

**All-Ireland Institute  
for  
Hospice and Palliative Care**

**Outline proposal**

**11<sup>th</sup> May 2007**

**Prepared by Prospectus Consultants**

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## Introduction

### 1.1 Background

Across many European countries, end of life care is on the agenda as never before. Although development remains patchy and is generally concentrated in the countries to the west of the region, there is growing evidence both at the national and the pan-European level that the provision of hospice and palliative care is attracting the interests of policy makers, funding bodies and non-government organisations – as well as health and social care professionals, patients, families and the wider public.

Ireland in particular has a rich culture of hospice and palliative care organisations involved in the direct delivery of care, as well as in grant giving, fund-raising, advocacy and public education. Recently, there have been a number of key reports, policy statements and government commitments reflecting increased attention to hospice and palliative care at Government level. To date, however, there has been little strategic thinking about the strategic development of education, training and research in hospice and palliative care on a national or all-Ireland level.

### 1.2 Origins of the Institute concept

Prof. David Clark is the current Visiting Professor of Hospice Studies at University College Dublin and Trinity College Dublin, a post which is funded by the Irish Hospice Foundation. Since his appointment, Prof. Clark has engaged in numerous discussions about the evolving needs in relation to supportive, palliative and end of life care in Ireland, and in particular about an idea for the creation of an all-Ireland Institute for Hospice and Palliative Care. Prof. Clark set out his thinking in relation to the Institute in a draft discussion paper in January 2007<sup>1</sup>.

### 1.3 Progression of the idea from concept to outline proposal

In support of Prof. Clark's work, the Irish Hospice Foundation engaged the services of Prospectus Consultants to assist in the development and testing of the case for an all-Ireland Institute for Hospice and Palliative Care.

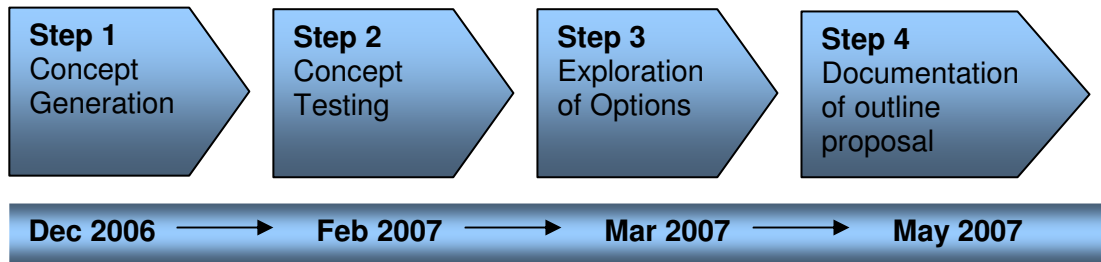
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<sup>1</sup> Clark, D. *An Institute for Hospice and Palliative Care in Ireland- Draft Discussion Paper*. 2007

## Section 1 – Introduction

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A four step process was employed to develop this outline proposal for the Institute.



In **Step 1**, Prospectus was briefed on the background to the concept, identified the key issues in relation to the Institute, and agreed the project approach.

In **Step 2**, Prof. Clark's discussion paper was circulated widely to relevant organisations, groups, and individuals to consider and discuss within their organisations. In February, Prof. Clark formally presented the paper to the National Council for Specialist Palliative Care. In parallel, Prospectus conducted interviews with a number of individuals working in academia, research and/or health policy, North and South, to obtain their views on the proposed Institute.

In **Step 3**, Prospectus facilitated an Exploratory Workshop on 6 March 2007 with approximately fifty representatives from relevant organisations and groups interested in hospice and palliative care in Ireland, North and South. The objective of this workshop was to explore a number of options in relation to the Institute, and to agree whether or not to proceed with further development of the concept. At the end of the workshop, workshop participants concluded that the concept of the Institute should be progressed and refined.

In **Step 4**, Prospectus held a working session at the Irish Hospice Foundation, with Prof. Clark, to flesh out a more detailed description of the aims and objectives of the Institute, building on Prof. Clark's discussion paper, the outcome of the Exploratory Workshop and the individual consultations. Prospectus then drafted this document.

### 1.4 Objective of this document

The purpose of this document is to outline the vision, objectives, activities and governance model for an all-Ireland Institute for Hospice and Palliative Care, and to describe the steps associated with getting the Institute up and running over the next number of years.

## Section 1 – Introduction

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### 1.5 Definitions

Within this document, a number of different terms are used in relation to the scope of the Institute. These terms are defined as follows:

#### **Supportive Care**

Supportive care helps the patient and their family to cope with their condition and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment<sup>2</sup>.

#### **Palliative Care**

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual<sup>3</sup>.

#### **End-of-life Care**

There is no exact definition of 'end of life'. However, the evidence indicates that end of life care is relevant where there is

- the presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate
- the symptoms or impairments resulting from the underlying irreversible disease require formal (paid, professional) or informal (unpaid) care and can lead to death

Older age and frailty may be surrogates for life-threatening illness and comorbidity; however, there is insufficient evidence for understanding these variables as components of end of life<sup>4</sup>.

#### **Hospice Care**

Hospice care is the total, active care of patient and family at that stage of serious illness when the focus has shifted from providing treatment aimed at cure to ensuring the best possible quality of life<sup>5</sup>. Hospices care for the whole person, aiming to meet all needs - physical, emotional, social and spiritual. At home, in day care and in the hospice, they care for the person who is facing the end of life and for those who love them. Nearly half of all people admitted to a hospice return home again.<sup>6</sup>

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<sup>2</sup> UK National Council for Palliative Care, [http://www.ncpc.org.uk/palliative\\_care.html](http://www.ncpc.org.uk/palliative_care.html)

<sup>3</sup> World Health Organisation 2002 <http://www.who.int/cancer/palliative/definition/en/>

<sup>4</sup> National Institutes of Health, *State-of-the-Science Conference Statement*, 2002

<sup>5</sup> Irish Hospice Foundation. <http://www.hospice-foundation.ie/>

<sup>6</sup> Help the Hospices, <http://www.helpthehospices.org.uk/>

## Context

### 2.1 European Context

We live in a society that is experiencing population ageing and in which expectations of a long life must also be matched with recognition that care at life's end is a matter that faces every individual and the whole of society.

Despite the important initiatives that are under way, hospice and palliative care development in Europe remains patchy and the development and recognition of the specialty has been slow in many countries<sup>7</sup>. The reasons behind this are varied.

- The field has ongoing **problems of definition, terminology and boundaries** relating to the cognate disciplines associated with oncology, the care of older people, chronic illness management and disability. 'Palliative care' is still not widely understood by the general public and its place within modern multi-disciplinary health and social care systems is still developing<sup>8</sup>.
- The individuals, groups and organisations across Europe that have sought to draw attention to supportive and palliative care issues have been **small in number and lacking political and professional influence**.
- **Levels of investment** in hospice and palliative care services have remained low.
- **Service coverage** is incomplete geographically and heavily concentrated on those with malignant disease.
- There has been little strategic thinking about how a **health and social care workforce** that is equipped to provide care at the end of life can be developed and sustained over time.

Perhaps most importantly of all, **the evidence that is so necessary for services to grow and for clinical practice to be improved is still only weakly established**. Most western European countries continue to lack an academic infrastructure to support the education and research requirements for further development of hospice and palliative care. Consequently, research into supportive and palliative care (SuPaC) accounts for only a small percentage of cancer research expenditure, and an even smaller percentage of research overall<sup>9</sup>. This manifests itself in the generally held view that the quality of research in hospice and palliative care is not high and often fails to impact on policy, education and practice. Such problems are compounded by a fragmentation of

<sup>7</sup> Clark D. and Centeno C. *Palliative Care in Europe: an emerging approach to comparative analysis*. Clinical Medicine, Vol 6 197-201, 2006.

<sup>8</sup> Clark, D From margins to centre: a review of the history of palliative care in cancer. The Lancet Oncology Vol 18 May: 431-38, 2007

<sup>9</sup> UK National Cancer Research Institute, UK National Cancer Research Institute Strategic Analysis, 2002

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effort and unnecessary competition between small academic and research groups that have yet to achieve effective critical mass.

In some European countries, steps are being taken to address some of these issues. For example, the UK National Cancer Research Institute (NCRI) is seeking to address the need for greater collaboration and the development of critical mass in SuPaC through the establishment of a number of Supportive and Palliative Care Research Collaboratives in the UK. The purpose of these research collaboratives is to create critical mass, to develop the necessary span of expertise, to develop methodological approaches, to increase capacity, to maximise the positive effects of research on policy and practice, and to nurture and develop high quality researchers for the future. Preliminary reports from those working on the collaboratives have indicated that they are resulting in less competition between the universities.

### 2.2 Irish Context

In the Republic of Ireland and Northern Ireland, similar challenges exist in relation to hospice and palliative care education and research:

- There is no clear leadership to promote academic endeavours in the field – Ireland has no full time professor in hospice or palliative care, there is no focus for research, and published studies are limited in number and impact
- Palliative care educational and research endeavours are highly localised, with little evidence of national planning or co-operation
- There is a tendency for local enthusiasts not to share plans and aspirations with other groups and organisations

At the same time, there are a number of positive factors which provide the foundations for the development of education and research in hospice and palliative care:

- There is a rich tradition in Ireland and Northern Ireland of hospice and palliative care that fosters the commitment of a growing number of professionals and volunteers who seek to improve end of life care
- There is a growing level of policy recognition directed at palliative care improvement
- Some palliative care organisations undertake excellent programmes of teaching and have good links with the world of higher education
- There is a small but growing body of research, much of it undertaken in pursuit of higher degrees and there is evidence of real enthusiasm for the further development of research
- Professional and non-government organisations exist to promote hospice and palliative care and these have a continuing role in shaping wider debate, influencing policy and practice and fostering critical mass

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Recently, there have been a number of reports, policy statements and government commitments reflecting increased attention to hospice and palliative care at Government level. Most notably, the **Report of the National Advisory Committee on Palliative Care**<sup>10</sup> which was published in 2001 and subsequently adopted as official policy in the Republic of Ireland for the development of palliative care services. The report argues that a strategy for developing education and research in palliative care in Ireland is vital to enable the specialty to develop to its full potential. This report made a number of key recommendations in relation to education, training and research, including:

- Current stakeholders, namely specialist palliative care services, universities, professional bodies and charities, should **work together towards supporting the provision of continuing educational and research opportunities** for those who work in this area
- **Academic departments** of palliative medicine should be established in each of the medical faculties, with the development of interdisciplinary courses for all professionals involved in the delivery of palliative care
- Each specialist palliative care unit should set up a **nursing practice development unit** to develop, implement, and monitor nursing practice in the unit. A clinical practice development coordinator should be employed in each specialist palliative care unit
- All health care professionals working in palliative care should have the **opportunity to engage in research**. A number of research centres linked to departments of palliative medicine should be established
- There should be **major public funding allocation** to promote palliative care research in Ireland and to put in place the necessary infrastructure to allow this to happen

This proposal seeks to build on the recommendations of the 2001 report, through the vision of an all-Ireland Institute for Hospice and Palliative Care. It also reflects current thinking about the development of health research, which has begun to feature on the agenda of health policymakers in Ireland.

In 2006, the Advisory Council for Science, Technology and Innovation published a report, **Towards Better Health: Achieving a Step Change in Health Research in Ireland**<sup>11</sup>. The report makes 21 recommendations on how policymakers, implementation bodies, universities, hospitals and business enterprise can meet the challenges facing the health research sector. The report recommends that the particular health research needs of the Irish population should be addressed by top quality, adequately funded research, both through the Department of Health and Children and through the Government's strategy for Science, Technology and Innovation, 2006-2013. It is clear from the report that in the future, funds for health research will be concentrated into organisations and groups that are well organised, with good governance and transparent procedures.

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<sup>10</sup> Department of Health and Children, *Report of the National Advisory Committee on Palliative Care*, 2001

<sup>11</sup> Forfas, *Towards Better Health: Achieving a Step Change in Health Research in Ireland*, 2006

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Northern Ireland policy in relation to palliative care is contained within the **NHS Cancer Plan**<sup>12</sup> (for the whole of the UK), and within two Northern Ireland policy documents, **Cancer Services: Investing in the future**<sup>13</sup> and **Partnership in Caring**<sup>14</sup>. The policy documents recommend:

- A multi-agency, multi-professional task force should be formed to develop a strategy for palliative care education and training, which will make best use of current resources, minimise duplication of effort, and make the best use of opportunities for shared learning.
- A research strategy for palliative care should be developed by a core palliative care group, linking in with the research framework and strategy of the Cancer Centre and the Research and Development Office.
- The establishment of Regional Cancer Networks (e.g. the Northern Ireland Cancer Network (NICAN)), which are inclusive partnerships of organisations working collaboratively with service user representatives to secure the effective planning, delivery and monitoring of cancer services

### 2.3 Manpower in Palliative Care in Ireland<sup>15,16,17</sup>

The report of the National Advisory Committee for Palliative Care provided staff-to-population ratios in order to calculate the number of multi-professional staff required for a comprehensive, multidisciplinary, specialist palliative care service nationally. At the end of 2005, there were 616 palliative care staff and approved posts, yet there will need to be a total of 1,274 palliative care posts in the Republic of Ireland to meet the needs of a population of over 4 million.

It is reasonable to assume that the population of Northern Ireland, at 1.7 million, will require corresponding proportions of palliative care staff to meet palliative care needs. Other patterns of service provision would bear this out. For example, there are currently 67 palliative care beds in Northern Ireland compared to 131 in the Republic of Ireland, and there are 12 palliative medicine consultants (WTEs) in Northern Ireland (NIMDTA, 2007) compared to 25 recommended (and approximately 16 already in place) for the Republic of Ireland.

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<sup>12</sup> NHS, *The NHS Cancer Plan: A Plan for investment, a Plan for Reform*, 2000

<sup>13</sup> The Cancer Working Group of the Department of Health and Social Services, *Cancer Services: Investing in the future ("The Campbell Report")*, 1996

<sup>14</sup> Department of Health, Social Services and Public Safety, *Partnerships in Caring...Standards for Service: A Review of Palliative Care*, 2000

<sup>15</sup> Northern Ireland Medical and Dental Training Agency,  
[http://www.nimdt.gov.uk/index.php?page\\_id=124](http://www.nimdt.gov.uk/index.php?page_id=124)

<sup>16</sup> Irish Hospice Foundation, *A Baseline Study on the Provision of Hospice/Specialist Palliative Care Services in Ireland*, adopted as National Policy, 2006

<sup>17</sup> Help the Hospices, *Hospice Information Directory, UK and Ireland directory*, 2007

## Section 2 –Context

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### 2.4 Education and Research in Palliative Care in Ireland

#### 2.4.1 Education and Training

In relation to education and training programmes, general training and programmes for continuous professional development are needed for all members of the multi-disciplinary team involved in the delivery of supportive, palliative and end of life care.

Palliative care education is delivered at three levels.

- **Level 1** is the **core education** for all who are involved in clinical care and necessitates an understanding of palliative care, of dying, of quality of life and family care.
- **Level 2** is education for those whose clinical work requires that they will be caring for dying patients and families frequently, thus requiring **a higher level of skill**.
- **Level 3** is palliative care education for **entry into the specialty**.

Integration of core competencies and curricula for Level 1 and Level 2 remains to be achieved for all health professionals. Currently there is great variation on undergraduate courses and there is a perceived need to accredit the current range of workshop training offered through the hospice education centres. A range of palliative care training (usually non-accredited) is offered through these Hospice/Specialist Palliative Care Unit education centres.

There are four palliative care centres in Northern Ireland providing education (Northern Ireland Hospice, Marie Curie, Newry and Foyle Hospice) and eight in the Republic of Ireland (Our Lady's Hospice, St Francis Hospice, Marymount Hospice, Milford Hospice, Galway Hospice Foundation, Northwest Hospice, Blackrock Hospice, and Letterkenny Hospice).

Palliative care inputs are incorporated into medical and nursing postgraduate programmes in Northern Ireland and the Republic of Ireland. Through the University of Ulster, a Certificate, Diploma and Postgraduate menu of palliative care inputs is offered to non-specialists.

Education programmes for nurses caring for children with life-limiting illness were introduced in the Republic of Ireland in 2007 with a target to train 390 nurses at introductory level and 60 nurses to intermediate level by year's end. A paediatric palliative care programme has already been convened in the Northern Ireland through Queen's University Belfast.

Postgraduate Diploma palliative care programmes for nursing are run out of the following universities, with hospice partners:

- National University of Ireland, Galway
- Trinity College Dublin
- University College Cork
- University College Dublin

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- University of Limerick
- University of Ulster

An interdisciplinary MSC in palliative care is scheduled to begin in Oct 2007, with TCD and St Francis Hospice, Dublin, as the partners. The University of Ulster together with Northern Ireland Hospice already offer such a programme.

The following table summarises the availability of Level 3 specialist palliative care training programmes in the Republic of Ireland. Some of the information in this table was taken from a baseline study carried out by the Irish Hospice Foundation.

**Table 1: Summary of Education Programmes for Specialist Palliative Care**

| Level 3 Specialist Palliative Care | Appropriate training available in Ireland | Republic of Ireland: Number of Education Centres (no. of places per annum) | Northern Ireland: Number of Education Centres (no. of places per annum) |
|------------------------------------|---|--|---|
| Consultant in Palliative Care      | SPR                                       | 9<br>(10)  | 5<br>(4)  |
| Nursing (Intermediate Pathway)     | H Dip Palliative Care                     | 5<br>(38)  | 1<br>(6)  |
| Interdisciplinary                  | Interdisciplinary MSC in Palliative Care  | 1<br>(20)  | 1<br>(12)   |
| Social Work                        | Generic Bachelor and Masters level        | 4<br>(201)   | 6<br>(300)  |
| Physiotherapy                      | Generic Bachelor and Masters level        | 4<br>(150)   | 1<br>(45)   |
| Occupational Therapy               | Generic Bachelor and Masters level        | 4<br>(115)   | 1<br>(45)   |

### 2.4.2 Research

Palliative care research has developed broadly in a similar manner in Northern Ireland and the Republic of Ireland:

- Currently, academic and palliative care links are still informal, with little protected time for research and few examples of coordinated research activities or priorities
- Individual university departments and hospices have developed relationships to support specific research agendas, including older people's quality of life
- Some universities have research groups focussing on palliative care dimensions
- In both Northern Ireland and the Republic of Ireland, there are imminent plans to advertise senior academic posts

There has been some palliative care research taking place on the island of Ireland, despite the absence of any academic Department of Palliative Care. While there is little

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multi-annual funding dedicated solely to palliative care research, in 2005 the Irish Hospice Foundation funded €135,000 on research grants, and the Health Research Board funded €102,000. Individual hospices have funded research studies and entered into agreements with local universities. Charities such as Macmillan are currently funding local needs assessments in Northern Ireland. Post-graduate research degrees (MDs and MScs) have been conducted across the island. A 2006 study by the Irish Hospice Foundation found that, over the past twenty-five years, 90 theses were written on bereavement and death-related topics by Irish researchers, of which 25 were from Northern Ireland universities.

There is little evidence on the extent to which palliative care research outputs are disseminated and adopted in Ireland. The Irish Association for Palliative Care (an all-Ireland body) has an Education and Research Committee which seeks to promote both the conduct and dissemination of research. Various individual organisations run “journal clubs” and most of the hospice/specialist palliative care units have libraries whose services include journal subscription.

### **2.5 Implications for Hospice and Palliative Care Development**

The current fragmentation of education, training and research, and the increased focus on hospice and palliative care at policy level, in both the Republic of Ireland and Northern Ireland, indicate:

- The need for coordinated academic leadership in hospice and palliative care, and
- That the timing is appropriate for consideration of an All-Ireland initiative which could facilitate this

## Stakeholder views on the Institute

### 3.1 Overview of consultation process

There has been substantial consultation about the concept of the Institute since the idea originated. Prof. Clark has engaged in informal discussions with individuals from a wide range of hospices and palliative care organisations, in Northern Ireland and the Republic of Ireland. Prof. Clark also formally presented the concept to the National Council for Specialist Palliative Care in early February.

In January and February 2007, Prospectus conducted face-to-face interviews with a number of individuals actively involved in the research, education and/or hospice, palliative and end of life-care sectors, in order to obtain their views on the potential role and scope of activities for the Institute.

Interviews were conducted with individuals in the following organisations:

- Department of Health and Children
- Health Research Board
- Health Service Executive
- Northern Ireland R&D Office
- NUI, Galway
- University College Dublin
- University of Ulster

In March 2007, Prospectus facilitated a half-day exploratory workshop with fifty representatives from relevant organisations, in Northern Ireland and the Republic of Ireland, to gauge support for the idea and to explore in greater detail some of the key issues associated with the establishment of the Institute. Appendix A contains a list of individuals (and their associated organisation) who participated in the Exploratory Workshop.

The key issues explored in the interviews and workshop were:

- Is there a need for such an Institute, and if so, what would it do (e.g., in relation to research, education, policy, service, etc)?
- Where should the Institute be located? (e.g., within a university, within an independent organisation, as a standalone entity, locations in Northern Ireland and the Republic of Ireland, virtual?)
- How should the Institute work with key players in palliative care?
- What are the potential sources of funding the Institute could pursue?
- Overall, is this Institute something that should be developed?

## Section 3 – Stakeholder Views on the Institute

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Prospectus would like to thank all of the individuals who contributed to the development of this proposal for the Institute by sharing their views with us during the consultation process. These contributions were enormously appreciated.

### 3.2 Stakeholder Views on the Institute

A summary of the findings from the consultation are outlined below, organised by topic.

#### 3.2.1 Overall Impressions

- There is broad agreement that **leadership in hospice, palliative and end of life-care education and research is greatly needed**; there is particular enthusiasm for the concept of an Institute in Northern Ireland and outside of Dublin
- Some feel that the **timing is good** for the Institute (new programmes being developed, research activity increasing, growing interest in palliative care among doctors, nurses, AHPs); others question if it is **too early** to develop an Institute, arguing that there is not enough activity to support its aims
- Substantial **challenges may lie ahead in gaining buy-in** from the wide range of different stakeholders

#### 3.2.2 Proposed Areas of Focus for the Institute

The Institute could:

- Enhance **research** in palliative care in Ireland, in Northern Ireland and the Republic of Ireland
- Emphasise the importance of **education and training** (undergraduate and postgraduate) including the ongoing training of healthcare professionals
- Facilitate more/better **collaboration** between universities, hospitals, and hospices to link research to care and prevent further segmentation of the sector

#### 3.2.3 All-Ireland Status

- The all-Ireland aspect is viewed as a **strong feature** of the Institute. Cited benefits of all-Ireland collaboration include:
  - Access to **funding** opportunities for North-South collaborations
  - Brings together **expertise** on both sides
  - Access to **large population base** for research studies
  - Promotes **exchange of learnings** from **two service delivery models**
  - Reduces/eliminates **replication/duplication/rivalry**

## Section 3 – Stakeholder Views on the Institute

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### 3.2.4 Funding

- Demonstration of **long-term financial sustainability** will be a key issue for the Institute
- Funding could be available from a range of sources, e.g.:
  - EU Framework Programme (FP7)
  - Programme for Research in Third Level Institutions (PRTLII)
  - Health Research Board/Northern Ireland R&D Office
  - Health Service Executive
  - Department of Health and Children/ Department of Health, Social Services and Public Safety

### 3.2.5 Location/Governance

- There is some support for a **virtual Institute**, such as a formal collaboration whereby partners would contribute their expertise in a particular area
- The Institute does not necessarily need to be completely **independent**. However, it must not be overly aligned with a single university, hospice or funder – it should work on a collaborative basis with all stakeholders

### 3.2.6 Relationships between the Institute and other organisations involved in Palliative Care

- Good governance will be needed to ensure **collaboration with other stakeholders**
- **Interface** with national and regional advisory bodies/other institutes will need to be defined (e.g., National Council for Specialist Palliative Care, ICRN, All-Ireland cancer collaborative, NCRI, SuPaC, ICGP, IHF, ICS, ICHMT, RCPI, NAPC, etc)

### 3.2.7 Level of support for the Institute concept

- At the Exploratory Workshop, participants agreed that the concept of an Institute should be progressed.
- If the Institute is to become a reality, leadership will be required from those within the sector, in Northern Ireland and the Republic of Ireland

# 4

## Proposed vision, objectives, principles and activities for the Institute

This chapter outlines the proposed vision, objectives, principles, and activities of the Institute and places a strong emphasis on its capacity building orientation, as well as its potential to catalyse development and leverage new resources.

### 4.1 What does the Institute want to achieve?

#### Vision

To improve the experience of supportive, palliative and end-of-life care on the island of Ireland,  
*by enhancing the capacity to:*  
develop knowledge, promote learning, influence policy and shape practice

### 4.2 How will the Institute achieve its aims?

#### Objectives of the Institute

1. Serve as a **centre of expertise and information** on education, research, policy and practice in supportive, palliative and end-of-life-care
2. Assist in the creation of a **sustainable and skillful workforce**, by providing a **focus for collaborative educational and training programmes** in supportive, palliative and end-of-life-care
3. **Contribute to the evidence base** by providing a **focus for collaborative research and development** in supportive, palliative and end-of-life care
4. Act as a **resource to service providers** and **policymakers**, seeking to shape practice and influence relevant policymaking.

## Section 4 – Proposed Vision, Objectives, Principles and Activities for the Institute

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### 4.3 Principles underpinning the Institute

There are a number of important principles that will be critical to delivering on the vision and objectives of the Institute.

- The Institute will operate on an **All-Ireland** basis.
- The Institute will **listen actively** to service users and providers concerned with supportive, palliative and end of life care.
- The Institute will provide strategic **leadership** for education and research in supportive, palliative and end of life care.
- The Institute will contribute to the development of palliative care, **building on, complementing and adding value to existing activities**.
- The Institute will **enable other organisations and individuals** to further their capabilities in supportive, palliative and end of life care
- The Institute will work on a **collaborative, inclusive and open** basis with all relevant stakeholders.
- The Institute will promote **inter-disciplinary** and **inter-professional** collaboration.
- The Institute will develop and maintain **international** partnerships in education and research, and contribute to efforts to improve supportive, palliative and end of life care globally.
- The **values** of the Institute will reflect the values of supportive, palliative and end of life care

## Section 4 – Proposed Vision, Objectives, Principles and Activities for the Institute

### 4.4 Potential activities of the Institute—What will the Institute do?

An initial view on the activities to be undertaken by the Institute is outlined below.

#### 4.4.1 Education & Training

- Assess the **education and training needs** of all those involved in supportive, palliative and end of life care (e.g. professionals, voluntary providers, families and carers)
- Support the strategic development of palliative care education at undergraduate, post-graduate and specialist levels through **monitoring the provision** and **uptake** of programmes, and advising on the **development of new programmes**
- Promote studies and collate existing evidence on the **effectiveness of education and training provision**
- Develop and maintain a **database of education and training programmes** in supportive, palliative and end of life care
- Host regular **meetings/symposia to promote innovation** in education and training
- Contribute to international discussions on **curriculum development** for supportive, palliative and end of life care education and training
- Assess the need for, and impact of, **wider public education initiatives** relating to advanced illness, dying and bereavement

Note: It is not envisaged that the Institute would deliver education and training programmes itself.

#### 4.4.2 Research

- Assess **gaps**, identify and promote **new research programmes**, and **increase the level of funding** available for clinical, organisational and social studies in supportive, palliative and end of life care.
- Develop and promote the implementation of an all-Ireland **strategic plan for research** in supportive, palliative and end of life-care
- Develop and maintain a comprehensive, searchable **database** of (all-Ireland and local) research on supportive, palliative and end of life-care
- Support the development **of all-Ireland, population based and multi-centre research projects** on supportive, palliative and end of life-care
- Support **research collaborations** to attract additional resources and improve quality and outcomes in research related to supportive, palliative and end of life-care
- Enable Irish participation in **international research projects** and funding streams related to supportive, palliative and end of life-care
- **Enhance research capacity** through mentoring, research training and career development programmes
- Support academic institutions and service providers in making **applications for research posts, programmes and funding**

Note: It is not envisaged that the Institute would conduct research itself.

## Section 4 – Proposed Vision, Objectives, Principles and Activities for the Institute

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### 4.4.3 Resource to service providers and policymakers

- Organise **networking events** to exchange information and best practice between organisations involved in supportive, palliative and end of life-care
- Develop and deliver **targeted communications/fact sheets** to key stakeholders in order to strengthen the links between research, policy, and practice
- Develop and maintain a **website** covering all of the Institute's activities, to include access to the research and education databases
- Undertake systematic reviews and compile information in relation to **best practice in service provision** in relation to supportive, palliative and end of life-care
- Facilitate **inter-sectoral** and **inter-disciplinary participation** in supportive, palliative and end of life-care initiatives
- Organise **international visits** to view models of excellence and exchange ideas internationally

# 5

## Proposed model for the Institute

### 5.1 Overview

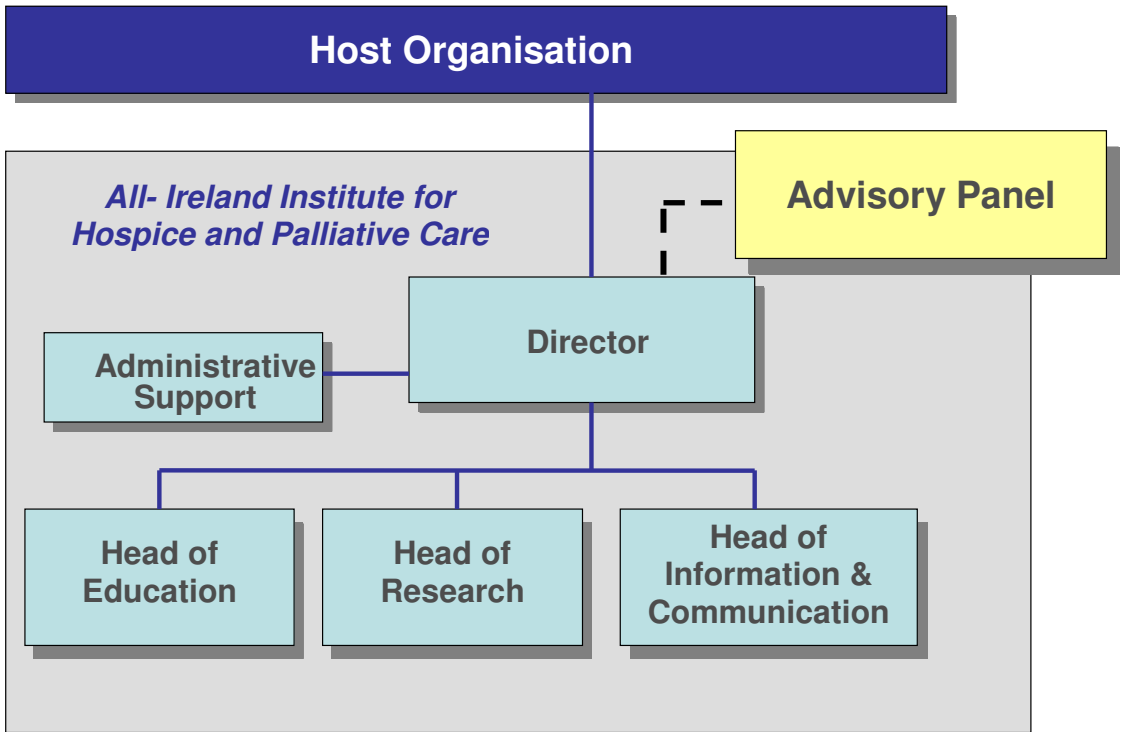
Based on the feedback from the consultation with the different stakeholders, in Northern Ireland and the Republic of Ireland, **it is proposed that an Institute should be established.**

The Institute should be established as a “**centre**” **within another host organisation** (university, hospice, other organisation).

The Institute should be established as **an entity with a limited lifespan** (e.g., 5-8 years), for the purpose of **building capacity** in education and research in supportive, palliative and end of life care.

Funding to establish and support the Institute should be **awarded to a host organisation on the basis of a competitive bidding process.** The bidding process could be brokered/managed by an organisation(s) familiar with assessing and awarding grant applications (such as the Health Research Board or the R&D Office).

### 5.2 Proposed Governance and Management Structures



## Section 5 – Proposed Model for the Institute

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The Institute would operate within the **governance institutions of the host organisation**.

An Institute **Advisory Panel** would be established to provide ongoing advice in relation to education and research in supportive, palliative and end of life care. The Advisory Panel would consist of 12-15 individuals, representing key stakeholders from academic institutions, service providers, and policy organisations, in Northern Ireland and the Republic of Ireland. It should also include 1-2 international experts.

The role of the Advisory Panel would be to:

- Advise on key developments in relation to supportive, palliative and end of life care
- Secure and maintain the support of key stakeholders in supportive, palliative and end of life care
- Link the Institute with the broader national and international community involved in education and research in supportive, palliative and end of life care
- Provide feedback on the Institute's priorities and activities as proposed by the Director

The **staff of the Institute** would be employed by the host organisation. The staff complement is likely to include:

- A Director
- A Head of Education
- A Head of Research
- A Head of Information and Communication
- Support Staff, e.g., a Database/Web Administrator, an Administrative Assistant, etc

Note: The precise staff roles and complement need to be examined in more detail, going forward.

## Section 5 – Proposed Model for the Institute

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### 5.3 Implementation steps for the Institute

It is proposed that the following steps should be taken to establish the Institute.

**Step 1 – Complete consultation** on the outline proposal

**Step 2 –A Steering Group** should be established to oversee the development of a full **business case** for the Institute and of a draft **Invitation to Tender** document. Based on these documents, the Steering Group should be in a position to **seek funding** for the establishment of the Institute from a number of potential funders.

**Step 3** –Third party broker(s) should manage the **tender process** and select the host organisation

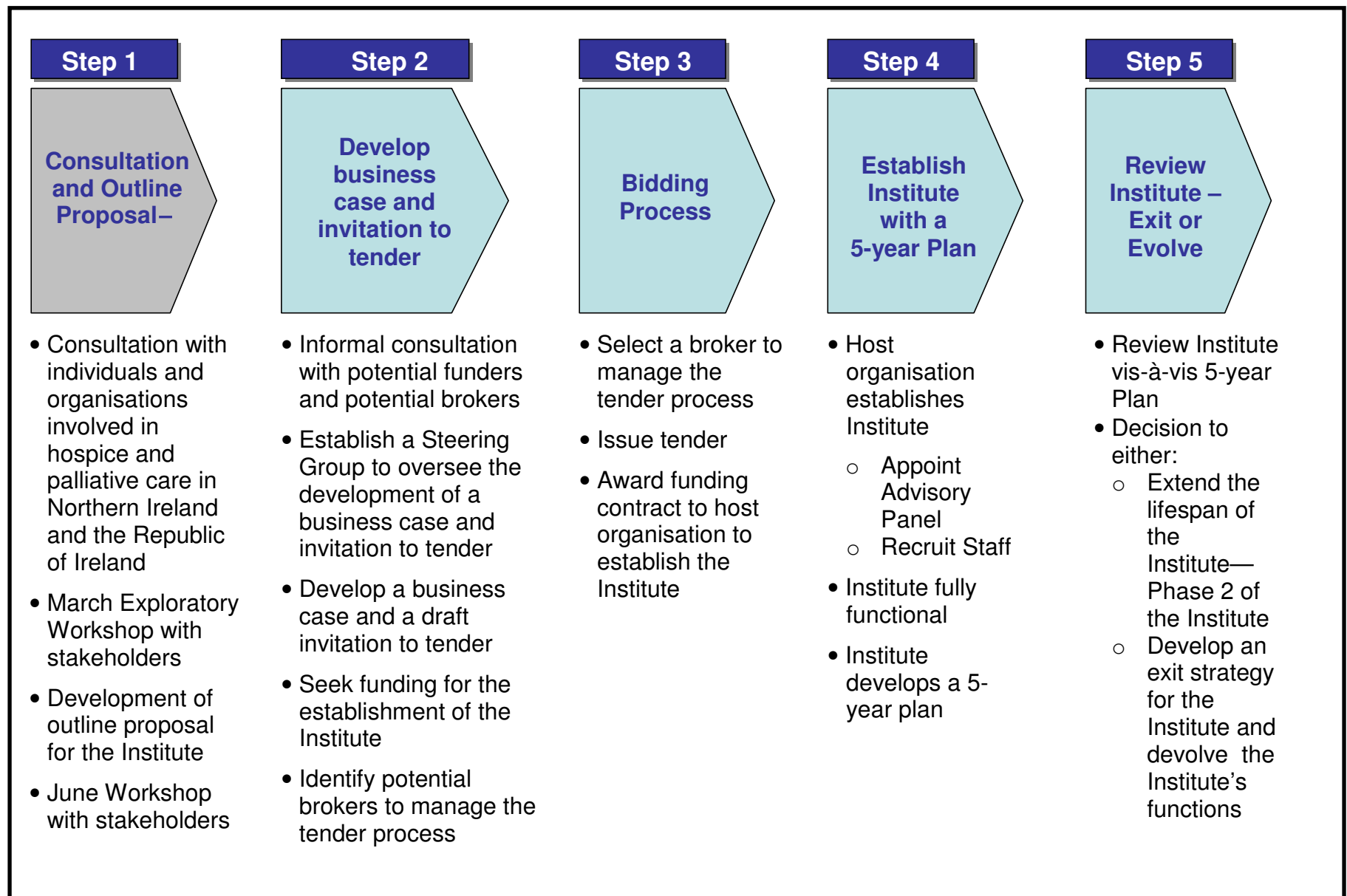
**Step 4** –The Institute should be **formally established** by the host organisation, with a view to achieving specific, measurable outcomes within its 5-8 year lifespan

**Step 5** –After 4-5 years, the Institute should be **reviewed vis-à-vis its 5-year targets**. A recommendation should be made to either:

- Extend the lifespan of the Institute, continuing the current activities or modifying the activities of the Institute to meet the evolving needs of education and research in supportive, palliative and end of life care [a Phase 2 for the Institute]
- Develop an exit strategy whereby the functions and activities of the Institute would be devolved to other organisations in supportive, palliative and end of life care, and the Institute would cease to exist

The diagram on the next page summarises the key elements of these implementation steps.

## Section 5 – Proposed Model for the Institute



## Proposed next steps

An outline proposal for an all-Ireland Institute for Hospice and Palliative Care has been developed. Support for the Institute, its vision, objectives, and possible models, was tested in the initial and middle stages of this proposal development, and a mandate was given to encourage further development of the concept.

At this stage, there is likely to be strong merit in once again meeting with key stakeholders to test what has been developed. Therefore, the proposed next steps in relation to this proposal are:

1. Present this proposal to a **second workshop** of key stakeholders (proposed date of **19<sup>th</sup> June**) to collect their feedback on this outline proposal
2. **Further consultation** with relevant philanthropic and other organisations, to sound out views on the proposal
3. Establish an **Institute Steering Group** of 7-8 key interested stakeholders, who will develop the business case for the Institute and the draft invitation to tender
4. Develop a **business case** for the Institute. The business case would:
  - a. Specify the precise functions/activities of the Institute
  - b. Outline a stakeholder map describing the different functions of key stakeholders in hospice, in Northern Ireland and the Republic of Ireland, which would interact with the Institute
  - c. Define the governance and management structures for the Institute
  - d. Identify the staffing levels and skills required in the Institute
  - e. Identify specific outcomes to be achieved by the Institute within a 5-year timeframe
  - f. Describe the phases involved in setting up the Institute
  - g. Estimate the costs associated with the Institute and potential sources of revenue for the Institute
5. Develop a draft **Invitation to Tender**
6. The Steering Group should approach a number of funders to **obtain financial backing for the establishment of the Institute**
7. Secure a broker to manage the competitive bidding process

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# Appendix A

# A

## Appendix A - Individuals who participated in Exploratory Workshop, 6<sup>th</sup> March 2007

| Name              | Organisation                               |
|-------------------|--|
| Emma Balmaine     | Blackrock Hospice                          |
| Helen Chambers    | NI Hospice                                 |
| David Clark       | Visiting professor                         |
| Barbara Cochrane  | Northern Ireland Palliative Care           |
| Kevin Connaire    | St. Francis Hospice                        |
| James Conway      | HSE<br>Consultant, Northern Ireland        |
| Bernie Corchrane  | St. Francis Hospice                        |
| Martina Corrigan  | Health Research Board                      |
| Margaret Devitt   | University of Ulster                       |
| Frank Dobbs       | Irish Hospice Foundation                   |
| Ginny Dunn        | UCD  |
| Muiris Fitzgerald | Crumlin Children's Hospital                |
| Mary Godfrey      | NI Hospice                                 |
| Judith Hill       | Our Lady's Hospice Harold's Cross          |
| Noreen Holland    | Marie Curie                                |
| Maeve Hully       | MacMillan                                  |
| Gail Johnston     | Irish Hospice Foundation                   |
| Orla Keegan       | Irish Cancer Society                       |
| Joan Kelly        | Northern Ireland Palliative Medicine Group |
| Sheila Kelly      | NUI Galway<br>Dept of Health and Children  |
| Philip Larkin     | Marymount Hospice                          |
| Julie Ling        | UCC Nursing                                |
| Geraldine Lynch   | TCD Nursing                                |
| Anne McAuliffe    |  |
| Mary McCarron     |  |

| Name                  | Organisation                                      |
|-----------------------|---|
| Joan McCarthy         | UCC Nursing                                       |
| Sonja McIlfrack       | Northern Ireland                                  |
| Dory McLoughlin       | Northern Ireland                                  |
| Regina McQuillan      | St Francis Hospice                                |
| Owen Metcalfe         | Institute of Public Health                        |
| Mary Morrissey        | Population Health, HSE                            |
| Michael Neely         | NI R&D Office                                     |
| Lorna Nevin           | NI Cancer Network                                 |
| Charles Normand       | TCD   |
| Doiminic O'Brannagain | Consultant, Northeast                             |
| Tony O'Brien          | Marymount/ Chair NCSPC                            |
| Kevin O'Dwyer         | Marymount   |
| Siobhan O'Halloran    | HSE<br>Palliative Care Nursing, Southeast         |
| Eileen O'Leary        | Nursing and Midwifery Planning & Development, HSE |
| Joan Phelan           | CEO Milford Hospice/ IAPC                         |
| Pat Quinlan           | Irish Association for Palliative Care             |
| Leslie Ruthford       | Consultant / IAPC                                 |
| Karen Ryan            | Irish Association for Palliative Care             |
| Mary Sheridan         | UCD Nursing                                       |
| Pearl Treacy          | Consultant. Northern Ireland                      |
| Max Watson            | Irish Association for Palliative Care             |
| Barbara Whyte         |   |
| Katie Burke           | Prospectus  |
| Marie Nycz            | Prospectus  |

# B

## Appendix B - Options considered in relation to the model for the Institute

A number of options were considered in relation to the proposed model of the Institute. Six options were discussed at the Exploratory Workshop on 6 March.

|   |  |  |
|---|--|--|
| <b>Option A</b><br><br><i>"As-Is"–<br/>Academic Posts in<br/>Palliative Care</i>                | <b>Option B</b><br><br><i>Academic<br/>Programmes in<br/>Palliative Care</i> | <b>Option C</b><br><br><i>Formal Research<br/>Network/<br/>Collaboration</i> |
| <b>Option D</b><br><br><i>Institute contained<br/>within a university and/<br/>or a hospice</i> | <b>Option E</b><br><br><i>Independent<br/>Virtual Institute</i>              | <b>Option F</b><br><br><i>Independent<br/>(physical) Institute</i>           |

Note: These options are not mutually exclusive. Some are iterations/progressions of others.

In this Appendix, we describe at a high level each of the six options considered, and present the pros and cons of each, as determined by workshop participants

## Appendix B – Options considered in terms of the proposed model for the Institute

### Option A—“As-Is”- Academic Posts in Palliative Care

- Working on their own initiative, individual academic institutions and hospices develop academic posts in palliative care (individual academic posts, without the back up of a full academic programme, other academic staff, etc)
- This option describes the current situation in Ireland

| Pros  | Cons  |
|---|---|
| <ul style="list-style-type: none"> <li>• First step in building capacity in the palliative care research sector</li> <li>• In some universities, North and South, funding has been secured for posts and plans exist to implement programmes</li> <li>• This is a proven, traditional method of fostering education</li> <li>• The right people in individual academic posts would bring research funding/ generate research interest</li> <li>• Smallest investment required</li> <li>• In line with recommendations of Report of the National Advisory Committee on Palliative Care (2001)</li> </ul> | <ul style="list-style-type: none"> <li>• Success will be determined by enthusiasm of individual academic post holders</li> <li>• Without the support of an academic programme, it will be difficult to attract the highest quality candidates to academic posts</li> <li>• Could take a long time to develop critical mass of research using this approach</li> <li>• Does not address the sector issues/ challenges such as the need for better collaboration on research, communication of research findings, silo mentality within individual institutions/between disciplines</li> <li>• Time limited posts raise issue of sustainability (Northern Ireland experience)</li> <li>• Does not formally encourage North-South collaboration</li> <li>• Does not address equity issue, whereby palliative care services, research, and education are unevenly spread, with some areas having significant capability and others not</li> <li>• Does not facilitate interdisciplinary research</li> </ul> |

## Appendix B – Options considered in terms of the proposed model for the Institute

### Option B – Academic Programmes in Palliative Care

- A number of universities and hospices would establish academic programmes in palliative care (to include a professor post, a number of lecturers, researchers, and administrative support staff)
- Financial incentives could be introduced to:
  - Ensure research programmes in different universities/hospices have complementary areas of expertise
  - Encourage interdisciplinary work and work between universities/hospices

| Pros  | Cons  |
|---|---|
| <ul style="list-style-type: none"> <li>• Capability of an academic programme is much greater than that of a sole professor</li> <li>• Could provide leadership at university/ hospice level; potential to provide leadership at national level if the “right people” were appointed</li> <li>• Promotes palliative care within universities as a “solid” academic field</li> <li>• If the programme were to fit within the development programme of a particular university, the appointee would have the infrastructure in place to “hit-the-ground-running”</li> <li>• In line with recommendations of Report of the National Advisory Committee on Palliative Care (2001)</li> </ul> | <ul style="list-style-type: none"> <li>• Success will be determined by the enthusiasm of professors</li> <li>• Could provide leadership at the university / hospice level but not necessarily at the national/North-South level</li> <li>• Could potentially increase competition among the universities/hospices</li> <li>• Could take a long time to develop critical mass of research using this approach</li> <li>• Does not address the sector issues/ challenges such as the need for better collaboration on research, communication of research findings, etc.</li> </ul> |

## Appendix B – Options considered in terms of the proposed model for the Institute

### Option C – Formal Research Network/Collaboration

- A formal network of researchers/research teams, North and South, affiliated with the universities and hospices in Ireland
- Members of the network would meet formally a certain number of times a year, as well as collaborating on research
- The network could have an independent chairperson to chair these meetings
- Network participants/collaborators would, for example:
  - Agree areas of thematic lead/specialisation in terms of research
    - e.g., epidemiological and demographic analysis, studies of patient and carer experience, service evaluation and monitoring, ethical issues, service for the elderly, services for children, bereavement, RCTs, etc)
  - Form research collaboratives for large research projects
  - Support each other in the development of palliative care education programmes and service delivery

| Pros  | Cons   |
|---|--|
| <ul style="list-style-type: none"> <li>• A first step in the strategic development of palliative care on an all-Ireland basis - by creating a formal network and agreeing specialist research areas</li> <li>• Promotes communication/collaboration on research, on an all-Ireland basis</li> </ul> | <ul style="list-style-type: none"> <li>• Carried out on a voluntary basis– a financial incentive may be needed to drive ongoing participation</li> <li>• Is the “network” a formal enough structure?           <ul style="list-style-type: none"> <li>– e.g. EU funding guidelines and ACSTI “Towards Better Health” indicate that in the future, funds for health research will be directed towards organisations/groups that are well organised, with good governance and transparent procedures</li> </ul> </li> <li>• Greater infrastructure needed to develop and support a network, long term</li> <li>• Sustainability could become an issue, especially if:           <ul style="list-style-type: none"> <li>– There is no central coordinating support staff</li> <li>– There is no DOHC/DHSSPS involvement</li> <li>– There is not strong leadership</li> </ul> </li> <li>• Might be too focused on research and lose sight of education and policy aims           <ul style="list-style-type: none"> <li>– Sector development would be slow without parallel development of academic programmes, service infrastructure, etc</li> </ul> </li> <li>• Risks being an exclusive network, involving only established researchers and neglecting new/developing researchers</li> </ul> |

## Appendix B – Options considered in terms of the proposed model for the Institute

### Option D – Institute contained within a university and/or a hospice

- Institute established within one university/hospice, or two universities/hospices, one North and one South
- Guided by an Advisory Board
  - Governed by university/hospice board
- Staff complement to include a Director, senior staff, researchers, administrative staff
- Director would hold a Chair of Palliative Care in an appropriate university
- Partnerships between academic, policy, research and outreach organisations would be well defined
- Partners would collaborate with other academic institutions in developing and delivering education and training for palliative care
- University partners would take a thematic lead on some aspect of the research agenda
  - e.g., epidemiological and demographic analysis, studies of patient and carer experience, service evaluation and monitoring, ethical issues, service for the elderly, services for children, bereavement, RCTs, etc

| Pros  | Cons   |
|---|--|
| <ul style="list-style-type: none"> <li>• Would avail of university experience in establishing new institutes/centres</li> <li>• Access to resources and support functions (HR, IT, Finance, etc.) available in a university or hospice– no need to start from scratch</li> <li>• Creates a ‘hub’ for activity in palliative care in Ireland               <ul style="list-style-type: none"> <li>– Increased potential to undertake multi-centre and population based studies</li> <li>– Enhanced capability to support researchers and educators</li> </ul> </li> <li>• Supported by Government policy</li> <li>• Opportunities for third-party funding under existing HRB, PRTL, and other funding calls</li> </ul> | <ul style="list-style-type: none"> <li>• Not independent – linked to a university and hospice</li> <li>• Which university/hospice?</li> <li>• Risk that this would create one more ‘silo’</li> <li>• Interest in palliative care would be predominantly focused in one university; risk of decreased priority in others</li> <li>• If this option involved one university/hospice in the North and one university/hospice in the South               <ul style="list-style-type: none"> <li>– May not have a strong North/South dimension</li> <li>– Risk of “split leadership” between the various institutions</li> </ul> </li> <li>• Would this provide strong enough links to policy and practice?</li> <li>• Risk of opportunism trumping strategic planning</li> </ul> |

## Appendix B – Options considered in terms of the proposed model for the Institute

### Option E – Independent Virtual Institute

- A virtual Institute with a lean core staff (e.g., Director, Project Manager, Administrator, Board)
  - The Director should have a background in palliative care research and education
- The Institute could have membership – with membership open to any entity with an interest in palliative care (hospices, universities, members of the population, IAPC, IHF etc)
- The Institute would:
  - Work closely with key hospice, government, university and other stakeholders to advance palliative care research and education in Ireland
  - Draw on the expertise of researchers, North and South
  - Serve as a centre for the storage and conduit of information relating to palliative care research and education in Ireland
  - Be independent of any one university, hospice, or government agency/organisation
  - Not conduct research or provide training (itself)

| Pros   | Cons   |
|--|--|
| <ul style="list-style-type: none"> <li>• Creates an all-Ireland hub for activity in palliative care               <ul style="list-style-type: none"> <li>– Increased potential to undertake multi-centre and population based studies</li> <li>– Enhanced capability to support researchers and educators</li> </ul> </li> <li>• Promotes communication/collaboration on an all-Ireland basis</li> <li>• Has a stronger link to policy than Option C</li> <li>• Provides a stronger governance structure than Option C</li> <li>• Likelihood of third-party funding</li> </ul> <p><i>Note: Option C is the formal research network</i></p> | <ul style="list-style-type: none"> <li>• Difficult to make 'virtual' entities work on a sustained basis</li> <li>• Is there enough activity to justify administrative expense?</li> <li>• Are the links to education strong enough?</li> <li>• Would this compete with other national organisations involved in palliative care?</li> <li>• If this were to be a membership organisation, it may be a challenge to achieve a balanced membership, given the range of organisations and individuals which could be members</li> </ul> |

## Appendix B – Options considered in terms of the proposed model for the Institute

### Option F – Independent (physical) Institute

- Independent Institute, founded by a number of organisations (universities, hospices, etc.) who would agree a collective vision for hospice, palliative and end of life-care in Ireland, North and South
- Institute would complement (and not replicate) existing capability in the sector, North and South
- Could have membership – with membership open to any entity with an interest in palliative care (hospices, universities, members of the population, IAPC, IHF etc)
- Governed by a Board
- Staff complement to include a Director, senior staff, researchers, administrative staff
- Director would hold a Chair of Palliative Care in an appropriate university
- Partners would collaborate with other academic institutions in developing and delivering education and training for palliative care
- University partners or research collaboratives would take a thematic lead on some aspect of the research agenda
  - e.g., epidemiological and demographic analysis, studies of patient and carer experience, service evaluation and monitoring, ethical issues, service for the elderly, services for children, bereavement, RCTs, etc
  - Should reflect the focus on translational research, currently being emphasised by EU and Government strategies and funding
- The Institute should have strong international ties

| Pros  | Cons   |
|---|--|
| <ul style="list-style-type: none"> <li>• Potential to act as a catalyst and bring about a step change in palliative care in Ireland</li> <li>• Creates a more substantive ‘hub’ for activity in palliative care in Ireland               <ul style="list-style-type: none"> <li>– Increased potential to undertake multi-centre and population based studies</li> <li>– Enhanced capability to support researchers and educators</li> </ul> </li> <li>• Could have links to all universities/hospices in Ireland, North and South</li> <li>• Should attract and retain high calibre faculty and staff</li> <li>• Makes more effective use of scarce resources</li> <li>• Higher likelihood of third-party funding (given clarity on governance, etc)</li> <li>• Supported by Government policy</li> <li>• Promotes a more strategic approach to research</li> <li>• Structured, collaborative research programme provides enthusiasm/buy-in for sector</li> <li>• Interdependency/linkages with other bodies will be crucial to its sustainability</li> </ul> | <ul style="list-style-type: none"> <li>• Is it too much, too soon?</li> <li>• Substantial time and effort involved in establishing a new legal entity</li> <li>• Director being a chair in a university threatens independence of Institute</li> <li>• Strong link to research/universities; links to clinical sites also need to be strong</li> <li>• Could get bogged down in training and service issues at the expense of achieving aims</li> <li>• Unclear where the Institute’s legitimacy will come from</li> </ul> |