



AIHPC

All Ireland Institute of
Hospice and Palliative Care

AIHPC CONSULTATION RESPONSE

All Ireland Institute of Hospice and Palliative Care (AIHPC) is a collaborative of seventeen health care and academic institutions. Our aim is to improve the experience of palliative care for the populations of the Republic of Ireland and Northern Ireland through supporting the development of research, education, policy and practice. Our partners include the major hospice and palliative care providers as well as all nine Universities on the island of Ireland.

AIHPC has a Palliative Care Research Network (PCRN) which was established four years ago with investment from the Health Research Board and other charitable and philanthropic funding.

We are grateful for the opportunity to respond to this important Consultation paper. We note the eight key pillars to be considered in the formulation of a new strategy. We wish only to make only generic comments that we mean to cross-cut all relevant aspects of the various pillars and goes to the heart of the vision we would have for research in Ireland.

In relation to this vision we would comment that Ireland like many other developed (and developing) countries has a population whose health and social care has the potential to bankrupt the country unless radical and innovative means are found to manage the impact of demographic changes and levels of chronic diseases. It is well recognised that Ireland is of an opportune size and nature within which to develop and test solutions to these global problems. Clear direction and change in strategic approach is vital to effecting these changes.

The current proportion of percentage spend on Health realised via the Health Research Board is quite simply nowhere near sufficient to make the impact required. This is not a suggestion to merely tinker with the percentages but a call for a radically different approach for a radically different aim. Unless we think very differently about health and wellbeing in Irish society – all of Irish society will be overshadowed.

Ireland has a unique opportunity to test case new ways of addressing these problems that will have direct benefit to both the social well-being of our country but also to better support our economic status. An increase in funding to support reform of systems, approaches, use of technology and devices, enabling of increased levels of self-care are all aspects deserving of funding. Such increased funding must be targeted at these areas of system and societal development specifically with clear outcomes that impact the country's capacity to meet the health needs of our populations into the next fifty years.

Moreover funding in the various government departments and agencies should be reviewed to synergise programmes where at all possible for similar aims. Only when Ireland's industry, economy,

public services, education, technology are engaged in this direction will we realise the impact required and thus find a path to economic as well as societal well-being.

In relation to identifying research priorities an initiative AIHPC is engaged in (part of a UK/Ireland initiative) uses innovative means to engage the publics and end users views of research priorities and this is proving immensely salient – we will be happy to share details of the priorities setting exercise if required.

In terms of international collaboration AIHPC is well placed to engage internationally with colleagues around palliative care research development including knowledge transfer and exchange. Our chief challenge is the resource needed to embrace these opportunities and funding of research collaboratives should take this challenge into consideration and facilitate the identification of resources to achieve more of this.

Related to this and with significant potential are the opportunities afforded by a number of Horizon 2020 programmes – again the infrastructure costs required and the venture costs of attempting to go for this funding proves immensely challenging.

Fundamentally if only those centres that have been successful previously are likely to be the ones who are successful again the danger is evident – we may not get new but more of the same. Accepting good quality science as a given there has to be a way of levelling the playing field so that newer centres can break in and ensure that research investment remains dynamic and cutting edge.

It may be useful to add to your listing (page 9 of the Consultation Paper) of Ireland's global positioning that it ranked number 1 in the Good Country Guide in relation to the amount of good Ireland does externally¹ – our suggestion to focus more on health and well-being as a societal challenge and share that globally would do much to help sustain Ireland's position at the top of that ranking – it would also help improve our ranking in science and technology.

Lastly AIHPC have benefited greatly by the active and meaningful engagement with our all Ireland *users, carers and citizens with an interest* panel – called Voices4Care. As a model this should be replicated and implemented in all aspects of research activity in Ireland but it should be recognised that to do this effectively requires resources and effective approaches. AIHPC is happy to share details of our model. Research commissioners who appear to value this type of engagement must also look to ensure that engagement exercise are not tokenism and that it is appropriately financed as a legitimate research cost.

I hope these comments are helpful and I am more than happy to discuss further if that would be helpful.

This Consultation Response was coordinated by Paddie Blaney, Director AIHPC

¹ <http://www.goodcountry.org/overall>