

AIHPC Response to Northern Ireland Programme for Government draft Outcomes Framework (March 2021)

On 25 January 2021, the Northern Ireland Executive launched the public consultation on its Programme for Government draft Outcomes Framework. The draft Framework contains nine strategic Outcomes which, the consultation information states, will set a clear direction of travel for the NI Executive and provide a vision for the future of all citizens.

The draft Framework has no focus on the needs of people towards the end of life, on palliative and end of life care needs, no reference to adult and children's palliative care policies, nor to the role of bereavement support.

All Ireland Institute of Hospice and Palliative Care ([AIHPC](#)) is a collaborative of hospices, health and social care organisations, universities, and charities on the island of Ireland working to improve the experience of palliative care. With 11 partners in Northern Ireland and 15 partners in the Republic of Ireland, AIHPC is working with the health and social care systems across the two jurisdictions on the island to improve palliative care.

AIHPC's submission to the draft Outcomes Framework calls for it to be revised to incorporate a focus on the importance for society of:

- **opportunities for planning and discussing wishes for care when living with serious and progressive, life-limiting illnesses and conditions**
- **acknowledging the quality of life benefits of palliative and end of life care, for people with any serious and progressive illness or condition, of all ages, including children and young people**
- **providing opportunities for open conversations around death, dying, loss and care**
- **the role of bereavement support.**

AIHPC's response is focused on three of the nine outcomes as set out below.

Our children and young people have the best start in life

While very important that each child gets the best start in life, this outcome ignores the fact that many children are living with life-limiting conditions and sadly will die in childhood or as young adults.

The Key Priority Areas of Access to Education, Care and Early Years, which references meeting the complex needs of children, under this outcome are not specific enough in relation to encapsulating the needs of children with life-limiting or life-shortening conditions. These children's needs must be factored in across Access to Education, Care and Early Years specifically.

As acknowledged in A Strategy for Children's Palliative and End of Life Care 2016-26 (November 2016) [here](#), an estimated 1,300 children are living with life-threatening or life-limiting conditions and 150 children die each year in Northern Ireland.

The Strategy's Executive Summary states that it "adopts an outcomes-based approach to palliative and end-of-life care for children from 2016 to 2026". However, there is no acknowledgement in the draft Outcomes Framework of children living with life-threatening or life-limiting conditions, of their needs or of the needs of their families and those caring for them. The draft Outcomes Framework must address this gap.

The implications for the wellbeing of everyone involved were acknowledged by then Health Minister Michelle O’Neill in the strategy Foreword. Minister O’Neill stated: “I am confident that the implementation of this Strategy will go a long way to improve the experiences of everyone involved in the care of a seriously ill child; parents, siblings, carers, the wider family circle, friends, neighbours and the community at large are all hugely affected by the illness or death of a child.”

Our children and young people should have the best start in life, as the outcome states, but those whose length of years may be limited should be supported to have the best quality of life, whatever the life-threatening or life-limiting condition they may be living with. This support, or lack of support, has much wider implications for the whole community around the child and your person. This outcome must encompass this.

We all enjoy long, healthy active lives

While this outcome highlights the importance of addressing the factors which impact on mental and physical health, the emphasis is on healthy, active lives, with no consideration of the needs of people with serious, progressive, incurable illnesses or long-term serious health conditions. There is also an absence of any consideration of the needs of people living towards the end of life, or on palliative and end of life care.

The commitment to prevention and early intervention in relation to supporting citizens to lead long and healthy lives is welcome. The needs of those living with serious and progressive illnesses, for example, advanced cancer, advanced dementia, advanced respiratory and heart disease, and progressive neurological conditions must also be included.

People living with serious and progressive illness should be supported to have the best possible quality of life right up to the last day of their lives. Palliative care can help to improve and maintain a person’s quality of life, regardless of the person’s age or illness. Palliative care addresses the person’s physical, social, psychological and spiritual needs, and the needs of their family. For those who are in caring roles there is also a need for support for them, also taking account of social and economic circumstances, including impact on finances.

Current estimates suggest that approximately 75% of people approaching the end-of-life may benefit from palliative care, with the potential to support their quality of life for weeks, months and years, and this need is growing ([here](#)). As people are living longer and are more likely to be living with chronic illnesses, it may mean that an even higher percentage of the population may benefit from palliative care in the future.

In ‘An action plan for better palliative care’ ([here](#)), Cicely Saunders International reports that the COVID-19 pandemic has accelerated palliative care demand by 20 years. In 2017, due to changing population demographics and disease patterns, it was forecast that at least half a million people in England and Wales would need palliative or end of life care every year by 2040. But this level of demand was reached in 2020 due to the COVID-19 pandemic. Many people did not access the palliative care they needed during 2020.

The need for palliative care is increasing globally. The number of people dying in Northern Ireland over a 25-year period from 2016 to 2041 is projected to increase by 32 per cent (from 15,300 to 20,300). Growth among the Northern Ireland population aged 65 and over (65.1 per cent) is projected to exceed that in the rest of the United Kingdom (50.2 per cent) (NISRA Statistical Bulletin October 2017 available [here](#)).

Developments in how health conditions can be treated and managed means that as people get older, they are more likely to develop and live with one or more long term health conditions, as acknowledged in Northern Ireland’s Health and Wellbeing 2026: Delivering Together (2016) report.

In New Decade, New Approach 2020 ([here](#)), palliative and end of life care is highlighted as one of the priorities of the Restored Northern Ireland Executive. In relation to transforming the health service, New Decade, New Approach specifically refers to providing increased investment to fully implement service improvements for palliative and end of life care including enhancing the contribution of hospices; and to increase support for palliative perinatal care.

It is a noble aspiration to plan for and support people to live healthy, active lives into old age, but the outcome should not seek to avoid the fact that everyone will reach an end of life and die. The outcome must not overlook those whose physical and mental wellbeing is affected by serious and progressive illnesses and health conditions. This outcome must encompass the needs of people as their capacity for living physically healthy, active lives decreases, as they live with serious and progressive illnesses, and must consider end of life care, so that quality of life is supported until death.

We have a caring society that supports people throughout their lives

If this outcome is to truly enable everyone to live their lives in a fulfilling way, it must give greater recognition to how people living with serious and progressive illness are supported. This includes support for a person in their illness, and in society, so that people are supported to have conversations about what is important to them, particularly as they face serious and progressive illnesses. It is also important for society that opportunities are provided for open conversations around death, dying, loss and care. The health and social care system in Northern Ireland is encouraging these conversations, and AllHPC is supporting this work.

Palliative care has a role to play in promoting health and wellbeing. Serious illness, death, dying, loss and grief are universal experiences. A truly caring society must support those who are living through these experiences, which will touch everyone at some time in their lives. Palliative care maximises the quality of life for the person at the centre of care and those important to them and it continues that care into bereavement.

For the past seven years, with the support of the Health and Social Care system in Northern Ireland, including at Ministerial level, All Ireland Institute of Hospice and Palliative Care has delivered Palliative Care Week - a campaign to raise awareness and increase understanding about palliative care. The aim of the campaign is to prompt these conversations, so that people will be empowered to discuss, and ask about, how they could benefit from palliative care, and how their physical, psychological, social and spiritual needs can be addressed when they are living with a serious, progressive life-limiting illness or condition.

The Palliative Care Week campaign comes under the broad understanding of a public health approach to palliative care and is in line with Northern Ireland policy direction. This policy is reflected in Living Matters, Dying Matters: A palliative and end of life care strategy for adults in Northern Ireland (2010) and in the RQIA Review of the Implementation of the Palliative and End of Life Care Strategy (March 2010), January 2016.

The first recommendation from the RQIA Review ([here](#)) states: "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."

The Department of Health is supporting the development of a public health approach to palliative care for Northern Ireland. The regional palliative care programme for Northern Ireland - Palliative Care in Partnership - has agreed a definition which recognises the role of society and community in

enabling and supporting people living with life-limiting conditions, and those important to them, to live well. The full definition is available [here](#)

This definition encourages people to discuss their needs and to think about and plan for their future.

This is also being supported through the current development by the Department of Health of an Advance Care Planning Policy for Adults in Northern Ireland ([here](#)). Significant research results into public understanding and attitudes to palliative care and advance care planning were published recently by Ulster University ([here](#)). It recommends that palliative care and advance care planning discussions be integrated into bigger public health campaigns on healthy ageing as part of everyday conversations, instead of waiting for a diagnosis of a terminal illness.

Recognising the value of advance care planning for enhancing people's quality of life, increasing their autonomy and helping them face a diagnosis of serious ill health, led to the development of the Heart of Living and Dying initiative in the Southern Health and Social Care Trust ([here](#)).

Consumer Omnibus Surveys commissioned by AIHPC for Palliative Care Week also show that many people in Northern Ireland would like to begin a conversation about topics often considered too difficult to discuss. Sample population surveys of 500 people across Northern Ireland were carried out in June 2018 and July 2020.

In 2018, 73% agreed that if they thought palliative care could help them, they would discuss it with their GP, community nurse or hospital consultant and 72% agreed that if palliative care could help them, they would like a health care professional to discuss it with them.

In 2020, almost three out of four people (73%) in Northern Ireland indicated that they would like to be supported to discuss and write down their wishes and preferences for care at the end of life. 64% of adults have been thinking more about death and dying than before, due to the COVID-19 pandemic. Also, in relation to COVID-19, almost six in 10 people (58%) stated that the pandemic had increased the importance of discussing their wishes and preferences for care at the end of life.

In addition, the result of a major survey of palliative care experience across the island of Ireland coordinated by AIHPC published in 2016 showed more than two thirds (68%) of people with palliative care needs said that 'planning for the future' was their biggest worry. The findings in the Let's Talk About Palliative Care Survey Report ([here](#)) included experiences of 528 people with palliative care needs and carers across the island (109 in Northern Ireland and 419 in the Republic of Ireland). This survey emphasised the importance of raising awareness of palliative care and the benefits of the early integration of palliative care in the care of people with life-limiting conditions.

Palliative care supports those important to the person at the centre of care and continues care into bereavement. Death and bereavement, at some time, affect everyone. The COVID-19 pandemic, and its impact on the ways we have cared for and been with people at the end of life, and supported families in mourning, highlights the importance of support in bereavement. A report of a survey of bereavement care practitioners across the UK and Ireland just published ([here](#)) describes a "silent epidemic of grief" being experienced due to the pandemic. It has highlighted the need for bereavement care to be considered an integral part of health and social care provision.

If Northern Ireland is to have a caring society that supports people throughout their lives this outcome must be broadened. It must include the needs of those living with serious and progressive illnesses, promote open conversations around death, dying, loss and care, support people to plan for and discuss wishes for care, acknowledge and incorporate the quality of life benefits of palliative care, and include the role of bereavement support.