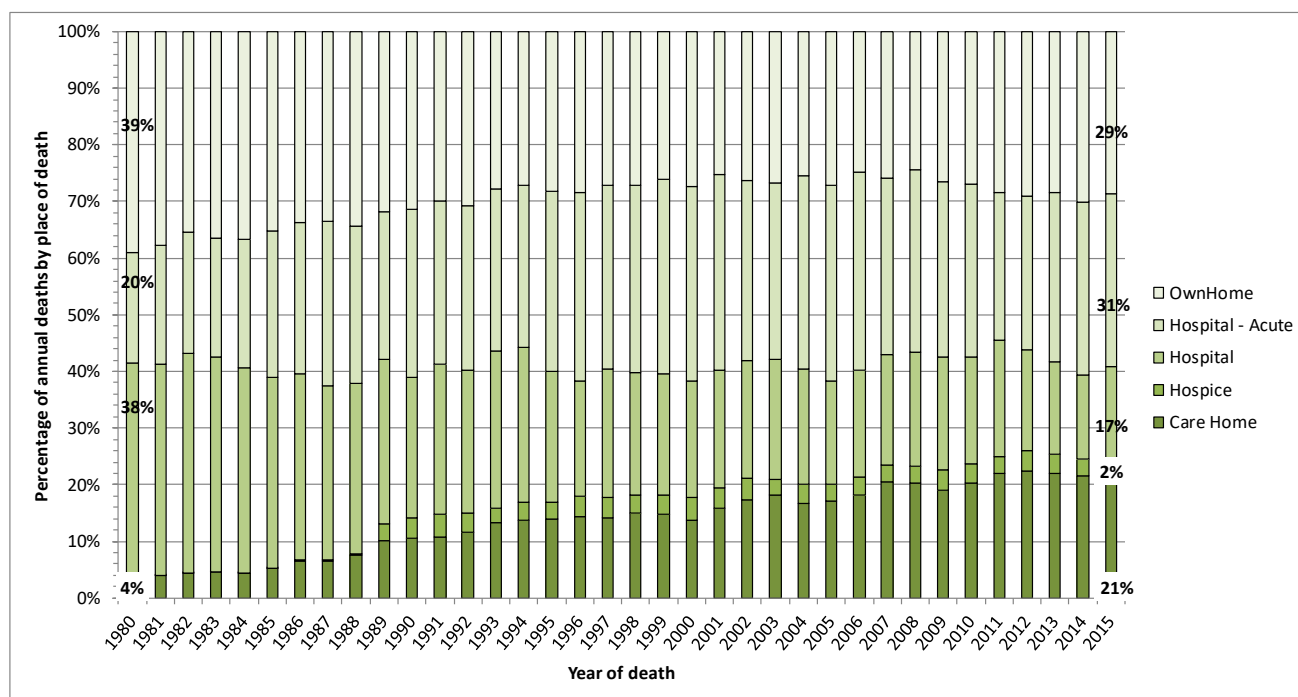


Source: Analysis of mortality data (NRS) by specific underlying causes of death relevant to palliative/EoL care (see table 1)

3.2.2 Potential end of life (EoL) care needs population by place of death

Over the period from 1980 to 2015, the percentage of all deaths from causes potentially requiring EoL care showed the following trends by place of death (figure 3): reduction dying in own home from 39% to 29%; decrease in dying in non-acute hospitals from 38% to 17%; increase in dying in care homes from 4% to 21%; increase in dying in acute hospitals from 20% to 31%; similar percentages (3-4%) dying in a hospice from 1989 onwards. Some of these trends most likely reflect changes in the availability of settings such as community hospital and care home places, but the inverse trends in rates of deaths in acute hospitals and in a person's own home possibly is the result of increased expectation for EoL care and the limited capacity in the community outside of nursing homes to deliver it.

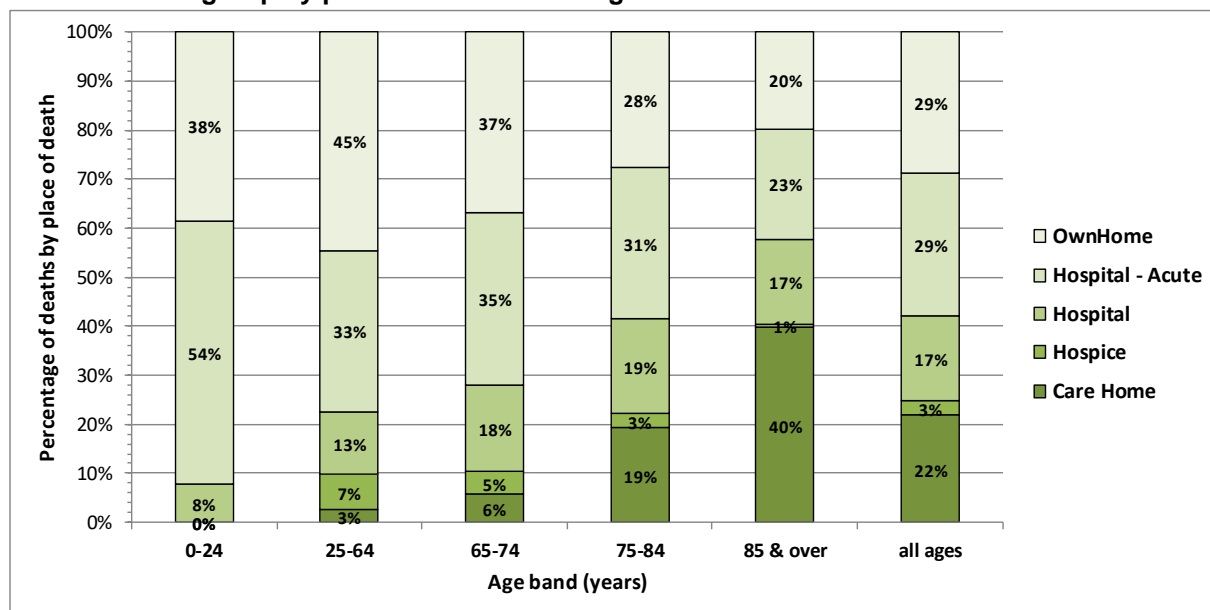
Figure 3: Trends in the percentage of total annual deaths with indicative end of life (EoL) care needs by place of death: 1980 to 2015 NHS Highland residents



Source: Analysis of mortality data (NRS) by specific underlying causes of death relevant to palliative/EoL care (see table 1)

The place of death varied with age group (Figure 4). The younger age group (0-24years) was more likely to die in an acute hospital, the 25 to 64 year age group, most likely to die at home (45%) and Care Homes were increasingly the place of death in those aged 65 years and over. For the oldest group (85 years & over), 60% died at home or in a Care Home compared to 43-47% for those aged 65 -74 and 75-84 years. Approximately one third (31-35%) of the EoL care population aged 25 to 84 years, died in an acute hospital. The proportion was lower (22%) in those aged 85 years and over.

Figure 4: The percentage of deaths¹ from causes relevant to end of life (EoL) care within each age group by place of death: NHS Highland residents

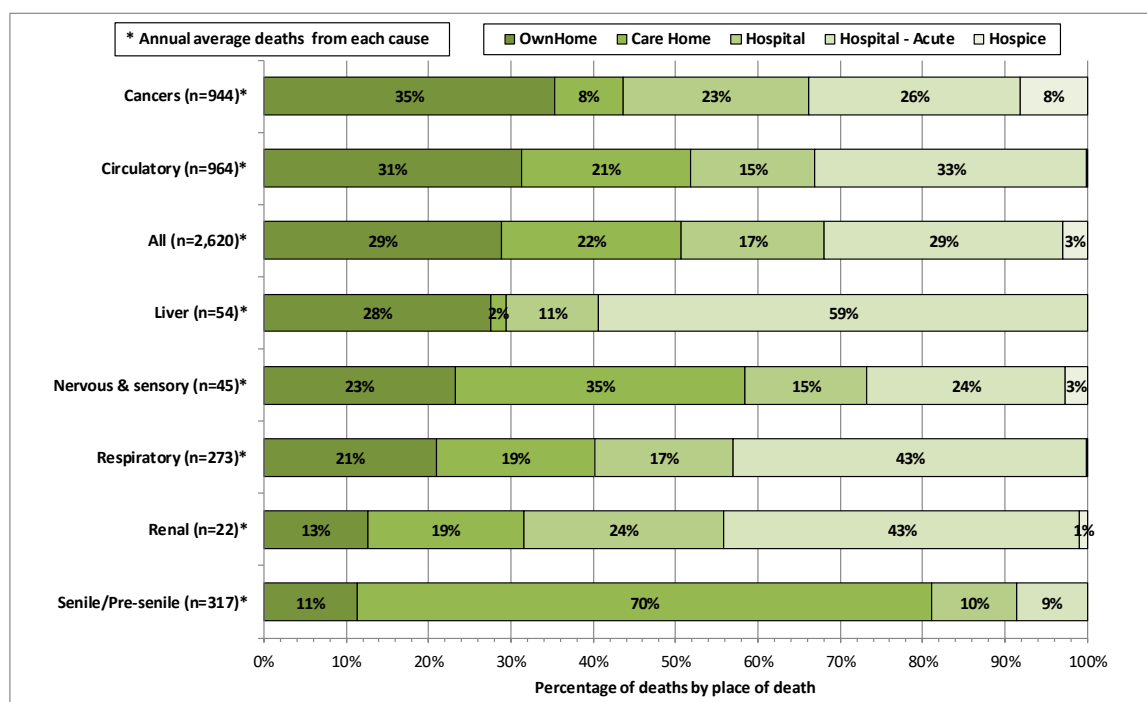


¹Numbers over the five year period 2011 to 2015;

Source: Analysis of mortality data (NRS) by specific underlying causes of death relevant to palliative/EoL care (see table 1)

The place of death also varied between the categories of the underlying causes of death (figure 5). The highest percentage dying at home was from cancer (35%) and the lowest was from senile/pre-senile conditions (11%). Those dying from liver, renal or respiratory conditions were more likely to die in an acute hospital (43-59%). Less than 10% of those with cancer died in the hospice but out of the other causes only those dying with kidney or nervous/sensory related conditions recorded some deaths in a hospice.

Figure 5: Potential end of life (EoL) care population¹ for each category of condition: proportion by place of death in descending order of the percentage dying at home



¹Numbers over the five year period 2011 to 2015;

Source: Analysis of mortality data (NRS) by specific underlying causes of death relevant to palliative/EoL care (see table 1)

There were also differences in the place of death between the genders (table 2). In most cases a greater proportion of men died at home than women (34% compared to 23% overall). The exceptions were again nervous/sensory or kidney related conditions where a higher percentage of females died at home.

Table 2 : Percentage of deaths potentially needing end of life (EoL) Care in the population of NHS Highland during the five year period 2011-2015 occurring in own home by gender for each main category of condition

Cause of death ¹	Gender	Dying in own home	Number of total deaths	Number of annual deaths
Cancers	F	33%	2,261	452
	M	38%	2,461	492
Circulatory	F	24%	2,423	485
	M	39%	2,399	480
all	F	24%	6,803	1,361
	M	34%	6,297	1,259
Liver	F	25%	102	20
	M	29%	166	33
Nervous & sensory	F	25%	117	23
	M	21%	107	21
Respiratory	F	21%	713	143
	M	21%	651	130
Renal	F	19%	54	11
	M	7%	57	11
Senile/Pre-senile	F	11%	1,133	227
	M	11%	453	91

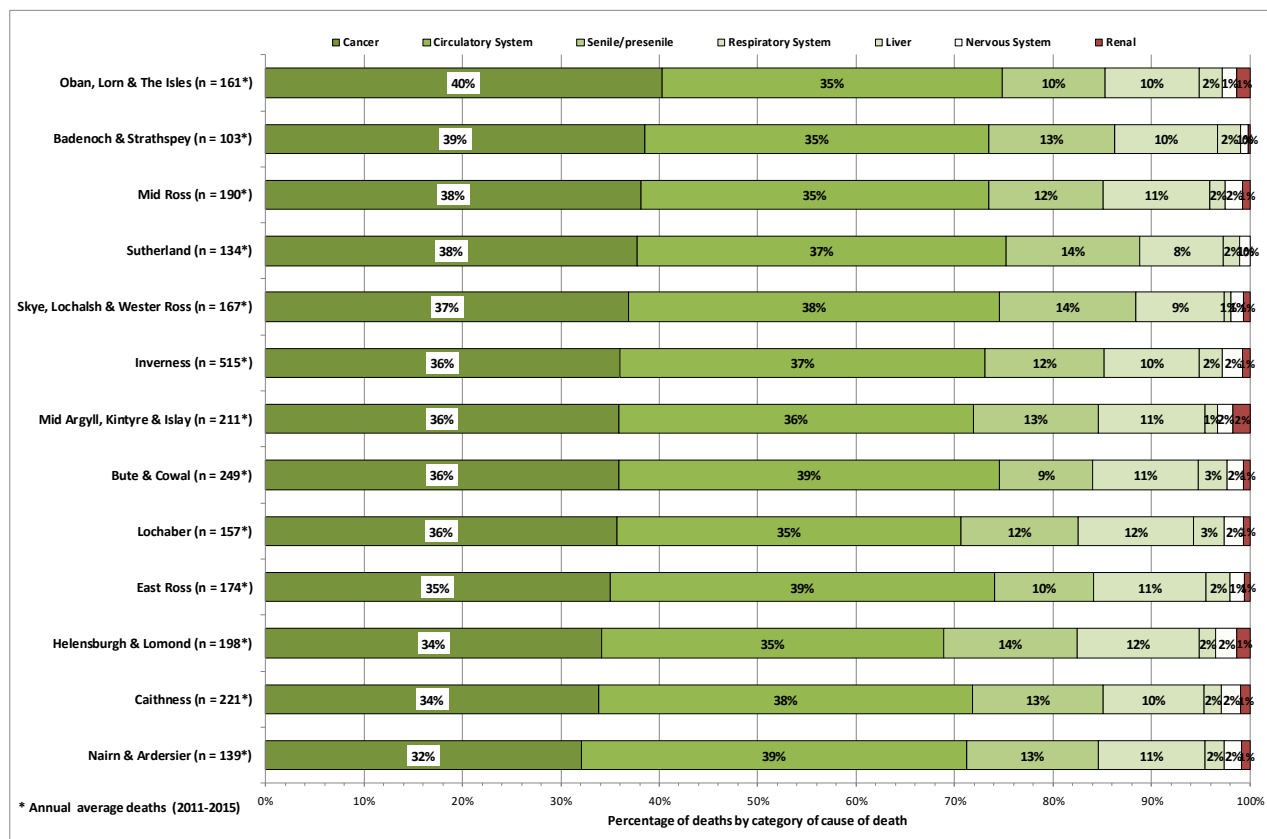
Source: Analysis of mortality data (NRS) by specific underlying causes of death¹ as defined in table 1

3.2.2 Potential EoL care needs population by geography (area of residence)

Using the postcodes of the normal place of residence recorded on the mortality data, the numbers and equivalent rates of those with potential end of life care need of the sub-areas of community partnerships (CPs), (9 CPs in Highland Health & Social Care Partnership (HHSCP) and localities (4 localities in Argyll & Bute Health & Social Care Partnership (HSCP)) of NHS Highland were derived. It should be noted that the boundaries of these CPs at the time of analysis were those provided to NHS Highland (NHS H) as at December 2016 and not updated in respect of Ardersier which was later withdrawn from Nairn and placed in Mid Ross by Highland Council.

The pattern by major cause of death amongst the EoL care population in each of the CPs and localities demonstrated the highest percentages from cancer in Oban, Lorn & the Isles, Badenoch & Strathspey, Mid Ross and Sutherland (figure 6).

Figure 6: Potential end of life care population¹ in each geographical area² in NHS Highland: proportion by cause of death in descending order of the proportion dying from cancer

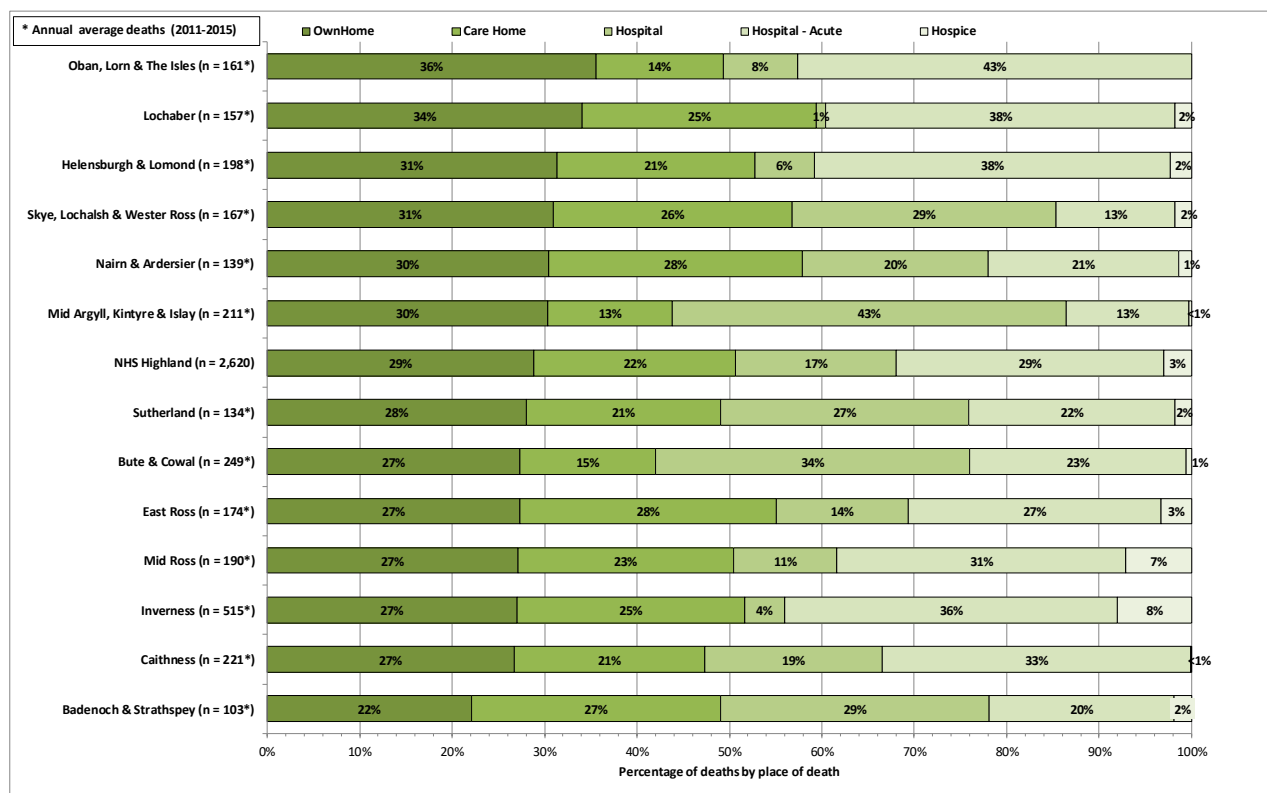


Source: Analysis of mortality data (NRS) by specific underlying causes of death¹ as defined in table 1; ² areas for the Community partnerships defined by Highland Council in December 2016 and localities within Argyll & Bute HSCP

The proportion of deaths occurring at home also varied across these geographies with the highest (36%) in Oban, Lorn & the Isles but this locality also recorded the highest percentage dying in acute hospitals (43%)., (figure 7). Higher than the average percentages of deaths occurring in an acute hospital (29% overall for NHS H), were recorded for residents living in areas with the nearest access to an acute hospital: OLI (43%); Lochaber (38%); Inverness (36%), Caithness (33%) although the higher rate in Helensburgh & Lomond (38%), may reflect its proximity to the Vale of Levens Hospital some 20 minutes' drive away. On average, around one half of the deaths occurred either in a person's own home or in a care home. Localities with higher than the average rate were Lochaber (59%); Nairn & Ardersier (58%); Skye, Lochalsh & Wester Ross (57%); Easter Ross (55%). Lower rates were recorded for Bute & Cowal (42%) and Mid Argyll, Kintyre & Islay (43%).

Deaths occurring in the hospice (3% overall) were more common in residents of areas nearest to the hospice in Inverness, Mid Ross, 7%; Inverness, 8%.

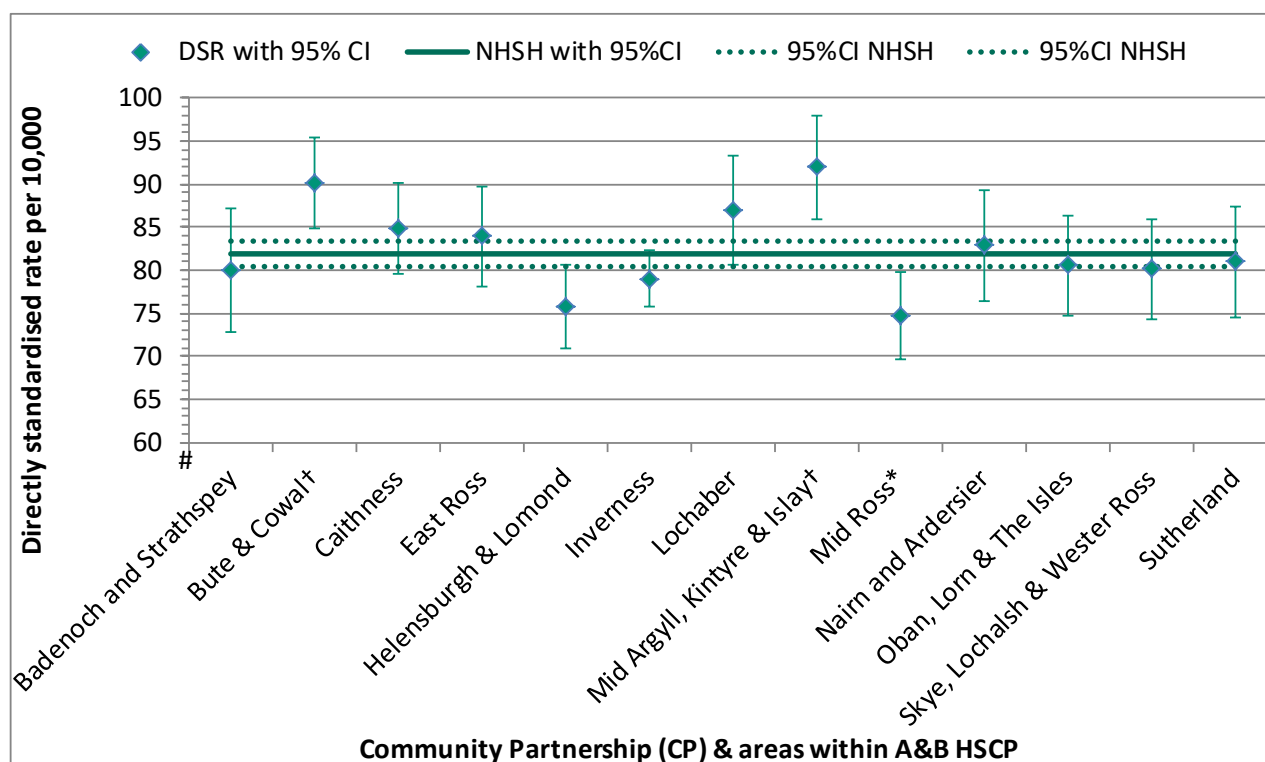
Figure 7: Potential end of life care population¹ in each geographical area² in NHS Highland: proportion by place of death in descending order of the percentage dying at home



Source: Analysis of mortality data (NRS) by specific underlying causes of death¹ as defined in table 1; ² areas for the Community partnership defined by highland Council in December 2016

The rates of deaths from causes relevant to the need for EoL care for each of the sub-geographies of NHS Highland were directly standardised to correct for any differences between the age and gender proportions of the different populations. There was a wide range in rates across the Health Board (figure 8). Amongst these, the rates of the EoL Care populations of Bute & Cowal and Mid Argyll, Kintyre & Islay were statistically higher than the overall rate for NHS Highland. Across the CPs of Highland HSCP, the population rate of Lochaber was the highest and that of Mid Ross the lowest but only the latter was statistically significant.

Figure 8: Directly standardised death rates (DSR)¹ from all causes likely to need palliative care pertaining to residents of each of the community partnerships² in Highland Health & Social Care Partnership (HSCP) and geographies in Argyll & Bute HSCP



¹Deaths 2011-2015 (NRS) based on 2011 datazone definition and 2011-2015 populations (Scottish Government) and directly standardised to the European standard population, 2013. ²Community Partnership areas defined by Highland Council as at December 2016; † statistically significantly higher; * statistically significantly lower than NHS Highland (NHS) rate

In terms of the category of condition, the rate for Mid Ross was statistically lower and that for Bute & Cowal and East Ross, statistically higher for circulatory causes than the Health Board average (table 3).

Table 3: Directly standardised mortality rates (DSR) (with 95% confidence intervals) from causes with potential end of life need: Average deaths and populations over the five year period 2011-2015

Geographic area ²	All Palliative causes		Cancer causes		Circulatory causes		Respiratory causes		Senile/Pre-senile	
	DSR + 95%CI ¹	Rank	DSR + 95%CI ¹	Rank	DSR + 95%CI ¹	Rank	DSR + 95%CI ¹	Rank	DSR + 95%CI ¹	Rank
Badenoch and Strathspey	70.0 ± 7.2	10	29.7 ± 4.3	4	29.2 ± 4.5	10	8.5 ± 2.4	9	10.4 ± 2.7	7
Bute & Cowal	90.2 ± 5.3	2	32.6 ± 3.1	1	35.2 ± 3.3	1	10.0 ± 1.8	3	7.9 ± 1.6	13
Caithness	84.8 ± 5.3	4	27.3 ± 2.9	10	33.3 ± 3.4	4	9.3 ± 1.8	7	11.3 ± 1.9	5
East Ross	83.9 ± 5.9	5	28.1 ± 3.3	8	34.4 ± 2.6	2	9.6 ± 1.4	4	8.6 ± 1.3	11
Helensburgh & Lomond	75.7 ± 4.9	12	25.6 ± 2.8	13	27.0 ± 3.0	12	9.5 ± 1.8	6	9.8 ± 1.8	8
Inverness	79.0 ± 3.2	11	27.7 ± 1.8	9	29.8 ± 2.0	9	8.0 ± 1.0	10	9.6 ± 1.1	9
Lochaber	87.0 ± 6.4	3	28.7 ± 3.5	7	30.1 ± 3.7	8	11.4 ± 2.5	1	11.9 ± 2.6	2
Mid Argyll, Kintyre & Islay	92.0 ± 6.0	1	31.5 ± 3.3	3	34.4 ± 3.8	3	10.4 ± 2.1	2	11.9 ± 2.3	1
Mid Ross	74.7 ± 5.0	13	27.3 ± 2.9	11	26.6 ± 3.0	13	8.9 ± 1.8	8	9.4 ± 1.9	10
Nairn and Ardersier	82.9 ± 6.4	6	26.5 ± 3.6	12	32.8 ± 4.1	5	9.6 ± 2.3	5	10.5 ± 2.2	6
Oban, Lorn & The Isles	80.6 ± 5.9	8	31.9 ± 3.6	2	28.8 ± 3.6	11	7.8 ± 1.0	11	8.1 ± 1.8	12
Skye, Lochalsh & Wester Ross	80.1 ± 5.8	9	28.8 ± 3.4	6	30.9 ± 3.6	7	7.6 ± 1.8	12	11.4 ± 2.2	3
Sutherland	81.0 ± 6.5	7	29.7 ± 3.8	5	31.1 ± 4.1	6	7.4 ± 2.0	13	11.3 ± 2.5	4
HHSCP	82.0 ± 1.5	-	28.7 ± 0.8	-	30.8 ± 0.9	-	9.0 ± 0.5	-	10.0 ± 0.5	-
NHSH	80.9 ± 1.8	-	28.0 ± 2.2	-	30.6 ± 2.4	-	8.7 ± 1.3	-	10.3 ± 1.4	-

Statistically significantly higher or lower than the average rate for NHS Highland (NHSH) overall

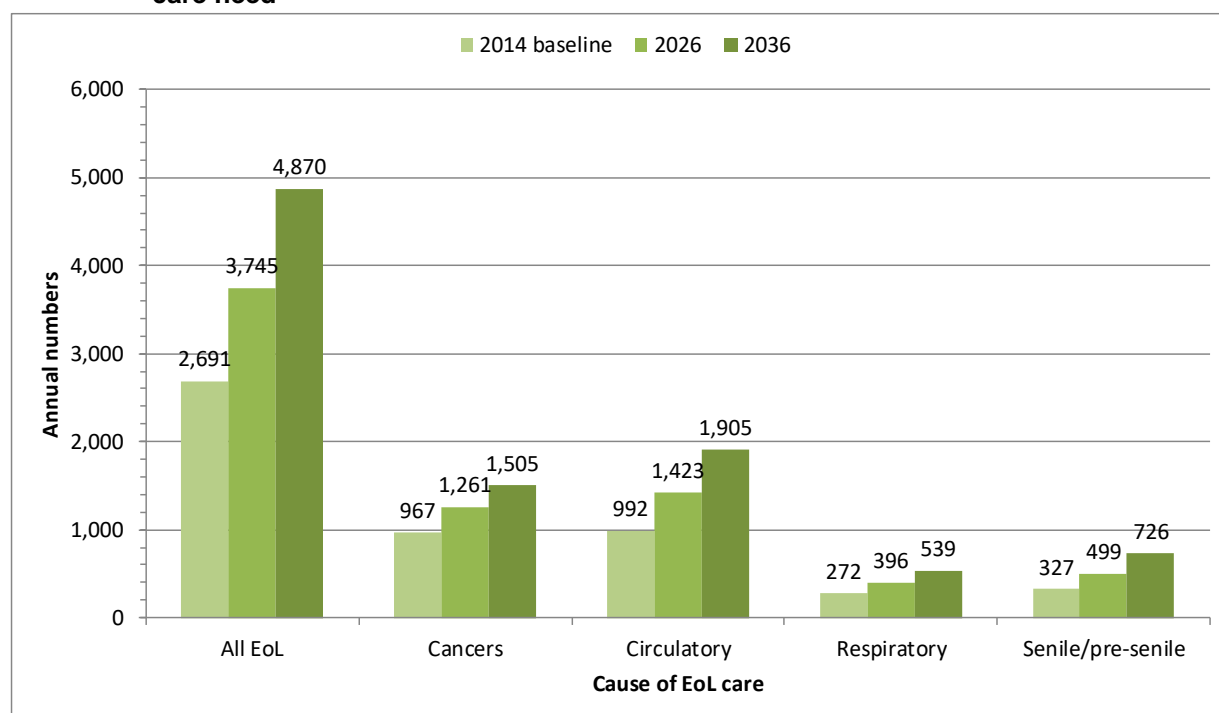
¹Directly standardised rates per 10,000 to the European standard population 2013: deaths 2011-2015 based on 2011 datazone definitions and 2011-2015 populations, NRS & Scottish Government

²Community Partnerships as defined by Highland Council as at Dec. 2016; Argyll & Bute HSCP

4.0 Projection of end of life (EoL) care populations

Assuming that the average age/sex specific rates for the period 2011-2015 apply for the next 10-20 years, the numbers expected on the basis of the annual average & gender rates applied to population projections are shown in figure 9.

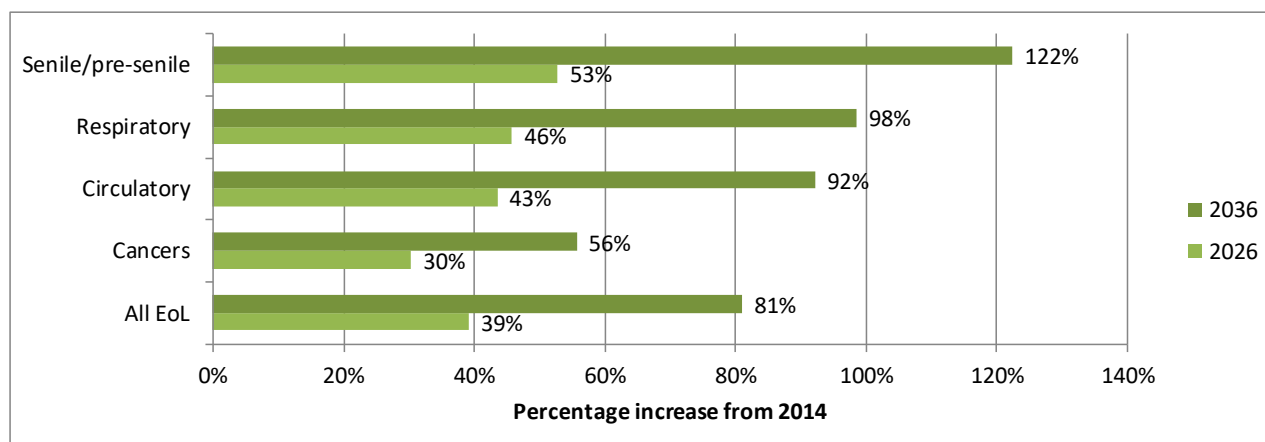
Figure 9: Baseline and projected numbers¹ of the NHS Highland population with end of life (EoL) care need



¹Actual age/sex death rates averaged for 2011-2015 applied to 2014-based mid year projections for Health Board areas (NRS & Scottish Government)

These increased EoL care populations represented the following percentage changes from 2014 annual numbers (figure 10):

Figure 10: Percentage increase from 2014 in the projected¹ end of life (EoL) care populations of NHS Highland in 2026 and 2036



¹Projections from 2011-15 rates applied to 2014-based population projections (NRS & Scottish Government)

The greatest increase is projected to be for those with senile/pre-senile conditions with 2.2 times the population in 2036 than in 2014 (figure 10).

The main caveat with these projections is that life-expectancy is increasing without a proportionate increase in healthy life expectancy. However, the modelling for this is complex and does not take account of any future improvement in community anticipatory care further upstream in the frailty status.

5.0 Summary

- The method for estimating numbers of people with potential end of life (EoL) care need in their last year of life was updated from the previous 2008 assessment but still involved analysis of mortality data in respect of specific causes of death. Caveats are that some numbers by category of condition will be over-estimated and others under-estimated depending on the course of their condition.
- Over the last 35 years there have been very significant trends in the numbers of the different types of conditions for which EoL care is needed: decreasing numbers associated with the circulatory system and increasing numbers with cancers and senile/pre-senile conditions. For the most recent year (2015) the percentage of the total EoL care population of NHS Highland, was 35% with cancers; 36% with circulatory conditions; 13% with senile/pre-senile conditions and 11% with conditions of the respiratory system.
- During 2011 to 2015 from the population of Highland HSCP, 51% died in either their own home (29%) or in a care home (22%). The remainder died in an acute hospital (29%), non-acute hospital (17%), or a hospice (3%)
- The place of death varied by type of condition. Relative to the overall profile (51%), lower percentages of deaths in community settings (own home/care home) were experienced by those dying from liver, renal, respiratory related conditions or cancers (30%, 32%, 40% and 43% respectively).

- Those dying from senile/pre-senile conditions or from conditions related to the nervous/sensory system were more likely than the overall profile (51%) to die in a community setting (81% and 58% respectively).
- Overall, 29% died in an acute hospital but those with liver (59%), renal (43%), respiratory (43%), or circulatory conditions (33%) were more likely to die in this setting.
- Men overall were more likely to die in their own home (34%) than women (24%). This was true for all conditions other than for Renal and Nervous/Sensory conditions where women were more likely to die at home and for respiratory conditions and for senile/presenile conditions, where similar rates applied.
- Within NHS Highland, the EoL care populations of geographies nearest to the hospice in Inverness had the highest proportions of deaths occurring in a hospice (Inverness, 8% and Mid Ross, 7%). Similarly, areas closest to an acute hospital had higher percentages of deaths there; Oban, Lorn & the Isles (43%), Lochaber (38%), Inverness (36%) and Caithness (33%) compared to the overall average rate of 29%. The rate relating to the population of Helensburgh & Lomand was relatively high (38%) considering the non-proximity to an acute hospital.
- Relative to the average for the overall population of NHS Highland, standardised rates of death with a potential for EoL care need were statistically significantly higher for the populations of Bute & Cowal and Mid Argyll, Kintyre & Islay but statistically significantly lower for Mid Ross. When compared by category of cause, the rates were found to be higher for the populations of Bute & Cowal and East Ross and lower in Mid Ross for circulatory causes of death.
- Projections suggest that there will be over 3,700 and 4,900 numbers of people with EoL care need in 2026 and 2036 respectively in NHS Highland. This equates to a 39% and 81% increase in current numbers respectively
- The largest projected increase is in those with senile/pre-senile conditions where the numbers could increase by 2.2 times in the next 20 years.

6.0 Implications for the future

Within the limitations of the indirect method of estimating the current and future populations in need of end of life care, it is likely that numerically they will at least double in the next 20 years and there will be relatively more of them dying with senile/pre-senile conditions and cancers. Both the numbers and the likely complexity of caring for those with senile/pre-senile conditions contribute to a substantial care need for future populations which demographically will be older with proportionately fewer younger people to support their care.

In the current context of NHS strategy to increase the care provided in the community, there have been trends over the last 35 years of increasing proportions of deaths occurring in an acute hospital and decreasing proportions in non-acute (community) hospitals. It is also likely that the increasing proportion of deaths occurring in Care Homes will not continue unless Care Home places increase in proportion to the ageing population. According to the care home census data for Scotland⁶, the number of care homes and the number of registered care home places for older people have decreased by 9% and 1% respectively from 2006 to 2016. Over the same 10 year period, the number of care home places for older people per population aged 65 years & over has reduced in Highland and Argyll & Bute council areas by 16% and 14% respectively. This means that for the future, residents of care homes (not necessarily those that self-fund) will have increasing complexity of need which is unlikely to be fully met. Therefore, other settings of care for those at the end of life need to be assessed and implemented in the next 20 years.

This report has used data from routinely available sources and does not provide the most useful information needed for planning for future effective care. A major limitation is that we have the place of death but not how much time was spent in different settings prior to death. The latter has now been adopted as a national quality outcome measure and provides the percentage of time spent in the last 6 months of life in a community setting. However, it does not take account of the cause of death which can be an important consideration for palliative and end of life care needs nor does it allow intelligence of any variation due to geographical location of populations and services within the Health Board area.

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