

# End of Life

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## JSNA Report

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## This report

This report has been prepared jointly by Knowsley Council, NHS Knowsley Clinical Commissioning Group (CCG) and partners of the Knowsley Health and Wellbeing Board (HWB).

### Purpose and scope of this report

Its purpose is to provide an analysis of end of life care in Knowsley, understanding this area helps the HWB determine the level of priority that the issue should be given in the Borough's Health and Wellbeing Strategy.

The report identifies the extent, variation and trends relating to mortality in Knowsley and covers a wide range of data relating to the Knowsley population. It presents analyses of the number of deaths in Knowsley, relative comparisons with national picture and variations across the borough. Where possible, the analysis looked at the historical trends to see whether needs had increased or decreased and whether this was part of a sustained trend.

The report also considers the range of services relating to end of life care as well as considering the evidence alongside national recommendations and ambitions in relation to end of life care.

### Quality of data and intelligence available

Data can sometimes lead to constructing misleading pictures, and some data is more vulnerable to misinterpretation than others. Some cautionary notes are included to highlight where data is not always fully complete, up to date, or is perhaps compiled by means of people self-reporting their behaviour.

This is one of a series of reports that comprise Knowsley's Joint Strategic Needs Assessment (JSNA).

## Contacts

For information about this report please contact:

Ian Burkinshaw, Research & Intelligence Manager, Knowsley Council

Phone: 0151 443 3067

Email: [ian.burkinshaw@knowsley.gov.uk](mailto:ian.burkinshaw@knowsley.gov.uk)

## Further information

For a PDF copy of this report, and other research intelligence products, visit **Knowsley Knowledge** – the website of Knowsley's JSNA

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# End Of Life Care

## 1. Introduction

### 1.1 Why end of life care is important

End of life (EOL) care relates to care experienced by people who have an incurable illness and are approaching death. It is about providing support that meets the needs of both the person who is dying but also those who are important to them. It includes not only the management of symptoms but also the provision of psychological, social, spiritual and practical support. Good care enables people to make choices about their care and to live in as much comfort as possible until they die. End of life care provides some unique challenges which differentiate it from many other areas of health and social care where, although treatment and care may be similar, the anticipated outcomes are significantly different. In particular it provides a challenge around communication, given the significance of end of life which, for patients, families and carers, may leave a legacy, positive or negative, that lasts for many years.

### 1.2 Scope of end of life care

Before considering end of life care in terms of any needs assessment it is important that we understand the scope of services which are relevant and it is helpful to illustrate this by using the North West end of life care pathway developed in 2009. This considers end of life care as something which relates to services in place from the point at which it is felt a particular disease trajectory is likely to result in a patient's death through to the period after the death and the impact on those people for whom that individual was important. This can be a relatively short period of time but can, in the case of progressive and degenerative diseases, be of considerable length, particularly relevant when an individual's mental capacity is reduced by the disease or condition.



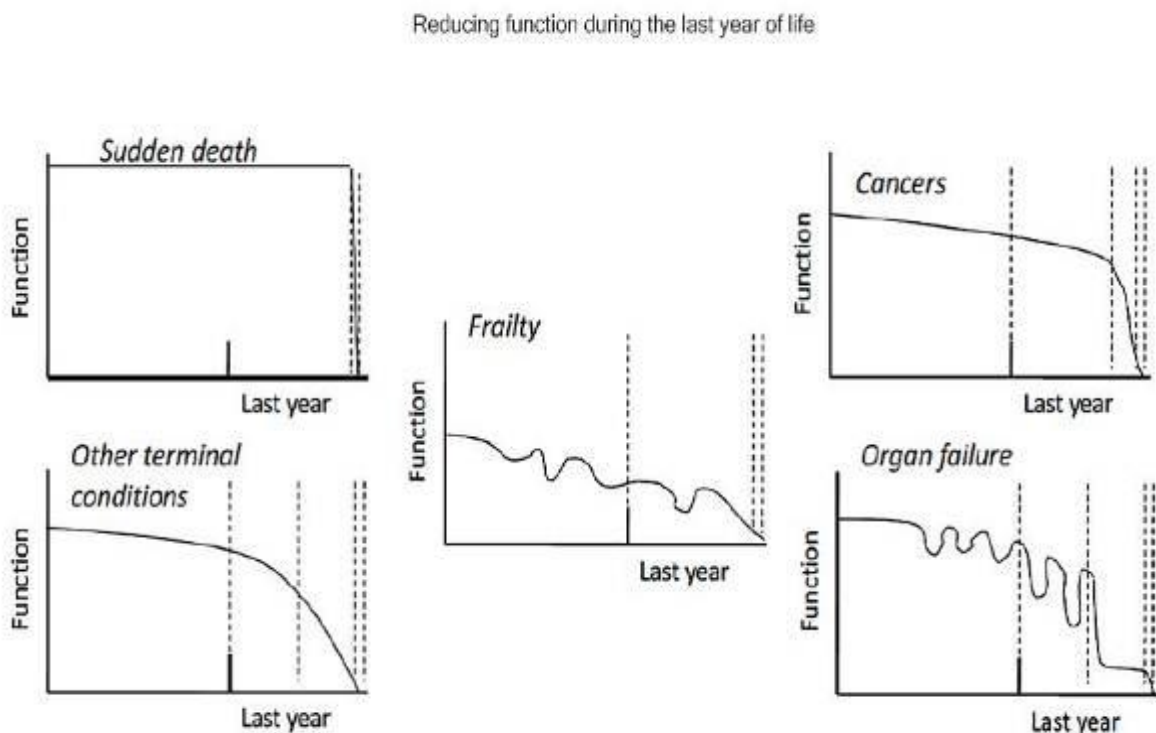
In Knowsley we aim to improve people's choice about their health and care, especially as they plan for the end of their lives. This includes helping those in their last years of life to live as well as possible, receive appropriate care and treatment in

their home, or as close to home as possible, and to die in a preferred place, where this is possible.

### 1.3 Disease Progression

It is important that we recognise the progressive nature of many diseases but also the uncertainty that often exists during such progression. It should also be recognised that the conditions involved are often unpredictable in terms of progression and also the fact that people who may be deemed at risk of dying may see improvement in their condition during their illness. This provides some challenges as exacerbation may present health care professionals, associated support staff and patients, families and carers with great uncertainty around actions and implications, including the possibility of unnecessary hospital admissions which may be against the preferences of those involved.

**Diagram 1. The differing patterns of disease progression at end of life**



Care processes should mirror this and need to be reactive to changing circumstances, either positive or negative. The emotional impact for both patients and those who are important to them is a major consideration in terms of care planning and related communication which requires consideration of the possible uncertainty involved.

## 2. Needs Assessment

### 2.1 Key Data Findings from the 2014 CCG review of end of life care

In the 2014, as part of a review of end of life care, the CCG examined available data and other evidence. This review suggested some significant areas for Knowsley, including:

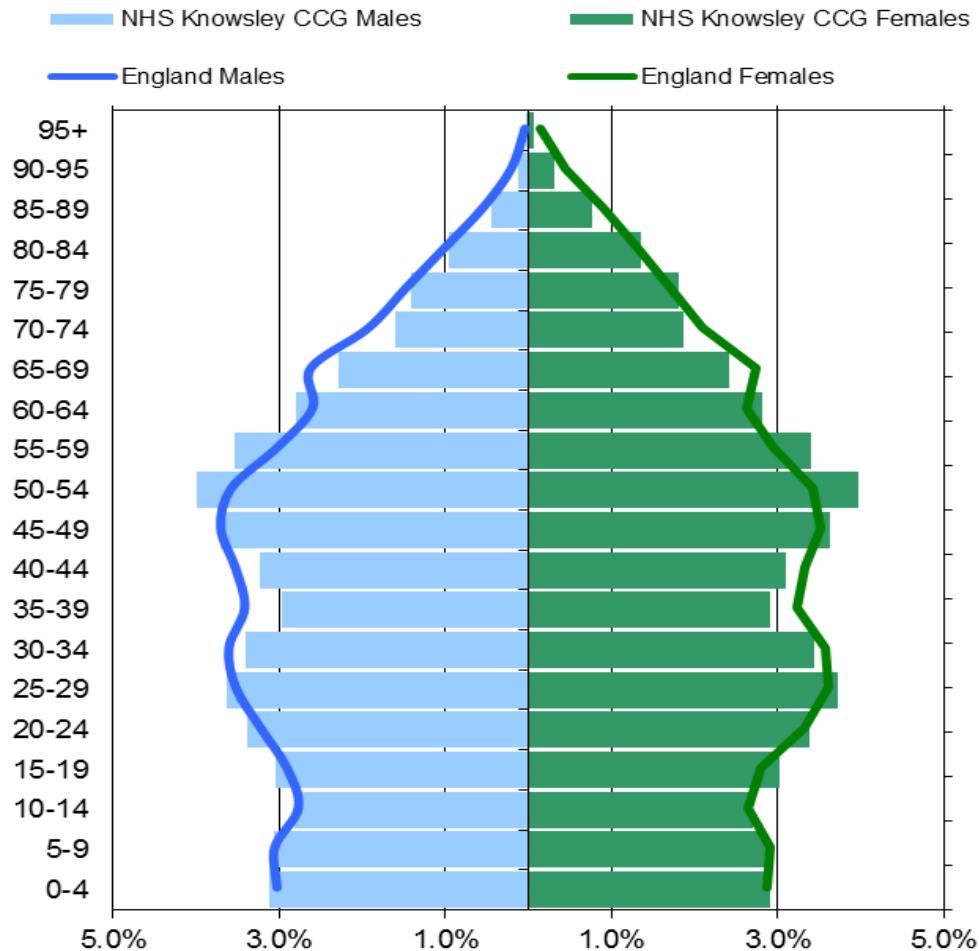
- There is expected to be significant growth in numbers of the very elderly in the next 5-10 years with a 20% rise in the numbers over 85 before 2020;
- An anticipated significant growth in the numbers of people with a dementia diagnosis, an increase of 18% for persons over 85 by 2020;
- An anticipated increase in the numbers of elderly people who live alone;
- Data indicates some positive improvements in recent years in the numbers of people supported to die outside hospital with the figure rising from 40% to 50% over the last decade;
- Relative to national statistics, high levels of deaths at home (22%, 2013) and in hospital (49%, 2013). Some caution should be taken when comparing such figures as variations will occur due to the differing nature of provision between areas;
- Evidence of variation relating to place of death in relation to non-malignant conditions, especially respiratory conditions where the numbers of deaths in hospital are more than double than for deaths from cancer;
- Some evidence that the numbers of people dying in Accident and Emergency departments has declined recently, particularly deaths related to Cardiovascular Disease (CVD) and respiratory conditions.

The following needs assessment data provides evidence relating to some of the above issues identified in the review and key data from the local area relating to end of life care, background data indicating the scale of the issues and challenges faced but also more detailed data relating to trends and variations around mortality data.

### 2.2 Relevant demography

The population of Knowsley is anticipated to experience a rate of growth of 1.23% over the period 2010-2037. This is slower growth than in other neighbouring areas including Liverpool (+5%), St. Helens (+7%) and England average (+16%) although the number of people aged 65 and over is estimated to increase by 56% between 2010 and 2037 (23,700 to 37,100 people). As the number of older people increases,

so it is anticipated there will be an increase in the prevalence of long term conditions which affect their health and wellbeing. As at September 2015, 21% or 34,196 people in Knowsley were aged 60 and over which was slightly lower than England at 23% as indicated by the population pyramid below, Fig.1



**Figure 1: Population pyramid for Knowsley Sept 15 – HSCIC**

Knowsley faces a significant growing number of the very elderly in coming years, many of whom may also face (*or currently have*) a diagnosis of dementia; this will impact upon the nature of end of life care as disease patterns shift and frailty and dementia increase in their significance.

<b>Table 1: Population aged 65 and over, projected to 2020</b>					
	<b>2012</b>	<b>2014</b>	<b>2016</b>	<b>2018</b>	<b>2020</b>
Knowsley: People aged 65-69	6,700	7,100	7,600	7,600	7,800
Knowsley: People aged 70-74	5,500	5,400	5,500	6,200	6,600
Knowsley: People aged 75-79	5,100	5,000	4,800	4,500	4,600
Knowsley: People aged 80-84	3,700	3,800	3,900	3,900	3,800
Knowsley: People aged 85-89	1,800	2,000	2,300	2,500	2,600
Knowsley: People aged 90 and over	800	1,000	1,100	1,300	1,500
Knowsley: Total population 65 and over	23,600	24,300	25,200	26,000	26,900

Source: Office for National Statistics (ONS) subnational population projections

At the same time this will also impact upon the place of care and support important to many people as the numbers requiring residential and nursing care increase. This provides further challenges in terms of the nature of end of life care provision.

	2012	2014	2016	2018	2020
Aged 65-74 living in a LA care home with/without nursing	0	0	0	0	0
Aged 75-84 living in a LA care home with/without nursing	0	0	0	0	0
Aged 85+ living in a LA care home with/without nursing	0	0	0	0	0
Aged 65-74 living in a non LA care home with/without nursing	73	75	78	83	86
Aged 75-84 living in a non LA care home with/without nursing	304	304	301	290	290
Aged 85+ living in a non LA care home with/ without nursing	363	419	474	530	572
Aged 65+ living in a care home with/without nursing	740	798	854	903	949

Source: Office for National Statistics (ONS) 2001 Census, Standard Tables)

An ageing population has implications in terms of social structures as the numbers of people who live alone increase, with a reduction in the support that might be anticipated from direct carers.

	2012	2014	2016	2018	2020
Knowsley: Males aged 65-74 predicted to live alone	1,140	1,180	1,240	1,300	1,360
Knowsley: Males aged 75+ predicted to live alone	1,530	1,598	1,632	1,700	1,734
Knowsley: Females aged 65-74 predicted to live alone	1,950	1,980	2,100	2,160	2,280
Knowsley: Females aged 75+ predicted to live alone	4,209	4,392	4,392	4,392	4,453
Knowsley: Population aged 65-74 predicted to live alone	3,090	3,160	3,340	3,460	3,640
Knowsley: Population aged 75+ predicted to live alone	5,739	5,990	6,024	6,092	6,187

We might also anticipate rising numbers of lone person households (table 3) further increasing the demands on residential and care home provision as well as domiciliary support.

	2012	2014	2016	2018	2020
Knowsley: People aged 65-69 predicted to have dementia	83	88	96	93	97
Knowsley: People aged 70-74 predicted to have dementia	150	147	150	169	180
Knowsley: People aged 75-79 predicted to have dementia	296	301	283	265	265
Knowsley: People aged 80-84 predicted to have dementia	459	459	459	469	456
Knowsley: People aged 85-89 predicted to have dementia	367	406	461	506	522
Knowsley: People aged 90 and over predicted to have dementia	240	299	357	416	447
Knowsley: Total population aged 65+ predicted to have dementia	1,594	1,699	1,805	1,917	1,966

Source : Dementia UK: A report into the prevalence and cost of dementia prepared by the Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry at King's College London, for the Alzheimer's Society



### 2.3 Causes of Death

During 2013, cancer accounted for 439 deaths, the biggest proportion of deaths in Knowsley (30.3%) which is slightly higher than nationally. Mortality from circulatory conditions accounted for the 24.2% (349), significantly lower than the national average. Respiratory conditions accounted for 17.7% of deaths (286) which is amongst the worst in the country. The full ranges of causes of death (2013) are shown below

Figure 2. Deaths in Knowsley 2013 (all causes)



The three biggest killers, and therefore those placing the most demand on palliative care services, are heart disease, cancer and respiratory diseases. This data should be treated with caution as this is based on primary cause of death and therefore would not recognise underlying causes of death or situations where patients have a number of co-existing conditions all of which are relevant to the nature of services required to support the patients. This might be particularly relevant when considering dementia patients who may well have a cause of death unrelated to their dementia but nevertheless require support, especially relating to advance care planning, at an early stage of their illness.



Figure 3: end of life profiles – underlying cause of Death

### 2.4 Mortality and Place of Death

In Knowsley, there were 1,496 deaths during 2013 of individuals aged 1 year or older. Of these, 1,442 (96%) were non-accidental deaths. Around half of these deaths occurred in hospital (53.1%), with 23% occurring at home. The number of deaths in hospital is higher than the national average as indicated by the spine chart below, fig.2, but comparable to the North West and ONS group averages. In terms of the proportion of deaths that occur in the persons home during 2013 then the CCG was higher than the England average at around 23% of recorded deaths, an increase on previous years.

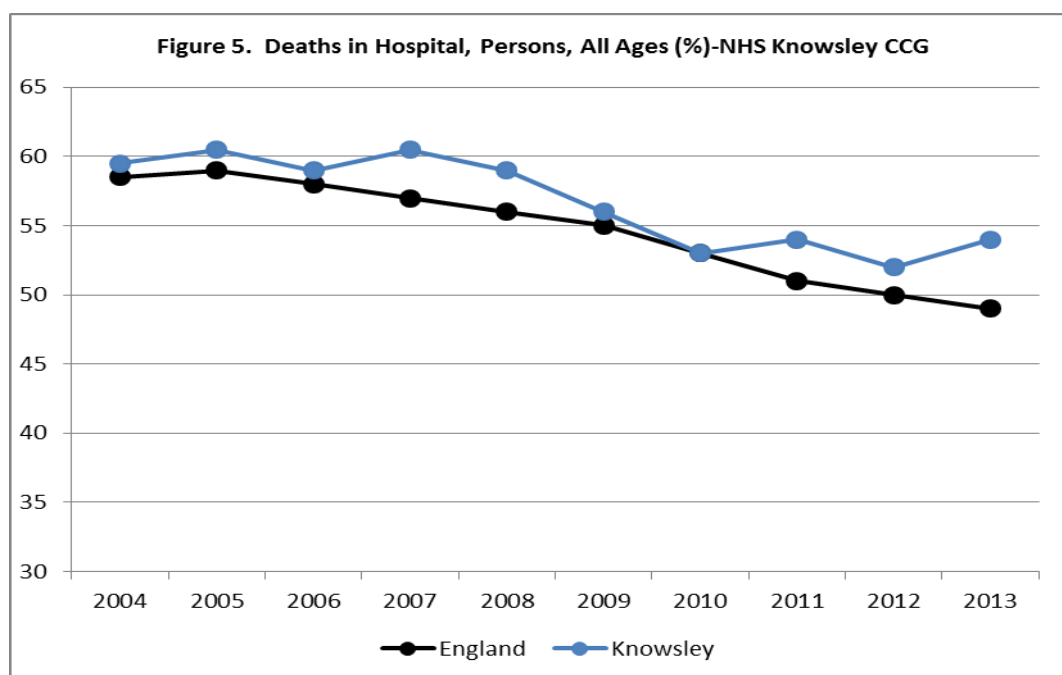
Figure 4: Public Health England end of life profiles – Place of Death (2013)



What follows summarises the position in terms of place of death. People dying in their preferred place, is, to a degree, a measure of quality of end of life care. Whilst difficult to measure, data from surveys helps us understand people's preferences (see page 21; 'Actions for End of Life Care: 2014-16') which consistently suggest that the majority of people in England would prefer to die at home when faced with serious illness while 29% of people preferred Hospices and Palliative care units.

#### 2.4.1 Deaths in Hospital

Figure 5 illustrates the numbers of people dying in an acute hospital setting, locally and nationally. This proportion has steadily fallen over recent years, although 2013 has seen a slight rise. It should be noted that it may be appropriate to patient needs, and in line with their wishes, that people die in an hospital setting.



**Table 6. Patient Deaths in Hospital by Age and Year**

Age	2010/2011	2011/2012	2012/2013	2013/2014
0 - 19	2	1	2	1
20 - 39	5	7	9	8
40 - 49	24	17	24	16
50 - 59	38	36	37	49
60 - 64	41	42	31	28
65 - 69	44	52	38	48
70 - 74	79	68	78	61
75 - 79	112	91	99	99
80 - 84	143	125	152	140
85 - 89	123	85	107	110
90 - 94	52	60	66	70
95 - 99	16	15	31	17
100 - 104	1	1	2	3
<b>Total</b>	<b>680</b>	<b>600</b>	<b>676</b>	<b>650</b>

Table 6 gives some indication of ages of those who die in hospital and does indicate the increasing numbers those age 90+ dying in acute settings.

**2.4.2 Emergency admissions resulting in death**

Given that expressed preferences consistently show a preference for people dying at their normal place of residence it is important therefore to consider the numbers dying in acute hospitals, especially where this has involved an emergency admission, although this may well be appropriate in many circumstances.

The latest figures (2013/2014) that compare terminal admissions in Knowsley (90.6%) to England showed no statistically significant difference between the England average (89.7%) and North West (91.7%) for the percentage of terminal admissions that are emergencies. In 2013/14, in Knowsley CCG, 3.7% of all emergency admissions were terminal (resulted in death). A report by the National Audit Office showed that in 2012/13 3.8% of all emergency admissions in England were terminal.

Reflecting the fact that life expectancy is statistically significantly lower in Knowsley than the England average, the percentage of terminal admissions for people over the age of 85 was not statistically significantly different in Knowsley (34.6%) than England as a whole (37.8%) in 2014/15. The majority of emergency admissions resulting in death are from people in the 65-84 age band for the CCG.

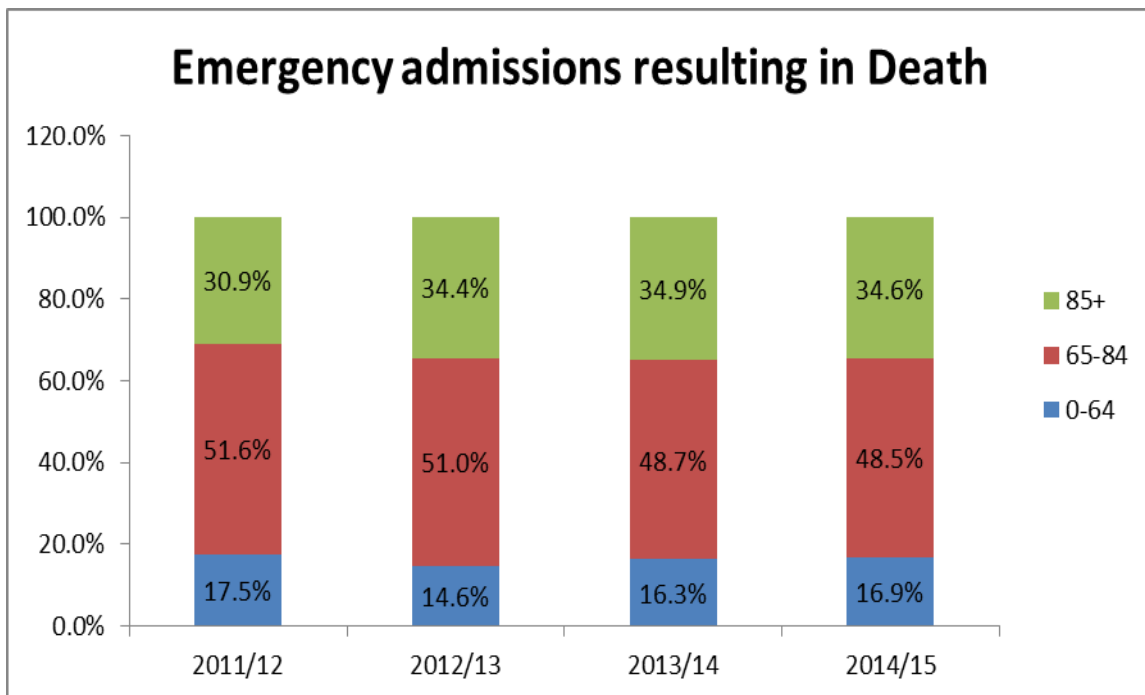


Figure 6: Emergency admissions resulting in death – DSCRO northwest

	0-18 years	19-64 years	65+ years
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	0-5 days	6-10 days	11+ days	0-5 days	6-10 days	11+ days	0-5 days	6-10 days	11+ days
2011/12	3	0	7	47	15	87	151	70	529
2012/13	1	0	13	64	12	89	220	86	741
2013/14	1	4	10	50	12	124	218	90	722
2014/15	1	0	3	65	19	129	229	101	738

Table 7: emergency admissions resulting in death by length of stay (numbers of people)

Table 7 illustrates that the number of people aged 19-64 years who die following an emergency admission has increased by around 48% compared to 2010/11 and have a longer admission which may be a measure of improved treatment. This picture is mirrored, albeit it to a lesser degree for people aged 65+ or over; a similar proportion die within 6 days but an increasingly large number have a longer length of stay before death as compared to 2010/11 volumes. The average length of stay during the period 2011-2015 was 12.4 days.

Table 8. Deaths In Accident & Emergency by Provider & Year (Knowsley Patients)

	St.Helens and Knowsley Teaching Hospitals NHS Trust	Aintree University Hospital NHS Foundation Trust	Royal Liverpool and Broadgreen University Hospitals NHS Trust	Alder Hey Children's NHS Foundation Trust	Other	Total
2010/2011	81	31	7	2	1	122
2011/2012	86	33	9	0	4	132
2012/2013	87	36	9	0	2	134

Table 9. Readmitted Patient Deaths by Year and Days between Admission & Readmission (Knowsley Patients)

Year	0 - 2 days	3 - 7 days	7+ days	Not specified
2010/11	4	7	27	0
2011/12	9	9	23	2
2012/13	15	10	33	0
2013/14	7	18	23	0
<b>Grand Total</b>	<b>35</b>	<b>44</b>	<b>106</b>	<b>2</b>

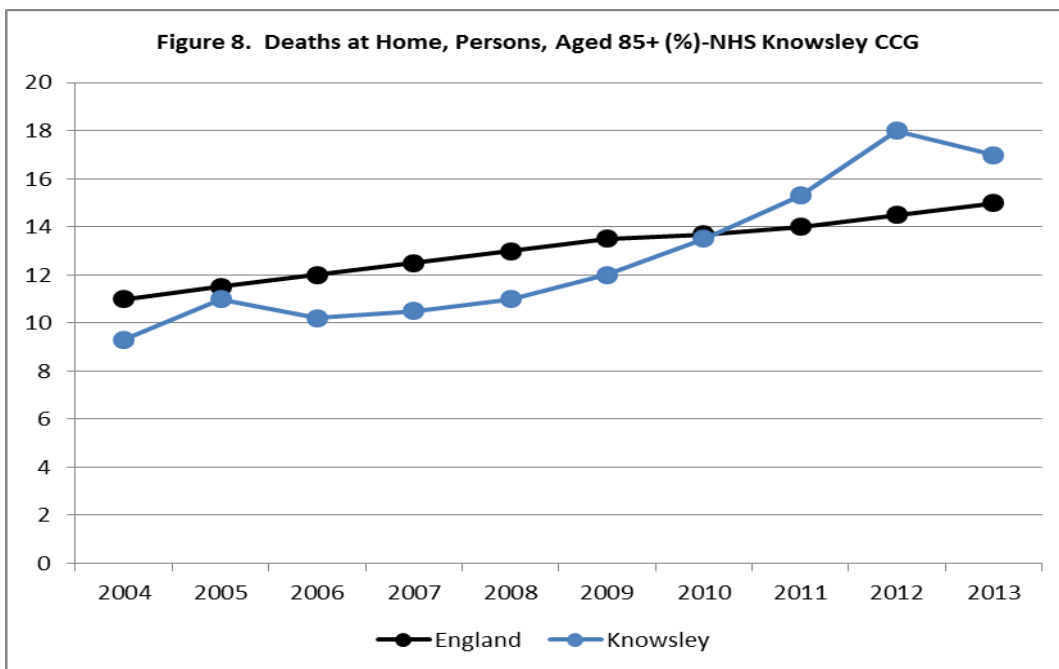
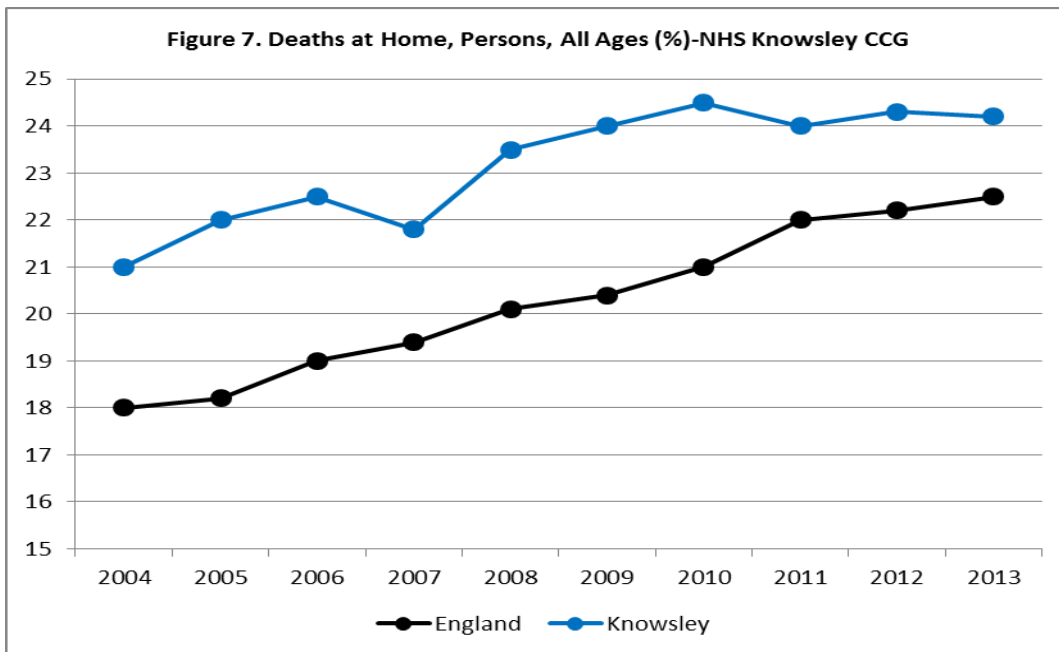
Table 10. Readmitted Patient Deaths by Year and Re-admitting Diagnosis (Knowsley Patients)

	Respiratory	Circulatory	Digestive system	Injury, poisoning and other external	Infectious and parasitic	Genitourinary system	Other	Total
2010/11	19	4	6	3	3	1	2	38
2011/12	19	8	5	2	1	2	6	43
2012/13	26	13	5	6	2	2	4	58
2013/14	26	8	4	2	2	3	3	48
<b>Total</b>	<b>90</b>	<b>33</b>	<b>20</b>	<b>13</b>	<b>8</b>	<b>8</b>	<b>15</b>	<b>187</b>

Tables 8-10 provide further information relating to deaths which have occurred where there has been an unanticipated hospital admission or attendance at A&E, whilst such deaths might be expected due to clinical issues involved it should be the aim to minimise the numbers involved and support people in their preferred location at this time, where possible.

### 2.4.3 Deaths at Home

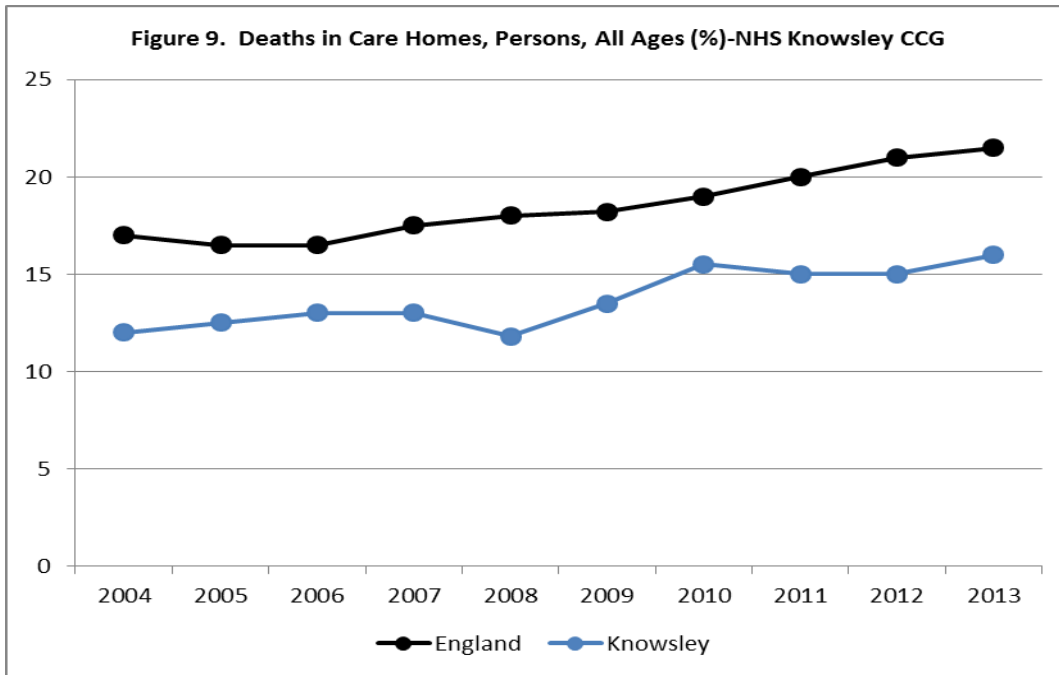
The proportion of people dying at home has been increasing both locally and nationally in recent years, although relatively small increases locally since 2010. However Knowsley remains above the England average.



The numbers of the those 85 plus who die at home, the group with the greatest vulnerability, due to frailty and the increased incidence of lone person households, has seen an increase in numbers dying at home as a proportion of total deaths

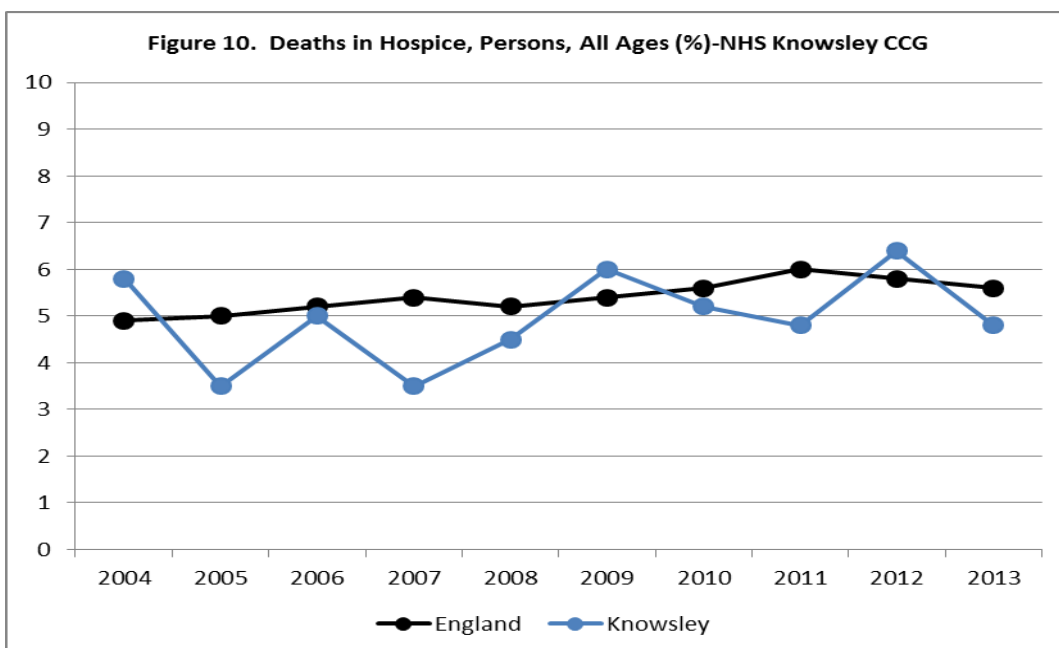
### 2.4.4 Deaths in Care Homes

The proportion of deaths in care homes have been steadily increasing in Knowsley since around 2008 although there is lower care home occupation than in England.



### 2.4.5 Deaths in Hospice

Deaths in Hospice vary from year to year and numbers are relatively small compared to other areas. (The variance observed is due to the small numbers involved.)



## 2.5 Place of death by disease group

These tables show place of death for different disease groups and illustrate the challenge of reducing hospital admissions for certain disease groups. Death rates in hospital for some disease groups are nearly double those for cancer which reflects these challenges.

**Table 11. Respiratory**

<b>Respiratory (all)</b>	<b>2006</b>	<b>2007</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>	<b>Total</b>	
Hospital	172	178	195	161	186	169	147	213	1421	68.4%
Home	33	33	42	45	30	39	49	56	327	15.8%
Hospice	0	1	3	1	0	0	5	1	11	0.5%
Care Home	42	31	30	38	48	42	32	43	306	14.7%
Elsewhere	1	0	2	0	1	4	1	2	11	0.5%
<b>Total</b>	<b>248</b>	<b>243</b>	<b>272</b>	<b>245</b>	<b>265</b>	<b>254</b>	<b>234</b>	<b>315</b>	<b>2076</b>	

This table indicates the rising significance of respiratory disease as a cause of death (although 2013 represents a significant variation in relation to the trend). It also illustrates the fact that increasingly more patients are dying in acute settings. It is possible that the nature of symptoms relating to respiratory conditions increase the likelihood of hospital admission at end of life as carers and those working in care homes find it harder to support the patient in their usual place of residence.

**Table 12. Respiratory (COPD)**

<b>Respiratory (COPD)</b>	<b>2006</b>	<b>2007</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>	<b>Total</b>	
Hospital	84	82	92	74	82	80	76	100	670	65.4%
Home	25	23	23	33	28	28	48	30	238	23.2%
Hospice	0	0	1	1	0	0	3	1	6	0.6%
Care Home	7	6	11	14	13	11	18	18	98	9.6%
Elsewhere	2	0	2	0	1	5	1	1	12	1.2%
<b>Total</b>	<b>118</b>	<b>111</b>	<b>129</b>	<b>122</b>	<b>124</b>	<b>124</b>	<b>146</b>	<b>150</b>	<b>1024</b>	

When purely COPD is shown these pattern remain

**Table 13. Respiratory disease is mentioned on the cause of death but not as primary cause**

<b>Mention of; Respiratory (COPD)</b>	<b>2006</b>	<b>2007</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>	<b>Total</b>	
Hospital	135	163	156	136	143	141	144	158	1176	66.4%
Home	49	43	49	52	48	41	56	64	402	22.7%
Hospice	3	1	3	2	3	4	5	3	24	1.4%
Care Home	12	6	14	21	19	19	29	32	152	8.6%
Elsewhere	1	1	1	1	4	5	3	1	17	1.0%
<b>Total</b>	<b>200</b>	<b>214</b>	<b>223</b>	<b>212</b>	<b>217</b>	<b>210</b>	<b>237</b>	<b>258</b>	<b>1771</b>	

Where COPD is present but not attributed as the principal cause of death then deaths in hospital are still high.



**Table 14. Cancer**

Cancer	2006	2007	2008	2009	2010	2011	2012	2013	Total	
Hospital	193	184	186	185	156	179	156	163	1402	39.0%
Home	139	151	159	152	158	137	142	158	1196	33.2%
Hospice	63	52	49	66	63	61	76	63	493	13.7%
Care Home	37	45	43	46	61	58	64	76	430	12.0%
Elsewhere	13	11	8	6	11	11	6	11	77	2.1%
<b>Total</b>	<b>445</b>	<b>443</b>	<b>445</b>	<b>455</b>	<b>449</b>	<b>446</b>	<b>444</b>	<b>471</b>	<b>3598</b>	

Deaths at Home and in Hospices from cancer are significantly higher than most other major causes of death and this reflects the emphasis placed upon this disease in recent years.

**Table 15. Liver disease**

Liver Disease	2006	2007	2008	2009	2010	2011	2012	2013	Total	
Hospital	23	31	21	24	28	16	24	33	200	73.8%
Home	7	9	8	9	9	10	7	6	65	24%
Hospice	0	0	0	0	0	0	0	0	0	0.0%
Care Home	0	0	0	0	0	2	2	0	4	1.5%
Elsewhere	0	0	0	0	1	1	0	0	2	0.7%
<b>Total</b>	<b>30</b>	<b>40</b>	<b>29</b>	<b>33</b>	<b>38</b>	<b>29</b>	<b>33</b>	<b>39</b>	<b>271</b>	

Liver disease is becoming a more common cause of death in line with the greater use of alcohol in society. Where this is a cause of death it is predominantly in an acute hospital setting.

**Table 16. Diseases of the Digestive System**

Digestive	2006	2007	2008	2009	2010	2011	2012	2013	Total	
Hospital	66	79	65	64	77	57	72	82	562	82.5%
Home	9	12	11	10	14	16	11	9	92	13.5%
Hospice	0	0	0	0	2	1	0	0	3	0.4%
Care Home	2	3	3	0	2	4	3	2	19	2.8%
Elsewhere	0	1	1	0	1	2	0	0	5	0.7%
<b>Total</b>	<b>77</b>	<b>95</b>	<b>80</b>	<b>74</b>	<b>96</b>	<b>80</b>	<b>86</b>	<b>93</b>	<b>681</b>	

Deaths relating to Digestive conditions have the highest rate of death in hospital settings

**Table 17. Diseases of the Circulatory System**

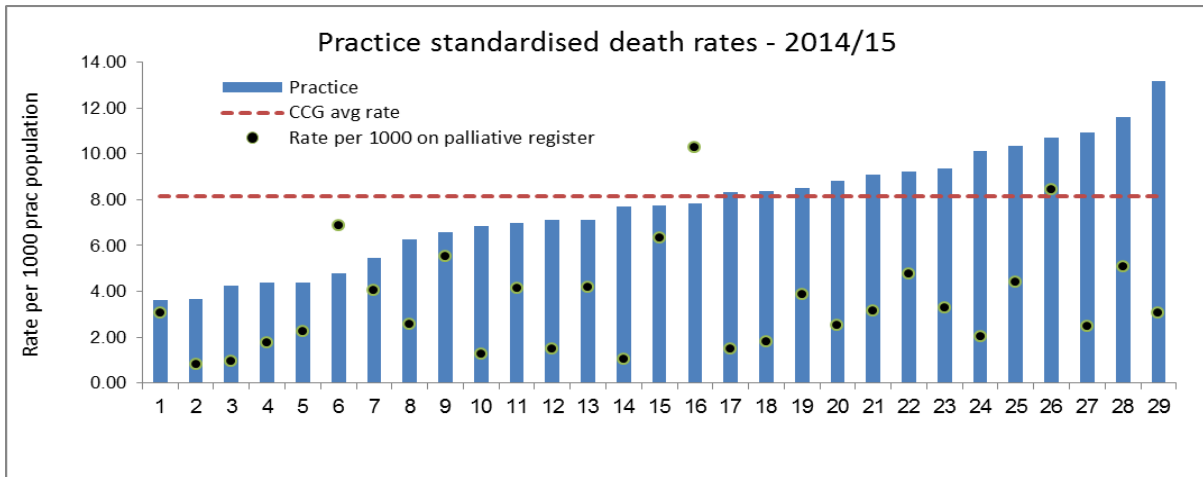
Circulatory Disease	2006	2007	2008	2009	2010	2011	2012	2013	Total	
Hospital	328	316	287	245	262	208	232	224	2102	63.0%
Home	101	116	108	87	101	94	86	92	785	23.5%
Hospice	5	1	3	1	2	2	0	2	16	0.5%
Care Home	65	53	42	48	61	35	48	39	391	11.7%
Elsewhere	8	8	3	4	7	4	8	3	45	1.3%
<b>Total</b>	<b>507</b>	<b>494</b>	<b>443</b>	<b>385</b>	<b>433</b>	<b>343</b>	<b>374</b>	<b>360</b>	<b>3339</b>	

Death relating to circulatory disease, which include cardio-vascular disease have a similar profile for place of death to respiratory but recent years have seen a decline in the overall total and also the numbers dying in hospital settings.

### 2.6 Variations across Knowsley practices

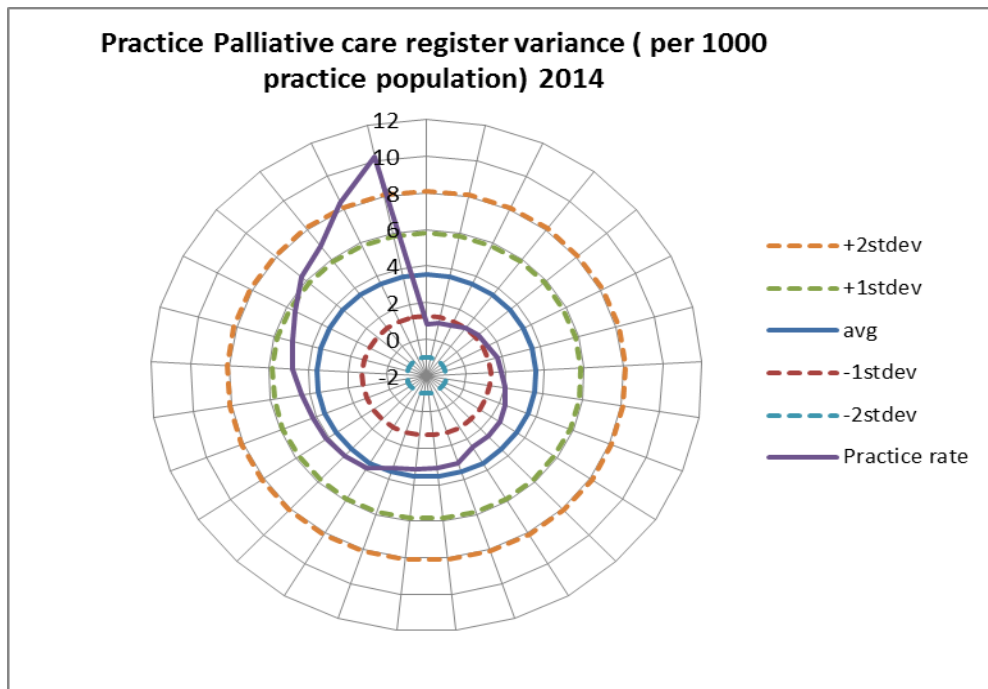
Data relating to those who might be expected to die within a year can be obtained through practice palliative care registers although some caution should be taken with such data as local practice in terms of recording may vary.

Figure 9 shows the practice standardised rate of mortality for the registered population within Knowsley during 2014/15 as reported via the Primary Care Mortality Database and also shows the practice standardised rates of the practice population on palliative care registers.



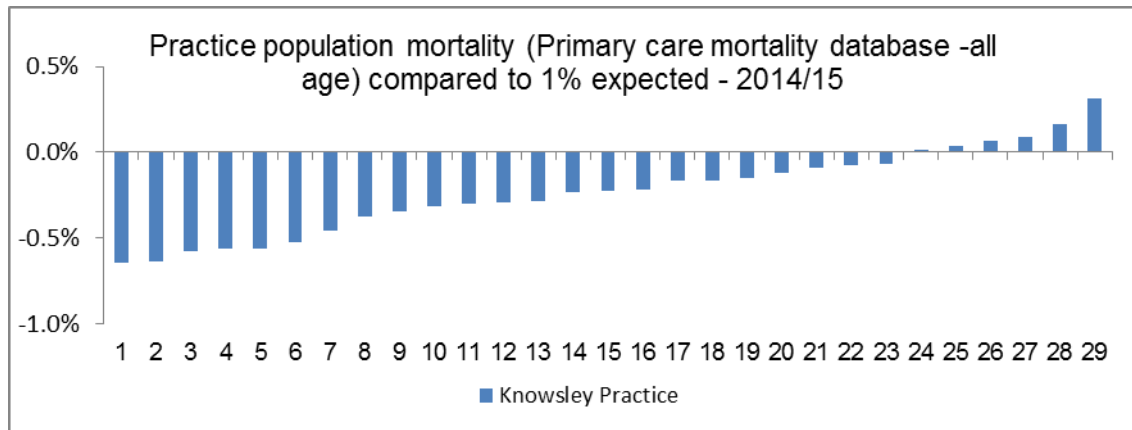
**Figure 9:** Practice standardised mortality rates for 2014/15 compared to practice standardised rates on palliative registers (excluding external causes)

Variation across practices is not statistically significant although there may be issues as recording processes differ from practice to practice.



**Figure 10:** Practice palliative care registers (standardised rate per 1000 practice populations)

It would be expected that around 1% of the population would die each year, so e.g. with a list size of 5,000 patients, an average practice would be expected to have about 50 patient deaths per year. The volume of deaths recorded at practice level when compared to this anticipated 1% shows the CCG with some 18% fewer than anticipated deaths in the period, although there will be variability over time relating to actual compared to anticipated deaths, this is depicted at practice level below.



**Figure 11:** Practice mortality compared to the anticipated - Primary Care Mortality Database

Figure 11 illustrates the variation across practice between the anticipated number of deaths in the Borough (1%) and the individual practice, the majority of practices have fewer deaths than would be expected for their demographic and this can be partly explained by the lower numbers at practice level but also differences in the age structure between practices.

### 3. How residents, communities, and stakeholders view this issue

#### 3.1 Local Engagement

An end of life patient experience event was held in Knowsley in late 2013, the evidence from which was incorporated into the 2014 review of end of life care. Held in conjunction with Healthwatch, a range of patient representatives, health professionals, service providers and community representatives were present who shared patient experience and feedback. Those present included third sector, community, housing, public health, council, ambulance services, faith/spiritual, lesbian, gay, bi-sexual, transgender communities and patients. Below are some of the key comments received in feedback from that event, such comments are not inconsistent with evidence produced nationally around how services for those at end of life are best provided;

- *Planning in advance is the only way to improve end of life care in a preferred location*

- *Processes should be in place to learn from events and improvement suggestions/experiences*
- *Many patients admitted with dementia could have their admission avoided if appropriate/best interest meetings had occurred*
- *Is there awareness of possible religious and cultural needs?*
- *Health and social care staff should signpost to carer services*
- *Improved communications between the patient, family, districts nurses, GPs and Macmillan needed*
- *People are unaware of how to make a will*
- *Nursing staff to be sensitive to the needs of families, staff may experience this on a daily basis but relatives don't*
- *Advanced care planning isn't discussed enough*
- *Often a call to out of hours turns into an unnecessary hospital admission*
- *Dignity when you are ill/end of life is important*
- *Better advance care planning/best interests meeting needed. Many of these patients would have been cared for better in their usual place of care*
- *A good attitude doesn't cost anything*
- *Most people's/relative's preferred place of care is home*
- *A holistic approach would ensure that patients spiritual needs are met*
- *Does the patient planning include family members both pre and post bereavement?*

Regular Healthwatch end of life care meetings are held where local people are invited to raise issues of concern or learn about current issues relating to end of life care with members of Knowsley's Advance Care Planning Team. Patient representatives also attend Knowsley's End of Life Clinical Reference Group where discussions have been held around a citizen's charter for end of life care and patient representatives were included in the CCG's end of life care review in 2014.

### 3.2 National Engagement

*Every Moment Counts* was produced by National Voices and the National Council for Palliative Care in partnership with the national clinical director for end of life care at NHS England, Dr Bee Wee. It drew on surveys, the testimonies of bereaved carers, the experience of end of life care charities and the reflections of professionals that highlighted failures in coordinating and personalising the different elements of end of life care. One of the challenges highlighted is that individuals working to support and care for the person are often generalists who may not have the confidence – or the training and preparation – to open up conversations about choices and preferences. Yet *Every Moment Counts* shows these are vital to the people and carers in question.

*Every Moment Counts* outlined five themes that people say are key to coordinated care near the end of life. These are summarised in the defining statement:

*“I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).”*

Further ‘I statements’ set out in more detail the things people have said they want their care and support to look like, such as:

*“I have timely and honest conversations with those engaged in my care, support and treatment.”*

*“I can remain in control as much as possible. This is recognised as a key goal in my care.”*

*“I am confident that the people who are important to me will have the opportunity to get support with bereavement before and after my death.”*

### **‘Actions for End of Life Care: 2014-16’ (2014)**

In this report, published in November 2014, NHS England identified a range of actions based upon a strong evidence based which included some key findings;

- The number of people dying in their ‘usual place of residence’, i.e. at home or in care homes has risen from under 38% in 2008 to 44.5%
- Population-based studies of preferences for place of death indicate that over 60% of people (including those who were not facing life-threatening illness at the time) would prefer to die at home. Whilst this has been an important driver for improving end of life care at home, the ‘place of death’ is not necessarily the highest priority for everybody. The need to be pain free (24%) came a close second to the presence of family and friends (28%), in terms of the most important aspects of their end of life care.
- Key findings from the 2013 National Survey of Bereaved People (VOICES-SF) which collected feedback from bereaved people between 8-11 months after the person’s death included: overall quality of care across all services in the last three months of life was rated as outstanding or excellent by 43% of respondents. Pain relief was reported to be inadequate for 53% of those who died at home, as compared to 32% in hospitals, 25% in care homes and 13% in hospices. almost 16% of respondents reported that services were not well coordinated in the last three months of life. Over 16% of carers and families did not receive adequate support despite asking for more help. 82% of respondents felt that the person had died in the right place.
- Nationally, people with learning disabilities are less likely to have access to specialist palliative care services, receive inadequate pain control in their final illness

and are more likely to have their deaths described as not being planned for, uncoordinated and poorly managed.

## 4. Service provision in Knowsley

### 4.1 Key enabling services across settings

As well as service provision there are a range of key areas which determine effective provision, namely;

- **Identification**

Identifying those who may be approaching the end of their lives, across differing disease groups. This is primarily a clinical judgement, often in acute hospitals, where it is felt a patient may not recover from the condition they face. Identification helps services to plan for patients and help relatives plan and support the individual although this is a complex and challenging area and may involve situations where disease progression slows or, in some cases, shows improvement.

- **Assessment & care planning**

Assessment of the social, emotional and psychological needs of the individual, assessing the needs of carers, advance care planning, end of life care plans, Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) plans, financial impact on families.

- **Co-ordination of care and supporting discharge**

Key worker(s), points of contact for patients, families & carers, information sharing and IT Systems, communication. Services to plan and support discharge.

- **Support for families and carers at end of life**

Services to support carers, access to bereavement support and information and support for families/carers

### 4.2 End of life care services for patients in the community

The support for patients in community settings involves a wide range of service inputs including GPs/primary care, community nursing, specialist palliative care, night sitting, out of hours services, urgent care services, specialist disease services, social care support, equipment, continuing healthcare, care homes, acute hospital provision, hospice provision, discharge from hospital or hospice and admiral nurses for dementia. In Knowsley this process is undertaken by a range of health professionals supported by the Advance Care Planning Team. Where patients are in the community their GP is often the central point around which information is co-ordinated with community and district nursing playing a vital role.

Community nursing input is provided by 5 Boroughs Partnership NHS Foundation Trust. Out of Hours GP support is provided through UC24 and St.Helens Rota. A range of other providers support end of life care including social care provision, bereavement support (Listening Ear), Residential and nursing homes are provided by a wide range of independent and private sector providers across the borough.

#### 4.3 Specialist Services in the community

Specialist palliative care inpatient provision and range of other services, including outpatient services provided by;

- Willowbrook Hospice
- Woodlands Hospice
- Marie Curie Hospice

with children's palliative care provided by

- Claire House Hospice.

Specialist support is also provided through a community based consultant and a specialist palliative care nursing service, working closely with Knowsley's advance care planning facilitators as part of an integrated team.

#### 4.4 End of life care in acute hospitals

The main hospitals relevant to Knowsley patients at end of life include;

- St.Helens and Knowsley Teaching Hospitals NHS Trust (StH&K)
- Aintree University Hospital NHS FoundationTrust (AUH)
- The Royal Liverpool & Broadgreen University Hospitals NHS Trust (RLBUH)

and, for children,

- Alder Hey Children's NHS Foundation Trust.

In these hospitals specialist palliative care teams support end of life care across a range of conditions and work with discharge teams to support patients when it is felt they should be supported at end of life in the community. Poorly planned and fragmented support upon patient discharge can mean patients, families and carers find themselves unable to cope with the practical and emotional challenges they face after discharge, increasing the likelihood of re-admission. Community nursing has a hospital based discharge team within StH&K and AUH, to coordinate transfer of care and liaise with relevant services including social care and equipment suppliers to facilitate safe timely supported discharge 7 days per week.

## 5. Evidence of What Works Nationally and Locally

### 5.1 National Evidence

Nationally there have been several major publications in recent years which identify best practice based on a wide local and national evidence base and which clearly define the priorities around good end of life care.

#### **One Chance to Get it Right (2014)**

This report, published in June 2014, was produced by a coalition of 21 organisations known as the Leadership Alliance for the Care of Dying People (LACDP). The report identified five key priorities as part of the Alliance's overall response.

#### **The Five Priorities for Care**

The Priorities for Care identified suggest that:

- The possibility that a person may die within the coming days and hours is recognised and communicated clearly, decisions about care are made in accordance with the person's needs and wishes, and these are reviewed and revised regularly by doctors and nurses.
- Sensitive communication takes place between staff and the person who is dying and those important to them.
- The dying person, and those identified as important to them, are involved in decisions about treatment and care.
- The people important to the dying person are listened to and their needs are respected.
- Care is tailored to the individual and delivered with compassion – with an individual care plan in place.

The aim is to promote a stronger culture of compassion in the NHS and social care, one that puts people and their families at the centre of decisions about their treatment and care.

#### **Ambitions for Palliative and End of Life Care**

This national framework for local action 2015-2020, published in 2015, by the National Palliative and End of Life Care Partnership, sets out 6 key areas to be supported over the next 5 years.



***Each person is seen as an individual*** - I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.

***Each person gets fair access to care*** - I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.

***Maximising comfort and wellbeing*** - My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.

***Care is coordinated*** - I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.

***All staff are prepared to care*** - Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.

***Each community is prepared to help*** - I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

### **Choice in end of life care**

An independent review into choice in end of life care and was Published by The Choice in End of Life Care Programme Board in February 2015.

It was requested by the Government to consider how the quality and experience of care for adults at the end of life and those close to them could be improved by expanding choice and identifies the issues people approaching the end of life are currently facing and offers a blueprint for how greater choice in end of life care can be achieved.

The review recommends a national choice offer for end of life care as follows: which should be;

- made as soon as is practicable after it is recognised that the person may die in the foreseeable future;
- based on honest conversations with health and care staff, which supports the person to make informed choices; and
- consistently reviewed through conversations with health and care staff.

In particular it includes many specific recommendations including;

- each person who has consented to and wishes to specify choices and preferences in their end of life care has these recorded in their individual plan of care, with its details held on an Electronic Palliative Care Coordination System (EPaCCS) or equivalent system; and
- each person who wishes to express their end of life care choices and preferences in advance is offered a way to do this through access to their own medical records and plans of care and the ability to add and amend information on personal choices and preferences.
- carers for people at the end of life should be formally identified as such by the relevant services, that their eligible needs for support be met in line with the provisions of the Care Act 2014, and that support be provided for carers following bereavement; and
- family members, carers and/or those important to the individual should be involved, where possible, in discussions about care preferences where the dying person has said they should be.
- every local area should establish 24/7 end of life care for people being cared for outside hospital, in line with the NICE quality standard for end of life care, which supports people's choices and preferences;
- each person in need of end of life care has a named responsible senior clinician who would have overall responsibility for their care and their preferences and is offered a care coordinator who would be their first point of contact in relation to their care and their preferences.

## 5.2 Local Evidence

In 2014 Knowsley CCG undertook a review of end of life care in the borough. The review considered a range of needs assessment data, national evidence and recommendation, the views of a wide range of stakeholders. The recommendations of this review were in line with national recommendations shown above with some local variations in line with some of data within this JSNA. The evidence suggested there are some key area of good practice in Knowsley.

There is a small but integrated community advance care planning team which has played a major role in taking forward recent national recommendations in particular;

- The development of a locally developed care and communication record and supporting its use through training and education.
- The training of staff across community settings, including care homes, around end of life care.
- Supporting practices, including Gold Standard Framework (GSF) co-ordinators in the role within primary care

- Leading engagement with local groups, including healthwatch.
- Supporting the roll-out of DNACPR
- Auditing the use of key tools for end of life Care
- Supporting the development of a locally developed patient charter in line with national recommendations.

The review also identified that community nursing teams are a key service in terms of addressing the needs of palliative care patients in the community and should attend multi-disciplinary meetings in primary care and maintain and develop appropriate skills relevant to end of life. It is important that primary care and community nursing have a close and stable working arrangement to enable this coordinated and multidisciplinary approach to end of life care in the community. Services need to be available 7 days per week both within and out of hours.

Whilst there have been improvements in care home provision at end of life there is a need to continue and build on the progress made so far. With advance care planning education and support from palliative care specialist care teams, the care home sector will be increasingly pivotal in supporting 24 hour out of hospital end of life care. Organisations will need to ensure staff have the necessary, knowledge, skills, capability and confidence to prevent unnecessary and avoidable hospital admissions. Good quality end of life care in care homes should be recognised and supported to ensure staff receive training to improve their skills around end of life issues and processes are in place which are in line with identified best practice.

## 6. Links to other priorities

### 6.1 Interdependencies with Council, CCG and Partnership priorities

End of life care is strongly linked to key priorities both for the CCG and the council, in particular programmes relating to;

- Safe supported discharge and support to remain at home
- Reduced hospital admissions and re-admissions
- Quality in Care homes
- Restructure of social work teams to align with Neighbourhubs
- Services to support carers
- The development of community navigators and access to services
- Community nursing in Neighbourhubs, with staff aligned to groups of practices
- Virtual Bed Management processes relating to assessment and patient flow
- Developing seven day working
- Data Sharing across Health and Social Care