# Vision for Palliative Care

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**Policy Author/Team:**

Pamela Craig  
Deputy Director – Primary and Community Care for Older People’s Services  
Dr Yvonne Duff  
Macmillan Consultant in Palliative Medicine

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**NHSCT Mission Statement**  
To provide for all the quality of services we would expect for our families and ourselves
VISION FOR PALLIATIVE CARE

NORTHERN HEALTH AND
SOCIAL CARE TRUST

March 2009
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- Pamela Craig, Deputy Director Emergency Primary Care & Older People’s Services (Chair)
- Dr Yvonne Duff, Macmillan Consultant in Palliative Medicine/Lead Clinician in Palliative Care
- Dr Jayne McAuley, Macmillan Consultant in Palliative Medicine
- Dr Gail Johnston, Macmillan Project Nurse
- Colleen Morrison, Service Improvement & Modernisation Manager, NHSCT
- Paula Heneghan, Area Manager (N.I.), Marie Curie Nursing Service
- Patrick Graham, Assistant Director Intermediate Care, Rehabilitation & Community Support Services
- Dr Shauna Fannin, Macmillan GP Facilitator
- Helen Chambers, Director of Clinical Services, N.I. Hospice
- Heather Monteverde, General Manager (N.I.), Macmillan Cancer Support
- Sonja McIlfatrick, Head of Nursing Research & Development
- Deborah McCord, Senior Service Performance Manager
- Linda Patton, General Manager Lifelong Illness
- Dr Charles Jack, Consultant Physician
- Una Cunning, Assistant Director Primary Care & Older People’s Services
- Nigel Jackson, Business Support Manager
- Heather Weir, Clinical Services Manager, In Patient Unit & Day Hospice Services

This vision paper was developed in conjunction with the findings of an extensive consultation process to include the outcomes of a strategy workshop and input from the NHSCT palliative care forum. Therefore thanks also to those individuals and organisations who provided data for information who are not listed above.

Pamela Craig
Deputy Director Emergency Primary Care and Older People’s Services

“How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and it is a litmus test for health and social care services”

End of Life Care Strategy (DOH, 2008)
1.0 Background to the Vision Paper

1.1 Introduction

The following paper gives a brief background to the overall process of reform and modernisation of palliative and end of life care in Northern Ireland and sets out a vision for the future direction of adult palliative care within the Northern Health and Social Care Trust. In doing so, it outlines the rationale and methods used for the development of a regional model for palliative care and the subsequent establishment of priority for action targets. Whilst the development of further policy is pending, the paper reflects on the existing policy context and brings together an overview of current service provision within the NHSCT to include a review of need. It begins to outline recommendations for service improvement, based on existing services and identified gaps in local service provision. It is proposed that the NHSCT Palliative Care Steering Group will use this paper, in conjunction with commissioners, to set out a service improvement programme to achieve these recommendations at Trust level.

1.2 Policy Context

Several policy documents have recognised the need to improve the way palliative care is delivered. Partnerships in caring … Standards for service (DHSSPS 2000) was the first local document to appreciate the complexity of supportive and palliative care, citing it to be integral to the trajectory of many diseases, appropriate to all age groups and requiring multi-professional integrated working for effective service delivery. This review highlighted, in particular, the need for partnership working with patients, families, care providers, service planners and commissioners.

The DHSSPS: Twenty Year Vision for Health and Wellbeing in Northern Ireland 2005 - 2025 (DHSSPSNI 2005) advocated a more effective and efficient way of working through multi-disciplinary teams to improve the quality of services. This is also in line with The Primary Care Strategy Framework, Caring for People Beyond Tomorrow (DHSSPSNI, 2004), which acknowledged 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.

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. 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 and equality of access to services inclusive of out of hour’s 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 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 and takes into consideration the needs of carers.

The End of Life Care Strategy (DOH, 2008) was developed to promote high quality care for all adults at the end of life and takes a whole system and care pathway approach very similar to that outlined in the Northern Ireland regional model.

The Northern Ireland Regional Bereavement Strategy, now out for consultation, lists six standards of care which Trusts should be achieving to improve end of life care and bereavement. These pertain to raising awareness, prioritising safe and effective care, communication, information and resources, creating a supportive environment, knowledge and skills and supporting staff.

1.3 Reform and Modernisation of Palliative Care

The need for the Reform and Modernisation of Palliative and End of Life Care reflects the growing acceptance nationally and internationally, amongst the public and professionals, that such care is not disease specific and not purely a specialist activity. In addition it has become clear that existing models of service, which were largely developed to support the needs of patients with cancer, no longer meet the needs of our population (which is living longer and often with non malignant chronic disease), nor do they truly reflect the holistic goals of palliative care.

This widespread recognition of the need for change has led to plans for the reform of palliative care services in England (End of Life Care Strategy, DOH, 2008), Scotland
(Review of Palliative Care Services, Audit Scotland, 2008), Wales, (Palliative Care Planning Report, 2008) and Southern Ireland (Palliative Care for All: Health Service Executive and Irish Hospice Foundation, 2008). Common themes in all of these reports are the need to increase the availability of and improve the quality of end of life care through the coordination of services, the identification of patients with palliative care needs, the increased provision of out of hours care and the education and training of staff.

1.4 Ministerial Mandate

In Northern Ireland 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”.

Developing services to achieve choice should result in:

- An enhanced experience for the patient and family
- Improved access to responsive services
- A reduction in inappropriate admissions and increase in achieved preference
- Equity of service responsive to need rather than diagnosis
- Appropriate comfort measures when a person is actively dying
- Positive satisfaction responses from patients, families and carers and a reduction in complaints relating to the experience of care during the last year of life

A much broader vision for palliative care was therefore developed which would provide the overall aim of the regional model.

1.5 Vision

To move towards a position where any patient, from diagnosis to the advanced non curative stage of disease, (cancer and non malignant 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 and retain control, choice and dignity to the end of their life.

(NiCaN 2008)
Later in this document a description will be given of how this service would function and how this vision could be fulfilled.

1.6 Development of Standards and a Regional Model

Improving care during the last year of life means ensuring that people get the appropriate care, at the right time, in the right place and in a way that they can rely on. This requires a shift in focus from prevention, treatment and cure to alleviating symptoms, making thoughtful decisions, supporting families and providing ongoing care in the appropriate setting.

The development of generic palliative and end of life care standards within the cardiovascular, respiratory and cancer service frameworks provide one mechanism to promote an equitable delivery of patient centred, safe, effective, efficient, equitable and timely palliative and end of life care for all people. These standards aim to improve the identification and communication of palliative care needs, the integration and co-ordination of care to meet these needs and the provision of appropriate end of life care to enable patients to die with dignity. They provide the building blocks for the development of a new model for delivering palliative care services regionally.

<table>
<thead>
<tr>
<th>GENERIC PALLIATIVE CARE STANDARDS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Standard 1</strong></td>
</tr>
<tr>
<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>
</tr>
</tbody>
</table>
1.7 The Model

The new regional model depicted diagrammatically below was refined through extensive consultation with commissioners, providers, stakeholders and users through a variety of methods including focus groups, questionnaires, workshops, the synthesis of existing research and professional shadowing.

The guiding principles of the model are patient and family centred care, with enhanced community provision supported by specialist and hospital provision.

Applicable to all conditions, the model consists of six main components:

1. Identification – of individual palliative and end of life care needs
2. Holistic assessment
3. Integration of Services
4. Coordination of Care
5. End of Life and Bereavement Care
6. Professional and Public awareness- that palliative care is applicable to all disease to help people live well until they die

The model is underpinned by the core values of equity, respect, empowerment and choice. These principles, embedded within robust education, support the quality of service delivery and influence policy and commissioning.
1.8 Development of Targets

Priority for Action Targets are set annually by the DHSSPS and the Trusts are required to demonstrate service development and activity to meet these targets. There may however be concern about purely numerical targets, which would diminish the delivery of the principles of palliative care in pursuit of achieving statistical output, rather than the holistic outcomes identified earlier. Quantifying expected performance is challenging for a number of reasons:

1. End of life care is arbitrarily defined as “care in the last year of life”. Recognition of the beginning of end of life care is variable, dependent on the patient and professional perspectives and the complex nature of some long term conditions. (Knowledge and application of prognostic indicators and use of a holistic assessment of supportive and palliative care need could enable mutual recognition of the last year of life.)

2. Palliative and end of life care is not always identified on disease specific care pathways or data sets across all chronic illnesses.

3. There are a limited number of systems that account for palliative care. With regards to information technology there are limited systems within primary care and specialist palliative care. Neither reflects all generalist activity nor enables a whole systems profile.

Following extensive consultation and refinement the following draft target supports the service improvement required to implement the regional palliative care model, the generic standards and recommendations from a number of NICaN Papers such as *Diagnosing Dying* (NICaN, 2008) and *Framework for Generalist, Specialist and End of Life Care Competencies* (NICaN 2008). The latter papers are all underpinned by the need to adopt a whole systems approach to change.
Trusts will be expected to ensure that palliative care teams are put in place to provide support and care to palliative and end-of-life patients in the community on a 24x7 basis, with the aim of decreasing the number of inappropriate admissions to hospital for these patients and wherever possible allowing them to be cared for and die in their place of choice in the community. In establishing multi-disciplinary palliative care teams, Trusts will need to put in place service improvement programmes to support them; these should be considered in the context of the Gold Standards Framework, Care Pathway for the Dying and the best standards of multi-professional education.

**Palliative care:** by March 2011, Trusts should establish multi-disciplinary palliative care teams and supporting service improvement programmes to provide appropriate palliative care in the community to adult patients requiring such services.

### 1.9 Local Service Improvement Plans

Phase 2 of the regional model requires that Trusts implement their own local service improvement plans to enable a patient and family centred, community orientated model for palliative care. The development of such plans should take into account the needs of the specific population, the geographical area and should be led by a regional coordinator.

Key enablers to this process include:

- Ownership and commitment to the reform from commissioners and providers
- Identified leadership at regional and local level
- Education and training
- Robust service improvement plans

The first part of this process involves the analysis of the principal factors which influence need. The core service components to meet those needs should be mapped to those services which are currently available in order to identify service gaps (Tebbitt, 2004). The following NHSCT needs assessment provides data for the analysis outlined above, using a combination of census information, local audits, service activity from palliative care specialists and qualitative research with patients and carers.
1.10 Local structure
To date the NHSCT Palliative care Forum has provided significant strategic direction in the planning and delivery of palliative care. A Director within the Trust should be designated to take overall responsibility for palliative care. The Palliative Care Forum will report and make recommendations to this Director.

2.0 Palliative Care Needs Assessment

2.1 Overview of Services
The Northern Health and Social Care Trust is one of five Trusts within Northern Ireland. These Trusts were formed in April 2007 following the ongoing Review of Public Administration to establish a new framework for the delivery of Health and Social Care Services across Northern Ireland. The NHSCT covers 10 local council areas, Ballymena, Antrim, Ballymoney, Carrickfergus, Coleraine, Cookstown, Larne, Magherafelt, Moyle and Newtownabbey. Community-based services are provided from around 150 different locations across the Trust and acute hospital services from four sites to include Causeway, Antrim, Whiteabbey and the Mid-Ulster hospitals. A range of out-patient and in-patient rehabilitative services and some palliative care services are also provided in Braid Valley, Dalriada, Moyle and the Robinson Hospitals (Modernising Health and Social Care Services, NHSCT, 2008).

2.2 Demographics
Table 1 shows the estimated distribution of population within NI Health and Social Care Trusts identified in 2007 (areas based on the 2001 census data). This data demonstrates a total regional population figure of 1,685,267, with the Northern Trust containing the greatest number of people since the establishment of two Trusts in the Eastern board.

<table>
<thead>
<tr>
<th>TRUST</th>
<th>POPULATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern Area Trust</td>
<td>426,965</td>
</tr>
<tr>
<td>Belfast Trust</td>
<td>343,879</td>
</tr>
<tr>
<td>South Eastern Area Trust</td>
<td>322,089</td>
</tr>
<tr>
<td>Southern Area Trust</td>
<td>311,119</td>
</tr>
<tr>
<td>Western Area Trust</td>
<td>281,215</td>
</tr>
</tbody>
</table>

NISRA Crown Copyright Census NISRA [Census.Nisra@dfpni.gov.uk]
Hospital services are provided within the Trust for a growing population some accessing hospitals in Belfast. Some regional services are also based in Belfast.

Population pyramid and age distribution tables for the Northern Trust show significant increases in the projected numbers of people aged 60 and over in 2017 (see appendix 1 tables 1 & 2 and charts 1 & 2) This is the section of the population most likely to need palliative care as the incidence of cancer and other degenerative non malignant diseases increases.

More elderly people aged 65 and over live alone than in households of two or more throughout the region (see appendix 1 table 3.) In the Northern Trust 19, 274 people aged 65 and over are living alone based on 2001 figures. As the presence of a carer living in the same household has been shown to be positively correlated with place of death in patients with cancer in Belfast (Davison et al, 2001), these figures have implications for the provision of community palliative care services if more patients are to be enabled to die at home and die at home well.

Ethnic and religious breakdown for the Trust's population is changing due to many factors including an increasing number of migrant workers (see appendix 1 table 4.) Though the majority of the population in the NHSCT as in other areas of the region are white, this may have implications for the level of palliative care resources needed e.g. interpreters (Tebbit, 2004).

Cultural variations in the way different ethnic minorities deal with death and bereavement may also have an impact on the way services are delivered in areas with different ethnic populations, if specific pre and post bereavement needs are to be accommodated. Comparison of population breakdown with that of England shows that ethnic diversity in Northern Ireland is significantly lower for all ethnic groups. There is a paucity of research in Northern Ireland which has looked at the palliative care needs of different ethnic populations. However, a study of the needs of the travelling community in Dublin has shown a reluctance to engage with palliative care services and specific issues around dying at home (Van Doorslaer and McQuillan, 2005).
There is also a need for more work to be done around the palliative care needs of other minority groups e.g. those with learning disabilities (Tuffrey-Wijne, 2003).
No significant conclusions regarding the need for palliative care services can be drawn from the religious breakdown of the population (see appendix 1 table 5.) Almost all of the population is Christian reflecting the low numbers of other ethnic groups. However, the importance of spiritual support in the overall holistic care of palliative patients should be emphasised as this is an area of care which it is difficult for staff to assess and monitor and therefore it is often neglected. In addition staff have difficulty in differentiating between spiritual and religious needs. It is important therefore that patients and carers have access to the spiritual or religious representatives of their choice and that staff feel confident in assessing the need for and the provision of spiritual support.

2.3 Deprivation

Tebbit (2004) suggests that “there is a consensus of professional opinion that caring for people in the most deprived areas requires more resources than in the most affluent places. There is also some evidence to show that the level of palliative care resources required to support people in the most deprived areas may be up to twice the level required in the most affluent areas. Consequently it is considered that, after the annual incidence of deaths, this is the most important factor affecting palliative care need in a population”.

The NHSCT area is often represented as relatively stable (see appendix 1 chart 3,) with low levels of deprivation and high levels of home and car ownership, but this overall positive picture is misleading and masks real inequalities within the population. Of the 180 electoral wards in the area, 33 are ranked within the most disadvantaged 25% as identified by the Noble Multiple Deprivation Measure (NIFHP Health Improvement Plan, 2003-8, p.10). This Multiple Deprivation Measure consists of several separate measures, covering areas such as income and employment, health deprivation and disability, education, skills and training, access to services, social environment and housing.

Though individual rankings provide an indication of overall deprivation for an area, it is important to highlight that there will be pockets of high deprivation in areas that are viewed as affluent and these areas also need to be addressed (Investing for Health, 2003-8, NHSC). However, they suggest that there are areas of the Trust where people with progressive illness and palliative care needs will already be challenged by factors like low income, poor housing and unemployment.
The financial implications of a cancer diagnosis are now well documented (Macmillan Cancer Support, 2006.) Macmillan Benefits Advisors, now established in the Eastern and Western Board areas, may be one resource for patients requiring help with accessing financial support. However to date, no such service exists in the NHSCT.

2.4 Annual Incidence of Deaths

There were 3607 deaths in the Northern Trust in 2006, of which 967 (27%) were due to cancer. This table highlights the fact that the majority of people die from non malignant disease.

<table>
<thead>
<tr>
<th>Trust</th>
<th>All Deaths 2006</th>
<th>Deaths due to Malignant Neoplasms 2006</th>
<th>Deaths due to Circulatory Diseases 2006</th>
<th>Deaths due to Respiratory Diseases 2006</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern Board</td>
<td>3,607</td>
<td>957</td>
<td>1282</td>
<td>476</td>
</tr>
<tr>
<td>Eastern Board</td>
<td>6,128</td>
<td>1633</td>
<td>2023</td>
<td>863</td>
</tr>
<tr>
<td>Southern Board</td>
<td>2,587</td>
<td>688</td>
<td>880</td>
<td>311</td>
</tr>
<tr>
<td>Western Board</td>
<td>2,210</td>
<td>570</td>
<td>694</td>
<td>332</td>
</tr>
</tbody>
</table>

Table 2
Annual Incidence of Deaths across all Boards in 2006

http://www.dhsspsni.gov.uk/index/stats_research.htm

2.5 Place of Death

One quantitative outcome measure of the quality of palliative care is place of death, although a complex interplay of variables will influence this choice and these relate to the individual, the illness and the environment (Higginson and Constantini, 2008). It is recognised that not everyone wants to die at home, although most people when asked do wish to die in their own bed surrounded by those who matter to them, or at least to have the majority of their care delivered at home. Northern Ireland figures for distribution of place of death reflect the national and worldwide picture when all deaths are considered, with 20% of deaths here occurring at home (see appendix 1 table 6.) More recent projections estimate that by 2020 home deaths could reduce by as much as 42% and that fewer than 1 in 10 patients will die at home by 2030 (Gomes and Higginson, 2008.)

When place of death was analysed regionally, the NHSCT had more patients dying in hospital than the rest of Northern Ireland, with 53% dying in hospital for the period 2000 to 2004. This figure may be contributed to by the absence of an in-patient specialist palliative care unit in the Trust compared to each of the other Trusts.
Examination of the data for patients with progressive non malignant disease shows that they are significantly more likely to die in hospital than patients with cancer and the general population and for some diseases this trend is increasing. (see appendix 1 tables 7 - 11.) Lower numbers dying in nursing homes in the Trust may reflect the shortage of these facilities per head of population when compared with other Trusts (see appendix 1 table 12.)

2.6 Symptom Prevalence

In her work on epidemiology based needs assessment, Higginson (1996) used the reports of bereaved carers and provided estimates of the prevalence/problems/symptoms in people in the last year of life in any given population (Cartwright, 1991.) Higginson and Constantini (2008) suggest that patients will have a median of 11 symptoms (see appendix 1 table 13.)

The symptom prevalence for patients with progressive non malignant disease may be calculated as percentages of two thirds of the numbers of total deaths less cancer deaths using symptom prevalence rates for cancer patients estimated by Higginson (Tebbit, 2004). Again patients will usually have several symptoms (see appendix 1 table 14) and it is difficult to estimate the numbers of these patients who will require specialist or generalist palliative care services. It may also be the case that symptoms particularly related to cancer, like pain, may be overestimated in this population while other symptoms e.g. dyspnoea may be more prevalent in patients with end stage respiratory and cardiac disease.
2.7 Specialist Palliative Care Services

This map illustrates the coverage of specialist services across N.I. geographically and is further broken down to identify if these services are voluntary or statutory. It is apparent from the map that there are large areas outside the greater Belfast area which are poorly covered by specialist palliative care services and the NHSCT is the poorest.

2.8 Specialist Palliative Care Beds

There is currently no definitive calculation of optimum specialist palliative care bed numbers but The Palliative Care Survey 1999 (for England) showed that the then average provision was 51 beds per million, however numbers have increased substantially since this date. The National Council for Palliative Care publication Palliative Care 2000 suggested that the needs of the non cancer patients for specialist palliative care beds were at least 50% of the needs of cancer patients. Application of these somewhat dated benchmarks implies that for a Northern Ireland regional population of 1.7 million, there should be 87 specialist palliative care beds for patients with cancer and 44 specialist palliative care beds for non cancer patients. Given the existing 63 specialist palliative care beds, this suggests a current shortfall
of 68 beds regionally and suggests that NHSCT should have at least 22 specialist palliative care beds for cancer patients and 11 for non-malignant palliative care.

This figure was confirmed in an audit of 184 patients which looked at the numbers of patients being referred for inpatient specialist palliative care, reasons why the service was not received and waiting times for the service in the NHSCT (Duff 2003 - see appendix 1 table 15.) The most common reasons for referral were symptom management (84%) psychosocial support (52%) and terminal care (46%). In 112 of these patients the referral to inpatient specialist palliative care was not pursued and the main reason for not proceeding with referral was the absence of a local unit (85% - see appendix 1 table 16.) Of the remaining 72 patients, 40 were eventually admitted and 32 were not.

In total, 40 out of the 184 patients (22%) known to specialist palliative care teams and assessed as needing inpatient specialist palliative care actually received it, some of these following a significant delay (see appendix 1 tables 17 - 18.) These findings suggest that the availability of specialist palliative care beds in the NHSCT would have improved care at the end of life for the majority of these patients.

The audit concluded that assuming an average length of stay of 2 weeks and a bed occupancy rate of 85% that a total of 33 specialist palliative care beds were needed in the NHSCT. The majority (>95%) of patients in this study had cancer, so a higher number would be required to cater for patients with non-malignant conditions.

There are currently no specialist palliative care beds in the NHSCT though 12 are to be provided in a new unit planned for Antrim Hospital and up to seven are accessed in the NI Hospice in North Belfast, mainly by East Antrim residents. This still leaves a shortfall of at least 14 beds.

2.9 Community Palliative Care Beds

There are currently 11-14 community palliative care beds provided in the NHSCT Area (see appendix 1 table 19) However, under Developing Better Services and other reforms, acute services in Whiteabbey and Mid-Ulster will be relocated, creating more capacity for outpatients, diagnostics and intermediate rehabilitation as well as palliative care. It is planned that 28 community palliative care beds will now be designated specifically for
palliative care throughout the Trust. Specialist Palliative Care input will be provided on an outreach basis by members of the hospital Specialist Palliative Care Teams.

2.10 Specialist Palliative Care Staff

Table 3
Numbers of Specialist Palliative Care Staff in Northern Ireland (WTE)

<table>
<thead>
<tr>
<th></th>
<th>Consultants</th>
<th>Other Medical Staff</th>
<th>Clinical Nurse Specialists</th>
<th>Other Nursing staff</th>
<th>Non Medical and Nursing Staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern Area Trust</td>
<td>1.8</td>
<td>0.4</td>
<td>15.8</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Belfast Trust</td>
<td>5.65</td>
<td>6.5</td>
<td>29.63</td>
<td>23.36</td>
<td>22.88</td>
</tr>
<tr>
<td>South Eastern Area Trust</td>
<td>3.03</td>
<td>4.4</td>
<td>20.71</td>
<td>32.01</td>
<td>19.49</td>
</tr>
<tr>
<td>Southern Area Trust</td>
<td>2</td>
<td>1</td>
<td>17</td>
<td>27.5</td>
<td>4.75</td>
</tr>
<tr>
<td>Western Area Trust</td>
<td>3</td>
<td>1</td>
<td>12.6</td>
<td>17</td>
<td>1.5</td>
</tr>
<tr>
<td>TOTAL</td>
<td>14.48</td>
<td>13.3</td>
<td>95.74</td>
<td>103.87</td>
<td>48.62</td>
</tr>
</tbody>
</table>

(NICAN Modernisation and Reform of Palliative Care 2008 Appendix 2)

Table 3 above shows the current level of specialist palliative care staff in hospital, community and hospice units across the region. In this table non medical and nursing staff refers to social workers, chaplains, psychologists, counsellors, speech and language therapists, dieticians and complementary therapists.

The key tasks and responsibilities of all specialist roles include:

- working in conjunction with generic colleagues in the management of complex palliative care cases
- skilling generic colleagues and other health and social care professionals for effective service delivery through education and training
- acting as the key resource for the generic service
- providing leadership in palliative care through the setting of professional standards
- identifying need and unmet need for service provision
- working at a strategic level to influence policy and practice.

The smaller numbers of specialist staff in the Trust overall compared to the rest of the region reflects the lack of a specialist palliative care unit, specialist day therapy facilities and an information centre. The figures include 1.00 WTE CNS for Parkinson’s Disease funded by NI Hospice and two part time GP facilitators. The absence of specialist allied health
professional posts demonstrate that within the NHSCT there are no multi-professional palliative care teams, although these are considered essential to providing specialist palliative care (NICE, 2004.)

2.11 Specialist Medical Staffing

There are currently two palliative medicine consultants in post within the NHSCT (1.8 WTE.) This equates to a very limited medical resource that is stretched very thinly to provide palliative medical support across two acute hospital sites (Antrim and Causeway,) two district general hospitals (Mid Ulster and Whiteabbey,) four community hospitals (currently 11 beds to increase to 28 beds,) one day hospice, three community specialist palliative nursing teams, three outpatient clinics and to facilitate regular multi-professional meetings including four cancer site-specific meetings. Medical support for the Loughside community specialist palliative care team is currently provided from the Northern Ireland Hospice.

The Royal College of Physicians report (2008) Consultant Physicians Working with Patients, recommends that there should be a minimum of 1.00 WTE consultant in palliative medicine for every 160,000 residents, assuming a full complement of junior staff. These figures were in line with the Workforce Review Team for the Department of Health, but did not take into account the new consultant contract or non malignant caseload and the document states therefore that a more pragmatic figure would be 2.00 WTE per 250,000 of the population. Given that the NHSCT has a population of 426,975, this would indicate that at least 3.5 WTE consultants are needed to meet the needs of the population; but given the large geographical area, time spent travelling (over 1 day in total per week) and lack of junior staff, 4.0 WTE would be more realistic.

In line with this directive it would appear that palliative medicine provision within the NHSCT needs enhancement and expansion. In order to achieve a more equitable and responsive service it is proposed that this capacity be increased to four palliative care consultants (3.8 WTE) to include consultant community sessions, cover for the 12 bed specialist inpatient unit including weekend cover, and increased teaching, training and supervision of junior medical staff including assessment and appraisal.

The first post is needed immediately to enhance and support community services, with the second additional post required prior to the opening of the 12 bed specialist inpatient unit.
2.12 Specialist Palliative Care Nurses

Specialist Palliative Care Nurses pioneered specialist palliative care services within the acute hospital setting in the NHSCT. The hospital posts were resourced initially through three year funding from Macmillan Cancer Support with ongoing funding by the Trust. There are four hospital based specialist palliative care Macmillan nursing teams (HSPCT) in the NHSCT covering Antrim and Braid Valley, Whiteabbey and Moyle, Mid-Ulster and Robinson, Causeway and Dalriada Hospitals to include five (4.8 WTE) palliative care clinical nurse specialists (CNS), 1.00 WTE lung cancer CNS and 1.00 WTE palliative care CNS with a priority for lung cancer.

1,143 patients were referred to the service in 2007-8 resulting in 6076 contacts. 76% of these referrals were graded as level 4 and 5, which require ongoing complex interventions and support for patients, carers and professional staff (see appendix 1 table 20.)

There are potential areas for development and redesign within the four recognised aspects of the Clinical Nurse Specialist role (clinical expertise, education, research and leadership). Initiatives such as providing outreach services to the community hospitals, holding nurse led clinics and using skills of holistic assessment and independent prescribing to fit within the modernisation and reform agenda.

*NICE Supportive and Palliative Care Guidelines (2004)* advocate the availability of Specialist Palliative Care throughout the whole week. This concept of seven day working requires creative planning to ensure an efficient and effective service is provided.

2.13 Community Specialist Palliative Care Nursing Staff

Specialist community palliative nursing care in the Northern Trust is provided by the Northern Ireland Hospice. There are four NIH Specialist Palliative Care Community Teams in the Northern Trust with 7.8 WTE hospice nurse specialists and 3.00 WTE hospice community nurses in Ballymena, Ballymoney, Loughside and Mid Ulster with 0.2 WTE of a vacancy to be filled in early 2009.
A total of 828 patients were referred to the service and 5,996 visits made in 2007-8 (see appendix 1 table 21.) The majority of patients had cancer.

These figures highlight the considerable need for specialist palliative care and the low numbers of non malignant patients currently receiving input. However the figures do not reflect the true number of contacts relating to telephone advice given by staff or the complexity of referrals in relation to patients’ problems.

2.14 Specialist Non Medical and Nursing Posts.
(This includes Allied Health Professionals, Social Workers and others e.g. Chaplains, Complementary Therapists)

NICE (2004) recommends that in order to provide an appropriate level of specialist physical, psychological, social and spiritual care to patients and carers, specialist palliative care teams require, in addition to nurses and doctors, a range of expertise provided by:

• physiotherapists
• occupational therapists
• dieticians
• pharmacists
• social workers
• chaplains/ spiritual care givers

In addition, NICE (2004) also recommends that specialist palliative care teams should have access to the full portfolio of supportive care services, including: psychological, social, rehabilitation and spiritual support services, input from site-specific cancer multidisciplinary teams, services for families and carers and pain specialists with expertise in nerve blocking and neuromodulation techniques.

Improvements in the treatment of cancer and other conditions have prolonged survival times, but frequently this means living within limitations resulting from the disease or its treatment, often for many years.

The National Council for Palliative Care in its publication *Fulfilling Lives (2000)* states:
“A rehabilitative approach can help people with advancing, life-threatening disease lead fulfilling lives within the constraints of their illness. This approach should be an integral part of all palliative care”.

The document goes on to state “there is some evidence that well co-ordinated care in the community is more cost-effective than unco-ordinated care. This is because it helps people stay at home and out of hospital for longer”.

In the NHSCT patients with palliative care needs are seen by generic hospital and community allied health professionals with no specifically designated time or specialist background. Waiting times for these services can be excessive for palliative care patients. Though there are some non medical and nursing posts in the Trust specifically aligned to cancer services and lymphoedema care, there are currently none specifically designated for palliative care. One specialist pharmacy post was not sustained following the completion of external funding. Yet such posts are deemed essential to the effective delivery of holistic multi-professional care, a core element of palliative care.

If care should be given as NICE recommends by professionals with expertise in cancer and palliative care and such care is given by general staff, then it could be said that every patient accessing the general service has a potential unmet need. Indeed, patterns of referrals to and from the specialist palliative care nursing teams show that a significant proportion of referrals were for complex psychological and social problems suggesting the value of further non medical and nursing posts in these areas (Brogan, 2007; Mawhinney, 2008; Adams, 2008).

While it is difficult to measure exactly the impact of specialist posts on patient outcomes, an evaluation of an initiative in the EHSSB to establish four community specialist multidisciplinary teams showed that the establishment of such posts have had several benefits both for patients and carers as well as their generic colleagues. These included improved patient care, timely response to needs, supporting patients to die at home, the provision of one point of referral, an expert resource, continuity of care and an increased profile and understanding of palliative care (Craig, 2006).

The recommendations for inpatient specialist units, specialist day therapy facilities and information centres provide opportunities for the establishment of these posts and equity with the services available in other areas in the region.
2.15 Specialist Palliative Care Day Therapy

Specialist palliative care day therapy facilities offer opportunities for assessment and review of patients’ needs and enable the provision of a range of physical, psychological and social care interventions within the context of interaction, mutual support and friendship. Although many of these services can be provided on an individual basis elsewhere, specialist day therapy enables them to be brought together in one setting. It also brings patients together, providing social support and access to facilities and can offer respite to carers (NICE, 2004). Continuity of care can be enhanced by developing multi-professional day therapy teams which operate on an outreach basis to local sites from a base in a specialist palliative care unit.

Aims of Specialist Palliative Care Day Therapy include:

- To enhance the independence and quality of life of patients living in the community
- To be a flexible service providing patients with skilled assessment and support from the multidisciplinary team
- To provide specific intervention depending on patient need, which may include outpatient appointments with individual team members
- That each patient attending Day Therapy will have a comprehensive and holistic assessment of their needs and problems and will be encouraged to participate in the development of their care plans and goals.
- The Day Therapy Team will strive to maintain high standards of communication and collaboration with the patient and their family/ carers, relevant health care professionals, Palliative Care Providers and others relevant to ensure a coordinated approach to patient care

(Marie Curie Cancer Care, 2006)

The absence of such a service in the NHSCT prevents patients who may be geographically isolated from benefiting from this type of support and puts them at a disadvantage to those elsewhere in the region already enjoying these facilities.

2.16 Information Services

There is no information centre or benefits advice service in NHSCT and patients and relatives have to travel outside the Trust to access these services.
2.17 NI Hospice Carers’ Services

The NI Hospice Carers’ service is a new initiative which, while not providing out of hours care, provides support for carers both pre and post bereavement. This support takes the form of a six week programme with carers working in partnership with professionals to set their own goals, a drop in centre, outreach complementary therapy and one to one support. This programme, initially developed as a pilot scheme, has just received lottery funding for a further five years. The service will be supported by Crossroads, Caring for Carers, to enable informal carers to have access to the services provided.

2.18 Bereavement Care

An essential element of holistic palliative care is pre bereavement and bereavement care, including family therapy and support of children. The number of voluntary agencies, such as CRUSE and NI Hospice, providing bereavement care and the amount of support available is difficult to quantify as is the quality of care they provide. The majority of people will access such support via their own informal networks and Primary Health Care Team. (Source: Regional Bereavement Coordinator).

2.19 General Community Palliative Care

General palliative care activity is difficult to track and evaluate. GP practices have palliative care registers which reflect a predominately malignant population; however the recording of actual activity is complex thus hindering the planning of effective services. As the community is where the majority of palliative care is delivered and where patients want to receive care, it is important to try to measure both the quantity and quality of care in this setting.

One of the objectives of the new GMS Contract (2004) was the incorporation of evidence based and quality focused clinical and organisational targets. 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 and are set below recognised benchmarks such as Gold Standards Framework and NICE guidelines. Regional figures show that the majority of practices are achieving almost maximum points (see appendix 1 table 22.) These figures suggest at the very least that the majority of GP practices in NHSCT:
• have a palliative care register of patients estimated to be in the last 6-12 months of life, with cancer and non-cancer illnesses, and

• hold regular (at least 3 monthly) multidisciplinary case review meetings where all patients on the palliative care register are discussed.

2.20 Community Nursing Care

The NI Cancer Registry (2004) estimated that over 39,000 people are living in Northern Ireland with a cancer diagnosis. Shipman et al (2000) estimate that 1 in 12 patients on a district nursing caseload will have palliative care needs, accounting for up to 40% of the workload, though a more recent Scottish report estimates this at 1 in 10 (Audit Scotland, 2008). These numbers increase when patients with non malignant palliative care needs are considered with Partnerships in Caring (2000) estimating that patients requiring palliative care for non malignant conditions in Northern Ireland may be as many as 11,000. However, a recent local audit showed that these needs tend to be underrepresented on the district nurse caseload (Graham, 2002). (Source; Caring Round the Clock, 2005).

The absence of a recording system which can accurately identify patients with palliative care needs, makes an exact calculation of the community nurses’ workload relating to palliative care currently impossible. Yet patients often identify them as their key worker in the palliative phase suggesting that visits to these patients will increase at this time. Studies of the views of users have also identified the need for a key worker who can coordinate the activities of other professionals coming in and out of the house at this time.

2.21 Marie Curie Nursing Service and Hospice at Home

Hands-on nursing and respite services are provided by Marie Curie and the NI Hospice. These two services work in partnership with the district nursing team to enable patients who wish to stay at home for end of life care.

Until recently patients who wished to die at home or be cared for at home with an acute exacerbation of palliative care needs have often had difficulty accessing a well-trained domiciliary support service in a timely fashion. They competed with all other Trust priorities for allocation of care packages and even when prioritised there was difficulty in accessing a suitable domiciliary care rota to meet their needs. As these patients do not have the life expectancy to accommodate delay, they require a service which can be activated immediately and which links with all of the other providers of palliative care services.
Hospice at Home provides care, usually in four hour periods, by trained staff nurses who work peripatetically throughout the Trust as well as the Eastern Board Area.

In total 9503.5 hours were commissioned in 2007-8 by the Trust for these services with the highest demand for these being in the East Antrim Area. 445 (15%) of the total number of hours provided were for non cancer care and the highest demand for this type of care was in the Mid-Ulster area. A total of 220 patients were seen by the Marie Curie Nursing Service and 217 by Hospice at Home with 1675 visits made by the former and 577 shifts by the latter including overnight (see appendix 1 table 23.) While some of these hours may refer to the same patients, figures suggest that the services are complimenting rather than duplicating each other.

### 2.23 Palliative Care Support Teams

A Palliative Care Support Team, comprising of nursing assistants who work under the supervision of the District Nursing Sister, was successfully piloted in the Causeway area in 2007-2008.

Further funding has recently been secured to provide Palliative Care Support Teams in the Carrickfergus/Newtownabbey area and Antrim/Magherafelt/Cookstown area. From November 2008 18 WTE dedicated palliative care support workers (NVQ Level 2/3) have been contracted from Marie Curie and have been phased into the areas as named above. The Larne/Ballymena area is developing a Palliative Care Support Team of 8 WTE palliative care support workers who are to be funded through resource release from Inver House. The Palliative Care Support service will cover the period 8am-11pm over seven days per week and will provide cover across the entire NHSCT area.

The teams will provide an immediate and urgent response to patients in the final stage of their illness wishing to be cared for at home. One roving Marie Curie registered nurse will be employed to work 10pm to 8am based in an out of hours centre to respond to unscheduled/scheduled palliative and non palliative care cases overnight. A further Registered Nurse is to be available on Saturdays and Sundays 12noon – 8pm for planned and unplanned review of palliative care patients and to ensure that need can be identified in the early part of the day. Coordination of care and good communication between all services will be vital.
2.24 Out of Hours Care

There is a growing recognition that palliative care should be provided around the clock and not just in office hours. Such provision can make the difference between patients being able to remain at home in their place of choice or having forced emergency admissions to hospital when symptoms become unmanageable or when carer support breaks down. Both the latter having a dramatic impact on patients’ quality of life (Storey, 2003).

NICE (2004) recommends that “commissioners should ensure that medical and nursing services are available 24/7 for patients with advanced cancer living at home. Where 24 hour district nursing services are unavailable alternatives must be sought”. Nursing initiatives as described above are a first step in attempting to meet this requirement, and should be extended and publicised.

However access to 24 hour care varies greatly throughout Northern Ireland and within the NHSCT. A recent report by the NHSSB palliative care forum: Caring Round the Clock (2005,) provided a comprehensive analysis of the availability of 24 hour care in the NHSCT as well as perceived gaps in care. This report provides the basis for the following section of this document.

In the NHSCT there is no provision of out of hours support from allied health professionals including physiotherapists, occupational therapists, dieticians, clinical psychologists or speech and language therapists. The NI Hospice no longer provides a telephone advice service for patients and families. There is a gap in psychological services for patients who need emotional support out of hours. Palliative care patients and their families can access the Samaritans 24/7 or the Crisis Response Mental Health Team, a generic service based on assessed need.

At the time of the report, a number of services existed by which carers could access support at home out of hours (see appendix 1 table 24.) While none of these services were intended to meet the needs of any specific group, they can all contribute if necessary to the care of palliative care patients. However, short term funding and high turnover of staff creates an unpredictable and inequitable service across the Trust.
2.25 Pharmacy services

Thomas (2001) highlighted that difficulty in accessing medication outside normal working hours was a problem for patients and families and increased the likelihood of hospital admissions. The NHSCT Pharmaceutical Palliative Care Network funded by the Big Lottery Fund in 2005 addressed a number of out of hour’s issues in accessing drugs for palliative care patients (see appendix 1 table 25.)

The work of the pharmacy network in association with Dalriada Urgent Care (DUC) and the NHSCT, has moved some way to the fulfilment of the recommendations set out by the DOH Out of Hours Review (2000,) in which the idea of a one stop shop approach to supplying medicines is advocated enabling palliative care patients to receive medications at the time and place of the out of hours consultation. Currently there are no formal arrangements in place for the transport of prescriptions/signed orders to the supplying pharmacy and/ or drugs to the patient. This is a particular issue for rural patients who may face a 90 mile round trip to get and collect a prescription. Healthcare professionals are not generally permitted to carry patients’ medication but inevitably transport arrangements are agreed on an individual basis and a district nurse may find him/herself as the only option increasing his/her own personal risk. Delays in transfer of medicines information across care settings and between professionals can lead to problems out of hours and poor understanding and confusion between professionals and for patients.

2.26 Medical care

Out of hours care by GPs since the new GMS contract has largely been provided by the GP co-operative in the NHSCT. This change has significantly reduced the number of doctors available out of hours. An ongoing issue with such provision is the transfer of information from in-hours services to on call doctors who do not necessarily know the patients.

Overall, the out of hours report suggested that while there are pockets of good practice in the provision of out of hours care across the Trust, services are not available universally and tend to favour those patients with cancer or in certain geographical areas. There is a complex system often hard to understand by staff and patients (Brogan, 2005).
2.27 Implementation of Tools to Improve the Quality End of Life Care

The implementation of practice development and audit tools designed to enhance end of life care is another indication of the quality and extent of palliative care being provided in hospital and the community. Three main tools are in use nationally (NICaN, 2008) and their scope and level of local coverage is discussed below.

One further locally developed resource is the Regional Guidelines for Breaking Bad News (DHSSPSNI, 2003).

The Liverpool Care Pathway for the Dying or Integrated Care Pathway

*The Liverpool Care of the Dying Pathway (LCP/ICP)* provides guidelines for the management of care in the last days / hours of life in the following areas of care:

- Comfort measures and symptom control
- Psychological / insight measures
- Religious / spiritual support
- Communication with patient / family
- Communication with the health professional

*(The Liverpool Care Pathway User Guide 2004 –2007)*

An adapted version of the LCP has now been implemented throughout Northern Ireland supported by dedicated pathway facilitators through time limited lottery funding. In the Northern Trust the pathway was implemented by one of these facilitators through a staged process of intensive training and practice support in eight hospital sites with 1680 staff attending 381 sessions during the project period (2004-2006).

By May 31\textsuperscript{st} 2006, 600 patients had had their care recorded using the ICP, and audits of a random selection of these pathways showed a positive impact on end of life care through:

- the facilitation of multi-professional education
- the empowerment of doctors and nurses to deliver optimum care of the dying
- improved, efficient documentation
- more appropriate referrals to the HSPCT
- appropriate cost effective prescribing
- equity of access to high quality end of life care
- tailored education

*(Duff, Deery, Stewart, 2006)*
However, further audits following the withdrawal of these dedicated posts have shown that compliance with the pathway may fall in the absence of a dedicated facilitator (Johnston, 2008) A number of pathways have been implemented in the NHSCT (see appendix 1 table 26.)

The community care pathway, an adapted version of the ICP, was initially piloted in the Mid Ulster area, which included Maghera, Coagh, Cookstown and Magherafelt. The pilot commenced in December 2006 and up to March 2008, 15 pathways were completed and have been returned to Liverpool for analysis. Further GP surgeries are now recruited to this project, including Fairhill, Magherafelt, Castledawson, Cookstown, Templepatrick, Antrim and Larne. There are two more surgeries expressing interest.

It is recommended that dedicated facilitator /facilitators be resourced to support the ongoing use of the Pathway in hospital and in the community.

**Gold Standards Framework (GSF)**

The GSF is aimed at enhancing generic palliative care in community/primary care teams by developing the skills and performance of practices around a predetermined organizational framework. The extent to which all practices are meeting every standard varies according to levels of commitment and resources. While there was initial interest and commitment in the GSF by some practices in the NHSCT, the new GP contract has meant that many practices are now under pressure to prioritise other areas of care.

**Preferred Place of Care Document (PPC)**

The PPC document is an advance care plan which the patient holds and takes with him/her if he/she receives care in another setting. It allows the patient to record his/her choices about care and in particular where he/she would wish to die. Information about the family can also be recorded in the plan, making it easy for any new care staff to read about who and what actually matters to the patient. Any changes to original choices or plan for care can also be recorded in the document making it easy to maintain and easily accessible, with up to date information. The Preferred Place of Care document has to date not been implemented in any care setting across Northern Ireland.

**The Regional Guidelines for Breaking Bad News**

These guidelines were developed in 2003 as a means of improving the skills of all staff in this important area. However, a recent audit conducted in the EHSSB showed that there was a lack of awareness of the guidelines and a lack of use by those who were aware of them.
particularly outside Palliative Care (Johnston, 2008). It is likely that these findings are replicated throughout the region. The audit recommended that these guidelines should be re-implemented and disentangled from the ownership of palliative care to increase their use in non cancer settings.

2.30 Education and Training

Studies of the educational needs of generic and specialist staff continue to show a demand for training and education in palliative care by generic staff (McIlfatrick, 2007, Bankhead et al, 2008.) However these educational needs often exist alongside many other competing demands. Ongoing challenges are faced by clinicians in maintaining skills and knowledge for an area of care which they may not be using everyday (Shipman, 2008). Education and training in palliative care is provided by a variety of agencies and disciplines and it is therefore difficult to comprehensively collate and quantify the range and coverage of what is provided across the Trust.

Regional Competencies in Palliative Care for Generalists and Specialists have now been produced by the NICaN Supportive and Palliative Care network, and Trusts should use these to direct the education and training of all staff.

Currently there is no Palliative Care Link Nurse scheme running in Antrim, Braid Valley, Whiteabbey, Mid Ulster or Causeway areas as the existing schemes were discontinued during the amalgamation of the three legacy Trusts. A new NHSCT Palliative Care Link Nurse initiative which will start in 2009 will involve nurses in primary and secondary care. This has recently been put forward for a practice development bid.

The palliative education subgroup of the NHSCT Palliative Care Forum chaired by a dedicated practice development facilitator helps to coordinates the delivery of palliative care education and training in the Trust. The group has identified a target audience of 6553 multidisciplinary staff eligible for palliative care awareness training throughout the Trust.

In the past year 97 sessions were provided to over 500 staff (see appendix 1 table 27,) covering a range of topics from palliative care awareness for home care workers and allied health professionals to more specialist subjects like syringe driver training, pain and symptom control and care of chemotherapy infuser bottles for community nurses.
An extensive programme of education and training is under way in the Trust targeting both trained and untrained staff in rolling programmes as well as providing information to the public (see appendix 1 table 28.) The needs of specialist staff in all disciplines are also important, however, and it is vital that they also have access to sources of advanced knowledge delivered by experts in addition to their role as providers of education for generic staff. Postgraduate courses in palliative care and specialist practice are now provided by both universities in the region, some of which are multidisciplinary. However, the majority of these courses require external funding and the commitment of managers to support the release of dedicated time. Not all potential students in the Trust feel that this support currently exists (McIlfatrick, 2007).

One identified gap in these programmes may be the needs of nursing home care staff, who play an important role in the palliative care of an increasingly elderly population. A recent pilot to improve the education of nursing home care assistants through the employment of two educational facilitators in the Northern and Eastern Boards (funded by the Big Lottery) showed that in an initial needs assessment, staff were often ill prepared to provide end of life care, lacked confidence in palliative care skills, and were confused about the definition of palliative care. The establishment of an education programme through a link nurse scheme improved confidence, knowledge, communication and team working in staff but such education requires continued investment and managerial support (Whittaker, E, et al, 2007; McMullan et al, 2007).

2.31 The Views of Users
(Please see Appendix 2)

The local research that has been conducted recently is distinctive in that it has been largely qualitative in nature and has been highly focused on specific populations, such as those defined by diagnosis (Rutherford et al 2008; Marley, 2008; Walsh, 2008), geographic location (McIlfatrick at al 2007) and professional grouping (Stockdale and Fitzsimons 2006)

The following section of the report details findings from the patient and carer perspective, as the main users of palliative care services in the NHSSB, in a study conducted by Dr Sonja McIlfatrick. In this study 24 interviews were conducted with patients (n=8), present carers (n=8) and past carers (n=8).

Following the detailed analysis the data were organized into themes which included defining the palliative care phase, co-ordination, communication and continuity, effects of caring,
palliative care needs and the value of local practice. A synopsis of this paper follows and highlights those issues which are most salient for users of palliative care services in the NHSCT.

**Defining the palliative care phase**

It was noted in the patient and carer interviews that there did not appear to be any clear demarcation in the patient journey called palliative care. It was evident from both the patient and lay carer perspective that their journey was viewed as a continuous series of events. The start of the journey was associated with a profound change in circumstances for both patients and carers. It was also evident from the participants that there was a difference in understanding and recognition of the palliative care phase for patients and carers with differing diagnoses.

**Communication, co-ordination, continuity and discharge**

There were several examples given by patients and carers of times when communication between professionals could have been better. These included poor communication in general and at time of discharge; a lack of co-ordination between members of the primary health care team; a lack of continuity of care; a sense of constantly struggling with the system and transport difficulties.

**Effects of care giving**

Many of the lay carers interviewed discussed what they perceived as the main effects of being a caregiver. These included both physical aspects such as fatigue and psychological aspects including anxiety and stress. These effects were compounded by the fact that many of the carers were elderly and had some difficulties with their own health. Many of the carers also highlighted that they felt that their needs were not taken into consideration in the overall care and discharge of the patient.

**Identified palliative care needs**

During the interviews the patients and carers were asked what they considered to be their main aspects of need. The needs identified included: social support including the provision of practical care; psychological and spiritual support; respite care; and information and choice.
Value of local general practice

Many of the respondents were generally positive in the way they spoke about their relationship with their local practice and particularly the GP and district nurse. Many examples and stories were given of GPs who provided great support and care for both the carers and patients when needed. These included giving the patients and carers their home phone numbers, calling for regular visits, and generally providing emotional support. It was again noted that many of these types of narratives were mostly related to patients with a cancer diagnosis. This again raises questions if this same relationship and service was provided for patients with non-malignant disease, especially whenever their disease progression was more gradual and prolonged.
3.0 Summary

The recent development of a regional model for the reform and modernisation of palliative care in Northern Ireland, as commissioned by the Department of Health, aims to improve the quality of care for patients across all diseases and in all settings. Core components of the model include the identification of individual palliative and end of life care needs, holistic assessment, integration of services, coordination of care, end of life and bereavement care and increased professional and public awareness. The model is underpinned by the core values of equity, respect, empowerment and choice which should support the quality of service delivery and influence policy and commissioning.

The subsequent establishment of PFA targets in response to this model dictate that Trusts prioritise appropriate processes and structures to ensure that it is not only implemented regionally, but locally adapted to the needs of the inherent populations. These targets emphasise the establishment of multi-disciplinary teams, the integration of services, the identification of patients in the community and the implementation of nationally agreed tools to improve the quality of care provided and to enable patients to be cared for in their place of choice.

A needs analysis for the NHSCT collating both quantitative and qualitative data from regional census figures and local audit and research has shown that the Trust has the largest population in Northern Ireland. As elsewhere, people are living longer with chronic conditions and increasingly alone without a live in carer. Figures also show that the majority of patients are still dying in hospital and that for some conditions, e.g. cancer and respiratory disease, the NHSCT has the lowest home death rate in the region. In addition, there are pockets of deprivation in the NHSCT which suggests that in some areas people with palliative care needs are already challenged by poor housing, rural isolation, low incomes and inadequate education.

Despite these findings, in comparison with the rest of the region, the NHSCT is poorest in terms of specialist palliative care resources with a shortfall of specialist palliative care beds, specialist palliative care nurses and palliative medicine consultants in the area. The absence of specialist non medical and nursing posts including allied health professionals, social workers, psychologists and chaplains also prevents true multidisciplinary working and holistic assessment in palliative care as recommended by NICE. Establishment of such posts elsewhere has been shown to improve the quality and coordination of care for patients and increase the professional support of generic staff. The lack of these specialist services is
contributing to reducing patients’ choice of place of care and death at the end of life.

While it is acknowledged that the majority of palliative care is delivered in the community by generalists and the new model endorses this emphasis, poor or inadequate mechanisms for identifying patients with palliative care needs in the community along with deficiencies in supporting community services mean that many patients do not have access to timely and appropriate care in their own homes at the end of life. Many professionals report difficulty in supporting patients and carers in their own homes because of difficulty accessing suitable care packages, equipment and support services out of hours. Despite the fact that there are areas of creative working and good practice in the community, it is apparent that there is also a lack of coordination between services with multiple agencies involved in providing palliative care but no identified key worker to synchronise these.

The views of people receiving palliative care suggest they often struggle to understand what services are available and most appropriate for them. This is particularly the case in care delivered out of hours where there may be either a dearth of services, geographical inequity or a failure by existing services to communicate with each other.

There is evidence that some national tools are being implemented in the Trust both in hospital and the community to enhance and improve the quality of end of life care. These tools, such as the care pathway for the dying phase, have been shown to positively impact on the quality of patients’ end of life care and death and to professionals’ documentation and communication. However, their implementation has depended on external time limited funding which has not been sustained. There is no contractual mechanism to support the implementation and sustainability of these tools, particularly for GPs, community pharmacists and other dedicated staff.

The extent of education and training being delivered in the Trust demonstrates an appetite for palliative care knowledge among generic staff but also the burden on specialist staff having to provide it. More resources are needed to ensure that regionally recognised competencies for palliative care are routinely embedded in all education and training being carried out within the Trust and that all staff have a basic level of competency in these skills. Particular attention needs to be focused on those settings where the delivery of palliative care has been shown to be particularly problematic, for example in nursing homes, where improvements in staff skills and knowledge could prevent inappropriate hospital admissions at the end of life.

In addition, there is a need to increase public awareness about the meaning of palliative care
and user involvement in shaping the delivery of services.

There is a growing awareness of the need to improve palliative care for all patients irrespective of their disease type or place of care. The Regional Model for palliative care and PFA targets now provide a framework to achieve this reform.
4.0 The NHSCT Vision

To move towards a position where any patient, from diagnosis to the advanced non curative stage of disease, (cancer and non malignant 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 and retain control, choice and dignity to the end of their life.

(NICaN 2008)

The need for a comprehensive palliative care service and the shortfall in existing services has been discussed in the previous sections.

Quite simply, the vision for the future of palliative care in the Northern Health and Social Services Trust is a service which will fulfil the Trust’s mission statement: “to provide for all the quality of service we expect for our families and ourselves”.

From the patient’s perspective, this will mean services focussed around supporting palliative care in the community, with timely access to specialist and in patient care when indicated. Services should be clearly described and signposted, with good communication and seamless transfer between services. An identified key worker for each patient will ensure appropriate care planning and liaison between services.

In the community, patients will be under the care of the primary health care team. Ongoing in service education, promotion of palliative care tools and implementation of the generic palliative and end of life care standards will enhance identification of patients with palliative care needs and recording of their preferences for care.

All disciplines in the community, in hours and out of hours, will have capacity, skills and knowledge to provide care, equipment and input as needed to care for the patient and support his/ her carers at home. In a crisis situation out of hours, relevant information will be available to the out of hours service and the patient/ family will have a single point of contact, with a face-to-face assessment from a health care professional available to reduce inappropriate admissions to hospital.
Further development of community specialist palliative care services including increased community consultant sessions and day therapy services will help maintain patients, including many with complex needs, in the community for as long as possible.

When in patient care becomes necessary, in many cases this will be appropriately provided in hospital, where indicated with the input of the hospital specialist palliative care teams. For those with the most complex physical and psychosocial palliative care needs, in patient care in a specialist palliative care unit will be needed. This will ensure direct admission to a patient and family friendly environment, where a specialist multiprofessional palliative care team will initiate and monitor care, resolving symptoms and other problems as soon as possible. Ideally, length of stay in specialist beds will be short, with well planned discharge home where feasible, or to a community palliative care bed or other place of care near to the patient’s home.
The regional model previously described will be expanded as follows:

**A Vision for Palliative Care**

- **Identification**
  - Agreed prognostic indicators across all conditions to promote the early identification of palliative care.
  - Development of Trust palliative care registers
  - Identification of need for specialist palliative care

- **Holistic Assessment**
  - Use of holistic assessment tool
  - Development of care plan in response to patient priorities and preferences
  - Effective communication of plan of care with patient and all multidisciplinary care team

- **Integration**
  - Integration between generalist and specialist
  - In-hours and out of hours
  - Primary and secondary care
  - Voluntary and Independent sector
  - Access to multidisciplinary team

- **Coordination**
  - Key worker
  - Choice of plan and place of care

- **Last Days of Life & Bereavement**
  - Ensuring dignity and quality of end of life care for patients and family

**Education**
- IT system
- Service Improvement

**Service Improvement**
- Pain Service, 24/7 care
- Multidisciplinary Teams: GSF, PPC, Day Care, Specialist and community palliative care beds

**Ongoing**
- Implementation of GSF
- Across care settings
- Key worker concept

**Implementation**
- Implementation of Care pathway, and Regional bereavement Strategy
INTEGRATED PALLIATIVE CARE across NHSCT

EVIDENCE OF INTEGRATION of services, joined up thinking and planning, reported through NHSCT Palliative Care Forum

Specialist Palliative Care Hospital Beds
Specialist Interdisciplinary Palliative Care Hospital Team
Ongoing generalist palliative care by disease specific specialist team

Primary Care Team
Integrated Care Team
? Named disease community teams?

Acute Hospital
Respiratory Team
Cancer Team
Cardiology Team
Renal
Eldercare

Patient and family managing and supported by GP and District Nurse
Implementation of Gold Standards Framework

Palliative Care Register

Recognition ofServices, joined up thinking and planning, reported through NHSCT Palliative Care Forum

Specialist Palliative Care Hospice Beds
Community Interdisciplinary Specialist Palliative Care Team
Specialist Interdisciplinary Palliative Day Care
Supported care in care homes
Community palliative care beds – Moyle, Dalriada, Robinson, Mid-Ulster

Patient and family supported by GP and District Nurse, Optional support
- Social care, Dal Doc, Marie Curie
- Hospice at Home
- Integrated palliative care teams
- Implementation of Preferred Place of Care

Practice Development and Champions across sectors

Recognising the Last Days of Life

Implementation of Care Pathway
Regional bereavement Strategy

Identификация

holistic assessment

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Community palliative care beds – Moyle, Dalriada, Robinson, Mid-Ulster

Coordination

- Key worker/Out of hours hand over/ Care planning response to patient priorities and preferences

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? Named disease community teams?
5.0 Recommendations

1. Multi-professional palliative care teams should be established and strengthened within the NHSCT. (PFA target by March 2011). Specialist non medical and nursing posts should be created specifically for palliative care including occupational therapy, physiotherapy, dietician, pharmacy, social work, clinical psychology, counselling and chaplaincy posts.

2. Service improvement programmes should be developed to provide appropriate generalist and specialist palliative care in the community to adult patients requiring such services (PFA target by March 2011).

3. A designated Champion (member of Trust Senior Management Team) with responsibility for palliative care should be identified to give management support and strategic leadership within the management structure of the Northern Health and Social Care Trust.

4. A Director within the Trust should be designated to take overall responsibility for palliative care. The Palliative Care Forum will report and make recommendations to this Director.

5. Twelve specialist palliative care beds should be provided on the Antrim hospital site and twelve in the Causeway area.

6. Community palliative care beds should be increased to 28 in Braid Valley, Moyle, Whiteabbey, Robinson, Mid-Ulster and Dalriada Hospitals.

7. A third palliative medicine consultant should be appointed immediately to increase the capacity for community and out of hours provision. A fourth post should be established prior to the Inpatient Unit opening at Antrim.
8. Specialist Palliative Care Day Therapy Services should be provided across the NHSCT area to improve support for those patients geographically distant from the two acute hospital sites.

9. There should be access within the Trust to a comprehensive pain service with expertise in palliative care and availability of anaesthetic pain interventions including intrathecal analgesia.

10. The community pharmacy palliative care service should be continued, developed and resourced.

11. Resources should be made available to ensure full implementation and sustainability of the Integrated Pathway for the Dying Phase, the Gold Standards Framework, Preferred Place of Care and Regional Guidelines for Breaking Bad News.

12. IT systems should be developed to ensure recording of all necessary palliative care information and safe transmission across all care providers and settings.

13. A comprehensive education and training programme in palliative care should be developed by the Trust. The NICaN educational competencies for palliative and supportive care should be embedded in all Trust training programmes. Research and audit should be supported and resourced.

14. A strategy for bereavement care within the NHSCT should be developed and implemented.

15. An information service with benefits advice should be provided, located to ensure maximum accessibility to such a service from all areas within the NHSCT
APPENDIX 1 Palliative Care Needs Assessment

The following population pyramid and age distribution tables for the Northern Sector show the projected numbers of people aged 60 and over in 2017. This is the section of the population most likely to need palliative care as the incidence of cancer and other degenerative non malignant diseases increase.

Table 1
Northern Trust Age Structure (Census 2001)

<table>
<thead>
<tr>
<th>Age Range (5 year gap)</th>
<th>Males</th>
<th>Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4</td>
<td>14904</td>
<td>14067</td>
</tr>
<tr>
<td>5-9</td>
<td>15544</td>
<td>14853</td>
</tr>
<tr>
<td>10-14</td>
<td>16732</td>
<td>15867</td>
</tr>
<tr>
<td>15-19</td>
<td>15714</td>
<td>15312</td>
</tr>
<tr>
<td>20-24</td>
<td>13224</td>
<td>13278</td>
</tr>
<tr>
<td>25-29</td>
<td>14343</td>
<td>14596</td>
</tr>
<tr>
<td>30-34</td>
<td>16414</td>
<td>16724</td>
</tr>
<tr>
<td>35-39</td>
<td>16369</td>
<td>16862</td>
</tr>
<tr>
<td>40-44</td>
<td>14851</td>
<td>15109</td>
</tr>
<tr>
<td>45-49</td>
<td>13524</td>
<td>13098</td>
</tr>
<tr>
<td>50-54</td>
<td>12751</td>
<td>12999</td>
</tr>
<tr>
<td>55-59</td>
<td>11610</td>
<td>12003</td>
</tr>
<tr>
<td>60-64</td>
<td>9397</td>
<td>10212</td>
</tr>
<tr>
<td>65-69</td>
<td>8052</td>
<td>8860</td>
</tr>
<tr>
<td>70-74</td>
<td>6539</td>
<td>8210</td>
</tr>
<tr>
<td>75-79</td>
<td>4852</td>
<td>6919</td>
</tr>
<tr>
<td>80-84</td>
<td>2837</td>
<td>4746</td>
</tr>
<tr>
<td>85-89</td>
<td>907</td>
<td>2811</td>
</tr>
<tr>
<td>90-94</td>
<td>227</td>
<td>1080</td>
</tr>
<tr>
<td>95-99</td>
<td>77</td>
<td>232</td>
</tr>
<tr>
<td>100+</td>
<td>3</td>
<td>36</td>
</tr>
</tbody>
</table>

![Northern Trust Age Structure](image)
Table 2

Northern Trust Age Projections between 2007-17
based on 2002 projections shown in Chart 2 as above

<table>
<thead>
<tr>
<th>Ages</th>
<th>2007</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>60-64</td>
<td>23,759</td>
<td>25,610</td>
</tr>
<tr>
<td>65-69</td>
<td>19,132</td>
<td>22,971</td>
</tr>
<tr>
<td>70-74</td>
<td>15,868</td>
<td>20,888</td>
</tr>
<tr>
<td>75-79</td>
<td>12,550</td>
<td>15,547</td>
</tr>
<tr>
<td>80-84</td>
<td>9,016</td>
<td>11,006</td>
</tr>
<tr>
<td>85+</td>
<td>7,122</td>
<td>10,109</td>
</tr>
<tr>
<td></td>
<td>87,447</td>
<td>106,131</td>
</tr>
</tbody>
</table>

NISRA Crown Copyright Census NISRA [Census.Nisra@dfpni.gov.uk]
Table 3
Number of People Aged 65 and Over Living Alone and in Households of Two Or More by Trust Based on 2001 Census

<table>
<thead>
<tr>
<th>Trust Area</th>
<th>Lone Males</th>
<th></th>
<th>Lone Females</th>
<th></th>
<th>2 or more persons – All Pensioners</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>65 to 74</td>
<td>75 to 84</td>
<td>85 and over</td>
<td>60 to 74</td>
<td>75 to 84</td>
<td>85 and over</td>
</tr>
<tr>
<td>Northern Trust</td>
<td>2387</td>
<td>1876</td>
<td>481</td>
<td>7224</td>
<td>5506</td>
<td>1800</td>
</tr>
<tr>
<td>Belfast Trust</td>
<td>2567</td>
<td>2046</td>
<td>547</td>
<td>8145</td>
<td>6334</td>
<td>2170</td>
</tr>
<tr>
<td>South Eastern Trust</td>
<td>1767</td>
<td>1478</td>
<td>467</td>
<td>5466</td>
<td>4564</td>
<td>1667</td>
</tr>
<tr>
<td>Southern Trust</td>
<td>1767</td>
<td>1319</td>
<td>354</td>
<td>5084</td>
<td>3771</td>
<td>1181</td>
</tr>
<tr>
<td>Western Trust</td>
<td>1646</td>
<td>986</td>
<td>251</td>
<td>3936</td>
<td>2897</td>
<td>837</td>
</tr>
<tr>
<td>Total</td>
<td>10,134</td>
<td>7705</td>
<td>2100</td>
<td>29,855</td>
<td>23,072</td>
<td>7655</td>
</tr>
</tbody>
</table>

Source: NISRA, Census 2001, Crown Copyright Census NISRA [Census.Nisra@dfpni.gov.uk]

Table 3 above shows that more elderly people aged 65 years and over live alone than in households of two or more throughout the region. In the NHSCT 19,274 people aged 65 years and over are living alone based on 2001 figures.

Table 4
Breakdown of Ethnic Groups for all New Health Trust Areas

<table>
<thead>
<tr>
<th>Trust Area</th>
<th>All persons</th>
<th>White</th>
<th>Irish Traveller</th>
<th>Mixed</th>
<th>Indian</th>
<th>Black</th>
<th>Chinese</th>
<th>Other ethnic group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern Trust</td>
<td>426952</td>
<td>423939</td>
<td>220</td>
<td>772</td>
<td>624</td>
<td>212</td>
<td>982</td>
<td>232</td>
</tr>
<tr>
<td>Belfast Trust</td>
<td>343879</td>
<td>339183</td>
<td>269</td>
<td>894</td>
<td>709</td>
<td>471</td>
<td>1721</td>
<td>532</td>
</tr>
<tr>
<td>South Eastern Trust</td>
<td>322087</td>
<td>319699</td>
<td>136</td>
<td>706</td>
<td>390</td>
<td>254</td>
<td>705</td>
<td>235</td>
</tr>
<tr>
<td>Southern Trust</td>
<td>311111</td>
<td>308996</td>
<td>634</td>
<td>424</td>
<td>337</td>
<td>125</td>
<td>461</td>
<td>141</td>
</tr>
<tr>
<td>Western Trust</td>
<td>281212</td>
<td>279171</td>
<td>451</td>
<td>523</td>
<td>403</td>
<td>251</td>
<td>276</td>
<td>150</td>
</tr>
<tr>
<td>England</td>
<td>90.9%</td>
<td>NA</td>
<td>1.3%</td>
<td>4.6%</td>
<td>2.1%</td>
<td>0.9%</td>
<td>NA</td>
<td></td>
</tr>
</tbody>
</table>

Source: NISRA, Census 2001, Crown Copyright Census NISRA [Census.Nisra@dfpni.gov.uk]
Tables 4 and 5 detail the ethnic and religious breakdown of the population both regionally and within the NHSCT.

### Table 5

**Breakdown of Religion for all New Health Trust Areas**

<table>
<thead>
<tr>
<th>Trust</th>
<th>All persons</th>
<th>Christian (including Christian related)</th>
<th>Other religions and philosophies</th>
<th>No religion or religion not stated</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Northern Trust</strong></td>
<td>426975</td>
<td>364 305 (85.3%)</td>
<td>1015 (0.2%)</td>
<td>61655 (14.4%)</td>
</tr>
<tr>
<td><strong>Belfast Trust</strong></td>
<td>343879</td>
<td>282 447 (82.1%)</td>
<td>1960 (0.6%)</td>
<td>59472 (17.3%)</td>
</tr>
<tr>
<td><strong>South Eastern Trust</strong></td>
<td>322063</td>
<td>285589 (88.6%)</td>
<td>851 (0.3%)</td>
<td>60437 (18.8%)</td>
</tr>
<tr>
<td><strong>Southern Trust</strong></td>
<td>311119</td>
<td>281156 (90.4%)</td>
<td>578 (0.2%)</td>
<td>29385 (9.4%)</td>
</tr>
<tr>
<td><strong>Western Trust</strong></td>
<td>281191</td>
<td>257717 (91.7%)</td>
<td>586 (0.2%)</td>
<td>22888 (8.1%)</td>
</tr>
</tbody>
</table>

Source: NISRA, Census 2001, Crown Copyright. Census NISRA [Census.Nisra@dfpni.gov.uk]

The bar chart below gives the breakdown of the ranking wards in the NHSCT. Of 180 electoral wards in the area 33 are ranked within the most disadvantaged 25% as identified by the Noble Multiple Deprivation Measure (NIFHP Health Improvement Plan 2003-8 p.10)

**Chart 3**

![Multiple Deprivation Measure Average Rank (of 582 NI Wards)](chart3)

(Source: Northern Investing for Health Partnership, [http://www.northernifhpartners.co.uk/ifhplan.php](http://www.northernifhpartners.co.uk/ifhplan.php), from data provided by NISRA)
Table 6
Comparative figures showing preferred and actual place of death in England 2003

<table>
<thead>
<tr>
<th>Place of death</th>
<th>Preferred Place of death</th>
<th>Actual place of death-all</th>
<th>Actual place of death-cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>56%</td>
<td>20%</td>
<td>25%</td>
</tr>
<tr>
<td>Hospice</td>
<td>24%</td>
<td>4%</td>
<td>17%</td>
</tr>
<tr>
<td>Hospital</td>
<td>11%</td>
<td>56%</td>
<td>47%</td>
</tr>
<tr>
<td>Care Home</td>
<td>4%</td>
<td>20%</td>
<td>12%</td>
</tr>
</tbody>
</table>


Table 6 gives a breakdown of the preferred and actual place of death in all causes and where cancer was the principle cause based on findings from a telephone survey in England. This shows Northern Ireland figures for distribution of place of death reflect the national and worldwide picture when all deaths are considered with 20% of deaths here occurring at home.

Table 7
Actual Number of Cancer Deaths between 1995 & 1999 and between 2000 & 2004 by Place of Death and New Trust Area

<table>
<thead>
<tr>
<th>Trust Area</th>
<th>Hospital '95 to '99</th>
<th>'00 to '04</th>
<th>Nursing Home '95 to '99</th>
<th>'00 to '04</th>
<th>All Other Places '95 to '99</th>
<th>'00 to '04</th>
<th>Total '95 to '99</th>
<th>'00 to '04</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern</td>
<td>2097 (48%)</td>
<td>2418 (53%)</td>
<td>792 (18%)</td>
<td>738 (16%)</td>
<td>1485 (34%)</td>
<td>1420 (31%)</td>
<td>4374</td>
<td>4576</td>
</tr>
<tr>
<td>Belfast</td>
<td>1866 (40%)</td>
<td>2097 (45%)</td>
<td>1475 (31%)</td>
<td>1265 (27%)</td>
<td>1350 (29%)</td>
<td>1314 (28%)</td>
<td>4691</td>
<td>4676</td>
</tr>
<tr>
<td>South Eastern</td>
<td>1445 (43%)</td>
<td>1533 (45%)</td>
<td>821 (24%)</td>
<td>829 (25%)</td>
<td>1117 (33%)</td>
<td>1015 (30%)</td>
<td>3383</td>
<td>3377</td>
</tr>
<tr>
<td>Southern</td>
<td>1183 (41%)</td>
<td>1246 (41%)</td>
<td>593 (21%)</td>
<td>721 (23%)</td>
<td>1108 (38%)</td>
<td>1117 (36%)</td>
<td>2884</td>
<td>3084</td>
</tr>
<tr>
<td>Western</td>
<td>1013 (39%)</td>
<td>1154 (43%)</td>
<td>534 (21%)</td>
<td>526 (20%)</td>
<td>1024 (39%)</td>
<td>1010 (38%)</td>
<td>2571</td>
<td>2690</td>
</tr>
</tbody>
</table>

(Source: NISRA, Crown Copyright, 2006, Cancer deaths have been defined by ICD09 codes 140-208 between 1995 to 2000 and ICD10 codes C00-C97 between 2001 and 2004). Census NISRA [Census.Nisra@dfpni.gov.uk]

Table 7 shows that the NHSCT had more patients dying in hospital than the rest of Northern Ireland with 53% dying in hospital for the period 2000 to 2004. This figure may be contributed to by the absence of an inpatient palliative care unit in the NHSCT compared to each of the other Trusts.
Table 8
Actual Number of Heart Failure Deaths between 1995 & 1999 and between 2000 & 2004 by place of Death and new Trust Area

<table>
<thead>
<tr>
<th>Trust Area</th>
<th>Hospital '95 to '99</th>
<th>Hospital '00 to '04</th>
<th>Nursing Home '95 to '99</th>
<th>Nursing Home '00 to '04</th>
<th>All Other Places '95 to '99</th>
<th>All Other Places '00 to '04</th>
<th>Total '95 to '99</th>
<th>Total '00 to '04</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern</td>
<td>262 (62%)</td>
<td>284 (64%)</td>
<td>78 (18%)</td>
<td>102 (23%)</td>
<td>83 (20%)</td>
<td>56 (13%)</td>
<td>423</td>
<td>442</td>
</tr>
<tr>
<td>Belfast</td>
<td>306 (71%)</td>
<td>298 (74%)</td>
<td>77 (18%)</td>
<td>64 (16%)</td>
<td>50 (11%)</td>
<td>43 (11%)</td>
<td>433</td>
<td>405</td>
</tr>
<tr>
<td>South Eastern</td>
<td>240 (63%)</td>
<td>264 (62%)</td>
<td>93 (24%)</td>
<td>115 (27%)</td>
<td>50 (13%)</td>
<td>48 (11%)</td>
<td>383</td>
<td>427</td>
</tr>
<tr>
<td>Southern</td>
<td>293 (63%)</td>
<td>219 (68%)</td>
<td>87 (19%)</td>
<td>59 (18%)</td>
<td>85 (18%)</td>
<td>46 (14%)</td>
<td>465</td>
<td>324</td>
</tr>
<tr>
<td>Western</td>
<td>216 (60%)</td>
<td>204 (67%)</td>
<td>91 (25%)</td>
<td>66 (21%)</td>
<td>53 (15%)</td>
<td>37 (12%)</td>
<td>360</td>
<td>307</td>
</tr>
</tbody>
</table>


Examination of data for patients with progressive non malignant disease are significantly more likely to die in hospital than patients with cancer and the general population and for some diseases this trend is increasing as shown in table 8.

Table 9
Actual Number of Deaths from Respiratory Disease between 1995 & 1999 and between 2000 & 2004 by Place of Death and New Trust Area

<table>
<thead>
<tr>
<th>Trust Area</th>
<th>Hospital '95 to '99</th>
<th>Hospital '00 to '04</th>
<th>Nursing Home '95 to '99</th>
<th>Nursing Home '00 to '04</th>
<th>All Other Places '95 to '99</th>
<th>All Other Places '00 to '04</th>
<th>Total '95 to '99</th>
<th>Total '00 to '04</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern</td>
<td>496 (65%)</td>
<td>535 (66%)</td>
<td>106 (14%)</td>
<td>105 (14%)</td>
<td>162 (21%)</td>
<td>176 (23%)</td>
<td>764</td>
<td>816</td>
</tr>
<tr>
<td>Belfast</td>
<td>633 (63%)</td>
<td>592 (64%)</td>
<td>149 (15%)</td>
<td>102 (11%)</td>
<td>222 (22%)</td>
<td>231 (25%)</td>
<td>1004</td>
<td>925</td>
</tr>
<tr>
<td>South Eastern</td>
<td>417 (62%)</td>
<td>357 (60%)</td>
<td>108 (16%)</td>
<td>105 (18%)</td>
<td>145 (22%)</td>
<td>136 (23%)</td>
<td>670</td>
<td>598</td>
</tr>
<tr>
<td>Southern</td>
<td>373 (60%)</td>
<td>341 (63%)</td>
<td>94 (15%)</td>
<td>83 (16%)</td>
<td>155 (25%)</td>
<td>119 (22%)</td>
<td>622</td>
<td>543</td>
</tr>
<tr>
<td>Western</td>
<td>336 (56%)</td>
<td>350 (57%)</td>
<td>98 (16%)</td>
<td>103 (17%)</td>
<td>163 (27%)</td>
<td>159 (26%)</td>
<td>597</td>
<td>612</td>
</tr>
</tbody>
</table>


Table 9 shows that overall patients with respiratory disease are also more likely to die in hospital than patients with cancer and the general population in the NHSCT as elsewhere.
Table 10
Actual Number of Deaths from End Stage Renal Disease
between 1995 & 1999 and between 2000 & 2004 by Place of Death and New Trust Area

<table>
<thead>
<tr>
<th>Trust Area</th>
<th>Hospital '95 to '99</th>
<th>Hospital '00 to '04</th>
<th>Nursing Home '95 to '99</th>
<th>Nursing Home '00 to '04</th>
<th>All Other Places '95 to '99</th>
<th>All Other Places '00 to '04</th>
<th>Total '95 to '99</th>
<th>Total '00 to '04</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern</td>
<td>132 (64%)</td>
<td>176 (72%)</td>
<td>52 (25%)</td>
<td>49 (20%)</td>
<td>22 (11%)</td>
<td>20 (8%)</td>
<td>206</td>
<td>245</td>
</tr>
<tr>
<td>Belfast</td>
<td>115 (75%)</td>
<td>171 (75%)</td>
<td>30 (19%)</td>
<td>35 (15%)</td>
<td>9 (6%)</td>
<td>21 (10%)</td>
<td>154</td>
<td>227</td>
</tr>
<tr>
<td>South Eastern</td>
<td>96 (58%)</td>
<td>117 (65%)</td>
<td>53 (32%)</td>
<td>50 (28%)</td>
<td>16 (10%)</td>
<td>14 (7%)</td>
<td>165</td>
<td>181</td>
</tr>
<tr>
<td>Southern</td>
<td>83 (63%)</td>
<td>112 (66%)</td>
<td>38 (29%)</td>
<td>35 (21%)</td>
<td>11 (8%)</td>
<td>23 (13%)</td>
<td>132</td>
<td>170</td>
</tr>
<tr>
<td>Western</td>
<td>100 (73%)</td>
<td>142 (76%)</td>
<td>24 (18%)</td>
<td>27 (14%)</td>
<td>13 (9%)</td>
<td>19 (10%)</td>
<td>137</td>
<td>188</td>
</tr>
</tbody>
</table>


Table 10 shows almost three quarters of patients with end stage renal disease die in hospital perhaps also reflecting the termination of a long illness trajectory and continued contact with inpatient services. This has also been shown for patients with haematological cancer (Davison et al 2001.)

Table 11
Actual Number of Deaths from Progressive Neurological Disease
between 1995 & 1999 and between 2000 & 2004 by Place of Death and New Trust Area

<table>
<thead>
<tr>
<th>Trust Area</th>
<th>Hospital '95 to '99</th>
<th>Hospital '00 to '04</th>
<th>Nursing Home '95 to '99</th>
<th>Nursing Home '00 to '04</th>
<th>All Other Places '95 to '99</th>
<th>All Other Places '00 to '04</th>
<th>Total '95 to '99</th>
<th>Total '00 to '04</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern</td>
<td>54 (44%)</td>
<td>77 (42%)</td>
<td>42 (33%)</td>
<td>67 (36%)</td>
<td>28 (22%)</td>
<td>40 (22%)</td>
<td>124</td>
<td>184</td>
</tr>
<tr>
<td>Belfast</td>
<td>52 (48%)</td>
<td>97 (51%)</td>
<td>39 (36%)</td>
<td>47 (25%)</td>
<td>17 (16%)</td>
<td>45 (24%)</td>
<td>108</td>
<td>189</td>
</tr>
<tr>
<td>South Eastern</td>
<td>48 (45%)</td>
<td>69 (41%)</td>
<td>37 (35%)</td>
<td>68 (41%)</td>
<td>22 (21%)</td>
<td>32 (19%)</td>
<td>107</td>
<td>169</td>
</tr>
<tr>
<td>Southern</td>
<td>33 (39%)</td>
<td>45 (38%)</td>
<td>29 (34%)</td>
<td>47 (39%)</td>
<td>23 (27%)</td>
<td>28 (23%)</td>
<td>85</td>
<td>120</td>
</tr>
<tr>
<td>Western</td>
<td>36 (34%)</td>
<td>48 (41%)</td>
<td>18 (25%)</td>
<td>34 (29%)</td>
<td>17 (24%)</td>
<td>36 (31%)</td>
<td>71</td>
<td>118</td>
</tr>
</tbody>
</table>


Table 11 shows that patients with end stage neurological disease including Motor Neurone Disease, Multiple Sclerosis and Parkinson's Disease have similar rates of hospital deaths to patients with cancer and that trend is similar throughout the region.
Table 12
Availability of Nursing Home Beds at June 2008

<table>
<thead>
<tr>
<th>TRUST</th>
<th>No of premises providing care</th>
<th>No of Available Beds</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Statutory</td>
<td>Independent</td>
</tr>
<tr>
<td>Belfast</td>
<td>1</td>
<td>48</td>
</tr>
<tr>
<td>Northern</td>
<td>27</td>
<td>35</td>
</tr>
<tr>
<td>South Eastern</td>
<td>53</td>
<td>2</td>
</tr>
<tr>
<td>Southern</td>
<td>27</td>
<td>19</td>
</tr>
<tr>
<td>Western</td>
<td>25</td>
<td>12</td>
</tr>
<tr>
<td>N Ireland</td>
<td>1</td>
<td>100</td>
</tr>
</tbody>
</table>

(Source: Hospital Information Branch)

Table 12 shows the availability of nursing home beds in the NHSCT and the majority of these are in the independent sector. Lower numbers dying in the Trust may reflect the shortage of these facilities per head of population when compared with other Trusts.
### Table 13
Estimated Symptom Prevalence for patients dying with Cancer (2006)

<table>
<thead>
<tr>
<th>SYMPTOM</th>
<th>% With symptom</th>
<th>Northern Trust</th>
<th>Belfast Trust</th>
<th>South Eastern Trust</th>
<th>Southern Trust</th>
<th>Western Trust</th>
<th>Region Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>84</td>
<td>801</td>
<td>759</td>
<td>612</td>
<td>571</td>
<td>479</td>
<td>2747</td>
</tr>
<tr>
<td>Trouble breathing</td>
<td>49</td>
<td>467</td>
<td>443</td>
<td>357</td>
<td>353</td>
<td>279</td>
<td>1602</td>
</tr>
<tr>
<td>Vomiting or feeling sick</td>
<td>51</td>
<td>488</td>
<td>461</td>
<td>372</td>
<td>347</td>
<td>291</td>
<td>1667</td>
</tr>
<tr>
<td>Sleeplessness</td>
<td>51</td>
<td>488</td>
<td>461</td>
<td>372</td>
<td>347</td>
<td>291</td>
<td>1667</td>
</tr>
<tr>
<td>Mental confusion</td>
<td>33</td>
<td>316</td>
<td>296</td>
<td>247</td>
<td>224</td>
<td>168</td>
<td>1079</td>
</tr>
<tr>
<td>Depression</td>
<td>38</td>
<td>366</td>
<td>346</td>
<td>277</td>
<td>258</td>
<td>216</td>
<td>1243</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>71</td>
<td>679</td>
<td>642</td>
<td>518</td>
<td>463</td>
<td>465</td>
<td>2321</td>
</tr>
<tr>
<td>Constipation</td>
<td>47</td>
<td>450</td>
<td>425</td>
<td>343</td>
<td>320</td>
<td>268</td>
<td>1557</td>
</tr>
<tr>
<td>Bedsores</td>
<td>28</td>
<td>268</td>
<td>255</td>
<td>204</td>
<td>150</td>
<td>159</td>
<td>916</td>
</tr>
<tr>
<td>Loss of bladder control</td>
<td>37</td>
<td>354</td>
<td>334</td>
<td>266</td>
<td>252</td>
<td>211</td>
<td>1210</td>
</tr>
<tr>
<td>Loss of bowel control</td>
<td>25</td>
<td>239</td>
<td>226</td>
<td>182</td>
<td>170</td>
<td>142</td>
<td>817</td>
</tr>
<tr>
<td>Unpleasant smell</td>
<td>19</td>
<td>182</td>
<td>172</td>
<td>157</td>
<td>129</td>
<td>108</td>
<td>621</td>
</tr>
</tbody>
</table>

Table 13 provides an estimate of the prevalence of problems that may benefit from palliative care intervention in N.I.
Table 14
Estimated Symptom Prevalence for patients dying with Non-Malignant Disease in the Last Year of life (2006)

<table>
<thead>
<tr>
<th>SYMPTOM</th>
<th>% With symptom</th>
<th>Northern Trust</th>
<th>Belfast Trust</th>
<th>South Eastern Trust</th>
<th>Southern Trust</th>
<th>Western Trust</th>
<th>Region Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>84</td>
<td>1465</td>
<td>1374</td>
<td>1131</td>
<td>1053</td>
<td>892</td>
<td>5917</td>
</tr>
<tr>
<td>Trouble breathing</td>
<td>49</td>
<td>857</td>
<td>802</td>
<td>656</td>
<td>616</td>
<td>520</td>
<td>3453</td>
</tr>
<tr>
<td>Vomiting or feeling sick</td>
<td>51</td>
<td>892</td>
<td>834</td>
<td>686</td>
<td>635</td>
<td>542</td>
<td>3596</td>
</tr>
<tr>
<td>Sleeplessness</td>
<td>51</td>
<td>892</td>
<td>834</td>
<td>686</td>
<td>635</td>
<td>542</td>
<td>3596</td>
</tr>
<tr>
<td>Mental confusion</td>
<td>33</td>
<td>583</td>
<td>545</td>
<td>444</td>
<td>418</td>
<td>354</td>
<td>2325</td>
</tr>
<tr>
<td>Depression</td>
<td>38</td>
<td>665</td>
<td>622</td>
<td>511</td>
<td>476</td>
<td>403</td>
<td>2677</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>71</td>
<td>1242</td>
<td>1162</td>
<td>956</td>
<td>827</td>
<td>892</td>
<td>5003</td>
</tr>
<tr>
<td>Constipation</td>
<td>47</td>
<td>822</td>
<td>767</td>
<td>633</td>
<td>589</td>
<td>495</td>
<td>3311</td>
</tr>
<tr>
<td>Bedsores</td>
<td>28</td>
<td>486</td>
<td>456</td>
<td>377</td>
<td>351</td>
<td>297</td>
<td>1657</td>
</tr>
<tr>
<td>Loss of bladder control</td>
<td>37</td>
<td>647</td>
<td>605</td>
<td>496</td>
<td>464</td>
<td>393</td>
<td>2607</td>
</tr>
<tr>
<td>Loss of bowel control</td>
<td>25</td>
<td>437</td>
<td>409</td>
<td>337</td>
<td>316</td>
<td>266</td>
<td>1761</td>
</tr>
<tr>
<td>Unpleasant smell</td>
<td>19</td>
<td>332</td>
<td>311</td>
<td>256</td>
<td>240</td>
<td>202</td>
<td>1337</td>
</tr>
</tbody>
</table>

The symptom prevalence for patients with progressive non malignant disease may be calculated as percentages of two thirds of the numbers of total deaths less cancer deaths using symptom prevalence rates for cancer patients estimated by Higginson in table 14 (Tebbinson 2004.)
Table 15
Reason for Referral
(N=184)

<table>
<thead>
<tr>
<th>Reason for Inpatient Referral</th>
<th>Number of Patients (may be &gt;1 reason)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptom Management</td>
<td>155 (84%)</td>
</tr>
<tr>
<td>Crisis Intervention</td>
<td>22 (12%)</td>
</tr>
<tr>
<td>Psychosocial Support</td>
<td>95 (52%)</td>
</tr>
<tr>
<td>Rehabilitation</td>
<td>13 (7%)</td>
</tr>
<tr>
<td>Terminal Care</td>
<td>84 (46%)</td>
</tr>
<tr>
<td>Respite</td>
<td>35 (19%)</td>
</tr>
<tr>
<td>Other</td>
<td>29 (16%)</td>
</tr>
</tbody>
</table>

Table 15 shows that the reason for patients referral to inpatient specialist palliative care and shows that the most common reasons for referral were for symptom management (84%) psychological support (52%) and terminal care (46%).

Table 16
Reason for Not Proceeding with Referral
(N=112)

<table>
<thead>
<tr>
<th>Reason for not proceeding with Inpatient Referral</th>
<th>Number of Patients (may be &gt;1 reason)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care adequate in present setting</td>
<td>21 (19%)</td>
</tr>
<tr>
<td>Patient refused</td>
<td>12 (11%)</td>
</tr>
<tr>
<td>No local unit</td>
<td>95 (85%)</td>
</tr>
<tr>
<td>Relative/carer refused</td>
<td>2 (2%)</td>
</tr>
<tr>
<td>Excessive waiting list</td>
<td>14 (13%)</td>
</tr>
<tr>
<td>Other health care professional refused</td>
<td>2 (2%)</td>
</tr>
<tr>
<td>Other</td>
<td>20 (18%)</td>
</tr>
</tbody>
</table>

Table 16 shows that in 112 of these patients the referral to inpatient specialist palliative care was not pursued and the main reason for not proceeding with referral was the absence of a local unit (85%).
Table 17
Waiting Time between Referral and Eventual Admission
(N=72)

<table>
<thead>
<tr>
<th>Interval to admission</th>
<th>Number of Days</th>
</tr>
</thead>
<tbody>
<tr>
<td>Same Day</td>
<td>5 (7%)</td>
</tr>
<tr>
<td>1-7 Days</td>
<td>20 (28%)</td>
</tr>
<tr>
<td>8-14 Days</td>
<td>10 (14%)</td>
</tr>
<tr>
<td>15-21 Days</td>
<td>2 (3%)</td>
</tr>
<tr>
<td>22-28 Days</td>
<td>2 (3%)</td>
</tr>
<tr>
<td>&gt;29 Days</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>Never admitted</td>
<td>32 (44%)</td>
</tr>
</tbody>
</table>

Table 17 shows that of 40 clients admitted 5 (7%) were admitted on the same day, 20 (28%) were admitted within a week but 15 (21%) were admitted 8 or more days following referral.

Table 18
Reason why patients were not admitted
(N=32)

<table>
<thead>
<tr>
<th>Reason not admitted</th>
<th>Number of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient refused</td>
<td>7 (22%)</td>
</tr>
<tr>
<td>Relative/carer refused</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Other HC professional refused</td>
<td></td>
</tr>
<tr>
<td>Bed not available</td>
<td>8 (25%)</td>
</tr>
<tr>
<td>Too far from home</td>
<td>2 (6%)</td>
</tr>
<tr>
<td>Problem Resolved</td>
<td>2 (6%)</td>
</tr>
<tr>
<td>Patient too ill for transfer</td>
<td>2 (6%)</td>
</tr>
<tr>
<td>Died before bed available</td>
<td>4 (13%)</td>
</tr>
<tr>
<td>Transferred to other unit</td>
<td>8 (25%)</td>
</tr>
<tr>
<td>Other</td>
<td>9 (28%)</td>
</tr>
</tbody>
</table>

Table 18 shows that the main reasons for non admission in 32 patients were transfer to another unit (25%) lack of an available bed (25%) with 4 (13%) patients dying before a bed became available.
Table 19
Number of community palliative care beds in the Northern Health and Social Care Trust

<table>
<thead>
<tr>
<th>Location</th>
<th>Current Beds</th>
<th>To Be Designated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Braid Valley Hospital</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Moyle Hospital</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Robinson Hospital</td>
<td>5-8</td>
<td>8</td>
</tr>
<tr>
<td>Dalriada Hospital</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Mid Ulster Hospital</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Whiteabbey Hospital</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>11-14</strong></td>
<td><strong>28</strong></td>
</tr>
</tbody>
</table>

Table 19 shows the number and placement of community palliative care beds currently provided in the NHSCT totalling 11-14 beds. However under developing better services and other reforms acute services in Whiteabbey and MidUlster will be relocated creating more capacity for outpatients diagnostics and intermediate rehabilitation as well as palliative care. It is planned that 28 palliative care beds will now be designated for palliative care throughout the NHSCT. Specialist palliative care input will be provided on an out reach basis by members of the hospital Specialist Palliative Care Teams.
Table 20

Service Activity of Specialist Palliative Care Hospital Teams 2007-8

<table>
<thead>
<tr>
<th></th>
<th>Antrim and Braid Valley</th>
<th>Mid-Ulster</th>
<th>Causeway Robinson and Dalriada</th>
<th>Whiteabbey and Moyle</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>All Referrals</strong></td>
<td>479</td>
<td>156</td>
<td>298</td>
<td>210</td>
</tr>
<tr>
<td><strong>New In-patients</strong></td>
<td>306</td>
<td>88</td>
<td>198</td>
<td>169</td>
</tr>
<tr>
<td><strong>Readmissions</strong></td>
<td>134</td>
<td>68</td>
<td>70</td>
<td>34</td>
</tr>
<tr>
<td><strong>Out-patients</strong></td>
<td>39</td>
<td>4</td>
<td>30</td>
<td>7</td>
</tr>
<tr>
<td><strong>No of Contacts</strong></td>
<td>2223</td>
<td>1296</td>
<td>1673</td>
<td>884</td>
</tr>
<tr>
<td><strong>Level 1</strong></td>
<td>56</td>
<td>51</td>
<td>32</td>
<td>48</td>
</tr>
<tr>
<td><strong>Level 2</strong></td>
<td>42</td>
<td>0</td>
<td>38</td>
<td>9</td>
</tr>
<tr>
<td><strong>Level 3</strong></td>
<td>6</td>
<td>1</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td><strong>Level 4</strong></td>
<td>323</td>
<td>155</td>
<td>228</td>
<td>128</td>
</tr>
<tr>
<td><strong>Level 5</strong></td>
<td>67</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Type of Disease</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>278</td>
<td>147</td>
<td>184</td>
<td>143</td>
</tr>
<tr>
<td>Non Cancer</td>
<td>28</td>
<td>9</td>
<td>44</td>
<td>26</td>
</tr>
<tr>
<td><strong>Outcome of referral</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deaths</td>
<td>147</td>
<td>38</td>
<td>133</td>
<td>60</td>
</tr>
<tr>
<td>Home</td>
<td>223</td>
<td>106</td>
<td>26</td>
<td>58</td>
</tr>
<tr>
<td>SPCU</td>
<td>9</td>
<td>0</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Hospital</td>
<td>46</td>
<td>8</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Nursing Home</td>
<td>6</td>
<td>3</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Discharged from HSPCT</td>
<td>16</td>
<td>1</td>
<td>64</td>
<td>60</td>
</tr>
</tbody>
</table>

Table 20 shows the service activity of the Specialist Palliative Care Hospital Teams for 2007/8 and the levels of contact of their referrals. It can be seen that 1143 patients were referred to the service resulting in 6076 contacts. 76% of these referrals were graded as level 4 and 5 which require ongoing complex interventions and support for patients, carers and professional staff.

(The figures for Antrim & Braid Valley do not include the Lung Cancer Nurse)
Table 21 details the current case load of the Community Specialist Teams.

### Table 21

<table>
<thead>
<tr>
<th>Service Activity of NI Hospice Community Specialist Teams 2007-8</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>WTE staff</strong></td>
</tr>
<tr>
<td>Referrals</td>
</tr>
<tr>
<td>Total Visits</td>
</tr>
<tr>
<td><strong>Outcome</strong></td>
</tr>
<tr>
<td>Deaths</td>
</tr>
<tr>
<td>Discharged</td>
</tr>
<tr>
<td><strong>Age</strong></td>
</tr>
<tr>
<td>&lt;65</td>
</tr>
<tr>
<td>65+</td>
</tr>
<tr>
<td><strong>Disease</strong></td>
</tr>
<tr>
<td>Cancer</td>
</tr>
<tr>
<td>Non Cancer</td>
</tr>
</tbody>
</table>

### Table 22

<table>
<thead>
<tr>
<th>General Practitioners’ QOF points for Palliative Care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HSSB</strong></td>
</tr>
<tr>
<td>Number of Practices Participating</td>
</tr>
<tr>
<td>Northern</td>
</tr>
<tr>
<td>Southern</td>
</tr>
<tr>
<td>Western</td>
</tr>
<tr>
<td>Eastern</td>
</tr>
<tr>
<td>N. Ireland</td>
</tr>
</tbody>
</table>

Regional figures presented above show that the majority of practices are achieving almost maximum points. These figures suggest at the very least that the majority of GP practices in NHSCT:
• have a palliative care register of patients estimated to be in the last 6-12 months of life, with cancer and non-cancer illnesses, and
• hold regular (at least 3 monthly) multidisciplinary case review meetings where all patients on the palliative care register are discussed.

However, more detailed information is difficult to obtain and this data may be underestimating the palliative care activity of certain practices or overestimating others.

Table 23

| Hours Provided By Marie Curie Nursing Service and Hospice at Home by area 2007-8 |
|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
|                 | Mid-Ulster      | Antrim/Ballymena| East Antrim     | Moyle           | Coleraine       | Ballymoney      | Total           |
| MCNS            |                 |                 |                 |                 |                 |                 |                 |
| Cancer          | 146             | 1549.5          | 1740.5          | 0               | 1080            | 1115            | 5631            |
| Non Cancer      | 2               | 5               | 118             | 0               | 48              | 104             | 277             |
| Total           | 148             | 1554.5          | 1858.5          | 0               | 1128            | 1219            | 5908            |
| HAH             |                 |                 |                 |                 |                 |                 |                 |
| Cancer          | 334.5           | 390.5           | 916.5           | 64              | 593             | 129             | 2427.5          |
| Non Cancer      | 523             | 43.5            | 188.5           | 107             | 112             | 194             | 1168            |
| Total           | 857.5           | 434             | 1105            | 171             | 705             | 323             | 3595.5          |

It can be seen in Table 23 that in total 9503.5 hours were commissioned by the Trust for these services with the highest demand for these being in the East Antrim Area. The table also highlights that 1445 (15%) of the total number of hours provided were for non cancer care and the highest demand for this type of care was in the Mid-Ulster area. While some of these hours may refer to the same patients, figures suggest that the services are complementing rather than duplicating each other. A total of 220 patients were seen by the Marie Curie Nursing Service and 217 by Hospice At Home with 1675 visits made by the former and 577 shifts by the latter including overnight.
### Table 24
**Availability of Out of Hours Social Care**

<table>
<thead>
<tr>
<th>Service</th>
<th>Availability out of hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Core Teams of Homecare workers</td>
<td>Mostly on contracted hours working in rotas or as individual workers-7am-11pm</td>
</tr>
<tr>
<td>Extra Care</td>
<td>Contracted to provide a range of personal care. Varying hours of work but generally 7am-11pm and very occasionally overnight.</td>
</tr>
<tr>
<td>Crossroads</td>
<td>Night sitting service 7am-11pm subject to funding</td>
</tr>
<tr>
<td>Home Care NI</td>
<td>Day/Night Sitting Service for people with dementia but only available in some areas of Trust</td>
</tr>
<tr>
<td>Mobile Night Support Service</td>
<td>2 person teams providing put to bed service, security checks and toileting between 10pm and 2am.</td>
</tr>
<tr>
<td>Out of Hours Emergency social work service</td>
<td>After 5pm daily, weekends and public holidays. Provides emergency response, assessment and crisis management.</td>
</tr>
</tbody>
</table>

At the time of the report, a number of services existed by which carers could access support at home out of hours (summarised in table 24 above). While none of these services were intended to meet the needs of any specific group they can all contribute if necessary to the care of palliative care patients. However, short term funding and high turnover of staff creates an unpredictable and inequitable service across the Trust.

### Table 25
**Current Pharmacy Availability Out of Hours**

<table>
<thead>
<tr>
<th>Access to Medication</th>
<th>Via 12 identified palliative care community pharmacists holding stock list of commonly used medicines in palliative care (this is a contracted agreement with the NHSCT but is not a formal on call arrangement due to lack of funding and evidence of need)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>GPs or non network pharmacists can use out of hours contact numbers to relay a prescription (Phone or fax unacceptable for controlled drugs).</td>
</tr>
<tr>
<td></td>
<td>If unavailable from network pharmacy back up supply is available from Antrim Hospital pharmacy in an emergency out of hours</td>
</tr>
<tr>
<td></td>
<td>Drugs will not be released from Antrim Hospital pharmacy without a signed order and the recipient will be invoiced for them</td>
</tr>
<tr>
<td></td>
<td>The pharmaceutical wholesalers’ emergency out of hours service is available to account holders. Call out fee plus courier costs. CSA may consider remuneration on a case by case basis.</td>
</tr>
</tbody>
</table>
Thomas (2001) highlighted that difficulty in accessing medication outside normal working hours was a problem for patients and families and increased the likelihood of hospital admissions. The NHSCT Pharmaceutical Palliative Care Network funded by the Big Lottery Fund in 2005 addressed a number of out of hours issues in accessing drugs for palliative care patients. Current provision is detailed in Table 25.

Table 26
Number of ICPS implemented in acute sites in NHSCT 2007-8

<table>
<thead>
<tr>
<th>Site</th>
<th>Number of pathways implemented</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whiteabbey and Moyle</td>
<td>53</td>
</tr>
<tr>
<td>Antrim and Braid Valley</td>
<td>201</td>
</tr>
<tr>
<td>Mid-Ulster</td>
<td>31</td>
</tr>
<tr>
<td>Causeway</td>
<td>50</td>
</tr>
<tr>
<td>Robinson</td>
<td>40</td>
</tr>
<tr>
<td>Dalriada</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>377</strong></td>
</tr>
</tbody>
</table>

Table 26 above shows the number of pathways implemented in NHSCT acute sites in 2007-8. While it is not possible to tell if all appropriate patients were commenced on the pathway, the table gives some indication of the extent the ICP is now being used in the Trust.

Table 27
Training provided by hospice community nurses and NEDC 2007 – 2008

<table>
<thead>
<tr>
<th>Number of sessions</th>
<th>Content</th>
<th>Target Audience</th>
</tr>
</thead>
<tbody>
<tr>
<td>65</td>
<td>Pain and symptom control</td>
<td>Community Nurses</td>
</tr>
<tr>
<td></td>
<td>Syringe driver training</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Care of chemotherapy infuser bottles</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Care of central lines</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Palliative Care Awareness</td>
<td>Home Care Workers (Community)</td>
</tr>
<tr>
<td>14</td>
<td>Palliative Care Awareness Training</td>
<td>Home Care Workers (Fern House)</td>
</tr>
<tr>
<td>5</td>
<td>Palliative Care Awareness Training</td>
<td>Allied Health Professionals</td>
</tr>
</tbody>
</table>

Table 27 shows that in the past year 97 sessions were provided to over 500 staff covering palliative care awareness for home care workers and allied health professionals to more specialist subjects like syringe driver training, pain and symptom control and care of chemotherapy infuser bottles for community nurses.
<table>
<thead>
<tr>
<th>Hospital</th>
<th>Number</th>
<th>Provided by</th>
<th>Content</th>
<th>Target Audience</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whiteabbey and Moyle</td>
<td>20</td>
<td>Macmillan Nurse and Consultant</td>
<td>Management of Syringe Drivers Role of Specialist Team ICP in dying phase End of life care Pain &amp; symptom management Pall care emergencies Management of malignant wounds</td>
<td>Induction programme, F1s and F2s, medical and nursing staff, post registered nursing students, QUB, public</td>
</tr>
<tr>
<td>Antrim and Braid Valley</td>
<td>27</td>
<td>Macmillan Nurses and Consultants</td>
<td>Principles of pain and symptom control ICP Role of Lung Nurse/HSPCT Communication skills Palliative Care Emergencies Breathlessness Fungating Wounds</td>
<td>Nurses, GPs, GP Registrars, QUB students AAH staff Medical students</td>
</tr>
<tr>
<td>Mid-Ulster</td>
<td>25</td>
<td>Macmillan Nurse and Consultants</td>
<td>Management of symptoms Pain Management Syringe Driver training Cancer and PC Role of Macmillan Nurse Palliative Care Awareness</td>
<td>Nurses Community Groups School pupils and staff Allied Health Professionals Nurse Prescribers</td>
</tr>
<tr>
<td>Causeway, Robinson, Dalriada</td>
<td>43</td>
<td>Macmillan Nurses Consultants Outside speakers</td>
<td>Management of Symptoms Breaking Bad News End of Life Care Syringe Driver training Psychosocial Issues Role of Macmillan Nurse Introduction to Palliative Care Management of HIV/ AIDS ICP Dealing with</td>
<td>RGNs Nursing Auxiliaries Occupational Therapists Healthcare workers Junior doctors Medical students District Nurses</td>
</tr>
</tbody>
</table>
Table 28 details the education programme provided by the Macmillan hospital specialist palliative care teams. Although based in four separate sites, the teams work closely together and regularly provide educational and training sessions to multi-professional audiences both in hospital and the community as a core component of their role.
Appendix 2 - The Views of Users

The local research 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; Marley, 2008; Walsh, 2008), geographic location (McIlfatrick et al. 2007) or professional grouping (Stockdale and Fitzsimons 2006). Data has been generated from a variety of perspectives including patients, carers and healthcare professionals. In total the views of approximately 82 patients, 91 carers (active and bereaved) and 123 professionals have been sought through the combined efforts of these studies. Despite the recognised variations in methodology and focus, it is interesting that there is much common ground in these research findings.

The following section of the report details findings from the patient and carer perspective, as the main users of palliative care services in the NHSSB, in a study conducted by Dr Sonja McIlfatrick. In this study 24 interviews were conducted with patients (n=8), present carers (n=8) and past carers (n=8).

Following the detailed analysis the data were organized into themes which included defining the palliative care phase, co-ordination, communication and continuity, effects of caring, palliative care needs and the value of local practice. Full findings from this paper are described elsewhere (McIlfatrick, 2007) but the following excerpt provides a synopsis of this paper and highlights those issues which are most salient for users of palliative care services in the NHSCT.

DEFINING PALLIATIVE CARE PHASE

It was noted in the patient and carer interviews that there did not appear to be any clear demarcation in the patient journey called palliative care. Rather it was evident from both the patient and lay carer perspective that their journey was viewed as a continuous series of events. This idea of no clear demarcation of palliative care raises questions around what impact the start of the patient and carer pathway has on the whole journey. Therefore it could be suggested that improvements at the beginning of the patient journey could help to develop quality of life issues in the palliative care phase. This start of the journey was also associated with a profound change in circumstances for both patients and carers.
“It was really horrendous at the start because it was a new way of living to start looking after someone who couldn't look after himself”
(Carer - 77 year old woman for man with pulmonary fibrosis)

It was also evident from the participants that there was a difference in understanding and recognition of the palliative care phase for patients and carers with differing diagnoses.

Communication, co-ordination, continuity and discharge

There were several examples given by patients and carers of times when communication between professionals could have been better. These included poor communication in general and at time of discharge; a lack of co-ordination between members of the primary health care team; a lack of continuity of care; a sense of constantly struggling with the system and transport difficulties.

“whenever she was being discharged I just felt I didn’t know whether I was coming or going, what’s going to happen here”
(55 year old carer for 88 year old patient with colon cancer)

These gaps in co-ordination also extended beyond the acute and community sector and included perceived poor communication between members of the primary health care team and between patients/ carers and health and social care professionals.

Effects of care giving

Many of the lay carers interviewed discussed what they perceived as the main effects of being a caregiver. These included both physical aspects such as fatigue and psychological aspects including anxiety and stress. These effects were compounded by the fact that many of the carers were elderly and had some difficulties with their own health. Many of the carers also highlighted that they felt that their needs were not taken into consideration in the overall care and discharge of the patient. These carers noted that they were being asked what did they need and yet they said they had no idea what to respond. They felt that a professional should have better assessed their needs and the needs of the patient.

“I was asked on the Friday before [husband] was getting out what I needed and I said, look you tell me cos this is new to me, I have never done this before… which I was disappointed they didn’t say right here you need that, you need this, you need the other thing, you had to question them”
(41 year old carer; husband malignant melanoma)

Identified palliative care needs
During the interviews the patients and carers were asked what they considered to be their main aspects of need. The needs identified included: social support including the provision of practical care; psychological and spiritual support; respite care; and information and choice.

**Value of local general practice**

Many of the respondents were generally positive in the way they spoke about their relationship with their local practice and particularly the GP and district nurse. Many examples and stories were given of GPs who provided great support and care for both the carers and patients when needed. These included giving the patients and carers their home phone numbers, calling for regular visits, and generally providing emotional support.

It was again noted that many of these types of narratives were mostly related to patients with a cancer diagnosis. This again raises questions if this same relationship and service was provided for patients with non-malignant disease, especially whenever their disease progression was more gradual and prolonged.

“I could not have existed without the support of my GP. It was beyond anything…, the initiative came from him and he just came and gave me his home phone number and permission to ring if I felt at any hour of the day or night, that I needed him. Now that is a very special privilege”
(63 year old carer, husband died with lung cancer)

The interviews conducted with the patients and carers (both present and past) help to provide a user perspective for assessing palliative care needs. It was notable in these interviews that the patients and carers had difficulty in defining a clear palliative care phase; rather their journey was viewed as one continuous event. This again reinforces the issues associated with timing and terminology associated with palliative care. It was also noteworthy that many of the issues overlapped between the professional, stakeholder and user perspective.

The following case study, supplied from her research by Dr Sonja McIlfatrick, illustrates the components of the regional model mapped against the patient/ family journey.
Palliative care case study - Community

Background
This patient was a 68-year-old lady diagnosed with lung cancer. She had three daughters who all lived close by but went to stay with one daughter and her husband. She had quite severe pain and breathless exacerbated with recurrent chest infections. At the time of diagnosis the plan was for surgery however her condition deteriorated and she was not considered suitable for surgery. She received palliative radiotherapy.

Patient's needs
The patient needed help with all aspects of daily care. She required hospital bed, commode and home oxygen. Pain medication was continually being reviewed and discussed with the GP. As the patient experienced breathless she needed to be nursed in an upright position and required regular oxygen, diuretics and antibiotics to relieve breathlessness.

Services provided
This patient had good family support and a lot of the care was provided by her family, namely her daughters. The patient also had Marie Curie and Hospice at Home service (one night each per week owing to funding issues, total 2 nights a week). The district nurse called three times a week and a palliative care support team were introduced twice per week as a sitting service. This service allowed some respite for the daughter (main carer) to attend a psychological/ counselling service. The GP undertook home visits once per week. The hospice nurse specialist also attended the home and undertook an assessment. It was noted that on two separate occasions the family had contacted the out of hours services at weekends. The main reasons documented for this contact included chest infection, not sleeping, vomiting, anxiety requiring some reassurance around medications. This service was provided both in terms of phone support and home visits and the patient remained at home. As the patient’s condition was deteriorating a joint visit with the district nurse and Hospice at Home nurse was arranged to assess the patient and family together. This patient remained at home until death.

Mapped Against Components of Regional Model
Identification of palliative care phase.
Professional awareness of prognostic indicators
Communication and agreement/discussion amongst professionals across boundaries of care
Effective communication with the patient and family
Active central register of palliative care patients
Identification, recording and discussion of treatment intent
Holistic assessment of care
Care pathways with identified points when patient will have an holistic assessment of need, for example:
- during exacerbations of condition
- active deterioration
- requested by carers or professionals
Staff competency to undertake holistic assessment
Plan of care developed in consultation with patient and family
Plan of care shared with all professionals responsible for delivery of care
Carer assessment
Holistic assessment tool
Coordination of care
Communication and information:
- In hours and out of hours;
- Acute to community
- Professionals to families and carers
Appropriate psychological and counselling assessment
hospice nurse specialist took place. At this time changes were made in terms of symptom management for pain. It was noted that during the weekend before the patient died three calls were again made to the out of hours services. The issues highlighted related to the families anxiety around their mother and her deterioration. Following this weekend the patient was commenced on a syringe driver and subsequently died within 24 hours.

Issues
The family had expressed a lot of anxiety and frustration at the delay in waiting for ‘treatment’ following the patient’s diagnosis. Overall the family reflected that the care they received was positive and they were able to care for their mother at home until she died. There did seem to be some issues around weekends and evenings in terms of anxiety and distress resulting in calls to the out of hours services and the need to give the same information to several people in turn. This was despite having the district nurse calling at weekends and Marie Curie nurse input. At one point it was noted that the family had been offered the option of a hospital admission and had declined this.

Enhancing community palliative care services
Integration of care
Accessible responsive generalist palliative care services
Accessible responsive specialist palliative care services

24 hour services:
- Nursing
- Palliative care support teams
- 24 hour access to advice
- Expansion of palliative consultant sessions in community

Active end of life care:
- Equity and choice of service provision
- Bereavement care

Liverpool care pathway
End of life care
Assessment tools for effective symptom management

Documented discussion regarding choice and preferred place of care and death
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