THE IRISH HOSPICE FOUNDATION

The Hospice Friendly Hospitals Programme

Overview 2007-2013

Foreword

This report describes how care for people who die in Irish hospitals is planned and provided for; and how those processes evolved over the period 2007-2013. The report details a journey and we do not claim to have reached journey's end. The 'Hospice Friendly Hospitals' (HFH) programme, as an aspiration or an idea, meets with very little resistance. Its aim - to transform the culture of hospital care for dying patients is a shared and transparent aim which we believe has now made its way into Irish discourse. While the aim may be agreeable, the means for change are not so straightforward.

Culture change is not simple; the very founding premis being that those who are a part of and members of a particular culture are often the last to see what is good, and what is not so good about a system. Rather people carry on doing these good things and not so good things as they represent 'the way things are done around here'. Culture is a powerful maintenance mechanism precisely because of its shared and unquestioned beliefs and values.

HFH set out to introduce newer ways of doing things, to (re)introduce core values, to question and unsettle some of the assumptions and to provide support, tools and forums. As an example, in her introduction to the HFH standards President Mary McALeese gave us a vision of a 'care-full death'.

We believe a narrative approach is crucial to communicate and record some of the complexity of this type of programme. The authors of the HFH narrative, Graham and Clark, were able to trace the programme's development in real time, attending meetings, listening to discussions and talking with people about the past, the present and the future. This report reflects that depth of familiarity.

Projects are planned in one time (now the past) and unfold in another. If the past is indeed another country we believe it is important to have a map of that terrain. Consequently, in addition to the story of HFH we have commissioned a review of the activities, outputs and outcomes associated with the programme as it developed across hospitals; and of the resources that were developed to fuel it. This second report – the Walsh report represents this map and details what remains to be built upon if end of life care in our hospitals is to reach the excellent heights we desire.

The time through which the HFH journey has evolved has been one of exceptional societal, economic and structural change in Ireland. Much has been said and written on the straightened situation of our health services. The impact on staff should not be underestimated and it is a tribute to their commitment that so many maintained end of life committees in their hospitals, engaged in audits, attended network meetings and somehow managed to get released for training. A negative impact on patients and their families cannot, however, be tolerated and I state again our mantra that there 'is only one chance to get it right'.

The Hospice Friendly Hospitals movement may never have a definitive end, we consider that a good thing. Core to the programme is questioning, review and change with a balance of head and heart. The Irish Hospice Foundation continues to support networks and activities in order to maintain a HFH ethos in Ireland. We support through financial contribution and harnessing the strong partnerships we have developed with health service providers. A very crucial ongoing support is provided by IHF through the experience and dedication of core HFH programme staff.

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ISBN: 978-0-9566590-7-1

Contents

1 Background, Context and Overview 4

1.1 Report Purpose 4
1.2 Dying and Death in Ireland 4
1.3 The Irish Hospice Foundation 5
1.4 The Hospice Friendly Hospitals Programme 5
1.5 HFH Programme Governance and Staffing 7

2 Review of Activities, Outputs and Outcomes 9

2.1 Introduction 9
2.2 Standards and Audit 10
2.3 Culture Change 16
2.4 Capacity Development 22
2.5 Influencing the System 30
2.6 Overall Achievements 36

3 Key Learning and Next Steps 38

3.1 Key Learning Overview 38
3.2 Sharing the Vision 38
3.3 Governance and Management 39
3.4 Engagement 40
3.5 Key Drivers 41
3.6 Tools Generated 42

Bibliography 43

1. Background, Context and Overview

1.1 Report Purpose

The purpose of this report[1] is to provide an objective identification and discussion of the outputs and outcomes of the Hospice Friendly Hospitals (HFH) Programme over the period 1st April 2007 to 30th April 2013. It also assesses the extent to which the Programme has achieved what it set out to achieve, as well as the learning that has emerged to date.

'Nobody should die alone, frightened and in pain. A good death in hospital is possible. Our challenge is to make it happen'.

HFH News, May 2010

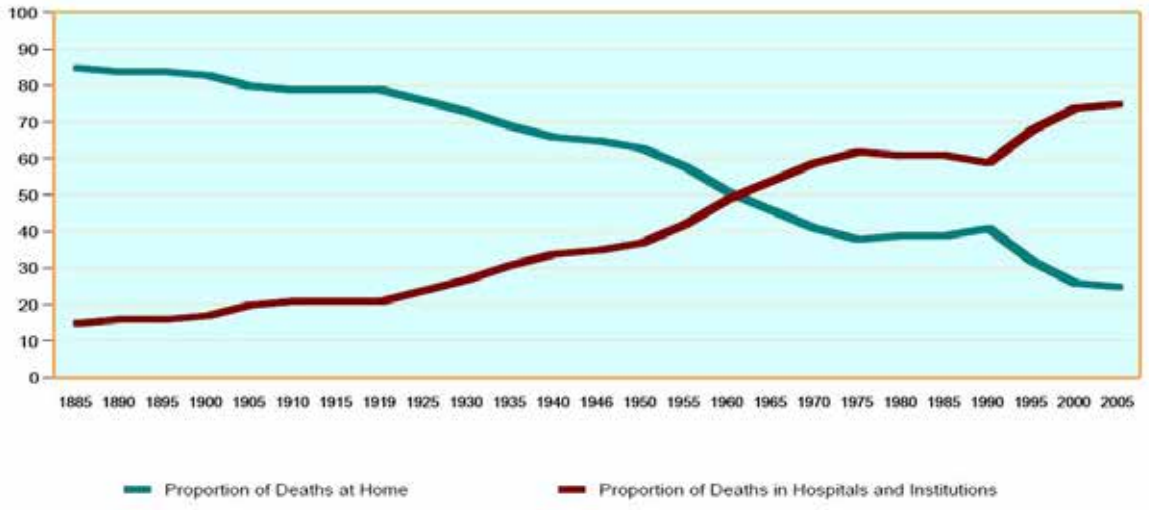
'In a National Survey 67% of Irish people indicated that they would like to die at home.

Weafer and Associates, 2004: p10-11

1.2 Dying and Death in Ireland

In Ireland, there has been a long-term trend towards the hospitalisation of people who are dying (Figure 1.1). Over 29,000[2] people die every year, and*'68% of these deaths occur in hospitals and long-term care settings'*[3].

Figure 1.1 *Trends for the hospitalisation of people who are dying (1885-2005)*



This means that end-of-life care and other issues associated with dying, death and bereavement are very relevant to all hospitals, acute and community.

International research suggests that not only does good end-of-life care impact positively on patients and their families, it also has the potential to reduce costs[4].

1 This report was compiled based on an analysis of secondary data detailed in the bibliography. It was overseen by the HFH Evaluation Project Advisory Group.
2 CSO, (2011) Principal CSO Statistics – Number of Births, Deaths and Marriages.
3 McKeown, K. (2012). Key Performance Indicators for End-of-Life Care: A Review of Data on Place of Care and Place of Death in Ireland, Dublin: Irish Hospice Foundation
4 National Audit Office (2008) End-of-Life Care. Report by the Comptroller and Auditor General, HC 1043 Session 2007-2008 (London)

1.2 The Irish Hospice Foundation (IHF)

The Irish Hospice Foundation is a national charity whose mission is to achieve dignity and comfort for all people facing the end of life in Ireland. Its vision is that no one should face death or bereavement without the appropriate care and support they need.

As a development organisation concerned with all issues related to dying, death and bereavement, the Foundation's concerns about dying in hospitals can be traced back to the mid-1990s.

An IHF-funded exploratory project undertaken in St. James's Hospital, Dublin, in 1999 led to a planning document on end-of-life care prepared by the Royal College of Surgeons in Ireland. This in turn generated a joint IHF/Health Service Executive (HSE) pilot project (2004-2006) at Our Lady of Lourdes Hospital, Drogheda, which looked to develop a systematic approach to changing the culture of care and organisation around dying, death and bereavement in hospitals. This project generated significant learning and confirmed the feasibility and value of initiating a national programme to improve end-of-life care in hospitals.

> End-of-life care is care in relation to all aspects of end-of-life, dying, death and bereavement, regardless of the service user's age or diagnosis or whether death is anticipated or unexpected. It includes care for those with advanced, progressive, incurable illness. Aspects of end-of-life care may include management of pain and other symptoms and provision of psychological, social, and other supports.
>
> ***HIQA National Standards for Safer Better Healthcare (2012)***

1.3 The Hospice Friendly Hospitals (HFH) Programme

1.3.1 Background

Formal planning for the development of a national programme to instil hospice principles into hospital care for the dying got under way in 2006, with the support of Atlantic Philanthropies (AP). Some 50% of acute hospitals expressed an interest in participating, as did a significant number of non-acute community hospitals and care facilities for older people.

Following a successful application to AP for funding, the €10m project was officially launched by President Mary McAleese in May 2007 as the *Hospice Friendly Hospitals* Programme, a five-year initiative of the IHF in partnership with the HSE. With 50% funding from Atlantic Philanthropies, it also received financial support from the Dormant Accounts Fund and the Health Services National Partnership Forum, as well as from the IHF's own resources

1.3.2 Aim and purpose

The aim of the HFH Programme was '*to put hospice principles into hospital practice and to ensure that a systematic quality approach exists within the public health services to facilitate, in so far as is humanly possible, a good death, when it is expected or can be predicted, and supportive systems when death occurs unexpectedly*' (Grant proposal to Atlantic Philanthropies).

The Programme's purpose was – and remains – to ensure that end-of-life care becomes

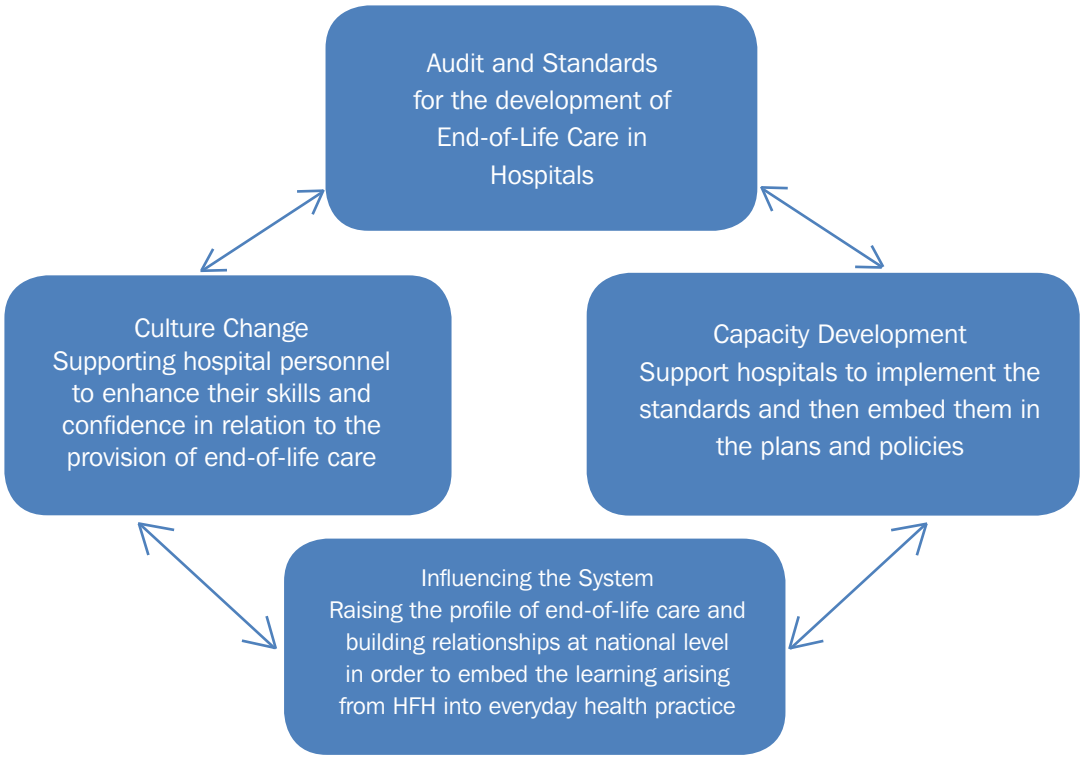
central to the mission and everyday business of hospitals. It promotes high-quality care for all people at the end of life, regardless of the nature of their illness, whether their death is expected or sudden. In doing this, it acknowledges the role of *all* staff – clinical, administrative and support – in improving the end-of-life experience of patients and families in acute and community hospitals.

To achieve its mission, the Programme set out to:

- identify what constitutes end-of-life care and develop quality standards for such care in hospitals
- develop capacity to meet these standards
- improve the culture of care in relation to all aspects of dying, death and bereavement in hospitals and residential care settings
- influence the health system to raise the profile and standards of end-of-life care.

An overview of the resulting overarching areas of work is provided in Figure 1.2.

Figure 1.2 *Overarching areas of work of the HFH Programme*

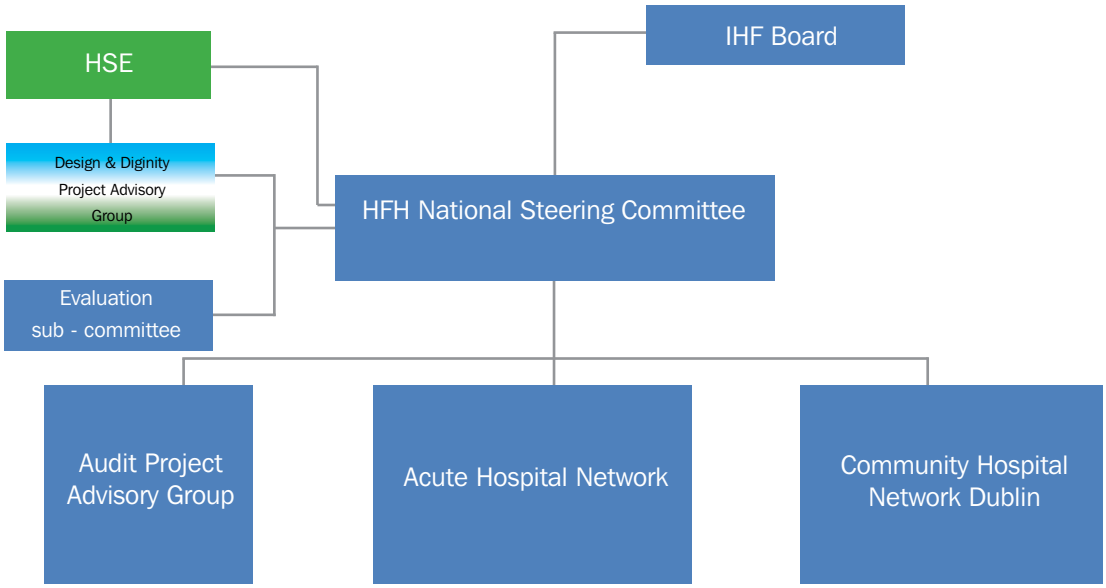


1.5 HFH Programme Governance and Staffing

1.5.1 *Programme Governance*

A National Steering Committee made up of senior representatives of various relevant organisations was established in 2006 to oversee the operation and development of the HFH Programme. This group met monthly in the first year and thereafter quarterly until January 2013, when, following a refocusing of the Programme's objectives, overall responsibility transferred to the IHF Board. Membership of the committee was revised in 2011 to facilitate greater linkages between the committee and the HFH Acute Hospitals Network. As the Programme was rolled out, a number of sub-committees/advisory groups/networks were established to oversee the implementation of specific elements. See Figure 1.3 for details of these Programme structures and their relationship to one another over the period 2007-2012.

Figure 1.3 *Overview of HFH Programme structures (2007-2012)*



1.5.2 *Programme staffing*

Throughout the period 2007-2013, the HFH Programme team based in the IHF's offices comprised approximately three to four whole-time equivalent posts at any one time, including the Programme Manager, a Standards and Audit Officer/Co-ordinator and an Administrator. The exact focus and role of these staff changed over time to meet changing needs.
The Programme also appointed a team of contract staff (up to 12.5 whole-time equivalent posts) to act as End-of-Life Development Coordinators. Three of these posts were based in large teaching hospitals: the Mater, St. James's and Beaumont. The rest of the team worked across regions, supporting clusters of acute hospitals, while one team member supported community hospitals in the greater Dublin area. These Coordinators were in post for an average of approximately two years and were supported and mentored in their roles by the HFH core staff team.

1.5.3 *Programme roll-out*

The Programme's initial focus was on building relationships with acute and community hospitals interested in engaging, and ultimately in getting the Programme established within these hospitals. At the time of its formal launch in May 2007, 18 acute and 19 community hospitals had expressed an interest in becoming involved.

Participation required hospitals to sign a local Memorandum of Understanding (MOU 2007-2010) with the Programme. In 2010 acute hospitals wishing to continue their participation or those interested in getting involved were required to sign a new MOU (2010-2012), designed to formalise the relationships, enhance accountability and strengthen reporting. Further MOUs – one for acute hospitals, the other for residential care settings – were introduced for the period 2013-2015. These required hospitals to continue progressing their work on end-of-life care, but also specified the need to submit quarterly reports on progress in relation to development plans, using an agreed template.

A formal MOU (2013-2015) has recently been signed by the HFH Programme and the HSE.

1.5.4 *Programme monitoring and evaluation*

A HFH Programme evaluation sub-committee was established in 2007. This sub-committee reported directly to the National Steering Committee. Following a review of proposed evaluation approaches, the sub-committee noted a lack of baseline information on end-of-life care in hospitals in Ireland and made a recommendation that a large-scale baseline audit be conducted. The purpose of the audit baseline was:

- To provide baseline data for evaluation purposes
- To provide data to shape and support developments at local hospital level.

This was to be supplemented with qualitative studies. A formal qualitative study on the impact of the Programme as an advocacy initiative was commissioned and undertaken by Prof. David Clark and Dr Fiona Graham (2013)[5] over the period 2009-2012. This study used a mix of methods, including interviews with key stakeholders, attendance at meetings, a review of Programme and hospital progress reports and other Programme documentation. After a series of interim reports, the final report was submitted in May 2013. Particular aspects of the Programme were also subject to internal review, while the first phase of the *Final Journeys* staff development programme was the subject of a specific evaluation.

The evaluation sub-committee was disbanded in 2010 when the National Steering Committee took over responsibility for this function.

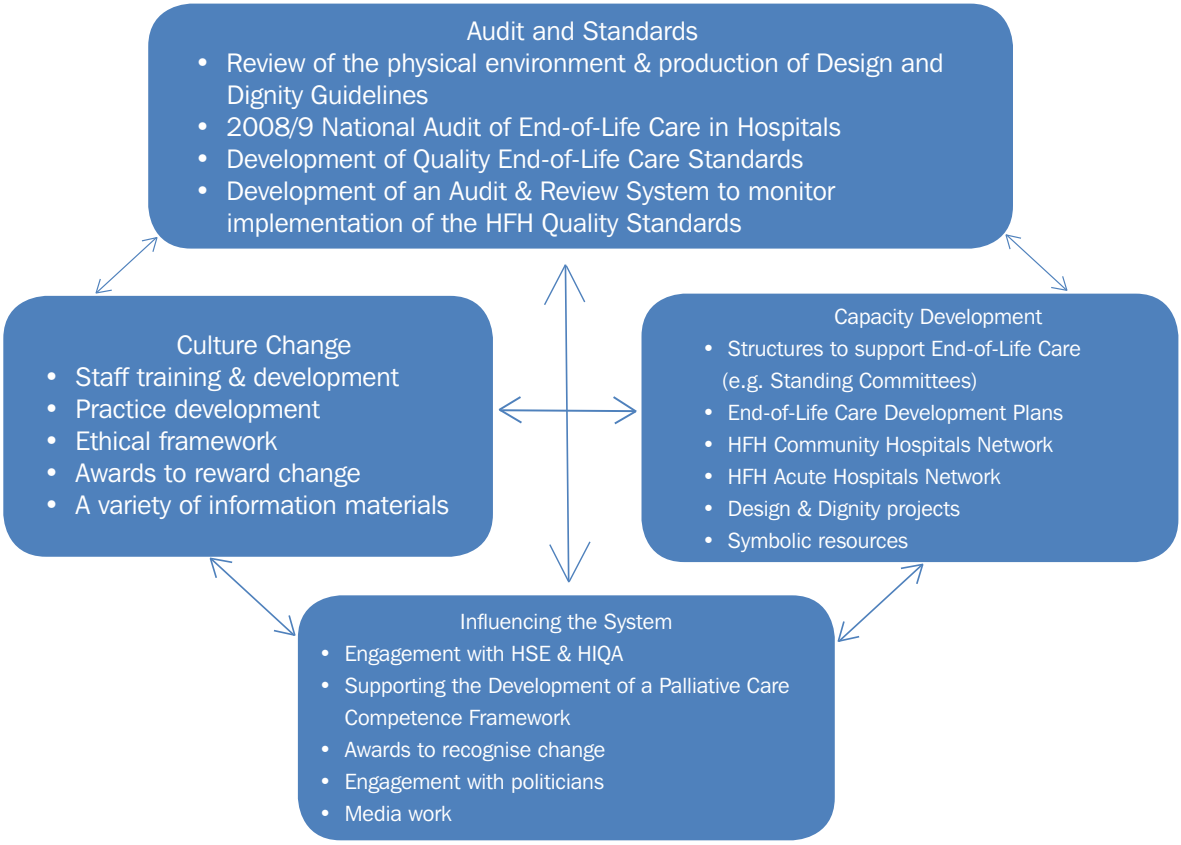
5 Clark, G & Graham, F (2013) The Hospice Friendly Hospitals Programme in Ireland: Narrative Report.

2. Review of Activities, Outputs and Outcomes

2.1 Introduction

HFH Programme activities have been many and varied and could be examined in a number of ways. For the purposes of this review, key activities have been linked to one of the Programme's four core areas of work/strategies.

Figure 2.1 *HFH Programme core areas of work and key activities*



While in this review each activity is examined under a particular area of work/strategy, many activities support more than one strategy. For example, the Ethical Framework for End-of-Life Care contributes not only to culture change in hospitals but also to the achievement of the HFH Quality Standards for End-of-Life Care and to the development of hospitals' capacity to provide better end-of-life care. In many cases the HFH Programme worked with others to progress and support the activities.

Each of the four Programme areas of work is examined in turn in this section, first by providing an outline of the activities carried out under that heading, and then by assessing these activities using the RE-AIM framework (**R**each **E**ffectiveness **A**doption **I**mplementation

Maintenance). This facilitates examination of the following key questions:

Reach: What is known about numbers of staff, patients and families involved in the activity/strategy?
Effectiveness: What is known about the overall impact of the activity/strategy?
Adoption: What is known about the extent and nature of the adoption of the activity/strategy? Where did the activities happen (number of hospitals participating, etc.)?
Implementation: What is known about the ways in which activities may have been adapted or changed?
Maintenance: What is known about the extent to which the activity/strategy has become embedded/'institutionalised'?

The final part of this section looks at the Programme's overall achievements.

2.2 Audit and Standards

2.2.1 Activities

Figure 2.2 *Audit and Standards: key activities*

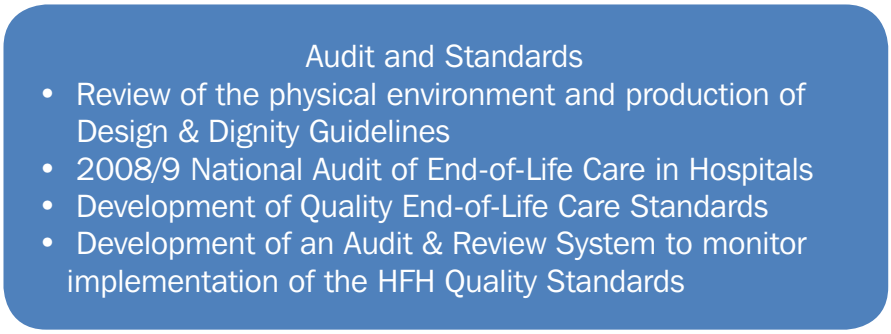


Figure 2.2 summarises the key activities undertaken in this area, these include:

1. **Review of the physical environment and production of *Design & Dignity* Guidelines to enhance end-of-life care in hospitals**.
   This review began with consultations and a review of the literature on hospital design,[6] published in November 2007. The physical environment of 20 hospitals (including five community hospitals) was assessed as part of this review. The findings were subsequently used as the basis for developing the draft *Design & Dignity* Guidelines, which were finalised in 2008 following a period of public consultation. To support the development of exemplar projects that put these guidelines into practice, a *Design & Dignity* Grants Scheme was developed by the HFH Programme in 2010 in partnership with the HSE. (See Section 2.4 for details).

6 Hugodot & Normand (2007) 'Design, Dignity and Privacy in Care at the End of Life in Hospitals'. Centre of Health Policy and Management, TCD.

2. 2008/9 National Audit of End-of-Life Care in Hospitals

The National Audit involved a review of patient cases across a number of acute and community hospital settings. It concluded that the 'quality of end-of-life care in Irish hospitals was high by international standards, but that significant opportunities for improvement existed'. A new audit and review system is currently in development. See below)

3. Quality Standards for End-of-Life Care in Hospitals

The development of the HFH Quality Standards was central to the work of the Programme as a whole.

The standards were influenced by the learning generated by the National Audit, together with a review of international research. They were finalised in light of feedback received from a public consultation process.

> The quality standards reflect this unity of the profound and the practical. They encourage us as individuals to reflect carefully on how we can honour the sacredness of every human life through responding with equal honour to the issues and experiences that are an essential part of being an individual.'
>
> ***President Mary McAleese Foreword to the HFH Quality Standards***

4. Development of an Audit & Review System for End-of-Life Care

A new audit and review system designed to support the monitoring and implementation of the Quality Standards is currently under development in collaboration with the HSE (Quality, Safety & Risk Directorate and Clinical Strategy & Programmes Directorate). This work is supported by a Project Advisory Group, which is co-chaired by the CEO of the IHF and the Clinical Lead for the HSE's Clinical Programme for Palliative Care, and includes representatives of HIQA and the HSE's National Audit Office. A number of healthcare sites are involved in piloting the new system.

Analysis of key activities under Standards and Audit, using RE-AIM

Table 2.1(a) An analysis of activities under *Standards and Audit*, using RE-AIM

Activity	Reach	Effectiveness	Adoption	Implementation	Maintenance
Design & Dignity **2008/9 Baseline Review** ↓ **Guidelines** ↓ **Grants Scheme**	20 hospitals (including 5 community hospitals) participated in the 2008/9 Baseline Review 11 acute hospitals awarded grants under the Design & Dignity Grants Scheme	First baseline data in place for the physical environment of hospitals. Design & Dignity Guidelines informed the development of the HFH Quality Standards Enhanced awareness of the importance of the physical environment in end-of-life care. The guidelines are listed in the *Resources* section of HIQA's national healthcare standards.	Future HSE development and refurbishment projects will be required by HSE Estates to refer to the Design & Dignity Guidelines	The Design & Dignity Grants Scheme was developed and jointly funded by the HFH Programme and the HSE in 2010 to support the development of exemplar projects. Over €1.5m. has been allocated to fund 11 hospital-based projects.	The commitment of HSE Estates in the development and administration of the grants scheme shows enhanced awareness at national level of the importance of the physical environment in the provision of quality end-of-life care. The exemplar sites developed with the support of the grants scheme will be key to generating momentum at local and national level.

Table 2.1(b) An analysis of activities under *Standards and Audit*, using RE-AIM

Activity	Reach	Effectiveness	Adoption	Implementation	Maintenance
Quality Standards for End-of-Life Care	32 acute hospitals are implementing the Quality Standards in the context of their participation in the HFH Acute Hospital Network.	The Quality Standards set out a shared vision of the care that each person should receive at end of life and of what hospitals should aim to provide. A framework and standards are now in place to assist hospitals to develop and enhance their end-of-life care.	See under *Reach*	Given that the Quality Standards are not mandatory, ongoing support is needed for their prioritisation and implementation. HFH hospitals are supporting this through their Networks. Through their engagement with the HFH Programme 32 acute hospitals have demonstrated their support for the Standards. The Standards achieved significant external endorsement from NESC in 2012 report, *Quality and Standards in Ireland: End-of-Life Care in Hospitals*.	End-of-life care is specifically mentioned in HIQA's 2012 *National Standards for Safer Better Healthcare* (Standard 1.7.3.). The HFH Quality Standards and HIQA's national standards share a focus on roles, outcomes and quality improvement. The HFH Standards are listed in the *Resources* section of the HIQA national standards. Highlighting their potential to assist in demonstrating compliance with the latter may be a good mechanism to encourage their wider implementation.

Table 2.1(c) An analysis of activities under Standards and Audit, using RE-AIM

Activity	Reach	Effectiveness	Adoption	Implementation	Maintenance
2008/9 National Audit  *This audit 'is a representative sample of 10% of acute hospital deaths and 29% of community hospital deaths'.* HFH Quality Standards for End-of-Life Care in Hospitals (p.29) **New Audit and Review System (2010)**	The national audit involved 24 acute hospitals and 19 community hospitals; and reviewed 1,000 deaths. The 6,413 informants involved included: 461 bereaved relatives (46% response rate). 737 doctors. 999 nurses. 2,358 ward staff. 1,858 other hospital staff. The new s**ystem** is being piloted in 35 sites: 6 acute hospitals. 5 community hospitals. 7 private nursing homes. 4 specialist palliative care services. 4 intellectual disability services. 9 GP/primary care centres.	The audit was a huge undertaking by busy hospitals. Overview of end-of-life care in hospitals in place for the first time in 2010. Local feedback reports provided to participating hospitals. The new system builds on the learning from the 2008/9 audit. When finalised, it will offer the HSE and HIQA a methodology to measure the achievement of the HFH Quality Standards and relevant national standards.	Staff responses to the initial phase of the pilot indicates that there is an appetite for an audit tool of this nature *'The audit provided significant opportunity for feedback to be given to staff members across different disciplines which would not have happened in the absence of the (review) meeting'.* Local Audit Facilitator *'The Audit Tool raised consciousness of issues that the team had not considered. It was very positive as it brought all key care providers together and significant learning was shared'.* Local Audit Facilitator	The audit was very resource intensive, with limited opportunities for team reflection. The new 2010 audit and review system was developed in partnership with the HSE's Palliative Care Clinical Care Directorate and in consultation with HIQA. Bereaved relatives' feedback in both the 2008/9 national audit and the pilot of the 2010 audit have highlighted many concerns, e.g. the quality of communications and the ability of hospitals to facilitate people in being with their relative as much as possible, including at the time of death. Care is needed to ensure that this feedback is managed in a constructive, non-threatening manner. The role of the HSE Advocacy Unit is key in relation to this issue.	HSE Palliative Care Clinical Care Directorate and HIQA involvement in the development of the new audit is vital to its implementation. Action will be required to ensure that the audit system, once finalised, is firmly embedded within the HSE, with a designated person responsible for driving its implementation nationally. At hospital level dedicated drivers and skilled facilitators are essential to the roll-out of the audit locally.

	Over the period April 2012-13: 120 deaths audited. 59 bereaved relatives surveys returned. 23 independent assessments conducted.			Local implementation of the audit has proved challenging in terms of the time required to set up audit meetings, as well as a level of anxiety among doctors in relation to conducting audits in the absence of the relevant FOI legislation. *'Not doing the audit would be just another day without stopping to press the pause button'* Audit Manager and Director of Nursing in a residential care service for older people	

***Standards and Audit*: Summary of achievements and challenges**

Activities in the area of the HFH Programme's Audit of End-of-Life Care and Quality Standards for End-of-Life Care have had a considerable and growing reach.
Securing the engagement of the HSE – and to a lesser extent, HIQA – in the process of developing and implementing the standards and audit has been a key challenge, not helped by the significant ongoing changes in the HSE in relation to its future direction, organisation and structures.
The establishment in 2011 of the new HSE Directorate of Clinical Strategy & Programmes and Directorate of Quality & Patient Safety were very welcome. The HFH Programme has managed to establish useful working relationships and linkages with both Directorates.

2.3 Culture Change

Training in end-of-life care positively affects the overall care outcome. Very few staff (13%) had received this kind of training.

National Audit of End-of-Life Care in Hospitals in Ireland, 2008/9 (2010)

2.3.1 *Activities*

Figure 2.3 *Culture Change: key activities*

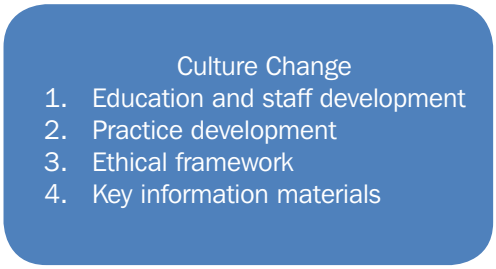


Figure 2.3 summarises the key activities undertaken in this area, these include:

1. **Education and staff development activities** instigated by the HFH Programme included three accredited training initiatives aimed at hospital staff: *Final Journeys*, a one-day workshop targeting all healthcare staff; *Dealing with Bad News*, a half-day workshop for all hospital staff who have a role in breaking bad news; and *What Matters to Me* – a one-day workshop designed for staff working in community hospitals/long-term care settings. The programme also provided bursaries to enable hospital staff to participate in the well-recognised eight-week European Certificate in Essential Palliative Care.

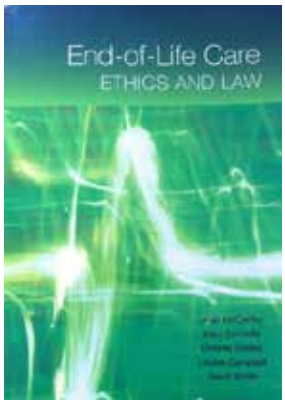
   I feel much more confident as a Health Care Assistant ...before this I would have avoided talking to patients and their families about dying and left all the decisions to the nurse to make. I didn't realise that I had a role to play too and that it was an important role.

   Healthcare Assistant who participated in HFH Programme training

2. **The Practice Development Programme**, which ran for a period of two years, was jointly initiated by the HFH Programme and the HSE's Office of the Director of Nursing Services. Its purpose was to equip key nursing and healthcare assistance staff with the skills to provide more effective person-centred end-of-life care to patients and their families. The programme had five strands, including one for major acute hospitals, another for acute and community care settings in the North West, and a national introductory practice development summer school. It also involved the provision of workshops for end-of-life care and a programme for nurses working in intellectual disability services.

> The Practice Development initiative … captured the imagination of senior nurses in the hospitals, who had met together to improve communication skills and strategies and then proceeded to implement specific projects at ward level, to create a 'cascading' effect. The emphasis here was on culture change and challenge within, giving people the tools to challenge the things that they see [are] wrong.
>
> ***Clark & Graham (2013, p.24)***

3. **The Ethical Framework for End-of-Life Care** was developed as an educational tool for professionals. It aims to foster and support ethically and legally sound clinical practice and decisions during difficult times in end-of-life treatment and care in Irish healthcare settings. Based on the experiences and practices of patients, families, the general public, the media, health professionals, hospital staff and legislators, the Framework also benefited from the learning arising from a study of practitioners' perspectives on autonomy at end-of-life (Quinlan & O'Neill, 2010), commissioned by the HFH Programme.



4. **Key information materials** produced by the Programme included the *Competence and Compassion* Map; a resources folder and a short animation entitled *A Wish*.

   The **map** provides healthcare staff with practical, easily accessible advice and prompts for the provision of end-of-life care, as well as information on the actions required following a patient's death. The second edition of the map was reviewed by the HSE's Clinical Programme for Palliative Care and includes the HSE logo.

   The **resources folder** was developed as a way of storing guidelines, leaflets, checklists and other end-of-life care materials in one place. It was designed using similar headings as the map.

   The **short animation**, *A Wish*, articulates in very human terms what dying in hospital may feel like for the patient, and how good end-of-life care can have a significant impact on his/her life and death.

   The HFH Programme website is also a very useful source of information on end-of-life care.

2.3.2 *Analysis of key activities under Culture Change, using RE-AIM*

Table 2.2(a) An analysis of activities under Culture Change, using RE-AIM

Activity	Reach	Effectiveness	Adoption	Implementation	Maintenance
Education & Staff Development	Approx. 4,438 people took part in training, Aug. 2010-Apr. 2013: 3,053 *Final Journeys*. 584 *Dealing with Bad News*. 801 *What Matters to Me*. 194 participants equipped & trained to facilitate & deliver the training: • 139 for *Final Journeys*. • 27 for *Dealing with Bad News*. • 28 for *What Matters to Me*. 278 healthcare staff (83% nurses, 13% doctors, 4% other) were awarded a bursary to undertake the European Certificate in Essential Palliative Care.	Participants have indicated that they: • have an increased awareness of end-of-life issues; • are better able to impart bad news; • share learning and knowledge with colleagues; • are better able to discuss end-of-life care concerns with residents in long-stay settings. Hospitals can deliver training in house. 73% of bursary recipients obtained certificate *Having participated in the training I now have the courage to answer questions that families might ask me* Team member, Nursing Home	Participant profile: *Final Journeys:* • 61% nursing • 1% medicine. *Dealing with Bad News* (10 acute hospitals & other care settings): • 30% medics • 4% nurses • 53% students (4th Med.) *What Matters to Me*: • 52% nursing • 1% medicine. Bursary applicants: • 82% from acute hospitals; the remainder from other healthcare settings.	*Final Journeys* spawned the two other workshops, one specifically targeting staff in long-term care settings. Uptake of all three was high. Trained participants strengthen the work of the local End-of-Life Standing Committees. With hospital staff trained as facilitators, hospitals can deliver the training from within their own resources. The long-term strategy for staff development programmes had been to roll them out through formal HSE training structures & other providers with individual facilitators within the hospital system. However, changes in the HSE and a moratorium on staff release for training over 2012-13 has made this challenging. As a result, the IHF made a decision to (a) focus on residential care settings and the regional development of *What Matters To Me* in 2012-13; and (b) continue to support *Final Journeys* facilitator training in acute hospitals.	Since 2012, responsibility for the various staff development programmes rests with the IHF education team. A key challenge remains the extent to which hospitals will be able/ prepared to free staff (particularly nursing staff) to attend training, given that the use of locums and agency nursing has been hugely curtailed. The Sept. 2013 'Haddington Road. Agreement' has added an extra shift to the workload of many healthcare staff, increasing reluctance to take on anything extra, such as training.

				Delivering *Dealing with Bad News* to medical students in association with the Royal College of Physicians of Ireland (RCPI) worked well initially, but has become more challenging following changes in RCPI personnel. Initially the HFH bursary covered the full cost of the European Certificate. Following a decision to request a 20% contribution from participants, applications fell – but the percentage successfully completing the training rose.	

Table 2.2(b) An analysis of activities under Culture Change, using RE-AIM

Activity	Reach	Effectiveness	Adoption	Implementation	Maintenance
Practice Development Programme	226 healthcare professionals participated 8 Band 1 Acute Hospitals participated: • The Mater • Tallaght • Galway University • St. James's • Mid- Western (Dooradoyle) • Cork University • Connolly • Beaumont 2 Nursing Homes participated: Beneavin Nursing Home Churchview Nursing Home	Participants developed: • A better understanding of end-of-life care practices. • Confidence to supportively challenge poor practice • Enhanced communication skills to sensitively relate to the dying person & family. • Capacities to share learning with their colleagues	The following engaged in the Programme: • 10 Acute Hospitals • 1 hospice in the North West • 4 Community Hospitals, • 2 Nursing Homes • 13 intellectual disability services • 50 individual participants in the Midlands and South-East	Participants used practice development processes to facilitate: • Critical review of environments to evaluate what clinical work areas feel like for a dying patient & their family. • The use of person-centred language when addressing patients/residents & families, and communicating with other team members • Enhanced levels of Individualised care planning. • The use of validated tools to critically evaluate practices and change 22 participants trained as Practice Development Facilitators. *'This process over anything else I have done for years has affected the way I reflect, act and the language I use, the way I think and work, how I see my life, what and where are my priorities. I am in a better space for it'.* Practice Development Participant	Hospitals involved have educated practice development facilitators within their staff, who are capable of facilitating further practice development initiatives. The extent to which hospitals will be prepared to free staff (particularly nursing staff) to participate is an issue. Management support is vital to support individuals engaged in practice development.

Ethical Framework	Available as an 8-module online document, with accompanying study sessions. Available as an academic text book.	The Framework is useful, relevant and accessible. The Framework inspired the development of the M.Sc. in End-of-Life Ethics at UCC.	Unclear to what extent staff working in hospitals and other healthcare settings are aware of this resource. Unclear to what extent it is used.	The Framework document is accessible online, but no record is available of the number of downloads or identity of downloaders. The Framework is used as the case book by M.Sc. Palliative Care students in UCC. This new two-year programme had its first intake of 9 students in 2011. Two scholarships were offered by the IHF.	There is scope for the Framework, the *Competence & Compassion* map and the animation (*A Wish*) to be used in training for: • Medical personnel • Wider healthcare personnel • Staff training and induction in hospitals
Key Information Materials	The *Competence & Compassion* map, resources folder and short animation (*A Wish*) were distributed across hospitals and other healthcare settings, and to professional training bodies, e.g. RCPI.	Staff have access to a pocket-sized practical guide and other resources to assist them in providing enhanced levels of end-of-life care. The animation makes the patient's end-of-life experience in hospital very real. Anecdotal feedback has been very positive.	The exact extent to which the map, resources folder and animation have been used is unknown.	Copies of the map, the resources folder and the animation were circulated to hospitals and healthcare settings participating in the Programme, and are also available to download on-line.	

Culture Change: Summary of achievements and challenges

Over 4,500 healthcare staff participated in dedicated end-of-life care training, and as a result, report being more familiar with end-of-life care issues and more confident in dealing with patients facing the end of life and their families.
8 major acute hospitals participated in practice development work; however, sustaining this learning culture in these busy hospitals is a challenge.
An ethical framework now exists to guide and support healthcare staff involved in end-of-life care; its use needs to be more widely promoted.
A variety of practical information materials on end-of-life care are now available to all healthcare staff in a variety of healthcare settings.

2.4 Capacity Development

Figure 2.4 *Capacity Development: key activities*

Capacity Development

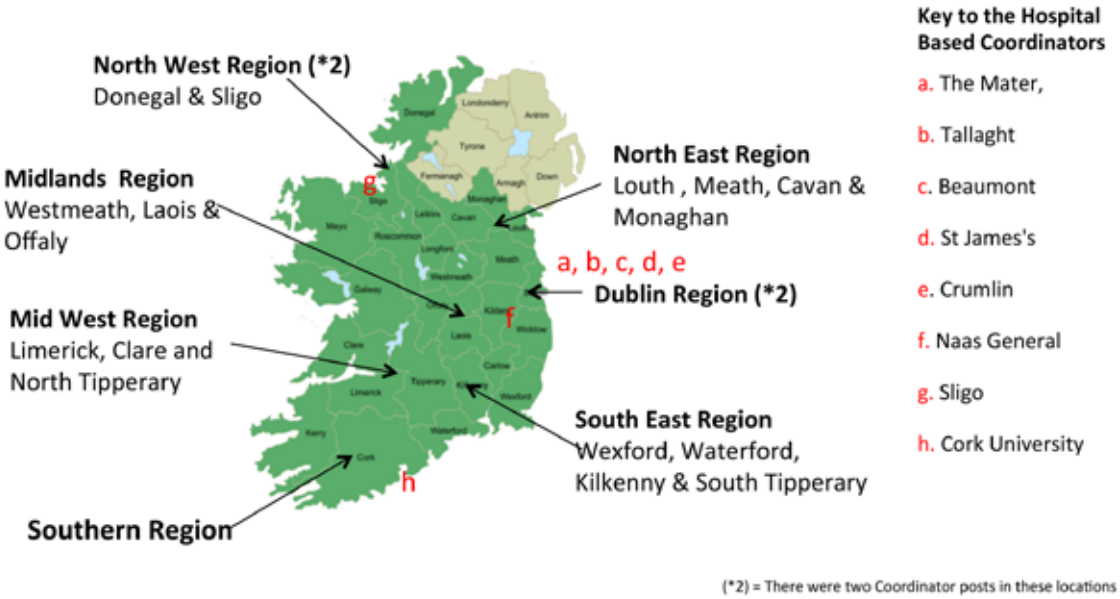
1. Structures to support End-of-Life Care
2. End-of-Life Care Development Plans
3. HFH Community Hospitals Network
4. HFH Acute Hospitals Network
5. Design & Dignity projects
6. Symbolic resources

2.4.1 *Activities*

Figure 2.4 above summarises the key activities undertaken in this area, which are as follows

1. **Structures to support end-of-life care.**
   These included the HFH Programme's employment of either (a) regional or (b) hospital-based End-of-Life Care Development Coordinators (at CNM3[7] level) to take responsibility for progressing and winning support for the end-of-life care agenda. See Figure 2.5 for the location of these posts. These Coordinators were in post for an average of two years.

Figure 2.5 *Location of End-of-Life Care Development Coordinator posts (full time/part time)*



An alternative approach was to charge an existing staff member with responsibility for progressing end-of-life care. The first task of the designated person/Coordinator was to establish a hospital-based End-of-Life Care Standing Committee. The key initial task of these Standing Committees and their sub-committees was to get end-of-life care included in wider hospital plans.

2. **End-of-Life Care Development Plans** were developed and implemented by the hospital-based Standing Committees as the key vehicle to ensure progress on the implementation of the end-of-life agenda and specifically the HFH Quality Standards for End-of-Life Care in Hospitals. Once a plan was in place, the expectation was that it would be reported on quarterly.

3. **The HFH Community Hospitals Network** was established in 2009 with a small core group of Dublin-based community hospitals and community nursing units. Its purpose was to facilitate collaboration between these care settings and to identify common challenges and possible solutions in the provision of end-of-life care. Network members include representatives from participating centres: staff nurses, nurse managers, directors of nursing, healthcare assistants, doctors, allied health professionals and chaplains, as well as representatives of the HSE's Older Persons Service, acute hospital geriatricians, community intervention teams, specialist palliative care services and advocacy groups. The group meets four times yearly, supported by a Community Hospital Development Coordinator, who is also responsible for rolling out the *What Matters to Me* training initiative, targeted at those working in community hospitals and long-term care settings.

4. **The HFH Acute Hospitals Network** was established in 2010 to develop the capacity of acute hospitals to meet the HFH Quality Standards for End-of-Life Care in Hospitals. Its purpose was to facilitate a collaborative approach to improving end-of-life care in acute hospitals nationally. Hospitals are represented on the Network by the Chair/Vice Chair of their HFH End-of-Life Care Standing Committee, and it also includes a representative of the HSE's Clinical Programme for Palliative Care as well as an Acute Hospitals Manager. The Network meets three times a year. See Figure 2.6 for membership.

Figure 2.6 *Members of the HFH Acute Hospitals Network*

5. **The Design and Dignity Grants Scheme** was developed in 2010, jointly funded by HSE Estates and the IHF, to the tune of €1.5m. Its purpose was to develop a range of exemplar projects to guide the future development of hospital facilities of relevance to end-of-life care, by putting into practice the 2008 HFH *Design and Dignity* Guidelines. Initiatives funded ranged from extensive development projects, such as a significant renovation of Beaumont Hospital's mortuary, to more modest refurbishment work, such as the creation of a bereavement/infant viewing room at St Luke's Hospital in Kilkenny.

6. **The symbolic resources** produced for use in hospitals included:
   - a sign featuring the end-of-life spiral, to subtly notify staff that a patient is dying or has died;
   - a mortuary trolley drape, used to promote respect and a sense of ceremony;
   - a mobile altar, to facilitate the provision of spiritual care on the ward;
   - a family 'handover' bag, for respectful return of a patient's belongings to relatives; and
   - a sympathy card to be sent by staff on a ward where a patient has died (preferably before the hospital bill).

Figure 2.7 *End-of-life spiral signage*

Figure 2.8 *Trolley drape*

Figure 2.9 *Ward altar*

Figure 2.10 *Family handover bag*

2.4.2 *Analysis of key activities under Capacity Development, using RE-AIM*

Table 2.3(a) An analysis of activities under *Capacity Development*, using RE-AIM

Activity	Reach	Effectiveness	Adoption	Implementation	Maintenance
Structures to support end-of-life care – End-of-Life Care Development Coordinators and Standing Committees	Development Coordinator posts served 18 acute hospitals. 8 acute hospitals had a *dedicated* Coordinator. Over 35 community hospitals located around the country. *'Love and Steel' were required of the Development Coordinators* (Clark & Graham, 2013)	End-of-Life Care Standing Committees were established in 16 acute hospitals, with consistent attendance from all staff groups 9 of the 11 acute hospitals that developed End-of-Life Care Development Plans had the support of a Coordinator.	21 senior managers responsible for the end-of-life care agenda in 21 acute hospital settings. Few doctors attend or are members of hospital Standing Committees.	Having Development Coordinators in post, while resource intensive, facilitated the more rapid establishment of the Standing Committees. The Coordinator role was challenging. with a high turnover. A lot of time and support was provided to the Coordinators by core Programme staff. The question arises as to whether the HFH Programme should have sought a % contribution from the hospitals for the Coordinator post. Coordinator posts have been re-established with hospital funding in 3 sites: Beaumont, the Mater and the Mid-West hospital group. Work is under way to re-establish 2 further posts.	Sustaining momentum for HFH initiatives in hospitals which do *not* have the support of a Coordinator is an issue in busy acute hospitals. 5 hospitals have indicated that they are prepared to contribute to the cost of the post. There may also be scope for other posts to be funded jointly with hospitals.

2.4.2 *Analysis of key activities under Capacity Development, using RE-AIM*

Table 2.3(a) (continued) An analysis of activities under *Capacity Development*, using RE-AIM

Activity	Reach	Effectiveness	Adoption	Implementation	Maintenance
End-of-Life Care Development Plans	Development Plans in place in 12 sites (11 public acute hospitals, 1 private hospital). Plans in development in 7 more sites, with end-of-life care objectives included in their annual service plans.	Having a Development Plan in place within a hospital supports the prioritisation of end-of-life care issues across the hospital.	Development Plans in place in hospitals: • Dublin (4) • Connolly; Mater; Mater Private, • St James's. • North East (2) • Our Lady of Lourdes, Drogheda; Cavan/ Monaghan Hospital Group. • Cork (1) – Mercy • The West (1) • Sligo General • The Mid West (4) • Limerick, Nenagh, MW Maternity, • Ennis. Plans in development in: • Our Lady's, Navan • Beaumont • South Tipperary • Wexford General • Galway University • Midland Regional (Portlaoise, Tullamore)	Not all hospitals have reached the same level of progress re an End-of-Life Care Development Plan. Getting end-of-life care objectives into hospitals' annual service plans is a pragmatic way of ensuring that end-of-life care concerns are on their agenda. Putting a dedicated End-of-Life Care Development Plan in place at a time of scarce resources is a significant undertaking, representing a clear commitment. Some hospitals do not submit quarterly reports; in these cases it is not known whether the Development Plan is still being used.	Monitoring the implementation of the plans in place will be key. Plans to be monitored on an ongoing basis. Work also needs to continue to encourage others to develop similar plans.

Table 2.3(b) An analysis of key activities under *Capacity Development* using RE-AIM

Activity	Reach	Effectiveness	Adoption	Implementation	Maintenance
HFH Community Hospitals Network (Greater Dublin area)	Membership grew from 7 to 26 in the period November 2009-May 2013.	26 hospitals receive ongoing inputs and information in relation to the HFH Quality Standards. Meetings provide a unique opportunity to network with peers.	Membership focused on the greater Dublin area. 11 well-attended meetings of the Network (individual attendance records not kept.)	Meetings involve: • input from Network members • input from HFH Programme staff and others • input from specialists, e.g. coroners • time for networking.	The Network is working well. A key challenge is to maintain focus on end-of-life care rather than care in general. Based on increasing membership and good attendance in Dublin, there may be scope to establish a Community Hospitals Network/s in another region/s. Resources would be required to support it.
HFH Acute Hospitals Network (National)	Membership has grown to 31 acute public hospitals (representing 62% of the total) plus 1 private hospital, with 2 more due to join.	Participants get support in relation to the HFH Quality Standards. Internal surveys of members (undertaken by HFH staff) found awareness of: • how to prepare End-of-Life Care Development Plan; • correct use of end-of-life care symbol • value of HFH Programme training. The Network provides a unique opportunity to engage with personnel from the HSE's Clinical Programme for Palliative Care and with peers.	Hospitals involved from across Ireland. Network has met on 12 occasions. Meetings generally well attended (individual attendance levels not kept).	Initially, Network meetings involved two days and an overnight stay, which was considered a useful, if costly, networking opportunity. As time progressed meetings have been condensed into a day to enable busy participants to better balance their involvement in the Network with their other commitments. *'I am aware that a number of Network participants attend meetings in their own time, because they find the meetings useful and because their workplace will not give them time to attend'.* (HFH Programme Manager, April 2013)	Maintaining the Network is critical to providing ongoing support for the implementation of the HFH Quality Standards. Links between the Network, its Members and the HSE's Clinical Programme for Palliative Care need to continue to be developed. The Network could be developed as a support and testing ground for the policies and practices of the HSE's Clinical Programme for Palliative Care.

Table 2.3(c) An analysis of key activities under Capacity Development, using RE-AIM

Activity	Reach	Effectiveness	Adoption	Implementation	Maintenance
***Design & Dignity* projects**	11 projects shared €1.5m. funding. Projects varied from extensive development work, e.g. the creation of viewing rooms and/or family rooms to more modest refurbishment work.	The full value of the *Design and Dignity* grants scheme has yet to be known, with just 3 projects completed. Six more are to be completed by end 2013; and 2 more in 2014 *This building has … given us a space that is dignified, that is bright, that is airy, that's embracing of all religions and none.* Margaret McKiernan Assistant Director of Nursing Mercy University Hospital	Projects were funded in hospitals in: Dublin (4) the West (4) the South (2) the North East (1) Before we had these rooms, we'd have to bring families from the room where we break the bad news to them on to the corridor. Cliona O'Beirne Clinical Nurse Manager St James's Hospital	Applicants rarely made provision for contingencies, or for additional costs associated with the use of materials acceptable to the Infection Control Team. As a consequence, many projects had to make additional requests for financial support. *The family room is a wonderful addition to the ward .– there was nowhere to relax when I was here. The pictures are beautiful and a great addition to the room. Well done on all the great work!* Mater Hospital Patient	By early 2014, 11 exemplar projects will be in place which can be used as guides for the future design and development of end-of-life care facilities. It is unlikely in the current climate that much additional infrastructural development will take place in the short term. A strong working partnership has been established between the HFH Programme and HSE Estates.

Symbolic resources	Resources used in over 20 acute hospitals and various community hospitals around the country.	Resources make a difference to families and to staff engaged in providing end-of-life care. *… Appropriate symbols… remind staff that a resident was receiving end-of-life care. This was a sensitive way of reminding staff, in a busy & possibly noisy unit, that a resident was dying'* HIQA Inspection Report Clonakilty Community Hospital	There has been a good uptake of resources: End-of-life spiral sign: 20 hospitals. Trolley drape & family handover bag: 17 hospitals Sympathy card: 19 hospitals. Records are not kept in community hospitals/ long-stay care settings.	Simplicity and practicality of resources has made their usefulness apparent. In 2012 the HFH Programme published guidelines on the correct use of the end-of-life spiral symbol. Questions exist as to why approximately 30% of acute hospitals participating in the Programme are not using these resources. *You're on a ward … fire fighting, you don't have time to say 'how could we be doing things differently?' but when somebody sees the handover bag they're always, like, 'oh yeah, I always had a bit of an issue with the plastic bag actually, here's a practical solution'* Interview 18, (Clark & Graham, 2013)	The simplicity, practicality and relatively low cost of these resources make it likely that they will continue to be used. It is hard to know if the resources are being used consistently.

Capacity Development: Summary of achievements and challenges

- The establishment of hospital End-of-Life Care Standing Committees was accelerated with the support of dedicated End-of-Life Care Development Coordinators, particularly in the early stages of the HFH Programme's development.
- Getting End-of-Life Care Development Plans put in place has been a challenge: about 35% of the acute public hospitals participating in the HFH Programme have achieved this. A further 22% are working on plans. Others have opted to include end-of-life care objectives in existing service plans. It remains to be seen which is the more effective route to progressing the end-of-life care agenda.
- Membership of the Community Hospitals Network and Acute Hospitals Networks has grown. Meetings are well attended, suggesting they are useful fora.
- 11 *Design & Dignity* projects have been funded. When fully completed, these will enhance the physical environment of end-of-life care facilities for patients, their families and the staff supporting them in eight locations around the country.
- A variety of symbolic end-of-life care resources are in place and in use across a range of healthcare settings.

2.5 Influencing the Health System

2.5.1 *Activities*

A key concern of the HFH Programme has been to liaise and work with the HSE and HIQA in order to ensure that the learning generated by the Programme in relation to end-of-life care in hospitals and long-stay care settings transferred at national level to these bodies.

Figure 2.11 provides a chronological overview of developments within the health system and the HFH Programme, and the interaction between them, which have implications for end-of-life care.

My mother died in the busy stroke unit at an overstretched hospital but nurses behaved in keeping with what is a profound, almost sacred moment for the family. They lit candles and placed a Celtic "Triskele" (HFH end-of-life spiral symbol) on the door of her room to alert other staff and patients. They covered her in an elegant purple drape and, when we eventually left, they hugged us, handing over a woven bag, her things neatly folded inside. When it seems unbearable that your mother has just died and the rest of the world is carrying on as normal, these gestures are comforting.

Butler, K. The Independent, 3 September, 2013: At that hour: dealing with death

The Irish health system is currently engaged in an ongoing process of change and transformation at every level. The key focus is to ensure that all our resources are directed towards better services for our population.

Síle Fleming, Assistant National HR Director for Organisation Development & Design,

Figure 2.11 *Key developments within the health system and the HFH Programme, and their interaction, with implications for end-of-life care*

Year	Health system developments	Points of contact/collaboration	HFH Programme developments
2005	**HSE established.**	Joint IHF and HSE pilot project, ***Care for People Dying in Hospitals,*** in Our Lady of Lourdes Hospital, Drogheda.	Funding secured for HFH Programme.
2006	**HSE agree to be involved in HFH.**		
2007	**HIQA established.**	From inception to Oct. 2007 the HFH National Steering Committee chaired by a former Deputy Chief Executive of the HSE	HFH Programme launched. Work begins on the development of HFH Quality Standards for End-of-Life Care.
2008			Publication by the HFH and National Council on Ageing and Older People of the study, ***End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland***.
2009	**HIQA launch National Quality Standards for Residential Care Settings for Older People in Ireland.**		HFH Community Hospitals Network established.
2010		Launch of the jointly funded HSE/ HFH ***Design and Dignity*** Challenge Fund	HFH Acute Hospital Network established. Launch of Quality Standards for End-of-Life Care in Hospitals and 2008-9 Baseline Review
2011	**Establishment of HSE Directorates of (a) Clinical Strategy and Programmes and (b) Quality and Patient Safety.**	Meeting with HSE CEO to discuss implications of HFH Quality Standards. Workshop held to explore potential for closer collaboration between the IHF/ HFH Programme and the HSE in the area of end-of-life and palliative care. HFH Programme and HSE begin work on an end-of-life audit and review system. The work is supported by a Project Advisory Group which includes representatives of HIQA.	
2012-2013	**HIQA publication of general healthcare standards – HFH Quality Standards acknowledged.**	Joint work continues on the development of the end-of-life audit system. The HSE Clinical Programme for Palliative Care, the All Ireland Institute for Hospice and Palliative Care, the IHF and the Irish Association for Palliative Care work together to oversee the development of a Palliative Care Competence Framework. HSE palliative care personnel regularly attend Acute Hospitals Network meetings.	

Figure 2.12 *Influencing the Health System: key activities*

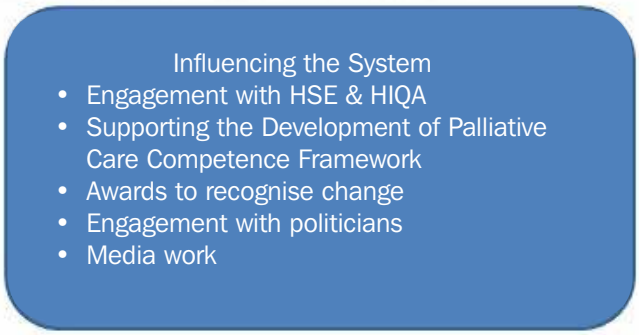


Figure 2.12 above summaries the activities undertaken in this area, which are as follows:

1. **Engagement with the HSE and HIQA**
   Cooperation between the Irish Hospice Foundation and the national health service on end-of-life care in hospitals pre-dates the HFH Programme proper, having begun with the joint pilot project (*Care for People Dying in Hospitals*) which ran in Our Lady of Lourdes, Drogheda, from 2004 to 2006. For the HFH Programme, however, sustaining that engagement was challenging, given that the Programme got under way against a backdrop of significant re-structuring of the health service, and in the absence of a dedicated unit within it with responsibility for end-of-life care.
   The year 2010 saw the first substantial practical collaboration between the Programme and HSE, with the joint funding of the *Design & Dignity* Fund, and with the development of the Practice Development Programme. In 2011 a meeting took place with the new CEO of the HSE to discuss the potential for wider application of the HFH Quality Standards and greater collaboration between the HSE and the Programme. This was made easier by the establishment in 2011 of the HSE's Clinical Strategy and Programmes Directorate and Quality and Patient Safety Directorate. Since then, there has been more ongoing engagement, particularly in relation to the Acute Hospitals Network. Engagement with HIQA has also progressed over this time, and HIQA and the HSE are now actively involved in the development of the end-of-life audit and review process.

2. **Supporting the development of a Palliative Care Competence Framework**
   The HSE's Clinical Programme for Palliative Care, the All-Ireland Institute of Hospice and Palliative Care (AIIHPC), the IHF and the Irish Association for Palliative Care (IAPC) are partners on the Steering Group for the HSE Palliative Care Competence Framework, supporting, guiding and overseeing this work. Initially, this framework was to focus on nursing, but a decision was made subsequently to extend it to other healthcare disciplines, including medicine, social work, occupational therapy, pharmacy, physiotherapy and healthcare assistance. The objective is 'to generate a clear framework to support evidence-based, safe and effective palliative care for generalist and specialist practitioners, irrespective of place of practice'.[8] An earlier project sponsored by the HFH Programme and the HSE Office of Nursing and Midwifery, which focused on end-of-life care education (pre- and post-registration)

8 Connolly, M. & Charnley, K. (undated) A Palliative Care Competence Framework for Ireland- Implications for Public Health Nursing.

and continuing professional development, was subsumed into this framework.

3. Engagement with politicians and the political system

The HFH Programme team, together with IHF staff engaged in advocacy, have met with politicians from across the political spectrum throughout the lifetime of the Programme to try and win support for enhanced end-of-life care across healthcare settings. In 2008, for example, the HFH team took Enda Kenny, TD (in his capacity as leader of the Fine Gael party) to visit Leopardstown Park Hospital and see the situation there. This led him to raise the issue of the poor conditions he had witnessed at Leader's Questions in the Dáil. In 2009, the HFH Programme worked to support independent Senator, Ronan Mullen, to jointly sponsor a debate under Private Members' Business in the Senate on end-of-life care, with reference to the HFH National Audit of End-of-Life Care in Hospitals and Quality Standards for End-of-Life Care in Hospitals. In 2010 the Programme had the (then) Minister for Health & Children, Mary Harney, TD, launch the joint HFH Programme/HSE *Design and Dignity* Challenge Fund, while in the same year the former President, Mary McAleese, wrote the foreword to the HFH Quality Standards.

4. Raising the profile of end-of-life care in the media

While the HFH Programme did not have a specific targeted communications strategy, it was successful in securing positive newspaper coverage of its work and of the end-of-life care agenda. The use of high-profile public figures, particularly in the early stages of the Programme, was a good technique for attracting media coverage.
As part of its work to raise the profile of end-of-life issues, the IHF sponsored a HFH Award as part of the Irish Healthcare Awards. The first award was made in 2012 to the Mater Hospital.

2.5.2 *Analysis of key activities under Influencing the Health System, using RE-AIM*

Table 2.4(a) An analysis of activities under *Influencing the Health System*, using RE-AIM

Activity	Reach	Effectiveness	Adoption	Implementation	Maintenance
Engagement with the HSE and HIQA	On-going engagement with: HSE Estates. HSE Clinical Strategy & Programmes Directorate, incl. the Clinical Programme for Palliative Care. HSE Quality & Patient Safety Directorate. HIQA (in relation to the end-of-life care audit).	HSE and HIQA involvement is critical to ensuring that the learning arising from the HFH Programme is translated into national policy and practice.	Useful linkages have been established. Examples of strong partnership include work on the new audit and review system and activities related to *Design & Dignity*.	In the Programme's start-up phase, much was done to engage with the HSE at corporate level. This waned somewhat in subsequent years for a variety of reasons, some of them beyond the Programme's control. The establishment of relevant dedicated Directorates within the HSE has since made engagement easier.	Sustaining the engagement of the HSE and other key organisations is critical to promoting the end-of-life care agenda. The HFH Programme will ensure a planned approach is in place to facilitate ongoing engagement. Changes in relation to the HSE's future direction, organisation and structures will continue to pose challenges.
Palliative Care Competence Framework	When complete, the Framework will cover nursing, medicine, social work, occupational therapy, pharmacy, physiotherapy and healthcare assistance.	The active involvement in the Framework's development of the HSE's Clinical Programme for Palliative Care; the AIIHPC; the IHF and the IAPC, is ensuring that best use is made of existing skills and competencies.	When complete, the Framework will ensure that palliative care is embedded in the competencies of a variety of health and social care professionals.	The lead provided by the HSE in the development of the Framework should support its implementation in practice.	

Raising the profile of End-of-Life Care Profile in the Media	Since its launch in May 2007 to April 2013 the Programme achieved the following coverage: Coverage of the Launch of the Ethical Framework on RTE Radio 1's Programme. *Today with Pat Kenny* 67 articles in the national media / radio/TV including 23 editorials in the Irish Times 18 articles in the health/ medical media 20 articles in the local papers/radio and online media	Ongoing reportage of HFH Programme and end-of-life issues to higher social groupings* in the Leinster area. (**Irish Times has a higher percentage of ABC1 readers than any other Irish daily, with 71% of its readers in Leinster and 57% in the Greater Dublin area.*) Hospital-based staff engage with local media.	Good coverage in one daily paper particularly in the early days of the programme. Developing interest among other media which needs to be further exploited.	Need to develop enhanced linkages with the media in all its forms.
Engagement with politicians	Meetings held across the political spectrum.	Contact with senior politicians concentrated in the earlier stages of the Programme's development.	Scope for more contact with senior politicians with an interest/ involvement in the health agenda and reform process.	Need to develop enhanced links with politicians who have a health brief, given that the HSE is now a delivery agent of the Department of Health.

Influencing the Health System: Summary of achievements and challenges

- Engagement and relationships with the HSE have grown and deepened over the lifetime of the HFH Programme. The establishment of the HSE Directorates with responsibility for end-of-life care has supported this process.
- The shared development of a national Palliative Care Competence Framework is a key way of ensuring that end-of-life care becomes the business of all working in the health sector
- Engagement with politicians has taken place throughout the lifetime of the Programme; there is a need for more intense engagement with those who have a health remit, given that the HSE now reports directly to the Department of Health.
- Media coverage of the Programme has ranged from excellent in the Irish Times to virtually non-existent in some other media.

2.6 Overall Achievements

In general:

- Very significant funds won for a national initiative to improve end-of-life care in hospitals.
- A coalition of support established across state and philanthropic agencies, while also involving a wide range of lay, professional and academic groups.
- A programme team assembled under strong leadership supported by the Irish Hospice Foundation.
- Many examples occurred of 'thinking outside the box' of healthcare reform.
- A host of workshops, conferences, expert meetings and consultations tackled end-of-life issues in the hospital from a variety of perspectives.
- Imaginative use made of the evidence base; original research commissioned; and senior academics harnessed to the cause.
- Extensive information/training materials, guidelines and symbolic resources developed for use in hospitals.
- The HFH Programme website provides a comprehensive and up to date portal to the vast range of programme activities and outputs.

  Source: Clark & Graham (2013)

Audit and Standards

- Activities in relation to the HFH Quality Standards and Audit of End-of-Life Care have had a considerable and growing reach.
- 32 acute hospitals are implementing the standards and 35 healthcare sites are participating in piloting the new audit system designed to monitor the implementation of the standards.
- The 2008/9 National Audit involved a review of 1,000 deaths across 24 acute hospitals and 19 community hospitals and involved almost 6,500 informants.

Culture Change

- 4,438 participants took part in staff development programmes, while 194 people were trained to deliver these programmes.
- 278 individuals received financial support to enable them achieve recognised certification in essential palliative care.
- 226 individuals participated in practice development initiatives.
- An Ethical Framework for End-of-Life Care was made available to hospital staff for the first time.
- A variety of relevant and accessible end-of-life information materials and resources were made available to hospital staff.

Capacity Development

- End-of Life Care Development Plans in place in 11 large public acute hospitals.
- End-of-life care objectives included in the annual service plans of a further 7 acute hospitals which are in the process of developing End-of-Life Care Development Plans.
- 18 acute hospitals and more than 35 community hospitals benefited from the support of an End-of-Life Care Development Coordinator over an average two-year period.
- HFH Community Hospitals Network established, with growing membership (currently

26) and good attendance at meetings.
- HFH Acute Hospitals Network established, with growing membership (currently 31) and good attendance at meetings.
- 11 projects shared €1.5m. in funding aimed at the physical improvement of end-of-life care facilities, ranging from extensive development work to more modest refurbishments.
- Symbolic end-of-life resources developed by the HFH Programme are now in use in more than 20 acute hospitals and various community hospitals around the country.

Influencing the Health System

- Positive and sustained linkages have been developed with the relevant HSE Directorates and with HIQA.
- A number of partnership arrangements have been developed to progress particular projects, including the new end-of-life audit system, and the further development of the role of the Acute Hospitals Network.
- Media coverage of the HFH Programme has been excellent in the Irish Times, but limited in other media.
- Engagement with politicians has been ongoing, with particularly strong engagement with senior politicians in the Programme's earlier stages.

3. Key Learning and Next Steps

3.1 Key Learning Overview

The HFH Programme has successfully managed to raise the profile of end-of-life care in hospitals and other healthcare settings at both hospital and national level. Through its investment in people, systems and facilities, it has made a very positive contribution to the case for making end-of-life care central to the work of hospitals, other healthcare settings and health service providers.

The Programme has also generated a range of learning, both strategic and operational, across a number of areas. The HFH Evaluation Advisory Group worked with the author of this report to identify and prioritise this learning under five main headings, as follows:

- Sharing the vision
- Governance
- Engagement
- Key drivers
- Tools generated.

The purpose of this prioritisation is to provide direction for the Programme for the next phase of its operation.

3.2 Sharing the Vision

3.2.1 *Learning*

Large-scale philanthropic funding enabled the HFH Programme to engage in a very wide range of activities – such as the audits and the *Design and Dignity* review – that built an evidence base to support its vision. The sheer scale of the actions undertaken and the variety of language used within the Programme can at times, however, be seen to have diluted its overall vision and purpose. Interestingly, as implementation of the Programme progressed, certain areas were prioritised over others and HFH became more clearly focused on a smaller range of topics more clearly related to its vision.

The use of the word ‘hospice’ in the Programme name was a source of difficulty for both the specialist palliative care sector and more general hospital staff. Concerned to ensure that palliative care should be understood as applying throughout the trajectory of chronic and life-limiting illness, specialist palliative care professionals had issues with the emphasis on care for the dying (Clark & Graham, 2013). The more generalist view, in contrast, related to the fact that end-of-life care was largely considered to be the domain of a medical specialty that deals with expected rather than sudden death. More positively, however, the use of the term ‘hospice-friendly’ enabled the IHF to build a clear brand for the Programme, an important element in introducing a new concept.

Making end-of-life care the concern of all hospital staff required massive change at both hospital and national level. It required firstly a sharing of the vision and securing the engagement of senior health service staff within hospitals and nationally.

Getting this 'buy in' was a challenge: at national level, because of ongoing changes in health service structures, along with limited awareness of end-of-life care needs. The formation in 2011 of the new HSE directorates of Clinical Strategy and Programmes and Quality and Patient Safety respectively has led to the development of a series of very useful joint initiatives and closer working relationships between the HFH Programme and the HSE, in particular.
At hospital level the difficulty lay with a general overload of work coupled with diminishing resources, both financial and human, resulting in a general reluctance to take on any additional activities. There was also a particular challenge associated with winning the engagement of medical staff, who tended to consider end-of-life care as the exclusive domain of specialist palliative care and therefore not their responsibility. Notwithstanding all of these issues and challenges, the Programme managed to share its vision and secure the engagement of 32 public acute hospitals and over 35 other community hospitals/healthcare settings.

3.2.2 *Next steps*

The HFH Programme needs to:

- Sustain the hard-won 'buy in' of the public acute hospitals in particular, in the face of strong and growing anecdotal evidence of growing levels of work overload. This is critical to the further development and future success of the Programme.
- Find ways to nurture and sustain the support of key locally-based hospital staff for the end-of-life care agenda, in order to encourage and sustain individual hospital participation.
- Support and inspire greater buy-in from medical staff.
- Continue to work at national level to sustain the engagement of the HSE and HIQA.
- Reinvigorate the Programme in order to ensure that end-of-life care (a) remains a priority for hospitals participating in the Programme and (b) becomes a priority for those considering participation.

3.3 Governance

3.3.1 *Learning*

The HFH Programme was managed – particularly in the first few years of its operation – at some remove from the IHF executive and Board. Mediated through the National Steering Committee, the Programme's reporting to the IHF Board tended to be more operational than strategic. Because of its budget and the scale of activities it supported, the HFH Programme 'brand' could in some ways be seen as competing with the IHF brand over this period.
The development of the IHF's 2012-2015 Strategic Plan[9] saw the Foundation clearly state its commitment to the HFH Programme, and as part of that process, management structures were reviewed and the IHF Board took over full responsibility for the oversight and management of the Programme.

9 IHF (2012) Strategic Plan 2012-2015. IHF, Dublin.

3.3.2 *Next steps*

The IHF needs to continue to oversee the management of the HFH Programme, with Programme reporting aligned with the Foundation's strategic plan and priorities.

3.4 Engagement

3.4.1 *Learning*

At national level, the health services have been been in a constant state of flux over the lifetime of the HFH Programme, with ongoing associated budgetary problems. For the Programme (and indeed the IHF), engaging with a constantly changing system has been a challenge, particularly as end-of-life care only became the responsibility of dedicated HSE directorates in 2011. The formation of these directorates has provided the Programme with a clear route into the HSE, which in turn has resulted in a closer working relationship.
At hospital level, experience has shown that whatever the scale of the hospital, it has taken courage for individuals to advocate for their hospital to engage in the end-of-life care agenda and specifically in the HFH Programme. Many of these individuals have continued to act as advocates for the Programme as it has developed. They have been a powerhouse of support, and ways need to be found to continue to encourage them and others leading end-of-life care initiatives at hospital level.

Experience has also shown that active and sustained engagement with the end-of-life care agenda at hospital level requires dedicated resources. In the early stages of the HFH Programme, the End-of-Life Care Coordinators fulfilled this role. As the lifetime of these posts came to an end (in the majority of HFH hospitals), responsibility has passed back to the hospital to provide this support. The most effective way to do this would be for hospitals to commit protected staff hours to the Programme.

The busy reality of hospitals is that those who join the Programme cannot take on all its elements simultaneously. Individual hospitals therefore need to be supported to take more local ownership of the Programme as a *process* and to pursue the core elements that are relevant to them, with an option to implement non-core elements in time.

3.4.2 *Next steps*

At national level, the HFH Programme needs to continue to engage with the dedicated HSE directorates. With no guarantee that these will be protected in the future, it also needs to continue to develop its engagement with HIQA and particularly with the Department of Health, in order to pursue national policy developments in relation to end-of-life care.

At hospital level, continued involvement in the HFH Programme requires hospitals to commit protected staff hours to support its implementation, while staff charged with this responsibility need to be supported to enable them to fulfil it.

Hospital participation in the various HFH networks is an important source of peer and overall Programme support. The HFH team also needs to be 'visible' at hospital level and supportive of key staff on the ground, which means more site visits. In addition, the Programme needs to find ways to highlight the work of exemplar hospitals and encourage the newly emerging

hospital groupings, as well as to consider how best it can reach out to hospitals not yet participating in the Programme with its current level of resources.
At the level of the Programme, there is a need to:

- Assist hospitals to make the business case and promote the value of the HFH Programme at a hospital level.
- Clarify the core elements required to implement the Programme at (a) hospital level and (b) within the new hospital groupings that will represent several hospitals.

3.5 Key Drivers

3.5.1 *Learning*

At national level, having large-scale philanthropic funding enabled the HFH Programme to engage with and access the ongoing input and support of senior health professionals and policy makers who could open doors. This in turn was supported by the belief and enthusiasm of the IHF's Board and CEO, as well as the Programme team itself.

At hospital level, the Programme's success in securing the buy-in of acute hospitals, particularly in the early stages, can be at least partly attributed to its ability to provide them with hospital-based support in the form of the End-of-Life Care Development Coordinators. The Development Coordinator posts were fully funded by the Programme, and their departure often left a significant gap. In hindsight, it may have been better had hospitals been asked to provide some level of co-funding for these posts, or to have engaged in a phased movement towards co-funding, in order to ensure their recognition that participation in the Programme would require dedicated and on-going resourcing in the longer term.

The success of the HFH Programme at hospital level can also be related to the commitment and enthusiasm of particular individuals who were interested in and supportive of the end-of-life care agenda and who believed that things could be changed for the better. The Programme's ongoing support of these individuals, both formal (training opportunities, participation in the networks) and informal (phone support, casual meetings) was also important.

3.5.2 *Next steps*

The future success of the HFH Programme will depend on its ability to consolidate and mainstream key end-of-life care drivers at both national and hospital level.

At national level, this will mean working with national health agencies/bodies to progress national end-of-life care policy and practice.

At hospital level, the key drivers include buy-in at senior management level and the provision of dedicated hospital-based personnel to pursue the end-of-life care agenda. With momentum lost in a number of hospital locations following the departure of the End-of-Life Care Development Coordinator, and in the absence of adequate provision by the hospital of protected time for existing staff to progress the agenda, it is imperative that ways be found to ensure no further loss of momentum.

At the level of the Programme, there is a need to continue to progress and support the work at both national and hospital level.

3.6 Tools Generated

3.6.1 *Learning*

The breadth of the HFH Programme and the fact that it was run by an independent national charity (the IHF) facilitated significant use of creativity that might not have been possible otherwise. Particularly in the early stages, the Programme's work involved considerable investigation, piloting and capacity building, which in turn generated a wide range of innovative tools to support enhanced levels of end-of-life care. Used consistently, some of these tools (e.g. the end-of-life spiral symbol, as used on a ward), have the capacity to contribute to a transformative experience for patient, family and hospital staff. There is, for example, anecdotal evidence[10] that *Design and Dignity* initiatives facilitated by the Programme in association with HSE Estates have had a positive effect on staff morale. Interestingly, the most frequently used tools (including the Quality Standards) appear to be those that are embedded in practical action and activities.

3.6.2 *Next steps*

The HFH Programme needs to continue to find ways to foster creativity, while also prioritising the provision of simple practical supports for end-of-life care.
A wide variety of the tools and learning generated by the Programme have a resonance that is wider than end-of-life care. This needs to be constructively fed into the wider health system in order to maximise their impact.

It is a challenge to measure the outcomes of a project as diverse as the HFH Programme. Ways need to developed to do this, both directly, e.g. through the use of comparative attitudinal and/or behavioural studies, and indirectly, e.g. by observing reductions in the numbers of complaints and controversies.

10 On-going informal feedback from the staff in the Mater Hospital to HFH Programme Team members.

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