Palliative Care Health Needs Assessment in Northern Ireland

Commissioned by the Palliative Care and End of Life Commissioning Service Team

PHASE ONE REPORT – NOVEMBER 2017

Foreword

This paper sets out the findings of the first phase of a Palliative and End of Life Care needs assessment undertaken by the Health and Social Care Board (HSCB) and Public Health Agency's (PHA) Commissioning Service Team. The consideration of an in depth needs assessment process was highlighted in the Regulation and Quality Improvement Authority's (RQIA) 2016 report findings and has represented a priority action within the Commissioning Service Team's current work plan.

The approach to this needs assessment has been modelled on the work undertaken by the Palliative Care Council in New Zealand, with the development of a Phase 1 Report to provide the first estimates of need for Palliative Care across NI. The planned second report will endeavour to confirm Palliative Care capacity. This will be a considerable task, involving hospices, Independent sector organisations, Trusts and primary care and will be influenced by the outcomes of the specialist palliative care work force review currently underway and anticipated to report at the end of 2017/18.

This Phase 1 report establishes a comprehensive analysis of the number of people in NI who could benefit from a Palliative Care approach using mortality and hospital data as well as data from other sources, such as the Registrar General Office. The report focuses on adult palliative care needs only.

The Commissioning Service Team notes that this analysis will not be a one-off event, rather it will be part of an on-going process of continual needs analysis and as such would welcome comments and/or suggestions from partners as to other approaches or other aspects of need that should be considered for research in the future. The presentation of data by the new Local Government District has already been recorded as an important data set in the context of community planning approaches and will be considered in future updates.

The Commissioning Service Team acknowledges the input of the PHA's Health Intelligence Unit in the production of this report.

1 EXECUTIVE SUMMARY

The two main objectives for palliative and end of life care in Northern Ireland (NI) are:

> (1) Provision of equitable, high quality and patient centred care particularly in the last year of life that improves quality of life and
> (2) Supporting people to die in their preferred place of care.

The Regional Palliative Care and End of Life Commissioning Service Team, undertook a Health Needs Assessment (HNA) to help understand and quantify current services to inform the strategic development and investment in palliative care need. This HNA aims to provide information on cancer and non-cancer related palliative care needs of approximately 1.85 million people of NI (*2015 Mid-Year Estimates, NISRA, published 2016*).

Estimations for palliative care need and identification of current community and voluntary sector specialist palliative care (SPC) services were made for NI and for each LCG. The methodology used to identify palliative care need was based on a population-based approach developed from the original work of Peter Tebbit from the National Council of Specialist and Palliative Care Services.[8] The methodology used to identify community and voluntary sector SPC services used a number of different sources: a benchmarking exercise of SPC provision; completion of a questionnaire on SPC services by lead staff; findings from a regional audit of configuration & delivery of specialist palliative care services. Future phases will utilise more recent research to determine need.

There are two distinct categories of palliative care: generalist palliative care (GPC) and specialist palliative care. (SPC). This HNA has concentrated on mapping existing SPC services, although it is recognised that palliative care needs can often be met by GPC alone.

1.1 POPULATION ASSESSED

Latest mid year estimates indicate that there are approximately 1.85m people living in NI. This Needs Assessment is focused on the adult population as the Palliative Care in Partnership Programme does not deal with children's needs. The planning team for Palliative and End of Life Care works closely with the Child Health Planning team in respect of Children with life limiting conditions transitioning to adult services. There are a total of 292,000 older people (65+ yrs) in NI. Current population projections (2014 based) anticipate the population will rise to 1.954m by 2026. This increase is characterized by a marked rise in the proportion of older people from 2015 up to 2026, the

number of people aged 65+ is estimated to increase by 30% (88,000) to 380,000 while the numbers aged 85+ are estimated to increase by 46%(16,000) by 2026. Those aged 65+ will represent 19% of the total population compared with 16% currently. The 2014 based projections suggest, at sub-regional levels, the area with the highest projected growth overall is the Southern LCG (+11%), for the 65+ aged cohort of the population is the Western and Southern LCGs at +34%, and for aged 85+ years is in the Southern (+56%) and Northern LCGs (+53%).

In 2014 14,678 deaths were registered in NI. Having declined during the 1980's, the number of deaths have been relatively stable since 2000 although rates have continued to drop. The main cause of death was cancer accounting for 30% of deaths in NI (4323).

1.2 IDENTIFICATION OF NEED

Identification of palliative care needs was estimated using a population-based approach developed from the original work of Peter Tebbit from the National Council of Specialist and Palliative Care Services, which includes estimations from mortality, epidemiological and demographic data. The following areas were therefore analysed in considering N.I. palliative care requirements.

1.2.1 Age

The number of people aged 65 years and over is a key factor in determining the needs of palliative care services in a population. As expected, mortality is greatest the older one becomes and most palliative care needs arise in the last year of life. It is important to acknowledge that the 19-64 years cohort also have palliative care requirements, particularly in respect of early cancers. Further analysis of this age grouping will be dealt with in the next iteration of this report.

Approximately 16% of residents (292,000) in NI in 2014 were over 65 years of age, with 9% 65-74 years of age (162,600), 5% 75-84 years of age (93,700) and 2% older than 85 years (35,500). The proportion of residents over the age of 65 years ranges from a high of 17.6% and 16.7 % in South Eastern LCG and Northern LCG, respectively, to a low of 14.2% and 14.7%, in Southern LCG and Western LCG, respectively. Belfast and South Eastern LCG have the highest proportion of over 85 year olds and Western and Southern LCG the lowest.

The number of people over 65 years of age is projected to increase by around 30% in the next 11 years, so that a bigger proportion of the population will be over 65 years than there are currently (19% versus 16%). The biggest increases will be seen in people aged 85 years and older, quadrupling by 2051.

1.2.2 Gender

As the population ages, the proportion of women forms an ever larger share of the elderly population, with female predominance more marked with increasing age There are a third more women over 65 years of age than there are men, with more than the double the number of women over 85 years of age than men. The differences between the number of women and men are greatest in LCGs with the highest proportion of elderly people. Approximately 30% of those over 65 years are living alone (~80,000 people). It is therefore much more likely that women will survive men, live alone and ultimately need to be cared for.

1.2.3 Ethnic composition

Ethnic composition may also have implications on the level of resources needed. The 2011 Census estimates that 32,414 (1.8%) residents of NI are non-white ethnicity with approximately one third living within Belfast LCG (12,195). Census 2011 figures have not been broken down by age group. The biggest ethnicity groups are the Chinese, Indian and other Asian populations.

1.2.4 Deprivation

Evidence has shown that deprivation impacts on the level of palliative care need and type of resources required. Belfast and Western LCGs include Local Governmental Districts (LGDs) which have over 40% of their population living in the 20% most deprived LGDs. Southern LCG also includes two LGDs within the 20% most deprived LGDs in NI. In contrast, Northern and South Eastern LCGs each include two LGDs living in 20% of least deprived areas. Information has been analysed on the basis of the pre-RPA LGD.

1.2.5 Mortality

Annual incidence of deaths is the single most important indicator of palliative care need in a population since most palliative care needs arise in the last year of life. There are approximately 14,600 deaths in NI each year (average 2011-2014), with over a quarter caused by cancer (28%).

Looking at 2014 deaths Northern LCG has the largest number of deaths, followed by Belfast. When taking population size into account, Belfast LCG (934 per 100,000) and South Eastern LCG (822 per 100,000) have higher death rates than the NI average. Southern LCG, Northern and Western LCG are both lower than NI average (712 per 100,000, 788 and 752 per 100,000 respectively). The NI average was 798 per 100,000.

Belfast LCG and South Eastern LCG also have higher rates of cancer deaths than the NI average (275 per 100,000 and 245 per 100,000 respectively), and similarly the highest number of cancer deaths is seen in Northern LCG of residence. Belfast and Southern LCGs have a higher proportion of cancer deaths by all deaths than the NI average (30.1% and 30.0% respectively). The NI average was 235 cancer deaths per 100,000

Another important measure for estimating palliative care need is the number of deaths in people over 65 years of age because advanced progressive illnesses are more common with advancing age. In 2014, 11,926 (81%) of deaths in NI were in those over 65 years, with the numbers increasing with age (2,569 deaths in 65-75 years compared to 4,988 deaths in 85+ years). Northern LCG has the largest number of deaths in people over 65 years, followed by Belfast and South Eastern LCGs. Western and Southern LCGs have the smallest number.

1.2.6 Place of death

The evidence shows that the majority of people with an advanced progressive illness would prefer to die at home. To reflect this, *'Living Matters, Dying Matters' (LMDM)* recommends the need for provision of palliative care services that address people's expectations of choice in how and where their care is delivered. The findings show (based on a 5 year average 2011-15) that a substantial proportion of the population die in a hospital (47%), followed by the home (30%), nursing homes (19%) and hospices (4%).

Variation in the places people die was seen across LCGs. A higher proportion of people were dying in an acute hospital in Belfast and Western LCGs (51 and 48% respectively) than the NI average (47%). South Eastern LCG had the largest proportion of people dying in a nursing home (24%), followed by Northern LCG (19%). The Northern LCG had the highest proportion of people dying in a hospice, 5% as opposed to the NI average of 4%. Southern and Western LCGs had the highest proportion of people dying at home (at 33%) compared with the NI average (30%). These variations are likely to be because of a number of factors, for example, the level and type of GPC available in communities, access to acute hospitals, family support and geographical variation of type and level of SPC services.

We can however deduce that:

- Approximately one third of acute hospital deaths occurred in those over 85 years of age (33.4%), with largest numbers seen in Northern, Belfast and South Eastern LCGs;
- Acute hospital deaths contribute to more bed-days with increasing age; individuals over 85 years who died in an acute hospital occupied over

one third of bed-days of all acute hospital deaths aged 65 years and over;
- Approximately one in three individuals who died in an acute hospital did so within four days of admission (2,323);
- Approximately 14% (927) of acute hospital deaths had a primary diagnosis that was cancer related and almost eight out of ten of these deaths (726) were admitted as an emergency.

1.2.7 Nursing home deaths

In NI there are approximately 2800 deaths every year among individuals who reside in a nursing home, with just under a quarter of those dying in hospital. The highest number of deaths in people residing in a nursing home is in the Northern LCG (721) and South Eastern LCG (698) and the lowest number in Southern LCG (474) and Western LCG (343).

1.2.8 Estimated palliative care need

The number of deaths in the population is used as a starting point for estimating need for palliative care. Different approaches have been developed that use combinations of mortality statistics, symptom prevalence and disease prevalence. One of the approaches in the UK, adopted by Higginson in 2007, uses the number of deaths from cancer and six selected non-cancer disease groups multiplied by disease prevalence in those groups for the key symptoms requiring care, to derive estimates of need. The Higginson model estimates that all cancer deaths and approximately two-thirds of non-cancer deaths will have palliative care needs. This HNA estimates that approximately 11,200 people in NI who die each year have some form of palliative care requirement need.

Palliative care needs vary between LCGs according to the size of the population, the demographics and deprivation of the area. The biggest burden is seen in LCGs with ageing populations (Belfast, South Eastern and Northern LCGs). Deprivation levels in Belfast LCG, together with a high proportion of people over 65 years, are likely to explain the particularly high level of palliative care need. Although the absolute numbers of people requiring palliative care in Western LCG are smaller due to the younger, smaller population, there are higher levels of deprivation, which is reflected in the higher proportion of deaths from diseases linked with deprivation.

1.2.9 Palliative care data systems

Identification of palliative care needs for this HNA has been based on estimations from demographic, epidemiological and mortality data. The estimations enable us only to make assumptions on the level of need and not the true numbers. Data is collected for those requiring palliative care, both in

secondary care (PAS) and primary care (QOF), although the information is incomplete and so does not provide a full picture of need.

The Quality and Outcomes Framework (QOF) is a system to remunerate general practices for providing good quality care to their patients, and to help fund work to further improve the quality of health care delivered. Holding a complete palliative care register was introduced to QOF in 2006. Nearly 100% of practices in NI participate in holding a palliative care register. On 31 March 2016 approximately 5,400 people were recorded as requiring palliative care in NI (prevalence rate 2.78/1000).

1.3 Required Specialist Palliative Care Services

The essential elements of palliative and end of life care are based on recommendations from the following key documents:

1. *Living Matters, Dying Matters: Palliative and end of life strategy for adults living in NI, DHSSPS, 2010*
2. *Improving supportive and palliative care for adults with cancer: the Manual, National Institute of Clinical Excellence (NICE), 2004*
3. *NICE Guidance – Care of dying adults in the last days of life, 2015*
4. *RQIA Review of The Palliative and End of Life Care Strategy, January 2016*

1.4 Identification of current SPC services

In NI, SPC services are provided in four ways: in-patient specialist care units, hospital based teams, community based teams and day hospices. As part of the Palliative Care in Partnership work plan a inter-disciplinary specialist workforce review is currently underway.

1.4.1 SPC in-patient specialist care units

There are 5 in-patient specialist care units across the region providing 69 SPC beds. The SPC beds are provided by four voluntary sector hospices and, since 2011, the Macmillan Unit in Antrim Area Hospital. Most beds are used for cancer conditions. There is variation in the availability of beds for palliative care needs across LCGs. Northern and Belfast LCG has the highest number per 1000 of the population (7.3 and 6.9 respectively) and South Eastern LCG the lowest (5.1).

1.4.2 SPC hospital based teams

Hospital based teams provide SPC support to in-patients, mainly cancer patients. They occasionally have out-patient clinics and are supported by multi-disciplinary teams. They are available in all acute hospital Trusts across the region. In addition, there are units providing general beds supported by

SPC teams in Tyrone County, Ballymoney, Ards and Bangor Community Hospitals.

1.4.3 SPC community based teams

There are six SPC community teams covering NI; one in four of five LCGs and two in Western LCG (Northern and Southern). All localities have specialist palliative care consultant support and input from specialist palliative care nursing staff. There is dedicated AHP and social work support across the community teams and dedicated Pharmacists in some settings. There are different models of care across the region.

1.4.4 SPC day hospices

The Day Hospice is one of the specialist services providing a link between the Hospice and the community setting for patients who need on-going monitoring and review. It consists of a multi-professional service offering therapeutic support to patients in the community and their carers' with the aim of symptom control; rehabilitation to the patients' maximum potential; providing respite and helps to prevent hospital admission.

Over 40 clinical interventions are offered by Day Hospices in NI ranging from holistic assessment, advance care planning, pain and symptom management to treatment interventions including IV therapies and blood transfusions.

Ten percent of day Hospice places are accessed by patients with non-cancer conditions. Day Hospices are provided in each LCG area by the voluntary sector. There is variation in the number of day hospice places and services models across the region. A day hospice service re-design commenced through the Transforming Your End of Life Programme and is now part of the Palliative Care in Partnership work plan.

(It should be noted that Phase 2 of this report will focus on current palliative care capacity across all sectors to align current provision of assessed needs)

1.5 CONCLUSIONS

In line with other western countries, the population is ageing with an increasing number and proportion of the population living to over 85 years of age. As a result, there will be greater numbers of people with cancer, long-term conditions and co-morbidities in the future. Mortality is greater the older one becomes, so palliative care need is predicted to increase in the future particularly for those LCGs with the greatest elderly population projections of elderly the most.

Research of acute hospital deaths suggest that some acute hospital deaths could be managed elsewhere, which would enable people to die in their preferred place of care. One of the Palliative Care in Partnership Programme's objectives is the development of appropriate support and services to enable people in the dying phase of their illness to die in their preferred place of care, which is usually their home or nursing home.

Variation in the places people die was seen across LCGs which is likely to be due to a number of factors. SPC services are mainly utilised by cancer patients, which accounts for only approximately 30% of all deaths. Historically SPC services have been availed of by the cancer population and less so by non-cancer population.

Identification of palliative care needs for this HNA was based on estimations from mortality, epidemiological and demographic data. Challenges exist in data collection to support monitoring of palliative care services. The QOF palliative care register only provides point prevalence information on 1 day of the year and there is no diagnostic data. However, steps are already been taken by the Commissioning Service Team to enhance the monitoring and recording across primary and secondary care and the findings of this HNA would therefore support a standardised, continuous palliative care register that can be accessed across secondary and primary settings.

By doing so we value the way we care for patients at the end of their lives and meet their preferences for dying. In moving to more community based service provision, we need to ensure that Primary and community-based settings are supported and enhanced to enable home deaths, with appropriate services, 24 hours a day, 7 days a week. Services should be tailored to meet the different demographics of LCG populations (elderly, deprived and ethnic minorities). Particular focus should be on enhancing support for nursing homes.

If palliative care needs are identified earlier by health professionals involved in their care, both in primary and secondary care, and with the appropriate community services in place, acute hospital admissions resulting in death may be significantly reduced. To enable this, education and training for healthcare professionals, particularly those working as generalists, to recognise people likely to be in their last year of life is paramount. The Living Matters Dying Matters Programme has developed the End of Life Care Operational System (ELCOS), which will support palliative care support closer to home. This Needs Assessment will support the delivery of the Palliative Care in Partnership programme in NI.

Significant opportunities exist for the voluntary and community sector to engage with developments in service delivery through redesigned services and developing new roles. Hospices in NI already know and value the benefits

of working in partnership with HSC Trusts and other partners and have the expertise in a range of assessment, diagnosis, treatment and rehabilitation interventions that can be more fully exploited in improving care and management of patients at the end of life.

2 INTRODUCTION

This HNA aims to provide information on cancer and non-cancer related palliative care needs of approximately 1.8 million people of NI. Population demographics in NI have changed over time. The population is increasing, becoming more ethnically diverse, has a larger number and proportion of elderly people and more people living with chronic medical conditions. Family structures are also changing with increasing numbers of single parents families and more people living alone into old age. As a result, palliative care need is likely to increase and services need to be able to continue to meet the demand of the changing population.

In 2009, the Department of Health, Social Services and Public Safety (DHSSPS) launched a five year strategy document, *Palliative and End of Life Care Strategy for Adults in NI: Living Matters, Dying Matters*, requiring palliative care services to be prioritised [(1)]. The Regulation and Quality Improvement Authority (RQIA) reviewed the *Living Matters, Dying Matters* in 2016 and concluded that there was very significant progress for this implementation and made 8 recommendations. In addition, DHSSPS Service Frameworks for Health and Well-being in NI all contain explicit standards for palliative care. [(2)]

In 2011, the Minister for Health, Social Services and Public Safety asked for a review of the provision of Health and Social Care Services in NI. The report, '*Transforming Your Care (TYC*): *A Review of Health and Social Care in NI'* was published, which outlined the need to integrate services at local level, provide more community-based services and care for people at home when safe and appropriate to do so. Ten major programmes of care were identified for change, one of which was Palliative and End of Life Care. [(3)] In October 2012, the consultation, '*Transforming Your Care: From Vision to Action,* was published, setting out the strategic way forward and outlining key proposals to be taken forward over the next 3 to 5 years. [(4)]

A review of progress on the implementation of 'Living Matters:Dying Matters was carried out in 2015 by the Independent RQIA to assess progress in the implementation of the LMDM strategy and the 25 recommendations included in the strategy's action plan. The review found that there had been very significant progress made during the period 2010 to 2015 towards implementing the recommendations of the strategy despite a period of financial constraints. The review recognised that this was facilitated by strongly committed leadership from both statutory and voluntary sector organisations with clear evidence of strong partnership working.

The review report noted that the increasing demand for palliative and end of life care services in NI is likely to continue and that many patients accessing hospice services now have more complex needs, impacting on the delivery of

other services such as short breaks. The review found that there was a significant commitment to service development in palliative and end of life care, with plans developed for a programme of service improvement initiatives. Finally the review concluded that the vision and broad strategic direction set out in LMDM remain valid for the next phase in the development of palliative and end of life care services.

Following on from the RQIA review, new structures to support the further development of palliative and end of life care were put in place during 2016 to replace the Living Matters:Dying Matters Implementation Board and the Transforming Your Palliative and End Of Life Care (TYPELC) Board with a new Regional Palliative Care Programme Board, a Clinical Engagement Group and a Service User and Carers Engagement Group.

The Health and Social Care Board (HSCB), supported by the Public Health Agency (PHA), commission palliative care services regionally through the Palliative Care and End of Life Commissioning Service Team. The Commissioning Service Team and the RQIA review have identified the need for a comprehensive needs assessment to help understand and identify unmet need in order to inform the strategic development and investment in palliative care services in line with key proposals.

The aim of the HNA is therefore to:

- Identify the current palliative care needs in each Local Commissioning Group (LCG) area of residence;
- Make comparisons on the level of palliative care need between LCGs;

It should be noted that there are two distinct categories of palliative care: Generalist Palliative Care (GPC) and Specialist Palliative Care (SPC).

The document is divided into two parts:

1. Part 1: defines the population being assessed;
2. Part 2: describes the methodology for identifying palliative care need and the findings of the need for the population of NI and LCGs.

2.1 PALLIATIVE CARE

Individuals with an advanced progressive illness and those important to them, should have their needs identified and met. Palliative Care has been defined by the World Health Organisation (WHO) as;

'...the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and those important to them. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.'

Provision of palliative care often begins early in the course of the illness and co-exists with active treatment and treatment of acute exacerbations of the illness along the course of the disease progression. Early identification of an individual's palliative care needs enables the best quality of life into their last year of life. The aim is to:

- Affirm life and regard dying as a normal process
- Provide relief from pain and other distressing symptoms
- Integrate the psychological and spiritual aspects of patient care
- Offer a support system to help patients live as actively as possible until death
- Offer a support system to help the family cope during the patient's illness and in their own bereavement

Palliative care is provided by generalist (Tier 1 and 2) and specialist staff (Tier 3), within three tiers distinct categories of health and social care professionals:

Define Tiers

Tier 1 (TI)	Infrequently provide palliative and end-of-life care as part of role
Tier 2 (T2)	Frequently provide palliative and end-of-life care as part of role
Tier 3 (T3)	Provide specialist palliative and end-of-life care

2.1.1 Generalist Palliative Care (GPC)

This level of care is required by most people and is provided by non-palliative care specialists. Non-palliative care specialists should be able to:

- Assess the care needs of each patient, and those important to them, across the domains of physical, psychological, social spiritual and information needs
- Meet those needs within the limits of their knowledge, skills, competence in palliative care
- Know when to seek advice from or refer to specialist palliative care services.

GPC is delivered by multi-disciplinary teams (MDT) in primary and community care settings, secondary care settings. MDTs include a range of health care workers such as: General Practitioners (GP); district nurses; allied health

professionals (AHP); social workers; health and social care professionals in particular fields, for example, respiratory, heart failure, renal, dementia; and the voluntary sector, for example Marie Curie nursing services and NI Hospice (NIH) at home services.

All general health care workers should have access to education and training of palliative care principles and be able to access specialist services when required.

2.1.2 Specialist Palliative Care (SPC)

In 1995, the DHSSPS published the Campbell report, '*Cancer services: Investing for the future'* [5] to reflect the Calman Report in Great Britain. [6] The primary aim of the report was the development of high quality cancer services in NI. As a result, SPC care was increased for cancer patients and posts within acute hospitals were funded by the statutory sector and a variety of arrangements were set up in the community.

SPC supports GPC and relates to the management of unresolved symptoms, more demanding care needs and complex psychosocial issues. It is provided by specialist MDTs, which should include: palliative care medical consultants; SPC nurses; pharmacists; AHPs; social workers; chaplain; counsellors and volunteers. SPC services include:

- Inpatient facilities for terminal care, management of unresolved/complex symptoms where 24 hour care is required, rehabilitation and respite, again for complex symptoms
- Intensive co-ordinated home support for patients with complex needs who wish to stay at home. This may involve the service providing specialist advice alongside the patient's own doctor and district nurse; or extended specialist palliative nursing, medical, social and emotional support and care in the patient's home, often known as 'hospice at home'
- Day Hospice facilities that offer a range of opportunities for assessment and review of patients' needs and enable the provision of physical, psychological and social interventions within a context of social interaction, support and friendship. Many also offer creative and complementary therapies
- Pre and post bereavement support services, which provide advice and support to the patient, those important to them and also the staff involved in their care.
- Advice and support to all the people involved in a patient's care
- Education and training in palliative care.

In NI this level of care is provided by the health and social care acute and community palliative care services in partnership with the voluntary and community sector.

2.2 End of Life Care

End of life care is an integral part of the wider concept of palliative care and relates to the last year of life for adults. The UK General Medical Council (GMC) defines end of life care in 2010 as [7]:

'*… People are approaching the end of life when they are likely to die within the next 12 months.'*

This includes people whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions;
- General frailty and co-existing conditions that mean they are expected to die within 12 months;
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition;
- Life-threatening acute conditions caused by sudden catastrophic events.

When an individual is diagnosed with cancer or an advanced progressive illness the early identification of their palliative care needs enables better planning of the end-of-life phase of the illness, enabling patients and those important to them to receive the best quality of care so they may die according to their wishes and ensure their dignity is preserved.

3 PART 1: POPULATION TO BE ASSESSED

Palliative care needs will be assessed for **adult residents living in NI** with both cancer and non-cancer related advanced progressive illness.

Table 1 shows the estimated 2015 mid-year population for NI and LCG of residence. As of 2015, the population of NI was approximately 1.85 million. Northern LCG has the largest number of residents, accounting for 25.5% of the region's population, and Western LCG the smallest, accounting for 16.2%.

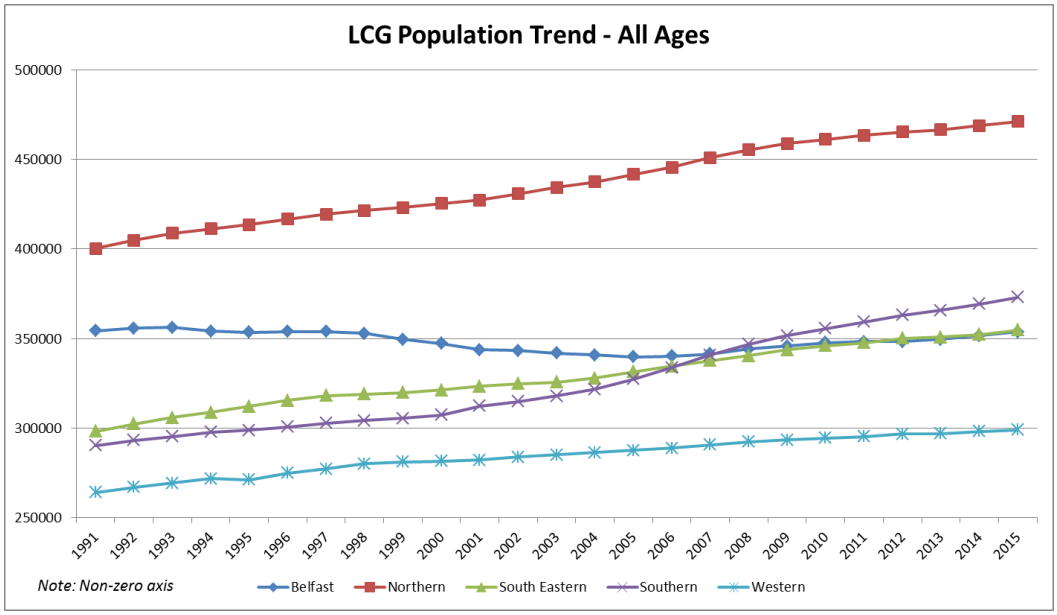
Table 1: 2015 mid-year population estimates for NI and LCGs

LCG	Population	Proportion
Belfast	353,778	19.11%
Northern	471,188	25.45%
South Eastern	354,651	19.15%
Southern	372,976	20.14%
Western	299,028	16.15%
NI	1,851,621	

Data Source: 2015 mid-year population estimates, NISRA 2016

The population of NI has increased by 15%, from 1.6m in 1991 to 1.85m in 2015. Figure 1 show the trend for each LCG population during the same time period.

Figure 1: Trend of LCG populations, 1991-2015



Data Source: 2015 mid-year population estimates, NISRA, 2016

The population for all LCGs has increased except Belfast, which has decreased by <1%. The biggest change in population is seen in the Southern

LCG (28.5%), followed by South Eastern LCG (18.9%). Northern LCG, which always has the largest actual population, has increased by 17.7%.

Table 2 provides detail on the population increase in respect of various age bands.

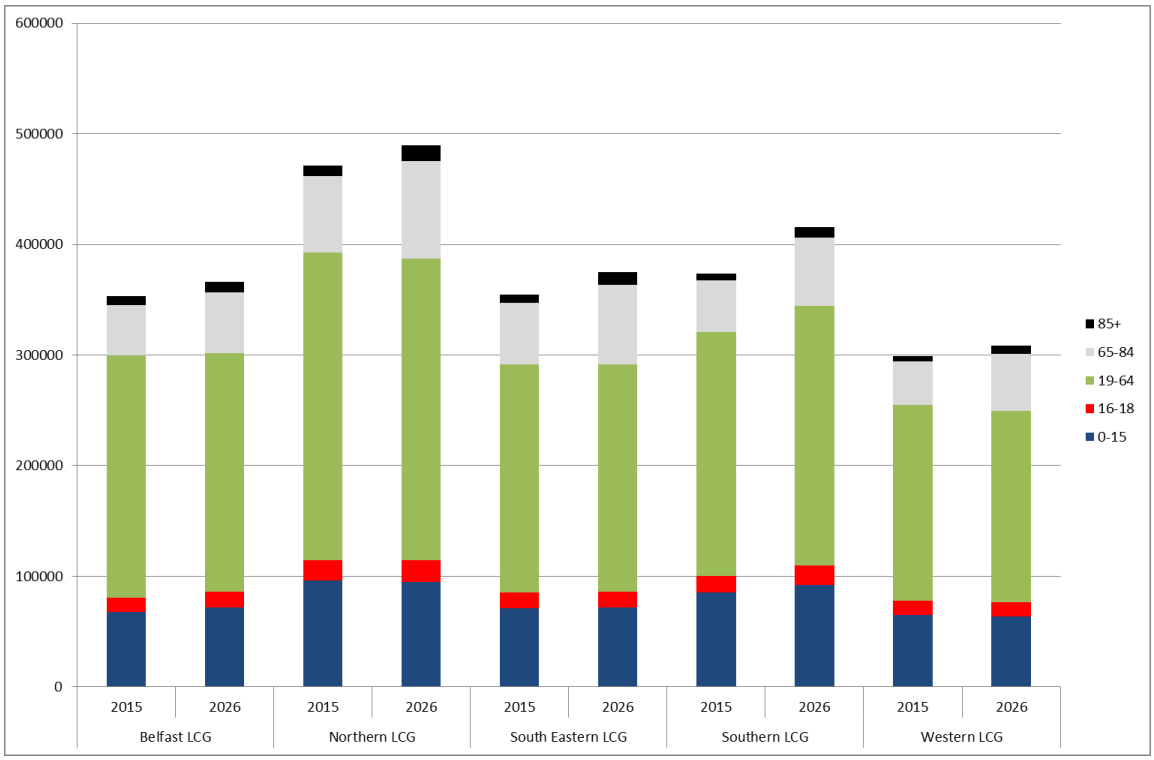
Table 2: 2015 mid-year population estimates for NI and LCGs by age band

Area of Residence	Age Band (years)	1991 Population	2015 Population	% Change
Belfast LCG	0-15	79,583	67,685	-15.0%
	16-18	14,588	12,950	-11.2%
	19-64	204,054	219,283	7.5%
	65-84	50,746	46,106	-9.1%
	85+	5,463	7,754	41.9%
Northern LCG	0-15	100,953	96,281	-4.6%
	16-18	20,129	18,631	-7.4%
	19-64	229,656	277,806	21.0%
	65-84	45,103	69,157	53.3%
	85+	4,557	9,313	104.4%
South Eastern LCG	0-15	74,833	71,532	-4.4%
	16-18	13,752	13,924	1.3%
	19-64	170,320	206,664	21.3%
	65-84	35,478	55,065	55.2%
	85+	3,780	7,466	97.5%
Southern LCG	0-15	81,793	84,875	3.8%
	16-18	14,955	15,259	2.0%
	19-64	159,230	219,966	38.1%
	65-84	31,450	46,844	48.9%
	85+	2,927	6,032	106.1%
Western LCG	0-15	79,377	64,827	-18.3%
	16-18	14,494	13,042	-10.0%
	19-64	141,304	177,072	25.3%
	65-84	26,315	39,192	48.9%
	85+	2,455	4,895	99.4%
NI	0-15	416,539	385,200	-7.5%
	16-18	77,918	73,806	-5.3%
	19-64	904,564	1,100,791	21.7%
	65-84	189,092	256,364	35.6%
	85+	19,182	35,460	84.9%

Source: NISRA 2015 MYE

Projected figures for NI show that the population will continue to grow with the population projected to rise by 5.5% over the next eleven years (2015-26), reaching 1.9545 million by 2026 *(NISRA population projections (2014 based figures).*

Figure 2: Projected LCG populations by age group, 2014-2026



Source: NISRA 2014 based population projections

4 PART 2: IDENTIFICATION OF PALLIATIVE CARE NEED

4.1 METHODOLOGY

Identification of palliative care need has been estimated using a population based approach developed from the original work of Peter Tebbit from the National Council of Specialist and Palliative Care Services.[8]

Data on epidemiological, demographic and socio-economic factors has been obtained and analysed to assess the aggregate population needs of the region and each LCG area of residence.

Data was collected from a number of pre-existing data sources:

- Population estimates from the NI Statistics and Research Agency (NISRA)
- 2015 population midyear estimates, NISRA
- NI Multiple Deprivation Index (NIMDI) 2010
- Mortality data by the Register General Office (RGO)
- Patient hospital in-patient system (PAS)
- National confidential enquiry into patient outcome and death (NCEPOD)
- Quality and Outcome Framework (QOF)
- Cancer registry
- NI CENSUS, 2011 (NISRA)

It should be noted that needs assessment for palliative care is based on estimates, as the techniques currently available do not lead to absolute measurements of need. Despite this, they do provide analyses of the principal factors that influence need.

The Palliative and End of Life Commissioning Service Team utilises other sources of information such as regional complaints, 10,000 Voices and the specific commissioned piece led by the All Ireland Institute for Hospice and Palliative Care (AIIHPC) "*Let's Talk About*" to inform the Palliative Care in Partnership programme in respect of needs assessment.

4.2 DEMOGRAPHIC FACTORS

4.2.1 Age Structure

A key factor in determining the needs of palliative care services in a population is the number of people aged 65 years and over.

Table 3 shows the 2015 mid-year population estimates for NI and LCG by age group. Approximately 15.8% of residents in NI are over 65 years of age, with just under 10% 65-74 years of age, 5% 75-84 years of age and 2% older than 85 years.

Table 3: 2015 mid-year populations for over 65 year olds in LCG and NI

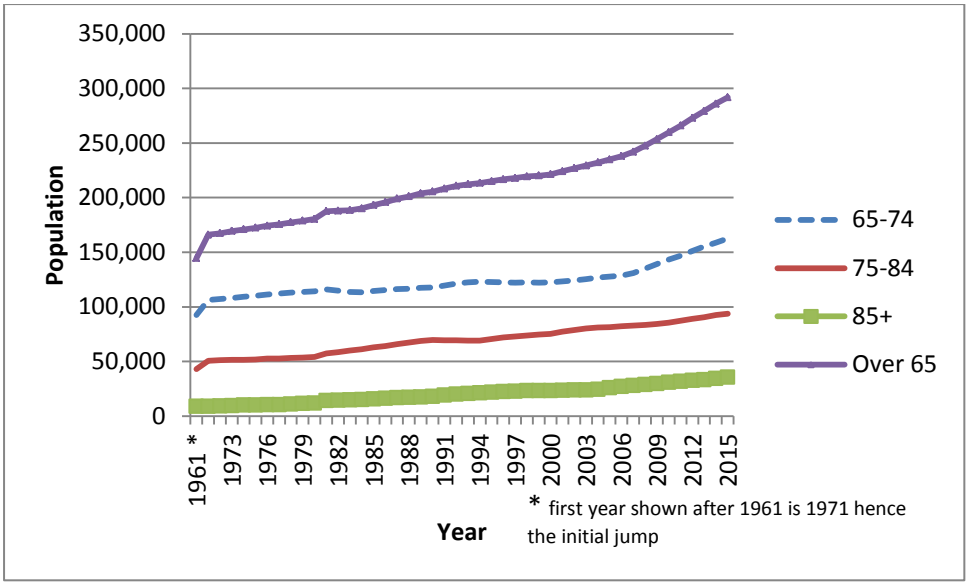
LCG	Over 65 years	65-74	75-84	85+
	(% of total pop)	(% of total pop)	(% of total pop)	(% of total pop)
Belfast	53,860	27,338	18,768	**7,754**
	15.2%	7.7%	5.3%	**2.2%**
Northern	78,470	43,865	25,292	**9,313**
	16.7%	9.3%	5.4%	**2.0%**
South Eastern	62,531	36,002	19,063	**7,466**
	17.6%	10.2%	5.4%	**2.1%**
Southern	52,876	29,889	16,955	**6,032**
	14.2%	8.0%	4.5%	**1.6%**
Western	44,087	25,525	13,667	**4,895**
	14.7%	8.5%	4.6%	**1.6%**
NI	291,824	162,619	93,745	**35,460**
	15.8%	8.8%	5.1%	**1.9%**

Data Source: 2015 mi-year population estimates, NISRA, 2016

The proportion of residents over the age of 65 years ranges from a high of 17.6% and 16.7%, in South Eastern LCG and Northern LCG, respectively, to a low of 14.7% and 14.2%, in Western LCG and Southern LCG, respectively. Belfast and South Eastern LCG also have the highest proportion of over 85 year olds and Western and Southern LCG the lowest.

Figure 3 shows the trends for NI for over 65 year olds, 65-75 years, 75-84 years and over 85 year olds. The number of people over 65 years has increased by 102% from 144,522 in 1961 to 291,824 in 2015, with those over 85 years of age increasing the most at 304%.

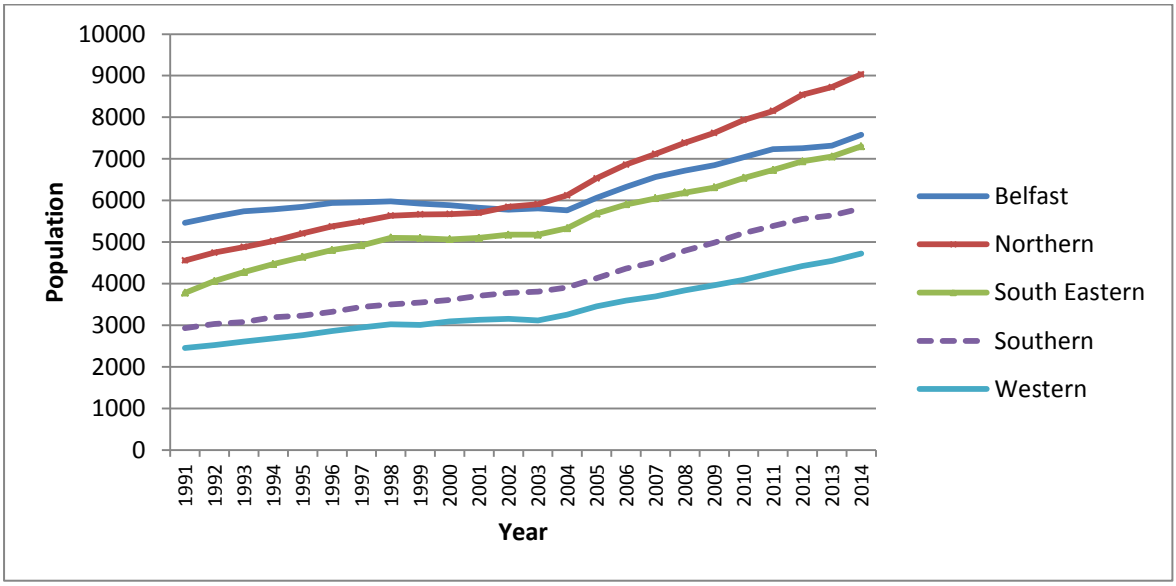
Figure 3: Age trends in NI



Data Source: 2015 mid-population estimates, NISRA 2016

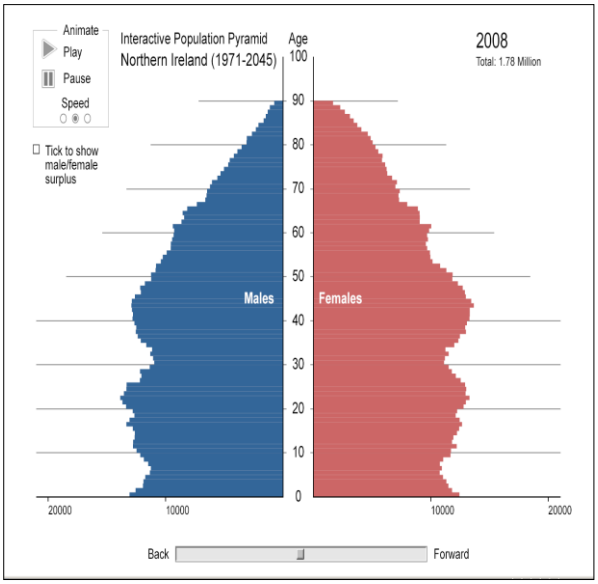
The number of people over 85 years has increased in all LCGs of residence (figure 4). The change is largest in Northern and South Eastern LCGs, 98% and 99% respectively, and lowest in Belfast, 39%.

Figure 4: Trend of size of 85+ years population by LCG of residence, 1991-2014



Data Source: 1991-2014 mid-population estimates, NISRA 2016

Population projections indicate continued increases in the size of the older population, with figures 5 and 6 showing the change in the population pyramids for NI between 2008 and 2045. The number of people aged 65 years and over increased by 12% in the last five years (2010-15) and is projected to increase by around 45% in the next 15 years (2015-30).



Figures 5 and 6: population pyramids for NI based on 2010 estimates

4.2.2 Gender structure

The proportion of men and women in the population of NI and each LCG is broadly similar at 49.1 % and 50.9% respectively (table 4).

Table 4: 2015 mid-year population by gender for NI and LCG of residence

LCG	Population	Male	Female
Belfast	353,778	171,061 48.4%	182,717 51.6%
Northern	471,188	231,229 49.1%	239,959 50.9%
South Eastern	354,651	172,862 48.7%	181,789 51.3%
Southern	372,976	185,592 49.8%	187,384 50.2%
Western	299,028	148,385 49.6%	150,643 50.4%
N.I	**1,851,621**	**909,129** **49.1%**	**942492** **50.9%**

Data Source: 2015 mid-population estimates, NISRA, 2016

As the population ages the proportion of women forms an ever larger share of the elderly population, with female predominance more marked with increasing age (tables 5 and 6).

Women now represent 55.4% of the population over 65 years of age in NI, ranging from a high of 58.3% in Belfast LCG to a low of 53.5% in Western LCG.

Table 5: 2015 mid-year 65 + population by gender for NI and LCG of residence

LCG	65 + Population	Male	Female
Belfast	53,860	22,478 (41.7%)	31,382 (58.3%)
Northern	78,470	35,098 (44.7%)	43,372 (55.3%)
S. Eastern	62,531	28,123 (45.0%)	34,408 (55.0%)
Southern	52,876	23,818 (45.0%)	29,058 (55.0%)
Western	44,087	20,491 (46.5%)	23,596 (53.5%)
N.I	**291,824**	**130,008 (44.6%)**	**161,816 (55.4%)**

Data Source: 2015 mid-population estimates, NISRA, 2016

In those over 85 year olds almost 70% are female in NI with similar proportions in each LCG.

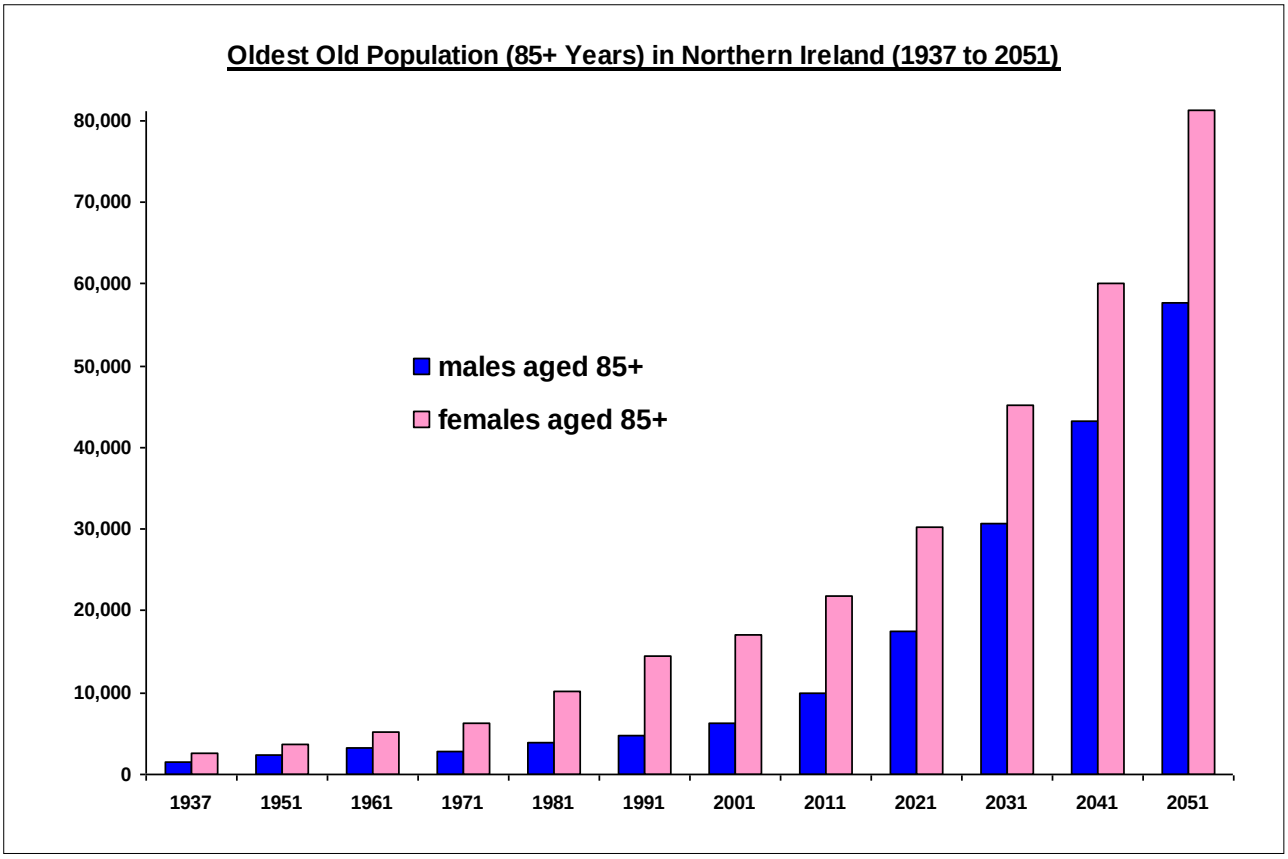
Table 6: 2015 mid-year 85 + population by gender for NI and LCG of residence

LCG	85 + Population	Male	Female
Belfast	7,754	2,410 (31.1%)	5,344 (68.9%)
Northern	9,313	3,062 (32.9%)	6,251 (67.1%)
S. Eastern	7,466	2,410 (32.3%)	5,056 (67.7%)
Southern	6,032	2,030 (33.7%)	4,002 (66.3%)
Western	4,895	1,688 (34.5%)	3,207 (65.5%)
N.I	**35,460**	**11,600 (32.7%)**	**23,860 (67.3%)**

Data Source: 2015 mid-population estimates, NISRA, 2016

Population projections for NI show that the proportion of women and men over 85 years of age will continue to widen (figure 7).

Figure 7: Population projections for those over 85 years in NI



4.2.3 Ethnic composition

The ethnic composition of the population may also have implications for the level of resources needed, for example, educational and training requirements for health professionals to deliver palliative care with an understanding of cultural differences and the use of interpreters for those whose first language in not English.

Historically, NI has had a very small number of individuals of non-white origin living in the region. The 2011 census estimates that 32,414 (1.8%) residents of NI are non-white ethnicity with approximately one third living within Belfast LCG (12,195) (table 7). Census 2011 figures have not been broken down by age group. The biggest ethnicity group is the Chinese, Indian and other Asian populations.

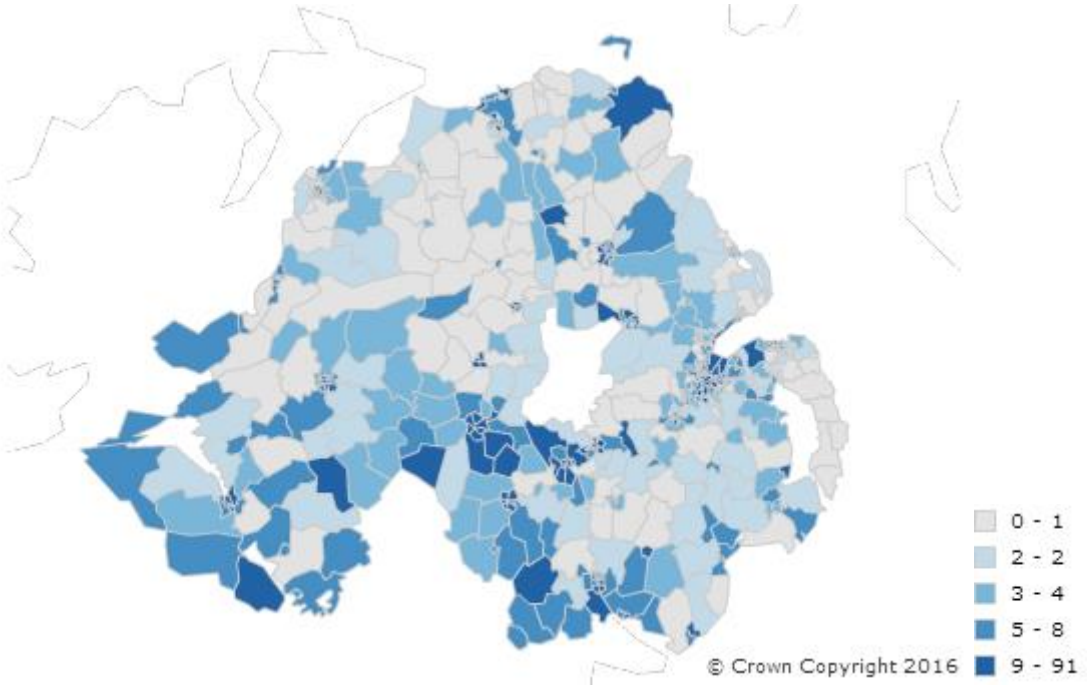
Table 7: Ethnic composition in NI and at LCG of residence, 2011

LCG	All usual residents	White ethnic group (%)	Non-white ethnic group (%)
NI	1,810,863	1,778,449 (98.2%)	32,414 (1.8%)
Belfast	348,204	336,009 (96.5%)	12,195 (3.5%)
Northern	463,297	457092 (98.7%)	6,205 (1.3%)
South Eastern	346,911	341721 (98.5%)	5,190 (1.5%)
Southern	358,034	352704 (98.5%)	5,330 (1.5%)
Western	294,417	290923 (98.8%)	3,494 (1.3%)

Data Source: 2011 Census

Census ethnicity data does not capture individuals of white ethnicity who have migrated to the country, in particular those from A8 and A2 accession countries (see Appendix 1). Between 2004 and 2009 there was marked in-migration into NI, however, in the year to mid-2011 net migration has dropped to zero net population gain. Figure 8 shows the average annual health care registrations for non-UK nationals by electoral ward per 1000 population.

Figure 8: Health card registration from non-UK nationals, by electoral ward per 1000 population (2015)



Data Source: NISRA,NINIS 2015

Belfast and Southern LCGs have the highest number of registrations. The majority of new migrants are between 18 and 35 years of age who have migrated for work, education and family reasons and are thus less likely to impact on current resource need of palliative care services.

4.3 SOCIO-ECONOMIC FACTORS

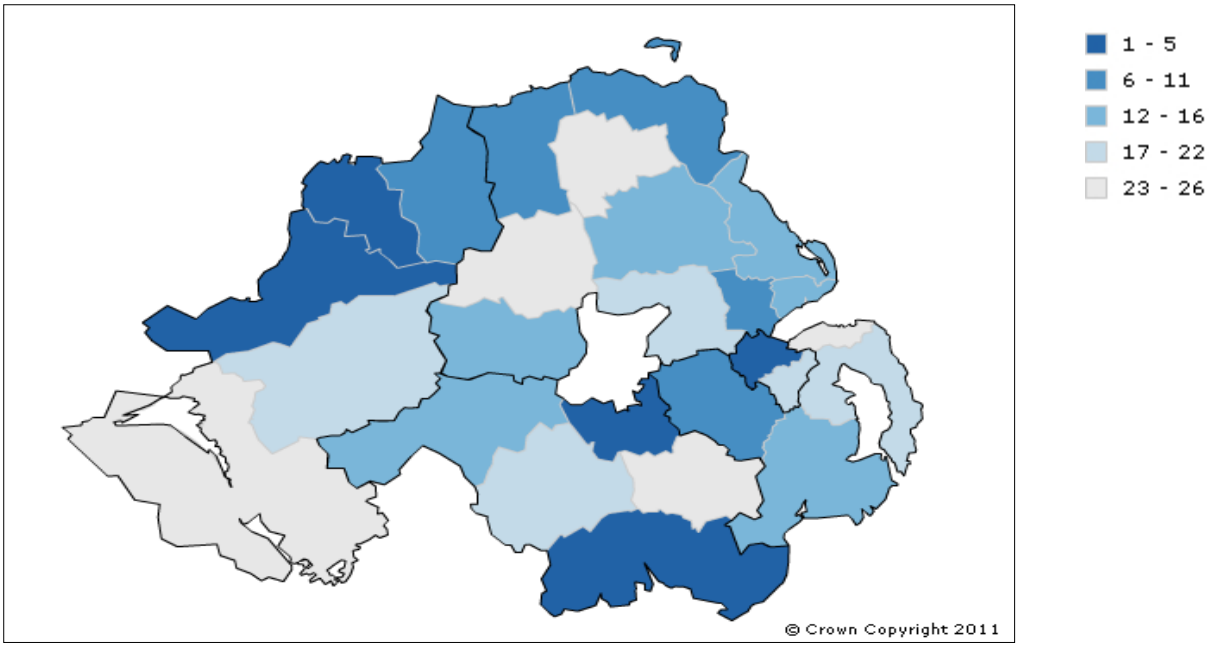
4.3.1 Deprivation

There is growing evidence to suggest that socioeconomic deprivation is a major determinant of where, when and how people die. [9] A key finding from the report, *Deprivation and death: variation in place and cause of death* showed that people from the most deprived quintile were, on average, 29% more likely to die in hospital than the least deprived quintile. [9] After mortality, deprivation is the most important factor influencing need of palliative care services. This section examines the impact deprivation in NI may have on palliative care need.

The NI Multiple Deprivation Index (NIMDI) 2010 provides a relative measure of deprivation [10]. NIMDI 2010 comprises of seven domains of deprivation which are combined to produce a single measure. A NIMDI measure is calculated for each geographical area, where 1 is most deprived and 890 is least deprived for Super Output Area (SOA) or 26 for the former Local Government Districts (LGD).

The map below shows each LGD according to deprivation. NIMDI measures have been presented in quintiles, with LGDs in the 20% most deprived populations in dark blue (1-5) and LGDs with the 20% least deprived populations in white (23-26); the sold lines represent the LCG boundaries.

Figure 9: Map of NI showing deprivation quintiles according to LGD



Data source; NIMDI, NISRA, 2010

Belfast and Western LCGs include LGDs which have over 40% of their population living in the 20% most deprived LGDs (Belfast LGD, Derry LGD and Strabane LGD). Southern LCG also includes two LGDs within the 20% most deprived LGDs in NI (Craigavon LGD and Newry and Mourne LGD). In contrast, Northern and South Eastern LCGs each include two LGDs living in 20% of least deprived areas.

4.3.2 Elderly people living alone

In NI, there are approximately 80,000 households with an individual over 65 years of age living on their own, with approximately one third of the over 65 year old population living alone (table 8).

Table 8: Number of elderly people living alone

LCG of residence	Size of population > 65 yrs	No. households where the sole occupancy is an individual > 65 yrs	Proportion of population > 65 yrs that lives alone
NI	266,255	78,101	29%

Data Source: Census 2011

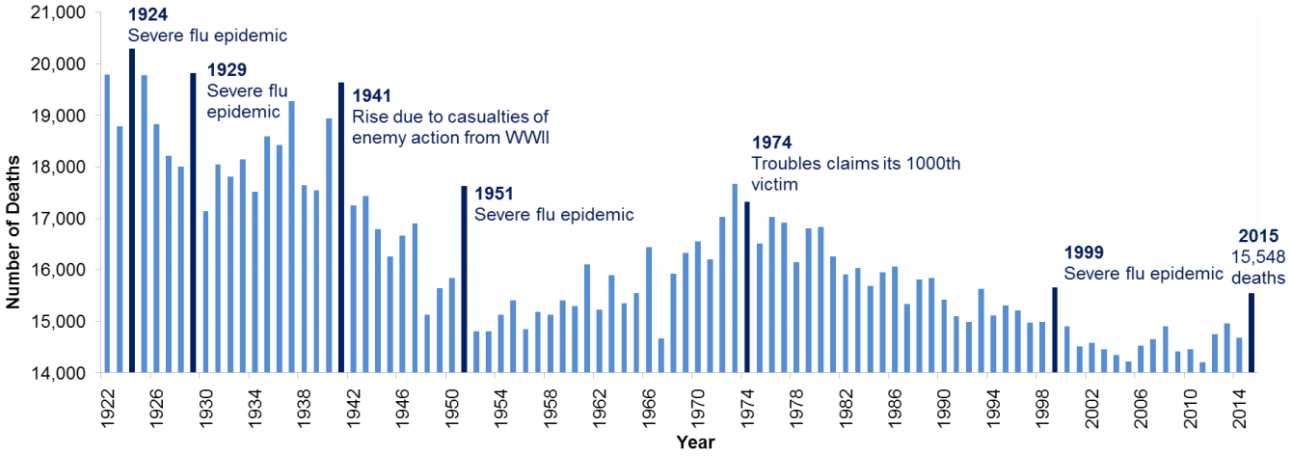
4.4 MORTALITY

4.4.1 Trends in mortality

Annual incidence of deaths is the **single most important indicator of palliative care need in a population** since most palliative care needs arise in the last year of life. While standardised mortality rates are useful in examining trends in diseases over time, or comparing between areas, the actual numbers of deaths and the crude mortality rates are the more relevant here in order to determine the level of palliative care needed in NI.

The profile of deaths in NI has changed noticeably over time as shown in **Figure 10** below. The number of deaths peaked in 1924 when over 20,000 deaths were registered that year with the severe flu epidemic being a major driver in the high number of deaths. Since then, there has been a general decrease in the number of deaths registered. This decrease has not been constant and some years have seen an increase in total number of deaths in comparison to previous years. During this time period, there has also been a substantial growth in the total population.

Figure 10: Number of deaths registered (1922 to 2015) – non-zero y-axis



Source: Registrar General Annual Report 2015, NI Statistics and Research Agency

Between 2000 and 2014, the number of deaths recorded have remained relatively stable, ranging between 14,204 (2011) and 14,968 (2013). However 2015 has seen a growth in the number of deaths registered (15,548), representing an increase of 6% on 2014 (14,678). This increase has been driven by various different causes of deaths however deaths due to diseases of the respiratory system and mental and behavioural disorders, such as dementia, had the greatest increase in terms of absolute numbers.

Table 9 provides an overview of the average number of deaths between 2011 and 2015 in NI and each LCG, alongside the actual numbers of deaths. As

shown in the table, the Northern LCG had the largest absolute number of deaths, followed by Belfast. When taking population size into account, Belfast LCG (943 per 100,000) and South Eastern LCG (835 per 100,000) have higher death rates than the NI average. In contrast, Southern LCG (716 per 100,000), Western LCG (740 per 100,000) and Northern LCG (807 per 100,000) are all lower than the NI average.

Table 9: Five year average of incidence of deaths (2011-15)

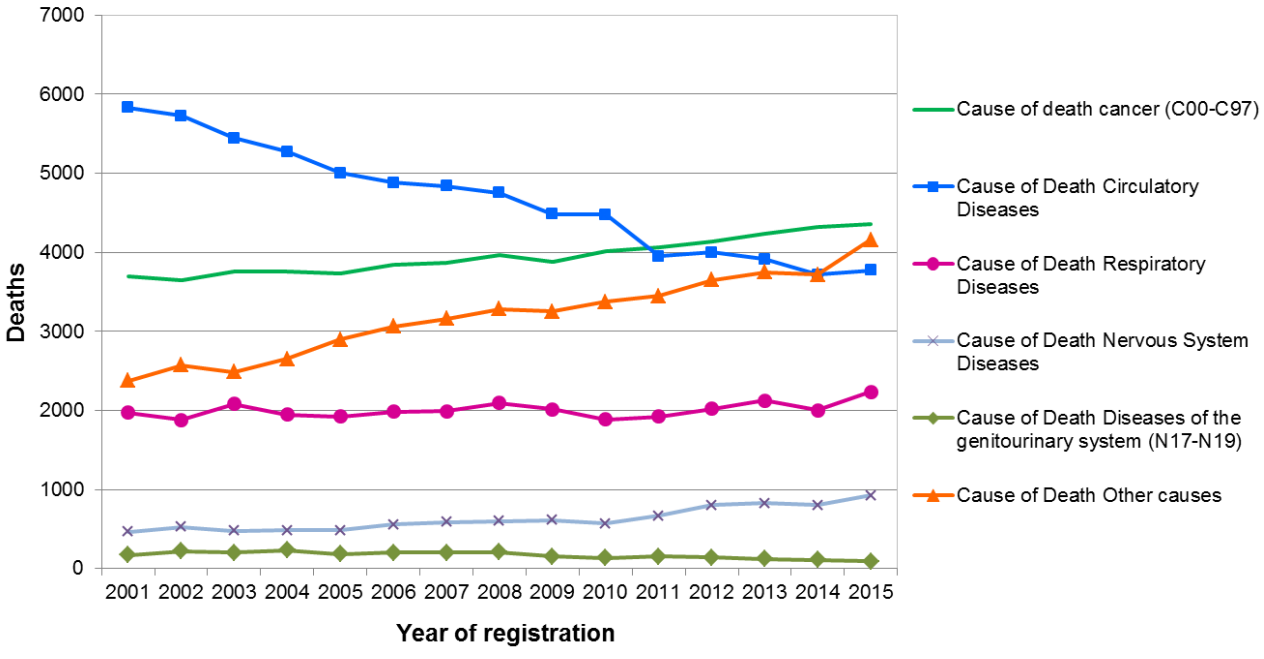
LCG	N	All deaths per 100,000 of population**	Average number per year
Belfast	16,517	943	3,303
Northern	18,841	807	3,768
South Eastern	14,656	835	2,931
Southern	13,109	716	2,622
Western	11,004	740	2,201
NI	74,154	810	14,831

*Note: 27 deaths recorded in this period were not assigned an LCG
**Note: Rates are per 100,000 of the population and are not age standardised
Data source: Population: NISRA (figures represent 2015 mid-year estimates)
Annual incidence of deaths: General Register Office, 2015

4.4.2 Causes of deaths

Figure 11 shows the trend in deaths by major cause in NI from 2001-2015 (see Table A in Appendix for numbers per year).

Figure 11: Deaths by major causes (2001-2015)



Data source: Health Intelligence analysis of General Register Office data

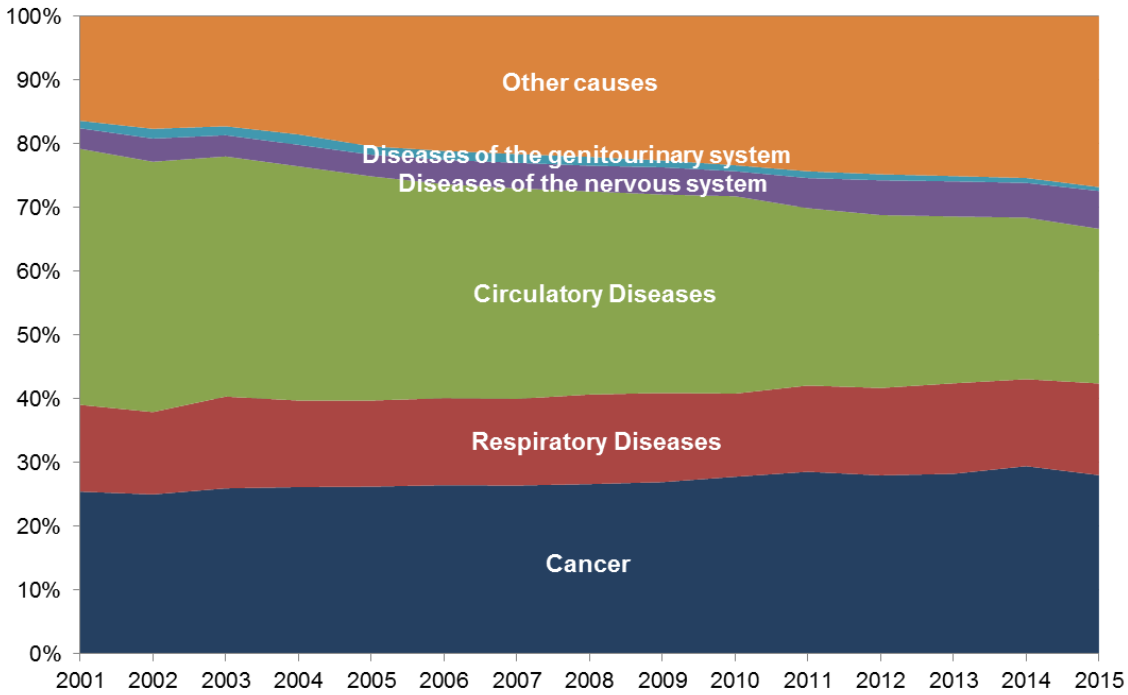
Between 2001 and 2015 there has been a gradual increase in the number of deaths due to cancer, peaking in 2015 with 4,361 deaths. There has also been an increase in the number of deaths caused by nervous system diseases. Indeed, the number of deaths almost doubled in 2015 (923) compared to 2001 (467). This has been primarily driven by an increase in deaths due to Alzheimer's disease.

Whilst deaths due to respiratory diseases and diseases of the genitourinary system (N17-N19) have remained relatively stable with slight increases, there has been a gradual decrease in the number of deaths due to circulatory diseases since 2001, with the sharpest decrease of 12% occurring between 2010 (4,476) and 2011 (3,951). This decrease has been primarily driven by a decline in the number of strokes, not specified as haemorrhage or infarction which have more than halved between 2001 (915) and 2015 (441). There has also been a reduction of almost 50% in deaths due to acute myocardial infarction, unspecified between 2001 (2,254) and 2015 (1,175).

There has also been an increase in the number of deaths due to other causes between 2001 and 2015. Whilst there has been an increase in various different causes of deaths, the largest increase has been seen in deaths due to mental and behavioural disorders which have more than tripled between 2001 (381) and 2015 (1,330). This increase has been primarily driven by a growth in deaths due to unspecified dementia which have increased from 282 in 2001 to 991 in 2015.

Figure 12 shows the percentages represented by each major cause over time (see Appendix 4, Table A). Deaths due to cancer have continuously accounted for around a quarter of all deaths between 2001 and 2015. Deaths due to respiratory diseases or diseases of the nervous system have remained relatively stable in terms of proportion of all deaths. In contrast, deaths due to circulatory diseases have seen a decrease in absolute numbers and also in proportion to all deaths. Deaths due to other causes have also seen an increase in their proportion in relation to all deaths. As noted earlier, this has primarily been driven by a growth in deaths due to mental and behavioural disorders such as dementia.

Figure 12: Percentage of deaths by major causes (2001-2015)



Data source: Health Intelligence analysis of General Register Office data

Table 10 outlines the average incidence of major causes of deaths for each LCG between 2011 and 2015, and the actual number. In this period, deaths due to cancer accounted for 28% of all deaths, with Belfast (271 per 100,000) and South Eastern (235 per 100,000) LCGs higher than the NI rate.

Table 10: Major causes of death for LCG of residence 2011-2015 – Total Deaths & Five year average

LCG		Belfast LCG	Northern LCG	South Eastern LCG	Southern LCG	Western LCG	N.I.
Cancer deaths	**No.**	4746	5279	4134	3773	3172	**21107**
	Rate*	271	226	235	206	213	**230**
	Average	949	1056	827	755	634	**4221**
Respiratory diseases	**No.**	2427	2635	1913	1611	1722	**10310**
	Rate*	139	113	109	88	116	**113**
	Average	485	527	383	322	344	**2062**
Circulatory diseases	**No.**	4054	5135	3784	3591	2793	**19361**
	Rate*	231	220	216	196	188	**211**
	Average	811	1027	757	718	559	**3872**
Diseases of the nervous system	**No.**	940	1020	985	561	520	**4026**
	Rate	54	44	56	31	35	**44**
	Average	188	204	197	112	104	**805**
Diseases of the genitourinary system (N17-N19)	**No.**	123	185	98	119	98	**624**
	Rate*	7	8	6	7	7	**7**
	Average	25	37	20	24	20	**125**
Other causes	**No.**	4227	4587	3742	3454	2699	**18726**
	Rate*	241	196	213	189	182	**204**
	Average	845	917	748	691	540	**3745**

Data source: Health Intelligence analysis of General Register Office data;
*Annualised rate per 100,000 (not age adjusted)
Note: Not all deaths were assigned an LCG (3 cancer deaths; 2 respiratory deaths; 4 circulatory deaths; 1 genitourary system death; 17 other causes)

As set out in **Table 11,** when excluding cancer from all deaths, there were just over 53,000 non cancer deaths in NI between 2011 and 2015. The highest death rates were seen in Belfast (672 per 100,000), South Eastern (599) and Northern LCGs (581) respectively.

Table 11: Incidence of non-cancer deaths for NI – Five year average (2011-2015)

LCG	N	Rate per 100,000	Average
Belfast	11,771	672	2354
Northern	13,562	581	2712
South Eastern	10,522	599	2104
Southern	9,336	510	1867
Western	7,832	527	1566
N.I.	**53,047**	**579**	**10,609**

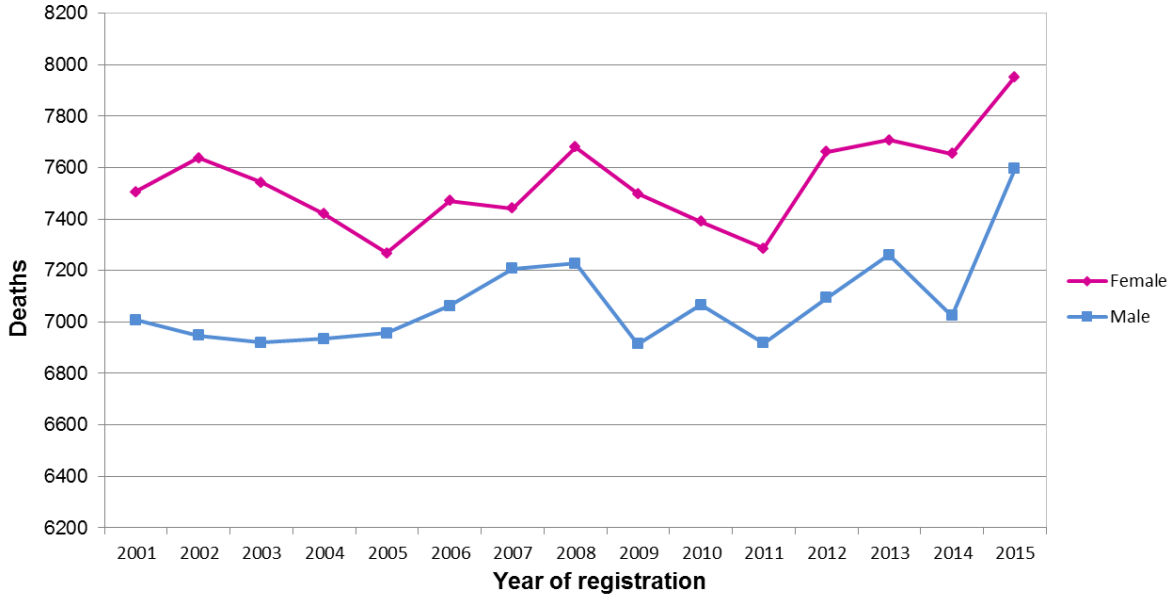
Data source: Health Intelligence analysis of General Register Office data;
Annualised rate per 100,000 (not age adjusted)
(Note 24 deaths recorded in this period were not assigned an LCG

Deaths due to circulatory diseases account for 36% of non-cancer deaths and deaths due to respiratory diseases account for 19%. A further 35% are caused by other causes. Alzheimer's disease (ICD10 Codes G30) and other dementias (ICD10 Codes F00-F07) are coded within "Other Causes" and they represent approximately 14% of non-cancer deaths (7,267/53,047) in NI between 2011 and 2015. This number has increased substantially in recent years which may reflect better awareness of these conditions.

4.4.3 Deaths by gender

Between 2001 and 2015, the number of female deaths has consistently outnumbered that of males (see Table B in Appendix for numbers per year). The number of deaths recorded peaked in 2015 for both females (7,953) and males (7,595), giving a sex ratio of 105 female deaths for every 100 male deaths (see **Figure 13**). In 2015, the average age of death for males was 73 and 79 for females.

Figure 13: Trend in number of deaths by gender (2001 – 2015)



Data source: Health Intelligence analysis of General Register Office data

Whilst this increase has been driven by a rise in various different causes of death, the largest increase in female deaths involved deaths due to diseases of the respiratory system, mental and behavioural disorders, such as dementia and diseases of the nervous system, such as Alzheimer's disease. The largest increase in male deaths in 2015 also involved a growth in the number of deaths due to diseases of the respiratory system and mental and behavioural disorders, such as dementia; alongside deaths due to neoplasms.

Table 12 provides an overview of the average incidence of deaths by gender between 2011 and 2015 according to LCG. The Northern LCG had the largest absolute number of deaths for both males and females. When taking population size into account, Belfast LCG (926 male deaths per 100,000 and 959 female deaths per 100,000), South Eastern LCG (810 male deaths per 100,000 and 859 females deaths per 100,000) and Northern LCG (804 male deaths per 100,000 and 809 female deaths per 100,000) have higher death rates than the NI average.

Table 12: Five year average incidence of deaths by gender (2011-2015)

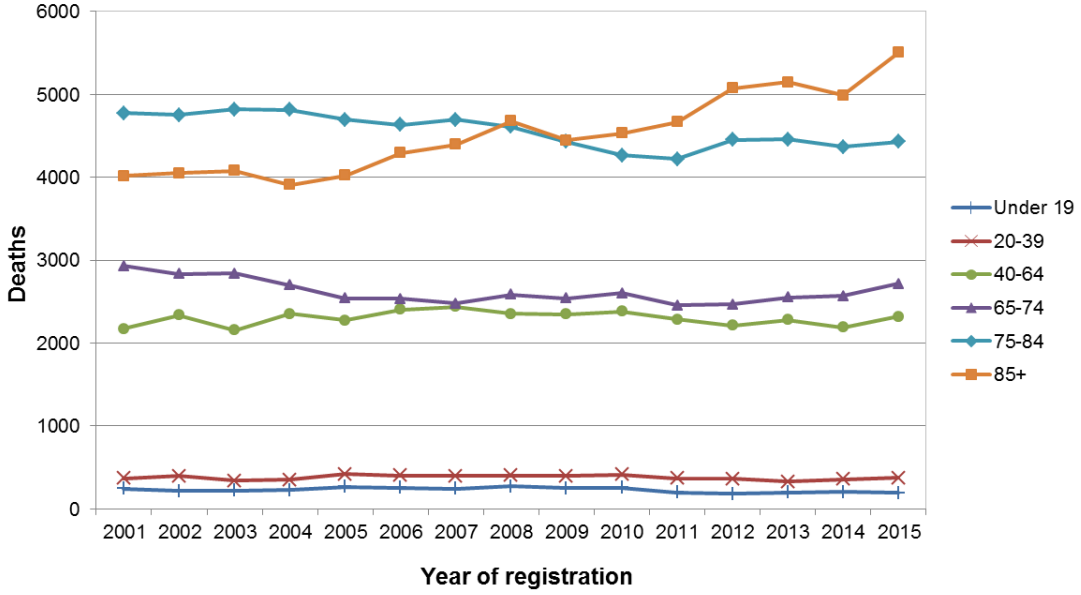
LCG of residence	Male deaths			Female deaths		
	N	Deaths per 100,000	Average per year	N	Deaths per 100,000	Average per year
Belfast LCG	7,826	926	1,565	8,691	959	1,738
Northern LCG	9,214	804	1,843	9,627	809	1,925
South Eastern LCG	6,927	810	1,385	7,729	859	1,546
Southern LCG	6,388	702	1,278	6,721	730	1,344
Western LCG	5,515	748	1,103	5,489	733	1,098
N.I.	35,892	799	7,178	38,262	820	7,652

*Note: 22 male deaths and 5 female deaths did not have an LCG assigned; Annualised rate per 100,000 (not age adjusted)
Data source: Health Intelligence analysis of General Register Office data

4.4.4 Deaths by age

Figure 14 outlines the number of deaths for all age groups between 2001 and 2015 (see Table C in Appendix for numbers per year). Whilst there has been slight variation in the number of deaths recorded for all age groups, deaths of those aged 85+ have seen the highest increase, peaking at 5,506 in 2015. This represents an increase of 37% in comparison to 2001 (4,018). This is consistent with an increasing population aged over 85+.

Figure 14: Trend in number of deaths by age group (2001 – 2015)



Data source: Health Intelligence analysis of General Register Office data

In 2015, 81% (12,655) of all deaths were in those over 65 years. **Table 13** provides an overview of the number of deaths by major causes in those aged

over 65 in 2015. Eighty-five plus year olds accounted for 43% of deaths in those aged over 65 years, with the highest number of deaths in this age group being caused by other causes. Specifically, 673 deaths in 85+ year olds were due to unspecified dementia (F03) in 2015. Deaths from cancer accounted for the most deaths in both 65-74 year olds and 75-84 year olds.

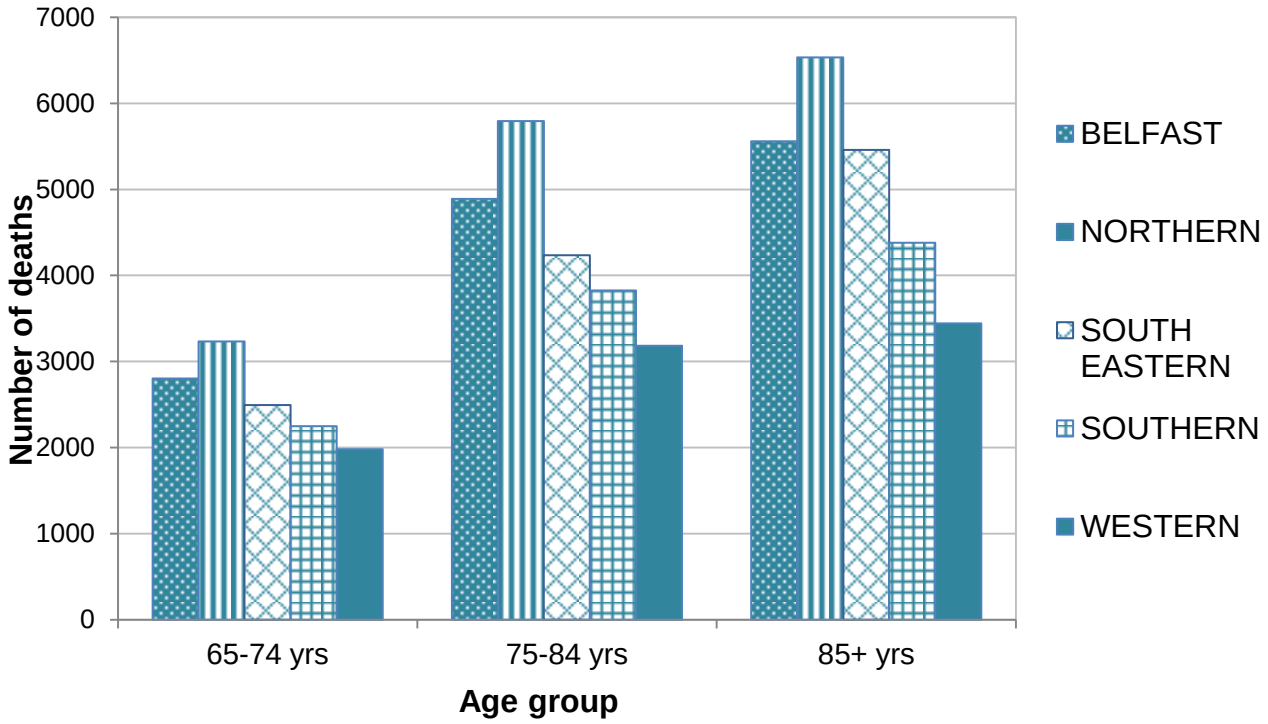
Table 13: Major causes of deaths by older age groups (2015)

Cause of death	65-74 years		75-84 years		85+ years		All deaths over 65	% of over 65 deaths by cause of death
	N	% of all deaths over 65	N	% of all deaths over 65	N	% of all deaths over 65		
Diseases of the circulatory system	611	5%	1163	9%	1523	12%	3,297	27%
Deaths from Cancer (C00-C97)	1182	9%	1348	11%	831	7%	3,361	26%
Diseases of the genitourinary system (N17-N19)	8	0.1%	33	0.3%	50	0.4%	91	16%
Diseases of the nervous system	119	1%	262	2%	413	3%	794	6%
Diseases of the respiratory system	365	3%	682	5%	1025	8%	2,072	1%
Other causes	434	3%	942	7%	1664	13%	3,040	24%
Total	**2,719**	**21%**	**4,430**	**35%**	**5,506**	**43%**	**12,655**	**100%**

Data source: Health Intelligence analysis of General Register Office data

Figure 15 shows the number of deaths in each LCG by older age groups between 2011 and 2015 (see Table D in Appendix for numbers per LCG). Northern LCG has the largest number of deaths in each year group. The number of deaths also increases with advancing age in each LCG.

Figure 15: Deaths by age group for each LCG of residence (2011-2015)



Data source: Health Intelligence analysis of General Register Office data
Note 11 deaths recorded were not assigned an LCG

4.4.5 Deaths by deprivation

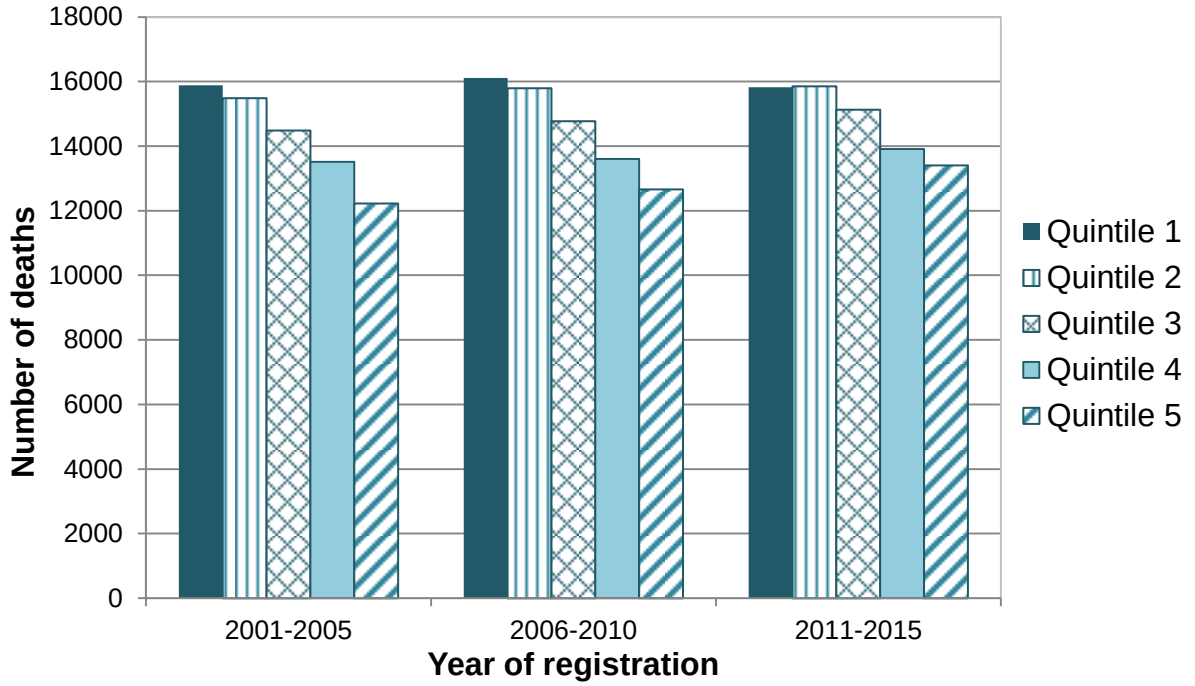
There is growing evidence that socioeconomic deprivation is a major determinant of where, when and how people die. A key finding from the report, *Deprivation and death: variation in place and cause of death* showed that people from the most deprived quintile were, on average, 29% more likely to die in hospital than the least deprived quintile.[1]

The NI Multiple Deprivation Measure (NIMDM) comprises seven domains of deprivation, each developed to measure a distinct form or type of deprivation; income, employment, health, education, proximity to services, living environment and crime.

As shown in **Figure 16**, the number of deaths have consistently been highest in most deprived areas, with MDM Quintile 1 registering the most deaths during the periods 2001-2005 and 2006-2010 (see Table E in Appendix for numbers per MDM Quintile). In the period 2011-2015, MDM Quintile 2 had slightly more deaths than MDM Quintile 1 (15,858 and 15,828 respectively).

[1] National End of Life Care Intelligence Network. Deprivation and death: variation in place and cause of death. Bristol: National End of Life Care Intelligence Network, 2012.

Figure 16: Deaths by MDM Quintile (2001-2015)



Data source: Health Intelligence analysis of General Register Office data
*Note: MDM Quintile was unknown for 27 deaths in this period

The higher number of deaths in more deprived areas is consistent with the lower levels of life expectancy and the higher rates of premature deaths in the most deprived areas (age standardised rates). Those who live in most deprived areas are twice as likely to die prematurely compared to those who live in the least deprived areas.[2]

4.4.6 Place of death

'*Living Matters, Dying Matters*' recommends the need for provision of palliative care services that address people's expectations of choice in how and where their care is delivered and suggests that people with an advanced progressive condition would prefer to die at home.[3]

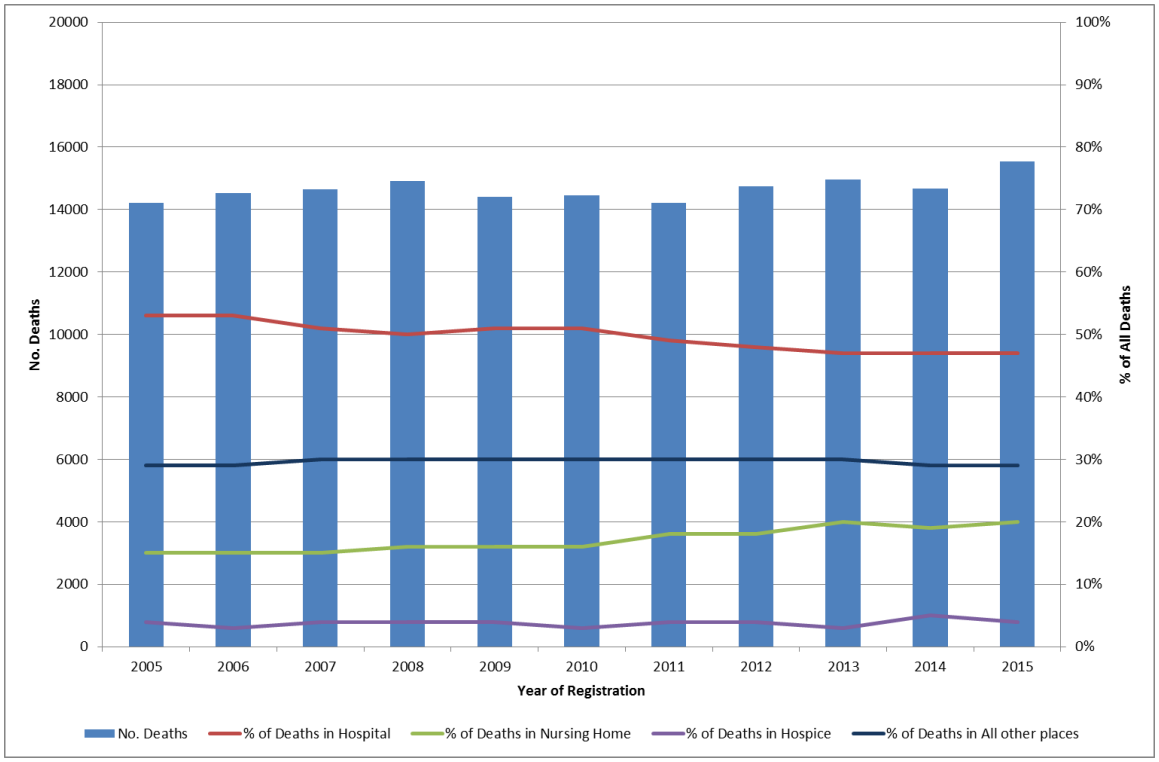
Figure 17 shows the actual trend in place of death in NI from 2005-2015 (see Table F in Appendix for numbers per year). The Macmillan Unit in Antrim Area Hospital is a specialist palliative care unit based within the hospital. Deaths in this unit are coded under hospital in the General Register Office data. For the purpose of this report, an adjustment has been applied to account for deaths in the Macmillan Unit and these deaths are presented in the hospice data in the data analysed. This means that the numbers will not correspond with the numbers published by NISRA. 'All other places' refers to

[2] Department of Health, *Health Inequalities Regional Report.* Belfast: DoH, 2016.
[3]Department of Health, Social Services and Public Safety. *Living Matters, Dying Matters*. Belfast: DHSSPS, 2009.

any place other than a hospital, nursing home or hospice and is used as a proxy for dying at home.

Whilst there has been slight variation in the number of deaths recorded for all places of deaths, the largest numbers of deaths have consistently occurred in hospitals each year. There was however a gradual decrease in the number of deaths in hospitals between 2006 and 2011. There has also been a growth in the number of deaths in nursing homes and all other places between 2001 and 2015, peaking in 2015 (3,074 nursing home deaths and 4,511 all other place deaths).

Figure 17: Trends in place of death in NI (2005-2015)



Data source: Health Intelligence analysis of General Register Office data

Note: The Macmillan Unit in Antrim Area Hospital is a specialist palliative care unit based within the hospital. Deaths in this unit are coded under hospital in the General Register Office data. An adjustment has been applied to account for deaths in the Macmillan Unit and these deaths are presented in the hospice data in the data analysed. This means that the numbers will not correspond with the numbers published by NISRA.

There was however an increase of 7% in the number of hospital deaths in 2015 (7,334) compared to 2014 (6,884). However, whilst the number has increased, the proportion in relation to all deaths is consistent with previous years.

Figure 17 shows the percentages represented by each place of death over time (see Appendix 4, Table F). There has been a decrease in the proportion of hospital deaths over time from 53% in 2005 to 47% in 2013 – 2015. There

has been a corresponding increase in the proportion of nursing home deaths from 15% in 2005 to 20% of all deaths in 2015. The proportion of hospice deaths (ranging from 3-5%) and all other place deaths (ranging from 29%-30%) have remained relatively consistent during this period.

In 2015, 47% of all deaths occurred in a hospital, 29% in all other places, 20% in a nursing home and 4% in a hospice.

Table 14 provides an overview of the number of deaths by place of death and the percentage of deaths by major causes in each setting between 2011 and 2015. Cancer deaths accounted for 93% of all hospice deaths between 2011 and 2015.

Table 14: Place of death by major causes – Total & Five year average (2011-2015)

Cause of Death	Hospital			Nursing Home			Hospice			All Other Places		
	N	% of hospital deaths	Average per Year	N	% of hospital deaths	Average per Year	N	% of hospital deaths	Average per Year	N	% of hospital deaths	Average per Year
Disease of Circulatory System	9,415	27%	1,883	3,265	23%	653	34	1%	7	6,647	30%	1,329
Cancer (C00-C97)	8,207	23%	1,641	2,246	16%	449	2,763	93%	553	7,891	36%	1,578
Disease of the Nervous System	1,362	4%	272	1,925	14%	385	59	2%	12	680	3%	136
Disease of the Respiratory System	6,363	18%	1,273	2,034	14%	407	56	2%	11	1,857	8%	371
Disease of the Genitourinary System (N17-N19)	333	1%	67	170	1%	34	5	0.2%	1	116	1%	23
Other Causes	9,513	27%	1,903	4,633	32%	893	59	2%	12	4,691	21%	938
Total	**35,193**	**100%**	**7,039**	**14,103**	**100%**	**2,821**	**2,976**	**100%**	**595**	**21,882**	**100%**	**4,376**

Data source: Health Intelligence analysis of General Register Office data
Note: The Macmillan Unit in Antrim Area Hospital is a specialist palliative care unit based within the hospital. Deaths in this unit are coded under hospital in the General Register Office data. An adjustment has been applied to account for deaths in the Macmillan Unit and these deaths are presented in the hospice data in the data analysed. This means that the numbers will not correspond with the numbers published by NISRA.

Table 15 provides an overview of the major causes of deaths by place of death between 2011 and 2015. Hospitals accounted for most deaths due to diseases of the circulatory system (49%), deaths from cancer (39%), deaths from diseases of the respiratory system (62%) and deaths due to other causes (47%). Most deaths due to diseases of the nervous system (48%) occurred in nursing homes.

Table 15: Major causes of deaths by place of death – Total deaths (2011 – 2015)

Cause of death	Hospital	Nursing home	Hospice	All other places	Total
Diseases of the circulatory system	9,415 (49%)	3,265 (17%)	34 (0.2%)	6,647 (34%)	**19,361 (100%)**
Deaths from Cancer (C00-C97)	8,207 (39%)	2,246 (11%)	2,763 (13%)	7,891 (37%)	**21,107 (100%)**
Diseases of the nervous system	1,362 (34%)	1,925 (48%)	59 (1%)	680 (17%)	**4,026 (100%)**
Diseases of the respiratory system	6,363 (62%)	2,034 (20%)	56 (1%)	1,857 (18%)	**10,310 (100%)**
Diseases of the genitourinary system (N17-N19)	333 (53%)	170 (27%)	5 (1%)	116 (19%)	**624 (100%)**
Other causes	9,513 (47%)	4,463 (19%)	59 (4%)	4,691 (30%)	**18,726 (100%)**
Total	**35,193**	**14,103**	**2,976**	**21,882**	**74,154**

Data source: Health Intelligence analysis of General Register Office data

Note: The Macmillan Unit in Antrim Area Hospital is a specialist palliative care unit based within the hospital. Deaths in this unit are coded under hospital in the General Register Office data. An adjustment has been applied to account for deaths in the Macmillan Unit and these deaths are presented in the hospice data in the data analysed. This means that the numbers will not correspond with the numbers published by NISRA.

Table 16 outlines the average number of deaths in NI and each LCG according to place of death for the period 2011-2015. The figures shown are average figures calculated for the five year period, 2011-2015, in order to smooth out year to year variability.

A higher proportion of people die in hospital in Belfast and Western LCGs (51% and 48% respectively) than the NI average. South Eastern LCG has the largest proportion of people dying in a nursing home (24%). Northern LCG has a higher proportion of people dying in a hospice than the NI average (5%). Southern and Western LCG also have the highest proportion of people dying at home compared with the NI average (both 33%).

Table 16: Average number of deaths from any cause according to place of death – Five year average (NI and LCG, 2011-2015)

LCG of residence	Hospital	Nursing home	Hospice	All other places	Total
Belfast	1,670 (51%)	585 (18%)	142 (4%)	907 (27%)	**3,303 (100%)**
Northern**	1,790 (47%)	721 (19%)	181 (5%)	1077 (29%)	**3,768 (100%)**
South Eastern	1,349 (46%)	698 (24%)	84 (3%)	801 (27%)	**2,931 (100%)**
Southern	1,171 (45%)	474 (18%)	117 (4%)	860 (33%)	**2,622 (100%)**
Western	1,058 (48%)	343 (16%)	72 (3%)	728 (33%)	**2,201 (100%)**
N.I.	**7,038 (47%)**	**2,821 (19%)**	**595 (4%)**	**4,376 (30%)**	**14,831 (100%)**

Data source: Health Intelligence analysis of General Register Office data

*Note: 27 deaths recorded in this period were not assigned an LCG

**Note: The Macmillan Unit in Antrim Area Hospital is a specialist palliative care unit based within the hospital. Deaths in this unit are coded under hospital in the General Register Office data. An adjustment has been applied to account for deaths in the Macmillan Unit and these deaths are presented in the hospice data in the data analysed. This means that the numbers will not correspond with the numbers published by NISRA.

Table 17: Average number of cancer deaths (C00-C97) according to place of death – Five year average (NI and LCG, 2011-2015)

LCG of residence	Hospital	Nursing home	Hospice	All other places	Total
Belfast	399 (42%)	107 (11%)	131 (14%)	312 (33%)	**949 (100%)**
Northern	416 (39%)	106 (10%)	163 (15%)	371 (35%)	**1,056 (100%)**
South Eastern	322 (39%)	111 (13%)	81 (10%)	312 (38%)	**827 (100%)**
Southern	252 (33%)	75 (10%)	112 (15%)	315 (42%)	**755 (100%)**
Western	252 (40%)	50 (8%)	65 (10%)	268 (42%)	**634 (100%)**
N.I.	**1,641 (39%)**	**449 (11%)**	**553 (13%)**	**1578 (37%)**	**4221 (100%)**

Data source: Health Intelligence analysis of General Register Office data

*Note: 3 cancer deaths recorded in this period were not assigned an LCG

**Note: The Macmillan Unit in Antrim Area Hospital is a specialist palliative care unit based within the hospital. Deaths in this unit are coded under hospital in the General Register Office data. An adjustment has been applied to account for deaths in the Macmillan Unit and these deaths are presented in the hospice data in the data analysed. This means that the numbers will not correspond with the numbers published by NISRA.

Table 17 illustrates place of death figures for cancer deaths only, with average figures calculated for the five year period 2011-2015. The largest proportion of cancer deaths also occurs in hospital (39%), although this is lower than all-cause mortality. This is followed by all other places (37%), hospice settings (13%) and nursing homes (11%).

Belfast LCG and Western LCG have the highest proportion and number of cancer deaths dying in hospital (42% and 40% respectively). The number of cancer deaths in nursing homes is highest for the South Eastern LCG (13%). Northern and Southern LCGs have the highest proportion of cancer deaths dying in a hospice (both 15%).

The proportion of people dying at home with cancer is larger than for deaths from any cause. The largest proportion of people dying at home is seen in the Southern and Western LCG of residence (both 42%).

Appendix 4 provides a range of other tables covering death by major causes, gender, age group, residence and deprivation.

4.5 DEATHS IN ACUTE HOSPITALS

4.5.1 Acute hospital deaths

Mortality figures from the Register General Office (RGO) (highlighted in section 4.4.6) show that approximately half of all deaths in NI occur in a hospital setting. This section describes the number and type of deaths occurring in *acute* hospitals, in an aim to help the Palliative Care In Partnership Programme to develop palliative care services that address more appropriately patient's choice. *For the purpose of the figures quoted below the Macmillan unit in Antrim hospital is excluded.*

Data has been obtained only on acute hospital deaths using the Patient Admission System (PAS) in contrast with RGO data, which includes all hospitals in NI. Data in this section only includes **adults over 19 years (i.e. 20 years and over)** and has excluded some deaths, so absolute figures may be less in PAS than RGO data.

Table 18 illustrates the number of acute hospital deaths in NI and LCGs. Rates per 100,000 of the population over 19 years of age have also been calculated.

Table 18: Deaths in acute hospitals for NI and LCG of residence, 2015

LCG of residence	Number of Acute Hospital deaths	2015 Mid-Yr population estimates	Rate per 100,000 population
Belfast	1,628	267,113	609
Northern	1,668	350,423	476
South Eastern	1,332	265,230	502
Southern	1,060	268,734	394
Western	946	217,490	435
NI	**6,634**	**1,368,990**	**487**

Data Source: PAS, January 2017
Totals exclude those with no LCG of residence recorded or from outside NI (n=31)

There were approximately 6,600 acute hospital deaths in individuals over 19 years. Northern LCG had the highest number of deaths, followed by Belfast and South Eastern LCGs, with the fewest number of seen in Western and Southern LCG in line with their overall population numbers.

The rate of acute hospital deaths per 100,000 of the over 19 year population was highest in Belfast LCG (609) with South Eastern LCG (502) rate also higher than the NI average (487). Rates in Northern, Southern and Western LCGs were lower than the NI average (476, 394 and 435 respectively).

4.5.2 Individuals over 85 years

Approximately one third of acute hospital deaths occur in those over 85 years of age (2,223) (table 19). The largest numbers are in Northern, Belfast and South Eastern LCGs (564, 550 and 479, respectively). When taking population size into account, acute hospital death rates in those over 85 years are highest in Belfast, South Eastern and Northern LCGs (63.5, 60.0 and 59.2 respectively).

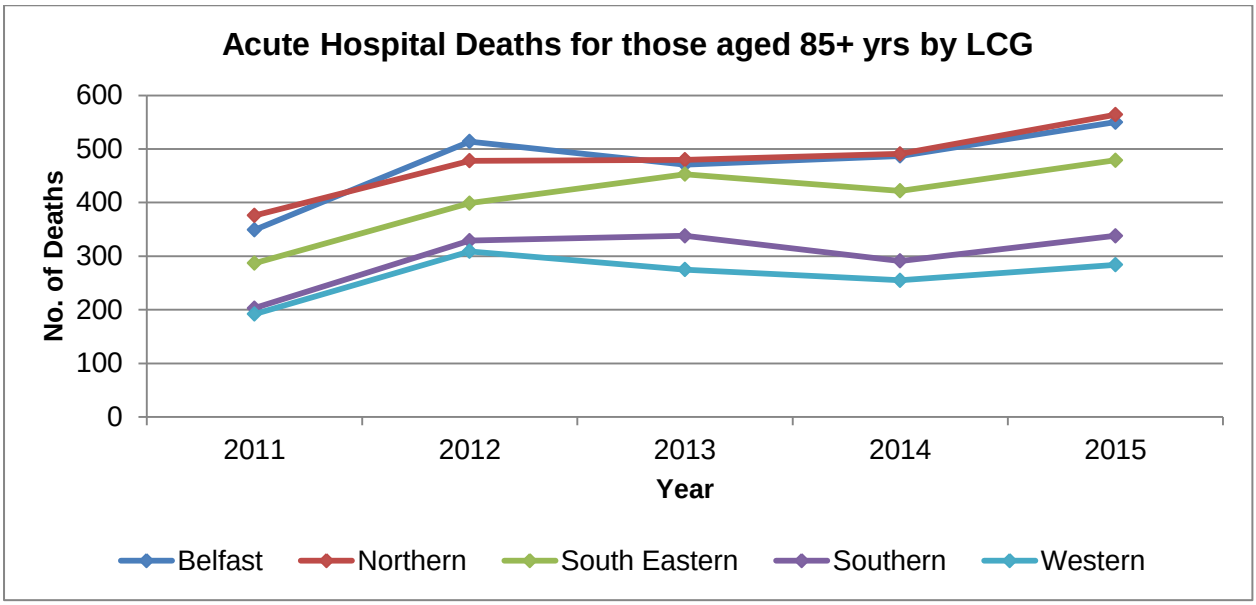
Table 19: Deaths in acute hospitals for NI and LCG (2015)

LCG of residence	Number of Acute Hospital deaths - 85+ yrs	2015 Mid-Yr population estimates (85+yrs)	Rate per 100,000 85+ yrs population	Acute Hospital deaths in 85+ yrs as % of all deaths
Belfast	550	7,754	7,093	33.8%
Northern	564	9,313	6,056	33.8%
South Eastern	479	7,466	6,416	36.0%
Southern	338	6,032	5,603	31.9%
Western	284	4,895	5,802	30.0%
NI	**2,215**	**35,460**	**6,269**	**33.4%**

Data Source: PAS, January 2017
Totals excludes those with no LCG of residence recorded or from outside NI

Acute hospital deaths in over 85 years have increased by 58% from 1,411 in 2011 to 2,223 in 2015. The biggest proportional increase, between 2011 and 2015, has been in Southern LCG residents with 70%, Western LCGs residents rising by 48%. This is expected as the 85+ population continues to grow. Figure 18 shows the rise in these numbers since 2011

Figure 18: Trend of acute hospital deaths for those over 85 years by LCG (2011-2015)



Data Source: PAS, January 2017

4.5.3 Elective and emergency admissions

Almost 90% of patients dying in an acute hospital are admitted as an emergency, which is broadly similar in all Trust's acute hospitals (Table 20).

Table 20: Hospital deaths in individuals admitted as an emergency, 2015

Hospitals in LCG	Deaths Over 19 yrs where Admission was an Emergency	Total Deaths Over 19	Deaths where Admissions was Emergency as % Total Deaths
Belfast	1,649	2,175	75.8%
Northern	1,143	1,218	93.8%
South Eastern	1,217	1,293	94.1%
Southern	926	1,040	89.0%
Western	884	939	94.1%
NI	**5,819**	**6,665**	**87.3%**

Data Source: PAS, January 2017
Total deaths include those with no LCG of residence

Table 21 shows the number and rate per 100,000 of all emergency admissions in NI according to age for those deaths 65 years and over.

Table 21: Emergency admissions in NI according to age (2015)

	2015 mid-yr population estimate	No. admitted as an emergency	Rate per 100,000 population
65-69	88,813	9,610	10,820
70-74	73,806	11,205	15,182
75-79	54,811	11,710	21,364
80-84	38,934	12,190	31,309
85+	35,460	16,357	46,128
Total	**291,824**	**61,072**	**20,928**

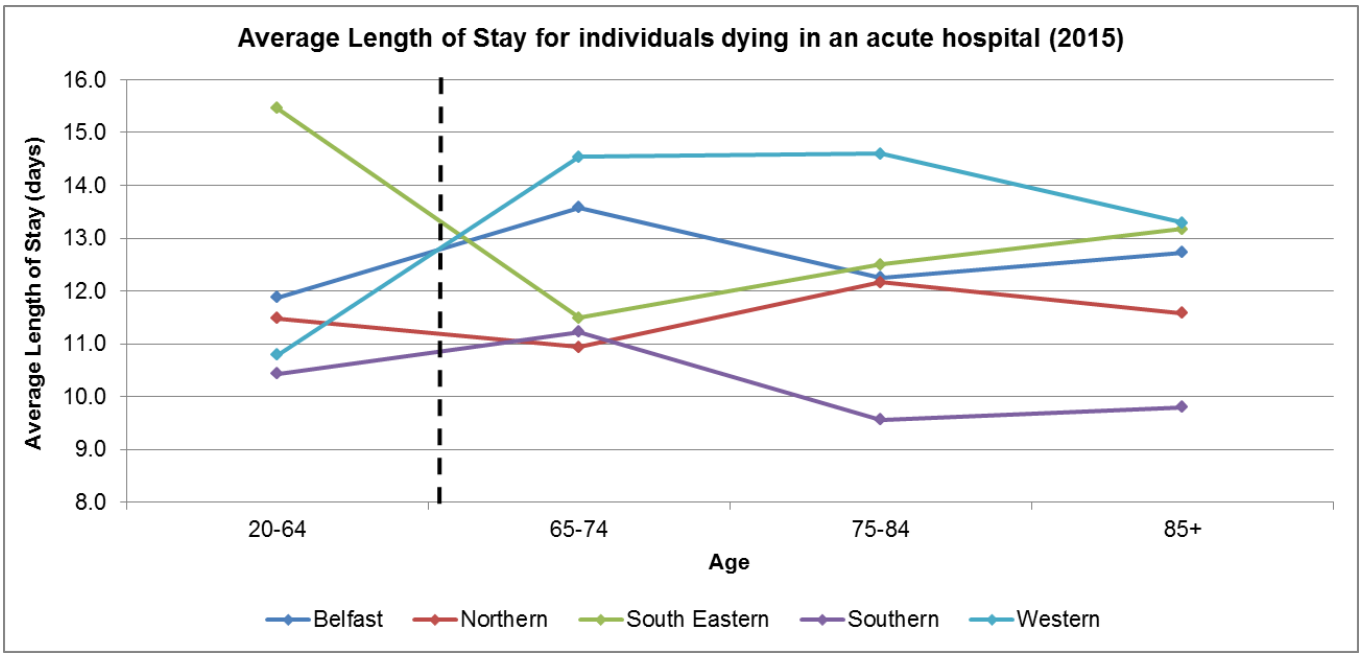
Data Source: PAS, January 2017

Approximately 21% of people over 65 years of age require an emergency admission every year (61,072). As individuals get older they are more likely to have an emergency admission, with approximately 45% of those over 85 years admitted as an emergency every year compared to approximately 11% aged 65- 69 years.

4.5.4 Average length of stay of individuals dying in an acute hospital

Figure 19 shows the average length of stay for individuals dying in an acute hospital by age group. The average length of stay for all ages over 19 years in 2015 for NI was 12.7 days. Individuals dying in Belfast, Western and South Eastern Trusts' acute hospitals have longer lengths of stay than the NI average (13.6, 13.6 and 13.0 days respectively).

Figure 19: Average length of stay for individuals dying in an acute hospital by age and hospitals within each



Individuals aged 65 and over dying in acute hospitals stay less time in hospital as they get older in Northern, South Eastern and Southern Trust hospitals. Average length of stay for individuals in Belfast and Western Trust acute hospitals gets longer as they age.

4.5.5 Occupied bed-days for acute hospital deaths

The number of occupied bed days is defined as the total number of days of stay for patients who were admitted overnight for an episode of care in the financial year (average length of stay multiplied by number of admissions). Bed-days can therefore be reduced either by reducing admissions resulting in death or reducing the average length of stay.

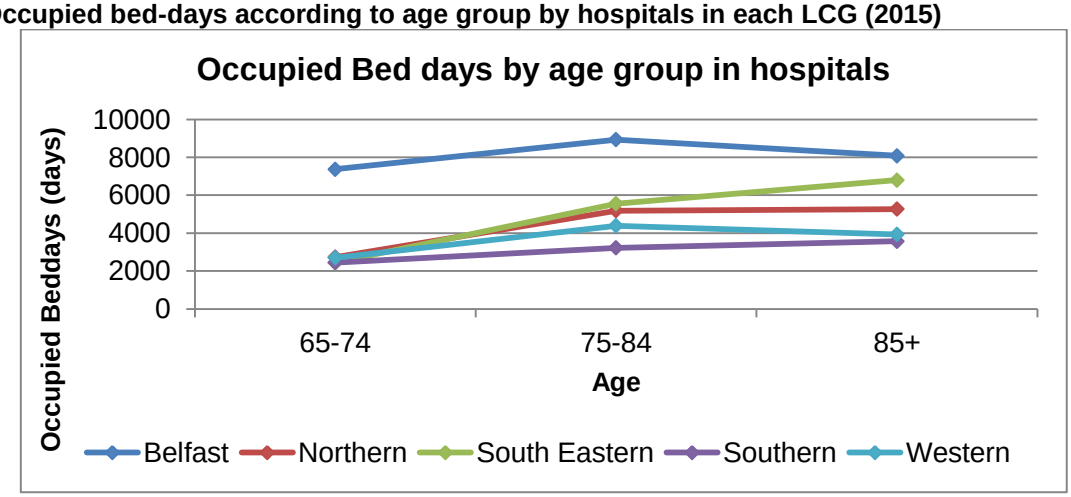
In 2015, acute hospital deaths for those aged 65 and over in NI contributed to 72,638 bed-days. Acute hospital deaths cause more bed-days with increasing age, (Table 22).

Table 22: Occupied bed-days for acute hospital deaths in NI according to age group (2015)

	65-74		75-84		85+		Total Bed days for 65+
	No. Bed days	% of Total Bed days for 65+	No. Bed days	% of Total Bed days for 65+	No. Bed days	% of Total Bed days for 65+	
NI	17,699	24%	27,279	38%	27,660	38%	**72,638**
Belfast	7,373	30%	8,932	37%	8,084	33%	**24,389**
Northern	2,736	21%	5,181	39%	5,272	40%	**13,189**
South Eastern	2,440	16%	5,553	38%	6,801	46%	**14,794**
Southern	2,449	26%	3,226	35%	3,571	39%	**9,246**
Western	2,701	25%	4,387	40%	3,932	36%	**11,020**

Figure 20 shows the number of occupied bed-days that contribute to acute hospital deaths, by age group and LCG. Acute hospital deaths in Belfast LCG have the longest number of bed-days for each age group.

Figure 20: Occupied bed-days according to age group by hospitals in each LCG (2015)



Similar to the regional figures, acute hospital deaths in each Trust cause more bed-days with increasing age, until 75 years of age. There is less difference in the number of bed-days in acute hospital deaths between individuals who are 75-85 years and over 85 years.

4.5.6 Individuals with primary diagnosis of cancer

In 2015, 14% (927) of acute hospital deaths had a primary diagnosis that was cancer related. Eight out of ten of these deaths (726/927; 78.3%) were admitted as an emergency.

Table 23 shows the number of occupied bed-days for patients who were admitted to an acute hospital with a primary diagnosis of cancer and subsequently died.

Table 23: Average length of stay and bed-days in acute hospital deaths with primary diagnosis of cancer, 2015

Trust	Cancer Deaths	Cancer Average Length of Stay	Cancer Bed-days	Non-Cancer* Bed-days	Other Causes Bed-days	Bed-days for all acute hospital deaths
Belfast	367	18	6,659 (23%)	10,096	12,802	29,557
Northern	131	13	1,735 (12%)	7,532	5,587	14,854
South Eastern	172	15	2,575 (15%)	8,291	5,907	16,773
Southern	142	13	1,854 (17%)	3,951	5,174	10,979
Western	115	16	1,812 (14%)	5,006	5,951	12,769
NI	**927**	**16**	**14,635** (17%)	**34,876**	**35,421**	**84,932**

Source: PAS January 2017

**includes Respiratory, Heart Disease, Liver, Renal, Neurodegenerative, Alzheimer's, Dementia and senility and Aids/HIV as per Murtagh (2014)*

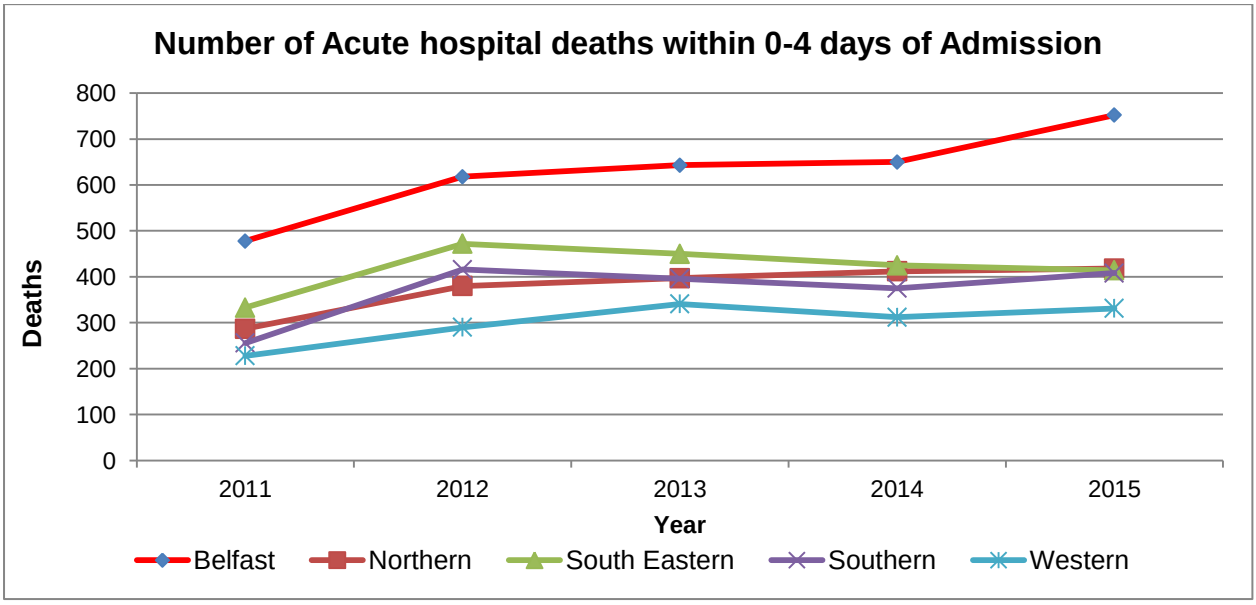
Less than one fifth (17%) of acute hospital death bed-days in NI are related to cancer. Belfast Trust has the highest number and proportion of acute hospital death bed-days due to cancer. This is due to both longer lengths of stay for cancer and more admissions due to cancer. The fact that the Regional Cancer Centre is located in Belfast will contribute to this analysis. The number of acute hospital death bed-days in the Southern Trust is the lowest in the region, but has the second highest proportion of all their acute hospital death bed-days due to cancer. Western Trust has the least number of acute hospital death bed-days due to cancer. This is due to both longer lengths of stay for cancer and more admissions due to cancer. The number of acute hospital death bed-days in the Northern Trust is fewer than Belfast, but has high proportion of all their acute hospital death bed-days due to cancer than the Belfast Trust. Western Trust has the least number and proportion of acute hospital death bed-days due to cancer.

4.5.7 Acute hospital deaths that die within 4 days

The 2009 NCEPOD report: '*Caring to the End? A review of the care of patients who died in hospital within 4 days of admission'* looked at all patients older than 28 days who died in hospital within 4 days of admission.[12] A key finding from the report was that 49.8% of patients who died within 4 days of admission were not expected to survive on admission. Using the same criteria as the NCEPOD report, the same data was collected for patients in NI from the PAS, although it was not possible to establish whether people were dying from acute onset conditions or were at the end of life.

In 2015, 34.8% (2,323) of all patients who died in an acute hospital had a duration of stay less than or equal to 4 days. Of those who were admitted non-electively (n=6,497), 35.3% had a duration of stay less than 4 days. This was an increasing trend with the number of deaths, and proportion of deaths, that die within 4 days increasing over time (figure 21) but has decreased in recent years.

Figure 21: Trend of number of acute hospital deaths who die < 4 days



The data analysed below refers to those > 19 years only.

The following tables shows a breakdown of the number of people over 19 yrs. by Trust who died < 4 days after admission, by year with % of acute hospital deaths.

Table 24: Deaths < than 4 days from admission for those over 19 yrs

Trust	Year				
	2011	**2012**	**2013**	**2014**	**2015**
Belfast	478 (33%)	618 (33%)	643 (35%)	650 (35%)	752 (35%)
Northern	287 (37%)	380 (38%)	397 (39%)	412 (37%)	418 (34%)
South Eastern	333 (36%)	472 (36%)	450 (35%)	425 (33%)	414 (32%)
Southern	256 (40%)	416 (42%)	396 (40%)	375 (40%)	408 (39%)
Western	228 (37%)	290 (33%)	341 (38%)	312 (35%)	331 (35%)
NI	**1582** (36%)	**2176** (36%)	**2227** (37%)	**2174** (36%)	**2323** (35%)

The following table shows a breakdown of the number of people aged 65 yrs. and over by Trust who died < 4 days, by year with % of deaths for 65 and over.

Table 25: Deaths < than 4 days from admission for those 65 years and older

Trust	Year				
	2011	**2012**	**2013**	**2014**	**2015**
Belfast	357 (32%)	483 (32%)	495 (34%)	525 (35%)	570 (33%)
Northern	260 (38%)	330 (37%)	348 (38%)	358 (36%)	363 (34%)
South Eastern	294 (36%)	416 (35%)	402 (34%)	383 (34%)	374 (32%)
Southern	206 (38%)	352 (42%)	338 (40%)	311 (39%)	334 (38%)
Western	182 (36%)	249 (32%)	273 (36%)	255 (34%)	266 (34%)
NI	**1299** (35%)	**1830** (35%)	**1856** (36%)	**1832** (35%)	**1907** (34%)

4.5.8 Admissions from a Nursing Home

Figures for admissions from Nursing Homes have been inaccurate or misleading due to different recording practices that were in place across hospitals in NI. Definitional issues as to what should be recorded as home or usual residence of the person being admitted were addressed during a pilot of new guidance during 2016, which has subsequently been agreed for implementation by all Trusts during 2017. Updates will be provided in subsequent additions to this document.

4.6 PALLIATIVE CARE DATA SYSTEMS

Identification of palliative care needs for this HNA has been based on estimations from demographic, epidemiological and mortality data. The estimations enable us only to make assumptions on the level of need and not the true numbers.

Data is collected for those requiring palliative care, both in secondary care (PAS) and primary care (QOF), although the information is incomplete and so does not provide an accurate picture of need. The following sections provide information on the data available from each system.

4.6.1 Quality and Outcome Framework Palliative Care Register

The Quality and Outcomes Framework (QOF) is a system to remunerate general practices for providing good quality care to their patients, and to help fund work to further improve the quality of health care delivered. It is a fundamental part of the General Medical Services (GMS) contract, introduced on 1 April 2004. It measures practice achievement against a range of evidence-based indicators. [13]

Holding a complete palliative care register was introduced to QOF in 2006: '*the practice has a complete register available of all patients in need of palliative care/support*' (Indicator: PC3).

QOF registers can be used to measure the burden of disease or condition in a population at a particular point in time (prevalence). The prevalence is the number of patients on the register on 31 March as a proportion of patients on the practice list as at 1 February of the same year. Due to the nature of palliative care, patients may only be only the register for a short period of time; as a result the practice palliative care register can only give an indication of the situation at the time the register was taken (prevalence day) and may not be a true reflection of practice prevalence throughout the rest of the year.

Table 26 shows the QOF palliative care register for NI and LCGs in 2015/16. There are approximately 350 GP practices in NI so nearly 100% of practices participate in holding a register, so the list size can be assumed to be for the total population.

Table 26: QOF palliative care register details according to NI and LCG

LCG	Number of practices	Combined list size at 1 January 2016	Register size at 31 March 2016	Unadjusted prevalence (%)
Belfast	84	435,757	1,273	0.29
Northern	76	460,846	1,454	0.32
South Eastern	54	321,210	1,101	0.34
Southern	76	407,165	841	0.21
Western	57	326,090	757	0.23
NI	**347**	**1,951,068**	**5,426**	**0.28**

On 31 March 2016 approximately 5,500 people were recorded as requiring palliative care in NI. The largest prevalence was seen in South Eastern LCG, Southern the least – based on rate per 1000 GP list size. This figure falls short of the estimated 10,000 people with palliative care need, and does not reflect the burden identified previously.

Table 27 shows the number of people on a QOF palliative care register, and prevalence, from 2009 to 2016.

Table 27: Palliative Care registers and prevalence 2009-2016

	31st March 2009	31st March 2010	31st March 2011	31st March 2012	31st March 2013	31st March 2014	31st March 2015	31st March 2016
NI Total Register	1,419	1,814	2,133	2,510	4,852	5,568	5,862	5,426
NI Rate / 1000 List size	0.77	0.97	1.13	1.32	2.54	2.90	3.03	2.78
Belfast Register		438	527	563	1,280	1,350	1,428	1,273
Belfast rate/1000		1.03	1.24	1.32	2.98	3.13	3.29	2.92
Northern Register		420	420	443	945	1,248	1,494	1,454
Northern rate/1000		0.95	0.94	0.99	2.10	2.75	3.27	3.16
South Eastern Register		320	418	495	1,153	1,214	1,244	1,101
South Eastern rate/1000		1.01	1.29	1.58	3.66	3.83	3.90	3.43
Southern Register		370	408	542	816	913	880	841
Southern rate/1000		1.01	1.10	1.39	2.08	2.3	2.19	2.07
Western Register		266	360	467	658	843	816	757
Western rate/1000		0.84	1.13	1.46	2.04	2.61	2.51	2.32

4.7 SUMMARY OF PALLIATIVE CARE NEEDS IN NI

Current palliative care assessment

- Mortality has been identified as the single most important indicator of palliative care need as most patients will require some form of palliative care in their last year of life. The Higginson model calculates the number of people that have palliative care need as all cancer deaths plus two-thirds non-cancer deaths([11]). Current palliative care need in NI is therefore estimated to be 11,157 people.

- Palliative care needs vary between LCGs according to the size of the population, the demographics and deprivation of the area.

- The analysis show that the greatest palliative care needs are in Belfast, South Eastern and Northern LCGs. Northern LCG has the largest population overall and also the largest number of people over the age of 65 years. South Eastern also has an ageing population, and has the highest proportion of people over 85 years. Deprivation levels in Belfast LCG, together with a high proportion of people over 65 years, are likely to explain the particularly high level of palliative care need.

- Although the absolute numbers of people requiring palliative care in Western LCG are smaller due to the younger, smaller population, there are higher levels of deprivation, which is reflected in the higher proportion of deaths from diseases associated with deprivation (cancer deaths and respiratory illness).

- Evidence has shown that deprivation impacts on the level of palliative care need and type of resources required. The findings show that acute hospital deaths in Belfast and Western LCGs use more beddays, which may reflect difficulties in accessing community services.

- As the population ages, the proportion of women increases. There are a third more women over 65 years of age than there are men, with more than double the number of women over 85 years of age than men. The differences between the number of women and men are greatest in LCGs with the highest proportion of elderly people.

- Approximately one third of those over 65 years are living alone (~80,000 people). Data on the elderly people living alone according to LCG and gender was not available from the Census 2011. However, a Health Needs Assessment on palliative care services carried out in NHS Greater Glasgow and Clyde showed that older people living alone are more likely to be female than male. [(14)] It is therefore much more likely that women will survive men, live alone and ultimately need to be cared for. This is an important consideration when developing community support services.

- Although the numbers of ethnic communities are small, there is still a small but important number of the ageing ethnic communities (Chinese), one third of who live in Belfast LCG. The ethnic minority population is unlikely to largely impact on the overall resource need for palliative care services, but it will still be important to ensure that

services are prepared to provide appropriate care to members of all ethnic groups particularly within Belfast and Southern LCGs.

Future palliative care need

- The population of NI is projected to increase from 1.8m to 1.954m by 2026. Contributing to the increase will be the increasing number of elderly people; with the number of people over 65 years projected to increase a further 34% by 2026 so that a bigger proportion of the population will be over 65 years than currently (19%). The biggest increases will be seen in people aged 85 years and older, quadrupling by 2051. As a consequence, palliative care needs are likely to be greater and services will need to be able to cope with the demand.

- The projected increase in palliative care need is likely to vary across LCGs. All LCGs are projected to increase in size by 2026, with the biggest proportional increase in Southern LCG (11%) and South Eastern LCG (6%), Northern LCG (4% and Belfast and Western LCGs (3%) when compared to 2015. Much of the projected increase in the Southern LCG will be due to migration, with resulting younger populations and less palliative care need. The biggest increase in the older population (aged 65 and over) numbers is projected to be seen in Northern and South Eastern LCGs with an additional 23,500 and 20,400 respectively by 2026.

Potential areas for change to meet increased demand

- Currently it is likely that much palliative care need in the region is being met in acute hospital settings as 47% of deaths occur in an acute hospital. Whilst the figure is slightly lower for cancer, 39% still occur in this setting. This is despite the evidence showing that individuals' preference is to die at home and the recommendations from *Living Matters, Dying Matters*.

- The findings show that, with appropriate support and services in place, more people may be able to die in a place of their choice. One third of the acute hospital deaths occurred in those over 85 years of age, with the number of bed-days increasing in all Trusts with age. 87% of people who died in an acute hospital were admitted as an emergency, 14% of people who died in an acute hospital were admitted with a primary diagnosis of cancer; one third died within four days of admission and approximately 20% of deaths in 2015 were in a nursing home.

- Whilst acute hospitals are the most common place of death in all LCGs (ranging from 45% to 51% of deaths), Belfast and Northern LCGs has the highest proportion of people dying in hospital and Southern LCG the lowest.

- There was also variation across LCGs in other places of death.

- Northern LCG had the greatest number and proportion of people dying in a hospice.

- Belfast LCG had the greatest number dying in an acute hospital, followed by nursing home, with the least in a hospice, although this could reflect the fact that data was collected before the Macmillan Unit in AAH had opened.

- South Eastern LCG had the largest proportion of all deaths occurring in nursing homes compared to other LCGs.

- Southern had the lowest proportion of acute hospital deaths, more hospice deaths, particularly cancer, and more home deaths.

- Western LCGs had the biggest proportion of people dying in their own home but the lowest dying in a hospice or nursing home.

- It is difficult to know to what extent these differences are as a result of patient choice, availability of extended family, enhanced community services, access to hospice beds, deprivation or other factors. If services can adapt to address any barriers to community care then there is potential to increase the number of people dying in their preferred place of care.

- Identification of palliative care needs was based on estimations from demographic, epidemiological and mortality data rather than true numbers. The findings show that the current palliative care monitoring systems do not accurately monitor need as data is either incomplete or, as in the case for QOF data, only provides the burden of need on one day of the year. Consequently neither reflected the findings from the rest of the HNA. QOF data showed that burden was greatest in Western and Southern, which could be because cancer patients are more likely to be put on the register and for younger populations, any palliative care need identified is more likely to be as a result of cancer. Enhanced monitoring systems will need to be developed to monitor the need and demand

Future Needs Assessment Analysis

This Needs Assessment for Palliative and End of life Care will continue to be updated by the Commissioning Service Team on an annual basis, firstly to reflect the availability of more up to date data and secondly to expand the document to include other areas of interest for service planning.

The Commissioning Service Team have identified a number of areas that merit consideration in the next 12mths for inclusion in the next iteration, they include the following –

- Presentation of key information on the basis of the 11 new Local Government Districts
- Nursing Home Data analysis

5 APPENDICES

5.1 APPENDIX 1: A8 AND A2 ACCESSION COUNTRIES

A8 countries

- Poland
- Slovakia
- Czech republic
- Estonia
- Hungary
- Slovenia
- Latvia
- Lithuania

A2 countries

- Romania
- Bulgaria

5.2 APPENDIX 2: ACUTE HOSPITALS INCLUDED IN PATIENT ADMISSION SYSTEM DATA

- Belfast City
- Ulster
- Royal Victoria
- Mater
- Lagan Valley
- Downe
- Causeway
- Antrim
- Craigavon
- Daisy Hill
- Altnagelvin
- South West Acute

5.3 APPENDIX 3: DEATHS EXCLUDED FROM PATIENT ADMISSION SYSTEM DATA

Deaths excluded with the following ICD10 code as a primary diagnosis:

- B00 - B19: Viral infections characterized by skin and mucous membrane lesions & viral hepatitis
- B25 - B94: Other viral diseases, Mycoses, Protozoal diseases, Helminthiases, Pediculosis, acariasis and other infestations.
- F10 - F69: F80 - F99Mental and behavioural disorders
- L00 - L99: Diseases of skin and subcutaneous tissue
- O00 - O99: Pregnancy, child birth and the puerperium
- P00 - P96: Certain conditions originating in the perinatal period
- V01 - Y98: External causes of mortality

5.4 APPENDIX4: ADDITIONAL TABLES

Table A: Number & percentage of deaths by major cause (2001 – 2015)

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	Total
Cancer (C00-C97)	3696 25.5%	3651 25.0%	3757 26.0%	3757 26.2%	3733 26.2%	3848 26.5%	3870 26.4%	3971 26.6%	3885 27.0%	4018 27.8%	4059 28.6%	4134 28.0%	4230 28.3%	4323 29.5%	4361 28.0%	59,293
Circulatory Diseases	5829 40.2%	5729 39.3%	5448 37.7%	5272 36.7%	5002 13.5%	4879 33.6%	4838 33.0%	4752 31.9%	4485 31.1%	4476 31.0%	3951 27.8%	4001 27.1%	3917 26.2%	3719 25.3%	3773 24.3%	70,071
Respiratory Diseases	1975 13.6%	1883 12.9%	2082 14.4%	1950 13.6%	1922 13.5%	1982 13.6%	1992 13.6%	2096 14.1%	2017 14.0%	1886 13.0%	1923 13.5%	2023 13.7%	2124 14.2%	2004 13.7%	2236 14.4%	30,095
Nervous System Diseases	467 3.2%	530 3.6%	481 3.3%	486 3.4%	484 3.4%	557 3.8%	588 4.0%	599 4.0%	616 4.3%	568 3.9%	671 4.7%	806 5.5%	825 5.5%	801 5.5%	923 5.9%	9,402
Diseases of the genitourinary system (N17-N19)	172 1.2%	223 1.5%	204 1.4%	234 1.6%	186 1.3%	202 1.4%	200 1.4%	207 1.4%	156 1.1%	135 0.9%	151 1.1%	140 0.9%	126 0.8%	113 0.8%	94 0.6%	2,543
Other causes	2374 16.4%	2570 17.6%	2490 17.2%	2655 18.5%	2897 20.4%	3064 21.1%	3161 21.6%	3282 22.0%	3254 22.6%	3374 23.3%	3449 24.3%	3652 24.7%	3746 25.0%	3718 25.3%	4161 26.8%	47,847
Total deaths per year	**14,513**	**14,586**	**14,462**	**14,354**	**14,224**	**14,532**	**14,649**	**14,907**	**14,413**	**14,457**	**14,204**	**14,756**	**14,968**	**14,678**	**15,548**	**219,251**

Data source: Health Intelligence analysis of General Register Office data

Table B: Number of deaths by gender (2001 – 2015)

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	Total
Female	7506	7638	7542	7419	7267	7470	7441	7680	7499	7391	7286	7662	7707	7654	7953	113115
Male	7007	6948	6920	6935	6957	7062	7208	7227	6914	7066	6918	7094	7261	7024	7595	106136
Total	**14513**	**14586**	**14462**	**14354**	**14224**	**14532**	**14649**	**14907**	**14413**	**14457**	**14204**	**14756**	**14968**	**14678**	**15548**	**219251**

Data source: Health Intelligence analysis of General Register Office data

Table C: Number of deaths by age group (2001 – 2015)

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	Total
Under 19	247	216	223	228	268	259	243	276	249	254	202	184	197	203	193	3442
20-39	369	397	344	354	418	402	395	403	398	416	370	366	331	357	377	5697
40-64	2172	2339	2157	2353	2275	2407	2442	2352	2351	2382	2284	2211	2282	2192	2323	34522
65-74	2933	2833	2838	2697	2542	2538	2476	2584	2539	2606	2457	2469	2554	2569	2719	39354
75-84	4774	4752	4821	4813	4698	4631	4696	4611	4427	4268	4223	4454	4457	4369	4430	68424
85+	4018	4049	4079	3909	4023	4295	4397	4681	4449	4531	4668	5072	5147	4988	5506	67812
Total	**14513**	**14586**	**14462**	**14354**	**14224**	**14532**	**14649**	**14907**	**14413**	**14457**	**14204**	**14756**	**14968**	**14678**	**15548**	**219251**

Data source: Health Intelligence analysis of General Register Office data

Table D: Deaths by older age groups for each LCG of residence (2011 – 2015)

Age group	Belfast	Northern	South Eastern	Southern	Western	Grand Total
65-74 years	2804	3234	2495	2248	1983	12768
75-84 years	4889	5795	4237	3826	3182	21933
85+ years	5561	6535	5461	4379	3442	25381
Total	**13254**	**15564**	**12193**	**10453**	**8607**	**60082**

Data source: Health Intelligence analysis of General Register Office data

Table E: Deaths by MDM Quintile (2001 – 2015)

	Quintile 1	Quintile 2	Quintile 3	Quintile 4	Quintile 5	Total
2001-2005	15880	15491	14486	13519	12230	71606
2006-2010	16111	15791	14775	13605	12657	72939
2011-2015	15828	15858	15127	13911	13403	74127
Total	**47819**	**47140**	**44388**	**41035**	**38290**	**218672**

Data source: Health Intelligence analysis of General Register Office data
*Note: MDM Quintile was unknown for 27 deaths in this period

Table F: Percentage and number of deaths by place of death in NI (2005 – 2015)

Place of death	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	Total
Hospital	7506 53%	7705 53%	7520 51%	7515 50%	7355 51%	7311 51%	6923 49%	7036 48%	7015 47%	6884 47%	7334 47%	80104
Nursing home	2085 15%	2111 15%	2259 15%	2427 16%	2241 16%	2309 16%	2496 18%	2711 18%	3015 20%	2807 19%	3074 20%	27535
Hospice	515 4%	490 3%	523 4%	550 4%	505 4%	501 3%	558 4%	620 4%	469 3%	701 5%	629 4%	6061
All other places	4118 29%	4226 29%	4347 30%	4415 30%	4312 30%	4336 30%	4227 30%	4389 30%	4469 30%	4286 29%	4511 29%	47636
Total	**14224**	**14532**	**14649**	**14907**	**14413**	**14457**	**14204**	**14756**	**14968**	**14678**	**15548**	**161336**

Data source: Health Intelligence analysis of General Register Office data

Note: The Macmillan Unit in Antrim Area Hospital is a specialist palliative care unit based within the hospital. Deaths in this unit are coded under hospital in the General Register Office data. An adjustment has been applied to account for deaths in the Macmillan Unit and these deaths are presented in the hospice data in the data analysed. This means that the numbers will not correspond with the numbers published by NISRA.

6 GLOSSARY

AHP	Allied Health Professionals
AIIHPC	All Ireland Institute for Hospice and Palliative Care
DHSSPS	Department of Health, Social Services and Public Safety
ELCOS	End of Life Care Operational System
GMC	General Medical Council
GP	General Practitioner
GMS	General Medical Services
GPC	Generalist Palliative Care
GRO	General Register Office
HNA	Health Needs Assessment
HSCB	Health and Social Care Board
ICD10	10th revision of the International Classification of Diseases and Related Health Problems
LCG	Local Commissioning Group
LGD	Local Government District
LMDM	Living Matters Dying Matters
MDM	Multiple Deprivation Measure (can also be prefixed with NI)
MDT	Multidisciplinary Team
MYE	Mid-Year Population Estimates
NCEPOD	National confidential enquiry into patient outcome and death
NI	Northern Ireland
NICE	National Institute of Clinical Excellence
NIMDI	NI Multiple Deprivation Index
NIH	NI Hospice
NINIS	Northern Ireland Neighbourhood Information Service
NISRA	NI Statistics and Research Agency
PAS	Patient Admission System
PHA	Public Health Agency

QOF	Quality and Outcome Framework
RGO	Register General Office
RQIA	The Regulation and Quality Improvement Authority
SPC	Specialist Palliative Care
TYC	Transforming Your Care
TYPELC	Transforming Your Palliative and End of Life Care
UK	United Kingdom
WHO	World Health Organisation

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