

Hertfordshire Community NHS Trust

End of Life Care Vision and Strategy for Adults and Children

Introduction:

Hertfordshire Community NHS Trust (HCT) provides community and specialist health services to local communities across Hertfordshire as well as specialist children's services in West Essex.

Context:

The HCT Clinical Strategy 2015

Provision of high quality End of Life Care is a fundamental aspiration of the high quality care provided by HCT. "Ensure health and wellbeing is maximised in the last year of life and that patients and carers are supported to access appropriate services and jointly plan treatment thresholds and a preferred place of death."

The HCT Vision

To maintain and improve the health and wellbeing of the people of Hertfordshire and others served by the Trust

Underpinning this vision are the HCT Values:

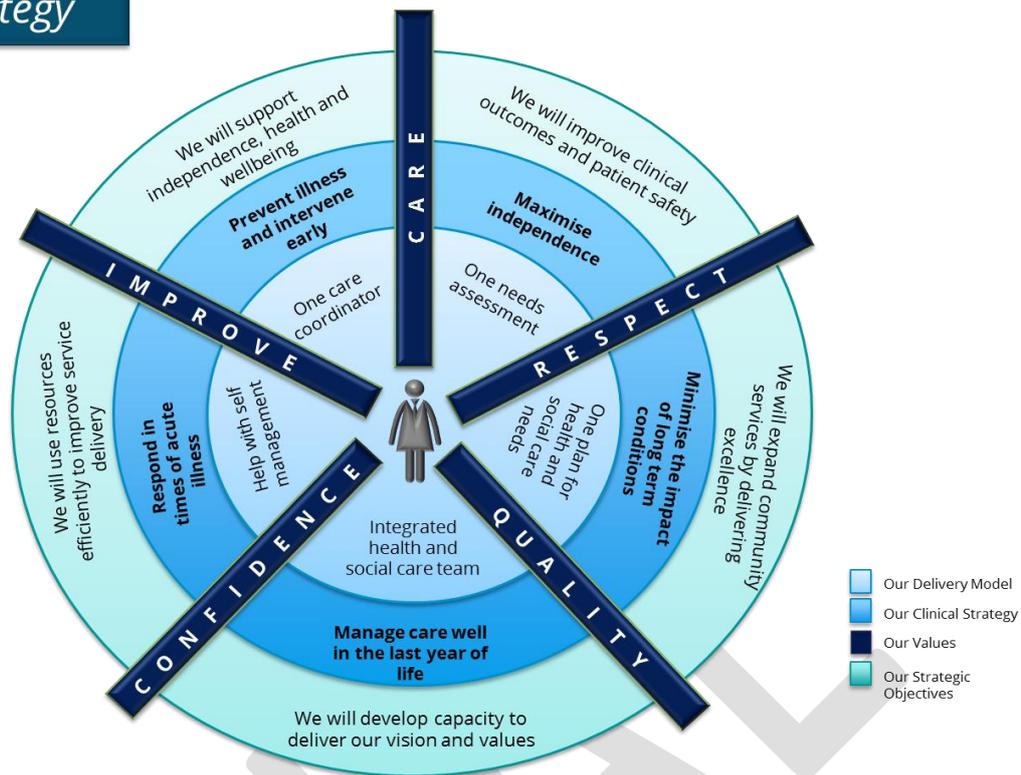
- **Care** - We put patients at the heart of everything we do.
- **Respect** - We always respect patient privacy and confidentiality.
- **Quality** - We strive for excellence and effectiveness at all times.
- **Confidence** - We do what we say we will do
- **Improve** - We will improve through continuous learning and innovation.

HCT's Adult Delivery Model

We will be guided by these basic principles:

- We will listen to patients, their families, children and carers and keep their needs central.
- We ask staff to take responsibility, make decisions and behave consistently with our values.
- We will work positively in partnership with other organisations to maintain people's health and wellbeing.

Our Strategy



The HCT Vision for End of Life Care is to:

“To be the leading community provider for personalised, accessible, well-coordinated, high quality end of life care for everyone in the last year of life, along with supporting their carers. Through planning with the patient and emphasis on informed choices, we will help them live the life they wish to the best of their ability. Our skilled and caring staff will collaborate with local organisations and communities to maximise patient wellbeing, independence, comfort and dignity in their preferred place of care.”

Definition of End of Life Care (EoLC) - “care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die”. Patients are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with: (a) advanced, progressive, incurable conditions (b) general frailty and co-existing conditions that mean they are expected to die within 12 months (c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition (d) life-threatening acute conditions caused by sudden catastrophic events (General Medical Council, 2010).

Definition of Generalist Palliative Care - Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organisation).

Definition of Specialist Palliative Care - Specialist palliative care is the active, total care of patients with progressive, advanced disease and [of] their families. Care is provided by a

multi-professional team who have undergone recognised specialist palliative care training. (World Health Organisation)

The National Ambitions for Palliative and End of Life Care (2015)

This document states:

“End of life care is care that affects us all, at all ages, the living, the dying and the bereaved. It is not a response to a particular illness or condition. It is not the parochial concern of a particular group or section of society.”

“We cannot defeat death. However, we can change the way we talk about dying, death and bereavement and prepare, plan, care and support those who are dying and the people who are close to them. We must strengthen and improve our ability to provide care whatever the circumstances of our dying.

Reports and investigations too frequently identify poor care. The consistency of their critique tells us that we have a collective responsibility to do better. With a rapidly ageing society and changing patterns of illness many more people will live with long term conditions. Each year more of us will die and many more of us will face the challenges of dying, death and bereavement.

We also know that more children are living with complex life-limiting illness with huge caring responsibilities placed on their families. Now is the time for shared ambition and urgency.”

The six national ambitions are:

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

Adults Palliative and End of Life Care:

HCT provides End of life Care to all residents of Hertfordshire within the Integrated Community Teams, community hospitals and specialist services, supported by the Specialist Palliative Care team.

Specialist Palliative Care is provided by HCT for adults in the majority of Hertfordshire (with the exception of the four localities in East Hertfordshire and areas of Dacorum). There are several other providers of specialist palliative care for adults in Herts including community services, outpatient services and inpatient bed based care. These include Peace Hospice, Iain Rennie Grove House, Hospice of St Francis in West Herts and Isabel Hospice and Garden House Hospice in East and North Herts. Acute trusts, mental health trust and social care partners in Hertfordshire also provide health and social care to this group of people.

Children’s Palliative and End of Life Care:

HCT provides Palliative care for children from the Children’s Community Nursing service (CCN) in Herts Valley CCG and West Essex. In North and East Hertfordshire the Children’s Community Services are provided by East and North Hertfordshire NHS Trust. There is

hospice provision provided by Keech Hospice in Luton and Rennie Grove (for parts of Hertfordshire), Milton in Cambridge and areas of West Essex plus Haven House in Woodford Green Essex.

Nascot Lawn provides short breaks for children with complex health needs (all of Hertfordshire) and this includes care in the last year of life. However it would not be planned for Nascot Lawn to be the place of death. The Children's Community Nursing Services are supported in providing this care, particularly at the end of life, by Great Ormond Street's Symptom Care Team. This support is crucial for prescribing expertise at the end of life. As HCT does not provide End of Life Care for Children in East and North Hertfordshire this document will focus on care delivered to Children in Herts Valley CCG and West Essex which is provided by HCT.

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Where we want to be (Adults and Children):

HCT aspire to deliver equitable systematic access to high quality coordinated person-centred care, independent of disease and geography so that each person can say:

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

(From Ambitions for Palliative and End of Life Care 2015)

HCT Eight Aspirations:

In 2014 a wide range of inputs from multi-professional staff, patients and carers (including bereaved carers) and Macmillan were used to develop eight aspirations for End of Life Care which were supported by the HCT Executive team. These aspirations were agreed as:

1. All community patients thought to be in the last year of life are identified as such.
2. All community patients identified as EoL are offered an holistic needs assessment
3. All community patients at EoL have an identified community keyworker / case manager
4. All patients at EoL offered Advance Care Planning discussion
5. Reduction in % of identified community patients at EoL dying in hospital
6. Patients at End of Life spend more time in their preferred place of care
7. Measured improvement in patient / carer experience
8. Increased confidence of non-specialists managing patients at EoL in the community and all staff involved in End of Life Care feel supported in their roles

These eight aspirations have formed the basis of a three year work plan which the Palliative and End of Life Care Network began progressing in August 2014. SystemOne changes have been made to allow the clinical record keeping required.

From the above aspirations the Palliative Care and End of Life Clinical Network have developed a number of interventions to improve the consistency and quality of End of Life Care provided to all. These interventions are detailed below with identified patient outcomes measures and measurement indicators:-

1. Education and training programme for staff to support the delivery of the End of Life Care strategy, End of Life Care Policy and increase the competence and confidence of staff in maximising comfort and wellbeing for patients in the last year of life. (appendix 4)

2. Deployment of *Five Priorities for Care* to guide all care and documentation in the last few days of life (appendix 2)
3. Improvement of awareness, coordination and involvement in End of Life Care for all services/teams within HCT (appendix 2)
4. Specialist Palliative Care access based on clinical need supported by robust caseload supervision and development of skills and competencies.
5. Development of clinical leadership for End of Life Care in Children's Services

Outcome Measure: All staff will be competent and feel confident in providing high quality coordinated person-centred end of life care.

Measurement Indicator:

- Number of patients identified in the last year of life
 - Educating & training trajectory
 - Staff confidence questionnaires
 - Staff appraisal and personal development plans
 - Local and organisational staff surveys
 - Common data set and End of Life Care dashboard/SystemOne
 - Clinical Audit including, but not limited to, advance care planning, holistic needs assessment, pain management and use of five priorities for care
6. The pathway of care in Long Term Conditions management supports the identification of people approaching the last year of life and would involve offering conversations about End of Life Care and Advance Care Planning.
 7. Use of prognostic indicator tool which supports identification of the last year of life to all people known to HCT with all conditions. (appendix 2)

Outcome measure: Number of patients identified to be in the last year of life

Measurement Indicator:

- Common data set on End of Life Care dashboard/SystemOne
 - HCT annual clinical audit cycle
8. Systematic access for each identified patient in the last year of life to the End of Life Care pathway (see appendix 2)
 9. Person-centred approach to all care
 10. People able to spend more time in their usual place of residence rather than admission to care home or hospital (appendix 2)
 11. Seamless transition from care in children's services into adult services.
 12. Care which optimises independence, patient comfort, wellbeing and self-management.

Outcome measure: All patients will receive and there will be evidence of high quality coordinated person-centred care

Measurement Indicators:

- Common data set on EoLC dashboard/SystemOne
- Patient experience questionnaire
- Patient complaints/compliments
- Pain scoring audits
- Bereavement questionnaire
- Named keyworker

13. Patient and carer choice in how they live their individual life, through advance care planning, person-centred coordinated care and documentation.
14. Assessment, support and signposting for carers' wellbeing.

Outcome Measure: Patients and carers will be supported in identifying and living the life they wish.

Measurement Indicators:

- Common data set on EoLC dashboard/SystemOne
- Patient and carer experience/satisfaction audits
- Bereavement questionnaire

15. Single Point of Access to Specialist Palliative Care advice and support and End of Life Care including access to Electronic Palliative Care Coordination System (EPaCC's) (appendix 2)

Outcome Measure: Accessible and timely proactive contact for

Measure Indicators:

- Referral criteria/specification
- CCG contract monitoring
- Common data set on EoLC dashboard/SystemOne
- Professionals satisfaction questionnaire
- Patient experience/satisfaction audits
- Bereavement questionnaire
- Patient complaints/compliments
- Number of deaths in preferred place
- % of deaths in usual place of residence

16. Improve the knowledge and data regarding delivery of Specialist Palliative and End of Life Care Service across all services in HCT to enable improved influencing of commissioning intentions with local CCG's, local authority and voluntary sector partners.
17. Systematic use of patient and carer feedback to inform service delivery and development
18. Routine use and reporting of clinical outcome measures in Palliative and End of Life Care

Outcome Measures: Robust and accurate clinical and numeric data which is evidenced based, supported by patient stories, to enable development of Specialist Palliative Care and End of Life service developments.

Measurement Indicators:

- Common data set on EoLC dashboard/SystemOne
- Professionals satisfaction questionnaire
- Patient experience/satisfaction audits
- Patient complaints/compliments
- Clinical audit cycle – bereavement questionnaire (appendix 4)

How are we going to get there?

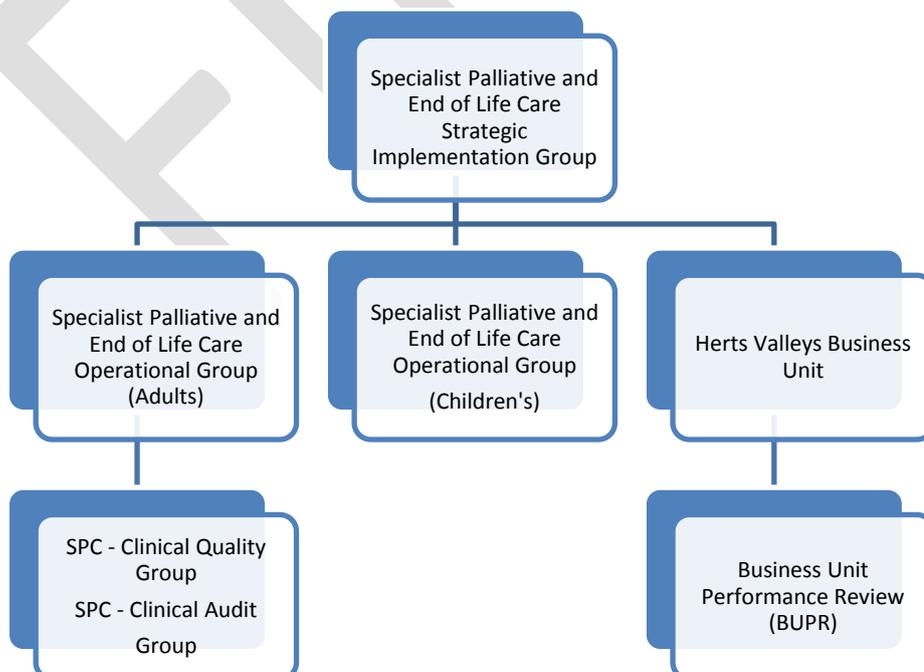
HCT is committed to delivering this End of Life Care Vision and Strategy for Adults and Children. There are committed, highly skilled experienced and enthusiastic professionals already providing high quality, person centred coordinated End of Life Care for some patients. What this strategy will provide is the framework to enable all staff in all services to deliver the high quality, person centred coordinated care every patient deserves and needs.

To enable the delivery of the work streams required, a Strategic Implementation Group (SIG) will be developed to oversee the strategic direction, performance management and ensure overall assurance is provided to HCT, the CCG's and the Palliative Care System including our partner organisations.

This SIG will require an Operational Group of stakeholders to ensure development and delivery of a robust work plan. Working groups will be required.

Alongside the Strategic and Operational framework will remain the HCT Business Unit structure to ensure the on-going contractual requirements with local CCG's.

Proposed Governance structure:



Dependencies:

This is a supporting strategy of the clinical Strategy and has dependencies to a greater or lesser extent with all other strategies. There is a golden thread of connection between the End of Life Care Vision and Strategy for Adults and Children and the following HCT organisational strategies:

Estates

End of Life Care will be provided in the most appropriate setting according to the patient's needs. The needs of this group of service users and their carers will be taken into account as the Estates Strategy is implemented.

Workforce

The delivery of the workforce strategy is vital to the delivery of the End of Life Care strategy as a core component is having the appropriate number of well trained and competent staff to deliver EOL care and leadership.

IM&T

The IM&T strategy supports the delivery of the End of Life Care strategy through development of internal and external systems and capability.

Quality

The End of Life Care strategy relies upon the delivery and measurement of quality within HCT services to provide assurance and focus on areas for improvement, and therefore the quality strategy is vital to the delivery of the End of Life Care strategy.

Appendix 1:

Influencing factors on access and quality of End of Life Care in HCT:

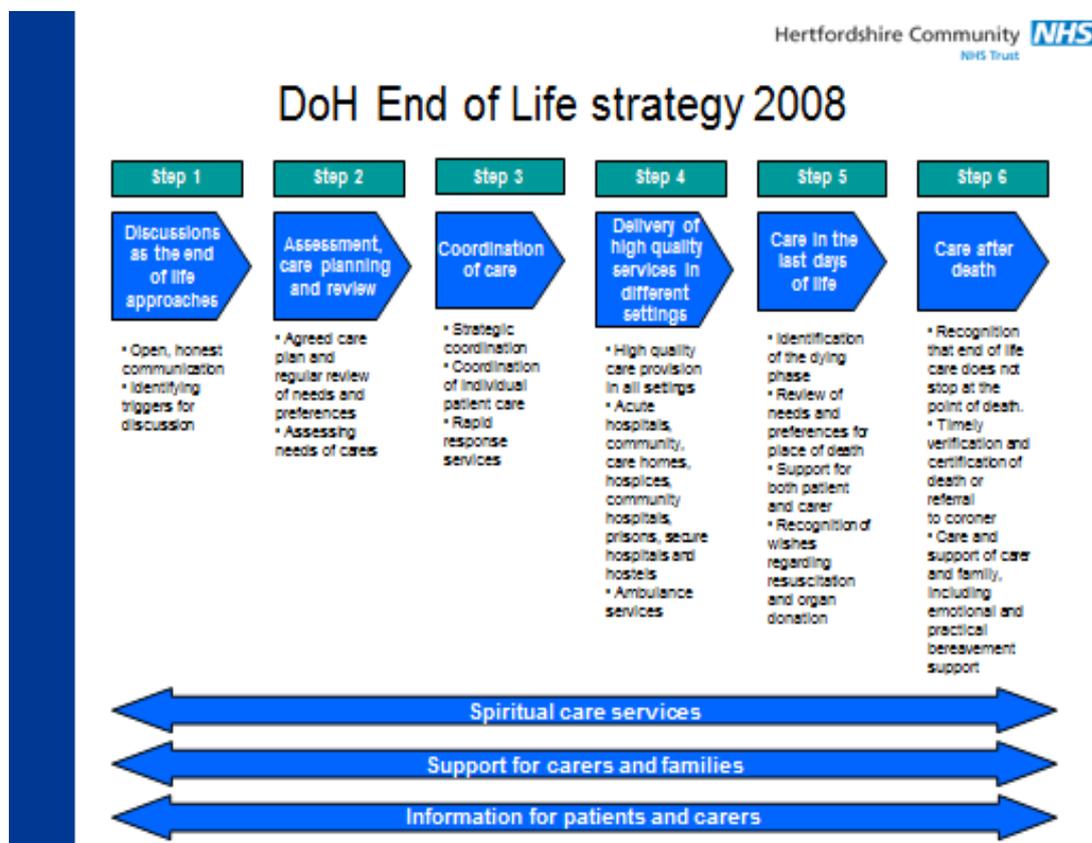
HCT has identified for adult services the following influencing factors on access and quality but recognise in some cases these are also applicable across children's services.

1. Limited identification of people likely to be in the last year of life;
 - A. There is variable awareness of how to identify and document those who are likely to be in the last year of life. This involves use of the 'surprise' question "Would I be surprised if this person died within the next 6-12 months?"
 - B. Prognostic indicator tools provide some guidance on life expectancy, but it can be difficult to identify the last year of life and staff may be concerned about the impact if the prediction proves inaccurate.
2. Social factors and fear of talking about and facing death as a society;
 - A. This affects staff as well as patients, their carer's and families
 - B. It can result in delayed access to services and reduced community support
3. Variable competence and confidence of non-specialist palliative care staff;
 - A. Not all staff delivering care in the last year of life will have received any specific education or training.
 - B. Variable confidence of staff in delivering End of Life Care
 - C. Some Staff not aware that End of Life Care is part of their role.
 - D. Not all staff know how to access support and timely advice
4. Capacity and referral criteria of HCT Specialist Palliative Care Services
 - A. There has been an annual increase in the number of patients seen by Specialist Palliative Care services in HCT
 - B. Specialist Palliative Care services deliver complex care and support others in the delivery of all other End of Life Care through clinical triage and education
 - C. Once the episode of specialist palliative care is complete, the patient is discharged to generalist services e.g. District Nurse or General Practitioner
5. Variable care coordination and proactive care planning
 - A. Case management is variable and the coordinator role is currently undefined
 - B. Capacity of generalist staff can be an issue
 - C. Variable opportunities for patients to do advance care planning
6. Delays in access to relevant equipment
7. Several points of access to services for patients, carers and staff to receive the support they require resulting in confusion and a lack of consistency for those trying to access the service
8. Culture of care which does not always maximise self-management or maintaining independence
 - A. Late referrals in last days or weeks of life do not allow early self-management
9. lack of accurate timely data regarding current HCT performance and clinical outcomes

- A. variation in clinical tools used makes routine meaningful data collection challenging
 - B. data completion by clinical staff is variable in End of Life Care
 - C. no clinical outcomes routinely collected trust-wide in End of Life Care
 - D. activity within Core Services for delivering End of Life Care is not routinely and consistently recorded or known
10. Lack of regular organisational clinical audit of End of Life Care
- A. Clinical audit has been carried out in Specialist Palliative Care with limited influence over improving End of Life Care across the whole organisation.
 - B. An audit of End of Life Care was carried out in ICT Teams in 2012
11. Lack of agreed HCT-wide policy, guidelines and processes to guide all clinical staff to ensure each patient receives high quality, equitable and person-centred End of Life Care
12. End of Life Care is delivered by multiple agencies including statutory and voluntary sectors
- A. This can mean uncertainty around accountability
 - B. This can lead to delays which result in increased patient suffering or unnecessary admission to hospice / hospital
 - C. It is confusing for patients to know who to contact and what they do
 - D. It is confusing for professionals to know who to contact

Appendix 2:

End of Life Care Pathway



This approach has been routine in HCT specialist palliative care service for many years. The challenge is how this approach can be experienced by a larger number of people

Systematic approach - the End of Life Care pathway:

The National six step standardised quality care pathway approach for delivery of care for individuals will become *routine* and expected for all people in the last year of life in Hertfordshire.

Step 1: Identification of people approaching the end of life and initiating discussions about preferences for end of life care;

We will work with local partners, both statutory and independent sectors, to ensure early identification of many more people in the last year of life and addition to the Register held in Primary care. Through prioritisation and appropriate staff training, these people will be given the opportunity to discuss their preferences for end of life care which will be suitably documented.

Promoting community awareness and involvement in End of Life Care:

We will develop and take opportunities to improve community awareness of End of Life Care including our own staff, through communications and attendance at relevant events. We will

work with partners, carers and voluntary organisations to promote community engagement and thinking agree better ways to deliver End of Life Care within their communities.

Step 2: Care Planning – assessing needs and preferences, agreeing a care plan to reflect these and reviewing these regularly

Following recognition of any person in the community as likely to be in the last year of life, clinical triage and a Holistic Needs Assessment will be carried out. This will be carried out by the right professional, who is part of a much larger trained workforce, including Allied Healthcare Professionals, delivering End of Life Care. The assessment will incorporate physical, psychological, social and spiritual needs along with information needs, current physical activity and carer's needs.

Following a Holistic Needs Assessment, the single care plan will include appropriate information, signposting, self-management, advance care planning, carer support and subsequent access to coordinated care as required. A feedback system via the integrated care team will enable discussion at GP surgery-based Palliative Care MDTs, (also called Gold Standards Framework meetings). Specialist palliative care intervention, either within HCT or hospice provided, will be accessed swiftly when needed.

Advance Care Planning:

This is a voluntary process, resulting in a patient-held document. This process will be offered early where appropriate, and it is helpful if a patient has already begun to address these issues through community awareness or other healthcare professionals. It is usually a process rather than a one-off event, and patients and staff will use accurate information in order for it to be done well. The plan might include personalised goals and wishes, ceilings of treatment, advance decisions to refuse treatment, preferred place of care and death. It will be revisited with the patient as circumstances change, and electronic documentation updated accordingly, including Electronic Palliative Care Coordination system (EPaCCs) when available.

Step 3: Coordination of Care

This will be at locality level within the Integrated Care teams, working closely with GPs and other specialists involved.

At GP Practice level clinical coordination will happen at the Palliative Care meetings (also called Gold Standard Framework meetings) with local community NHS and hospice teams. Through careful preparation by HCT staff, these meetings will be an opportunity to discuss adding people to the GP End of Life Care Register.

Within each locality Integrated Care Team there will be regular multidisciplinary clinical meetings about patients at the end of life to ensure high quality care is delivered in an effective, coordinated way. We will proactively engage hospice staff to participate in these meetings and base themselves within localities to drive up the overall quality of seamless End of Life Care.

Care Coordination through keyworker role:

There will be a named keyworker for each patient in the last year of life. The role will be clearly defined across Herts and the named keyworker will take responsibility for ensuring access to proactive coordinated healthcare in keeping with the patient's preferences and goals. The keyworker may be any suitably qualified and trained Healthcare Professional. It is acknowledged that the keyworker may change as the person's needs and preferences change.

Electronic Palliative Care Coordination Systems:

We will engage with local CCGs and other providers to maximise the opportunities available to improve coordination and to provide care according to people's wishes with the introduction of Electronic Palliative Care Coordination Systems (EPaCCs). This will allow timely information to be available to those caring and evidence from elsewhere suggests it will reduce hospital admissions.

Single Point of Access to Palliative and End of Life Care:

There will be a single telephone number for community referrals, and for patients and carers to ring when they require urgent help 24/7. Following triage, telephone advice and face to face assessment by the most appropriate professional, including the voluntary sector, will rapidly follow where required in order to maximise the chance of patients remaining at home, and reduce the likelihood of inappropriate hospital admission. The telephone centre will have access to EPaCCs which will allow those providers without access to this system to request important details to inform urgent care.

Access to equipment and medicines:

There will be a clear understanding of how to access medicines and equipment in advance and as part of a rapid response to changing condition.

Step 4: Delivery of High Quality Services in all locations:

Through training and by creating locality End of Life Care champions we will ensure high quality person-centred services are delivered by all staff. We will develop an End of Life Care policy, ensure accurate timely data is captured, create guidelines and routinely monitor clinical outcomes,

We will agree triggers for a Specialist Palliative Care review to ensure access for patients who most need specialist intervention. We will work with other health and social care providers to ensure patient's and carer's needs are addressed, and patient preferences are prioritised.

We will enable early hospital discharge and prevention of hospital admission at the End of Life through seamless proactive care and rapid response.

To supplement formal training, End of Life Care will be routinely highlighted through trust internal and external communications to increase awareness and link to the 6Cs. Staff will increasingly understand how psychological, social and spiritual needs

affect patients suffering and be competent to provide a person-centred approach to care.

Step 5: Management of the last days of life:

We will ensure the Five Priorities for Care, described in One Chance to get it Right 2014, are systematically used by all staff in providing individualized care for people in the last days of life. Following a decision by the patient's Senior Responsible Clinician, which in the community would usually be the patient's GP, that the patient is thought to be in the last few days of life, we will use the Five Priorities for Care to guide all input. This will be documented on a Care Plan which is designed for the last few days of life and shared with other providers (e.g. Hospice at Home) as appropriate to ensure the best care.

Five Priorities for Care

When it is thought that a person may die within the next few days or hours of life:

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

Step 6: Care after death and bereavement:

We will ensure best practice after death, including meeting the patient's cultural and religious needs.

We will ensure systematic access to bereavement assessment using the agreed Hertfordshire-wide tool and signpost bereaved carers and family to available information and support. Skilled staff will recognise people at increased risk of complicated bereavement and know where they can access pre-bereavement support as well as access urgent bereavement support when required.

Support for carers, both during a person's illness and after their death:

We will improve support of carers through education of all clinical staff regarding identification and support of carers. This will involve assessment of what they need to help them care, provision of timely information and signposting, including bereavement support.

Specialist advice:

We will work with other providers to ensure that specialist nursing face to face assessments remains available 7 days a week 9-5 and actively explore opportunities to extend this service, and telephone advice is available 24hrs a day. The specialist advisor will be able to view the clinical record to give more individualised guidance.

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NICE End of Life/Palliative Care Quality Statements:

1. People approaching the end of life are identified in a timely way.
2. People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.
3. People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.
4. People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.
5. People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.
6. People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.
7. Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.
8. People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.
9. People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.
10. People approaching the end of life that may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.
11. People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication.
12. The body of a person who has died is cared for in a culturally sensitive and dignified manner.
13. Families and carers of people who have died receive timely verification and certification of the death.
14. People closely affected by a death are communicated with in a sensitive way and are offered immediate and on-going bereavement, emotional and spiritual support appropriate to their needs and preferences.
15. Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.
16. Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support.

Actions taken to date:

Leadership:

In 2014 a HCT Executive Lead and Non-Executive Lead for End of Life Care were agreed and appointed.

Changes were made to the existing Consultant in Palliative Medicine role in 2014 to become Hertfordshire-wide and Lead Clinician for a new HCT Palliative and End of Life Care Clinical Network for Adults. Both palliative care team CNS managers became Clinical Quality Leads (CQLs) for palliative care in March 2014, and the North CQL remit was expanded to include East Hertfordshire.

Clinical Leadership in End of life and palliative care for children has been identified and needs to be established formally within HCT

The clinical leads and manager control the work plan agenda.

Formation of HCT Palliative and End of Life Care Clinical Network August 2014:

In adult services currently there are four clinical leads (2 clinical quality leads, 1 Consultant, 1 psychologist) plus management and all Specialist Palliative Care clinical staff are members of the clinical network. There are agreed Terms of Reference, updated after six months, then annually, and a role description for the Network Chair. There is executive and non-executive attendance at the 2 monthly network committee meetings to oversee the work plan, risk register, specialist palliative care quality meeting and other relevant matters. The work feeds into the HCT Adult Delivery Model group, and the Lead Clinician updates the HCT Executive lead for End of Life Care regularly.

October 2015 it was agreed to widen network membership, separate strategic and operational meetings and that the Executive Lead for End of Life Care should attend the meetings, rather than rolling Executive attendance.

There is also a quality meeting attended only by Specialist Palliative Care clinicians every two months. This group oversees Specialist Palliative Care risks, patient experience, audit, practice-changing learning from education, sharing of new clinical guidelines and other required updates relating to Specialist Palliative Care and End of Life Care.

Engagement:

During a public Trust Board Event in May 2013 the Trust show-cased its Palliative and End of Life Care service to attendees of the event. This included feedback from individual patients and carers about their experiences, and discussions involving commissioners, patients, carers and other stakeholders. This set the scene as a start to creating a dialogue with the public including partners and commissioners within the Hertfordshire community, towards developing our End of Life Care Strategy. This event was focussed on Adult Services.

At the HCT Leading Lights event in June 2015 and also the HCT AGM in September 2015, Palliative and End of Life Care network has engaged with people to increase understanding of Palliative and End of Life Care within HCT. There was particular emphasis on both individual choice at the end of life and the Five Priorities for Care.

The Children's Community Nursing Service (West Hertfordshire) was recognised in the Leading Lights awards in 2014 for their end of life care for children at home. The award recognised that in one particular example the team had worked with great ambition to be able to persuade a tertiary centre that home care which was desperately wanted by the child was possible and appropriate.

In September 2015 there was a presentation to the HCT Board of the Parliamentary Ombudsman report "*Dying without Dignity*" and local patient qualitative feedback on patient questionnaire (PROMs 2015) and bereavement survey was themed accordingly.

The Consultant and Clinical Quality Leads (CQL's) and other members of the wider SPC senior team attend both CCG stakeholder groups and are engaged in discussions with other providers and Commissioners to improve integration and patient care.

Integration of Specialist Palliative Care Community Nurse Specialists:

In March 2014 the HCT palliative CNS's were moved into the Integrated Community Teams in six of the localities of Hertfordshire (West Herts and North Herts). The purpose of this was to maximise their impact on Palliative Care/End of Life services that patients receive by working more closely with wider members of the team, most notably community nurses. This involved change of managers for palliative care staff and expansion of responsibility within each locality involved. East Hertfordshire has no SPC staff as this role is covered by Isabel Hospice, so no changes were made within these four localities for adult services.

Introduction of patient reported outcome measures and bereavement survey:

A survey was developed using VOICES I-statements to measure integration and this baseline Patient Reported Outcome Measures questionnaire was completed in 2014. Results were presented widely to CCGs, social care and all Hertfordshire providers of palliative care. The work has recently been repeated in 2015 to inform on progress made to date.

In addition the first specialist palliative care bereavement survey of consecutive deaths in summer 2014 took place and recommendations have been developed to inform adult's service improvement.

Education:

The specialist palliative care team have been involved in multi-organisational delivery of Herts / Beds education on Palliative and End of Life Care for many years. In 2013-14 HCT also took part in a GP End of Life Care education project through East of England (survey of adult

services only). Since 2015 a 2 day palliative care induction programme is in place for all non-clinical staff.

Measurement of Adult workforce confidence in adult End of Life Care:

A workforce confidence questionnaire for all adult services clinicians in HCT was adapted and implemented early 2015 and demonstrates lack of confidence in some specific important areas such as Advance Care Planning.

Macmillan Adult Workforce Transformation:

Through working with Macmillan, we have successfully bid for 50% funding for four educators for two years to help transform our whole adult services workforce into one which is much more confident and competent to deliver person-centred End of Life Care. Included in the bid is evaluation of our whole programme, which includes other changes made within integration.

Increasing Palliative and End of Life Care beyond Cancer:

There are regular monthly meetings with HCT specialist palliative care and each of the following services working together to raise awareness of Palliative and End of Life Care, plan complex care and improve joint education for adults.

Neuro-palliative Multidisciplinary Team Meetings - Established 2008. In 2012 a designated coordinator role was put in place to further improve the coordination of care

Learning disability / Palliative Care Multidisciplinary Meetings - Established in 2010. A joint resource pack has been produced as a result.

Heart Failure / Palliative Care

Multidisciplinary Meeting established in 2012 in West Hertfordshire

In North Herts a Care of the Elderly consultant refers patients with heart failure to SPC when no longer able to attend hospital appointments.

Appendix 5:

Size of the gap – statistics & evidence:

Population studies suggest that 69%-82% (average 75%) of all deaths have palliative care needs. Specialist Palliative Care providers, both statutory and independent, across Hertfordshire assessed approximately 25% of all those who died in 2012 (Mount Vernon Cancer Network specialist palliative care mapping).

With annual deaths in Hertfordshire at approximately 9,200 per year, 75% of this number equates to approx. 6900 deaths who will have palliative care needs. The studies above and local mapping suggest 25% of patients (approximately 2300) are accessing specialist palliative care services, either statutory or voluntary. More importantly, the studies suggest a further approximately 4600 patients may be receiving some elements of palliative care or no palliative care support at all.

Profile of Adult deaths by age:

Of the 9200 deaths per year in Hertfordshire, 85% of them are in people over 65 years old. The number of Hertfordshire people aged 65 and over is estimated to increase by 70% between 2010 and 2035 (171,400 to 294,000 people) and the numbers of people dying each year in Hertfordshire will continue to increase accordingly. The age at which death occurs will increase. The aging population in Hertfordshire will have a substantial impact on the requirements for effective End of Life Care within the community.

In Hertfordshire, the number of deaths in people aged over 85 increased between 2004 and 2012, while the number decreased for people aged 65-84, similar to national trends. Those who are the most elderly or the 'oldest old' have a greater propensity to frailty and multiple co-morbidities. In 2012, 9,249 people died, of which 1,357 (14.7%) were aged 0-64 years, 4,120 (44.5%) were 65-84 years and 3,772 (40.8%) were 85 and over (see Fig 1).

Figure 1: Number of Adult Deaths in Hertfordshire by Age Group (2004 – 2012)



Profile of Children’s Death by age:

The number of child deaths within the West Essex CCG catchment for the last year is currently not available but on current evidence would be expected to be 27 based on population.

Figure 2 - Number of deaths in children by CCG in Hertfordshire for the last year

Deaths from Child Health information in last year														
CCG Group	Age Groups	Month of Death											Grand Total	
		2014 11	2014 12	2015 01	2015 02	2015 03	2015 04	2015 05	2015 06	2015 07	2015 08	2015 09		2015 10
NHS East and North Hertfordshire CCG	under 1 year	2	4	5	7	3	4	5	4	1	4	3		42
	1-4 years	1	2				1	1			2	1		8
	5-18 years		1						2		2			5
NHS Herts Valleys CCG	under 1 year	5	4	3	2	5	3	3	7	1	2	1	5	41
	1-4 years	1			1			1					2	5
	5-18 years		2	2		2		1	1	1			1	10
Unknown - Herts Address	under 1 year	3	2	2	2	3	1	2	1	1		3	2	22
	5-18 years			1										1
Other	under 1 year		2	1		1		2	2		2			10
	1-4 years			1			1		1					3
	5-18 years							1				1		2
Grand Total		12	17	15	12	14	10	16	18	4	12	9	10	149

Profile of Adult deaths by diagnosis of those patients known to HCT:

In 2014 a snapshot analysis in HCT demonstrated a disproportionate number of the sample had cancer (57%) and neurological conditions (8%) with relatively few people with dementia (2%), heart failure (5%) or respiratory conditions (10%). This suggests that the numbers of people with heart failure, COPD and dementia are vastly under-identified (see Fig 3).

Figure 3: HCT Snapshot of Adult Deaths by Diagnosis in 2014:

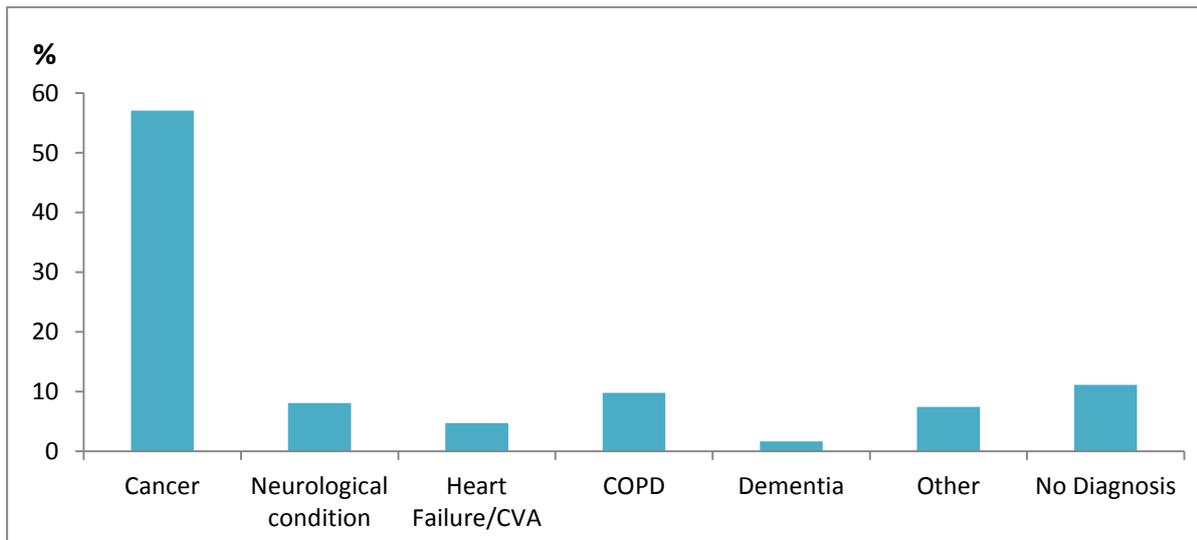
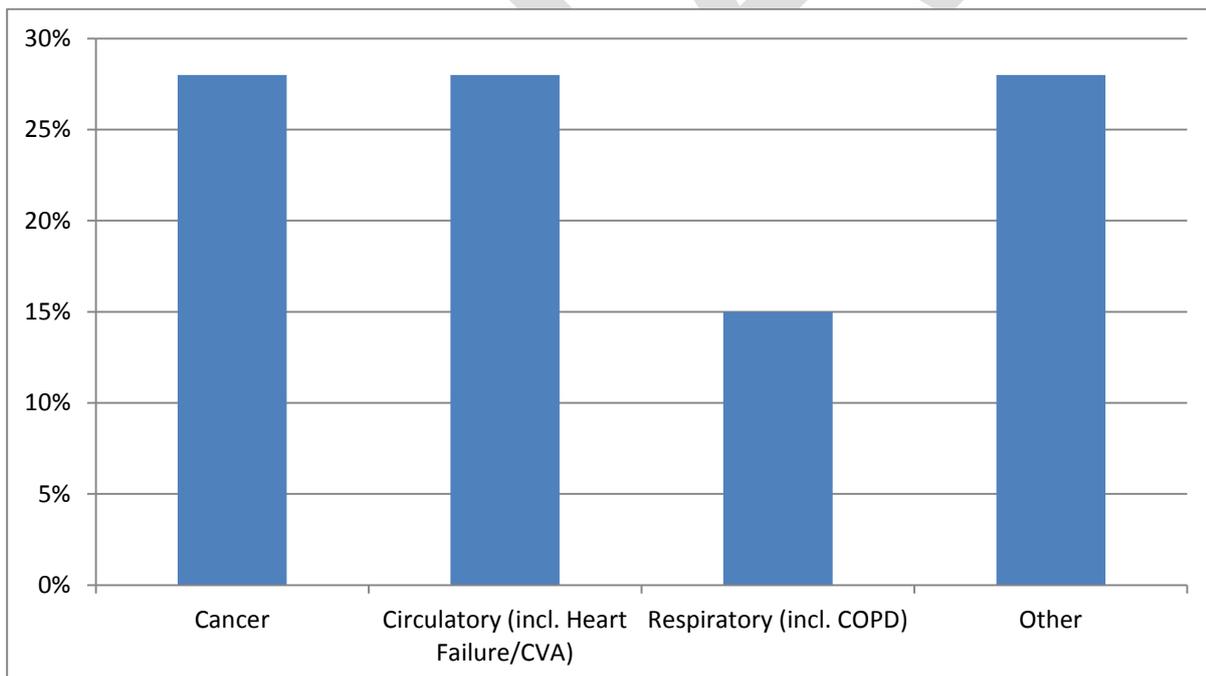


Figure 4: Hertfordshire Causes of Adult Death by Diagnosis



Profile of identification of Adults in last year of life by geography:

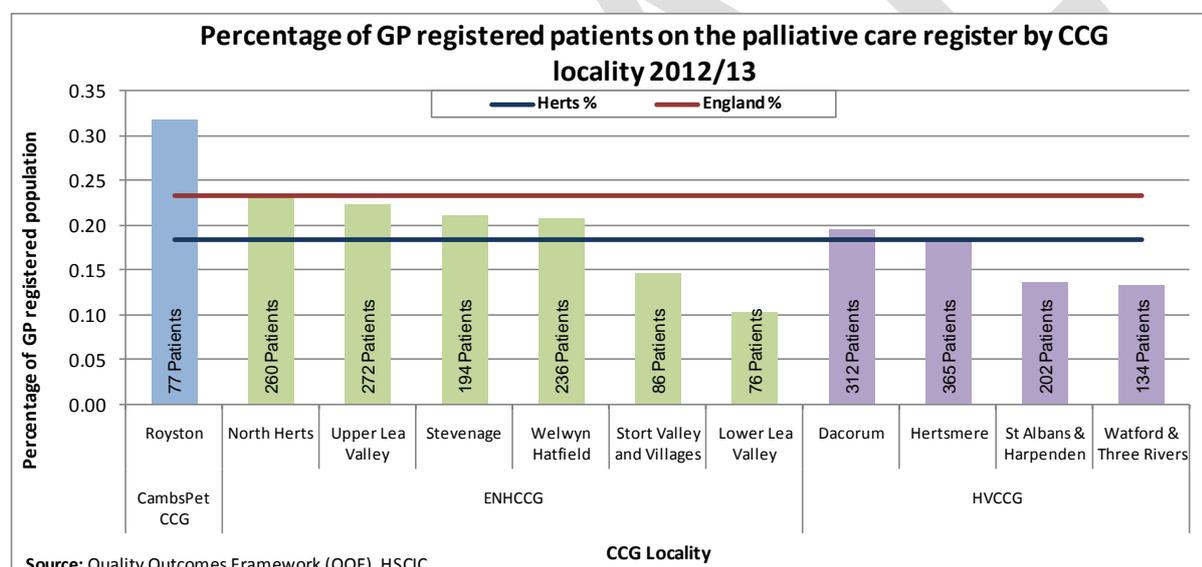
An End of Life Care GP register for adults was implemented as part of the Quality and Outcome Framework to improve the identification of people thought to be in the last year of life and drive up the quality of care they received. The percentage of patients on the End of Life Care register across Hertfordshire was lower than the England average. The Dying Matters “*Know Your 1%*” campaign is targeted towards

GPs and is based on the premise that around 1% of a practice’s population will die in any year and that the majority of these deaths could be predicted.

Both CCG’s in Hertfordshire are looking to extend the percentage to 3% in order to capture those in the last years of life where prognosis is difficult to predict, incorporating more people with frailty and multiple Long Term Conditions requiring multidisciplinary proactive care.

The graph below (Figure 4) shows that in 2012/13 GP practices had significant variation of GP registered patients on a palliative care register. Overall NHS East and North Herts CCG has a higher proportion than NHS Herts Valleys CCG (0.21% compared to 0.17%) although there is variation across the CCG localities.

Figure 4: Percentage of GP Registered Patients on the Palliative Care Register by CCG Locality 2012 – 13



In Herts Community Trust two Systm1 snapshots a year apart in 2014 and 2015 have shown an increase from 512 to 529 patients known to be in the last year of life at any one time (see Fig 5). However, there are significant geographical variations within that, with least numbers identified in East Herts quadrant (4 localities) and most in North Herts/Royston.

It is suspected that many more patients are known to HCT staff, but not identified and appropriately documented as being at the End of Life. According to national statistics, the total could be around ten times the current figure if everyone was to be identified.

Profile of identification of Adults in last year of life by geography:

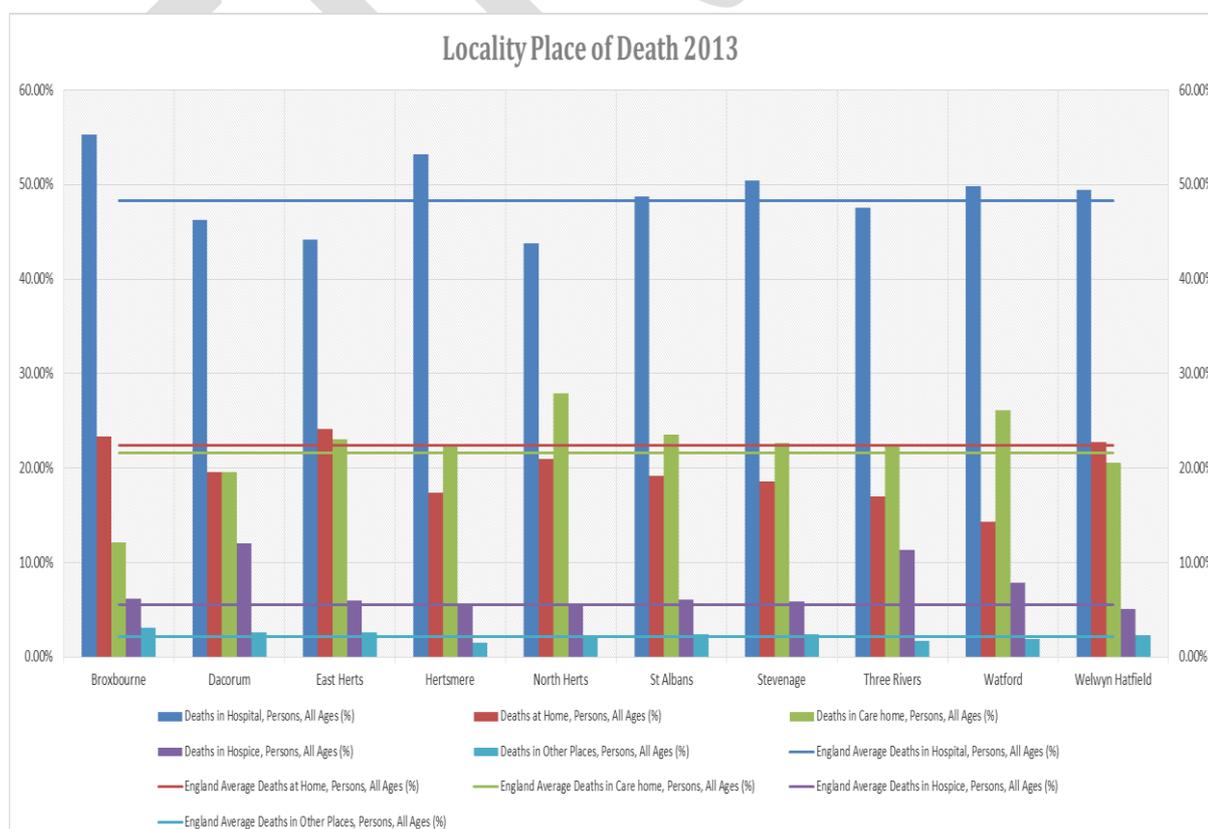
Figure 5: Snapshots number of Adults identified as being in last year of life on SystmOne in 2014 and 2015:

	March 2014	March 2015
Total	512	529
East Herts	71	68
North Herts	183	223
NW Herts	104	112
SW Herts	155	126

IMPACT:

Figure 6: Profile of where people currently die by geography:

The chart below demonstrates variation in place of death across different localities



Variation in whether people are able to die in their Preferred Place of Death:

A Mount Vernon Cancer Network prospective audit of 708 consecutive patients “*Do patients referred to Specialist Palliative Care die where they wish?*” Dr. C. Scholes, R. Allan, 2011.” showed that of the 60% with known Preferred Place of Death, 82% of these patients died there and 13% died in hospital. Of the 40% of patients with no known preferred place of death, 76% of these patients died in hospital. This was followed by an Analysis of the post-death audit tools completed in primary care in Hertfordshire 2012 (A Jamali, C Scholes). This showed that twice as many patients had the opportunity for Advance Care Planning if known to Specialist Palliative Care. Overall 50% of patients not known to SPC were deemed inappropriate for advance care planning compared to 14% known to SPC.

F E M I N A L

Appendix 6:

OUTCOME:

Hospital admissions and deaths in hospital for Adults:

National data indicates that in the final 30 days of life the number of hospital episodes is three times the figure for the penultimate month. In addition recent evidence suggests that nearly 30% of adult hospital inpatients at any one time are in the last year of life (Scott Murray, 2015).

Patients involved with a Specialist Palliative Care service tend to have better outcomes, both nationally and locally. This is exemplified by the higher numbers offered advance care planning and dying in their preferred place within the adult service.

Pain management has been highlighted in the National Survey of Bereaved People (VOICES), 2013 as needing improvement in adult community End of Life Care with just 18% reporting effective pain relief compared with 62% in hospices.

Recent patient outcomes questionnaire and bereavement questionnaires in HCT demonstrate excellence in practice, but some feedback also indicates a variation from this practice in some cases. For example, there is variation in whether people are offered Advance Care Planning, coordinated care through named keyworker and emotional support for carers.

In recent years in England, 51% of people have died in hospital while 22% have died at home. This is broadly comparable with the Hertfordshire position where 52% die in hospital and around 19% die at home.

Recent analysis of East and North Herts Hospitals Trust Standardised Hospital Mortality Index (SHMI) suggests that more patients in last days and weeks of life are referred there and die, compared to the national average for adults.

Hospital admissions and deaths in hospital for Children:

Data for children is much smaller but in the last two years there has only been one young person who was expected to die that did so in Watford General Hospital. There have been six children each year choosing to die at home.

Preference on place of death for adults:

A survey, funded by the European commission to coordinate end of life care research, found that 64% of those who live in England would prefer to die at their home when they were faced with serious illness or less than one year to live while 29% of people preferred Hospices and Palliative care units.

In Hertfordshire patients known to HCT in the last year of life in 2014-15, of those who had a documented preferred place of death, 65% expressed a preference for a home death, 25% a hospice death, 8% a care home death and 2% a hospital death. This closely reflects the preferences expressed by the general population.

The Integrated Community Teams support people in the last few days of life who wish to die at home, and a recent snapshot audit of place of death 2015 showed that half of patients cared for in the last year of life by HCT died in their usual place of residence, a third died in a local hospice and a sixth died in hospital.

Preference on place of death for children:

Home is usually the place of choice for children and young people.

F E M A L E