MODERNISATION AND REFORM
OF PALLIATIVE CARE

Developing a Regional Model for
Palliative Care

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Authors

Dr Sonja McIlfatrick
Dr Donna Fitzsimmons
Professor Roy McConkey
Dr Gail Johnston
Dr Margaret Cupples
Dr Owen Barr
Felicity Hasson

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*Copies of the Appendices are available from:
NICan Palliative & Supportive Care Network,
Northern Ireland Cancer Network
Knockbracken Healthcare Park
Belfast.
Tel: 02890565860
Fax: 02890565861
Or they can be downloaded from: www.nican.n-i.nhs.uk

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We also acknowledge the DHSSPS and Northern Ireland Cancer Network for funding this work.
1.0 Introduction

“**It’s always good to have an end to a journey but it is the journey that counts in the end**”

Often the success of our health and social care service is reflected in the increased life expectancy of our population. People are now living longer with long term conditions. Such demographic changes require services to adapt and the Modernisation and Reform agenda within Northern Ireland is the mechanism that enables a responsive change.

The aim of this phase one project, agreed by the project steering group, was to initiate the development and prioritisation of new models of service responding to the holistic palliative care needs of all patients, their carers and families.

In particular the main objective was to:

*Identify a prioritised primary/community facing integrated service model, based on identified need acknowledging that a phased approach is being taken to the overall modernisation and reform of palliative care across Northern Ireland.*

From the outset it was recognised that this model/s should be:-

- integrated across all care settings
- based on agreed generic standards
- patient focused,
- primary / community facing care
- applicable across all conditions including both malignant and non-malignant disease;
- respecting the 24-hour supportive, palliative and end of life care needs of the patient and their family.
- taking into account the urban and rural settings and cultural differences across Northern Ireland;
- based on the examination of the evidence for effectiveness nationally and internationally;
- demonstrating the interface with developing and existing strategies.

As the work progressed it was also recognised that there was real complexity and uniqueness to this work in terms of the sensitivities around palliative care and professional and public awareness alongside encompassing cross sectors, cross-disciplines, and cross-organisations. Therefore it was essential that the model would also be creative, responsive, flexible, and inclusive with clear ownership from all participants.
1.1 Background

Some early needs assessment work was progressed by the NICaN Supportive and Palliative Care Network during 2006. Challenged by the capacity to collate complete and reliable comparable data at local and regional level and across organisations, a presentation to the DHSSPSNI in May 2007 highlighted the need for dedicated project support to enable the process. Around this time the Department invited the NICaN Supportive & Palliative Care network to collaborate with the Service Framework Leads to develop standards for palliative and end of life care. The Generic Palliative Care Standards within the developing Regional Service Frameworks provide the rationale for the development of a regional model (table 1). The standards encompass the quality dimensions of patient centred, equity, effectiveness, timeliness, safety and efficiency.

Table 1: Generic Palliative Care Standards

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<th>Standard 1</th>
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<td>Health and social care professionals, in consultation with the patient, will identify, assess and communicate the unique supportive, palliative and end of life care needs of that person, their caregiver/s and family.</td>
<td>Patients, carers and families have access to responsive, integrated services which are co-ordinated by an identified team member according to an agreed plan of care, based on their needs</td>
<td>People with advanced progressive conditions, their caregivers and families, will be informed about the choices available to them, by an identified team member, and have their dignity protected through the management of symptoms and provision of comfort in end of life care</td>
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Ministerial Mandate

An Assembly Debate in December 2007 recognised that “75% of terminally ill people in Northern Ireland are unable to die in the place of their choice.” Parties were united and supportive of the Minister’s commitment “to make choice a right and not a privilege”. Whilst recognising that services for patients with palliative needs in Northern Ireland have developed considerably over the past decade through the joint efforts of the voluntary and statutory organisations the Minister announced the need to develop a regional model for supportive and palliative care, to provide quality, comprehensive, consistent services across Northern Ireland.
1.2 Policy Context

The policy and legislative context for service provision has been well defined in a variety of reports and policy documents. This has been set at both national and regional levels and thus the intention of this report is merely to summarise key features of the policy context, rather than provide a detailed analysis.

**Partnerships in caring ...Standards for service** (DHSSPS, 2000) was the first document to appreciate the complexity of supportive and palliative care, integral to the trajectory of many diseases, appropriate to all age groups and requiring multi-professional integrated working for effective service delivery. The review highlighted, in particular, the need for partnership with patients, families, care providers, service planners and commissioners, "commissioners and providers must work in partnership to ensure that patient/carer needs are identified and resources made available to meet these needs" (DHSSPS, 2000).

Current regional perspective is shaped by **The DHSSPS, Twenty Year Vision for Health and Wellbeing in Northern Ireland 2005 - 2025** (DHSSPSNI 2005). Significant to this is the development of “responsive and integrated services aiming to treat people in communities rather than hospitals” (pg 6). The document advocates a more effective and efficient way of working through multi-disciplinary teams to improve the quality of services. This is also coupled with **The Primary Care Strategy Framework, Caring for People Beyond Tomorrow** (DHSSPSNI, 2004). This report acknowledges the shift in workload from the hospital sector to primary care, and the emergence of new service developments to prevent inappropriate hospital admission or facilitate early discharge.

One of the objectives of the new **GMS Contract (2004)** was the incorporation of evidence based and quality focused clinical and organisational targets. In this regard it has been beneficial that palliative care is now recognised as a clinical domain within the Quality and Outcomes Framework (QOF). However, it should be recognised that current QOF palliative care targets lack the detail and rigour required to guarantee best practice for all. **National Service Frameworks** (NSF) have been developed in England and Wales as evidence-based standards to increase quality and address variations in treatment and care. Northern Ireland has just embarked on a significant programme of service framework development across a number of clinical areas, many of which encompass end of life care.

The **Cancer Control Programme** (DHSSPSNI, 2006) is the first in a series of documents, which will form a Regional Cancer Framework within Northern Ireland. Within the recommendations it advocates the enhancement of service provision in the community to enable intensive coordinated home support, equality of access to services inclusive of out of hours service provision. **Guidance on Improving Supportive and Palliative Care for Adults with Cancer** (NICE, 2004) provides direction and comprehensive recommendations, which reflect holistic care. These
recognise the importance of, for example, user involvement, coordination of care, assessment and response to holistic needs, information giving, psychological support services and access to specialist palliative care services. The principal standards and targets highlighted in *Priorities for Action 2007-08* (DHSSPSNI, 2007) call for fully integrated care and support in the community. They advocate care which is person centred, multi-disciplinary, flexible and responsive taking into consideration the needs of carers.

### 1.3 Values Underpinning Service Provision

At the outset it was important to specify the values and principles that guide service provision for palliative and end of life care. These values are encapsulated in the vision statement for the Northern Ireland Supportive & Palliative Care (S&PC) Network and were adopted as the overall aim for this project.

To move towards a position where any patient, from diagnosis to the advanced non-curative stage of disease, in any setting, lives well and dies well, in the place of their choosing. This requires a person-centred, integrated and holistic approach to service planning and delivery. This focus will ensure that all patients will receive high quality reliable care, retain control, choice and dignity to the end of their life.

Throughout the project a number of key values were re-iterated by professionals and these have been explicitly stated so that common ownership is gained around these values (Table 2). These reflect many of the values inherent in the NICE guidelines for Supportive and Palliative Care (DoH, 2004) & in ‘dignity preserving care’, which focuses on attitude, behaviour, compassion and dialogue (Chochinov, 2007).

### Table 2: Values for Palliative and End of life Care

Quality dimensions: patient centred, equity, effectiveness, timeliness, safety and efficiency

1. **Dignity** of patient and family
2. **Compassionate, effective and timely** patient and family centred care
3. **Equity** in access to palliative care services
4. **Respect** for patient, family and care providers
5. **Advocacy** on behalf of patients and families
6. **Empowerment** and informed **choice**
7. **Accountability** to patients, families and wider community: to provide effective, timely, safe and efficient care
8. **Partnership working** across disciplines, sectors and organisations is essential
1.4 Summary of the project methodology

The project team consulted with the Marie Curie ‘Delivering Choice’ programme team during the development and refinement of the methodology. The methods to achieve the key objectives were agreed by the Project Steering Group. Figures 1 & 2 summarise the various processes and stages that were involved in this project. The aim was to have a process that was inclusive and participative in order to ensure a sense of ownership from all stakeholder groups and communities.

The process was inclusive of patients, carers, front line staff, commissioners, managers as well as those working in community settings, acute sectors, and the voluntary sector. To ensure widespread knowledge of the project, communiqué were widely circulated in January and March 2008. Participation was achieved through various formats. Participation for patients and carers was through the use of questionnaires and interviews, whilst professional participation was through email consultation, focus group meetings and round table discussion. Other more innovative approaches to information gathering were also included. This included the shadowing of district nurses during their daily work with patients who were identified at the end of their life.

Scope of the Project

For the purposes of this project, the project team agreed to focus on those elements of palliative care likely to be delivered to any adult in the last 12 months of life, including general and specialist palliative care. Whilst recognising that the principles of palliative care should be applied to all patient groups, the focus of this work was with conditions that were already engaged with the development of the generic palliative care standards, such as congestive heart failure, respiratory and renal disease.
Figure 1: Project Work Strands

A prioritised primary/community facing integrated service model, Based on identified need acknowledging that a phased Approach is being taken to the overall modernisation and reform of palliative care across Northern Ireland

**Work Strands within Phase 1**

**Validation of Service Model**
Round Table discussion event

**Stakeholder Consultation on model development**
• Build on the data already collated
• Professional Focus groups

**Patients’ and Carers’ Views**
Adapted VOICES questionnaire

**Assessment of Need**
• Epidemiological Data
• Accumulated audit data
• Service Provision

**Literature Review**
Section 1 The palliative care needs of Patients and families
Section 2 Models of Palliative Care Delivery
Section 3 Key components of effective model
### 1.5 Project Board and Project Steering Committee

Two groups were established to oversee and guide the work. The project steering group had direct responsibility for the work and met 4 times during the time of the work from Jan-May 2008.

**Figure 2: Process for Project Management**

- **Project Board**
  - NICaN Board
  - Chair of Project Steering Group

- **Project Steering Group**
  - Small & focused steering group with regional geographic spread
  - Representation drawn from core constituent members of the NICaN supportive & palliative care network to include providers (primary & Secondary), commissioners, independent, voluntary other regional networks
  - Department & HSCA, Project Lead from UU tech.

- **Project Team**
  - Dr Sonja McIlfatrick, Dr Donna Fitzsimons, Prof Roy McConkey, Dr Owen Barr, Dr Margaret Cupples, Dr Gail Johnston, Felicity Hasson

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**Audit of service provision**

The information gathered for the project was considered as an audit of service provision rather than research. This was confirmed by the Office for Research Ethics in Northern Ireland. Nonetheless strict ethical guidelines and principles were adopted throughout all stages of the project. These included ensuring confidentiality, consent and sensitivity particularly when conducting the interviews with bereaved carers.
2.0: Lessons from the Literature

The project team undertook a review of the literature around three themes.

1. Palliative care needs of patients and family
2. Models of Palliative Care
3. Key components of a palliative care model

The literature consisted mainly of articles in international journals, supplemented by reports and local research currently being undertaken in Northern Ireland. These reviews are provided in Appendix 1 with the key messages from each summarised below.

2.1 Palliative Care Needs of Patients and Family

The delivery of palliative care is widely advocated and this is reflected in various international, national and regional frameworks. Palliative care patients present a great challenge to professional service providers linked with the complex physical needs but also the emotional context in which care is provided. The uniqueness of the individual and personal experience of palliative care differs according to diagnosis, symptoms, and holistic assessment of palliative care needs. In seeking to provide palliative care to patients and their carers it is important to respond to the main areas of need identified in the literature, such as the need for:

- effective information and communication
- psychological support services
- social support services, including financial support and assessment
- empowerment and involvement in care, with considerations of choice and preferred place of care and death
- effective symptom control
- co-ordinated and integrated services

In developing future services consideration needs to be taken around the hallmarks of good practice, such as those included the NICE (2006) guidelines for adult cancer patients and their carers, and key principles to guide service delivery. They include:

Table 3: Principles to Guide Palliative Care Delivery

- User and carer choice and involvement
- Needs led intervention
- Access available according to need
- Accurate and timely communication
- Integration of system of care
- Quality
- Information
- Education

(Adapted from Clark 2006; NiCaN 2007)
Another key message relates to the lack of standardised definition of palliative care in the literature, policy and practice. Whilst a heightened agenda is evolving in relation to palliative and end of life care, clarity around definitions of terms and professional and public awareness is crucial.

### 2.2 Service Models of Palliative Care

Palliative care is provided in a variety of different settings, including hospice, hospitals, patients’ homes, residential and nursing homes and has broadened to embrace care in the early stage in the disease trajectory and encompasses the care of adults and children with non-malignant life-limiting conditions. A range of issues and areas of concern currently face palliative care service model provision in Northern Ireland which impact upon meeting patients’ and carers’ needs. These include:

1. Increased demand for palliative care
2. A lack of adequate palliative care facilities in some services (gaps in service provision)
3. Variable access to palliative care services
4. Lack of integration and inflexibility of palliative care services
5. A lack of workforce planning for palliative care
6. A lack of standard specifications
7. Variability in the funding of palliative care services.

### 2.3 Key Components of an Effective Model for Palliative Care

The review of the service models and research highlighted a number of key characteristics that are required to achieve effective, timely and seamless palliative care delivery.
Table 4: Key Features of Palliative Care Model

- Recognition that the patient and family and general population all require care/education/training
- Clear identification of palliative care phase
- Responsiveness to needs and preferences of patients and carers
- Provision patient centred, holistic and multi-disciplinary care on the basis of identified care needs and informed choices.
- Access to a flexible service model to ensure a holistic continuum of care
- Service configuration required to ensure access to co-ordinated quality palliative care services that are culturally appropriate.
- Integrate/co-ordinate palliative care services and referrals at a local, regional and national level to ensure continuity of care
- Provision of social, emotional, financial and spiritual support through all the stages from diagnosis to bereavement care
- Commitment by palliative care services and professionals to quality improvement and the ongoing evaluation of services
- Integration, co-ordination and continuity of services and care across various care settings
- Provision of effective and empathic inter professional communication
- A skilled and competent workforce that is committed to developing palliative care
- Need for transparent and ongoing funding to enhance capacity and capability of services to meet need
- Continuous evaluation and evidence base to inform service delivery and development
- 24/7 availability of a health professional knowledgeable about the case
- Facilitates ongoing communication among patients, families and providers
3.0: Lessons from Demographic & Epidemiological Data

Data on existing palliative care services were gathered across the region with a view to identifying potential gaps and future needs. These data were interpreted using guidelines recommended by the National Council for Specialist Palliative Care Services for population-based needs assessment for palliative care (Tebbit, 2004). Epidemiological data have therefore been gleaned from a variety of sources including the census 2001 and NISRA, and where possible extrapolated for the new Trust areas. Data have been augmented by regional audits and information from specialist palliative care teams. Data, therefore, represent different years depending on availability. Full details of this needs assessment can be accessed in Appendix 2.

Key messages are summarised as follows:

1. By 2017 projections for the Regional Population based on the 2001 census data suggest that 392, 363 people will be aged 65 years and over. This is the section of the population with the highest incidence and mortality from cancer and other diseases and therefore those most likely to need palliative care.

2. Currently there are more people aged 65 years and over who live in single person households than in households of one or more, suggesting the absence of a carer and the reduced likelihood of dying at home.

3. The majority of patients requiring palliative care, irrespective of type of disease, still die in hospital despite most people’s preference to die at home and this trend is increasing for most diseases and in most areas.

4. Figures showing religious and ethnic breakdown of the population for the region based on the 2001 census show that most people are Christian and the number and variety of ethnic minorities low. However, these figures do not take account of the recent influx of Eastern Europeans or the needs of other minority groups in Northern Ireland relating to palliative care e.g. the travelling community, prisoners or those with learning disabilities.

5. Specialist palliative care teams now exist in every hospital in Northern Ireland but the number and type of members varies with some hospitals having a dedicated multi-disciplinary palliative care team and others only single post holders. The majority of these staff has been pump primed by the Cancer Charities or partly or fully funded by the Voluntary Hospice Sector.

6. There are various levels of provision for specialist and generalist palliative care in Northern Ireland. Access to specialists is more limited in certain areas. This is highlighted in the map illustrating the coverage of services geographically and the breakdown by voluntary or statutory services. It is apparent from this map that there are large areas outside the greater Belfast area which are still poorly covered by community specialist palliative care services.
8. Accurate figures regarding patterns of referral and caseload are missing for both generalist and specialist palliative care services due to the absence of a uniform shared database and the ability to follow patients.

9. Examination of audit data for general palliative care services suggests that there are areas of good practice but these could be improved with further training and resources.

10. Given the dearth of information and limitations of the existing data sources it may be useful to conduct more comprehensive audits of current service utilisation. For example: palliative care accident and emergency admissions; discharge audit, and average length of care in hospital palliative care teams.
4.0: Consultation with Professional Groups and Users

Engagement of key stakeholders regarding the development of a service model was an essential feature of this project and achieved by a variety of different activities, such as email discussions, focus groups and interviews. These included:

1. An email consultation to update information from 2007 regional workshop (145 delegates)
2. Focus groups with Palliative Care Forums in 4 Board areas (51 delegates)
3. Focus groups with primary care professional community: district nursing (29 participants); General Practitioners (5 participants); semi-structured interviews with District Nurses (2) and GPs (6);
4. Focus groups with non-malignant regional groups such as Heart failure Respiratory and Renal (n=34 participants).

These groups were asked to focus on four issues:

1. The main challenges / problems with current service provision
2. The changes required to the current service (in order of consensus)
3. The core elements of an ideal model for palliative care
4. The main stakeholders in the "ideal" service model.

4.1 Key Messages from Professional Groups

A report detailing the information gathered is summarised in Appendix 3. However some key messages from this professional consultation included:

- **Need for improved communication and information**
  
  Participants articulated a need for improved communication between all groups: patients, carers and all professionals. This was related to the need for **improved public and professional awareness** about palliative care.

- **Difficulties in identifying palliative care phase**

  Difficulties in actually identifying palliative care were highlighted and participants indicated the importance of ‘naming’ this phase for all concerned. Thus it appears that an ideal model should be underpinned by a clear definition of term, which is subscribed to by all relevant professionals and understood by patients, their carers and wider community.
• Equity and choice for service provision

It was acknowledged by participants that services across Northern Ireland had developed at different rates and were configured in different ways across HSS Board and Trust areas. Although some attempts had been made to increase the uniformity and equity of service some perceived geographic differences existed.

• Integration between services, professionals and organisations

The need for a regional approach to the integration of palliative care was echoed throughout all the focus groups.

• Co-ordination of care provision

The role of a named key worker for patients and carers and a single point of contact for professionals delivering the care was highlighted in discussions as being of particular value in the co-ordination of care.

• Enhanced generalist services

The provision of generic palliative care services was acknowledged as a major component of services that support and care for patients with palliative care needs and their carers. Some professional groups that were considered as having a central role were the General Practitioners and District nurses.

4.2 Views of Users and Carers

Two pieces of work attempted to extrapolate the main views and experiences of patients and bereaved carers. One gathered evidence from studies that have been undertaken in the local context gathering data from patients, active and bereaved carers alongside professionals. The second sought to gather the opinions of bereaved carers using the VOICES (Views Of Informal Carers - Evaluation of Services) questionnaire (Addington-Hall & McCarthy, 1995, Addington Hall, et al, 1998).

The VOICES tool has been used retrospectively to evaluate the quality of care provided to patients (and to their families) in the last months of life, irrespective of diagnosis. This retrospective approach to collecting information about the quality of services for dying people has been adopted in a number of studies over the past forty years, as a means to collect data on carer satisfaction across the illness trajectory. For this project, data were collected from 10 participants and this indicated variability in terms of the services that were provided and the bereaved carers’ satisfaction. However, the weakness illustrated in this study was that data were often contradictory in nature. For example carers appeared to have constructed a narrative around the last phase of their loved one’s life that could not be evidenced through the questions asked. More details around this issue are discussed in Appendix 4.
4.3 Studies Undertake in Local Context

The local literature that has been conducted recently is distinctive in that it has been largely qualitative in nature and been highly focused on specific populations, such as those defined by diagnosis (Rutherford et al. 2008), geographic location (McIlfatrick et al. 2007) or professional grouping (Stockdale and Fitzsimons, 2006). Data have been generated from a variety of perspectives including patients, carers and healthcare professionals. In total the views of approximately 82 patients, 91 carers (both active and bereaved) and 123 professionals have been sought through the combined efforts of these studies (Table 5: Local Studies).

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<th>Stockdale</th>
<th>Distinct nurse re card</th>
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Modernisation and Reform of Palliative Care
Given that these research projects were conducted completely independently of each other and funded by separate sources, the similarities of the conclusions drawn are quite remarkable. Indeed, there is additional weight to the strength of these findings when the evidence is accumulated in this way. Common themes emerging from the combined analysis of these reports and quotations where appropriate are presented in Appendix 4 to illustrate meaning and significance.

### 4.3 Case Study Analysis

District nursing shadowing visits were undertaken in each of the five Health and Social care Trusts. This resulted in the presentation of case studies that helped to provide important insights and reflective accounts around the challenges of maintaining patients at home, and ensuring that the full range of services is available to them. These case studies highlighted various aspects of good and more negative issues, which can then be mapped against the emerging components of service model to further elucidate and validate these components. Further detail on these case studies is presented in Appendix 5.

Some of the key messages emerging from these diverse case studies included:

- The need for communication and information which can aid understanding and reduce anxiety
- Organisation of services can be complex and time consuming, so the responsibility for the 24 hour organisation of care requires dedicated time.
- Duplication of assessment and lack of integration of this process is not effective use of time
- Shared records across the voluntary and statutory services could bring continuity to shared planning of care with the patient and across all professionals and carers.
- A strong emphasis on care packages to address physical needs was apparent with some questions existing around psychosocial assessment
- Access to responsive out of hours services are important, with clear contingency planning
- The important role of the family in enabling care at home needs to be recognised and sustaining this role requires responsiveness from all professional groups
- Education, training & support required for informal, formal and professional carers.
5.0 Building the proposed regional model for palliative care

The central objective of this project from the outset was to initiate the development of a regional model of palliative service provision that reflected local needs and priorities. For the purposes of this report a model has been defined as “a hypothetical or visual description of a complex entity or process.” Throughout the various stages of information gathering, analysis and consultation the project team’s goal was to synthesise this data and appropriately reflect it in the creation of an innovative model of palliative service delivery. The intention of this section of the report is to present and provide a concise rationale for the development of this model, although the detailed evidence base is provided in the preceding chapters and appendices.

Following the review of the data obtained from all the strands of work undertaken the key guiding principles and core components of service model were identified. These guiding principles and core components were recognised as complex entities and yet a simplistic diagrammatic representation of these aspects was required. It was important to show the interdependence of these complex and integrated components of palliative care provision. The proposed method of representing this model was as a cylindrical, three-dimensional object held aloft on a stand or pedestal.

5.1 Guiding Principles

The guiding principles for this model were viewed as the core elements of this cylindrical object, visible from an aerial view and included:

- Patient and Family Centred Care
- Enhanced Community Provision
- Supported by Specialist and Hospital Provision
Patient and Family Centred

The impetus to create a patient and family centred model was derived from a combination of recent policy documents (NICE 2004) and consultation with patients, carers and health care professionals. It is recognised that palliative services are provided within a situation that is often physically and emotionally challenging for patients and their families. Despite the complexities of care provision from a professional and commissioning level, it is imperative that all such care is very clearly focused on the needs of the individual patient and their family (National Advisory Committee on Palliative Care 2000). The requirement that this model should be patient and family centred received a strong mandate within professional focus groups that were conducted as part of this study, but is further evidenced in Walsh et al’s (2008) study:

“I think professionals get into a box and they don’t see people as people. They see a treatment and they don’t think outside that by thinking of the family, until it comes to the crunch, when it’s going to be a life changing thing that maybe they are going to pass away – they don’t think before that – to sit down and talk to people”.

The patient and family are therefore visualised at the heart of this model, and central to every other component.
Enhanced Community Provision

The original brief for this work was to create a model that was “community facing”, because the recent policy and legislative context within the UK and Northern Ireland is committed to delivering as much care as possible in the community, where the community is defined as including local Nursing Homes, Hospices, Intermediate care beds and community hospitals. It is intended that this second component of the model which encompasses “enhanced community provision” would be understood as including both generalist and specialist palliative care professionals, and also extend to formal and informal support networks within the community such as designated palliative care beds, spiritual advisors and social support packages.

Analysis of the data in this study has demonstrated that there is considerable geographic variation in the availability of these resources, but that areas of innovative practice have also been established, often reflecting the integrated development of generalist and specialist services such as Hospital at Home, Rapid Response Teams, Hospice Day Care, Integrated Multiprofessional Community Palliative Care Teams and Palliative Care Support Team (a team of nursing care assistants that are managed and deployed by District Nursing Sisters). There is no doubt that for a proportion of people with palliative care needs, hospital services are required and appropriate, however this report has demonstrated (Appendix 2), that currently more people die in hospital in Northern Ireland, than wish to do so. While there was plenty of evidence that this did facilitate more effective symptom control and relieve patient and family distress, there are serious implications of such an approach. As a doctor in Marley’s (2008) study observed:

“Unless the whole subject of death and dying has been raised and discussed and agreed and planned for, then they are likely to die in the corner of a hospital ward, where they will be seen as a treatment failure”

All people with palliative care needs deserve to have choices and their families require support to enable this to be delivered with a minimum of distress and discomfort for all concerned. Thus, further development of both generalist and specialist palliative care in the community is required. A strategy for the provision of specialist and/or intermediate care should be considered but such developments should be carefully planned and deliver measurable improvements to the quality of care provided.

Supported by Specialist and Hospital Provision

There is recognition in the literature and local policy documentation, that there is a pyramid of palliative care provision, which basically indicates that the level of specialist palliative care in-put should closely align with the complexity of the patient’s needs. Thus the majority of patients with palliative care needs can be managed effectively with generalist services, and it is only if a patients’ needs are more complex, greater in-put from specialist services is required (Palliative Care Australia 2005).
The third element of this model is therefore the specialist support that is provided through specialist clinical teams and tertiary hospitals. There was a strong endorsement within the data reviewed in this project for the valued contribution specialist clinical and palliative care teams make to effective palliative care provision. In the view of a carer in Walsh et al's (2008) study:

“The good bit was whenever (Specialist Palliative Care Professional) came in, because she was controlling his pain and was in liaison with us and them”.

There was widespread recognition that specialist palliative care personnel and services are a scarce and expert resource, that should be regarded as the “touch stone” of palliative care provision - for a large part supporting other professionals to deliver effective care, but where necessary providing a specialist service to those patients and families that have complex needs.

Much of the consultation and evidence reviewed in the course of this project has confirmed that there are disparities in palliative care provision in Northern Ireland and that those people who have a non-malignant diagnosis do not receive the same resource input or quality of service as people with cancer. This situation must be addressed urgently, as people should have access to palliative care provision solely on the basis of need, rather than diagnosis. Chronic illnesses such as respiratory and heart failure currently kill more people in Northern Ireland than cancer, as is represented in the segments of this model below, and any model of palliative care provision must deliver appropriate and equitable services. Further consultation or pilot work is required to determine the specific needs of patients with chronic illness and the capacity of current service providers to deliver the high volume of palliative care that will be required by them in the immediate future.

5.2 Core Components of Model

The core components of the model have been derived from local needs assessment, consultation and previous research. They are represented within this model as layers of the image and consist of six main components:

1. Identification of Palliative Care

A strong theme in much of the consultation on this report emphasises the need for the accurate and timely identification of the patient with palliative care needs. This essential first step seems to be a major stumbling block in many of the cases cited and is recognised as a problem for people with a variety of diagnoses. There was recognition from many sources that identifying palliative care needs is a complex and challenging process in the course of any individual’s
care. This is true for a variety of reasons from both the patient and professional perspective. It clearly requires shrewd clinical judgement and well developed communication skills. A hospital consultant in Fitzsimons et al’s (2007) study described the challenges involved:

“You can’t assess every single patient, you don’t have the time to sit for half an hour and ask them how they are getting on at home. A lot of the time you can see they are deteriorating, but what are you meant to do? You might know there are difficulties, but how are you meant to go forward? It’s so hard to know”.

It is also evident that difficulties associated with prognostic uncertainty can obscure the point at which patients’ palliative care needs should be identified. Data provided in the following tables demonstrate that there are substantial differences in illness trajectory depending on the patient’s diagnosis.

Table 6: Different Illness Trajectories

This typifies the traditional pattern of cancer, and yet with advances in treatment some forms of cancer are becoming more chronic and are now seen as long-term conditions with more parallels to the organ failure type of disease. This trajectory may span up to six months.
These tables from the Gold Standards Framework, Prognostic Indicator Guidance (vs 2.25, June 2006) emphasise that there is much less predictability for patients with a non-cancer diagnosis. Findings in the local research (Appendix 4), have demonstrated that professionals are reluctant to address palliative care issues when prognosis is uncertain. Thus, these patients may never have their palliative care needs identified, or this may take place very late in their illness trajectory. In addition patients and their families can find it difficult to deal with their condition reaching a palliative stage. They frequently use denial as a coping mechanism and this has the potential to further complicate the identification of palliative care need.

Data from many sources within this project has emphasised the importance of identification, and it is further advanced within the first palliative care standard. The literature has indicated that there are evidence based indicators which specify when such an assessment is warranted for many conditions, but further
work is required to specify who should undertake the assessment and to clarify the most effective mechanism by which this identification should be communicated throughout the multidisciplinary team in each of the sectors of healthcare that are relevant for the individual patient.

2. Holistic Assessment

When the patient’s palliative care needs have been identified the next critical step is that of holistic assessment. From the consultation process and local research it was evident that there was much need for improvement on this issue. It would seem that all too often this assessment is neglected by healthcare professionals and is not holistic in nature. As data from McIlfatrick et al’s (2007) study substantiates patients and carers were often frustrated by the lack of appropriate assessment:

“I think there should be more co-ordination between doctors, nurses, carers, social workers… … It’s all crazy, I says, ‘Why they don’t just get together, have a case conference, see what the woman needs and then provide it - But maybe that’s too simplistic an attitude.”

(55 yr old informal carer for 88 yr patient with colon cancer)

There was a clear imperative not just to focus on physical assessment, but to include the psychological and social needs of the patient and their family members as well. It is also evident that this assessment should be effectively communicated throughout the team, so that all providers are aware of the patient’s needs and are providing appropriate care.

3. Integration of Services

There is no doubt that palliative care provision is challenging, due to the variety of professionals involved and the need to move across primary, secondary and voluntary care sectors. A key message coming out of the consultation and many of these local studies was the need for care to be more integrated and “joined up”, as a Stakeholder in McIlfatrick’s (2007) study asserted:

“No service should stand alone. Integration must be at the cornerstone, as integration is about making the best use of skills and resources…It’s about the patients’ journey, and no one professional can provide all that’s needed. Integration has to happen to make this work”.

Local qualitative research studies provided strong evidence regarding the need for integration with patients facing problems such as fragmented care, poor communication and inadequate access to resources. It is clear that further work will be required to develop a more integrated approach to palliative care provision and to determine its effectiveness.
4. Co-ordination of Care

The co-ordination of care to patients and families with palliative care needs is closely linked to integration, but warrants particular attention in its own right due to the weight of evidence in local research which confirms it as a problem. There was great frustration exhibited by carers at the lack of co-ordination in the care provided to their loved one, as illustrated in this quotation from Brown’s (2008) study:

“There were times during my treatment when I felt abandoned...when I was being moved from the hospital to the hospice I felt like a bundle of dirty clothes that was being shifted from one place to the next – like the laundry – and The Palliative Care Consultant helped me with this. I felt I wasn’t a person at all, just dirty laundry being shoved from one place to the other”.

Given the physical and emotional challenges faced by patients and their families at this time, it is understandable that they can feel overwhelmed and in need of professional help to negotiate this journey with less difficulty. Consultation with healthcare professionals also emphasised the importance of this issue and outlined the potential for a “key worker”, defined as the professional who knows the patient best, taking on a co-ordinating role. There was also a view expressed that the administrative aspects of co-ordination could be undertaken by a non-professional, specifically tasked with expediting the patient's journey through the various organisations required to provide diagnosis, treatment and support.

5. End of life & Bereavement Care

While end of life and bereavement care are regarded as defining features of palliative provision, evidence gathered in this study demonstrate that there is still a long way to go to deliver good quality care to patients and their families in the final chapters of life, irrespective of diagnosis. In McIlfatrick’s (2007) study the 41 year old wife of a patient dying from malignant melanoma asserted:

“You only have once to do it and try and get it right, especially when someone is dying – that care should be there – no matter what it costs! No one should be coming back to me saying – “I can’t get these carers for you”.

There is no doubt that limited resource availability and a combination of the other factors discussed in earlier sections of this model conspire to undermine effective end of life and bereavement provision. However, the importance of this component of the model was re-affirmed on many stages of the consultation process. There is an urgent need to provide improved end of life and bereavement services to dying patients and their families. Many initiatives such as Preferred Place of Care and the Liverpool Care Pathway have the potential to
enhance provision, but these should be taken forward in a planned and systematic approach that assures buy in from all concerned, and can evidence improved outcomes.

6. Professional and Public Awareness

An over-arching theme that was derived from many strands of this project confirmed that one of the most pressing challenges to the development of more effective palliative care provision in Northern Ireland was ambiguity in terminology and lack of understanding regarding the benefits of this approach. Indeed clarity on both these issues was required not just for the public, but also for healthcare professionals who frequently held misconceptions regarding, what palliative care involved, when it should be initiated and the range of benefits it had to offer. In many instances professionals regarded palliative care as being synonymous with end of life care, and there was little understanding that it could be initiated at an early stage of the disease process, in parallel with “active treatment”. Patients and their carers were also reluctant to engage with the services either because of stereotyped views of what palliative care involved and how it was delivered, or because they did not accept that their illness was life-limiting. As a carer in Kernohan et al’s (2008) study observed:

“I’m not totally sure what would be available (palliative care services). It’s hard to say when I have no experience of it. I mean would I have to go to them, or would they come out to me?”

It would seem that an essential pre-requisite to the development of improved palliative care provision is education of both the public and professionals regarding the fundamentals of palliative care, so that it is not regarded as a passive, or last ditch option, but embraced as a mechanism by which to provide for the complex and holistic needs of patients and their families.

5.3 The Foundations of the Model

In order to explain the context required for effective delivery of this model, the image was regarded as being built upon several fundamental features. Aspects such as service delivery, commissioning and policy provide a sound foundation on which this model of palliative care provision sits. In order to be held aloft and viewed to its full potential, the model requires something robust to rest upon. Here the pedestal of the stand represents education, defined in its widest sense. It is also imperative that this new model of palliative service provision is underpinned by the core values of equity, respect, empowerment and choice. These values form the base of the stand. The strength of these values in policy, commissioning and service delivery of palliative care within any care setting is what ensures that the components are prioritized. These foundations are represented visually in Table 2 (p.8).
Regional Model for Palliative Care

Figure 4: Regional Model for Palliative Care

Some consideration was then given to the process to deliver these components, enabling factors and gaps and barriers. This information has been summarised in Table 6 (Appendix A). This table was used to inform the discussions that took place at the consultation workshop.
6.0: Validation of Model: Consultation Workshop

A three hour consultation workshop was held attended by over 60 participants from a range of health and social care sectors. This had three main aims:

- To gain an endorsement for the core components of the emerging model;
- To elaborate on the what must be done by service commissioners and providers to implement the model;
- To identify the critical steps for its implementation.

A briefing paper was distributed prior to the meeting and a summary of project and a description of the emerging model was presented. Each group was allocated one theme from the emerging model with a summary sheet that identified possible processes to deliver on that particular component and enabling tools that had been identified by the Project. The group was asked to identify what must be done at a commissioning level, and at a service delivery level, to achieve this component of the model and who/what can support this process. Appendix 6 details the recommendations that emerged in the discussions.

Across the six groups a number of themes re-echoed which suggest that these are critical to the implementation of the model. These were:

- The need for education and training of the HPSS workforce in relation to Palliative Care especially in non-malignant diseases.
- The untapped potential of IT systems to allow for timely exchange of information across systems and practitioners.
- The need to involve and empower patients and their carers in all decision-making.
- The value of having a nominated person (key-worker/coordinator) who can effect the linkages that are required within and across service systems.
- An equitable service across Northern Ireland will be attained if there is stronger commissioning of palliative services, with explicit care pathways and enforcement mechanisms and regular monitoring of outcomes.
- Enhancement of community services; notably the availability of 24 hour support.

The proposed implementation plan for the model elaborates how these steps might be actioned in the next section of the report.
7.0: Conclusions & Possible Next Steps

The proposed model provides a framework around which palliative care services in Northern Ireland can be made more accessible and effective to the growing numbers of people who will require them. However these gains can only be fully realised if the model is actively promoted, understood and acted upon. This will require a co-ordinated response across various agencies over a sustained period. Our experiences suggest that this may best be undertaken on a phased basis. Moreover it is crucial that the model can be integrated with existing structures and processes rather than creating new systems, although in some aspects this may be unavoidable. However there may also need to be additional resources available to palliative care service to fund service improvements and the increased demand.

The issues raised in relation to palliative care resonate with those experienced with other client groups who have more complex needs. Hence there is an urgent need to extract the common lessons so that the necessary changes can have a common application in services. These revolve around:

- the interface between acute and community services;
- the balance between generic and specialist provision;
- co-ordinating multi-professional and multi-agencies inputs;
- the effective transfer of information;
- the need for patient/carer involvement and empowerment; and
- the need to increase public and professional awareness.

It is crucial that changes are monitored to ensure that they produce the desired outcomes. Already there are examples of good practice in specific areas, which deserve to be documented so that they can be replicated. Equally new initiatives might commence in a designated geographical area and their impact assessed before rolled out on a regional basis. However for local improvements to impact on regional practice, mechanisms are needed to promote an ethos of sharing across disciplines and agencies.

7.1 Conclusions

The conclusions emerging from this project have been grouped into the six core components of the proposed model.

- Professional and Public Awareness
- Identification of Palliative Care
- Holistic Assessment
• Integration of Services
• Co-ordination of Care
• End of Life and Bereavement Care

These model components are considered in light of the possible processes to deliver the components, the enabling tools and any gaps and barriers around these aspects. This information has been summarised in Appendix A. Whilst the conclusions are presented under these components it is important to note that they are interrelated, as progress in one area will impact on another area. Furthermore, it is a pre-requisite that these conclusions are underpinned with the core values for palliative care, education and leadership at policy, commissioning, and service delivery levels.

7.1.1 Public and Professional Awareness of Palliative Care

This component of the model has a consequence for all the other layers and encompasses all the other components. It must be addressed so that the public and professionals understand better what palliative care is.

The key message needs to be made clear- ‘palliative care is applicable to all disease, it will help people live well until they do die; society needs to understand the limitations of treatment so that informed choices can be made’.

Some possible mechanisms for educating society are more proactive engagement with the whole community and the use of media, websites, school curriculum, community development groups, service open days and charity awareness. Education for health professionals will include the inclusion of palliative care in all initial professional training courses, ongoing professional awareness training and consideration of palliative care core competencies across all disciplines.

7.1.2 Identification of Palliative care Phase

This is a particularly challenging aspect of the model but it is important that appropriate mechanisms are developed by which all patients with palliative care needs are identified and communicated through the multidisciplinary teams. Developments around the identification of palliative care are needed, especially for non-malignant patients. There is a need to clarify how definitions, diagnosis and standards are measured so that performance improvement can be articulated. More detailed process mapping would also assist the process of identifying patients with chronic illness and the subsequent capacity of service providers to deliver care.

Education and training is needed for all health and social care professionals about the broader definition of palliative care and considerations around communicating palliative care issues.
Some possible mechanisms to assist in the identification process would include:

- An integrated palliative care pathway, building on the work of the generic palliative care standards. This would embrace those pathways that already exist for non-malignant conditions but with the addition of a palliative care focus.
- The use and development of existing registers for palliative care such as QoF (Quality Outcomes Framework) register.
- Multidisciplinary team meetings across boundaries of care
- Continuation and expansion of prognostic indicators and Gold Standards Framework in GP practices and nursing homes across Northern Ireland.

7.1.3. Holistic Assessment

Following the identification of palliative care needs the next critical step is that of holistic assessment. Care pathways could help to provide identified trigger points when a holistic assessment should take place. For example: during exacerbations of a condition, when active deterioration is evident or when carers or other professionals make a request. However, professional competency to undertake a holistic assessment, to address physical, psychological, social, financial and spiritual needs, is vital.

Some potential processes to improve holistic assessment are:

- The use of a single assessment tool, reflecting holistic need, to avoid duplication of assessments.
- Developing the plan in consultation with the patient and family, reflecting the values of palliative care
- Facilitating decision making to ensure choice
- To ensure choice and preferred place of care
- Effective Communication of this assessment to all involved in care delivery

7.1.4. Integration of Care

A key message emanating from this project was the need for care to be more integrated and 'joined up', with the recognition that currently systems and processes are not always conducive to achieve true integration of care. A priority area is the need to enhance community services in all geographical areas and to work with health and social care providers in primary care. This is particularly related to the availability of 24-hour services, with access to specialist palliative care advice.

In order to enhance integration, systems need to be developed to improve the information flow across various sectors and organisations:

- From primary to secondary care (and vice versa) on admission and discharge, with identified dedicated staff to act as the interface between sectors for palliative care patients regardless of diagnosis;
• Between generalist and specialist palliative care;
• Between in-hours and out of hours service provision.

This would include developing IT systems to improve the information flow across interfaces alongside some manual systems that could be used in the interim such as discharge and hand over forms; shared records in the patient’s homes and shared caseloads.

7.1.5. Co-ordination of Care

Whilst co-ordination of care can be closely linked to integration, this component warranted individual attention due to the evidence from all strands of the project, alongside the focus being around the ‘process of bringing together’. A standardised commissioned palliative care service is needed for Northern Ireland. This links to the need for a key worker/coordinator role or system at a local level that will be able to track services, monitor need and adjust services as required. This role could be at two levels:

• Administrative (tracking services) complementing
• Practitioner/ professional level.

The key coordinator would provide community and hospital staff with a central point of contact to arrange care across a range of providers in the statutory and voluntary sector. It is important, however that training and recognition for this role is provided.

8. End of Life and Bereavement Care

End of life and bereavement care can be considered as defining features of palliative care. This component of the model was continually reinforced throughout all the strands of the project, with the recognised need to provide improved end of life care and bereavement services to dying patients and their families. Some methods of developing this focus on:

• Empowering patients and families to be involved in all decision making, considering patient choice around preferred place of care; and

• Continue the implementation of initiatives such as the Preferred Place of Care and Liverpool Care Pathway in all settings at the end of life.

Consideration needs to be made about the systems and management of complex needs at the end of life. This includes timely access to a range of specialist provision, such as hospice at home, specialist palliative care beds and locally accessible beds that will accommodate patients whilst complex issues are resolved.

Education and training for all professionals is also essential to help avoid fragmentary approaches. This education and training should include opportunities for shared learning and experiences such as apprenticeship models, reflection from practice, clinical supervision and other educational provision. Advanced
communication skills training would enable the implementation of breaking bad news guidelines and the subsequent assessment of effectiveness.

### 7.2 Possible Strategies for Implementation

It is against this background that the some proposals around implementation are made (see Appendix B).

1. Five stages of implementation are proposed. These stages interlink and the implementation of each stage should overlap. However major investments in service additionality are seen as occurring in Stage 5 on the grounds that the work in early stages will prepare the case of these improvements but also ensure that the necessary ground-work is there to maximise the value of the new investment. However some extra resources will be required to fund certain initiatives in the earlier phases.

2. The principal actors with responsibility for implementation are identified: DHSSPS; Commissioners; HSC Trusts; General Practitioners; Non-Statutory Providers; Patient/Carers; and Public. Of course, the interactions among these stake-holders will ensure that all these steps are developed to some extent corporately and that they are co-ordinated as much as possible by service providers.

### 7.3 Drivers for Implementation

There are a number of possible drivers for co-ordinating and promoting the various implementation proposals once they are confirmed as departmental policy. These include:

- NICaN either in its present form or by a wider subgroup under its aegis to focus specifically on palliative care (i.e. including non-malignant interests).
- Major specialist non-statutory voluntary providers.
- The proposed Regional Health and Social Care Board will develop a commissioning statement in relation to palliative care and produce Care Standards or an Integrated Care Pathway. This could include the provision of ring-fenced funding for designated palliative care services. This could be done in partnership with local commissioning group to address some of the variations that presently exist across Northern Ireland.
- Each Trust will identify a senior officer with responsibility for palliative care services across acute and community provision, and primary care. These officers would meet as a group quarterly to share good practice and develop common strategies to service improvements.
Incentives are developed for primary care services – notably GPs, district nursing, social services – to achieve recognition for exemplary practice in palliative care, for example by bidding for specific service development monies.

The proposed Public Health Authority will instigate a public education strategy around palliative care in association with the major charitable bodies.

RQIA would undertake specific inspections of palliative care services or certain aspects of them.

Health and Social Care Councils in association with Patient and Carer organisations in Northern Ireland may undertake focussed evaluations of patient and carer support in relation to palliative care.

In conclusion, an ambitious but attainable programme of work has been identified. Resolving some of the issues highlighted throughout this phase of the project should bring benefits to patients with palliative care needs and provide a ‘test-bed’ for new methods of co-ordinating the planning and delivery of services that can be progressed in Phase two of the Reform and Modernisation of palliative care in Northern Ireland.
REFERENCES


Northern Ireland Cancer Network (2008). A framework for Generalist and Specialist Palliative and End of Life Care Competency, NICaN

Northern Ireland Cancer Network (2008). Diagnosing Dying: Defining End of life Care for people with cancer and non-cancer diagnoses. NICaN


### APPENDIX A: Process to deliver model components

<table>
<thead>
<tr>
<th>Core Components</th>
<th>Process to deliver component</th>
<th>Enabling Tools</th>
<th>Gaps and Barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public and Professional Awareness of Palliative Care</td>
<td>• Proactive engagement with the whole community</td>
<td>Regional Approach</td>
<td>Lack of dedicated personnel to ensure website is kept up to date</td>
</tr>
<tr>
<td></td>
<td>• Empowerment of patients and clients</td>
<td>Use of media</td>
<td>Language and cultural differences</td>
</tr>
<tr>
<td></td>
<td>• Access to information about services, in all forms</td>
<td>Palliative care website</td>
<td>Cost</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Palliative care directory</td>
<td>Training needs analysis</td>
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<td></td>
<td></td>
<td>Politicians/Commissioners</td>
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<td></td>
<td></td>
<td>Cancer Network</td>
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<tr>
<td></td>
<td></td>
<td>Core competencies across all disciplines – Access to training and competency framework NICan</td>
<td></td>
</tr>
<tr>
<td>Regional Approach</td>
<td>Regional Approach</td>
<td>Use of media</td>
<td>Lack of dedicated personnel to ensure website is kept up to date</td>
</tr>
<tr>
<td></td>
<td>Use of media</td>
<td>Palliative care directory</td>
<td>Language and cultural differences</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Politicians/Commissioners</td>
<td>Cost</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cancer Network</td>
<td>Training needs analysis</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Core competencies across all disciplines – Access to training and competency framework NICan</td>
<td></td>
</tr>
<tr>
<td>Identification of palliative care phase</td>
<td>Professional awareness of prognostic indicators</td>
<td>Generic Standard 1 key Performance Indicator (KPI) 1 &amp; 3</td>
<td>Identification is currently not formally noted as a treatment intent across all diagnosis.</td>
</tr>
<tr>
<td></td>
<td>Communication and agreement/discussion amongst professionals across boundaries of care</td>
<td>Multiprofessional/disciplinary team meetings</td>
<td>Inconsistent approach to identifying palliative care</td>
</tr>
<tr>
<td></td>
<td>Effective communication with the patient and family</td>
<td>Effective communication systems (IT)</td>
<td>GP tend to record only palliative care patients with diagnosis of cancer</td>
</tr>
<tr>
<td></td>
<td>Assessment and identification: near to patient i.e. in A&amp;E; at home</td>
<td>General Standard 3 KPI 3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Active central register of palliative care patients</td>
<td>Advanced communication skills</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Identification, recording and discussion of treatment intent</td>
<td>Breaking Bad News Guidelines</td>
<td></td>
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<td></td>
<td></td>
<td>Management plans – proactive</td>
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<td>GP Register, QOF, GSF</td>
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<td></td>
<td></td>
<td>Service Frameworks</td>
<td></td>
</tr>
<tr>
<td>Core Components</td>
<td>Process to deliver component</td>
<td>Enabling Tools</td>
<td>Gaps and Barriers</td>
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<tr>
<td>Holistic Assessment</td>
<td>Care pathways with identified points when patient will have an holistic assessment of need.</td>
<td>Education of staff – generally physicians</td>
<td>Treatment intent</td>
</tr>
<tr>
<td></td>
<td>For example: during exacerbations of condition; active deterioration; requested by carers or professionals</td>
<td>‘Name it’</td>
<td>Lack of education</td>
</tr>
<tr>
<td></td>
<td>Staff competency to undertake holistic assessment</td>
<td>Generic Standard 1 KPI 2</td>
<td>Care pathways for all disease need to identify point for holistic assessment</td>
</tr>
<tr>
<td></td>
<td>Plan of care developed in consultation with patient and family</td>
<td>Integration point (stage a fact about integration)</td>
<td></td>
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<tr>
<td></td>
<td>Plan of care shared with all professionals responsible for delivery of care</td>
<td>Carer Assessment Tool</td>
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<tr>
<td></td>
<td>Carer Assessment</td>
<td></td>
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<tr>
<td></td>
<td>Holistic assessment tool</td>
<td></td>
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<tr>
<td>Core Components</td>
<td>Process to deliver component</td>
<td>Enabling Tools</td>
<td>Gaps and Barriers</td>
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<tr>
<td>Coordination of Care</td>
<td>Co-ordination of services; professional; organisations</td>
<td>End of Life Care Paper &quot;Diagnosing Dying&quot; (NICAN, 2008)</td>
<td>Need for definitive driver to implement change</td>
</tr>
<tr>
<td>Coordination def: to bring together and cause to work efficiently</td>
<td>Standardised service</td>
<td>Growth of Patient and Public Involvement in Palliative Care Service Frame work</td>
<td>Lack of definition of key worker and understanding of role</td>
</tr>
<tr>
<td></td>
<td>User led service</td>
<td>Leadership and drivers for change</td>
<td>Multiple morbidities – no programme to address needs e.g. CHF, COPD, Renal failure and malignant disease</td>
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<td></td>
<td>Uniform Assessment Tool</td>
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<td>Clarity around the integration between services</td>
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<tr>
<td></td>
<td>Equitable outcomes</td>
<td></td>
<td>Identified funding for multiprofessional posts responsive to all palliative care need, not just cancer related</td>
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<tr>
<td>Workforce:</td>
<td></td>
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<td>Collaborative not competitive working</td>
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<tr>
<td></td>
<td>• In-reach teams</td>
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<tr>
<td></td>
<td>• Dedicated posts within core services: joint funded acute &amp; community; acute &amp; voluntary</td>
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<td></td>
<td>Intermediate care – non-specialist palliative care in patient beds</td>
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<td></td>
<td>Long Term Conditions prioritisation</td>
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<td>Communication &amp; Information:</td>
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<tr>
<td></td>
<td>• In hours and out of hours;</td>
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<td></td>
<td>• Acute to community</td>
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<td></td>
<td>• Professionals to families and carers</td>
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<td></td>
<td>• Ambulance and transport services</td>
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<td>• Discharge planning</td>
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<td>Pathways with triggers at transition points</td>
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<td>Multidisciplinary Teams</td>
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<td>Appropriate psychological and counselling assessment</td>
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<td>Pastoral care</td>
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<td>Complementary therapies</td>
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<td>Co-ordination and management of tailored care packages and respite services for carers</td>
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<td>Seamless Services</td>
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<td>Key worker roles</td>
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<td>Timely access to equipment</td>
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<td>IT systems</td>
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<td></td>
<td>Generic Standard 2 KPI 1</td>
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<td>Integrated database (IT)</td>
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<td>Tools</td>
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<td>• LCP;</td>
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<td>• Preferred place of care;</td>
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<td>• GSF</td>
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<td>Care pathways</td>
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<td>Key worker roles</td>
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<tr>
<td>Case finder roles – early identification of patients in A &amp; E; reviewed at home</td>
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<tr>
<td>In-reach and out-reach models of care</td>
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<tr>
<td>Case management</td>
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<td>Core Components</td>
<td>Process to deliver component</td>
<td>Enabling Tools</td>
<td>Gaps and Barriers</td>
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<tr>
<td>Integration of Care</td>
<td>Enhancing community palliative care services</td>
<td>General Standard 2 KPI 2</td>
<td>Clarity of Role of the generalist</td>
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<tr>
<td>Accessible Responsive Generalist Palliative Care Services</td>
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<tr>
<td>Accessible Responsive Specialist Palliative Care Services</td>
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<tr>
<td>Equity and choice of service provision</td>
<td>24 hours services</td>
<td>Management plans – proactive</td>
<td>Balance and review this</td>
</tr>
<tr>
<td>Integration def: to combine into a whole</td>
<td>• Nursing</td>
<td>Enhanced services on discharge – social support</td>
<td>Phased approach</td>
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<tr>
<td></td>
<td>• Palliative Care support teams</td>
<td>and care management packages</td>
<td>Satellite services: nursing; pharmacy, GPs, specialist</td>
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<td>• 24 hr access to advice</td>
<td>Out reach clinics</td>
<td>palliative care advice</td>
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<td></td>
<td>• Expansion of palliative consultants into community</td>
<td>In-reach assessments</td>
<td>Lack of 24 hour nursing cover or 24/7 services in community</td>
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<td></td>
<td>• Consultant on call rotas across organisations</td>
<td>Palliative link nurses</td>
<td>Problematic access to equipment</td>
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<td></td>
<td>• Prompt intervention from AHP and other services in the community</td>
<td>Palliative care support teams</td>
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<td>• Day sitting</td>
<td>Home care workers</td>
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<td></td>
<td>• Night sitting</td>
<td>Intermediate palliative care beds good generalist pc</td>
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<td></td>
<td>Out of hours</td>
<td>Provision of equipment – fast track</td>
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<td></td>
<td>• Hand over forms</td>
<td>Virtual communication - telemedicine</td>
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<td></td>
<td>• Out of hours health and social care services</td>
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<td></td>
<td>• Improved in-hours management</td>
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<td></td>
<td>Education and Training</td>
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<tr>
<td></td>
<td>• Needs analysis and scoping</td>
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<td></td>
<td>• Palliative care approach and palliative care competencies</td>
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<td></td>
<td>Integration between generalist and specialist</td>
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<td></td>
<td>palliative care</td>
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<td></td>
<td>• Common referral forms</td>
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<td></td>
<td>Intermediate care beds</td>
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<tr>
<td></td>
<td>Day therapy services</td>
<td></td>
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<td></td>
<td>Key worker/co-coordinator</td>
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</tbody>
</table>

<p>| Enhanced services on discharge – social support and care management packages |
| Out reach clinics |
| In-reach assessments |
| Palliative link nurses |
| Palliative care support teams |
| Home care workers |
| Intermediate palliative care beds good generalist pc |
| Provision of equipment – fast track |
| Virtual communication - telemedicine |</p>
<table>
<thead>
<tr>
<th>Core Components</th>
<th>Process to deliver component</th>
<th>Enabling Tools</th>
<th>Gaps and Barriers</th>
</tr>
</thead>
</table>
| **Active end of life care**  
  - Equity and choice of service provision  
  - Bereavement care | Liverpool Care Pathway  
End of life paper  
Assessment tools for effective symptom management  
Documented discussion regarding choice and preferred place of care and death  
Confidence of professionals to have discussion  
Pre and post bereavement assessment/identification and support  
Gaining understanding and avoid confusion of terms | Generic Stand KPI 2  
Health promoting palliative care – awareness of dying  
Communication training  
Breaking bad news  
Regional bereavement strategy  
Bereavement assessment tools  
Bereavement co-ordinators  
Voluntary sector - CRUSE | Understanding of term  
Professional and public awareness  
Lack of advanced communication training  
Lack of identified champions to lead of implementation of tools |
## Appendix B: Summary of possible implementation strategies

<table>
<thead>
<tr>
<th>Stage 1: Distributing Information about the model and refining it for local application</th>
<th>DHSSPS</th>
<th>Commissioners &amp; Quality</th>
<th>HSC Trusts &amp; General Practice</th>
<th>Non-statutory</th>
<th>Patient/Carer</th>
<th>Public</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Departmental Board considers the model and sends it out for public consultation</td>
<td>Each HSS Board requests a response to the model from all its commissioning teams; identifying issues that commissioners can address within the model and those that need most urgent attention.</td>
<td>Each HSC Trust consults with all relevant directorates including co-ordinators for services to carers. Issues that need to be addressed within each trust are identified.</td>
<td>Each service produces an information sheet outlining how its services link to those provided by the statutory sector. Issues that need to be addressed from the perspective of the sector are identified.</td>
<td>An easy-to-read booklet is produced explaining palliative care and providing a directory of contacts.</td>
<td>Media interest in Palliative Care promoted. Political briefings held for MLAs and local councillors.</td>
<td>An easy-to-read booklet is produced explaining palliative care and providing a directory of contacts.</td>
</tr>
</tbody>
</table>

| Stage 2: Preparation of personnel | The DHSSPS will ensure that Palliative Care features in all the initial training courses it commissions. Specialist, multi-disciplinary modules in Palliative Care will be commissioned | Multi-disciplinary and cross-agency training in Palliative Care is commissioned on a regional basis. Integrated registrar training | Induction and in-service training in Palliative Care will become mandatory for all staff whose work involves patients and carers with palliative care needs. This could be available in a variety of formats including e-learning. Foundation training days linked with staff appraisal Focus on communication and counselling skills | Specialist Palliative Care staff are funded to undertake training of generic staff in their locality and regionally as part of their role—which is further defined. Training is provided for Nursing Home staff in preventing inappropriate hospital admissions for palliative care. | An individual Care Plan is drawn up for each patient and their family carers. The rationale is explained and sources of additional information and knowledge are provided. | Volunteer recruitment, induction and support is provided by Palliative Care Teams. |
### Stage 3: Information exchange on patient assessment and care plans.

<table>
<thead>
<tr>
<th><strong>DHSSPS</strong></th>
<th><strong>Commissioners &amp; Quality</strong></th>
<th><strong>HSC Trusts &amp; General Practice</strong></th>
<th><strong>Non-statutory</strong></th>
<th><strong>Patient/Carer</strong></th>
<th><strong>Public</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>IT systems supporting the transfer of patient information across acute/community interfaces are instigated. Manual systems used in the interim e.g. discharge forms; shared records, hand over forms. Service Delivery Unit monitor Hospital deaths – both for quantity and quality.</td>
<td>Monitor Key agreed standards and outcomes</td>
<td>Access of all staff to IT. Common assessment tool in acute, community. Palliative Care flag on patient records. Palliative care registers using QoF data. Hand over forms for out of hours.</td>
<td>Non-statutory providers should align their information systems with those used by statutory bodies. Shared records</td>
<td>Patient held records</td>
<td>Through media and other means, issues around death and preferred place of death are discussed and people encouraged to make their views known to their families.</td>
</tr>
</tbody>
</table>

### Stage 4: Co-ordinating mechanisms

<table>
<thead>
<tr>
<th><strong>Policy directives addressing common co-ordinating issues for patients with more complex needs</strong></th>
<th><strong>Expanded NICAN for Palliative Care</strong></th>
<th><strong>Senior officer with responsibility for Palliative Care Services.</strong></th>
<th><strong>Secondments and sharing of staff across agencies</strong></th>
<th><strong>Shared care plan</strong></th>
<th><strong>Shared care plan</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic disease Management</td>
<td>Local Palliative Care Planning Forums representative of main stake-holders.</td>
<td>Key-worker/coordinator system for Palliative Care Services across statutory and voluntary sectors.</td>
<td>Key-worker/coordinator system for Palliative Care Services</td>
<td>Named co-ordinator</td>
<td>24 hour access to support service</td>
</tr>
<tr>
<td></td>
<td>Palliative Care Standards/Integrated Care Pathway is produced for Northern Ireland embracing primary, secondary and specialist care.</td>
<td>Cross sector, multi-disciplinary teams – defined roles; shared caseloads. Single assessment tool Secondments and sharing of staff</td>
<td>Membership of cross-sector multi-disciplinary teams</td>
<td>24 hour access to support service</td>
<td>24 hour access to support service</td>
</tr>
</tbody>
</table>

### Stage 5: Investment in Palliative Care Services

<table>
<thead>
<tr>
<th><strong>Bids in next CSR</strong></th>
<th><strong>Identifying additioanlity required</strong></th>
<th><strong>24 hour support</strong></th>
<th><strong>Extension of Care at Home Services</strong></th>
<th><strong>Direct Payments.</strong></th>
<th><strong>Health Insurance cover for Palliative Care</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>24 hour support Respite options for carers</td>
<td></td>
<td>Development of holistic approaches.</td>
<td></td>
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</tbody>
</table>