

All Ireland Institute of Hospice and Palliative Care
Second Floor, Education & Research Centre
Our Lady's Hospice
Harold's Cross
Dublin 6W
Ireland

Tel: +353 (0)1 491 2948

Email: info@aiahpc.org



AIHPC

All Ireland Institute of
Hospice and Palliative Care

21 October 2013

Your ref: 31/H&C/06/B2013

Joint Committee on Health and Children
Houses of the Oireachtas
Leinster House
Dublin 2

Dear Joint Committee,

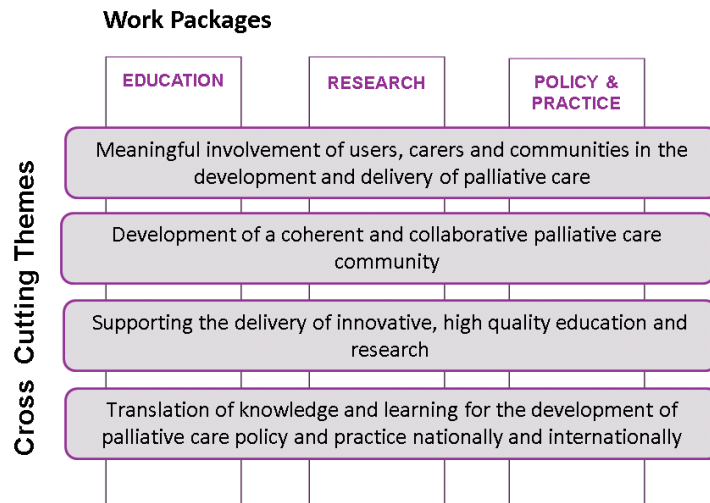
Re: Presentation on end of life care specifically the role of specialist palliative care establishing what needs to happen to ensure that people die well in Ireland.

I am delighted to offer this written submission on behalf of All Ireland Institute of Hospice and Palliative Care (AIHPC).

We wish to commend the Committee for giving their attention to the various aspects of palliative care in the series of public hearings. In aiming to ensure that people die well in Ireland the Committee's aim is wholly congruent with the Institutes aim of an improved experience of care on the island of Ireland.

AIHPC is a collaborative of partner organisations and are a mixture of care providers and academic institutions from the Republic of Ireland and Northern Ireland. Originally twelve, partner organisations now number fourteen with three more organisations in the process of joining (see end of document). This is a collaborative spanning all major hospice and palliative care providers and all nine universities on the island of Ireland. It is from this rich and diverse collaborative base that AIHPC seeks to achieve its aim. Key specialist palliative care experts from across the globe are also collaborating with the Institute.

As requested by the Committee the scope of this submission is specifically focused on specialist palliative care and we will seek to identify what we believe needs to happen to ensure that people in Ireland die well within that context. It should however be noted that the remit of the Institute embraces general palliative care provision in the wider health and social care setting as well as significant work with users, carers and communities to help achieve greater awareness and understanding as well as engagement so as to inform palliative care provision and development. This wider remit is illustrated in the Institutes work packages and cross-cutting themes illustrated below.



The vision for the Institute is that people across the island of Ireland living with a progressive or long term illness experience the best care possible up to and including the very last days of their lives. Our vision recognises this is a journey that may span a number of years not just months. In this vision best care is synonymous with the goal of the best possible quality of life. AIHPC is helping making this happen by working closely with all those involved in specialist palliative care looking at increasing research, enhancing education, creating resources and influencing policy;

Research helps us to know how and if we are providing the best possible care for patients and their families and research can also tell us how we might change improve and develop. Funding has helped lay the foundations of a Palliative Care Research Network (PCRN) on the island of Ireland. Initial research includes four studies aimed at addressing social justice aspects of palliative care services and three studies aimed at better measurement and evaluation. A further study is looking at how to facilitate the transfer of learning from those research studies into practice and thus to enhancing the experience of palliative care by people in Ireland. Further work identifying research priorities and informing a research strategy for the island of Ireland is also underway. The Institute partners constituting all academic institutions and all key specialist palliative care providers on the island affords opportunities to collaborate for high quality, focused and meaningful research including the translation of research for an improved experience of palliative care. Research work is also underway exploring the application of technology sector solutions in helping meet the needs of the palliative care population. The PCRN also affords excellent opportunities initially for European and international partnerships ultimately becoming a global player in palliative care research and development. What is needed?

- Infrastructure support to ensure the basic research network architecture is sustainable, continues to develop and achieves impact

- Support to pursue research programmes aimed at meeting the identified priorities for palliative care research on the island of Ireland such as;
 - ✓ addressing the management of the significant symptom burden of people requiring palliative care,
 - ✓ addressing accessibility for marginalised groups
 - ✓ systems research looking at cost effectiveness of various models of palliative care provision
 - ✓ developing technological solutions to help meet specialist palliative care needs
 - Funding for projects to address research priorities including assistance to secure support from European Union programmes and initiatives and to secure international and global partnerships
 - Wider system recognition of the vital contribution to be made by the specialist palliative care community to population based health challenges across chronic disease trajectories, with the frail elderly and with those people living with complex and multiple diseases
 - A tangible programme of support for early career researchers to ensure we build a cohort of research leaders steering the thinking, policy and provision of specialist palliative care services
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The right education is vital and we are working to ensure that the right education is available and accessible and to ensure that gaps in education provision are addressed. We have worked with the Health Service Executive to identify in partnership with key agencies palliative care competencies that can underpin all undergraduate and postgraduate professional education in Ireland. We have also worked with partner organisations to expand information on available education programmes both across the island of Ireland and internationally. We are working with hospice education providers to ensure that duplication of programme provision is avoided and that more core education provision is made widely available on a modern electronic learning platform and where providers will increasingly use these methods to deliver contemporary palliative care education. We have supported education fellowships facilitating specialist palliative care professionals to travel to and learn from exemplar care and education sites across Europe and internationally and to share that learning with the Irish palliative care community. What is needed?

- Workforce planning must include funding to release professionals to undertake a range of education and development activities ensuring that specialist palliative care is delivered by competent and up-to-date skilled practitioners
- Palliative care practitioner's must be supported in their efforts to assist in the education and development of general palliative care provision

- Support for the leadership development of palliative care practitioners in all relevant sectors including; policy making, commissioning, management and service improvement of palliative care
 - Investment in programme development and contemporary provision by specialist palliative care educators to help educate users and carers in important aspects of palliative care as well as enhancing the skills and provision of colleagues in the wider health and social care setting
 - Regulatory bodies should seek to ensure that palliative care principles underpin all undergraduate and post graduate education programmes
 - Palliative care education providers should be supported to contribute to other areas of health and social care education to ensure contemporary palliative care education is available and accessible
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The Institute is also working to develop infrastructure and resources to better support specialist palliative care. We are leading an initiative aimed at providing a modern communications and learning hub with four components aimed at three main audiences; a 'professional interests' component aimed at palliative care professionals across the health and social care sector and beyond, two service user and carers components, one aimed at 'adults receiving palliative care' and one aimed at 'children and young people receiving palliative care'. All three audiences will be able to avail of education, skill building and awareness raising programmes housed in the fourth component – a modern interactive learning platform. Coordinating one point of access to a myriad of palliative care information and provision both on the island of Ireland and internationally will have profound benefits for all these audiences and will establish a valuable resource on the island contributing to the awareness, understanding and experience of palliative care for our populations. It should prove to be a valuable asset in achieving the goal of dying well in Ireland. What is needed?

- Commissioners and providers of palliative care services within both jurisdictions must engage with and help resource this development ensuring accurate and timely service information sources for professionals involved in delivering services as well as for people using or caring for someone using palliative care services
- Government support for a wide marketing and awareness campaign will help direct people to this important resource and ensure it can have maximum benefit contributing positively to the experience of palliative care and achieving the goal of best possible quality of life
- Opportunities being taken at the national level to collaborate with the technology sector might also support the wider utilisation of the communications and learning hub initiative.

- More funding to support ‘content’ building and to allow specialist palliative care professionals to contribute to the build and development of the ‘professional interest’ component.
 - Funding to support the engagement of service user and carers in the development and content building along with support for specialist palliative care professionals to assist with credible and reliable information for the public adult, children and young people audiences.
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The Institute representing the research, education, practice and policy interests of palliative care providers are working to contribute to policy development and evaluation. The Institute is inviting and facilitating discussions around key policy developments, trends and emerging issues and are seeking to do this on an all island basis between the two jurisdictions recognising that there is significant opportunity for synergy and possible joint policy drivers. Support has been given by Ministerial colleagues in both jurisdictions for AIIHPC to provide a presentation on its work at a forthcoming North/South Ministerial Council. What needs to happen?

- AIIHPC should be included in policy and service developments so as to contribute and where possible align work activities of the Institute with key national priorities
 - AIIHPC need mechanisms to allow outputs from its research and other institute activities to be fed into and influence service and policy activities at the national and where relevant local area level
 - AIIHPC could contribute to the Republic of Ireland’s Department of Health’s World Health Assembly delegation where appropriate to ensure Ireland’s palliative care thinking is contributed and to help influence relevant WHO resolutions that might assist national and international palliative care policy developments
 - AIIHPC would be in a position to assist with any required evaluation of palliative care policy or strategy developments where required
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A palliative approach to care may be appropriate for many people across the age range from a baby born with such serious difficulties that they are unlikely to survive to a young person with a condition that will shorten or severely limit their life, to an adult coping with a diagnosis of for example cancer or motor-neurone disease to an older person facing a progressive condition such as dementia or with a number of conditions that could significantly affect their quality of life – for all of these people the *goal* of care is *quality of life*. For many people their palliative needs are complex and challenging and they require the help of the members of specialist palliative care teams – these specialists may be found in our hospitals, in hospices, and working within our community and primary care settings. We recognise that not all people who require it receive this type of care and many do not receive it early enough. In establishing the Institute palliative care leaders are hopeful that as our health care systems seek to provide the right palliative care resources in the right

places that the Institute can support the quality and capacity of those specialist palliative care resources on the island of Ireland resulting in a better experience of care – helping ensure that people die well having had the best possible quality of life.

We wish the Joint Committee on Health and Children well in its round of public hearings and hope that this submission has helped inform members of the role and scope of the contribution being made by AIHPC as well as identifying what else may be done to help maximise that contribution in order to achieve a good quality of death for people in Ireland. We will be delighted to provide any further information that may assist the Committee in its deliberations.

Yours sincerely,



Paddie Blaney
Director AIHPC

| AIHPC Consortium Partners | Shadow Partners |
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| Our Lady's Hospice and Care Services in Dublin Northern Ireland Hospice Milford Care Centre in Limerick St Francis Hospice in Dublin Marie Curie Hospice in Belfast St James Hospital in Dublin Trinity College Dublin Queens University Belfast University of Ulster University of Limerick University College Dublin Dublin Academic Medical Centre University College Cork Dublin City University | National University of Ireland Galway National University of Ireland Maynooth St Patricks Marymount University Hospice, Cork |