

Evaluation of the programme to support palliative and hospice care in the Republic of Ireland: Final report

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**until December 2010*

EVALUATION OF THE
PROGRAMME TO
SUPPORT PALLIATIVE
AND HOSPICE CARE
IN THE REPUBLIC OF
IRELAND

FINAL REPORT



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GLOSSARY

AGH.....	Acute General Hospital
AIHPC.....	All-Ireland Institute for Hospice and Palliative Care
AP.....	The Atlantic Philanthropies
CNS.....	Clinical Nurse Specialist
DoH.....	Department of Health (1947-1997; 2011-)
DoHC.....	Department of Health and Children (1997-2011)
DRGs	Diagnostic-Related Groups
EAPC	European Association for Palliative Care
EoL	End of Life
H@H	Hospice-at-Home project
HfH	Hospice-friendly Hospitals project
HIPE.....	Hospital In-patient Enquiry
HIQA	Health Information and Quality Authority
HSE.....	Health Service Executive
GP.....	General Practitioner
IAPC.....	Irish Association for Palliative Care
ICS.....	Irish Cancer Society
IEAG	International Expert Advisory Group
IHF	Irish Hospice Foundation
MCC.....	Milford Care Centre
MDS.....	Minimum Data Sets
MDT	Multi-disciplinary Team
MWHB.....	Mid-Western Health Board
NACPC.....	National Advisory Committee on Palliative Care
NAGH	Non-acute General Hospital
NCAOP	National Council on Ageing and Older People
NIH.....	Northern Ireland Hospice
PC.....	Palliative Care
PHN.....	Public Health Nurse
QCCD	Quality and Clinical Care Directorate
SEHB	South Eastern Health Board
SIP	Specialist In-patient Unit (hospice)
SPC	Specialist Palliative Care
VfM.....	Value for Money
WHO.....	World Health Organization



DEFINITIONS AND TERMS

The following are drawn from the Report of the National Advisory Committee on Palliative Care (Department of Health and Children, 2001).

Palliative Care is defined by the World Health Organization (WHO) as the active, total care of patients whose disease is no longer responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best possible quality of life for patients and their families.

Palliative care:

- affirms life and regards dying as a normal process;
- neither hastens nor postpones death;
- provides relief from pain and other distressing symptoms;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death; and,
- offers a support system to help the family cope during the patient's illness and in their own bereavement.

The palliative care approach aims to promote both physical and psychosocial well-being. It is a vital and integral part of all clinical practice, whatever the illness or its stage, informed by a knowledge and practice of palliative care principles.

Palliative medicine is the appropriate medical care of patients with active, progressive and advanced disease, for whom the prognosis is limited, and the focus of care is the quality of life. Palliative medicine includes consideration of the family's needs before and after the patient's death.

Specialist palliative care services are those services with palliative care as their core speciality and which are provided by an inter-disciplinary team, under the direction of a consultant physician in palliative medicine.

Terminal care is a continuum of palliative care and is usually used to describe the care that is offered during the period when death is imminent, and life expectancy is limited to a short number of days, hours or less.

Hospice care is a term that is often used to describe the care offered to patients when the disease process is at an advanced stage. The term may be used to describe both a place of care (i.e., institution), or a philosophy of care, which may be applied in a wide range of care settings. In this report, the term 'palliative care' will be used in preference to 'hospice care', when appropriate. However, when referring to other research or reports, the word 'hospice' may be used at times.

In the context of palliative care, the **family** is defined as any person who is significant to the patient.

LEVELS OF PALLIATIVE CARE

The Report of the National Advisory Committee on Palliative Care (Department of Health & Children, 2001:32) recommended that 'palliative care services should be structured in three levels of ascending specialisation. These levels refer to the expertise of the health professionals delivering the palliative care services.

Level One - Palliative Care Approach:

Palliative care principles should be practiced by all healthcare professionals. The palliative care approach should be a core skill of every clinician at hospital and community level. Many patients with progressive and advanced disease will have their care needs met comprehensively and satisfactorily without referral to specialist palliative care units or personnel.

Level Two - General Palliative Care:

At an intermediate level, a proportion of patients and families will benefit from the expertise of healthcare professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care, perhaps to diploma level. Such intermediate-level expertise may be available in hospital or community settings.

Healthcare professionals who wish to undertake additional training in palliative care should be supported in this regard by the health board or other employing authority.

Level Three - Specialist Palliative Care:

Specialist palliative care (SPC) services are those services whose core activity is limited to the provision of palliative care. These services are involved in the care of patients with more complex and demanding care needs, and consequently require a greater degree of training, staff and other resources. At present, most staff at level three in Ireland are trained to diploma level as well, with only a few having the opportunity to go on to higher specialist training. There is a need for ongoing education and training at this level.

SPC services, because of the nature of the needs they are designed to meet, are analogous to secondary or tertiary healthcare services. Within each health board region, the SPC service should be capable of supporting the delivery of services in all care settings across the region.

All healthcare professionals should be able to access advice and support from specialist service providers when necessary. In each health board area, all three levels of palliative care expertise should be available. All patients should be able to engage easily with the level of expertise most appropriate to their needs. At each level of care, there should be a constant focus on rehabilitation, irrespective of how advanced the condition' (Department of Health and Children, 2001:32).



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EXECUTIVE SUMMARY

INTRODUCTION

This executive summary will explain the remit of the evaluation undertaken and its associated methods; review some of the key findings and recommendations that emerged; and explain what the reader will find in the report's subsequent chapters.

There has been significant expansion in palliative care services in Ireland over the last 25 years, although gaps in provision remain (Irish Hospice Foundation, 2006). The Atlantic Philanthropies entered the field of hospice and palliative care in Ireland in 2004. The first project supported by The Atlantic Philanthropies was a baseline study of actual specialist palliative care (SPC) provision, as compared to that detailed by official government policy (Irish Hospice Foundation, 2006). The Atlantic Philanthropies issued a further 14 grants, totalling approximately €25 million, in an initiative called the 'End of Life' programme (Appendix 1). The earliest 'End of Life' project began in 2004 and the latest is scheduled to continue until at least 2014. The programme encompasses both specialist and generalist palliative care service development, and sought to reach patients and their families across care settings and irrespective of diagnosis.

This report presents the findings of a five-phased evaluation of the programme, which assessed the progress and impact of the programme to date, and the strategic learning for the field. This assessment considered both the context of historical and contemporary development of hospice and palliative care across Ireland, and a changing economic and policy landscape. Note that, throughout the report, the terms 'End of Life' programme and Hospice and Palliative Care programme are used interchangeably.

EVALUATION OBJECTIVES

The evaluation had three broad objectives. These were to document:

1) Progress and impact of the 'End of Life' programme to date

This was to be achieved by:

- outlining the inputs and activities involved in the programme;
- assessing the progress made on programme outcomes; and,
- evidencing specific gains in policy and practice, with particular regard to those attributable to the programme.

2) Strategic learning for the field

This was to be achieved by:

- identifying relationships between activities and impacts attributable, at least in part, to funding from The Atlantic

- Philanthropies, including systems-level change;
- identifying potential obstacles or weaknesses in the programme strategy to date; and,
- considering how programme activities have or can convert to systematic policy changes.

3) Potential for provision advances to be sustained

This was to be achieved by:

- assessing the strengths and challenges in sustaining provision advances;
- making recommendations on how The Atlantic Philanthropies and the programmes it supported can assist in sustaining and expanding capacity in the field, particularly in the context of the current economic climate; and,
- detailing key learning from the programme that can inform strategic thinking as The Atlantic Philanthropies exits from the field.

METHODOLOGY

A mixed method approach, with the RE-AIM framework (Green & Glasgow, 2006) as the organising framework, was used to examine the reach, effectiveness, adoption, implementation and maintenance of the programme. This involved:

- 1) detailed documentary analysis including baseline, current and desired picture of hospice and palliative care in Ireland;
- 2) interview data analysis drawn from interviews with key stakeholders from the programme and individual projects;
- 3) in-depth organisational case studies documenting changes in mature and new palliative and hospice-care involved organisations;
- 4) convening of grantees and other key stakeholders to review achievements, assess development of collaborations and potential for sustainability; and,
- 5) analysis of policy issues previously identified to be addressed, new issues that have emerged, success and barriers in policy development and implementation and next steps in policy and regulatory approaches.

DATA COLLECTION

Research and 'grey' literature for this evaluation spanned all proposals, progress reports and strategic development reports for 'End of Life' programme grants; Irish policy and review reports; international reviews and available analyses of policy development, best-practice provision and service organisation. For the case study, regional needs analysis and annual reports on health services were reviewed for both regions.

In support of all of these activities, some 95 interviews were held with 91 hospice and palliative-care stakeholder informants, including healthcare professionals, managers, administrators,

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fundraisers, educators and academic researchers. They encompassed those from specialist and generalist palliative care backgrounds, persons drawn from rural and urban settings, and statutory and voluntary organisations. Interviews with stakeholders in Northern Ireland were included for the two all-island 'End of Life' projects and expert informants from overseas helped to provide an international perspective.¹

Three grantee convening meetings were conducted, at which senior staff from 'End of Life' programme grants were invited to give their experiences of the programme and their wider strategic view of the field, and offer commentary on preliminary evaluation findings at interim and final stages of this project.

DATA ANALYSIS

The RE-AIM framework provided the conceptual framework for the evaluation. It places emphasis on the potential implications for delivering interventions in applied settings, and on assessing implementation for different components of a programme and across diverse intervention staff. The five elements of the RE-AIM framework are:

- **Reach**, the penetration of the programme into its intended audience;
- **Efficacy/Effectiveness**, the programme outcomes and their impact on targeted groups;
- **Adoption**, the readiness and willingness of project settings to include (adopt) the programme components in their operations;
- **Implementation**, the level and consistency in delivery of programme components throughout projects, regardless of staffing; and
- **Maintenance**, sustaining the programme into the future.

CHAPTER-BY-CHAPTER BREAKDOWN

The report is organised into an introduction and five chapters.

Introduction Evaluation Plan and Approach

The introduction will describe the remit of the evaluation and the strategies utilised, and will introduce the evaluation team led by Professor Mary McCarron.

Chapter 1 History of Hospice and Palliative Care in Ireland

The chapter describes how, upon entering hospice and palliative care in 2004, The Atlantic Philanthropies joined a field that had developed considerably in two decades, though one where there were still critical gaps, inequities and an absence of recognised models of excellence. While, 20 years previous to The Atlantic Philanthropies and statutory investment, most dying patients could not access care relevant to their needs and their families received minimal support, thousands now

receive expert treatment and support annually. These free-to-access services, which rank among the best in the EU, have their roots in community activism. How local champions led the establishment of palliative care teams in hospices and at home is described, as well as the development of a patient-centred model of care through formidable fundraising and voluntary effort. Most services were initiated with voluntary funds but statutory support has increased substantially since; this chapter also looks at how this support has brought new challenges in the developing statutory-voluntary partnership. The history concludes with a consideration of how, despite official government policy proposing universal palliative care provision on the basis of need in 2001, significant gaps remained when The Atlantic Philanthropies entered in 2004. Most notably, access to services was primarily determined by where the patient lived and by diagnosis; these inequities were observable for children and young people as well as for adults.

Chapter 2 The Atlantic Philanthropies' 'End of Life' programme

The Atlantic Philanthropies entered the field of hospice and palliative care in Ireland in 2004, issuing 14 grants totalling approximately €25 million. The 'End of Life' programme is described in five broad grantee programmes: the Milford Care Centre (MCC); the Hospice-friendly Hospitals programme (HfH), incorporating the new audit and end-of-life standards; Marymount Hospice and the International Expert Advisory Group (IEAG); the All-Ireland Institute for Hospice and Palliative Care; and the Irish Association for Palliative Care (IAPC). The programmes and their roll-out are described as well as their considerable achievements to date across the core activities of service delivery, education and research, and accreditation and advocacy.

Chapter 3 Two-Region Case Study

A case study was undertaken of palliative care services in two regions, the South East and the Mid-West, chosen because of their differences in financing and provision. The case study examined how palliative care developed in both regions from 2001 onwards. Analysis drew on policy documents, regional and national reports, Health Information and Quality Authority (HIQA) inspection reports on residential care settings, and interviews with staff from across acute, non-acute, continuing and community care settings, and SPC healthcare teams. Findings highlight considerable service expansion and increased penetration across both regions, but remaining differences also emerge. The Mid-West has an established specialist in-patient unit (SIP) and was well positioned to capitalise on increased available funding. As a result, a comprehensive palliative care service developed, supported by a tailored education programme. The continued absence of an SIP unit in the South East resulted in a focus

on building a shared model of care between SPC and GPs. The South East approach of supporting GPs in addressing increasingly complex care needs of patients who are discharged from hospital is more fully considered, as it may reflect future trends in care delivery.

Chapter 4 Policy, Measurement and Funding Challenges

The principle issues emerging both from the two-region case study and informant reports from throughout Ireland were geographical inequity and the generalist-specialist debate. Both are well-established concerns in the field, and this chapter offers a detailed consideration of what is happening on the ground. In particular, there is further examination of the alternative organisation of care in the South East, in particular its different balance in the use of generalist-specialist services to that imagined by the Department of Health and Children's report (2001). This alternative organisation poses questions for the future development of SPC and End-of-Life (EoL) care for those regions that have not received sufficient funding to fulfil official policy and are now unlikely to do so. Value-for-money (VfM) measurement is also examined as a source of considerable tension between statutory funders and palliative care providers. Suggestions are advanced for improving the portrayal of the VfM picture for palliative care in Ireland through improvements of both measurement tools and their use by statutory bodies.

Chapter 5 Conclusions

This chapter summarises the findings in terms of: (1) what are the key issues in sustaining and expanding upon programme advances?; (2) how The Atlantic Philanthropies and the programmes it has funded can assist in sustaining and expanding capacity, particularly in the context of the current economic climate?; and (3) what are the key strategic lessons from the programme as The Atlantic Philanthropies prepares to exit the field?

SUMMARY OF KEY FINDINGS

The 'End of Life' programme has had considerable success in expanding and improving the provision of end-of-life care. These include:

- increased access to care in all settings following investment in services in hospice, hospital and at home;
- increased awareness of hospice and palliative care nationally, among both patients and healthcare professionals;
- increased access to care for non-cancer patients, reflecting The Atlantic Philanthropies' promotion of inclusive admissions criteria;
- established SPC-led providers supported by the programme have increased the quality and quantity of care consistent with government policy;
- education programmes spanning basic to specialist levels of palliative care delivered from regional and hospice education centres across the country;
- the movement of advocacy research into government policy and public debate;
- implementation of higher standards in service provision and monitoring;
- The Atlantic Philanthropies' funding of advocacy related and evidence-based research, notably through the Irish Hospice Foundation (2006) and Marymount and The Atlantic Philanthropies (2006), has contributed substantially to the enhanced status of hospice and palliative care on the policy agenda; and,
- the establishment of the All-Ireland Institute for Hospice and Palliative Care (AIHPC), the first of its kind, with a mandate to strengthen further research, training, standards and policy influence.

There are also continuing gaps and challenges in hospice and palliative care provision despite the 'End of Life' programme activities, as summarised below.

- Hospice and palliative care in Ireland are still marked by substantial geographical inequity.
- The programme has increased capacity in previously low-resource regions but has not fully addressed geographical inequities.
- The programme strategy invested in both specialist and generalist palliative care provision, with one project (Hospice-friendly Hospitals) successfully engaging generalist audiences. Nevertheless, a marked specialist-generalist debate continues. This is visible geographically, between well-resourced regions with extensive SPC services and less well-resourced regions where palliative care is integrated within generalist EoL care. But this issue transcends geographical differences, reflecting poor communication and integration between SPC and EoL groups.
- The programme strategy anticipated a cascading service development throughout the country, with SPC-led programme projects 'setting the standard' and advancing the nationwide implementation of official government policy, as outlined by the Department of Health and Children (2001). However, economic restrictions and insufficient government funding has meant that services have developed differently than envisioned, particularly in low-resource, EoL-led areas. Instead, the development of services at a national level has evidenced a somewhat unpredictable evolution.
- There has been insufficient statutory support to implement comprehensive SPC provision in what were identified as low-resource regions. The provision of palliative care in these regions, typically delivered within wider EoL care, varies within and across regions. At present, there is

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little data on this intermediate care and so the first step in sustaining and advancing it is to research a nationwide picture of actual provision.

- The initial programme strategy did not address what has become a key concern of statutory bodies – value-for-money measurement and cost-effectiveness. However, following the evaluation's interim report highlighting this deficit, a grant for a two-year health economics study was issued in January 2011 to address the issue.

Nevertheless, there is considerable potential for many advances to be sustained. Advances through the in-patient hospice and homecare projects and across the South East appear to be well-established with strong regional statutory support and broad fundraising bases. Developments in other care settings and among generalist EoL and primary care practitioners also have strong potential to be sustained. The sustaining of all advances will be enhanced by expanded efforts to measure performance and evaluate outcomes.

As investments by The Atlantic Philanthropies end, there remain several key challenges for consideration: (1) sustaining advances while responding to geographic inequities and supporting palliative care provision in low-resource areas where SPC is typically limited and intermediate care varies considerably; (2) addressing the on-going generalist/palliative debate, promoting communication and integration between specialist and generalist palliative care; and (3) using evidence-based research to inform policy and service organisation, particularly in regard to understanding 'intermediate/level 2' provision nationwide and addressing statutory concerns around VfM and performance measurement.

The Atlantic Philanthropies may wish to consider ways to stay directly involved, opportunities to partner with statutory bodies and how it wishes to see already funded groups such as the AIIHPC assume leadership roles.

¹ A majority of interviews were conducted one-on-one, but in a number of cases interviewees were in pairs or larger groups. A majority of informants were interviewed once, but in a number of cases twice or three times. A majority of informants contributed to more than one phase of the evaluation.

EVALUATION PLAN AND APPROACH

The overall objective of the 'End of Life' programme initiated and funded by The Atlantic Philanthropies was: *By 2010 there will be evidence established of effective ways to care for older adults in the hospice and community settings and within the wider healthcare system towards the end of their lives. Applied research of an international standard on policy and practice will be completed and a cadre of multi-disciplinary care workers and clinicians will be trained in best practice in centres focusing on end-of-life care.*

Given this overall objective, the goal of the evaluation was to document the progress and impact of the 'End of Life' programme to date and to identify resulting strategic learning for the field.

In pursuit of this goal the evaluation was designed to:

- document a baseline state of palliative care in Ireland that the 'End of Life' programme sought to address;
- outline the inputs and principal activities involved in the programme to support palliative and hospice care;
- assess the progress made on specific programme outcomes including workforce development;
- detail specific policy and practice gains;
- identify causal relationships between activities and impacts attributable to funding from The Atlantic Philanthropies including policy and systems level change;
- assess the potential for advances in palliative care provision to be sustained;
- identify opportunities, obstacles and challenges in the implementation of the programme; and,
- make recommendations to inform future policy and practice in palliative care, and future decision-making by The Atlantic Philanthropies.²

EVALUATION DESIGN

The RE-AIM framework was used as a conceptual framework as it places emphasis on the potential implications for delivering interventions in applied settings, and on assessing implementation for different components of programmes and across diverse intervention staff (Green and Glasgow, 2006). The five elements, or dimensions, of the RE-AIM framework are:

- **Reach**, the penetration of the programme into its intended audience;
- **Efficacy/Effectiveness**, the programme outcomes and their impact on targeted groups;
- **Adoption**, participation rates and representativeness of the project settings;
- **Implementation**, level and consistency of delivery components throughout projects regardless of staffing;

and,

- **Maintenance**, sustaining the programme into the future at individual and organisational level and for the programme as a whole.

The RE-AIM framework which has been applied to both policy and practice implementation (McCallion, 2009) guided the study design and incorporated five phases of data collection and analysis over a 15-month study period.

FIVE PHASES OF THE EVALUATION

Phase	Key Activities	Timeframe
1	<i>Documentary Analysis:</i> projects' proposals and grants; policy documents and reports	Months 1-3
2	<i>Grantee Convenings:</i> 3 managed group discussions with End of Life programme stakeholders	1st convening: month 2; 2nd convening: month 7; 3rd convening: month 11
3	<i>Key Informant Interviews:</i> 95 semi-structured interviews with palliative care stakeholders in Ireland	Months 2-14
4	<i>Two-Region Case Study:</i> regions with differing histories and levels of resources for provision	Months 7-13
5	<i>Workforce Study:</i> assessing the impact of the programme on Ireland's palliative care workforce	Months 7-13

• Phase 1

A detailed documentary analysis was undertaken to examine the baseline picture of the prior state of palliative and hospice care provision, the programme's pre-identified desired end state, and reports available from the projects and related statutory and voluntary agencies. This approach elicited information on the **reach and implementation** of the programme to indicate the extent to which project goals were actualised.

Sample: Contemporary reports on palliative and hospice care provision including original proposals submitted by project principal investigators (PIs), for projects funded by The Atlantic Philanthropies, as well as publications from

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the Irish Hospice Foundation (IHF), the Health Service Executive (HSE), the Department of Health and Children, and the Central Statistics Office (CSO), on the subjects of palliative and end-of-life care, and ageing and health.

Data collection procedures: Data was gathered from the background sections of key reports and planning documents, the proposals underpinning projects funded by the programme and interviews with key policy, advocacy and service provision stakeholders. Contacts with project PIs, The Atlantic Philanthropies staff, state and semi-state bodies and key advocacy organisations helped in the gathering of relevant documents.

Analysis: Detailed review of these documents yielded data on both potential and actual reach, and on success in implementation of projects. This involved establishing the number of participants in education/professional development projects, evidence of embedding of activities to improve end-of-life care, anticipated and achieved project outcomes, and factors associated with the achievement, or not, of particular outcomes.

- *Phase 2*
Grantee convening meetings were organised on three occasions, involving key stakeholders from the programme and projects, as well as from the HSE, the DoHC, the National Council on Ageing and Older People (NCAOP), the IHF, the Irish Cancer Society, the Alzheimer's Society and the All-Ireland Institute for Hospice and Palliative Care.

The first convening took place early in the project and helped in engaging the various stakeholders in assisting with the phases of data collection, in framing the questions and in identifying relevant documents. The second convening helped to review and expand the interim findings. The third convening helped in reviewing and finalising the overall findings.

Data collection procedures: Focus groups and managed discussions addressed:

- developments in palliative and end-of-life care service delivery at local, regional and national levels;
- trends in policy discourse on palliative and end-of-life care with specific reference to older persons; and,
- implications of policy trends and current service provision for future palliative and end-of-life care service development.

Additional key documents were identified, potential interviewees engaged, cross-discipline and cross-provider discussions initiated and background data gathered to inform question development for semi-structured interviews.

During the second convening, findings emerging from the phases 1-4 of data collection were reviewed and there were focused discussions on the advocacy/policy interface and on lessons learned from policy success and challenges.

During the third convening (late in the project timeline), discussion focused on differences between programme expectations and actual programme delivery; barriers and facilitators to the expansion and embedding of palliative approaches in different regions of the country and with different populations; policy successes and policy challenges; effectiveness in attaining long-term programme objectives; and the potential for sustainability in the context of Ireland's changed economic circumstances.

Analysis: The convenors and assigned note-takers compiled write-ups of the discussions at each of the three convening meetings and the reports generated were reviewed to identify both key themes and potential questions for follow-up, particularly in any interviews subsequent to the first two meetings.

- *Phase 3*
Key informant interviews and document reviews supported analysis of policy issues in previous programme and other reports. They also identified new issues that emerged, successes and barriers encountered in policy development and implementation, and future steps in policy and regulatory approaches.

Sample: Policy documents gathered in Phase 1 were examined in this phase. Also, in collaboration with The Atlantic Philanthropies, a list of interviewees was compiled to include PIs of policy related projects, advocates, authors of key policy documents and reports and HSE and government officials responsible for palliative care and hospice services, their funding and policy development.

Data collection procedures: A semi-structured interview protocol was developed to gather data on the status and process of key policy issues considered in the programme, new issues that have arisen, barriers to policy development, status of regulatory development, implementation and next steps.

Analysis: Data from detailed reviews of policy documents was triangulated with interview data to develop a narrative of the policy development process and progress, with a goal of documenting key learning around the building of coalitions and change efforts, barriers and facilitators, progress to date and what will be needed both to sustain progress made and to advance it further.

- *Phase 4*

In-depth organisational case studies were conducted of two geographic areas that received programme investment. One had pre-existing palliative care and hospice services and one had limited pre-existing services. The case studies addressed the extension of palliative care, development of workforce and demonstrated improvements in services and outcomes. An unexpected opportunity arose to consider the implications of less funding than anticipated and the development of alternative forms of care delivery when anticipated investments did not occur.

Sample: Two regions were selected with different histories and levels of resources for service provision.

Data collection procedures: Document review, site visits, in-person interviews and follow-up telephone calls supported detailed data collection; sources including:

- field-notes on local resources, support for professional development in palliative care, working arrangements and observed factors likely to influence the project outcomes;
- local documents and reports; and,
- socio-demographic data on the local population.

Analysis: The sources yielded a complex array of quantitative and qualitative data, which required careful management and analysis, and benefited from a rigorous approach to triangulation (Foss and Ellefsen, 2002).

- *Phase 5*

Key informant interviews with providers and professional groups specifically assessed the impact of the programme on both the size of the palliative and hospice care workforce and the depth of preparation.

Sample: Samples were accumulated of administrators; providers of palliative and hospice services in hospice, hospital and day settings; staff working in hospice, hospital and day settings; and representatives of physician, nursing and social work professions.

Data collection procedures: Semi-structured interviews considered: both the prior and current state of the workforce; the specific ways in which the funded projects have increased numbers of trained staff; engagement of specific professions; embedding of palliative care principles and approaches in new environments; and the potential for continued development of the workforce.

Analysis: Key themes were extracted; rich descriptions developed of the associated learning and of barriers and facilitators to workforce development; and conclusions drawn on the changed state of readiness of providers and of specific professions.

- *Additional strands:* After three phases of the project, the evaluation team and The Atlantic Philanthropies agreed two strands in addition to the original research proposal. These were: (i) a history of hospice and palliative care in Ireland, to provide a rich background to the field prior to The Atlantic Philanthropies' arrival in 2004 and the origins of the modern hospice movement; and (ii) an examination of value-for-money issues and performance measurement in the field, to reflect statutory concerns and health service reconfiguration against a changing economic landscape.

All of these activities are reported on with relevant reports and interviews listed for each chapter and copies of instruments and protocols provided in the appendices. The extensive evaluation was possible using an evaluation team led by Professor Mary McCarron, which comprised national and international members, several disciplines and experienced systems-level evaluators.

THE EVALUATION TEAM

McCarron: Prof. McCarron is the project PI and managed all aspects of evaluation design, implementation and development of deliverables. Mary McCarron, PhD is Head of School, School of Nursing and Midwifery, Trinity College Dublin, and is co-chair of the School's Ageing, Disability and Palliative Care Research group and policy advisor to the Daughters of Charity Service on intellectual disabilities (ID) and dementia. Funded by the Health Research Board, the IHF, the Alzheimer's Society, the Irish Cancer Society and numerous intellectual disabilities services, McCarron's work has focused upon the development of knowledge of ageing and of palliative care, systems change and collaboration between ID services and palliative care and hospice organisations; workforce development and the expansion of services to new locations such as day programmes. Prof. McCarron is the PI for the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing. In demand as a speaker and presenter nationally and internationally, Prof. McCarron has successfully led, managed and completed both research grants and tender projects.

Higgins: Prof. Higgins assisted with structuring the convening meetings and the related focus groups and interviews as well as with the document analysis portion of the study. Agnes Higgins is an Associate Professor in Mental Health Nursing at the School of Nursing and Midwifery, Trinity College Dublin. She has worked in the areas of mental health and palliative care, and was the director of education and development in St Francis Hospice, before coming to TCD. She has a strong track record in evaluative research and has received research grants from the Health Research Board, the Mental Health Commission, the Irish Family Planning Association, the IHF, the National Disability Authority, Gay Lesbian Equality

EXECUTIVE SUMMARY

Network, and the National Council for Nursing and Midwifery. She has published numerous papers in peer reviewed journals and a number of book chapters and is a reviewer for nursing and mental health journals. Higgins has research expertise in evaluation methodologies, action research and qualitative methods.

Hynes: Geralyn Hynes, PhD, was the project manager and supported Professor McCarron in all aspects of project implementation, data collection and analysis. Geralyn Hynes' own research background comprises action research approaches to developing respiratory nursing practice to address palliative care needs of patients with advanced chronic obstructive pulmonary disease. She was also involved with the IHF in the Extending Palliative Care for All Project. A lecturer practitioner in the Royal College of Surgeons in Ireland since 1998, she was also funded by a charitable trust to develop practice at primary care level in a deprived area of Dublin and was previously involved in research and resource development work in Bangladesh and Zambia.

McCallion: Prof. McCallion has assisted with the use of RE-AIM, logic models and the analysis of systems change, workforce development and policy innovation. Philip McCallion, PhD, ACSW is Professor in the School of Social Welfare at the University at Albany, Director of the Center for Excellence in Aging Services and Visiting Professor in Ageing, Disability and Palliative Care at the School of Nursing and Midwifery, Trinity College Dublin. Prof. McCallion's research is focused on the interaction of informal care with formal services and collaboration across service systems. His work has included the development and evaluation of innovative systems change and demonstration projects designed to maintain ageing persons in the community, and associated translation of evidence based interventions. McCallion's research has been supported by grants and awards from the National Institute on Drug Abuse, the US Administration on Aging, the John A. Hartford Foundation, the Joseph P. Kennedy Jr. Foundation, the Retirement Research Foundation, the Alzheimer's Association, the Agency for Health Quality Research, the Health Research Board of Ireland, the Irish Hospice Foundation and New York State's Legislature and its Department of Health, Office for the Aging, Office for Children and Family Services and Developmental Disabilities Planning Council. Prof. McCallion has over 70 publications on interventions with caregivers of frail older people, persons with Alzheimer's disease and persons with intellectual/developmental disabilities, and work on systems change and the expansion of palliative care to new populations.

Larkin: Prof. Larkin assisted with the policy analysis aspects of the study and in facilitating interaction with key palliative care and hospice stakeholders. Philip. J. Larkin, RN, RSCN, RHV, NDN cert, B.Sc (Hons), MSc, RNT, PhD, has worked

in Palliative Care in Ireland since 1992. He was Director of Education at Our Lady's Hospice, Harold's Cross, Dublin, from 1998-2001, before taking up a pilot post as Regional Co-ordinator for Palliative Nursing Services in the West of Ireland. In 2008, he was appointed Associate Professor of Clinical Nursing (Palliative Care) at University College Dublin and Our Lady's Hospice, Harold's Cross Dublin. He is director of the Masters in Palliative Care programme and leads the palliative care research programme within the School of Nursing, Midwifery and Health Systems. He was a member of the National Council for Palliative Care in Ireland with specific responsibility for palliative care education. Larkin was Vice-President of the European Association for Palliative Care, Milan, Italy, until April 2007 and received the Lifetime Achievement Award from Macmillan Cancer Support and the *International Journal of Palliative Nursing* in recognition of his European and International work. He has published extensively on issues relative to palliative care, palliative care nursing and education, and current research interests include the place of compassion in the delivery of 21st century palliative care, clinical assessment and the management of opioid-induced constipation.

Drennan: Jonathan Drennan, PhD, worked with Prof. Larkin and Prof. McCarron on policy and workforce aspects of the evaluation. Dr Drennan is a lecturer at the School of Nursing, Midwifery and Health Systems, University College Dublin (UCD). Dr Drennan has had a number of papers published in the areas of ageing, education research, adolescent health and psychometrics, in leading journals including *Ageing and Society*, *Journal of Advanced Nursing*, *Social Science and Medicine*, *Journal of Nursing Scholarship*, *Studies in Higher Education* and *Nurse Education Today*. He has extensive experience of large-scale research projects having worked as PI and co-applicant on a number of funded studies including: coordinator, *Loneliness and Social Isolation among Older Irish People*. He is currently co-director within the School of a Centre for Research into the Protection of Older People funded through the Health Service Executive. He was the lead investigator of the *National Evaluation of Nurse and Midwife Prescribing Initiative in Ireland* funded by the HSE. Currently, he is the co-principal investigator in a European Science Foundation funded programme of research entitled: *The Academic Profession in Europe: Responses to Societal Change*.

Payne: Prof. Payne assisted with critical incident analysis, the development of case studies and with qualitative analyses. Prof. Payne is director of the International Observatory on End of Life Care at Lancaster University and specialises in bereavement, palliative care in cancer and chronic illness. She is a former nurse and health psychologist and worked clinically before going into academia 20 years ago. She has been conducting research into palliative care since the early 1990s, setting up research groups in the UK. She is also a

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trustee of St Luke's Hospice in Sheffield and is co-director of the Cancer Experiences Collaborative.

May: Peter May was the principal project researcher, working closely with the project manager and other team members across all phases of data collection and analysis. Mr May MA (Hons), MSc has worked for five years in economics and public policy analysis in the UK and Ireland.

² Note: The original tender document included a role for the evaluation informing the final palliative care investments for The Atlantic Philanthropies. As the evaluation progressed, the remit of the evaluators was changed to no longer include this task.

1. A SHORT HISTORY OF HOSPICE AND PALLIATIVE CARE IN IRELAND

1. A SHORT HISTORY OF HOSPICE AND PALLIATIVE CARE IN IRELAND

Key research questions

- How has the modern hospice movement in Ireland developed?
- What were the key drivers, values and events that contributed to the establishment of specialist palliative care (SPC) teams across all regions and the current service provision?
- What was the background to and baseline state of the field that the 'End of Life' programme sought to address?

Data sources

A thorough documentary analysis of key policy documents and associated research in Ireland and internationally was performed at the outset of the evaluation. This chapter was further informed by relevant histories and analysis of healthcare and end-of-life care in Ireland, including Igoe et al (1997), Wiley (2000) and Ling and O'Sioráin (2005); as well as hospice-specific histories, namely Holland (2007) and McCarthy (2004). The baseline state of services was taken from the Irish Hospice Foundation (IHF, 2006), with reference to official government policy and other Department of Health (DoH)/ Department of Health and Children (DoHC) reports (1996, 2001, 2005).

Twenty-nine key informant semi-structured interviews tracked the development of modern hospice in Ireland over the last 30 years. Informants included healthcare professionals, managers, statutory and voluntary sector administrators, fundraisers, educators and academic researchers across the country throughout this period.

A NEW MODEL OF CARE

Between 1980 and 1989, the economic recession in Ireland prompted a 16 per cent decline in health expenditure, resulting in almost a one-third reduction in acute hospital beds (Wiley, 2000).

A renewed emphasis on curative care, relying on technology and new treatment approaches that promised to prolong life and improve outcomes, coupled with increased competition for budgets, increased the potential for the neglect of dying patients in Irish healthcare; dying was seen as a failure. Within care for the dying, patients viewed hospices with reverence and fear (Ling and O'Sioráin, 2005). One informant who worked in hospice care during this period told us:

'There was a real stigma about us at that time. People didn't want to come in. Hospice was somewhere you went into and didn't leave.'

The inadequacy of care approaches for those at end-of-life was clear, but solutions were not immediately obvious. A model was emerging in the UK, pioneered by Dr Cicely Saunders

at St Christopher's, London (founded in 1967) and informed by the practice of the Macmillan nurses (started in 1975). But no systematic guide to implementing or expanding such care existed, and central strategic leadership in Ireland was lacking. An approach rooted in acute care persisted, and the long-standing dissatisfaction among dying patients and their families became ever more entrenched (Holland, 2007).

THE RELIGIOUS SISTERS OF CHARITY AND LITTLE COMPANY OF MARY

Local champions began to grasp the nettle and seek alternatives to the provision of end-of-life care. Three established services had foundations on which to build. At Our Lady's Hospice in Harold's Cross, Dublin3 and St Patrick's Hospital, Cork, care centres for the dying had existed since the late nineteenth century, founded by the Religious Sisters of Charity. In Limerick, the Congregation of the Little Company of Mary first established services at Milford Care Centre in 1928 (Ling and O'Sioráin, 2005). But as one informant with a long-standing association with the hospice in Harold's Cross told us:

'By the late 1970s, the hospice was no longer fulfilling its intended function to provide care for the dying poor. It was acting more as a nursing home, mirroring the wider health system by prioritising cure and control of disease for long-stay patients without meeting the specific needs of dying patients.'

A nurse who worked in St Patrick's Hospital in Cork adds:

'The "caring" was excellent and we had a wonderful rapport with the patients. But the treatment, resources and expertise were nothing like they are now.'

In Dublin, Cork and Limerick, the religious sisters and their nursing colleagues initiated change. They recognised the need and opportunity to implement a new model of care for the dying that sought to minimise suffering, maintain dignity and autonomy, and improve quality of life for patients and families.

For Our Lady's Hospice in Dublin, the initial priority was an overhaul of care provision inside the hospice, replacing 'Nightingale wards' with a setting that offered privacy for patients and the bereaved, free at the point of delivery for those who needed them. By 1980, staff with experience had been recruited and a former general practitioner (GP) appointed as a dedicated medical director. A purpose-built setting opened in 1993 (Holland, 2007). Milford Care Centre in Limerick opened a nine-bed hospice unit within the Milford House Nursing Home in 1977 and six years later opened a second, purpose-built 20-bed hospice unit. At St Patrick's Hospital in Cork, the 25-bed Marymount Hospice was officially opened in 1984,

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redesigning the first floor of the hospital with subdivided bays and improved facilities for patients and visitors (McCarthy, 2004).

Strong collaboration with St Christopher's and St Joseph's hospices in London informed the development of these services. An information-driven ethos ensured that new staff had experience of caring for and treating dying patients and received training in managing symptoms, meeting the needs of the individual, and improving communication and choice. Hence, in-patient hospice care developed on the basis of knowledge, competence and education.

This step-change in organisation was clearly manifested in delivery. By the mid-1980s, in Dublin, Cork and Limerick, a model of in-hospice care for the dying was in place that recognised and cherished individuals and their family. In one informant's words:

'You have to hand it to the nuns. They and one or two others were visionary people. They saw what had to be done by asking, "How do we support the patient and the family?" And then they did it.'

BEYOND HOSPICE PROVISION

The overhaul of in-hospice provision was merely the beginning. Here was established a patient-centred care that respected choice. However, in a great many cases patients were not able to avail of that choice.

One informant who worked in Dublin during the early-1980s transition told us:

'We were following what was happening in the UK. Many patients would have preferred to receive palliative care – care more appropriate to their needs – at home and to die at home. Often, patients were spending weekends at home in any case.'

The Religious Sisters of Charity had experience of and access to a new homecare service through their hospice in Hackney and adopted the approach in Ireland. The first homecare team in the state was established out of Harold's Cross in 1985, comprising a doctor and two nurses (Holland, 2007). The following year, Marymount initiated its own homecare service, initially comprising only one nurse making home visits to discharged patients on a part-time basis but rapidly growing to meet demand (McCarthy, 2004).

Following the example of the Macmillan nurses, the homecare team was a support service for the local GP. The GPs and public health nurses (PHNs) remained the primary carers; homecare teams operated in an advisory role and never

prescribed drugs. This relationship was carefully managed in line with a commitment to excellent communication across the service. Dialogue with the GP began on day one and early contact was made with both the patient and family to establish precisely what was and wasn't to be expected from these new arrangements.

The immediate success of the homecare innovation, reflected in both patient and practitioner satisfaction, kindled interest further afield. Across Ireland, communities and their healthcare professionals were recognising the need for and value of palliative care provision. Local champions here too began to build links with St Christopher's as well as with the inaugural Harold's Cross homecare team, whose members were frequently invited to provide introductory presentations. One member of that team recalls:

'I remember working a full day in the hospice or making visits in Dublin and then at 5pm the three of us would get in the car and drive somewhere to give a presentation. We went across the country meeting nurses, GPs, local charities. We'd give presentations and take meetings. And we'd be back at work at 9am the next morning. They called us "the road show".'

A NATIONAL MOVEMENT

From these beginnings, the late 1980s saw palliative care grow rapidly across Ireland. With only three hospices in the country, the emphasis was very much on homecare, driven by leadership and funding from the Irish Cancer Society (ICS).

The ICS had funded the first homecare team in Harold's Cross for three years with the expectation that, within this period, the level of efficacy of the service would be demonstrated, after which it would be integrated into statutory provision. Facing demand from across the country, it took up the responsibility of leadership, as one ICS informant explained:

'People were beginning to ask for services because they'd heard how valuable it was. And so we drove homecare development nationally. Our model was a three-way partnership between ourselves, the local community groups and the regional health board. Initially we provided 90 per cent of funding and over the years reduced this as the service became integrated into statutory provision.'

The central fundraising initiative was the annual Daffodil Day, inaugurated in 1988. Alongside homecare, the ICS established a free night nursing service and appointed a nurse as patient care co-ordinator to push service development across the country:

'We were in every part of Ireland. We went from Donegal

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to Kerry. We were the honest broker, with no allegiances between local groups and the health board. And as well as the care delivery we ran workshops for GPs and public health nurses, which was key. We were a resource for those areas who were really out on their own.'

The subsequent local demand for homecare teams as they developed throughout the country appeared to support beliefs that these services are efficacious. But statutory support for these services in the long run remained contingent on the decisions of regional health boards, whose beliefs about efficacy varied across the country.

THE ROLE OF EDUCATION

Central to this rapid service expansion was education, both for new homecare teams and in integrating palliative care into existing community provision. The first courses were instituted at Our Lady's Hospice in Harold's Cross in 1987, mirroring those in the UK under the title 'Continuing Care of the Dying Patient and their Family'.

Initially comprising a six-week curriculum and attended only by nurses, these were quickly extended to eight weeks and included multi-disciplinary components with participation from social workers, occupational therapists, physiotherapists, art therapists and chaplains. Recognising the need to broaden education beyond care of the patient with advanced cancer, programmes were also developed that took account of, for example, the needs of patients with motor neurone disease and those with HIV. In developing education programmes, close links were formed with palliative education centres both in Northern Ireland and Great Britain. In 1997, the first two-year Higher Diploma in Palliative Nursing was set up by Our Lady's Hospice in partnership with University College, Dublin.

As the only provider of education at that time, Our Lady's Hospice played a key role in service development and later worked closely with the ICS in preparing newly appointed palliative homecare nurses throughout the country. One informant told us:

'Every week we would look at a map of Ireland and ask, "Where are we going next?"'

Marymount and Milford opened their own education centres and a higher diploma for palliative care was inaugurated in the 1990s. In more recent times, a tertiary sector link-up has been central to education but, in each of the three long-established hospices, the provision of education remains very active.

LOCAL ACTIVISM

While the ICS's funding and strategic direction were indispensable, the hospice and palliative care movement in Ireland is in essence a local one. The formation of homecare teams was instigated by communities themselves, local groups who saw the need for a hospice.

While Our Lady's Hospice had found support from the Department of Health (DoH) for their early activities, most rural services had to be entirely self-sufficient in the face of sceptical regional health boards. Formidable local fundraising efforts, drawing on community goodwill and volunteer commitment, generated substantial funds towards services and buildings. From 1989 to 2003, new hospices were opened in Galway, Sligo, Donegal, and Raheny and Blackrock⁴ in Co. Dublin, and capacity expanded substantially in the three established hospices.

A notable facet of this local activism was that individuals with first-hand experience of end-of-life care for a family member were often moved to initiate change:

'Those with experience realise that people can often be cared for at home if they have the right support. Where those who have never experienced it may be scared or discouraged, those who have been involved want to do something about it.'

A high-profile example was Mary Redmond, who founded the IHF in 1986 after witnessing first-hand the benefits of care to those with terminal illness (Irish Hospice Foundation, 2006b). As well as raising awareness and access locally, the IHF funded the building of the Education Centre at Our Lady's Hospice, which opened in 1987, and the first SPC provision in hospitals in the 1990s.

There were many other local champions. One informant from the voluntary sector recalls:

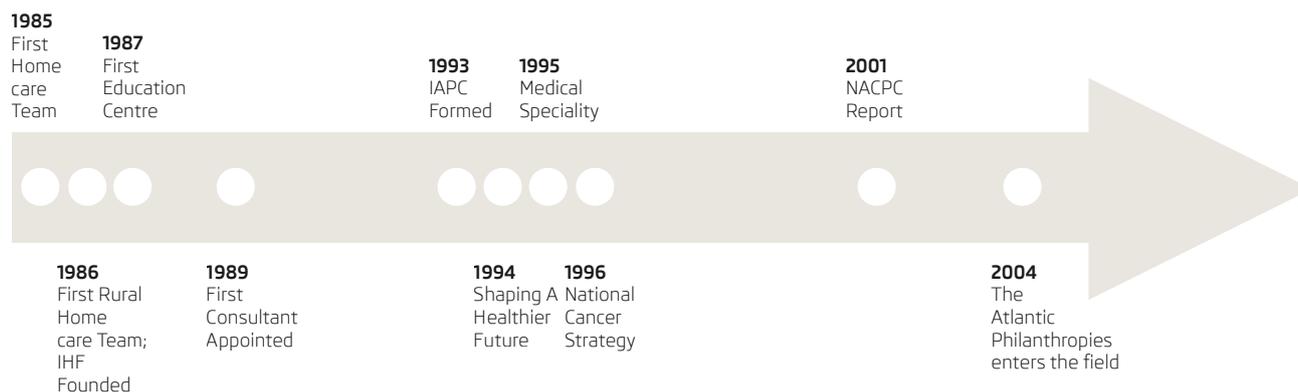
'People came from all over. A man arrived on my doorstep and said, "Give me a nurse". He was from Co. Clare, where there was no hospital. His wife had been a nurse and died recently, and he wanted homecare to be available in Clare. He had fundraised £32,000 in a single weekend. He just said to me, "Give me a nurse!"'

A CONSULTANT-LED SERVICE

During the rapid service development of the 1990s, changes occurred in how services were organised and led. The first consultants in palliative care in Ireland were appointed at

1. A SHORT HISTORY OF HOSPICE AND PALLIATIVE CARE IN IRELAND

FIGURE 1.1 TIMELINE: PALLIATIVE CARE IN IRELAND 1985-2004



Harold's Cross in 1989 and Marymount in 1991; both doctors had experience of St Christopher's in London.

In 1993, the Irish Association for Palliative Care (IAPC) was formed, establishing an all-island group with both nursing and medical constituencies, as well as a hospice management forum. Two years later, Ireland followed the UK to become only the second European country to recognise palliative care as a medical specialism. One informant explained:

'In the early days there was only one doctor working in palliative care in the country. The formation of the IAPC and adoption as a specialism were very important in helping palliative care become an integral part of healthcare in Ireland. The consultants gave new leadership to their teams and ensured the most up-to-date treatment.'

By 2004, there were 12 palliative care consultants in Ireland, with only the Midland Health Board region lacking any consultant input (Irish Hospice Foundation, 2006).⁵

OFFICIAL RECOGNITION AND POLICY

Alongside the wide-ranging developments in services and education from the mid-1980s, the profile of hospice and palliative care also grew within health policy. When *Shaping A Healthier Future* was published in 1994 it represented the first official recognition of palliative care by an Irish government (Department of Health, 1994). There then followed formal acknowledgement of palliative care as a medical speciality in 1995 and its inclusion in the national cancer strategy a year later (Department of Health, 1996).

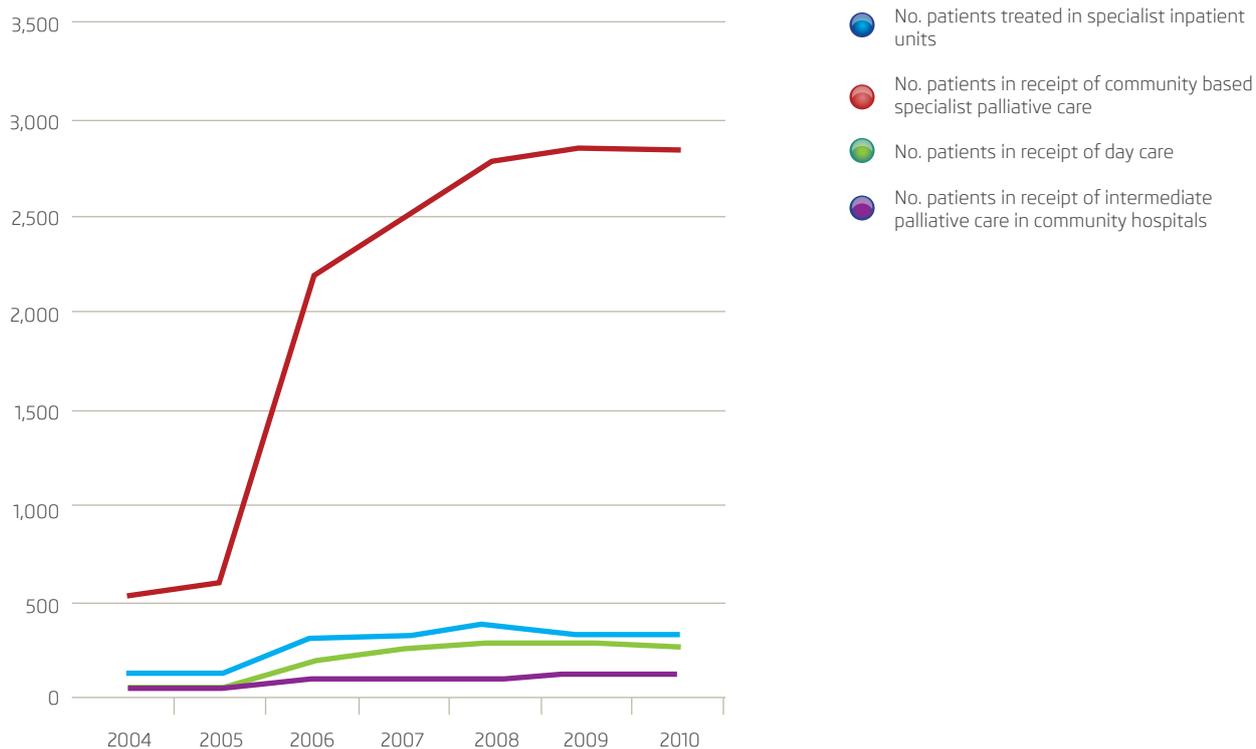
The origination of the hospice in local communities meant that, initially, development was driven at community level without a coherent national strategy. The increases in statutory

funding were welcome but entailed their own challenges. A voluntary movement, modern hospice has independence as a core concept (Ling and O'Sioráin, 2005) and informants from the voluntary sector spoke of the tension prompted by new requirements and increased bureaucratic burden. Reports differed regarding the nature of partnership across the country, with varying levels of financial support among regional health authorities for capital and staff expenditure.

The report of the National Advisory Committee on Palliative Care (NACPC) (Department of Health and Children, 2001) for the first time mapped out a strategy for the development of comprehensive hospice and palliative care services in Ireland over a five-to-seven-year period, identifying the number of beds, staff and capital facilities required on a per capita basis. In adopting the NACPC report as official policy, the Irish Government accepted in principle the intent to provide universal palliative care on the basis of need. It was into this scenario, policy context and history that The Atlantic Philanthropies entered the field of hospice and palliative care in Ireland.

Prior to initiating their 'End of Life' programme, in 2004 The Atlantic Philanthropies funded a baseline study of all hospice and palliative care services in the state (Irish Hospice Foundation, 2006). It found that statutory funding was around 50 per cent of that promised in 2001, with huge geographical inequity – access to services was primarily determined by where the patient lived. A second issue was treatment for non-cancer patients. The proportion of patients with a non-cancer diagnosis who received care was five per cent in 2004, against a target of 25 per cent (O'Leary and Tiernan, 2008; Irish Hospice Foundation, 2010a). Similar inequities were present in palliative care for children and young people (Department of Health and Children, 2005). Subsequent IHF research

1. A SHORT HISTORY OF HOSPICE AND PALLIATIVE CARE IN IRELAND



found that even where promised funding had materialised, it had not always been used for the intended purpose.⁶

Despite these gaps the scale of service development over two decades had been substantial with the most rapid growth coinciding with The Atlantic Philanthropies' investments. Figure 1.2 shows numbers of patients seen monthly in each key care setting from 2004 to 2010, according to HSE Service Plan estimates (2006-2010) and the Baseline report (2004): (see figure 1.2 above).

The excellence of palliative care services in Ireland was recognised in a review of palliative care services in the WHO European region (Centeno et al, 2007).

SUMMARY

Upon entering hospice and palliative care in 2004, The Atlantic Philanthropies joined a field that had developed considerably in two decades, though one where there were still critical gaps, inequities and an absence of recognised models of excellence. Local champions had led the establishment of palliative care teams in hospices and at home, initiating a patient-centred

model of care with the support of formidable fundraising and voluntary effort. Most services were initiated with voluntary funds but statutory support has increased substantially since then; this support has brought new challenges as statutory-voluntary partnerships develop. In 2001, official government policy became universal palliative care provision on the basis of need, but when The Atlantic Philanthropies entered three years later significant gaps remained. Access to services was primarily determined by where the patient lived and by diagnosis; these inequities were as true for children and young people as for adults.

³ Now Our Lady's Hospice and Care Services.

⁴ Blackrock, Co. Dublin, was distinct from the other new hospices in that, while those in Galway, Sligo and Donegal were built following many years of fundraising and voluntary effort, Blackrock was funded by a single benefactor during the Celtic Tiger economic boom. It is managed by Our Lady's Hospice in Harold's Cross.

⁵ A first consultant has been appointed to the midlands since publication of the baseline report.

⁶ See http://www.hospice-foundation.ie/up_documents/Oireachtas_presentation_May_08.pdf

2. THE ATLANTIC PHILANTHROPIES 'HOSPICE AND PALLIATIVE CARE' PROGRAMME

2. THE ATLANTIC PHILANTHROPIES' 'END OF LIFE' PROGRAMME

Key research questions
<ul style="list-style-type: none"> • What were the inputs and principle activities in the 'End of Life' programme? • Have programme goals been realised or remained on target? • To what extent are wider developments in the field attributable to the programme? • What are the significant outstanding challenges in the field following the programme's implementation?
Data sources
<p>A thorough documentary analysis of key policy documents and associated research in Ireland and internationally was performed at the outset of the evaluation. This chapter was further informed by the original tender documents, funded grant proposals, progress reports on projects to date, and grantee convenings with key 'End of Life' programme stakeholders</p> <p>Forty key informant semi-structured interviews analysed the progress and impact of the 'End of Life' programme. Informants included healthcare professionals, managers, statutory and voluntary sector administrators, fundraisers, educators and academic researchers.</p>

THE PROJECTS

The Atlantic Philanthropies entered the field of hospice and palliative care in Ireland in 2004, eventually issuing 14 grants to a total approximate value of €25 million. This initiative was titled the 'End of Life' programme (Appendix 1).

The resultant projects are engaged in a range of core activities, summarised below.

- **Services:** this includes care provision across hospital, hospice and home settings, variously offering (i) specialist palliative care (SPC) and (ii) a generalist, public-health approach.
- **Education and research:** activities include training multidisciplinary care workers and clinicians in best practice, and co-ordinating and pursuing applied research of an international standard on policy and practice.
- **Accreditation and advocacy:** work involves supporting the establishment of standards, monitoring and accreditation; raising awareness and access to palliative care in all settings nationally; and influencing government policy.

At the level of care delivery, the programme has supported a range of best practice models spanning acute, hospice and homecare, designed to better meet patients' changing needs during end-of-life (EoL) care.

For the purposes of this chapter, the 'End of Life' programme has been organised into five grantee groupings (Table 2.1):

TABLE 2.1 GRANTEES AND PROJECTS

Grantee	Project focus
Milford Care Centre, Limerick (including Hospice-at-Home (H@H))	<p>Intended to enable more patients to die at home through the provision of practical nursing and care assistant support in the home, as well as timely supports spanning equipment, day and respite care, and emotional support</p> <p>Since late 2006, the range of services available to patients has increased with the engagement of a specialist palliative multidisciplinary team, which is based in a new, The Atlantic Philanthropies-funded, addition to an existing building. Milford Care Centre also pursued accreditation with an additional grant from The Atlantic Philanthropies</p>
Hospice-friendly Hospitals (HfH) Five Year Programme and Baseline Audit	<p>Intended to improve EoL care in acute and continuing care hospitals in Ireland, specifically:</p> <ul style="list-style-type: none"> • to develop the capacity of acute and community hospitals to meet, and, where possible, to exceed the quality of standards for end-of-life care in hospitals; and, • to change the overall culture in hospitals and residential facilities in relation to all aspects of dying, death and bereavement <p>As part of the project, the first ever National Audit of End-of-Life Care in Hospitals and a set of standards for EoL care were launched in May 2010</p>
Marymount Hospice, Cork and International Expert Advisory Group (IEAG)	<p>Intended to improve the quality and quantity of care provided in the region as well as acting as a design model for national and international centres of excellence. Increases number of SIPU beds from 24 to 44</p> <p>The IEAG component was intended to deliver a comprehensive set of standards for design and practice in hospice and palliative care. Its recommendations encompassed the structure and organisation of services, design and planning considerations, education and research, and benchmarking</p>
All-Ireland Institute for Hospice and Palliative Care (the Institute)	<p>Intended to improve the experience and understanding of palliative and EoL care on the island of Ireland. Its key functions are to enhance knowledge-development capacity, to promote learning, to influence policy and to shape practice</p>
Irish Association for Palliative Care (IAPC)	<p>Intended to strengthen the size and scope of this all-island expert body that exists to promote palliative care nationally and internationally through networking, education, publications and representation on national bodies and sought to:</p> <ul style="list-style-type: none"> • increase a 300-strong membership base to 900; • build stronger partnerships in the sector; • grow policy influence and public profile; • develop its membership through education and networking

2. THE ATLANTIC PHILANTHROPIES 'HOSPICE AND PALLIATIVE CARE' PROGRAMME

While many of the projects are still in progress, there have been significant achievements to date. Specific examples are outlined below.

MILFORD CARE CENTRE, LIMERICK (INCLUDING HOSPICE-AT-HOME (H@H))

The H@H project addresses palliative care for all, irrespective of condition, and established specialist multi-disciplinary palliative care in the community. The project has been rolled out on a phased basis and a full multi-disciplinary team was operating across the intended region by the end of 2009. The number of referrals to the service stood at 606 in 2006 and a total of 2,004 by 2009. Over the period 2008-2010, non-cancer referrals rose from 13 per cent to 30 per cent.⁷

A key feature of the H@H project has been collaborative resource development with the Health Service Executive (HSE), which now funds three nurse positions. Additionally, Milford Care Centre has expanded its education programmes to meet the needs of healthcare professionals who come into contact with the H@H programme, enabling both increased awareness and more effective cross service and disciplinary collaboration.⁸ In addition, The Atlantic Philanthropies' capital funding has supported improved day care and ancillary services, and accommodation for the expanded services including the H@H multi-disciplinary team.

An additional grant to pursue accreditation⁹ was issued to Milford Care Centre, but movement by government to a licensing model has diminished the relevance of the project.

Summary: Milford Achievements

- Phased development and implementation of full multidisciplinary team according to NACPC recommendations.
- This team is now operating across the region.
- Three-fold increase in the total number of referrals to the service.
- Substantial increase in number of non-cancer referrals, addressing inequity by diagnosis.
- Extra building capacity to house growing staff.
- Excellent relationship with regional HSE aiding the development of the service.

HOSPICE-FRIENDLY HOSPITALS (HFH) AND BASELINE AUDIT

The HfH programme has focused on four key themes: competence and compassion; planning and coordination; the physical environment; and ethical approaches.

The project has included the first ever National Audit of End-of-Life Care in Hospitals and supported the launch of a set of standards for EoL care in May 2010. The 2008/9 baseline data picture of services established will be followed up in

2011/12. It is expected that the audit will enable comparison over time of hospital performance, measurement of quality and experience, and compliance with standards.

A stakeholder network structure, which was developed with the funding provided has supported the tailoring of education programmes and the funding of support for hospitals to develop end-of-life care.¹⁰ The staff development packages developed are linked directly with proposed standards on EoL care communication.¹¹ An independent review of the physical environment of 15 acute and five community hospitals¹² identified areas for improvement, which are now being addressed with funds from the National Lottery Fund and HSE Estates. Other achievements include the development of an ethical framework for EoL care, launched in 2010, and the establishment of a National Council for the Forum of End-of-life Care.

Challenges remain in relation to greater inclusion of EoL care in hospital and HSE service plans, but informants believe that HfH has succeeded in raising the profile of EoL care in the media¹³, legislative committees¹⁴ and political debate¹⁵. Addressing the physical environment was a successful early focus for the HfH, as was the Final Journeys training programme, which focused upon developing a culture of awareness and communication of EoL care issues among staff. Less clear or tangible, however, are advances in the two other areas to be addressed by HfH – integrated care and patient autonomy.

Summary: HfH Programme Achievements

- First ever National Audit of End-of-Life Care in Hospitals and supported the launch of a set of standards for EoL care in May 2010. It is expected that the audit will enable comparison over time of hospital performance, measurement of quality and experience, and compliance with standards.
- A stakeholder network structure to support tailored education programmes and the funding of support for hospitals to develop end-of-life care.
- Staff development packages developed are linked directly with proposed standards on EoL care communication.
- An ethical framework for EoL care, launched in 2010.
- The establishment of a National Council for the Forum of End-of-life Care. The Forum has subsequently been active in publishing reports on its website.
- Addressing the physical environment in hospitals to meet the requirements of palliative care provision.
- Appointment of end of life care coordinators in hospitals in the same point as the stakeholder network. The coordinators support the implementation of HfH at local level.

Informants pointed out that integrated care and patient autonomy are conceptually complex and require organisational approaches that engage policy and protocols across management, risk assessment and clinical domains.

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They encourage active involvement and buy-in on the part of consultants and their medical teams. Advancing these approaches was reported to be proving difficult.

MARYMOUNT HOSPICE, CORK, AND THE IEAG

The IEAG included recommendations for the structure and organisation of services, design and planning considerations, education and research, and benchmarking (Marymount and The Atlantic Philanthropies, 2006). Informants said that the report had provided Marymount with significant leverage in negotiations with the Department of Health and Children (DoHC) as they prepared to build their new €52 million facility and supported their success in moving away from the standard design advocated by the Department and the embracing of new standards of quality and privacy.

The new Marymount hospice opened in September 2011. It has an additional 20 beds to the 24 on the original Marymount site at St Patrick's Hospital, bringing to 44 the number of hospice beds. The number of beds for elderly respite care remains at 63. Marymount acts as the specialist hub for palliative care provision in the Southern HSE region, which covers all of Cork and Kerry, serving a population of over 650,000. A 15-bed specialist unit is planned for Kerry Hospital, which would bring the region close to meeting NACPC recommendations for SIPU beds per capita, but that project will not be completed before 2013 at the earliest.

The IEAG recommendations have also been partially taken up by another hospice facility currently under construction and are being considered by a third in the planning stage. Both the report and the new Marymount facility were conceived in part as legacy projects, offering a design model and accompanying guidelines for national and international centres of excellence. It is as yet too early to appreciate their full impact. However, there is widespread optimism that the new hospice will offer improved access to care and education.

From across acute and non-acute care settings, informants for this evaluation commented on what they saw as a clear link between the physical environment and the quality of clinical care. This raises questions as to the potential for the IEAG report to also inform EoL care environments beyond the walls of hospice.

The recommended model for hospice design is not without controversy; one nurse manager with a SPC team raised concerns that the model will prove too prescriptive in its insistence that beds be available only in single rooms, a concern confirmed in research findings elsewhere (Lawton, 2003; Payne et al, 2004). It is thought that a significant number of patients will prefer an environment with the opportunity for interaction, and that a design specifying single-room-only layout therefore limits patient choice.

Summary: Marymount Programme Achievements

- Completed construction of state-of-the-art, expert-led capital build.
- This will act as the new specialist hub for palliative care services in Cork and surrounding areas.
- 44 beds represent around three quarters of those needed to meet NACPC recommendations for SIPU beds per capita.
- Along with the IEAG recommendations, Marymount provides a blueprint nationally and internationally for future hospice development.
- Further achievements will follow as the facility embeds itself into service provision, the local community and wider health service structures.

ALL-IRELAND INSTITUTE FOR HOSPICE AND PALLIATIVE CARE (AIIHPC)¹⁶

After extensive consultation across sectors, the AIIHPC held its first meeting in October 2010. The director has been appointed and is due to take up her post in May 2011. Further appointments of heads of education and research and programme managers are scheduled in 2011. Other structures include an expert advisory group to help shape its structures and functions, and two steering groups to examine respectively research and education. The original research, education and policy pillars proposed for the AIIHPC have been replaced by four over-arching programmes (Table 2.2).

TABLE 2.2 AIIHPC PROGRAMME STRUCTURE

Programme	Work Package
Involvement of users, carers, communities in the development and delivery of palliative care education, research, policy and practice	<ol style="list-style-type: none"> 1. Users, carers and communities forum 2. Public engagement with death, dying and loss
Supporting the delivery of innovative high quality palliative care education and research	<ol style="list-style-type: none"> 3. Education network for availability, accessibility and transferability of learning 4. Leadership and capacity building through individual learning and experience 5. A coherent research community 6. Research capacity building
Development of a coherent and collaborative palliative care community	<ol style="list-style-type: none"> 7. All-Ireland palliative care communications hub 8. Collaborative networks between service providers Translation of knowledge and learning for the development of palliative care policy and practice nationally and internationally 9. Policy development and implementation.

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While it is much too early to examine the impact of the AIIHPC in detail, its establishment represents a substantial achievement. No such institute has been created previously anywhere in the world and the relationships required for such a venture did not exist at the outset. One key beneficial outcome already achieved is improved collaboration between previously fragmented areas of palliative care and the wider health sector. The all-Ireland aspect is viewed as a strong feature as well, drawing on expertise and experience from different models on either side of the border, offering opportunities to pursue funding for north-south collaborations and helping to avoid duplication.

IRISH ASSOCIATION FOR PALLIATIVE CARE (IAPC)

The IAPC (founded in 1993) underwent a strategic review and planning process with the help of The Atlantic Philanthropies, establishing a five-year plan (2008-2013) and, with continued support from The Atlantic Philanthropies, initiating a restructuring process. One informant saw the future role of the IAPC as bringing a professional voice to public debates and awareness-raising on matters related to EoL and palliative care. As part of this restructuring, a project manager (now the CEO) was appointed with responsibility for implementation of the five-year strategic plan and is supported by an administrative assistant. The IAPC has also become a limited company.

Progress to date has focused on establishing foundation structures within the organisation, including a board of directors and executive steering committee. Short-term outcomes arising from the review have also been addressed. These include development of a communication strategy; putting in place organisational structures to address governance; and establishing mechanisms for improving networking and continuing professional development, education and research.

In light of the instigation of the AIIHPC, the IAPC is planning to seek areas of mutual working. But a challenge identified by informants was that of finding a means of working alongside the AIIHOC while maintaining an IAPC identity. Some informants saw the IAPC and the AIIHPC as having a reciprocal relationship, each acting as a resource for the other.

All were concerned with the importance of the IAPC having a clearly defined professional voice, separate to that of the AIIHOC, which was viewed as having a focus that included and went beyond SPC. The Quality and Clinical Care Directorate (QCCD)¹⁷ within the HSE seeks to ascertain whether this professional voice can be formally placed in the palliative care programme. Having funded two projects, IPAC and the AIIHPC, with sometimes similar goals and aspirations, it will

be important to determine how they will work collaboratively and without duplication.

ACHIEVEMENTS AND IMPACT OF PROJECTS

The 'End of Life' projects have had significant impact across a range of core activities. Returning to RE-AIM considerations, as can be seen in Table 2.3, each of the projects has resulted in improvements in reach and efficacy, and there is more widespread adoption of palliative and end-of-life care approaches with success in implementation of planned steps. Each project is committed to maintenance of what has begun but several are concerned about the need for additional statutory commitments to on-going funding.

Some cross-project findings of interest are highlighted relates to (1) services, (2) education and research, (3) collaboration, and (4) advocacy and accreditation. Outstanding challenges are also described.

SERVICES

- *Increased access to care in home, hospice and hospital settings*

In broad terms, the combined projects have advanced the development of EoL care through specialist and non-SPC initiatives. The initiatives reflect the three levels of palliative care (Department of Health and Children, 2001) and are positioned across acute, non-acute, continuing and community care settings.

Today, Ireland ranks second in European Association for Palliative Care (EAPC) mapping of palliative care (Centeno et al, 2007)¹⁸. There has been SPC development across the country and multi-disciplinary centres of excellence now span hospice, hospital and community-based programmes. There has also been an overall increase in the number of specialist services, community-based care and concomitant changes in work practices. These changes in work practice include the development of end-of-life care beds in community hospital settings. In addition, in some areas, the specialist palliative care teams are expanded to include multi-disciplinary teams, while H@H represents a newly established community specialist service.¹⁹

Viewing the field of hospice and palliative care as a whole, there has been an increase over time in opportunities to access and utilise palliative care in all care settings. Some of this expansion reflects increases in healthcare expenditure and the roll-out of the 2001 recommendations.²⁰ However, the activities and changes are consistent with the intent of the 'End of Life' programme and the specific contributions of The Atlantic Philanthropies are discernible. For example, the HfH programme has achieved a national profile, with participating

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hospitals from around the country actively engaging in service development to address EoL care. The increased presence of ancillary staff in homecare teams nationwide, bringing multi-disciplinary team input to homecare, also reflects the considerable investment in community-based care and in workforce development.

- *Increased awareness of palliative care and changing culture in end-of-life care*

Key informant interviews identified that The Atlantic Philanthropies' support has helped to change organisational culture in respect of EoL care. One hospital-based senior manager referred to the HfH process as 'making us focus' on EoL care in a public and sustained way.

Throughout this evaluation process, informants referred to increased awareness as the prominent feature of palliative and end-of-life care development in recent years. In particular, the expansion of education programmes in palliative care to address specialist and non-specialist palliative and end-of-life care, the integration of end-of-life care across training programmes for care assistants and the HfH's national profile were cited as evidence of increased EoL care awareness, with informants identifying The Atlantic Philanthropies' support as critical. Similarly, participation in and response to the national audit and standards for end-of-life care (Irish Hospice

Foundation, 2010a, 2010b) was cited by informants as evidence of a growing EoL care movement across the services which benefited from The Atlantic Philanthropies' investment.

- *Increased access to care for patients with non-malignancy*
Looking specifically at the programme's long-term outcomes, access to care increased across all care settings, and this access became increasingly inclusive. For example, both Milford and Marymount provide care on the basis of need rather than diagnosis. Equally, the HfH project's focus on acute and continuing-care hospitals has increased access to EoL care across the country. The H@H project has made an explicit commitment to extending care to those patients with conditions other than cancer, in line with The Atlantic Philanthropies' commitment to extend palliative care to all.²¹ The H@H project has already reported an increase in the proportion of non-malignancy referrals.²² Over the course of this evaluation, informants from EoL care services gave examples of increased development of EoL care pathways in their services to address EoL care needs of all patients.

TABLE 2.3 RE-AIM SUMMARY: CONSIDERATION OF PROGRAMME IMPACT

Programme component		Milford	Hospice Friendly Hospitals	Marymount	AIHPC & IAPC
Project summary		Enable more patients to die at home through the provision of practical nursing and care-assistant support in the home, as well as timely supports spanning equipment, day and respite care, and emotional support	Improve EoL care in acute and continuing care hospitals in Ireland, specifically: Develop the capacity of acute and community hospitals to meet, and, where possible, exceed the quality of standards for end-of-life care in hospitals Change the overall culture in hospitals and residential facilities in relation to all aspects of dying, death and bereavement	Improve the quality and quantity of care provided in the region, as well as acting as a design model for national and international centres of excellence <i>IEAG</i> : deliver a comprehensive set of standards for design and practice in hospice and palliative care	<i>AIHPC</i> : Improve the experience and understanding of palliative and EoL care on the island of Ireland <i>IAPC</i> : Strengthen the size and scope of this all-island expert body that exists to promote palliative care nationally and internationally through networking, education, publications and representation on national bodies

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Element	Associated Guiding RE-AIM Questions				
Reach	<p>Has percent of the target population reached increased?</p> <p>Does programme reach those most in need?</p> <p>Do participants reflect the targeted population?</p>	<p>Three-fold increase in the total number of referrals to the service</p> <p>Care is delivered on a needs basis</p> <p>Substantial increase in number of noncancer referrals, addressing inequity by diagnosis</p>	<p>A network of 25 acute hospitals is participating in the programme</p> <p>A network of community hospitals in the greater Dublin area launched November 2009</p> <p>In terms of patients, HfH is reaching the target population of hospital patients who were not previously receiving palliative care</p>	<p>An additional 20 hospice beds (bringing no. to 44). Maintenance of elderly respite care beds at 63</p> <p>With new facility open, users are intended to be all those in the region served on a needs basis irrespective of diagnosis</p>	<p>All-island networks established and enhanced by the institute, expanding strategic reach of palliative care across Ireland</p> <p>IAPC has established a communication strategy, structures to address governance and mechanisms to improve networking and continuing professional development, education and research</p>
Efficacy	<p>Does programme achieve key targeted outcomes?</p>	<p>A region-wide model of specialist, multidisciplinary homecare delivery</p> <p>Enhanced community understanding of the role of palliative care</p> <p>New building and better facilities have enabled provision of enhanced day care</p> <p>Ongoing research to make the case for cost-effectiveness, quality of life outcomes for end of life and palliative care</p>	<p>Developed comprehensive standards for all hospitals in relation to dying, death and bereavement</p> <p>Developed capacity for acute and community hospitals to introduce and sustain standards Participating hospitals have the following structures in place:</p> <ul style="list-style-type: none"> • Commitment to improve end-of-life care within their regional/hospital service plans • A senior manager (at executive level) responsible for end-of-life care • Plans to implement quality standards and address audit findings • Standing committees with multi-perspective representatives including an independent public interest representative • Establishment of a National Practice Development Programme for End-of-Life Care involving seven out of eight of the academic teaching hospitals in Ireland • Establishment of networks of champions with representatives from HSE, acute and community hospitals, primary care services and voluntary organisations • Higher education institutes to develop end-of-life care component in professional education for nurses <p>Permanent, dedicated end-of-life care coordinator</p> <p>The Quality Standards for End-of-Life Care in Hospitals launched</p> <p>Final Journeys: an interactive staff development programme for all hospital staff. By end of 2010 there were 56 facilitators</p>	<p>Hospice build has been completed, but did not open until September 2010</p> <p>New prototype hospice in a green field site meeting expert recommendations</p> <p>Improved regional access to SPC</p> <p>Improved facilities for patients and families</p> <p>Increased beds, education and training; improved administrative facilities</p> <p>First example of another hospice build in Ireland consulting with Marymount on design</p>	<p>Institute established and functioning effectively on an all-Ireland basis with appropriate management and governance</p> <p>Research and education activity expanded through the issuance of grants addressing crosscutting work packages</p> <p>Meaningful involvement of users, carers and communities</p> <p>Development of a coherent and collaborative palliative care community</p> <p>Translation of knowledge and learning for the development of palliative care policy and practice</p> <p>Support of innovative, high quality palliative care education and research</p> <p>IAPC: A stronger, higher-profile, more impactful all-island body realised</p>

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Element	Associated Guiding RE-AIM Questions				
			<p>Increased awareness of 'a good death' within the HFH hospitals</p> <p>Commitment from HIQA to include the Quality Standards as a 'core care process' in their emerging National Standards for Safer Better Healthcare</p>		
Adoption	<p>Has organisation al use of hospice/ palliative care increased?</p> <p>Do users include underserved populations?</p> <p>Does programme help organisations address their primary mission?</p>	<p>The full multidisciplinary team is now operating across the region</p> <p>Expanded homecare teams are now serving populations previously underserved by homecare</p> <p>Milford Care Centre is now better equipped to address their primary missions of providing palliative and end-of-life care to patients across the Mid-West region, guided by 2001 report best practice</p>	<p>Organisational use of palliative care in acute and community hospitals has expanded considerably</p> <p>Users previously underserved now included by palliative care in hospital settings</p>	<p>Increased capacity of SIPU beds by 82%</p> <p>Specialist, purpose-built facility is now a hub for SPC homecare and other end-of-life care activity in the south</p> <p>Marymount now better equipped to address providing best practice palliative and end-of-life care to patients across the southern region</p>	<p>The institute was not fully operational upon completion of the evaluation but efforts were clearly underway to establish and increase education and research activity</p>
Implementation	<p>Are components delivered as intended?</p>	<p>Phased development and implementation of full multidisciplinary team according to NACPC recommendations</p> <p>This team is now operating across the region</p> <p>Increased numbers of trained workers available</p>	<p>Milestones achieved:</p> <ul style="list-style-type: none"> • Launch of Quality Standards for End-of-Life Care in Hospitals • Engagement of increased numbers of acute hospitals based on the Quality Standards • Completion of the National Audit of End-of-Life Care in Hospitals • Launch of the Ethical Framework for End-of-Life Care – an online resource to support ethical and legal challenges relating to end-of-life care • Consistent media presence; e.g. 14 <i>Irish Times</i> editorials in 30 months have referred to the work of the programme 	<p>Completed construction of state-of-the-art hospice unit</p> <p>Contingent on statutory funding for running costs, Marymount will deliver expanded SIPU services as intended</p>	<p>Institute has experienced challenges in engaging necessary statutory stakeholders but components are now being delivered as intended</p> <p>IAPC has organised itself into a series of workgroups: palliative nursing, pharmacy, social work, children's issues, ethics, education and research and pastoral care</p> <p>An established IAPC online knowledge centre to disseminate knowledge, best practice, research and leading edge thinking in palliative care</p>

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Element	Associated Guiding RE-AIM Questions				
Maintenance	<p>Does the programme produce lasting effects?</p> <p>Can organisations sustain the program over time?</p> <p>Are those persons and settings that show maintenance those most in need?</p>	<p>Excellent relationship with regional HSE aiding further development of the service</p> <p>Milford is now compliant with the NACPC's homecare recommendations, the blueprint for long-term service development in Ireland</p> <p>Stakeholders stressed that the greatest challenge remained securing and increasing statutory funding</p>	<p>The establishment of HfH networks with linkages to the HSE and the Irish Hospice Foundation</p> <p>National Audit of End-of-Life Care in Hospitals with a set of standards for EoL care</p> <p>Ethical framework for EoL care</p> <p>A National Council of the Forum on End-of-Life Care has been established and 10 action areas have been agreed to guide its work over the next 3 years</p> <p>Publication of Design and Dignity Guidelines for Physical Environments of Hospitals Supporting End-of-Life Care with HSE agreement to incorporate these guidelines into new builds and refurbishment projects</p> <p>Engagement with the HSE's Office of the CEO to secure inclusion of a requirement for end-of-life care development plans by hospitals</p>	<p>The IEAG recommendations and the Marymount construction provide a national and international blueprint for future hospice development</p> <p>The facility has embedded itself into service provision, the local community and wider health service structures</p> <p>The infrastructure for long-term maintenance is now in place with the greatest challenge securing and increasing statutory funding</p>	<p>The Institute was not fully operational upon completion of the evaluation so it was not possible to assess potential for sustainability</p> <p>IPAC activities are ongoing and continuing</p>

- *Collaboration with existing services*

An integral part of the H@H and HfH programmes was, and continues to be, engagement with services; this was supported in interviews with informants from across the hospital and community services. For example, in the south-east region a shared-care approach to palliative care has led to intensive collaboration with other clinical teams and with GPs. Other specialist centres such as Marymount have developed close working relationships at management levels with community services with a view to further developing and expanding homecare.

Across the services, informants for this evaluation reported increased collaboration with SPC teams. This was particularly evident in interviews with community/district hospitals, residential care settings and community services.

EDUCATION AND RESEARCH

Since 2005, there has been a significant increase in EoL care focus across different education programmes and also in research. While this cannot be directly attributed to The Atlantic Philanthropies, neither can it be separated from the spread effect of increased awareness that has arisen from projects such as the H@H and the HfH. The HfH project,

for example, provides funding to encourage the uptake of palliative care certificate-level programmes. It is difficult to separate such initiatives from a wider increased demand within healthcare for (i) ongoing EoL care training across different care settings and (ii) embedding EoL care training in all undergraduate, healthcare assistant training and service induction programmes. Nevertheless, advances in education and research-related hospice, palliative and end-of-life care education are evident.

EDUCATION

Education programmes spanning basic to specialist levels of palliative care are now delivered from regional and hospice education centres across the country. The IHF education database currently lists 40 courses addressing bereavement; 121 on palliative care and 10 on spirituality. EoL care is now part of the care assistants and undergraduate nurses' programmes. In addition, the HfH has rolled out a series of packages to support staff development. On-line education and training resources have become available from palliative education centres and the HfH website. Outside of The Atlantic Philanthropies' programme, a substantial tertiary education system for palliative care now exists in Ireland.

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RESEARCH

Building on their support from The Atlantic Philanthropies, the IHF promotes substantive research through the Thérèse Brady Scholarship and The Irish Hospice Foundation/Health Research Board Palliative Care fellowship. The IHF also hosts a research database that cites over 100 research projects.²³ With additional support from The Atlantic Philanthropies, the IAPC and the AIIHPC have also established structures that specifically target research promotion.

CROSS-BORDER COLLABORATION IN RESEARCH

The 'End of Life' programme had an explicitly cross-border approach to two projects, the IAPC and AIIHPC, both of which have an emphasis on improved networking and relationships. Both are at early stages but the AIIHPC is credited by informants for providing impetus for the formation of a palliative care research forum in Northern Ireland.²⁴

Informants reported that at the strategic and capacity-building stages of the AIIHPC project, cross-border collaboration in research was already visible:

'Relationships are being formed and conversations are being had. I see a lot of potential for impact. People are quite hopeful, quite optimistic. There is a feeling of real opportunity here for research to impact on practice.'

Further to these cross-border relationships, Northern Ireland Hospice (NIH) is developing global partnerships, notably with research centres in the United States, as part of their capital redevelopment project in north Belfast. Informants cited the 'End of Life' programme as valuable to this process:

'Our aim is to develop global partnerships, building on the international work we have undertaken at NI Hospice and the benefits of the AIIHPC, to which The Atlantic Philanthropies has made such a significant contribution. The new hospice in Belfast will become a global centre to impact improvements in palliative care – we already have links with Nepal, India and South Africa.'

The new hospice project is designed for an 18-bed purpose-built facility as well as an education and research hub. The NIH has currently raised £1 million of the £9.8 million total estimated cost.

COLLABORATION WITHIN THE FIELD

Key informants referred to gains in collaborative working in the planning and early establishment of the AIIHPC and a shift from a culture where hospices historically competed with one another for voluntary funding. The Atlantic Philanthropies'

support for collaborative working was viewed by several informants as essential to the growing coherent approach to research and education.

ACCREDITATION AND ADVOCACY

• *The 2006 baseline report*

The baseline report (Irish Hospice Foundation, 2006) completed with The Atlantic Philanthropies' support was not strictly a project within the 'End of Life' programme, but this initiative was repeatedly and widely cited as having a substantial impact on government policy and public debate. For example, it was argued that the report illustrated that government was in arrears on its 2001 policy promises and offered support for pressure that in turn brought renewed promises for staff funding (albeit not all fulfilled²⁵) and the plans for outstanding capital projects laid out in the HSE framework document (Health Service Executive, 2009).

Similarly, the highlighting of differential SPC expenditures between regions encouraged further service planning and provision, resulting in the South East and North East regions agreeing on development plans for future provision. However, the Midlands region is still without an agreed plan (Irish Hospice Foundation, 2006).

• *IEAG report and a centre of excellence*

The IEAG report (Marymount and The Atlantic Philanthropies, 2006) is similarly praised by informants for having important effects while representing a relatively small investment.

The expert group also laid out recommendations for service organisation, education and research, design and construction, and benchmarking. These were essentially in line with the NACPC report (2001) and have constituted a valuable additional tool in advocating the universal provision of SPC. Finally, Marymount is expected to provide a model of excellence for other SPC hospices to follow nationally and internationally.

Informants cited the value of both the baseline and IEAG documents in lobbying and advocacy, and in raising the profile of palliative care on the policy agenda. At the same time, some informants stressed that the field should be careful to distinguish between advocacy and research. There were concerns that the reports, while speaking strongly to SPC interests, did not take a wide enough account of non-SPC voices or provide a detailed evidence base for its recommendations.

• *Published audit and set of standards*

A number of developments provide evidence of the growing reach and effectiveness of 'End of Life' projects: the implementation of higher standards in service provision and monitoring in recent Health Information and Quality

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Authority (HIQA) (2009) and IHF (2010b) initiatives; the participation of 75 per cent of acute hospitals in the national audit of EoL care; HSE partnerships focused upon developing best models of care; and increasing funding for SPC, including support of expanded staffing for a region-wide extension of the H@H project.

OUTSTANDING CHALLENGES

Inevitably, the field faces outstanding challenges, some enduring since 2004 and others that have emerged or grown in influence since The Atlantic Philanthropies' entry.

ENDURING INEQUITY BY GEOGRAPHICAL REGION AND DIAGNOSIS

Perhaps the best-established concern in the field was and remains inequity by geographical region and diagnosis. When the 'End of Life' programme began, access to SPC services was primarily determined by where the patient lived, and this largely remains the case today. A second equity issue was treatment for non-cancer patients. The proportion of patients seen with a non-cancer diagnosis was five per cent in 2004 against a target of 25 per cent (Irish Hospice Foundation, 2010a; O'Leary and Tiernan, 2008), although it is reported that there has been additional progress on this issue in more recent years. Similar inequities in provision by geographical region and diagnosis are prevalent in palliative care for children (Department of Health and Children, 2005).

The 'End of Life' programme has largely supported well-established SPC-led providers and there are arguments that this has not been as helpful as hoped in mitigating inequities and fostering service development in new areas. Commitments made in the HSE 2009-2013 Development Framework to effectively build a comprehensive nationwide specialist service are largely for capital development (Health Service Executive, 2009). For services to be extended as envisioned under the 'End of Life' programme, informants argued budget allocations for staffing must also be found and ring-fenced.

'VALUE-FOR-MONEY' (VFM) MEASUREMENT

A key recurrent issue in interviews, among statutory sources in particular, was 'value for money' (VfM), with informants seeking greater evidence of the performance and cost-effectiveness of SPC services.

At the DoHC and the HSE, there was considerable desire for the field to move away from SPC and towards greater integration with generalist EoL care. Local statutory opposition, often pre-dating the HSE, was also reported. For example, in the West region a local hospice movement has promised to pay for capital expenditure that is fully compliant with the National Advisory Committee on Palliative Care (NACPC) but the

regional HSE board will not commit to funding staff salaries, and so the facilities have not been built. This is a continuation of the prior regional health board's stance, reflecting concerns that SPC in particular does not offer value for money.

Findings from the evaluation suggest that palliative care has not sufficiently addressed issues of value for money and performance measurement (a concern by no means unique to Ireland), and that it must now do so.

Palliative care in the wider context of a strategy for end-of-life care: generalist and specialist palliative care
Throughout the project, informants raised the issue of tensions between generalist and SPC, and emphasised the benefits of improving integration between the two. They also recognised the value and scope of generalist palliative care in hospitals and the community.

The H@H project was reported to have advanced that integration by actively engaging in an SPC/generalist approach in which homecare teams, GPs and PHNs have access to EoL care education and contact with SPC team members. The HfH is by definition engaged in developing generalist-oriented EoL care.

HSE and DoHC informants repeatedly referred to the cost of SPC and of their desire for a more 'generalist' approach to EoL care that would reach a greater proportion of patients nearing end-of-life stages of advanced illness. Interest was expressed in seeing the development of a dual service that has both a generalist and a SPC element. Similar debates and developments are taking place internationally.²⁶ There are also calls for establishing an evidence base around service provision (Shipman et al, 2008).

In further pursuit of such integration, there were informants who wished to encourage a proactive engagement by the IAPC, with healthcare professionals providing 'generalist' EoL care, arguing that this would have the effect of increasing membership and the voice of the IAPC, and would create a forum for conversations between generalist and specialists by:

- articulating the core differences between generalist and specialist care and support needs;
- promoting cross fertilisation of knowledge and skills in relation to EoL care generally; and,
- establishing a strong healthcare professional voice on EoL and PC delivery.

The future position and role of SPC in a changing landscape was also recommended as needing to be explored, in particular the role of SPC in level one and level two palliative care.

2. THE ATLANTIC PHILANTHROPIES 'HOSPICE AND PALLIATIVE CARE' PROGRAMME

When invited to comment on next steps as The Atlantic Philanthropies exits, some HSE informants spoke of the need for an 'honest broker' to bring together EoL and SPC stakeholders in order to explore how EoL care might be developed within the current economic constraints and means of realising the HSE framework document (Health Service Executive, 2009) in ways that acknowledge all concerns and vested interests.

SCOPE TO REVIEW THE 2001 NACPC REPORT

The NACPC report was described as the dominant document on palliative care for a decade and represents official government policy. Yet there is disagreement in the field, with many in SPC referring to it only half-jokingly as 'the bible' while others in the public health community expressing concern that it is a symbol of the imperfect integration of generalist and specialist care.

What is notable is that on both sides of the generalist/specialist divide there is support for a review of the NACPC report (2001). Many from a generalist background would prefer to see a concerted move towards a national policy that integrates and embraces the wider EoL care agenda, including the development of intermediate care in those regions not well served by SPC.

'The NACPC report was no longer "fit for purpose". It has been superseded by healthcare reform and increasing attention on wider EoL care.'

Well-established, SPC-focused providers are also keen for a strategic review.

'So much has changed since 2001. We need to quantify what has happened and recognise the development of care, which makes the NACPC report (2001) out of date. We should perform a structural review, reflecting everything that has changed, and the institute [AIHPC] is the place to do this.'

In addition to the development of care, there have been structural changes over the last decade that need to be taken account of; most notably, the establishment of the HSE between 2004 and 2005. More recently, within the HSE, the Quality and Clinical Care Directorate (QCCD) was created to 'ensure that patients with life-limiting conditions and families can easily access a level of palliative care service that is appropriate to their needs regardless of care setting or diagnosis.'²⁷

And any review would have the 2001 foundation on which to build:

'No-one at this point really disputes that some review of the 2001 report is needed, particularly the fiscal elements. I would suggest, however, that in any such review, we do not "throw the baby out with the bathwater" and start again. The original report still has relevant work which would contribute going forward.'

Of those working on the ground, managers and practitioners supportive of SPC also reported that guidelines such as staff levels dictated by bed numbers rather than patient dependency were unhelpfully prescriptive.

Despite the broad support for a review, significant blocks remain. Some oppose a review until the NACPC report (2001) has been realised in full. The differences of opinion prompted by the NACPC report (2001) and its implementation were notable in the National Council for Specialist Palliative Care, which last met in 2007.²⁸

One informant, familiar with the field but without a direct stake in any area of palliative care, observed that, for all its controversies, adherence to the NACPC report (2001) has served palliative care very well:

'I know there are still gaps but palliative care is so well established now, has grown so quickly. Why? Because they are organised. There are more consultants in palliative care than in oncology, which is crazy but it shows how well they've done. The 2001 report has served them very well.'

POORLY INTEGRATED SPC KNOWLEDGE AND STRUCTURES AT PRIMARY CARE LEVEL

The 'End of Life' programme has encompassed care in hospice, hospital and home settings. The major clinical environment still to receive sustained, targeted investment and education is primary care.

While these gaps are being addressed to an extent by education programmes and SPC input in primary care, there is clearly an opportunity to target investment in primary care if the appetite for a new programme exists. The H@H project has already targeted community care through expansion of education programmes to meet the needs of PHNs and GPs.²⁹

THE ECONOMIC CRISIS AND FUTURE FINANCE

The Atlantic Philanthropies' entry into hospice and palliative care coincided with the peak of the HSE's palliative care investment. Since the severe economic downturn in 2007, a series of budget cuts has had an inevitable impact on current services and future plans. Budgetary cuts in healthcare have and will include the closure of hospital and respite care beds,

2. THE ATLANTIC PHILANTHROPIES 'HOSPICE AND PALLIATIVE CARE' PROGRAMME

and the reduction of homecare support. Any moratorium on recruitment is likely to interrupt the reach of existing funded programmes.

The more recently published HSE framework document (Health Service Executive, 2009) was intended to map out service development for continuing EoL and PC development but with the economic downturn, the framework was referred to by HSE informants as an aspiration the implementation of which was improbable. This leaves a substantial shortfall in both running costs and capital expenditure. The economic downturn has also impacted badly on local fundraising efforts, which in turn affects disproportionately those areas without established services, local HSE support and The Atlantic Philanthropies' funds.

SUMMARY

The Atlantic Philanthropies entered the field of hospice and palliative care in Ireland in 2004, issuing 14 grants to a total approximate value of €25 million. This initiative was titled the 'End of Life' programme and can be broken down into five grantee programmes: the Milford Care Centre (MCC); the Hospice friendly Hospitals programme (HfH), incorporating the new audit and end-of-life standards; Marymount Hospice and the International Expert Advisory Group (IEAG); the All-Ireland Institute for Hospice and Palliative Care (AIHPC); and the Irish Association for Palliative Care (IAPC). The roll-out of these programmes is still on-going, making it early to assess their full impact but considerable achievements are already visible across the core activities of service delivery, education and research, and accreditation and advocacy. Significant challenges remain, some of which predate The Atlantic Philanthropies' entry into the field and some which have emerged since 2004.

⁷ Personal communication with Milford Care Centre (MCC).

⁸ MCC's Education Centre provided 60 courses to 800 participants in 2009.

⁹ The Irish Health Services Accreditation Board (IHSAB) proposed to extend the Acute Care Accreditation Scheme (ACAS) for hospitals to palliative care services. However, the IHSAB was later subsumed by the Health Information Quality Authority (HIQA) and the accreditation process abandoned in favour of a proposed licensing model.

¹⁰ The importance of these factors in supporting end-of-life care development was reiterated during our interviews with service-based informants for this evaluation.

¹¹ See http://www.hiqa.ie/media/pdfs/Safer_better_care_draft_standards_A4.pdf

¹² This was undertaken by Tribal Consulting. See http://www.hospicefriendlyhospitals.net/media/k2/attachments/Tribal_Report_Design_and_Dignity___Baseline_Review_Nov_07.pdf

¹³ Editorials in *The Irish Times*

¹⁴ Law Reform Commission

¹⁵ See http://www.hospice-foundation.ie/up_documents/Oireachtas_presentation_May_08.pdf
<http://www.kildarestreet.com/sendebates/?id=2010-09-29.212.0>

¹⁶ <http://aiihpc.org/>

¹⁷ <http://www.hse.ie/eng/about/Who/ONMSD/NMPDU/DNE/amucork.pdf>

¹⁸ Ireland was also ranked fourth in the world by the Economist Intelligence Unit on behalf of the Lien Foundation in 2010. See http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

¹⁹ See figure 1.2 for a national picture of expansion of patient numbers over time. Appendix 3, table 9 details changes in services provision and staffing at regional level for two regions with contrasting resources and prior existing services.

²⁰ In 2007, the OECD reported Ireland spending per capita is \$3,424(US) compared with an OECD average of \$2,964. Health spending per capita in Ireland grew, in real terms, by an average of 6.4 per cent per year between 2000 and 2007. This was the third-fastest growth rate of all OECD countries during this period (after Korea and Greece), and significantly higher than the OECD average of 3.7 per cent per year. See <http://www.oecd.org/dataoecd/45/53/43216301.pdf>

²¹ <http://www.atlanticphilanthropies.org/news/palliative-care-all-not-just-cancer-patients-hospice-urges>

²² Non cancer referrals over a three month period in the years 2008-2010 accounted for 13 per cent; 38 per cent and 30 per cent respectively.

²³ This database is likely to underestimate end-of-life care research activity that is generated from outside the field, for example that arising from gerontological policy, educational and clinical programmes.

²⁴ For the strategy framework for palliative care as whole in Northern Ireland, see Department of Health Social Services and Public Safety (NI) (2010).

²⁵ See http://www.hospice-foundation.ie/up_documents/Oireachtas_presentation_May_08.pdf

²⁶ See <http://www.goldstandardsframework.nhs.uk/>

²⁷ See <http://hse.ie/eng/about/Who/clinical/natclinprogrammes/natclinprogmeeting28thjan.pdf>

²⁸ The National Council for Specialist Palliative Care was instigated at the request of the then Minister for Health to advise on palliative care matters and since 2007 has not been required to meet together to fulfil this role. It is not clear what future direction the National Council might take.

²⁹ See <http://www.milfordcarecentre.ie/education/index.htm>

3. CASE STUDY: A COMPARISON OF TWO REGIONS

3. CASE STUDY: A COMPARISON OF TWO REGIONS

Key research questions

- During the 'End of Life' programme, what has been the comparative development of services in a region well resourced with established pre-existing hospice and palliative care services, and a region with limited resources and pre-existing services?
- How has end-of-life (EoL) care evolved across the two regions with specific reference to both specialist and non-specialist or generalist care?
- What are the implications for policy and service development, and workforce planning?
- What has been the impact on policy?

Data sources

Forty-two key informant semi-structured interviews were analysed and compared the development of services in these two regions in terms of services, workforce and policy. A total of 51 informants were drawn from healthcare professionals, managers and administrators across a range of settings (homecare, hospice and home) and backgrounds, namely specialist palliative care (SPC) and generalist settings.

A documentary analysis of annual health board, and regional and corporate Health Service Executive (HSE) reports from the selected regions, and reports from hospice and palliative care services was undertaken. In addition, regional needs analyses and strategies following the publication of the NACPC report (2001) were reviewed. International research reports on EoL care and strategies were also reviewed. Demographics and broader research data on the regions' profiles were drawn from CSO and local government reports. Parliamentary questions and responses in relation to service development in the regions were traced and examined. Health Information and Quality Authority (HIQA) inspection reports on residential care settings were also reviewed, with specific reference to standard 16 of the National Quality Standards for Residential Care Settings for Older People in Ireland (Health Information and Quality Authority, 2009).

INTRODUCTION

Delivery of SPC provision in Ireland has been and continues to be marked by geographical inequity. This case study examined two regions, the South East and Mid-West that reflect this inequity.³⁰ The study was designed to examine how palliative and EoL care is currently provided, its drivers and enablers, and how it fits within current policy, HSE agendas and changed economic realities, by answering two key questions:

1. How has palliative and end-of-life care developed in both regions since the NACPC report (2001) (Department of Health and Children, 2001)?
2. What lessons for palliative care development and delivery can be drawn from experiences in both regions?

DEFINITIONS

An absence of standardised definitions for hospice and palliative care, including the designation of 'hospice' beds in general hospitals, was previously highlighted in the 2006 base line report and was reflected in service planning and annual reports.³¹ We were therefore guided by how individual informants and reports understood the terms 'hospice', 'palliative' and 'EoL care' rather than imposing any pre-determined definitions.

METHOD

The information included here was collected from: a review of policy documents, annual reports, and service plans from the South Eastern Health Board (SEHB) and the Mid-Western Health Board (MWHB)³², the HSE and the Department of Health and Children (DoHC);

a review of inspection reports on residential care settings for older persons, including community and district hospitals and with specific reference to their listed facilities, services and standard 16 of the National Quality Standards for Residential Care Settings for Older People in Ireland (Health Information and Quality Authority, 2009)³³;

- interviews with providers of EoL and palliative care at clinical and managerial levels;
- interviews with staff at acute, district and community hospitals and residential units providing care of older persons; and,
- interviews with key informants at national and regional level in respect of policy, and voluntary and statutory initiatives.

TABLE 3.1 BELOW LISTS THE SERVICES REPRESENTED BY INFORMANTS.³⁴

Service	Number of Informants	Comment
Specialist Palliative Care	13	Includes consultants, clinical nurse specialists and clinical nurse managers
Acute General Hospital	5	Includes administrators, nursing management and practice development
Non-acute General Hospitals	8	Includes management and clinical staff from district and community hospitals
Residential Care Facilities	12	Includes long-stay care settings
Regional Management	2	Includes those responsible for SPC
Primary Care	16	Includes senior public health nurses (PHNs) and general practitioners (GPs).

3. CASE STUDY: A COMPARISON OF TWO REGIONS

DATA ANALYSIS

A content analysis was undertaken of:

- interview and review notes, using the broad interview questions or headings as a guide;
- annual reports and service plans on palliative, EoL and hospice care;
- HIQA inspection reports on palliative and EoL facilities and services; and,
- status of implementation of standard 16 of the National Quality Standards for Residential Care Settings for Older People in Ireland (Health Information and Quality Authority, 2009).

FINDINGS

REGIONAL PROFILES AND EXISTING PALLIATIVE CARE SERVICES

The age distribution and other demographic characteristics are similar for both regions. The Mid-West total population is smaller, at 361,02, compared to 460,838 in the South East (see Appendix 3).

- *Palliative and hospice care provision at primary care level*

At primary care level, both regions are served by a 24-hour GP service; in addition to their general practice care, GPs provide medical care to patients in private and public residential care settings. A summary of residential care is provided in Table 3.2.

TABLE 3.2 SUMMARY OF RESIDENTIAL CARE

		Mid-West	South-East
Services for Older People	Registered private nursing homes (beds)	44 (2,004)	58 (2,315)
	Total public settings (beds)	9 (660)	7 (1,102)
	Of which number of long-stay beds	447	826 ³⁵
	Number of palliative care beds	21	13

Residential care facilities vary in size, ranging from ten to over 100 beds. The services they provide vary from high to low dependency care and some residential care settings offer some level of palliative care.³⁶ More formally, each region has dedicated intermediate level-two beds³⁷ that are linked with SPC through to EoL care support (see Table 3.3).

TABLE 3.3 INTERMEDIATE LEVEL-TWO BEDS

Region/County	Base	Number of Beds
Carlow	Carlow	2
Kilkenny	Castlecomer	2
South Tipperary	Carron Reddy	1
	Clogheen	2
	Carrick on Suir	1
Waterford	Dungarvan	2
Wexford	Barntown	2
	Gorey	2
Clare	Kilrush	2
	Ennis	5
	Ennistymon	2
Limerick	Raheen	2
	Milford	2
	Newcastlewest	5
North Tipperary	Nenagh	2
	Thurles	2
	Roscrea	2

Both regions are also served by homecare teams with consultant support.

The South East region remains without an in-patient hospice care centre and has 13 intermediate palliative care beds across community/district hospitals. In theory at least, any palliative care patient with complex symptom management needs has access to consultant led multi-disciplinary support on an as-needed basis.

The Mid-West region is supported by the Milford Care Centre (MCC), which consists of a 30-bed specialist in-patient unit (SIP); community-based palliative care services and palliative day care. In addition, the centre has a nursing home. There are 24 intermediate, level-two palliative care beds across the region. MCC has a large education centre and this has enabled the service to provide ongoing education support for primary care staff including GPs, public health nurses (PHNs) and residential care settings which has dovetailed and been tailored to service developments. The MCC's Hospice at Home (H@H) project, phased in since 2006, provides a comprehensive specialist multi-disciplinary palliative care service across the region. At the time of writing, an evaluation of the impact of H@H is underway and a final report is due towards the end of 2011.

- *Acute care*

Each region has a large regional hospital and three small

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general hospitals but reconfiguration will mean new roles and loss of some existing acute services.

In summary, both regions have a SPC infrastructure across acute, continuing and community care services. However, there are considerable regional differences in the scope and penetration of palliative care services. The number of designated level-two intermediate beds and access to in-patient specialist care both favour patients in the Mid-West.

REGIONAL STRATEGY DEVELOPMENT

Both regions undertook a regional needs analysis in 2003, which informed five-year strategic plans in 2004 (Mid-West) and 2005 (South East) to address palliative care service development, benchmarked against the NACPC report (2001) (HSE South, 2005; Milford Care Centre, 2006). See Table 3.4.

TABLE 3.4 NEEDS ANALYSIS FINDINGS BY REGION

Service	South East Region	Mid-Western Region
Specialist Inpatient Unit	None	20-bedded unit with an identified need for additional 10 beds
Homecare Services	Regional coverage by nurse led teams but limited capacity beyond office hours No MDT* support	Regional cover with consultant support No MDT input
Intermediate bed cover	11 beds No palliative medicine consultant input	23 beds No palliative medicine consultant input
Acute General Hospital	Two of the four hospitals without a palliative care CNS** One palliative medicine consultant only with need for two more	All 4 hospitals with CNS cover All have palliative medicine consultant cover but need to expand from two to four consultants
Day Services	None	Available but running at 50 per cent capacity

*MDT: multi-disciplinary team; ** CNS: clinical nurse specialist

Sources: Mid-Western Health Board, 2004; South East Health Board, 2005

The capital and revenue investments required were respectively €18.921 million and €11.246 million (SEHB), and €12.344 million and €5.58 million (MWHB). Among the short-term priorities (commencing 2006) listed by the SEHB, that have yet to be implemented or addressed, are the development of three day-care units; establishment of a 34-bed specialist in-patient unit³⁸ and establishment of ancillary support across the SPC services³⁹; development of an end-of-life (EoL) care pathway for acute general hospitals and provision of 24/7 nursing and non-nursing services in

the homecare settings. In contrast, the short-term priorities listed by the MWHB that focused on development of physical structures and service expansion have already been met, albeit outside of the original timeframe.

SERVICE DEVELOPMENT

The baseline study and follow-up review on service capacity (Irish Hospice Foundation, 2006 and 2007) found both increased services and staffing and continuing differences between the regions (see Appendix 3). In the Mid-West, specialist in-patient beds were just four short of the NACPC recommendations; community-based teams were expanded and community-based care attendants introduced. MCC, in agreement with the HSE, focused on further developing home and day care rather than further increasing in-patient beds.

In marked contrast, the South East remains without an in-patient unit, does not have recommended medical staffing levels and has made little progress in expanding teams. Per capita expenditures have increased from €2.75 in 2004 to €7.90 in 2007 but this is well below Mid-West levels of €24.49 in 2004 and €29.90 in 2007. The HSE palliative care services framework report (Health Service Executive, 2009) cites addressing homecare, capital development and acute hospital deficits in the South East region as among the key national priorities for palliative care provision. For the South East then, capital and basic service development remain critical needs while, in the Mid-West region, the focus is on enhanced care delivery and multi-disciplinary team input.

RESPONDING TO INCREASED FUNDING SUPPORT

Despite these differences, the South East presents some interesting developments significantly supported in 2006 and 2007 when additional funds were made available to better address NACPC Report recommendations.⁴⁰ As can be seen more graphically in the South East Region timeline (see Appendix 4), this increased investment resulted in increased SPC staff and expanded services and service agreements on consultant-led support of specialist homecare teams, which have become the hub for SPC in the absence of a specialist in-patient (SIP) unit. The Carlow Kilkenny homecare team was one of the first of its kind in the country and the first in rural Ireland; now homecare teams, acute general hospitals and GPs in this region have ready and easy access to palliative medicine consultants for advice in a shared model approach to care, with the voluntary sector funding 60 per cent of homecare team costs.

A timeline for the Mid-West regions (see Appendix 4) illustrates expansion that developed from the MCC as the regional hub for palliative care. Here, funding arising from the National Cancer Strategy (Department of Health, 1996),

3. CASE STUDY: A COMPARISON OF TWO REGIONS

pre-existing palliative care nurses and a social worker, and links with University of Limerick supported service planning and development. As the palliative care hub for the region, the MCC responded quickly (post the NCAPC 2001 report) to directives from the Department of Health and Children (DoHC).⁴¹

Informants repeatedly emphasised that with MCC as the hub for palliative care across the region, service development and workforce planning has occurred on a planned and phased basis, allowing cohesion across services and county boundaries. Examples cited were the phased introduction of the multi-disciplinary team into the community through the H@H project and the launch of a communications strategy. Similarly, the education centre was reported to have developed a raft of programmes aimed at different disciplines, services and communities, as regional developments have been rolled out. More recently, links have been forged with international centres, consolidating the position of MCC as a national centre of expertise and as a leader in the field.

VIEWS OF KEY INFORMANTS FROM ACROSS DIFFERENT SERVICES

Interviews with informants from across different care settings highlighted emerging issues arising from developments over the past decade and five years, specifically. Informants were asked for their view on how the service had developed, the strengths and weaknesses of developments to date, gaps, new issues and how these matters might be addressed. Themes from interviews with clinical informants are listed in the Table 3.5 below.

- *Increased awareness*

Increased awareness among staff was cited as the most significant development in palliative and EoL care across all acute, non-acute, continuing and primary care settings. This was largely attributed to education, though a cascading effect of education and initiatives such as the HfH and EoL care pathways was also noted. A number of structural challenges remain across services including the environment of care, limited number of single rooms and insufficient intermediate level-two beds. Local problem solving initiatives were described, including the assigning of an area in the acute hospital as a designated EoL care ward and partnering communities to refurbish wards in continuing and non-acute care settings. A number of care and process problems were also highlighted, such as the need for knowledge development in the area of advanced chronic illness and complex co-morbidity in older persons, questions about the skill and competency base of inexperienced nurses, and multi-disciplinary team decision-making.

- *Workforce planning*

In residential care settings, staff uptake of short education programmes covering EoL care was reported to be in excess of 70 per cent in both regions. However, informants also referred to difficulties in reaching medical teams and poor attendance by doctors at information sessions. Across different care of older persons and acute care settings, informants believed EoL care training should be mandatory with communications training seen as a priority.

In the Mid-West, informants referred to MCC as the hub for all training. In the South East, the centre for education in Waterford which provides continuing education for healthcare

TABLE 3.5 THEMES FROM CASE STUDY INTERVIEWS

Theme	Description
1. Increased awareness	Addressing care needs Preceding the Hospice Friendly Hospitals project (HfH), but HfH bringing momentum Environment as major issue and impacting directly on practice Response to structural and clinical deficiencies including dedicated wards in acute care/beds in continuing care/district/community hospitals
2. Workforce planning	Current interest and uptake Gaps in continuing education and undergraduate education Challenges relating to medical education and uptake Clinical skills and competencies
3. Significance of consultant-led homecare positioning palliative care in the community	Shared care approach Performance measurement challenges
4. End-of-life/palliative care for older persons	Skills and role of district/community hospitals Response to increased awareness: adapted Liverpool Care Pathway (LCP) Engaging with delineating EoL care from overarching care philosophy which is palliative but by another name Small number of deaths/year

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staff was the main base for education. Training programmes were organised with the support of Marymount Hospice and local SPC homecare teams. The homecare team informants referred to the importance of this in developing links with different care settings. While MCC education programmes also involve members of the SPC team, in the South East the significance of SPC input was greater given the absence of a hospice 'hub' and therefore the more limited visibility of hospice and palliative care in the region. A feature of the district hospital and residential care interviews in the South East was the value attributed to close links with and consequent continuing education offered by individual SPC team members.

In residential care settings and district/community hospitals, one or more members of the nursing staff had or were currently undertaking specialist education programme in palliative care. However, the number of deaths per year in the residential care facilities visited for the case study was declining year on year as beds were being taken out of the system.⁴² The ongoing decline in number of deaths in public facilities is linked with the growth in privately run nursing homes as a consequence of financial incentives for developers and HIQA standards for residential care.⁴³ The private nursing homes do not compare with the size of the older public facilities that often had in excess of 100-150 beds. The number of residential beds within the private sector has risen from 10,500 (1995) to 15,000 (2000)⁴⁴ to 20,500 (2010).⁴⁵

- *Significance of consultant-led homecare: positioning palliative care in the community*

Informants from across different care settings referred to the importance of supporting the widely-held assumption that most people prefer to die at home. In the South East, specialist and non-SPC informants referred to the significance of consultants leading the homecare teams and working closely with GPs and other medical teams. However, while this shared model approach to care necessarily requires that patients with very complex care needs be managed by GPs, informants also pointed out that this also places a significant burden on the homecare team to provide support on a day-to-day basis. One team had begun logging support telephone calls and were recording 650 calls per month, with many lasting in excess of 30 minutes.

There were common concerns within SPC about performance measurement and these were heightened in the South East because of concerns that activities were not being picked up by existing measures and methods. Informants acknowledged that a minimum data set to record homecare activity was being rolled out but pointed out that teams are not computerised, the intensity of support by GPs and other providers is not being captured and, with consultants based in the regional hospital, their shared care work with GPs was also not being recorded through the normal methods of measuring hospital activity.

In contrast, with the MCC as the hub for palliative care recording of all activity including Hospice at Home activities, informants in the Mid-West had fewer concerns. However, there were concerns at the mismatch between activity data reported to regional administrators and that subsequently published in national reports (see also chapters 4 and 5.) The shared model in the South East appeared to have poor visibility in terms of performance measurement compared to data on palliative care in the Mid-West. The obvious impact of limited visibility of SPC activities in the South East is the teams' vulnerability to accusations of under-performance. However, a further impact would appear to be the lost opportunities for clinicians, administrators and policymakers in evaluating the shared care approach and potential for informing the wider hospice and palliative care community.

- *EoL/Palliative Care for older persons*

Informants from both regions and across care settings referred to a continuing gap in skills and knowledge in the symptom management of patients in end stages of chronic diseases, notably cardiac failure and chronic obstructive pulmonary disease (COPD). For one nursing manager in a 145-bedded facility, EoL care in non-malignancy was the main challenge, particularly in terms of managing pain. In acute care settings, informants referred to difficulties in anticipating death and insufficient intermediate level-two palliative care beds.

In settings with intermediate beds, informants referred to patients being admitted with complex care needs but who frequently recovered enough to be discharged home, if only for a short period before being readmitted. In meetings with nursing staff from two district hospitals, questions were raised about the role and function of intermediate beds when the boundaries between convalescence and EoL care were increasingly blurred by the nature of advanced illness trajectories and pressures on acute general hospitals to discharge patients who nevertheless were too ill to be cared for at home. In the South East, informants from acute hospitals referred to the importance of the intermediate beds in the absence of a regional hospice. However, it was not clear if the value of the designated intermediate care beds lay in their role as enabling early discharge of patients with advanced chronic illness or as providing additional palliative care through the support of SPC.

All informants from district hospitals in both regions referred to the importance of their relationship with local communities and their desire to be centres for EoL care for local residents. In the South East, examples were given by informants in district hospital and residential care settings of working actively with local communities to develop EoL care through improving the physical environment. Nurses were also proactive in developing and rolling out end-of-life care pathways without engagement of regional SPC teams. In the Mid-West, some informants referred to working with the MCC to develop EoL

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care; none of those interviewed had independently developed EoL pathways. However, informants from across both regions raised concerns regarding complex symptom management in older and frail patients.

END-OF-LIFE CARE DELIVERY IN THE TWO REGIONS

Since the mid 2000s there has been considerable planned expansion of SPC across both regions. Both regions received government investment and, in the case of the Mid-West, partnership with The Atlantic Philanthropies enabled additional expansion and further positioned MCC as a hub for palliative care. However, the geographical inequities in 2001 were not effectively or sufficiently addressed during the following decade's unprecedented government spending on healthcare.

Palliative care in the Mid-West developed in line with stated policy across the three levels of palliative care. As a consequence, informants supported the view that the service was in a good position to measure performance and impact. Services developed in the South East in the absence of an in-patient hub are inconsistent with stated policies but SPC has extended its reach into acute care and the community. However, non-SPC informants in both regions highlighted difficulties in providing palliative care to patients with advanced chronic illnesses in the acute care settings. SPC informants referred to continuing challenges in increasing referrals at an earlier point in the illness trajectory.

INTERMEDIATE LEVEL-TWO BEDS

From a review of the interviews and documentation, it appears that an unintended consequence of community activism, service expansion and changing approaches to acute care has been growing confusion regarding how palliative care beds are understood or defined. Refurbished single rooms in non-acute hospitals and residential care facilities are often referred to as palliative care beds. Designated intermediate level-two beds are also increasingly used by patients who were discharged from acute care services but who may subsequently recover and be discharged. In other words, these beds are sometimes providing convalescence care rather than EoL care. While this reflects the vagaries of advanced chronic illness trajectories, questions arise as to how these designated beds are monitored or evaluated. It is possible that there are particular skills being developed in relation to care of people in the final stages of advanced chronic illness. It is also possible that there is an increasing understanding of the specialist-generalist interface because of the SPC support in care provision for patients in designated level-two beds. However, the lack of any collaborative inquiry between district hospital and SPC staff into the use of these beds was a repeated concern for informants.

STANDARD FOR END-OF-LIFE CARE

Level one palliative care has also developed across both regions but with notable gaps and new challenges. Informants from residential care settings referred to gaps in existing knowledge on EoL care while residents are living longer but with complex care needs. They raised questions about the need for knowledge to be developed from within their service to address the contextual factors influencing care needs. A review of HIQA inspection reports on residential care settings pointed to a number of facilities claiming palliative care beds, but there was limited comment from the inspectors within the reports as to how the standard for EoL care is being met. This raises the risk of a false sense of security in assuming that a standard on EoL care equates with the provision of quality care delivery. This also raises questions for future EoL care standard development. In a joint statement on EoL care in acute and long-stay care settings, the National Council on Ageing and Older Persons (NCAOP)⁴⁶ and the IHF recommended 'that the same end-of-life care standard be applied in all healthcare facilities, including acute hospitals, and furthermore that the same criteria by which implementation of the standard is judged be adopted' (National Council on Ageing and Older People and Hospice Friendly Hospitals Programme, 2008:12).

Private nursing homes have an increasing presence in the care of older persons in Ireland; there are over 4,300 beds across the South East and Mid-West regions.⁴⁷ From the HIQA inspection reports, the majority of these homes are purpose built with single and double en suite rooms. The staff skill mix in the nursing homes was reported by informants to point to the need for a focus on care assistant training. This was supported by concerns among acute hospital manager informants in both regions that patients with complex challenges sometimes exceed the capacity in private nursing homes to provide EoL care to residents.

From the interviews, it appeared there has been considerable effort and investment in providing education and training to staff, designed to improve EoL care. However, the on-going removal of beds from the system was reported to mean that the number of deaths per year in each facility is declining, raising questions about how staff can maintain skills and competencies in EoL care and may encourage greater reliance on the specialist palliative homecare teams.

SUMMARY

Both regions (South East and Mid-West) have experienced SPC expansion and the penetration of EoL care into acute, non-acute, residential and community care services. However, the nature of development differed between regions and reflected

3. CASE STUDY: A COMPARISON OF TWO REGIONS

both historic inequities in services and the absence of a SPC hub in the South East to drive development.

Yet the case study regions had common concerns regarding the delivery of care, skills needed and measurement of different levels of palliative and EoL care. Gaps also remain in the interface between acute care and intermediate level-two beds; SPC and EoL care in non-acute and residential care service; the capacity of SPC to adequately support increasingly complex care needs of patients who are discharged home to the community; and challenges in measuring palliative care across all levels and settings.

³⁰ Geographically, we defined these according to the boundaries of health board regions that comprised service structures prior to the establishment of the Health Service Executive (HSE) in 2005.

³¹ For example, in the HSE service plan for 2011 reference is made to the provision of a Palliative Care Unit extension at St. Ita's Newcastle West, Limerick, which is a long-term residential care facility. This unit is not comparable to that MCC.

³² Prior to 2005, the publicly funded health services for South East and Mid-West regions were provided by the South East Health Board (SEHB) and the Mid-Western Health Board.

³³ Standard 16 specifically addresses end-of-life (EoL) care, with 13 criteria to be met.

³⁴ The number of interviews (29) is less than that of informants because some from the same service chose to meet the research team in pairs or small groups.

³⁵ This number is based on 2008 data from the HSE. See [http://www.hse.ie/eng/staff/FactFile/County Information/](http://www.hse.ie/eng/staff/FactFile/County%20Information/) The number of public long-stay beds is falling across the service as a combined result of funding cuts and HIQA requirements for the environment of care.

³⁶ SPC teams provide support to designated intermediate palliative care beds. Informants from residential care services referred to palliative care beds as single en-suite rooms that are made available for patients who are dying. These are not necessarily classified by administrators as 'designated' palliative care beds and would therefore not have specialist palliative care support.

³⁷ GPs and SPC consultants refer patients for intermediate level two palliative care. The hospice homecare team provides support and care on an as-needed basis. Intermediate palliative care beds are viewed as an integral element of SPC support.

³⁸ The plans for a new specialist palliative in-patient facility are progressing but building had not yet commenced in 2011.

³⁹ Some progress has been made with ancillary support for the Waterford homecare team.

⁴⁰ See <http://debates.oireachtas.ie/dail/2007/03/22/00122.asp>

⁴¹ Following the launch of the 2001 National Advisory Committee on Palliative Care report, the DoHC issued a directive to all health boards to each undertake a regional review of existing hospice and palliative care services and then a regional strategy for service development based on the national report.

⁴² Informants from each residential care setting visited during this evaluation were asked the number of deaths in the previous year (2009). Some informants spoke from memory while others had registers to hand to check, so the numbers should be treated with considerable caution. The numbers ranged from 12 to 72 with an average of 36. These numbers are declining year on year due to the on-going closure of beds. Typically, in one care facility the number of deaths in 2009 was 50 and in 2010 dropped to 27.

⁴³ As a consequence of HIQA's standards, the physical environment of older public facilities is more often seen as unsuitable, particularly in relation to large wards and limited en suite facilities.

⁴⁴ See <http://www.lenus.ie/hse/bitstream/10147/81014/1/NursingHomeCostofCare.pdf>

⁴⁵ Personal communication with DoHC. This figure accounts for 70 per cent of residential care beds for older persons.

⁴⁶ The National Council on Ageing and Older People was dissolved with effect from 1 September 2009 under the Health (Miscellaneous Provisions) Act 2009.

⁴⁷ We received no response from within the sector to our invitation to interview.

4. POLICY, MEASUREMENT AND FUNDING CHALLENGES

4. POLICY, MEASUREMENT AND FUNDING CHALLENGES

Key research questions

- Among the outstanding challenges facing the field today, which are the most significant obstacles to the progress made since the programme began?
- What are the gaps in the strategic approach of the programme?
- What does the evidence emerging from the evaluation suggest in terms of addressing these challenges?

Data sources

Forty-two key informant interviews, using semi-structured questionnaires, contributed to the analysis of issues emerging from the two-region case study. The 51 informants were drawn from healthcare professionals, managers and administrators across a range of settings (homecare, hospice, and home) and backgrounds, namely specialist palliative care (SPC) and generalist settings.

A documentary analysis of annual health board, regional and corporate HSE reports, and reports from hospice and palliative care services was undertaken. In addition, regional needs analyses and strategies following the publication of the NACPC report (2001) were reviewed. International research reports on end-of-life care and strategies were also reviewed. Demographics and broader research data were drawn from CSO and local government reports. Parliamentary questions and responses in relation to service development in the regions were reviewed. Health Information and Quality Authority (HIQA) inspection reports on residential care settings with specific reference to standard 16 of the National Quality Standards for Residential Care Settings for Older People in Ireland (Health Information and Quality Authority, 2009); the Acute Medicine Programme Report, the current programme for government and HSE corporate annual reports were also reviewed.

An additional 14 key informant interviews using semi-structured questionnaires contributed to the consideration of value-for-money measurement. These informants were drawn from healthcare professionals, administrators from the statutory and voluntary sectors, clinical leads from the QCCD and academic experts in Ireland and internationally. This section was further informed by a systematic review of relevant economic evaluations in the field to date.

The evaluation highlighted the following three particular challenges in hospice and palliative care in the Republic of Ireland in 2011:

- enduring inequity of SPC by geographical region and diagnosis;
- the specialist/generalist debate; and,
- a paucity of evidence-based value-for-money measurement.

GEOGRAPHICAL INEQUITIES

It was argued by some informants that the inequities present in the system in 2001 placed those regions without a specialist in-patient (SIP) unit or established service at a disadvantage, in terms of capitalising on rapidly increased government investment from 2004 onwards. In 2008, unspent government money was axed. However, one informant from a well-resourced region challenged this description, arguing that 'money has gone to many places' and 'some regions spent their money wisely'.

Historically, palliative care services first developed with the establishment of a hospice and nurses, and this was followed by the appointment of SPC consultants. More recently in some regions, SPC teams were appointed before a hospice was built. The issue may be less the order in which services were developed and more the sudden deterioration of the Irish economy and its likely impact on investment in palliative care development. Geographical inequities are likely to continue.

What is less clear is how these inequities will manifest in the future. There is a continuing lack of standardisation of definitions and eligibility which will continue to drive some of the inequities noted. Hospice, palliative and EoL care now span different disease groups and services. The stated overarching aim for the Quality and Clinical Care Directorate (QCCD) Palliative Care Programme is to ensure that patients with life-limiting conditions and their families can easily access a level of palliative care service that is appropriate to their needs, regardless of care setting or diagnosis. However, reports from informants and reviews of reports both highlighted that some services focus on the active phase of dying as the point of entry for EoL care, despite acknowledging that patients have increasingly complex co-morbidity that requires support.

SPC is increasingly associated with addressing complex care needs. The Report of the Acute Medical Programme (Royal College of Physicians of Ireland, 2010) highlights the increasing challenge of addressing care needs of older persons.⁴⁸ This concerns the capacity of less well-resourced services to address these issues and the capacity of government to fund continuing needs.

Against that, the South East region's (see chapter 3) shared care approach reflects the QCCD agenda by working closely with other services, addressing complex care needs of patients and enabling GPs and other specialist teams to become more skilled in EoL care and palliative care. The extent to which such approaches are becoming embedded in practice warrants evaluative research. It is conceivable that the South East's shared care approach fosters a more reciprocal partnership between specialist and non-SPC. Such a partnership may prove to be an effective way to address what residential

4. POLICY, MEASUREMENT AND FUNDING CHALLENGES

care informants saw as a skill deficit, across SPC and older persons' care alike, to address complex care needs of frail older persons.

THE SPECIALIST-GENERALIST DEBATE

The changing models for palliative care and, more specifically, the HfH agenda and its current focus on integrative care have heightened awareness and activity around EoL care across acute services. The early focus addressed the 'design and dignity', and 'communication' themes, both of which were easily understood. 'Design and dignity' with supporting grants to hospitals to improve the environment achieved 'quick wins' in gaining support for the programme. The HfH is now focusing on integrated care. The challenges in these approaches were well recognised by HfH staff and hospital personnel in interviews over the course of this evaluation.

A striking feature of the case study interviews reviewed in chapter 3 was the distinction drawn by informants working in care of older persons' services, between EoL care and palliative care. The former was viewed as an integral part of care, while the latter was associated with SPC. The distinction was significant in that informants saw the need to develop knowledge and skills in EoL care from within their service and considered that they were best placed to do so. Several informants referred to their residents having complex needs as a result of co-morbidity and, while greater knowledge in how to address these was needed, it was their belief that SPC did not offer this. One informant referred to the need to develop EoL care units within their large facility to facilitate knowledge development. Other informants referred to the development of EoL care pathways without involving SPC.

On the other hand, informants in the larger residential care facilities reported an increasing number of nurses who had completed SPC programmes; these nurses were seen as important in forging links with SPC and addressing pain management. However, the downsizing of public residential care facilities and the growth of private nursing homes with different skill mixes among staff were reported to mean that large numbers of staff are likely to be less prepared and have insufficient exposure to palliative/EoL care to develop and maintain competencies in the area. Questions therefore arise as to how community-based palliative care teams might interface with continuing care to provide ongoing support in the future. One question arises as to whether or not palliative care of older frail people is of itself a sub-speciality intervention for which SPC teams might provide region-wide support in continuing care settings. Again, in the context of changing service systems and evolving funding, this remains to be investigated.

A further dimension to the specialist/generalist debate is the role of intermediate level-two palliative care beds. Anticipating death in complex co-morbidity and life-limiting illnesses is notoriously difficult. There were reports that, where available, designated intermediate level-two beds were increasingly used by acute care services to facilitate early discharge. How these intermediate beds are defined, used and measured is far from clear. SPC homecare teams provide support to these hospitals and the nature of that support has not been evaluated. The extent to which the care received by patients in these beds differs from other patients in the same facility is also far from clear. Nevertheless, informants repeatedly referred to the increasing importance of these small hospitals as places for EoL care within their local community. Manager informants referred to the 'next step' in EoL care as one that will focus on the interface between acute care and intermediate level-two beds and residential care. Informants in Northern Ireland agreed that the need to examine intermediate provision 'resonated' with their own experiences in recent times.

VALUE-FOR-MONEY MEASUREMENT

STATUTORY-VOLUNTARY TENSION

Among statutory sources in particular there was a concern for 'value for money', questioning the evidence for performance and cost-effectiveness of SPC services. For example, a senior DoHC official told us:

'If asked to choose between cutting palliative care and cutting other services for the elderly, I would be looking at palliative care. I am just not seeing the [patient] numbers to justify the expenditure.'

A senior HSE official went further still:

'Palliative care budgets are vulnerable in the forthcoming period of fiscal restriction.'

Despite these reservations, official government health policy is a comprehensive palliative care service on the basis of need. This has been the case since 2001, yet a decade on there is a €70 million shortfall in promised public funding for palliative care services – equivalent to 49 per cent of the required budget.⁴⁹ Rather than statutory bodies considering funding cuts, therefore, informants from providers argued that substantial further spending is necessary.

The NACPC report (2001) also makes specific provision for the implementation of standards and measurement: 'Suitable performance indicators and outcome measures should be identified and utilised in SPC services in order to evaluate

4. POLICY, MEASUREMENT AND FUNDING CHALLENGES

and maintain quality standards' (Department of Health and Children, 2001:121).

While the National Audit does include EoL standards, outcome measures in SPC are few. The initiation of minimum data sets (MDS) – also recommended since 2001 – has been problematic and delayed. While new data measures were introduced in 2010, annual HSE service development plans have been published with only the rudimentary performance indicators of patient numbers.⁵⁰

Informants from providers therefore had a two-fold response to criticism of their performance and effectiveness: there is insufficient funding and little in the way of consistent national measurement, which they saw as reflecting strategic leadership from central government in palliative care.

Value for money (VfM) is consequently a source of considerable tension between statutory and voluntary bodies in palliative care.

VALUE-FOR-MONEY EVIDENCE BASE

Expert informants in Ireland and internationally stressed that the current evidence from research on VfM in palliative care is encouraging. However, they also observed that the evidence base is too small to be able to make emphatic statements on cost-effectiveness.

More than once, informants highlighted the verdict of an international think tank in 2009: The available studies suggest that palliative care is cost-saving. 'However, caution on conclusions was recommended, as the quality of the evaluation was poor, the methods were heterogeneous, informal costs were rarely captured, and there were problems with analysis, particularly relating to the skewness of cost data' (Gomes et al, 2008:8). In all, these studies appeared difficult to interpret with inconclusive evidence (Gomes et al, 2008; Zimmerman et al, 2008).

As such, informants said that palliative care, both in Ireland and internationally, must continue to grow its VfM evidence base as part of a wider set of agreed health economics priorities in the field (Harding et al, 2009). This in turn will require more focused efforts to break down more accurately and often the costs and benefits of palliative care provision to better evaluate the net economic impact of these services (Higginson et al, 2009; Temel et al, 2010). But informants were also interested in methodological approaches that capture and incorporate qualitative dimensions in these services, arguing that palliative care will not always be the minimal cost option but may offer other benefits that need to be better described (Normand, 2009).

THE NEED FOR MEASUREMENT

Informants from providers, funders and practitioners acknowledged the long-term need to improve measurement of services in Ireland. In the short term, statutory informants argued that performance and cost-effectiveness needed to be demonstrated, in order to reduce vulnerability to funding cuts and to increase the prospects of future investment. As one statutory informant said:

'There will not be a cent for new spending without outcomes specifying what will be provided for the money.'

In the longer term, with competing claims for scarce resources, services were described as needing to be delivered efficiently, subject to ongoing measurement and comparison with alternative arrangements. Health services will always face competing claims for scarce resources. One informant with experience as a healthcare professional and administrator said:

'It is sometimes hard for people in palliative care to understand this, but this is the way it's going. To ensure the best quality of care across the health service, all resources have to be used efficiently. That means decisions (a) between funding palliative care and other types of care and (b) within palliative care between various models of care.'

A further challenge is around the optimal organisation of all palliative care; some informants noted that level-two beds are playing a prominent role in delivery, as part of EoL care in general and as a means of treating long-term chronicity, but that this may be inconsistent with the 2001 NACPC plans.

In summary, it seems that improving performance measurement is an operational necessity for the short-term protection and long-term development of hospice and palliative care services. However, there are organisational and policy issues that must be clarified to support such efforts.

CURRENT MEASUREMENT IN IRELAND

Performance measurement in palliative care in Ireland has historically been minimal, although the landscape is changing. The 'suitable performance indicators and outcome measures' foreseen in the NACPC report (2001), and the benchmarks and outcome measures proposed by the IEAG (Marymount Hospice and The Atlantic Philanthropies, 2006:44-51) are yet to be applied in any consistent way.

Hospitals in Ireland use an activity-based performance system, Hospital In-Patient Inquiry (HIPE), and hospice and homecare have recently implemented MDS.

4. POLICY, MEASUREMENT AND FUNDING CHALLENGES

HIPE is a computer-based system designed to collect demographic, clinical and administrative data on discharges and deaths from acute hospitals nationally.⁵¹ Data are recorded by coders who catalogue patients' chart activity using diagnosis-related groupings (DRGs).

Three concerns emerged during the course of interviews. Firstly, DRG systems are not well suited to measuring EoL care since palliative care is not one of the prescribed primary diagnoses. Secondly, the 'auxiliary' activity of a palliative care consultant visiting and treating patients is not picked up and accurately recorded by the coder unless this is highlighted in the chart. Thirdly, the role of SPC consultants in support of patients in acute beds or in earlier support of patients in shared care models is also not captured, unless consultants make a concerted effort to make an entry on the patient chart and coders pick up on it.

Senior managers and administrators from within the health system accepted the inadequacy of HIPE for measuring palliative care in hospitals, acknowledging that there is substantial under-reporting. However, there is also an unknown level of over-reporting in the absence of unique patient identifier numbers in Irish healthcare, notably when there are multiple admissions in the end stage of disease.

New MDS have recently been developed for hospice, homecare and day care. These represent an expansion and improvement on the basic 'average no. of patients accessing ...' data that have been used in the annual HSE Service Plan since 2007 (Health Service Executive, 2007:48).⁵² On the one hand, statutory sources have indicated that these basic data informed funding decisions while, on the other hand, providers have expressed concerns that they already supply more data but that there appears to be a failure of communication between the HSE and DoHC.

It is hoped that the new MDS will provide a richer source of granulated data on activity and experience. Measures such as length of stay; location prior to admission and following discharge; bed:patient ratios; and waiting-list numbers all represent an improvement but, as one informant with a role in the development of the new MDS warned us:

'Minimum is the operative word. There isn't the capacity, especially in rural areas, to record the level and detail of data we'd like.'

Another added:

'Too much of what we return isn't relevant. What does it matter where you died if we don't know how and where you spent the last year of life?'

Again, there are issues of unrecorded activity. One homecare team in a region with no hospice said that they receive 650 calls per month from GPs, PHNs and families seeking advice and support. Many of these calls are necessarily long, lasting 30 minutes or more. This work is a considerable burden, likely replicated nationwide, and not picked up on any official data set. As in hospital data, there is an inevitable but unknown level of over-reporting in hospice and homecare MDS due to double-counting of patients.

Finally, effective use of the data relies on unblocking the perceived statutory bottleneck that restricted previous data use.

SUMMARY

The stated overarching aim for the Quality and Clinical Care Directorate (QCCD) palliative care programme is to ensure that patients with life-limiting conditions and their families can easily access a level of palliative care service that is appropriate to their needs, regardless of care setting or diagnosis. The realisation of these goals is thwarted by continuing geographic inequities in service provision, contradictions between stated policy around SPC and hospice provision, and realities of more integrated and shared care approaches responding to historical developments, extant resources and fiscal realities. Those same fiscal realities are increasing the focus on VfM measurement, which is a source of considerable tension between statutory funders and palliative care providers, particularly those in the voluntary sector. Government has been slow to implement good measures despite accepting their benefits in official policy. It may be possible to improve the VfM picture for palliative care in Ireland more quickly if current measurement tools – and their use by statutory bodies – are improved.

⁴⁸ See <http://www.hse.ie/eng/services/Publications/services/Hospitals/AMP.pdf>

⁴⁹ The 2006 baseline report (Irish Hospice Foundation, 2006) estimates the cost of a comprehensive service at €144 million (p 16). The HSE National Service Plan 2011 set the budget at €74 million (pg 47). In addition there is a substantial outstanding capital outlay required to meet equity commitments nationwide.

⁵⁰ See for example the HSE service plan for 2010 (Health Service Executive, 2010:42).

⁵¹ See http://www.esri.ie/health_information/hipe/

⁵² The 2006 Service Plan included figures from IHF (2006).

CONCLUSIONS

CONCLUSIONS

Key research questions

- What are the key issues in sustaining and expanding upon programme advances?
- How can The Atlantic Philanthropies assist in sustaining and expanding capacity, particularly in the context of the current economic climate?
- What are the key strategic lessons from the programme as The Atlantic Philanthropies prepares to exit the field?

Data sources

Ninety-five key informant interviews contributed to this evaluation in total, and all 91 informants were invited to put forward their perspectives on sustaining and advancing current arrangements in the field. This chapter synthesises these answers with other data sources, including the documentary analysis.

PROGRESS AND IMPACT OF THE 'END OF LIFE' PROGRAMME TO DATE

As shown in previous chapters, the 'End of Life' programme has made significant investments throughout Ireland, with measurable achievements. These are summarised below.

- Access to care in all settings has increased, following investment in services in hospice, hospital and at home.
- Awareness of hospice and palliative care has increased nationally, among both patients and healthcare professionals.
- Access to care for non-cancer patients has increased, reflecting The Atlantic Philanthropies' promotion of inclusive admissions criteria.
- Specialist palliative care (SPC) led providers have been established, supported by the programme, which have increased the quality and quantity of care consistent with government policy.
- Education programmes have been initiated, spanning basic to specialist levels of palliative care delivered from regional and hospice education centres across the country.
- Advocacy research has moved into government policy and public debate.
- Higher standards in service provision and monitoring have been implemented.
- The Atlantic Philanthropies has funded advocacy related and evidence-based research, notably through the Irish Hospice Foundation (2006) and Marymount and The Atlantic Philanthropies (2006) which has contributed substantially to the enhanced status of hospice and palliative care on the policy agenda.
- The All-Ireland Institute for Hospice and Palliative Care

(AIIHPC) was established, the first of its kind, with a mandate to strengthen further research, training, standards and policy influence.

There are also continuing gaps and challenges in hospice and palliative care provision despite the 'End of Life' programme activities. These are summarised here.

- Hospice and palliative care in Ireland is still marked by substantial geographical inequity.
- The programme has increased capacity in previously low-resource regions but has not been the means to fully address geographical inequities.
- The programme strategy invested in both specialist and generalist palliative care provision, with one project – Hospice-friendly Hospitals (HfH) – successfully engaging generalist audiences. Nevertheless, a marked specialist-generalist debate continues. This is visible geographically, between well-resourced regions with extensive SPC services and less well-resourced regions where palliative care is integrated within generalist end of life (EoL) care. But it is also an issue irrespective of geographical region, reflecting poor communication and integration between SPC and EoL groups.
- The programme strategy anticipated cascading service development throughout the country, with SPC-led programme projects 'setting the standard' and advancing the nationwide implementation of official government policy (Department of Health and Children, 2001). However, economic restrictions and insufficient government funding has meant that services have developed differently than envisioned, particularly in low-resource, EoL-led areas. The development of services at a national level has instead evidenced a somewhat unpredictable evolution.
- There has been insufficient statutory support to implement comprehensive SPC provision in what were identified as low-resource regions. The provision of palliative care in these regions, typically delivered within wider EoL care, varies within and across regions. At present, there is little data on this intermediate care and so the first step in sustaining and advancing it is to conduct research in order to present a nationwide picture of actual provision.
- The programme strategy has yet to address central concern of statutory bodies - value-for-money (VfM) measurement and cost-effectiveness.

Nevertheless, there is considerable potential for many advances to be sustained. Advances through the in-patient hospice and homecare projects and across the South East appear to be well-established with strong regional statutory support and broad fundraising bases. Developments in several regions in other care settings such as acute hospitals, and among generalist EoL and primary care practitioners, also have strong potential

to be sustained and advanced. The sustaining of all these advances will be enhanced by expanding efforts to measure performance and evaluate outcomes.

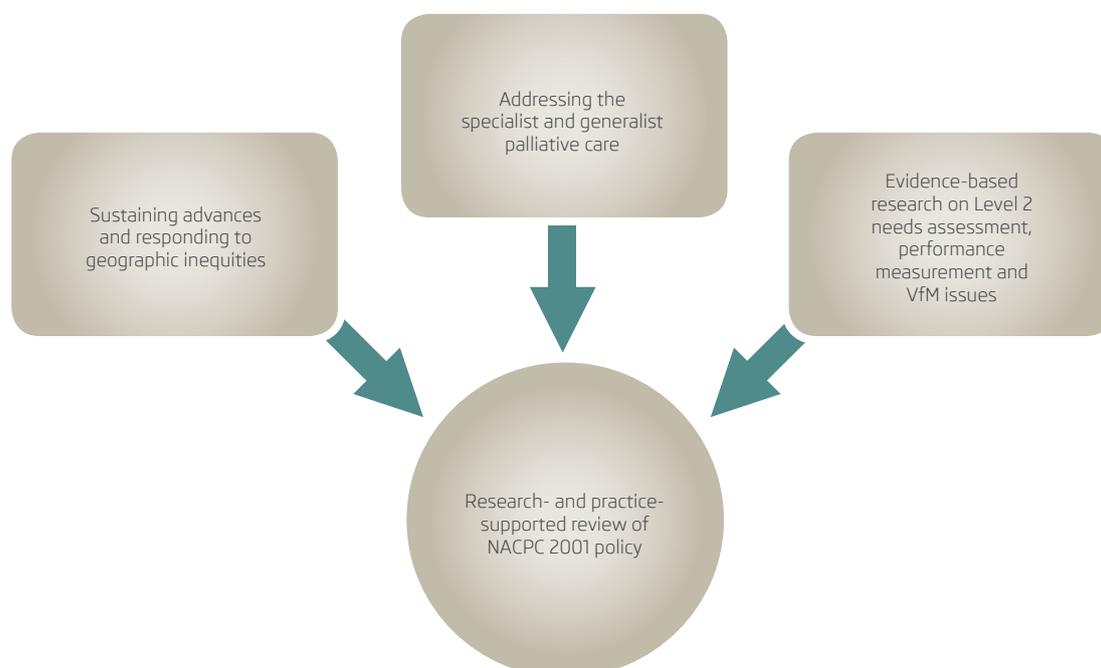
NEXT STEPS

The purpose of this section is to outline a strategic approach to consolidate and broaden the impact of advances in the context of policy, service and economic developments since the 'End of Life' programme began.

The interviews with informants and the review of related materials undertaken in this evaluation suggest that a thorough and inclusive review of the NACPC report (2001) is an essential challenge for the field. However, the evidence of the evaluation also highlights challenges that have an immediate impact on sustaining and expanding programme advances.

Next steps for the field should address (1) how to sustain advances while responding to geographic inequities and supporting palliative care provision in low-resource areas where SPC is typically limited and intermediate care varies considerably; (2) the on-going generalist/palliative debate, promoting communication and integration between specialist and generalist palliative care; and (3) using evidence-based research to inform policy and service organisation, particularly in regard to understanding 'intermediate/level two' provision nationwide and addressing statutory concerns around VfM and performance measurement.

FIGURE 1 FRAMING A WAY FORWARD



SUSTAINING ADVANCES IN PROVISION

The starting point for the 'End of Life' programme was hospice and SPC. The investments in Marymount hospice and Milford Care Centre (MCC) homecare projects have led to expanded service provision in their regions. These well-established SPC-led providers, with strong local statutory support and broad fundraising bases, were in a strong position to expand existing programmes. Indeed, they increased the quality and quantity of care not only in line with government policy but also in ways that influence it. Their expansions appear to be in a strong position to be sustained and, at a primary care level, are significant given their strong links with, and educational support for, GPs and community-based healthcare professionals.

Marymount has also successfully built on the International Expert Advisory Group (IEAG) report recommendations by establishing a model of excellence. It remains to be seen the degree to which Marymount's design and implementation of the IEAG report will inform hospice development in Ireland.

The H@H programme has not yet been replicated beyond one region. Efforts by other hospices in Dublin and Cork to bring SPC teams into the community have been limited by available resources. The degree to which the extensive educational support offered by MCC has facilitated the development of fully integrated levels of palliative care remains unclear and deserves further investigation. It was also notable that informants from the region viewed palliative care as the domain of MCC. This contrasted with the South East region, where generalist, EoL and public health carers continued to consider palliative care as 'their business'. Some argued that

CONCLUSIONS

there is a danger that well resourced and developed services such as Marymount and MCC become islands of best practice, rather than being engaged with hospice, palliative and end-of-life care across care settings and regions. Informants considered that future service expansion should be mindful of this danger. Further investments should ensure that centres of excellence broaden and share their impact across multiple regions.

Informants also particularly noted that the programme's HfH project has had a significant cascade effect in raising awareness among patients, professionals and hospitals across the country. The HfH programme was reported to have optimised its early visibility and support through engagement of mortuary and accident and emergency staff, building momentum through on-site and regional committee structures and a focus on 'quick-win' initiatives such as refurbishment and improvements to the physical environment of care. Next-level activities around integrated care will be more challenging and are likely to benefit from close engagement with SPC and acute medicine programmes. Such closer engagement will play a central role in addressing the specialist-generalist debate. Engagement with the AIIHPC was also recommended; this will also promote specialist-generalist collaboration and knowledge development. While hospice and acute care environments differ greatly, the IEAG report and HfH share an interest in the environment of care and their recommendations for the improvement of care may also benefit future collaboration between SPC and acute care settings.

GEOGRAPHICAL INEQUITY

The disparity between funding and provision across different regions remains the greatest issue in palliative care in Ireland, as was the case when The Atlantic Philanthropies entered the field.

In regions where statutory investment falls substantially short of that promised by official policy, informants report that services have developed differently to what was envisaged by the NACPC report in 2001. In the absence of funding for staffing for in-patient hospice care, patient needs were largely met within intermediate EoL care. Informants felt such advances and adaptations were not thoroughly understood or catalogued, and that this information shortfall must be addressed if the provision of palliative care in under-resourced regions is to be organised in the future.

Informants among palliative care providers stressed the importance of statutory commitment to funding the 2001 blueprint for staffing SPC in in-patient hospices. If The Atlantic Philanthropies were interested in further SPC investment then it might consider partnering with SPC providers and statutory

fundors in areas interested in, but currently without, a hospice, to explore options for funding hospice and/or homecare staff, at least for an initial period. Any such investment should take account of on-going health service configuration and the probability of statutory support for SPC staff in the long term, which varies from region to region.

SPECIALIST-GENERALIST DEBATE

The 'End of Life' programme invested in both specialist and generalist palliative provision, with the HfH project engaging a generalist audience and acute hospital communities, and SPC centres offering expanded education support to non-specialist and generalist healthcare professionals.

These efforts have increased awareness of specialist supports but a marked specialist-generalist debate continues. Many informants took 'either/or' positions and pointed to tensions between SPC and other care teams, and between policymakers and managers, particularly around the cost-effectiveness of SPC.

The specialist-generalist debate was also manifest at service level. HfH programme-related interviews with hospital staff highlighted limited involvement by SPC but interviewees among residential and community care staff in well-resourced regions referred to palliative care as SPC. Some SPC and non-SPC healthcare staff informants perceived that palliative and EoL care were not exclusive to SPC and envisioned residential care settings developing pathways without the involvement of SPC.

This is an issue that remains to be resolved. There are concerns about the cost of SPC but equally there are questions about inappropriate or non-referral of patients to SPC, the level of training among generalist staff and the capacity and the sustaining of local capacity to meet the needs of complex and very ill patients and residents.

As part of the HSE reform programme, the Quality and Clinical Care Directorate (QCCD) is seeking to improve standards of care in all key health specialties. Among its targeted palliative care activities, it includes the production of a role delineation framework supplementing the Acute Medicine Programme (AMP) (see Appendix 6), detailing the interface of palliative care and services.

Now seems to be a good time to address these concerns. Offering evidence-based guidance to resolve the generalist-specialist debate will play a key role in the sustainability and continued development and expansion of The Atlantic Philanthropies' overall programme. Improving communication and integration between SPC and generalist services would substantially benefit future provision, given the new emphasis

on integrated care. The Atlantic Philanthropies, through its investments and perhaps through the designating of the AIIHPC as an honest broker, could promote such resolution for the benefit of all Irish people likely to benefit from hospice and palliative care.

'INTERMEDIATE/LEVEL-TWO' PALLIATIVE CARE

In hospice and homecare, the 'End of Life' programme has supported well-established, SPC-led providers in regions with strong statutory support and these services appear comparatively well placed to sustain themselves. However, the provision of palliative care in less resourced regions varies and is typically classified under the broad umbrella of 'intermediate/level-two care'. Future statutory investment will be contingent on evidence-based outcomes. Next steps include investments in a nationwide examination of how intermediate provision operates, what service it provides, the workforce planning implications and the patient/family experience, to provide essential information for a fuller picture of palliative care provision in Ireland. A strong economics/performance measurement component would also speak to statutory funder interests to which the ongoing health economics analysis supported by The Atlantic Philanthropies may make important contributions.

Given the linkages that emerged between acute and long-term care of older people with chronic conditions and the actual use of 'intermediate/level-two' beds, analysis would also benefit from including:

- a picture of the changing profile of co-morbidity, frailty and complex symptom management for Ireland's older population;
- consideration of the potential for linkage between supportive, palliative and EoL care and philosophies of care and support being advanced by campaign bodies such as Older and Bolder; and,
- examination of specialist support needs for community and residential care settings.

PERFORMANCE MEASUREMENT IN IRISH HOSPICES AND HOSPITALS

The first project funded by The Atlantic Philanthropies in palliative care in Ireland, pre-dating the 'End of Life' programme, established that statutory funding was around 50 per cent of that promised in official government policy (Irish Hospice Foundation, 2006). Informant interviews indicated that there was limited scope to significantly increase this figure in the short term. In the longer term, managerial informants in both the statutory and voluntary sectors acknowledged that a growing ageing population will require significant further increases in budgets. Yet, the ongoing economic recession

has placed ever greater pressure on healthcare budgets and statutory sources indicated that future investment will depend upon the results of evidence-based outcome measurement.

Opportunities do exist to both examine how existing measures may be used and improved, and to develop a coherent strategy for demonstrating the VfM of hospice and palliative care. The development of comprehensive economic and quality of life delivery tools and the building of an evidence base for the effectiveness and VfM of palliative care are on-going in Ireland and elsewhere but remain next steps to be fulfilled.

There is also a pressing concern about data that is currently collected. Informants reported significant problems with both the types of information being collected on palliative care and the use (or lack of use) of data that is collected. Here too, work is needed to better understand how HIPE and MDS data collection may be improved and to determine how data collected may best be used to support determinations of the value of palliative care.

The HSE's QCCD is exploring the idea of undertaking pilot work to understand and potentially address some of the limitations in current data collection. Collaboration between voluntary and statutory groups in the development of measurement tools is most likely to result in fair and effective tools that support the maintenance of funding and possible expansion when economic circumstances change. Current pilot efforts and proposals appear limited to specific localities and providers. Support for a more extensive consideration of measurement issues and use of data may be a role suited to the AIIHPC.

RE-ENGAGEMENT AROUND POLICY ISSUES

Given the geographical inequity, the matter of specialist-generalist integration, measurement issues and finance challenges, many informants, regardless of their view of the NACPC report (2001) in and of itself, agreed that a review of the report would bring value, provided it involved input from across all palliative care sectors and full support and participation by statutory stakeholders.

It was perceived by some that while the NACPC report (2001) was accepted as policy by the then Minister for Health, there was not widespread buy-in within the Department of Health and Children (DoHC) and the HSE, and this was now playing out in ongoing disputes over appropriate levels of funding.

Acceptance of a need for a review was not universal. Some informants from SPC and advocacy organisations remained insistent that there was no need for any reconsideration of the report's recommendations and strategies; all regions of Ireland are 'at different points on the same trajectory' towards

CONCLUSIONS

comprehensive SPC provision. These informants were concerned that a review would deflect attention from the real issue: shortfalls in policy implementation.

The evaluation found wide differences in views regarding the value of the strategy laid out in the NACPC report (2001); concerns about both differential implementation by region and the feasibility of further implementation in the current economic environment; the need to include VfM and evidence-based measurement; and a desire for generalist/specialist concepts to be recognised and incorporated.

As has been indicated, several informants identified a need for further work to inform all of these considerations and potentially to influence future policy directions. The success of any policy review will depend upon the engagement of key stakeholders, including the HSE and the Department of Health (DoH), and is likely optimised by linking such a review to the Acute Medicine Programme and wider healthcare policy regarding chronic disease management and community support.

Any review will be more robust if it involves an honest broker as well as support and engagement by policymakers, administrators, service managers and clinical staff from specialist and non-SPC. Again this may be a role for the AIIHPC.

SUMMARY

Voluntary effort, the building of professional practice and advocacy, government policy and the 'End of Life' programme funded by The Atlantic Philanthropies have greatly benefited people in Ireland in need of EoL supports and care.

Through the programme, palliative care and EoL care have been strengthened, centres of excellence and standards for quality care have emerged, as have newer community and hospital-based models, and the trained workforce has greatly expanded.

There are still geographic inequities, challenges around the generalist/specialist distribution of care and, most of all, concerns about the availability of resources to sustain existing provision and address outstanding gaps.

The very success of the programme has raised concerns about how well quality and VfM may be demonstrated to ensure continued and expanded support.

The programme has also supported the development of research and advocacy capacity. As the economics of care and of Irish society challenge what has been created, leadership, research activity and advocacy will be needed. It is likely

that these activities will occur through the mechanisms that The Atlantic Philanthropies has created, including AIIHPC, and those it has supported, including the Irish Association for Palliative Care (IAPC) and the Irish Hospice Foundation (IHF).

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APPENDIX ONE: THE ATLANTIC PHILANTHROPIES' HOSPICE AND PALLIATIVE CARE PROGRAMME

The Atlantic Philanthropies Support for Hospice and Palliative Care in Ireland

By 2010, there will be evidence established of effective ways to care for older adults in the hospice and community settings and within the wider healthcare system towards the end of their lives. Applied research of an international standard on policy and practice will be completed and a cadre of multi-

disciplinary care workers and clinicians will be trained in best practice in centres focusing on end-of-life care.

To date, approximately one-third of the ageing programme spent in the Republic of Ireland has been on the end-of life programme, circa €25 million. The logic model driving this programme is as follows:

Programme Activities	Outputs	Short-Term Outcomes	Long-Term Outcomes
Development of hospice values and skills in all care settings serving older people; applied research, education, training, evaluation and accreditation; expansion of specialist palliative care services nationally	National education programme in palliative care for all care settings including homecare; multi-disciplinary centres of excellence in hospice and palliative care; increased number of specialist palliative care services	Increased awareness and access to palliative care in all care settings nationally; increased knowledge, education and training for all relevant carers across medical and social disciplines	Older people have access to quality end-of-life services; higher standards in service provision and monitoring; government funds redirected into proven best models of care including palliative care

APPENDIX TWO: RE-AIM FRAMEWORK

The RE-AIM framework puts a greater focus on the intervention setting level and on the staff delivering the programme and what they do, rather than on the individual participant who receives a programme. Both are important, but RE-AIM places emphasis on the potential implications for delivering interventions in applied settings, and on assessing implementation for different components of the programme and across diverse intervention staff. There are five elements, or dimensions, of the RE-AIM framework:

Reach, the absolute number, proportion, and representativeness of individuals who participate in a given programme.

Efficacy/Effectiveness, the impact of an intervention on important outcomes. This includes potential negative effects, quality of life and costs.

Adoption, the absolute number, proportion, and representativeness of settings and staff who are willing to offer a programme.

Implementation, at the setting level, implementation refers to how closely staff members follow the programme that the developers provide. This includes consistency of delivery as intended and the time and cost of the programme.

Maintenance, the extent to which a programme or policy becomes part of the routine organisational practices and policies.

Source: Glasgow et al (2006)

APPENDIX THREE: CASE STUDY DATA

TABLE 1 CSO TOTAL POPULATION⁵³

Age	Male	Female	Total 2006
0-14	443,044	421,405	864,449
15-24	321,007	311,725	632,732
25-44	681,988	663,885	1,345,873
45-64	468,037	460,831	928,868
65 +	207,095	260,831	467,926
Total	2,121,171	2,118,677	4,239,848

TABLE 2 POPULATION OF CASE-STUDY REGIONS BY COUNTY AND GENDER

Region and county	Males	Females	Total persons
Carlow	25,611	24,738	50,349
Kilkenny	44,263	43,295	87,558
South Tipperary	42,250	40,971	83,221
Waterford	53,932	54,029	107,961
Wexford	66,070	65,679	131,749
Total South East Region	232,126	228,712	460,838
Clare	56,048	54,902	110,950
Limerick	92,680	91,375	184,055
North Tipperary	33,568	32,455	66,023
Total Mid-West Region	182,296	178,732	361,028

APPENDIX THREE

TABLE 3 POPULATION OF CASE-STUDY REGIONS BY COUNTY AND AGE COHORT

Region and county	Age cohort						Total
	0-4	5-14	15-24	25-44	45-64	65 +	
Carlow	3,842	6,728	7,881	15,754	10,846	5,298	50,349
Kilkenny	6,340	12,513	11,948	26,474	20,291	9,992	87,558
South Tipperary	5,776	11,752	11,436	23,929	19,677	10,651	83,221
Waterford	7,801	14,616	15,696	32,274	24,398	13,174	107,961
Wexford	10,025	19,213	17,530	3,9919	29,738	15,324	131,749
Total South East Region	33,784	64,822	64,491	138,350	104,950	54,439	460,838
Clare	8,206	15,767	14,322	33,573	26,161	12,921	110,950
Limerick	10,104	19,431	24,163	45,968	34,151	17,473	151,290
North Tipperary Incl. East Limerick	6,894	13,616	15,922	29,034	22,105	11,217	98,788
Total Mid-West Region	25,204	48,814	54,407	108,575	82,417	41,611	361,028

TABLE 4 SUMMARY OF HEALTH SERVICES

		Mid-West	South East
Services for older people	Registered private nursing homes (beds)	44 (2004)	58 (2,315)
	Total public settings (beds)	9 (660)	7 (1,102)
	Long-stay palliative care	447 21	826 ⁵⁴ 13

TABLE 5 INTERMEDIATE OR LEVEL-TWO PALLIATIVE CARE

Region/County	Base	Number of Beds
Carlow/Kilkenny	Carlow	4
	Castlecomer	4
South Tipperary	Carron Reddy	1
	Clogheen	2
	Carrick on Suir	1
Waterford	Dungarvan	2
Wexford	Barntown	2
	Gorey	2
Clare	Kilrush	2
	Ennis	5
	Ennistymon	2
	Raheen	2
Limerick	Milford	2
	Newcastlewest	5
North Tipperary	Nenagh	2
	Thurles	2
	Roscrea	2

TABLE 6 ACUTE CARE SERVICES IN BOTH REGIONS

Acute care hospitals and SPC	Bed capacity	SPC team	Acute care PC beds	SPC clinics
Mid-West Regional Hospital	375	Consultant-led with palliative CNSs in each hospital	0	1
Ennis General Hospital	80		0	0
St. John's Hospital	93		0	0
South East	317*	Consultant-led with two palliative CNSs* in each hospital	0	1
St Luke's Hospital	255		0	1
South Tip General Hospital	537*		2	1
Waterford Regional	237		0	1
Wexford General Hospital	*includes maternity beds		0	1

TABLE 7 BASED ON NEEDS ANALYSES UNDERTAKEN BY HEALTH AUTHORITIES OF BOTH REGIONS

Service	South Eastern Region	Mid-Western Region
Specialist in-patient unit	None	20-bedded unit with need for additional 10 bed
Homecare services	Regional coverage by nurse-led teams but limited capacity beyond office hours No MDT* support	Regional cover with consultant support No MDT input
Intermediate bed cover	5 beds No consultant input	15 beds No consultant input
Acute general hospital	Two of the four hospitals without a palliative care CNSs** One consultant only with need for two more	All four hospitals with CNS cover All have consultant cover but need to expand from two to four consultants
Day services	None	Available but running at 50 per cent capacity

*MDT: multi-disciplinary team; ** CNS: clinical nurse specialist
Sources: Mid-Western Health Board (2004); South Eastern Health Board (2005)

TABLE 8 STAKEHOLDER VIEWS, 2001

Stakeholders	South Eastern Region	Mid-Western Region
Community hospitals	Access to consultant support Ancillary support needed Education for all staff needed Integrated services	Need for ancillary support Complementary therapy Consultant input
GPs	SPC services inadequate Needs of patients with non-malignancy not met Reimbursement for palliative care services they provide	24hour access to services needed Needs of patients with non-malignancy not met Ancillary support needed
PHNs	More respite beds Improved communication in all aspects of services Counselling and bereavement services Improved support for community-based staff	Sharing of workload between PHNs and homecare teams 24-hour PC care Improved communication across services
Specialist providers	Hospice facilities More respite beds Inclusion of patients with non-malignancy Ancillary support Counselling/bereavement service	Development of ancillary services Improved communication Development of education support
Service providers	Hospice facilities Counselling and bereavement services 24-hour service More respite beds	Education support Increased SPC support through staffing and PC OPD service development Radiology service development

APPENDIX THREE

TABLE 9 SERVICE PROVISION INCLUDING STAFFING*

	NACPC** Min recommendations	Mid-Western Region		South Eastern Region	
		2004	2007 (change)	2004	2007 (change)
SPC# medical staff	1 WTE consultant per 160 population 3 non-consultant hospital doctors per consultant	1 4	2 (+1) 6 (+2)	1 3	2 (+1) 4 (+1)
SPC nurses	Hospices/SPC beds: 1 WTE per bed Community: 1 WTE per 25,000 population AGH##team 1 per 150 beds Day care units: 1 per 7 daily attendees	28 12.5 6 1	36.5 (+8.5) 16 (+3.5) 6 2 (+1)	0 17.5 4 0	0 19 (+1.5) 5 (+1) 1 (+1)
Physio-therapists	Hospices/SPC beds: 1 WTE per 10 beds Community: 1 WTE per 125,000 population	2.5 0	3 (+0.5) 1 (+1)	0 0	0 0
Occupational therapists	Hospices/SPC beds: 1 WTE per 10 beds Community: 1 WTE per 125,000 population	2.5 0	3 (+0.5) 1 (+1)	0 0	0 2 (+2)
Social workers	Hospices/SPC beds: 1 WTE per 10 beds Community: 1 WTE per 125,000 population AGH: 1 WTE for hospitals with SPC team	2.5 0.5 1	4 (+1.5) 1 (+0.5) 0 (-1)	0 0 0	0 1 (+1) 0
Spiritual care	2 chaplains per SPC unit	3	3.5 (+0.5)	0	0
Speech and language therapy	1 session per week per SPC unit	0	0.1 (+0.1)	0	0
Clinical nutritionists	1 session per week per SPC unit	0.2	1 (+0.8)	0	0
Pharmacists	1 per SPC unit	0.5	1.5 (+1)	0	0
Care attendants	SPC units: .5 per bed Community (number not specified)	18 3	18.5 (+0.5) 2 (-1)	0 0	0 0
Medical secretaries	AGH: 1 WTE with team	0	0	1	2.5 (+1.5)
Librarian/Education		1.5	1.5	1	0 (-1)
Volunteer coordinators	1 per SPC unit	1	1	0	0
Total		88.7	110.6	27.5	36.5

*based on the Baseline Study (Irish Hospice Foundation, 2006) and subsequent update (Irish Hospice Foundation, 2007)

** National Advisory Committee on Palliative Care (Department of Health & Children, 2001)

#Specialist Palliative Care

Acute general hospital

TABLE 10 CASE STUDY INFORMANTS

Service	Number	Comment
Specialist palliative care	13	Includes consultants, clinical nurse specialists and clinical nurse managers
Acute general hospital	5	Includes administrators, nursing management and practice development
Non-acute general hospitals	8	Includes management and clinical staff from district and community hospitals
Residential care facilities	12	Includes long-stay care settings
Regional management	2	Includes those responsible for specialist palliative care
Primary care	6	Includes senior public health nurses (PHNs) and GPs

TABLE 11 INTERVIEW THEMES

	Theme	Description
1	Increased awareness	Addressing care needs Preceding HfH but HfH bringing momentum Environment as major issue and impacting directly on practice Response to structural and clinical deficiencies: dedicated wards in acute care/beds in continuing care/district/community hospitals
2	Workforce planning	Current interest and uptake Gaps in continuing education and undergraduate education Challenges relating to medical education and uptake; Clinical skills and competencies.
3	Significance of consultant led homecare: positioning palliative care in the community	Shared care approach Performance measurement challenges
4	End-of-life/palliative care for older persons	Skills and role of district/community hospitals Response to increased awareness: adapted LCP Engaging with delineating end-of-life care from overarching care philosophy which is palliative but by another name Small number of deaths/year

⁵³ See: http://www.cso.ie/Quicktables/GetQuickTables.aspx?FileName=CNA15.asp&TableName=Population+by+Age+2006&StatisticalProduct=DB_CN, accessed 9 March 2011.

⁵⁴ This number is based on 2008 data from the HSE. See [http://www.hse.ie/eng/staff/FactFile/County Information/](http://www.hse.ie/eng/staff/FactFile/County%20Information/)
The number of public long stay beds is falling across the service as a combined result of funding and HIQA requirements for the environment of care.

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APPENDIX FOUR: TIMELINES

PALLIATIVE CARE

First homecare team	1985	Harold's Cross
First rural homecare team	1986	
Irish Hospice Foundation	1986	Founded
IAPC formation	1993	
Shaping a Healthier Future	1994	
Cancer Services in Ireland: A National Strategy	1996	
Report of the National Advisory Committee on Palliative Care	2001	
Individual health boards response to NACPC report	2002/	Needs assessment directive to each health board
Roll out of additional appointments of additional consultants in palliative medicine, CNSs and members of MDT	2003/	
IHF: HfH	2004	Care for People Dying in Hospitals project: precursor to the HfH programme
IHF/HRB-supporting research	2003	Research Fellowship in Palliative Care
Establishment of the HSE and dissolution of the health boards and Eastern Regional Health Authority	2005	
National Council for Specialist Palliative Care	2005	Last met in 2007
Design guidelines for specialist palliative care settings	2005	
Palliative care needs assessment for children	2005	
Towards 2016: Ten-Year Framework Social Partnership Agreement, 2006-2015	2006	...'further developing palliative care throughout Ireland, with particular reference to the Baseline Study on the Provision of Hospice/Specialist Palliative Care Services'
A Strategy for Cancer Control in Ireland	2006	Reference to need to enhance palliative care capacity
Baseline Study on the Provision of Hospice/Specialist Palliative Care Services in Ireland	2006	Baseline Study on the Provision of Hospice/Specialist Palliative Care Services in Ireland
Exploring palliative care in Ireland	2006	IHF
Future of palliative care education in Ireland	2007	IHF
Increased palliative care activity	2007	Number of patients in specialist in-patient units showed a 23.3 per cent increase from 2006 to 2007; Number of patients accessing homecare services showed a 22.2 per cent increase from 2006-2007; Number of patients accessing intermediate care in community hospitals showed a 7.8 per cent increase (see earlier note on intermediate care bed reporting)

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Staffing Levels and Bed Numbers in Specialist Palliative Care in Ireland, 2007: Update of Baseline Study (2005) data	2007	
New service developments	2008	24.8 of the 35.8 new posts filled
Activity focus	2008	In-patient target not met (-13% variance); Homecare services target exceeded (18%) Intermediate care access target exceeded 66% Day care target exceeded 12%
Publication of End-of-Life Care for Older People in Acute Care Settings	2008	
HSE audit of palliative care service provision conducted	2007	
St Ita's Hospice Newcastle	2008	Ready for opening but posts not sanctioned
Publication of Palliative Care - A Five Year/Medium Term Development Framework	2009	
Publication of Palliative Care Service - A Five Year/Medium Term Development Framework 2009-2013	2009	
Publication of Palliative Care for All - Integrating Palliative Care into Disease Management Frameworks	2009	
National Integrated Services Directorate set up	2009	
Quality and Clinical Care Directorate (QCCD) also set up	2009	
Palliative Care suite opened in Tuam	2009	
Report published on palliative care across EU	2009	Ireland ranking second
HSE Integrated Services Directorate	2009	
Publication of Palliative Care for Children with Life Limiting Conditions	2010	
Publication of HSE Integrated Services Directorate	2009	
National Clinical Programmes including palliative care	2009/2010	
All Ireland Institute for Hospice and Palliative Care	2010	

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SOUTH EASTERN REGION TIMELINE

Homecare team	1986	Kilkenny/Carlow – first in rural Ireland 1986; followed by South Tipp; Waterford in 1988
Waterford Hospice Movement	1988	Established to provide 'palliative care' services for patients with life threatening illnesses in Waterford City, County and in South Kilkenny, covering a population of 120,000 people. Hospice target 2013
Increase commitment to provision of palliative care beds	1997	Plans to DoH for 5 bed palliative care unit Sth Tip (may be related to Cashel/ Clonmel hospital re-configuration; Development of second hospice room in Carlow District Hospital
National Cancer Strategy	1998	Addressing supportive and palliative care (page 2)
Additional PC bed	1999	New hospice room in Gorey District Hospital
First SPC consultant	2000	Appointed initially to St Luke's Hospital, Kilkenny
New regional palliative care service	2000	Based in St Luke's Hospital, Kilkenny, with outreach services in the other general hospitals in the South East
New IT system for clinical and admin support (PC)	2000	Server established in Kilkenny with links to Waterford (not yet fully linked up; not speaking to HIPE)
Statutory New Development Funding	2001	€0.521 million to region
First Palliative CNS (Acute Care)	2001	Appointed to St Luke's Hospital Kilkenny
Statutory New Development Funding	2002	€0.578 million to region
Project Officer Appointment	2002	Appointed to undertake a needs assessment
Additional registrar	2002	Appointed to the consultant led team at Waterford Regional Hospital to support and develop the outreach in-patient, outpatient and community based service provision
Increased grant aid to homecare	2002	This increased the overall SEHB proportion of funding for homecare teams
Statutory New Development Funding	2003	€0.213m to region
Current situation in the South Eastern Health Board in relation to recommendations of the NACPC	2003	Needs assessment
Regional Nurse Specialist in Palliative Care to the NMPDU	2003	Appointed to play a lead role in co-ordinating the development of nursing practice in palliative care in region
Intermediate care patient numbers reported	2003	First explicit citing of intermediate care numbers but patients grouped as respite/short stay and palliative care It remains unclear in published reports how many patients in intermediate beds are admitted for end-of-life care Note: intermediate care beds not funded from palliative care budget
First reference to three levels of palliative care	2003	The three levels are defined and linked to the NACPC report (2001)
Statutory New Development Funding	2004	€0.216m to region
First Palliative Care CNS (Acute Care)	2004	South Tipperary, Waterford and Wexford
Statutory New Development Funding	2005	€0.216 million to region

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Sub-regional development strategy	2005	Sub-regional development strategy for palliative care services in the HSE South East Area Note: LCP cited for acute care settings
€2 million allocated to palliative care nationally	2005	Money for additional consultant, nursing and MDT posts
Increased number of discharges to intermediate care beds noted in HSE annual report	2005	Not clear if this reflects increased palliative care activity in acute care but contributes to increased end-of-life care focus in district/community hospitals.
National Level: Additional €9m allocated to palliative care in Budget 2006	2006	€1.2m allocated to South East for hospice funding
Homecare team under consultant led care	2006	Integrated care with consultant sessional commitment of set hours/week to the homecare team Translated to ½ MDT meetings/week with each homecare team in which care of patients is discussed Patients remain under GP care and consultants increasingly focused on GP support through MDT meetings, support to CareDoc and engagement with ICGP regarding ICGP SHO post
LCP introduced	2006	First applied in two district hospitals now spanning 6 district/community hospitals
National Level: Additional €5 million allocated to palliative care in Budget 2007	2007	€4 million was carried over from previous year bringing additional funding to €9 million for the year
Two further SPC consultants	2007	To support the integrated care approach
Additional CNSs appointed	2007	One each to each hospital bringing total of eight in the region
Susie Long Foundation	2007	The Susie Long Hospice Fund was set up in October 2007 to provide the highest possible quality of end-of-life care for patients and their families through the establishment of a 12-bed hospice in Kilkenny, for the people of Kilkenny and Carlow Charity status in 2008
Carlow Hospice	2007	The County Carlow Hospice movement formally commenced with an open meeting held in the Seven Oaks Hotel in 2007 A working committee was formed. An open public meeting was held in the Seven Oaks Hotel in December 2008 Following this meeting the Carlow County Hospice charity was formed in January 2009 and momentum and support continues to grow locally for the charity and its aims
Dungarvan Community Hospital	2009	Development of three intermediate beds for end-of-life care
National PC funding to be reduced	2009	
Homecare team service	2010	Each team now seeing approximately 100 patients per month. One team logging calls and are averaging 650 phone calls/month relating to patient management
Quality Clinical Care Directorate	2010	Palliative care clinical lead established and palliative care positioned as umbrella speciality
Planning for specialist palliative care centre	2010	Project team established for phase 1 to progress development onto the National Capital Programme plus continued collaboration with Susie Long Foundation for provision of hospice/palliative care unit in Kilkenny
HSE South Regional service plan 2011	2011	Evidence from the acute hospital programmes of the need and benefits of smaller hospitals in the provision of key growth areas in healthcare including day surgery, ambulatory care, outpatients, rehabilitation and palliative care

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MID-WESTERN REGION

Hospice Service	1977	Establishment of a nine bedded hospice unit, Milford Care Centre (MCC)
Partnership agreement with Mid-Western Health Board (MWHB)	1989	Agreement with MWHB
Development of the homecare nursing services	1989	Three nurses funded by the Irish Cancer Society
MCC and MWHB**Partnership agreement formalised	1991	MWHB policy to provide all palliative care services throughout the region in conjunction with MCC as the regional service provider
Report on future development of services for region	1991	Working party report led to recommendation to appoint a consultant physician in palliative medicine and need to better coordinate primary care services
Submission of working party and University of Limerick (UL) research report	1995	Adoption of recommendations as MWHB policy
Establishment of a working group	1996	Function was to implement a three year action plan arising from the working party report
Palliative care nurses approved	1998	Appointed in 1998-1999 in all acute general hospitals in the region under the Cancer strategy
Social worker appointed	1998	Appointed to MCC
Approval for expansion of MCC	2000	Increase bed number to 30; develop day care, and education and research facilities
Appointment of consultant in palliative medicine	2000	First in the region
Acute general hospital specialist palliative care	2000	Service begun in the acute hospitals in the region
Appointment of CNS in palliative care	2000	Acute hospitals
Milford's day care centre	2000	Becomes operational
Specialist palliative care needs assessment	2002	In response to the NACPC report (2001)
Establishment of regional consultative and development committees in palliative care	2002	Brief was to develop a five-to-seven year strategy for palliative care
Appointment of palliative care staff	2002	Including medical (2), nursing (2) and admin staff (5 WTE)
Recognised increased need in annual reporting	2002	PC admissions increased by 46 per cent to 79 and discharges increased by 35 per cent to 74
Additional Palliative Care CNM IIs appointed	2003	Mid-West Regional Hospital and to provide locum cover at two other general hospitals
Strategic Plan for the Development of specialist palliative care services in the Mid-West region	2004	
Appointment of second consultant in palliative medicine	2005	(Sanctioned in 2003)
Accreditation of day care centre	2005	Day centres were awarded Nursing Development Unit Accreditation by the University of Leeds

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Opening of ten additional beds in Milford	2006	Brings total bed number to 30; admissions for year show a 25 per cent increase (to 426) from previous year reflecting increased bed number plus second consultant
New building project commenced MCC	2007	Supported by The Atlantic Philanthropies, statutory and other partners
Opening of additional day-centre space, assessment and therapy areas, office accommodation for increased community-based clinical staff, out-patient rooms, and education and library facilities	2008	Providing the base for development of multi-disciplinary team synergy and expansion of education support across the region in response
Launch of communication strategy	2008	Responding to the expansion of services and stakeholder engagement; need for information dissemination with stakeholders and respond to evolving palliative approaches e.g. public health model
Expansion of the Hospice at Home team with the appointment of additional staff across a number of disciplines	2008	Clinical Nurse Specialists and a Social Worker providing a service across the three counties A multidisciplinary team (including RGNs, care assistants and allied healthcare professionals) was rolled out on a phased basis Initially this operated within a six-mile radius of the centre and was increased to within a 25-mile radius by end of 2008 Service operating primarily on a Monday to Friday basis with reduced nursing/care assistant cover available during the weekend
Expansion of education team	2008	1.5 WTE nurse tutors and a 0.5 WTE librarian
Initial impact of HSE moratorium	2008-2009	55.3% of the planned 85 courses were delivered: the reduction in the number of courses delivered was primarily due to difficulties associated with the HSE's moratorium on training and its associated policy of not releasing staff for training courses However, number of courses increased
Development of monitoring systems (MCC)	2008	Introduction of pal care and MDS
Increased number of patients cared for in H@H	2009	Number passes 1,000 mark
Completion of three-phased building project (MCC)	2009	Expanded facilities, office space, education centre, ancillary support space, kitchen and restaurant
Milford's education support increasing	2009	Number of courses increases (60) with 800 participants; expansion of programmes in partnership with IHF to address private nursing home and public facilities' needs
Milford's education centre becomes Irish co-ordinating centre for the 8-week distance learning course Essential Palliative Care	2009	The course is now facilitated in Milford Care Centre, Limerick, and Our Lady's Hospice, Dublin, increasing available places from 80 to 160 nationally
Education and professional development expansion (Milford Library)	2009	New library management system (Heritage) and access to full text e-journals and databases is now available for all staff on and off site via CINAHL. Grant funding was sought successfully to enable staff working in the service to participate in international education opportunities and to attend the First International Public Health and Palliative Care Conference in Kerala, India
Initiating a public Health approach (Milford)		Establishment of an internal steering committee to examine the standards for Health Promoting Palliative Care Units
Evaluation of H@H project commenced	2010	UL

APPENDIX FIVE: CASE STUDY INTERVIEW GUIDES

MANAGERS AND EDUCATIONALISTS SPECIFIC

- Extent of current workforce planning including specialist and generalist staff and addressing the multi-disciplinary team needs
 - What is listed in the IHF database?
 - What are the trends in course development?
 - What developments are taking place in undergraduate education related to end-of-life (EoL) care?
- What changes have emerged in the past five years?
- HfH programme end-of-life training:
 - Who is targeted?
 - Who is missing?
- What are the gaps in the system in respect of embedding palliative and EoL care?
 - How is HIQA responding?
 - What quality indicators are currently being used by services in respect of:
 - embedding palliative and EoL care?
 - education and practice development programmes?
- What are the current challenges and issues relating to education support for EoL care?

HOSPITAL MANAGEMENT SPECIFIC

- Clarify definition of EoL and palliative care (PC) from HSE perspective
- Note AP's interest in older people
- How has EoL and PC service changed over past ten years: what was it like before the 2001 document and what is it like now? What factors influenced the changes of the last 10 years?
- What are the gaps in terms of system structures and processes?
- (structures meaning beds, teams in place etc; processes meaning voluntary/statutory interface; PC linked with chronic illness and ageing; also tertiary/secondary/primary care interface, etc.)

SERVICE RELATED

- What are the gains and challenges to PC interface with services beyond cancer care (older persons included)?
- Who is responsible for addressing these gaps?
 - Policy related:
 - How has EoL and PC policy landscape changed over past ten years and what factors influenced this?
 - Service and policy
 - What are the emerging questions in relation to policy and service development?
 - What are emerging issues in relation to primary/secondary/tertiary service development and palliative care, specifically in terms of the current gaps in the system?
 - What about continuing care? This should move discussion towards a focus on the future

OLDER PERSONS' SERVICES SPECIFIC

- Factors indicating effective ways to care for older adults
- Understanding of EoL
- If and how EoL is defined by the service
- Coordination of care including, specifically:
 - Named person(s) responsible for navigation through system and teams
 - Team meetings
 - Care plan that includes EoL phase
 - Collection of stats and review of referral (to SPC and non-specialist) teams
 - Shifts in care planning and co-ordination practices in past five years
- Communication
 - Discussion of care and choice with patient and family
 - Choice in place of care
- Care of dying
 - Use of instrument for care needs assessment, planning, treatment and evaluation e.g. Liverpool care pathways
- Symptom management including, specifically:

- Pain
- Constipation
- Nausea and vomiting
- Fatigue
- Complex symptoms
- Disease specific symptoms
- Whether specific focus and awareness in EoL care
- Whether subject of in-service training
- Whether easy and prompt access to SPC for symptom management (24/7)
- Resources
 - Supports for choice in place of care (coordination, symptom management)
- Policies in place for supporting end-of-life care
 - Access to specialist palliative care as needed
- Training and support for all healthcare professionals involved in care
 - End-of-life care included in induction for new staff
 - Palliative and EoL care addressed in service plans

SPECIALIST PALLIATIVE CARE SPECIFIC

- Main trends in the delivery of PC across the region and nationally?
- Key drivers that are driving these trends?
- Current strengths and limitations in delivery of PC across the region?
 - How might these be enhanced/reduced?
- Gaps in the system?
- Regional Needs analysis and response
- On performance measurement

APPENDIX SIX: NATIONAL CLINICAL PROGRAMMES

2011

Programme Name	Acute Medicine Programme
Overarching Aims	<ul style="list-style-type: none"> • A better patient experience in an appropriate environment • Elimination of trolley waits • Safe quality care, expedited diagnosis and correct treatment • Timely care from a senior medical doctor working within a dedicated multi-disciplinary team
Key Solution Areas	<ul style="list-style-type: none"> • Standardisation of access to, and delivery of, high quality, safe acute medicine services nationally • Hospital models which enhance the safe provision of patient care • Navigation hubs to support the streaming of patients to the most appropriate available care setting and enhance communication between primary care, community services and hospital-based services. • Management of acute medical patients in dedicated acute medical units, acute medical assessment units and medical assessment units • Timely care from a senior medical doctor • National implementation of early warning score to help in the early detection of patients who are likely to deteriorate • Access to same day diagnostics • Expedited discharges (including integrated discharge planning seven days per week) • Rapid access to OPD
Working group team	<ul style="list-style-type: none"> • Prof. Shane O'Neill and Prof. Garry Courtney – Programme Leads • Dr Jennifer Carroll – Consultant Geriatrician • Dr Una Geary – Consultant in Emergency Medicine • Dr Orlaith O'Reilly – Director of Public Health • Dr Máire O'Connor – Specialist in Public Health Medicine • Dr Barbara Kearns – ICGP representative • Ms Eilish Croke – Programme Service Planner • Ms Ellen Whelan – Joint Lead Clinical Nurse • Ms Siobhan Scanlon – Joint Lead Clinical Nurse • Ms Anne-Marie Keown – Therapy Lead • Ms Maura Flynn – Clinical Informationist • Mr Paul Rafferty – Programme Manager
Deliverables for 2011	<ul style="list-style-type: none"> • Support focused on the implementation of the programme in 12 sites (a site may incorporate a number of hospitals) • Provide direction to other sites who wish to progress the acute medicine model • Engage with a number of national initiatives which will support the Programmes (e.g. early warning score, retrieval service, • Community intervention team development, out-patient parenteral antimicrobial therapy)
Programme Name	Primary Care
Overarching Aims	<p>Aim To provide quality, easily accessed care to patients in their own community</p>
Objectives	<p><i>Quality</i></p> <ul style="list-style-type: none"> • Save x number of lives • Prevent heart attack, stroke, amputation, blindness, kidney failure, asthma, heart failure, COPD, falls and fractures • Promote clinical governance and leadership structure in primary care <p><i>Access</i></p> <ul style="list-style-type: none"> • All patients with major chronic diseases to be managed in an integrated seamless fashion allowing patients dignity and ability to stay in their homes • Maintain high satisfaction with primary care services • Facilitate no wait times for appropriate patients when they need to be referred to secondary care <p><i>Cost</i></p> <ul style="list-style-type: none"> • Reduce community drug costs • Maintain patients in the community and avoid costly hospital admissions by effective chronic disease management in primary care

Working Group Team	<p>Working Group</p> <ul style="list-style-type: none"> • Dr Joe Clarke – HSE Primary Care Clinical Lead • Dr Margaret O’Riordan – Head of Quality and Standards ICGP • Dr Brian O’Mahony – National ICT Project Manager • Mr Brian Murphy – National Primary Care Manager, • Prof Colin Bradley – University Representative • Ms Kathy Taaffe – Practice Nurse Coordinator • Ms Gráinne Ryan – Public Health Nursing • Emma Benton – AHP representative • Grace Turner – Programme Manager <p>GP Leads (ICGP)</p> <ul style="list-style-type: none"> • Dr Barbara Kearns – Acute Medicine • Dr Dermot Nolan – Asthma • Dr Tony Lee – Care of the Elderly • Dr Derek Forde – COPD • Dr Johnny Loughnane – Dermatology • Dr Velma Harkins – Diabetes • Dr Joe Gallagher – Heart failure • Dr David Gibney – Rheumatology • Dr Pat Durcan – Stroke
Deliverables for 2011	<ul style="list-style-type: none"> • Completion of phase 1 of electronic referral project • Blue print document describing chronic disease watch, including pilot of sites • Development and Implementation of a Falls Prevention Programme in Primary Care in accordance with the Falls and Fractures Strategy 2008
Programme Name	Care of the Elderly
Overarching Aims Objectives	<p>Aim Every older person has access to the right care and support</p> <p>Quality</p> <ul style="list-style-type: none"> • Improve the management of acutely-ill frail older adults in the acute hospital • Increase independence in the home/reduce inappropriate admission to nursing homes • Reduce the number of falls in older people (Implement 2008 falls and fracture prevention policy) • Improve education – of the public, medical professionals, allied health professionals and policy decision shapers <p>Access</p> <ul style="list-style-type: none"> • Every patient has quick access to right care • Integrate acute and community services for elderly • Integration with private sector – ensure appropriate services available for their client group <p>Cost Overall reduction of ED attendances, readmissions, hospital bed days and nursing home bed days by the following:</p> <ul style="list-style-type: none"> • Reduce delayed discharges • Decrease AVLOS for > 65 years, > 75 yrs, > 85 yrs • Reduce risk of re-admission following discharge • Decrease risk of re-attendance at ED • Improved access to funding for homecare support services • Reduce percentage of inappropriate admissions to long-term care

APPENDIX SIX

<p>Working Group Team</p>	<p>Working Group</p> <ul style="list-style-type: none"> • Programme Lead – Diarmuid O’Shea • Advanced Nurse Practitioner – Neil Dunne • GP lead – Tony Lee • HSE Assistant National Director – Noel Mulvihill • HSE Reconfiguration – Kevin Molloy • HSE Service Planner – Carmel Hoey • OT representative – Alice Gormely • Physio representative – Louise Broderick • Practice Nurse Rep – Rita Lawlor • Programme Manager – Grace Turner <p>Regional Leads</p> <ul style="list-style-type: none"> • Shaun O’Keeffe – West • Michael O’Connor – South • Conal Cunningham – HSE Mid Leinster • Patricia McCormack – HSE North East
<p>Deliverables for 2011</p>	<p>Blueprint document including site visits</p> <ul style="list-style-type: none"> • Implementation of Falls and Fractures Strategy • Advance Care Planning
<p>Programme Name</p>	<p>Palliative Care</p>
<p>Overarching Aims</p>	<p>To ensure that patients with life-limiting conditions and families can easily access a level of palliative care service that is appropriate to their needs regardless of care setting or diagnosis</p>
<p>Objectives</p>	<p><i>Quality</i> To improve the quality of life of patients and families facing the problems associated with life-limiting conditions through care planning and the assessment and treatment of pain and other physical, psychosocial and spiritual problems</p> <p><i>Access</i> To improve access so that >90% of patients with urgent palliative care needs are assessed within one working day of referral to specialist palliative care services</p> <p><i>Cost</i> To enable patients with life-limiting conditions who wish to be cared for in the community setting achieve this with the appropriate support of palliative care services</p>
<p>Working Group Team</p>	<p>Working Group</p> <ul style="list-style-type: none"> • Karen Ryan – Clinical Lead • Grace Turner – Programme Manager • Norma O’Leary – Regional Lead, DNE • Stephen Higgins – Regional Lead DML • Brian Creedon – Regional Lead, South • Cathryn Bogan – Regional Lead, West • Maeve O’Reilly – Paediatric Lead • Ger Treacy – Nursing representative • Mary Marsden – Nursing representative • Mona Brannigan – AHP representative • Valerie Keane – Social Work representative • Eileen O’Leary – HSE representative • Kevin Molloy – HSE representative • Mo Flynn – Voluntary Hospices CEO Group • Eugene Murray – Irish Hospice Foundation
<p>Deliverables for 2011</p>	<ul style="list-style-type: none"> • Production of role delineation framework for palliative care services and supplement to Acute Medicine Programme document detailing interface of palliative care and AMP • Review of Five Year Framework document for Palliative Care and production of plan for implementation • Production of national eligibility criteria and referral form to specialist palliative care services • Development of national process of assessment of need for specialist palliative care services • Development of National Advance Care Planning programme comprising documentation, system to ensure choices are respected and education for both healthcare professionals and public • Production of clinical guidelines on pain management in the palliative care setting





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