

Response to Draft NI Programme for Government – December 2016

All Ireland Institute of Hospice and Palliative Care (AIHPC)

All Ireland Institute of Hospice and Palliative Care (AIHPC) is a collaborative of hospices, health and social care organisations and universities on the island of Ireland. Eleven of AIHPC's 24 partners are health care providers, agencies and universities in Northern Ireland.

AIHPC advances education, research and practice to improve the palliative care experience of people with life limiting conditions and their families. As the palliative care sector's institute, AIHPC is:

- 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.

While the programme for government sets out to be 'focused on delivering improvements to multiple aspects of people's lives' (PfG Consultation Document, 2016: 4) an acknowledgment of the importance of good care as one moves towards the end of life would be welcomed. The absence of good palliative and end of life care negatively impacts on the individual, their families and the wider community.

What is missing from this outcome?

Outcome 4. We enjoy long, healthy, active lives

The commitment to prevention and early intervention in relation to supporting citizens to lead long and healthy lives is welcome. However, the needs of those living with serious and progressive life-threatening illnesses, such as advanced cancer, advanced dementia, and progressive neurological conditions must also be included.

Although the needs of people living with long term conditions is acknowledged and that people live many years of life in poor health, there is a need for explicit recognition of supporting people to live well with an illness which is life-limiting, seeking to help them achieve the best quality of life as their illness progresses and they move towards end of life.

Identification of people with needs and early intervention and support should include those with a life-limiting illness. Referral to palliative care services has been found to be beneficial in ensuring better quality of life outcomes, increasing survival time¹ as well as resulting in significantly lower treatment costs².

Integrated services through new models of care should factor in palliative and end of life care. This care should be provided mainly in primary care but with access to specialist palliative care support where required. Two thirds (68%) of those service users and carers who responded to the 'Let's Talk About' Palliative Care Survey report³ signified that planning for the future was their biggest practical

worry. People must be supported when they are living with a life-limiting illness and facing end of life.

The role of 'confidence and capability of communities' in supporting people to live as independently as much as possible is welcomed. The 'assets based' approach as set out in the delivery plan associated with Outcome 4 could benefit from considering the compassionate community model espoused by a public health approach to palliative care which envisages end of life care as everyone's responsibility.⁴

In relation to the indicator '% people who are satisfied with health and social care', identification of the need to support service users in co-designing services is welcomed. Investment to support this will help to embed service user, carer and interested citizens' involvement in healthcare delivery, building on work such as that of members of AllHPC's Voices4Care⁵ service user, carer and interested citizen group supporting the NI Palliative Care in Partnership programme, led by the Public Health Agency and Health and Social Care Board.⁶

To avoid feeding a perception of information being gathered rather than changes being made on feedback, efforts should be made to support the dissemination and learning from initiatives where service user and carer views have been expressed, such as AllHPC's all-island 'Let's Talk About' Palliative Care Survey report³ for which 528 responses were received. This survey used a methodology similar to 10,000 Voices and was supported by the Public Health Agency.

Research is a vital component of service development and improvement. An explicit commitment to the contribution of research would be welcomed in relation to the delivery plan supporting Outcome 4. A systematic process was carried out by AllHPC in 2015 which culminated in a prioritisation of the top 10 unanswered research questions, or evidence uncertainties, in palliative and end of life care on the island of Ireland as identified by health care providers, patients and carers, which could assist in informing a research agenda.⁷

1. Temel, Jennifer S., et. al., "Early palliative care for patients with metastatic non-small-cell lung cancer." *New England Journal of Medicine* 363, no. 8 (2010): 733-742.
2. Brick, Aoife, et al., *Economic Evaluation of Palliative Care in Ireland (2015) Report prepared for The Atlantic Philanthropies.*
http://www.medicine.tcd.ie/health_policy_management/assets/pdf/Final-report-July-2015.pdf p.xvi
3. <http://aiihpc.org/wp-content/uploads/2016/05/LTA-Survey-FINAL.pdf> (accessed December 2016)
4. Kellehear, A. Compassionate communities: end-of-life care as everyone's responsibility, *QJ Med* 2013; 106:1071-1075 <http://qjmed.oxfordjournals.org/content/106/12/1071> (accessed December 2016)
5. <http://aiihpc.org/policy-practice/voices4care/> (accessed December 2016)
6. <http://www.publichealth.hscni.net/news/making-palliative-care-everyone%E2%80%99s-business>
7. AllHPC (2015) *Palliative and End of Life Research Priority Setting Project for Northern Ireland and Republic of Ireland: Putting patients, carers and clinicians at the heart of palliative and end of life care research.* Dublin: AllHPC. Available from <http://aiihpc.org/wp->

<content/uploads/2015/06/PeolcPSP-AllHPC-report.-FINAL.-april.15.pdf> (accessed December 2016)

Outcome 14. We give our children and young people the best start in life

While the commitment to giving the ‘youngest citizens the best start in life’ is welcome, due consideration must be given to those children and young people who are living with a life-limiting or life-threatening condition. As the Health Minister states, ‘each year in the North around 150 children pass away, and an estimated 1,300 are living with life-limiting or life-threatening conditions’ (2016:4). It is important that this outcome, as the recently published strategy sets out to do, ‘encompasses everyone who requires paediatric palliative support, and those who are approaching the end of their lives’.⁸

8. Providing High Quality Palliative Care For Our Children – A Strategy for Children’s Palliative and End of Life Care 2016-26 <https://www.health-ni.gov.uk/publications/strategy-childrens-palliative-and-end-life-care-2016-26> (accessed December 2016)

Final comment in on-line submission

The only further comment is that All Ireland Institute of Hospice and Palliative Care wishes its comments to relate specifically to Outcomes 4 and 14, which is where information has been provided in relation to this online survey tool, as these were the areas of most relevant to the work of the Institute. Boxes for other outcomes have been ticked, to enable a submission to be made to Outcomes 4 and 14, rather than as an indication of assent to every aspect of work contained around each of these other outcomes.

Thank you for the opportunity to comment.

December 2016