Birmingham East and North NHS
Primary Care Trust

Redesign and Commissioning Directorate

September 2007

Business Case for Redesign of End of Life Care

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1. Executive Summary

The Palliative and Supportive Care Strategy for Birmingham East and North PCT (BEN PCT) [1], describes an aim to provide a 'gold standard' of care for all patients in their last year of life. ' All patients nearing the End of Life Care (EoLC) are identified as being special people or VIPs, their needs assessed and care planned and provided for, enabling them to live well and die well in the place and in the manner of their choosing'.

There are many local and national themes that support the redesign of End of Life and Palliative Care services such as: the White paper: 'Our Health, Our Care, Our Say' [2], patient choice, the Pan Birmingham Palliative Care Network Strategy [3] and the developing national strategy for EoLC

Current provision of EoLC services within BEN PCT is mixed and lacking in defined patient pathways. These services are also generally provided for patients with cancer, but not those with other life limiting illness such as heart failure, renal failure and chronic obstructive pulmonary disease. There are, at present, limited resources to provide EoLC services within the community, and with an ageing population who are more likely to suffer from conditions that need EoLC services, demand is likely to continue rising.

Few people die at home which would generally be the preference for the majority. Therefore, the aim is to adapt and commission a range of services for EoLC which are owned by clinicians, patients and carers. These commissioned services will reduce gaps in service provision and increase choice.

This document sets out the proposal to commission a redesigned care pathway for all patients identified as suffering from an advanced disease from which they will die. This will include will increasing capacity within EoLC services in the community. The cost of redesign will be offset by reductions in emergency hospital admissions and individual complex care packages.

The redesigned care pathway will also take into account the diversity of our population to ensure that the cultural, religious and personal beliefs of individuals will be respected and services tailored to take these into account.

2. Introduction

The purpose of this business case is to outline the plans for redesign of EoLC within BEN PCT, and the commissioning of a range of new and / or redesigned serv ices to address the identified service gaps in the EoLC pathway.

The document will detail the drivers for redesign, the different care models that have been considered, the financial impact of any changes and the impact upon patients and stakeholders. In addition, the business case also considers actions and timescales that will affect implementation of any changes to the care pathway.

It is intended that the business case will be used during public and stakeholder consultation. In particular, we will engage the different cultural and religious communities in BEN PCT to ensure their points of view are fed into this consultation. The final draft will be modified to accommodate the views expressed during consultation and will become the blue print for the redesign of EoLC services in BEN PCT.

It should be noted that the remodelled services are aimed at the needs of the majority. As such, the needs of children in their EoLC phase have not been specifically considered as these are rare within the BEN PCT population. However, the service model is not discriminatory and the services provided will be available to all adults in their EoLC phase, regardless of race, age, gender or disability.

3. Background

EoLC refers to the period when a patient with advanced and progressing disease, lives with the condition from which they will die. It includes patients with any chronic, progressive, eventually fatal illness and could be a period of weeks, months or years. There is much debate nationally about how the EoLC period is defined and how EoLC patients are identified.

Palliative care Is ‘an approach that improves the quality of life of patient and their families facing the problems 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 symptoms; physical psychological and spiritual. (World Health Organisation definition 2002).

Currently, service provision within BEN PCT is mixed and the quality of EoLC varies greatly depending upon a persons GP, disease area and local facilities. It is important that EoLC becomes mainstream with equal access and common pathways for all people within the BEN PCT population.

3.1 National Drivers

There are a number of national guidelines and policy documents which will inform any redesign of EoLC services. These are:

- The NHS Cancer Plan (2000) [5]
- National Service Framework (NSF) for Coronary Heart Disease (2000) [6]
- Building on the best: Choice, Responsiveness and Equity in the new NHS (2003) [7]
- NHS EoLC Programme (2004) [8]
- NICE guidance on Improving Supportive and Palliative Care for adults with cancer (2004) [9]
- Supportive and Palliative Care for advanced heart failure (2004) [10]
- The Health Select Committee inquiry into palliative care (2004) [11]
- NSF for long term Conditions (2005) [12]
- NSF for renal services (2005) [13]
- NHS Confederation recommendation on EoLC planning (Oct 2005) [14]
- The White Paper- our health our care our say (2006) [2]
- NHS Equality Scheme [15]
- Race Relations (Amendment) Act 2000 [16]
- Equality Act 2006 [17]

In addition, the National EoLC Strategy is due to be published in Autumn 2007. Early indications are that the Pan-Birmingham Palliative Care Strategy, and the contents of this document reflect National intentions.

'Our health, Our care, Our say'
The health and social care White Paper,: 'Our health, our care, our say" [2] was published in February 2006. It estimates that the number of over-65s with a chronic condition is doubling every decade, and that those who care for them are twice as likely as others to have health problems themselves.

There are a number of themes in this white paper which should influence the design of EoLC services:

- The promotion of flexible services that are tailored more to the health or social care needs of individuals and that offer service users more control and choice with the treatment they receive particularly for those with long term conditions.

- To ensure an urgent care strategy is developed that reduces unnecessary hospital admissions, improves the patient experience and results in patients being assessed and directed first time round to the right services.

- To improve the quality, care should be consistent regardless of where treatment is provided and that all health and social care providers should work together with a system-wide coordinated approach to urgent care.

- By 2008, the establishment of EoLC Networks to ensure that patients with terminal illness are cared for in a coordinated manner bringing in primary care services, social services, palliative care and hospital services. This will

necessitate investment in specialist palliative care, community services to provide rapid-response hospice-at-home services to patients in need.

- Carers will be supported by the New Deal for Carers and information service. An expert carers program, similar to the expert patient programs, will be established and provide training for carers to develop the skills required to take greater control over their health and the health of their dependents. Finally, short-term home-based respite support will be provided in every area for carers in crisis situations.

3.2 Local Drivers

Pan-Birmingham Palliative Care Network
The Network is a sub-group of the Pan Birmingham Cancer Network. These networks were set up to steer the direction of Cancer and Palliative Care Services at a Strategic Health Authority level in line with the National Cancer Action Plan.[5] The Palliative Care Network has finalised its strategy which was agreed by the predecessor Birmingham and Black Country Strategic Health Authority (BBCSHA).

BEN PCT Palliative and Supportive Care Strategy, [3] is aligned to the Pan Birmingham Strategy and the West Midlands Strategic Health Authority Strategy 'Investing in Health'[18], and supports the commissioning and redesign of current services to improve the range, appropriateness, effectiveness and responsiveness of EoLC services for local people.

4. The Vision

Dying in a place of their choosing is one of the most important ways people can take control in planning their own death. National research (Higginson 2003)[19] concluded that 11% of the population wanted to die in hospital, 26% in a hospice and 56% at home. The BBCSHA ran a similar study of its cancer patients and concluded that in BEN 10% would choose to die in hospital and 75% at home.

In reality, BBCSHA data shows that 43 %of BEN PCT residents with a diagnosis of cancer, died in hospital between 1996 and 2002, and 20% died in hospice settings. A higher percentage of patients with a diagnosis other than cancer died in hospital.

North Birmingham PCT - Place of Death Figures (2005)

	Hospice	Home	Care Home	Hospital
Cancer	20% **Decrease from 26% in 2003**	19% **Decrease from 25% in 2003**	8%	52% **Increase from 40% in 2003**
Pulmonary related	0%	16%	7%	77%
Heart Failure	0%	11%	14%	75%
Renal Failure	0%	6%	8%	85%
Dementia	0%	5%	47%	48%

Source: Cotterill S (2005)Deaths by PCT and establishment type, Department of Public Health and Epidemiology, University of Birmingham /ONS (2003)

East Birmingham PCT - Place of Death Figures (2005)

	Hospice	Home	Care Home	Hospital
Cancer	18% **Decrease from 24% in 2003**	23% **Decrease from 26% in 2003**	6%	52% **Increase from 43% in 2003**
Pulmonary related	0%	21%	6%	72%
Heart Failure	1%	12%	13%	74%
Renal Failure	0%	1%	6%	93%
Dementia	0%	5%	40%	55%

Source: Cotterill S (2005)Deaths by PCT and establishment type, Department of Public Health and Epidemiology, University of Birmingham /ONS (2003)

Therefore, a significant change in service provision needs to be made to enable people to die at home. (Or in a nursing home or special care centre if that is there usual place of residence).

Age Concern has undertaken significant research which concluded that the 'principles of a good death' [20] are:

- To know when death is coming and to understand what can be expected
- To be able to retain control of what happens
- To be afforded dignity and privacy
- To have control over pain relief and other symptoms
- To have choice and control over where death occurs (i.e. a home or elsewhere)
- To have access to any spiritual and emotional support required
- To have access to hospice care in any location, not only in hospital
- To have control over who is present and who shares the end
- To be able to issue advance directives which ensure wishes are respected
- To have time to say goodbye and control over other aspects of timing

- To be able to die when it is time to go and not have life prolonged pointlessly.

Therefore BEN PCT must ensure that each individual in their EoLC phase has access to a range of palliative and supportive care services, including alternative therapies, support groups and spiritual support. The patient and carer should feel supported throughout the entire EoLC pathway. Most importantly, people should be enabled to die in dignity in their place of choice. The EoLC pathway will reflect the 'principles of a good death'.

The vision is to provide a range of commissioned services for EoLC, which are owned by clinicians, patients and carers. These commissioned services will address gaps in service provision, provide care tailored to individual need and increase choice, whilst giving recognition to the fact that there are no formal guidelines for identification of patients in the EoLC phase and patients are not always easily identified.

5. Proposed Service Model

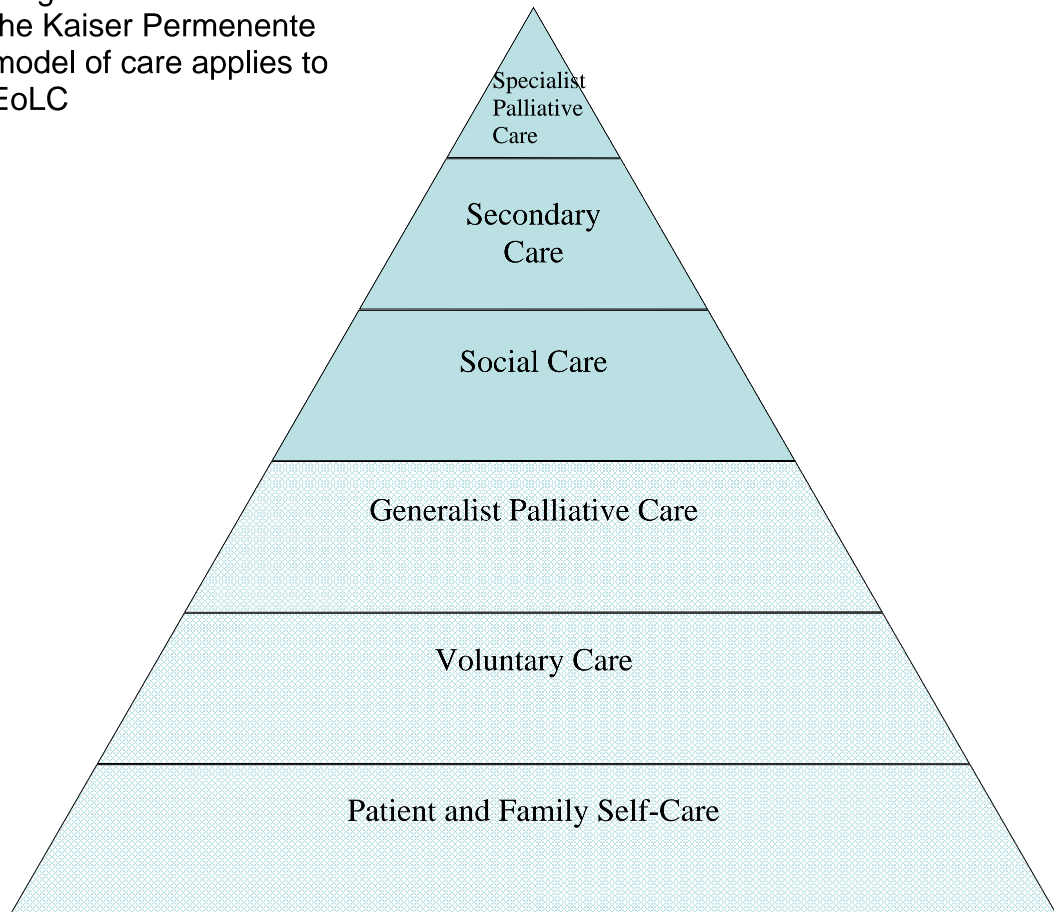
Patient choice is a major part of national policy to enable patients to choose where they wish to be treated. Palliative care patients in BEN PCT currently have little involvement in planning their own care. Options for care that would enable people to die at home are limited by resource and lack of co-ordination. As a result, whilst most of the BEN PCT population would choose to die at home, very few actually do.

The expression of personal choice, partly in the form of an advanced care plan and a statement on the preferred place of death, is the most important factor in enabling patient choice to be effected.

It is, therefore, essential that BEN PCT commissions local services that reflect the care preferences of its population.

The proposed palliative care and EoLC service would be an integrated approach following the Kaiser Permanente model for care provision. This reflects the Pan-Birmingham Palliative Care Network strategy [3] as well as BEN PCTs' commissioning strategy [1].

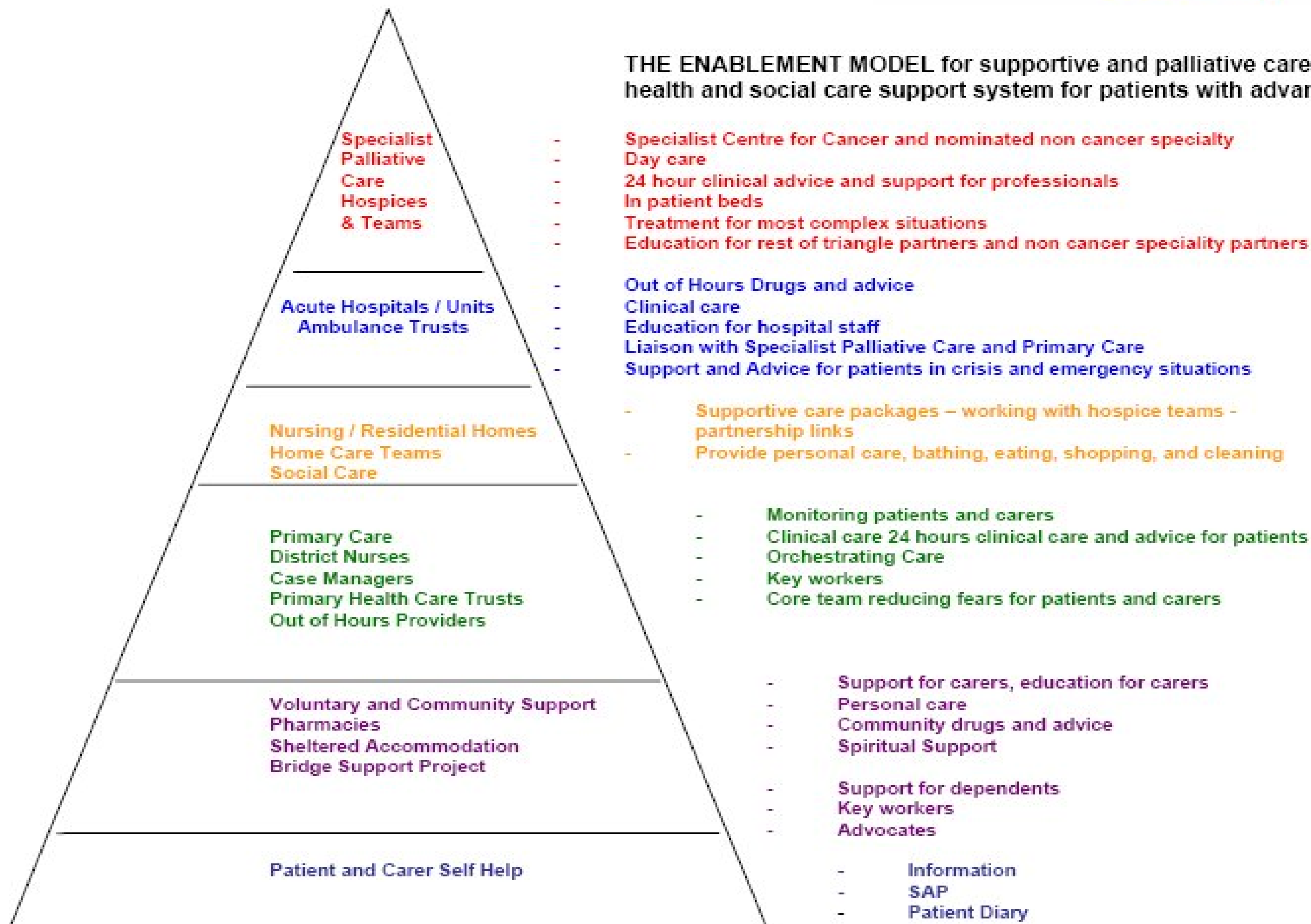
The diagram below shows how the Kaiser Permenante model applies to EoLC services. The aim being to keep the majority of patients in their own home by increasing support as it is needed. This support could be in the form of voluntary, generalist palliative and social care. Patients may receive specialist care in their own homes or in hospice settings. Patients may be admitted to hospital / hospice where it is necessary to stabilise their symptoms. Specialist palliative care services would be reserved for those patients with complex needs who are in their EoLC phase and for whom the other services are no longer sufficiently specialist to control symptoms and ensure a 'good death'. Patients may move up or down the care model as their individual needs and condition dictate.



This model is at the core of Birmingham's palliative care and cancer networks strategies, PCT's can benefit from economies of scale gained through joint commissioning of some of the services needed to deliver the remodelled care pathway.

As the model is a composite model it is important to realise that unless all elements of the model are in place, the care pathway will not deliver and patients will fall through service gaps into Acute care where they are likely to experience a poor death.

The model relies on a combined health and social care support system for patients with advanced disease and the following diagram provided by the pan-Birmingham Cancer Network, shows the services needed to deliver this model of care.


Pan-Birmingham NHS
Cancer Network
THE ENABLEMENT MODEL for supportive and palliative care - a combined health and social care support system for patients with advanced disease
Specialist Palliative Care Hospices & Teams
- Specialist Centre for Cancer and nominated non cancer specialty
- Day care
- 24 hour clinical advice and support for professionals
- In patient beds
- Treatment for most complex situations
- Education for rest of triangle partners and non cancer speciality partners
Acute Hospitals / Units Ambulance Trusts
- Out of Hours Drugs and advice
- Clinical care
- Education for hospital staff
- Liaison with Specialist Palliative Care and Primary Care
- Support and Advice for patients in crisis and emergency situations
Nursing / Residential Homes
Home Care Teams
Social Care
- Supportive care packages – working with hospice teams - partnership links
- Provide personal care, bathing, eating, shopping, and cleaning
Primary Care
District Nurses
Case Managers
Primary Health Care Trusts
Out of Hours Providers
- Monitoring patients and carers
- Clinical care 24 hours clinical care and advice for patients
- Orchestrating Care
- Key workers
- Core team reducing fears for patients and carers
Voluntary and Community Support
Pharmacies
Sheltered Accommodation
Bridge Support Project
- Support for carers, education for carers
- Personal care
- Community drugs and advice
- Spiritual Support
- Support for dependents
- Key workers
- Advocates
Patient and Carer Self Help
- Information
- SAP
- Patient Diary

6. Future Demand

Clinicians are traditionally reluctant to gauge life span or ‘risk of dying’ as it is difficult to be accurate. There have been cases where patients have survived a number of months or years beyond clinicians’ expectations.

The estimated demand for EoLC can be determined by the number of deaths per year.

In the financial year ending April 2007, there were 4375 deaths amongst the BEN PCT population. Of these, it is estimated that 2% were sudden or ‘surprise deaths’. This means that there were 4,287 deaths which could have been planned.

If 75% of the BEN PCT population have a home death, this means BEN PCT needs to build capacity for a minimum of 3,215 people to die at home each year. This estimate is based on a population survey and it is recognised that individuals may have expressed a different preference based upon the actual social, family and medical circumstances during their EoLC phase.

In addition, Britain has an ageing population this could also impact upon demand for palliative care and EoLC services as well as the ability of relatives and friends to undertake active roles as carers for people during their EoLC phase. The Office of National Statistics estimates that the proportion of the populations aged 65 and over is projected to increase from 16% in 2004 to 21% by 2024 when 10% of the population will be aged 75 or over.

Currently 1.5% of BEN PCT is aged 85 or over. Of these, many live alone and it is expected that the proportion of elderly people who live alone will increase as the population ages. The ratio of working age people to retired will fall from 7:1 to 4:1 in the next 20 years. Therefore, significant provision needs to be made for palliative and EoLC services in the years to come as there will be fewer friends and relatives able to care for people during their EoLC phase.

The proportion of minority ethnic groups varies greatly between wards in the PCT from 71% in Bordesley Green to 6% in Sheldon. Certain ethnic groups are more likely to be living in extended families, therefore, the introduction of new and different service models will take this into account.

The intermediate care team has commissioned a ‘point prevalence’ study. [21] The aim of this study is to determine the requirement for rehabilitation and EoLC for patients located in community intermediate care units and hospitals in North and East Birmingham as part of the modelling process for the two Care Centres in Perry Common and Sheldon Heath. The results of this study are expected to be published in Autumn 2007 and will further inform commissioning and redesign of EoLC services.

7. Current Service Provision

The service provision is generally reactive and often driven by crisis admission. This approach results in many inconsistencies in care which is determined by the individual healthcare professionals involved, the type of disease a patient has, finance and service availability at the time. Supportive care given to enable a patient and their family or carer to cope better with their illness is mainly only given to oncology patients. This random approach to patient care results in a high dependency upon hospital based care and Acute services.

The providers of community – based EoLC within BEN PCT are described in the table below which also details current capacity within each service. Specialist care is delivered by staff qualified to manage complex care needs during the EoLC phase. Generalist Care is provided by qualified and unqualified staff and volunteers

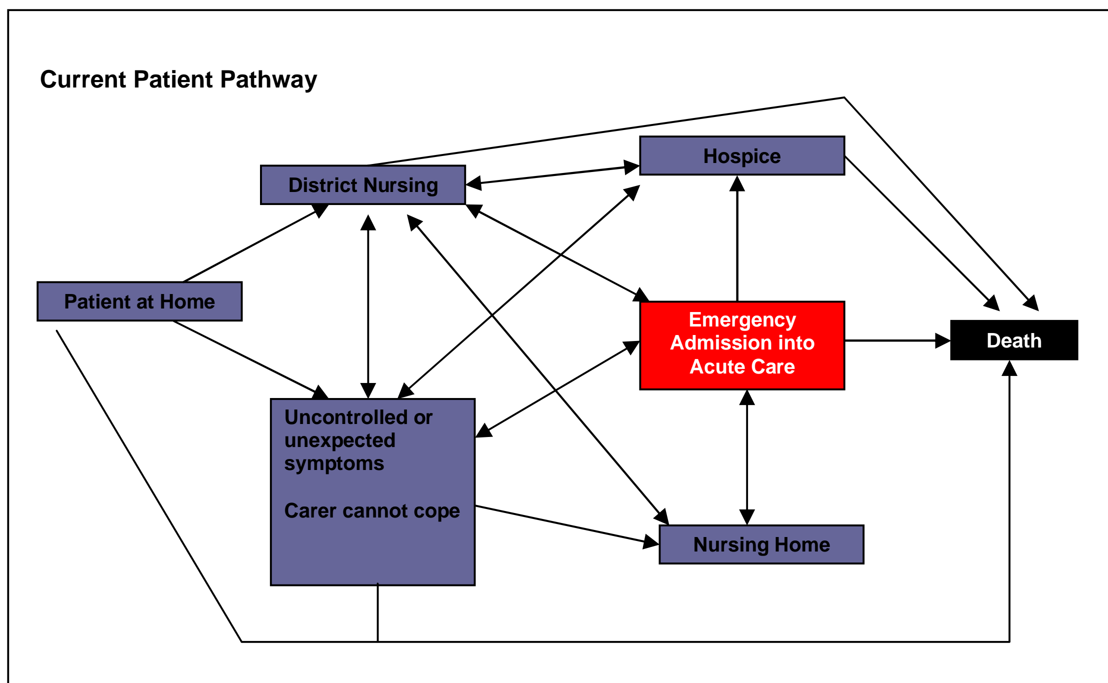
John Taylor Hospice *Specialist & Generalist Care*	16 Beds (Capacity for 21 but lacks funding). Provides inpatient unit, day therapy, complimentary therapies and a range of supportive, counselling and bereavement services for adults.
Marie Curie Hospice *Specialist & Generalist Care*	16 Beds. Because of location, patients are normally residents of the South parts of BEN PCT only. Provides inpatient unit, day therapy and range of supportive, counselling and bereavement services for adults and children.
St Giles Hospice *Specialist & Generalist Care*	24 Beds of which 4.5 beds are used by BEN PCT residents. Because of location, patients are normally the North residents of BEN PCT. In addition to the inpatient unit, the hospice has a hospice at home service, supportive programmes of care and specialist palliative care outpatients clinics . These services are to be relocated to a dedicated unit in the Sutton area in Autumn 2007. The hospice is a member of the NHS W Midlands Palliative Care Education Consortium and provides free palliative care training to all NHS staff within the old West Midlands Strategic Health Authority. .

St Mary's Hospice *Specialist & Generalist Care* *Specialist & Generalist Care*	Limited service provision for patients in Small Heath and Yardley Green. The hospice is a member of the NHS W Midlands Palliative Care Education Consortium and provides free palliative care training to all NHS staff within the old West Midlands Strategic Health Authority.
Macmillan Community CNS Support Team *Specialist Care*	4 WTE work with GP's and District Nurses giving advice on pain relief. These nurses do not provide hands-on patient care. They do have patient contact and provide symptom control advice and support for GP's and District Nurses. The service is hosted by John Taylor hospice. A smaller Macmillan team is hosted in Solihull and offers limited support to Yardley and Sheldon residents.
Hospice at Home *Generalist managed by Specialist Team*	Based at John Taylor Hospice this service was initially lottery funded. 5 WTE care assistants and 1 supervisor (trained nurse) provide general domestic support, direct patient care and 24 hour sitting services.
Nursing Home (Various) *Specialist Care*	45 city-wide contracted beds provide respite and EoLC.
District Nursing Team and Assertive Case Managers *Generalist Care*	This service is not consistent in its provision of services across the PCT because of local difference in referral criteria. However, in general the following are provided across the patch on a 24 hr basis: o Pain Relief o Assessments for equipment and homecare packages o Support and training for carers o Monitor patient and liaise with clinicians District Nurses do not provide personal care and domestic support.
Community Healthcare Co-ordinators *Generalist Care*	6WTE. Co-ordinators conduct reviews of patients in nursing homes on behalf of PCT's. There is some overlap with district nursing services and this can lead to confusion about the division of responsibilities for care management.
Complex Care Nursing Team *Generalist Care*	Provide health and personal care in peoples' homes for people who meet the Continuing Health Care criteria. They spend an average 4 hrs a day with each patient and also offer a night sitting service.

Freshwinds *Supportive Care*	Operating across the BEN PCT population, this organisation provides alternative therapies to people in their EoLC phase.

Because patients have no defined supportive care plan, and no single healthcare professional to take responsibility for their complete EoLC and palliative care, services are fragmented. In particular, there are no strong links between heart failure and respiratory care teams and palliative care services. Communication and referral routes are unclear and so only assertive patients or those cared for by some practitioners get proper access to the services they need. Little or no support is provided for carers.

There is no common patient pathway for a typical patient and care is difficult to cost on a per patient basis for this reason. The diagram below describes the current care pathway:



8. Gap Analysis

8.1 Death in Hospital Audit

43% of BEN PCT residents died in hospital between 1996 and 2002. The Birmingham Palliative Care Network undertook an audit of deaths in March 2007,[22] in Good Hope Hospital in the North of the BEN PCT area. The audit looked at people who died within 14 days of admission. The results showed that a significant number of these admissions could have been avoided if sufficient supportive care, including enhanced community based clinical support, for example dietetics, was available at home.

The audit concluded that the majority of these hospital admissions would have been avoided had appropriate supportive and palliative care services been available in the community. Few of these patients actually needed to access specialist hospital services.

8.2 Gold Standard Framework Register Audit

Dr George Young recently audited the notes of 59 patients all of whom died whilst on the Gold Standard Framework Register.[24] 67% of the patients were over the age of 70, more or less equal male to female ratio. His findings were as follows:

- Carer status is well noted, but social care access much less so.
- Nobody identified a key worker for each patient
- 101 emergency admissions in 6 months across the 59 patients, 17 of the patients had multiple admissions.
- Only one patient had an advanced care plan
- 37% of the patients did not have their EoLC symptoms recorded.
- 19 patients out of the 59 who died had monitoring of a treatment plan.
- 40% of the patients had recorded out of hour's communication.
- Only 22% of emergency admissions for these patients were for urgent complex medical care.
- 30% died at home.
- Good support for residential homes evident, as well as good evidence of noting emotional needs of patients.

Dr Young concluded that: from the notes, it is clear that there is little information recorded for each patient which would enable anything other than a reactive approach. It is assumed that the District Nurses' notes are more complete. There is no evidence that the practice has a systematic noting and priority of patients with EoLC symptoms, or that GPs are not routinely taking anticipatory steps to support patients in achieving a home death. The number of emergency admissions and hospital deaths would be reduced if a more reliable system were in place and if all District Nurses agreed to work in accordance with the Birmingham Palliative Care Network's competencies and responsibilities framework.

8.3 Carer Feedback

The Pan Birmingham Palliative Care Network has collected some patient and carer stories (See Appendix A) These contain important lessons for commissioners and service providers. Common themes include:

- Carers of patients in the EoLC phase need to be adequately educated and supported
- Support needs to be tailored to meet the needs of a culturally diverse population
- Nursing Home staff need to be properly trained and involved in EoLC to ensure their confidence to follow a patients' care plan and avoid unnecessary hospital admissions
- Any pathway redesign needs to include adequate quality assurance tools to ensure quality and consistence of service provision
- Commissioning of appropriate home and social support services are vital in reducing hospital admissions and improving patient and carer experience

8.4 Service Gap Analysis

The table below details current service provision and the gap in that service that would need to be met in order to apply the proposed service model and meet the vision for future service provision.

Service Area	Current Service	Service Gap
Patient Information	Ad Hoc delivery of information to those patients and carers who are able to ask questions	All carers and patients should be well-informed about their condition and choices during the EoLC phase
Patient Choice	Limited choice as service driven by crisis admission	Patients should be offered choice of care in different locations including at home wherever possible
Carer Support	Carer support is limited and variable in its range.	Carers should always be well informed and supported. This is intrinsic to the success of the new service model
Supportive Care	Very limited for non-oncology EoLC patients. Includes access to holistic therapies, support groups and counselling. Limited access to physiotherapy and occupational therapy services in some areas of BEN PCT for all EoLC patients.	Consistent delivery of supportive care to all patients and their carers during their EoLC phase
GP and District Nurse Involvement	Varies according to local interest, capacity and capability	All District Nurses and GP's should be well informed about the EoLC pathways, care plans and current status of all patients

Consultant Involvement	Reactive, hospital based and relate to emergency admissions of various levels of severity	Marginal role in community based service supporting nurse and GP specialists to undertake routine work and manage difficult cases in a community setting
Specialist Palliative Care Nurse Involvement	Mainly hospital based supporting consultants other than in the hospice services.	Should move to community based model
Social Work	Reactive and driven to facilitate hospital discharge. Locality based and variable. Not always able to undertake hospital assessments due to rapid discharge of patients	Proactive referrals to care manages to ensure carer support packages are in place to support care in the community rather than facilitate discharge
Monitoring of disease progression	Limited and ad hoc depending on clinicians involved and their interest and workload	Proactive, regular approach to ensure early interventions to avoid unnecessary hospital admissions
Management of exacerbations / acute emergencies	Ad hoc and reactive either in GP surgery or in hospital as result of emergency admission. Although introduction of Assertive Case Management model has supported amore proactive approach.	Proactive monitoring, early interventions, ambulance service awareness and commitment to remodelled pathway and formal EoLC planning process linked to current Assertive Case Management model.
Service footprint	Hospital based care is the default due to unplanned admissions and reactive management	Community based as the default with planned care pathways, regular monitoring and early interventions

The common themes that need to be addressed are patient and carer involvement, information availability and pro-active rather than reactive management of the symptoms during a patients' EoLC phase.

9. Commissioner Levers to Achieve Change

There are a number of levers to support commissioning and redesign of the current EoLC pathway:

There are national drivers to offer patient choice and to move care out into community settings wherever it is practicable and clinically safe to do so. In addition, there is the need to reduce emergency admissions into hospital thus releasing resources for planned admissions and care in community settings.

The plans for remodelling the EoLC pathway will achieve all these national aims whilst also meeting the demands of the Palliative Care Network Strategy endorsed by the BBCSHA.

The current care pathway is so chaotic that there are significant differences in care received by patients with similar conditions within the PCT population. These differences result from the differing level of interest of individual health professionals and where patients live. This differential level of care is at odds

with PCT Commissioning strategy and it is vital that a first class service is provided for all people within the PCT population.

The patient and carer audit highlighted that patients in BEN PCT do not all have positive experiences of their EoLC and it is vital that we change the service to meet the needs of the population by offering more choice and involvement in care.

Better use of financial resources can be achieved by providing more community support to keep patients in their own homes, and thus reducing demand for emergency admissions and individual continuing care packages for EoLC patients.

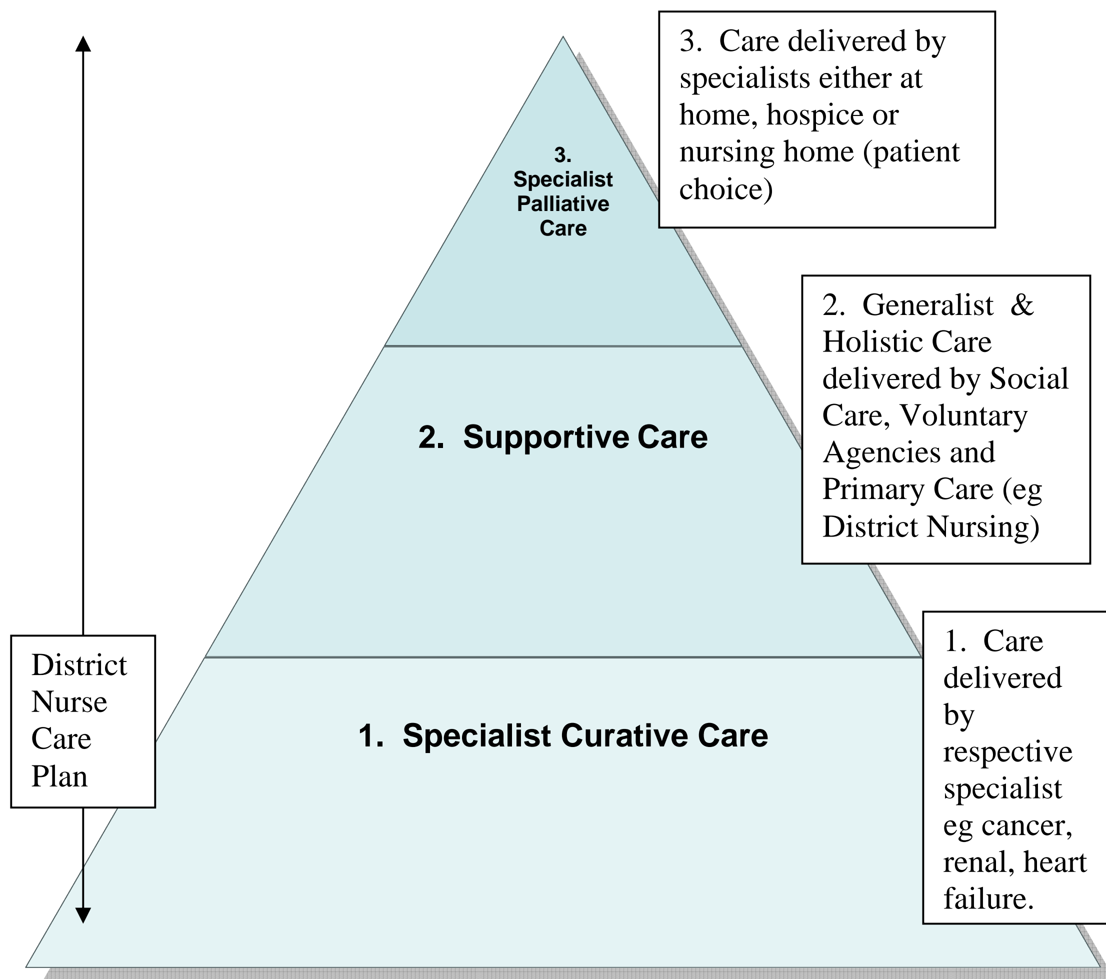
An ageing population means there will be increased demand for EoLC services within BEN PCT. Re-designing the service will create additional capacity to meet the future demand and provide the opportunity to ensure the service reflects the cultural and religious diversity of the population.

10. Commissioners Service Options

Commissioners have considered three possible options for the delivery of a redesigned service.

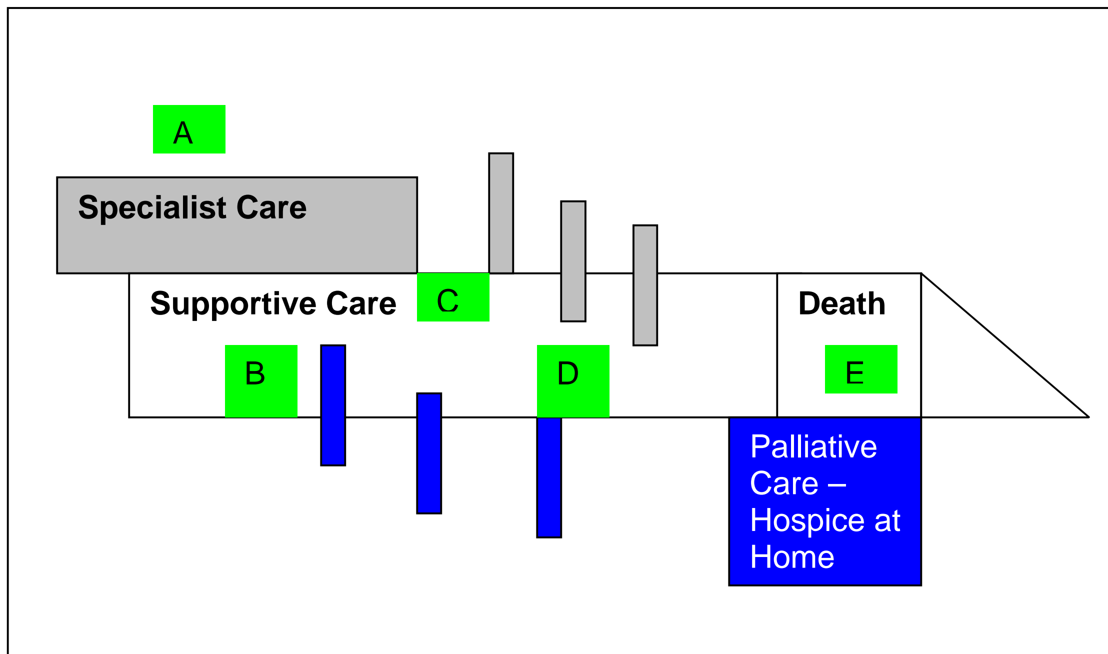
10.1 Option One – District Nurse led EoLC Pathway

The diagram below illustrates this service model. Patients are initially receiving treatment for their condition, and may progress to receive a mix of supportive and curative care before advancing to mainly supportive and eventually palliative care. Specialist palliative care is provided on a short-stay basis and wherever possible the aim is to stabilise a patient so that he or she could return home with supportive care whenever appropriate to do so. Therefore, Specialist Palliative Care can be provided at any point in the patient pathway according to individual need.



The new service model would mean that palliative care is integrated within the core role of the District Nurse. The District Nurse would be the focal point of the service provision and co-ordinate all other care providers. The following diagram outlines various phases of the clinical pathway that are proposed in this model.

At the heart of the model is the supportive care register that is not only maintained by the patients GP, but provides regular monitoring through monthly review meetings at a practice to discuss patient care, careful documentation of advanced care plans and proactive management of symptoms. The pathway consists of two phases; active management of the underlying condition (the curative management) and the transition / handover of the patient to an EoLC pathway which is ultimately focussed on actively managing symptoms to ensure a good death. Because of the difficulty identifying EoLC patients, these two phases in the pathway will usually overlap. Care and transition will be tailored to meet the needs of the individual. The elements of the pathway are described below.



Each stage is highlighted in green and described below

A. Patients are seen by their respective specialist – cancer, renal, heart failure etc etc. This care is balanced between specialist and primary care setting as occurs at present. The main aim of treatment is curative and the conditions are treated actively.

B. Supportive care is introduced. Provided by a variety of agencies and co-ordinated by the District Nurse who also informs the patient of the support that is available to people with similar conditions.

C. A point in time is reached when an individual is no longer able to benefit from the curative management of their condition. The District Nurse continues to co-ordinate support and care for the individual.

D. This needs to be undertaken in close coordination with GPs who at this point in time should have placed the patient on their supportive register. Many other agencies public sector, voluntary, spiritual and charitable will be involved in supporting the patient and their carers through the palliative phase of management. This might include home care, day care, respite and even care home services depending on the circumstances particular to the individual. This care is co-ordinated by the District Nurse.

E. Hospice at home and District Nursing services working in close cooperation with GPs and who are the main providers of palliative care during the EoLC phase and particularly within the final few days of life.

The key to the palliative phase is the orchestration of care and services as directed by the GP and district nurse. It is best effected by using the supportive care registers and also having specialist facilities and teams available in the community to enable difficult to treat patients to be managed appropriately.

10.2 Option Two – Independently Co-ordinated Service Model

This model is essentially the same as that described in Option 1. However, rather than the District Nursing Team co-ordinating care, an independent provider would act as co-ordinator of services. This would save significant District Nursing resource, but would have cost implications for commissioners.

The co-ordinator would have to be recognised by all charitable and Private and NHS care providers operating in the BEN PCT area, including acute trusts, the ambulance trust, Community Nurses and GP's.

The co-ordinator would have 24 hour access to care plans and would be able to refer patients directly into appropriate services.

Palliative care registers are now part of the Quality and Outcome Framework points in the current GP contracts. The registers must be kept in accordance with the guidance set out in the Gold Standards Framework. This is a Macmillan initiative widely seen as an important approach to improving the management of patients who need supportive care.

Under the Gold Standards Service Framework GP's are encouraged to undertake responsibility for EoLC planning working with both the patient and local community nursing staff. The responsibility for implementation of this plan falls naturally to the District Nurses and GP's thus providing one point of contact for patients and Carers.

10.3 Option Three – No Change

This is the legacy option. We would maintain the status quo, however, the following issues would remain:

- Large amount of unplanned care
- Little or no choice about place of death
- Limited community and home support
- Poor utilisation of health service resources
- Lack of equitable service provision (present focus is on cancer)

Given the PCT commitment to enabling independence, tackling inequalities, excellence in chronic disease management, 10 more years of quality life and an informed and empowered community this does not appear to be an acceptable option.

BEN PCT is committed to commissioning EoLC services to provide access to all adults in their end of life phase. The current service model of unplanned, responsive care gives limited opportunity for patients to be involved in choosing the type of care and planning a death that best meets their individual needs. BEN PCT is committed to providing patients with choice and to do this the current service needs to be re-modelled to enhance community and home-based care provision.

In addition, demand for intermediate care is expected to rise as the population in Britain ages. It is vital that BEN PCT ensures there is adequate capacity within the system to meet future demand.

10.4 The Preferred Service Model

The preferred option is option one. This is because it appears to offer the best opportunity to:

- Enhance patient experience and dignity
- Support individuals to maintain independence and control for as long as possible
- Builds on recognised best practice
- Establishes a consistent foundation of services which facilitates choice and ready access to effective and appropriate services across the PCT
- Reflect our health economy values of ‘Patients as Partners’, ‘ Care in the Right Place, ‘Promoting Self Care’.

11. Delivering the New Service Model – Issues to be addressed

For the new service model to be effective BEN PCT needs to ensure the following are in place:

- Dedicated project and implementation management
- Carer support systems and Expert Patient support
- Improvement in Out of hours drug access
- Rapid response everyday/night nurse teams to support district nurse services
- Adequate social and personal supportive care services including culturally and religious specific services
- Care delivered by people with appropriate knowledge, skills and resources at every point in the patient pathway
- Rapid access to community equipment network wide
- Education consortium
- Network psychology service
- Out of hours specialist advice to generalist staff.
- Sufficient provision of supportive care, respite care and hospice beds

- Sufficient hospice at home services
- Acute Trust awareness and commitment to implementation of new pathway
- Ambulance Trust awareness and commitment to implementation of new pathway
- Performance management
- Key pieces of equipment are readily available e.g. syringe drivers, hi low beds
- Clinicians have a protocol led guidance to symptom control advice, and access to a palliative care pharmacist, specialist nurses and specialist Doctors, 24/7 via agreed protocols with specialist Patient held notes. – Including SAP and a care plan
- Carer support through good information
- District nurse and GP as the key workers and core team.
- Patient and carer support and education
- GP practices are signed up to GSF and implemented.
- District Nurse teams aim to have a consistent 24hr approach to all patients with end stage disease although currently capacity is reduced outside normal working hours.
- All patients have advanced care plans, and preferred place of care is specified
- Hospital units are participating in the supportive care pathway.
- Clinicians, patients and carers have a rapid access route to out of hour's drugs and oxygen in case of emergencies.
- Clinicians have access to a rapid response hands on home care team to support the patient and carers in crises at the EoLC
- Access to pain management specialist teams
- Access to respite care
- Adequate capacity in Allied Health Professional support to maximise the lifestyles of patients and carers throughout the EoLC phase.

To realise the new service model, a range of additional services would need to be commissioned / de-commissioned:

Supportive Care
NICE [9] recommends that systems are in place to support patients and carers to participate in their own care, it also recognises the need to provide a wider variety of therapies within day services. The holistic and supportive care service available to all BEN PCT residents' needs to be expanded, in addition, it needs to include a wider range of alternative therapies (as approved by NICE). The patient stories in Appendix B demonstrate the benefits of holistic and supportive care.

The proposal would be to commission the provision of access to a full range of domestic and social support services as well as access to holistic therapies and carer support.

Domestic care would include; housework, shopping, religious support, dog walking, transport, advocacy and telephone support. This service will enable people who need help to carry out normal household duties to remain in their own homes. The intention is also to provide help and advice to carers, empowering them to take control of the care the patient receives and supporting them with help and advice about the patients' condition resulting in greater understanding of the patients symptoms and fewer emergency calls.

In addition, it is proposed to commission a range of alternative therapies, counselling, spiritual services, courses in self-care and access to self-help groups for all EoLC patients, their families and carers.

Hospice at Home
The current Hospice at Home service is small and inadequate for the volume of patients who could potentially make use of this service.

There are currently two hospice at home services. One is run from John Taylor hospice and the other is run by St Giles Hospice and covers the North of the PCT area. Hospice at home services provide specialist palliative care and advice in the community to patients wishing to die at home in conjunction with other community based teams for example, District Nurses.

The Hospice at Home services need to be expanded to become a core part of the EoLC service offered to all patients in BEN PCT. The service needs to ensure it is able to operate on a 24hr basis across the BEN PCT population, in order to have the biggest impact in preventing unnecessary admissions into Acute care.

It should be noted that the Hospice at Home team at John Taylor Hospice, also currently undertakes ad-hoc requests to provide care to residents of Heart of Birmingham PCT (HoB PCT). Any decision about further investment in this service needs to also consider HoB PCT residents and to seek investment for expansion from HoB PCT who may wish to enter into a joint commissioning arrangement.

Supportive Care Beds
Additional supportive care beds need to be commissioned in order to meet additional demand. Currently these beds are mainly used for patients dying of cancer. Deaths due to cancer were just 6.4% of all deaths within BEN PCT in the year ending April 2007. The new service model should enable more people to die in their own homes using dedicated supportive care beds for short stays to provide respite for carers or to stabilise a patient suffering from unexpected or uncontrolled symptoms, or for planned admissions to provide short-term respite to carers. These beds should be used in preference to those in Acute Trusts.

District Nurse and GP Training
District Nurses and GP's need additional training in EoLC to enable them to fully understand their responsibilities for patients in this phase. They need to be aware of the needs and care options available for people during this time and be fully equipped to deliver the care in the most appropriate way. Training must also cover the implications of the Mental Health Capacity Act [23] to ensure paramedics and clinicians have confidence to act upon the wishes of the individual which should have been expressed in an EoLC Plan.

Ambulance Trust Care Pathways
Ambulance Trusts need to sign up to care pathways agreed through the Palliative Care Network. These care pathways enable Paramedics to honour the patients' wishes as detailed within the individuals' EoLC plan contained within hand-held notes. The pathways are designed to avoid emergency admissions for patients who could be offered alternative services or supportive care beds with an emphasis upon allowing the patient to die in dignity at home wherever possible.

Allied Health Professionals
Commissioning of additional resource should be considered within the PCT's Allied Health Professional division. Currently there is limited access to Physiotherapy (0.1 WTE) and Occupational Therapy (0.45 WTE) services at the John Taylor Hospice. These services are supplemented by the existing locality based Occupational and Physiotherapy services who provide additional domiciliary visits. However, this results in a disjointed service which is inferior to the level of service provision within St Giles Hospice and other local voluntary managed hospices. The BEN PCT Palliative and Supportive Care Strategy identifies the need for input from Physiotherapists, Occupational Therapists and Social Workers in order to speed patient discharge and to offer more support to people in their own homes. Commissioning an increase in establishment would enable a whole-systems approach to palliative care. Although it is envisaged that the staff would be based at John Taylor hospice, it is expected that the staff would work as part of a multi-professional support team providing community services to patients linking with St Giles and Marie Curie Hospices as well as District Nursing teams throughout BEN PCT population. It is, therefore, vital that consideration is given to employing staff who reflect the language and cultural diversity of the population of BEN PCT. Adequate provision of Allied Health

Professionals would further ensure support for Hospice at Home teams thus enabling patients to avoid unnecessary admissions into supportive care beds and speeding up discharge back to their own homes.

Disinvestment in Nursing Home Placements and Nightsitting.
Deaths in nursing homes are not considered to be desirable within the new service model, unless the nursing home is the patients' usual residence. In this instance services should be provided at that location in the same way they would be provided if the patient lived in a private residence. Therefore, people should not be admitted to a nursing home as an alternative to a hospice or supportive care bed during their EoLC phase. The intention being that people are not admitted into nursing homes simply to die. This means there may be significant disinvestment in nursing home beds for this purpose alone.

Consideration should be given to commissioning nominated homes to provide planned respite care , thus minimising the impact upon staff and continuing services.

Disinvestment in current night sitting arrangements, would release funding for a more cost-effective hospice at home service.

Capacity of Additional Services
Currently, none of the other Birmingham PCT's are operating an EoLC model similar to the one proposed in this document. As a result, there are no opportunities for benchmarking the service in terms of necessary capacity and actual cost. However, the National Council for Palliative Care (NCPC) has issued a commissioning guide [25] advising on palliative care provision. The document provides advice on Community Palliative care provision. The table below applies the service levels suggested against the BEN PCT population.

<table>
<tr><th>Service Element</th><th>NCPC No. per million population</th><th>Applied to BENPCT Population (440,000)</th><th>Current BEN PCT Provision</th><th>Additional Service to be commissioned</th></tr>
<tr><td>Specialist Palliative Care Nurse (Cancer & Non-Cancer)</td><td>23 wte</td><td>11 wte</td><td>6</td><td>5 Specialist Nurses</td></tr>
<tr><td>Day places per year</td><td>13000 (35 beds)</td><td>6,500 (18 beds)</td><td rowspan="3">20.5</td><td rowspan="3">36.5</td></tr>
<tr><td>Cancer Palliative & Supportive Care Beds</td><td>52 beds</td><td>26 beds</td></tr>
<tr><td>Non-Cancer Palliative & Supportive Care Beds</td><td>26 beds</td><td>13 beds</td></tr>
</table>

To meet the BEN PCT Palliative and Supportive Care Strategy requirements, staffing levels have been calculated using recognised modelling tools: Williams J. Calculating staffing levels in physiotherapy services. Rotheram: PAMPAS; 1991 [26] and Directory of Hospice and Palliative Services. St Christopher's hospice ;2001 [27] These models both take into account bed occupancy rates, admittance rates, case time and referral ratios to calculate ideal staffing levels. In addition, it is vital that there is sufficient administrative support to ensure clinical letters and Community PAS activity data gathering requirements are met.

The models calculate the need for the following uplift in current staff provision:

Post	Band	Point	WTE	Total Cost 2007/8
Occupational Therapist	7	Midpoint	1	£39,698
Physiotherapist	7	Midpoint	1	£39,698
Physiotherapist	6	Midpoint	1	£33,332
Social Worker	6	Midpoint	1	£33,332
Administrative and Clerical	4	Midpoint	1	£22,193
Multi-skilled Assistant	3	Midpoint	2	£37,738
Administrative and Clerical	3	Midpoint	1	£18,869
			Total Pay	£241,526

The total cost of these additional staff should also account for non-pay at 22% and an allowance of £10,000 for training. This brings the total cost to £304,662.

There is no recognised methodology for calculating the amount of Social Work Care Management time required. However, currently all Social Assessment and Care Management is provided via the Birmingham City Council Adults and Communities Directorate on a geographical referral basis. However, Marie Curie has negotiated a local agreement with Solihull Social Care Trust for direct referrals. Despite the evidence that this has reduced delays in discharge from supportive care beds, a similar arrangement has not been made available to Birmingham residents. On the basis of the Solihull model, it is proposed that 1 WTE Social Worker is employed to work across the BEN PCT area.

No additional resource has been considered for the District Nursing service at this stage, as the District Nursing Manager believes that EoLC plan management and co-ordination of services is an integral part of the District Nursing role and should already be undertaken within their core duties. Therefore, in theory there is no need to increase establishment to deliver the re-modelled service. However, the impact of increased capacity in the Hospice at Home team, and potentially greater number of people dying in their

own home is not yet known. Therefore, a review of demand and capacity in the District Nursing Team would need to take place on a monthly basis for at least 6 months after implementation of the new service model.

Community Equipment

Additional resource will also need to be made available for purchase of community equipment to enable nursing teams to care for more people in their own homes. In particular, bariatric equipment is needed to enable patients weighing up to 40 stone to be cared for in their own homes. With ever increasing numbers of obese people within the population, demand for this equipment is rising. It is estimated that purchase of 4 beds and a specialist frame and hoist will enable BEN to continue to meet demand based on the last 12 months' activity. District Nurses are currently unable to provide a service to people using the current range of specialist beds available. Purchase of this equipment would cost £10,000.

In addition, a further £10,000 should be allowed for purchase of equipment to enable additional loans of small items (such as zimmer frames), by therapists to maintain more people in their own homes.

12. Resource

Currently, many people are admitted into hospital and die, when that would not be their preference. The proposed commissioning and redesign of community services for EoLC patients, will prevent inappropriate hospital admissions for EoLC patients, releasing resources for re-investment:

Projected resources for re-investment in 2007/8 – based on all 2006/7 planned deaths within BEN PCT

	Activity	Average Cost	Total Cost	Note
Total planned deaths for 2006/7	4,287			1
Based on 2005 statistics – 52% deaths occur within hospital	2,229			2
Less 10% of patients whose preference was a hospital	-223			3
Less 5% of patients where hospital was most appropriate setting	-111			
Cost of admissions that could be saved with new service model	1,895	£1,229.81	£2,330,305.23	

1. These relate to planned deaths only and exclude those related to road accidents, still births etc.
2. This includes admission types and not restricted to just death within 14 days of admission
3. Based on a study by the St HA. Even under new service model it is expected that 10% of people will chose to die in hospital

There are two other scenario where resources for re-investment could be achieved, but there is no way of identifying the current cost of these admissions: The first scenario is where there is a planned admission, but once the new model of care is in place and there is improved support in the community, that admission may not be needed. The second scenario is where there may be people who are currently discharged alive after an unplanned admission, and who are in their EoLC phase and would not be admitted into acute care at all once the new model of care is introduced.

Further resources for re-investment can be achieved from resources currently spent on providing Individual Community Care Packages to people in their EoLC phase. These packages are normally provided for people within their last 8-12 weeks. The PCT's expenditure was £411,000 and provided nursing home placements for these patients in the financial year ending 2007. An additional £500,000provided palliative and EoLC for people at home These services are charged based on the hourly rate of the night sitter and this can vary considerably depending on the qualifications of the sitter. Consideration is being given to redirecting this investment to increase the number of care assistants through the Hospice at Home service.

The above resource for re-investment is in addition to any that could be made through widespread provision of adequate supportive care and hospice at home services. An audit of the supportive care model in Sandwell PCT, provided by Bridges, found that additional resources for re-investment can be achieved in other services such as bereavement counselling by developing different commissioning models.

BEN PCT also currently spends in the region of £120k per anum on night sitting provided by Marie Curie. This would finance 6 wte Care Assistants for a Hospice at Home Service.

These figures show that if investment is made in provision of appropriate levels of Supportive and Palliative Care within the community, there are potential resources for re-investment in excess of £3.25 million that could fund the care pathway redesign and additional capacity within the District Nursing team if necessary.

13. Delivering the New Service Model

There are a number of potential service providers for both supportive, generalist and palliative care. These include:
The PCT's Community Health Services Provider
Bridges
The Cancer Support Centre
Freshwinds
John Taylor Hospice
Macmillan Community Nurses Support Team
Marie Curie Hospice
Nursing Homes (Various)
St Giles Hospice
St Mary's Hospice

The PCT proposes to use a range of commissioning approaches to procure services that meet the needs of the individuals within the community, providing patient choice and ensuring services are delivered in the right place at the right time.

The PCT will seek to identify all potential service providers and ensure that procurement of new services will be in line with best procurement practice, and that new services meet the cultural needs of the population, as well as demonstrating best value.

14. Cost of delivering the new service model

BEN PCT is leading the way with innovative community based provision of EoLC care. As a result, there are few opportunities to learn from others in terms of the scale and cost of service provision. However, sensible estimates can be derived based upon existing services. Where costs have been estimated on this basis, no conclusions should be drawn about the service model or provider who will eventually be commissioned in accordance with statements in paragraph 13 of this document.

14.1 Supportive Care

Bridges is a voluntary organisation already operating successfully in Sandwell PCT. It has a small operation within BEN PCT operating from the John Taylor Hospice. Bridges currently provides range of social and domestic assistance including; travel to and from medical appointments and overnight sitting. Although under procurement rules consideration would need to be given to source other possible providers, the Birmingham Palliative Care Network is not currently aware of any other similar service providers within the Birmingham area.

The roll out cost of providing Bridges in Sandwell, is £155,000 for 1,179 referrals. Adjusted for the size of the BEN PCT population, the cost would be £422,668 per anum.

It is important that this service is commissioned to provide services to all patients and carers within their EoLC phase
Savings could be made through joint commissioning with Social Care and Health.

Freshwinds provides an average of 1000 alternative therapy sessions to approximately 90 patients living in BEN PCT each year, at a cost of £54,000 (£54 per session, £540 per patient).

The Cancer Centre provides an average of 2281 attendances to approximately 228 cancer patients and carers Each year,at a cost of £70,000 (£30 per session, £300 per patient)

Under procurement rules, consideration will be given to source other possible providers of similar services.

14.2 Hospice at Home

The cost of expanding the hospice at home service is difficult to gauge, because the service model currently operating in BEN PCT differs from that applied in other PCT's. However, Sandwell PCT has recently conducted a review of their hospice at home service with positive conclusions. It is recommended that BEN PCT reviews its current service model when specifying the expansion of the hospice at home service and consideration is given to adopting the same model of service as in Sandwell. The cost of the Sandwell service, with adjustments for population size is £290,000 per anum

14.3 Supportive and Palliative Care Beds

St Giles Hospice is a charitable organisation with premises in the North of the BEN PCT area. This hospice is generously supported and looking for opportunities to expand. 41/2 beds at St Giles currently cost £267k per anum (£59.5k per bed). This cost includes clinical nursing, specialist consultant domiciliary care, lymphoedema services, complimentary therapies, supportive outpatient care, and bereavement and day hospice services.

The John Taylor Hospice has five beds that are not currently in use. With additional funding these beds could be used for supportive care. The building is already deemed suitable for provision of care to those people during their EoLC phase. Staff would have immediate access to palliative care specialists should they need them. The infrastructure is already in place. The cost of opening these beds is estimated to be £219,860 per anum (£43,972 per bed). This includes funding for 1 Medical Officer working 6 sessions, 4wte Band 5 Nurses and 4wte Band 2 Care Assistants.

In addition, Birmingham City Council is about to commence building works on an additional two Care Centres in the PCT area. The PCT will have the option of using the 32 single, en-suite bedded facility on the top floor of each of these

centres. Consideration should be given to use of this facility to commission additional supportive care beds.

For the purpose of this business case, the additional 36.5 palliative and supportive care beds have been costed on the basis of the John Taylor Hospice bed costs. This is because some of these beds will be commissioned for respite care and the cost of these is expected to be significantly less than £43,972 per bed because these beds will require less clinical support.

15. Financial Summary

	Activity	Average Cost	Total Cost	Note
Cost Savings				
Total planned deaths for 2006/7	4,287			a
Based on 2005 statistics – 52% deaths occur within hospital	2,229			b
Less 10% of patients whose preference was a hospital	-223			c
Less 5% of patients where hospital was most appropriate setting	-111			
Cost of admissions that could be saved with new service model	1,895	£1,229.81	£2,330,305.23	
Complex Individual Packages <40k packages currently commissioned from SBPCT			£411,000.00	d
Marie Curie Night Sitting			£120,000.00	e
Home Support Packages			£500,000.00	d
Freshwinds			£54,000.00	
Total Expected Resource for Re-Investment			**£3,415,305.23**	
Cost of Re-Provision – 3215 new referrals per anum (75% of planned deaths in 2007)				
Supportive Care			£522,668.00	f
Hospice at Home			£290,000.00	
Supportive Care Beds at John Taylor	5	£46,750.00	£233,750.00	
Supportive Care Beds based on John Taylor model	31.5	£46,750.00	£1,472,625	
AHP Staffing (Pay + non-pay + training)			£304,662.00	
Total Cost of Re-Provision			**£2,823,705.00**	
Net Resource for Re-investment from Re-design			**£591,600.23**	g

a. These relate to planned deaths only and exclude those related to road accidents, still births etc.
b. This includes admission types and not restricted to just death within 14 days of admission
c. Based on a study by the St HA. Even under new service model it is expected that 10% of people will chose to die in hospital

d. These are based on figures provided by the complex care team at South Birmingham PCT and verified by finance at BEN PCT
e. This is based on the actual 2006/7 outturn for BEN PCT
f. The figures are based on the provision of 3,215 new referrals each year and uses the existing Sandwell PCT model. Existing model is based on infrastructure cost of £155,000 for 1,139 new referrals each year.
g. Please note that there is an additional £10,000 to be invested in additional community equipment in the first year.

16. Measuring Achievement

The PCT has been developing its outcome framework to monitor and assess the impact of investment. It is based on five domains; organisational, satisfaction, clinical, activity and resource utilisation. Further work is underway to define the appropriate outcome measure for each domain in EoLC. Below are examples of how the metrics could be applied to EoLC services.

- **Organisational**
  Measured through successful partnership working between Acute Trusts, BEN PCT, Bridges, Hospice at Home, Hospices, and Nursing Homes.

- **Satisfaction**
  Measured through District Nurse job satisfaction, carer and patient satisfaction. Including meeting the cultural and religious needs of the population. Also can be measured by looking at actual outcome for patient compared to care plan intentions.

- **Clinical**
  The new care pathway should result in fewer unexpected exacerbations or symptoms and more planned interventions.

- **Activity**
  If successful, the new care pathway should allow for fewer deaths in hospital and more deaths at home. In addition, there should be fewer emergency admissions of people in their EoLC phase. Deaths within 14 days of admission to hospital should be significantly reduced.

- **Resources**
  Reduced expenditure in acute hospitals and nursing homes should at least match spend on newly commissioned services within the community.

17. Governance and Risk Management.

It is intended to set up an EoLC commissioning group to oversee the implementation of the Commissioning intentions described in this business case. Members of this group will be:

Andrew Donald, Director - Redesign and Commissioning (Executive Sponsor)
Julie Asbury (Project Manager and BEN PCT Commissioning Lead for EoLC Care)
Michael Hau –BEN PCT Commissioning Finance Team
Mel Young – Macmillan Birmingham Palliative Care Network Leader
Anna Shaw – BEN PCT Communications
Dave Collins – Social Care and Health
Khesh Sidhu – Public Health Consultant in Palliative Care

This group will report directly to the PEC and through the PEC to the PCT Board.

A number of sub-groups will be set up to deliver the commissioning intentions. Membership of these groups will include providers, in particular people already sitting on the Supportive Care Board. It is acknowledged that the operational and clinical experience of Board members is vital to ensuring the successful implementation of this business case.

There are a number of risks to the successful implementation of this commissioning business plan; these are listed in the table in Appendix D. During the implementation of the business case, the commissioning group for EoLC care will monitor and report on additions or changes to this risk register.

17.1 Clinical Governance

Clinical governance will be assured using the agreed guidelines and standards developed through the Palliative Care Network specialist palliative care audit and guidelines group (SPAG). See Appendix C. Hospital governance committees will view any new guidance for use in hospital units.

18. Consulting on the Business Case

This business case has been developed with close involvement of key clinicians and managers of existing services, as well as the Birmingham Palliative Care Network.

The Palliative Care Network in Birmingham has already undertaken some consultation with regard to redesign of EoLC pathways and this could be taken into account. However, given the significant service developments proposed by this case, a full consultation will be undertaken in accordance with BEN PCT's communications and involvement strategic framework, and the statutory requirements placed on public bodies. The process will ensure

specific consultations take place with members of ethnic minority populations who may not readily engage with the generic process.

19. Actions and Timescales

Consultation with BEN PCT Supportive Care Board Members	By 15th August 2007
Discussion at BEN PCT PEC	19th September 2007
Presentation at BEN PCT Board	26th September 2007
Public and Stakeholder Consultation (13 weeks)	October 2007 to January 2008
Overview and Scrutiny Committee	November 2007
Amend Business Case as per consultation and present with Project Initiation Document at BEN PCT PEC and Boards	February 2008

20. Bibliography

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DoH 2000

6 NSF for Coronary Heart Disease
DoH 2006

7 Building on the best: Choice, Responsiveness and Equity in the new NHS
DoH 2003

8 The NHS EoLC Programme
DoH 2004

9 NICE Guidance on Improving Supportive and Palliative Care for Adults with Cancer
2004

10 Supportive and Palliative Care for advanced heart failure
DoH 2004

11 The Health Select Committee Inquiry into Palliative Care
2004

12 NSF for Long Term Conditions
DoH 2005

13 NSF for Renal Services
DoH 2005

14 NHS Confederation recommendation on EoLC planning
Oct 2005

15 NHS Equality Scheme

16 Race Relations (Amendment) Act 2000

17 Equality Act 2006

18 Investing in Health
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19 Priorities for EOLC in England, Wales and Scotland: National Council for Palliative Care
I.Higginson 2003

20 A Good Death
R Smith 2006 – BMJ 320 129-30

21 Location, Location, Location: A Point Prevalence Study
A. O'Leary, Heart of England Foundation Trust, August 2007

22 Birmingham Palliative Care Network audit of Deaths
M Young 2007

23 Mental Health Capacity Act 2005

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Appendix A

Patient Stories and service design, 2006-2007
Pan Birmingham Palliative Care Network
April 2007

User involvement in EoLC services has been traditionally difficult to access. This situation is easing in our Network, as we have a strong User Partnership Group allied to the Cancer Network, many active support groups and a User group in one of our hospices. Some members have cared for patients who have died, and help to represent the views of carers of patients with cancer. Other patients are in the advanced stage of disease.
Birmingham St Mary's Hospice has a monthly meeting of its patient user group, and this group give fascinating insight into the kind of services patients require. The Network managers and members of the cancer and palliative care board are active members of the user groups. The Network works with Birmingham Carers on a regular basis.

In addition, Bridges, one of the Network voluntary sector providers hosts the Black and ethnic minority cancer support group Friends, who are very active in their work with us, as indeed is the main Bridges user group. Bridges conduct their assessment of the patient by listening to their story. We find that this method of patient and carer assessment of need to be the most effective on a number of levels.

Detailed below are some of the patient and carer stories that have helped to shape our strategy and implementation plans. The names have been changed.

Carol's story

Carol is in her mid fifties and lives alone in Tipton. She was diagnosed with a gynaecological cancer, and relates her story after her third cycle of chemotherapy. 'I was so poorly during the second lot of chemo that I couldn't leave my flat, couldn't even leave the chair really. I felt so bad….there wasn't even anyone to help make me a cup of tea, I felt so low. I didn't have any food in the house… The sickness was overwhelming. I decided I wasn't going to have anymore treatment, I felt I had no choice. I couldn't really look after myself properly –couldn't get the energy to go to the shops to get anything.

Carol didn't need social services or complex nursing care –she needed a reliable friend who could help out. Her GP helped her to access Bridges, who found a volunteer who could reliably be there for Carole during her treatment. Carol decided she would continue with her chemotherapy.

Edward's story

Edward lives with his wife in Oldbury. He is seventy four years old, and was diagnosed with lung cancer. Due to his failing eyesight, he is unable to drive. 'The hospital told me that they would get an ambulance to pick me up from my house to bring me to the Queen Elizabeth for my treatment. I was pleased to begin with I wouldn't have to get the bus. They said they would pick me up early, so I was ready. The journey took about an hour and a half because we ad to pick up lots of other people. It was the same on the way back, but it took longer. By the time I got home, it was dark; it had taken three hours to get home. I couldn't manage it again. I tried to get the bus next time, but it was three different stops. I couldn't do it. I had decided I couldn't carry on with my treatment, even the doctor was cross about the ambulances but he couldn't do anything about it. Then Manjula from Bridges sorted out a volunteer driver who could take me and pick me up, it was like a dream come true.'

The roll out of Bridges across the Network opens up the necessary availability of a volunteer work force. In terms of demographics, it is our only realistic way of delivering future services to an increasingly older population , with a decreasing available formal younger workforce.

Sally's story

Sally was in her mid thirties when her husband was diagnosed with an advanced stage cancer. Both working professionals, Sally relates how she felt at the end of his life.' I was stressed out all the time –work was making it really hard for me to spend time at home. My manager and the team I work with understood to begin with, but after a few weeks, I felt uncomfortable having time off. Stephen was so scared though that he couldn't really go to the hospital alone, even when he was able to in case they told him any more bad news. '

'. At the end, Stephen wanted to die at home, and the GP sent some nurses to help us, but they didn't know how to give Stephen the drugs. I lost confidence that he would be ok at home, so I called an ambulance and we went to hospital. The doctors and nurses varied so much in how they related to us. Some of them were fantastic, but some wouldn't even make eye contact with me when I asked for help. Some of them acted as if we were not there. They kept saying they would come, but it took hours. They acted as though his death didn't matter. Sometimes they just stood around nattering about last nights TV, and I wanted to scream. I know they have probably seen it all before, but they didn't seem to understand how terrified we both were. '

The public awareness campaign 'Living well to the EoLC' helps to raise the issues associated with EoLC in all arenas, including the workplace, and the impact that informal carers can have, and the individual challenges they face. The roll out of the supportive care pathway and its educational element will do

much to improve hospital care for cancer patients, and indeed for all patients in their last months of life.

Maria's story

I took Dad to see the specialist, Dad's English isn't very good, so I went in with him. He said Dad had a tumour. I could tell Dad hadn't understood, but I was too scared to ask if that meant cancer. I realised after a bit that it did, but I couldn't explain to Dad, I didn't want to ask how bad it was. We left the clinic, and I felt terrible. I didn't know how to tell him. I didn't know what to tell mum.'

The Network outpatients supportive care pathway for patients, allied with the advanced communications skills training and Bridges would help to address the issues raised by Maria's story.

Sue's story

Sue's father was admitted from a nursing home to a hospital in his last week of life. He had advanced Parkinson's disease and dementia. 'Dad loved it at the home; they were really good with him. I wanted him to spend his last days there, and as he got more poorly, they were really looking after him well. One night we got a phone call that they had called an ambulance to take him to hospital as an emergency. The hospital was terrible, he got a bug and had constant diahorrea, I couldn't leave him there. We fund raise for our local hospice, so I called them, and they helped me get him to my home, as the nursing home wouldn't take him back because of the bug. The hospice at home team helped us look after him and he died a peaceful death. I was glad I could do that for him.'

The Network wide Care homes service improvement programme will help Nursing home staff feel more confident in the management of EoLC.

Jessie's story

'The Doctor told me about the hospice, but I was too scared to go because I thought that that is where you go to die, and it would be horrible. In the end my neighbour said she would come with me because the nurse kept saying how nice it was, so we visited, and it was lovely! Now I go every Wednesday and Friday morning, and I have got my hope back. I know the cancer is bad, but I know they will look after me here when I get really poorly. I feel like I have got my life back.'

The Network in partnership with the St Mary's hospice user group is producing a 5 minute DVD, featuring patients from the user group, talking about hospice care, so people can see how it really is. The DVD will be available for download or viewing from the website birminghampalliativecare.nhs.uk.

Derek's story

. 'I thought I just had a hernia or something, and I went into hospital just before Christmas for some tests. The day after my exploratory op, they told me that I could go home if no one came to see me before 12, so I got dressed and was waiting for my wife to collect me. It was Christmas Eve. A young lad who turned out to be a doctor came, and he just said "you have got an inoperable cancer and you have got about 6 weeks to live. Go home and enjoy your last Christmas." Then he just walked away. I couldn't believe it, I thought he had got the wrong patient, so I asked the nurse and she didn't know anything about it. My wife came after a few minutes, and I told her, she too thought they had made a mistake. The nurse came and said we could go home now, so we thought it definitely must be a mistake, because surely my consultant or someone from his team would come and talk to us about it if it was true, or tell us something. We rang my consultant's secretary on the way home, but she didn't know anything. We didn't know what to do. After a while, my consultant called us and said it was true. I don't think it sank in really. We just went home in a daze.

The next day, we told our son, and he got so mad he called the GP surgery, but it was Christmas day, and the out of hours doctors didn't know anything or know what to do. We drove to the Priory the next day and asked to see a consultant cancer specialist. He was brilliant, and he spoke to my GP who got the district nurse to come to see us. She is brilliant, and really makes sure we are OK. I won't go back to the hospital now. I have spent my life in public service and they don't care. '

Derek died a peaceful death at the Priory after 9 months, supported by his primary care team whilst he was at home. Derek and his family did not want to waste what was left of his time by complaining to the hospital. The family contacted the palliative care network manager, who visited Derek and his wife before his death to hear his story.

The Networks advanced communications skills strategy and training plan, along with the roll out of the supportive care pathway, are some of the quality assurance tools required to address the many issues raised by Derek's story. It is also clear that we need a network wide, independent of provider patient and carer questionnaire to ensure we can capture information on quality of service.

Elvira's story

'My husband Tony was dying of cancer, and I wanted to look after him at home. He just got weaker and weaker, and then just wanted to sit in the chair. It was really hard for me to help to lift him to help him walk to the toilet. I didn't want to ask my daughter to help; I didn't want her to see her father like this. I wanted to see my own GP who is really good, because I knew he would help, but I couldn't get an appointment for weeks with him. I got very tired, and Tony was admitted one night by the on call doctor because I was crying, I couldn't

clean him up anymore. The hospital was really nice to him, but he wanted to come home. The hospital arranged for someone to come and see what equipment he needed, but it took two weeks, and Tony became very depressed on the ward. He couldn't sleep there, it was very noisy, and some of the old people shouted all the time. We got him home two days before he died. The district nurse was fantastic, but she couldn't get me help at night. I was just afraid to be on my own when he died, I didn't know what happens if he has pain, or how I could get a doctor there quickly.'

Our primary care service improvement plan, building on GSF, and Bridges will help to address many of Elvira and Tony's issues. The implementation of network EoLC pathways would ensure that we can proactively manage patients such as Tony, rather than having to constantly react, leaving patients and carers uninformed and afraid. The commissioning of appropriate home support services are vital in reducing hospital admissions. The competence of cares must be maintained.

Sarah's story

'My sister was diagnosed with breast cancer and we were all devastated. It was really bad by the time they discovered it, and it was awful, she has got 2 young children under 10. She just got worse and worse, and the treatment wasn't working. Me and mum tried to help as much as we could, but mum has got arthritis and I work full time….. she couldn't look after the kids, go to the shops, clean, anything. She kept crying all the time, and the kids were really upset.'

'She kept trying to be OK though, but it was too much, and she finally went to bed one morning, and couldn't really move. She looked terrible. The nurse who had been visiting (who was really nice) asked her if she would like to go to hospital, she had tried to get her into a hospice but they didn't have a bed. Jane said no, she wanted to see the kids as much as she could. The nurse kept trying to get the GP to come to visit Jane, to give her some oxygen and drugs that would help, but he wouldn't come out –he even shouted at the nurse and said Jane should be in hospital. He called an ambulance, but Jane wouldn't leave the house, she was crying so much. The nurse was really upset. Later that night, an out of hours doctor came and he was really kind , he called the district nurse and they put up a machine with drugs in it that helped her breathing , and she seemed at peace. She went to sleep, and died the next day. I complained to the GP about him not coming out but he just said my sister was stupid not to go to hospital and it wasn't his job. I still feel angry now.'

GSF is not enough, it's a good start, but really, the system need to change. The Network primary care service model and pathways allied with GP education and district nurse empowerment, and key performance indicators should quality assure home deaths. The out of hours drug access , syringe driver guidance , network distribution of symptom control guidance pocket booklets to every out of hours doctor and district nurse education programme

helped here at the end(Jane died in the summer of 2006), but clearly there is still much left to do. Bridges would have been able to provide family and domestic support from a volunteer basis

Appendix B

Supportive and Holistic Care - Patient Testimonials

Angela
'.... The people who work here are so kind, I have made many new friends. I have received treatment from the many different treatments on offer and all the therapists are caring and understanding. I enjoy the variety of events from Irish dancing to 'beauty evenings'. The Centre has certainly helped aid my recovery from breast cancer.'

Barbara
I have been coming to the centre since May 2004, having been diagnosed with advanced breast cancer, affecting my spine, ribs and pelvis in March 2004. The centre has been like a "safe house" for me; a place to cry when I felt like it, a place where no-one was going to ring home to tell my family how upset I was. Meeting other clients in similar positions to me and learning techniques such as hypnotherapy and relaxation. With my ongoing treatment and pain problems, I would not be living the high quality of life that I am now, without the therapies and support I receive at the centre.

Diana
I have been coming to this centre for about eighteen months. I can't begin to tell you how much it means to me. When I needed somewhere to have a chat or a laugh, this was the place to be. Everyone here was so friendly, caring and above all they understood how I was feeling. If you feel like having a chat someone always has time to listen – but if you are feeling like being quiet, that's OK too.

Great therapists always on hand and lots of different things organised including talks, singing, dancing, day trips and great friends. Wouldn't be without it!

Peter
I'm 53, a father of two children and grandfather to Jack and Max. I live with my wife Norma and have enjoyed a very healthy life and lifestyle. In December 2006 I was diagnosed with Lung Cancer. I was as you can probably imagine quite devastated particularly as I had given up smoking some thirty years ago and as said live a healthy lifestyle.

Obviously it was and still is an extremely distressing time for both me and my family. However medical treatment began with a high degree of urgency and has continued to be of the highest quality. The NHS should be proud.

I had not considered complimentary therapies or indeed any other type of support. I am by nature an optimist and very positive about everything I do but this was challenge I could have never envisaged. I have had friends and family who had been stricken with cancer and had passed away, but as said, nothing could have prepared me for this.

My sister who had lost her husband from lung cancer talked to me about support structures and gave me information she had sourced about Midland Drive. They had found a similar centre to be invaluable to them. During my first chemotherapy session I got talking with a guy who had used the centre and was full of praise. Without further hesitation I contacted the centre and within a few days met with Mavis. Immediately feeling at ease she talked through my circumstances and we agreed a plan of action. The only cost was a £5 registration but even this was only if I could afford it. Fortunately I can.

Since January 2007 I have received a number of Counselling, Rekei and Reflexology sessions. This has proven invaluable. The compassion, the empathy, the commitment, the professionalism of volunteers and therapists has been second to none. Always made to feel welcome, always treated as an individual. The support from the centre has enabled me to deal with this extremely stressful situation and remain motivated and positive during high dose chemotherapy and radiotherapy.

The strength of all who work in the centre is their unswerving commitment, their understanding and above all their dedication and determination to enhance and support the quality of life of all of us who attend. It's a like minded environment where there is a single common goal and those of us that have been diagnosed with this terrifying illness should not be deprived of this outstanding support.

Quantum Touch

Help with pain relief is an important part of support for clients and one very helpful therapy we use is called Quantum Touch. It is a type of hands-on healing using simple breathing and body awareness techniques.

A current client presented with pain in lower back and hips which were 10+ on pain analogue scale. Within 20 minutes she scored her lower back as being 1; and hips at 3.

Over 3 subsequent sessions her presenting symptoms reduced gradually, the most recent being hips 2-3; and lower back on arrival with no pain felt after 20 minutes of Quantum Touch.

Appendix C

Network Governance Committee
Communications Policy

Purpose
All recommendations and decisions made by the Network Governance Committee must be communicated widely to the responsible persons within the constituent organisations. This document summarises the policy for the communication of recommendations, and dissemination of approved guidance for implementation within the Pan Birmingham Cancer Network and EoLC Network, and should be read in conjunction with the Terms of Reference for the Committee.

General
The Chair of the Governance Committee shall report items of interest or significance to the Network Board as they arise. Likewise, items of relevance to commissioners, neighbouring networks or network site specific groups shall be communicated directly to the relevant lead.
It is the responsibility of each Committee member to communicate relevant issues within their organisation/ interest group.

Minutes
Minutes will be posted on the network website and be distributed to all Committee members all Board Sub Committee Chairs, Cancer Managers and the Network Executive.

Standards
Standards which have been agreed by a network site specific group shall be bought to the Governance committee for endorsement. All documentation supplied to the Committee must include a signed cover sheet (Appendix 1).
Once a standard has been endorsed by the Committee, the Chair shall communicate this, in writing, to those listed below. This communication will request confirmation of receipt of the document and advise of the expected timetable for implementation. All endorsed standards will be communicated to the Network Board.
A register of approved standards and their review dates, and a copy of the distribution list for each standard will be held at the Network office. Approved Guidance will be posted on the network website.

Standards Distribution list

- PCT Governance Committee contact
- Trust Managers (responsible for onward distribution to Trust Services Committees, Trust Multidisciplinary Team Leads, Trust Cancer Clinicians, Trust Lead Nurses)
- Network Group members

Appendix D

Risk Register

Risk	High / Med / Low / Risk	Actions to Manage Risk
The assumptions around demand and capacity within the business case are incorrect.	Medium	The PCT will have to continue to monitor admissions to hospitals resulting in death within 14 days of admission to ensure adequate capacity within the community. In addition, utilisation of community services and bedded facilities will have to be monitored to ensure there is not over-provision of services.
That GP's will fail to update their Gold Standard Framework Register	Low	To be monitored through the PCT's performance management framework for GP's.
People in BEN PCT would actually chose to die in hospital	Low	This is unlikely given the level and type of research undertaken on the subject.
The demand on District Nurses is greater than their capacity for provision of care	Medium	Through close monitoring of workloads in initial 6 months any need for additional capacity can be identified / quantified and addressed at an early stage
Insufficient availability of suitable facilities for additional supportive care beds	High	In the short-term this is likely, however, in the longer-term, with the opportunity to occupy the Councils, next 2 Care Centres the risk will significantly drop.
Reduction in emergency & unnecessary admissions into secondary care not realised	High	In the short-term this is likely due to necessary changes in clinical approach, and the possibility that it may take time to commission all the community services needed to deliver the new model of care.
Cost of drugs in primary care is prohibitive	Low	As the savings from emergency and unnecessary admissions are significant, it is unlikely that the additional cost of drugs in primary care will be greater than the savings made.