

**DRAFT**

**Bolton Palliative and End Of  
Life Care Strategy**

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## Acknowledgement

The strategy has been developed with our partners and users, we would like to thank everyone for the continued partnership working in developing the strategy:

Bolton Hospice  
Royal Bolton Foundation trust  
Bolton Council  
Bolton Public Health  
Macmillan Cancer Support  
Bolton Dementia Carers Support Group



# Better Bolton.

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# 1. Foreword

## Foreword

Bolton Clinical Commissioning Group are the commissioners of Palliative and End of Life Care (EoLC) and sees End of Life Care as a priority in their commissioning plans. Providing high quality care for people nearing their end of life is a national and local priority. In Bolton we have a history of working well together to provide high quality of care, engaging all providers and the public. We have been working in partnership with lead organisations to help develop a new Bolton Palliative and End of Life Care Strategy.

Nationally there have been major challenges around End of Life Care with scrutiny and withdrawal of the Liverpool Care Pathway. Many national documents have since come out giving direction and guidance on good quality care, however this overwhelming quantity of information can create confusion. Our aim is to consolidate the guidance and structure our strategy to address issues in our local population.

A joint Bolton End of Life Care Strategy Partnership Group was formed to promote collaboration between commissioners and providers in the development of this strategy. Through partnership working we have attempted to ensure that the strategy for Bolton reflects both the national and local context for End of Life Care, Bolton's Joint Strategic Needs Assessment, and any gaps in services, which would inform a new strategy for Bolton. These detailed documents are given in the appendix and summarized in the executive summary.

This strategy consolidates the partnership vision and sets out Bolton's 5 year forward strategic direction around Adult Palliative and End of Life Care for Bolton.

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## 2. Executive Summary

## Executive summary

Around half a million people die in England each year many of which are elderly. Of these three quarters are expected deaths. Large number of deaths are due to chronic illness such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia<sup>3</sup>. There is forecasted increase in the number of expected deaths by 17% by 2030 as people live longer with more long-term conditions.<sup>4</sup>

Nationally most deaths occur in NHS hospitals (51%), with around 22% occurring at home, 19% in care homes, 6% in hospices and 2% elsewhere<sup>5</sup>. In a recent national survey of the bereaved it highlighted that most people (79%) would prefer to die at home<sup>6</sup>. In Bolton, around 53% of deaths occur in hospital and 22% of deaths occur at home which is a slightly lower than our peer average of 23.1%<sup>23</sup>.

This reflects significant change in death and culture, in 1900, 85% of deaths occurred at home yet today most deaths occur in hospitals. Compared to some countries such as the Netherlands where 34% die in hospital, we are lagging behind. The challenge around this is not about getting end of life patients to die at home, but to enable preference and choice so we can encourage patient centred care.

In Bolton, 0.71% of the population will have a palliative care need<sup>25</sup>, which is around 2000 patients. Recent primary care palliative care registers show around 988 end of life patients are on the GP registers in April 2016<sup>26</sup>. This has increased by 17% from 2015 as Bolton primary care is proactively trying to identify these patients through a recent quality initiative<sup>26</sup>.

There are increasing number of patients with long term conditions in England, at present there are 15 million which is expected to rise to 18 million by 2025<sup>4</sup>. There are also the increasing frail elderly, with 10-11% of over 65s being frail<sup>4</sup>. 71% of those on a primary care register had a primary diagnosis of cancer<sup>7</sup>, yet cancer accounts for 29% of deaths<sup>8</sup>. There are many challenges around identifying the end of life patient especially in non-cancer conditions such as dementia, COPD, heart failure, neurological conditions and frailty. Often these patients do not get the same level of end of life care that cancer patients do. Identifying this in cohort patients earlier is essential to help provide high quality coordinated care and support. In Bolton we have a clear ambition to help identify these patients earlier through local initiatives and it is hoped this strategy will facilitate better systems to achieve this.

Presently Palliative and End of Life Care in England costs around £460 million<sup>4</sup>, a considerable portion of this funding comes from fund raising. The secretary of health is collecting data to create a transparent per-patient funding system based on NHS tariff system to reduce the massive variation in cost of care for palliative patients<sup>4</sup>, although there is currently some doubt as to whether the tariff system will actually ever be introduced. The cost is much wider when one looks at the enormous contribution that carers undertake day to day. It is estimated that half a million carers look after terminally ill patients at home<sup>4</sup>. Carers form an essential part of the network of support for palliative care patients, and so it is vital we provide a support structure for carers.

There is some data around the spend on end of life care from the Marie Curie data tool<sup>21</sup>. Although this is older data it does highlight that Bolton has the 2<sup>nd</sup> lowest spend on palliative care across Greater Manchester.

A national review of the Liverpool Care Pathway (LCP)<sup>14</sup> was commissioned by the Department of Health in response to reports of poor practice around the use of the LCP. The document was titled 'More Care Less Pathways: a review of the Liverpool care pathway'. This gave 44 recommendations for better practice.

Since then there has been many strategic documents produced by various national organisations such as the 'Once Chance To get It Right' document which provides clear good practice guidance on the care for people in the last few days and hours of life<sup>15</sup>. This document was produced in response to the LCP review by the Leadership Alliance for the Care of Dying People, a coalition of 21 national organisations.

The 'Ambitions for Palliative and End of Life Care' document<sup>17</sup> is a more recent document produced by the National Palliative and End of Life Care Partnership, which gives high level guidance and strategic vision for good quality Palliative and End of Life Care. This document focuses on six core ambitions, and highlights the key themes of good Palliative and End of Life Care.

The 'NHS England Actions for End of Life Care' document sets out NHS England's commitments for better End of Life Care<sup>4</sup>. It is one component of a wider ambition to develop a vision for end of life care beyond 2015 and helps support the many other key national strategic documents.

'Supporting People to Live and Die Well; a framework for social care at the end of life'<sup>16</sup> developed by the National End of Life Care Program (NEoLCP) with the involvement of a group of stakeholders in social care, sets out the direction of travel for social care at end of life. The framework sets out key objectives for social care around Palliative and End of Life Care, it seeks to strengthen the specialism of palliative care social work and promotes understanding and best practice in holistic assessment of individuals, their families and carers.

There are also key national clinical guidance and standards around EoL care produced by the National Institute of Clinical Excellence (NICE)<sup>13,18</sup> which gives valuable direction for clinicians working around end of life care. This guidance is supported by the Northwest End of Life Care Model<sup>10</sup> and Gold Standard Framework (GSF) model<sup>11</sup>, all of which enable structured guidance for clinicians managing Palliative and End of Life patients. These models are widely used across Bolton.

The Unified DNACPR (Do Not Attempt Cardio-Pulmonary Resuscitation) policy was developed by NHS England and NW Ambulance Service in 2014<sup>19</sup>. The key aim of the policy was to have a consistent policy and form used through the northwest health and social care sectors to aid improved quality in delivery of DNACPR decisions. Bolton CCG along with our partners have taken this forward and have now implemented the policy fully across primary and secondary care. We will be monitoring the delivery of the policy through the Bolton Palliative and EoL Care Strategy Group.

EPaCCS (Electronic Palliative Care Coordination System) originates from the National End of Life Programme). The purpose of EPaCCS is to support the co-ordination of care so that the person's choice about where they die, and the nature of the care they receive throughout that process is respected and achieved. The information provided through EPaCCS is designed to be accessible



24 hours a day to team members, in order to allow the person to experience 'a good death' and have appropriate interventions to support their care. Presently Bolton CCG is in the process of developing an EPaCCS and system to be used in Bolton.

Measuring the quality of Palliative and EoL Care can be often challenging to capture. Over the past few years the Department of Health has commissioned a survey of bereaved people called 'VOICES'. This provides valuable insight into quality of care of palliative and EoL patients in the last 3 months of life. The survey consisted of a sample of 20,173 completed responses that were received from informants. The recent survey highlights the need for better integrated and personalised care for the dying across health and social care.

In Bolton, basic palliative and EoL care services are provided through General Practice and community nursing. This is supported by specialist services for patients with more complex needs, which is mainly provided by the Royal Bolton Foundation Trust and Bolton Hospice. Also third sector organisations such as Marie Curie and Macmillan also provide a valuable adjunct service. Although there is a comprehensive level of specialist service provided in Bolton, the challenge is how to link all these services to provide a seamless responsive financially sustainable service tailored around the patient. Full details of the services can be found in the appendix.

Currently there is a strategic drive in Bolton to integrate services and this is already on the way with integrated neighborhood teams whose roles are to coordinate and manage patients who are at high risk of social and health care needs, including palliative and EoL care patients. This will be a key driver to help enable better-coordinated care across the health and social care sectors.

Nationally education and training especially around communication has been highlighted as a priority in providing better end of life care. There are a wide range of educational programs provided by RBH, Bolton University, Bolton Hospice and Bolton CCG. However the challenge really has been around uptake of the courses and linking in resources from different sectors. There needs to be clear links between the educational resources and vision of partnership working to provide a clear robust educational resources for all health and social care staff in Bolton.

After death care is vital to help support the patients family and friend. Bereavement support is provided through various avenues through primary care, hospital, hospice and voluntary sector. However the services needs to be a more coordinated approach to after death support and how we all link in with local communities and faiths.

Bolton CCG undertook an engagement exercise with the Bolton public and also health care professionals involved in EoL care to ensure the views and comments of our local population were included to help inform the strategy. NHS staff, staff in care homes and members of the public were invited to give their views on end of life care through an online questionnaire, one to one interviews and focus groups. There was a good overall response, with 68 members of staff completing the survey online, and 8 GP's completing paper versions of the survey, one focus group made up of 18 members of the public taking place, and a one on one interview with a retired Macmillan nurse. The full engagement results can be seen in Appendix D. The result of the engagement task was very interesting. A lot of the comments given either in person or via a survey, highlighted the fact that it is vital for a patient to have the choice of where to die and for all arrangements to be as easy and as stress free as possible. Good communication was also

highlighted several times as being extremely important between all teams involved and with the patient and family members. It has been difficult to get people to volunteer and speak about their experiences, as obviously this is a very sensitive topic for them, so the engagement has not been as wide as would have been preferred. However, from those who have volunteered to speak to Bolton CCG about end of life care, it is clear that they are in agreement with the health professionals that the care needs to be patient centred, involving professionals who have excellent skills in communication.

In Bolton we pride ourselves as a community working together to help provide good Palliative and EoL care. There are many areas where Bolton is doing well around end of life care, however there are also many challenges. This strategy sets out how we can work in partnership with all stakeholders and the public to overcome these challenges and enable Bolton to provide high quality care for patients nearing the end of their lives.

### **3. Definition of Palliative and End Of Life Care**

### 3. Definition of Palliative and End Of Life Care

Palliative Care and End of Life Care (EoLC) involves care to all of those with any advanced progressive 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 the management of pain and other symptoms and the provision of psychological, social, spiritual and practical support<sup>1</sup>.

#### Palliative Care

Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments<sup>2</sup>. It is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual<sup>21</sup>.

#### End of Life Care

End of life care is caring for patients who are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with<sup>15</sup>:

- (a) Advanced, progressive, incurable conditions
- (b) General frailty and co-existing conditions that mean they are expected to die within 12 months
- (c) Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- (d) Life-threatening acute conditions caused by sudden catastrophic events.

## 4. Vision and Ambitions

## 4. Bolton Vision for High Quality Palliative and End of Life Care

All people in Bolton approaching the end of life, their carers and family receive well-coordinated, high-quality care and support in alignment with their wishes and preferences.

This is our vision of care for Bolton patients, which we will help to deliver through high quality commissioning and engagement with our partners and the Bolton public. Our vision is shared by all our partners across the health and social care sector.

### Bolton Priorities and Values

Bolton priorities and ambitions around end of life care reflect the national priorities and ambitions set out in national strategic documents<sup>15,17</sup>.

**Priority 1** This possibility that a person may die within the next few days or hours is recognized 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, co-ordinated and delivered with compassion.

Our values and ambitions mirror national consensus<sup>17</sup> of delivering high quality personalised care around the individual by ensuring that:

1. Each person is seen as an individual
2. Each person gets fair access to care
3. Maximising comfort and wellbeing
4. Care is coordinated
5. All staff are prepared to care
6. Each community is prepared to help

## Our Commitments and Strategic Objectives

We are committed to delivering the vision, which is underpinned, by our key priorities and values to meet the needs of the Bolton population. We endeavor to focus our strategic actions in 5 keys areas set out below.



### Key Strategic Objectives

**Objective 1:** Awareness, recognition and communication

**Objective 2 :** Education and training

**Objective 3 :** Integrated, coordinated and patient centered equitable care

**Objective 4 :** Supporting families and carers

**Objective 5 :** Monitoring good quality care

### Objective 1: Awareness, recognition and communication

- a) Encourage a culture of empathy and professionalism in all people working with patients nearing end of life.
- b) Facilitate wider early recognition of patients reaching end of life particularly around non cancer conditions such as COPD, heart failure, dementia and frailty
- c) Have effective systems to ensure all people identified as being in their last 12 months of life are identified on a register which is linked across the social and health care sector
- d) Health and social care staff working across primary and secondary care have the skills need to enable a well informed, sensitive and honest conversation about dying with people who are nearing end of life.
- e) Ensure patients know what they are entitled to and what to expect as they reach the end of their lives.
- f) Engage the public and local communities to help improve awareness around the challenges surrounding the dying person and how we can work collaboratively to overcome these challenges.

This objective has been set to address the key challenges around better recognition of the dying person and enabling effective communication with patients and families who are nearing end of life. We also hope to collaborate better with communities to help improve awareness around the dying person and work together to help support them.

### Objective 2 : Education and training

- a) Health and social care professionals who are caring for people reaching the end of life will have the necessary communication skills and training to have sensitive conversations with the people involved and provide high quality care and support.
- b) Health and social care professionals who are caring for people reaching the end of life will have the necessary skills and training to assess and manage symptoms in an effective, holistic patient centered way.

National documents have highlighted the need for improved education and training of people looking after patients nearing end of life. This objective focuses on these challenges around ensuring that every person who is involved in the care of the dying have the necessary skills and training. With the ever-diminishing educational and learning budgets, partnership working will be vital to help achieve this objective.



### Objective 3 : Integrated, coordinated and patient centered equitable care

- a) Develop a 24/7 responsive patient centered model of integrated health and social care service for people nearing end of life.
- b) Develop and implement an Electronic Palliative Care Coordination System (EPaCCS) shared care records, which will help coordinate care for patients across the health and social care sector.
- c) Work in partnership with health care, social care, hospice, voluntary sector and the public to co-design a sustainable and well-resourced service for patients nearing end of life.
- d) Work with people nearing end of life to enable them to be at the heart of their care, ensuring effective assessments, care coordination, care planning which will recognize their wishes, goals and aspiration.
- e) Ensure services and staff assess and treat patients holistically addressing their social, psychological, physical and spiritual needs.
- f) Ensure services are equitable and easily accessible by all members of the public regardless of their background.
- g) Ensure patients have access to rapid specialist palliative care when needed.

Coordinated 24/7 responsive patient centered care is a key ingredient in providing high quality safe care to patients nearing end of life. Nationally and locally this has been identified as a challenge, and this objective sets out to address this by working with innovative solutions, working with our partners and working with patients.

### Objective 4: Supporting families and carers

- a) Develop and coordinate services to support families, friends, carers, other loved ones and their communities to help prepare them for loss, grief and bereavement
- b) Ensure an adequate and well resourced bereavement service
- c) Enable systems to help identify carers, enabling a carers register to be formulated with the offer of structure carers review to be undertaken by a trained health or social care staff.

Families, friend and carers are an important support network for patients nearing end of life and are often left unsupported, struggling with the physical and psychological demands of caring for a dying person. After death support can sometimes be underestimated, and lack of proper support and care can lead to significant impact on families, friends and carers. This objective addresses these two key areas and makes sure it forms a core part of our strategy.

**Objective 5: Monitoring good quality care**

- a) Use existing local and national data sets to identify needs and gaps to ensure service development is targeted to address these issues
- b) Develop a robust set of quality outcome measures, including patient related outcomes around palliative and EoL care to help monitor good quality, safe and patient centered care.

Due to the nature of this area it can be challenging to objectively monitor the quality of end of life care the dying person receives. We aim to help develop a robust set of hard and soft outcome measures, which will help us address the issues and guide improvements in quality of care.



## 4. Conclusion

In the journey to build this strategy we have reviewed national guidance, analysed local service provisions and listened to people delivering care and the public. This has lead us to develop our 5 overarching objectives which are key to helping Bolton deliver better End of Life Care.

In Bolton we have a history of working well towards achieving better care for end of life patients, however we still face many challenges. This strategy provides a robust framework to help reach our vision, but importantly we aim to work together as a whole Bolton in partnership to achieve this. Our ambition in this strategy will set the foundation and vision to help drive even better patient centered care to our patients nearing end of life.

## **Appendix : Supporting documents**

# **a) National and Regional Context, Drivers and Standards**

**Document produced by the Bolton Palliative and  
End of Life care Strategy Group**

## 1. National and Regional Context, Drivers and Standards

### 1.1 National context

Around half a million people die in England each year many of which are elderly. Of these three quarters are expected deaths. Many deaths are due to chronic illness such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia<sup>3</sup>. It is forecasted that the number of deaths will increase by 17% by 2030.<sup>4</sup>

Most deaths occur in NHS hospitals (51%), with around 22% occurring at home, 19% in care homes, 6% in hospices and 2% elsewhere<sup>5</sup>. In national survey it has shown that most (79%) would prefer to die at home<sup>6</sup>.

This reflects massive change in death and culture, in 1900, 85% of deaths occurs at home yet now most deaths occur in hospital<sup>3</sup>. The challenge around this is not simply about increasing deaths at home but enabling preference and choice so we encourage patient centred care.

Palliative and end of life care is provided by primary care and hospital services with the support of specialist palliative care services. Currently around 170,000 patients receive specialist palliative in England, these patients with complex needs benefit from specialist palliative care (commissioning guidance for specialist care). With expected increase in patient with palliative needs and recognition of patients earlier in the pathway and there will need to be increased resources and access to specialist palliative care services. As at January 2006, in England, Wales and Northern Ireland there were<sup>1</sup>:

- 193 specialist in-patient units providing 2,774 beds, of which 20% were NHS beds.
- 295 home care services – at present this figure will include both primarily advisory services delivered by hospice or NHS based community palliative care teams and other more sustained care provided in the patient's home.
- 314 hospital based services.
- 234 day care services.
- 314 bereavement support services.

The number of patients with long term conditions, at present there are 15 million in England and this is expected to rise to 18 million by 2025<sup>4</sup>. There are also increasing frail elderly with 10-11% of over 65s being frail<sup>4</sup>. 71% of those on a palliative care registers had a primary diagnosis of cancer<sup>7</sup> yet cancer accounts for 29% of deaths<sup>8</sup>. It is therefore clear there is a challenge of identifying the end of life patient especially in non-cancer conditions such as dementia, COPD, heart failure, neurological conditions and frailty. Identifying patients at the end of life is essential to help provide coordinated proactive care and support and there is a clear unmet need here.

Presently end of life care costs around £460 million<sup>4</sup> a considerable portion of funding comes from charity and fund raising. Presently the secretary of health is collecting data to create a transparent per-patient funding system based on NHS tariff system to reduce the massive variation in cost of care for palliative patients<sup>4</sup>, although there is currently some doubt about as to whether the tariff system will actually ever be introduced. The cost is much wider when one

looks at the enormous contribution that carers undertake day to day. It is estimated half a million carers look after terminally ill patients at home<sup>4</sup>. Carers form an essential part of the network of support for palliative care patients.

## 1.2 National Survey of Bereaved People (VOICES)

Palliative and end of life care quality monitoring can be challenging to capture. Over the past few years the Department of Health has commissioned a survey of bereaved people called 'VOICES'. This provides valuable insight into quality of care for of palliative and end of life patients in the last 3 months of life. The latest survey consisted of a sample of 20,173 completed responses were received from informants. The latest survey highlights the following key areas<sup>6</sup>:

- 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.
- Overall quality of care for females was rated significantly higher than males with 44% of respondents rating the care as outstanding or excellent compared with 39% for males.
- 7 out of 10 people (69%) rated hospital care as outstanding, excellent or good which is significantly lower compared with care homes (82%), hospice care (79%) or care at home (79%).
- Ratings of fair or poor quality of care are significantly higher for those living in the most deprived areas (29%) compared with the least deprived areas (22%).
- 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%) disagreed that the patient had support to eat or receive nutrition.
- More than 3 out of 4 bereaved people (78%) agreed that the patient had support to drink or receive fluid in the last 2 days of life, almost 1 out of 8 (12%) disagreed that the patient had support to drink or receive fluid.
- More than 5 out of 6 bereaved people (86%) understood the information provided by health care professionals, but 1 out of 6 (16%) said they did not have time to ask questions to health care professionals.
- Almost 3 out of 4 (74%) respondents felt hospital was the right place for the patient to die, despite only 3% of all respondents stating patients wanted to die in hospital.

## 1.3 National End of Life Care Strategy 2008

The previous End of Life Care Strategy was published in 2008<sup>3</sup>, setting out a framework for raising the profile and quality of care provided at the end of life care for adult patients in England and Wales, irrespective of their background or place of care. It takes a whole systems approach and covers:

- The identification of patients who may be in the final 12 months of life
- Care planning in keeping with needs and wishes
- High quality coordinated care responsive to needs
- Better management of the final days of life
- Care that involves and supports carers
- Care after death and bereavement



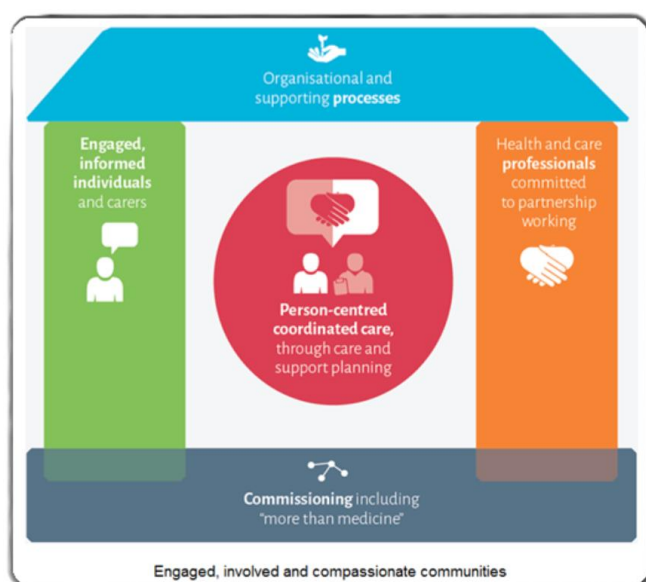
- Education and training, measurement and research

The strategy recognised 3 key elements of change: societal (raising awareness of death and dying), individual (providing integrated care) and infrastructure (work force development, funding and national support). It has promoted the development of systems of care, improved understanding of the needs of dying patients and their families and has driven investment.

#### 1.4 NHS England Actions for End of Life Care : 2015 -16

This is a document by NHS England, which sets out to sets out NHS England's commitments for adults and children's end of life care<sup>4</sup>. It is one component of a wider ambition to develop a vision for end of life care beyond 2015. Here the house of care framework (figure 1) is used to explore how NHS England will support better end of life care.

**Figure 1**



Key components of the framework are:

1. Engaged, informed individuals and carers
2. Health and care professionals committed to partnership working
3. Organisational and supporting processes
4. Commissioning support

#### 1.5 NICE Quality Standards for End of Life Care in Adults

The NICE quality standards for end of life care for adults<sup>9</sup> were published in 2011 and updated in 2013. They set robust standards to facilitate better care for patients nearing end of life. Table 1 summarises all 16 standards. Most of the standards encourage an integrated approach to providing care, which is a key aspect of our vision in Bolton. The quality standards can guide

commissioners to develop a robust framework to deliver better, high quality EoL care in their locality.

**Table 1: Nice Quality Standards<sup>9</sup>**

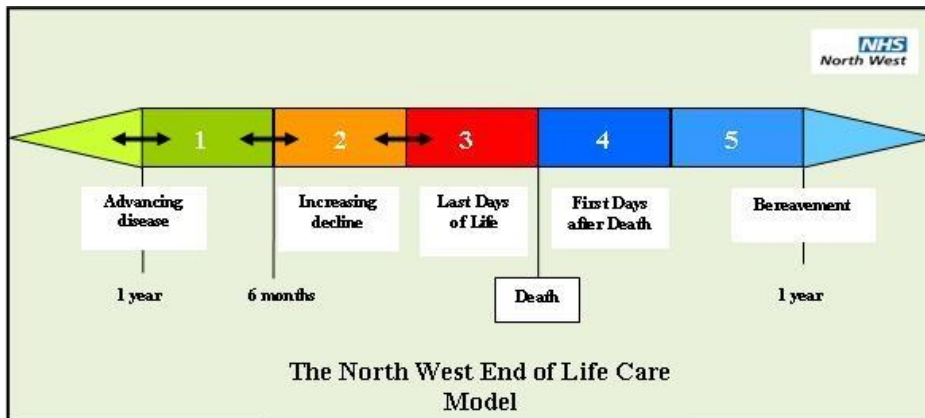
Statement	Summary
Statement 1	People approaching the end of life are identified in a timely way.
Statement 2	People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.
Statement 3	People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.
Statement 4	People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.
Statement 5	People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.
Statement 6	People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.
Statement 7	Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.
Statement 8	People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.
Statement 9	People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.
Statement 10	People approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at

	any time of day or night.
<b>Statement 11</b>	People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication.
<b>Statement 12</b>	The body of a person who has died is cared for in a culturally sensitive and dignified manner.
<b>Statement 13</b>	Families and carers of people who have died receive timely verification and certification of the death.
<b>Statement 14</b>	People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.
<b>Statement 15</b>	Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.
<b>Statement 16</b>	Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support

## 1.6 Northwest End of Life Care Model

The NHS NW EoLC model was developed in response to the National EoLC Strategy (2008)<sup>3</sup> by the Greater Manchester, Lancashire and South Cumbria Strategic Network<sup>10</sup>. The principles behind the model are to allow earlier identification and stratification of those at the EoL to ensure a more proactive approach to care in a timely manner ( figure 2)

Figure 2



Currently those who are recognised as being in the last 12 months of their life could have their care delivered by many services from health and social care. Each service could have a named key worker but the reality is that care coordination is fragmented and not always easy for the person and their families/carers to navigate. As the person's condition starts to deteriorate and increased services are required the complexity and urgency of their need also increases. When faced with uncoordinated care which cannot be delivered timely, there is an increased risk of hospital admission and /or dissatisfaction.

As the newly formed strategic network becomes developed, new guidance and policies will help underpin quality in the northwest.

### 1.7 Gold Standards Framework

The Gold standards Framework (GSF)<sup>11</sup> is a systematic, evidence based approach to optimizing and coordinating care for all patients approaching the end of their life, delivered by generalist care providers (primary care).

GPs are in an ideal position to provide and coordinate this care for a number of reasons:

- They have long established relationships with their patients, which are so important at this critical time in a patient's life
- They are used to dealing with co morbidity and uncertainty
- They are trained to treat patients holistically which is central to the palliative care approach

#### GSF involves 3 steps each involving good communication

1. Identify people in need of supportive and end of life care

GSF suggests the following methods to identify those in the last 12 months of life, this can be done using the surprise question 'would you be surprised if your patient were to die in the next 6-12 months?' This is an intuitive question integrating co morbidity, clinical, social

and other factors which give a whole picture of deterioration. The other way is to use clinical indicators of advanced disease such as the RCGP Prognostic Indicator Guide<sup>12</sup>

On average 1% of your practice population will die each year<sup>13</sup> but nationally we often fall short of this, particularly around identification of non-cancer end of life conditions which can be challenging.

## 2. Assess and record

This part is to assess the patient's physical, psychological and spiritual needs involving patients, family and carers to help proactively plan their care in a patient centered way. Patient can be prioritized using the NW end of life model, which helps risk stratify the patients likely to need the highest level of input soon.

## 3. Plan

Multidisciplinary teams offer advanced care planning and proactive coordinate care for the patients, family and carer. This is often done by coordinating regular GSF meetings which are undertaken in General Practice. This is vital in helping provide effective quality care to patients. The key worker is the District Nurse who coordinates and delivers most of the care. Communication is vital to ensure the patients, carers, community nurses, GPs, out of hours service, ambulance services and specialist service are all linked in and are up to date with the patient's care.

### 1.8 More Care, Less Pathway: a review of the Liverpool Care Pathway

A national review of the Liverpool Care Pathway (LCP)<sup>14</sup> was commissioned by the Department of Health in response to reports of poor practice around the use of the LCP. The document was titled 'More care, less pathway: a review of the Liverpool care pathway'

The review panel chaired by Baroness Julia Neuberger, was independent of the Government and NHS, and much of the evidence and the focus of the report relate to hospital practice. However the recommendations apply across all services and setting where end of life care is delivered.

44 recommendations are contained within the report including the phasing out of the LCP. Care should be guided by the principles of care and support for the dying person.

It was also suggested that more immediate issues needed to be addressed:

- Each dying patient should have an identified senior clinician who is responsible for their care including out of hours.
- Unless clearly unavoidable, major management decisions about withdrawing or not starting potentially life prolonging treatment should take place during the working day by the senior clinician and team
- Those dealing with decision making should be adequately trained

- There should be open discussion of nutrition and hydration by those competent to do so, and decisions made with reference to GMC guidance.
- Patients who are able to take some fluids or food orally should be enabled to do so up to death, failure to do so should be regarded as professional misconduct
- The use of a syringe driver should be explained and discussed with the patient/carers and the clinical indications documented.
- A named registered nurse should be allocated for each shift, to take responsibility for the dying patient and communication with their relatives
- A senior clinician should document in clinical records a face-to-face conversation with the patients, relatives and carers, which includes an explanation that the patient is dying, the basis for this and the discussion of questions from the relatives.
- Availability of support whenever needed from the Specialist Palliative Care Team in both hospital and community.
- There is a need for education, training and competency checks for those involved with care at the end of life
- The Boards of health care providers who care for the dying should give responsibility for this to a lay member who will focus on the provision of care and support to those who are dying and those close to them

With reference to commissioning and our CCG responsibilities the recommendation states 'using its full powers and mindful of its general duties, NHS England should work with clinical commissioning groups to address what are clearly considerable inconsistencies in the quality of care for the dying, to drive up quality by means of considerably better commissioning practices than persist at present'.

### 1.9 On Change To Get It Right: Leadership Alliance for the Care of Dying People

In response to the LCP review the Leadership alliance for the care of Dying People (LacDP), a coalition of 21 national organisations have developed 'Once Chance To get It Right' document and guidance to ensure high quality, consistent care for people in the last few days and hours of life<sup>15</sup>.

The document highlights key areas for improvement. It sets out the approach to caring for dying people that health and care organisations and staff caring for dying people in England should adopt in future. The approach should be applied irrespective of the place in which someone is dying: hospital, hospice, own or other home and during transfers between different settings.

It refers to 5 **Priorities for Care for the Dying person** in the last days/hours of life:

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, coordinated and delivered with compassion.

The Leadership Alliance will continue to work together to support improvements in the delivery of end of life care

### **1.10 Supporting People to Live and Die Well. A Framework for Social Care at the End of Life**

This framework<sup>16</sup> developed by the National End of Life Care Program (NEoLCP) with the involvement of a group of stakeholders in social care set out the direction of travel for social care at end of life. The framework sets out key objectives for social care around palliative and End of Life Care, it seeks to strengthen the specialism of palliative care social work and promotes understanding and best practice in holistic assessment of individuals their families and carer's

The implementation of the Care Act 2012 reinforces the statutory rights of carer's and further promotes integration.

The contribution social care makes to the delivery of End of life Care in Bolton is acknowledged in this strategy

### **1.11 Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020**

Ambitions for palliative and End of Life Care document<sup>17</sup> is a relatively recent document produced by the National Palliative and End of Life Care Partnership which gives some overarching guidance and strategic vision for good quality palliative and end of life care. The document focuses on six ambitions, which tries to pull in various aspects of good palliative and end of life care:

1. Each person is seen as an individual
2. Each person gets fair access to care
3. Maximizing comfort and wellbeing
4. Care is coordinated
5. All staff are prepared to care
6. Each community is prepared to help

It also focuses on the key foundation that will help achieve the vision which includes:

- Personalized care planning
- Shared care records
- Evidence and information
- Those important to the dying person
- Education and training
- 24/7 access
- Co-design
- Leadership

This is a really vision orientated document which hopefully will guide organization to set out their vision and strategy around developing high quality palliative and end of life care services

### **1.12 NICE: Care of the dying in adults in the last days of life 2015**

The NICE guideline covers the clinical care of adults (18 years and over) who are dying during the last 2 to 3 days of life<sup>18</sup>. It covers all aspects from recognition of the dying person, communication to symptoms control. 7 sections are explored:

- Recognising when a person may be in the last days of life
- Communication
- Shared decision-making
- Providing individualised care
- Maintaining hydration
- Pharmacological interventions
- Anticipatory prescribing

Overall this guidance is a comprehensive evidence based guidance to direct good clinical care and support better care for patients nearing end of life.

### **1.13 DNACPR policy**

The Unified Northwest DNACPR (Do Not Attempt Cardio-Pulmonary Resuscitation) policy has been developed by NHS England and NW Ambulance Service in 2014<sup>19</sup>. The key aim of the policy was to have a consistent policy and form, to be used through the northwest across health and social care sectors to aid improved quality in delivery of DNACPR decisions. Bolton CCG along with our partners at Bolton Hospice and Bolton FT have taken this forward and have now implemented the policy fully across primary and secondary care. We will now be monitoring the delivery of the policy through the Bolton palliative and EoL Care Strategy Group.



### 1.14 Electronic Palliative Care Coordination System- EPaCCS

EPaCCS (Electronic Palliative Care Coordination System), originates from the National End of Life Programme and reinforced by commitments in the Actions for End of Life Care 2014-16<sup>4</sup>.

The purpose of EPaCCS is to support the co-ordination of care so that the person's choice about where they die, and the nature of the care they receive throughout that process is respected and achieved. The information provided through EPaCCS is designed to be accessible 24 hours a day to team members, in order to allow the person to experience 'a good death' and have appropriate interventions to support their care.

'The System', supports the communication of key medical information to health and social care professionals involved in patient's care, and also acts as a facilitative tool to manage the patient better.

In the Northwest of England many areas have already developed EPaCCS or in the process of developing this. At Bolton CCG we are yet to develop the system but have made the first steps and initiated discussions through the Bolton Palliative and EoL care Strategy group. Our vision is to set up a local EPaCCS system by 2017.

#### Key Messages

- Half a million patients die in England every years with the number to increase by 17% by 2030 with increasing numbers of elderly patients
- A lot of patients die in hospital yet most people preference is at home.
- A lot of work is needed in training people around end of life care in primary and secondary care, as well as improving culture within the organisations to help provide empathic and well coordinated care.
- Specialist care services are a vital part of providing care for complex palliative care but are largely funded voluntarily.
- There needs to be better identification of non cancer conditions which is an unmet need
- Many new national documents with key message around better communication, supportive care, education and training and involvement of senior clinicians.
- NICE have clear standards and clinical guidance around good palliative and end of life care
- The 5 priorities of care and ambitions set out clear a strategic framework for better quality Palliative and EoL care.
- There are clear opportunities in having an EPaCCS system which can help better coordinated care for end of life patients.

## **b) Current Palliative and End Of Life Care Services and Provision in Bolton**

## Current Palliative and EoL Care Services and provision in Bolton

### 1.1 Specialist Palliative Care Services

The Bolton NHS Foundation Trust Specialist Palliative Care Team provides Specialist Palliative Care in both primary and secondary care and endeavors to provide a seamless service between both settings. To achieve this team is located on three sites, the Royal Bolton Hospital, Great Lever Health Centre and Bolton Hospice.

The Royal Bolton FT Specialist Palliative Care team has close working relationships with Bolton Hospice services, Primary care and all services within the Foundation Trust.

#### The Team consists of

• Clinical Service Lead	1wte
• Palliative care consultants	1.4wte
• Specialist Palliative Care nurses – Hospital and Community	7.4wte
• Specialist Palliative care therapy team	6.68wte
• Bereavement Specialist Practitioners	1wte
• Palliative and End of life care educator	1wte
• Palliative and End of life care facilitator	1wte
• Clerical Support	2.68wte

This Specialist Palliative Care Team offers:

- Advisory and support service for all inpatients within Royal Bolton Hospital
- Advisory and support service for patients in the community living
- Palliative Medicine outpatient clinics for all patients attending Royal Bolton Hospital
- Community Palliative Care AHP team (physiotherapy, occupational therapy) for patients living within the borough of Bolton
- Bereavement support for patients and families within the Royal Bolton Hospital
- Education and training

#### Service Provision

The core working hours of the team are :

- Consultant working hours are 9-5pm, Monday to Friday
- Specialist Palliative care nurses (Hospital and Community) Monday to Friday 8.30am till 4.30pm
- Weekend cover for hospital and community provided by 1 specialist nurse on duty Saturday and Sunday available 8.30am till 4.30am
- Specialist Palliative Care Therapy team Monday to Friday 7.30am till 5pm
- Specialist Bereavement Practitioners Monday to Friday 9am till 5pm

- Out of these hours there is a 24 hour support from Bolton Hospice Telephone Advice service
- There are 3 consultant led clinics each week within the hospital, Bolton one and the Hospice

## 1.2 Bolton Hospice

Bolton hospice provides specialist palliative care, complex end of life care, family care, bereavement support and 24 hour specialist advice to professionals, patients and families. This is a 24 hour consultant led service, supported by medical cover and delivered by a fully trained nursing staff team. This includes 1 consultant, 2 specialty doctors, 2 service leads, 25 registered nurses and 16 clinical support nurses.

There are inpatient facilities with capacity of 18 beds. The inpatient beds are essential in providing care and support for patients with more complex needs.

The hospice also provides:

*Out-patients* : The provision of specialist assessment and development of a jointly negotiated management plan for those patients with cancer and life-limiting illness, where concerns and/or complex symptoms are either anticipated or have been identified. It enables multi-disciplinary and multi-professional involvement across the Hospice, hospital and community.

*Day-therapy* : the provision of a range of services for patients who have advanced, progressive, life-limiting illness and who have associated complex palliative care needs.

- Symptom management
- Assessment of problems.
- Rehabilitation.
- Respite for carers
- Complementary therapies. (Hair & Image/ creative therapy/aromatherapy etc)
- Psychosocial support
- 1:1 nurse led consultations and nursing assessments
- Bathing/shower service.
- Blood transfusions.
- Medication/hydration infusions

*Hospice at Home*: (7 days a week 8.30 – 17.00) to take the Hospice philosophy into the home environment, working with community teams and care homes. The team is supported by medical staff based within the Hospice.

*Lymphedema clinic*: to provide a service of assessment and management to those patients known to the Hospice suffering from lymphedema.

*Bereavement Support:* Support is available via our chaplaincy and bereavement support team who offer spiritual and wellbeing support for patients and their loved ones, and who have any contact or connection with the hospice. There is Multi-faith (and no faith) provisions as well.

*Education and Training* – we provide a variety of courses to a broad range of care staff across the Bolton Health Care community, who are caring for people with life limiting illness and end of life care.

- Opening the Spiritual Gate
- Forgotten Conversations – (Dementia)
- Children's loss and Bereavement
- Sage and Thyme communication training
- LEAP – Communication training
- Internal training – Skills Blitz days for trained and untrained nurses
- Level 6/7 Multi-disciplinary end of life care module accredited by the University of Bolton

Bolton hospice provides an essential service for patients in Bolton and underpins the values of high quality care. Certainly there is a vision and drive to provide better care in the community and certain needs identifies such as expansion of Hospice at Home to a 24 hour service and lymphedema service outside of the hospice. The hospice provides a valuable buffer for complex palliative and end of life care patients, and often can help reduce unnecessary admission to the hospital. The ethos of right care by the right person in the right person clearly applies here and where there are ever increasing need for palliative and end of life care services there is a need for expansion of the service.

### **1.3 General Palliative Care Services: Primary and Community Care**

The majority of people nearing end of life will receive care and support from a wide range of services than is coordinated by their GP. Care will be provided in their own home, in hospital or in other care settings. Community services in Bolton that deliver day to day care to people at their end of life include; GPs, district nurses, care homes, social workers, home care providers, intermediate care and voluntary services. We recognise that in many cases, care and support will also be predominantly provided by a carer often a family member. So carer's assessment, support and education are vital part of the overall service we provide.

Within primary care, end of life patients are identified and managed in accordance to the Gold Standards Framework<sup>11</sup>. The principles of these are implemented through incentivised QoF scheme to ensure GP practices coordinate end of life community care for their patients through MDT meetings. It is the district nurses who are the key workers and link in the with GP practice. As the new integrated neighborhood teams develop in Bolton they will help link in with GPs to provide better-coordinated care for EoL care patients.

The CCG primary care team undertook an audit of end of life patients in primary care in 2013. Although the numbers were small it did high light keys areas of development. Only 61% of these patients on the GSF register have their preferred place of care recorded. 87% patients achieved

their preferred place of care. Only 50.5% of patients had some form of care pathway in place. Out of hours was informed in 59% of cases. The data illustrate that there is a need for improvements in primary care when ensuring better coordinated quality care for patients.

## 1.4 Integrated Care

Integrated joined up care is vital to help support high quality end of life care. Closer integration of health and social care has been a recurrent theme of public policy and empowering vision for Bolton CCG. The national framework document, *Integrated Care and Support*<sup>20</sup> clearly signals the Government's commitment to integrated care and the willingness of national organisations to work together to ensure that policy and regulatory levers support this approach.

The development of an integrated model for the delivery of health and social care across Bolton is a joint programme between NHS Bolton Clinical Commissioning Group, Bolton NHS Hospital Foundation Trust, Bolton Metropolitan Borough Council and Greater Manchester West NHS Mental Health Foundation Trust. There is full commitment from the Council Cabinet and Boards of each of the 4 organisations to the delivery of an Integrated Health and Social Care system by 2015/16, which is evidenced through the strategic intentions/plans of each organisation.

Bolton's model for integrated care which is currently being developed is based around the needs of individual patients. A multi-disciplinary health and social care team will serve a population cluster of approximately 21,000 to 30,000 people formed from groups of general practices.

The multi-disciplinary team will include adult community nurses, social workers, physiotherapists, occupational therapists, community psychiatric nurses, general practitioners and generic workers.

People who will be cared for within the Integrated Teams will be identified and case managed through a risk stratification model. The population of Bolton can be broadly classified into 5 groups on a tier system, at the top of the tier are those who require intensive support and input from the health and social care system, predominantly people who are very unwell and reaching the end of their life. So integration of services is a vital part of enabling better coordinated EoL care services. In fact end of life care forms an important part of the integrated care strategy.

Improvements in service delivery and care will be gained by the provision of better coordinated care with the GP and the allocation of a designated care coordinator who knows the system to act as a single point of contact. The care coordinator will be responsible for ensuring the care pathway for the individual is as seamless as possible. Key features of this role will include

- Discussions as the end of life approaches
- Holistic assessment of need
- Care planning and thinking ahead
- The delivery of personalized care which will include access to personal budgets to promote self management of care needs.
- Care in the last days of life

- Care after death.

The ultimate aim is to improve the experience of dying for the individual and everyone around them.

### 1.5 Bereavement services

1 point is a not-for-profit Community Benefit Company owned by its members and provides a single point of access to talking therapy services across Bolton. The majority of the referrals are from local GPs, although many patients self-refer after being sign-posted to this service by local agencies (including statutory, third and private sector organisations). An appointment is offered within 28 days of first contact with a qualified clinical assessor.

1point is currently funded by Bolton CCG, this covers the provision of the 1point service and on-going remedial appointments undertaken on behalf of 1 point by their members/partners.

Since June 2012 the service has had contact with over 4,000 people. They receive over 60 contacts a week; on average 42 patients a week attend a clinical assessment, with about 88 per cent electing to go forward for on-going treatment. Patients present with a multitude of concerns which affect their current mental wellbeing, but 1Point's own research into patient profiles would suggest that approximately 30 per cent of people directly access counselling for bereavement issues. When taking into consideration additional issues that surface during therapy, they estimate that more than 70 per cent of patients refer to historic or unresolved bereavement issues impacting on their present situation.

Because of the high level of local need for bereavement therapy, 1point has considered developing additional services specifically targeted at patients facing abnormal or long term bereavement related issues.

Bereavement services are also provided by the Royal Bolton Hospital and Bolton Hospice where patients have had contact with their service. Bolton Hospital has a specific bereavement liaison nurse.

There is currently a gap in local provision of specialist bereavement therapy, and some people do not wish to be referred on to mental health services. Beacon and Simeon Centre are the predominant providers of bereavement support.

### 1.6 Education and Training

Palliative & EoLC training programme is delivered across Bolton Foundation Trust and Hospice by the Palliative & EoLC team.

The Palliative & EoLC Education Alliance made up of Bolton Hospice, University of Bolton and Bolton Foundation Trust also deliver a training & education program which is currently funded via non-recurrent funding. The priority of Bolton NHS Foundation Trust Palliative and End of Life

Care Core Education program is to ensure that Bolton health and social care staff have the skills and confidence to respond effectively and sensitively to the needs of all patient and carers affected by a life limiting illness. Good palliative care delivered by a confident and competent multi-professional team will increase the number of patients who die in their preferred place of care, enhance dignity and respect whilst improving support to make informed choices regarding end of life care. Recent reports published such as 'one chance to get it right' and the 'LCP review more care less pathway' highlight the need for good quality education and training around end of life care and communication training.

Training is delivered around 3 areas.

- Communication Skills
- End of Life Care Tools
- Symptom Management

Bolton CCG also delivers end of life education session through their GP education events. The challenge around deliver of education and training has been uptake from a wider audience and grass roots clinicians who are often very busy with limited time. We need to think of other methods of learning such an online modules and e-learning to overcome this challenge.

Bolton Hospice also provides specialist training including BSc Palliative Care, Post Graduate Certificate in Palliative and EOL care, Good Grief – exploring childhood loss and bereavement, Opening the Spiritual Gate – spirituality in health care, Enhanced Communication Skills and Forgotten Conversations- dementia and EOL care.

### 1.7 Third sector provision: Marie Curie, Macmillan and Voluntary Sector

The Third Sector (charities and/or voluntary groups) have a long history of providing a range of health care and support services within local communities. In more recent times much of this work has been done in collaboration with their statutory sector partners (NHS/Local Authority/Central Government) and increasingly over the past decade or so via commissioning processes whereby specific services have been funded by the statutory sector for the third sector to provide them in line with an agreed service specification.

In relation to palliative and end of life care in Bolton there are currently three third sector organisations that provide specific services, Marie Curie, Macmillan Clinical Nurse Specialist Service (CNC) and Bolton Hospice.

**Macmillan Clinical Nurse Specialist Service (CNS)** – provides Specialist palliative care and advice for patients with complex physical and psychological, social and spiritual needs. This can be indirectly to other health and social care professionals or through direct patient contact. The CNS also has a responsibility to provide training and education to generalist staff to ensure equitable and quality delivery of palliative and end of life care.

**Marie Curie Service** – aims to prevent patients from being admitted to hospital and to support the patient and family by working to the district nurses care plan and assessment, working with stable, changing and urgent patients. The service provides registered nurses or health care assistants depending on what has been requested and what the patient's needs are. Working



with cancer and non- cancer patients aged over 18, mainly during the night but days also if needed.

## 1.8 Social Care

### Specialist Services

Funded by Bolton NHS Foundation Trust Bolton Adult Social Care provide a designated specialist social worker for palliative and end of life care who works as part of the specialist services provided by Bolton NHS Foundation Trust.

As well as undertaking the general statutory duties of social work the specialist social worker provide a social care contribution to the multi - disciplinary team that supports patients and their families at end of their life.

They work specifically to

- enable the individual and their family to talk about their end-of-life wishes when ready and establish their needs, aspirations and concerns now and in the future
- enable families to access practical help and resources and advocate for them in doing so where necessary
- liaise with care providers to ensure smooth transition between settings and act as a point of contact for families during transfers

### Generic Services

The vast majority of social care services for people in the last year of their life are accessed following an assessment under the Care Act by Bolton Adult Social Care Services generic area teams. Just under 3500 Bolton residents die every year and approximately 1000 of them receive some form of support from adult social care in the year before their death.

A large amount of this support is delivered in the form of Care Home placements where in one year Bolton Council can expect to fund 11,500 weeks of Care Home Placements. These placements are delivered by independent sector care home providers throughout the borough in nursing and residential homes.

Many people also receive support in the form of home care packages and in 2014 Bolton Council purchased 102,500 hours of home care for people in the last year of their life. This is expected to rise by an additional 15,000 hours in 2015. Other residents choose to access this support in the form of a direct payment or personal budget which in total were used to purchase a further 70,000 hours of support, again provided by independent sector care provider or personal assistants.

In addition many of the people also who remain at home receive support in the form of equipment and adaptations from Bolton's Integrated Equipment Services.

Many other forms of support are also provided to a smaller number of people who are in the last year of their life and these include:

- Day Care
- Extra Care

- Intermediate Care
- Supported Living
- Adult Placement
- Reablement
- Respite

Bolton Councils recent average expenditure on the social care needs of people in the last year of their life is in excess of £10m per annum and whilst these services may have experience of caring for people in the last year of their life and have received training they are not specialist in nature.

### 1.9 Children's and Adolescent Palliative and EoL Care Services

This is an End of Life Care Strategy for adults but it is acknowledged that services which deliver End of Life Care for children and young people is an important area, which needs to be considered in detail separately. There are also circumstances when adults and children's services must work together for the benefit of patients either around transition into adult services or when a child experiences the death of a parent.

Bolton CCG commission children's nursing services, Bolton Children's Continuing Care Nursing Team (CCCNT) provide and support any child or young person and their families with a choice about their preferred place of 'end of Life care' i.e. home, hospice or hospital. If the preferred place for 'end of life' is at home, the CCCNT will provide skilled, trained nursing staff to deliver a symptom management plan. This service will be available 24/7 to meet the nursing needs of the child and following death provide individualised post bereavement support.

In the event of a child being EoL, the team will request additional funding from the CCG for 'call outs' during the night or additional hours to enhance current healthcare package.

As the 'end of life' approaches the CCCNT will visit the child and family as necessary and the family will be provided with an 'on call rota' with the teams individuals mobile numbers. Principle key worker will be liaising with all professionals, arranging equipment, symptom management, supervising support staff to provide short break care, responding to the changing needs of the child and family and offering pre and post bereavement support.

The CCCNT can facilitate rapid discharge from hospital to home or hospice depending on the families preferred place for their child's 'end of life care'.

Specialist Hospice Care is also commissioned by Bolton CCG but these Hospices are outside of the borough.

Specialist Bereavement support will routinely be offered to those parents whose children have received Hospice care.

## Spirituality

Spiritual needs at the end of life care is important to many people. There are many forms of spirituality, religions, models of spiritual care and various routes for patients and relatives to access this. In Bolton there are local religious groups of various faiths in the community, there is a chaplaincy service at the foundation trust and at the Hospice.

The Hospice Chaplaincy is patient led, responding to the needs of others and proactive when appropriate. Doctors, Nurses, Chaplains and all staff try to listen to the patient and hear what is important to them. Spirituality may well be within a faith but it is also whatever is important or essential to the person, e.g.; family, employment, home, holidays, the list is varied and long. If patients want to talk, attend a service, or to see their own faith leader it can be arranged. The choice is the decision of the patient not the Chaplain. Chaplaincy is there for patients, their loved ones and for staff and volunteers.

The hospice holds a list of contacts of representatives from different faith or denominations and will contact them if a request is made, but would never make a contact without a request being made. The hospice space with ablution rooms adjoining for the use of those in the Hospice, it is a Multi Faith Centre called the 'Prayer and Reflection Room' and is open to everyone, services are held there, there is space to pray, meditate or just be. There are artifacts and the Holy Scriptures of the major world faiths and also space for those who have none.

Our Bolton challenge is to help link spiritual services within the care pathway so patient and relatives are able to access them if they wish.

## Key Messages

- There are comprehensive specialists care services in place within Bolton. However there seem to be a need to develop and integrate pathways so the services between various sectors of the health and social care are joined up and work more efficiently.
- Bolton Hospice provides a valuable comprehensive specialized service for the more complex palliative care needs. The service is supportive to other health and social care sectors and vital in preventing unnecessary admission to hospital. There is a need for a more 24-hour hospice at home service.
- Primary care and community services plays an essential role in providing palliative and end of life care but there need for better coordination and integration of service and care.
- There are a wide range of educational and training resources available locally and the challenge really lies with how we encourage wider uptake by anyone who is involved in end of life care, and facilitating partnership working to develop one education stream in Bolton.
- There are bereavement services available, there seems to be increasing demand for the service.
- Palliative and EoL care services are available across various organisations from primary care, secondary care, hospice, social services and voluntary sector. However there is still a lack of coordinated and integrated pathway between the services.
- Integrated care in the community is already evolving in Bolton and the key challenge is how the various organisations, services and schemes can work together in a patient centered single pathway. More work is needed around this area.

## **c) The Bolton Local Context: Local Data and Bench Marking**

## The Bolton Local context : data and bench marking

In Bolton, 0.71% of the population will have a palliative care need<sup>35</sup> which is around 2000 patients. Recent primary care registers show around 988 on the GP registers in April 2016<sup>36</sup>. This has increased by 17% from 2015 as primary care through quality initiative is much more focussed on detecting end of life patients<sup>36</sup>. At least 50% of end of life patients are palliative cancer patients, however there are growing numbers of patients with terminal long term conditions such as COPD, heart failure, dementia and frailty. Often these patients do not get the same level of end of life care that cancer patients do. There are many reasons for this gap but the key is to identify these patients earlier which can sometimes be challenging. In Bolton we have a clear ambition to help identify these patients better and earlier through local initiatives and it is hoped this strategy will facilitate better systems to achieve this.

### 1.1 Bolton CCG Strategic Commissioning Plan 2014-2019

Our Strategic Commissioning Plan prioritises our need to transform services and describes our aim in the following areas:

- Experience of care in and out of hospital is amongst the best in the country
- Reduce avoidable deaths
- Reduce time spent in hospital
- People living independently at home
- Improving health related quality of life for people with long term conditions including mental health
- Secure additional years of life for people particularly in deprived areas.

To achieve this we want to integrate health and social care professionals to enable services and service users to manage their care in new, innovative and more effective ways. We want to increase the scope of services delivered remotely, and implement the “Think Home First” ethos.

Local issues which need to be addressed:

- 5 of the 7 wards in the Bolton area are in the 20% most deprived in the country for barriers to housing and services.
- Potential increase in the number of over 65s from 6,000 to 7,200 in 2021
- 6.2% residents in Bolton consider themselves to be in bad or very bad health. This is higher than the national average of 5.5%
- Over one fifth of the residents in Bolton have limiting long term illness or disability. This is higher than the national figure of 17.5%.
- The proportion of people in the Bolton area who provide one hour or more of unpaid care is also higher than the national average.
- Quality of Outcomes data shows a higher prevalence of some diseases including COPD, HF and CHD, asthma and hypertension. Adult obesity rates are also higher than the national average.
- Rates of A&E attendances in the over 65 age range have increased by 31% since 2010.
- Excess bed days are common in the over 65s
- The most common cases of non-elective admissions in the over 65s are

respiratory and circulatory disease

## 1.2 Local data and benchmarking

### Benchmarking

The aim of this section is to benchmark Bolton's current performance regarding end of life care against our statistical neighbours. Our statistical neighbours are those areas most similar to Bolton across a range of demographic indicators. Toward this end, a range of officially published outcomes have been selected to give a sense of Bolton's position before the present strategy has been implemented.

Benchmarked outcomes have been selected to cover the following domains of end of life care:

1. Identification of palliative care need;
2. Place of death;
3. Deaths in hospital;
4. Cause of death;
5. Care homes;
6. Social Care.

Within each domain are a number of indicators that measure Bolton's present performance relative to our statistical neighbours. Some data, for instance mortality data, is frequently a couple of years out of date but local more up-to-date data we may have is inappropriate for benchmarking as we cannot use data from other areas. Therefore, the data here presented is the latest 'official' picture; but local data can be used for internal monitoring, for instance to give an in-year picture of improvements in increasing the proportion of deaths at home. Finally, the above domains do not include issues pertaining to patient or carer satisfaction with services at the end of life; this is because the majority of published data relating specifically to end of life care ('Quality of care rated outstanding/excellent by bereaved relatives', 'Excellent relief of pain rated by bereaved relatives' etc.) is released at Greater Manchester CCG Cluster level and so cannot be used for comparison with our peers.

All data is latest available at time of publication.

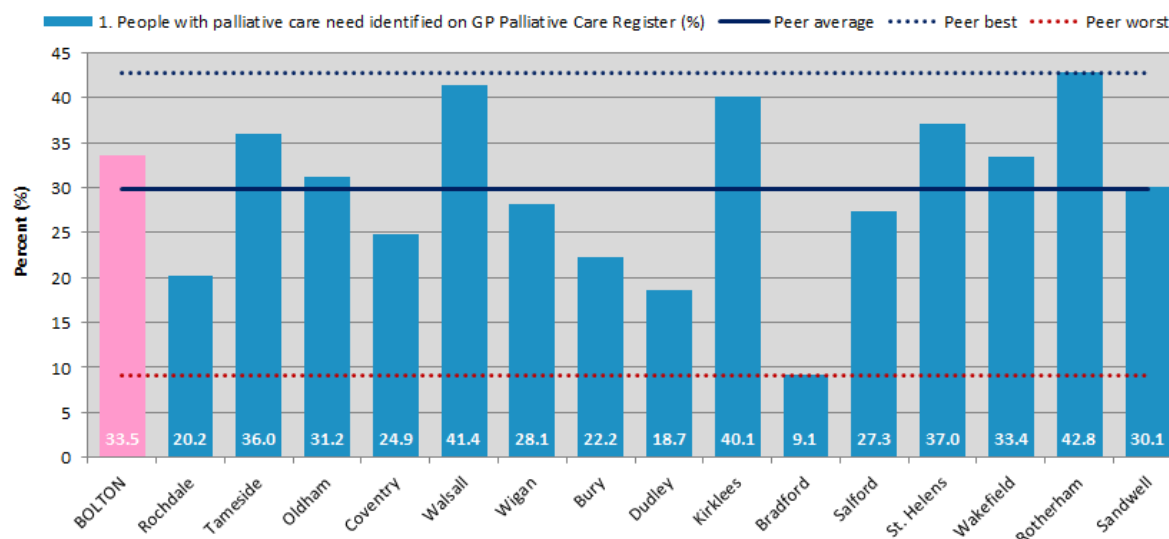
### The current local context

The areas that Bolton performs the best – and as statistical neighbours face similar demographic and deprivation-related challenges to Bolton – are Bradford, Kirklees, Rotherham, and Bury. However, there are differences by domain.

#### Identification of palliative care need<sup>21</sup>

Bolton performs relatively average regarding identification of need with 33.5% of people with a palliative care need identified on the GP Palliative Care Register, compared a peer best of 42.8% (Rotherham). A similar picture is seen for the same identification indicator relating to deaths. All our peers within Greater Manchester (Oldham, Tameside, Wigan, Salford, and Bury) perform similar to Bolton regarding identification; the notable exception being Rochdale which has the lowest proportion of our peer group.

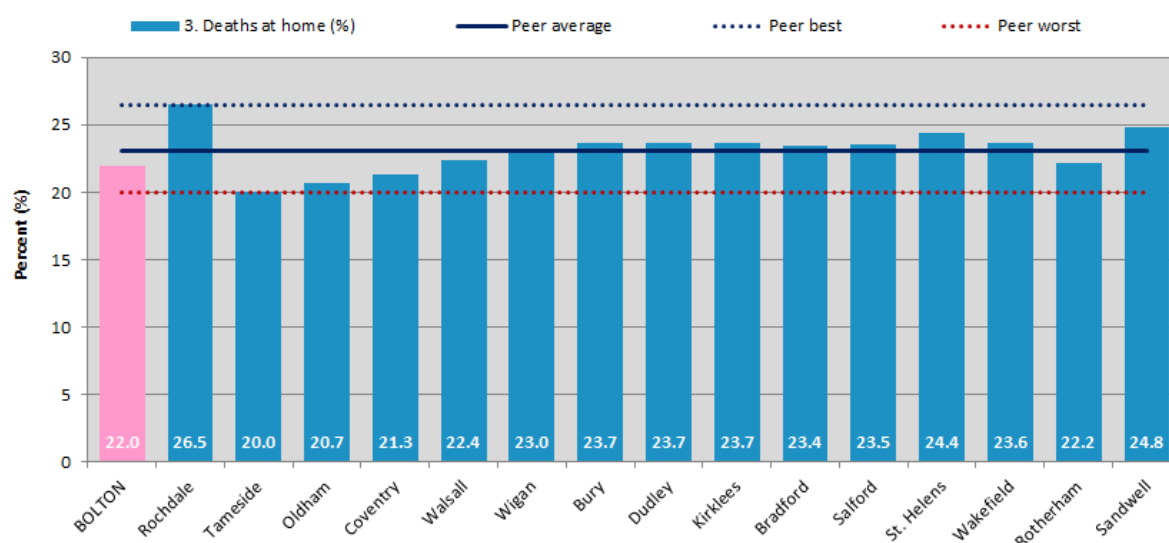
### Identification of palliative care need



### Place of death<sup>22</sup>

Bolton performs less well regarding deaths at home (22.0%). Though this proportion is similar to our peer average (23.1%) and our highest peer is just 26.5%, indicating a common problem, the reason in Bolton is largely due to the higher than average number of deaths in hospital (53.1%). In the best of our statistical neighbours (Bradford) 42.1% of all local deaths occur in hospital. Lowering the proportion of deaths in hospital with a view to increasing the number dying at home should be a key outcome of this strategy.

### Deaths at home



### Deaths in hospital<sup>5</sup>

Given the previous, this is a vital benchmarking domain for end of life care in Bolton. Bolton tends to perform just slightly worse than average across all relevant indicators (terminal admissions that are emergencies, terminal admissions that are eight days or longer, average



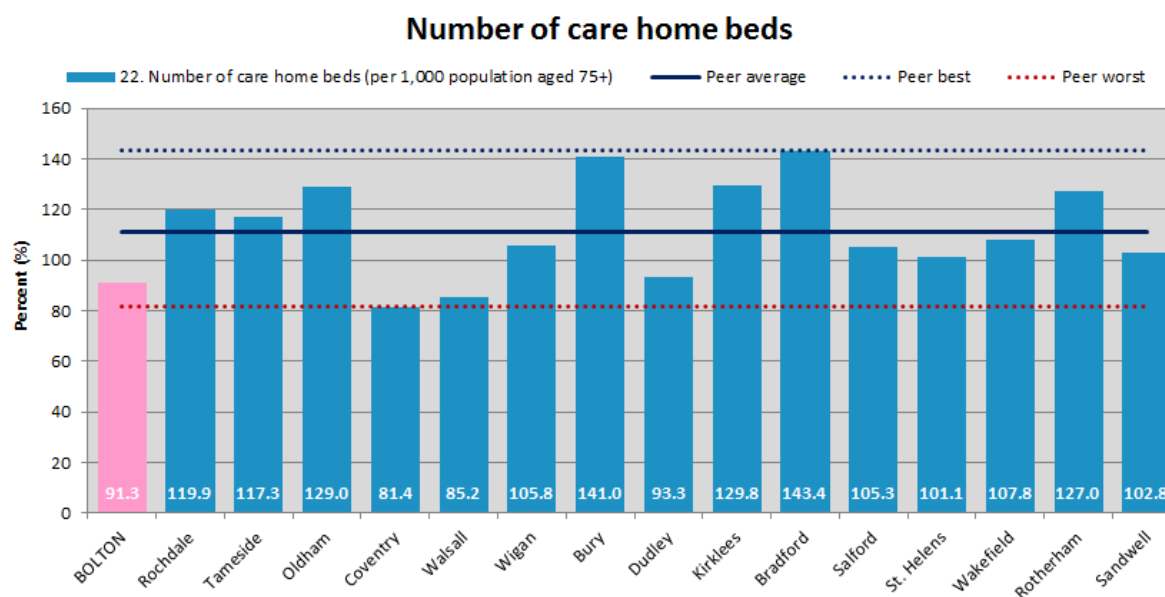
number of bed days per admission ending in death) with the exception of terminal admissions aged 85 years and over where we are notably worse than our best performing peers – with 37.4% of all terminal admissions aged 85 years and above compared to 29.6% in Rochdale. Those over 85 years are at a very increased likelihood of living with chronic long-term conditions and as such death may be predictable in many cases, meaning that appropriate planning can work to prevent the end of their life involving and emergency admission.

### Cause of death<sup>22</sup>

The above brings us onto cause of death, where in Bolton the key disease areas having a particularly negative impact on end of life are CVD, respiratory disease, and liver disease. As discussed previously, of all the Bolton residents who die in hospital the greatest number die from CVD or respiratory disease. End of life is particularly complicated for these conditions due to comorbidities and exacerbations that must also be dealt with at the end of life. Finally, a very high proportion of people who die of liver disease die in hospital and the number of liver disease deaths is increasing in Bolton, which is likely to negatively impact upon Bolton's deaths at home in the future, as well as the number of terminal admissions that are emergencies given the younger age at which people die of liver disease.

### Care homes<sup>5</sup>

When benchmarked against our statistical neighbours Bolton has the lowest number of care homes per 1,000 people aged 75 years and over (2.6) and as the population ages this rate will fall unless more care homes are created. The statistical neighbour with the highest rate of care homes (4.9) is Bury. Also, of the fifteen peers, Bolton has the third lowest number of care home beds per 1,000 people aged 75 years and over (91.3 compared to the rate of our best peer (Bradford) of 143.4).



### Social care<sup>22</sup>

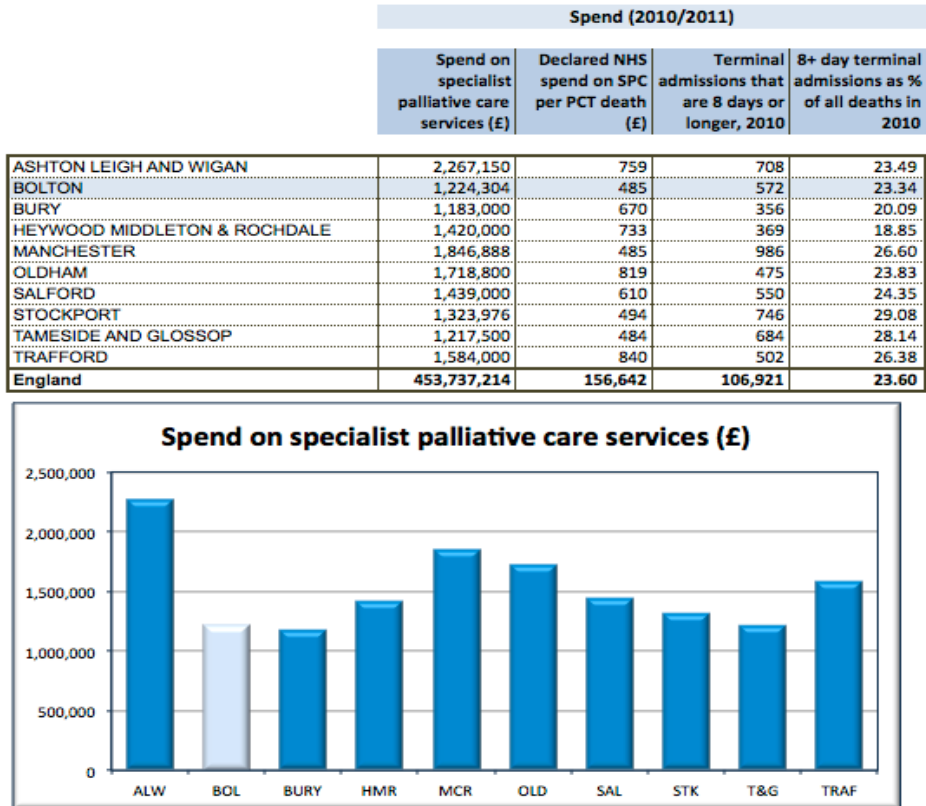
The key nationally indicator of polarity available for social care related to end of life regards delayed transfers of care for people aged 65 years and over, where Bolton performs average for our peer group and much better than the worst of our statistical neighbors.

END OF LIFE BENCHMARKING DATA AGAINST STATISTICAL PEERS						
DOMAIN	INDICATORS		BOLTON	PEER AVERAGE	PEER BEST	PEER WORST
IDENTIFICATION OF PALLIATIVE CARE NEED	1. People with palliative care need identified on GP Palliative Care Register (%)		33.5	29.7	42.8	9.1
	2. Palliative care deaths identified on GP Palliative Care Register (%)		0.3	0.2	0.3	0.1
PLACE OF DEATH	3. Deaths at home (%)		22.0	23.1	26.5	20.0
	4. Deaths in care home (%)		18.3	18.8	13.3	23.8
	5. Deaths in hospice (%)		5.1	6.1	1.8	10.2
	6. Deaths in hospital (%)		53.1	49.9	42.1	55.4
DEATHS IN HOSPITAL	7. Terminal admissions that are emergencies (%)		91.2	92.2	89.0	94.3
	8. Terminal admissions aged 85+ (%)		37.4	34.5	29.6	39.3
	9. Terminal admissions that are 8 days or longer (%)		47.2	46.9	40.8	51.7
	10. Terminal admissions that are 8 days or longer as proportion of all deaths (%)		23.3	23.2	17.8	29.4
	11. Average number of bed days per admission ending in death (days)		13.0	12.3	11.0	14.0
	12. Deaths aged 75+ (%)		63.5	63.6	67.2	60.4
CAUSE OF DEATH	13. Deaths aged 85+ (%)		33.3	33.6	38.8	28.1
	14. Deaths from respiratory disease (underlying cause) (%)		15.7	14.0	11.5	15.7
	15. Deaths from cancer (underlying cause) (%)		27.3	28.1	25.5	31.0
	16. Deaths from CVD (underlying cause) (%)		25.2	26.6	25.2	29.6
	17. Deaths from liver disease (mentions) (%)		4.8	4.4	3.5	5.3
	18. Deaths from renal disease (mentions) (%)		5.0	6.1	4.4	8.2
	19. Deaths from Alzheimer's, dementia and senility (mentions) (%)		13.4	16.1	12.2	21.5
	20. Alzheimer's, dementia, and senility deaths in hospital (mentions) (%)		31.4	38.8	24.2	56.5
	21. Number of care homes (per 1,000 population aged 75+)		2.6	3.7	4.9	2.6
	22. Number of care home beds (per 1,000 population aged 75+)		91.3	111.3	143.4	81.4
CARE HOMES	23. Persons discharged from hospital offered reablement aged 65+ (%)		6.3	3.6	NO POLARITY	NO POLARITY
	24. Persons receiving Self Directed Support aged 65+ (%)		66.3	66.9	NO POLARITY	NO POLARITY
	25. Delayed transfers of care: persons (per 100,000 aged 65+)		550.0	507.6	59.0	1302.0
	26. Delayed transfers of care: days (per 100,000 aged 65+)		15880.0	14206.2	1498.0	42387.0
	27. Persons with completed assessment (per 100,000 aged 65+)		6988.0	6163.5	NO POLARITY	NO POLARITY
	28. Persons with care package delivered (per 100,000 aged 65+)		4429.0	3794.1	NO POLARITY	NO POLARITY
	29. Carers who received social care support (per 100,000 aged 65+)		1232.0	2136.2	NO POLARITY	NO POLARITY
	30. Older people supported by adult social care throughout the year (per 100,000 aged 65+)		9198.0	11138.8	NO POLARITY	NO POLARITY

### 1. 3 Financial spend on palliative care services

Figure 1 shows the spend on EoL care which is from the Marrie Currie data tool. Although this is older data it does demonstrate that Bolton spends significantly less compared to its peers

Figure 1



## **d) Stakeholder Survey and User Engagement**

## Engagement Analysis

### End of Life care plans – Engagement Analysis

#### **Introduction:**

Bolton Clinical Commissioning Group, Royal Bolton Hospital FT, and Bolton Council had a joint strategy for end of life care covering 2006 - 2011. A new strategy needed to be produced and is currently in the process of being rewritten. Subsequently, NHS Bolton Clinical Commissioning Group (CCG) set out to engage with Bolton people to ensure the views and comments of our local population were included.

As a result, from May till December 2014 NHS staff, staff in care homes and members of the public was invited to give their views on end of life care plans through an online questionnaire, one to one interviews and in focus groups.

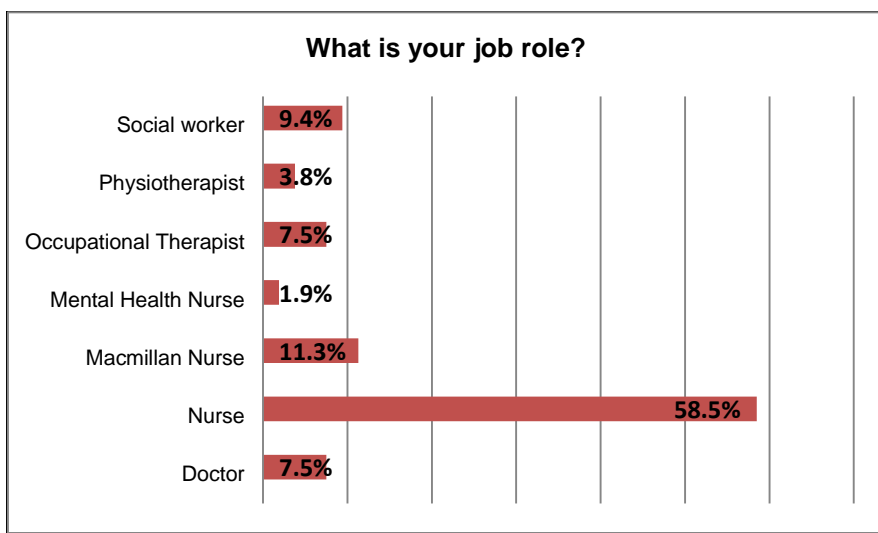
There was a good overall response, with 68 members of staff completing the survey online, and 8 GP's completing paper versions of the survey, one focus group made up of 18 members of the public taking place, and a one on one interview with a retired Macmillan nurse. However, there was some difficulty getting members of the public to talk about their experiences as this is a sensitive topic for them.

#### **Results from the online surveys:**

The online surveys asked staff who worked in the NHS in Bolton and also in care homes all over Bolton a range of questions on end of life care.

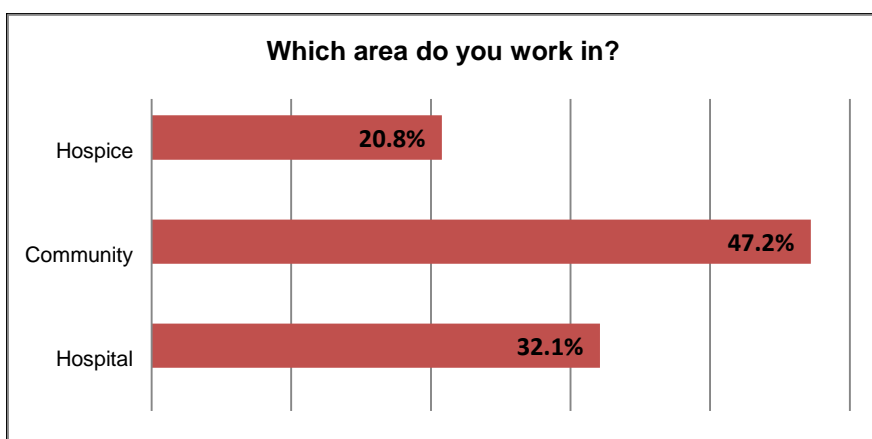
#### **Type of Respondents:**

The first question asked of staff was about what their role was in the NHS.

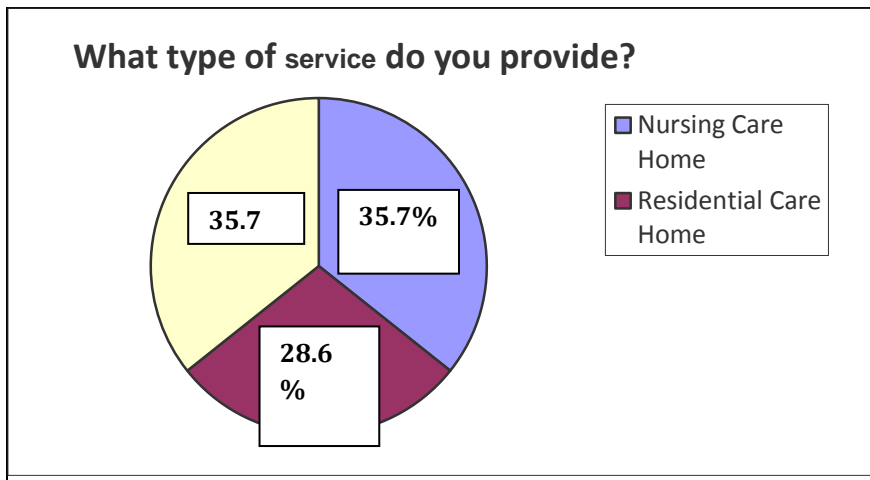


As can be clearly seen from the chart above, 58.5% of respondents were nurses, with a further 11.3% stated they were Macmillan nurses. There were a further sixteen responses given under the 'Other' category and these included a OT Technical Instructor, a cook, a Community Macmillan Nurse, HCAs, Bereavement and Donor Officer, clinical support nurse, CEO, midwife, speech and language therapist, support workers, specialist nurse, admin, councillor and an office manager.

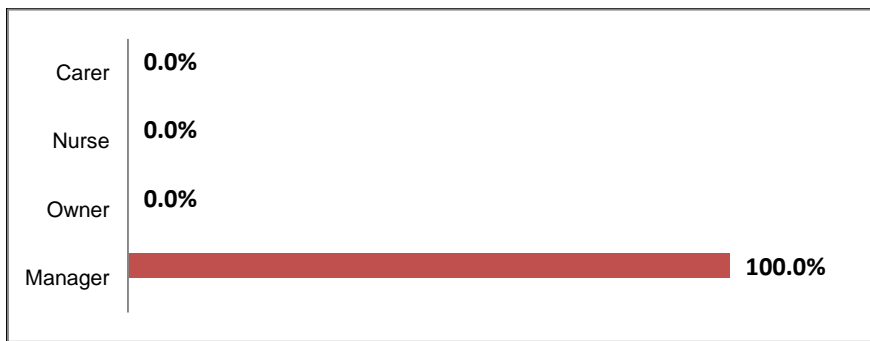
Staff members were then asked which area of the end of life care service they worked in. As shown below, 47.2% stated that they worked in the community, while 32.1% said they worked in the hospital and 20.8% which demonstrated that there was a good mix of responses from all areas.



Meanwhile, members of staff in care homes were initially asked in their online survey what type of service they provided and what their role was in the care home.

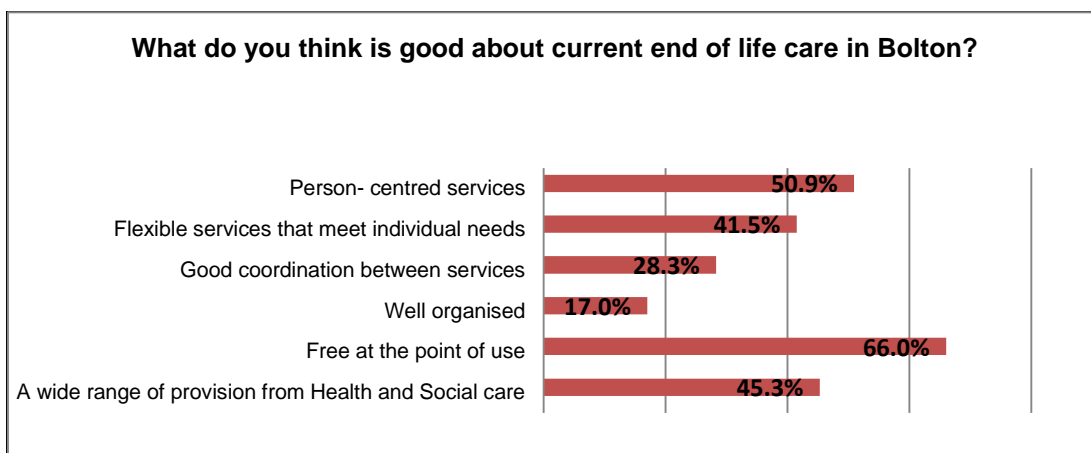


As shown by the charts above and below, the vast majority of respondents stated that they either worked for a nursing care home or for domiciliary home care and were all management level.



#### Results from the staff survey:

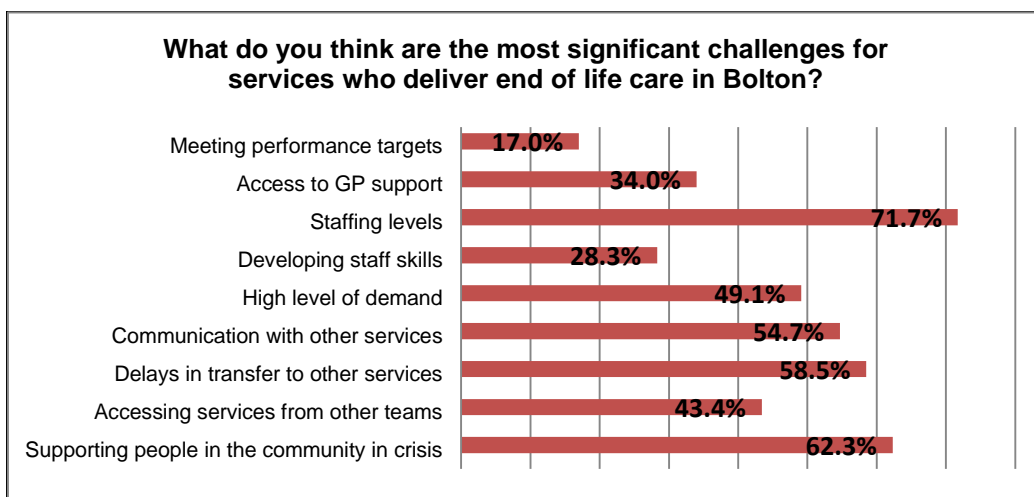
As mentioned previously, all NHS staff involved in end of life care in Bolton were asked to complete an online survey through their staff bulletins. Respondents to this survey were firstly asked what they thought worked well in the current care provided in Bolton.



As shown above, 66% stated the fact it was free at point of use was the best part of the current service. Staff also felt that the person centred services and a wide range of provision which is flexible and meets individual needs were also good parts of the service.

The survey then moved on to ask what staff thought were the most significant challenges for the end of life care services in Bolton.

Staff could chose as many options as needed, and as clearly shown in the chart below, 71.7% stated that the main concern was to do with staffing levels. Respondents also said that the delay in getting transfers to other services, and difficulties in supporting people in the community when they are in crisis were also significant challenges.



Additional comments given under the 'Other' section included concerns to do with too much time being taken to get a decision about pathways or when a patient is being fast-tracked, access to training, patients not getting services required as they are not getting referred, and having the right level of staffing as previously mentioned.



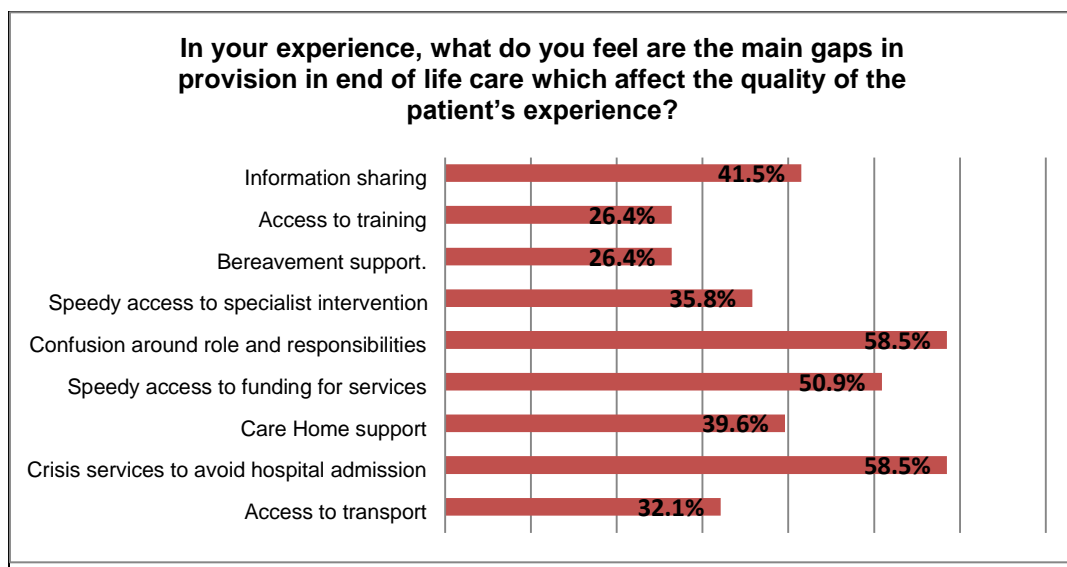
Respondents were then asked which areas of end of life care they felt would benefit most from better integration between health and social care. This was an open text option in the survey, and there was a detailed response.

Below are the suggestions given by the respondents:

- Home-care support
- Out of hours services
- Better timescales, including transfer times
- Improved communication between all services, and in particular between staff and patients/families
- Support and greater involvement for families throughout
- More training in end of life prescribing for GP's
- For severely deprived patients, nutrition and ongoing support
- Making sure relevant services are involved before it crisis point
- The need for more care overnight to keep people at home if this is their preferred place of care.
- Care in the last few days
- Carers support for patients who do not meet CHC funding
- Qualified staff to provide EOLC night sitters
- CHC Funded packages of care need to be trained to support people in last weeks of life/ quicker adaptations to home environment enabling people to stay in their own homes

Overall, staff said that there needed to be a standard end of life care plan across all services that can be used as a basis, and is fully integrated from day one with good communication between all teams, the patient and their family.

Staff members were then asked what they felt were the main gaps in provision of end of life care in Bolton. They were again given multiple options and could choose as many as they felt necessary. As shown in the below chart, the confusion around roles and responsibilities amongst staff and crisis admissions to avoid hospital admissions were the main gaps that affected a patient's experience.



The survey then went on to ask staff professionally and personally what mattered to them most about end of life care. There were again a lot of detailed responses to this question, but overall staff said the following:

- Helping someone to have a dignified and respectful death that fully respected their wishes
- Good communication between all staff, patients and their families
- Care to be given by caring and professional staff
- Full support to be given to the patient's family before and after the patient's death
- A personalised care plan that includes all teams and is in line exactly with the patient's wishes.

The quote below is an excellent example of what staff said in answer to this question:

'As a nurse, I want patients at the end of their life to have an excellent plan of care in place which encompasses a whole team approach. I want every member of that team to understand their responsibility for that patient. I want the patient's systems managed effectively and I want the medical team for that patient to ensure that things are prescribed pre-emptively. I want my patient to die with dignity and in comfort.'

The survey then moved on and asked staff if they were in charge of end of life care services overall in Bolton, what three things would they change. There was an excellent response to this question and again there were a large variety of suggestions given.

Below are the main themes to emerge from the responses:

- More end of life care training for staff, in particular for GPs so they have greater awareness
- The whole end of life care service to be more joined up
- Better communication between all staff, patients and their families
- More support for families before and after a patient's death

- Staff to use a standardised care plan approved by all services
- More funding to be given for end of life care services
- Reduce number of people in hospital who do not need to be there
- All services to run 24/7
- More staff in all services, but particularly nurses and day and night sitters

To conclude the survey respondents were then asked if they had any further issues around end of life care that they would like to raise.

The following issues were raised by staff:

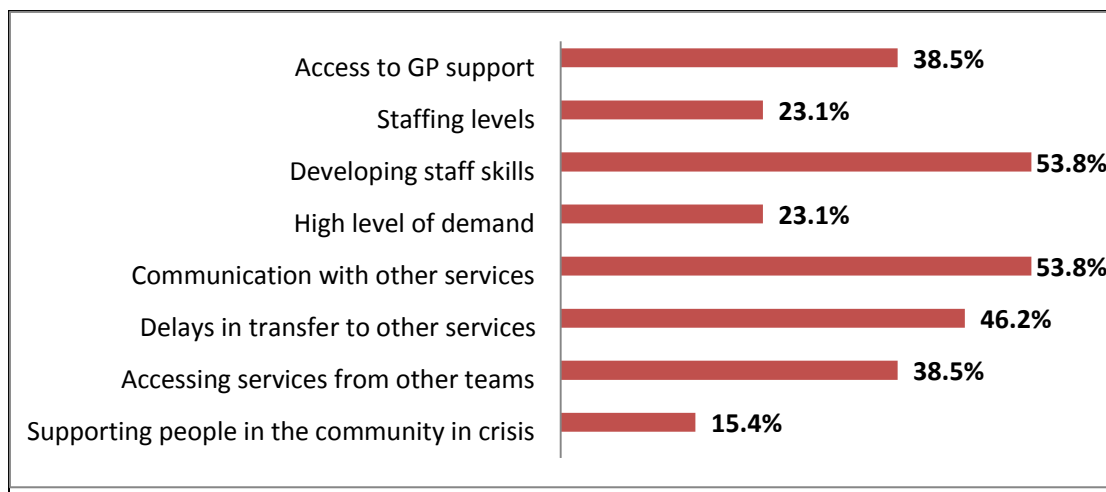
- The need for a more integrated approach with GP's to avoid hospital admissions and prevent patients from dying in hospital
- All paperwork to be filled in and quickly passed between services so there are no delays
- Full support for patients and their family on a regular basis

Overall, staff stated that they felt that good work was being done in end of life care in Bolton, but all services needed to be more integrated and have access to more funding so that full support could be given to end of life patients and their families.

#### Results from care home staff survey:

In addition to the above engagement, an online survey was also circulated amongst staff at care homes in order to gain their thoughts on end of life care services.

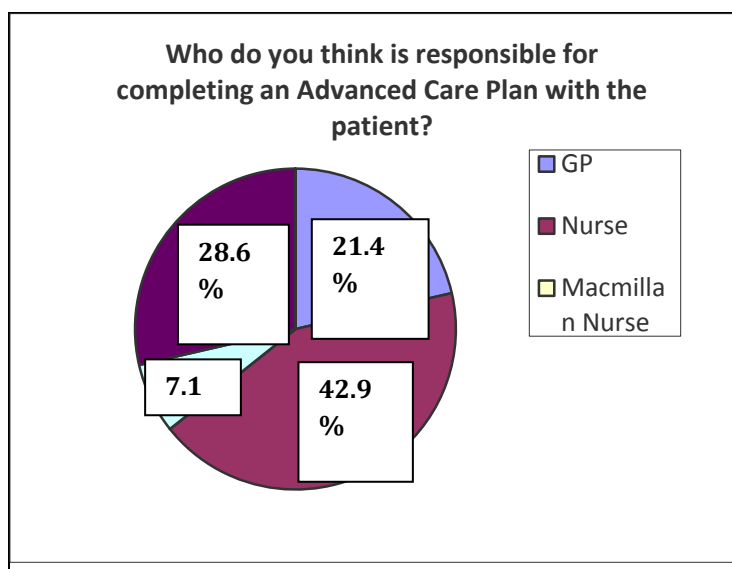
They were also asked what they thought were the most significant challenges for service who provide end of life care. As can be seen in the graph below, communication with other services, developing staff skills and delays in transfers to other services were the main challenges to delivering excellent end of life care in Bolton.



Care home staff members were then asked whether they understood what was meant by 'Advanced Care Planning'. Out of 13 responses to this question, twelve people stated that they did know what Advanced Care Planning with only one person stating they didn't but would like to. Some of the responses included descriptions of what the respondent understood Advanced Care Planning to be, which are displayed below:

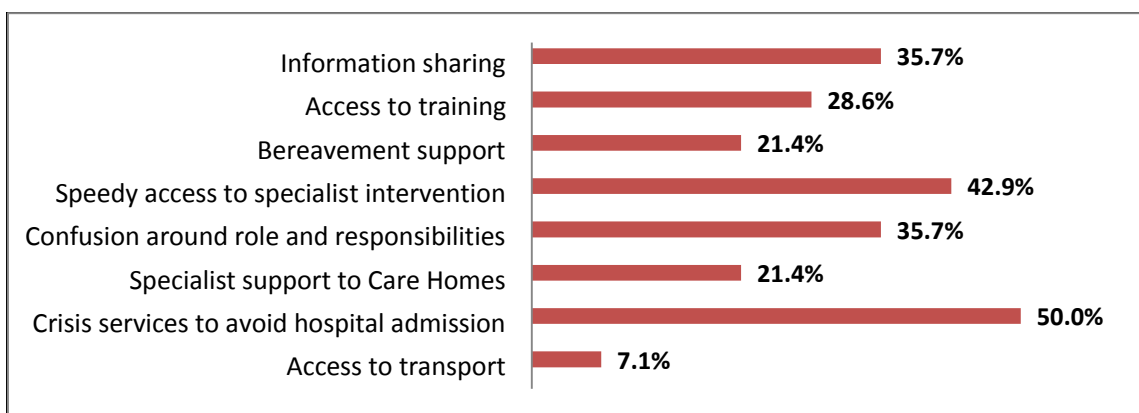
- 'Planning ahead for how someone wants to be cared for at the end of life, what is important to them and their family, and their preferred place of care'
- 'A person has written down their choices and preferences as to how and where they are to be cared for leading up to the end of their life whilst they have the capacity to do so. Also important to write down what they do not want too'
- 'Planning ahead'

Following on from this question, respondents were then asked who they thought the responsibility of completing an advanced care plan with the patient should lie with. As shown in the graph below, 42.9% felt the responsibility should lie with nurses, while 28.6% felt carers or relatives should be responsible for the plan.



Other suggestions given by respondents stated that it would depend where the care was being provided, while the majority stated that the plan should have input from all involved.

Respondents were then asked what they felt were the main gaps in the provision of end of life care in Bolton. As demonstrated in the chart below, most felt that crisis services to avoid hospital admissions was the main gap, along with speedy access to specialist intervention and staff confusion about roles and responsibilities. Obviously this is a similar response to the one given by hospital staff when asked the same question. However, the results showed that hospital staff felt there was more confusion about roles and responsibilities than care home staff do.



Care home staff were then asked what they felt professionally and personally was what mattered most about end of life care. There was a good and detailed response to this question, and the main themes are described below:

- Making sure someone is allowed to die with dignity and pain free
- To support the family throughout and after their relative's death
- Good communication between professionals and families

Below is a quote of one of the responses given that demonstrates the overall feeling staff have on this:

'Everyone deserves to have quality of life until such time they have a quality, pain free death'.

Again the responses to this question are very similar to the responses given by hospital staff, and shows that all staff has the same aim when it comes to end of life care in Bolton.

### **Results from the GP's survey:**

A paper survey was sent around to all GP's surgeries in Bolton asking for GPs to complete them and give their views on end of life care.

There was quite a low response unfortunately to this survey, with only eight completed and not all questions had a response. However, despite that some very interesting and detailed feedback was given by some GPs, as discussed below.

GPs were initially asked what they thought was good currently about end of life care in Bolton. The respondents stated that the fact that it was free at the point of use and that it was a person centred service was what they felt was good about the current system. This response clearly matches the response given by hospital staff and care home staff.

The survey then moved on to ask GPs what they felt were the most significant challenges they faced in their work supporting people at the end of their lives. There were three clear themes emerging from the response to this question which are:

1. Supporting people in the community in crisis
2. Managing unstable symptoms in the community
3. Finding the time to make home visits

Two of the respondents also made additional comments which are included below for consideration

*'Reduction in district nurse service and workload reduces the availability of DN's for this.'*

*'Disjointed social and health e.g. old age psychiatry refer to PT to social services and no contact made as there are too many departments in SS.'*

The third question asked GPs which areas of end of life care did they feel would benefit most from better integration between Health & Social care. There was a low response to this question but three suggestions were given –

1. More care workers
2. Elderly and dementia patients. Especially elderly patients who do not have any family support, and mental health patients in crisis
3. Dementia, cancer, heart failure/COPD, frail elderly, long term conditions

The survey then moved onto ask GPs what they thought, in their experience, were the main gaps in the provision of end of life care in Bolton which affected the quality of the patient's experience. The respondents very clearly stated that they felt there were gaps in crisis services which prevent hospital admissions, and there was confusion amongst staff around their roles and responsibilities. Again, this response matches the response given by hospital and care home staff.

Respondents were then asked what professionally and personally mattered to them the most about end of life care. There were three responses to this question -

1. Compassionate care for the whole family
2. Joint working
3. Not enough support for carers and no continuity of care or formal follow up

GPs were then asked what three things they would change if they were in overall control of end of life care in Bolton. Again there was a low response to this question, but two comments were given that I have included below:

1. Improve understanding of roles and responsibilities of social and health services
2. More instant specialist support

Finally, the survey asked if any of the respondents had any other issues around end of life care that they would like to raise. The following answers were given –

*‘District nursing service already under tremendous pressure’*

*‘Increase liaison with faith groups e.g. Bolton Council of Mosques to provide spiritual support on gaps present in ethnic minorities, as lack of awareness of facilities in these hard to reach vulnerable groups’*

Overall, it is clear that similar thoughts and themes have emerged from this survey completed by GPs, as they did from the surveys completed by all staff involved in end of life care in Bolton. Staff and GPs clearly want to make sure that they act in a compassionate way and support the patient and their family, while having concerns with communication and links between different services.

### **Results from focus group with the Dementia carers support group:**

As part of the engagement, it was decided that not only was it important for a patient at end of life to give their views but also for the families of those at end of life to have their say as well. As a result, on the 1<sup>st</sup> July 2014, Bolton CCG met with the Dementia Carers support group who meet every week to support each other, and have experience of looking after loved ones who are at end of life.

While some of the family members engaged did not currently have an end of life care plan in place, they had a very clear idea of what the plan should include.

The group was firstly asked what problems or challenges they thought they could have if supporting someone who had an end of life care plan. The following feedback was given:

- Needs to be flexibility in the plan – families may need to be able to change things.
- Families would like to see GPs and doctors to speak to their relatives on a pastoral side, and not just about the clinical side.
- Patients should continue to receive fluids and food despite being at the end of life – those consulted said they felt that the basics get missed.
- Support from the various religions should be available and accessible as required.
- GPs should be able to give the families a guide on wills/power of attorney etc. This is so the families know what needs to be done, as with the upset of dealing with a relative at end of life, it’s hard to think of all the other things that need to be done and some things may get missed. There was a suggestion that maybe a tick list of things that need to be considered should be included in the care plan.

- The DNR order should go into a plan and the process made easier. The carer or close family members should be consulted about DNR in these cases as well.
- All authorities should honour the request to die where the patient wishes - if requested, patients should be allowed to die in hospital and not moved in order to get a hospital bed available.
- The general issue of getting access to the GP was raised as an issue.
- Many felt that a lot of GPs don't seem to have any understanding of dementia and as a consequence they have a very poor bedside manner with these patients.
- The timing of when a GP talks about an end of life plan needs to be flexible according to the illness or condition.
- Power of attorney takes a long time to arrange so should be mentioned as early as possible to patients and their families.
- Some of those consulted reported that they are aware that sometimes there have been issues with GPs not being prepared to sign death certificates if they weren't there at the time of death, so post mortems have been ordered and this adds time and prevents burial which is an additional stress and upset.
- It was mentioned that there have been difficulties that have arisen due to patients seeing different GPs and locums all the time as there's no consistency or support. Means the patient and the family have to go through all conditions every time they speak to a GP.
- Files should be very clear marked with relatives' details who must be contacted immediately in an emergency or death.

The group was then asked what mattered most to them about the care given to their relatives at end of life. They felt that -

- Patients should be pain free at the end.
- Preference of place to die in should always be honoured if possible.
- Practical advice and support should be available for carers / family members and patient on administering medicines and feeding and washing and mobility.
- Support should be available for carers / family left behind after death.
- Information and advice on how to get equipment and aids to help with patients such as incontinence pads; hoists; hospital beds etc should be freely available as families don't know what's available or what could be asked for. Also, supplies of these things should be delivered and then collected quickly when not needed to avoid waste of resources and money.

Finally, the group was asked what three things they would change if they were in charge of end of life care services overall in Bolton. Again there was an excellent response to this question and the following suggestions were given:

- Information point – all info on what the family should do.
- Make services and information accessible to all.
- Allow people to die at home if they want to.
- Have a drop in centre in town for help, support and advice or just someone to talk to.
- Information point for support groups to help carers and family members.



- Home help to help with some jobs at home – staff can't achieve anything in 15 minute visits.
- Timings were seen as inappropriate – some people in the group had found out their relatives had been put to bed at 5pm to fit in with the home help's timings and not considered the patient's.
- Help available with finding care homes and support whilst a carer or family member is unwell or away for a break.

Overall, the group very much felt that end of life plans should include lots of topics, including non-medical information, and that they felt at times they were not communicated with properly and that was the key area they felt should be improved.

#### **One on one interview with a patient:**

On the 3<sup>rd</sup> December, a recently retired Macmillan clinical nurse volunteered to speak to Bolton CCG about her experiences of providing end of life care in Bolton. Within that post she obviously had a lot of contact with patients right through from diagnosis to end of life.

From her experience, she recommended that patients needed more support from primary care. She felt a lot of GPs didn't really get involved with patients who have potential spinal cord compression, and didn't seem to have enough understanding of palliative care and symptom control.

She also felt that what worked well in end of life care was that the patient sees a seamless service from hospital to hospice. She also felt that services like Macmillan providing grants to projects such as 'Keep Warm' to help patients with their finances, heating etc was a good thing, but in her experience patients are not aware that these services are available and do not know how to access them.

She also recommended more support for carers to allow the patient to be where they want to be and have that choice. She felt that support for carers was a major gap for end of life care in Bolton, which would obviously impact on the patient.

What mattered to her professionally and personally was that the patient would get the full range of services available, they are kept symptom free as much as possible and the carer received plenty of support.

The three things she would change about end of life care in Bolton if she could would be -

1. More education for patients about their options
2. Further awareness raising for GPs
3. Full communication and support for all those involved.

Overall she felt that Bolton provided good end of life care but the pathway needed to be tightened up more by involving the GPs more.

**Conclusion:**

From all the comments given either in person or via a survey, it is clear regardless of whether it was a member of staff or member of the public, that it is vital for a patient to have the choice of where to die and for all arrangements to be as easy and as stress free as possible. Good communication was also highlighted several times as being extremely important between all teams involved and with the patient and family members.

It has been difficult to get patients to volunteer and speak about their experiences, as obviously this is a very sensitive topic for them, so the engagement has not be as wide as would have been preferred. However, from those who have volunteered to speak to Bolton CCG about end of life care, it is clear that they are in agreement with the health professionals, and the care needs to be centred on the patient and his or her wishes.

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