All Ireland Institute of Hospice and Palliative Care

All Ireland Institute of Hospice and Palliative Care (AIIHPC) is a leading organisation with national and international influence promoting excellence in palliative care. AIIHPC is a collaborative of hospices, health and social care organisations, charities and universities on the island of Ireland. AIIHPC's aim, with our twenty-eight member organisations, is to ensure excellent palliative care is available for everyone at the right time and place across the island of Ireland.

- involving service users, carers and communities in palliative care delivery and development
- working to integrate palliative care across the health system so people are supported
  as early as possible
- supporting the development of specialist palliative care services for everyone who needs them.

The Institute's submission is informed by feedback from our member organisations from Northern Ireland which were gathered via on online meeting and email correspondence. In addition, the Institute linked in with organisations such as Hospice UK.

CURRENT STATE OF PALLIATIVE CARE SERVICES

In your view what is the current state of palliative care services in Northern Ireland?

In light of the Institute's years of working within the sector and the input provided by our member organisations from Northern Ireland, we believe there are disparities between palliative care services delivered in Northern Ireland. Where and when people can access services, they are excellent and have a person-centred approach. However, due to levels of inequity across the region, not everyone is able to access services when and where they need them. The population living in urban areas are better served than those living in rural areas and there is a lack of consistency in service delivery, commissioning, and care at home. Considering population growth projections, palliative care services are not sustainable and they will not meet the growing needs of the population. Northern Ireland Statistics and Research Agency estimate that by 2046 the population of Northern Ireland will be over 2 million and those aged 65+ will practically double (49.2%). Older people living with multimorbidity's are projected to become the main recipients of palliative care in the coming decades. The lack of recurrent and long-term funding makes planning for future population needs difficult and thus increases the overall inequality in service delivery for future generations. Also, the lack of consistent, cohesive and comparable data collection across all services, does not allow for the collection of information to identify the needs that the system is designed to address.

The Institute's members highlighted the need for a clear policy/strategy for Northern Ireland regarding palliative care, along with an implementation plan with key deliverables and detailed activities and timelines, a review panel and accountable parties.

Do you think there is an understanding by the public of what palliative care is? If no, what are the main barriers to the public understanding palliative care?

There is limited but growing awareness of palliative care amongst the public in Northern Ireland. Misconceptions persist, as the public tends to associate palliative care with end of life and cancer only; there is a lack of understanding about the breadth and depth of the services which means people may be missing out on improved quality of life.

Research has been carried out by different organisations and thus there is ample evidence that showcases the public's misunderstanding about palliative care:

- Life and times survey 2018 for example noted in 2018 that 14% of people had never heard of palliative care.
- Life and time survey 2022 for example noted 24% of people believe palliative care is exclusively for people who are in the last 6 months of life in 2022.
- Public awareness and attitudes toward palliative care in Northern Ireland results noted, Responses indicated limited knowledge about palliative care. Female gender and previous experience influenced awareness in a positive direction. Respondents who worked in healthcare themselves or who had a close relative or friend who had used a palliative care service were more aware of palliative care and the availability of different palliative care services. (…) The main barriers to raising awareness were fear, lack of interaction with health services and perception of lack of resources.

Including the Institute's annual research carried out for Palliative Care Week regarding the public's perceptions which noted in 2024:

- 69% of adults in Northern Ireland feel fearful when they hear the term palliative care
- 64% of adults in Northern Ireland think palliative care is for people with cancer
- 17% of adults in Northern Ireland neither agree or disagree with the statement: *'I know that Palliative Care can benefit people over long periods and not just at end of life'* -- and 8% of adults disagree with this statement completely

To see the full results see the 2024 Palliative Care Week Survey.

It is also interesting to look at the survey carried out in 2023, when we used the same survey questions that were used in 2016 and 2018 in order to try and see the changes in people's perceptions. Overall, in both jurisdictions there was a slight decrease in knowledge and awareness since 2016 and 2018 which could be due to a range of reasons including that the Covid-19 pandemic forced the campaign online from 2020 – 2022 which could have affected the momentum that the campaign was generating in earlier years.

For example, in Northern Ireland the percentage of adults who think that palliative care is beneficial for anyone with a life limiting illness increased from 84% in 2016 to 88% in 2018. However, this decreased to 80% in 2023.

The percentage of adults who think that palliative care cares for all aspects of the person increased from 85% in 2016 to 87% in 2018. However, this decreased to 75% in 2023.

There was also a significant increase in adults in Northern Ireland who prefer not to think about palliative care: 25% in 2016 to 40% in 2023.

To look back on survey results from 2020 onward see: Palliative Care Week surveys.

The main barriers to public understanding, include: the taboo around death and general feeling of fear, which makes this a difficult area to discuss openly. People often do not want to consider palliative care before they need to, because they associate it with end of life only. If death was approached the same way that we approach birth i.e. having a birth plan, it could start to normalise the conversation. Also, if education regarding palliative care started at primary and secondary school level, a foundation of knowledge would already be established, and conversations might be easier to be had in the future.

Another barrier is lack of knowledge or information held about palliative care. If people understood the depth and breadth of the services and how it can support them through long periods of time, how it can improve their quality of life, they might be more open to it.

Advance care planning should be part of any adult's journey, regardless of their stage of illness. The Department of Health's Advance Care Planning: For Now and For the Future policy document launched in October 2022, should be fully implemented as this would be support to the new palliative care policy/ strategy, that we recommend in question 20. Furthermore, it is part of the recommendations of the 2022/2023 NACEL Report: 'Ensure that every opportunity is taken to give dying people the option to participate in advance care planning, to reflect their choices and wishes at the end of their life. This should include documenting in the patient's care records, the preferred place to die (if known), discussions regarding recommendations for cardiopulmonary resuscitation, and facilitating this wherever possible.'

A third barrier is the lack of funding and resources dedicated to promoting palliative care and engaging with communities. Further support towards Palliative Care Week, which is led by All Ireland Institute of Hospice and Palliative Care and supported by key stakeholders including its members organisations, would ensure that awareness continues to be raised about the benefits of palliative care and that different audiences are reached, would ensure that awareness continues to be raised about the benefits of palliative care and that different audiences are reached.

Lack of interaction with health services is another barrier which has been highlighted by research (Public awareness and attitudes toward palliative care in Northern Ireland - PMC). And is reinforced by a lack of continuity and coordination between health care services.

Further information regarding these barriers can be found in the following papers:

- Public awareness and attitudes towards palliative care in Northern Ireland.
- Building public engagement and access to palliative care and advance care planning: a qualitative study – PMC
- WHAT DO THE PUBLIC IN NORTHERN IRELAND KNOW AND THINK ABOUT PALLIATIVE CARE AND ADVANCE CARE PLANNING?

In addition to the public's misunderstandings about what palliative care is, there is also a lack of understanding from health and social care professionals who don't work within specialist palliative care. This means referrals to palliative care services can be late, if at all, and people are therefore not accessing the services as soon as they could to support and improve their quality of life. Embedding palliative care education as a core model within the curriculum of all health and social care professionals would be greatly beneficial to improve this lack of understanding. This is aligned with recommendation 9 of the 2022/2023 NACEL Report: *Work towards end of life care training programmes becoming embedded as part of induction programmes and also as part of mandatory/priority training programmes in Northern Ireland. Advanced communication skills training should be available for health and social care staff to access. End of life care training should develop staff competence and confidence to; recognise imminent death, communicate with the dying person and people important to them as early and sensitively as possible, and deliver end of life care.*

ACCESS TO SERVICES

Are palliative care services equally accessible to all who need them?

Palliative care services are not equally accessible to all who need them. Urban populations have better access than rural areas; there is currently a postcode lottery in terms of access to the right services at the right time. *Also, the lack of understanding of what palliative care is and what it can achieve for people with conditions other than cancer by both professionals and people with a terminal illness and their families mean people are not accessing the services* (Triggers for Palliative Care – Marie Curie).

Research also shows that people want to stay and be cared for at home. However, if we are focussed on shifting people out of hospital to be cared for at home, there are many factors to consider. Research by Marie Curie shows: Terminally ill people may experience a vicious cycle of fuel poverty. Their deteriorating health means they have to spend a lot more to heat their homes sufficiently, which some may struggle to afford due to depleted incomes and the other significant costs associated with their illness. However, the consequences of living in a cold home can be severe. It can lead to new infections, make existing symptoms flare up or become worse, affect their mental wellbeing and, in the worst cases, even hasten their death. (Triggers for Palliative Care – Marie Curie).

To provide holistic care, different factors need to be looked at besides health. And thus, a cross-departmental approach of government which brings the Departments of Health and Social Protection together to tackle this issue, would be ideal.

There is lack of reliable data to properly understand how accessible services are to individuals who have life limiting conditions other than cancer. Although there 'is significant anecdotal evidence which suggests those who have terminal conditions other than cancer are less likely to be offered or to access palliative care services.' (Triggers for Palliative Care Marie Curie). Again, this highlights the need to support the implementation of consistent collection of data across services to have a better understanding of population needs.

Addressing inequitable access to hospice care is a report that provides interesting perspective on how to address inequitable access, including the role of hospices in advocating for increasing community capacity, sharing knowledge, skills and brining networks together to avoid a postcode lottery.

From your experience where are the gaps in the provision of service?

Gaps in the provision of palliative care services:

- Lack of comprehensive out of hour services
- Absence of regional central point of referral across Northern Ireland
- Single point of contact of reliable, comprehensive and consistent information available 24/7. In line with recommendation 7 from the 2022/2023 NACEL report; *Work towards having specialist palliative care doctor and/or nurse telephone advice availability 24 hours a day, seven days a week*
- Services are not geared to deal with the needs of different population groups including people with disabilities, LGBTQIA+, multi-cultural backgrounds
- The end-of-life experience for prison populations
- The end-of-life experience for homeless populations
- Lack of uniformed, consistent and comparable data collection across services
- Lack of co-ordinated effort to gather the peoples experience of end of life care services in a similar way to the HIQA End of Life Care Survey About the survey - National Care Experience Programme
- Lack of cohesive IT and communication systems across services (Encompass does not include hospices)
- Lack of emotional support for health and social care professionals working in the sector
- Need for improvement in communication skills of health and social care professionals supported by the findings and recommendations of the 2022/2023 NACEL report.

Do you believe barriers exist that prevent equitable access to these services? If yes, please provide examples in the box provided.

Yes, it is the Institute's view along with its member organisations that barriers exist which prevent equitable access to services, for example:

- Lack of clear and consistent data across all services which makes it difficult to articulate the true service level needs; cannot identify the number of unique patients accessing services
- Insufficient funding across the sector; unreliable model of funding for hospices that rely on public fundraising to deliver vital services
- Geographic barriers, socio-economical barriers, cultural barriers, religion and social barriers; services could be more embracing and inclusive
- Staff capacity and capabilities across the entire workforce. For example, end of life training has been identified as an area for improvement in the 2022/2023 NACEL report
- Lack of infrastructure to provide comprehensive community care including home care

- Lack of comprehensive out of hour services, especially in rural areas
- Not being always able to access equipment in a timely manner
- Not being always able to access medication or pharmacists that provide weekly medication dispensed packs in a timely manner which can result in increased stress and anxiety for families as medication changes frequently
- IT systems that are not talking to each other – for example GP surgeries systems not integrating with hospital systems and Encompass does not include hospices

What additional services could/should be provided?

- Encompass roll out going forward should include hospices as well.
- Help line like 111 – staffed by palliative care specialist nurses who can triage and ensure appropriate care is delivered particularly out of hours. A working example of this service is Goldline - Airedale NHS Foundation Trust and Highland Hospice's 4/7 Palliative Care Helpline and the Palliative Care Response Service
- Community palliative hubs that are multidisciplinary where people can access a range of services
- Education for carers to support their loved ones with practical needs if they choose to do this (medicine administration, etc)
- More robust support for bereaved children in different settings (schools, hospitals, hospices, community services, etc)

INTEGRATION OF SERVICES

How well are palliative care services integrated across the health system, through primary, secondary and specialist care?

In line with our member organisation's feedback and the Institute's experience within the sector, we consider palliative care services are not fully integrated across the health and social care system including through primary, secondary and specialist care. Starting from the terminology '*primary, secondary, specialist'* which does not encompass all the services and should be reviewed and expanded. Generalist palliative care and non-statutory services should also be considered as well.

The current inconsistent levels of funding across services, further increases the lack of integration as some services are dependent on fundraising which means long-term planning and long-term services cannot be provided nor well integrated across the services i.e. Encompass (only part of the health service is included).

Furthermore, hospices, community services, hospital services, health and social care trusts all work with different systems and software; which means there is no one single communication system. The lack of consistent systems/software/communication also makes the collection of consistent and comparable data an issue, which is an issue for future population-based planning.

Wider workforce pressures across the whole system (GP, community services and social care, for example) further negatively impacts on integration. There are many pressure points that do not create conditions for integration or clear pathways for patients. In addition, the lack of coordination across the health care system leads to unclear pathways which further exacerbates the pressures across the system.

Integration should be considered from a wider perspective, not only at a service level. For example, trends show that people want to be cared for at home and when this is possible (depending on diagnosis and treatments required) some people are still unable to stay at home due to the high costs of heating their homes or having to make home adaptations. Marie Curie's research highlights these issues. In order to support those who cannot afford to be cared for at home, integration at a government level across different departments (Health, Communities, Social Protection, Enterprise), would be beneficial. Thus, when financial support is required, a single contact could automatically trigger the different benefits that some departments/companies provide i.e. NIE Networks Medical Customer Care Register, NI Water, instead of people needing to spend significate amounts of time navigating and liaising with different services trying to access the range of different benefits which are available.

Should palliative care be a regional service? Please outline your reasons in the box provided.

Yes, the Institute and its member organisations consider there is a need for an overarching regional service that is adequately funded and ensures collaboration between the different actors within the health and social care system/sector including HSC Trusts and hospices. While a regional service would be beneficial, it is important that local services are supported and brought along in the process to ensure comprehensive and equitable access across the region.

A regional service would also allow more flexibility for health and social care professionals who live and work along the border to be able to cross regions but not have to worry about differing policies or professional care provision.

What can be done to improve integration?

Research shows that 'integrated palliative care is viewed as having the potential to improve service coordination, efficiency and quality outcomes for patients and family carers' (A Call for Integrated and Coordinated Palliative Care). The Institute and its Member organisations believe integration in Northern Ireland can be improved by:

- Overarching policy/strategy to support standardised approach to care provision for those facing terminal illness and those that support them.
- Policy/strategy based on a public health approach which brings all actors togethers (health and social care trusts, hospices, nursing and residential care settings, community care, community and voluntary organisations etc).
- Continue to raise public awareness about palliative and end of life care through sector wide coordination and support.
- Supporting all palliative care services to transition towards working with the same system/software/communication (bring all hospices into Encompass).

- Support uniform data-based approach across the different palliative care services to support future planning based on population needs as well as work-force planning
- Creating a single point of contact for people to call where they can access reliable, comprehensive and consistent information 24/7.
- Expanding and supporting the Frailty Network; embracing the community to provide services for the population.
- Palliative care needs to be embedded as core modules in curriculums of healthcare courses/ degrees and further opportunities for post graduate education should be made more available.
- An All-Island approach to palliative and end of life care; there are a lot of shared learnings and opportunities that can come from working with colleagues in the Republic of Ireland and the Department of Health published the National Adult Palliative Care Policy in September 2024 and is working towards an implementation plan.
- Integration at government level as well to look at issues from a holistic perspective, with holistic solutions i.e. addressing the fuel poverty that affects some people with terminal illness from the health and social care perspective.

BEST PRACTICE

Do you have any examples of good practice or pilots in palliative care that are meeting the needs of patients and families/carers? If so, is this best practice happening widely across Northern Ireland?

There are examples of good practices in palliative care that meets the needs of patients and families/carers however it is not happening across all areas of Northern Ireland:

- Marie Curie’s Rapid Response Service
- Marie Curie’s School Bereavement Programme
- Single point of access – Belfast Health and Social Care Trust
- Encompass, but needs to be rolled out widely to all organisations
- Life and Time is an example of good practice in meeting the needs of patients, families and carers across South Down NI within SHSCT.
- Highlands Hospice- 24/7 Palliative Care Helpline and the Palliative Care Response Service Goldline - Airedale NHS Foundation Trust

Do you think that families receive sufficient support when accessing services? Please outline your reasons in the box provided.

No, based on the feedback received from our Member organisations, we believe families could receive improved support when accessing services. As mentioned before, quality and availability of services depends on where you live. Also, the lack of integration and coordination amongst services means families do not have clear pathways to support their navigation of services.

Given the public's lack of understanding about palliative care, not everyone is aware of what services are available. People tend to think services are only available for specific life limiting conditions, such as cancer, or at a specific time, such as final days, and as thus they are deterred from accessing services.

Furthermore, there is a growing trend of people wanting to be taken cared at home, however this increases home bills and due to the lack of integration across health and social care government departments and agencies, this may result in people struggling financially with insufficient support at an already stressful time. Further information can be found through Marie Curie's campaign to end fuel poverty.

FUNDING AND STRATEGY

Do you think the current funding for palliative care is sufficient? Please outline your reasons in the box provided.

No, palliative care funding is not sufficient to meet current and future needs.

Northern Ireland Statistics and Research Agency estimate that by 2046 the population of Northern Ireland will be over 2 million and those aged 65+ will practically double (49.2%). Older people living with multimorbidity are projected to become the main recipients of palliative care in the coming decades. More complex illness as well as younger cohort of patients with late diagnosis or advanced cancer, will create significant pressure on services. Northern Ireland faces a very vulnerable position moving forward into the future, as services are not equipped to meet the future needs of all of its population.

Is the current model for the funding of hospices, including hospice at home/community care/rapid response support, sustainable and sufficient to meet needs now and in the future? Please outline your reasons in the box provided.

Based on our Member organisations input as well as the Institute's experience within the sector, we do not consider the current model for funding of hospices is sustainable.

Our colleagues at Queen's University Belfast note: *Hospices have for over four decades not been fully state funded. They rely on fundraising contributions to provide essential palliative care services. This mixed economy has led to an unnecessary tension, which is almost unique in the UK, and is not seen in any other speciality of healthcare. The hospice sector has reported that is facing financial crisis [1], with the current state funding model which both underpins and undermines hospice provision proving untenable [2]. A sustainable state income model is required for hospices to ensure optimal palliative care delivery. The rising aging population, particularly those with co-morbidities, underscores the importance of ensuring high quality palliative care provision [3-5], which is essential to achieve Universal Health coverage, sustainable development goals (SDGs) target 3.8 [6].*[1]

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[1] Hospice Financial Benchmarking report (2024) Hospice UKhttps://hospiceuk-files-prod.s3.eu-west-2.amazonaws.com/s3fs-public/2024-09/Hospice%20Financial%20Benchmarking%20Report%20Sep24%20v3.pdf Accessed 07/11/2024

There is currently an over reliance on public fundraising for vital hospice services and in the future, there will be growing population numbers of people living with multi morbidities and complex needs requiring palliative care services. The lack of multi annual funding also makes planning for future service developments difficult. It has been positive that one off sources of funding have been provided to the sector by the Department of Health but the lack of longer-term consistency of funding negatively impacts on consistent service delivery.

If hospices become fully state funded, the fundraising from the public would still be needed to support measures such as innovations in patient care, capital builds, additional comfort services for patients and their families, education and research. An example of this can be seen in the Republic of Ireland, where hospices are now fully state funded.

A sustainable funding model for hospice care is essential to ensure that these services are protected and continue to provide invaluable care across the region.

Is there a need for a new Palliative Care Strategy for Northern Ireland? If yes, what should it include? If no, why not? Please outline your reasons in the box provided.

In accordance with the conversations held with our member organisations, we believe there is a need for a Palliative Care Strategy/Policy for Northern Ireland. Northern Ireland's palliative care policy lags behind other UK regions. Northern Ireland's most recent palliative care strategy, "Living Matters, Dying Matters," was published in 2010 and expired over a decade ago. In contrast, other UK governments either have active palliative care strategies / frameworks or have committed to developing new ones. The priority for NI should be to develop a palliative and end-of-life care agenda at a strategic policy level.

The strategy should be:

- comprehensive, including adult and children palliative care services
- have specific and tangible outcomes that are reviewed periodically and adjusted with realistic and specific timeframes
- clear lines of responsibility and accountability
- have an implementation/operational plan
- realistic and committed funding
- recognise different demographics/cultural needs

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3. Finucane AM, et al How many people will need palliative care in Scotland by 2040? A mixed-method study of projected palliative care need and recommendations for service delivery BMJ Open 2021;11:e041317. doi: 10.1136/bmjopen-2020-041317

4. McKeaveney, et al (2020). Population-based projections of place of death for Northern Ireland by 2040. Palliative Medicine and Hospice Care , 6(2), 22-33.

5. Etkind SN, et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. BMC Med2017;15:102. doi:10.1186/s12916-017-0860-2. https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-017-0860-2#citeas. pmid:28514961

6. World Health Organization. The global Health observatory https://www.who.int/data/gho/data/themes/topics/indicator-groups/indicator-group-details/GHO/sdg-target-3.8-achieve-universal-health-coverage-(uhc)-including-financial-risk-protection Accessed 07/11/2024

- recognise different levels of palliative care
- integration (through common systems/software/communication)
- seek to include sector wide policy papers and initiatives such as Advance Care Planning: For Now and For the Future and ResPect
- have a body/Board responsible for monitoring implementation of the policy

Our colleagues at Queen’s University Belfast recommend reviewing the Canadian Consensus Statement, Palliative Care Matters: How Canada’s Health System Needs to Change, which is broad enough to apply to the NI context.

Any other comments

The Institute’s views have been shaped by input gathered from our Northern Ireland member organisations and the years of experience working within the sector.

As the sector’s Institute, we understand our member organisations frustrations while being thankful that palliative care is high on the agenda. Moving forward and acknowledging change takes time and the limited funding available, the sector would greatly benefit from at least the following items being delivered within a short time frame:

1. Establish a clinical lead in palliative medicine who can speak directly into government and minister
2. Commitment to producing palliative care strategy/policy, with committed funding, accountability and implementation plan within the next 3 years
3. All hospices in Northern Ireland be brought into Encompass
4. Commitment to ensure the ReSPECT paperwork is finished
5. Single point of contact. People can get access to reliable, consistent, and comprehensive information 24/7.

The Institute makes itself available for further discussions including with its patient and public involvement group, Voices4Care, and any other way it can support to ensure the inquiry is successful in obtaining the necessary information.