Carers NI is Northern Ireland’s membership body for unpaid carers. We’re here to listen, to give carers expert information and tailored advice. We champion the rights of Northern Ireland’s 220,000 carers and support them in finding new ways to manage at home, at work, or in their community. We’re here to make life better for carers.

We are submitting an organisational response to this NI Assembly Health Committee palliative care inquiry. Carers NI has not polled its members on this topic rather this is a summary of feedback, insights and knowledge we have garnered from across Carers UK as a whole. We are also a supporter of the Palliative Hub website[1] which is a source of information about palliative care on the island of Ireland. The following points represent our core issues:

- Our ageing population means that deaths from chronic illness in all four nations are projected to increase substantially in the next two decades, and this will increase demand for and pressure on palliative and end of life care services.

- We believe that all adults in NI should have equitable access to well-coordinated, timely and high-quality palliative care and bereavement support based on what matters to them. We also want any new palliative care strategy for NI to specifically recognise the unique challenges faced by unpaid carers providing care and support for someone with a terminal illness, approaching the end of life, at the time of death, and following it through bereavement and grief. This should include recommendations and identify specific support for them such as access to training, respite care, financial support, mental health support and bereavement services.

- Unpaid carers play a key role in palliative care and should be considered as equal partners alongside health and social care practitioners in the care they provide to the person they are looking after. This should include all decision-making around the care of the terminally ill person.

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[1] https://thepalliativehub.com/

- Carers should also be explicitly referenced in governance frameworks and innovation initiatives. Their insights can inform practical improvements in care delivery. Any new strategy on palliative care should clearly state their position as equal partners in care.

- Any new plans to instigate a specific palliative care strategy for NI should aim to erode regional postcode disparities and differing access points of information and support across each of the health trusts.

- We believe there is a need for greater discussion on both future care planning and dying, death and bereavement. We believe that this conversation must extend beyond community and family conversations into our whole social fabric to ensure the development of good outcomes across health and social care systems as well as wider local authority services that support housing, community planning, employability and employment issues. It is critical that the Strategy also aims to develop a conversation more widely than only within families and communities but extends this to include employers – and does so explicitly. Juggling paid employment and caring responsibilities is already challenging and extremely stressful, with many carers unable to sustain their careers, but this can be even more intense when facing end of life care (whether the carer is providing this care at home or it is being provided elsewhere, such as a hospice or care home).

- A general understanding of what good palliative care involves, is lacking in NI. Many people do not understand that palliative care helps adults with a serious or terminal illness or children with serious health conditions to live as well as possible. Some people think they can only get palliative care in the last weeks or days of life. In fact, some adults and children can benefit from palliative care over many years.

- Carer support services in the third sector supporting unpaid carers should be included as key partners and supported and provided with additional funding through the commissioning process to provide dedicated support. They should also be involved in strategic planning at a local and national level in the delivery of palliative care services and approaches.

- Carers must be equipped to understand how palliative care may assist the person they care for, and how best to support them whilst also looking after their own health and wellbeing.

- Supportive employers and employment practices, and the promotion of employers' role of being part of the community that supports palliative care, could prevent carers losing employment and the financial insecurity that follows.

- Finances: Carers need and should be entitled to financial advice after the death of the person they have cared for.

- Gender: There is a specific gendered element to caring which needs careful attention and targeted action. In Northern Ireland nearly 60% of unpaid carers are women. Research we undertook with the Women's Regional Consortium published in 2024 found 1 in 3 (34%) women with unpaid caring roles have given up employment to care. 1 in 4 (28%) have decreased their working hours because of caring and 1 in 6 (17%) have taken on a less qualified job or turned down promotion to fit around their caring responsibilities.

- Communications: The public and carers need to understand palliative care better. Unpaid carers from NI's BME communities have reported significant issues in terms of accessing services, including linguistic barriers and a lack of culturally appropriate services (such as dietary, religious or gender requirements). It is therefore important when undertaking work to ensure equalities in palliative care services that the needs of unpaid carers and cared-for people within BME communities are therefore considered. This need to ensure that unpaid carers with protected characteristics have equity of access, including to information, is also illustrated by Marie Curie's research[2] which highlights how LGBTQ+ people face challenges in accessing the person-centred palliative care and support that they need. Further Uk research conducted for Marie Curie by QUB and Cardiff Universities explores 'Public attitudes to death and dying in the UK' further and provides recommendations about what people want at end of life[3].

- Resources: Any palliative care resources should be available in a variety of languages and make use of audio-visual resources for those with limited literacy. A wide variety of communication methods will help ensure wider uptake, especially amongst those people who reported in the NI census as English not being their main language. The 2021 Census shows there is an increasing number of people living in Northern Ireland who do not have English as their main language. Ten years ago, in 2011, English was not the main language of 54,500 people aged 3 and over (3.1%); this increased to 85,100 people (4.6%) in 2021. Resources should also be available in non-digital formats as some BME communities are more likely to be digitally excluded, such as many members of the Traveller community.

- Carers health: We need to improve access to national screening programmes and health checks for unpaid carers. There is convincing evidence that caring impacts upon physical health and in the NI State of Caring 2023 survey, we found that more than 1 in 3 have put off health treatment for themselves because of the demands of caring. Earlier diagnosis of significant illness is vital, as is the ability to be provided with the right support to enable carers to attend appointments and treatment. Specific attention should also be paid to those carers with protected characteristics and who are in employment to ensure equity of access.

- Greater information, better communication and earlier conversations are needed around palliative care for adults and children, care around dying,

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[2] https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/lgbtq
[3] https://www.mariecurie.org.uk/document/creating-a-death-literate-society-ni-2022

advance care planning and DNACPR, including developing publicly available resources to support informed decisions around future care planning. During the COVID 19 pandemic, people with learning disabilities and older people experienced these being placed on their files without their knowledge or consent, or that of their unpaid carer. This was a deeply distressing experience and eroded trust in those providing care.

- Inclusive: The development of a public information leaflet/campaign would be helpful and people with lived experience of bereavement should be involved in any of these activities. Public information and awareness efforts should always be suitable for all members of the community e.g. with specific and culturally appropriate information available for minority ethnic people, easy read versions, and information available in a variety of formats (audio, written, video).

- Transitions are a challenging time for all parent carers but particularly so for those with a young person with a life limiting condition. This inquiry should consider availability of dedicated resources, including hospice and short break provision, for older young people and their families to give confidence that support for quality complex and palliative care will be a priority. This should include working with benefit/welfare systems on the impact of financial changes when their child reaches the end of their education – a time where family resources can shrink significantly.

- The broad themes of this inquiry do not appear to focus strongly on bereavement. Bereavement and bereavement support (including pre-bereavement/grief) is key for carers and there should a strong focus on this in any review of services in NI. Bereavement is a significant part of palliative care and should be available to all family members and carers from the point of need, which may come well before the person they are caring for has died. Understanding bereavement and supporting bereaved people is a key part of the wider conversation piece, and crucial for employers to understand as they manage a person back into employment or re-entering the labour market.

- Finally, support for carers post-bereavement should be part of this review and addressed in any connected public policy. Many carers will get no support from the state following the death of the person they are caring for, whether that is financial, emotional, bereavement, or rebuilding lives, e.g. return to work and employment. This is often a bit of black hole in carer policy, and we feel it should be identified and recommended for further action.

Dear PC inquiry

Sharing an important research paper on “The contributions of family care-givers at end of life: A national post-bereavement census survey of cancer carers’ hours of care and expenditures.” I also attach the RQIA’s review of the Implementation of the Palliative and End of Life Care Strategy (March 2010) dated January 2016 which discusses the need for “development of care plans which are continually reviewed for those in the last year of life. (These should include do not attempt resuscitation (DNAR) wishes, place of care and **referral for carer’s assessment**).”

It also flags the question ‘What information and training do carers and families need to provide the best care for their loved one who is dying?’ and highlights the need for **respite breaks** as well as a colour coded system to assist practitioners in the development of an individual care plan for a patient and their **carer** and family, depending on the stage in the patient journey.

We also hope the inquiry interlinks with DfC officials in relation to Carers Allowance which stops 8 weeks after a person dies which would add to any financial strain for a carer coping with the death of their loved one. Within Carers UK we are campaigning for this benefit to be extended to 6 months. In the interim we offer links to EOL planning https://www.carersuk.org/help-and-advice/practical-support/end-of-life-planning/ and coping with bereavement https://www.carersuk.org/help-and-advice/practical-support/coping-with-bereavement/

Carers Northern Ireland and Carers Scotland

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The contributions of family care-givers at end of life: A national post-bereavement census survey of cancer carers' hours of care and expenditures

Christine Rowland[1], Barbara Hanratty[2], Mark Pilling[1], Bernard van den Berg[3] and Gunn Grande[1]

Abstract

Background: Family members provide vital care at end of life, enabling patients to remain at home. Such informal care contributes significantly to the economy while supporting patients' preferences and government policy. However, the value of care-givers' contributions is often underestimated or overlooked in evaluations. Without information on the activities and expenditures involved in informal care-giving, it is impossible to provide an accurate assessment of carers' contribution to end-of-life care.
Aim: The aim of this study was to investigate the contributions and expenditure of informal, family care-giving in end-of-life cancer care.
Design: A national census survey of English cancer carers was conducted. Survey packs were mailed to 5271 people who registered the death of a relative to cancer during 1–16 May 2015. Data were collected on decedents' health and situation, care support given, financial expenditure resulting from care, carer well-being and general background information.
Results: In all, 1504 completed surveys were returned (28.5%). Over 90% of respondents reported spending time on care-giving in the last 3 months of the decedent's life, contributing a median 69 h 30 min of care-giving each week. Those who reported details of expenditure (72.5%) spent a median £370 in the last 3 months of the decedent's life.
Conclusion: Carers contribute a great deal of time and money for day-to-day support and care of patients. This study has yielded a unique, population-level data set of end-of-life care-giving and future analyses will provide estimates of the economic value of family care-givers' contributions.

Keywords

Informal care-giving, cancer, palliative care, care-givers, cost analysis

What is already known about the topic?

- Family carers make a substantial contribution to end-of-life care, but few studies have considered the hours of care-giving provided and carers' out-of-pocket expenditure.
- Estimates of end-of-life care-giving contributions and/or out-of-pocket expenditures are mainly derived from studies that are either small in size or lack detailed information on this issue.

What this paper adds?

- This study is the first to provide population-based information on the scale of cancer-related carer activity and out-of-pocket expenditures to enable the economic value of carers' contribution to end-of-life care to be calculated.

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- We have collected detailed data directly from carers using a bespoke census survey, overcoming many limitations of previous work.
- We find that carers' contribution to end-of-life care is substantial and could be much higher than some previous estimates suggest.

Implications for practice, theory or policy

- These data provide important information for policy makers and service planners who should take into account carers' contributions, both in terms of hours worked and out-of-pocket expenditure, and the value of these contributions to the economy.

Introduction

A majority of patients prefer to stay at home at the end of life[1] and government policy supports this choice.[2] For many people with cancer, the final period of illness is characterised by increasingly complex and intense care needs.[3] Family members often take on prolonged caring roles and are pivotal to ensuring that patients' needs are met.[4] Without family support, many people would be unable to remain at home in their final illness.[5,6] Indeed, national-level data from countries worldwide indicate that married patients are able to die at home more frequently than those who are divorced, widowed or unmarried, indicating the importance of family carers.[7,8]

The scale of family members' contribution and the financial burden on families are often overlooked in considerations of end-of-life caring although costs and consequences may be profound.[9,10]

Support for carers was explicitly excluded from the NHS Palliative Care Tariff recommended by the Palliative Care Funding Review 4 (PCFR) for England, despite its emphasis on enabling patient death at home.[2] The National End of Life Care Programme (NEnd-of-lifeCP)[11] identified critical success factors that enable people to die in their preferred place of death, but omitted family carers from the list, despite empirical evidence that carers play a crucial role in this respect.[5] NEnd-of-lifeCP[12] estimated end-of-life community care to be cheaper than acute hospital care, but this calculation only considered health and social care costs, not carers' contribution. Evidence syntheses suggest that palliative care is cheaper than standard care, but carers' time and out-of-pocket costs are consistently excluded from economic evaluations.[13,14]

Within the current literature, important aspects relating to carer contributions (hours of care given, type of task and out-of-pocket expenditure) are routinely omitted from estimates, or where they are included, samples are small and unrepresentative. Specifically for UK cancer carers, much evidence has been from analysis of secondary data, which were not designed to consider these issues in detail, and has omitted both carer time and out-of-pocket expenditure.[15–17] Round et al.[18] estimated that informal care during the end-of-life period (defined as time since patient began using strong opioids – 243 days) equates to £3265 GBP per patient (approximately \$4641USD). However, this relied on secondary data, where out-of-pocket or other expenses were not included. Some international studies have included carer time and out-of-pocket expenditure in their estimations of the value of carers' contributions. Van Houtven et al.[19] estimated the value of 24.5 h of care per week at \$2164USD per month per patient (approximately £1774GBP/\$2877CAD). This estimate was calculated at 2005 prices and does not account for inflation. Based on more recent data, estimates have valued care hours at \$5077CAD[20] and \$11334CAD[21] per patient per month (approximately £3148GBP/\$3808USD (2012 data);[20] £7027GBP/\$8501USD (2011 data)[21] (number of care hours not defined)), while monthly out-of-pocket expenditure ranged from \$209USD[19] to \$839CAD[20] (approximately £171GBP/\$278CAD–£520GBP/\$629USD). However, these studies were small scale ($n = 129$;[21] $n = 138$;[20] $n = 144$[19]) and not based on nationally representative data.

While the above studies provide much needed estimates, they all have limitations, and comprehensive figures for informal carer contributions and their associated economic value are still absent from the literature. This could lead to cost-shifting and overburdening of family and friends, ultimately compromising care quality.[22] While broad population estimates of hours of care exist for carers in general,[23] the intensity of end-of-life care-giving demands specific consideration. As a first step to address the need for comprehensive information on family care contributions at end of life, and given the predominance of cancer within palliative care literature, we focus our research on cancer care.

In this article, we report data from a population-based study of cancer-related family care-giving activity at end of life in England. Working with the Office for National Statistics (ONS), we are uniquely able to report a comprehensive national overview of carers and their care-giving context, detailed information on the time spent on care tasks during patients' last 3 months of life and out-of-pocket expenditure. This extensive data set will form the basis for future, more in-depth analyses of the economic value of carers' contributions, impact of care-giving on carers' situation and well-being, and factors related to these.

Methods

Design

Post-bereavement, cross sectional and national postal survey.

Sample

The ONS drew a census sample of everyone (5271 people) who registered a cancer death in England over a 2-week period, that is, 1–16 May 2015. Unlike other causes of death, cancer does not display seasonal variation[24,25] and ONS data show no variation in cancer deaths by day of week or time of month.[26] Dates were chosen to avoid other ONS post-bereavement surveys while allowing appropriate time post-bereavement for those contacted.

Inclusion criteria were as follows: death occurred during the designated period, in England, was caused by cancer (International Classification of Diseases, 10th revision (ICD)-10 codes C000-C979) and the decedent was aged over 18 years. Exclusion criteria were as follows: death occurred somewhere other than home, hospital, care home or hospice, was reported to the coroner, the person who registered the death was not a relative, the address of the person registering the death was missing, or sex or age of deceased was missing.

The University of Manchester's Research Ethics Committee approved the study (Ref: 14430).

Procedure

The research team worked with the ONS team, carer groups and bereaved individuals to develop the survey content and ensure materials were sensitive, relevant and understandable. This included discussing content and formatting with a lay end-of-life research advisory group, carer cognitive-debriefing interviews ($n = 5$) and pilot surveys ($n = 19$).

ONS mailed surveys to the identified sample. No personal information was shared with the research team. People received (1) personalised covering letter (name, address, name of decedent), (2) information sheet emphasising the option to decline and avoid reminders, (3) decline slip, (4) survey and (5) reply-paid return envelope to the research team. Survey packs were sent to the person registering the death, who was invited to pass the survey to the person who provided most care, if appropriate.

Surveys were mailed to participants 4 months after registering a death (September 2016). Non-responders (no survey or decline slip returned) were sent a reminder letter 1 month later and another full survey the following month.

Participants could respond via online survey or telephone interview. Large print or non-English version of the survey was available on request.

Questionnaire

Questions were predominantly closed, single response from multiple choices. We report here the following items:

1. *General background.* Demographic information, work status, and relationship and proximity to the decedent.
2. *Decedent's health and situation.* Date and type of diagnosis.
3. *Carer contribution – care tasks.* Types of care tasks were presented under the headings: household tasks (six items), personal care (one item), health care and medicine (two items) and social and emotional care (one item). Participants estimated how much time (hours:minutes) they spent on each task in a typical week in the last 3 months of the decedent's life. The list was derived from survey development work and previous publications.[27–29] Participants were instructed not to count any activity twice and to write '0' if they had not done a particular task.

We conceptualised care-giving as any task the participant undertook which provided care and/or assistance. While many respondents may have been the patient's spouse and may therefore have undertaken some tasks as part of this role, distinct from the impact of illness, we reasoned that had the spouse been unable to perform those tasks, then the state/another person would have to fulfil those duties. Given this logic, we incorporated all associated care-giving tasks within our estimates.

4. *Carer contribution – Out-of-pocket expenditure.* Participants were asked to estimate financial expenditure resulting from care provision for the decedent during the last 3 months of life. Items were presented under the headings: help from others, social activity and direct expenses. Details about any large, one-off expenses as a result of diagnosis (i.e. moving home) were also collected.

ONS provided anonymised data for the whole sampling frame linked by study identification (Study ID) number on the following variables: age and sex of deceased, date of death, date of death registration, final underlying cause of death by ICD-10 codes, place of death and index of multiple deprivation (IMD).[30]

Analysis

Analyses were conducted using SPSS v22.[31] Descriptive data are presented for respondent and decedent characteristics, types of care tasks and time taken, and care-related expenditure. Differences between decedent demographics, as supplied by ONS, were explored by response type (survey, decline, no response) using chi-square for categorical variables and analysis of variance (ANOVA) for continuous data. Due to non-homogeneous variance (indicated by Levene's statistic), the Brown–Forsythe *F* statistic is reported for ANOVAs as it is robust to violations of this assumption. Post hoc comparisons of significant chi-square tests were made using *z*-tests to compare column proportions, with Bonferroni adjustment for multiple testing. The responder by cancer type chi-square had expected frequencies <5 in 12.8% of cells, which was acceptable given the large number of variables.[32]

These data did show evidence of non-normality (skew and kurtosis) but as sample sizes were large and groups roughly equal data were not transformed to achieve normality.[32] We did not make adjustments where data were missing, but have reported the number of missing values within the tables. We refer to median values throughout the results unless otherwise specified.

Results

Response rates

Surveys were completed by 28.5% (n=1504), 1851 (35.1%) declined to participate and n=1915 (36.3%) made no response.

Table 1 presents the differences in response rates and shows statistically significant differences in demographic characteristics of decedents between those who completed the survey (participants/responders), those who declined and those who made no response. Participants were significantly more likely to have registered the death of someone who died at home (35.9%; 29.6% non-responders, 28.1% decliners), who was older (76 years) than for non-responders (74 years) and younger than for decliners (78 years). Participants were also significantly more likely to be from less deprived areas (IMD 5: 24.6% participants, 19.9% decliners, 14.9% non-responders). There was no significant difference in the cancer site of decedent by responder group.

Participant characteristics

The majority of participants were female (64.2%), White (95.7%), with a median age of 60 years (mean: 60.4 (SD: 12.28)) and were qualified at school-leaver level (16 years) or higher (74.4%; Table 2).

Just under half of participants (44.5%) were the spouse/partner of the decedent and many had cared for their parent (43.2%). Half of decedents and respondents lived together (50.6%) and 33.7% lived within a 30-min journey of each other. A majority of participants (53.7%) were employed and 36.4% were retired when the decedent first became ill (Table 3).

In the last 3 months of life, three-quarters (75.3%) of decedents were 'usually resident' at home, 9.7% were 'usually resident' in hospital, 7.0% in care home, 2.3% in hospice (2.3%) and 2.8% in other locations (e.g. sheltered accommodation, someone else's home, palliative care unit; Table 3).

Contributions and costs of care-giving

During the last 3 months of life, 90.0% of participants reported spending time on care-giving which is 99.1% of those who responded to this question. These carers spent a median total of 69 h 30 min each in a typical week on care-giving – representing a mean of 9:56 h/day, every day of a typical week (Table 4).

The majority of participants (82.9%) reported providing social and emotional support, for a median of 20 h/week. This was followed by shopping (79.1%; 3 h), cleaning (72.7%; 7 h) and preparing food and drink (72.1%, 10 h). Fewest participants helped with maintenance and odd jobs (55.3%, 3 h).

In total, 76.1% of participants reported out-of-pocket expenditure which arose as a result of care-giving in the last 3 months of life (Table 5). Not everyone who reported a cost gave expenditure amount and as such data in Table 5 are calculated including only those who supplied figures (72.5%).

The most frequent expenditure was for travel expenses (47.9%) at a median cost of £100 per person over the last 3 months of life, followed by expenditure on meals and snacks while out with the patient (42.0%, £50), medical equipment and care supplies (25.1%, £100), and increased household bills (24.1%, £129). The biggest expenditure was nursing home/private care home (4.9%, £2000). Participants had a median total of £370 of out-of-pocket expenditure during the last 3 months of care-giving.

Additionally, 16.9% had 'one-off expenses' during their whole time care-giving. The median reported cost was £2000 and included payment for car, mobility equipment, furniture, house adaptations, cashing endowments/drawing on house capital, private medical care – including Swiss clinics/'Dignitas' and funeral costs.

Discussion

Our study provides national estimates of the contributions and out-of-pocket expenditure of family care-giving at end of life using a census survey completed by recently bereaved cancer carers.

Furthermore, our methods demonstrate that it is feasible to retrospectively collect very detailed data on carers' contributions and that carers find this acceptable. A substantial proportion of those we approached made some response to the survey invite (63.7%). Those who reported the death of a younger person and who were from more disadvantaged areas were less likely to respond, which is commensurate with survey response theory.[33]

Table 1. Differences in decedent characteristics between responders, non-responders and decliners ($N = 5270$[a]).

	Total sample	Non-responders	Responders	Decliners	Test (*df*)	*p* value
n	5271	1915	1504	1851		
Patient age (years) (SD)	74.41 (12.27)	72.56 (12.5)$_A$	74.36 (12.4)$_B$	76.35 (11.6)$_C$	F[b] (25,087) = 45.58	<0.001
Median (min–max) (SD)	76 (18–102)	74 (18–99)	76 (19–100)	78 (25–102)		
Patient gender					$\chi^2 = 5.254$ (2)	0.072
Males	2775 (52.6)	969 (50.6)	802 (53.3)	1003 (54.2)		
Place of death					$\chi^2 = 40.989$ (6)	<0.001
Hospital	1863 (35.3)	715 (37.3)$_A$	448 (29.8)$_B$	699 (37.8)$_A$		
Care home	766 (14.5)	256 (13.4)$_A$	219 (14.6)$_A$	291 (15.7)$_A$		
Home	1627 (30.9)	566 (29.6)$_A$	540 (35.9)$_B$	521 (28.1)$_A$		
Hospice	1015 (19.3)	378 (19.7)$_A$	297 (19.7)$_A$	340 (18.4)$_A$		
Multiple indices of deprivation (decedent)					$\chi^2 = 126.384$ (8)	<0.001
1 (most deprived)	1059 (20.1)	491 (25.6)$_A$	204 (13.6)$_B$	363 (19.6)$_C$		
2	981 (18.6)	407 (21.3)$_A$	255 (17.0)$_B$	319 (17.2)$_B$		
3	1146 (21.7)	388 (20.3)$_A$	335 (22.3)$_A$	423 (22.9)$_A$		
4	1062 (20.1)	344 (18.0)$_A$	340 (22.6)$_B$	378 (20.4)$_{A,B}$		
5 (least deprived)	1023 (19.4)	285 (14.9)$_A$	370 (24.6)$_B$	368 (19.9)$_C$		
Primary cause of death: cancer site (ICD-10 classification)					$\chi^2 = 60.004$ (50)	0.157
Lung (C33–34)	1139 (21.6)	444 (23.2)	302 (20.1)	393 (21.2)		
Colorectal (C18–20)	499 (9.5)	161 (8.4)	152 (10.1)	186 (10.0)		
Prostate (C61)	401 (7.6)	134 (7.0)	119 (7.9)	147 (7.9)		
Breast (C50)	375 (7.1)	143 (7.5)	110 (7.3)	122 (6.6)		
Pancreas (C25)	284 (5.4)	110 (5.7)	82 (5.5)	92 (5.0)		
Oesophagus (C15)	265 (5.0)	76 (4.0)	93 (6.2)	96 (5.2)		
All other malignant cancers (excl. C44)[c]	2308 (43.8)	847 (44.2)	646 (42.9)	815 (44.0)		

NB: un-matching subscripts (along the row) (e.g. A, B) denote statistically significant difference, whereas matching subscripts denote no significant difference (e.g. A, A).

Values are represented in frequencies (%) or means and standard deviations.

[a] Due to researcher error, one participant's response status could not be determined (non-response or decline). Therefore, their ONS-linked data were excluded from analyses by response type as it could not be attributed to a response category. However, their data are included in descriptives of the sample overall.

[b] Mean (SD). Browne–Forsythe statistic reported due to non-homogeneity of variance.

[c] Analysis was conducted by individual cancer category. The largest groups are detailed and other cancer types are presented as a summery category 'All other …' for conciseness. Includes other cancer categories – lip oral and pharynx, C00–14; stomach, C16; liver, C22 and C25; larynx, C32; melanoma of skin, C43; skin (other malignant neoplasm), C44; mesothelioma, C45; cervix, C53; uterus, C54–55; ovary, C56–57.4; testis, C62; kidney, C64–66 and 68; bladder, C67; brain, including other central nervous system (CNS) and intracranial tumours, C70–72, C75.1–C75.3, D32–D33, D35.2–D35.4, D42–D43, D44.3–D44.5; thyroid, C73; Hodgkin's disease, C81; non-Hodgkin's lymphoma, C82–85; multiple myeloma, C90; leukaemia, C91–95; and all other malignant cancers.

Non-surprisingly, almost all participants provided informal care in a typical week in the last 3 months of life. The median hours of care provided by each individual totalled 69:30 h (almost 10 h/day) and 25% of participants provided 115:15 h of care, or more, per week; over 16 h/day.

The main type of care provided was social/emotional support. The majority reported contributing to the very practical tasks of everyday living and to the medical care of the patient. Those who helped with personal care spent a high number of hours doing so. These data were supplied as a 'typical' week; a greater volume and intensity of care may occur in the final weeks or days before death. We also hypothesise that intensity of care-giving would vary by care-giver context and we plan to explore this in future analyses. Round et al.[18] estimate informal care provision of 15 h/week and Van Houtven et al.[19] estimate 24.5 h. Given the number of hours of care identified in our study, the financial value of care-giving is likely to be greater than these estimates, even without out-of-pocket expenditure.

Fewer people reported out-of-pocket expenditure than care tasks, but the expenditure reported facilitated vital care for patients. For example, to provide care 50.6% incurred costs travelling, 44.6% spent money on sustenance while they were doing this and 25.1% spent money

Table 2. Participant characteristics ($N = 1504$).

	Frequency (%)
Age (years) (missing $n = 24$ (1.6%))	
Mean (SD)	60.4 (12.28)
Median (min-max)	60 (21–94)
Gender	
Male	517 (34.4)
Female	966 (64.2)
Missing	21 (1.4)
Ethnicity	
White	1439 (95.7)
Mixed/multiple ethnic group	7 (0.5)
Asian/British Asian	16 (1.1)
Black/African-Caribbean/Black British	7 (0.5)
Other ethnic group	6 (0.4)
Missing	29 (1.9)
Educational level	
None	226 (15.0)
Exams at 16 years/equivalent	405 (26.9)
'A'/'AS' Levels/college/equivalent	334 (22.2)
University degree	381 (25.3)
Other	51 (3.4)
Missing	107 (7.1)
Mode of response	
Paper	1395 (92.8)
Online	88 (5.9)
Telephone	21 (1.4)

Frequencies (%) unless otherwise stated.

on medical equipment and care supplies in addition to those supplied by the National Health Service. Participants also reported spending money on one-off costs which may have included care home expenses, house moves or funerals. In adopting a wide definition of care-related costs, such as these, a comprehensive picture of the types of financial expenditure that families are exposed to emerges. Although some of these costs may be seen as outside the remit of care-giving (e.g. funeral expenses), ultimately, these costs are often borne by the family of the dying person and may form part of the contribution a carer makes to support a dying person.

It has been estimated that out-of-pocket expenditure in the last month of life could total \$379CAD (approximately £235GBP/\$284USD)[21] or \$839CAD(approximately £520GBP/\$629USD).[20] Converted to a 3-month estimate of £705, or £1561, these figures are much higher than the £370 we report over 3 months. Differences between the Canadian and UK health systems are likely to lead to different resource needs for carers which may explain some variation in out-of-pocket expenditure reported (e.g. insurance payments). This expenditure represents a sizable contribution to the care-giving process and may have a considerable negative impact for those who incur these costs.

Table 3. Care-giving context ($n = 1504$).

	Frequency (%)
Decedent's relationship to respondent	
Spouse/partner	669 (44.5)
Parent	650 (43.2)
Someone else	157 (10.4)
Missing	28 (1.9)
Proximity to decedent	
In the same house	761 (50.6)
Within walking distance	145 (9.6)
Within 10-min drive/bus or train journey	177 (11.8)
Within 30-min drive/bus or train journey	185 (12.3)
Within 1-h drive/bus or train journey	77 (5.1)
Over 1-h drive/bus or train journey	142 (9.4)
Missing	17 (1.1)
Decedent's primary location in last 3 months of life	
Home	1133 (75.3)
Hospice	34 (2.3)
Hospital	146 (9.7)
Care home	105 (7.0)
Other (including combinations of above categories)	42 (2.8)
Missing	44 (2.9)
Employment status when decedent became ill	
Employed full time	488 (32.4)
Employed part time	202 (13.4)
Self-employed	118 (7.8)
Homemaker	45 (3.0)
Unemployed	25 (1.7)
Retired	548 (36.4)
Other	59 (3.9)
Missing	19 (1.3)

Frequencies (%) unless otherwise stated.

Implications and recommendations

Informal care-giving represents a substantial contribution to society and is vital to the provision of end-of-life care. However, many informal care-givers would be unwilling to provide care again.[34] It is therefore essential that appropriate support, particularly palliative support, is available for family members to ensure the continued provision of care.[35] Our data indicate that carers provide care beyond the safe working hours recommended to preserve health and well-being.[36] It behoves us as a society to support informal care-givers, provide respite when needed and otherwise ensure that hours of care-giving entail the minimum distress and strain. Given the hours that informal care-givers invest in care, and subsequent savings to society, society should invest in them.

Our work suggests that economic analyses of interventions and location of care should, as a matter of course, include contributions given by care-givers in terms of time

Table 4. Time spent on care-giving tasks in a typical week in last 3 months of life (*n* = 1504) (hours:minutes – calculations based on '*n* responded > 0').

	n responded '0 h' (%)	*n* responded > '0 h' (%)	Mean (SD)	Median	Inter-quartile range (25–75)	Missing *n* (%)
Household tasks						
Preparing food and drink	163 (10.8)	1084 (72.1)	13:30 (27:47)	10:00	04:45–14:30	257 (17.1)
Cleaning	159 (10.6)	1093 (72.7)	10:51 (24:09)	07:00	03:00–14:00	252 (16.8)
Maintenance/odd jobs	307 (20.4)	831 (55.3)	04:55 (08:29)	03:00	01:30–06:00	366 (24.3)
Shopping	84 (5.6)	1190 (79.1)	05:23 (21:38)	03:00	02:00–06:00	230 (15.3)
General administration	159 (10.6)	1084 (72.1)	04:02 (09:52)	02:00	01:00–04:00	261 (17.4)
Travelling with patient	286 (19.0)	876 (58.2)	07:09 (18:56)	04:00	02:00–08:00	342 (22.7)
Personal care	231 (15.4)	956 (63.6)	14:07 (22:47)	07:00	03:00–14:00	317 (21.1)
Organising/attending appointments	148 (9.8)	1069 (71.1)	06:14 (12:37)	03:00	02:00–07:00	287 (19.1)
Helping with symptoms	169 (11.2)	1047 (69.6)	11:52 (30:01)	05:00	02:00–10:00	288 (19.1)
Social and emotional support	26 (1.7)	1247 (82.9)	36.03 (54:25)	20:00	08:00–40:00	231 (15.4)
Other	177 (11.8)	153 (10.20)	21:23 (42:20)	06:00	02:30–14:00	1174 (78.1)
Total time spent on care-giving	12 (0.8)	1353 (90.0)	94:59 (123:15)	69:30	28:37–115.15	139 (9.2)

Table 5. Money spent as a result of care-giving (*n* = 1504) (£GBP – calculations based on '*n* responded > 0').

	Indicated $n^{\wedge}$ (%)	Reported n^{+} (%)	Mean (SD)	Median	Inter-quartile range (25–75)	Missing *n* (%)
In last 3 months of life						
Help from others						
Nursing home/private care home	82 (5.5)	74 (4.9)	3138.58 (3384.28)	2000.00	487.50–5000	1422 (94.5)
Privately employing nurse/carer	67 (4.5)	63 (4.2)	1785.90 (2979.05)	500.00	160–1500	1437 (95.5)
Child care	22 (1.5)	21 (1.4)	545.90 (566.73)	400.00	100–852	1482 (98.5)
Odd jobs not normally paid for	250 (16.6)	244 (16.2)	371.74 (901.14)	150.00	60–337.5	1254 (83.4%)
Respite/holidays/day trips	129 (8.6)	125 (8.3)	780.08 (1085.06)	350.00	150–1000	1375 (91.4)
Direct expenses						
Medical equipment/care supplies	390 (25.9)	377 (25.1)	289.10 (907.79)	100.00	50–200	1114 (74.1)
Prescription/non-prescription drugs	128 (8.5)	119 (7.9)	107.47 (279.26)	30.00	20–80	1376 (91.5)
Household bills	410 (27.3)	363 (24.1)	235.62 (395.03)	129.00	80–300	1094 (72.7)
Travel expenses	760 (50.6)	720 (47.9)	208.20 (424.17)	100.00	48.5–207.5	744 (49.5)
Meals/snacks while out	670 (44.6)	631 (42.0)	113.10 (213.40)	50.00	30–100	834 (55.5)
Extra food/supplements/vitamins	323 (21.5)	296 (19.7)	123.03 (313.98)	55.00	30–120	1181 (78.5)
Other	194 (12.8)	179 (11.9)	602.27 (1481.12)	150.00	60–400	1310 (87.1)
Total spend (sum)[a]	–	1090 (72.5)	1025.00 (2024.75)	370.00	150–919	414 (27.5)
Any time since diagnosis						
One-off expense	254 (16.9)	240 (16.0)	8759.84 (44902.50)	2000	756.25–5875	1250 (83.1)

[^] NB: Indicated *n* – participants who indicated they *did* spend money on that item. Total who indicated spending money in last 3 months of life is *n* = 1145 (76.1%); total missing data *n* = 359 (23.9%).

[+] Reported *n* – participants who reported the amount they spent on that item – for 'one-off expenses' respondents reported up to three expenses, which were totalled.

A large proportion of missing data is likely to be systematic, rather than missing due to incomplete reporting, as participants were not asked to indicate if they had *not* spent money.

[a] Only those who reported spending money were included.

and expenditure and our data provide a basis for economic estimates of carer contributions. We adopted, and would recommend, a strong programme of participant engagement in the development of further economic evaluation work in order to maximise response rates among this vulnerable group.

Strengths and limitations

To our knowledge, this study is the first to provide detailed population-based information on the scale of cancer-related care activity and its contribution to end-of-life care. We collected data directly from respondents, using a bespoke survey with a census sample, thereby overcoming limitations of other estimates of carer contributions, and consequently the economic value of informal care, within the UK which have utilised secondary data.

Some post-bereavement surveys of quality of care have achieved response rates of 39%–46%.[37,38] Our survey, which was arguably more cognitively demanding and of a potentially more sensitive nature due to the level of care-giving detail required, reached 28.5% participation. Furthermore, comparisons between participants, decliners and non-responders indicate that our sample was representative of the general population, with only minor differences, which may be partially accounted for by the self-selecting nature of self-report surveys. However, there may be potential bias in reported care-giving by targeting only relatives who reported a death, as they may have provided different support compared to non-relatives.

A lot of palliative care research and economic evaluations rely on retrospective recall and this is also a limitation of this study. Retrospective recall can introduce bias due to inaccuracy in reporting past events, selective memory of the events and double counting or joint production of tasks – where tasks completed simultaneously are reported several times under multiple headings.[39] While it is in principle possible to control for joint production to a certain extent during analyses,[27,40] we added to the survey the instruction to participants not to count any ask twice in order to minimise this type of bias at source. Due to these effects, the data we report on hours of care may be inflated, but to not include certain aspects of care at all to minimise the risk of joint production would involve underestimation.[40] We also tried to overcome bias by being specific about the time frame that tasks were completed, referring to a typical week during the last 3 months of life. However, at end of life few weeks are 'typical' and as such challenging for some participants to conceptualise and report. Retrospective data collection does have disadvantages, but it does elicit more complete data compared with other methods such as diaries.[39] Furthermore, these limitations should be weighed against the advantage of obtaining population-level data for an 'anchored' time period, rather than alternative methods which may have involved a much smaller, resource intensive, less representative sample which would probably include data that vary in time relative to death.

Future research

This article provides a national census overview of cancer care-giving. Further analyses will consider the socio-demographic patterns of care-giving, the impact of care on carers' well-being and estimate the full economic value of end-of-life care provided by family carers of people with cancer comparing different methods for estimation.

We hope that the results of this study will form the basis for further national and international research comparing contribution and costs at end of life for other disease groups and other countries.

Conclusion

The contributions by informal care-givers of cancer patients within the UK may be higher than estimates previously indicated given that we report 69:30 median hours of care compared to previous research based on 15–24.5 h. This study has yielded a unique data set which will allow, for the first time, estimates of the full economic value of family care-giving for cancer patients at end of life based on population-level data within the UK.

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The Regulation and Quality Improvement Authority

Review of the Implementation of the Palliative and End of Life Care Strategy (March 2010)

January 2016

Assurance, Challenge and Improvement in Health and Social Care

www.rqia.org.uk

The Regulation and Quality Improvement Authority

The Regulation and Quality Improvement Authority (RQIA) is the independent body responsible for regulating and inspecting the quality and availability of health and social care (HSC) services in Northern Ireland.

RQIA's reviews aim to identify best practice, to highlight gaps or shortfalls in services requiring improvement and to protect the public interest. Our reviews are carried out by teams of independent assessors, who are either experienced practitioners or experts by experience.

Our reports are submitted to the Minister for Health, Social Services and Public Safety, and are available on our website at **www.rqia.org.uk**.

RQIA is committed to conducting inspections and reviews and reporting on three key stakeholder outcomes:

- Is care safe?
- Is care effective?
- Is care compassionate?

These stakeholder outcomes are aligned with Quality 2020[1], and define how RQIA intends to demonstrate its effectiveness and impact as a regulator.

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[1] Quality 2020 - A 10-Year Strategy to Protect and Improve Quality in Health and Social Care in Northern Ireland - http://www.dhsspsni.gov.uk/quality2020.pdf

Section 3 – Background

Executive Summary

In March 2010, the Minister for Health, Social Services and Public Safety published a new strategy Living Matters Dying Matters (LMDM) for the five year period from 2010 to 2015. The aim of the strategy was to improve the quality of palliative and end of life care for adults in Northern Ireland, irrespective of condition or care setting.

RQIA has reviewed the progress made in taking forward the action plan for the implementation of Living Matters Dying Matters.

RQIA has concluded that significant progress was made during the period 2010 to 2015 towards implementing the recommendations of the strategy. This was facilitated by strongly committed leaders from both statutory and voluntary sector organisations. There is clear evidence of strong partnership working to achieve the objectives of the strategy.

Progress was made during a period of constrained resources, with limited statutory funding to take forward the strategy.

During the period of the strategy, new partnership initiatives developed and the roles of implementation structures changed and evolved. RQIA found some lack of clarity among organisations as to how the range of regional structures fitted together.

Although many initiatives have been developed to raise awareness of palliative and end of life care, there remains a significant lack of understanding about these services amongst service users and staff. There is a continuing need for a coordinated approach to raising public awareness about palliative and end of life care.

RQIA found that there are differences in the availability of services across Northern Ireland, for example during the out of hours period. A priority for the next strategic planning period should be to standardise the availability of core services across populations, while recognising that these services can be provided by different provider organisations for different localities.

One of the principal elements set out in LMDM was that each person with palliative and end of life care needs should have a key worker to coordinate the delivery of their care. RQIA found that while this approach is being actively taken forward in community settings, it is less clear as to how it operates within hospital settings. Different models are operating in different trust areas in both hospitals and the community and it is recommended that the learning from different approaches is evaluated and shared.

During the life of the strategy, there has been an increasing recognition of the importance of having information systems to underpin the delivery of services. There have been important developments in this area, including the Electronic Care Record.

The linked development of a key information summary for palliative and end of life care will enhance the sharing of information between professionals.

During the implementation period, challenges to taking forward the recommendations included the concerns which arose in relation to the Liverpool Care Pathway and its subsequent removal from care settings.

There is an increasing demand for palliative and end of life care services and this is projected to continue in line with changes in the demography of the population and increasing awareness of the importance and value of these services.

RQIA was advised that many patients accessing hospice services now have more complex needs and that this is impacting on the delivery of other services such as respite care.

RQIA found a significant commitment to service development in palliative and end of life care with plans developed for a programme of service improvement initiatives. Organisations advised that additional resources will be required to ensure the full benefits of these initiatives are realised.

The planned implementation timescale for LMDM was 2010 to 2015. In discussion with stakeholders, there is a clear view that the vision set out in the strategy remains valid. A new action plan needs to be developed for the next planning period, building on the work which has been completed to date.

RQIA has made eight recommendations for improvement as a result of this review.

Section 1 Introduction

1.1 Living Matters Dying Matters: Palliative and End of Life Care Strategy

In March 2010, following a period of consultation, the Department of Health, Social Services and Public Safety (DHSSPS) launched the strategy Living Matters Dying Matters (LMDM) at a meeting of the Northern Ireland Group of the National Council for Palliative Care[1]. The overall aim of the Strategy was to improve the quality of palliative and end of life care for adults in Northern Ireland, irrespective of condition or care setting. Palliative care is the active holistic care of patients with advanced, progressive illness such as advanced cancer, heart failure, COPD, dementia, stroke or other chronic conditions[2].

At that time, the Minister for Health, Social Services and Public Safety said: “Living Matters: Dying Matters is a person-centered approach to care that allows people to retain control, dignity and choice in how and where their care is provided to the end of life”.

The vision set by the strategy is that any person with an advanced non-curative condition lives well and dies well, irrespective of their condition or care setting. It recommends the concept of a model for Palliative and End of Life Care as a vehicle for delivering high quality care.

The 25 recommendations contained in the strategy were built into an action plan to enable the planning and delivery of quality palliative and end of life care.

1.2 Action Plan

The 25 recommendations of the strategy are divided up into four sections: Developing; Commissioning; Delivering; and A Model for Quality Palliative and End of Life Care.

(a) Developing Quality Palliative and End of Life Care

The first six recommendations focus on raising awareness and understanding of palliative and end of life care amongst professionals and the public.
They include the need for information, education, development and support for staff, patients, families and carers and development of a research environment.

The strategy highlights the importance of increasing public and professional awareness and understanding about what palliative and end of life care is, and ensuring that those responsible for its delivery have the knowledge, skills and competences necessary to deliver care effectively. The strategy states that individuals receiving palliative and subsequently end of life care should feel confident in the skills and knowledge of their health and social care

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[1] http://www.dhsspsni.gov.uk/8555_palliative_final.pdf

[2] World Health Organisation definition. 2002

professionals and know that their individual expertise is enhanced through good teamwork and the accessibility of 24-hour support.

(b) Commissioning Quality Palliative and End of Life Care

Two recommendations are included to ensure that accountability and leadership for palliative and end of life care would be identified at regional and local levels. There should be evidence that regional and local plans were led by named commissioning leads. There also should be evidence that robust data capture systems were developed and implemented.

(c) Delivering Quality Palliative and End of Life Care

The strategy highlights the need for care to be planned, organised and delivered across care settings which will require significant coordination. The three recommendations in this section include putting in place a key worker for each patient with end of life care needs. There should also be an agreed transfer plan for children to adult services. Organisations were asked to explore the possibility of setting up a managed clinical network.

The key worker role within the strategy is seen as crucial, with responsibility for co-ordinating services and facilitating effective communication of information. The Transforming Your Care (TYC) model of delivery of future health services in Northern Ireland also supports the model for the continuous, holistic assessment of palliative and end of life care, coordinated by a key worker[3].

(d) A Model for Quality Palliative and End of Life Care

This section of the plan sets out actions designed to implement a proposed model of delivery of palliative and end of life care. The actions include ensuring that staff have been appropriately trained in undertaking holistic needs assessments. These form the basis of an individualised patient-centred care plan, agreed with the patient and aimed at planning and delivering care that best meets their capacity/circumstances and requirements. There should be access to 24 hour essential services, with tools and frameworks for providers and planners of palliative care services.

The action plan includes putting in place a locality based register for palliative care patients so as to identify them and address their ongoing needs.
Other aspects of the action plan include providing respite care for families and carers; advance care planning (ACP) to enable patients to have choice over their treatment decisions; timely provision of transport and equipment to help patients and their families to receive care and support in a home environment, as well as good access to appropriate and relevant information for patients and their families.

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[3] http://www.dhsspsni.gov.uk/transforming-your-care-review-of-hsc-ni-final-report.pdf

1.3 Implementation of the Strategy

The Public Health Agency, through its Director of Nursing, Midwifery and Allied Health Professions was tasked with leading the implementation of the strategy's recommendations through a Regional Implementation Board, comprising representation from key stakeholders.

The strategy implementation was delegated by DHSSPS to the Public Health Agency (PHA), with representation from key stakeholders. The remit was to ensure that all the recommendations were developed and embedded into practice.

Service improvement leads were appointed in each of the five trust areas with service improvement programmes, steering groups and implementation projects established in each area.

The timeframe for the implementation of the strategy was over a five-year period from 2010-2015. Timescales were identified for delivery of recommendations and defined as: short (0-12 months); medium (one to three years); and long (three to five years).

The recommendations of the strategy were linked within the wider context of Transforming Your Care (DHSSPS, 2011)[4], which provides a strategic review of health and social care services. The HSC Annual Commissioning Plan also sets out key strategic priorities that include those for palliative and end of life care.

The Transforming Your Palliative and End of Life Care (TYPELC) programme developed in 2013 has supported the delivery of some of the recommendations in the LMDM strategy.

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[4] http://www.dhsspsni.gov.uk/transforming-your-care-review-of-hsc-ni-final-report.pdf

Section 2 Methodology

2.1 Terms of Reference

The terms of reference for this review were:

1. To assess progress against the regional strategy on the action plan for palliative and end of life care[5].

2. To determine the extent of partnership working between stakeholders (statutory, voluntary, community and Independent sector) in the delivery of palliative and end of life care.

3. To report on service user views using a range of relevant reports on palliative and end of life care.

4. To assess any ongoing developments beyond the scope of the regional strategy in relation to future planning of palliative and end of life care.

5. To report on findings and make recommendations as a single report for publication.

Exclusions

The review has not included children and young people which form part of another strategy for this group in palliative care services.

Circulars, guidance, standards, reviews and reports which were issued during the course of this review were not assessed.

2.2 Stages of the Review

The main aspects of the review involved the following:

1. Background review of key strategic work undertaken in relation to the regional palliative and end of life care strategy, including examination of all relevant documentation.

2. Completion of a questionnaire proforma by HSC trusts, HSC Board and independent sector providers (hospices) to assess progress of the implementation of the LMDM regional strategy against the 25 recommendations included in the action plan.

3. Meetings were held in May and June 2015. RQIA's review team met with senior management of the trusts, HSC Board, PHA, and Independent sector service providers (hospices) to discuss progress of the implementation of the strategy.

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[5] Living Matters, Dying Matters: A Palliative and End of Life Care Strategy (2010). DHSSPS.

4. Meeting with team members of the Transforming Your Palliative and End of Life Care (TYPEOLC) programme developed to support the implementation of the recommendations in the regional strategy.

5. Meeting with General Practitioner (GP) Macmillan facilitators representative of HSC trusts.

6. A stakeholder summit event was held in June 2015 to inform stakeholders about the main findings from the review.

7. This event included a presentation on the Transforming Your Palliative and End of Life Care programme to provide an overview of the work of the programme to date.

8. A presentation was given by the All Ireland Institute of Hospice and Palliative Care (AIIHPC) on the findings from the Let's Talk About survey. The survey is a two stage initiative being conducted during 2014 and 2015 to find out the views and experiences of service users and carers of palliative care services in the Republic of Ireland and Northern Ireland.

9. The findings from the information submitted and from the meetings were used to produce the final overview report with recommendations.

2.3 Membership of the Review Team

Dr Conn Haughey	Specialist trainee in Palliative Medicine, NIMDTA
Dr David Stewart	Director of Reviews and Medical Director, RQIA
Janine Campbell	Project Administrator
Patricia Corrigan	Project Administrator
Dean McAllister	Project Administrator
Mary McClean	Project Manager

Section 3.0 Background

3.1 Palliative and End of Life Care (PELC)

Good palliative and end of life care is an important part of health and social care. Living Matters Dying Matters (LMDM) defines palliative and end of life care as “the active, holistic care of patients with advanced progressive illness”.

Around half of all deaths occur in hospital in the United Kingdom[6]and almost three in every 10 hospital inpatients are in their last year of life[7].

In the past, palliative care near the end of life was mainly offered to patients with cancer, but it is recognised that it should now be offered for a wider range of serious illnesses. [8] Long-term conditions, such as chronic obstructive pulmonary disease (COPD), dementia and heart failure, account for around 60 per cent of all deaths.

In a survey, it was found that almost a fifth of people in Northern Ireland have no understanding of the term palliative care. A repeated theme, borne out in this survey, was that having a close friend or relative accessing palliative care services was associated with increased awareness and familiarity with the concept and services**.** [9]

There are gaps in and issues with the provision of palliative and end of life care that countries in the United Kingdom are seeking to address through national end of life care strategies and delivery plans. The End of Life Care Strategy[10] published by the Department of Health in 2008, identified a number of significant issues affecting dying and death in England:

- Some people die as they would have wished, but many do not. Many people do not die in the place they would choose to; many do not receive quality care at the end of their lives; and there are reports that people have not been treated with dignity and respect.

- In the past, the profile of end of life care across the NHS and across society has been relatively low, leading to variability in access to and the quality of end of life care across the country and in different communities.

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[6] ONS (2014) Deaths: area of usual residence and sex, by place of occurrence, numbers and percentages, 2013. England and Wales; Deaths, by sex, cause and place of occurrence and whether post mortem performed, Scotland, 2012 provided by the General Register Office for Scotland; NISRA (2013) Statistical Bulletin: Death in Northern Ireland 2012

[7] Clark D et al. (2014). Imminence of death among hospital inpatients: Prevalence cohort study. Palliative Medicine28 (6) pp. 474–479. June 2014.

[8] Joined up thinking, Joined up care, Scottish Partnership for Palliative Care, 2006

[9] Sonja McIlfatrick, Felicity Hasson, Dorry McLaughlin, Gail Johnston, Audrey Roulston, Lesley Rutherford, Helen Noble, Sheila Kelly, Avril Craig and W George Kernohan BMC Palliative Care 2013, 12:34.
www.biomedcentral.com/1472-684X/12/34

[10] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf

- People are uncomfortable talking about dying and death, meaning that when they come to the end of their lives, friends and loved ones are not aware of their preferences.

3.2 Key Components of Palliative and End of Life Care

Palliative and end of life care refer to the care of people who have an incurable and progressive illness. It enables the palliative care needs of both patient and family to be identified and met throughout the last phases of life and into bereavement. The LMDM strategy identifies end of life as the period of time during which an individual's condition deteriorates to the point where death is either probable or would not be an unexpected event within the ensuing 12 months; however, a specific timescale cannot always be applied.

The key components of palliative and end of life care are:

- Management of physical symptoms which include nausea and vomiting, constipation, loss of appetite and pain.

- Provision of psychological, social and spiritual support to the person and their friends and family. The National Institute for Health and Care Excellence (NICE) has set a quality standard for palliative care for adults that includes social and practical support[11]. NICE recommends that lower levels of need should be met by health professionals providing the person's day-to-day care, and higher levels of need met through intensive services provided by specialists.

- Advance care planning is a structured discussion between health and social care professionals with the dying person and their family and carers about their wishes, needs and preferences for future treatment and support. Any decisions made can be recorded to ensure that care is planned and delivered according to their wishes. This process has been shown to help the person to live and die in the place and the manner of their choosing.

3.3 General and Specialist Palliative and End of Life Care

General palliative and end of life care is delivered by multidisciplinary teams in primary and community care settings, hospital units and wards. This is the level of care required by most people and is provided by GPs, district nurses, allied health professions (AHPs) and social workers.

Specialist palliative and end of life care is the management of unresolved symptoms and more demanding care needs including complex psychosocial, end of life and bereavement issues. This is provided by specialist personnel with expert knowledge, skills and competences, based in hospitals, specialist

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[11] National Institute for Health and Care Excellence (2011). Quality standard for end of life care for adults. Quality statement 5: Holistic support – social, practical and emotional. London: NICE.

hospice units, and in the community, providing support through community specialist palliative care teams and palliative medicine outpatient clinics.[12]

Most patients will not require specialist palliative care; however when there are unresolved or complex physical, psychological, social or spiritual issues, then specialist palliative care teams will be involved.

Specialist palliative care was initially developed as a means of providing support to people with cancer nearing the end of life. However, specialist palliative care teams within Health and Social Care (HSC) and voluntary sector organisations now deliver this care for people at much earlier stages of illness, including those with non-cancer palliative conditions[13] [14]. There is emphasis in policy on community-based specialist palliative care teams supporting people with more complex palliative care needs, with generalists providing wider care.

3.4 Changing Roles of Specialist Services

There is increasing recognition among healthcare professionals that a palliative care approach may be beneficial for a person with a non-curable condition at any point, from diagnosis through to end of life care.

As specialist palliative teams are increasingly involved in the care of patients at earlier stages of illness, where active investigations and treatment for their underlying condition are often ongoing, the complexity of symptom management and level of acute interventions delivered by specialist palliative teams has shifted, including in hospice settings.

These changes in levels of intervention, particularly in hospice settings, have also been driven by patient, professional and public expectations of what is delivered in specialist hospice units and very often the wish of patients to avoid hospital admissions.

Having a cancer diagnosis is at present the most common reason for access to specialist palliative care. In 2012-13, across England, Wales and Northern Ireland, 88 per cent of palliative care inpatients and 75 per cent of new referrals to hospital support and outpatient services were for people with a cancer diagnosis, even though cancer accounts for only around 29 per cent of deaths.[4]

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[12] Living Matters Dying Matters: A Palliative and End of Life Care Strategy For Adults in Northern Ireland. March 2010**.** DHSSPS.

[13] *From margins to centre: a review of the history of palliative care in cancer*, Clark D, Lancet Oncol, 2007.

[14] *Continuity in Palliative Care. Key Issues and Perspectives*, Munday D, Shipman C, eds, Royal College of General Practitioners, London, 2007.

3.5 Development of Services in Northern Ireland

3.5.1 Palliative Care HSC Services in Northern Ireland

Palliative care is provided by a wide range of organisations that include HSC trusts, hospices and by GPs in primary care. Acute services have seen a change in the demographics over recent years with an increase in complexity of referral and the inclusion of referrals being received from all life limiting disease groups. Responding to these changes has been a particular focus for the development of services.

The regional LMDM strategy reported that HSC services for people with palliative and end of life care needs have improved considerably over recent years. Much of this improvement has been attributed to the work of the hospice movement, which has provided an important impetus. Other contributing factors have been the development of creative partnerships, such as the NICaN supportive and palliative care network, between public, independent, community and voluntary sector organisations, working together to design, develop and deliver services.

Local HSC trusts have a responsibility for the development of palliative care services. This includes the development of specialist palliative care teams and the appointment of palliative care consultants who work in partnership and in collaboration with the hospices, and other voluntary organisations in designing and developing services.

3.5.2 Hospices

Hospice care also takes into consideration concurrent stressful symptoms, for example, loss of appetite, nausea, as well as depression, anxiety and incontinence[15]. At the Northern Ireland Hospice for example, the average number of medications taken by a patient admitted is now thirteen. The high use of intravenous antibiotics and syringe driver medications is further indication of the fact that the patient population being treated is increasingly medically complex. Multidisciplinary approach including medical and nursing input, AHP, social work, pharmacy and chaplaincy care includes control of these symptoms.

The change in demographics observed over recent years has led to increasing complexity in the patient population cared for in hospices. In the past, hospices provided care and support for people with advanced cancer. Today, the focus of hospice care is for patients diagnosed with a non-curable illness who require specialist palliative support, which may include end of life care. This can apply to a wide range of conditions, as well as for those with cancer.

Hospices are viewed very positively by the general public. More than two-thirds of people (69 per cent) in a poll of 2,036 adults carried out for Help the Hospices regard hospices as ”a place that offers compassionate care”.[16] However, only

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[15] Hospice: Rehabilitation in reverse. Senthilkumar Jevaraman et al. Indian J Palliat Care 2010

[16] Populus. (2013) Attitudes to hospice care. [Fieldwork conducted 20 and 22 September 2013.] www.populus.co.uk/Poll/Help-the-Hospices

20 per cent of patients diagnosed with organ failure (heart, lung, liver or kidney) or dementia, either requested or were identified for palliative care before dying, compared to 75 per cent of cancer patients.[17]

3.5.3 Respite Care Short Breaks

Respite care, also referred to as short breaks can be identified as a need for the individual themselves, as well as for family and carers. It should be accessible in a variety of ways including within the patient's home or care home, in a community hospital or within hospices.

The LMDM strategy indicates that respite care should be flexible in its accessibility as well as age appropriate to the patient, and available irrespective of condition. Respite care offers carers valuable and necessary independent time and provides patients with the opportunity to experience a change of environment and stimulus. (p58, LMDM).

Respite care is usually provided on a short-term and time limited basis, from a few hours per week, to a number of weeks, and can be either planned or provided in response to an emergency. It can be provided in a variety of ways, either outside or inside the patient's home, and should be tailored to the needs of individual families and carers (p98, LMDM).

3.5.4 Rehabilitation

Rehabilitation aims to improve quality of life by enabling people to be as active and productive as possible, with minimum dependence on others regardless of life expectancy**.**

Rehabilitation is provided by a wide range of health professionals, including physiotherapists, occupational therapists, dietitians and speech and language therapists. This is an essential part of the journey for anyone living with the physical, functional and psychological impact of a long-term condition and its consequences. Rehabilitation support is widely recognised as being preventative, restorative, supportive and palliative.

Rehabilitation includes exploring the process of functional adaptation and occupational engagement on a daily basis. Throughout each phase of decline during the dying process, new or adapted skills and abilities are learned by the patient, as well as the care givers, to maximise functional independence and safety.

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[17] Zheng L, Finucane AM, Oxenham D, McLoughlin P, McCutcheon H, Murray SA. How good is primary care at identifying patients who need palliative care? A mixed-methods study. European Journal of Palliative Care 2013; 20: 216–222 www.palliativecarescotland.org.uk/content/publications/How-good-is-primary-care-at-identifying-patients-who-need-palliative-care---a-mixed-methods-study.pdf

3.6 Equitable Access to Palliative Care

It has been reported that over the next 25 years the number of deaths in the United Kingdom is set to increase by around 100,000[18]. For Northern Ireland, the number of deaths is projected to increase gradually, from 14,200 in 2012 to 15,800 in 2027[19].

The research also shows that around three-quarters of these people will benefit from some form of palliative care[20].

A report published by the Royal College of Physicians in 2007,[21] made 33 recommendations relating to service development, service provision, workforce, training and research, which include standards of care that need to be delivered by health care services for those with palliative care needs. These included that clinicians dealing with people who are dying should have a clear understanding of how to discuss the needs of their patients with them and their loved ones.

In a recent report commissioned by Marie Curie,[22] Equity in the Provision of Palliative Care in the United Kingdom, has argued that diagnosis, ethnicity, social background and age can all be barriers to receiving palliative and end of life care. The report states that there are approximately 3,000 people a year in Northern Ireland who would benefit from palliative care but who are currently not receiving it.

In a paper relevant to Northern Ireland produced by Marie Curie, a number of recommendations were made to significantly improve equitable access to palliative care for everyone, regardless of their condition. [23] Marie Curie indicated that there is a "clear need for integrated care across conditions, across primary and secondary care, between health and social care, and between medical care and self-management". The recommendations made are shown in Figure 1.

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[18] ONS (2014). 2012-based National Population Projections

[19] NISRA Statistical Report 2012-based population projections

[20] Murtagh FEM, Bausewein C, Verne J, Groeneveld EI. (2014). *How many people need palliative care? A study developing and comparingmethods for population-based estimates*. Palliative Medicine, January 2014, vol 28, no. 1, pp 49–58

[21] Royal College of Physicians (2007) Palliative care services: meeting the needs of patients. Report of a working party, RCP, London.

[22] Josie Dixon, Derek King, Tihana Matosevic, Michael Clark and Martin Knapp. Equity in the Provision of Palliative Care in the UK: Review of Evidence April 2015

[23] Marie Curie. Triggers for palliative care. Improving access to care for people with diseases other than cancer Implications for Northern Ireland. June 2015.

Figure 1: Recommendations made from Marie Curie report on improving access to care for people with diseases other than cancer. These recommendations are directed to health care professionals; health care bodies and researchers.

For the Northern Ireland Executive:

- The DHSSPS should commit to providing the resources required to ensure all those who need palliative care in Northern Ireland can access palliative services, regardless of their condition.
- A future palliative care strategy (replacing LMDM) should outline resources for supporting those who need palliative care.
- Mandatory practice based palliative care training to be undertaken as part of continuing professional development for all staff involved in the healthcare of people with a terminal illness

For health and social care bodies:

- All health and social care bodies should recognise in their planning (service, financial and workforce) the importance of ensuring that everyone understands what palliative care is, what it can offer patients across all disease conditions and how it can be accessed.
- Develop clear care pathways and guidance which can be used in service planning and commissioning. This guidance should recognise the triggers identified in this report. Where this already exists it should be reviewed against best practice and greater efforts should be made to encourage awareness and implementation.
- Health and social care bodies should ensure their palliative care strategies and service delivery plans recognise the important role that can be played by disease specific nurse specialists. Nurse specialists should receive training and support to enable them to deliver palliative care.

For health and social care professionals:

- Carry out regular holistic needs assessments for all those living with terminal conditions and, where it is in the best interest of the patient, introduce a palliative care approach or make referrals to specialist palliative care based on this assessment.
- Facilitate well-coordinated care by developing stronger relationships between condition-specific health professionals and palliative care specialists in both acute and community care settings.

For researchers:

- Need for more research which focuses on need and outcomes.
- To develop a robust population-level assessment of need (including unmet need) for specialist and generalist palliative care in Northern Ireland.
- To develop standard quality and outcome indicators which focus on palliative care for people for whom it would be beneficial across all disease conditions, and which translate across care settings.

3.7 Transforming Your Care

Transforming Your Care: A Review of Health and Social Care in Northern Ireland (TYC) was published in December 2011. It described a new model of service delivery to ensure the HSC was able to meet future challenges. The report made 99 proposals for change to implement the new service model. The proposals included:

- Individual assessment, planning, delivery and coordination of end of life care needs by a key worker. (TYC Proposal 82)

- Electronic patient records in place for palliative patients, their families and staff. (TYC Proposal 83)

The HSC Board, in response to the 99 TYC proposals, developed a strategic implementation plan in 2013 to provide a coherent, controlled and managed framework to bring existing programmes together and initiate new ones, to deliver the proposals in an integrated manner. The plan contained a number of objectives for delivery of palliative and end of life care. Key areas include:

- Development of HSC trust information systems to identify patients approaching the end of life.

- Development of care plans which are continually reviewed for those in the last year of life. (These should include do not attempt resuscitation (DNAR) wishes, place of care and referral for carer’s assessment).

- Ensuring that people identified as being in the last year of life have been offered the opportunity to have advance care plans developed.

- Increased access to specialist palliative support out of hours and enhanced links between specialist and generalist services.

- End of life and palliative care standards should be met for those with long term conditions, such as cancer, heart failure, renal disease, stroke and respiratory disease by March 2014.

A key TYC proposal was the development of integrated care partnerships (ICPs), which were established in 2013 as collaborative networks to join together the full range of health and social care services to determine the needs of local populations, and planning and delivering integrated services.

The 17 ICPs established across Northern Ireland have an initial focus on frail elderly and aspects of long-term conditions namely diabetes, respiratory conditions and stroke (including end of life and palliative care in respect of these areas).

3.7.1 Palliative Care Service Delivery

Figures produced as part of the TYC review showed that two-thirds of all deaths in Northern Ireland would benefit from a palliative care approach in the last year of life, but do not receive it. Currently, 20,000 bed days per annum are used in Northern Ireland for people dying in hospital from cancer conditions alone[24].

The HSC Board commissioning plan 2014-15 put forward a number of proposals to be delivered in relation to palliative and end of life care. These are shown in Figure 2.

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[24] Transforming Your Care: A Review of Health and Social Care in Northern Ireland. December 2011. (p111).

Figure 2: HSC Board Proposals for Palliative Care (Commissioning Plan, 2014-15)

The main priority to be taken forward by the five LCGs during 2014-15 is:

- Provision of primary care aligned 24/7 community nursing services, including district nursing to deliver acute and complex care at home and palliative and end of life care at home or in the most appropriate Community facility. As part of this at a local level, ICPs are expected to bring forward proposals for the effective management of palliative and end of life care, in respect of the agreed condition groups, which avoids admission to hospital wherever appropriate.

Other commissioning priorities to be taken forward by the five LCGs during 2014-15 include:

- Access to more options for carers in the provision or arrangement of their respite/short breaks. (TYC Recommendation 13 and 19).
- In conjunction with the ICPs the Transforming Your Palliative and End of Life Care programme will redesign service across sectors to improve the quality of life for those in the last year of life.
- ICP's will also be contributing to the Transforming Your Palliative and End of Life Care programme.
- ICPs will give consideration to the role of community pharmacy in supporting palliative care (in respect of the agreed condition groups), including urgent response out-of-hours.

3.8 Service Frameworks

The DHSSPS has established a programme for the development of service frameworks for health and social care services in Northern Ireland.

Service frameworks set out the standards of care that patients, carers and any wider family network can expect to get in order to help prevent disease or harm; manage health and wellbeing (i.e. by knowing how to reduce their risk of poor health and knowing what to do if they become ill); be aware of the types of treatment and care available within health and social care; and be clear about the standards of treatment and care to expect to receive.

The standards seek to ensure that health and social care services are safe, effective, efficient, accessible, patient/client centred and equitable.

A number of frameworks have been developed as regional priorities that include generic standards related to palliative and end of life care. For example, the service framework for respiratory services, shown in Figure 3 describes the standard for patients with palliative and end of life care needs.

Figure 3: Generic standard for palliative and end of life care (Respiratory services framework November 2009)

Overarching Standard 53:

Palliative Care
Health and social care professionals, in consultation with the patient, should identify, assess and communicate the unique supportive, palliative and end of life care needs of that person, their caregiver/s and family.

Overarching Standard 54:

Palliative Care
All patients, carers and families should have access to responsive, integrated services which are coordinated by an identified team member according to an agreed plan of care, based on their needs.

Overarching Standard 55:

End of Life Care
All people with advanced progressive conditions, their caregivers and families, will be informed about the choices available to them, by an identified team member, and have their dignity protected through the management of symptoms and maximising comfort in end of life care.

3.9 The Liverpool Care Pathway

The Liverpool Care Pathway for the Dying Patient (LCP) was developed as a generic approach to care for the dying, which was intended to ensure that uniformly good care was given to everyone thought to be dying, within hours or days, whether they are in hospitals, nursing homes, or in their own homes.

Following concerns expressed by bereaved relatives, Norman Lamb, MP, Minister of State for Community and Social Care, asked Baroness Julia Neuberger to chair an independent review into the use and experience of the LCP in England[25]. The review, More Care, Less Pathway, acknowledged that where the LCP was used well, it facilitated good care of dying people, but found many instances where its use was associated with poor experiences of care.

The review panel made 44 recommendations, including the phasing out of the LCP within six to twelve months of the date of the report. Many of the problems in the care of the dying highlighted in the review report, were due to poor understanding among clinicians of existing guidance in care for the dying, and an unwillingness to discuss with patients, their relatives and carers the prospect of death and the clinical uncertainties that accompany it.

At the time of publication of LMDM, the use of the LCP was considered as an example of good practice. Following consideration of the recommendations of the More Care, Less Pathway report, and the implications for Northern Ireland, on 30 July 2014 the Chief Medical Officer issued advice to the HSC that:[26]

"…the Liverpool Care Pathway (LCP) should be phased out in Northern Ireland as soon as practicable and by the end of October 2014 at the latest. In light of this, the recommendation in the Department's Living Matters: Dying Matters Strategy (Recommendation 23) – which states that tools to enable the delivery of good palliative and end of life care, such as the Liverpool Care Pathway, should be embedded into practice across all care settings with ongoing facilitation is no longer applicable insofar as it relates to the use of the Liverpool Care Pathway. The recommendation is however still appropriate for other tools that support palliative and end of life care, such as the Gold Standards Framework and the Preferred Priorities for Care".

New draft NICE guidelines (consulted on during 2015) set out a range of good practice, many of which reflect lessons from the Neuberger report.

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[25] Independent Review of the Liverpool Care Pathway: More Care Less Pathway (2013).https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf

[26] www.dhsspsni.gov.uk/index/phealth/professional/cmo_communications.htm

3.10 Initiatives Supporting the Development of Palliative and End of Life Care Services

3.10.1 Development of GAIN Guidelines for Residential Settings

In December 2013, the Guidelines and Audit Implementation Network (GAIN) published Guidelines for Palliative and End of Life Care in Nursing Homes and Residential Homes, for Northern Ireland[27].

The guidelines were developed in the context that nursing and residential homes are increasingly the place where people nearing the end of life will live and be cared for until their death. They were designed to build on what has already been achieved through implementation of DHSSPS nursing home and residential care home minimum standards[28].

The guidelines were developed by a multi- professional and multiagency group and link to the End of Life Care Operational System (ELCOS) model. The guidelines are supported by a self-assessment audit tool.

Each year, RQIA identifies standards for particular focus during the inspection year for nursing and residential homes. During 2015-16 RQIA included palliative and end of life care as a particular area of focus.

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[27] http://www.rqia.org.uk/cms_resources/Palliative_Care_Guidelines-20_November2013.pdf
[28] http://www.dhsspsni.gov.uk/nursing_homes_consultation_-_standards.pdf

3.10.2 The Transforming Your Palliative and End of Life Care Programme

Transforming Your Palliative and End of Life Care[29] (TYPEOLC), is an initiative developed by Marie Curie and supported by the HSC Board and PHA. It is based on the delivering choice approach. Delivering choice programmes (DCP) had previously been delivered in 19 sites across the United Kingdom by Marie Curie, with a key aspect being a collaborative approach involving all relevant partners and sectors, to design and deliver high quality palliative and end of life care.

The programme was not set up as an initiative of LMDM and had a separate governance structure.

This programme (initiated in August 2013 and currently in place to December 2015) was commissioned to work alongside any work underway through LMDM, TYC and ICPs. TYPEOLC supports a key principle of TYC that care should be provided at home or as close to home as possible, where this is safe and appropriate.

Eight initiatives were developed under the programme, with the support of a design group for each initiative.

The initiatives are:

- identification and planning for people with palliative care needs
- enhanced access to palliative care services at home
- day hospice
- support for patients and carers
- palliative pharmacy
- ambulance service
- supporting planned discharge and provision of equipment
- training for healthcare providers

Each design group is jointly chaired by two senior leaders from Northern Ireland voluntary or statutory bodies. The work of the design groups has led to agreed deliverables which are dependent on moving to an implementation phase to be taken forward.

RQIA found that there was strong support for the work of this programme, but that there was concern that lack of resources may prevent full implementation of the proposals that have been developed. RQIA was advised that the development of a business case would be required to seek funding to take this work forward.

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[29] http://www.transformingyourcare.hscni.net/tyc-in-action/palliative-and-end-of-life-care/

3.10.3 All Ireland Institute of Hospice and Palliative Care

The All Ireland Institute of Hospice and Palliative Care (AIIHPC)[30] was formally established in October 2010 following a successful bid by a Consortium of members to secure funding for the organisation. The members of the Consortium from Northern Ireland include: Marie Curie Centre Belfast; Northern Ireland Hospice Belfast; Queen's University Belfast; and Ulster University. The PHA contributes to the funding of the institute.

AIIHPC is committed to working towards seven strategic outcomes:

1. Palliative care provision and developments are informed by user, carer and community voices.

2. Palliative care information is accessible through a single point to all stakeholders.

3. Palliative care education, relevant to individual need, is available and accessible.

4. Increased leadership capacity supports palliative care policy development and provision.

5. High quality innovative research support evidence-based palliative care.

6. Public awareness and understanding of hospice and palliative care is increased.

7. All-island partnerships and networks promote shared learning in palliative care.

AIIHPC has participated in a United Kingdom and Ireland project, developed by the palliative and end of life care priority setting partnership initiated by Marie Curie. This process has identified a top 10 list of research priorities identified in a report for palliative and end of life care relevant for the island of Ireland [31]. These priorities are shown in figure 4. The top priority was improving out-of-hours care; followed by providing care in the patient's home; and then pain and symptom relief.

The Palliative and end of life care Priority Setting Partnership (PeolcPSP) was initiated by Marie Curie in 2013 and involved 30 other organisations and groups. The partnership undertook a survey of 1,403 people from across the four nations who were likely to be within the last years of life and also included current and bereaved carers and health and social care professionals. As part of the survey a list of the top 10 unanswered research questions were identified and prioritised in a published report[32].

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[30] http://aiihpc.org/

[31] http://aiihpc.org/wp-content/uploads/2015/06/PeolcPSP-AIIHPC-report.-FINAL.-april.15.pdf

[32] http://www.palliativecarepsp.org.uk/wp-ontent/uploads/2015/01/PeolcPSP_Final_Report.pdf

The United Kingdom and Ireland project top 10 list of priorities differs from the AIIHPC group. These focused on how access to palliative care services could be improved for everyone, regardless of where they are in the United Kingdom; followed by the benefits of advance care planning; information and training for carers and families; ensuring that staff, including healthcare assistants, are adequately trained to deliver palliative care. Also, the best ways to determine a person's palliative care needs; core palliative care services that should be provided; benefits, and best ways, of providing care in the patient's home; continuity for patients at the end of life and best ways to assess and treat pain and discomfort.

A palliative care research network has been established for Northern Ireland with work streams relating to social justice and measurement and evaluation.

AIIHPC is developing a palliative care hub to act as a gateway to information about palliative care on the island of Ireland. The hub is being designed to deliver information and resources through four different components; children and young people palliative hub; adult palliative hub; learning platform and professional palliative hub.

Figure 4: The top 10 priorities for palliative and end of life care in order of priority, on the island of Ireland

1. What are the best ways of providing palliative care outside of ‘working hours’ to avoid crises and help patients to stay in their place of choice? This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families?

2. What are the benefits, and best ways, of providing care in the patient’s home and how can home care be maintained as long as possible? Does good co-ordination of services affect this?

3. What are the best ways to make sure that palliative care patients receive adequate pain and symptom relief and which drugs for pain management are best in terms of side-effects, such as drowsiness?

4. What are the best ways for healthcare professionals to tell patients, carers and families that a patient’s illness is terminal and also explain the dying process compassionately and honestly? Can literature, including leaflets, be helpful? Who is the best person to provide this information and communication?

5. What are the benefits of Advance Care Planning and other approaches to listening to and incorporating patients’ preferences? Who should implement this and when?

6. What are the best ways to make sure there is continuity for patients at the end of life, in terms of the staff that they have contact with, and does this improve quality of palliative care? Would having a designated case-coordinator improve this process?

7. What are the best ways to support children and young people when someone close to them is dying or has died? This includes communicating with them about the diagnosis and dying process, enabling them to talk about their experience and providing bereavement support.

8. What information and training do carers and families need to provide the best care for their loved one who is dying?

9. What are the best ways to begin and deliver palliative care for patients with non-cancer diseases (such as COPD, heart failure, MND, AIDS, multiple sclerosis, Crohn’s disease and stroke)?

10. Are hospices, hospitals and care homes providing adequate staff training to deliver specialist palliative care, and to what extent does funding affect this? How can high quality trained staff be ensured no matter where the care is being delivered?

Section 4 Service Profile of Palliative and End of Life Care Services in Northern Ireland

In Northern Ireland, around 30 per cent of deaths are due to cancer, 25 per cent due to circulatory conditions and 14 per cent due to respiratory disease[33]. Changing demographics mean that people are living longer and often with one or more chronic conditions. As a result, over time, increasing numbers of people will require more complex care for longer.

By 2020, population projections (based on 2012 estimates) suggest that the number of people in Northern Ireland aged 65 and over will increase by a quarter in ten years (2012-22), from 273,000 to 344,000[34]. This represents 16 per cent of the total population. It is within this section of the population that the highest incidence and mortality from cancer and other chronic conditions exists. Given that the prevalence of chronic conditions and dementia increases with age, demand for palliative and end of life care services is likely to increase as the population ages and more people live with the consequences of physical and cognitive frailty[35].

4.1 Palliative Care Services

Palliative and end of life care is delivered by all HSC trusts and by voluntary and independent sector providers across Northern Ireland.

The HSC Board commissions both generalist and specialist palliative services. Generalist palliative care is care that is delivered by multi-professional teams in primary and community care settings, hospital units and wards. This is the level of care required by most people and is provided by non-palliative and end of life care specialists.

Specialist palliative care is the management of unresolved symptoms and more demanding care needs, including complex psychosocial, end of life and bereavement issues. It is provided by specialist palliative care professionals with expert knowledge, skills and competences.

Appendix 1 shows a summary of palliative and end of life care services delivered by each HSC trust. Appendix 2 shows a summary of services provided by each of the four independent sector hospices in Northern Ireland. Figure 5 shows a map to indicate the location of palliative care services. Statutory HSC services deliver for community specialist palliative care, acute specialist palliative care and primary/generalist palliative care. The majority of palliative care is delivered through general palliative care services, including primary care, while specialist palliative care teams are available within the acute hospital and community services.

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[33] Northern Ireland Statistics and Research Agency (NISRA), 2014
[34] Northern Ireland Statistics and Research Agency (NISRA), 2012 population projections
[35] http://www.pallcareni.net/palliativecareinni/whatshappeninginnorthernireland

4.2 Northern Ireland Ambulance Service

The Northern Ireland Ambulance Service Trust (NIAS) plays a key role within the regional strategy to help provide equipment, transport and adaptations, for all patients who have rapidly changing needs.

As part of the implementation of the LMDM palliative care strategy NIAS was commissioned by the HSC Board to develop an enhanced service for palliative care.

This led to the development of the treat and leave/referral pathway, which came into being at end of April 2015. The benefit of this referral pathway is that patients are safely and appropriately treated in their preferred place of care without the need to transport them to an emergency department.

The palliative care service is provided by Marie Curie and community nurses in the HSC trusts and supported by GP out-of-hours in all LCG areas except for the southern sector of the Western Trust.

During daytime hours from Monday to Friday, an ambulance crew can refer to the patient’s own GP if they are is available. However, if the GP is unable to attend, the patient is then transported to a hospital emergency department. NIAS has advised that the preferred approach would be to have a single point of contact for in-hours referrals similar to out-of-hours. With the expansion of community nursing services, this may be possible in the future.

Information markers can be used by NIAS to identify an address and a specific individual within that address. Currently, NIAS personnel have limited information regarding the patient they are attending to; however by using information markers, the ambulance control room staff will be able to pass patient specific protocols to the responding crew before they arrive on scene. Having early access to this information will assist the crew with their clinical decision making.

4.3 GP Macmillan Facilitators

Each HSC trust has access to GP Macmillan facilitators who are usually GPs, and who are part of the trust community specialist palliative care team. These posts are provided on a sessional basis and the number of sessions can vary between trusts.

The GP Macmillan facilitators provide advice and information to the multidisciplinary team and meet regularly with a range of multidisciplinary staff to contribute to raising awareness about palliative and end of life care initiatives.

The facilitators can be involved in training for GPs and other health care staff; for example providing training in having difficult conversations through programmes such as Sage and Thyme, referenced in the LMDM strategy[36] to provide enhanced communication skills for staff who need to speak to family members, carers and patients. They also can have a strategic role reflecting the views and opinions of GPs at meetings within respective HSC trusts.

As part of the GP contract, GP practices keep a register of patients who require palliative care and the practices hold multidisciplinary case reviews of all patients on the palliative care register. This process is monitored by the HSC Board and is discussed at practice review meetings.

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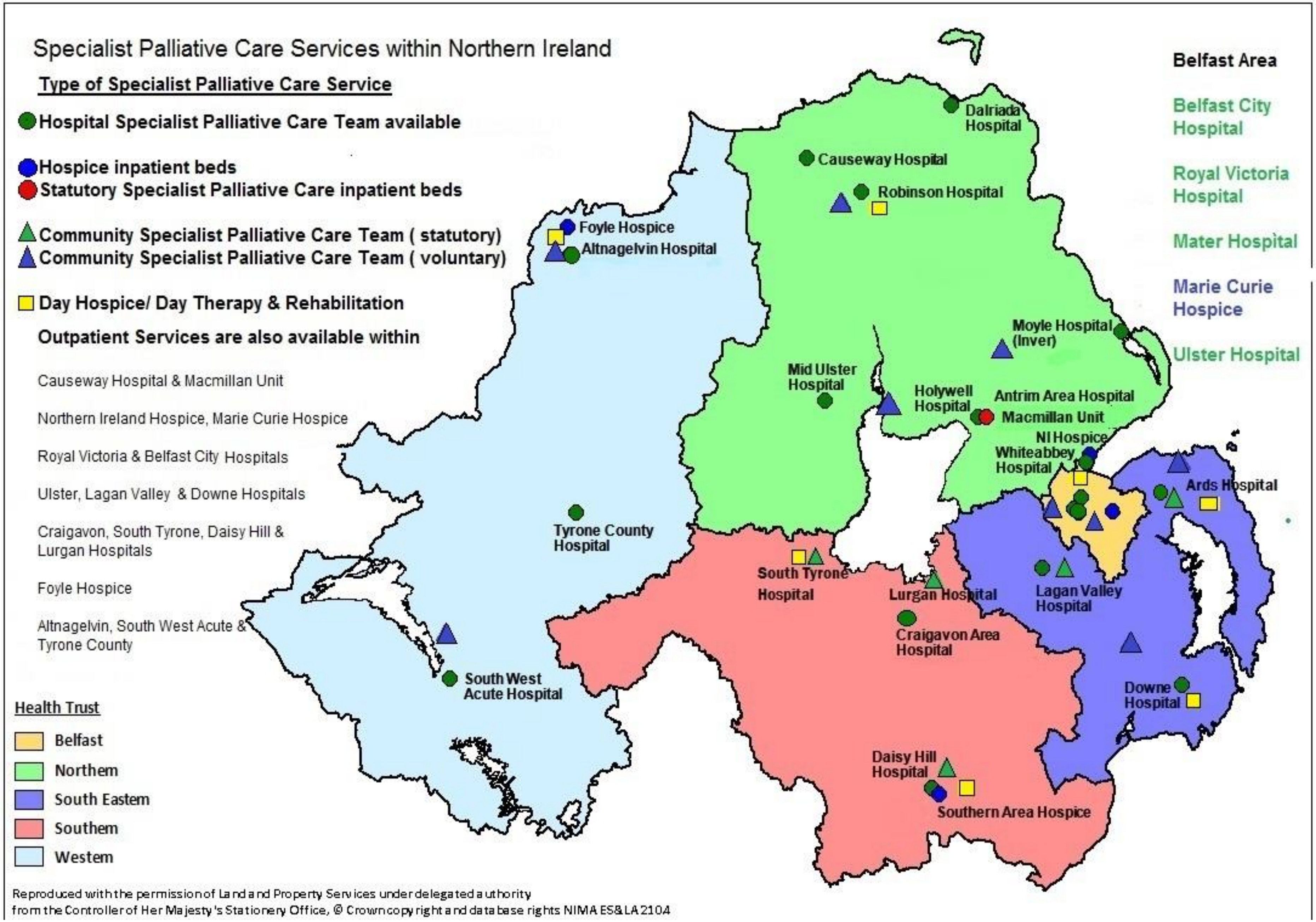
[36] A model for training health and social care professionals in patient–focused support Referenced in LMDM strategy; p58.

Figure 5: Location of Specialist Palliative Care Services in Northern Ireland (August 2015)



4.4 Input from the Voluntary Sector in the Planning and Provision of Services

The HSC Board has contracts in place with community and voluntary sector organisations which provide support to patients and their families/carers with palliative and end of life care needs. HSC trusts can also have contracts in place within community and voluntary organisations.

Some of the aspects of care delivered by the voluntary sector for palliative care provision include the following[37]:

- specialist palliative inpatient and outpatient services
- jointly funded posts
- funding and provision of education and training
- funding and participation in research
- loans and assistance to purchase equipment
- day services
- support for carers
- patient information
- fundraising and public awareness
- health promotion
- respite care
- bereavement services

The HSC Board and PHA, along with the voluntary and community sectors, are progressing work streams with representation from stakeholders from the relevant sectors (HSC trusts, DHSSPS, HSC Board, PHA and voluntary and community sectors, PCC). For example:

- advance care planning
- HSC Board/PHA/Hospice Interface meetings
- advanced communication skills training facilitators forum

The National Council for Palliative Care initially was formed in the late 1980s as a single body to represent service providers delivering specialist palliative care services which include hospices. The charity has developed since that time to include a focus on other life limiting conditions such as heart failure and dementia. The charity works with the government and the NHS, as well as voluntary and private sectors, patients, carers and their families to shape future strategies and plans. The charity extends to all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland.

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[37] http://www.pallcareni.net/palliativecareinni/roleofthevoluntarysectorintheprovisionofservices

4.5 Volunteering

The LMDM strategy recognises the unique contribution of carers, families and communities which provide valuable services that complement the care provided by paid palliative care professionals. The strategy states that as more palliative and end of life care is provided in the community, families, carers and local communities, including volunteers, are essential partners in caring and it is crucial that they have the confidence and competence to take on these roles and responsibilities.

Voluntary sector hospices have led the way in developing roles for volunteers within palliative care.

These roles encompass a wide range of skills, expertise and resources from both personal and professional lives ranging from fundraising to practical support for people and their families.

The accumulative hours freely given by volunteers are a major contribution to enhancing the experience of palliative care for individuals. Volunteers complement the existing services. A Study by Help the Hospices; 2006, considered the contribution of volunteers within hospice care within the United Kingdom, including inpatient and day care services, and home based care. The study highlighted that their contribution reduced hospice costs by an estimated 23 per cent[38].

Within Northern Ireland, volunteering, alongside a palliative care service is growing within the voluntary and statutory services. The Marie Curie Helper Service have trained volunteers who are matched with families in need of companionship and support. They visit people in their homes to provide emotional and practical support, helping to reduce the social isolation faced by some terminally ill people and their families.

The added value of the volunteer service within the Macmillan Unit, Northern HSC Trust has been evaluated from the perspective of individual personal development of the volunteer and their impact on staff, carers and patients.

With many roles including: meal time companions, meeting and greeting, volunteer drivers, complementary therapists and recording of oral histories, the evidence echoed the value of the contribution of volunteers in palliative care. The roles played by volunteers can bring significant positive benefits for patients and their families and carers.

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[38] Help the Hospices: Volunteer Value: a pilot survey of UK hospices. London, 2006

Section 5 Findings

5.1 Vision for Quality Palliative End of Life Care

The vision for palliative end of life care set out in LMDM is "that any person with an advanced non-curative condition lives well and dies well irrespective of their condition or care setting".[39] This requires a philosophy of palliative and end of life care that is person-centred and which takes a holistic approach to planning, coordinating and delivering high quality reliable care, enabling patients to retain control, dignity and crucially, choice in how and where their care is delivered to the end of their life.

To make this vision a reality, the strategy stated that commitment to change culture and practice would be required in five key areas:

- understanding palliative and end of life care
- developing skills and knowledge
- identifying needs and talking about what matters
- planning care – timely information and choice
- delivering and co-ordinating care, support and continuity

To inform this review, RQIA met with organisations and individuals involved in the planning and delivery of general and specialist palliative care across Northern Ireland. There is a widely held view that the vision and broad strategic direction set out in LMDM remains valid for the next phase in the development of services.

5.2 Implementation of Living Matters Dying Matters

LMDM included an action plan to provide clear direction to support organisations in achievement of the strategic vision. The action plan defined organisational responsibility; expected timescales for implementation; identified outcomes; and how these should be measured. An implementation board was established to support the reform of care.

During this review, RQIA identified significant strengths in the arrangements put in place to take forward implementation of the strategy, but also that challenges had emerged to impact on its full delivery.

Strengths

a. RQIA found that there were strongly committed leaders and teams, in both statutory and voluntary organisations, who worked towards the implementation of the strategy.
b. The inclusion of an action plan, with defined responsibilities, facilitated organisations to begin to implement the recommendations of the new strategy.

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[39] Living Matters Dying Matters: A Palliative and End of Life Care Strategy for Adults in Northern Ireland, March 2010, (Page 10)

c. A regional multi-sector LMDM Strategic Implementation Board was quickly established, chaired by the PHA’s Executive Director of Nursing and Allied Health Professionals, who had been a member of the group who developed the strategy.

Three subgroups were set up to take forward work in areas encompassing each of the 25 recommendations:

- education and development.
- raising awareness and understanding.
- research forum.

Initially there were four subgroups, with a fourth group to address systems and processes. This work was then devolved for each trust to take forward. A clinical engagement forum was also later introduced as a means of engaging with clinicians on proposals and developments, alongside an information sub group.

d. A regional service improvement lead was appointed for one year. Service improvement leads were appointed in each trust area.

e. Local delivery structures for palliative and end of life care in each trust area took forward action in line with the strategy. In some trusts these structures were already in place. In others they were established after the strategy was published.

f. Actions in support of the recommendations were taken by a wide range of organisations and networks including; voluntary organisations, individually and collectively; the Northern Ireland Cancer Network; professional networks such as the Regional Palliative Care Consultants Group; LCGs; ICPs; the TYPELC programme; and the AIIHPC.

Challenges

a. The strategy was published at a time when there was limited resource for service development. No specific new funding was allocated to take forward the action plan.

Funding was provided through the commissioning process for specific developments in some trust areas such as additional specialist posts and expansion of out of hours services.

Significant funding was made available over the life of the strategy by voluntary sector organisations which facilitated the implementation process. Examples included:

- Macmillan Cancer Support provided two-year funding to enable the appointment of the service improvement leads.

- Marie Curie jointly funded with the HSC Board in the TYPELC Programme, which was developed from the Delivering Choice approach used in Great Britain.
- Hospices provided funding to develop services and for important education and awareness raising initiatives.
- The All Ireland Institute for Palliative and End of Life Care used funding provided by Atlantic Philanthropies, to take forward research initiatives, including surveys of user experience across Ireland.

b. Between 2010 and 2015 the landscape in which the strategy was being taken forward changed considerably. People involved in the development and early implementation of the strategy changed roles; the new regional Transforming Your Care strategy was published; resources became increasingly constrained; concerns about the implementation of the Liverpool Care Pathway led to it being removed.

Against this background, RQIA found that processes to improve services continued to be taken forward. New structures evolved to promote cooperation. There continued to be a strong body of leaders within organisations to advocate for service development and to drive improvement.

c. Following the publication of the strategy, RQIA was advised that there was a clear implementation structure with monitoring arrangements put in place to assess progress on the recommendations.

By 2015, however, RQIA found that there was less clarity about the roles and responsibilities of different structures and how they fitted together. Examples of issues that arose included:

- Policies or procedures developed by regional groups to standardise arrangements across organisations were not always finalised or published. RQIA was informed by several organisations that they were waiting for particular documents to be issued and were not clear as to whether to proceed unilaterally, or await further clarification.
- Some organisations advised RQIA that it was not clear as to how coordination of service improvements would now be taken forward, or whether pilot initiatives would be rolled out.
- Considerable effort has been employed to reach agreement on models of care, such as day hospice models. Without an agreed strategy for resourcing and implementation, it was considered that this may have been nugatory work.

RECOMMENDATION 1

DHSSPS, in partnership with stakeholders should develop a new Living Matters Dying Matters Action Plan for a three-year period for 2016 to 2019 building on the work which has been completed since the strategy was developed in 2010. The action plan should include defined timescales, organisational responsibilities and monitoring arrangements.

5.3 Progress on Delivery of the Action Plan

Introduction

LMDM made 25 recommendations which were built into an action plan, to enable the planning and delivery of quality palliative and end of life care over the period from 2010 to 2015.

The action plan included:

- Developing Quality Palliative and End of Life Care
- Commissioning Quality Palliative and End of Life Care
- Delivering Quality Palliative and End of Life Care
- A Model for Quality Palliative and End of Life Care

The action plan set out the organisations which were responsible for taking forward the recommendations; the proposed timescale; quality outcomes; and measures of success.

To inform this review, RQIA asked individual organisations to complete a template in relation to those actions for which responsibility had been allocated to them. RQIA's review team then met with the organisations to discuss these responses further.

Developing Quality Palliative and End of Life Care

Six recommendations were included in this section of the action plan (Appendix 3) which focused on actions designed to:

- raise awareness and understanding of palliative and end of life care among the public
- increase, awareness, knowledge and skills of health and social care staff
- improve information for families, carers and volunteers
- coordinate research and development in relation to palliative and end of life care

Strengths

a. RQIA found that there have been extensive programmes of activities designed to raise awareness among the public and health and social care staff about palliative and end of life care. These have included collaborative programmes across organisations and organisation-specific initiatives.

b. A wide range of training programmes have been delivered by both statutory and voluntary providers.

c. Palliative and end of life care is included in undergraduate medical and nursing programmes.

   Opportunities are now provided for Queen's University undergraduate medical students to visit local hospices during fourth year.

d. A Palliative Care Research Forum has been established[40]. It aims to encourage collaborative research initiatives and to work in partnership, to make substantive progress in research capacity and the quality of palliative care research in Northern Ireland. An objective of the forum is to participate appropriately in the work of the All Ireland Institute of Hospice and Palliative Care.

e. Organisations have taken forward a range of initiatives to provide information for patients, carers and families about palliative care and end of life issues.

Challenges

a. RQIA was advised by organisations that a continuing constraint to the delivery of timely palliative and end of life care is reluctance by some staff and patients to discuss palliative care and end of life issues.

b. The meaning of the term palliative care and other terms such as advance care planning are not always understood, creating difficulties in communication between patients and clinicians.

c. Significant efforts have been made to raise public and staff awareness about the roles of palliative and end of life care. Nevertheless, it was considered that there is an ongoing need for coordinated approaches to achieve greater understanding and thus enhance the appropriate use of services. RQIA was also advised that there was potential for greater regional coordination and delivery of initiatives designed to raise awareness.

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[40] Palliative Care Research Forum, Northern Ireland: **www.research.pallcareni.net**

d. Organisations have delivered a wide range of training in relation to both generic and specialist palliative and end of life care. RQIA found that it was an ongoing challenge for organisations to ensure that staff accessed the training most appropriate to their individual needs. The take up of some training opportunities has sometimes been less than anticipated.

RECOMMENDATION 2

Raising public and professional awareness of palliative and end of life care should be a core component of the new action plan.

Commissioning Quality Palliative and End of Life Care

Two recommendations were included in the action plan (Appendix 3) relating to the commissioning of services.

- To identify a lead commissioner for palliative and end of life care at regional level and within all LCGs.
- To have systems in place to capture qualitative and quantitative population needs relating to palliative and end of life care.

Strengths

a. HSC Board and PHA appointed lead officers for palliative and end of life care who co-chaired a joint Palliative and End of Life Commissioning Service team on behalf of both organisations.

LCGs identified a lead commissioner for palliative care matters. In some, this is an LCG officer, whereas in others it is a representative on the LCG Management Board.

b. A health needs assessment, was completed by the PHA to help understand and quantify current services to inform strategic development and investment decisions.

c. Developments in information systems at local and regional level have taken place, or are planned, which will provide enhanced knowledge to inform the commissioning of palliative and end of life care.

d. Initiatives have taken place to help standardise the commissioning arrangements for hospice services.

Challenges

a. RQIA found that a particular challenge for commissioning palliative and end of life care is to ensure that there is the right balance between fostering local innovation in the provision of services, while ensuring standardisation of service delivery across Northern Ireland, where appropriate.

b. Palliative care and end of life services are provided by strongly committed statutory and voluntary providers. Voluntary sector providers may serve particular catchment populations, reflecting the location of a service such as a hospice, the methods by which the service was developed, or sometimes the specific contracts in place with commissioners. It is a challenge for commissioners and providers to ensure there is a comprehensive, integrated model of service delivery for a particular geographic area.

c. Some trusts advised that the present commissioning arrangements did not facilitate their input to discussions on the future direction of services, or on priorities for service development. They would welcome more engagement with the Palliative and End of Life Commissioning Service team on these issues.

d. RQIA was advised that work has been undertaken to develop a service specification in relation to palliative and end of life care, although this was not taken fully to completion. Some providers considered that this would have been helpful in setting a clear picture of what services would be provided in each area. A particular approach which can help underpin the delivery of a strategy is to develop a service specification which describes expectations that should be delivered to a specific population, regardless of whether there is a single or several providers. In particular, this was found to be very helpful in the work to take forward the delivery of the regional respiratory framework.[41]

RECOMMENDATION 3

The Public Health Agency should lead on the development of a new needs assessment exercise to assess the impact of projected demographic, epidemiological and service changes on the delivery of palliative and end of life care and to inform the future specification of services.

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[41] http://www.rqia.org.uk/cms_resources/Independent%20Review%20of%20the%20Implementation%20of%20the%20Respiratory%20Service%20Framework_ISBN.pdf

Delivering Quality Palliative and End of Life Care

Three recommendations in the action plan (Appendix 3) focused on the delivery of quality palliative and end of life care:

- Each patient, identified as having end of life care needs, should have a key worker.

- Every child and family should have an agreed transfer plan to adult services in both acute hospital and community services.

- The potential for a managed clinical network should be explored.

Strengths

a. Regional guidelines were agreed, setting out the function of key workers and the skills and competencies they require. The key information summary (KIS) for palliative and end of life care will have the key worker as one of the required fields for completion.

HSC trusts have taken forward the regional guidance in the development of specific guidelines within their respective areas:

- The Belfast Trust records the name of the current key worker on the trust's electronic Palliative and End of Life Care Coordination System on PARIS. Trust specific guidance has been developed, including a quick reference guide as to how to identify a key worker.

- The Northern Trust set up a subgroup to take forward the implementation of the palliative care key worker. The group took forward actions including: developing operational guidance; developing and implementing training; including the key worker as a mandatory field on the trust electronic LCID palliative care register[42]; and identifying the community nurse band 6 as the key worker in the first instance.

- The South Eastern Trust agreed that nursing would take responsibility for the coordination of management of palliative and end of life care. The trust recognised that the person who undertakes the role can change. The key worker role in the acute setting was agreed to be carried out by the ward manager/ consultant and in the community the district nursing sister/GP.

- The Southern Trust developed palliative care guidelines and provided training for teams to facilitate the introduction of the key worker function. The key worker is recorded on caseload databases for specialist palliative care, COPD[43] and heart failure teams.

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[42] http://www.northerntrust.hscni.net/pdf/Trust_Performance_Report_May13_v4.pdf

[43] COPD – Chronic Obstructive Pulmonary Disease

- The Western Trust developed guidelines for the key worker function, setting out core principles and good practice to support health and social care staff in undertaking the role. The trust has also developed a draft protocol: Adult Complex Health Care Conditions - The Keyworker Role of the District Nurse.

b. The focus of this review is on adult services; however, RQIA was advised that there are draft strategies in development on paediatric healthcare and on palliative care for children, which will be relevant to enhancing transition arrangements between children and adult services. A regional transition working group has also been established.

c. RQIA was also advised of a number of relevant local initiatives in relation to transition planning:

- The Belfast Partnership Palliative and End of Life Steering Group has a current three year prioritisation schedule, with the transitional needs of young people due to be considered as part of the 2016-17 work plan.

- In the Northern Trust, transition arrangements are developed 12 months prior to transfer to adult services for children with complex physical healthcare needs. There is a trust-wide post of a discharge/transitions nurse to coordinate the transition arrangements.

- In the South Eastern Trust, care pathways are individually tailored to meet the needs of the individual child or young person who requires palliative and end of life care. The trust advised that the Regional Paediatric Complex Healthcare Needs Discharge Pathway[44] facilitates closer working relationships between regional and local services.

- In the Southern Trust, a medical palliative care lead for children has been identified. A multi-professional working group has been established to develop local palliative care pathways for children and young people, including the development of transition plans for both acute and community services. The Southern Trust has nursing and social work transition coordinators in post.

- In the Western Trust, anticipatory plans are developed jointly by consultants in palliative medicine and hospital and community paediatricians for young people approaching adulthood.

Challenges

a. While significant work has progressed in relation to establishing the role of the key worker in palliative and end of life care, RQIA was advised of a number of challenges which emerged in taking this forward.

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[44] http://www.dhsspsni.gov.uk/integrated_care_pathway-july09.pdf

To ensure clarity of who the current key worker is requires an agreed source of information, which keeps these details up to date and which can be easily accessed by all relevant staff. HSC trusts have different systems in place, not all of which can be accessed by everyone involved in the care of the patient, particularly voluntary sector staff. The KIS, when implemented, will help to overcome this challenge.

In community settings the concept of having a key worker appears to be clearly articulated and several organisations advised RQIA that this role is being taken forward by the district nurse. RQIA was advised that in the hospital setting, the role definition appears less clear with the emphasis on ensuring that there is a well-coordinated multidisciplinary team and the key worker function shared between members of the team, relevant to their specific professional background.

At the time of the review, work to embed the key worker function was still being progressed. RQIA recommends that the models in place in different trust areas are evaluated to determine if the regional guidelines should be modified in the light of experience.

b. LMDM recommended that the potential for a managed clinical network (MCN) should be explored as part of the implementation process. It was considered that this approach would be particularly suitable as palliative and end of life care is delivered in a broad range of care settings, by a wide spectrum of healthcare professionals, and requires good communication and cooperation.

During the period from 2010 to 2015, there is clear evidence of individuals and organisations cooperating together in a range of partnerships and networks to develop palliative and end of life care.

However, RQIA was not provided with any evidence that the potential for establishing a MCN was explored during this period, leading to uncertainty as to whether this approach should be taken forward or not.

In discussion with stakeholders, RQIA was provided with a range of views as to whether it would be useful to implement a MCN now.

It is recognised that some of the potential functions of a MCN have been taken forward through other partnership approaches, including the development of shared guidelines and protocols. However, some groups have been established, such as the regional consultants group, which could usefully have been linked more formally into a regional process, which a MCN could have provided.

RQIA recommends that the regional coordination arrangements for palliative and end of life care are reviewed, to ensure clarity of how the roles of different partnerships and groups link together and to avoid duplication of effort. This review could inform a decision whether to establish a MCN or determine if this approach is no longer appropriate.

RECOMMENDATION 4

DHSSPS and HSC organisations should evaluate the roles of key workers for palliative and end of life care to determine if regional guidelines for this function should be modified in the light of experience.

RECOMMENDATION 5

The HSC Board, in partnership with stakeholders, should review the regional coordination arrangements for developing palliative and end of life care, to ensure clarity about the roles of different partnerships and groups. This review should inform a decision whether to establish a managed clinical network for palliative and end of life care, or determine if this approach is no longer appropriate.

A Model for Quality Palliative and End of Life Care

Fourteen of the 25 recommendations of LMDM related to the implementation of the system of care model set out in the strategy. The action plan for these recommendations specified systems and processes which should be put in place to establish the model in practice. These included:

- arrangements to communicate with, and provide support for, individuals receiving significant information
- implementing tools and triggers to identify people with palliative and end of life care needs and their preferences for care
- establishing locality based registers to support improved access to information
- condition specific care pathways should have appropriate trigger points for holistic assessment of patients' needs
- providing respite care for families and carers
- involving patients, their families and carers in planning services and providing services in a flexible manner to meet individual and changing needs
- ensuring access for patients, families and carers to appropriate and relevant information
- prioritising equipment, transport and adaptions for patients with rapidly changing needs
- policies for advance care planning for patients with palliative and end of life care needs

- embedding appropriate tools for the delivery of good palliative and end of life care into practice

- ensuring that out-of-hours teams are competent to provide responsive end of life care and advice across all community settings

- ensuring access to specialist palliative care advice and support on a 24/7 basis across all care settings

Strengths

RQIA found that a wide range of actions have been taken forward by organisations, individually and collectively, in relation to this set of recommendations.

Examples included:

a. HSC trusts and hospices advised that they adhered to the regional guidelines on breaking bad news[45]. Individual organisations have developed and revised local policies and procedures based on regional guidance. Training has been delivered to many staff on implementing their local arrangements. RQIA was advised that the regional breaking bad news guidelines are currently being reviewed and recommends that an action plan is developed to implement the new guidelines when they have been finalised.

b. A regional approach has been developed to support practitioners and organisations in implementing the model of care set out in LMDM. This is called the End of Life Care Operational System (ELCOS) and is set out in two diagrams (appendix 5 and 6).

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[45] http://www.dhsspsni.gov.uk/breaking_bad_news.pdf

ELCOS provides a colour coded system to assist practitioners in the development of an individual care plan for a patient and their carer and family, depending on the stage in the patient journey. It strongly emphasises the need for effective communication and the provision of information for patients at all stages.

RQIA found that the ELCOS model has been widely shared across Northern Ireland and has been very useful in designing information systems to support the delivery of high quality palliative and end of life care. It has been found to be a useful framework to underpin holistic assessment and is widely used in training initiatives.

c. RQIA was advised that general practices hold the only locality based palliative care registers, as directed by the LMDM Implementation Board.

HSC trusts were directed to develop and implement community information systems for palliative care, which aim to mirror GP registers and the agreed dataset, to enable continuation of provision of palliative care across care settings. Trusts are developing information systems to support the delivery of palliative and end of life care.

- In 2012 the Belfast Trust introduced an electronic palliative and end of life coordination system, as an integral part of the PARIS community information system. This supports staff to ensure the elements of the strategy are offered to each identified individual as well as recording the regionally agreed dataset, alongside additional information. The system was rolled out fully across the trust by 2015 in line with the implementation of PARIS in the trust.

- In the Northern Trust, a Palliative Care Register was implemented on the LCID system in 2012, which delivers the agreed regional data set.

- The South Eastern Trust, as part of the Peninsula Project[46], has worked with a number of GPs to test a model where information is taken from GP registers to inform a stand-alone palliative and end of life care register. An on-line data collection tool has been developed for LCID in partnership with the Northern Trust and the system developer.

- The Southern Trust is implementing the PARIS community information system which will be able to house a locality based register, based on the regional data set.

- The Western Trust has developed and implemented a palliative care database for community district nursing to enable the trust to collate

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[46] The South Eastern HSC trust piloted an operational model within the Ards peninsula area. As part of this project (Peninsula Project) patients were offered the opportunity to complete an advance care plan.

information relating to patients receiving palliative care. Discussions are taking place with regard to the future development of the PARIS information system which has been recently introduced.

Hospices across Northern Ireland are working jointly to commission a common information system to meet the needs of their services.

d. The development of the electronic care record (ECR)[47] is regarded as a significant step forward in accessing key information about palliative and end of life care. Hospices can now access information using the ECR and strongly welcomed this development.

It was recognised that there were limits to the information that is on the ECR in relation to palliative and end of life care. A project is being taken forward to deliver a KIS through the ECR relating to palliative and end of life care. The KIS, which is completed by GPs, has been designed to identify patients with complex needs that includes those requiring palliative care.

e. RQIA found that all providers of palliative and end of life care have a strong emphasis on the importance of holistic assessment being carried out by a multi-disciplinary approach.

Each hospice carries out holistic assessment of patients when they first attend, either as an inpatient or a day patient. This is updated on a regular basis.

HSC trusts advised that the regional e- NISAT (Northern Ireland Single Assessment Tool) is being utilised to support holistic assessment[48].

Assessment of patients’ needs is recorded using NISAT, which is currently implemented in Northern Trust community integrated teams. This forms the basis of an individualised patient-centred care plan, which is regularly reviewed throughout phases B, C and D, of the ELCOS, and a record of the patients or families changing needs documented.

The Northern Trust has developed an aide-memoire to complement the NISAT already in existence and enhance the focus of what matters for patients with palliative care needs. This enables all practitioners to acknowledge and value the dynamics of holistic palliative care and respond to the needs of the individual patient and their family through their own knowledge and skills.

This holistic assessment aide memoire has been adapted from a previous tool developed by the Northern Ireland Cancer Network (NICaN) supportive and palliative care guidelines subgroup. The tool has been adapted from the NHS National Cancer Action Team’s Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer (2007).

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[47] http://www.ehealthandcare.hscni.net/niecr/niecr.aspx

[48] http://www.dhsspsni.gov.uk/ec-northern-ireland-single-assessment-tool

Some trusts have developed personal and public involvement (PPI) groups for palliative care.

HSC trusts have established arrangements for multidisciplinary team meetings in both community and hospital settings.

Joint posts have been created in some areas, with consultant staff having hospice, hospital and community roles which facilitate joint working and sharing information.

In primary care, RQIA was advised that the approach advocated in the gold standards framework[49], for multi-professional meetings at practice level, to discuss patients on the GP register, has been widely adopted in some areas. This has been supported to a significant extent through the work of Macmillan GP facilitators. Hospice nurses take part in some areas. Where these meetings occur, the frequency can vary depending on local circumstances.

However, RQIA found that there is not a consistent pattern and meetings do not take place in all practices. RQIA recommends that the arrangements for holding multi-professional palliative care meetings at practice level are reviewed in each trust to identify and address any constraints to establishing these meetings as routine for all practices.

f. There has been a strong focus on the provision of relevant information for patients, carers and families by voluntary and statutory organisations. A specific work stream is being taken forward through the TYPEOLC programme which is focusing on support for patients and carers, including the provision of information.

g. RQIA was provided with a range of examples where patients, families and carers have been involved in the planning of developments in palliative and end of life care in both the voluntary and statutory sector. Examples included involvement in: development of organisational strategies and policies; design of buildings; decisions of what equipment to purchase for new facilities; approaches to provision of information; and the design and implementation of new models such as the ELCOS model.

h. HSC trusts advised that they have systems in place to prioritise patients with end of life care needs to access equipment and adaptations when necessary. Examples include; fast tracking for non-stock items for procurement; provision of urgent transport to deliver equipment; purchase of additional specialist appliances to be available when required; and holding equipment in satellite stores to assist with weekend or out of hours needs.

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[49] http://www.goldstandardsframework.org.uk/cd-content/uploads/files/GSF%20Primary%20care%20Going%20for%20Gold%20updated%20v2.%2014.11%20Final.pdf

i. There have been regional and local initiatives in relation to advance care planning. The booklet Your Life and Your Choices: Plan Ahead, Northern Ireland’[50] was jointly produced by the PHA and Macmillan Cancer Support. It includes information on advance care plans, enduring power of attorney and advance decisions to refuse treatment. Service providers are supporting the roll out of this booklet.

A range of stakeholders have been involved in the development of a record of my wishes, which was developed by the Belfast Trust and endorsed in 2015 as the regional template for discussions on advance wishes. It is to be attached to the Your Life and Your Choices booklet.

The NIAS has been working with the TYPEOLC programme to ensure that patients with palliative and end of life care needs receive the most supportive and appropriate response. As part of this work, NIAS is taking forward several initiatives for improvements in services including:

- A NIAS Palliative and End of Life Care Guideline.
- A NIAS Out-of-Hours Palliative Care Referral Pathway to enable patients to be safely and appropriately treated in their preferred place of care without the need to transport them to an emergency department.

NIAS is working on internal processes regarding Information markers. Other TYPEOLC programme initiatives are considering arrangements to ensure that there is clinical information in a patient’s home to instruct the ambulance service in the appropriate intervention for the patient or to ensure information is passed to ambulance control in anticipation of a call to NIAS by the patient or their family.

Challenges

a. RQIA was advised that there are differences in the availability of palliative and end of life care services and advice out-of-hours across Northern Ireland. Differences may reflect historic patterns of provision and availability of staffing and the catchment areas of particular service providers.

Voluntary sector providers contribute significantly to the provision of out-of-hours services in some trust areas, including specialist telephone advice services for patients, and for both statutory and voluntary sector staff, and through the provision of palliative care nursing.

Developments have taken place to extend provision in certain areas. For example, at the time of the review, pilots were being taken forward in the Western Trust to provide a Marie Curie unscheduled out-of-hours service seven days a week (10pm – 8am) to the northern sector of the Western Trust.

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[50] http://be.macmillan.org.uk/be/p-21065-your-life-and-your-choices-plan-ahead-northern-ireland.aspx

Also included was a 24 hour Marie Curie rapid response service on bank holidays and weekends. The bank holidays and weekends pilot was also extended to the Southern and Northern trusts.

A range of providers may be involved in the provision of the services in a particular geographic area who together can deliver the specified list of services.

b. RQIA was informed by hospices that there has been an increased demand for inpatient provision, with many patients having increased levels of complex needs. This has impacted on their ability to respond to requests for respite care on an inpatient basis.

Day hospice provision can be an important element of respite care.
A specific project under TYPEOLC has developed an agreed model for all providers of day hospice services.

HSC Board advised that all LCGs invest in short breaks as part of their support arrangements for carers.

c. While recognising that developments have taken place in relation to advance care planning, RQIA was advised by some providers that their experience is that only a small number of people wish to engage in a conversation about their future care needs and few want to complete an advance care plan.

d. The impact of the removal of the Liverpool Care Pathway in 2014 led to a challenge for clinicians and organisations while they were waiting for regional guidance to be developed for the management of the symptoms for adults in the last days of their life.[51] Regional guidelines have recently been distributed on the management of symptoms.

e. During the period from 2014 to 2015, there was an increasing focus on the development of services in the community to wherever possible reduce the need for hospital admission and to enable patients to die at home if that was their wish. This is in keeping with the strategic direction set out in Transforming Your Care and the subsequent work to take forward Transforming Your Palliative and End of Life Care.

While recognising the strategic importance of this work, a number of providers advised RQIA that there was a need to ensure that this focus did not take away from the need to ensure that good quality of palliative and end of life care is delivered in hospital settings, which continues to be the place of death for many patients.

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[51] HSS(MD) 21/2014 - Advice To Health And Social Care Professionals For The Care Of The Dying Person In The Final Days And Hours Of Life – Phasing Out Of The Liverpool Care Pathway In Northern Ireland By 31 October 2014. DHSSPS Circular.

RECOMMENDATION 6

HSC Board should develop a service specification for out of hour's provision for palliative and end of life care in both hospital and community settings to increase standardisation of the availability of services across Northern Ireland.

RECOMMENDATION 7

HSC Board in conjunction with HSC trusts should review the arrangements for holding multi-professional palliative care meetings at practice level to identify and address any constraints to establishing these as routine practice in all areas.

RECOMMENDATION 8

Raising public and professional awareness of the Breaking Bad News Guidance, once revised, should be a core component of the new action plan.

5.4 Views of Service Users

The All Ireland Institute of Hospice and Palliative Care (AIIHPC): The Let's Talk About survey

As part of the terms of reference of this review to report on service user views, RQIA consulted with the All Ireland Institute of Hospice and Palliative Care for service user views on palliative care. The Institute, which has a broad range of expertise in hospice and palliative care in Ireland has produced a report on a recent survey. The Let's Talk About survey is a two stage initiative being conducted over 2014 and 2015 to elicit the views and experiences of service users and carers of palliative care services in the Republic of Ireland and Northern Ireland. The initiative is being coordinated by AIIHPC and is partially funded by the Health Service Executive (HSE) in the Republic of Ireland and the PHA in Northern Ireland.

The survey was designed to address the first of the seven strategic outcomes of the Institute:

"That Palliative Care provision and developments are informed by user, carer and community voices".

The method collects individual narratives about high impact good or bad experiences of palliative care services.

The overall purpose of the Let's Talk About survey was to better understand the issues that matter the most to individuals and their carers who live with a serious progressive medical condition that is unlikely to be cured.

The aim is to provide a picture of the perceived quality of services, to identify what areas of service are valued and what areas of service may need improvement. The findings will be used to develop an all-island qualitative knowledge resource of how such care is experienced directly by those who require it. The evidence obtained from the survey will be used to help support practice, inform policy, shape strategy and assist with achieving the most positive experiences for users and carers.

Table 1: Profile of person whose experience was spoken about[52]

	Informants	Population
Total	367	6.406m
Republic of Ireland	***281 (77%)***	***72%***
Northern Ireland	**86 (23%)**	**28%**

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[52] The All Ireland Institute of Hospice and Palliative Care (AIIHPC): The Let's Talk About survey

The key themes from the survey showed that the majority of people:

1. need help to plan for the future
2. feel helpless and frustrated
3. value clear and sensitive communication
4. value timely and appropriate information
5. experience too little autonomy
6. have emotional and psychological needs that are not met
7. better coordination of care and treatment
8. would like their family and friends more involved

Where respondents were asked to choose an option as to their biggest practical worry from a selection of choices, 63 per cent chose planning for the future.

The Palliative and End of Life Care Strategy indicated the need to address people's expectations of options and choice in how and where care is delivered, and to promote open discussion through the media, education and awareness programmes.

A study of public perceptions of palliative and end of life care was undertaken in 2013[53]. Some of the findings taken from 600 people who participated in the survey showed that:

- The majority of people had little or no knowledge of the meaning of palliative care.
- Knowledge and perception was mainly influenced by personal experiences.
- The family home was the main place identified as the preferred place of care for a patient with palliative care needs.
- Most people believed that palliative care was delivered in hospice and at home, followed by hospital.
- The majority believed that a member of the generalist practice team (GP or district nurse) or a specialist hospice nurse would be best placed to discuss palliative care needs.

The top three key sources of information on palliative care were:

1. through a close friend or relative who had received care
2. via a health care setting
3. newspapers and magazines

The findings showed that a range of approaches, such as publicity campaigns, posters, talks, open days and clear signposting from health professionals could enhance awareness, as well as the use of education, by taking a broad approach that targeted secondary schools and discussion groups.

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[53] Exploring public awareness of palliative care. April 2013. PCC. UU & PHA

Section 6 Conclusions

RQIA has concluded that very significant progress was made during the period 2010 to 2015 to implement the recommendations of the Living Matters Dying Matters strategy. This was greatly facilitated by strongly committed leaders from both statutory and voluntary sector organisations.

This progress was made during a period of very constrained resources with provision of limited statutory funding to take forward the strategy.

Key elements in taking forward the action plan for the strategy included the appointment of regional and HSC trust service improvement leads; regional and local delivery structures; actions taken individually and collectively by both statutory and voluntary organisations; and not least by a strong sense of collective ownership of the goals of the strategy.

The planned implementation timescale for the strategy was 2010 to 2015. In discussion with stakeholders, there is a clear view that the vision set out in the strategy remains valid and that there is not a need for a new strategic direction for palliative and end of life care. There is a recognised need for a new coordinated action plan for the next planning period to take forward the further implementation of the vision set out in LMDM. RQIA considers that a three year planning period would be appropriate, given the changing landscape for service development.

RQIA recommends that DHSSPS, in partnership with stakeholders, develops a new Living Matters Dying Matters action plan for a three-year period for 2016 to 2019, building on the work which has been completed since the strategy was developed in 2010. RQIA has concluded that there is strong evidence of effective partnership working between statutory and voluntary organisations.

During the period of the strategy, new partnership initiatives developed and the roles of implementation structures changed and evolved. RQIA found lack of clarity among organisations as to how the range of regional structures fitted together. The regional coordination arrangements for developing palliative and end of life care should be reviewed, to ensure clarity about the roles of different partnerships and groups.

Although many initiatives have been developed to raise awareness of palliative and end of life care, RQIA was advised that there remains significant lack of understanding about these services. A coordinated approach to raising awareness with consistent messages across organisations continues to be required. RQIA recommends that raising awareness should be a core component of a new action plan for taking forward LMDM.

To support the development and implementation of a new action plan, RQIA recommends that a revised needs assessment is carried out to assess the impact of projected demographic, epidemiological and service changes on the delivery of palliative and end of life care.

RQIA found differences in the availability of services across Northern Ireland, for example during the out of hours period. A priority for the next strategic planning period should be to standardise the availability of core services across populations, while recognising that these services can be provided by different provider organisations, for different localities.

One of the principal elements set out in LMDM was that each person with palliative and end of life care needs should have a key worker to coordinate the delivery of their care needs. RQIA found that while this approach is being actively taken forward in community settings, it is less clear as to how it operates within hospital settings. Different models are operating in different trust areas in both hospitals and the community and it is recommended that the learning from different approaches is shared and evaluated.

During the life of the strategy, there has been an increasing recognition of the importance of having information systems to underpin the delivery of services. There have been important developments in this area including the Electronic Care Record. The linked development of a key information summary for palliative and end of life care will enhance the sharing of information between professionals.

LMDM sets out a series of recommendations to implement a model for quality palliative and end of life care and a wide range of actions have been taken to this end.

During the implementation period, there were challenges to taking forward these recommendations, including the concerns which arose in relation to the Liverpool Care Pathway and its subsequent removal from care settings.

An emerging challenge is that there is an increasing demand for palliative and end of life care and this is projected to continue, with changes in the demography of the population and increasing awareness of the importance and value of these services. RQIA was advised that many patients accessing hospice services now have more complex needs and that this is impacting on the delivery of other services such as respite.

RQIA found that significant work has been completed on the design of a programme of initiatives to take forward service development. There is concern among organisations that a lack of resources may impact on realising the full benefits of these initiatives

In conclusion, this review found that the regional strategy LMDM has played a key role in improving palliative and end of life care in Northern Ireland. There is strong commitment to develop services further and to tackle the challenges which are continuing to emerge.

Section 7 Summary of Recommendations

The recommendations have been prioritised in relation to the timescales in which they should be implemented, following the publication of the report.

Priority 1 - completed within 6 months of publication of report
Priority 2 - completed within 12 months of publication of report
Priority 3 - completed within 18 months of publication of report

Recommendation 1	**Priority 1**
DHSSPS, in partnership with stakeholders should develop a new Living Matters Dying Matters Action Plan for a three- year period for 2016 to 2019 building on the work which has been completed since the strategy was developed in 2010. The action plan should include defined timescales, organisational responsibilities and monitoring arrangements.	
Recommendation 2	**Priority 1**
Raising public and professional awareness of palliative and end of life care should be a core component of the new action plan.	
Recommendation 3	**Priority 1**
The Public Health Agency should lead on the development of a new needs assessment exercise to assess the impact of projected demographic, epidemiological and service changes on the delivery of palliative and end of life care and to inform the future specification of services.	
Recommendation 4	**Priority 2**
DHSSPS and HSC organisations should evaluate the roles of key workers for palliative and end of life care to determine if regional guidelines for this function should be modified in the light of experience.	
Recommendation 5	**Priority 1**
The HSC Board, in partnership with stakeholders, should review the regional coordination arrangements for developing palliative and end of life care to ensure clarity about the roles of different partnerships and groups. This review should inform a decision whether to establish a managed clinical network for palliative and end of life care, or determine if this approach is no longer appropriate.	

Recommendation 6	Priority 2
HSC Board should develop a service specification for out of hour’s provision for palliative and end of life care in both hospital and community settings to increase standardisation of the availability of services across Northern Ireland.	
Recommendation 7	**Priority 2**
HSC Board in conjunction with HSC trusts should review the arrangements for holding multi-professional palliative care meetings at practice level to identify and address any constraints to establishing these as routine practice in all areas.	
Recommendation 8	**Priority 3**
Raising public and professional awareness of the Breaking Bad News guidance, once revised, should be a core component of the new action plan	

Appendix 1: Summary of Palliative Care Services Delivered within Health and Social Care Trusts

Belfast Trust **Trust services**	**Northern Trust** **Trust services**	**Southern Trust** **Trust services**	**South Eastern Trust** **Trust services**	**Western Trust** **Trust services**
Palliative care in the community is delivered by Trust services, supported by independent/ contracted services. **Trust services** • Integrated care teams • District nursing/24 hour community nursing • Community AHPs and social workers • Community specialist teams • Oncology and palliative care team • Community out of hours nursing teams • GP out of hours • Emergency on call social work service	The NHSCT provide palliative care across all care environments within the trust geographical area, including • Patients' own homes irrespective of setting to include Care Homes, Trust residential units and the independent sector residential and nursing care homes, supported by 85 GP practices and community teams across all directorates • GP practices have palliative care registers • Practice meetings, attended by DN and Hospice team • Palliative Care Keyworker (District Nurse) being rolled out • Interface with other services primary care colleagues & core trust services • Hand over / alert form between primary care & Dalriada Urgent Care	• The majority of palliative care is delivered through general services: ward based doctors, nurses, AHP's, SW's, chaplains, support staff and in community by GP's, Integrated Care Teams, non-malignant specialist multi-disciplinary teams, and domiciliary homecare staff. • Specialist palliative care teams are available within the acute hospital and community services to support all staff delivering palliative and end of life care, when complex needs arise.	• Patients with progressive advanced disease will have core needs met by GP and District Nurse. • District nurses access Hospice at Home services or The Marie Curie Nursing Service at home. • District nurses are advised by telephone, by the ward teams and/or the palliative care nurse specialist, of patients with palliative care needs who are being discharged to primary care. Clinical information relating to these patients is also forwarded to the GP/DN team. • District nurses can access Hospice at Home services or The Marie Curie Nursing Service at home via a telephone referral system to the relevant organisation	• Palliative and end of life care services are coordinated within General Practice, with support from community specialist palliative care. • Referrals for community service are made via the Foyle Hospice or the Northern Ireland Hospice.

Belfast Trust **Community services**	**Northern Trust** **Community services**	**Southern Trust** **Community services**	**South Eastern Trust** **Community services**	**Western Trust** **Community services**
Community independent /contracted services • GP • NI Hospice community nurse specialists • NI Hospice at home • Marie Curie nursing service in the community.	• In the NHSCT there are 3 community hospitals, Dalriada, Inver & Robinson. In these and in other hospitals in the trust generalist palliative and end of life care, irrespective of condition, is delivered by multidisciplinary teams who are non-palliative and end of life care specialists. • In the community the Hospice at Home service, delivered by the Northern Ireland Hospice & Marie Curie Service, provide nursing care at home for people with palliative and end of life care needs irrespective of disease. Staff offer both practical, emotional and respite support.	• The acute and community specialist palliative care teams are both consultant-led multi-disciplinary teams • The community team has Palliative medicine consultant input, specialist nursing & dietetic input with recruitment for physiotherapy, occupational therapy, speech & language therapy and social work. • The Southern Trust has a community Palliative Medicine Consultant for medical domiciliary visits and for specialist palliative care telephone advice service for GP's.	Community Specialist Palliative Care Teams. Includes Consultants, Nurse Specialists (NIH), and AHP Team For SET the addition of: - Marie Curie - NI Hospice community Nurse Specialists - Specialist Palliative Care Teams The Trust partners with CRUSE Bereavement Support and referral can be made for those families who may require further support after death occurs. The Trust's bereavement coordinator along with chaplaincy and psychology department also assist families and patients both pre and post death	• Community specialist palliative care pathways accessed by referral to Foyle Hospice (Londonderry, Limavady and Strabane) & Northern Ireland Hospice (Omagh and Fermanagh). • The Marie Curie Nursing Service provides both a planned and a Rapid Response Service in the Western trust.

Belfast Trust **Palliative care in hospital**	**Northern Trust** **Specialist palliative care**	**Southern Trust** **Palliative care in hospital**	**South Eastern Trust** **Palliative care in hospital**	**Western Trust** **Palliative care in hospital**
• General and condition specific multidisciplinary ward and clinic staff across all hospital settings. • Multidisciplinary hospital palliative care teams based at BCH, RVH and MIH	Specialist palliative care –The range of service components accessible to patients and their families within the NHSCT are: • Macmillan Unit at Antrim, an Inpatient Unit with specialist multidisciplinary palliative care team • Macmillan Hospital Specialist Palliative Care Team (HSPCT) • NI Hospice Services, including Hospice Inpatient Unit, Community Palliative Care Nurse Specialists, Day Hospice • Medical domiciliary visits • Outpatient clinics, with potential to develop ambulatory services e.g. day case interventions, therapies	• General Palliative Care provided in all hospitals. • Specialist Palliative Care teams based in: Craigavon area Hospital Daisy Hill Hospital Community specialist palliative care teams in to Lurgan, South Tyrone and St Luke' Hospitals. • SHSCT have a Bereavement Forum to promote quality of end of life care through development of information & education for staff, & the development of bereavement information for relatives.	Referrals to Hospital based specialist palliative care Teams are for adults with advanced and progressing life limiting illness; this includes both malignant and non-malignant disease where the treatment intent is thought to be palliative. Referrals can be for: • Unresolved complex physical, emotional, social or spiritual symptoms; • Patient/family or carer in need of specialist end of life support; terminal care and bereavement services; • Need for specialist palliative rehabilitation. • Period of respite in a specialist palliative care inpatient unit in the case of emergency crisis.	Specialist Palliative Care Team • Altnagelvin Area Hospital • South West Acute Hospital providing a service to Tyrone County Hospital. • Palliative Care Inpatient Unit Tyrone County Hospital. Palliative care hospital teams provide specialist outpatients support and also support effective and timely discharge planning to the community

Appendix 2: Summary of Palliative Care Services Delivered within Hospices

Northern Ireland Hospice	Foyle Hospice	Southern Area Hospice	Marie Curie
• Northern Ireland Hospice Inpatient Unit has capacity for 17 patients on a daily basis. This service is operational 24hrs/day x 365 days/ annum. • Day Hospice has the capacity to care for 15 patients at Whiteabbey and is operational 3 days per week and to care for 7 patients in Ballymoney operational 1 day per week.	• Deliver care to all adult patients, over the age of 18 years of age, with malignant or non-malignant life-limiting illness. • 10 bedded inpatient unit	• 12 bedded Inpatient Unit • 2 Day Therapy Units based in Newry and Dungannon; providing 52 places each week • 24/7 Telephone advice to patients(known to Hospice) and Healthcare professionals • Domiciliary Visits; Medical, Nursing, Social Work and chaplaincy	• provides specialist palliative care for adults with cancer And life limiting illnesses. • 18 beds and offers palliative care 24hrs a day 7 days a week • end of life care, complex symptom management,
There are 8 specialist palliative care nursing teams within the Northern (3), Belfast (2), South Eastern Trusts (2) and Southern sector of the Western Trust (1). Hospice at Home provides a service within the Northern, Belfast and South Eastern Trusts.	The 24 hour telephone advice line available to health professionals, patients, families and carers.	Along with the SHSCT:3 OP clinics: • Daisy Hill Hospital, • Craigavon Area Hospital, • South Tyrone Hospital, • 1 Specialist Palliative Community Nurse in Armagh/ Dungannon area • Hospital Specialist Palliative Support in Daisy hill Hospital	• Operates from Belfast site on 2 days per week and at satellite sites on 2 days covering Newtownards and Downpatrick. • Cover both the Belfast and South Eastern Trust • Contracts with trusts and HSC Board
• All referrals to hospice are via a central triage point. • Patients are referred who have advancing progressive, malignant and non-malignant disease.	Referral criteria include: • Complex Symptom Management. • End of Life Care. • Respite Care	• Refers to hospice from Hospitals, GPs and Specialist palliative Nurses • Consultants and GP's can refer patients directly to our outpatient clinics or request domiciliary visits	• Requests for care are by both primary and secondary health or other agreed professionals.
Carers' services until 30th June 2015 provided a 6 week supportive programme, monthly drop in, one to one advice, telephone advice and complementary therapy for patient's carers within the Northern, Belfast and South Eastern Trusts.	• Inpatient Nursing & Medical • Community Specialist Teams • Day Hospice Team • The Adult 'Forget-Me-Not' Bereavement Support Group • Children's & Young Persons 'Healing Hearts' support service	• Social work team organise 'packages' of care to enable patients to go home, for short time at home before returning to hospice to die.	• Has out of hours emergency request for admission • The hospice has an Expert Voices committee which actively seeks feedback on services provided and includes service users and patients.

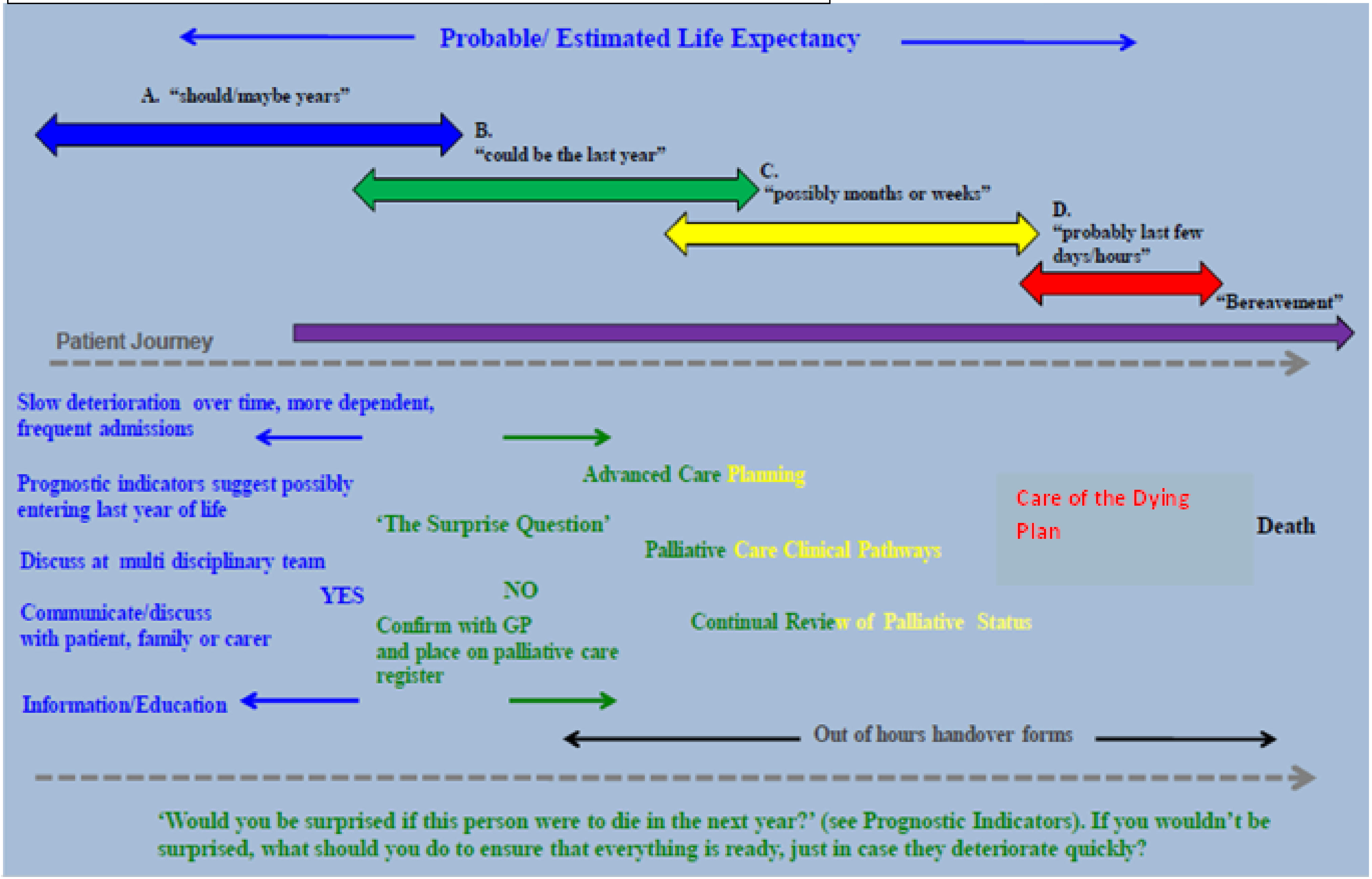
Appendix 3: Living Matters Dying Matters Recommendations

	Recommendations
	Section 3 – Developing Quality Palliative and End of Life Care
1.	Open discussion about palliative and end of life care should be promoted and encouraged through media, education and awareness programmes aimed at the public and the health and social care sector.
2.	The core principles of palliative and end of life care should be a generic component in all pre-registration training programmes in health and social care and in staff induction programmes across all care settings.
3.	Mechanisms to identify the education, development and support needs of staff, patients, families, carers and volunteers should be in place to allow person-centred programmes to be developed which promote optimal health and well-being through information, counselling and support skills for people with palliative and end of life care needs.
4.	A range of inter-professional education and development programmes should be available to enhance the knowledge, skills and competence of all staff who come into contact with patients who have palliative and end of life care needs.
5.	Arrangements should be in place which provide families and carers with appropriate, relevant and accessible information and training to enable them to carry out their caring responsibilities.
6.	A collaborative and collegiate approach to research and development should be established and promoted to inform planning and delivery, drive up quality and improve outcomes in palliative and end of life care.
	Section 4 – Commissioning Quality Palliative and End of Life Care
7.	A lead commissioner should be identified for palliative and end of life care at regional level and within all Local Commissioning Groups.
8.	Systems should be in place which capture qualitative and quantitative population needs relating to palliative and end of life care.
	Section 5 – Delivering Quality Palliative and End of Life Care
9.	Each patient identified as having end of life care needs should have a key worker.
10.	Every child and family should have an agreed transfer plan to adult services in both acute hospital and community services with no loss of needed service experienced as a result of the transfer.

11.	The potential for a Managed Clinical Network should be explored to ensure leadership, integration and governance of palliative and end of life care across all conditions and care settings.
	Section 6 – A Model for Quality Palliative and End of Life Care
12.	Arrangements should be put in place which allow for the most appropriate person (be that clinical staff, carers, spiritual care providers or family members) to communicate with, and provide support for, an individual receiving significant information.
13.	Appropriate tools and triggers should be implemented to identify people with palliative and end of life care needs and their preferences for care.
14.	A locality based register should be in place to ensure (with the permission of the individual) that appropriate information about patient, family and carer needs and preferences is available and accessible both within organisations and across care settings to ensure co-ordination and continuity of quality care.
15.	Condition specific care pathways should have appropriate trigger points for holistic assessment of patients' needs.
16.	Timely holistic assessments by a multi-disciplinary care team should be undertaken with people who have palliative and end of life care needs to ensure that changing needs and complexity are identified, recorded, addressed and reviewed.
17.	Timely holistic assessments by a multi-disciplinary care team should be undertaken with the family and carers of people who have palliative and end of life care needs to ensure that their needs are identified, recorded, addressed and reviewed.
18.	Respite care should be available to people with palliative and end of life care needs in settings appropriate to their need.
19.	Patients, their families and carers should have access to appropriate and relevant information.
20.	Palliative and end of life care services should be planned and developed with meaningful patient, family and carer involvement, facilitated and supported as appropriate and provided in a flexible manner to meet individual and changing needs.
21.	Services should be prioritised for the provision of equipment, transport and adaptations, for all patients who have rapidly changing needs.
22.	Policies should be in place in respect of advance care planning for patients with palliative and end of life care needs.
23.	Tools to enable the delivery of good palliative and end of life care, for

	example, the Gold Standards Framework, Preferred Priorities for Care, Macmillan Out-of-Hours Toolkit or the Liverpool Care Pathway, should be embedded into practice across all care settings with ongoing facilitation.
24.	All out-of-hours teams should be competent to provide responsive generalist palliative and end of life care and advice to patients, carers, families and staff across all community based care settings.
25.	Access to specialist palliative care advice and support should be available across all care settings 24/7.

Appendix 4: End of Life Care Operational System



'Would you be surprised if this person were to die in the next year?' (see Prognostic Indicators). If you wouldn't be surprised, what should you do to ensure that everything is ready, just in case they deteriorate quickly?

Appendix 5: ELCOS End of Life Care Operational System: Triggers for Action

Should / may be years **A**	**Could be last year** **B**	**Possibly months or weeks** **C**	**Probably last few days or hours** **D**	**First Days after Death and Bereavement**
Holistic Assessment ☐ Medical & Nursing Care Plan completed ☐ Key worker nominated ☐ *(see Keyworker Guidance)*	Holistic Assessment ☐ Medical & Nursing Care Plan completed ☐ Key worker nominated ☐ *(see Keyworker Guidance)*	Holistic Assessment ☐ Medical & Nursing Care Plan completed ☐ Symptom management ☐ Key worker nominated ☐ *(see Keyworker Guidance)*	Holistic Assessment ☐ Medical & Nursing Care Plan completed ☐ Symptom management ☐ Key worker nominated ☐ *(see Keyworker Guidance)*	Verification of death ☐ Care of the Dying Plan completed ☐ Certification of death ☐ Key worker nominated ☐ *(see Keyworker Guidance)*
Advance Care Planning: Offered ☐ Completed ☐ Declined ☐	Advance Care Planning: Offered ☐ Completed ☐ Reviewed ☐ Declined ☐	Advance Care Planning: Offered ☐ Completed ☐ Reviewed ☐ Declined ☐	Advance Care Planning: Offered ☐ Completed ☐ Reviewed ☐ Declined ☐	Bereavement support offered to Relatives ☐ Staff ☐ Other residents ☐

Prognostic indicators suggest possibly entering last year ☐ (see Prognostic Indicator Guidance)	Patient identified and added to GP Register ☐ Care Homes Register ☐	GP register updated ☐ Care Home updated ☐	Multidisciplinary Team, patient and family agree decision to commence Care of the Dying Plan. ☐	Signpost relative to bereavement counselling services if necessary ☐
Decisions agreed and communicated to patient and relatives/carers. Needs reviewed ☐ Needs addressed ☐	Decisions agreed and communicated to patient and relatives/carers. Needs reviewed ☐ Needs addressed ☐	Decisions agreed and communicated to patient and relatives/carers. Needs reviewed ☐ Needs addressed ☐	Decisions agreed and communicated to patient and relatives/carers. Needs reviewed ☐ Needs addressed ☐	Decisions agreed and communicated to relatives/carers. Needs reviewed ☐ Needs addressed ☐
Appropriate leaflets given to patients & family	Appropriate leaflets given to patients & family ☐	Appropriate leaflets given to patients & family ☐	Appropriate leaflets given to patients & family ☐	Offer bereavement leaflet ☐

Should / may be years **A**	**Could be last year** **B**	**Possibly months or weeks** **C**	**Probably last few days or hours** **D**	**First Days after Death and Bereavement**
Equipment assessment Needs reviewed ☐ Needs addressed ☐	Equipment assessment Needs reviewed ☐ Needs addressed ☐	Equipment assessment Needs reviewed ☐ Needs addressed ☐	Equipment assessment Needs reviewed ☐ Needs addressed ☐	Ensure all equipment is collected ☐ Advise family on safe disposal/ return of medication ☐
		Request assessment: GP DN ☐ Other ☐	GP assessment requested ☐	Notify all health and social care professionals involved in the care of the patient ☐ Ambulance Service updated ☐
		DNAR-CPR status considered, documented and communicated. ☐ Ambulance service updated ☐	Symptoms addressed and actioned as per Care of the Dying Plan/ local medication guidelines ☐	Significant Event Analysis. Complete post death information audit form ☐

		Update: GP OOH service ☐ District Nurses ☐	Update: GP OOH service ☐ District Nurses ☐	
		Review targets, medication and therapies discontinue non-essential medications when appropriate ☐	Review targets, medication and therapies discontinue non-essential medications when appropriate ☐	
		Anticipatory prescribing considered. ☐ Actioned ☐ Obtain/ source Syringe Driver ☐	Anticipatory prescribing considered. ☐ Actioned ☐	

Appendix 6: List of Organisations Consulted

- Health and Social Care Trusts
- Public Health Agency
- Health and Social Care Board
- Northern Ireland Hospice
- Foyle Hospice
- Marie Curie Hospice
- Southern Hospice
- All Ireland Institute of Hospice and Palliative Care (AIIHPC)

Appendix 7: Glossary

Supportive and palliative care is the care given to patients and their families whose disease is not responsive to curative treatment. This care can be provided by practitioners not exclusively concerned with specialist palliative care i.e. primary care teams; hospital teams and healthcare professionals in a variety of settings (National Institute for Health Research, 2007).

Palliative care is the active holistic care of patients with advanced, progressive illness such as advanced cancer, heart failure, COPD, dementia, stroke or other chronic conditions. 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 their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments. (WHO, 2002).

End of life care helps all those with advanced, progressive, incurable conditions to live as well as possible until they die. It enables the supportive and palliative care needs of both the patient and the family to be identified and met throughout the last phase of life and into bereavement. It includes physical care, management of pain and other symptoms and provision of psychological, social, spiritual and practical support. (National Council for Palliative Care, Focus on Commissioning, Feb 2007).

RQIA Published Reviews

Review	Published
Review of the Lessons Arising from the Death of Mrs Janine Murtagh	October 2005
RQIA Governance Review of the Northern Ireland Breast Screening Programme	March 2006
Cherry Lodge Children's Home: Independent Review into Safe and Effective Respite Care for Children and Young People with Disabilities	September 2007
Review of Clinical and Social Care Governance Arrangements in Health and Personal Social Services Organisations in Northern Ireland	February 2008
Review of Assessment and Management of Risk in Adult Mental Health Services in Health and Social Care Trusts in Northern Ireland	March 2008
Reducing the Risk of Hyponatraemia When Administering Intravenous Infusions to Children	April 2008
Clostridium Difficile – RQIA Independent Review, Protecting Patients – Reducing Risks	June 2008
Review of The "Safeguards in Place for Children And Vulnerable Adults in Mental Health and Learning Disability Hospitals" in HSC Trust	June 2008
Review of the Outbreak of Clostridium Difficile in the Northern Health and Social Care Trust	August 2008
Review of General Practitioner Appraisal Arrangements in Northern Ireland	September 2008
Review of Consultant Medical Appraisal Across Health and Social Care Trusts	September 2008
Review of Actions Taken on Recommendations From a Critical Incident Review within Maternity Services, Altnagelvin Hospital, Western Health and Social Care Trust	October 2008
Review of Intravenous Sedation in General Dental Practice	May 2009
Blood Safety Review	February 2010
Review of Intrapartum Care	May 2010
Follow-Up Review: Reducing the Risk of Hyponatraemia When Administering Intravenous Infusions to Children	July 2010
Review of General Practitioner Out-of-Hours Services	September 2010
RQIA Independent Review of the McDermott Brothers' Case	November 2010
Review of Health and Social Care Trust Readiness for Medical Revalidation	December 2010
Follow-Up Review of Intravenous Sedation in General Dental Practice	December 2010
Clinical and Social Care Governance Review of the Northern Ireland Ambulance Service Trust	February 2011
RQIA Independent Review of Child and Adolescent Mental Health Services (CAMHS) in Northern Ireland	February 2011
A Report on the Inspection of the Care Pathways of a Select Group of Young People who Met the Criteria for Secure Accommodation in Northern Ireland	March 2011
An Independent Review of Reporting Arrangements for Radiological Investigations – Phase One	March 2011
Review of Child Protection Arrangements in Northern Ireland	July 2011

Review	Published
Review of Sensory Support Services	September 2011
Care Management in respect of Implementation of the Northern Ireland Single Assessment Tool (NISAT)	October 2011
Revalidation in Primary Care Services	December 2011
Review of the Implementation of the Protocol for the Joint Investigation of Alleged and Suspected Cases of Abuse of Vulnerable Adults	February 2012
RQIA Independent Review of Pseudomonas - Interim Report	March 2012
RQIA Independent Review of Pseudomonas - Final Report	May 2012
An Independent Review of Reporting Arrangements for Radiological Investigations – Phase Two	May 2012
Mixed Gender Accommodation in Hospitals	August 2012
Independent Review of the Western Health and Social Care Trust Safeguarding Arrangements for Ralphs Close Residential Care Home	October 2012
Review of the Implementation of Promoting Quality Care (PQC) Good Practice Guidance on the Assessment and Management of Risk in Mental Health and Learning Disability Services	October 2012
Review of the Northern Ireland Single Assessment Tool - Stage Two	November 2012
Review of the Implementation of the Cardiovascular Disease Service Framework	November 2012
RQIA Baseline Assessment of the Care of Children Under 18 Admitted to Adult Wards In Northern Ireland	December 2012
Safeguarding of Children and Vulnerable Adults in Mental Health and Learning Disability Hospitals in Northern Ireland, Overview Report	February 2013
Independent Review of the Governance Arrangements of the Northern Ireland Guardian Ad Litem Agency	March 2013
Independent Review of the Management of Controlled Drug Use in Trust Hospitals	June 2013
Review of Acute Hospitals at Night and Weekends	July 2013
National Institute for Health and Care Excellence Guidance: Baseline Review of the Implementation Process in Health and Social Care Organisations	July 2013
A Baseline Assessment and Review of Community Services for Adults with a Learning Disability	August 2013
A Baseline Assessment and Review of Community Services for Children with a Disability	August 2013
Review of Specialist Sexual Health Services in Northern Ireland	October 2013
Review of Statutory Fostering Services	December 2013
Respiratory Service Framework	March 2014
Review of the Implementation of NICE Clinical Guideline 42: Dementia	June 2014
Overview of Service Users' Finances in Residential Settings	June 2014
Review of Effective Management of Practice in Theatre Settings across Northern Ireland	June 2014
Independent Review of Arrangements for Management and Coordination of Unscheduled Care in the Belfast Health and Social Care Trust and Related Regional Considerations	July 2014
Review of the Actions Taken in Relation to Concerns Raised about the Care Delivered at Cherry Tree House	July 2014
Review of Actions Taken in Response to the Health and Social Care Board Report Respite Support (December 2010) and of the Development of Future	August 2014

Review	Published
Respite Care/Short Break Provision in Northern Ireland	
Child Sexual Exploitation in Northern Ireland - Report of the Independent Inquiry	November 2014
Discharge Arrangements from Acute Hospital	November 2014
Review of the Implementation of the Dental Hospital Inquiry Action Plan 2011	December 2014
Review of Stroke Services in Northern Ireland	December 2014
Review of the Implementation of GAIN Guidelines on Caring for People with a Learning Disability in General Hospital Settings	December 2014
Baseline Assessment of Access to Services by Disadvantaged Groups in Northern Ireland (Scoping Paper)	December 2014
Review of the Care of Older People in Acute Hospitals	March 2015
RQIA Quality Assurance of the Review of Handling of all Serious Adverse Incidents Reported between January 2009 and December 2013	December 2014
Review of the Diabetic Retinopathy Screening Programme	May 2015
Review of Risk Assessment and Management in Addiction Services	June 2015
Review of Medicines Optimisation in Primary Care	July 2015
Review of Brain Injury Services in Northern Ireland	September 2015
Review of the HSC Trusts' Arrangements for the Registration and Inspection of Early Years Services	December 2015
Review of Eating Disorder Services in Northern	December 2015
Review of Advocacy Services for Children and Adults in Northern Ireland	January 2016

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