



**NHS Next Stage Review
NHS Yorkshire and the Humber**

**Report of End of Life
Clinical Pathway Group**

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End of Life Clinical Pathway Group Report

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1. End of Life Care - Executive Summary.

1.1. Introduction

Approximately 50,000 people die each year in Yorkshire and the Humber. Many of these people, (their carers and families) will have needed significant support during their last year of life. However the quality of the end of life care provided across Yorkshire and the Humber is variable. There is evidence of some excellent practice but this is not consistent across all areas.

The majority of people die in Hospital and whilst some will have received excellent levels of care, others will not. 54% of all hospital complaints in England received by the Health Care Commission in 2007¹ were about end of life care.

There is a lack of public awareness about end of life issues, death and dying are not discussed and health services tend to focus on treatment and cure. This makes it difficult for individuals, carers and professionals to discuss death and dying, and professionals often find it difficult to identify when an individual is entering the last year of life. Therefore advance planning for end of life is not consistently undertaken so that patients preferred place of care, and care choices are not always recorded to inform last days of life care.

Patient's preferences for place of care are not well met. The majority of patients (60%) indicate that they would wish to be cared for and die at home, however only 18% of patients currently have this wish met².

The sharing of appropriate patient and carer information is poor across care agencies involved in providing end of life care leading to gaps and delays in services and inappropriate admissions to hospital. Patients and carers often find it difficult to secure appropriate help and support.

Better conversations, simple access points, coordination of care across services, choice, wider implementation of integrated care pathways with minimum standards, advance care planning, the implementation of good practice tools and support for families and carers at all stages can make a significant difference to care experienced at the end of life

1.2. Key recommendations for change from the Clinical Pathway Group

1.2.1. Culture shift in society.

Social Marketing Campaign

There is a prevailing "live for ever" mindset amongst society at large and amongst the majority of health and social care professionals, which works against the normality of death and dying, and therefore hinders advance planning for end of life and gets in the way of a good death in the place where patients choose to die.

¹ Healthcare Commission "spotlight on complaints, A report on second stage complaints about the NHS in England 2007"

² Office for National Statistics, Mortality Statistics 2004

Significant work needs to be undertaken to challenge this through the use of social marketing techniques, public service broadcasting, education, and more visible dialogue and activity which breaks down taboos around death and dying, bearing in mind the cultural diversity that exists within our society.

1.2.2. End of life care needs to be seen as a core part of service planning and delivery

Operating framework, Inspection standards, and a few national targets

Insufficient focus is placed on End of Life (EoL) Care such that the experience of patients and carers is not of the consistently high standard it should be. EoL should be highlighted as a priority in the Operating Framework, and EoL care standards should form part of HCC and CSCI assessments. A range of targets should be set as part of the National Strategy, to help drive forward improvements.

1.2.3. Effective strategic Joint commissioning/contracting for the provision of End of Life services

Minimum standards and a common pathway

Driving up the quality and availability of appropriate EoL Care which is responsive to patient's needs and choices is a key Commissioner role. Commissioners to put in place clear commissioning frameworks based on national minimum standards to be delivered across all settings, with a consistent end of life care pathway across their area of responsibility which ensures the following

Starting the conversation, assessment and care planning, coordination and register, integrated service delivery, review, last days of life, care after death, support for carers.

This should be combined with local flexibility in relation to how the pathway and standards are best delivered to suit local circumstances.

1.2.4. Access to appropriate services

Use of commissioning to incentivise and improve access

Commissioners need to specify clearly what needs to be in place to deliver good quality end of life care to their populations. They need to ensure that there is sufficient spread of care services providers available to deliver this. This includes sufficient specialist Palliative care services (comprising full multi-professional teams as defined by NICE³), Hospice beds, services in hospitals and the community, and access to 24/7 nursing and support care, pharmacy services and equipment. Patients and carers should also have access to bereavement services, spiritual care and information.

³ *Improving supportive and palliative Care for Adults with Cancer* - NICE guidance 2004

1.2.5. Co-ordination of Care,

Single end of life service provider co-ordinator in each area, supported by high quality information management system

A single Care Co-ordinator is required at PCT level to co-ordinate End of Life Service Providers, with the authority to broker and assure care and support from a range of providers to patients and families

Every EoL patient and family should have access to an identified Key Worker, at GP Practice level.

Patients and families should also be able to access 24/7 support through a dedicated number

The district nurse would usually be identified as the Key worker, and PCTs should put in place a district nursing service delivery framework for end of life care which clearly specifies roles and responsibilities and facilitates close working with an identified GP for every EoL patient.

GPs, district nurses and hospital staff should have access to 24/7 Specialist Palliative Care advice.

Integrated communication systems between services is required with the effective use of IM&T, to support shared information and seamless care to ensure patient choices, DNR etc are known, shared and worked with.

1.2.6. Advance care planning

Real choice in place of care and death - Shift in place of dying from Hospital to home

This needs to be undertaken in all settings for all individuals with diseases which are acknowledged as being incurable and progressive, with the aim of seeing a significant shift in achieving patients preferred place of dying.

1.2.7. Workforce development -Mandatory Education and training on EoL,

Palliative care as everyone's business

Training and education on End of life should be part of core curricula, professional CPD and revalidation tailored for the range of workforces involved in providing services at the end of life. Key skills would include communication, palliative care and advance care planning. This will involve national work with the GMC, NMC, and Royal Colleges.

1.2.8. Research, audit, review and measurement of improvements in end of life care

Systematic Patient and carer driven review, and investment in research

There should be a few key measures set nationally as part of the EoL Care strategy and incorporated into assessment processes by the HCC and CSCI. Crucial to this is the collection of systematic feedback from Patients, Carers and families. Commissioners should also ensure effective audit processes are built into contracting processes. Research will be needed to assess the impact upon the quality of care of best practice.

1.2.9. Funding

Joint commissioning between health and social care and robust alliances with the third sector

Identified funding to support the development and provision of EoL care, from pooled budgets across Health and social services is required to enable joint commissioning and investment.

Clear partnership arrangements with Charities and other voluntary sector providers are required to ensure the balance of resource investment is appropriate across all areas.

1.3. Action to maintain momentum

- 1.3.1. It is important to maintain the momentum generated through this review, the CPG recognises that strong clinical and managerial partnership and leadership is needed. Change will only occur if clinicians are fully engaged and driving implementation, and patients and their families are involved and are at the centre of such changes.
- 1.3.2. PCTs need to use the information from their base line reviews along with the information in this report to inform their commissioning plans for 08/09, and work together across Yorkshire and the Humber to put in place a clear End of Life Commissioning framework to ensure the provision of consistently high quality end of life services where ever patients live.
- 1.3.3. PCTs should also develop a clear action plan to address the recommendations in this report which in the short term should,
- deliver the use of Liverpool Care Pathway in all nursing and residential homes, and as a matter of course throughout all hospitals, and roll out the use of Preferred Priorities of Care (PPC) and Gold Standards Framework (GSF) to level 4 across primary care.
 - ensure there is a single point of contact for Patients, carers and families to access help and support for end of life issues, and that every end of life patient has a Key Worker.
 - ensure Out of Hours services specifications address end of life requirements.
 - roll out the comprehensive use of end of life registers.
 - ensure the introduction of mandatory training and education on end of life issues in to continuing professional development for all staff involved in delivering end of life care
 - address any gaps in 24/7 access to district nursing services
- 1.3.4. The SHA should ensure robust mechanisms are in place to support the implementation of the National End of Life Care Strategy, and the recommendations contained within this report, including
- working with PCT Commissioners, Service Providers and Local Authorities to ensure appropriate Clinical and professional leadership, and engagement to sustain change.
 - Working with partners to develop meaningful ways of securing patient and carer feedback about end of life Care
 - working with partners at all levels to develop interventions and social marketing campaigns to change the nature of discussions in amongst NHS professionals and in society about death and dying
 - working with national bodies to develop national standards for application at local level and inclusion in HCC and CSCI assessments, and to develop core competencies for EoL training for inclusion in undergraduate and postgraduate education.

End of Life Clinical Pathway Group Report

2. Introduction

“Palliative care is everyone’s business, as part of good-quality general care, not just a specialist area of care associated with complex cases.”

- 2.1 This report from the End of life (EoL) Clinical Pathway Group sets out the themes from the discussions regarding the development of a good quality end of life clinical pathway.
- 2.2. With the development of a National End of Life Care Strategy by Professor Mike Richards the group has had access to supporting information, data and evidence developed by the Department of Health to support the work of Clinical Chairs and the Yorkshire and Humber NHS End of Life Clinical pathway group
- 2.3. The Clinical Pathway Group (Membership attached at appendix 6) met on four occasions on the 18th and 30th October 2007, 13th November 2007 and 13th March 2008 and discussed the following key questions
 - What is meant by end of life Care?
 - What does the evidence, and our knowledge and expertise suggest are the key issues in end of life care generally and specific to Yorkshire and the Humber?
 - What does a good quality end of life care pathway look like, how would we measure success and what are the critical factors in realising this?
 - What are Patients and the Public saying about the end of life in Yorkshire and the Humber?
 - What are the key recommendations for change, and what might be the barriers to making change?
 - Where is the best practice in our Region that might help drive improvement?
- 2.4. This report attempts to capture the discussions of the Group and illustrate the background information which informed the debate.
- 2.5. This report is also informed by extensive feedback from local health and social care communities across Yorkshire and the Humber, and consultation with a wide group of stakeholders, patients, carers, general public, staff and partner organisations as part of the wider work on the NHS Next stage Review in Yorkshire and the Humber.
- 2.6. How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and a litmus test for health and social services⁴. The aim of this report is to generate action to ensure high quality care for all people approaching the end of life.
- 2.7. It challenges the NHS and Social care in Yorkshire and the Humber to extend the quality of care for the minority of patients (mainly cancer) who currently have access to excellent care to all people who are approaching end of life.

⁴ End of Life Care Strategy Working Paper, Department of Health, September 2007

3. The Definition of End of Life Care

- 3.1. The Group agreed that the scope of end of life care expressed in the DH working paper⁵ on end of life care should be adopted, this states that end of life care should encompass
- Adults with advanced, progressive, incurable illness (e.g. advanced cancer, heart failure, COPD, stroke, chronic neurological conditions, dementia).
 - Care given in all settings (e.g. home, acute hospital, ambulance, residential/care home, nursing home, hospice, community hospital, prison or other institution).
 - Care given in the last year(s) of life
 - Patients, carers and family members(including Bereavement care)
- 3.2. Also helpful in this context is the Operating Framework 2007-08: PCT baseline review of services for end of life care www.dh.gov.uk)
- The phase 'end of life' ends in death. Definition of its beginning is variable according to individual patient and professional perspectives. In some cases it may be the patient who first recognises its beginning. In other cases the principal factor may be the judgement of the health/social care professional/team responsible for the care of the patient. In all cases, subject to patient consent, the beginning is marked by a comprehensive holistic assessment of supportive and palliative care needs.
 - End of life care helps all those with 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 management of pain and other symptoms and provision of psychological, social, spiritual and practical support.
- 3.3. Whilst the Group believes the above definition is helpful they acknowledge that it can be difficult to identify when an individual may be approaching the end of life, and that this in itself is a significant challenge in ensuring quality care during end of life.
- 3.4. For life limiting disease there are wide and varying patterns of decline over varying timescales such that it is often underestimated when a patient is entering the end of life phase, especially for those with non-malignant illnesses.
- 3.5. However the majority of deaths occur following a period of chronic illness related to conditions such as heart disease, stroke, cancer, chronic respiratory disease, neurological disease and dementia, and most deaths occur in the over 65s. Whilst it is difficult to put timescales on this for many it maybe possible to consider end of life care beginning 6 to 12 months before death, and ending for family and carers 6 to 12 months after death (bereavement).
- 3.6. Exactly when end of life care begins will vary for each individual, but typically people become frailer, less mobile, and their symptoms and treatment needs may increase. There are a number of generic and disease specific prognostic indicators that can be triggers for Health and Social Care professionals to begin advance care planning for end of life for example

⁵ End of life Care Strategy Working Paper, Department of Health, September 2007.

- The intuitive question – “Would you be surprised if this patient were to die in the next 6 to 12 months?”
 - A patient with an advanced disease makes a choice for supportive care only not active treatment
 - Patient is considered by the attending care team to be in special need of supportive/palliative care
 - Eligibility for DS 1500 (attendance allowance and disability living allowance in the last 6 months of life)
- 3.7. With the development of the Hospice movement and Specialist Palliative Care the main focus of end of life care has been for patients with a cancer diagnosis. It is however likely those patients with long term conditions will have the same physical and holistic needs, and **it is therefore essential all patients with a long term condition have a palliative and end of life component to their pathway**. This is equally true of patients with dementia where numbers are rising and whose needs are complex.
- 3.8. With careful and effective identification, at least 90% of people who die could benefit from the application of the End of Life care pathway. For those who are suddenly taken ill, elements of the pathway should also be readily available to support them in the last days of life and support their families and carers in bereavement. (See appendix 1)
- 3.9. This report does not deal directly with Palliative care for children and young people; the Children’s Clinical Pathway Group is tasked with this. However some children have chronic life limiting illnesses which will require transition in to adult services.
- 3.10. This transition needs to be planned, managed and staged at the time appropriate to the individual and the illness, as a shift from family to young person centred care. To aid this we recommend
- as a trigger point at age 14 consideration should be given to transition and to when appropriate discussions should begin.
 - two key workers should be assigned one from Paediatrics and one from Adult services
 - Single assessments should be undertaken
 - Reciprocal services and funding should be identified in adult services
 - Dedicated young peoples services should be developed
 - Training should be provided for adult and paediatric providers

4. The Case for Change

Current Issues and Challenges in end of life care

- 4.1. The Group agreed with the observations set out in the DH Supporting Information, Data and evidence pack which highlights the following 12 issues
1. Lack of public and professional awareness and discussion about death and dying across society as a whole
 2. Low priority given to end of life care within the NHS and social care both commissioners and providers.
 3. Lack of recognition in identifying people who may be approaching the end of life and initiating discussions about people’s preferences for end of life care
 4. Inadequate assessment and review of people’s needs and preferences.

5. Poor coordination of care across the sectors, which leads to delays in setting up packages of care to meet people's needs
6. Suboptimal delivery of care in hospitals, care homes and the community
7. Poor care in the last days of life
8. Problems with verification and certification of death, viewing the body at mortuary and with return of the person's property to their family.
9. Inadequate support for carers
10. Inadequate education and training and support
11. The lack of robust measures to assess the quality and effectiveness of care
12. Inequalities in access to and provision of end of life care within a diverse population

4.2. In particular the Group emphasised the need for Commissioners and Providers to take on and resolve the following challenges of

- **Ensuring that End of Life Care is seen as a core issue for both Commissioners and Providers**, not an optional extra or an area to be forgotten when other pressures and priorities dominate
- **Ensuring good quality general nursing and medical care is provided in all settings.**
- **Providing patients with choice so that place of care and death can be moved to home including care homes**, whilst continuing to maintain the focus in Hospital settings on improving EoL care.
- **Developing a clear understanding of the real costs** of shifting place of death
- **Addressing the barrier associated with the effective transfer of information** across service and organizational boundaries which can lead to inappropriate decisions being made about care provision. The need for N3 connectivity for hospices and access to shared information for all involved in EoL care, and maximization of effective information management and technology(IMT)
- **Ensuring timely and appropriate discussions of and recording of advance care planning (ACP) and do not attempt resuscitation decisions (DNAR)**, outlining when and how patients and families should be involved in decisions, and enabling the transfer of DNAR documents between services.
- **Effective co-ordination across service providers** both NHS and independent sector, in primary, secondary care settings and with integrated social care
- **Addressing the difficulties Health care professionals experience in supporting patients at end of life** in secondary care settings where the focus is on saving lives, and cure, when palliative care and support is required to enable patients to have a good death
- **Facilitating the difficult conversation** about dying, preferences, advance directives etc, who has it, when and is the workforce sufficiently skilled to handle this.
- **The reluctance of professionals** to acknowledge that individuals are dying which can delay effective care planning for end of life
- **Availability** of specialist community palliative care and Hospice Provision.
- **The capacity and structure of primary care services** such as access to 24 hour District Nursing services, and the difficulties of seamless provision from Health to social care.
- **Providing access to good supportive bereavement and psychological services**, covering all end of life situations.
- **Responding to the spiritual and religious needs** of diverse populations
- **Rapid access to additional equipment** to support individuals' choice to remain at home.
- **Actively facilitating safe patient discharge** to home in a timely manner at the end stage of life – last 24/48 hours.

- 4.3. The Group also identified the need to ensure that palliative care is seen as everyone's business, as part of good quality general care, not just a specialist area of care associated with complex cases.

What the evidence tells us

Place of Death

- 4.4. Figures taken from the Office for National Statistics, Mortality Statistics 2004 reveal significant variation across regions in England about place of death (see appendix 1)
- 4.5. Most people die in Hospitals. On average in England 58% of patients die in Hospital, in Yorkshire and Humber 56% of patients die in hospital.
- 4.6. Approximately 18% of patients die in Care Homes in England, in Yorkshire and the Humber 19% of Patients die in Care Homes.
- 4.7. Just over 4% of Patients in England die in Hospices, the figure in Yorkshire and the Humber is approximately 5%
- 4.8. On average in England around 18% of Patients die at Home, this is approximately the same in Yorkshire and the Humber
- 4.9. Figures from the Yorkshire and Humber Public Health Observatory illustrates there is significant variation across Yorkshire and the Humber with regard to place of dying, possibly reflected in the nature of localities, urban, rural and metropolitan and the distribution of and access to services. (See appendix 1)

Preferred Place of death

- 4.10. Figures from I.J Higginson, "Priorities and preferences for end of life care in England, Wales and Scotland", National Council for Hospice and Specialist Palliative Care Services, 2002, and from the Office for National Statistics, Mortality Statistics 2004 indicate, although there is some regional variation the majority of people would prefer to die in their own homes. (See Appendix 1)
- 4.11. In Yorkshire and the Humber almost 60% of patients indicate a preference for dying at home.
- 4.12. 24% of Patients in Yorkshire and the Humber would prefer to die in a hospice.
- 4.13. In Yorkshire and the Humber around 40% of patients do not have their preferences met to die at home, and a further 19% do not have their preferences met to die in a Hospice setting.
- 4.14. Approximately 20% of patients in Yorkshire and Humber would prefer to die in a Hospital, Care Home or settings other than Home or Hospice, however approximately 70% die in such settings.
- 4.15. These statistics reveal how far we have to go to get anywhere near meeting patient preferences for place of dying, and highlight further a number of key issues about
- Who is having, when are they having and how are they having "the conversation" with Patients, carers and family regarding preferences and choices at end of life?

- How are such choices recorded, reviewed and communicated to the variety of service providers who may be involved in the care of patients at end of life?
- How robust are care co-ordination processes so that care at end of life is given in the appropriate setting?
- Are the current patterns of service sufficiently robust to provide appropriate care at end of life?

5. Messages from Patients and the Public in Yorkshire and the Humber

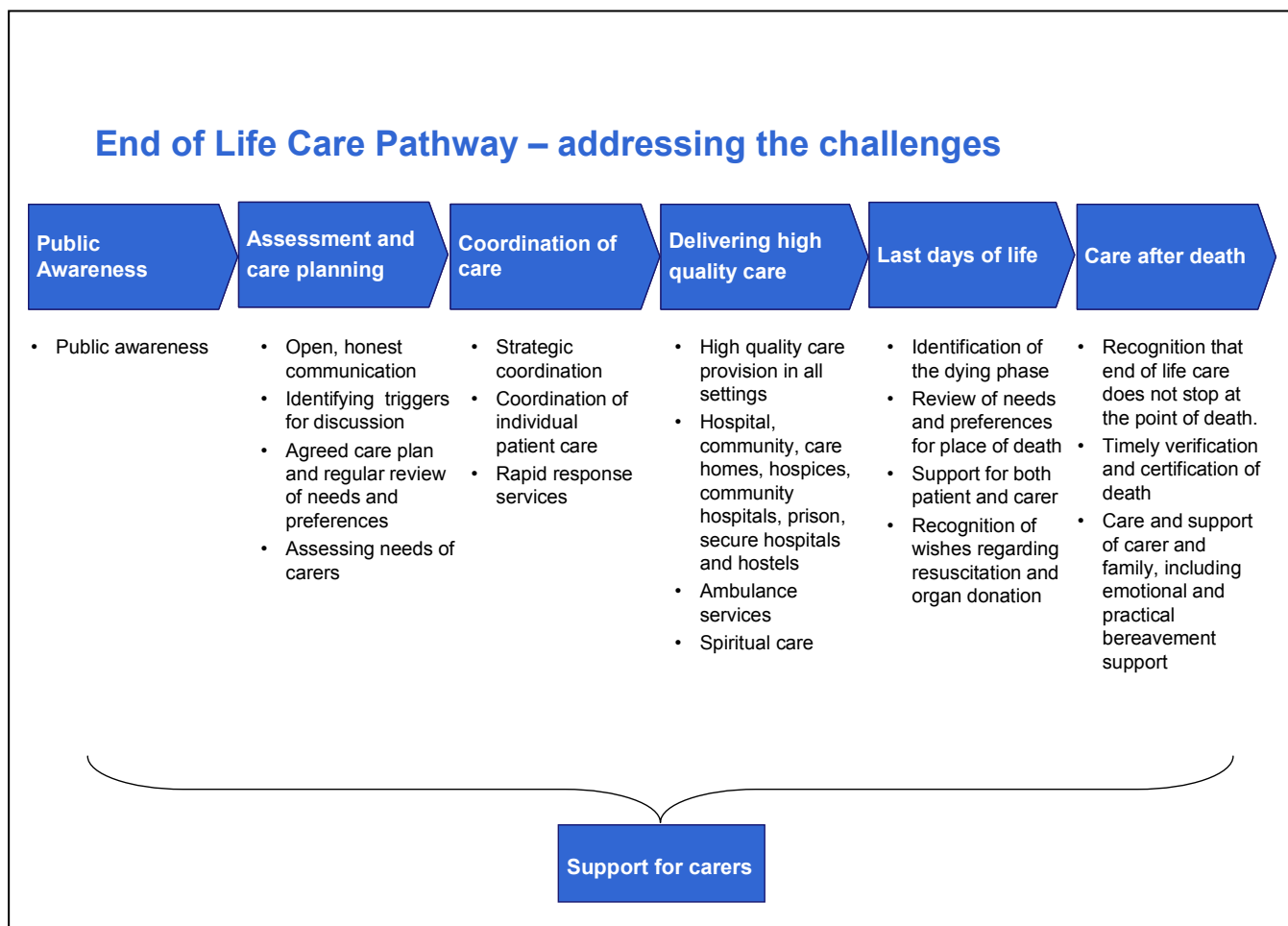
- 5.1. The CPG was careful to consider the outcomes from a range of consultation events which took place between September and the end of January. This included two Public focus groups specifically on end of life care, the outcomes from the Yorkshire Cancer Network User Partnership Group End of Life event and information from the two broader deliberative events on the Next Stage Review held in September and January.
- 5.2. The key messages from these consultation exercises are set out in appendix 5 and have helped to shape this report and the recommendations it contains.
- 5.3. The experiences of patients, families, carers and the public resonate clearly with Professional and Clinical Staffs assessment of what needs to be put right to provide quality end of life care.
- 5.4. In particular they were concerned about poor communications between services, variable care for patients at the end of life, difficulties because patients are not identified as entering the end of life, so that they and their families are not treated appropriately and prepared for this, patchy bereavement support, and a lack of confidence that appropriate and available support will be available to enable patients to have real choice about their place of care and death.
- 5.5. Their recognition of what good looks like is also strikingly similar, based often upon experience and knowledge of the care they or someone they know has received. They were very supportive of the idea of a single care co-ordinator and point of contact for end of life care, improvements in our services, better access to equipment at home, training for staff to recognise and deal appropriately with patients and their families receiving end of life care, and consistently available and appropriate support to make death at home a realistic choice.
- 5.6. The message is that the aspiration for high quality end of life care is ambitious but realistic, we already have pockets of excellence and the work ahead is to ensure consistently high quality care for all at the end of life, providing individuals and families with real choice about preferred place of care and dying, as one member of the public puts it

"This is the most important choice that a person will ever make and this is why it is so important that their choice is respected."

- 5.7. The following sections of this report set out a vision of high quality care for end of life and recommendations to overcome the barriers that stand in the way of realising that vision

6. What does a good quality end of life care pathway look like?

- 6.1. The Group agreed with the model end of life care pathway set out on page 18 of the DH End of Life – Supporting Information, data and evidence for Clinical Chairs



- 6.2. This sets out the key elements which need to be in place to ensure good quality care at end of life. The Group worked on this Pathway taking time to describe and expand upon each stage what good looks like, identifying how we could measure success, and considering the critical factors crucial to implementing such a pathway. This work is detailed in Appendix 2, and could be used as ***the basis of a commissioning specification for end of life care.***
- 6.3. Two broad areas which set the context within which end of life care is delivered were identified for high level attention
- 6.4. The first of these is ***the need to talk more about death and dying in society as a whole, as a natural process so that end of life care can be planned more effectively.*** There has been a significant shift in society over the last hundred years in 1900 85% of people died in their own homes, people were used to seeing and dealing with the end of life, to the current position where

most people, 70% die in hospital. Only 34% of the general Public reported⁶ that they had discussed their wishes for how they would like to die

- 6.5. The second of these is ***the need for good quality training and development around end of life issues to be made available and provided to staff in all sectors***. There is a perception amongst health professionals that death represents failure, this can reinforce public and societies view in general expectations of health care. 4 out of 5 people say they wish to be told when they are dying⁷ but it is not clear how many are. Professionals find open and honest conversation difficult, and need time, confidence, and skills to do this.
- 6.6 Further key Issues which emerged focussed upon getting it right at health and social community level
- The need for strong sector wide commissioning for EoL which encompasses each and every element of the pathway
 - The need for Gold Standards Framework (GSF)/Liverpool Care Pathway (LCP)/Preferred Priorities of Care (PPC) or equivalents to be adopted and implemented fully across all sectors where EoL care is provided.
 - The need for effective reliable cross sector information sharing and communication regarding patients on end of life registers, their choices, and care plan, and the IM&T to support this.
 - The need for a single point of access and care management co-ordination for EoL patients and their carers and families-one telephone number
 - The need for access to good quality services 24/7 e.g. 24 hour district nursing services
 - The need for effective audit and review processes to ensure the implementation of quality care standards, and to systematically collect feedback from patients, carers and families
 - The need for specialist palliative care services to be provided in all settings in a timely fashion for those patients with the most complex needs.
 - The need for access to good quality bereavement support, including for sudden and violent death, with appropriate referral and access to psychological therapies if required
- 6.7. On this latter point of care after death, ***bereavement care is vitally important*** to support families and carers to come to terms with the death of a loved one. At the present time a large proportion of this care is provided by the voluntary sector, not within main stream service provision, not equitably available and without identified funding. This needs to be addressed.

Implementation of good Practice

- 6.8. The Group is already aware of many areas of excellence and good practice
- Many Voluntary Hospices have been beacons of excellence in end of life care since the foundation of the modern hospice movement

⁶ ICM research for Endemol UK, Bereaved Carers, England, Scotland and Wales 2005

⁷ ICM /Endemol/ BBC Poll, General Public, England, Scotland and Wales 2005

- The Delivering Choice Programme run by Marie Curie Cancer Care has highlighted the benefits of taking a whole system approach, a programme is currently running in Leeds
- There are many good practice initiatives and examples from across the Yorkshire and Humber region which have been gathered as part of the process of developing this report and which are captured in Appendix 3
- 2004 – 2007 End of life Care Programme has contributed to the roll out of programmes such as Gold Standards Framework, Liverpool Care Pathway, and Preferred Priorities for Care tool.

6.9. The Group concluded that implementing known good practice as illustrated above and in particular recognised protocols which have been recommended by NICE⁸ as below can significantly improve end of life care.

1. **The Gold standards framework (GSF)** – has significantly improved care for people with advanced, progressive incurable illness in the primary care setting, enabling GPs to identify patients for inclusion on the palliative care register (which attracts QOF points). It also helps primary care teams to work together in ensuring continuity of care, setting in place advance care planning, symptom control and patient, carer and staff support.
2. **The Liverpool Care Pathway (LCP)** - This framework enables clinical staff to deliver high quality care as death approaches, providing guidance on comfort measures, anticipatory prescribing, psychological, spiritual care and family support. It is mainly used by staff in hospitals and hospices but is increasingly being adopted for use in other care settings.
3. **Preferred Priorities for Care (PPC)** -This is a process for advance care planning. It is a patient held document designed to support patient choice, ensuring that the information is shared with all health and social care professionals involved in their care. The explicit recording of preferences and wishes of patient and carer helps to direct the planning and continuity of care and service delivery by the multidisciplinary team and other agencies.

6.10. The Group considered that the roll out and effective implementation of the key elements of these three tools in Yorkshire and the Humber would greatly enhance the quality of care for patients at the end of life. Data gathered from the NHS EOLC Programme and CSCI indicate the following.

1. The uptake of GSF – In Yorkshire and the Humber approximately 40% of GP Practices, and less than 2% of Care Homes.
2. The uptake of LCP – In Yorkshire and the Humber approximately 90% of Acute Trusts use LCP in some wards, but coverage is patchy, 21% of GP Practices, 3% of Care Homes and 41% of Community Hospitals
3. The uptake of PPC – In Yorkshire and the Humber approximately 11% of GP Practices, and 0.2% of Care Homes
4. Uptake/coverage of one or more of the tools – In Yorkshire and the Humber for GP Practices this averages approximately 50%, the average for England is 70%. For Care Homes just over 4%, the average for England being just over 6%. For Hospices c38%, the average for England being 70%. For Community Hospitals around 40% which is the average for England.

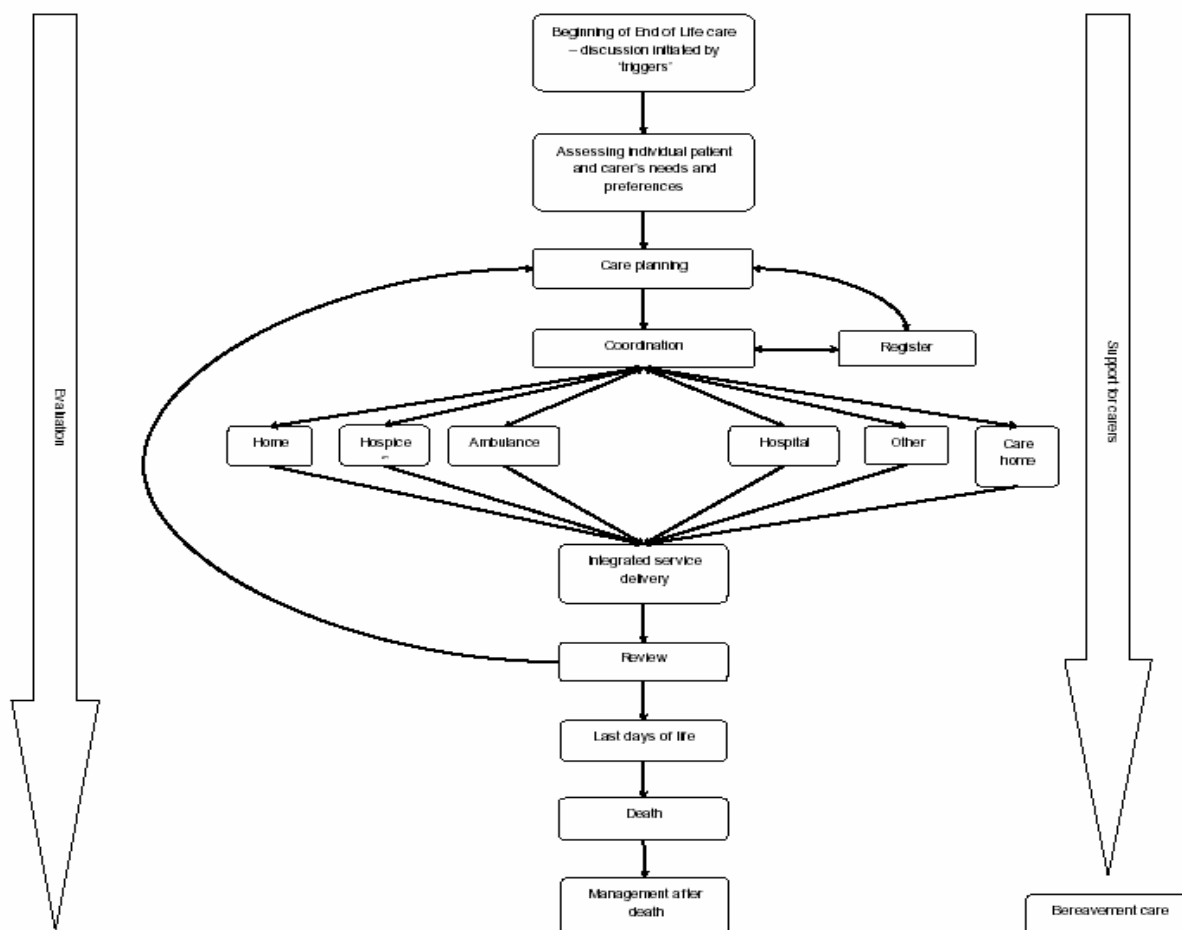
⁸ *Improving supportive and palliative Care for Adults with Cancer* - NICE guidance 2004

6.11. The Group recommended

- That there should be Universal uptake by all providers of EoL care of these tools as a way of significantly improving end of life care for many patients and families, full implementation of GSF to level 4 should be an immediate aim.
- That these tools should be effectively supported by education, training and active implementation to make them successful. Funding from the SHA and PCTs to deliver this will be required.
- That there should be effective national and regional audit of these tools and the continuing development of a research and evidence base to assess impact on the quality of care.
- That the HCC and CSCI should look at compliance with such tools as part of their assessment and inspection regimes

7. Adopting a high quality end of life Care pathway

- 7.1. The Clinical Pathway Group emphasized the need to ensure universal adoption of a consistent end of life care pathway as illustrated in the London End of Life Clinical Working Group Report.



7.2. In adopting this model the Group identified the following

- Advance care plan preferences need to be recorded and shared between all current and prospective care providers to guide future care management, and these need to be regularly reviewed, preferred place of care tool should be used and discussions documented on DNAR, and organ/tissue donation and cultural and religious needs.
- Coordinated care is crucial, including managed networks of providers in each PCT, EoL registers, a single point of access for EoL care, for referral, assessment, provision, triage, sign posting, rapid response, supported by a 24 hour helpline (888). Every EoL patient should have a Key worker, and standard patient information and documentation should be shared across services
- Key to delivering high quality care, is the use of GSF, LCP, PPC in all settings, 24 hour District Nursing services or alternative arrangements for palliative care, ready access to pharmacy and drugs services, access to equipment within 24hours, access to psychological support services (see NICE guidance⁹), and religious and spiritual support, culturally sensitive services, access to social services support benefits
- In the last days of life, LCP should be adopted for all dying patients and ACP implemented, there should be access to 24/7 rapid response services and specialist palliative care

7.3. The Group highlighted that getting the following four elements in place was central to ensuring the above

- The appropriate timing of the conversation about end of life care, to be undertaken preferably at an early enough stage to ensure that Patient preferences are recorded and communicated to and available to all services involved in providing care.
- The recording and communication, and regular review of the patient and carers care plan, inclusion on the end of life register.
- A single named contact/co-ordinator of care in General Practice for patients entering end of life, responsible for ensuring access to services and support, communication across services and advice and support
- Effective audit and evaluation to assure consistent quality of care in the last days of life in whatever setting an individual is being cared for.

7.4. The Group also identified the need for Commissioners and Service providers to give careful considerations to the needs of the diverse range of communities they serve when planning and delivering end of life care. This is relevant in all PCT areas but is particularly important in areas where BME populations are significant in number and/or growing rapidly.

7.5. The Group also suggested that it was crucial to ensure that progress to realising this model was measured at all levels. A number of key performance indicators will be recommended by the National Strategy, these should be adopted by all those involved in End of Life care. Minimally the SHA should be looking at **changes in place of death, changes in the number of deaths within 24 hours of hospital admission**, and **the uptake and implementation of GSF, LCP, PPC**

⁹ National Institute for Clinical Excellence *Guidance on Cancer services, improving supportive and palliative care for adults with cancer* 2004

8. Barriers to delivering a high quality end of life Care pathway

- 8.1. Identification of patients entering the end of life, is a significant challenge, this is hampered by society's views in general about death and dying, and the difficulties which patients, families and clinicians have in planning for a good death. Some professionals still see death as failure and this can reinforce this challenge
- 8.2. A lack of clear joined up action to secure good end of life care, what needs to be available in the pattern of care and support and equipment services to patients and families.
- 8.3. Competing pressures for time and funding tend to drive out a focus upon end of life care for commissioners and mainstream providers. This combined with the complex mix of funding arrangements and care givers from health, social care, independent and private sectors makes EoL care vulnerable especially when resources are tight.
- 8.4. The plurality of services can cause confusion amongst patients, carers and staff, it creates challenges for ensuring consistently high standards, and it creates problems in meeting patients and carer needs of having the right person with the right skills in the right place at the right time. Patients can often fall between services where there is lack of agreement about who provides what.
- 8.5. Language, terminology and differing expectations across the different sectors can also play its part in reducing quality of care, this is magnified where there is lack of coordination and communication, a lack of shared understanding of the EoL pathway, and a lack of acceptance that good palliative care is everyone's business.
- 8.6. Often staff do not possess the skills or do not recognise their responsibility for providing palliative care and end of life care, professional education and training at present does not provide effective emphasis on the care of the dying.
- 8.7. The availability of services, and the pattern and distribution of such services can appear inconsistent, such that patients in certain areas have access to, for example, hospice care while others don't. This seems dependent upon local funding decisions, and priorities, and geographic considerations rather than any coherent strategic assessment.
- 8.8. A lack of protected funding to support end of life care, a reliance upon charitable organizations and voluntary and community services which whilst possessing relevant skills and expertise are often financially vulnerable

9. Some emerging pre-requisites for success

- 9.1. The above are recurring themes which are reflected through out this report and the recommendations set out in section 10.
- 9.2. The Group felt that a clear consistent pathway for EoL care, combined with a number of core national quality standards which could be assessed by the Health Care Commission is required. But that this should be combined with local flexibility in relation to how the pathway and standards are best delivered to suit local circumstances.

- 9.3. To support such an approach the Clinical Pathway Group agreed the following were prerequisites
1. Identified funding to support the provision of EoL care, from pooled budgets across Health and social services to be jointly invested.
 2. Clear partnership arrangements with Charities and other voluntary sector providers to ensure appropriate support across all areas
 3. A workforce adequate in numbers in all settings to plan and implement care, service provision driven by generalists with access to specialist advice and support, working with a single record and single point of access.
 4. Patients and carers who have access to good quality written and verbal information who are confident that they will be supported in their choices, who know who to contact and who will receive a prompt response to access good physical, psychosocial and spiritual care.
 5. Effective quality measures based upon a sensible range of key performance indicators, such as Patient and Carer satisfaction, preferred place of care, hospital admissions, place of death, registers, out-of-hours calls, and complaints.
 6. Good quality research into the impact of the implementation of good practice tools into the quality of care and experience of dying patients and their carers
 7. Effective recognition and support for relatives who provide the main carer roles for individuals requiring EoL care, not only from Health and Social services, but from employers and others

10. Recommendations for Change

10.1. *Culture shift in society.*

- 10.1.1. Major work needs to be undertaken to effect a change where the general public and health and social care professionals recognise the normality of death and dying, and where advance planning for end of life is accepted. This is a major task and needs to be seen in the context of how people relate to society as a whole and not just health care. It relates to physical, mental, social and spiritual wellbeing.
- 10.1.2. This could be helped by action both nationally, regionally and locally through effective social marketing activities, including for example, the use of multimedia e.g. Esther Rantzen programme repeated on prime time TV, Radio, more BBC involvement, more information on wills, the Mental Capacity Act, advance decisions as part of public service broadcasting, Hospice, Crematorium open days, open days for the Public organised by Funeral directors. Positive publicity about advances in end of life care would also be helpful.
- 10.1.3. Other key activities could include, incorporation in to school curricula – PHSE lessons by teachers not visitors, part of professional training ,extension of the use of Macmillan tools, wider dissemination of Marie Curie booklet on end of life care, incorporating elements of advanced planning Expert Patient Programme

10.2. *End of life care needs to be seen as a core part of service planning and delivery*

10.2.1. EoL Care should be highlighted as a priority in the Operating Framework

10.2.2. EoL care standards should form part of HCC and CSCI assessments

10.2.3. A range of targets should be set nationally for EoL care as part of the National Strategy, e.g. GSF, LPC, PPC etc to help drive forward improvements with regular audits performed and published in the public domain.

10.3. *Effective strategic Joint commissioning/contracting for the provision of End of Life services*

10.3.1. Commissioners need to put in place clear commissioning frameworks, underpinned by robust local delivery strategies with strong service level agreements, effective contract monitoring, and effective quality indicators to ensure and assure provision

10.3.2. Commissioners should commission for consistently applied minimum standards for EoL across all settings, Hospitals, Community and Primary care, Care Homes, Hospices etc and require the roll out of audited LCP, PPC, GSF.

10.3.3. Commissioners should commission for the consistent adoption of a common End of Life care pathway as set out below with clarity of terminology, consistent use of language, and understanding of who makes the decisions at each point, and what the trigger points and mechanisms might be for moving between the phases

- Starting the conversation
- Assessment and care planning
- Coordination and register
- Integrated service delivery
- Review
- Last days of life
- Care after death
 - Support for carers

10.3.4. PCT's must drive up the quality of Provision in primary care – through both Commissioning and delivery

10.3.5. Managed clinical networks of specialist providers need to be created, to protect and support the implementation of EoL Care strategy

10.4. *Access to appropriate services*

10.4.1. Commissioners need to specify clearly what needs to be in place to deliver good quality end of life care to their populations, and work to ensure that there is sufficient spread of care services providers available to deliver this

10.4.2. Commissioners should pay special attention to ensure there is sufficient access to specialist palliative care services as defined by NICE¹⁰, Hospice beds, services in hospitals and community, access to 24/7 pharmacy services and equipment, so that patients can exercise real choice about their preferred place of care. They should also ensure Patients and Carers have access to spiritual care, bereavement and information services.

10.4.3. ***Urgent attention needs to be paid to Out of Hours services to ensure that a co-ordinated joined up approach to end of life care is maintained 24/7***

10.5. Co-ordination of Care,

10.5.1. A single Care Co-ordinator is required to co-ordinate End of Life Service Providers across a PCT area, with the authority to broker and assure care and support to patients and families

10.5.2. Patients and families should be able to access 24/7 advice and support through a dedicated telephone number.

10.5.3. Every EoL patient and family should have access to an identified key Worker, care co-ordinator at GP Practice level.

10.5.4. GPs, district nurses and hospital and social services staff should have access to 24/7 Specialist Palliative Care advice.

10.5.4. Health and social care need to work together to ensure integrated multi-agency approach, ensuring clarity regarding the Key Worker/Care Coordinator role. The district nurse would usually be identified as the Key worker, and PCTs should put in place a district nursing service delivery framework for end of life care which clearly specifies roles and responsibilities and facilitates close working with an identified GP for every EoL patient.

10.5.5. Integrated communication systems between services is required with the effective use of IM&T, to support shared information and seamless care to ensure patient choices, DNAR etc are known, shared and worked with, e.g. letters in and out of hospital

10.6. Advance care planning

10.6.1. This needs to be undertaken for all individuals with diseases which are acknowledged as being incurable and progressive.

10.6.2. The aim should be to see a significant shift in achieving patients preferred place of dying.

10.7. Workforce development -Mandatory Education and training on EoL,

10.7.1. Training and education on End of life should be part of core curricula, professional CPD and revalidation tailored for the range of workforces involved in providing services at the end of life, Key skills would including communication, palliative care and advance planning.

¹⁰ *Improving supportive and palliative Care for Adults with Cancer* - NICE guidance 2004

10.8. *Research, audit, review and measurement of improvements in end of life care,*

- 10.8.1. Further work is required to develop a range of good measures to assess improvement in end of life care.
- 10.8.2. There should be a few key measures set nationally as part of the EoL Care strategy and incorporated into assessment processes by the HCC and CSCI. Commissioners should also ensure effective audit processes are built into contracting processes
- 10.8.3. Crucial to this is the collection of systematic feedback from Patients, Carers and families.
- 10.8.4. Research is required to assess the impact upon the quality of care of a number of best practice EoL care tools

10.9. *Funding*

- 10.9.1. Identified funding to support the development and provision of EoL care, from pooled budgets across Health and social services is required to enable joint commissioning and investment.
- 10.9.2. Further work is required to ensure that financial systems and incentives are aligned to support the delivery of the end of life pathway.
- 10.9.3. Clear partnership arrangements with Charities and other voluntary sector providers is required to ensure the balance of resource investment is appropriate to ensure equity of good quality support across all areas

11. Looking forward

- 11.1. The group considered the future, what would society and care be like in 2020 as a way of future testing our recommendations. Information from the Yorkshire Public Health Observatory, attached at appendix 4 suggests the following
 - A population which is older, living longer and with more significant complex illness
 - A decreasing number of economically active younger people to support the growing grey population
 - Increasing difference between urban and rural settings with significantly fewer numbers of young people and children in rural settings
 - Large variations in population make up in terms of ethnicity, across PCT areas
- 11.2. This confirms that the pattern of services available to support good end of life care will need to be tailored to local population needs, and the mix of care givers/providers will also be different according to locality. It also confirms that the importance of end of life care is increasing and that actions proposed in this report to address existing challenges are valid for the future
- 11.3. In the immediate future it is crucial that system wide action is required involving the SHA, PCTs, Local Authorities and Providers to

- Ensure the universal implementation of the three national end of life programme tools – PPC, GSF, LPC. In particular training and support to deliver LCP in nursing and residential homes, and delivering LCP coverage in all hospitals.
- Ensure in each area that there is a single point of contact for Patients, carers and families to access help and support for end of life issues.
- The introduction of mandatory training and education on end of life issues in to continuing professional development for all staff involved in delivering end of life care.
- 24/7 access to district nursing services.

11.4. PCTs should also use the information from their base line reviews required in the operating framework 2007/8 along with the information in this report to inform their commissioning plans for 08/09.

11.5. Further work is required to develop national standards for application at local level and inclusion in HCC and CSCI assessments, and to develop meaningful ways of securing patient and carer feedback

11.6 In the medium term it is crucial that PCT Commissioners drive forward investment in

- Integrated and innovative information technology to support integrated care delivery
- The provision of 24/7 home care services.
- Workforce planning to ensure sufficient specialist palliative care professionals are available to provide advice and care for non cancer patients, and to increase input into Care Homes and Community Hospitals.
- Work with Local Authorities to develop joint commissioning and investment strategies for end of life care based on the pathway in this report.
- Build robust relationships with the Voluntary and Charitable sector to develop the capacity to deliver the comprehensive support envisaged in this report to people at the end of life.
- Raising the awareness in the public of social responsibility, and encourage more people to volunteer to help and support the delivery of good EoL care

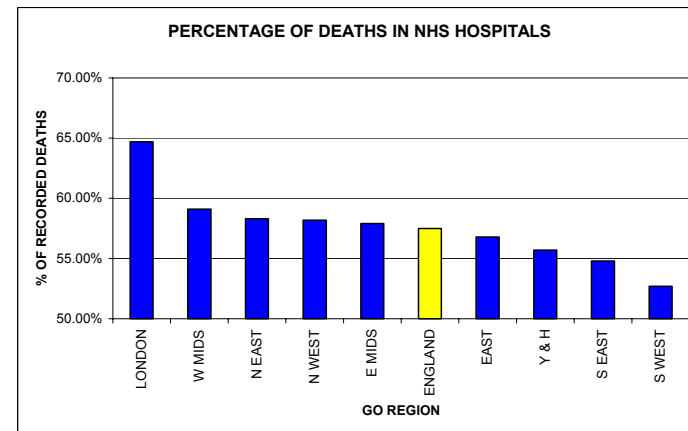
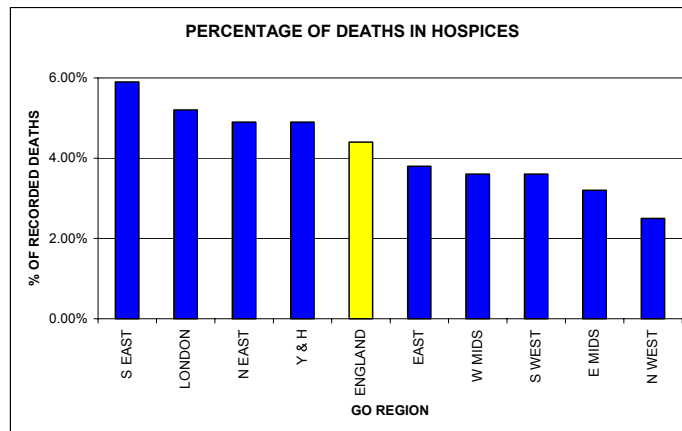
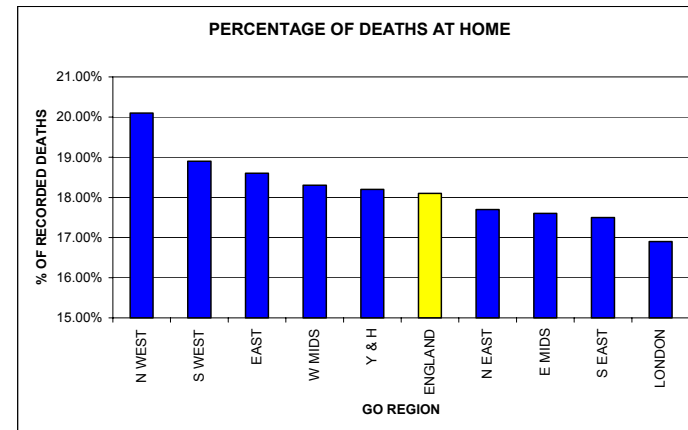
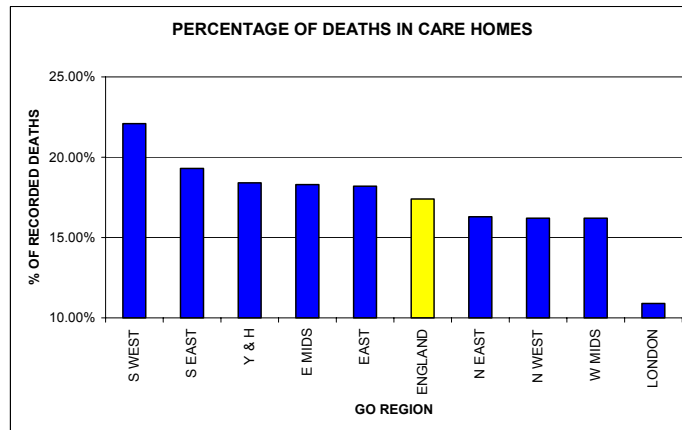
12. Conclusion

One of the only certainties of life is death, and high quality EoL care should be a priority for health and social care commissioners and providers. The present level of EoL care has been identified as patchy and uncoordinated with the main focus around patients with a diagnosis of cancer.

This report has identified that utilising a coordinated pathway of care approach, the wider adoption and implementation of the EoL tools, (GSF/LCP/PPC), and the commissioning and provision of integrated 24 hour services across the health, social and voluntary sector EoL care can be significantly improved.

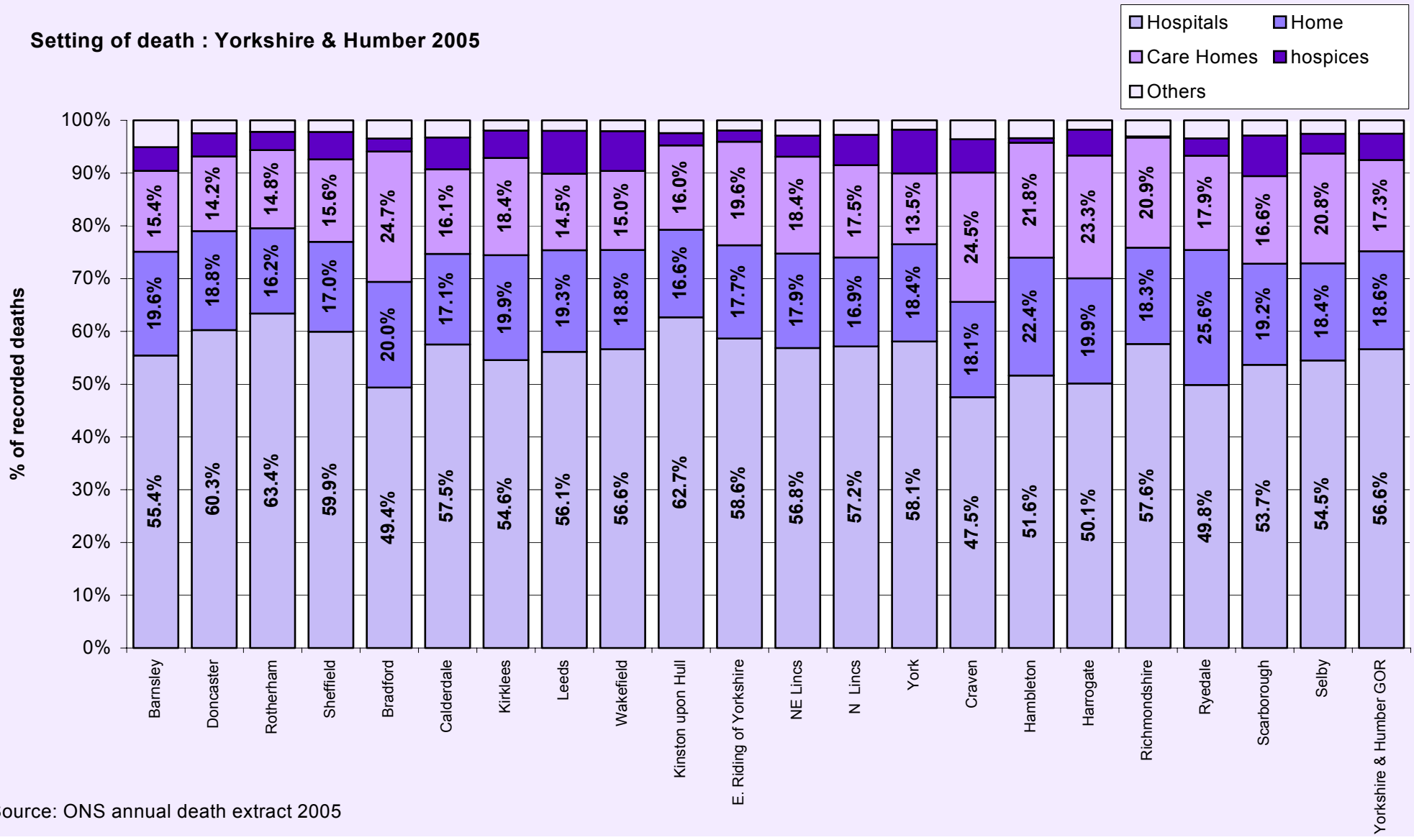
The development and implementation of national standards for EoL care has also been identified as an appropriate driver for the required changes in service provision.

There is some variation over setting of death across the English regions, especially for death in care homes



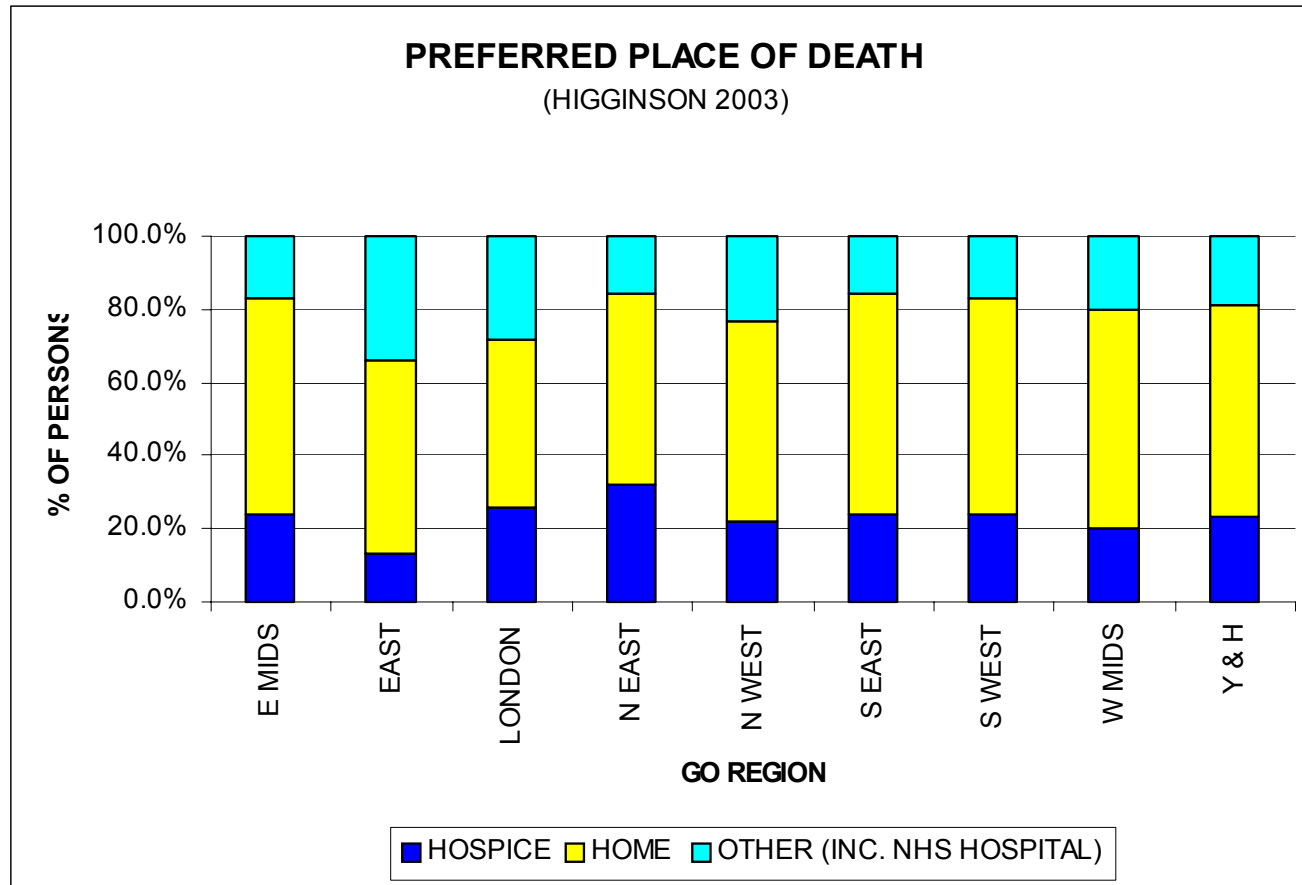
Source: Adapted from Table 19 in: Office for National Statistics, Mortality Statistics 2004

Setting of death : Yorkshire & Humber 2005



Source: ONS annual death extract 2005

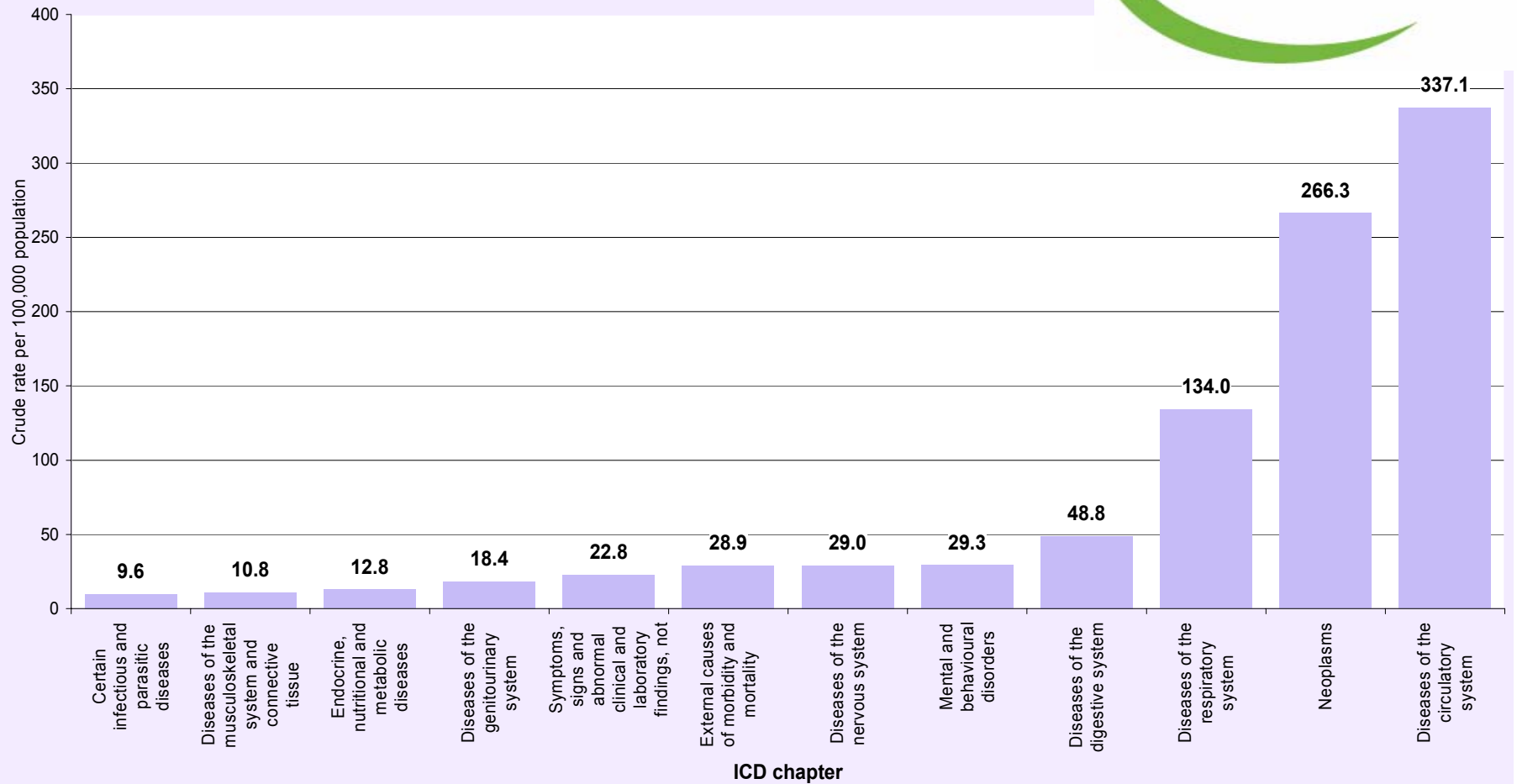
The majority of people would prefer to die in their own home



Source:
National

I.J. Higginson, "Priorities and preferences for end of life care in England, Wales and Scotland",
Council for Hospice and Specialist Palliative Care Services, 2002

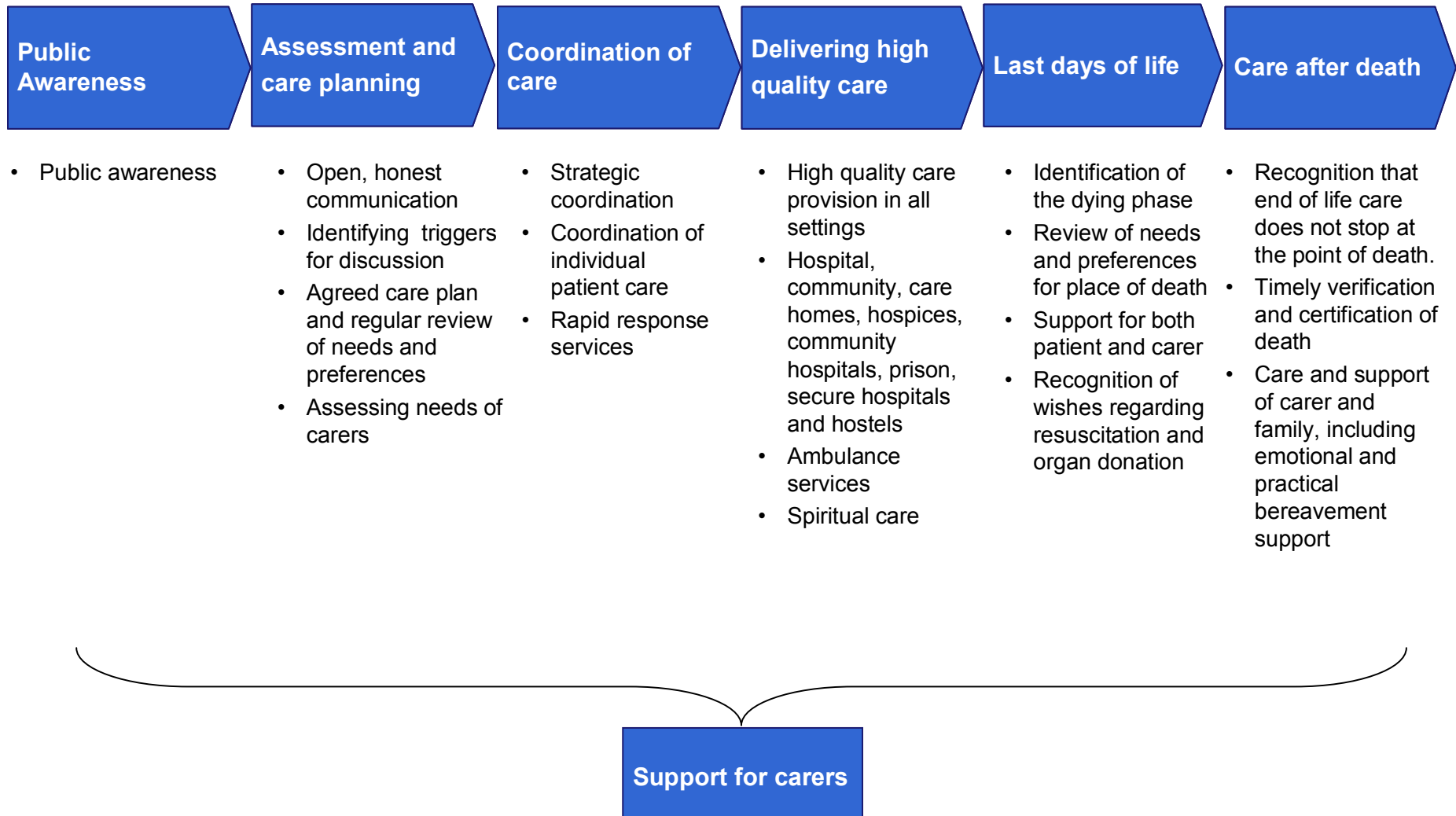
Crude Mortality rate by ICD chapter within the Yorkshire & Humber GOR, 2006



Source: ONS Births and Deaths Extract for PHOs, crown copyright

What good looks like

End of Life Care Pathway – addressing the challenges



Public Awareness

What good looks like	Success Measures	Factors critical to success
<ul style="list-style-type: none"> • Public awareness about end of life good • There is open discussion about death and dying it is seen as a normal process, not a taboo subject 	<ul style="list-style-type: none"> • Increasing numbers of patients and carers using PPC, LCP and advanced care planning • Increasing numbers of patients given choice regarding place of death, and achieving preferred place of death • Increasing % advance decisions to refuse treatment set out in clinical primary/secondary care notes • Review regular PPC involving family/carer • Plans in place such as wills, funeral arrangements, organ donation • Uptake of designated services • Market research in to Public attitudes to death and dying 	<ul style="list-style-type: none"> • PCTs and LAs promote awareness and develop process, programmes to do this with variety of partners • Life cycle and loss included in school curriculum – part of PHSE, plus include the family not just children • Ethnic liaison officers – cultural input • Engagement of Media in managing and talking about end of life • Awareness of choice • A ‘have to’ approach EOL – supporting a cultural shift, access, and availability to advise, support and service • More training in EOL issues for social/health workers • Educate Solicitors to address EoL planning as part of will making, power of attorney etc • Incorporate into Expert patient programmes

Assessment and Care Planning

What good looks like	Success Measures	Factors critical to success
<ul style="list-style-type: none"> • Normalised discussion/assessment of EOL care issues, open communication between professionals, patients and carers early in the pathway • Mandatory training and development as part of skills framework, set of core competencies which ensures professionals to enable people to die as well as possible • Clear, quality information elicited at diagnosis and discussion about the care which the individual wishes to receive. • Everyone to have a clear care plan setting out needs, recorded and reviewed regularly • Information shared in a timely and appropriate manner across services • MDT principles in place across services • Gold standard framework implemented consistently in oncology and beyond. • Agreement regarding access to respite care 	<ul style="list-style-type: none"> • Formalised skills set out and adhered to i.e. in job descriptions, training plans • End of Life care would form part of the MDT assessment and all professionals working • Patient and carers involved in formulating and have access to Care plan • End of life choices documented, including advance decisions to refuse treatment • Auditable outcomes from gold standards framework (GSF) • Professionals to see palliative care as a positive alternative when giving patients choice and knowledge available to services • Significant event analysis of each death to be recorded and audit of actions generated and some form of reporting process 	<ul style="list-style-type: none"> • Gold standard framework or similar applied to death in secondary care, • As above relating to care homes, hospices, voluntary sector • Commissioners of services must ensure service specifications ensure best practice in assessment and care planning. • Assessment around End of Life care needs to be integral to nursing process

Co-ordination of Care

What good looks like	Success Measures	Factors critical to success
<ul style="list-style-type: none"> • EoL Services across health and social care, ambulance, hospital, care home sector etc driven by common clear national standards. • Specification for co-ordination set out as a multi-agency partnership so patients and carers experience services as seamless • Clear set of milestones/measures and mechanisms for assessing this is in place • Locality wide EoL care registers are in place, with triggers which would help access services such as rapid response, etc • Integrated information system cross services in place which flags up immediately if a patient is on the EoL care register, to enable all services, OOH, Ambulance services in particular to respond appropriately 24/365, including preferred place of death, DNAR, advance decisions to refuse treatment • Strengthened QoF incentives for GPs to engage with EoL care, GSF, MDT attendance • Regular/monthly meetings MDT to review register/deaths/bereavement • Managed EoL clinical network for each patch • Single Point of Access and telephone number for Patients and families to obtain support, Single patient record across sector • A key worker at Practice level for every EoL patient • Clear 24/7 District Nurse service specification • All sector district wide DNAR guidelines, clear and valid in all settings • Rapid Response services and hospice at home services or equivalent are in place • Hospitals with clear processes for providing care to the dying, professionals with relevant skills, access to specialist support, working with and fully aware of community services to ensure rapid discharge for those wishing to die at home • Recognition of the role of carer and assessment of their needs and provision of support and training 	<ul style="list-style-type: none"> • How many patients on register, how long before expected death • Strategic plan in place and mechanism in place to discharge strategy, good multi-agency working/engagement • Death in preferred place of death • Robust commissioning SLAs in place with standards set with all organisations 'across the market place' • Patient feels service is seamless – complaints, comparative information across providers • Single telephone number to access advice and activate services for patients and families • Access to specialist palliative care advice and support for DNs, GPs and other Health and social care professionals 	<ul style="list-style-type: none"> • Ownership at Board level of EoL, ED or NED/PEC • Multi-agency co-ordination at district level, driven by commissioners • Strong clinical leadership • Incentives for GPs – for high level provision where over delivered, accreditation/recognition • Single point of access and care management co-ordination for EoL patients • Regular audit and review • Managed clinical networks

Delivering high quality care

What good looks like	Success Measures	Factors critical to success
<ul style="list-style-type: none"> • Core competencies in place for all staff involved in EoL care – all sectors • Adoption of GSF, LCP, PPC or equivalent standards all sectors • 24/7 access to DNs/out of hours GPs/night sitters, plus rapid access to– specialist advice and assistance, access to pharmacy, OT ,equipment etc to enable people to stay in their preferred place • Rapid response and Hospice at home services or equivalent in place, plus ability for Hospice admission at short notice, including weekends and evenings • Hospice care for people with complex problems based on need rather than diagnosis is available • Care plans are recorded communicated and accessible to relevant Health and social care staff, including OOH services. • Carer and families feel supported, and have access to paid leave. • Transport systems provide rapid and flexible responses, and payment is uncomplicated • Transition services for 'young people' are effective • Specialist Palliative care teams in hospitals with beds in hospital (step down/step up beds) • Specialist Palliative Care teams in the community to support EoL care at home, in care homes and community Hospitals • Beds in nursing homes for respite/ manage crisis for short term • Transition from one service place to another is well managed and co-ordinated • Every member of staff seeing it as part of their job – positively motivated/using skills at top of license • Continuity of care from Community Nurses with authority to prescribe, sanction DNAR and certify death • Visitor access to patients in Hospital in last days of life is easy 	<ul style="list-style-type: none"> • Increasing staff satisfaction and engagement • Choice – and access to timely and appropriate care • Time of discharge to home, readmission rates to hospital • LCP /GSF/PPC coverage in all sectors • EoL in core curriculum and training and education process, and core District Nurse role • Board reporting on EoL performance • Hospice Care coverage • Patient, Carers families and Public experience of EoL care continuously improving 	<ul style="list-style-type: none"> • Effective commissioning framework/specification • Training and development and competencies for the workforce • Cross sector communication – electronic patient record • Appropriate mix of service provision at local PCT population level and where appropriate at a wider sub regional level • Effective audit and review and gathering of systematic feedback from Patients and Carers

Last days of life

What good looks like	Success Measures	Factors critical to success
<ul style="list-style-type: none"> • Identification of end of life phase is done well and care plan is in place, which supports dignity and comfort, appropriate use of and discontinuation of interventions, and carers and families. • Access 24 hour care to competent well trained district nurses • Advance information pathways in place <ul style="list-style-type: none"> ○ PPC documentation – key professionals ○ Contacts for who, when, what 24/7 ○ Access – SP care ○ Anticipate problems – plan ahead for any crisis (private hospitals links to NHS care. Prison access advance planning/NHS/Social care. Care homes – training/provision of competent support to keep patient in care home) • All GPs use GSF/LCP/PPC and implementation on all wards • Co-ordination primary/secondary care/social care • Rapid co-ordinated discharge from Hospital to home is readily available and working • Resus/organ donation sorted a long time before • Specialist Palliative care is available in all settings for patients with complex needs • Ready access to medication • Symptom management guidelines in place for generic professionals • Clear written and verbal information for families and the patient on the preparation for and what to expect as death approaches 	<ul style="list-style-type: none"> • Integrated care pathway (Liverpool care pathway) • Increasing % dying at/in preferred place • Carers satisfaction survey • Evidence of choice/discussion clearly documented including district nurses notes • All patients offered a PPC • Reducing complaints related to death 	<ul style="list-style-type: none"> • Staff with the skills to identify patients are entering the last days/hours of life • Use of GSF/LCP/PPC • Co-ordination of support services and communication between these to ensure appropriate interventions take place • Support to carers and family

Care after death

What good looks like	Success Measures	Factors critical to success
<ul style="list-style-type: none"> • Staff who are confident and skilled in providing initial emotional and practical support. • Recognition of role in care after death especially within secondary care • Handling of body in appropriate way related to wishes of family and carers, linked back to early stages of assessment • Time in the community for visits to family and carers, and access for family and carers to information • Management at point of death do well – verification and certification, procedure in place for OOH services • An appropriate range of bereavement support services are available • Good information is available to families about what happens after death and what to do 	<ul style="list-style-type: none"> • All relatives have access to bereavement services. consistent with minimum standards of bereavement support services • Care plan includes a care after death element • Personal point of contact for care after death arrangements • Quality measurement of EOL care experience – specific to relatives • Quality outcome measures of support services • EOL care T&D as part of development programme • Continuing improvements in Patient survey relating to end of life care and national survey 	<ul style="list-style-type: none"> • Carer support pre and post death • Information (good quality) • Inter service working • Good quality training and development for staff dealing with end of life • Consistent commissioning of care after death as part of standard service provision

Support for Carers

What good looks like	Success Measures	Factors critical to success
<ul style="list-style-type: none"> • Assessment of Carer needs undertaken as part of care planning process • Carer needs regularly reviewed • Resources and services readily available to support Caring responsibilities <ul style="list-style-type: none"> - good quality information - access to respite beds - available day care - drop in services - psychological support 	<ul style="list-style-type: none"> • Carer satisfaction levels • Levels of Carer complaints • Reduction in emergency admissions 	<ul style="list-style-type: none"> • Incorporation of requirements into commissioning specifications

Bereavement services/support

What good looks like	Success Measures	Factors critical to success
<ul style="list-style-type: none"> • Support available to all who need it, in what ever setting, or what ever reason bereavement occurs • A range of appropriate support is known and easily accessible – from support groups to psychological services • Support planned for and commissioned/coordinated 	<ul style="list-style-type: none"> • User surveys and satisfaction • Coverage of available support • Quality of information provided to bereaved 	<ul style="list-style-type: none"> • Minimum standards in Commissioning specifications • Quality measure as part of HCC and CSCI inspections

Workforce Development

What good looks like	Success Measures	Factors critical to success
<ul style="list-style-type: none"> • A workforce adequate in numbers in all settings to plan and implement care • A workforce with access to 24/7 specialist advice and who know how to use it. • A workforce with good communication skills capable of support patients and carers in decision making and to support advanced planning • A workforce which can identify end of life provide care which enables a good death • A workforce which recognizes that palliative care is everyone's business • A well trained confident workforce who are respected by and in whom patients and carers have confidence 	<ul style="list-style-type: none"> • Patient and care satisfaction levels • Increasing numbers achieving PPC • Register of patients EoL choices in all settings • Reductions in appropriate hospital admissions • Reduction in calls to OOH services • A single record and effective communication of choices, needs between services and professionals 	<ul style="list-style-type: none"> • A clear workforce model – majority of EoL care being provide by generalists with access to specialist support where need • Effective workforce planning • The inclusion of EoL issues in undergraduate and post graduate training and development curricula • Tailored CPD for the different workforces working with people at end of life, as a part of KSF, PDP and revalidation expectations • Clarity around core competencies fro both general and specialist palliative care

Best Practice across Yorkshire and the Humber

The Group listed the following as examples of local innovations, developments or services which positively impact upon the quality of end of life care, a number of these are illustrated as case studies in the text boxes.

Assessment and care planning

- Advanced care planning documents also incorporating 'softer' aspects of patient care in Bridgewater park, Scunthorpe
- Preferred place of care document – audited and developed in Hull PCT
- Cardiac care Community Nurses supported by British Heart Foundation in Barnsley and Rotherham
- 'Breathing Space' Rotherham – coalfield initiative
- Community Matrons/Case Managers in Barnsley, Wakefield, Rotherham and Sheffield
- MacMillan Community Nurses working in care homes. Wakefield, Doncaster and Huddersfield, Kirklees and Leeds providing education, information and support
- Uniform palliative care assessment forms are in place across service in Kirklees and Calderdale
- Referral Pathway for new diagnosis of motor neurone disease in Kirklees PCT, providing a central data base kept by the Community Advice and Support team to enable onward referral as required
- Kirkwood Hospice provides a drop in service, which includes self referral, assessment and access to complementary therapists, counsellors and a Chaplain
- There are a number of dedicated palliative medicine clinics for Non- Malignant diseases in Leeds e.g., renal, motor neurone disease
- Mental Capacity Act Assessment Tool – Dove House Hospice

System One

The palliative care services in Bradford and Airedale have developed a shared electronic record system which is made available by CSC as part of the NHS National Programme for IT. The application is called System One and is produced by the company The Phoenix Partnership (www.tpp-uk.com). It has been developed as a shared community clinical record system for GPs, district nurses and other members of the primary care team. The system is used by all the palliative care services within the locality for recording detailed clinical notes. It provides 24 hour access to up to date clinical information about patients, many of who frequently move between hospital, hospice and community settings. It has been in use by them for the past 6 years.

As well as recording a holistic assessment under key headings in line with recent NICE guidance, clinical notes are added by hospital and community palliative care teams and by the hospice day therapy and inpatient units, regarding Patients' wishes for future care, including preferred place of death and resuscitation status.

The palliative care records can be accessed by staff in the following locations, Hospices, Hospital palliative care teams, Community palliative care team offices, Hospice at Home team offices, Oncology and haematology wards, A&E, Medical Admissions Unit, GP surgeries, District Nursing and Rapid Response offices, Out of hours primary care centres

Coordination of Care

- On line Specialist Palliative Care Resource File and Directory available to health professionals, in GP practices, PCTs, Hospitals and Local Hospices in York
- Palliative Care call system in Scarborough – helpline
- PPM (Patient Pathway Manager) IT system in Leeds Trust hospital
- ‘System One’ IT data management system in Rotherham and Sheffield, Bradford and Airedale
- Shared referral documentation between hospital and community nursing services in York.

Delivering High Quality Care

- Dedicated palliative care ambulance service in Leeds
- Rapid Access ‘Specialist Palliative Care Beds’ in Oncology unit Hull Acute Hospitals Trust
- Step up/step down beds for oncology patients in Hull Acute Trust at Princess Royal Hospital
- Rapid Access, nurse led palliative care clinics at PRH – Hull to help keep patients at home
- Extensive complimentary therapies service linked to hospice at home and drop in St Johns Hospice, Doncaster
- Outreach Marie Curie evening service, 6.00pm – 11.00pm, East Riding PCT (1st in country)
- 24 hour helpline – Specialist Palliative Care Services in Barnsley, Wakefield, Rotherham and Sheffield
- Nursing home Community Nurses in Barnsley, Wakefield and Rotherham
- Gold Standard Framework implementation in primary care in Barnsley, Wakefield, Rotherham, Sheffield and Kirklees
- Liverpool Care pathway implementation programme in Barnsley, Wakefield, Rotherham, Sheffield, and Kirklees

End of life Delivery Framework

An End of life Service Delivery Framework for community nursing teams has been developed in Leeds which is influential in standardising practice across community nursing teams. It provides clarity regarding processes for continuing care support for this client group. The PCT Practice and Professional Development Team have linked widely with colleagues (District Nursing, Continuing Care, and Specialist Palliative Care Clinical Nurse Specialists) for this piece of work in terms of critical friends’ feedback and developing the educational programme. Verification of death policies in place across PCT and has enabled District Nurse and Nurses working out of hours to verify death sooner. City-wide roll-out of syringe driver training is also in place so unified policies and consistent education is offered.

Rapid Response services

There is a 24 hr “fast response team” who will provide care at home for Rotherham patients over a 72hr period or more. This is a generic service that provides nursing care and support for all. This service for all patients and carers is delivered by 6 support workers and 6 nurses. It keeps patients at home during a crisis offering end of life care as well as integrating with “Hospice at Home” It has run for 10 years and cares for up to 20 patients at a time.

Just In case Drug Boxes

These were launched September 2005 in Hull and East Yorkshire, and distributed to District Nurses, enabling in a 2 year period 108 patients out of 126 to remain at home helping to reduce Hospital admissions, enabling patients to be nursed and die at home, saving time for Nurses and GPs, and helping families to feel supported and secure in the knowledge that drugs were in place if needed.

- Ethnic minorities liaison worker – Bradford
- Drug Boxes in patients homes – Hambleton and Richmondshire locality of North Yorkshire and York PCT
- Manorlands in Bradford provide Day Therapy services in Skipton to enable patients from Craven to access services
- A follow up lymphoedema clinic is run at Kirkwood Hospice, reducing waiting times and providing care closer to home
- Access to admission to specialist Palliative Care Unit 24/7 if appropriate, and a 24hour palliative Care advice line for Health professionals in Leeds
- A weekly nurse led out patients clinic for pain and symptom management, enabling rapid access to treatment – Humber and Yorkshire Coast
- Specialist Palliative Care dietetic services in Barnsley and Rotherham.
- North East Lincolnshire Specialist Palliative Care is delivered by a Multi agency MDT

Last days of life

- ‘Pan Rotherham’ across agency DNAR in Rotherham
- Hospice to home/intensive nursing at home in Rotherham
- Cardiac failure service, St Catherine’s Hospice, Scarborough – patient choice given re place of care (hospice or hospital)
- Support to Care homes and Nursing Homes from Specialist Palliative Care Team in Wakefield

Care after death

- Wakefield Hospice drop in services, drop in bereavement services with benefits advisor/complementary therapies support.
- STAR (children’s bereavement service – Wakefield)
- Bereavement Groups for 6-13 year and 14 – 21year olds – Bradford and Airedale

Provision of supportive and palliative care to service users in care homes

Specialist palliative care teams in Wakefield are providing support and advice to all care home staff in the area in order to prevent inappropriate hospital admission in the last days of residents' lives. The scheme, initially funded by Macmillan Cancer Support but now taken on by Wakefield District PCT, has enabled patients to be discharged earlier from secondary care and led to fewer hospital admissions at the end of life.

As the service has developed there has been a massive increase in referrals and requests for education. Specialist palliative care provision to patients with non-malignant disease (particularly those with cognitive impairment) has also increased.

The service has developed and 'Introduction to Palliative Care' training for all newly appointed staff in care homes. It has also produced a directory of services for all care homes and set up palliative care link nurses (care homes) meetings four times a year as well as loaning out syringe driver equipment.

The aim now is to roll out the GSF and End of Life pathways in more care homes and coordinate all services that visit care homes more effectively.

Bereavement care

Family Support Team run two bereavement groups, one for young people(14-21) open to pre-bereaved as well as bereaved, which is held twice a year. The second for younger people (6-13) both provide access to peer support, a time for fun as well as reflection and problem solving.

Support for carers and patients

- Special companions project for 'end of life care', Doncaster Acute Trust (training and chaplain support)
- Dove House Hospice Drop in Service increased flexibility for patients and support for friends, relative and carers
- St Catherine's Hospice resource support for Carers of Patients admitted to Hospice
- Cancer Information Support and Advice Service – Scarborough, Whitby and Rye

Workforce Education and development

- Education learning disabilities – Kirkwood
- Range of Education and development initiatives in York, including one stop EoL updates, Communication skills for Receptionists, Award winning End of Life programme for Nurses and AHP's in partnership with York University, Practical Palliative Care Programme for HCAs, GP Certificate in Palliative Care sponsored by Macmillan Cancer Relief.
- Rolling programme basic PC to care home/social services regularly co-ordinated by Kirkwood Hospice, Huddersfield
- Foundations in palliative care modules roll out to NH/SS/Care homes in East Riding
- 4 key drugs audit in East Riding PCT looking at impact of independent nurse prescribing in specialist palliative care in supporting home care of complex patients
- Locality based education programmes and practice based education in Barnsley, Wakefield, Rotherham and Sheffield

Delivering Choice Programme in Leeds

Working in partnership with Marie Curie Cancer Care, Health, social care and voluntary sector providers in Leeds are currently undertaking a major redesign of services for patients at the end of life, and their carers.

A discharge facilitator streamlines and expedites the discharge process from hospital or hospice, and a Marie Curie "Meet and Greet" service is in place providing a member of staff to accompany a patient home and give support for up to 24 hours. This is supported by a dedicated palliative care ambulance available 365 days/year with specially trained crew.

A new service delivery framework for district nurses has put them at the heart of co-ordination and provision of palliative care services in the home, and an education and development programme for care homes (CHESS) is being run in 33 care homes developing staff skills to provide end of life care for their residents when appropriate.

A palliative care website is under development for Leeds, which will provide information on services available in each area and how they are accessed both in and out of hours, and a worker has been appointed to look at provision of services for BME communities.

An innovative model of day hospice provision, developed by both Leeds hospices, Marie Curie and the PCT is planned to run in a poorly served part of the city, and a data integration analyst is undertaking a feasibility study on developing an electronic palliative care register that can be shared across providers, to enhance co-ordination of care across settings.

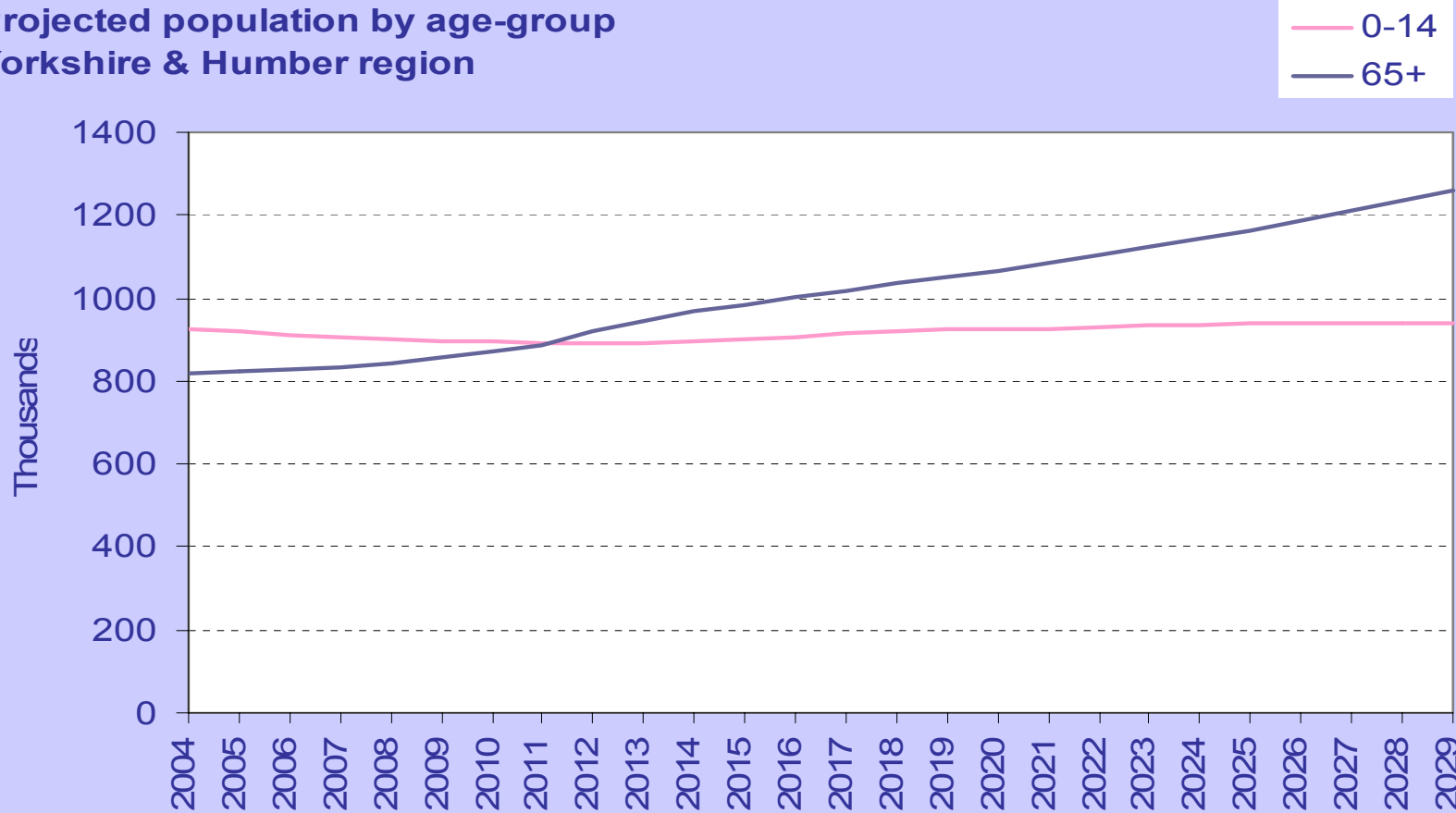
Collaborative development

A range of good practice initiatives in Kirklees PCT and Calderdale & Huddersfield NHS Foundation Trust, in addition to the use of GSF and LCP the following contribute to improving end of life care

An Education project for unqualified staff caring for dying people at home in collaboration with Social Services, health care assistants (community) and Crossroads, has been running for several years. Topics covered include an overview of palliative care, skin care and hygiene, mouth care, nutrition, pressure area care, and pain management, recognising when a person may be dying, what to do when finding someone unconscious, and after the person has died.

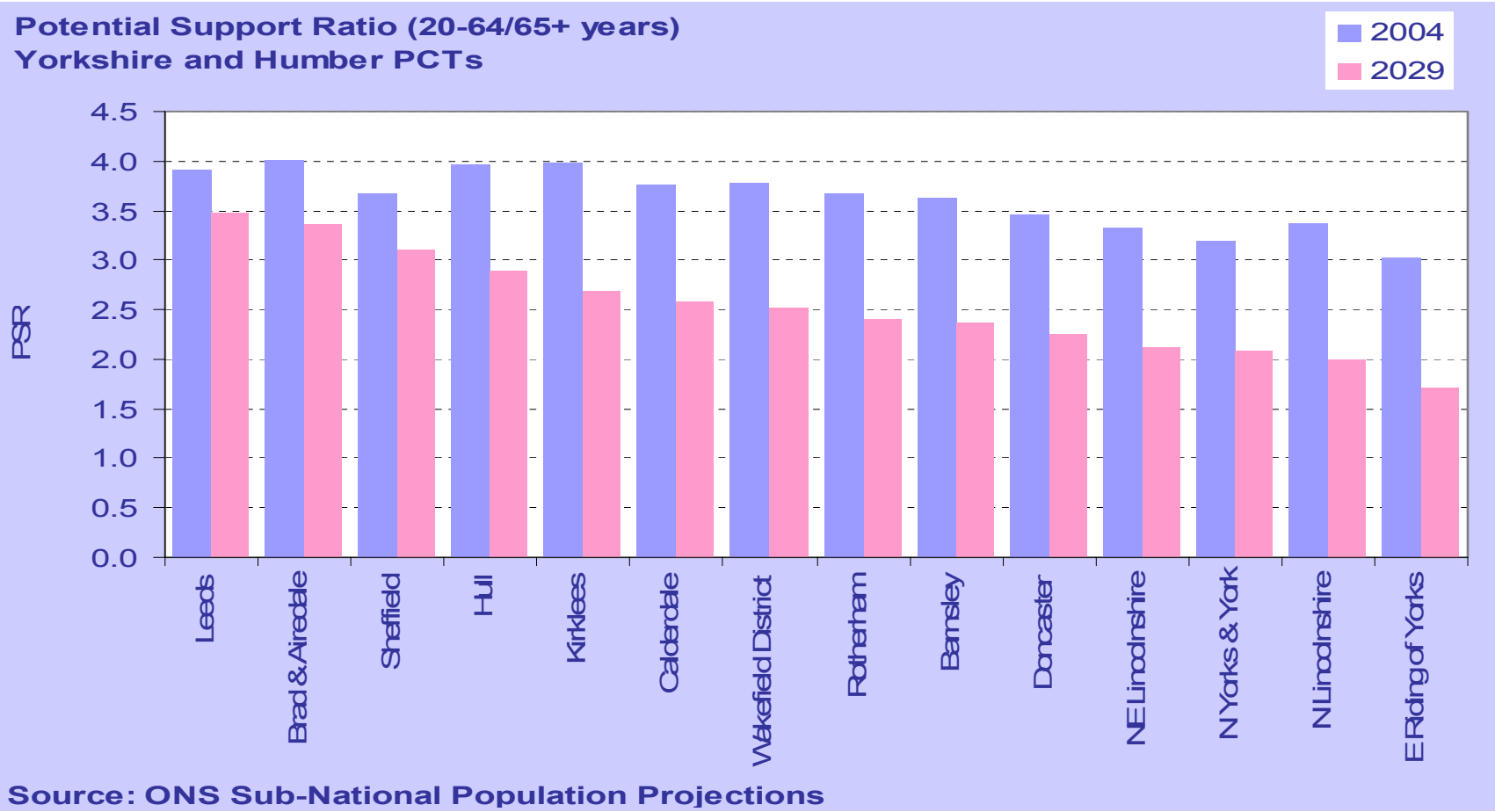
Future planning – population change

Projected population by age-group
Yorkshire & Humber region

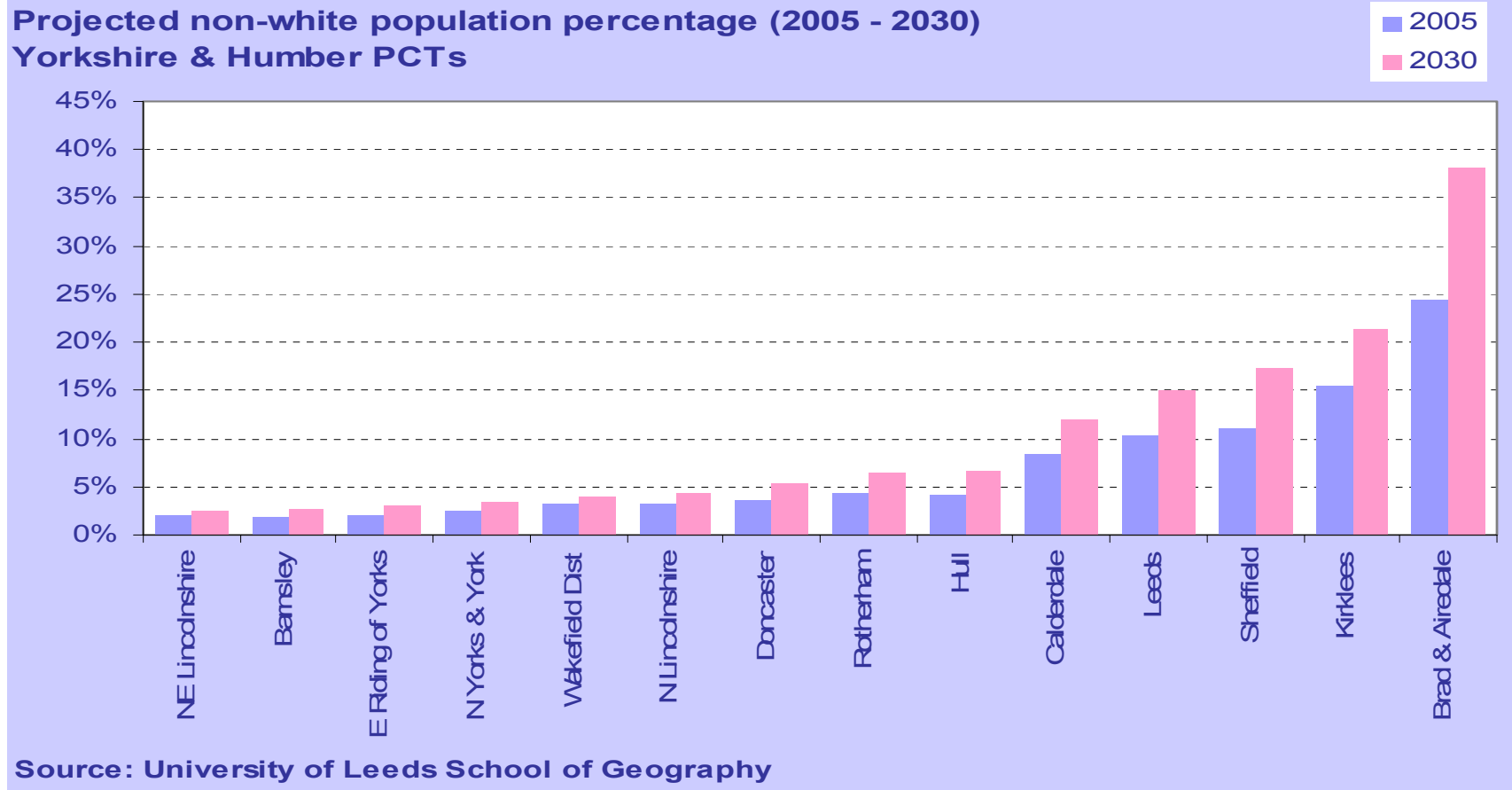


Source: ONS Sub-National Population Projections

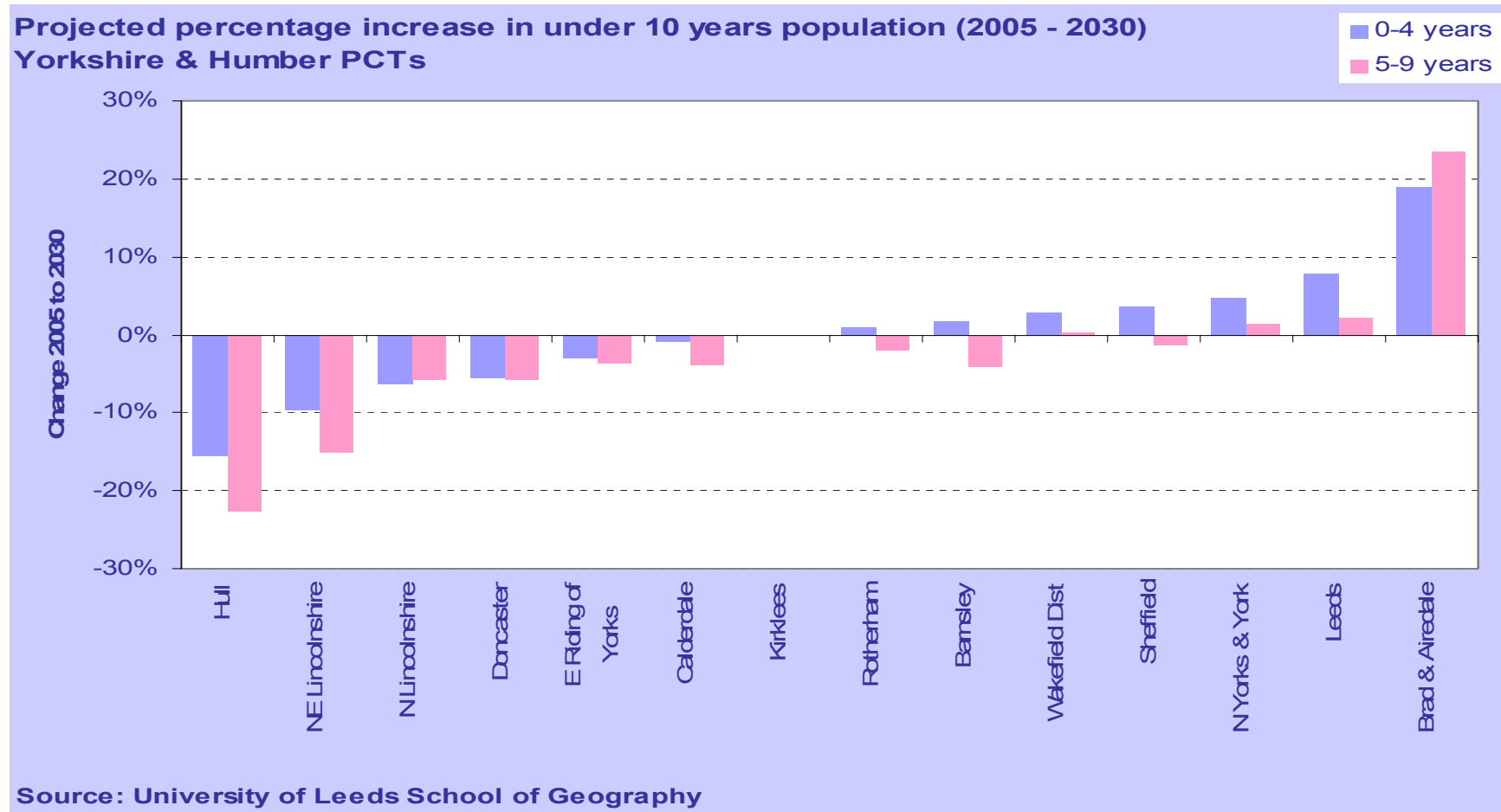
Future planning – population change



Future planning – population change (ethnicity)



Future planning – population change (children)



Messages from Patients and the Public in Yorkshire and the Humber

1. Group considered the outcomes from the Public focus groups on this topic held in York at the end of September, and December and information from the two deliberative events held in September and January.
2. The Group also considered the outcomes from the Yorkshire Cancer Network User Partnership Group End of Life event which took place in October.
3. The key messages from the initial focus group are set out below

Key Changes to Service Suggested

PEOPLE	FACILITIES	COMMUNICATION AND INFORMATION
<ul style="list-style-type: none"> • Treat patients with understanding and respect <ul style="list-style-type: none"> – no “bullying” – no neglect • Allow patients to live their last days with dignity 	<ul style="list-style-type: none"> • FUNDAMENTALLY: more facilities for end care patients in hospital (both beds and staff) • More nursing staff in both community and secondary care • Better out of hours GP service <ul style="list-style-type: none"> – or defined GP role in emergency services • Care homes in convenient locations • Shorten waiting times in hospital pharmacy • Improve non-emergency ambulance service (shorter waits) • Improve hygiene/infection control in hospital • Improved/faster supply of essential items (wheelchairs, commodes) 	<ul style="list-style-type: none"> • Ensure notes are written up and read • Improve communications between NHS and patients <ul style="list-style-type: none"> – patients (and carers) require clear, jargon-free explanations of their situation so they know what to expect • Improve communications between NHS primary and secondary care staff <ul style="list-style-type: none"> – and, by implication, any others (e.g. social services, Macmillan nurses) involved

4. The experiences related by the general public of end of life care, confirmed what others have highlighted previously;
 - Poor communication between services, the sense that patients and carers are being juggled between services, that OOH services are not aware of patient needs, and that often the general standard of care provided to older people is not good enough. There is also a sense of patients and carers not being communicated with, kept informed and involved appropriately.
 - Patients entering the last phase of end of life are not identified and treated appropriately, and that carers and families are often not prepared for this either.
 - In instances where end of life was identified as approaching the general public report positively about the care and, support given and the attitude and skills of staff.

- The stories related in this focus group of frail elderly people falling ill with seemingly minor infections, where a pattern of problems then develop and which leads to deterioration and death, are quite striking. This is seen by carers and families as lack of interest in the needs of older people, ageism, and older people being seen as nuisance – a bed blocker, or someone who the system doesn't know what to do with, and who is passed from service to service.
 - This suggests that for a significant group of older people, identifying they are approaching the end of life, and responding appropriately to their needs is not happening, such that at the time when respect and dignity are most needed, this appears to be lacking.
5. The key messages from the Cancer Network User Group end of life event (See below) reinforce the messages from the focus group and resonate with the Clinical Pathway Groups sense of the need to promote consistency in the quality of support and care offered in all settings.

Yorkshire Cancer Network User Partnership Group – End of Life Event 19th October 2007	
Issues Identified	Recommendations
<ul style="list-style-type: none"> • Communication – the need for timely, personalised communication • Documentation – clear recording of decisions made available to all involved in care • Information – clear good quality written information for patient and carers • Key Worker/Co ordinator – single point of contact • Education and training – to equip professionals with the skills to undertake advanced care planning • Commissioning – need for consistent pathway models to be commissioned 	<ul style="list-style-type: none"> • Collaborative working between all care settings and providers of care • Promotion of Advanced Care Planning • Education of professionals, inclusion in undergraduate and post graduate programmes • Unified system for electronic recording of decisions and access to records 24/7 • A key worker to be appointed with appropriate skills and authority • Universal implementation of LCP and GSF • Standardised documentation and information • Evaluation of changes to demonstrate improvements in quality

6. A further Focus Group was run in early December, and some of the emerging ideas set out in our initial report were tested with the Group members. At this event Patient and the Public indicted their support for
7. A further Focus Group was run in early December, and some of the emerging ideas set out in our initial report were tested with the Group members. At this event Patient and the Public indicted their support for the following set out below

Key areas Supported

- Improving out of hours services, in particular a need for continuity of care by same carer and involvement of the GP
- Better access to essential and appropriate equipment at home at the time when patients needed them, and welcomed anything that would improve consistency.
- Staff training, to recognise and deal effectively with patients and their families receiving end of life care, in particular the hope was to change the attitudes of receptionists and managers who they felt can become impatient with such patients.
- More comprehensive and standardised information about end of life issues, for patients and families facing this, they felt a better understanding of what to expect, what to do, where to get help would lessen anxiety and help in the care of their loved ones, this included information about what to expect after a family member has died.
- The introduction of national standards for end of life care, but there was some concern about their practicality in practice and what these standards would measure. Members of the group were interested in seeing standards in care settings around meals, cleanliness, hygiene, care, communications, record keeping and treatment of patients with dignity and respect.
- The idea of a standard end of life pathway guided by Patients, carers and Professionals agreeing what is needed, documenting this, and funding being available to deliver it.
- The Single Care Co-Ordinator for EoL Care, some thought this was already in place in some areas, but needed to be the same across the patch

7. At the deliberative event in January Members of the public explored how the end of life pathway as outlined later in this report might work for an individual who was terminally ill, and there was an overwhelming positive response because
 - The patient's choice was respected and he was provided with dignity in dying in the place he preferred, supported by specialists trained in end of life care.
 - The whole family was involved and was offered support, with time and space to plan what is required.
8. Although members of the public recognised that it might be difficult to discuss end of life with some patients and families they felt a trained key worker to help this process was very valuable. They also felt it was very important to continue to support the family emotionally and practically after the death.
9. Members of the Public recognised that care and dying at home might not always be possible or the preferred option and it was felt that hospitals should provide more comfortable familiar facilities (as pioneered in birth units) where patients might die in privacy with their family around them.
10. There were some concerns express about whether the pathway is realistic due to resources, funds, lack of community/Macmillan nurses and communication difficulties between different organisations and agencies, and it was seen as essential that health and social care work effectively together.
11. Members of the public also questioned the availability of staff to provide home support particularly for people without family

12. They also identified a key requirement that Bereavement support should be formalised and tailored to the individual because at present it is seen as piecemeal.

Clinical Pathway Group – End of Life

Members Details

Name	Title	Organisation
David Levy	Consultant Clinical Oncologist	Sheffield Teaching Hospitals NHS Trust
June Toovey	Nurse Director	Yorkshire Cancer Network
Paul Harrison	Associate Director of Leadership and OD - SHA Project Lead EoL	NHS Yorkshire & Humber
Janet Owen	MacMillan Nurses	Barnsley PCT
Dr Ian Fenwick	GP	Bradford & Airedale PCT
Dr Rosemary Lennard	Consultant in Palliative Care Medicine	Community Palliative Care Team, Bradford
Dr Lindsey Turton	Macmillan Lead Nurse for Palliative Care	Hull and East Riding of Yorkshire PCTs
Dr Angela Harley	GP	East Riding of Yorkshire PCT
Sue Pender	Team Co-ordinator for OOH Palliative Care Team	Hull PCT
Rosie Norbury	District Nurse	Kirkees PCT
Pam Selby	Primary Care Lead, Palliative Care	Leeds PCT
Dr Ann Morris	End of Life Care Lead	North Lincolnshire PCT
Chris Ward	Nurse Consultant, Palliative Care	North Yorkshire & York PCT
Dr Kevin Bolster	GP	Rotherham PCT
Siobhan McFeely	PEC Member & Community Matron	Sheffield PCT
Professor Sam Ahmedzai	Academic, Unit of Supportive Care	Sheffield University
Marian Oakhill	MacMillan Team Leader	Wakefield District PCT
Dr Charlotte Clare	GP	Calderdale & Huddersfield NHS Trust
Dr Fiona Hicks	Consultant in Palliative Medicine	Leeds Teaching Hospitals NHS Trust
Dr Rob Lane	Associate Medical Director	Mid Yorkshire Hospitals NHS Trust
Anne-Marie Seymour	Consultant Palliative Care	Mid Yorkshire Hospitals NHS Trust
Val Derks	Palliative Care Nurse	Doncaster PCT
Janine Birley	Cancer Lead Nurse	Rotherham General Hospitals NHS Trust
Nasir Choudhary	Senior Dietician for Oncology Services	Rotherham General Hospitals NHS Trust
Liz Pengelly	Business Change Manager	NHS Yorkshire & Humber
Tim Allison	Director of Public Health	East Riding of York PCT
Peter Mortimer	Clinical Excellence Manager	Yorkshire Ambulance Service
Joan Beck	Director of Health Communities and Vulnerable people	Doncaster Metropolitan Borough Council
Joy Waldock	MacMillan Nurses	Barnsley PCT
Colin Pollock	Deputy Regional Director Public Health	Department of Health
Alan Wittrick	Chief Executive	Wakefield PCT
Val Revill	Macmillan Lead for Palliative Care	North East Lincs PCT

