Delivering the best end of life experience for all

Evidence paper on place of death trends and issues in Northern Ireland to 2040

Marie Curie

Care and support through terminal illness

Contents

Introduction

Pre-covid-19 estimates suggested that, between 2020-2040, nearly 390,000 deaths would be recorded in Northern Ireland. [i] That represents an average of over 18,500 deaths per year, an increase of around 17% on the number recorded in 2019.

Unsurprisingly, most of these deaths will be among people aged 75 and over. At least two-thirds of this group can be expected to be living with multi-morbidity (the presence of multiple different health conditions) [ii] and complex needs. While we don't have robust cause of death projections in Northern Ireland, research suggests that common causes of death across the UK – including from dementia [iii] and certain types of cancer [iv] – will continue to increase in the years ahead.

Knowing not only what people will die from in the future, but where they are going to die, is critical for health, social, palliative and end of life care planning. Without this knowledge, it becomes much more difficult to ensure we have the workforce, capacity, funding, and other resources available in the care settings where they will be needed most.

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Historically, place of death trends in Northern Ireland have been examined retrospectively, with limited forward-looking data available. This paper seeks to help bridge that evidence gap.

The paper is based on two workstreams:

- Projections of place of death trends in Northern Ireland by 2040, based on modelling of data from the period 2004-2018. This research was commissioned by Marie Curie and carried out by the School of Nursing and Midwifery, Queen's University Belfast, in 2020.
- A digital consultative workshop which examined the measures needed to ensure people can live and die well in different care settings in the future, based on the modelling above. The workshop took place in April 2021, with contributions from expert stakeholders from Health and Social Care, General Practice, the Community and Voluntary Sector, and academia.

The pages that follow provide an overview of these place of death projections and the key themes raised during the expert consultation event. Where appropriate, these findings have been supplemented with wider research, evidence, and analysis.

The consultation event was held under Chatham House Rules, therefore neither the names of the stakeholders who participated or the organisation they represented are disclosed.

Where will people be dying in Northern Ireland by 2040?

Marie Curie commissioned the School of Nursing and Midwifery at Queen's University Belfast to carry out a population-based trend analysis of place of death for people who died in Northern Ireland during the period 2004-2018. Using linear modelling, the researchers then made projections on future place of death trends to the period 2040. [v]

Three different scenarios were modelled:

- **Scenario 1** assumed no change in the age and gender specific proportions of deaths observed in 2018 in each place of death.
- **Scenario 2** assumed that the mean yearly change in age and gender specific proportions of deaths in each setting that occurred between 2004-2018, continues to 2040.
- **Scenario 3** assumed that the yearly change in age and gender specific proportions of deaths in each setting that occurred between 2004-2018 continues to 2040, but that – due to capped capacity in care homes – care home deaths don't increase above the number observed in 2018, with any additional deaths instead occurring in hospital.

A summary of the results of each scenario is provided in Table 1 (*pg 6*). Under Scenario 1, proportional place of death trends by 2040 would remain broadly similar to 2018 – with hospitals accounting for the greatest proportion of deaths (48%), followed by private homes (26%), care homes (21%) and hospices (3%).

Under Scenario 2, there would be an increase in the proportion of deaths occurring in care homes compared to 2018 (+5%) and private homes (+4), but a notable decrease in the proportion of deaths in hospitals (-7%) – although that setting would still account for the largest proportion of deaths (41%).

Under Scenario 3, the proportion of deaths in care homes would fall by 6% compared to 2018 levels, with over half (52%) of all deaths in Northern Ireland taking place in the hospital setting – for the first time since 2010. There would be an increase in the proportion of deaths occurring in private homes (+4%) under this scenario, with a moderate fall in deaths in hospices (-0.2%).

This modelling highlights several key themes and issues for consideration. Scenario 2 suggests that the community setting could be the main growth area for deaths in Northern Ireland – with the projected number of deaths in private homes and care homes in 2040 (12,823) representing a staggering 74% rise compared to 2018 (7,390). The community could account for over half (55%) of all deaths by 2040, a 9% increase on 2018.

This data poses serious questions about whether the workforce, capacity and resourcing currently exists in community settings to provide the best end of life experience possible for all these extra patients. Measures to help achieve this are discussed at length in this paper.

74%

The number of deaths in the community could rise by 74% in 2040

Northern Ireland has, to a certain degree, been successful at reducing the number of deaths occurring in hospitals – with the proportion dropping from 53% in 2006 to 48% in 2018. Our modelling suggests that could drop further, to 41%, by 2040 – but that is still too high.

When asked where they would prefer to die, very few people in Northern Ireland chose a hospital. [vi] [vii] In some cases, achieving a patient's preferred place of death isn't possible. Sometimes, hospital is the best place for them to be. But often, with the right services in place, their needs could be met equally – if not better – in a different setting. One where they are surrounded by loved ones and in an environment that is most comfortable and familiar to them.

We should strive to achieve this type of death whenever possible. But as this paper highlights, lack of capacity and barriers to accessing community services have the potential to drive more and more dying patients into hospital when they may not need to be there.

Indeed, Scenario 3 illustrates the potential situation if capacity in the care home sector isn't bolstered, leading to over half of all deaths in Northern Ireland occurring in a hospital by 2040. We are already off to a stuttering start: while the number of people aged 65+ in Northern Ireland grew by 8% between 2015 and 2019, the number of nursing and residential home beds remained largely static. [viii]

This trend will need to be reversed if we are to both avoid a growing number of people experiencing an unnecessary death in hospital and prevent even greater pressure being placed on the hospital sector.

Overall, our modelling highlights that place of deaths trends in Northern Ireland have the potential to change considerably over the next two decades. Planning is required now to ensure that as many people as possible can have the best end of life experience possible no matter where they die.

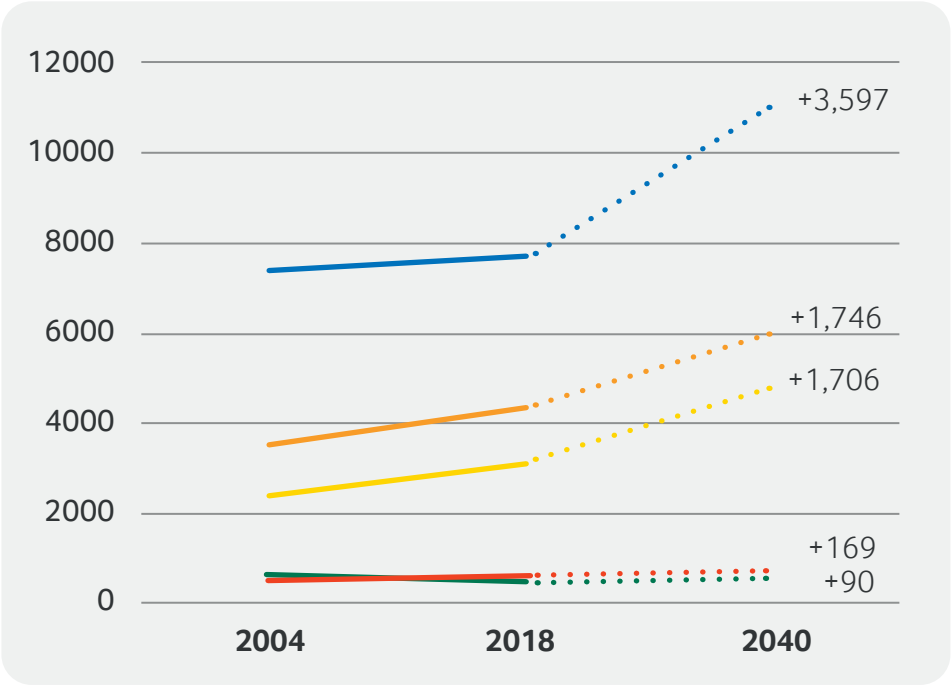
Table 1. Observed and projected place of death trends in Northern Ireland

	Observed deaths				Projected deaths in 2040					
	2004		2018		Scenario 1		Scenario 2		Scenario 3	
	N	%	N	%	N	%	N	%	N	%
Hospital	7,447	51.9%	7,578	47.6%	11,175	48.1%	9,474	40.8%	12,013	51.7%
Care home	2,340	16.3%	3,092	19.4%	4,798	20.7%	5,631	24.2%	3,092	13.3%
Own home	3,513	24.5%	4,298	27%	6,044	26%	7,192	31%	7,192	31%
Hospice	501	3.5%	523	3.3%	692	3%	716	3.1%	716	3.1%
Other	553	3.9%	431	2.7%	521	2.2%	218	0.9%	218	0.9%
Total	14,354		15,922		23,231		23,231		23,231	

Number of observed and projected deaths in Northern Ireland by setting

Scenario 1

Assumed no change in the age and gender specific proportions of deaths observed in 2018 in each place of death.



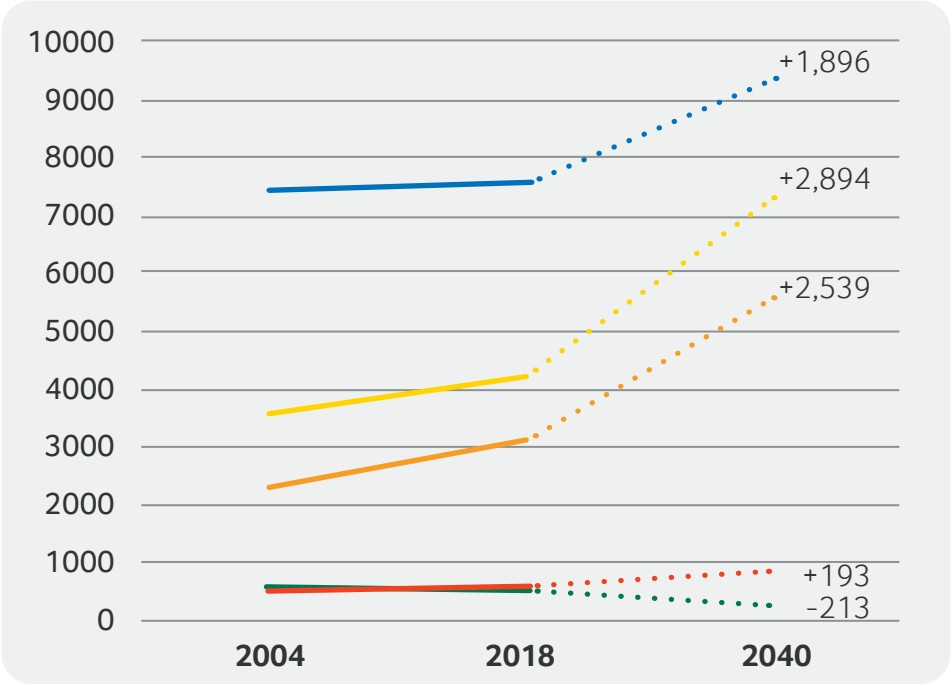
Key

- Hospital
- Care home
- Own home
- Hospice
- Other setting

Projected +/- in no. deaths vs 2018

Scenario 2

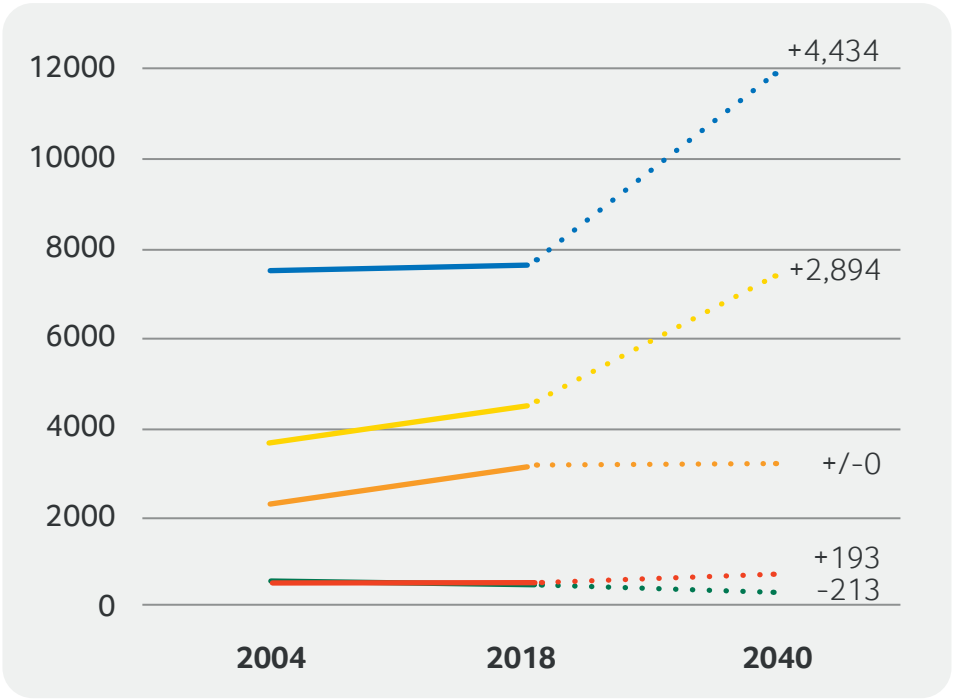
Assumed that the mean yearly change in age and gender specific proportions of deaths in each setting that occurred between 2004-2018, continues to 2040.



Number of observed and projected deaths in Northern Ireland by setting cont.

Scenario 3

Assumed that the yearly change in age and gender specific proportions of deaths in each setting that occurred between 2004-2018 continues to 2040, but that – due to capped capacity in care homes – care home deaths don't increase above the number observed in 2018, with any additional deaths instead occurring in hospital.

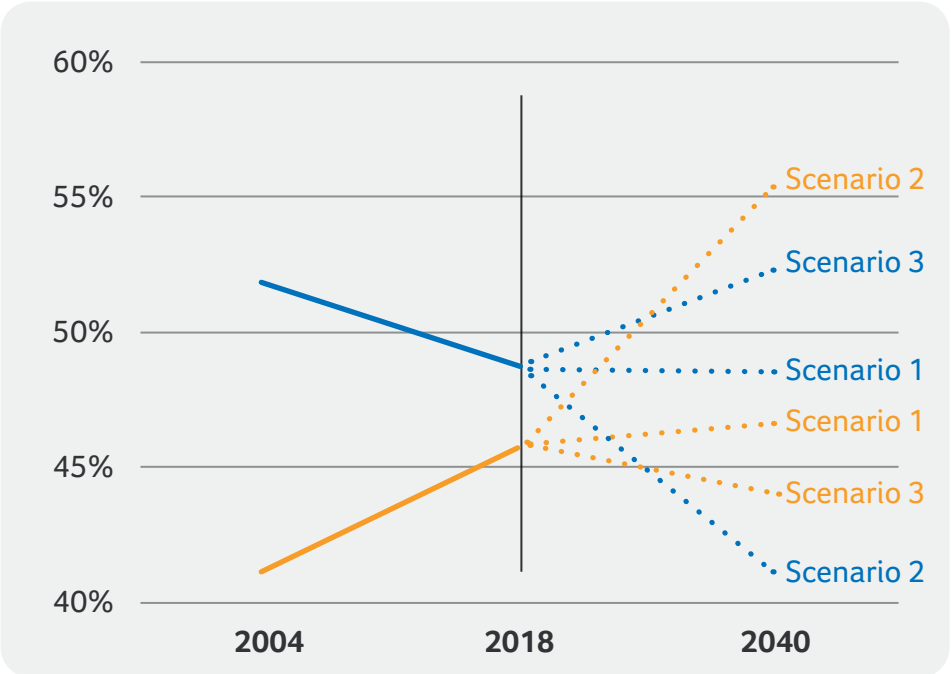


Key

- Hospital
- Care home
- Own home
- Hospice
- Other setting

Projected +/- in no. deaths vs 2018

Proportion of deaths in hospital vs the community



Key

- Hospital
- Community

Ensuring the best end of life experience for all: Insights from health and social care experts

This chapter provides an overview of the key themes discussed during the consultation event with expert health and social care stakeholders (hereafter referred to as 'expert consultees'). Foregrounded in the modelling above, the event examined the actions needed to ensure the best end of life experience possible for dying people in Northern Ireland in different care settings by 2040.

The analysis that follows is both thematic and setting specific. It has been highlighted when themes were identified that related to one care setting exclusively.

Palliative and end of life care training and education

People who are terminally ill or reaching the end of their lives require care and support from a wide range of health and social care professionals. Palliative specialists play a critical role, but most of this care is provided by non-specialist teams. Our expert consultees discussed the importance of ongoing palliative and end of life care education and training for these teams. In this context, particular attention was paid to two groups:

Social care staff

With Scenarios 1 and 2 projecting a notable growth in the number of community deaths, it was recognised that regular and high-quality palliative care training is needed for all social care staff. This should cover core themes including delivering palliative care and recognising when someone is dying. With a staggering 95% projected increase in the number of older people living with dementia in Northern Ireland by 2040, [iii] expert consultees highlighted the particular importance of greater levels of dementia care training.

Many care home and domiciliary care providers already deliver regular and high-quality training for their staff. However, this isn't universal, and gaps exist in levels of training, education and experience. This issue is far from unique to palliative care competency and is a symptom of much wider, entrenched, and systematic workforce issues in the social care sector.

As the Power to People report on social care reform in Northern Ireland makes clear, low levels of pay, poor employment terms and limited progression opportunities are creating significant workforce 'churn' in the sector, with fewer and fewer experienced and well-trained care workers. [ix] Therefore, the wider social care reform agenda will play an important role in addressing gaps in palliative care competency in the sector.

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Beyond this, expert consultees also discussed the potential for dedicated facilitators to be put in place to deliver ongoing palliative care training to care workers. This could be considered under the Department of Health's new framework on nursing, medical and multidisciplinary in-reach into care homes in Northern Ireland. [x]

Multi-disciplinary teams in hospitals

1/4

Just 25% of NI hospitals have mandatory/ priority training programmes on end of life care.

Expert consultees recognised the importance of palliative care confidence and competence among MDTs in the hospital setting. This chimes with the recommendations from the second round of the National Audit of Care at the End of Life (NACEL) in Northern Ireland, which found that end of life care training was included within induction programmes in just over half (55%) of hospitals in Northern Ireland, and within just 25% of mandatory or priority training programmes. [xi]

Across every modelled scenario, deaths in hospital are predicted to rise by 2040. Action is needed to increase access to this vital training in every hospital in Northern Ireland.

Workforce capacity

In parallel with greater palliative and end of life care training and education, expert consultees also highlighted the need for action to bolster capacity in the health and social care workforce – particularly among those 'generalist' teams which provide the bulk of care for dying patients.

For example, data published by the Department of Health showed that one in 10 registered nursing and midwifery roles in Northern Ireland were unfilled at the end of March 2021. There were 350 vacancies across physio, occupational and speech and language therapies, while the social work vacancy rate stood at over 7% – nearly double that of the same period in 2017. [xii]

Tackling health and social care workforce shortages has been a long-standing challenge, made all the harder by the additional pressure and burn-out caused by the covid-19 pandemic. Key services for dying people – including Allied Health Professions and community nursing – have been severely disrupted and diverted to deal with covid-related pressures. [xiii] There were an additional 58,000 hours of HSC (Health and Social Care) staff absence attributable to mental ill-health in April 2020 compared to March 2020, [xiv] while a fifth of health professionals across the UK told a survey in 2020 that covid-19 had made them more likely to leave the profession. [xv] This also comes against a backdrop of growing waiting lists.

These two factors – pre-existing workforce shortages and additional pandemic-related pressures – have created a perfect storm. Both will need to be addressed at their roots if Northern Ireland is to deliver a health and social care workforce that can provide the best end of life experience for all in the years ahead.

Rurality and end of life care at home

Expert consultees expressed concern about the potential for 'two-tier' palliative care services in rural areas compared to urban ones, particularly in terms of primary care input.

In 2016, the BMA warned that general practice in rural areas of Northern Ireland was facing a crisis, with practices at risk of closure due to workforce and workload issues. [xvi] Rural areas like Fermanagh, Dungannon and Portadown have all experienced the closure of GP practices in recent years, and expert consultees warned about the declining availability of GP services for dying patients the further away they live from Belfast or Derry~Londonderry.

In 2019, the Royal College of GPs published a manifesto for addressing the pressure facing general practice in Northern Ireland, including investment to increase the number of medical school places. [xvii] These measures would make an important difference to the current crisis facing general practice, including in rural areas of Northern Ireland.

Out of hours (OOH) support and advice

Expert consultees were clear that achieving the best death possible in the community setting is very difficult for many patients because of Northern Ireland's 'broken' system of out of hours support.

Provision of specialist and generalist palliative care advice and support – for both patients and their health and social care professionals – isn't standardised across all HSC Trust areas. Too often, access is dependent on factors like geographical location, capacity, and ad hoc arrangements. The latest NACEL report illustrates this point, finding that just a third of hospitals in Northern Ireland have a specialist palliative care telephone service available 24/7. [xi]

In line with the section above, a shortage of GPs is contributing to the out of hours (OOH) problem. The BMA warned in 2017 that an extra 400 GPs were needed to address pressures in out of hours services in Northern Ireland.[xviii] This capacity challenge has persisted, with insufficient numbers of GPs impacting significantly on OOH support, even leading to the suspension of some services over recent months. [xix]

Lack of appropriate OOH support is a contributing factor to dying patients attending A&E when they experience a deterioration or worsening of their symptoms. In 2015, two-thirds of emergency hospital admissions for people dying of cancer took place outside of normal Monday-Friday working hours. [xx] Not only does this put significant extra pressure on hospitals, but the data shows that a cancer patient with an emergency admission during the last 28 days of life is seven times more likely to die in that setting. [xx]

It's critical that generalist and specialist OOH services for palliative patients are standardised across Northern Ireland. Necessary workforce investment is required to ensure everyone can access this support when they need it.

Service integration

Expert consultees discussed the importance of palliative care integration with different services and providers across care settings.

It was argued that a siloed approach exists in acute hospital programmes – with action required to better link specialisms like frailty and mental health with palliative care – under the mantra that 'palliative care is everyone's business'. This should be supported by the introduction of a specialist palliative care MDT in every acute hospital.

Expert consultees also highlighted that early specialist care expertise would be beneficial in social care provision, both in people's own home and in care homes. Regarding the latter, it's hoped that the pending framework on nursing, medical and multidisciplinary in-reach into care homes from the Department of Health would help to foster that input.

Similarly, it was suggested that communities of practice involving GPs and care staff would help to create better integration and engagement for the benefit of dying patients.

7x

A cancer patient with an emergency hospital admission during the last 28 days of life is 7 times more likely to die there.

Discharge from hospital

Expert consultees suggested that new dedicated co-ordinator roles were needed in every HSC Trust area to facilitate more efficient discharge from hospital for dying people. They would be responsible for the whole discharge process, including arranging care packages and ensuring the necessary equipment and medicines were in place.

Smooth discharge from hospital is important for all patients, but especially for those who are terminally ill. They may not have long left to live, and unnecessary time spent in hospital eats into precious time that could be spent with loved ones or fulfilling end of life wishes.

Marie Curie research showed that in 2017-18, there were over 46,000 delayed bed days across the Northern Ireland health service, with more than 200 patients dying in hospital while waiting to be discharged. Lack of domiciliary care packages and issues with care planning were the two biggest causes, but delays were also caused by a multitude of other reasons. These included problems related to patient assessments and the availability of equipment. [xxi]

Dedicated discharge facilitator roles with an expert knowledge of the HSC system – alongside greater investment to ensure care packages are available for all patients who need them – could play a crucial part in mitigating these challenges and ensuring more efficient hospital discharge for those at the end of life.

Advance care planning

The importance of early/timely advance care planning (ACP) conversations for ensuring a good end of life experience was universally recognised by expert consultees, regardless of the care setting.

Challenges in identifying when patients are palliative and could benefit from an ACP conversation, as well as lack of awareness and understanding of the purpose and benefits of ACP among patients and their loved ones, have been major barrier to these conversations in Northern Ireland. At a practical level, we also lack a robust infrastructure for recording and sharing ACP conversations and decisions across care settings.

It's hoped that these issues will be addressed with the Department of Health's new ACP policy and through the Encompass IT system.

Support for unpaid carers

Expert consultees recognised the enormous end of life care burden shouldered by unpaid carers. This is only set to increase in the years ahead. Every modelled scenario projects growth in the number of deaths at home, while many of those who die in another setting are still likely to spend some time at home as they approach the end of life.

Caring for a terminally ill loved one has a significant impact on physical, mental, and emotional wellbeing. This may be particularly severe for older carers who are dealing with their own declining health and dwindling support networks. [xxii]

To help provide greater support end of life carers in Northern Ireland, expert consultees called for:

- Greater information and training for carers, to equip them with the skills and knowledge required to support their dying loved ones.
- Enhanced provision of over-night support from health and social care providers, to allow carers to take a break from caring and get proper rest.
- Greater service provision to support carers' mental wellbeing.
- Access to high-quality bereavement support for carers once their loved one dies.

Palliative care keyworkers

Expert consultees noted the partial implementation of the Palliative Care Keyworker Role (PCKW) across Northern Ireland.

Usually performed by District Nurses, the PCKW is responsible for co-ordinating care across interfaces and ensuring patients have the support, information, and advice that they need. It's a hugely important role and may take a significant burden off dying people and their loved ones, particularly those being cared for at home.

The Palliative Care in Partnership programme published a role and function profile for Palliative Care Keyworkers in 2017, but it has not been fully rolled out and embraced in every HSC Trust. Action is needed to deliver the role across Northern Ireland, so that all terminally ill patients can benefit from a PCKW when they need one.

Measures to boost capacity in the District Nursing workforce and raise awareness of the PCKW role among patients and their loved ones would also make an important difference.

Sustainability of community and voluntary sector (CVS) palliative and end of life care services

Expert consultees recognised the huge role played by non-statutory palliative and end of life care providers, and highlighted the precarious financial situation facing many of these organisations due to the impact of the coronavirus.

The covid-19 outbreak ground many charitable fundraising activities to a sudden halt and has continued to stifle income-generation ever since. While hospice providers have received welcomed extra funding injections from the NI Executive, the pandemic has underlined the unsustainable commissioning model for non-statutory palliative services. These services care for thousands of dying patients each year but are heavily reliant on charitable donations to survive.

Organisations like Marie Curie have called for a reassessment by the Departments of Health and Finance, commissioning bodies and CVS providers to ensure these services are put on a more stable, sustainable financial footing in the years ahead.

The role of volunteers

Expert consultees argued that volunteers are an important resource which could be better utilised to support people at the end of life in Northern Ireland, especially those at home. Volunteer support for dying patients can:

- Improve quality of life [xxiii]
- Provide emotional support and companionship, helping to reduce anxiety [xxiv] and loneliness [xxv]
- Enhance holistic care and help with physical symptoms [xxvi]
- Take pressure off unpaid carers
- Increase overall satisfaction with care [xxvii]
- Combat the unacceptable, but all too frequent, scenario where someone may die alone.

Expert consultees believed that the Department of Health's 'no more silos' approach could be used to bring the benefits of volunteers to palliative and end of life care in a more meaningful way than is currently being achieved.

Care home fees

With Scenarios 1 and 2 predicting notable increases in the number of people dying in care homes in Northern Ireland, expert consultees discussed the significant financial pressure facing many patients and families because of care home fees.

In 2019-20, the average weekly cost of residential are in Northern Ireland was £551 per week (£28,652 per year), with average nursing care costs standing at £706 per week (£36,712 per year). [xxviii] Although not every care home resident is a full or partial self-funder, the high fees may pose a serious financial challenge for many who are. This highlights the importance of delivering a social care funding model that ensures equitable access to care that is both high quality and, crucially, affordable for all who need it.

Social and financial issues at the end of life

Expert consultees noted the numerous non-clinical components which influence a patient's end of life experience, particularly issues around housing quality, heating, and nutrition.

280

Nearly 280 dementia deaths in Northern Ireland were attributable to cold, damp housing between 2014-2019

Living in insufficiently heated and poor-quality housing can have significant consequences for a terminally ill person's health and wellbeing. It can exacerbate existing symptoms, cause new infections, impact on their quality of life and, in the worse cases, even speed up their death. Between 2014-15 and 2018-19, over 475 deaths from respiratory diseases and nearly 280 deaths from dementia in Northern Ireland were attributable to cold, damp housing. [xxix]

Broader socioeconomic factors are also well-evidenced determinants of end of life outcomes. For example, average life expectancy in the most deprived areas of Northern Ireland is nearly 6 years shorter than in the least deprived areas, and the cancer mortality rate for people aged under 75 is 1.7 times greater in the most deprived areas compared to the least. [xxx]

Expert consultees agreed that good palliative care should take a wide, holistic view of people's needs. It should focus not only on their access to health care services, but interventions to address the socio-economic and financial issues impacting on their end of life experience as well.

Summary of recommendations

This paper has outlined a suite of actions and interventions to help ensure the best end of life experience for everyone in Northern Ireland in the future, no matter where they die. The following is a summary of those recommendations and ideas.

To ensure the best end of life experience for all by 2040, policymakers and health and social care leaders must:

- Deliver a programme of ongoing palliative and end of life care education and training for all of those involved in the care of terminally ill/dying patients, across care settings, with dedicated training facilitators for care workers.
- Boost workforce capacity in generalist and specialist palliative care services.
- Combat the GP crisis in rural areas of Northern Ireland.
- Ensure standardised and universal provision of generalist and specialist out of hours services to support palliative patients.
- Fulfil the mantra of "palliative care is everyone's business" by fostering greater integration between the different services and providers dying people rely on – including acute hospital programmes, palliative care systems, social care and primary care.
- Introduce specialist palliative care multidisciplinary teams in every acute hospital in Northern Ireland.
- Introduce dedicated hospital discharge facilitator roles for dying patients in every Health and Social Care Trust (HSCT).
- Break down barriers to early/ timely advance care planning (ACP) conversations and ensure ACP decisions can be recorded and shared across care settings.
- Provide greater support, information, and training for unpaid carers of terminally ill people, including overnight services, mental wellbeing, and bereavement support.
- Ensure the universal implementation of the Palliative Care Keyworker (PCKW) role across all HSCTs in Northern Ireland, with further measures to boost capacity in District Nursing and raise awareness of the PCKW role among patients and their loved ones.
- Put community and voluntary sector palliative and end of life care services on a more stable and sustainable financial footing.
- Better utilise Northern Ireland's volunteer population to support people at the end of life.
- Deliver a social care funding model that ensures equitable access to high-quality and affordable services.
- Support the social and financial needs of people at the end of life.

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