End of Life Care
<table>
<thead>
<tr>
<th>Reader information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Authors</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Contributors</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Reviewer</td>
</tr>
<tr>
<td>Number of pages</td>
</tr>
<tr>
<td>Date release</td>
</tr>
<tr>
<td>Description</td>
</tr>
<tr>
<td>Contact</td>
</tr>
<tr>
<td>Related documents</td>
</tr>
</tbody>
</table>

**Please quote the JSNA**

We would like to know when and how the JSNA is being used. One way, is to ask people who use the JSNA when developing strategies, service reviews and other work to quote the JSNA as their source of information.
List of Abbreviations

ACP   Advanced Care Planning
CCG   Clinical Commissioning Group
CIACPS  Community Integrated Advanced Care Planning Service
CQC   Care Quality Commission
EoLC  End of Life Care
GP    General Practitioner
GSF   Gold Standard Framework
HSCIC Health and Social Care Information Centre
JSNA  Joint Strategic Needs Assessment
LCP   Liverpool Care Pathway
LGBT  Lesbian, Gay, Bisexual and Transgender
NHS   National Health Service
NICE  National Institute for Health and Clinical Excellence
ONS   Office for National Statistics
PHE   Public Health England
PPC   Preferred Priorities of Care
QOF   Quality Outcomes Framework
VOICES Views of Informal Carers – Evaluation of Services
## Contents

Key findings and issues for consideration by commissioners ........................................ 7

1. Introduction ............................................................................................................. 9

2. Policy Context ....................................................................................................... 10

3. Level of need in the population .......................................................................... 16
   3.1 Why is End of Life Care important? .............................................................. 16
   3.2 Number of deaths ......................................................................................... 16
   3.3 Place of Death ............................................................................................... 16
      3.3.1 By age and gender .................................................................................. 18
      3.3.2 Trend in place of death all ages ............................................................ 20
      3.3.3 Deaths in hospital .................................................................................. 20
      3.3.4 Influence of deprivation on place and cause of death ....................... 23
   3.4 Causes of death ............................................................................................. 26
   3.5 End of Life Care and palliative care for specific communities ............... 28
      3.5.1 People with dementia ............................................................................ 28
      3.5.2 People with learning disabilities .......................................................... 30
      3.5.3 Lesbian, Gay, Bisexual and Transgender (LGBT) ............................. 31
      3.5.4 Homeless people .................................................................................. 31
      3.5.5 Children with terminal illness .............................................................. 32

4. Service provision ................................................................................................. 33
   4.1 Primary care ................................................................................................... 33
   4.2 Community care: End of Life Social Services ........................................... 35
   4.3 Secondary Care ............................................................................................... 35
   4.4 Specialist care .................................................................................................. 35
      4.4.1 Halton Haven Hospice ......................................................................... 35
      4.4.2 Macmillan Nursing Service ................................................................. 36
   4.5 Advance Care Planning ............................................................................... 37
   4.6 Palliative care and bereavement services for children and families ....... 39

5. Projected levels of need ....................................................................................... 41

6. User views ............................................................................................................ 42
   6.1 National Survey of Bereaved People (VOICES) 2014 ............................. 42

7. Unmet need and service gaps ............................................................................ 43

8. Best practice interventions ............................................................................... 44
Figures

Figure 1: Key areas of choice for end of life care

Figure 2: House of Care Model

Figure 3: Persons by age and place of death

Figure 4: Place of death by age band, Males (blue) and females (red)

Figure 5: Trend in place of death, Halton residents, all ages, 2014 to 2013

Figure 6: Headline findings, 2016 EOLC, Dying in Hospitals audit

Figure 7: Place of death by cause in each deprivation quintile, Halton residents, 2006 to 2015

Figure 8: Place of death by age in each deprivation quintile, Halton residents, 2006 to 2015

Figure 9: A framework for partnership practice between specialist palliative care and intellectual disability services

Figure 10: Halton Haven facilities, results of client survey

Figure 11: NICE Quality Standards for End of Life Care

Tables

Table 1: Deaths in usual residence, CCG level and comparators

Table 2: Number of deaths and proportion aged 65+

Table 3: Place of death by age band, Halton and comparators, 2013

Table 4: Dying in hospital national audit

Table 5: Deaths in hospital, 2010/11, Halton compared to England

Table 6: Percentage of all deaths by cause and place of death, 2010-2014

Table 7: Barriers to end of life care for people with dementia

Table 8: QOF prevalence of palliative care need, Halton CCG and comparators 2013/14 and 2014/15

Table 9: Palliative care need at Halton GP practice level, 2013/14 and 2014/15

Table 10: Percentage of Halton EOLC patients achieving their Preferred Place of Care, 2011/12 to January 2016

Table 11: Good practice in end of life care
Key findings and issues for consideration by commissioners

There has been a significant shift in the place where the majority of people die over the last century, from the majority of people dying at home to over half now dying in hospital. Yet, despite this, surveys show that home remains the preferred place of death for the majority of people.

People are generally regarded as approaching the end of life when they are likely to die within the coming 12 months. Palliative care supports people nearing the end of the lives to live as well as possible. This may be through specialist palliative care but for most generic services, well planned and provided will suffice. Whichever group of staff is involved, the complexity and personalised nature of need requires effective, multi-disciplinary working within and between health and social care services, which includes the active involvement of family and friends.

National research shows that most people express a wish to die at home but only about one in five do so. In Halton just under four out of ten (40%) die in their usual residence, defined as either the own home or a care home. This is lower than England and Cheshire & Merseyside (approximately 45% and 43.5% respectively). This places halton CCG 36th lowest in England out of 211 CCGs and lowest in Cheshire & Merseyside for the last reporting period available.

The majority of deaths occur in those aged 65 and over, nearly 8 out of 10. The percentage of deaths occurring in hospital varies little with age. Whilst the percentage who die in their own home decreases with age, the percentage dying in a care home increases from 13.5% amongst those aged 65-84 to 32.2% amongst those aged 85 and over.

From age 65, a slightly lower percentage of men die in their own residence compared to women. However, the most significant gender difference is the higher percentage of women dying in a care home; 16.4% amongst those aged 65-84 and 35.7% at age 85+ compared to 10.7% and 25.6% for men of the same age.

Whilst hospitals continue to be the dominant place of death, there has been a reduction in the percentage in recent years, with a corresponding increase in the percentage of deaths occurring in care homes and a small increase in the percentage dying in their own residence. This means a key role for hospitals remains the delivery of high quality EOLC including support to families. There have been improvements in access to specialist palliative care but still, only 4 out of 10 hospitals provide 9am-5pm, 7 days a week access in the 2014 national audit (compared to 3 out of 10 during the 2013 audit). In the 2014 audit bot Halton’s main acute hospital trusts reported they had this provision in place.

The 2014 hospital audits of palliative care showed that St Helens & Knowsley Hospital had a higher percentage of cases reviewed than Warrington Hospital Trust. Warrington did not have in-house training for staff but St Helens did. Overall, both trusts performed similar or better than the England average.

Halton has had a higher percentage of all age ‘terminal admissions’ admitted as an emergency than England but lower amongst those aged 85+. The most common cause of death is cancers at 30%,
followed by cardiovascular disease at 25% and respiratory disease at 15%. Overall people both nationally and locally are more likely to die in hospital if they live in more deprived areas.

National research shows that people with dementia, those who are Lesbian, Gay, Bisexual or Transgender (LGBT), are homeless or have a learning disability all face barriers/difficulties in accessing high-quality EOLC. Staff may be unaware of their particular needs and/or how to meet them. Families of children with terminal illnesses also have specialist needs.

Whilst in theory, the majority of deaths can be predicted and therefore EOLC planning established (NICE put this at about 75% predictable), in practice there is a wide margin for error, mostly due to over-optimism of prognosis. There are just over 1,000 deaths in Halton per year but only 382 people were on the palliative care register in 2014/15. Nevertheless this means the prevalence rate for palliative care for Halton CCG was similar to the North West and the same as the England average. All identified patients have regular reviews, a higher proportion than the North West and England.

Advanced Care Planning (ACP) is a key element of the end of life care pathway and policy which is reflected in the adoption of the Coordinate My Care tools to allow appropriate professionals involved in the care of the patients to access their care plan. Locally, people who are believed to be in the last year of life are coded using the North West End of Life care Model. The tool is used in care homes and all people on the GP Gold Standards Framework (GSF) are thus coded. The Community Integrated Advanced Care Planning Service provides ACP for Halton and delivers training to staff from key providers of EOLC.

Whilst only a couple of Halton’s care homes have achieved GSF for Care Homes, many more have received training and are at various stages of working towards it. Of the people with an ACP over 90% have achieved their Proffered Place of Care (PCC) consistently over the last five years.

Three important documents/guidance should be used in combination to scope and assess current service provision against best practice:

- North West Palliative and End of Life Care Model and Six Steps to Success guidance
- NICE quality standard and guidance for EOLC for adults and children (see section 8)
- National service specification (awaiting publication)

Not all care homes have GSF status. The ACP team have been training and offering support to care homes and this work should continue in order to reduce variations in care provided.
1. Introduction

Despite the fact that we all die, open discussions about the process of dying remain taboo amongst both general society and even amongst those whose job includes care of dying people. The King’s Fund note that the place where people die has changed over the past century with most deaths occurring in hospital and not at home. In 1900 approximately 85% of people died in their own homes, by the mid twentieth century this decreased to around 50% and in the early twenty-first century acute hospitals have become the most common place of death.

End of life care has been defined as care which:

“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.”

People are generally regarded as approaching the end of life when they are likely to die within the coming 12 months. This includes people for whom death may be imminent and also those facing an uncertain future due to progressive, incurable illness, life-threatening acute conditions or increasing frailty and/or life-limiting co-existing conditions. A palliative care approach supports those nearing the end of their lives to live as well as possible until they die by preventing or relieving suffering through early identification and treatment of pain and other physical, psychosocial and spiritual problems. As such, palliative care falls within the remit of all health and social care professionals. Some, but not all, people approaching the end of life also need the services of a specialist palliative care team to ensure that they receive the best possible care.

The national council for palliative care has categorised palliative care as being delivered by two groups of health and social care professionals. ‘General palliative care’ is provided by the usual professional carers of the patient and family with low to moderate complexity of palliative care need, and ‘Specialist palliative care’ is provided by multi-professional specialist teams to patients and families with moderate to high complexity of palliative care need. In practice the distinction between the two types of care can become blurred.

The needs of people approaching the end of life may be complex as well as highly individual, and are likely to span both health and social care. Movement between care settings occurs more frequently in the final year of life than at any other stage. Successful end of life care therefore requires effective multidisciplinary working within, and between, health and social care services across hospitals, hospices, care homes and the community. A large part of end of life care is provided not by health care professionals but by family members, that may include children, and by friends, carers and volunteers. The role of these supporters is essential to the provision of good quality care at the end of life, but caring for someone who is dying is both physically and mentally demanding and carers frequently have needs of their own before, during and after the person’s death that must be also addressed. End of life care must therefore include bereavement care and support.
2. Policy Context

National Strategy for End of Life Care

The Government made improving the quality of care at the end of life a priority with the publication of the National Strategy for End of Life Care in 2008.\textsuperscript{[8]} In 2012, the Government formally required the NHS to provide the highest standards of care to older people and those at the end of people’s lives.\textsuperscript{[9]} Responsibility for planning how to provide end of life care services became the remit of the NHS England in April 2013.

A new approach to end of life care was introduced following a review\textsuperscript{[10]} of the Liverpool Care Pathway. This focused on the needs and wishes of the dying person and those close to them, moving end of life care away from the previous pathway based approach to one focused on the following priorities for care:\textsuperscript{[11]}

**Priority 1:** The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person’s needs and wishes, and these are regularly reviewed and decisions revised accordingly.

**Priority 2:** Sensitive communication takes place between staff and the dying person, and those identified as important to them.

**Priority 3:** The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.

**Priority 4:** The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

**Priority 5:** An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.

It is recognised that, wherever possible, enabling individuals to plan for death should start well before a person reaches the end of their life and should be integral to personalised care. The End of Life Care Strategy 2008 highlighted the importance of the place of death, and choice in this, to dying people and their families. A key aim of the Strategy is to enable more people to be cared for and die where they choose, with dignity and respect. Research has shown that home is the preferred place of death for the majority of people\textsuperscript{[12][13]} and meeting the expectations of individuals in relation to this is an important measure of quality in end of life care. Responding to this priority, an independent review with the aim of expanding choice and improving the quality of end of life care was commissioned in 2014 and reported February 2015.\textsuperscript{[14]} This found that whilst choice was a key feature of the 2008 national strategy and much progress had been made, services often remain unable to meet people’s individual requirements and aspirations. They suggest a ‘national choice offer’ for all people in England at the end of life to provide everyone with the chance to benefit from a comprehensive and consistent approach that offers and fulfils individual choices and preferences, and can overcome the fear of lack of control felt by many. This means care and support services need to be focused around what is important to the person and those close to them, whether this is place of care, symptom control or decisions around treatment. The engagement activity undertaken for the review revealed some key areas of choice people want:
Figure 1: Key areas of choice for end of life care

<table>
<thead>
<tr>
<th>Ambitions</th>
<th>Foundations</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Each person is seen as an individual</td>
<td>• Personalised care planning</td>
</tr>
<tr>
<td>• Each person gets fair access to care</td>
<td>• Shared records</td>
</tr>
<tr>
<td>• Maximising comfort and wellbeing</td>
<td>• Evidence and information</td>
</tr>
<tr>
<td>• Care is coordinated</td>
<td>• Involving, supporting and caring for those important to the dying person</td>
</tr>
<tr>
<td>• All staff are prepared to care</td>
<td>• Education and training</td>
</tr>
<tr>
<td>• Each community is prepared to help</td>
<td>• 24/7 access</td>
</tr>
<tr>
<td></td>
<td>• Co-design</td>
</tr>
<tr>
<td></td>
<td>• Leadership</td>
</tr>
</tbody>
</table>

Implementation needs to be locally led and the report is a call for action for collaboration and cooperation by local agencies to deliver improvements in care.
This requires leadership and the Partnership asks specifically for Health and Wellbeing Boards, CCGs, and Local Authorities (or a composite) “to publicly designate an organisation to lead on making these ambitions the reality for the communities you serve”

**Gold Standards Framework**

The Gold Standards Framework (GSF) is an evidence based approach to optimising the care for patients nearing the end of life. It is concerned with helping people to live well until the end of life and includes care in the final year of life for people with any end stage illness in the community.

The British Medical Association QOF states that:

“GSF is key to thinking through and implementing high quality patient centred care at the end of life for patients with both cancer and non-cancer diagnoses”.

Previously hosted within the NHS, from 2011 the GSF is managed by a not-for-profit Social Enterprise – The Gold Standards Framework (GSF) Centre CIC. The centre is the national training and coordinating centre for all GSF programmes, enabling generalist frontline staff to provide a gold standard of care for people nearing the end of life

**Dying Matters**

The End of Life Care strategy announced the formation of a national coalition known as Dying Matters to support the implementation of the strategy with a focus on raising public awareness and challenging attitudes and behaviours towards death and dying.

**More Care, Less Pathway: A review of the Liverpool Care Pathway**

Following concerns raised over the implementation of the Liverpool Care Pathway (LCP) an independent review was commissioned. The review, More Care, Less Pathway concluded that a ‘one size fits all’ approach was not recommended and that the LCP should be phased out and replaced by an end of life care plan for each patient, backed up by condition specific good practice guidance

**One chance to get it right**

In response to the review of the LCP, a coalition of 21 national organisations formed the Leadership Alliance for the Care of Dying People and set out their recommended approach to care in the last few days and hours of life with the 5 Priorities of Care for the Dying Person. It set five priorities for the dying person:

1. This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person’s needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

**Care & Communication record**

To support the 5 priorities for care the Community Integrated Advance Care Planning Team (CIACPT) designed a document to evidence care in the last days and hours of life. The Care & Communication Record is a multidisciplinary care plan and replaces all documentation shifting the focus of care to symptom control, comfort and support for the person who may be dying and those important to them. During the consultation period there was extended discussion around similarities to the LCP, there was a large focus on the CIACPT not redeveloping or rebranding the LCP. The document is divided into 3 sections and colour coded to guide its use. There is much emphasis on communication within the daily evaluation inviting the person who may be dying and/or those important to them to contribute as they wish. There was a robust training programme to support the implementation and the document is subject to ongoing audit.

**Actions for End of Life Care: 2014-16**

NHS England and the Department of Health have recently acknowledged that the 2008 strategy must be refreshed in order to reflect current needs and changes in the health and social care system. Until this has been developed, NHS England have published their Actions for end of life care 2014-16 which outlines their commitment to end of life care for adults and children.

NHS England have adopted a House of Care model (developed for long term conditions) as a framework for setting out their commitments to end of life care. This is illustrated in the diagram below.

**Figure 2: House of Care Model**

![House of Care Model](image-url)
House of Commons Health Committee: End of Life Care

Drawing on a range of written and oral evidence from a range of key stakeholders, the House of Commons Health Committee (2015) considered the state of palliative and end of life care.

In line with other recent reviews the Committee identified significant variation in care quality and practice across both acute and community settings. A number of recommendations are made. Some of these are highlighted below.

Every care provider should have a model in place based on the Five Priorities for Care that will deliver personal, bespoke care to people at the end of life.

- A senior named person in each NHS Trust and care provider is given responsibility for monitoring how end of life care is being delivered within their organisation
- The Government and NHS England set out how universal, seven-day access to palliative care could become available to all patients, including those with non-cancer diagnoses
- Commissioners should explicitly set out how they will provide specialist palliative care services for people from all backgrounds in their locality, and how they will ensure that those with a non-cancer diagnosis can also access specialist palliative care
- All staff who provide palliative and end of life care to people with life limiting conditions should receive training in advance care planning.
- Health Education England and NHS England set out how they plan to address the shortfalls in the staffing of community care services. This should involve their plans for the recruitment and training of district nurses
- The Government to provide free social care at the end of life to ensure that no one dies in hospital for want of a social care package of support
- The Government set out what it intends to do to ensure sustainable, long term funding for the hospice sector as part of their response to the Palliative Care Funding Review
- Bereavement support for families should also be included consistently as part of end of life care
- Further research into measuring the quality of end of life care and the priorities that matter most to people with terminal illnesses, their families and carers.

These recommendations reflect a number of the findings of this JSNA. In October 2015, the Government published their response to the Health Select Committee report.

National care of the dying audit for hospitals

In 2013/14 the Royal College of Physicians and Marie Curie Palliative Care Institute Liverpool undertook an audit on the quality of care received by people who died in hospitals in England in May 2013.

Overall, the audit found that there was significant variation in care across hospitals in England. For example, only 21% of hospital sites had access to face to face palliative services 7 days per week. The audit highlights areas for future improvements and the need to ensure better care and support for people who are dying and their families and carers.
A new audit, titled End of Life Care Audit - Dying in Hospital, is currently underway and will focus on progressing with the recommendations above and will ensure that the Priorities of Care for the Dying Person (see above) are monitored at a national level.

**Dying without Dignity**

In 2015 the Parliamentary and Health Service Ombudsman reported on investigations it had completed into end of life care across the country and across the NHS, including GP practices, hospitals and mental health trusts. The role of the Ombudsman is to investigate complaints that people have been “treated unfairly or received poor service from government departments and other public organisations and the NHS in England.”

The themes identified from this report reflect those concerns and findings raised in other reports and include:

- Not recognising that people are dying, and not responding to their needs.
- Poor symptom control.
- Poor communication.
- Inadequate out-of-hours services.
- Poor care planning.
- Delays in diagnosis and referrals for treatment.

In Halton our aim is to ensure all patients who have been diagnosed with any advanced, progressive, incurable illness (e.g. advanced cancer, heart failure, Chronic Obstructive Pulmonary Disease (COPD), stroke, diabetes, chronic neurological conditions, dementia) have access to high quality end of life care which offers; dignity, choice and support to achieve their preferred priorities for care in the last year of life; whether this be in a hospital, care home or their own home.

This is because evidence indicates the majority of deaths occur in patients diagnosed with any advanced, progressive, incurable illness. Where a death is expected and could be anticipated it is our intention that patients should be identified in advance to ensure high quality services are in place to support patients to plan and achieve their preferred priorities for care at the end of life, which includes achieving a home death, where this is the patients preference.

This chapter focuses on the end of life care for all adults with any advanced, progressive, incurable illness regardless of their diagnosis.

Information in other JSNA chapters - cancer and long-term conditions such as cardiovascular disease, COPD and diabetes, older people and carers - should also be considered.
3. Level of need in the population

3.1 Why is End of Life Care important?

People who are approaching the end of their lives and their families are at risk of a poor experience at a difficult time if they receive inappropriate care either in hospital when they do not need hospital care or at home or in a care home when they are not supported adequately. The National Audit Office report on end of life care[^17] suggested that approximately 40% of patients dying in acute hospitals do not have medical needs requiring a hospital stay. In 2013/14 601 Halton CCG registered patients died in hospital. Applying the national percentage would equate to 240 people not having a medical need to be there.

Another study[^18] confirms the National Audit Office’s estimate. Both studies reviewed the clinical notes of patients dying in hospital against agreed criteria to assess whether the patients could have been cared for at home with the support of community services. The National Audit Office report on end of life care and the national strategy both describe appropriate community services for people who are dying and their families and carers.

The Royal College of General Practitioners has issued ‘Prognostic Indicator Guidance’ to help GPs to identify which patients are most likely to need end of life care in the next year so that their QOF registers provide a more realistic estimate of needs.[^19] The guidance is based on the Gold Standards Framework, a practice based system to improve the organization and quality of palliative care services for people at home in the last year of their lives. It covers specific clinical indicators for the three main end of life patient groups: cancer, organ failure and frail elderly with dementia.[^20]

3.2 Number of deaths

There have been between 1,100 and 1,200 deaths each year in Halton between 2010 and 2014. The majority, are amongst those aged 65 and over, 74% and more depending on year and gender. The following sections examine these deaths, considering place of death, age and gender breakdown, causes and other characteristics.

3.3. Place of Death

Most people (67%) express a wish to die at home, however, only 22% actually do. 7% of people wish to die in hospital but 51% do. However, 60% of those who initially express a preference to die at home say they would change this view if doing so without support.[^21]
Table 1: Deaths in usual residence, CCG level and comparators

<table>
<thead>
<tr>
<th>Year</th>
<th>NHS Halton</th>
<th>England</th>
<th>NHS England local area team: Merseyside</th>
<th>Strategic Clinical Network: Cheshire and Merseyside</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All deaths</td>
<td>Number deaths in usual resident</td>
<td>% deaths in usual residence</td>
<td></td>
</tr>
<tr>
<td>2010/11 Q1 - 2010/11 Q4</td>
<td>1,090</td>
<td>389</td>
<td>35.7</td>
<td>40.3</td>
</tr>
<tr>
<td>2010/11 Q2 - 2011/12 Q1</td>
<td>1,074</td>
<td>381</td>
<td>35.5</td>
<td>40.7</td>
</tr>
<tr>
<td>2010/11 Q3 - 2011/12 Q2</td>
<td>1,085</td>
<td>393</td>
<td>36.2</td>
<td>41.3</td>
</tr>
<tr>
<td>2010/11 Q4 - 2011/12 Q3</td>
<td>1,065</td>
<td>373</td>
<td>35.0</td>
<td>41.8</td>
</tr>
<tr>
<td>2011/12 Q1 - 2011/12 Q4</td>
<td>1,094</td>
<td>392</td>
<td>35.8</td>
<td>42.4</td>
</tr>
<tr>
<td>2011/12 Q2 - 2012/13 Q1</td>
<td>1,136</td>
<td>407</td>
<td>35.8</td>
<td>42.9</td>
</tr>
<tr>
<td>2011/12 Q3 - 2012/13 Q2</td>
<td>1,154</td>
<td>432</td>
<td>37.4</td>
<td>43.3</td>
</tr>
<tr>
<td>2011/12 Q4 - 2012/13 Q3</td>
<td>1,169</td>
<td>457</td>
<td>39.1</td>
<td>43.7</td>
</tr>
<tr>
<td>2012/13 Q1 - 2012/13 Q4</td>
<td>1,195</td>
<td>477</td>
<td>39.9</td>
<td>43.8</td>
</tr>
<tr>
<td>2012/13 Q2 - 2013/14 Q1</td>
<td>1,182</td>
<td>485</td>
<td>41.0</td>
<td>44.1</td>
</tr>
<tr>
<td>2012/13 Q3 - 2013/14 Q2</td>
<td>1,177</td>
<td>487</td>
<td>41.4</td>
<td>44.2</td>
</tr>
<tr>
<td>2012/13 Q4 - 2013/14 Q3</td>
<td>1,153</td>
<td>479</td>
<td>41.5</td>
<td>44.5</td>
</tr>
<tr>
<td>2013/14 Q1 - 2013/14 Q4</td>
<td>1,102</td>
<td>461</td>
<td>41.8</td>
<td>44.7</td>
</tr>
<tr>
<td>2013/14 Q2 - 2014/15 Q1</td>
<td>1,102</td>
<td>445</td>
<td>40.4</td>
<td>44.8</td>
</tr>
<tr>
<td>2013/14 Q3 - 2014/15 Q2</td>
<td>1,096</td>
<td>442</td>
<td>40.3</td>
<td>45.1</td>
</tr>
<tr>
<td>2013/14 Q4 - 2014/15 Q3</td>
<td>1,132</td>
<td>442</td>
<td>39.0</td>
<td>45.1</td>
</tr>
<tr>
<td>2014/15 Q1 - 2014/15 Q4</td>
<td>1,211</td>
<td>470</td>
<td>38.8</td>
<td>45.6</td>
</tr>
<tr>
<td>2014/15 Q2 - 2015/16 Q1</td>
<td>1,198</td>
<td>478</td>
<td>39.9</td>
<td>45.7</td>
</tr>
</tbody>
</table>

Source: ONS via End of Life Care Intelligence Network

Note: ‘Usual residence’ as used in the table above refers to home or care home, as opposed to other data in this section where home is separated from care homes and nursing homes. Therefore care should be taken in comparing the two directly.

The latest CCG deaths figures show that Halton is currently ranked 36 in the country for percentage of deaths in the usual residence out of 211 CCGs, where 1 represents the lowest percentage and 211 the highest. This rate has increased slowly over time but has been consistently below the England, Merseyside and Cheshire & Merseyside averages. For the majority of this time, it has been statistically lower than the England average but statistically not different to the other comparator areas. For the latest period (2014/15 quarter 2 to 2015/16 quarter 1) NHS Halton had the lowest percentage of deaths occurring in the person’s usual place of residence across Cheshire and Merseyside, with the highest percentage in NHS Southport & Formby at 52.5%.
3.3.1. By age and gender

The majority of deaths, over one in three, occur in people aged 65 and over, although the percentages are a little lower for men than women.

Table 2: Number of deaths and proportion aged 65+

<table>
<thead>
<tr>
<th>Year</th>
<th>Persons</th>
<th>Males</th>
<th>Females</th>
<th>Persons</th>
<th>Males</th>
<th>Females</th>
<th>Persons</th>
<th>Males</th>
<th>Females</th>
<th>deaths 65+ as proportion of total deaths (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
<td>1116</td>
<td>566</td>
<td>550</td>
<td>853</td>
<td>411</td>
<td>442</td>
<td>76.4%</td>
<td>72.6%</td>
<td>80.4%</td>
<td></td>
</tr>
<tr>
<td>2011</td>
<td>1108</td>
<td>546</td>
<td>562</td>
<td>869</td>
<td>410</td>
<td>459</td>
<td>78.4%</td>
<td>75.1%</td>
<td>81.7%</td>
<td></td>
</tr>
<tr>
<td>2012</td>
<td>1206</td>
<td>574</td>
<td>632</td>
<td>954</td>
<td>430</td>
<td>524</td>
<td>79.1%</td>
<td>74.9%</td>
<td>82.9%</td>
<td></td>
</tr>
<tr>
<td>2013</td>
<td>1210</td>
<td>576</td>
<td>634</td>
<td>990</td>
<td>442</td>
<td>548</td>
<td>81.8%</td>
<td>76.7%</td>
<td>86.4%</td>
<td></td>
</tr>
<tr>
<td>2014</td>
<td>1184</td>
<td>592</td>
<td>592</td>
<td>945</td>
<td>445</td>
<td>500</td>
<td>79.8%</td>
<td>75.2%</td>
<td>84.5%</td>
<td></td>
</tr>
</tbody>
</table>

Whilst the percentages of deaths occurring in hospital vary little by age, a higher percentage of deaths in those under the age of 65 occur in a person’s own home. However, when own residence and deaths in care homes are considered together as ‘usual residence, then the percentage dying in their usual residence increases with age, from 30.1% in those aged under 65, 37.8% in those aged 65-84 and 45% in those aged 85 and over (Figure 3). This is the same pattern for males and females (Figure 4).

Figure 3: Persons by age and place of death

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Hospital</th>
<th>Own Residence</th>
<th>Care Home</th>
<th>Hospice</th>
<th>Other Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>All ages</td>
<td>2.3</td>
<td>8.1</td>
<td>16.4</td>
<td>21.9</td>
<td>51.3</td>
</tr>
<tr>
<td>under 65</td>
<td>6.1</td>
<td>12.3</td>
<td>1.4</td>
<td>28.7</td>
<td>51.4</td>
</tr>
<tr>
<td>65-84</td>
<td>9.5</td>
<td>13.5</td>
<td>24.3</td>
<td>12.8</td>
<td>51.1</td>
</tr>
<tr>
<td>85+</td>
<td>0.9</td>
<td>32.2</td>
<td>12.8</td>
<td>51.4</td>
<td></td>
</tr>
</tbody>
</table>

Source: End of Life Intelligence Network, PHE 2015
2013 data shows that Halton has similar pattern of place of death by age group as the North West and England averages.

**Table 3: Place of death by age band, Halton and comparators, 2013**

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Halton</th>
<th>North West</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital deaths, Persons, All Ages (%)</td>
<td>48.09</td>
<td>50.78</td>
<td>48.28</td>
</tr>
<tr>
<td>Hospital deaths, Persons, Aged 0 to 64 years (%)</td>
<td>48.37</td>
<td>49.51</td>
<td>46.37</td>
</tr>
<tr>
<td>Hospital deaths, Persons, Aged 65-74 (%)</td>
<td>41.25</td>
<td>51.65</td>
<td>49.91</td>
</tr>
<tr>
<td>Hospital deaths, Persons, Aged 75-84 (%)</td>
<td>52.28</td>
<td>54.11</td>
<td>51.98</td>
</tr>
<tr>
<td>Hospital deaths, Persons, Aged 85+ (%)</td>
<td>48.48</td>
<td>48.10</td>
<td>45.58</td>
</tr>
<tr>
<td>Home deaths, Persons, All Ages (%)</td>
<td>23.47</td>
<td>21.77</td>
<td>22.42</td>
</tr>
<tr>
<td>Home deaths, Persons, Aged 0 to 64 years (%)</td>
<td>29.77</td>
<td>33.07</td>
<td>33.49</td>
</tr>
<tr>
<td>Home deaths, Persons, Aged 65-74 (%)</td>
<td>34.63</td>
<td>29.55</td>
<td>30.21</td>
</tr>
<tr>
<td>Home deaths, Persons, Aged 75-84 (%)</td>
<td>21.18</td>
<td>17.77</td>
<td>22.62</td>
</tr>
<tr>
<td>Home deaths, Persons, Aged 85+ (%)</td>
<td>14.13</td>
<td>13.10</td>
<td>14.76</td>
</tr>
<tr>
<td>Care home deaths, Persons, All Ages (%)</td>
<td>17.74</td>
<td>20.01</td>
<td>21.62</td>
</tr>
<tr>
<td>Care home deaths, Persons, Aged 0 to 64 years (%)</td>
<td>.47</td>
<td>2.37</td>
<td>2.85</td>
</tr>
<tr>
<td>Care home deaths, Persons, Aged 65-74 (%)</td>
<td>7.78</td>
<td>7.86</td>
<td>8.07</td>
</tr>
<tr>
<td>Care home deaths, Persons, Aged 75-84 (%)</td>
<td>18.77</td>
<td>18.23</td>
<td>18.64</td>
</tr>
<tr>
<td>Care home deaths, Persons, Aged 85+ (%)</td>
<td>34.07</td>
<td>35.90</td>
<td>36.73</td>
</tr>
<tr>
<td>Hospice deaths, Persons, All Ages (%)</td>
<td>8.87</td>
<td>5.52</td>
<td>5.53</td>
</tr>
<tr>
<td>Hospice deaths, Persons, Aged 0 to 64 years (%)</td>
<td>14.88</td>
<td>9.37</td>
<td>10.33</td>
</tr>
<tr>
<td>Hospice deaths, Persons, Aged 65-74 (%)</td>
<td>15.56</td>
<td>9.37</td>
<td>9.86</td>
</tr>
<tr>
<td>Hospice deaths, Persons, Aged 75-84 (%)</td>
<td>6.97</td>
<td>5.39</td>
<td>5.48</td>
</tr>
<tr>
<td>Hospice deaths, Persons, Aged 85+ (%)</td>
<td>2.49</td>
<td>1.90</td>
<td>1.92</td>
</tr>
<tr>
<td>Deaths in Other Places, Persons, All Ages (%)</td>
<td>1.82</td>
<td>1.92</td>
<td>2.15</td>
</tr>
<tr>
<td>Deaths in Other Places, Persons, Aged 0 to 64 years (%)</td>
<td>6.51</td>
<td>5.69</td>
<td>6.96</td>
</tr>
<tr>
<td>Deaths in Other Places, Persons aged 65-74 (%)</td>
<td>.78</td>
<td>1.57</td>
<td>1.95</td>
</tr>
<tr>
<td>Deaths in Other Places, Persons, Aged 75-84 (%)</td>
<td>.80</td>
<td>1.10</td>
<td>1.28</td>
</tr>
<tr>
<td>Deaths in Other Places, Persons, Aged 85+ (%)</td>
<td>.83</td>
<td>1.00</td>
<td>1.02</td>
</tr>
</tbody>
</table>

*Source: ONS via Public Health England*
3.3.2. Trend in place of death all ages
Whilst the percentage of deaths that occur in hospitals continues to be the dominant place of death, recent trends show a decrease in the percentage of deaths occurring in hospital with increase in deaths occurring in the home and in care homes, reflecting the aging of the population and increase in life expectancy. Figure 4 shows the relative percentages for all ages but the patterns are similar for those aged 0-64 and 65 and over (percentage of deaths in hospice have reduced for those aged 85+).

Figure 5: Trend in place of death, Halton residents, all ages, 2014 to 2013

3.3.3. Deaths in hospital
Nearly half of all deaths in England occur in hospitals – 223007 out of a total of 469975 in 2014.\textsuperscript{[22]}
For this reason, trust boards, managers and clinicians should recognise that a core responsibility of hospitals is to deliver high-quality care for patients in their final days of life and appropriate support to their families, carers and those close to them. Government policy in recent years has reinforced this requirement. The second biennial national audit of care of the dying in hospitals in England found that there had been improvements since 2013 but that there was still a long way to go before the goal of the 24/7 access to specialist palliative care in hospitals is achieved.
Data from the two main hospitals providing care for Halton’s population showed that St Helens & Knowsley Hospital Trust had a higher percentage of cases reviewed having the clinical indicators included in the audit than Warrington & Halton Hospitals Trust. Warrington’s cases had a lower percentage for clinical indicators one and two but both hospitals had higher percentages than nationally for indicators three to five. St Helens & Knowsley Hospital Trust had higher percentages than England for all five clinical indicators. Warrington & Halton Hospital Trust did not have in-house training for its staff on communication skills in the last hours or days of life whereas St Helens & Knowlsey Hospital Trust did for all staff groups included in the audit (Table 4).
Data from the latest End of Life Care Profile for Halton local authority uses 2010/11 hospital admissions data. Whilst somewhat dated no alternative analysis for more recent years is currently available. It shows, Halton has higher percentages of ‘terminal admissions’ admitted as emergency cases but lower percentages for terminal admissions 85+, terminal admissions that are 8 days of longer and average bed days ending in death than England (Table 5).
Locally, the great majority of deaths (92%) that occurred in hospital were in Warrington and Halton NHS Foundation Trust, (2014), with the remainder mostly at other Cheshire or Merseyside hospitals (6%). Only 2% were at hospitals outside Cheshire and Merseyside.

Deaths in hospital are more likely to occur in areas of high deprivation than areas of low deprivation,\(^{[23]}\) with people living in the most deprived quintile more likely to die in hospital (25%) than people living in most other quintiles (11%-29%). However, the middle quintile for deprivation in Halton accounts for the highest proportion of deaths occurring in hospital (29%).

### 3.3.4 Influence of deprivation on place and cause of death

Socioeconomic deprivation is a major determinant of where, when and how people die. Analysis by the National End of Life Care Intelligence Network\(^{[24]}\) shows that there are fewer deaths (16% of the total) in the least deprived quintile (20%) of the population. Much of the analysis shows clear socioeconomic gradients, which highlight how inequalities affect the whole of society, not just the most deprived.

#### Place of death

People living in the most deprived quintile are more likely to die in hospital (61%) than people living in other quintiles (54–58%). Even after taking into account the combined effects of deprivation quintile, age at death, gender and cause of death, death in hospital is more common in the most deprived quintile. Death in care or nursing homes, often the usual place of residence for the very elderly, was less common among people living in the most deprived quintile (11%) than any other quintile (16–20%).

#### Cause of death

For each underlying cause (cancer, cardiovascular disease, respiratory disease and ‘other’ causes), people living in the most deprived quintile were most likely to die in hospital. For each underlying cause (cancer, cardiovascular disease, respiratory disease and ‘other’ causes), within each age group (under 65, 65–84 and 85 and over), people living in the most deprived quintile were most likely to die in hospital, with the exception of deaths caused by cardiovascular disease and respiratory disease.
disease in the under 65 age group. There are more deaths caused by smoking related cancers in people living in the most deprived quintile than in the least deprived quintile, as well as more deaths caused by chronic respiratory disease in the most deprived quintile than in the least deprived quintile. There are fewer deaths from malignant melanoma, breast and prostate cancer in the most deprived quintile than any of the other quintiles.

**Age of death**

27% of deaths in the most deprived quintile were people aged 85 and over compared with 35–40% in each of the other quintiles. This is largely because people in the most deprived quintile die younger. There were twice as many deaths of people aged under 65 in the most deprived quintile as in the least deprived quintile. For those who survive to age 85 and over, the ultimate cause of death is less dependent on deprivation than it is for people who die before old age. Among deaths of people aged under 65 years cancers associated with smoking, heart disease and external causes (accidents, assaults, self-harm) caused twice as many deaths in the most deprived quintile as in the least deprived quintile. Deaths due to respiratory disease causing four times as many deaths in the most deprived quintile as in the least deprived quintile.

Among deaths of people aged between 65 and 84 years, cancer is the most common cause of death for each deprivation quintile, and most common in the least deprived quintile (38% of deaths compared to 32–35% in the other quintiles) Respiratory disease remains more prevalent in the more deprived areas being the cause of twice as many deaths in the most deprived quintile as in the least deprived quintile. Among deaths of people aged 85 years or older, less than 16% of people who die at this age live in the most deprived quintile; o heart disease and stroke cause more than a third of deaths at this age, a proportion that is consistent across deprivation quintiles.

**Picture of the influence of deprivation on place and cause of death in Halton**

As seen nationally, in Halton deprivation exerts an influence on both what people die of and where they die. Halton is generally quite a deprived area with nearly half of its residents living in the most deprived 20% nationally. This impacts on the pattern of death by deprivation even when using local deprivation scores as most people live in the more deprived parts of the borough. So, whilst the pattern is not as clear cut as seen nationally, it is nevertheless there. People in the most deprived parts of the borough are more likely to die in hospital. Those living in more deprived parts of the borough are least likely to die in a hospice or at home.
Figure 7: Place of death by cause in each deprivation quintile, Halton residents, 2006 to 2015
3.4 Causes of death

As indicated in the introduction to this chapter, the majority of these deaths occurred following a period of chronic illness, where death could be anticipated and care planned. The three main causes which contributed 70% of all deaths in 2014 were:

- Cancers: 355 deaths (30%)
- Cardiovascular Disease: 294 deaths (25%)
- Respiratory Disease: 177 deaths (15%)

Other causes included:

- 9.1% due to mental and behavioural disorders, of which all but two were due to dementia (106 out of 108 deaths)
- 61 deaths due to diseases of the nervous system (5.2% of total deaths), most notably due to Alzheimer’s (27 deaths or 2.3% of total) and Parkinson’s Disease (13 deaths or 1.1% of the total)
- 55 deaths were due to digestive diseases (5% of total)
- 22 were due to Endocrine Disorders (1.9%) with 18 of these due to Diabetes (1.5%)

Just over a third of people with ischemic heart disease die in hospital, just under a third die at home with the further third in a care home. However, for other conditions, the split is less even. For example two-thirds of all deaths from unspecified dementia happen in care homes, nearly four in ever ten deaths due to chronic obstructive pulmonary disease happen in hospital, whereas a significant proportion of all cancer (neoplasm) deaths occur in a hospice (see Table 6).
Table 6: Percentage of all deaths by cause and place of death, 2010-2014

<table>
<thead>
<tr>
<th>Primary cause of death</th>
<th>Care Home</th>
<th>Primary cause of death</th>
<th>Home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ischaemic heart diseases</td>
<td>29.9%</td>
<td>Ischaemic heart diseases</td>
<td>30.8%</td>
</tr>
<tr>
<td>Unspecified dementia</td>
<td>75.8%</td>
<td>Malignant neoplasm of bronchus and lung</td>
<td>37.1%</td>
</tr>
<tr>
<td>Cerebrovascular diseases</td>
<td>32.1%</td>
<td>Chronic Obstructive Pulmonary Disease</td>
<td>17.4%</td>
</tr>
<tr>
<td>Influenza and pneumonia</td>
<td>50.7%</td>
<td>Malignant neoplasms of ill-defined, secondary and unspecified sites</td>
<td>42.1%</td>
</tr>
<tr>
<td>Chronic Obstructive Pulmonary Disease</td>
<td>38.3%</td>
<td>Malignant neoplasm of breast</td>
<td>34.7%</td>
</tr>
<tr>
<td>Malignant neoplasm of bronchus and lung</td>
<td>21.0%</td>
<td>Cerebrovascular diseases</td>
<td>11.0%</td>
</tr>
<tr>
<td>Other degenerative diseases of the nervous system</td>
<td>80.3%</td>
<td>Influenza and pneumonia</td>
<td>12.7%</td>
</tr>
<tr>
<td>Vascular dementia</td>
<td>84.3%</td>
<td>Malignant neoplasm of pancreas</td>
<td>32.9%</td>
</tr>
<tr>
<td>Other forms of heart disease</td>
<td>61.7%</td>
<td>Malignant neoplasm of colon</td>
<td>30.5%</td>
</tr>
<tr>
<td>General symptoms and signs</td>
<td>64.8%</td>
<td>Intentional self-harm</td>
<td>55.8%</td>
</tr>
<tr>
<td>Other diseases of urinary system</td>
<td>51.3%</td>
<td>Other forms of heart disease</td>
<td>14.5%</td>
</tr>
<tr>
<td>Other diseases of intestines</td>
<td>46.3%</td>
<td>Diseases of arteries, arterioles and capillaries</td>
<td>23.0%</td>
</tr>
<tr>
<td>Lung diseases due to external agents</td>
<td>61.7%</td>
<td>Malignant neoplasm of oesophagus</td>
<td>30.7%</td>
</tr>
<tr>
<td>Malignant neoplasm of breast</td>
<td>30.5%</td>
<td>Unspecified dementia</td>
<td>7.1%</td>
</tr>
<tr>
<td>Diseases of arteries, arterioles and capillaries</td>
<td>36.0%</td>
<td>Malignant neoplasm of stomach</td>
<td>37.9%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Primary cause of death</th>
<th>Hospice</th>
<th>Primary cause of death</th>
<th>Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>Malignant neoplasm of bronchus and lung</td>
<td>21.2%</td>
<td>Ischaemic heart diseases</td>
<td>35.4%</td>
</tr>
<tr>
<td>Malignant neoplasm of colon</td>
<td>36.6%</td>
<td>Chronic Obstructive Pulmonary Disease</td>
<td>38.3%</td>
</tr>
<tr>
<td>Malignant neoplasm of breast</td>
<td>24.6%</td>
<td>Cerebrovascular diseases</td>
<td>23.5%</td>
</tr>
<tr>
<td>Malignant neoplasm of prostate</td>
<td>33.3%</td>
<td>Influenza and pneumonia</td>
<td>35.6%</td>
</tr>
<tr>
<td>Malignant neoplasm of oesophagus</td>
<td>33.3%</td>
<td>Malignant neoplasm of bronchus and lung</td>
<td>17.6%</td>
</tr>
<tr>
<td>Malignant neoplasm of pancreas</td>
<td>39.1%</td>
<td>Other forms of heart disease</td>
<td>51.3%</td>
</tr>
<tr>
<td>Malignant neoplasms of urinary tract</td>
<td>21.5%</td>
<td>Unspecified dementia</td>
<td>16.5%</td>
</tr>
<tr>
<td>Malignant neoplasms of mesothelial and soft tissue</td>
<td>45.2%</td>
<td>Other diseases of intestines</td>
<td>48.8%</td>
</tr>
<tr>
<td>Chronic Obstructive Pulmonary Disease</td>
<td>5.2%</td>
<td>Alcoholic liver disease</td>
<td>50.6%</td>
</tr>
<tr>
<td>Malignant neoplasm of rectum</td>
<td>33.3%</td>
<td>Diseases of arteries, arterioles and capillaries</td>
<td>37.0%</td>
</tr>
<tr>
<td>Malignant neoplasms of ill-defined, secondary and unspecified sites</td>
<td>13.2%</td>
<td>Other diseases of urinary system</td>
<td>42.1%</td>
</tr>
<tr>
<td>Malignant neoplasms of eye, brain and other parts of central nervous system</td>
<td>32.6%</td>
<td>Other respiratory diseases principally affecting the interstitium</td>
<td>34.8%</td>
</tr>
<tr>
<td>Malignant neoplasm of ovary</td>
<td>36.8%</td>
<td>Diabetes mellitus</td>
<td>35.4%</td>
</tr>
<tr>
<td>Malignant neoplasm of stomach</td>
<td>24.1%</td>
<td>Other degenerative diseases of the nervous system</td>
<td>15.7%</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>21.4%</td>
<td>Falls</td>
<td>55.9%</td>
</tr>
</tbody>
</table>

Source: Primary Care Mortality Database
3.5. End of Life Care and palliative care for specific communities

The NHS Improving Quality organisation have produced a guidance and advice on end of life care for those working with specific communities.\[25\]

A review\[26\] of equity in the provision of palliative care in the UK found that while many people receive high quality care there are still significant gaps in provision, and estimate that around 92,000 people a year in England who would benefit from palliative care do not receive it. The authors conclude that palliative care interventions are cost-effective and extending specialist and core palliative care services to those who would benefit could result in net savings of £36m in England.

There are a number of specific communities who may face challenges to accessing end of life or palliative care for various reasons. Whilst numbers may be small, it is important to consider how local services can meet the needs of common groups such as people with dementia or learning disabilities, Lesbian Gay, Bisexual or Transgender patients, as well as children and homeless patients.

3.5.1. People with dementia

Dementia has a significant impact on an individual’s health and quality of life (see Dementia chapter of the Older People’s JSNA). It can result in a range of health and social problems which can be challenging for the person with dementia, their carers, and health and social care professionals. People with dementia are likely to have significant physical and mental comorbidities, such as depression, hypertension and diabetes.

Estimates of rates of dementia vary. Whatever the true underlying prevalence is, services will currently be engaging with the majority of those at the more severe end of the spectrum. The number of these is likely to increase over the next 15 years given national projections of local population changes. This increase in the number of people with dementia means that diagnostic, treatment and care service provision may need to expand proportionately to meet this increasing need. This will include end of life care and palliative care services.

The importance of end of life care for people with dementia is also highlighted in the National Dementia Strategy\[27\] where improved end of life care for people with dementia, and the involvement of people with dementia, their families and carers in care planning is included as an objective in the strategy.

Research by the Alzheimer’s Society and Marie Curie\[28\] identified a number of barriers to receiving high quality end of life care for people with dementia, categorized into three themes. These are shown in the table below.
### Table 7: Barriers to end of life care for people with dementia

<table>
<thead>
<tr>
<th>Theme</th>
<th>Barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identification and planning</td>
<td>• lack of timely and appropriate diagnosis</td>
</tr>
<tr>
<td></td>
<td>• poor recognition of dementia as a terminal condition</td>
</tr>
<tr>
<td></td>
<td>• failure to identify dementia as a cause of death</td>
</tr>
<tr>
<td></td>
<td>• ineffective advance care planning</td>
</tr>
<tr>
<td>Inequality of access...</td>
<td>• to palliative care</td>
</tr>
<tr>
<td></td>
<td>• to hospice care</td>
</tr>
<tr>
<td></td>
<td>• to funding</td>
</tr>
<tr>
<td></td>
<td>• discrimination</td>
</tr>
<tr>
<td>Quality of care</td>
<td>• inconsistency in care standards in hospitals</td>
</tr>
<tr>
<td></td>
<td>• inappropriate hospital admissions</td>
</tr>
<tr>
<td></td>
<td>• lack of continuity of care</td>
</tr>
<tr>
<td></td>
<td>• poor pain management</td>
</tr>
<tr>
<td></td>
<td>• inappropriate interventions</td>
</tr>
<tr>
<td></td>
<td>• failure to adapt practice to reflect the different nature of dementia</td>
</tr>
<tr>
<td></td>
<td>• lack of support for carers</td>
</tr>
</tbody>
</table>

*Source: Alzheimer’s Society and Marie Curie (2014)*

The report concludes that the way services are designed, delivered and commissioned needs to change in order to ensure that people receive the care they need and meet the future challenges posed by the increase in dementia. A call for action is made to remove the barriers that prevent many people with dementia from accessing the high quality end of life care they need; transform core services that have primarily been designed in response to cancer patients; and work in partnership to raise understanding and awareness of dementia and end of life care.

Research conducted on the views of carers and professionals\(^{29}\) found that:

- A lack of communication between professional and carer may lead to a poor experience. Professionals should establish the carers’ perspectives and wishes on the care of the patient
- Cultural backgrounds, beliefs and experiences of professionals may influence choices over what kind of support and care is desired
- Advance care planning may be helpful to all parties, but may not always be desired
- Professionals need to be aware of the possibility of elder abuse or poor quality care when supporting people with dementia and should know their responsibilities
- Professionals may benefit from skills development and access to resources in seeking to implement a holistic approach to end-of-life care for people with dementia
3.5.2. People with learning disabilities

People with a learning disability are more likely than the general population to experience a range of health conditions, including heart disease, diabetes, respiratory disease, epilepsy, mental illness, dementia, and sensory impairment. Consequently this will have an impact on the end of life care needs of this group.

Overall, a number of challenges to providing end of life care for people with a learning disability are highlighted which, if addressed, may lead to a “good death” for the person with a learning disability and their family or carers.

The partnership between specialist palliative care services and learning disability services is also highlighted in a UK mixed-method study. Based on the findings from a questionnaire sent to a sample of 66 services in one UK region (including learning disability services, specialist palliative care services, and nursing homes for people with a learning disability) and semi-structured interviews with 30 selected health and social care professionals, the authors developed a partnership framework for learning disability and specialist palliative care services.

Figure 9: A framework for partnership practice between specialist palliative care and intellectual disability services

The study found examples of good practice existed but that partnership practice between services was infrequent and a number of unmet educational needs were identified. For palliative care teams this included understanding how and where to access local learning disability services, and issues around communication and assessment. For learning disability services, this included knowledge of
pain and symptom management, bereavement care, and self-care to cope with death and professional grief. Key factors for success were joint working and learning between services.

3.5.3. Lesbian, Gay, Bisexual and Transgender (LGBT)

The End of Life Care Strategy Equality Impact Assessment[^31] identifies sexual orientation and gender identity as the most likely area for inequality and discrimination to occur in end of life care. One of the key areas reported was that the nature of LGBT relationships may well be concealed, with the consequence that practitioners and staff may exclude key individuals from involvement in a person’s care.

NHS Improving Quality reports that LGBT experiences can be characterised by a number of factors which are likely to have an impact[^32]. These include living alone, social isolation, barriers to services and a lack of consultation, negative experiences related to their sexual orientation or gender identity, and ageism.

The CQC’s 2016 report[^33] found that people from certain groups in society continue to experience poorer quality care at the end of their lives than others because providers and commissioners do not always understand or fully consider their specific needs. This means that some commissioners and providers may not be fulfilling their duties under the Equality Act 2010 as all public bodies have a legal duty to consider the needs of a range of equality groups when carrying out their day-to-day work. The report found that discrimination continues to have an adverse impact on LGBT people’s access, needs and experience of services.

In response to this and previous work the National Council for Palliative Care[^34] has published a new guide on end of life care for older LGBT people called “Being Accepted Being Me: Understanding the end of life care needs for older LGBT people”. It is intended to help health and social care staff and volunteers to learn more about listening, understanding and responding to the unique needs of LGBT people.

Challenging the mindset that says “we treat everyone the same” it the need to treat people as individuals and therefore the need to make sure that LGBT people’s needs and preferences are understood at a personal level.

3.5.4. Homeless people

Homeless people experience poorer levels of physical and mental health than the general population, and there is a substantial international evidence base which documents multiple morbidities with many homeless people dying from treatable medical conditions, HIV, liver and other gastro-intestinal disease, respiratory disease, and consequences of drug and alcohol dependence.[^35] Research largely finds the average age of death of a homeless person as between 40-42 years of age. Crisis identified the average age of death for homeless people in England as 47 compared to 77 for the general population.[^36]

The National End of Life Care strategy[^37] states that high quality end of life care “should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere”.

[^31]: Joint Strategic Needs Assessment 2015/16
[^32]: NHS Improving Quality
[^33]: CQC’s 2016 report
[^34]: National Council for Palliative Care
[^35]: Research
[^36]: Crisis
[^37]: The National End of Life Care strategy
Recognising that homeless people are often overlooked when developing policy and are not often engaged in service development, and that consequently the implementation of the strategy poses particular challenges in relation to homeless people, the National End of Life Care Programme report[38] a range of key considerations for end of life care for homeless people, including:

- The existing environment may not encourage privacy or be suitable for care and it may not be practicable to consider rebuilding or remodelling hostels
- Access to services may be problematic because of other professionals’ misconceptions— for instance, homeless people are often stigmatised as non-compliant and unreliable
- The homeless population often decline to engage with health services
- Access to placement at end of life for people with substance misuse problems can be difficult because many care facilities do not accept people with drug or alcohol issues. Staff need to be aware of those providers who do accept and provide for this
- Some outreach services can have bureaucratic barriers
- Many hostels tend not to retain residents for a long time but help them move to supported or independent living. With collaborative working and planning this should also be possible for those with end of life care needs
- Many residents have very complex needs including a high incidence of learning difficulties, mental health problems and dependency issues. As a result hostels may not offer the best environment for end of life care

3.5.5. Children with terminal illness

The numbers of children who die locally are very low, and include neonates who die shortly after birth. Deaths in those aged 0-17 represent less than 1% of all deaths, and 0.04% of the population in this age group (compared to 11% in those aged 85 years and over). As you can see in Figure 8 in the Technical Document, most of the deaths in those aged 0-17 years are babies.

However, end of life care services need to be aware of different issues when working with children who are dying. The General Medical Council’s guidance on End of Life Care[39] includes guidance on Neonates, Children and Young People. The best practice recommends balancing the need to safeguard children’s health and wellbeing with enabling them to take part in decision making, listening to them and taking account of what they have to say about things that affect them if they have full capacity.

When dealing with infants and neonates, it is key to give parents or carers information and support and consistent and clear messages about their child’s care on condition.
4. Service provision

4.1. Primary care

The way primary care teams provide palliative care in the last months of life has changed and developed extensively in recent years with:

- since the introduction of the QOF palliative care indicator set over 99% of practices now use a palliative care register
- specific emphasis on the inclusion of patients with non-malignant disease and of all ages since April 2008
- patients and carers being offered more choice regarding their priorities and preferences for care including their preferred place of care in the last days of life (evidence shows that more patients achieve a home death if they have expressed a wish to do so)
- increasing use of anticipatory prescribing to enable rapid control of symptoms if needed and a protocol or integrated care pathway for the final days of life
- identification of areas needing improvement by the NAO e.g. unnecessary hospital admissions during the last months of life

The National EoLC Strategy suggests that all contractors adopt a systematic approach to EoLC and work to develop measures and markers of good care. They recommend the Gold Standards Framework (GSF) and the associated After Death Analysis (ADA) as examples of good practice. Evidence suggests that over 60% of practices across the UK now use GSF to some degree to improve provision of palliative care by their primary care team. The introduction of the GSF160 to primary care and its associated audit tool, the ADA, are associated with a considerable degree of research and evaluation. The GSF provides ideas and tools that help contractors to focus on implementing high quality patient-centred care.

Rationale for the establishment and maintenance of a register for palliative care

As noted earlier in this report, about 1% of the population in the UK die each year (over half a million), giving an average of 20 deaths per GP per year. A quarter of all deaths are due to cancer, a third from organ failure, a third from frailty or dementia and only one twelfth of patients have a sudden death. It may therefore be possible to predict the majority of deaths, however, this is difficult and errors occur 30% of the time. Two thirds of errors are based on over optimism and one third on pessimism. However, the considerable benefits of identifying these patients include providing the best health and social care to both patients and families and avoiding crises, by prioritising them and anticipating need. Identifying patients in need of palliative care, assessing their needs and preferences and proactively planning their care, are the key steps in the provision of high quality care at the end of life in general practice. This indicator set is focused on the maintenance of a register (identifying the patients) and on regular multidisciplinary meetings where the team can ensure that all aspects of a patient’s care have been assessed and future care can be co-ordinated and planned proactively. A patient is included on the register if any of the following apply:

- Their death in the next 12 months can be reasonably predicted (rather than trying to predict, clinicians often find it easier to ask ‘the ‘surprise question’ ‘Would I be surprised if this patient were still alive in 12 months?’).
- They have advanced or irreversible disease and clinical indicators of progressive deterioration and thereby a need for palliative care e.g. they have one core and one disease...
specific indicator in accordance with the GSF Prognostic Indicators Guidance (see QOF section of the GSF website).

- They are entitled to a DS 1500 form (the DS 1500 form is designed to speed up the payment of financial benefits and can be issued when a patient is considered to be approaching the terminal stage of their illness. For these purposes, a patient is considered as terminally ill if they are suffering from a progressive disease and are not expected to live longer than six months). The register applies to all patients fulfilling the criteria regardless of age or diagnosis. The creation of a register will not in itself improve care but it enables the wider practice team to provide more appropriate and patient focussed care.

Table 8: QOF prevalence of palliative care need, Halton CCG and comparators 2013/14 and 2014/15

<table>
<thead>
<tr>
<th></th>
<th>2013/14</th>
<th>Prevalence</th>
<th>Register</th>
<th>2014/15</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Halton CCG</td>
<td>364</td>
<td>0.3%</td>
<td>382</td>
<td>0.3%</td>
<td></td>
</tr>
<tr>
<td>North West</td>
<td>49763</td>
<td>0.3%</td>
<td>55931</td>
<td>0.4%</td>
<td></td>
</tr>
<tr>
<td>England</td>
<td>152099</td>
<td>0.3%</td>
<td>177329</td>
<td>0.3%</td>
<td></td>
</tr>
</tbody>
</table>

Source: QOF, HSCIC 2015

Table 9: Palliative care need at Halton GP practice level, 2013/14 and 2014/15

<table>
<thead>
<tr>
<th>Practice Code</th>
<th>Practice Name</th>
<th>2013-14</th>
<th>2014-15</th>
<th>Year on Year Change (percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>List Size</td>
<td>Register</td>
<td>Prevalence (percentage)</td>
</tr>
<tr>
<td>NB1011</td>
<td>Beaconsfield</td>
<td>11,317</td>
<td>22</td>
<td>0.19</td>
</tr>
<tr>
<td>NB1019</td>
<td>Castlefields</td>
<td>11,844</td>
<td>116</td>
<td>0.98</td>
</tr>
<tr>
<td>NB1035</td>
<td>Appleton</td>
<td>10,860</td>
<td>40</td>
<td>0.37</td>
</tr>
<tr>
<td>NB1037</td>
<td>The Beeches</td>
<td>7,914</td>
<td>22</td>
<td>0.28</td>
</tr>
<tr>
<td>NB1045</td>
<td>Peephouse</td>
<td>14,134</td>
<td>36</td>
<td>0.25</td>
</tr>
<tr>
<td>NB1054</td>
<td>Weaver Vale</td>
<td>9,110</td>
<td>10</td>
<td>0.11</td>
</tr>
<tr>
<td>NB1057</td>
<td>Tower House</td>
<td>13,189</td>
<td>12</td>
<td>0.09</td>
</tr>
<tr>
<td>NB1064</td>
<td>Newtown</td>
<td>7,898</td>
<td>23</td>
<td>0.29</td>
</tr>
<tr>
<td>NB1066</td>
<td>Grove House</td>
<td>10,592</td>
<td>7</td>
<td>0.07</td>
</tr>
<tr>
<td>NB1072</td>
<td>Murrishaw</td>
<td>7,121</td>
<td>12</td>
<td>0.17</td>
</tr>
<tr>
<td>NB1095</td>
<td>Brookvale</td>
<td>8,123</td>
<td>27</td>
<td>0.38</td>
</tr>
<tr>
<td>NB1119</td>
<td>Hough Green</td>
<td>3,667</td>
<td>7</td>
<td>0.19</td>
</tr>
<tr>
<td>NB1618</td>
<td>Heath Road</td>
<td>2,554</td>
<td>...</td>
<td>0.04</td>
</tr>
<tr>
<td>NB1619</td>
<td>Oaks Place</td>
<td>3,013</td>
<td>...</td>
<td>0.17</td>
</tr>
<tr>
<td>NB1625</td>
<td>West Bank</td>
<td>2,508</td>
<td>18</td>
<td>0.72</td>
</tr>
<tr>
<td>NB1651</td>
<td>Upton Rocks</td>
<td>2,897</td>
<td>...</td>
<td>0.17</td>
</tr>
<tr>
<td>O1F</td>
<td>Halton CCG</td>
<td>129,007</td>
<td>2,218</td>
<td>1.72</td>
</tr>
<tr>
<td>Q48</td>
<td>Merseyside Area Team</td>
<td>1,261,171</td>
<td>21,728</td>
<td>1.72</td>
</tr>
<tr>
<td>England</td>
<td></td>
<td>56,324,887</td>
<td>152,099</td>
<td>0.27</td>
</tr>
</tbody>
</table>

In additional to the register of patients in need of palliative care practices should have regular (at least 3 monthly) multi-disciplinary case review meetings where all patients on the palliative care register are discussed. The aims of multidisciplinary case review meetings are to:

- ensure all aspects of the patients care have been considered and documented in the patients records
- improve communication within the team and with other organisations (e.g. care home, hospital, community nurse specialist) and particularly improve handover of information to out-of-hours services
- co-ordinate each patient's management plan ensuring the most appropriate member of the team takes any action, avoiding duplication
- ensure patients are sensitively enabled to express their preferences and priorities for care, including preferred place of care
- ensure that the information and support needs of carers are discussed, anticipated and addressed where ever reasonably possible. Many staff directly employed by the contractor find use of a checklist during the meeting helpful, as it helps to ensure all aspects of care are covered e.g. supportive Framework guidance for GMS contract 2014/15 126 care register (SCR) templates SCR1 and SCR2 the assessment tools on the GSF website.

Halton has a 100% achievement rate for this indicator, compared to 98.21 for the Merseyside Area team and 96.68% for England as a whole.

Patients requiring intensive support receive GSF Advanced Care Planning. See section 4.5 for details.

4.2. Community care: End of Life Social Services

Halton’s Reablement Service provide short term, low level support to people to enable them to retain or regain their independence at a time of change in their physical and mental health circumstances. Halton’s End of Life service is attached to this service.

District Nurses have direct access to the service for their patients. They identify who requires care and support and forwards the information to the service. District Nurses complete an assessment of people’s needs and when required attend joint visits with the care and support workers to support them in their role, ensuring the care and support workers have the skills and expertise to complete the necessary agreed tasks.

The staff team work closely with health colleagues to provide care and support to individuals in the latter 12 weeks of their life, and their families and significant others. The care and support is flexible and is often increased as individuals need increase.

4.3. Secondary Care

See section 3.3.3 pages 18-21

4.4. Specialist care

4.4.1. Halton Haven Hospice

The Hospice is an independent charity co-funded by Halton CCG and the people of Halton through its fundraising activities. It offers consultant-led specialist palliative care in an in-patient and day hospice setting. The in-patient unit has 12 beds and the Day Hospice has 12 places per day, four days per week. The Hospice also runs a consultant-led an out-patient clinic once per week.

In addition the Hospice offers a full Family Support Service to help people with issues that arise from bereavement including licensed financial and welfare advice. It is also pioneering the concept of “Men’s Sheds” as a particular support to bereaved men.

The Hospice Advance Care Planning Team make quality improvements in the provision of End of Life Care within Halton by facilitating the implementation of National End of Life Care tools across the
Borough. These tools include the Gold Standards Framework (GSF) and Preferred Priorities for Care (PPC) and a key element is working with stakeholders to establish awareness of these tools, generating interest from GP Practices, Care Homes and other key stakeholders, providing information, guidance and education to support best practice in care delivery at end of life. Halton Haven did not take part in the last national audit, instead conducting their own client survey. Based on data for the 12 months ending Aug 2015, most people rated the facilities extremely well and nearly all would highly likely recommend it to family and friends.

Figure 10: Halton Haven facilities, results of client survey

98% felt that the needs of family and friends had been met with 96% percentage saying they would recommend the hospice to family and friends, a further 2% would likely recommend it. 2% did not answer.

4.4.2. Macmillan Nursing Service

The Halton Community Macmillan Specialist Palliative Care Team, employed by Bridgewater Community NHS Foundation trust, consists of four Macmillan Clinical Nurse Specialists’ and a Macmillan Development post (vacancy). Specialist Medical support if provided to the team from a Consultant in Palliative Medicine/Clinical lead and a Speciality Doctor. The office is based in the grounds of Halton Haven Hospice, Runcorn. The service provides Specialist Palliative support and advice seven days a week including bank holidays. Health Professionals in Halton also have access to Specialist Palliative Care Advice 24 hours a day via our telephone advice line.

We provide specialist support and advice to our colleagues in Primary care as well as to patients and their families in the palliative phase of their illness, regardless of diagnosis. This includes complex unresolved pain and other symptoms, complex psychosocial support and those patients that might be entering the last few days/weeks/months of life where Specialist assessment and or, support is required. This includes education, both formal and informal, incorporating research and audit. Attendance at the ‘dying matters week’ each May allows the general public and other health care professionals the opportunity to engage safely on the subject of death, dying and end of life care.
End of life care is an element of the service provided, the North West End of Life Care Model (based on recommended best practice, led by government initiatives, regionally and locally led) allows the team to build on the requirements that are needed to ‘meet the supportive and palliative needs for all those with an advanced incurable illness’. The team work closely with the Advanced Care Planning Team which includes education, DNACPR training and changes to out of hours working. The service has been involved with the education and cascade of the Care and Communication document that promotes an individual approach to care for those in the last few days of life (and replaced the Liverpool Care Pathway). Recent NICE guidelines have provided guidance on an individual approach to care assessment and prescribing at the end of life addressing some of the issues highlighted in the recent investigation of the Liverpool care pathway.

Support and guidance is also offered to colleagues in Primary care while employing and promoting the Gold standards framework, this includes regular monitoring of patients thought to be in the last year of life and includes regular meetings which we attend. Attendance at multi-disciplinary team meetings which including various allied health care professionals, social worker, pastoral care and Halton Integrated Bereavement Service (HIB’s).

4.5. Advance Care Planning

Advance care planning is a key element of the end of life care pathway and policy which is reflected in the adoption of the Coordinate My Care tool to allow appropriate professionals involved in the care of the patient to access their care plan. However, there is a lack of evidence on the implementation and effectiveness of care planning in achieving outcomes such as fewer hospital deaths or less use of life-prolonging treatments near the end of life. A feasibility study involving interviews and a workshop with GPs and community nurses, identified a number of barriers to early adoption of advance care plans:

- prognostic uncertainty
- limited collaboration with secondary care
- a desire to maintain hope
- resistance to any kind of ‘tick-box’ approach

Following the workshop there was an improvement in knowledge and skills, but there was no clear evidence of more proactive planning. Concerns were raised by GPs over implementing inflexible, policy-driven, care.

A trial involving 77 patients found that while an advance care planning intervention did demonstrate an increase in discussions about the future between patients and professionals or family, happiness with the communication was the same or worse, and satisfaction with services decreased. In all, 38 of the patients (51%) reported a preference for the intervention.

Qualitative research on the perceptions of pediatric consultants and nurses, identified four major themes:

- recognition of an illness as ‘life-limiting’
- Advance Care Planning as a multi-disciplinary, structured process
- the value of Advance Care Planning
the adverse consequences of inadequate Advance Care Planning

A number of potential benefits of ACP were recognised including providing the opportunity to make decisions regarding end-of-life care in a timely fashion and in partnership with patients, where possible, and their families. ACP is the voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline. If the individual wishes, their family and friends may be included. It is recommended that with the individual’s agreement this discussion is documented, regularly reviewed and communicated to key persons involved in their care. Often advance care planning can lead to discussions about where a person would like to be cared for when they are dying and what their Proffered Place of Care (PPC) would be. In Halton data shows over 90% achieve their PCC.

Table 10: Percentage of Halton EOLC patients achieving their Proffered Place of Care, 2011/12 to January 2016

<table>
<thead>
<tr>
<th>Year</th>
<th>Home</th>
<th>Care Homes: Nursing</th>
<th>Care Homes: Residential</th>
<th>Hospice</th>
<th>Hospital</th>
<th>PCC Achieved</th>
<th>PCC not achieved</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011/12</td>
<td>56.7%</td>
<td>29.9%</td>
<td>3.0%</td>
<td>9.0%</td>
<td>1.5%</td>
<td>98.5%</td>
<td>1.5%</td>
</tr>
<tr>
<td>2012/13</td>
<td>24.8%</td>
<td>58.2%</td>
<td>8.5%</td>
<td>3.0%</td>
<td>5.5%</td>
<td>94.5%</td>
<td>5.5%</td>
</tr>
<tr>
<td>2013/14</td>
<td>17.4%</td>
<td>55.7%</td>
<td>12.1%</td>
<td>10.1%</td>
<td>4.7%</td>
<td>95.3%</td>
<td>4.7%</td>
</tr>
<tr>
<td>2014/15</td>
<td>28.5%</td>
<td>35.8%</td>
<td>22.5%</td>
<td>5.3%</td>
<td>7.9%</td>
<td>92.1%</td>
<td>7.9%</td>
</tr>
<tr>
<td>April 2015 - Jan 2016</td>
<td>21.5%</td>
<td>46.2%</td>
<td>21.5%</td>
<td>4.6%</td>
<td>6.2%</td>
<td>93.8%</td>
<td>6.2%</td>
</tr>
</tbody>
</table>

Source: Halton Advanced Care Planning Team

Barriers to the process include the recognition of the life-limiting nature of an illness and gaining consensus of medical opinion. Organisational improvements towards earlier recognition of lifelimiting illness and subsequent ACP were recommended, including education and training, as well as the need for wider societal debate.

Locally people who are believed to be in the last year of life are coded using the North West End of Life Care Model. This tool is used as a prompt in care homes to anticipate needs. All residents on the GP GSF registers are generally coded in this way.

ACP is not seen as a one-off event; communication with patients and families is a continuous process and will be made available to patients with and without mental capacity, fully involving carers/relatives in best interest decisions.

The Community Integrated Advance Care Planning Service (CIACPS) was created in June 2012 as collaboration between 3 organisations; Halton Haven Hospice, 5 Boroughs Partnerships Community Health Services and Willowbrook Hospice. These organisations are all providers of Advance Care Planning Services for the localities of Halton, St Helens and Knowsley. The service aims to deliver consistent and high quality education on the implementation and sustained use of all nationally recognised End of Life tools, GSF, PPC and during 2014/15 developed a new tool – the Care and Communication Record - following the recommendations in One Chance to get it Right Report which has started to be implemented this across the 3 localities.
As at December 2015, in Halton one care home has achieved Commend status for the GSF in Care Homes (St Lukes) and there were two care homes working towards the award (Beechcroft and Milbrow). The remaining care homes have been offered the SIX STEPS to success programme of training. Two homes (Croftwood and Trewan House) have passed this programme, whilst a further 16 care homes were working through the program at different stages and needing varying support.

The GSF and SIX STEPS training programmes consist of core modules which cover all aspects within the aforementioned North West End of Life Care Model.

4.6. Palliative care and bereavement services for children and families

Better Care: Better Lives[^46] sets out the previous government plans for palliative care for children with life limiting conditions, to improve date collection, tackle inequalities in provision and encourage care in the most appropriate setting.

It sets out a vision that states:

“Every child and young person with a life-limiting or life-threatening condition will have equitable access to high-quality, family-centred, sustainable care and support, with services provided in a setting of choice, according to the child and family’s wishes” p: 11

Further, that it is “an active and total approach to care, embracing physical, emotional, social and spiritual elements. That is starts at diagnosis and is about making life experiences better” p: 14

It notes a number of challenges for commissioners:

- The change in the profile of children with life-limiting or life-threatening conditions over the last 20 years due to technological advances in improved survival rates of low birthweight babies
- Poor co-ordination of public services across the statutory and voluntary sector, particularly the transition between children’s and adult services
- Insufficient investment in prevention, early interventions and assessments or timely referral to specialist services
- High criteria thresholds and lack of co-ordination and agreement between budget holders
- Lack of capability, capacity and equity within universal services to meet the needs of these children
- Lack of information to children and their families
- The need for a range of specialist short breaks, as well as better co-ordinated specialist support.

In Halton End of Life Services are commissioned from:

- Claire House Children’s Hospice— support for children during out of hours -support existing staff with expertise and provides hands on support if required
• Urgent respite Care – this service is commissioned from Claire House to provide emergency respite care for children when the family/carer support network may breakdown due to unexpected issues such as illness in the care, relationship breakdown.

Typically there are about 12 continuing care children funded from the Continuing Care budget and the Complex Nursing Care team have about 40 children on their caseload.
5. Projected levels of need

The typical profile and trajectory of illness leading to death amongst those aged 18 and over in England is:[47]

<table>
<thead>
<tr>
<th>Category</th>
<th>Trajectory</th>
<th>% of deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fraility</td>
<td>Multiple co-morbidities accumulating with increasing age leading to a gradual decline and regular exacerbations before last days.</td>
<td>42%</td>
</tr>
<tr>
<td>Cancers</td>
<td>Gradual decline and then rapid end stages but without previous exacerbations or sudden changes in need.</td>
<td>21%</td>
</tr>
<tr>
<td>Organ Failure</td>
<td>One predominant chronic condition with regular or fairly frequent exacerbations and with end of life typically being the result of a crisis and therefore more rapid deterioration in functions (Includes IHD, COPD etc.)</td>
<td>19%</td>
</tr>
<tr>
<td>Sudden death</td>
<td>Any deaths where there was no obvious prognosis until last days (Includes acute myocardial infarction, stroke, pneumonia, accidents.)</td>
<td>14%</td>
</tr>
<tr>
<td>Other terminal</td>
<td>Gradual decline with some exacerbations in initial phase then rapid end stage (Includes Parkinson’s, MND, MS, diabetes and other diseases of the nervous system.)</td>
<td>4%</td>
</tr>
</tbody>
</table>

The proportion of people whose needs reflect the frailty trajectory will increase over time due to improved treatments for other potentially life-threatening conditions and the projected rise in the number of people with dementia (see dementia chapter).
6. User views

6.1. National Survey of Bereaved People (VOICES) 2014

The National Survey of Bereaved People (VOICES, Views of Informal Carers – Evaluation Of Services) collects information on bereaved peoples’ views on the quality of care provided to a friend or relative in the last three months of life. The survey has now been run for four years; administered by the Office for National Statistics (ONS), it was commissioned by the Department of Health in 2011 and 2012, and NHS England in 2013 and 2014.

Key findings:[48]

- 3 out of 4 bereaved people (75%) rate the overall quality of end of life care for their relative as outstanding, excellent or good; 1 out of 10 (10%) rated care as poor.
- 7 out of 10 bereaved people (69%) whose relative or friend died in a hospital, rated care as outstanding, excellent or good. This is significantly lower than outstanding, excellent and good ratings of care for those who died in a hospice (83%), care home (82%) or at home (79%).
- Ratings of fair or poor quality of care are significantly higher for those living in the most deprived areas (30%) compared to the least deprived areas (21%).
- 1 out of 3 (33%) reported that the hospital services did not work well together with GP and other services outside the hospital.
- 3 out of 4 bereaved people (75%) agreed that the patient’s nutritional needs were met in the last 2 days of life, 1 out of 8 (13%) responded that the patient did not have enough support to eat or receive nutrition.
- More than 5 out of 6 bereaved people (86%) understood the information provided by health care professionals, but 1 out of 6 (16%) disagreed they had time to ask questions with health care professionals.
- More than 7 out of 10 (73%) respondents felt hospital was the right place for their friend or relative to die, despite only 3% of all respondents stating patients wanted to die in hospital.
7. Unmet need and service gaps

Both local and national analysis of EOLC needs indicates that there is significant variation in the care experienced. Deprivation places a significant part in this variation with people living in more deprived areas being more likely to die young, more likely to die in hospital and less likely to die in their own homes or a hospice. Whilst prevalence of palliative care need at a GP registered population level is small, there is considerable variation. Some of this may be due to differences in practice population age structures but nevertheless it may be beneficial to investigate other reasons further to ensure as many people as need palliative care receive it. Both nationally and locally, those with cancer are more likely to receive hospice care than those with other EOLC needs.

A number of service gaps/areas for consideration have been identified by local professionals including:

- Lack of specialist palliative care consultant cover 24/7
- Equity of access to palliative care for all EoL conditions (not just cancer)
- Multi-disciplinary community care for frail/elderly patients
- Ensuring deaths at home are as good as possible

Three important documents/guidance should be used in combination to scope and assess current service provision against best practice:

- North West Palliative and End of Life Care Model and Six Steps to Success guidance
- NICE quality standard and guidance for EOLC for adults and children (see section 8)
- National service specification (awaiting publication)

Not all care homes have GSF status. The ACP team have been training and offering support to care homes and this work should continue in order to reduce variations in care provided.
8. Best practice interventions

NICE Quality standard August 2011: End of Life care for adults
https://www.nice.org.uk/guidance/qs13

Figure 11: NICE Quality Standards for End of Life Care

To accompany this NICE have also produced a commissioning guide for End of Life Care.[50]

Care of dying adults in the last days of life NICE guidelines [NG31] Published date: December 2015

This guideline covers the clinical care of adults (18 years and over) who are dying during the last 2 to 3 days of life. It aims to improve end of life care for people in their last days of life by communicating respectfully and involving them, and the people important to them, in decisions and by maintaining their comfort and dignity. The guideline covers how to manage common symptoms without causing unacceptable side effects and maintain hydration in the last days of life.

This guideline includes recommendations on:

- recognising when people are entering the last few days of life
- communicating and shared decision-making
- clinically assisted hydration
- medicines for managing pain, breathlessness, nausea and vomiting, anxiety, delirium, agitation, and noisy respiratory secretions
- anticipatory prescribing

End of life care for infants, children and young people NICE in development [GID-CGWAVE0730] Expected publication date: December 2016

There is wide regional variation in paediatric palliative and end of life care practice, particularly in how services are delivered. Children, young people and their parents or carers have varied ideas about what represents good care and what is a priority for them at different stages. This guideline covers the physical, emotional, social and spiritual elements of end of life care, and focuses on improving the child’s or young person’s quality of life and supporting their family. There are, for
instance, recommendations on managing distressing symptoms and providing care and bereavement support after death as well as on how services should be delivered.

A review of good practice by Addicott and Ross\textsuperscript{[51]} highlights a number of areas that should make up an end of life care pathway:

**Table 11: Good practice in end of life care**

| Discussions as the end of life approaches | There is the potential for inequality in access to end-of-life care, depending on both the patient’s diagnosis and the process of identifying needs used. These issues could be overcome by a combination of:  
|                                            | • training and improvement in the definition of prognoses  
|                                            | • multidisciplinary co-ordination of care  
|                                            | • inter-professional access to palliative care records  
|                                            | However, this potential is exacerbated by an apparent reluctance among some health care professionals to discuss issues relating to death and dying.  
|                                            | Specialist and general health care providers should work together to ensure that responsibility for alleviating some of the anxieties about initiating these conversations is shared, and to ensure that all providers are confident and competent in responding to questions from patients and carers.  
| Assessment, care planning and review      | Discharge arrangements designed specifically for patients who are nearing the end of their lives can be an effective mechanism for supporting ward staff in assessing the more complex cases and planning the delivery of end-of-life care in patients’ preferred location.  
|                                            | The development of models of discharge facilitation should take account of, and adapt to, factors within the local health economy to ensure that they work with rather than against existing processes and pressures on other end-of-life care providers. There is no one-size-fits-all approach to design and implementation.  
|                                            | Advance care planning (and communication of plans between and among health and social care teams) can help to ensure patients’ wishes are respected and accommodated. As an individual’s wishes about end-of-life care may change as the disease process progresses, it is important to update the advance care plan regularly on the basis of ongoing discussions.  
| Co-ordination of individual patient care  | Dedicated models of co-ordination can be effective in freeing up district nurses and other community-based health providers, as well as allowing greater oversight with regard to the prioritisation of resources. Such co-ordination models could consider widening their remit to include other functions, such as the booking of equipment and the co-ordination of, or advice on, care home placement.  
| Delivery of high-quality services in different settings | End-of-life care tools such as the Gold Standards Framework and the Liverpool Care Pathway are important mechanisms for ensuring high-quality, transparent provision of care that is more effectively able to accommodate patient preferences. |
A whole-systems approach to service improvement is necessary, combining expedition of discharge from the acute setting with increased and/or reconfigured provision of community services to cover patients 24 hours a day seven days a week.

Training and education are necessary to ensure the provision of high-quality end-of-life care in different settings. Areas specifically identified by our research include:
- identification of patients’ needs
- communication skills the physical management of patients nearing the end of their lives

### Care in the last days of life

Once a patient has been identified as nearing the end of his or her life, advance care plans should be reviewed continually to confirm that all of the resources are in place to provide the preferred end-of-life care services in the preferred location.

Particular consideration should also be given to the needs of carers for information and support, to be included in major decisions, and to participate in the physical care and emotional support of the person who is dying.
- In the last days of life it is considered important for patients to be: treated as individuals, with dignity and respect
- without pain and other symptoms
- in familiar surroundings
- in the company of close family and friends

### Care after death

Health and social care professionals should be aware of the procedures to follow after the death of a patient to show respect to the deceased and his or her carers.

Bereaved carers should have access to good-quality information about the practical steps they need to consider and how to access emotional support if they need it.

### Information for carers and relatives

Carers should be seen as key stakeholders involved in the decision-making and planning around end-of-life care needs.

Advance care planning and inclusive communication is a valuable process to make care preferences transparent and to ascertain gaps in carers’ ability to deliver care themselves, including their own health care needs (and issues of bereavement).

Health care professionals should be honest and transparent with patients and carers about the services and support that are available in the community to ensure that they have a realistic understanding and expectations.

**Source:** Addicott and Ross (2010)[44]

A Cochrane review[52] of home-based end of life care considered 4 trials from developed countries (2 from the US, 1 from the UK and 1 from Norway, and involving just over 1,000 participants). The authors found that those receiving home based care were more likely to die at home compared to...
those receiving usual care. There was no significant difference for functional status, psychological well-being or cognitive status. There was some evidence of greater patient satisfaction with home based care, but little evidence was available in relation to the impact on family and carers. The findings of this review do support the use of home based end of life care programmes although the authors note that the number of patients being admitted to hospital and the time spent at home while receiving end of life care should be monitored. All of the trials in the study highlighted the importance of access to 24 hour care.

A more recent Cochrane review[^53] – including 23 studies involving 37, 561 participants and 4042 family carers - has provided strong evidence that home palliative care increases the chance of dying at home and reduces symptom burden, in particular for patients with cancer, without impacting on caregiver grief. However, the authors do highlight that further work is required to study cost-effectiveness and to compare different models of palliative care.

**NHS England Commissioning person centred end of life care: A toolkit for health and social care Updated April 2016**


This updated toolkit has a range of practical resources to support those involved in commissioning for person centred end of life care. It was revised using example across the country as well as national research such as National Survey of Bereaved People (VOICES) and accounts from people in care homes distilled from Care Quality Commission (CQC) reports. It reflects the health and care landscape as it was in October 2015. It supports delivery of the National Institute for Health and Care Excellence’s (NICE) *quality standard 133 for end of life care*, NICE guideline NG31 *care of dying adults in the last days of life* and the five priorities identified in *One chance to get it right*, that collectively aim to ensure the right care in the right place at the right time with the right resource. The toolkit is intended to be a supporting resource for those who may find it helpful. It is largely to guide generalist care.

Public Health England published *Faith at end of life: public health approach resource for professionals*, January 2016. The resource aims to help frontline professionals and providers working in community settings and commissioners maintain a holistic approach to the people dying, caring or bereaved.

It provides information to help ensure that commissioning and delivery of services and practice takes account of spiritual needs of the largest 6 faith groups in England and remains appropriate to the community setting in which they work.
References


5. General Medical Council (2010) Treatment and care towards the end of life: good practice in decision making. General Medical Council

6. WHO Definition of Palliative Care, World Health Organisation


11. Leadership Alliance for the Care of Dying People (2014) One chance to get it right: Improving people’s experience of care in the last few days and hours of life. Leadership Alliance for the Care of Dying People


45. Leadership Alliance for the Care of Dying People (2014) One chance to get it right: Improving people’s experience of care in the last few days and hours of life


