THE IRISH
HOSPICE
FOUNDATION

The Hospice Friendly Hospitals Programme in Ireland

A Narrative History

Authors
Professsor David Clark
Dr Fiona Graham

Contents

Acknowledgements

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.

Denis Doherty
Chair, Evaulation Advisory Group, Hospice Friendly Hospitals Programme.

Executive Summary

Background

Hospice Friendly Hospitals (HFH) is a multi-centre intervention to develop end of life care capacity, advocate for patients and families and create systems level change in the delivery of hospital care at the end of life in Ireland. Its work and the ideas that contribute to it have been developed and supported by the Irish Hospice Foundation (IHF) since the late 1990s and it has occupied a key place within IHF strategy since 2004, when a pilot scheme was initiated. The HFH programme was a five-year work-stream (2007-2012) designed to improve the quality of end-of life care in acute and community hospitals in Ireland. It was implemented across two 'phases': 2007-10; 2010-12.

Initiated by the IHF in partnership with the Health Service Executive (HSE) and with a major grant from The Atlantic Philanthropies, as well as the support of the Dormant Accounts Fund and the Health Services National Partnership Forum, the programme had three goals:

- To develop comprehensive standards for all hospitals in relation to dying, death and bereavement.
- To develop the capacity of acute and community hospitals to introduce and sustain these standards.
- To change the overall culture in hospitals and care settings in relation to dying, death and bereavement.

Aims of the present study

1 To construct a narrative history of HFH from its earliest origins and covering its first five years (2007-12) of national roll out.

2 To answer key questions about its content, modes of operation, impacts and efficacy as a source of advocacy for end of life care in hospitals

3 To draw conclusions to influence its future development and sustainability in Ireland, as well as its possible applicability in other jurisdictions.

Research design

A range of methods was employed: analysis of programme documents, reports, minutes of meetings, media outputs, promotional and educational materials; qualitative interviews with HFH staff and stakeholders (n=35); field and ethnographic observations based on attendance at meetings, conferences and other key events.

Results

We identified key milestones in the development of HFH. 1996: Concerns about dying in hospitals led to a structured response by IHF; 1999: St James's Hospital study: 'Death must be afforded an important position in the business of the general hospital of contemporary Ireland[1], 2002: End of Life Care in General Hospitals, RCSI planning document for IHF; 2004 – 2006:

Pilot project, Our Lady of Lourdes Hospital, Drogheda; 2006-2007: Planning phase for HFH programme and launch; 2007-10: Implementation of Phase One of the programme; 2010-12: Implementation of Phase Two and the move to sustainability in the creation of a Network of Hospice Friendly Hospitals.

In the years 2007-12 the HFH programme consisted of four main components: 1) Design and dignity/the physical environment 2) Communication/competence and compassion 3) Integrated care/planning and co-ordination 4) Patient autonomy/an ethical approach. HFH developed a comprehensive set of National Quality Standards for End-of-life Care in Hospitals and sought to underpin these with a comprehensive National Audit System to provide a base-line of end of life care in hospital settings and to assist in evaluating the quality of hospital end of life care over time. The baseline audit of end of life care in Irish hospitals included 999 patient cases and was conducted in 2008-9, leading to a follow up that was piloted in late 2012. It was anticipated that by March 2013, there would be 200-300 cases captured by the pilot and ready for analysis. A plan had also been developed for the production of papers for publication, drawing in particular on work from the 2010 audit report.

HFH raised the profile of end of life care in hospitals through the four components of the programme, in the production of a set of recognised standards and in the conduct of the national audit. It also made significant headway with the Final Journeys training programme, the creation of an Ethical Framework for end of life care, the development of material resources for use at ward level, the conduct of a Practice Development initiative for end of life care and in the establishment of a Network of Hospice Friendly Hospitals and of Community Hospitals. Within individual participating hospitals, end of life care became included in service and development plans, standing committees for end of life care were established, senior managers became engaged in relevant issues and staff members were released for training of various kinds. Across all its activities the HFH programme supported hospital staff in a non-judgmental and practical way.

In total 32 out of 57 acute public hospitals engaged with the HFH programme in some way in the period 2007-12 (though only four hospitals were involved in all aspects of the programme). Among the 147 community hospitals in Ireland, 18 became actively involved in the HFH Community Hospitals Network, with some 50 hospitals engaged with the programme in some way.

Total funding for the HFH programme in 2007-12 was €10m.

Analysis

Our study set out to answer the following questions:

1. How did the HFH programme come about, what factors shaped its initial development and how consequential were these for the programme over time?

Hospice Friendly Hospitals had a gradual gestation, starting in the mid-1990s, when trustees of the Irish Hospice Foundation began to take an interest in how hospice principles could be fostered in the practice and organisation of acute hospitals. It was able to attract significant philanthropic funding and also led to a partnership arrangement with the Health Service Executive. The HFH programme has been widely praised for the inventiveness, richness and imaginative qualities of its various components. Sponsorship by IHF, philanthropic funding at a high level and partnership with a newly formed HSE were critical to the origins of HFH and also shaped its evolution. The programme was given considerable scope by IHF to act independently in the early years, but subsequently was folded back into IHF strategy. The partnership with HSE had some success at the operational level, but struggled to gain traction in ways that could influence wider priorities, policies and programmes within the health system.

2. What are the key factors and content of programme development and delivery, how did these change over time and with what consequences?

Over time HFH developed into a varied tapestry of resources, interventions and strategies. It also sought to forge a culture of optimism that change could be achieved and it was effective in finding local advocates for improved end of life care in hospitals who could support one another through the mechanisms that HFH provided. The Quality Standards for End of Life Care in Hospital were an important innovation and towards the end of the programme they achieved significant external endorsement – from National Economic and Social Council and to a lesser extent from Health Information Quality Authority. There were important messages in the National Audit of End of Life Care in Hospitals that attracted attention and action within the participating organisations.

At the same time, the programme could seem too complex and perhaps subject to too many changes in strategy and nomenclature. Rich in metaphor and symbol, it could be unclear in its main messages and too varied in content for some to readily understand and therefore engage with it. Our study uncovered examples where the inclusion of 'hospice' in the name of the initiative appeared to be a barrier and not a facilitator to progress. It is also clear that the palliative medicine community found difficulty with the strong emphasis on the care of the dying within HFH.

3. In what ways did HFH seek to bring about systems-change and to what extent – in the view of key stakeholders and in relation to the available audit data – was this achieved?

HFH explored the use of engineering models to look at patient flows through the hospital. It encouraged hospitals to see themselves as others see them. It also looked at the care system as a whole – where hospitals fitted into its culture and history and why they operate in the way they do. It introduced standards to achieve structural change across the hospital system. It fostered Practice Development to attend to the culture of hospital care – a notoriously obdurate and difficult area. It shed light on systems of care and the experiences of staff and relatives though a major baseline audit, the implementation of which as well as the results it delivered, also fostered systems thinking among hospital managers and clinical staff. It set up standing committees within the participating hospitals to provide leadership and direction to systems change. It supported these with the provision of dedicated Development Co-coordinators who could take forward new initiatives and provide resources to the hospital community as a whole. The views of stakeholders varied on how effectively HFH tackled this wider systems and policy agenda. One perspective was that HFH had been insufficiently attentive to policy linkage or to engagement with prevailing strategies and systems. Others considered that it had tried hard to engage but met with resistance and gate-keeping.

4. To what extent did HFH become a source of advocacy, both within hospital settings and beyond, and what forms did this take?

Undoubtedly HFH had a high profile, especially at the end of Phase One and the beginning of Phase Two – and this had the effect of raising awareness about hospital end of life issues within the national media and within wider discussions taking place in Irish society. This was in part due to the involvement of high profile figures from the world of arts and culture and may have been linked also to the work of the IHF-led Forum on End of Life Care. This involvement of well-known figures on the Irish cultural scene seemed not to be sustained through Phase Two. From the time of the pilot onwards, HFH gained further recognition by winning three awards for the merit of its activities: Public Sector Excellence Award (2006); Aramark Healthcare Awards (2008); Irish Healthcare Awards (2010). By the Spring of 2012 the distinction between the National Steering Committee (NSC) and the membership of the Network of Hospice Friendly Hospitals (which were now meeting back to back on the same day) was becoming blurred. Operational matters had come to dominate the NSC, and the space in which its members could give high level feedback, offer strategic direction and suggest new lines of development – in short advocate for HFH - appeared to have been lost.

5. What key lessons can be learned from the HFH programme that might i) inform future developments ii) be applied elsewhere?

By the time the 2012-15 IHF strategic plan concludes, the idea of the 'hospice friendly hospital' will have been in circulation in Ireland for nearly 20 years. Although its major external funding source has come to an end, it does therefore display significant indications of 'sustainability'. What can be achieved, realistically, over the period to 2015, with an investment from the IHF of c€1m and taking into account the extremely bleak wider context within the health care system and the wider economy? Lessons for the immediate period:

1 The Hospice Friendly Hospitals Network must be nurtured. The Network will require strong support and leadership from the IHF.

2 The relationship with the HSE must be taken onto a new footing by the IHF, working closely with senior clinicians and planners, but also attending to policy at ministerial level.

3 Potential sources of new philanthropic investment or partnership should be investigated. It is clear that reflective, development projects of the HFH kind are going to find no support within the straitened circumstance of the Irish public health economy in the next 3-5 years. Nevertheless, philanthropic partners may be drawn in – particularly if HFH could take on an international dimension. There is much that could be done (at low cost) to explore this in the next few years.

4 The HFH programme has produced a wealth of high quality publications and materials that have engaged interest and attention – and in some cases have been publically endorsed at ministerial level. A crucial ingredient remains absent however. There are no peer reviewed, evidence based publications to shed light on the value of HFH and its activities. It has now committed to a plan for generating such publications and this will be an extremely important goal in the next three years.

5 On the basis of the current evidence it would be hard to suggest that other jurisdictions should take up the format of HFH, in toto. The work in Ireland between 2007-12 remains exploratory, formative and unvalidated in many respects. Nevertheless, from the present study it should be possible to identify areas that could be taken up and adapted in other contexts. The IHF should remain an active resource in this context and might even consider hosting a workshop on such matters – for example at a major international conference.

Conclusions

The HFH programme was hugely ambitious in what it sought to achieve in five years. It was complex, multi-facetted and involved over 80 acute and community hospitals in some way. Significant successes occurred in the Design and Dignity work areas; in the spread of communications training and in the development of Final Journeys; in standards development; and in aspects of the audit. Activities relating to patient autonomy, the ethical framework and integrated care contained successful elements but overall made less traction. Despite the best efforts of the team however, HFH staff members were sometimes seen as outsiders intruding on local business, who failed to engage effectively with key clinicians, especially doctors.

The work of HFH now moves into a phase of more limited funding, when it will seek to 'mainstream' its activities within the participating hospitals and the IHF – aiming at achieving sustainable impact. The Irish Hospice Foundation has committed in its strategic plan for 2012-15 to continue to fund three key elements of HFH over three years. These elements are the Network of Hospice Friendly Hospitals; the new System of Audit and Review of End of Life Care to be used initially in acute hospitals; and the Final Journeys staff training programme.

The HFH programme contained some outstanding elements. We argue that these have yet to attain 'world class' significance due to the lack of validation, critical testing through evaluation and the imperative to locate the programme in the context of international best evidence. We can however be confident that HFH has helped prepare the terrain for better care of dying patients and their families in Irish hospitals. Many of its efforts were directed to framing an argument for the right to better hospital care at the end of life. It highlighted inequalities, poorly served groups, inadequate facilities, and inattention to dignity. It sought out public champions with wider appeal and recognition to help argue the case and to highlight injustice. There is no doubt HFH was a source of advocacy – for staff, for patients, for families and for the wider society. Its work must now continue under a new policy framework, with fewer resources – but in the face of continuing need and major challenges still to be overcome.

1

Background, study aims and methods

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Almost 30,000 people die each year in Ireland. The first ever nationwide public opinion survey of its kind conducted in November 2004 found that 67% of Irish people want to die at home and only 10% would wish to die in a hospital. The reality is that 66% of Irish people die in hospitals and other institutions[2].

It is well known that the concept and practice of hospice care developed outside the formal health care system. In Ireland its roots lay in the endeavours of religious sisters in the nineteenth century, from which grew the work of independent charitable organisations, providing care at the end of life alongside, but independent of mainstream services. Hospices have been successful for several reasons. They acknowledge the reality and imminence of death. They provide attention to detail and personalised care. They look beyond the diagnosis, the symptoms, the physical problems – to recognise the suffering and hopes of the whole person, the family, the carers and close ones – an approach brilliantly captured in Cicely Saunders's concept of 'total pain'[3]. As hospice care has gathered momentum, so too questions have arisen about how its practices, ideals and merits might be translated into wider contexts.

This report concerns one such attempt. It deals with an extended experiment in a single jurisdiction, that sought to inculcate the ideals of hospice within that major bastion of modern health care – the acute hospital. Over time the experiment extended its reach to community hospitals and in related projects even sought to raise questions about how hospice practice could influence systems of care in the community as well as the attitudes and beliefs about care at the end of life that exist in the wider society. We describe and assess the work of the Hospice Friendly Hospitals Programme in Ireland, in the years 2006-12, though we also dig back deeper to identify the roots of the programme, which first appeared some ten years before.

Making sense of what became a diverse array of strategies, interventions, sub-projects and initiatives has proved a complex task. How best to make sense of an initiative with so many aspects, so wide an ambition and such an extensive reach across a whole country? We have answered these questions by adopting a narrative approach to Hospice Friendly Hospitals. This report 'tells a story'. It begins with the early ideas that shaped the later programme, and then moves through a pilot scheme, to full roll out and dissemination – this over two distinct phases – and concludes as the programme faces the challenges of integration with the mainstream and of longer term 'sustainability'. But along with the unfolding narrative we also intersperse commentary, reflection and critical analysis. There are specific case illustrations, vignettes and examples where we look in more detail at some aspects of the programme and attempt to surround it in contextual detail. The participants should recognise the narrative thread as we develop it, but will also – we hope – see the value of a more external view of their actions that comes from the perspective of researchers at 'arm's length' from the programme itself.

On 7 October 1996, Therese Brady, honorary director of the Irish Hospice Foundation (IHF) Bereavement Service wrote a letter to the Foundation's Chairperson and founder, Mary Redmond - calling for the Foundation to become more involved in the 'application of hospice principles beyond traditional areas'. She alluded to work that Mary Redmond had already initiated at St James's Hospital, in Dublin and saw this as something which would stimulate other developments in general hospitals elsewhere. In language which would come to be used widely in the Foundation a decade later, she noted 'There are many other areas in which the

introduction of hospice principles would be of great benefit for patients, their families and the staff who care for them'[4]. The small exploratory project undertaken in St James's Hospital produced findings and recommendations which led first to a pilot project at Our Lady of Lourdes Hospital, in Drogheda, and in time to the roll out of a national initiative that would seek to bring hospice principles into all Irish hospitals.

This ambitious initiative came to be known as Hospice Friendly Hospitals. It seeks to change hospital cultures of care and organisation relating to death, dying and bereavement, using a 'systems level' approach that can impact across all areas of the hospital and its goal is a transformation in the way in which hospitals relate to an aspect of their core activity – caring for the dying, the dead and the bereaved. For several years the programme was supported by major philanthropic funding and it continues to occupy a key place within the overall strategy of the Irish Hospice Foundation. Over the years it has attracted resources, public interest, professional debate and a measure of controversy as it has sought to transform the culture of end of life care across the hospitals of Ireland.

This study sets out the history of the Hospice Friendly Hospitals (HFH) programme, from the ideas and work that fostered it in the mid-1990s, to the pilot project that tested out the concept from 2004, to a key point in its wider development in 2010 and on to its entry into a 'sustainability' phase in 2012 (Box 1). It traces the thinking, the initiatives and the processes that shaped the programme and explores the breakthroughs and successes, as well as some of the challenges and difficulties encountered along the way. It gives attention to Hospice Friendly Hospitals as a programme for advocacy, examining its role in influencing public debate and policy and exploring illustrations of advocacy in relation to specific programmes of work.

BOX 1

Key milestones 1996-2012

1996:	Concerns about dying in hospitals require a structured response by Irish Hospice Foundation
1999:	St James's Hospital study: 'Death must be afforded an important position in the business of the general hospital of contemporary Ireland' (Ref 9, p65)
2002:	End of Life Care in General Hospitals, RCSI planning document for IHF
2004 – 2006:	Pilot project, Our Lady of Lourdes Hospital, Drogheda (IHF & HSE)
2006-2007:	Planning phase for HFH Programme and launch
2007-10:	Implementation of Phase One of the programme
2010-12:	Implementation of Phase Two and the move to sustainability in the creation of a Network of Hospice Friendly Hospitals

Five research questions structured our enquiry and these were pre-determined for us by the Irish HospiceFoundation at the outset of the study, as part of the commissioning process. We saw two dimensions to them: first, a 'narrative' aspect that seeks to capture the unfolding natural history of HFH over time, in a manner that elucidates the ebbs and flows of activity, the breakthroughs, the blocks, the leadership, the impact on wider thinking and reactions to the programme as a whole; second, a focus on specific interventions, initiatives and projects that can be assessed from an 'advocacy' perspective. We have tried to present the findings of the study in such a way as to capture both of these dimensions; narrative history of the whole initiative and 'vignettes' or case studies of specific interventions and their success as forms of advocacy.

The five key questions:

1 How did the HFH programme come about, what factors shaped its initial development and how consequential were these for the programme over time?

2 What are the key factors and content of programme development and delivery, how did these change over time and with what consequences?

3 In what ways did HFH seek to bring about systems-change and to what extent – in the view of key stakeholders and in relation to the available audit data – was this achieved?

4 To what extent did HFH become a source of advocacy, both within hospital settings and beyond, and what forms did this take?

5 What key lessons can be learned from the HFH programme that might i) inform future developments ii) be applied elsewhere?

Our study draws on diverse methods and a research design which we have deployed successfully elsewhere[5]. We made use of a mix of methods, building on experience with other 'narrative' histories and evaluative studies:

1. We have conducted structured interviews with key players in the HFH initiative and those in cognate roles. These were carried out both face to face and by telephone and were informed by the principles of 'oral history'. The majority were carried out 'on the record', but in some cases our respondents preferred to speak anonymously and we have respected this. As the report was concluded we made a special point of contacting all of the in-post end of life co-ordinators and the persons responsible for the audit to gain a final up to date picture. In total 35 interviews were carried out. This generated over 26 hours of interview time. 'On the record' interviews were transcribed and yielded 312 pages of text. The interviews were content analysed using a bespoke coding system and thematic framework based on the interview schedule.

2. We have conducted a careful analysis of the extensive primary and secondary documentation associated with Hospice Friendly Hospitals. We have also made use

of relevant published literature and sought to contextualise our analysis in relation to the wider development of end of life care initiatives in settings beyond Ireland. The documentary analysis included materials generated by HFH: for example - grant applications, minutes of meetings, correspondence and emails, publications and materials; written materials and reports from HFH staff, presentations at meetings and conferences. We have also made extensive use of other primary sources, for example – press reports and coverage, key HSE/Department of Health and Children reports and policy materials, as well as wider contextual literature on end of life care issues, public health and advocacy.

3.   We have also made use of attendance at key meetings, when it has been possible to gain further contextual understanding, to explain the purposes and progress of our study and also to gain access to materials and to key people for interview. In total eight 'field' visits of this kind were made throughout the three year duration of the study.

This report is the product of three years' engagement with the life and times of the Hospice Friendly Hospitals programme. During that period (2010-12, inclusive) we have been in regular contact with programme staff, with senior colleagues at the Irish Hospice Foundation and with a wide range of individuals associated with the work. Throughout the process we have experienced exceptionally high levels of co-operation, facilitation and access to people involved with HFH, who were unfailingly attentive to our research needs and requirements. Across all the interviewees we sought out, only two persons did not make themselves available to participate. We have assessed new documents and publications as they have appeared, studied reactions to them, monitored wider coverage and commentary on the programme and tried to make sense of the shifting context in which Hospice Friendly Hospitals has been located, as Ireland moved from prosperity and boom into a deepening recession and then a period of enormous fiscal constraint. Throughout this we have tried to capture a moving picture – making sense of key staging posts and land marks, but aware also of the arbitrary conclusion to our study. Our account ends in December 2012, but we are very well aware that Hospice Friendly Hospitals continues beyond that date and in our conclusions we have tried to offer some sense of its prospects for sustainability and impact as it seeks to become more fully integrated within the mainstream of hospital services in Irish society.

When we began our work, it was not clear whether the study would require the approval of a research ethics committee. We addressed this issue in consultation with IHF staff and an application was made to the relevant committee at the Royal College of Surgeons in Ireland. The committee made some helpful comments on our proposal but judged that it did not have jurisdiction over such a study, which relied essentially on documents in the public domain and on the record interviews with professionals. We believe that the study has been conducted to high ethical standards. We obtained verbal informed consent for all the interviews and have respected the anonymity of those who requested it. All the primary documentary materials analysed were provided to us by HFH and IHF staff. In a few small cases where this included sensitive correspondence, we have used this material with care and discretion. We assumed throughout that open access would be granted to all or most HFH documents, records, personnel and materials and this proved to be the case.

This kind of study typically produces 'multiple realities' and perspectives on some issues and has the potential to highlight conflicts, major differences of view and controversial issues. This requires experienced researchers and an ability to balance and weigh differing viewpoints. In this kind of work, these are matters of interpretation that may not be easily resolved. We did gain access to conflicting views about the work of the HFH programme and its impact in Irish hospitals. We have strived to produce a balanced account of all the material we collected – even when there were inconsistencies or differences of view within it. There can never be a fully objective appraisal in a work of this kind. In our case, one of us (DC) was involved with the work of the HFH programme in its early days and for a period of time chaired its evaluation sub-committee. All such links had come to an end before the present study got underway. Nevertheless, this 'history' should be acknowledged – and seen for its positive benefits in terms of an earlier understanding of the programme. By contrast FG had no prior knowledge of the work of HFH until our study began – and this absence of pre-conceptions, coupled with a depth of clinical knowledge, brought further strengths to our research collaboration.

This work is not an evaluation in the formal sense, though it does have evaluative elements. The summative judgement as to the efficacy of the Hospice Friendly Hospitals and whether or it not it proved to be a costs effective intervention, will not be found in these pages - though we believe we have contributed a significant analysis to assist those who may in due course seek to make that judgement. Our purpose has been somewhat different. The goals of this study have been to produce a 'document of record' that captures the evolution and workings of the programme over time, through various stages and phases of development. In doing so we have tried to be faithful to the narratives and stories we have heard, and we have sought to integrate personal viewpoints and experiences into a broader understanding that comes from the analysis of documentary sources of various kinds, as well as our wider knowledge of end of life care initiatives in other contexts.

2

The Hospice Friendly Hospitals programme in context

2. The Hospice Friendly Hospitals programme in context

In this section we set out the narrative of how the Hospice Friendly Hospitals first developed, progressed through various development stages and then moved to a programme of full national 'roll out' between 2007-12. In subsequent sections we look in more detail at specific aspects of the HFH programme.

2.1 Pre-history, pilot project, wider ambitions

It emerged organically from what we were doing ... these hospitals lost interest when patients got beyond a stage when cure was possible ... from very simple examples the notion of 'hospice friendly hospitals' emerged[6].

The Irish Hospice Foundation (IHF) first became interested in 'hospice' care in hospital settings in 1996, inspired by the urgings of Therese Brady[7]. The Foundation went on to fund a palliative care initiative in St James' Hospital, Dublin and in 1998 sought to evaluate that initiative. The resulting study was derived from a methodology developed by Julia Addington-Hall and based on the views of 155 bereaved relatives, together with data from a general health questionnaire and a critical incident analysis. Four groups of bereaved persons were interviewed: relatives of patients dying in the hospital who received palliative care; relatives where no palliative care was received by the patient; relatives where palliative care was provided but where the patient died in hospice; relatives where palliative care was provided but where the patient died at home. The study was led by Orla Keegan; she noted:

What really came across was the scope to do more about the conditions in hospital ... It uncovered every issue that Hospice Friendly Hospitals has now come to identify – the communication issues, the fact that there was no joined up care, the fact that there were problems with privacy, and some patient management issues. So it had the bones of it[8].

The study showed that in the year before death, patients had a median of eight symptoms and in the last week of life a median of five symptoms. Most relatives said they knew the patient was dying and 69% felt that the patient themselves also knew. Despite this the majority of people (78%) did not talk about this to each other. Furthermore, 50% of relatives who thought the patient knew about the seriousness of their illness reported that the patient had not been told directly. Relatives gave clear accounts of unsatisfactory hospital experiences. These included delays at accident and emergency; a lack of dignity afforded to the patient - for example talking over or around the patient rather than to them; priorities given to hospital routines over patient preferences (such as at meal times); poor communication and sometimes interpersonal conflicts with staff. Conversely, the positive incidents which were recounted reflected the human dimension of care, for example taking time to sit and talk; sensitivity in breaking bad news; and communicating concern for patient and for relatives through the illness and after the death. Overall however, while relatives of deceased hospital patients made positive evaluations of their experience, the scope for further personalising and dignifying care was clear[9].

The need for general hospital care to be organised according to principles of hospice care can be seen in another aspect of the study which revealed a profile of those who died as patients of the hospital during a twelve month period. Only six per cent of deceased patients received

hospice care in a hospice location and a further 15% received specialist palliative care in the hospital setting only. Typically only cancer and AIDS patients were provided with the services of the hospital's palliative care team. The majority of deaths during the twelve month period took place in the general (non-palliative care associated) hospital wards. These patients were cared for by a wide range of health professionals as well as by hospital support staff including porters and catering staff. The study was giving a strong pointer to the fact that end of life care is a core part of hospital activity across all hospital settings, and could not be circumscribed solely by the activities of a specialist palliative care team.

The findings and launch of the study in 1999 led to a hospital-wide meeting at St James' concerned with what could be done about dying in the hospital. Each section of the organisation, from CEO to porters, was represented and a wide ranging discussion ensued. The meeting caused a 'bit of a sea change'[10] – a plan emerged to form a committee to take the issues forward. Progress was limited however and the momentum dissipated relatively quickly as staff members changed, and also following the death of Therese Brady herself, in 1999. At the same time the then CEO of the IHF, Clare Goddard, moved the emphasis somewhat away from the work in the hospital, to focus on other projects. When Louise Richardson became CEO, the board brought the hospital issue back into focus and in 2001 the Foundation commissioned The Royal College of Surgeons in Ireland to undertake a feasibility study that would inform the notion of a 'hospice friendly hospital'. The resulting document, published in 2002, set out an agenda for action. It put flesh on the bones of the earlier work. Indeed, it mapped out some of the core elements that were to follow in the national programme, stating:

> *The hospice friendly hospital concept is a wide-ranging multidisciplinary approach to care which needs to encompass organisational, interpersonal, individual and family issues ... A systems approach which takes into account the people, strategy, technology, environment, structure and culture of the hospital is necessary in order to successfully implement a hospice friendly hospital approach ... Defining appropriate 'hospice friendly' activities involves examining all aspects of the hospital context from a human perspective, but also from the perspective of supportive managerial, administrative and structural contexts. Assessment of the hospital environment is needed in order to determine what factors could facilitate or impede the introduction of a hospice friendly hospital approach into general hospitals. Consideration of individual patient and family preferences is crucial, but so too are the psychological needs of individual staff members[11].*

The report drew on a range of international models and sources of inspiration, including hospital based standards of care, assessment and audit approaches (focussed on care pathways), and a quality framework. It also included ideas about psychological contracts of caring, an examination of an approach to dealing with death in intensive care, a hospice led outreach project designed to empower nurses in promoting appropriate care, and a hospice led hospital support system. These were key elements in shaping the way forward and positioning the concept within some international models of good practice. Yet the authors also sounded a note of caution, particularly on the terminology of 'hospice friendly hospital', warning that it could be mistaken for creating a hospice 'space' within a hospital – rather than something that was more system-wide in character and which could be seen as the business of all staff:

While the last decades have seen the consolidation of hospice as a place and palliative care as a medical speciality in Ireland, the challenge now is to transfer the concept of hospice as a philosophy across the system such that all patients, regardless of their location or illness, would be managed from a hospice friendly perspective ... The time is right to transform not only hospital activities but hospital attitudes, norms and ways of being, in other words, the hospital culture of dying[12].

The vision and some of the required actions were becoming clear; the need was now to actualise these in a specific setting. By 2003, Jean Manahan was CEO at the Foundation and she saw this as a major project for development. Conversations got underway with the new palliative care consultant in Drogheda, an area where there was no in-patient hospice. He was keen to adopt the values of 'hospice friendly hospitals' and link them into the levels of palliative care outlined in the expert advisory group report of 2001, which had set out a framework for the whole country[13]. An opportunity was emerging to set up the 'pilot project' that was now clearly needed if the initiative was to go forward.

During 2003 however, there was further discussion and disagreement about the name of the initiative. The Foundation CEO favoured an Irish language term meaning tranquillity and peacefulness, but this was given strong challenge by one of the board members. At one stage 'The Newgrange Process' was favoured, referring to the Megalithic Passage Tomb in the area of Drogheda - the tri-spiral design from which had already featured in palliative care conference promotional material[14]. Some members of the Irish Hospice Foundation however wanted a more descriptive, perhaps more prosaic, name such as the 'care for people dying in hospitals project'. After May 2005 and with the support of the then IHF Chair, Denis Doherty, Hospice Friendly Hospitals came to be the name of choice and was fully adopted in order to 'bring a sort of brand identity' to hospitals associated with the enterprise[15]. The choice of name is interesting and consequential. For the IHF, it fore-grounded 'hospice' practices, values and identity. It may have been less appealing to those working inside the hospital environment however, not least the palliative medicine doctors, who sought to emphasise the credential of their specialty, rather than the power of the hospice 'brand'. There could also have been more substantive disadvantages, not least as the programme came to represent something wider, more encompassing and original than simply the idea of bringing 'hospice' into the hospital.

The pilot project

The 'pilot' project got under way in March 2004, at the 339 bed Our Lady of Lourdes Hospital, in Drogheda. It saw the Irish Hospice Foundation working together with the newly forming HSE Dublin North East[16]. The pilot lasted two years and had two key objectives:

1. To improve all aspects of care and organisational culture [at Our Lady of Lourdes] around dying, death and bereavement
2. To facilitate the adoption of these changes in other hospitals, nationally and perhaps internationally[17].

So from the outset there was a scale of ambition that was far reaching in character.
The initiative at Drogheda was championed by the local palliative medicine consultant, Dr Dominic O'Brannagain and its project manager was Mervyn Taylor, who had a background in

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public service and the voluntary sector, and who – crucially - came from outside the worlds of hospital and of hospice. Work now got underway, in a single local setting, with a focus on improving care of the dying and bereaved and supporting the staff in that goal. The host hospital was a challenging setting; it had faced a number of difficult operational issues in recent times and been the subject of considerable publicity and enquiry. The hospital was physically inadequate, it was having to provide a service well beyond its capacity and it had been the subject of some high profile scandals: 'It would have been easy for them to say - we have enough issues on our plate - but they courageously took it on'[18].

The challenges for the project manager were varied. There was limited preparation for his arrival, little in the way of supportive infrastructure, and his role and purpose were unclear to many in the hospital. Within a few months however there was secretarial assistance and then some grant income to support the initiative. Funding was obtained from the Health Partnership Scheme to appoint a development worker to engage with issues relating to care pathways and integrated care. Money was obtained to produce DVDs and booklets on training and communications skills. As the Programme Manager put it, the project was an eclectic process of 'getting people together, trying to give some sort of identity to what it is … a new sort of image associated with end of life and the hospital, but getting it around to people. In a sense you really had to … have a mixture of systems issues … symbolic issues, and a sort of political movement going within the hospital …'[19] For Taylor, the breadth of discussions at the hospital became far wider than was first anticipated, but the depth was rarely more than superficial. The hospital had other concerns and challenges that always took precedence over the improvement of end of life care. There were structural difficulties to be faced as senior hospital personnel moved on, just at a time when their support for the project was bearing fruit. Meanwhile the Irish health care system was undergoing root and branch reform, with the formation of the Health Service Executive (HSE) and all of its implications for organisations at the local level.

Nevertheless, over time, the achievements of the work at Drogheda were becoming more tangible. A permanent Standing Committee on Dying, Death & Bereavement was established in the North Eastern Area Hospital Network to sustain work after the close of the project. A pioneering set of publications had been devised which other hospitals could adapt. An educational awareness programme delivered to front-line staff within the hospital resulted in 96% of participants stating that their practice in caring for dying patients would change as a result. Work had begun on the first of eight rooms to enhance dignity, privacy and confidentiality for dying patients and for their families, and further improvements were being made to the hospital mortuary and family room.

The lessons of the pilot pointed to the need for more widespread action[20]. It seemed the system was failing its users. Care at the end of life should be developed as a core index of quality healthcare. Communication skills training should be seen as a necessity not a luxury. An urgent need existed to focus on the design of current and new facilities in ways which could promote privacy, dignity and confidentiality. It was also apparent that the provision of specialist palliative medicine alone in the hospital context was not the key to the issue – that would require something altogether more broadly based and systemic in conception. Over a short period of time, and faster than anticipated, it had become clear that that there were a lot of issues being raised which could not be addressed locally and where it would be necessary to create

'some sort of national agenda'[21]. As a platform to explore this, in May 2005 the Irish Hospice Foundation hosted a national conference at Dublin Airport on death and dying in hospitals, with the involvement of Pat Cox, a former President of the European Parliament taking part.

The conference argued that in Ireland each year thousands of patients died without privacy, confidentiality or dignity. There was a call for radical and pressing changes in hospital practices and facilities. The Foundation's then CEO Eugene Murray noted: 'Our own public opinion surveys show that over 80% of Irish people do not want to die in hospital, and we need to ask why ... Every hospital needs to give priority to the needs of the dying and their families, as well as those of staff and health managers. This must be done urgently[22]'. Acknowledging that over 15,000 people die in hospital in Ireland each year, keynote speaker Pat Cox said that 'priority must be given to the quality of facilities and care for those who die there - the professions and health managers, need to be made conscious that the structure and style of hospitals must change'. There was a need for space for people to die in dignity surrounded by the people they love; skills were required both technical and inter-personal, to manage pain and symptoms; support for patients, families and staff should be available within structures to develop a culture of compassionate care related to death, dying and bereavement[23].

Wider ambitions

By the end of the conference there appeared to be a mandate to move forward on a broader front. There was media interest, there was acknowledgment of the potency of the issue and there was recognition that death in hospitals was a matter of major public significance. The key to further development would be partnership - respecting the identity and ethos of the IHF as a champion of the initiative and respecting the statutory, regulatory framework and accountability of the HSE as a public service body. Could they work together, not just in one local setting, but in a range of hospitals across Ireland? It would mean challenges on a much bigger scale, yet one where every hospital saw its own situation and context as unique and requiring individual consideration. It would also require a more programmatic approach to the work itself, with greater precision and definition of focus. The national initiative came to be characterised by four themes: design and dignity; integrated care; communication and patient autonomy. These had been distilled down from a much wider range of issues that had been exposed in the pilot and now set the operating framework for the 'roll out'.

The year after the Dublin conference saw intense activity on the development of a national plan and in particular a strategy for generating substantial resources for the project. Discussions got underway with a major philanthropic funder, Atlantic Philanthropies, which had a special programme on ageing, led by a former CEO of the Irish Hospice Foundation. By September 2005, a planning grant had been applied for which led to an award of €0.25m, to fund a feasibility study for a national initiative on Hospice Friendly Hospitals. The IHF provided a further €100,000 to support the study. The scope of ambition was high. It sought to build a programme capable of changing the culture of dying across all Irish hospitals. Moreover it would be 'an early and significant test of the new Health Service Executive's ability to =engage in a partnership approach to an issue of emerging public concern ... galvanising the statutory and voluntary sectors into improving the quality, range and interconnectedness of services available at the end-of life'[24].

By 19 July 2006 a full grant application was submitted to Atlantic Philanthropies[25], seeking €4,928,620 over a five year period. The early indications were that it would be successful and this allowed further work to leverage additional resources. The Dormant Accounts Fund was applied to for €2,735,558 and an award of €1.5m was made. The IHF then pledged €3.25m to support the national programme over a five year period. On 20 December 2006, John O'Brien the temporary director of the National Hospitals Office at the HSE wrote a letter pledging interest and support[26].

Within a short period of time it became possible to talk about the Hospice Friendly Hospitals programme as a five year initiative, with a €10m budget. The scaling up was phenomenal and the challenges were commensurate.

2.2 The national programme 2006/7-12 - Phases one and two

The roll out of the programme was divided into two phases. In this section we describe its content, pacing and character. We give particular attention to some of the dynamics of the programme – its relations with the HSE, the emphases that were adopted at particular times, the opportunities that were taken as they arose. We also give some consideration to issues of sustainability as the major philanthropic funding came to an end and when, in much more straitened economic circumstances, there was a growing imperative to embed the activities of HFH within the responsibilities and routines of the health care system.

Former President Mary Mc Aleese launches the Hospice Friendly Hospitals programme in May 2007

Phase One

A National Steering Committee (NSC) was formed for the programme and this had its first meeting in November 2006. The membership was broadly based and gradually evolved, but undoubtedly included some senior figures and experienced individuals likely to have wider influence[27]. Over time the membership changed and arguably lost seniority and influence. At the initial meeting members were briefed on what the programme was seeking to achieve[28].

Prominent among the goals was the development of a comprehensive framework of standards on dying, death and bereavement for all Irish hospitals. Crucial to this would also be the development of capacity within the acute and community hospitals to introduce and sustain these standards. Thiswould require a change in the overall culture of care and organisation in Irish hospitals[29].

In the face of such challenges, the national programme was launched formally on 14 May 2007, by President Mary McAleese in St Mary's Hospital in Dublin's Phoenix Park. The list of participating hospitals at that point was impressive and included representation from 18 acute and 19 community hospitals across the state. In addition a core group of staff and advisors had been assembled[30]. The meeting of the National Steering Committee that took place on 6th June, just three weeks after the launch, heard a great deal by way of progress report. More hospitals were seeking to join the programme, local memoranda of understanding were being signed with individual hospitals, in addition to the MoU between the HSE and the programme as a whole. A project office for standards development had been formed and the first working group on the subject was getting underway – see below for a detailed account of the work on standards. Most of the Development Co-ordinators – key staff of the programme and each with responsibilities for particular hospitals - had negotiated some form of office facility in their respective hospitals and were proceeding to meet with senior hospital personnel in the various sites. The gathering of information on hospital activities and procedures relating to aspects of dying, death and bereavement in the context of 'integrated care' planning was starting to occur. A wide range of issues was surfacing and being logged by development staff. Examples included: the need for more dignified means of moving bodies from wards to mortuaries and for replacement of the many dilapidated coffin-trolleys currently in use in hospitals; a localised practice of not suturing bodies after post-mortem and leaving the procedure to funeral directors; and – most curiously - an industrial relations issue concerning which staff would be responsible for the blowing out of candles following a removal service at a hospital mortuary[31].

By the July 2007 meeting of the NSC, a plan had been formulated for 'Champions for Change' within each hospital, wherein development personnel would identify key individuals at local level to enable staff to recognise their personal and collective responsibility for the quality of care for people dying in their hospital[32]. At this point monthly gatherings of the NSC gave way to meetings every quarter, and by 3 October there was reference to the growing amount of media coverage gained by the programme - with articles appearing in the Irish Times and its Health Supplement, as well as in Ageing Matters, HSE Health Matters, Enterprise Ireland and the Irish Medical Times[33]. The NSC also saw a change of chair when Pat McLoughlin, former Deputy Chief Executive of the HSE and the NSC chair since inception, was appointed CEO of the Irish Payment Services Organisation and stepped down from October 2007, to be replaced by Cork-based geriatrician and NSC member, Professor Cillian Twomey[34]. He saw his role as facilitating

the multi-disciplinary and multi-sectoral interests and expertise of the committee, and in particular 'being an ambassador … for the philosophy of Hospice Friendly Hospitals.[35]'

This represented something much wider than the approach of palliative care as a specialty – seeking to improve the quality of care for all patients in all circumstances. Cillian Twomey proved to be an inspired Chair of the NSC, active in working with the programme manager and staff, respected in the hospitals and able to speak from a lifetime of clinical experience. The shift from a Chair with high level experience in the HSE to one with clinical and academic credentials may have been consequential later however, when traction with the HSE proved slow and efforts to gain integration within relevant policies and strategies were frustrated.

The Hospice Friendly Hospitals conference held at Clontarf Castle Hotel near Dublin in November 2007 was a major landmark. Ambitious in scope and with some 300 people attending, despite the HSE 'freeze' on travel and training activities, it did a great deal to highlight the key issues and challenges facing the programme. Entitled Hope and Opportunity: hospice principles, hospital practice, it ranged over the clinical and epidemiological aspects of death in Irish hospitals, and then to each of the four main themes of the programme: integrated care, communications, design and dignity, and patient autonomy – each of which we explore in detail below. There was special praise for a speech given by the Ombudsman, Emily O'Reilly who acknowledged the good practices recently identified in a study by Professor Eamon O'Shea[36] but also drew attention to a long list of complaints she had received concerning end of life care issues in hospitals.

For the Ombudsman the main theme running through the majority of complaints about hospitals and care homes appeared to revolve around poor communications, an issue that she saw as central to the Hospice Friendly Hospitals programme. She concluded by laying down a series of challenges. How difficult is it to devise a system whereby the tea lady is made aware of death on a ward? How difficult is it to devise a protocol for the collection and the return to a family of their relatives' belongings? How difficult is it to have mortuary facilities that are not shocking in their clinical and literal coldness? How difficult is it to have simple tea and coffee facilities made available to relatives in the pre-dawn as they await the death of a patient? 'These', she noted, ' are not huge logistical issues such as the creation of single bedded rooms in hospitals that are already stretching at the seams; these are the stuff of simple humanity, of a tiny imaginative leap into the souls of the dying and of those who surround them'[37].

One piece of feedback from the conference was particularly telling however

> *It is an excellent concept. The sad part however is that some of the most important features are utterly fundamental to being simply a good nurse or other health professional e.g. good communications, dignity and compassion. Can it be that those of us in specialist palliative care for many years have de-skilled many generalists, or simply made them feel inadequate in their care?[38]*

This reflection from within on the part of a palliative care specialist highlighted a continuing theme – that the Hospice Friendly Hospitals programme should necessarily be interpreted through the lens of the palliative care specialty. Such a perception seemed to miss the point that the programme's orientation to death and dying in the hospital was in fact wider than that of the specialty. Overall, however, the National Steering Committee was delighted with the conference, and had much to praise at its meeting on 5 December 2007.[39]

From the early days, HFH struggled to identify a specific reference group for its work: as the Programme Manager put it 'there weren't the people out there'[40]. There was a need to build capacity around a subject for which no specific group took responsibility. This shaped the early decision to use Development Co-ordinators as the spearhead for initiatives in the first phase. Were there alternatives at a lower cost? Could other approaches have been tried? These questions were certainly being actively considered by 2009, but in the earlier stages of the project, when the capacity of the hospitals to respond to the ideas coming from the programme was more limited, then the use of the Development Co-ordinator role seemed a defensible approach. Essentially, it was modelled on the experience taken from the pilot – and then rolled out to a larger number of people and settings.

A great deal of care was taken in the recruitment process for the first Development Co-ordinators and some were clearly individuals who were able to make a long term and lasting contribution to the programme. Others struggled with the challenges of the remit and did not stay the course. 'Love and steel'[41] was required of the applicants and these attributes, coupled with the requirement to be agents of systemic change in profoundly complex institutional settings, were hard to locate and to nurture. As one Development Co-ordinator commented in 2011[42].

> *The role to date is largely based on engagement and facilitation rather than authority, responsibility and accountability in terms of relationship to HSE sites*

Looking back from the perspective of early 2010, the Programme Manager could note:

> *… we couldn't have got where we are without having some people on the ground going around, waving flags and making a bit of noise and surfacing issues, even though it was done incoherently in some cases.*[43]

Like any staff group, the Development Co-ordinators had their own needs, sometimes compounded by changes in personal circumstances. It is clear that theirs was a demanding role, which required nurturing and support from the programme and its manager. At the hospital level there could be set-backs, indifference and a failure to make progress. As the Programme Manager noted, they needed to be 'Michael Collins in the morning and Mother Teresa in the afternoon'[44]. The Development Co-ordinators required a degree of facilitation in order to be flexible and entrepreneurial advocates for the highest quality care for those the dying in hospital: it was a flame to be kept alive that remained key to success throughout the whole initiative.

To mark the conclusion of Phase One the programme returned to Clontarf Caste on 19th May 2010 for a landmark conference; 340 people registered for the event and over 300 attended. Denis Doherty opened the proceedings and reminded the audience that every second death now takes place in some sort of acute hospital. In this context how might it be possible to make hospitals more hospice friendly – in a healthcare system judged by Roger Ulrich to be one of the worst in the developed world? Doherty celebrated the fact that three quarters of acute hospitals in Ireland had become involved in some sort of activity to do with HFH – compared to the three that had first signed up in 2007.

Dr. Kieran McKeown addressing the 2010 Hospice Friendly Hospitals conference.

Dr Kieran McKeown then presented the findings of the National Audit of End of Life Care in Irish hospitals. He emphasised that the quality of end of life care in Irish hospitals is high by international standards. But there also exist significant opportunities for improvement. Care is better when end of life provision features in the service plan of the hospital. Emergency admissions have poorer outcomes. This was echoed in the account of a bereaved relative, Catriona Crowe, who described the death of Padraig O'Faoláin, who was admitted with heart problems to Accident and Emergency in a hospital where no one knew him, and died among noisy drunken people 'loose' in the department, his body left on a trolley in the corridor. Eileen Whelan, Director of Nursing at Our Lady of Lourdes Hospital, Drogheda, echoed the point about A&E, saying admissions can occur there even when patients are known to the hospital. She also focussed on the patient's needs – 'why are we not asking them what they want, and instead turning our attention to the relatives'? The same point had been made earlier by the Ombudsman. Eileen Whelan who went on to state that the involvement of HFH in the hospital had been 'hugely positive'. Similar sentiments were echoed by Liam Duffy, CEO of Beaumont Hospital. He remarked: 'Hospice Friendly Hospitals has made us get the information. We didn't do hygiene until HIQA came along. We didn't do end of life care until Hospice Friendly Hospitals came along'[45].

The Health Minister, Mary Harney, praised the work of the audit and its influence on the standards document, which had been given the support of HIQA; but she also looked ahead to 2012 when statutory standards for all hospitals would be introduced. Encouragingly, she expressed a willingness to engage in dialogue about funding for a Design and Dignity Grants Scheme – which then came into being by the end of the year. Prof. Cillian Twomey, chair of the National Steering Committee, acknowledged the hard work and achievements of the first phase of the programme and saw the newly published standards as the key intervention that would make meaningful a further audit in a few years time.

At this point these two pillars of activity were centre stage in HFH thinking and seemed poised to breakthrough with a wider influence both at the hospital level and in the context of the HSE and HIQA. Behind the scenes however, it was clear that the HFH-HSE partnership was not reaching full potential. Within the HFH programme there may have been a nervousness at ceding influence to the HSE. From the health care system side, HFH could appear too idealistic, at

times inflexible and certainly not fully understanding that long term sustainability would depend on integration with prevailing policies, procedures and systems.

The Programme Manager brought the proceedings to a conclusion, acknowledging that phase one of Hospice Friendly Hospitals was coming to a close. End of life care in hospitals was now 'on the agenda'. It was in the hospitals that the concentration of effort should now take place. There were standing committees in most of the hospitals. New expressions of interest for participation in the next stage of the programme were being received. The standards would be taken forward through a network of 'champions for change', led by Úna Marren and successfully initiated at a meeting in Naas two months earlier. The autumn of 2010 would see the launch of an Ethical Framework for end of life care in hospitals. Phase two would be a short phase, and within it the four main themes of the Hospice Friendly Hospitals programme would be redefined as 1) Competence and compassion 2) Planning and co-ordination 3) The physical environment 4) An ethical approach. The Programme Manager concluded:

> *We close with a certain sense of quiet achievement, a sense of sadness – but a sense of so much work to be done across the whole of Ireland … We need to deal with the stories we have heard. They are not really to do with money, more to do with practices. We need more experience-based practice. Experiences aren't anecdotal[46].*

His remarks echo the focus of HFH at that point. The key goal was in generating a critical mass of activity across the programme, at the hospital level. This needed constant attention and advocacy. At the same time there were two other competing priorities – raising public awareness and influencing policy. These three dimensions were to stretch the capacity of HFH. Media attention was welcome, but difficult to assess in terms of impact. Working with senior colleagues in the HSE and HIQA presented other kinds of challenges – how to transform a largely marginal issue like end of life care into something central to strategy, a requirement of the system and with the necessary resources to make significant change? Meanwhile the day to day work in the hospitals was resource hungry but at the same time represented the key area where goals could be achieved and where change was most visible.

The successes of Phase One were numerous and considerable. A few years before major recession, very significant funds had been won for a national initiative on end of life care improvement in hospitals – hardly the easiest area to attract resources for reform and development. A coalition of support had been established across state and philanthropic agencies, which also involved a wide range of lay, professional and academic groups. A programme team had been assembled under strong leadership and assisted by the Irish Hospice Foundation. Some high profile advocacy had been developed involving leading figures from the worlds of politics, the arts and mass media.

Many examples occurred of 'thinking outside the box' of healthcare reform and there was a significant 'spin out' project in the the form of the National Forum on End of Life[47]. A host of workshops and conferences, expert meetings and consultations tackled end of life issues in the hospital from a variety of perspectives. Imaginative use was made of the evidence base, original research was commissioned, and senior academics were harnessed to the cause. Extensive materials were published to provide information, guidelines, training materials and symbolic

resources for use in hospitals, and the HFH website became a comprehensive and up to date portal into the vast range of programme activities and outputs. In the words of the Programme Manager:

> *I think that our biggest success has been to actually get it on the agenda. It's not a huge amount of progress you can say at one level, but compared to what it was ... I don't want to overemphasise that, but it is really significant because it is trying to give people a sense of their collective responsibility. The next achievement is in effect is to kind of bind together all of those people who have actually shown an interest and there is really genuine interest in some places ... and we have got to increasingly work to bring people with us ... We're now into a kind of thing of 'yeah, we're just part of normal your day to day business', you know ... and as resources tighten now in the second phase, the issue will be can we wisely identify the horses that are going to win the race?[48]*

Phase Two

Following the success of the 2010 Clontarf conference, the programme was now oriented to a more disciplined approach to involvement by the participating hospitals. A great deal of effort went into helping interested hospitals to sign up to a Memorandum of Understanding for Phase Two of the programme. This involved a much more detailed arrangement than previously, with a nominated person from the hospital senior management team to take a lead on end of life care (a proposal from the standards document). The work of the standing committees would continue, but this would be supplemented by development plans informed by the standards and the audit. There was a belief that the HFH standards gave a sense of authority to the hospital staff engaged in promoting HFH. As the Programme Manager put it – 'moral authority, to engage with the process in a more structured and more sophisticated way'[49].

By October 2010 the work of Hospice Friendly Hospitals was achieving national recognition, competing against 100 entries to win one of three Irish Healthcare Awards – for Excellence in Healthcare Management. The judges specially commended the development and implementation of 'Final Journeys', an interactive staff development programme, aimed at all hospital staff, as well as the 'Practice Development' framework to support the work of front-line staff in the care of patients and their families[50]. However, three years into the full 'roll out' of the HFH programme, it was clear there had been challenges as well as triumphs. In practice the four themes were not getting equal attention at all stages. 'Design and dignity' was an early focus and brought some 'quick wins'. 'Communication' had the benefit of being widely understood as an issue and could move forward through some concrete initiatives and projects. 'Integrated care' and 'Patient autonomy' were in turn proving more conceptual, slower to develop and perhaps more complex and challenging to mobilise.

From the perspective of advocacy, the programme had already seen some notable successes in attracting the support of media and political figures and in raising its profile in general. Unlike some healthcare initiatives in other settings, it recognised the power of these routes in facilitating progress. At a grass roots level it was having some success with advocating for

patients, family, staff and the hospital. This work would continue but keeping the concept of advocacy high on the agenda was again challenging, particularly with respect to empowering patients themselves.

The easier route was to develop more versions of professional advocacy, which, although worthwhile, seemed only the start of the journey to true empowerment and choice for dying people. Thus, for example, the Ethical Framework, as a tool for professionals, could be seen as a step forward in changing the culture of caring for the dying and not an end in itself. Indeed, under the theme of Patient Autonomy the programme identified, in the original grant application, the need for 'The establishment of a clear legislative framework to ensure patient and surrogate autonomy and to underpin the concept of a good death'[51]. There was some evidence of progress in respect to this in the interaction with The Law Reform Commission but inherent difficulties remained:

> *Those patients who suffer the greatest burden of symptoms and inadequate care are the patients who have the most to gain by becoming activists. But they are also the least able to do so[52].*

One of the continuing challenges for the programme was to keep engaging with these concepts and reviewing how the difficulties might be addressed. Some groups of professionals might be considered to have more power than others to influence the culture of care. In this context, doctors might be pivotal. Although one Development Co-ordinator felt that doctors had been receptive to their communications training, on the whole, it was felt that they had not engaged with the vision of HFH.

> *I suppose it's hard to get medical buy in I find because it's like, what are you selling me? That's what they want if you know what I mean; so I find that a bit frustrating.[53]*

> *We haven't had the influence with doctors yet, it's a very difficult group to crack … there's a huge demand on them and really from their point of view this is fluffy woolly jumper stuff.[54]*

Despite some notable medical advocates, it would seem that HFH found difficulty in rallying more doctors to its cause. The issues here are complex. Were physicians in general hostile to the aims of HFH? This raised a wider question of how doctors can specifically be empowered to take ownership of and promote end of life care in their hospitals? Too often this was not happening for HFH. As one public interest representative reflected: *I am distressed by the lack of medical involvement. It breaks my heart.*[55] On the other hand, as a Development Co-ordinator put it: *The programme is about cuture change and you're not going to do that overnight.*[56]

The challenge was therefore to persevere and keep reviewing the approach and the evidence whilst being true to the underlying principles of the programme - until a time came when 'all deaths are treated as important and significant'[57]. Alluding to the successes around design and dignity and the physical environment, it could be observed:

We've made a load of progress for the patients who have died and for the relatives that are newly bereaved in each hospital, I don't feel that we've yet done much for the patient who is dying.[58]

Phase Two of the HFH programme had to focus on ensuring that progress made in Phase One would be sustained, and that this could be maintained beyond 2012. More significant engagement with the HSE was key to this. As Phase Two got underway, it was clear that the achievements of the audit required greater exposure and an audit sub-committee was formed, chaired by barrister at law, Deidre Madden (see below) to examine how the 18 recommendations of the audit could be implemented in practice. Efforts were made, without success, to secure a meeting in 2010 with the outgoing CEO of the HSE, Professor Brendan Drum, to review the audit findings. In September 2010 a similar invitation was made to the incoming CEO, Mr Cathal Magee, and as we shall see below, this did result in a meeting 10 months later[59]. Letters were also sent at this time to the four HSE Regional Directors of Operations, offering a form of words that could be included in the HSE strategic plan for 2011: "In response to the National Audit of End-of-Life Care in Hospitals (2008-9), and the development of Quality Standards for End-of-Life Care in Hospitals, all hospitals will designate a member of senior management to oversee the preparation and implementation of an End-of-Life Care Development Plan". The letters even suggested a possible target: 'The number of deaths in acute hospitals will be reduced by 20% within 5 years as appropriate support services are developed at community level'". However, there was little substantive response from HSE and a desired goal was not achieved. The HFH Programme Manager took the view that, whilst work on the ground had continued in the period to late 2011, 'at the highest level there was a vacuum'[60].

At the same time the work of the HSE was changing in structure, with an increasing emphasis on the role of the Clinical and Strategy Programmes Directorate, led by Dr Barry White as the National Director, and consisting of some 33 programmes in total. The Directorate was established to improve and standardise patient care throughout the organisation by bringing together clinical disciplines and enabling them to share innovative solutions to deliver greater benefits to every user of HSE services. Within this structure, Dr Karen Ryan was appointed as the clinical lead for the palliative care programme. The aim of this programme is 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'[61]. The work was taken forward by an 18 strong multi-disciplinary working group[62] which listed no less than 25 deliverables for 2012.[63] Strategic partners of the working group but not members of it included the Irish Hospice Foundation and the Irish Association of Palliative Care. Up to late 2012 Dr Ryan's key link within the integrated services directorate of the HSE (its operational arm) was the Assistant National Director for all 52 acute hospitals, Dr Siobhán O'Halloran, who also took on the portfolio for palliative care (but moved from the HSE into a new role in the Department of Health, in late 2012).

Following a lengthy hiatus, eventually high level contact with the HSE was established by the programme. At the 13 July 2011 NSC, Dr O'Halloran reflected on the meeting earlier that morning between the HSE Chief Executive, Mr Cathal Magee and Professor Twomey, Sharon Foley (the new CEO of the Irish Hospice Foundation) and Mervyn Taylor, HFH programme manager. Dr O'Halloran stated that the HSE had great regard for the Irish Hospice Foundation and supported the need to embed the work developed by IHF/HFH within the wider healthcare

system.[64] Indeed the programme manager, speaking in October 2011, felt particularly encouraged by the meeting with the CEO[65]:

So you can say the engagement has been uneven but it hasn't been non-existent. Quite the contrary; at a number of levels the level of engagement and level of interest has been steadily building and the interesting part is that when we got to meet with the CEO, my memory of that meeting is very much that what struck him, what interested him was the potential of the Hospice Friendly Hospitals Programme, the synergy between that and the overall change agenda that he would want for the HSE and perhaps, without signalling it too directly, drawing links between the need for this type of work to be more integrated with the change programme … On the kind of negative, there is still no clear, powerful champion within the system, for the wider view of end of life care that we would take. There is no Mike Richards.[66]

During this period, there appears to have been considerable 'noise' in the system. At IHF discussions were underway about the sustainability of HFH, various options were put forward about how to obtain higher level engagement with the HSE, with the Programme Manager appearing to favour closer physical proximity, even co-location. At the same time the role of the new clinical lead for palliative care was being established, as was the newly formed All Ireland Institute for Hospice and Palliative Care. A workshop took place in Autumn 2011 as a result of the earlier meeting with Mr Magee and was to enable the Irish Hospice Foundation and key figures within the HSE providing end-of-life care and palliative care to explore the potential for closer collaboration. This workshop included representatives from other interested parties in the area of palliative care and end-of-life care with the aim of examining overarching mechanisms that could move all parties in the same direction. It appeared not to have a clear outcome however and one year later, as the work of this report concluded, the question of high level engagement with the HSE remained unresolved.

Two areas of significant progress stood out by late 2011 - the work of the Final Journeys initiative and the project on Practice Development. By that time some 1,000 HSE staff members were involved in the Final Journeys work and the HFH team members were delighted by their commitment and also by the reported feedback. There were examples of staff coming in for training on their days off or taking annual leave in order to undertake training. The Practice Development initiative had in turn 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'[67].

On the evening before the conference in Clontarf Castle, in May 2010, a second, informal, meeting of the 'Champions for Change' group had been held following the first gathering, in Naas in March of that year. The second meeting discussed draft terms of reference, the development of a formal identity and the broadening of membership and participation. The new name of Meitheal Ceannródaíochta – Network of Champions for Change, was adopted to reflect a desire to be as inclusive as possible.[68] This was followed by a meeting two months later in the Hodson Bay Hotel

in Athlone on 19/20 July which focussed on how hospitals can prepare their own development plan for end-of-life care and on the supports they are likely to need in the process of implementing the plans. The purpose of the group was to take the work of the programme closer to the 'coal face', to get more involvement from senior hospital staff, particularly Directors of Nursing, and to gradually shift the centre of gravity and responsibility for HFH away from the programme staff and towards the participating hospitals at the local level. It would therefore provide a forum for key people promoting improvements in end-of-life care in hospitals and provide input into the work of the National Steering Committee of HFH.[69]

A network of HFH Community Hospitals in the Dublin area had been established in 2009 and further informal networks of end-of-life care providers were slowly emerging in the North-West and South. At the November 2010 meeting of the NSC it was decided to link its work more closely with that of the Networks and, in effect, make the NSC the steering body for all service providers and organisations working to implement the concept of the Hospice Friendly Hospital. Crucial to this reorientation in the role of the NSC would be the need to ensure the widest possible range of perspectives by involving differing roles from each of the four HSE regions. The support of the two 'sponsoring' organisations, the Irish Hospice Foundation and the HSE, was also critical and it was agreed that, in addition to executive representation from the IHF and the HSE, a senior member of the Board of the IHF should continue to be a member of the NSC. This appears to have been a crucial decision, perhaps influenced by the arrival of a new CEO at IHF, and one which would seek to ensure that HFH remained a high priority for the IHF board and that no separation should develop between the foundation and the programme.

The Hospice friendly Hospitals Network photographed with the Irish Healthcare Award of Excellence in Healthcare Management (2010)

At this point it was therefore possible to re-articulate the aims of the HFH programme, as follows:

1 to implement the Quality Standards for End-of-Life Care in Hospitals on a planned basis and review progress in their implementation

2 to enhance culture and practice regarding all aspects of care at the end of life

3 to innovate to improve the experience of the patient and family journey into, within and out of the hospital setting.[70]

Was this 'mission drift' or a growing sense of understanding concerning the challenges faced? Certainly, the first aim was centrally concerned with the business of HFH. But the other two were arguably extremely wide and in the case of third particularly, almost impossible to monitor or evaluate. Perhaps there is a sense here of both the strengths and weaknesses of the HFH approach – always concerned to move on and to innovate but less strong when it came to the close definition of achievable and measureable goals. The four key themes in the process of developing Hospice Friendly Hospitals, which had been agreed by the NSC meeting in July 2010 remained, as stated: Competence and Compassion; Planning and Coordination; The Physical Environment; An Ethical Approach.

When Eugene Murray retired from his role as CEO of the IHF in the Spring of 2011, the incoming CEO, Sharon Foley, was quick to identify the strengths of HFH and to see continuities with her public health background:

> *I had a lot of involvement in years past from health promoting hospitals and baby friendly hospital initiatives, reasonably closely modelled on those WHO models of intervention in acute hospital settings, so I would have been very, very familiar with the concept and I would have seen it very close to my experience in healthcare and healthcare management. How we tried to achieve culture change in an acute hospital setting. But I would have been much more impressed by this programme than I was with the ones I had been involved in because the ones I had been involved in before had been very much project based. So each hospital had to do a series of projects and different things but they weren't systematic. They weren't getting at the inherent culture at the hospital. They weren't looking at systematic change in terms of policies and procedures. So those previous WHO models I thought were quite weak. Whereas this one, was very systematic, very strategic, highly polished standards developed, very thoughtful and insightful in approaches of what they were trying to do, very well considered[71].*

With the end of Phase Two coming into sight, the Programme Manager produced a document summarising the development of the programme and offering some considerations for the future sustainability of the Network of Hospice Friendly Hospitals[72]. On 29 February 2012, the IHF launched a strategic plan containing elements to take this forward to 2015. This had been a major piece of work led by the new CEO in the first months of her appointment. There was no direct mention of Hospice Friendly Hospitals in the accompanying press release[73] but a

commitment to the programme was clearly articulated in the plan itself, which stated that whilst the programme 'formally concludes in 2012; its work will be progressed and supported through the emerging Network of Hospice Friendly Hospitals'[74]. The plan also stated:

> We will sustain the work of the Hospice Friendly Hospitals Programme (2007-2012) by supporting its National Steering Committee and the growing Network of Hospice Friendly Hospitals in implementing development plans based on the National Audit and Quality Standards for End-of-Life Care in Hospitals.[75]

The plan sought to clarify and strengthen the IHF commitment to HFH for at least three more years. It was recognised that a need still existed. HFH would remain a core programme of the Foundation but there was a hesitancy about committing to major detail and a recognition that it would be very difficult to find another €10m again. It also had to be acknowledged that the creation of the clinical care programmes within the HSE and the major re-structuring of the health service were enormously important factors to take into consideration when thinking about the future of HFH.

By the Spring of 2012 phase two of the Hospice Friendly Hospitals Programme was coming to an end. The fully constituted Network of Hospice Friendly Hospitals met at Killashee on the 14th and 15th March and in the afternoon of the second day the National Steering Group met for the first time under its new Chair, Kate Bree, Co-ordinator of the Nurse Practice Development Unit at Sligo General Hospital. For the Programme Manager this shift was crucial: 'as the programme ends and the network begins, there is at least a statement in the strategy of the Irish Hospices Foundation supporting the network for another three years. But the position remains that ownership within the system, championing within the system, is no more advanced. This isn't unique to us, but it's still a huge problem'[76].

The next two months brought some further gains, which are explored in detail below (section 5). In June the long awaited HIQA publication on health care standards, did indeed acknowledge the HFH standards document[77]. Then in August a major report appeared from the National Economic and Social Council which praised the achievement of the HFH work on standards and made some wider and telling points on the challenges faced by programmes of this kind as they seek to engage with state agencies and systems[78]. The final HFH report to Atlantic Philanthropies, dated July 2012, explains that:

> As part of the Programme's sustainability plan, the work of Hospice Friendly Hospitals will continue through the Network of Hospice Friendly Hospitals supported by a core team of HFH personnel and funded by the Irish Hospice Foundation as part of its strategic plan 2012-2014, as follows: to implement the Quality Standards for End-of-Life Care in Hospitals on a phased basis and to review progress in their implementation to enhance culture and practice regarding all aspects of care at the end of life to innovate to improve the experience of the patient and family journey, into, within and out of the hospital setting. The Final Journeys Team has been integrated into the Education Department of the Irish Hospice[79].

This then, was the culmination of the pilot project in Drogheda (2004-6) and the two phases of the national roll out (2007-12). We include here at various points an indication of further HFH

activity in the period from the conclusion of Phase Two (when our study brief formally ended), to capture a flavour of developments in the period to the end of 2012. What would the years to 2015 hold in store and to what extent would the plans put in place to create sustainability for the Hospice Friendly Hospitals idea be effective? The Irish Hospice Foundation committed in its strategic plan for 2012-15 to continue to fund three key elements of the programme over three years. These elements are the Network of Hospice Friendly Hospitals; the new System of Audit and Review of End of Life Care to be used initially in acute hospitals; and the Final Journeys staff training programme. We will turn again to these issues and to wider questions of sustainability and focus in the final sections of this report.

3

The Hospice Friendly Hospitals Programme and Advocacy

3. The Hospice Friendly Hospitals Programme and Advocacy

One of the aims of this analysis is to reflect on the impact of the HFH programme as an advocacy project. Within the literature on advocacy[80] **self advocacy** is often seen as the purest form and ultimate aim[81]. Here the individual, often through confidence building and the provision of information and education, is enabled to advocate effectively for her or himself and not become marginalised in the process. Whatever form advocacy takes (for example in relation to policy, professionals, citizens or peers) there is, in general, consensus that it aims to represent or empower vulnerable people and that it must be independent, thereby limiting conflicts of interest for the advocate[82]. The HFH programme advocated for the best care for dying people in Ireland's hospitals. Clearly, its central focus was a group of individuals made vulnerable during the dying process and who are not able to complain subsequently about deficiencies in their care. The programme's name reflects an aspect of the hospice movement itself, which grew from the motivation to provide the highest quality care for the dying – itself an example of patient advocacy.[83]

HFH became a sophisticated, multifaceted advocacy programme – often going beyond the specific issue of advocacy for the patient. We can see that in addition to the patient, HFH advocates for the family and friends of the dying person, the frontline staff who care on a daily basis for those dying in the hospital and for their loved ones, as well as the hospital administrators and managers who wish to prioritise end of life care in the hospitals for which they are responsible. It might indeed be considered in turn that HFH advocates for all Irish citizens who will one day die and that it lobbies for a more civilised society by raising the profile of care of the dying and emphasising its importance.

From very early in the life of the programme there was a commitment to political lobbying and public policy advocacy. The programme leadership saw that this was essential if HFH was to have to have a wide-ranging and sustained impact. In this, HFH demonstrated a good fit with its main funder, The Atlantic Philanthropies, which aims to support lasting change by: addressing the root causes of social injustice; focusing on advocacy for change rather than filling gaps in services; funding efforts to challenge policies and institutions that systematically exclude or disadvantage people; building on the strengths of individuals, organisations, communities and movements to advocate on their own behalf and on behalf of others; supporting institutions and investing in leaders who can work for progressive change over decades; working in partnership with government, whenever it can advance its goals and those of the organisations supported[84]. Advocacy was not identified as a specific 'theme' within HFH, yet it can be seen to run through every aspect of its work – sometimes with high profile and public attention, sometimes in quiet and subtle ways that impact in specific and local circumstances.

We have seen that during the HFH pilot project at Drogheda, it became apparent that there were many issues related to the care of dying people in hospitals that could not be addressed at a local level and that a national approach was needed. As a result, the conference organised in May 2005, as we have seen, recognised the importance of political engagement and generated a 'mandate' for change.

Over the following five years the HFH programme endeavoured to engage with the political establishment to further its cause. For example, in 2008, Enda Kenny TD, then leader of Fine Gael, met with the programme leaders and visited Leopardstown Park Hospital to see for himself the situation there. At Leader's Questions in the Dáil he subsequently raised the

issue of the poor conditions he witnessed, suggesting that the elderly patients being cared for there were being treated without 'respect, dignity or integrity'[85]. This received some media attention, particularly as it coincided with Taoiseach Bertie Aherne handing over office to Brian Cowan. In late 2009, Independent Senator Ronan Mullen who had also contributed to the IHF inspired Forum on End of Life,[86] was joint sponsor of a debate on end of life care in the Irish Senate under Private Members Business and which was underpinned by reference to the HFH National Audit of End of Life Care in Hospitals and the Quality Standards for End of Life Care in Hospitals[87]. Whilst it is difficult to assess the impact of these initiatives, they certainly helped to raise discussion about end of life care within Irish society and drew specific attention to the HFH programme. As we shall see, there were also some notable gains in securing support and interest for Phase One of the programme on the part of the then Minister for Health and Children, Mary Harney.

In addition to direct political lobbying, the programme engaged with a variety of high profile figures from the world of politics, the arts and media. Former President Mary Robinson was invited by the Irish Hospice Foundation to deliver the first Mary Holland Memorial Lecture in 2005. Given in memory of the journalist, whom she described as 'a passionate and courageous advocate for the powerless'[88] she used Ms Holland's experience of poor quality care at the end of her life to highlight the importance of quality improvement: 'we are now required to honour her life and commitment to social progress by focussing on people who are dying in quiet desperation'. Likewise, then President Mary McAleese, also supported the work of the programme, speaking at the launch in 2007 and providing a message of support in 2010 as an introduction to the Quality Standards for End of Life Care in Hospitals.[89]

A meeting at the Hospice Friendly Hospitals Network, 2010

In the world of the media, the HFH programme cultivated some dedicated and powerful allies and advocates. Marian Finucane the broadcaster, almost brought Ireland to a standstill in her April 2008 interview with the writer Nuala O'Faolain, who was talking about her recent diagnosis of terminal cancer. Although it took place in New York, the account of how she was given her diagnosis in the middle of a busy emergency room in a brutal and inhumane way, seemed to strike a chord with Irish listeners[90]. Finucane, an IHF board member, went on to chair the inaugural meeting of the Chairs and Deputy-chairs of Standing Committees on Dying, Death and Bereavement from over 20 hospitals, held in Naas in March 2010, which later became the Network of Champions for Change. As part of this meeting, she facilitated a session in which she asked the attendees to imagine they were being interviewed by her about the HFH programme[91]. This inspiring event facilitated a discussion of what the programme meant to the hospitals represented and seemed to help those involved to take ownership of HFH, rather than seeing it as something being imposed upon them. In the session, some mentioned the importance of the wide remit – for example the inclusion of receptionists and porters in the communication training. Others mentioned the lack of appropriate facilities to promote good end of life care and the difficulties in obtaining funding to improve these. Certain speakers acknowledged the difference made by the Celtic symbol[92] used to indicate that a death had recently taken place on a ward. All this was aimed at developing these individuals as effective advocates for high quality end of life care in their hospitals. In doing this the programme was seeking to build a network of advocates across the country who would become 'champions for change'.

The highest profile advocate for HFH was undoubtedly the Irish Hollywood actor, Gabriel Byrne. A graduate in Archaeology and Linguistics from University College, Dublin, and famous for his roles in films such as The Usual Suspects and Miller's Crossing, Byrne had recently enjoyed a resurgence of popularity in the US TV series 'In Treatment'. He had been quoted as saying that he felt impelled to become an advocate for the dying after he witnessed the death of a friend in an Irish hospital with little privacy and dignity in his final hours[93]. Gabriel Byrne became a staunch and active supporter of HFH, often involved in raising the profile of the programme to wider audiences. He appeared on the homepage of the HFH website emphasising 'What Matters Most' (Coordinated care, good interpersonal skills, the quality of the physical environment and an ethical approach) and was featured in various examples of educational and promotional material for the programme. He brought an undeniable and invaluable glamour to the HFH programme and the cause of end of life care in general.

During both phases of HFH there was a strong emphasis on the four defining elements of the programme. In the next section we explore each of these in turn, giving illustrations of how the theme of advocacy runs through them, and also how they changed over time.

4

The Key Themes

4. The Key Themes

4.1 Design and Dignity/The Physical Environment

The Hospice Friendly Hospitals programme was significant in going beyond the immediate technologies and processes of 'care' to consider the influence of the physical environment upon end of life issues in hospitals. This saw the programme engaging with architects, with researchers interested in 'evidence based design' and with academics able to reflect on the culture and symbolism of the physical context in which care takes place. It was done against a backdrop of opinion which sees Ireland as having 'one of the worst physical health infrastructures of any country in the developed world' and where even in good economic times, the problem of the physical environment of hospitals has not been a priority for either government or opposition parties or indeed for many health related advocacy groups. In this context, the programme sought to develop a positive agenda based on shaping an awareness of the importance of high quality healthcare environments and the related clinical, social and economic benefits. HFH interests therefore came to include: building the capacity of hospital and network-based work groups to appreciate and engage with issues relating to the design, layout and organisation of the physical environment; providing resources to assist hospital staff to engage in practical projects as part of the process of implementing improvements linked to standards development; supporting the development of exemplar projects so that health care staff and planners might visit and learn from examples of good practice; promoting a clear focus on design related issues in the context of new service plans and policy developments; as well as proposing a grants scheme to encourage small scale improvements in existing hospitals.

Some early work was done to establish the evidence base in relation to design issues and hospital care at the end of life. The literature revealed six key themes: single rooms, internal environment, external environment, unit configuration and nurses' station, family and visitor facilities, family care.[94] It found descriptions of good practice from around the world, but concluded that there was little empirical evidence on how the built environment affects the dignity and privacy of the patient. Academic and student of health related architecture, Ken Worpole, also added to the debate. He was commissioned by the programme to write a reflective piece on hospital design in its cultural and historical context. He spent time in Ireland visiting hospitals and also looked at examples of hospital care of the dying in other countries, particularly Norway. In one former 18th century Irish military academy, now acting as a hospital for the elderly, he learned that up to a third of the older patients had no surviving family and some would die in an open 'Nightingale' ward - shocking to some, but not to others who believed that the staff and patients represented a surrogate family. Most hospitals, he observed, tried to provide single rooms for those for whom death was imminent, though some patients refused this option. A further dimension has been added to this by the MRSA problem, which requires single rooms for isolation. Worpole's argument is that no matter how good the care and the attentiveness of the staff and families, many of our hospitals are simply not good places from which to leave this world. A person's last days ought to be spent in conditions of tranquillity – not facing a windowless wall with a television blaring in the background. One senior manager Worpole met in Dublin said that the elderly and the dying are 'the canaries in the coal-mine'. Their inadequate treatment alerts us to something amiss in the system at a deeper level. Worpole observed:

Design ... is an organising principle of the highest order of institutional and clinical success. Appropriate design enables individuals and organisations to see more clearly what is really happening and to exercise greater control. The improved design of hospitals should enable people to establish and sustain better relationships to each other and to the living world outside, and to find themselves in a calm and restful place, especially as they approach their last hours.[95]

A key action of the HFH programme in this area was to review the physical environment of 15 acute and five community hospitals in Ireland. The results of this work, a Baseline Review, undertaken in 2007 by Tribal Consulting[96], provided cause for concern, most particularly with regard to: the lack of facilities for private consultations and conversations in situations where confidentiality is paramount; the extent to which already very limited single-room accommodation is denied to dying people and their families because of the priority given to infection control and isolation; the lack of facilities for families; and the poor quality of mortuary facilities. Following the launch of the report the Programme Manager said:

We see no point in simply listing the shortcomings that have been identified in our hospitals. We do, however, see value in constructively engaging with agencies and individuals so that agenda can be determined by 'what can be' rather than 'what is'[97].

As a result a Working Group was organised, including senior nurses, palliative care specialists, healthcare quality experts, HFH programme staff and consultant architect Ian Clarke - to develop a set of Design and Dignity Guidelines for Physical Environments of Hospitals Supporting End of Life Care, the draft of which was subject to public consultation in spring 2008 – receiving over 80 responses[98]. Published in June of that year, it was anticipated that the guidelines would be used primarily in project briefs for new hospitals but would also be a resource for refurbishment and to guide improvements. These guidelines, if implemented in a hospital, were considered to have benefits for patients, staff and visitors in general, not just for those who were dying and their families, concentrating as they did on evidence based design for hospitals. This highlighted the potential role of the HFH programme in improving care in general whilst concentrating specifically on the care of those close to death. The guidelines were a resource providing information on the important issues with respect to the hospital environment and how it might be improved. They assisted in making these issues more concrete – for example a pleasant environment had been shown to decrease the need for analgesia, and to emphasise that these factors are not optional or outside the hospital remit, but are essential and central to its work.
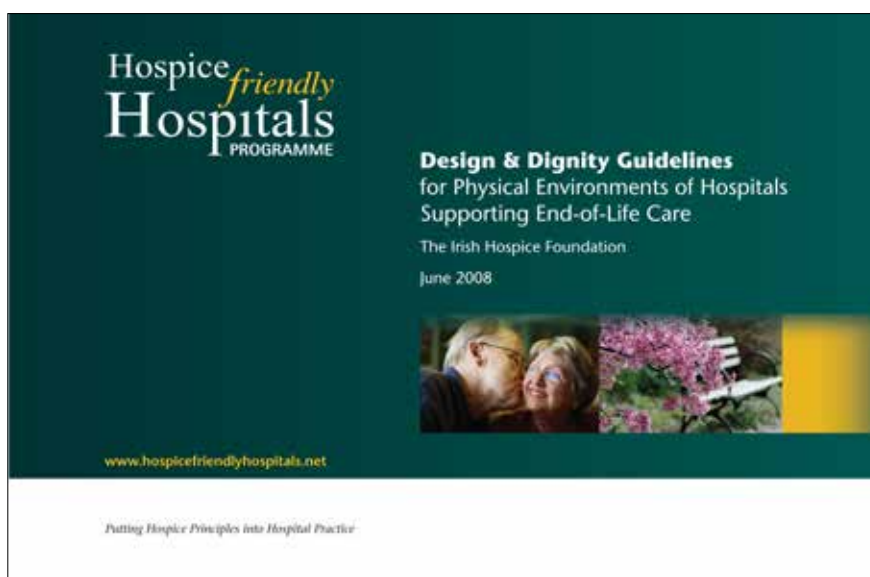
We can see here ways in which HFH was advocating for relatives and friends of the dying, specifically by its emphasis on the environmental challenges found within Irish hospitals. In the Baseline Review, one hospital was commended for its good practice with respect to a variety of innovations including some that had a particular impact on families:

- There was sufficient room at the bedside to allow nursing care and accommodate a reclining chair or folding bed for a relative's overnight stay.
- Dedicated parking was provided for bereaved relatives as well as taxis for those too upset to drive.
- A healing garden was provided as a retreat for relatives away from the ward environment.
- Separate accommodation was provided away from the ward for relatives to stay overnight both on and offsite.
- A sitting room and kitchen were available for relatives to prepare beverages and provide a space away from the bedside when required.

- A 'dead on arrival' room was available in the emergency department adjacent to the relatives room.
- The mortuary had a relatives waiting area with drinking water, toilet and washing facilities.[99]

These approaches, together with examples of good practice from elsewhere, were incorporated into the production of the HFH Design and Dignity Guidelines. From the relatives' perspective several of the guidelines had particular significance. First, they emphasised the need for clear 'way finding', such as unambiguous signage that is easy to use, 'you are here' maps, information desks and views of the local area to help with orientation. This reduces stress for relatives bringing a patient to hospital or visiting - and fosters a sense of control in an unfamiliar, sometimes apparently hostile, environment. Such recommendations could in some cases be quickly addressed at modest cost. Second, the guidelines promoted the importance of single rooms in allowing privacy for conversations that patients and families may need to have at the end of life, as well as in helping to preserve the dignity of the dying and allowing them and their families the space to express emotion. Third, they supported the development of facilities for families that enable them to have some time alone to reflect, to make a drink and to stay overnight if needs be. Specifically, the guidelines advised that a relative's room, with a shower and toilet should be provided near each ward and that the furnishings should be adaptable for sitting and resting. The guidelines also advised that the route to the mortuary should be covered and that mortuary waiting areas are provided that can be subdivided if needed for more than one family or if family members do not wish to be together. Viewing rooms should be adaptable for different faiths and, if possible, allow access to an enclosed garden area. Finally, bereavement services, the guidelines recommended, should be in quiet areas of the hospital and such facilities should promote a sense of calm and confidentiality.

The Baseline Review and, in turn, the guidelines were useful tools for the HFH Development Co-ordinators to raise the profile of the environment for end of life care and to begin discussions with those who had the influence or remit to consent to the process of review of their own hospitals. In this way and even with very limited resources, they were able to facilitate change. One recalled a hospital with few single rooms where the nursing staff wanted to make the patients' space in a six bedded ward more personal to them so they and their families could feel more at home with photographs and some personal effects[100]. Another facilitated the Director of Nursing in her hospital to come to the launch of the guidelines:

> And she was very impressed with the launch and with the guidelines and so the guidelines have been used and are being used for any further refurbishment of the hospital[101].

With this support behind her, this Development Co-ordinator was able to access money from the hospital foundation for a project she, in partnership with Emergency Department staff, had identified early on as a priority:

> I got funding for the refurbishment of the relatives' room in the emergency department, that's all been redone …and an ex patient … he did all of the stained glass windows in the churches around Ireland in the fifties and he did a beautiful stained glass window for us, for the room. When I went down to meet him he asked me if we wanted anything in particular and I asked him if we could incorporate the spiral symbol in the window[102].

By 2010 there was evidence that enthusiasm for these issues was growing within the hospitals themselves and that the Champions for Change initiative was beginning to reap rewards. The Chair of the Standing Committee on End of Life Care in Cavan/Monaghan hospitals described how she and others had, with modest funds, organised more appropriate relatives' facilities for the hospital's Accident and Emergency Department. In a powerful presentation at the 2nd Meeting of the Network of Champions for Change, she showed the transformation of a grim Portacabin, placed just outside a door of the department, into a bright, humane, flexible space that was adaptable to the needs of the families that would need to use it. Its worth was quickly realised when a member of the department's own staff was killed in an accident at work and many colleagues as well as family and friends, came to show their respects in an atmosphere of significant loss and emotion[103].

Another simple but effective initiative that had an impact on relatives in particular was the production of bags in which patient's belongings could be returned to families[104]. One of the factors that led to a complaint to the Ombudsman about the care received by a father at the Sligo Hospital in 2005 was that, after his death his family were asked to take away his belongings which were left in three bin bags under the ward Christmas tree[105]. The new 'Hospice Friendly' belongings bags, on the other hand, were made from jute and incorporated the Celtic spiral design. They represented a more dignified way to return the possessions of a deceased person and convey a message of care at a crucial time:

Symbolic Resouces -
The multi faith ward altar
and family handover bag.

You're on a ward and you're basically fire fighting, you don't have time to step out of role and 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 solution'[106].

The bags, together with the spiral symbol, used to indicate that a death has recently occurred on a ward, and the dignified purple mortuary trolley drapes[107] all helped to raise the profile of end of life care in hospitals as well as to facilitate respect, promote a thoughtful approach to the bereaved and allow staff, and families, the opportunity for reflection.

Those are really key pieces that have impacted at a ward level and for the patient, and further for the staff and families as well, these pieces have been key.[108]

The issues raised in the 2007 report by Tribal Consulting were subsequently referred to in the Joint Statement on End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland produced on behalf of the National Council on Ageing and Older People and the Irish Hospice Foundation, in June 2008. This statement indicated that 'One of the significant barriers to good quality end-of-life care is the physical and sensory environment in acute hospitals, psychiatric hospitals and voluntary hospitals/homes'. It asserted that 'hard questions must be asked about how we plan the physical environment in facilities where significant numbers of people are known to die' and specifically raised three key questions: 1) why do some facilities not provide the physical environment needed to allow their residents to live and to die in dignity, for example with only thin curtains separating the living from the dying, those eating from those using a commode? 2) why are so many older people allowed to die in busy wards against a background of noise from other patients, televisions, etc? (Keegan et al., 1999) and 3) why are appropriate facilities for the dying and amenities for those who accompany them not provided in the last hours?

The end of life symbol.

The work was also referred to in the Report of the Commission on Patient Safety and Quality Assurance - Building a Culture of Patient Safety (July 2008). The Commission indicated that it was

> … persuaded by such evidence as has been made available to it and by submissions made on this issue that the implementation of evidence-based design will result in safer and higher quality care for patients, with resultant economic benefits for the health system[109].

For HFH, the unit of accommodation in hospitals came to be a room, rather than a bed, and sharing a room with others at the end of life should, in so far as is possible, be reframed as a matter of choice for those concerned. These concerns were shared, from differing perspectives, by many others. Consequently, an opportunity arose to link an interest found in hospices with the agendas of health care providers, quality and risk managers, infection control experts, health economists, specific illness organisations, patient advocacy groups, political parties and the social partners.

The involvement of key international experts, such as Professor Roger Ulrich, was key to this and he was asked in 2008 to produce a briefing paper that would make the economic case for renewing Ireland's healthcare infrastructure and, in doing so, to address one of the commonest barriers, namely that good healthcare infrastructure is deemed not possible on grounds of financial cost.[110] When the HFH Programme Manager spoke to the Healthcare Ireland conference in April 2009, his chief points were therefore to highlight: how the physical environment of hospitals can enhance or detract from the dignity of patients; the role of evidence based design in planning new facilities; how bad design costs as much as good design; and why single rooms are central to creating safe and dignified hospital care.

Such work was original, ground breaking and enabled the HFH programme to gain a great deal of wider publicity, recognition and media coverage. It would lead, by late 2010, to the public announcement of a Design and Dignity Challenge Fund. Announcing the Fund on November 8th, Minister for Health and Children, Mary Harney TD, said:

> I am very pleased to make available National Lottery funding of €250,000 from my Department to the Irish Hospice Foundation towards this new Fund with a further €500,000 being made available from the HSE to develop this Initiative over 2011. This funding, which will be met by matching funding by the Irish Hospice Foundation, will progress the aims of the Fund into the future ... The difference that appropriate care at end-of-life can make to patients, their families and friends is immense. The provision of high quality care is paramount. I welcome the Design and Dignity Challenge Fund initiative. As many people will inevitably die in hospital it is important to ensure that the facilities, procedures, policies and staffing are arranged in ways that respect the needs of patients and their families at this most difficult time. This initiative will compliment the significant advances that have taken place in recent years in relation to end-of-life care generally.[111]

The National Audit of End-of-Life Care in Irish Hospitals (see below) conducted as part of the HFH programme, would show that some 15% of beds in acute and community hospitals are in

single rooms. Despite this, a third of patients (33%) spent most of their last week of life in a single room, and more than four in ten (44%) died in a single room. This suggests that hospital staff try to allocate single rooms to patients in order to facilitate a more dignified death, itself indicating an awareness of the importance of single rooms at the end of life. Nevertheless, the audit showed that nearly half of all patients who die in a shared room would have preferred a single room (45%). The Development Co-ordinators also saw how the environment served to shape the relatives' experience of care

> .. what relatives have said is that at the end of the day the actual physical space, while it's not the most important thing, it's about feeling they are being cared for[112]

The Design and Dignity Grants Scheme was opened to applications from HFH affiliated hospitals in December 2010. A Project Advisory Group (PAG) had been established to oversee the process[113] and anticipated around 12 applications by the closing date of 15th April 2011. In the event, by June, six hospitals had been awarded funding in Round 1 (Box 2). The aim was that these developments would act as 'exemplar, or demonstration projects, within a hospital facility, region or sector which would guide the future development of facilities related to end of life care'[114].

The Mater Misercordiae Hospital in Dublin applied for funding for a family room and was awarded €40,000 with an additional contribution from the hospital itself of €4000. The design produced by Ronan Rose Roberts, Architectural Consultant to HFH, was chosen and, therefore, he was also available on site to be actively involved in all aspects of the project. As a result of this and the commitment of the Mater Hospital team, the project was completed on time and within budget. By May 2012, the room was in regular use.

At the St James Hospital in Dublin it was planned to develop two viewing and family rooms, but there were difficulties staying within their award amount of €60,000 to complete the project. As a result, the PAG approved additional funding of €20,000 and the rooms were completed in September 2012. The other projects in the first round of funding took longer to develop. Beaumont Hospital had an extensive project of mortuary renovation planned and had an architect produce an ambitious and attractive brief that proved too expensive and had

Hospitals Awarded Round 1 Funding

- Beaumont Hospital, Dublin
- Cork University Hospital
- Mater Misercordiae University Hospital, Dublin
- St James Hospital, Dublin
- Sligo General Hospital
- Mercy University Hospital, Cork

to be trimmed back to fit their budget of €376,000. Work on this began in September 2012. With a similar budget supplemented by the hospital itself by €203,000, Sligo Hospital was able to seek planning permission in June 2012 for a mortuary extension and two family and viewing rooms. At the Mercy Hospital in Cork, mortuary renovation was postponed because the hospital withdrew its contribution which was to pay for the improvements needed to access the department, but it was hoped that the building work could proceed with the grant funds independently. Most disappointing, for those involved, was the withdrawal from the scheme of Cork University Hospital and its novel 'Serenity Suite'. Consisting of a viewing room, family room, kitchenette, study, ensuite and garden, it had reached the advanced stage of submission for construction tenders before the hospital withdrew.

Nine hospitals had been selected for funding on a phased basis (Box 3). Of these Mid-Western Regional Hospital, Dooradoyle, Limerick and Our Lady's, Navan, were awarded funding in May 2012. At the Mid-Western Hospital, it was planned that the grant would be used to upgrade the mortuary, including the entrance, a reception area, a second chapel of rest and a counselling area - with a covered walkway from the hospital to the mortuary planned for a later stage. The hospital also used the Design and Dignity Guidelines in the planning of their new buildings. Thus, in the Critical Care block that opened in September 2012, family areas were provided on each floor and the plans for the new Emergency Department included space for family members to be with a dead or dying individual and a private room suitable for breaking bad news was also included. Plans for a family room and garden at Our Lady's Navan were less extensive but needed an increase in budget when it was realised that a kitchenette and en suite facilities would make the room more useful and flexible.

HSE Estates emphasised its continued commitment to the scheme by confirming that a further €500,000 would be available to the Design and Dignity Grants Scheme and the IHF did likewise by engaging with the Ireland Fund[115] to raise matched funding. In October 2012, a further four hospitals were awarded funding (St Luke's, Kilkenny, Mid-Western Regional Hospital, Nenagh, Mayo General Hospital and Connolly Hospital, Dublin) making a total of 11 hospitals actively engaged in projects funded under the first Design and Dignity Grants Scheme call by the end of 2012.

The refurbished family room at the Mater Hospital. Funded through the Design and Dignity Project.

The Design and Dignity Grant Scheme was realised at a time of great financial hardship for Ireland and the successes and failures of the projects must be considered within that context. Some of the projects were modest but, even then, there was a tendency for budgets to be underestimated and no provision was made for contingencies. Ronan Rose Roberts, HFH Architectural Consultant, felt that it was very important that the quality of the finish of each project was high, and therefore more costly, otherwise the ambience of the facilities might be wrong and users might feel disappointed with the result. This was further complicated by the need for materials that were acceptable to the Infection Control Team in each hospital. Keeping hospital teams enthused and encouraging them to keep projects on track also proved challenging for the HFH team - but, for one team member at least, reflecting on the first completed project the outcome made it all worthwhile:

The refurbished viewing rooms in St. James's Hospital Emergency Department. Funded through the Design and Dignity Project.

Box 3

Hospitals to be funded on a phased basis

- Mid-Western Regional Hospital, Dooradoyle, Limerick
- Mayo General Hospital, Castlebar, Co. Mayo
- Our Lady's Hospital, Navan, Co Meath
- St Luke's general Hospital, Kilkenny
- Mid-Western Regional Hospital, Nenagh, Co. Tipperary
- Connolly Hospital, Dublin
- South Tipperary General Hospital
- Naas General Hospital, Co Kildare
- Midlands Regional Hospital, Tullamore, Co Offaly

They will make a huge difference to the lives of people using them and that was really brought home to me even just on the Mater project where I was meeting with a rep from a flooring company…and he was telling me how inspired he was by the actual sheer fact of the room existing at all, a family room on a ward for families to come and stay while their loved one is ill or dying and he told me that his wife had died in a hospital in Dublin and there wasn't anything like this for them to use. I thought – God, this is really important work[116].

4.2 Communication/Competence and Compassion

It was clear from the outset, that issues of communication would form a key part of the HFH strategy. They had featured strongly in Drogheda and had some immediate resonance with health professionals. In early 2008 a literature review on communication issues in the hospital, commissioned by HFH examined the following five areas[117]

- Interpersonal communication among patients, family members and healthcare providers.
- Systems of communication between groups, such as clinical teams and departments.
- Training and education on communication skills.
- Communication technologies.
- Written communication in the form of information resources such as brochures and written documents.

Within this interest in communication, a clear theme emerged relating to the process of advocating for the needs of hospital staff, and highlighting the HFH communications training activities. Members of hospital staff are a key component of high quality end of life care. The programme noted how, sometimes because of conflicting demands, such as staff shortages and pressure of work, hospital workers do not feel able to provide the best care or do not feel they have the necessary skills or resources to do so. Poor communication is often cited as an issue in complaints about end of life care and developing communication skills in a non-threatening, supportive way was seen as an important target for intervention:

I think that the staff want to do the best and provide the best death for somebody and their family and we provide them with an avenue to try do that and create those changes.[118]

In 2007 a Communications 'Training the Trainer' Programme was produced for HFH by Anette Kinne of Andec Communications. Its aim was to develop a cohort of hospital staff across Ireland with the skills to teach effective communication to colleagues with direct patient contact[119]. Informed by the experience of the pilot communications training in Drogheda, this new initiative, taking place over two days, included advice on preparation, learning theory and cultural issues as well as focussing on the development of high quality communication skills particularly with respect to breaking bad news. It used discussion, good practice guidelines, questionnaires, DVDs and role play as resources. Evaluation from Wexford General and Connolly Hospital where the training was delivered in 2008 was generally very positive:

This course was grounded in realism, practicality and experience. The best course I've attended on communications ever.

Everything was so positive, education very relevant to my position and also great life skills.

This course helped me develop personally and professionally.

I have enthusiasm to get out and do it now[120].

The HFH programme was committed to communications training for staff across the whole range of the hospital's activities. If a culture change was going to be achieved, then end of life care would have to become everybody's business – from doctors, nurses, cleaners, caterers, porters to reception staff and managers. There was evidence that this approach caused initial consternation in some cases, for example a medical consultant who observed:

I was sitting there, I was wondering, why is there someone from catering here? And … I only clocked on, later on, how significant that was. That they were actually a part of the team[121].

Nevertheless, this approach produced tangible results:

… in that training we had the catering staff who were saying 'look, we want to feel like we are doing something, so what we would suggest and what we'll follow up on is instead of families having plastic cups brought to them and a teabag with a bit of hot water, when their loved one's dying, maybe what we should look into is putting together a specific end of life tray, like a trolley for families with china cups on it, you know. We would have a specific area where we would keep that and when we knew a family was in, and in distress because there is someone dying, we would take that to them as opposed to just leaving them with a plastic cup[122].

What might seem a relatively unimportant detail, the use of a proper cup for tea, was seen here to transmit a significant caring message to the relatives of a dying patient. It was the communications training and resulting empowerment of these members of staff that allowed them to feel able to think about doing this for families. Furthermore, the training had noteworthy effects beyond end of life care. Two Development Co-ordinators noted:

… people have written on their feedback forms … 'this is something that I can not only use in the hospital, but is something that I can use at home, and in my neighbourhood, my community, this is a life skill, and nobody has ever taught me this before'[123].

… we've been running the communication programmes and again the DVD, the Communications DVD, was produced and I've done days where I've shown that over and over again, and I've brought that out to the wards, and I would always stress the message, that if you can communicate with somebody well at the end of life, then that will have a knock on effect for every single patient in the hospital, and for your own relationships with the colleagues that you're working with. So communication isn't just about … you don't just switch on the communication skills when you're dealing with a patient that's dying, or with a family that's

bereaved. You know, they're there all the time for you and they do make work life better for you if you've had that training and, so I suppose extending out from the end of life care, the communication has been a big thing[124].

For the HFH Development Co-ordinators, based in a variety of hospitals around the country, the communications training gave them a focus and something specific to work on with the staff in their local setting:

The communications, I think, has been one of the easier ... in the sense that it is a really interesting subject matter and when you get people to come onto the training they really enjoy it and it creates a really good buzz and I think it's key that everybody needs it[125].

Most of the Development Co-ordinators had some difficulties persuading the hospitals to allow staff the necessary time to attend the training and some resorted to imaginative approaches, with one offering to fill in an audit report in return. One Development Co-ordinator found specific staff groups much more receptive than they had anticipated:

... the doctors at the moment are much more receptive I feel, the notion [is] that their original training didn't include this element and they're seeing the need for the training, so in some ways that's very positive for me[126] .

Another was overwhelmed by the response of an individual staff member

I knew before they arrived, before she came at all, that she was a very difficult person to work with, and we'd had a lot of complaints about her sent in by relatives and patients, and she sat through the whole day, and I suppose I was quite intimidated by her, you know, because she ... didn't look like she was particularly enjoying herself. But at the end of the day, I ask them three questions for their evaluation, like, what I liked best, what I liked least, and what I learned, and she actually wrote in the bit what I learned 'it's never too late to change'[127].

In general, the communications training continued to be received positively by staff who felt it had given them some practical skills necessary for high quality end of life care as well as some time away from the demands of their role in the hospital, and in which they could reflect on their work[128].

These opportunities became increasingly rare in a climate of budget cuts and limited resources but seemed essential to promoting and sustaining the delivery of high quality care in any setting. Through its communications training, HFH could be seen to have helped facilitate staff to be more skilled and effective in their work and to have empowered them to provide the kind of care they want to deliver.

The Development Co-ordinators were key to this by organising and often delivering the training and recognising its importance and potential. They seemed to value this advocacy role on behalf of staff and realised that it provided the opportunity not only directly to improve care, but also to develop others as advocates for the dying. As one of them put it:

...one of the greatest gifts of the programme has been around this communications training[129].

Final Journeys

Despite the progress made with the communications training, the HFH management team, through monitoring and evaluation of the training, was looking at ways to further develop it. Shelagh Twomey, then the Deputy Programme Manager, had worked hard on this but had decided to return to clinical practice so, in 2009 the Programme Manager began discussions with Jackie Crinion about possible future directions for the communications training. She had a background in both the education and health services having originally trained as a teacher with experience in running a residential care facility for young offenders. With qualifications in education and business studies as well as a wealth of experience working in the HSE, Jackie Crinion was well placed to advise. Although the training had been well received, she was concerned that the planned 'cascading' of knowledge to other workers from those who had attended the courses was not happening and therefore there was little chance of changing the culture of care. In addition she felt that it was unrealistic for a small concern such as HFH to try to deliver the necessary training throughout the country. Here, her experience of the importance of effective facilitation came to the fore.

Working with Bryan Nolan, who had previously been HFH Development Co-ordinator for the North East acute hospitals, she sought to develop a programme that would be less clinically orientated, less didactic, more facilitative and be delivered by local practitioners with initial support and mentoring from the HFH team. Thus, they identified that the Centres for Nurse Education in most regions already had individuals for whom training was at least part of their remit and who could be trained as facilitators - for what would come to be known as the Final Journeys programme. This would promote local 'ownership' of Final Journeys but also, it was hoped, would avoid some of the issues around staff release for training that had been experienced with the communications training.

Building on the work done by Shelagh Twomey and informed by the Quality Standards for End of Life Care in Hospital (2010), the National Audit of End of Life Care in Ireland (2010) and knowledge of learning styles and adult education approaches, Jackie Crinion and the team developed Final Journeys 1 and 2, described as 'an introductory programme aimed at enhancing the quality of the interactions between patients at the end of life, their families and hospital staff'.

Final Journeys 1 (Developing Awareness in End of Life Care) aimed to increase awareness of the importance of end of life care among hospital staff and included contextual information such as the major causes of death and place of death in contemporary Ireland as well as the opportunity for staff to reflect on practice in their own workplace in relation to end of life care. Final Journeys 2 (Developing Communication Skills in End of Life Care) supported the development of the necessary communications skills for those with direct patient contact, and included reflection on the importance not only of the words used but on the tone of the voice, physical position and the communication of empathy. Crucially, both modules could be delivered in one, albeit long and demanding, day. Within each of the participating hospitals a key coordinator for the Final Journeys Programme was established: either a member of the HFH staff or a member of the hospital staff who had already had experience of the HFH programme. This individual would, in turn, identify those to attend the Final Journeys programme (usually 10-14 participants). Didactic teaching was avoided with much use of role play, the sharing of experience, and group work. Participants were provided with Learning Logs and encouraged to note down their reflections both during the day and on their return to their workplace. The Facilitators' Packs

produced by the Final Journeys team were detailed and thorough with the aim of supporting the new facilitators in building their confidence as much as possible. Indeed, Jackie Crinion was concerned that they might appear too prescriptive[130], perhaps stifling more creative approaches to facilitation. These fears seem to have been unfounded as the inexperienced facilitators welcomed the detailed packs and the supportive mentoring they received from the Final Journeys team.

Participants on Final Journeys.

Final Journeys 1 and 2: Evaluation

Forty nine sessions of the Final Journeys programme were run between 1st September 2010 and 1st May 2011 and these were evaluated by two medical students, Alana Byrne and Olivia Murphy of the University College Dublin, School of Medicine and Medical Science, supervised by Professor Philip Larkin. In their report **Final Journeys 1 and 2: evaluating an introductory training course about care at the end of life**[131] the authors described how 623 individuals had attended the training in that time with 365 having a background in nursing or nurse management. Other professional groups included Healthcare Assistants (98), Allied Health Professionals (47), chaplains (12), catering/household (13), porters (6), administration (26) and medical (4). The course was evaluated by:

- Feedback forms completed immediately after the course
- Postal survey of participants
- Postal survey of facilitators
- Workshops with Final Journeys facilitators and the HFH programme team.

From the initial feedback, 100% rated Final Journeys 1 as 'excellent' and 99.5% rated Final Journeys 2 as 'Excellent' or 'Good'. The participants particularly valued the group discussions, the holistic approach, the communications skills learned, the role play, DVDs and the advice on dealing with conflict.

The postal survey of the participants was prepared by a Project Advisory Team, piloted at the Beaumont and Mater Hospitals in May 2011 and subsequently distributed with a return date of 1st July. Despite the deadline being extended, the response rate was only 24%. Of this group, satisfaction with the course appeared to have dropped with time (around 85% of those completing the immediate post course feedback rated the course as excellent whereas 60% of those completing the subsequent postal survey rated the course as excellent). Nevertheless, a high proportion felt that the course had had a positive impact with respect to their awareness about issues relating to death and dying and their ability to communicate with patients and families about end of life issues. The majority of this group stated that they had had no problem in securing study leave to attend the course (83%).

The postal survey of facilitators sought their views with particular reference to the course content, method of delivery and resources. The response rate was 40% and 60% of these had previous training in facilitation. Of the 77 respondents, 33 had delivered the training themselves and 44 had not, citing lack of opportunity as the main reason this had not happened. Understandably, these facilitators were concerned that the skills and confidence gained by attending the Final Journeys Programme would be lost with time. Even those who had delivered training were cogniscent of the importance of actually facilitating regularly and a significant number of respondents suggested that regular updating and mentoring would be of value to them. Clearly, it was not good use of HFH resources and these professionals' time if they quickly lost the ability to be effective facilitators for the Final Journeys Programme.

An evaluation workshop for facilitators was held in July 2012, with independent facilitation from Professor Larkin. Of the 13 who attended, seven were 'active' facilitators and six 'potential' facilitators. Whether this group was representative of the whole body of facilitators is difficult

to gauge, but the group did report problems from ward staff, who had not been granted time to attend the courses, with the result that most participants were from the Allied Health Professions rather than from nursing. In one hospital this had been addressed by linking the Final Journeys Programme to the Hospital Service Plan with the Standing Committee on End of Life Care and the End of Life Co-ordinator promoting attendance. This again underlined the importance of an integrated approach to innovation in end of life care and suggested that 2-3 years into the HFH programme itself Integrated Care - one of HFH's foundations - remained an aspiration.

The evaluation team found that Final Journeys achieved its objectives with respect to enabling staff to become more confident, competent and comfortable with issues related to end of life care and communication, stating that these objectives were being met, with 93% of returned surveys reporting an increase in awareness and 92% reporting an increase in the ability to communicate with patients and family. From the evaluation results it was suggested that:

- Facilitators would need on-going support and mentorship
- Refresher courses for facilitators might be indicated
- The approach might need to be adapted for different care settings/specialties e.g. paediatrics
- That efforts be made to widen geographical cover (Dublin North East and Dublin Mid Leinster provided most of the participants) and professional involvement (very few doctors took part)
- A nationwide network of facilitators might be helpful

Whilst an interesting and rich review, the evaluation of the Final Journeys 1 and 2 Programme contained certain weaknesses that limit its value and impact. It provided no reference to the current state of the literature with respect to the evaluation of training programmes and it failed to acknowledge that the work was based largely on a course satisfaction survey. Relevant literature might have included, for example, Moore et al (2009) Cochrane Collaboration Review of communication skills training for health care professionals working with cancer patients, their families and/or carers[132]. Although it is challenging to evaluate objectively the impact of a training programme, it would have been helpful had the final conclusions of the study reflected on possible ways that this could be done. The impact and effectiveness of an intervention such as the Final Journeys Programme does not rest on large numbers attending, whether they enjoyed themselves and whether they felt they changed their practice for the better - but rather in identifying a way to demonstrate objectively improved outcomes. The Final Journeys initiative within HFH had face validity and some able and enthusiastic protagonists. Further robust evaluation is needed if the work it to be developed as a core resource for continuing professional education.

Final Journeys 3: Dealing with Bad News

The evaluation of Final Journeys 1 and 2 had highlighted that doctors had not attended in significant numbers and suggested this needed to be addressed. Within the team there was much debate about how to approach this. Fundamentally, a multi-professional orientation was preferred but despite this, it was decided that a course specifically aimed at doctors was needed and Final Journeys 3 - Dealing with Bad News - was developed. Provided over half a day, this course was once again interactive with context setting and role play, often based on scenarios provided by participants. Discussions took place with the Royal College of Physicians of Ireland (RCPI), the setting where many doctors already attended courses, which agreed to a pilot of Final Journeys 3 in 2011. This was much more successful than previous efforts to deliver training in hospital settings, where up to 12 doctors had registered but few, even none had attended[133]. Immediate post course participant evaluation was positive and the RCPI agreed to a programme of courses running in 2012. For such free and accredited courses, it was hoped that attendance would be high. Looking to the future, the team hoped to similarly engage with the Royal College of Surgeons of Ireland and crucially, to have the courses fully 'embedded' in the Colleges' training programmes.

Final Journeys 4: Long Term Care - 'What Matters to Me'

Led by Áoife O'Neill, Dublin Community Hospitals Network Co-ordinator, and incorporating features of Final Journeys 1 and 2 with resources such as Amanda Waring's 'What do you see?'[134] film, Final Journeys 4 aimed to be more appropriate for use with staff from long term care settings. Piloted in the first half of 2012 and still to be evaluated by the end of 2012, few would question its aims:

> So it would be for nurses and doctors and the focus would be about having … discussions in advance. So rather than it just being about… people responding to difficult situations it's about how do we actually get comfortable with initiating discussions and in creating opportunities for people to tell us what they want and what matters most to them[135].

Final Journeys: The Future

Developed from a well-received communications training programme by an enthusiastic and able team, the Final Journeys initiative had the potential not only to improve the care of patients and their families at the end of their lives but also to develop staff and promote job satisfaction.

At the end of Phase One of HFH, Final Journeys 1 and 2 had involved 2,472 participants. This figure includes 153 trained facilitators, of whom it was estimated 99 became actively involved in continuing work. Pilot sessions for 'Dealing with Bad News' involved c250 participants, over 90% of which were doctors. Pilot sessions for 'What Matters to Me' had involved 60 participants. By December 2012, Final Journeys/Dealing with Bad News/What Matters to Me had involved over 3,700 staff participants in total.

It was enormously ambitious to deliver Final Journeys 1 and 2 to the numbers the team achieved whilst at the same time developing Final Journeys 3 and 4 and engaging with other agencies such as the RCSI and RCPI. In addition, a request was received to deliver Final Journeys in Northern Ireland (101 participants by the end of 2012) and to work with key stakeholders in Services for People with Intellectual Disabilities to develop a programme tailored to these individuals. A Final Journeys Facilitator Network and Facilitator Development workshops were also established and an Advanced Skill Development Day for those outside the Dublin North East region took place in April 2012.

With the end of the HFH programme itself, Final Journeys was adopted for 'mainstreaming' as part of the Irish Hospice Foundation Education Programme and a new Education Coordinator was appointed to the team. Nevertheless, there were concerns, not least that the Final Journeys team was small and could not deliver the training to all. A better solution might have been for the HSE to take it over, but there were real obstacles to this, not least the economic situation and reductions in staffing levels in training departments. By late 2012, the team was continuing to raise the profile of the Final Journeys programme and to lobby for its adoption by the medical colleges as part of core training. In addition, Final Journeys received a Certificate of Outstanding Acheivement in the Irish Institute of Training and Development National Training Awards 2012, a notable marker of external recognition. Rigorous external evaluation in the context of the literature and benchmarking against other similar training would be a major contribution to its longer term development.

4.3 Integrated Care/Planning and Co-ordination

You know, some of the Integrated Care pieces we have done ... have been very rewarding for the staff doing them and they have been doing it in their own time[136].

The concept of 'integrated care' grew out of the HFH pilot and was sustained into the national roll out. In common with the other three themes of the programme, it was a broad, inclusive concept which aimed to develop systems and processes in Irish hospitals that would facilitate optimal care – across the organisation and throughout the trajectory of end of life. Integrated care has been defined as 'a concept bringing together inputs, delivery, management and organisation of services related to diagnosis, treatment, care, rehabilitation and health promotion'[137]. Using the concept in this way, from 2007 onwards, the HFH programme was quite specific about its commitment to developing and refining a definition and working model for Integrated Care at the end of life in Irish hospitals. In June of that year a workshop on the subject was held attended by HFH staff and led by Alison Kilduff of Tribal Consulting. At this workshop, there was a presentation entitled 'Integrated Care – Developing a Conceptual Framework', where an early definition appeared of what Integrated Care meant in the context of HFH:

A comprehensive approach to the planning and delivery of all hospital services, clinical and organisational, related to dying, death and bereavement from the perspective of patient and family needs. It concerns itself with every aspect of end of life care from breaking bad news through to bereavement[138].

Typically ambitious in its approach, the programme clearly did not want to limit itself to the introduction of Integrated Care Pathways, as developed elsewhere, but instead emphasised the aim of working towards a much broader and systemic change in the culture of hospital care. Throughout 2007 and 2008 much of the work within this theme was aimed at developing a framework for integrated care. To this end, a literature review was commissioned in early 2007 and whilst the researchers subsequently found the term 'integrated care' of 'limited utility[139]' their work did identify some key clusters of topics within the literature:

- Integrated care pathways
- Elements of palliative care (principles of care, pain and symptom management,family, communication, individual and team behaviour)
- Paediatric palliative care
- Intensive care
- End of life decisions (Do not resuscitate orders, advance care planning, ethics committees and policies, withdrawing life sustaining treatment)
- Bereavement

The review also underlined the importance of seeing the process of integrating care as multi-factorial. Care pathways, it concluded, did not address hospital-wide integration of care but could help to inform a programme of broader integration that would include elements of the other clusters: palliative care principles, ethical issues, bereavement issues and the specific factors involved in the care of children and those being looked after in intensive care at the end of life.

At the same time, work was progressing on the first draft of the HFH Integrated Care Framework which, it was hoped, might become an educational resource linking end of life planning, information, training, care pathways, protocols and standards. It was recognised even in early 2008 however, that because of the quality and disparity of resources available in the different hospitals, these efforts needed a more consistent focus if they were going to achieve their aims. Accordingly, by the end of 2008, Integrated Care was identified by the HFH Programme Manager as one of the areas where progress was slower than initially expected[140].

Despite these concerns, work continued on the framework, and the minutes of the National Steering Committee meeting of December 2008 record that a draft document had been circulated to members and that plans were being developed for a training DVD aimed at raising awareness of the importance of integrated care amongst hospital staff. The framework was on a large scale - identifying 10 stages on the patient journey where integrated care was crucial: pre arrival and access; arrival; initial examination and assessment; medical examination; admission; test, assess, treat, review; dying phase; death; mortuary; burial, post burial and review. In addition five core principles were made explicit.

- Facilitation of end of life culture across hospital – where death is not a failure
- Dignity and respect for cultural and religious diversity of patient, family and staff
- Effective, coordinated patient-focused communication
- Support services for patient, family, staff
- Education and training

Guidelines and resources (e.g. the Gold Standards Framework, Rapid Admissions Patients Alert, Liverpool Care Pathway, Marie Curie Discharge Pathway) were suggested for each stage.

In June 2008 another workshop on Integrated Care was held in which a presentation was made reviewing the Integrated Care Pathways (ICPs)[141] then available in relation to aspects of care at the end of life. The advantages and disadvantages of each were considered whilst acknowledging the fact that ICPs might contain both clinical and non-clinical interventions. Those considered were:

- Liverpool Care Pathway (LCP)[142]
- Care of the Dying Pathway – Christie Hospital Manchester (an adaptation of the LCP)
- Palliative Care for Advanced Disease - PCAD Care Path[143]
- Pan Birmingham Supportive Care Pathway[144]
- Rapid Discharge Pathway[145] (linked to LCP)
- Care After Death Pathway (RLBUHT) - Royal Liverpool and Broadgreen Hospitals Trust
- Care Pathway South Wales[146]

It appears that no one of these pathways was considered totally appropriate to the goals of HFH, though selected elements might be incorporated into the HFH ideal. Nevertheless, the possible advantages of care pathways were acknowledged – as educational tools, effective prompts (e.g. pain assessment scales), and as something tangible and empowering. On the negative side however, it was felt that pathways might raise a bigger educational need, were only as effective as those completing them, led to misconceptions, were often too basic and all too frequently were based on largely anecdotal evidence of effectiveness.

By the beginning of 2009, plans were still in hand for the integrated care framework to appear on the HFH website with a related pocket educational booklet to be available by the end of the year. The introductory module of the training DVD Journeys to the End of Life, had been produced but the framework was not yet clearly in evidence, seemingly replaced in the HFH literature by reference more specifically to Integrated Care Pathways. This may reflect the fact that by the autumn of 2009 a care pathway had been identified which was felt to be more sympathetic to the aspirations of HFH: the Nottinghamshire End of Life Care Pathway for all Diagnoses[147]. This ICP was developed by a partnership of NHS Nottinghamshire County, NHS Nottingham City, NHS Bassetlaw and several local authorities. A pathway based on the 'patient's journey', it could more accurately be considered, in fact, to be a 'framework', given that it incorporates many factors including prognostication, Advance Care Planning, the use of recognised tools such as Gold Standards Framework and the Liverpool Care Pathway, staff training, communication skills, symptom management and care after death - as well as recognising the importance of standards and audit. Many features of the information available on this pathway seemed to echo the wider approach and aspirations of HFH. Although the pathway aimed to be relevant across settings (primary and secondary care) the language and focus of the documentation, at that time, was more relevant to end of life contexts in secondary care - not necessarily a disadvantage from the perspective of HFH.
In March 2010 a meeting was held in Dublin that brought together colleagues from NHS Nottinghamshire along with Irish palliative care specialists, representatives of the Irish Hospice Foundation, healthcare providers and advocacy groups. The aim of the meeting was to advance

the development of the end of life framework within HFH. Here it was agreed that freestanding pathways were not enough and, indeed, had little evidence to support their introduction[148] and that the most important task was to develop a common understanding of core principles and practices for the promotion of good care at the end of life. For HFH, working towards this aim had already provided challenges in the Irish context. A review of public services in 2008 had found that within the health sector particularly, 'there are difficulties involved in leading system-level change, and in system wide coherence'[149]. Within the HFH project team itself there was recognition of this and a developing understanding of the size and complexity of the tasks that had been set within HFH.

> *Hospitals don't even have multidisciplinary team meetings … everybody very muc works in their own little silo. The morale is very low and there's a real sense of 'that's not my job'[150].*

But despite this there was a sense that, within the participating HFH hospitals there were examples of good practice and compassionate care and that there was evidence of a cohort of individuals interested in or motivated to become involved in facilitating the process of change. The challenge was to identify these individuals, particularly those in positions of influence, and empower them to lead such changes.

Each hospital involved in the programme had established a Standing Committee on Death, Dying and Bereavement. At the Mater Hospital in Dublin, the Chair of this committee was Úna Marren, an experienced senior nurse who had worked for many years in London teaching hospitals before returning home to Ireland. Enthusiastic about the quality of care provided at the end of life in her own hospital, she felt that her task at the Mater was made very much easier because of the culture of care. She recognised, however, that this may not be the case elsewhere and that support, mentoring and networking were necessary if HFH was to progress. As a result a group was set up to bring together the Chairs (or Deputy Chairs) of the Standing Committees (subsequently the Network of Champions for Change) that would meet, share ideas and provide support.

The idea was fully supported, philosophically and practically by HFH and the first meeting took place in March 2010 at Killashee House, Naas. This proved a great success, with the HFH Programme Manager enthusiastic about how it brought people together who were finding their feet as leaders and 'Champions for Change'. Likewise, a Standing Committee Chair commented that it had been 'very empowering'[151]. By the time of the next meeting (in Athlone July 2010) there was 'a real buzz'[152] with Aileen O'Meara, former Health Correspondent of RTE doing a presentation on the importance of raising the profile of the programme by engagement with the media. Also at this meeting there were updates on the programme generally and a useful practical session from the chair of the Cavan/Monaghan Standing Committee on end of life care development plans. Further well attended Network Meetings took place throughout the lifetime of the the HFH programme.

By seeking to empower those within the hospitals who were not only supportive of the aims of the programme but also in a position to influence change, HFH was promoting ownership of the process and thereby seeking to secure its sustainability. Supporting and developing those individuals, it was hoped, would in turn lead to the development of true Champions for Change who themselves could be effective advocates for the dying, their families and the staff caring for them. As Úna Marren noted:

> People have turned up … we are in very difficult financial circumstances and I saw some faces there where their hospitals are pushed to the limit but they still took the time to come because it's really important…and I think there is a future for us[153].

Following the meeting held in Dublin in March 2010 with the team from NHS Nottinghamshire, Dr Eoin Tiernan from St Vincent's Hospital and other key stakeholders, the concept of an overarching 'framework' for end of life care in Irish hospitals seemed to fall from the agenda. Certainly, Dr Greg Finn, Consultant in Palliative Medicine, who presented at the meeting stated that he had had no contact with the HFH team after the meeting[154] and in subsequent Progress Reports on the programme no further reference is made to the issues of frameworks or Integrated Care Pathways beyond acknowledging that, for the purposes of the HFH programme, Integrated Care Pathways in isolation were not desirable. The Competence and Compassion End of Life Care Map[155], envisaged as a pocket resource for clinicians, was however completed. With sections on recognising deteriorating health and impending death, communication, care planning, resuscitation, referral to specialist palliative care, care of the dying person and 'what happens after death?' - its accessibility and clarity seemed useful both for the individual practitioner as an aide memoire and as a resource for the integration and coordination of care, albeit on a more modest scale than was envisaged within the 'framework' ambition.

The attentions of the management team at the HFH programme seem then to have turned to the Cork Pathfinder Project (CPP) as something that developed out of the consideration of the integration of care from the perspective of the patient journey and that involved transitions cross care settings - acute hospital, community hospital, care home, hospice or home. Within the Pathfinder Project, a two year initiative (August 2011-13), it was recognised that many people, given the choice, would like to die in or closer to home and its aim was to identify and develop methods and resources to facilitate that. Similar projects were planned for Donegal and the Midlands.

David Walsh was appointed Project Manager for Cork in August 2011 and the first workshop for the Pathfinder Project was held in November 2011, at St Patrick's Hospital and Hospice, Curraheen, chaired by a retired Garda commissioner. Dr Kieran McKeown (a researcher well known to the HFH programme through his work on the National Audit) talked about 'What influences where people die in Cork?' Prof William Molly and Dr Suzanne Timmons from the Centre for Gerontology and Rehabilitation at University College Cork, Greta Crowley from HSE South, Marie Lynch from the IHF and Gerardine Lynch from St Patrick's Hospital and Hospice, were also involved in presenting and facilitating discussion. It was planned that feedback from the discussions would be used to develop a plan for the Pathfinder Project. An advisory group was also formed[156] that met twice in the first half of 2012 to develop the draft action plan for the project, produced by Dr McKeown. This resulting report was submitted to the Department of Health and the HSE in May of 2012[157] inviting, indeed challenging, them to support the CPP

in its next stage, of implementation - as 'this process cannot even begin without the active support of those in a position of authority and leadership in the health services, both locally and nationally' (p43, ref 145). In November 2012 the Chair of the Project Advisory Group and the CEO of the Irish Hospice Foundation met with Mr Pat Healy, Regional Director of Operations at HSE South to discuss the report. As a result, he nominated the Primary and Community Care Operations Manager, Deirdre Scully to the Advisory Group to work with its members on an action and implementation plan. David Walsh's role subsequently developed further and by the end of 2012, he was End of Life Coordinator for Cork City and County.

There can be little doubt that some useful and innovative work was done by the HFH programme under the headings of Integrated Care/Planning and Coordination. Some of the concepts developed in the context of the definition of Integrated Care adopted by HFH, while very ambitious, were exciting in their scope and ambition. For example, the early presentations on the design and implementation of a framework for end of life care, although detailed, seem intuitively appropriate - based as they are on the patient journey from arrival at the hospital to death, the mortuary and after-death review. At every stage of this journey, resources were highlighted that might be more, or less, relevant to the specific setting e.g. Emergency Department, acute admissions ward or point of care e.g. during medical assessment or during the dying phase. Using this approach - coordination of care supported by the best evidence and resources available - the HFH programme could have been expected to have had an impact on the care of the dying patient and family.

Within the framework, specific integrated care pathways were considered for inclusion probably with the ambition of facilitating individual wards to identify the core pathways most relevant to them. When, as part of this process, they identified the Nottingham EOLC pathway for All Diagnoses and asked the team members from Nottinghamshire to share their experience, it is possible that the HFH programme came tantalisingly close to producing the ambitious, yet workable and pragmatic framework for hospitals that they were seeking. It is not clear why attention moved so completely to the Cork Pathfinder Project, although with the establishment of the HSE Clinical Care Directorate, a Framework may have been deemed unnecessary.

Whilst in itself the Cork Pathfinder Project may be a worthy and worthwhile project, it might be considered outside the remit of the HFH programme (although perhaps not of the Irish Hospice Foundation). Facilitating care close to, or at home may be a noble aspiration and, combined with excellent care of the dying in other settings would constitute the best quality end of life care - but within this HFH might more appropriately have been a stakeholder, rather than a leader. It is possible that only the HFH programme had the enthusiasm at the time to engage with the issue of care at home but, given that the Irish College of General Practitioners was developing primary palliative care in partnership with the HSE and IHF, perhaps HFH experience and expertise should have been part of this, rather than focussed separately within the Pathfinder Project. Indeed, this may be how the approach was developing by the end of 2012, with a diverse group of stakeholders involved in the project group and higher profile involvement for the Irish Hospice Foundation itself, leaving the HFH team still tackling the mammoth task of better integrating and coordinating care at the end of life solely in hospital settings.

4.4 Patient Autonomy/An Ethical Approach

Patient autonomy, that's not something we have looked at on its own really…the palliative care consultant did a piece on Advanced Care Directives so that was kind of dealing with, in a way with patient autonomy.[158]

In a programme of activities which gave significant prominence to the physical environment, to staff skills and to systems of care, there was a danger that the chief beneficiary of end of life care in the hospital – the patient who is dying – might be seen to have less consideration within the framework of HFH. Certainly when considering the impact of HFH as an **advocacy** project, it is important to keep returning to the specific case of the patient for it can be difficult to ensure that the patient voice is not only being heard, but also given a measure of priority. Theories of advocacy suggest that the approach is at its most developed when **self advocacy** is in evidence - and this in turn presented huge challenges for HFH, where the emphasis was on staff, on systems and on cultures of care.

Nevertheless, and from the outset, the programme gave a prominent place to the concept of patient autonomy and methods whereby such autonomy might be promoted. HFH commissioned a piece of research that looked at practitioner perspectives on autonomy at the end of life[159]. This encountered problems before it had even begun because of what were seen as taboos around death and dying that permeate into the world of research. Despite the fact that the research involved clinicians and not patients directly, the researchers felt that Research Ethics Committees needed to balance concerns about non-maleficence with the autonomy of people to participate in research if they so wished. These paternalistic attitudes, they felt, impacted directly on our ability to develop the knowledge necessary to understand the needs and desires of seriously ill people. Similarly, the clinicians involved in the research were often unable to define the concept of patient autonomy and were unable to describe practices that might promote it. If a patient was unconscious or unable to make competent decisions they often referred to the family as proxies. The families, in turn, often felt uncomfortable with making these decisions and deferred back to the clinician. This, the research concluded, provided evidence in support of the need for Advanced Care Planning (ACP) where the patient can make their wishes known at a time when they are able to do so in a considered manner.

In March 2008, well before the results of the study were known, the Chief Executive Officer of the Irish Hospice Foundation, together with the HFH Programme Manager, met with the Law Reform Commission to discuss the issue of Advance Care Planning. By July of that year the Commission had produced a consultation paper[160] on the subject and in October 2008 focussed its annual conference in Dublin Castle on the theme of Advance Care Directives, where the consultation paper was launched. Speakers included David Smith, Member of the Irish Council for Bioethics and Associate Professor of Healthcare Ethics at the Royal College of Surgeons of Ireland, Patricia T Rickard-Clarke, Commisioner, Law Reform Commission and Mervyn Taylor, Programme Manager, Hospice Friendly Hospitals Programme. Mervyn Taylor's presentation emphasised the importance of a broad approach to establishing patient preferences: that advance care directives are only part of an overall process which 'aims to adjust and improve the culture of end of life treatment and care for all parties concerned'[161]. Drawing on HFH's own research, he showed that public knowledge and awareness of the issues was not well developed and that public education was an essential starting point for beginning

the process of change in order to allow patient preferences to be established and respected in end of life care[162]. In addition to public education other factors were needed: systems and resources; personal advice and guidance; communication skills; privacy and confidentiality; an ethical framework which recognises the value and limitations of autonomy; review systems; and legislation.

With respect to legislation, the presentations at the conference, submissions on the content of the consultation document and additional consultative meetings with relevant organisations and individuals were all taken into account in the preparation of the Law Reform Commission Report **Bioethics: Advance Care Directives**, published in September 2009[163]. The particular emphasis in the report on the facilitative nature of the legislation and the importance of it being part of the wider process of healthcare planning could be seen to have been influenced by the involvement of the HFH programme in the consultation process - as these points were not present in the consultation document. This clearly resonates with the ethos of HFH and its broad approach to improving end of life care in Irish hospitals – advanced care planning is part of that approach, particularly with respect to empowering patients, but it can only be effective as part of multi-factorial change in the culture of care.

Ethical Framework for End of Life Care

One angle on changing that culture was developed by HFH in partnership with University College Cork and the Royal College of Surgeons of Ireland – the **Ethical Framework for End of Life Care**[164]. Seen as an educational resource, it envisaged a wide audience, from professionals to patients' families, and the general public. Comprised of eight online study sessions (explaining ethics; ethics of breaking bad news; healthcare decision making and the role of rights; patient autonomy in law and practice; ethics of managing pain; ethics of life prolonging treatment; ethics of confidentiality; and ethical governance in clinical care) it was made available on the HFH website, as **…an educational resource that aims to foster and support ethically and legally sound clinical practice in end of life treatment and care in Irish hospitals**[165].

The Ethical Framework was developed on a background of research from Ireland and overseas. National studies were commissioned to ensure specific relevance. This work[166] indicated that:

- The general public and Irish legislators are largely unfamiliar with, or have little understanding of terms associated with end-of-life treatment and care, such as do not resuscitate orders, advance directives, artificial nutrition and hydration
- Most people want to be informed if they have a terminal condition
- Information about diagnoses and prognoses is often shared with families instead of patients (particularly older patients) at the end of life
- If they are unable to make decisions for themselves, most people prefer their families and/or loved ones (often, in conjunction with doctors) to make decisions about starting or stopping treatment for them
- One in five people have told someone how they would like to be treated if they were terminally ill and dying. One in twenty people have written a 'Living Will'

Clinicians, legal experts, ethicists, sociologists and theologians all contributed to the framework - helping to make it an accurate, relevant and comprehensive resource on end of life care ethics. It was hoped that it would be used, not only by healthcare professionals, but also by patients themselves, their families and the Irish population in general. With an accessible, engaging approach to its subject matter, the framework sought to demystify ethics and challenge the perception that ethics and ethics experts have all the answers. Rather, the framework emphasises that challenging issues occur almost daily in healthcare, that these can rarely be easily resolved, and that the framework can provide a supportive, well informed foundation from which to reach ethically sound decisions – thereby challenging prevailing assumptions and encouraging reflection. Launching the framework on 6th October 2010, the Lord Mayor of Cork, said

> *(The Ethical Framework) seeks to tackle complexity, rather than to assume there are black and white answers to the questions that can arise when a patient or someone we love is dying. These can involve pain management, breaking bad news, making decisions, confidentiality and treatments that prolong life[167].*

Building on this, Joan McCarthy, Lecturer in Healthcare Ethics and Project Manager for the ethical framework and her colleagues produced a book, published by the University College of Cork Press in October 2011, **End of Life Care: Ethics and Law,** now a key text on the Masters Degree in End of Life Ethics and which was launched at University College Cork in the autumn of 2011[168]. With Joan McCarthy as coordinator the Masters course recruited 12 students from a variety of professional backgrounds in its first year. The book was well received. One reviewer commented 'the book has much to commend it to those outside Ireland[169].'

The Ethical Framework and *End of Life Care: Ethics and Law* are useful, relevant and accessible resources aimed at and facilitating ethically sound decisions during difficult times at the end of life. It is hard to gauge how much these resources are being used. Clearly, the use of the book on the newly developed MSc in End of Life Ethics, itself inspired by the Ethical Framework, is significant and the students taking the course might be expected to disseminate the approach into ethically sound decision making espoused by it. But how many patients, how many family members are being inspired to use the framework? Indeed, how many are aware of it? If patient autonomy, is truly to be promoted it requires all parties involved in making challenging decisions and producing advanced care plans to have some understanding of the concepts and meanings involved in ethical decision making. It is a challenge for the HFH programme and its partners in the production of the ethical framework, to continue to highlight the importance of the framework and to encourage all, whatever their background or education, to feel empowered to tackle the modules, thus enhancing their chances of having the kind of death they would wish to have. As the Operations Manager of HFH commented in 2010: *Patient Autonomy? We now have the Ethical Framework and that's actually really significant to have that...the next question is really: What are we going to do with that?*[170]. Could such material provide a platform for self-advocacy? Certainly these online materials provide a useful resource in that area, with considerable further potential. In the shorter term however, the Ethical Framework and associated book stand out as key achievements within HFH and merit attention as sound outcomes in their own right. In particular, the 'elements for good end of life care' spelled out in *End of Life Care: Ethics and Law* (page 35) merit careful consideration in relation to HFH's stated intention in its grant application to Atlantic Philanthropies - that it would focus on articulating the nature of a 'good death' and the barriers to and opportunities for its realisation.
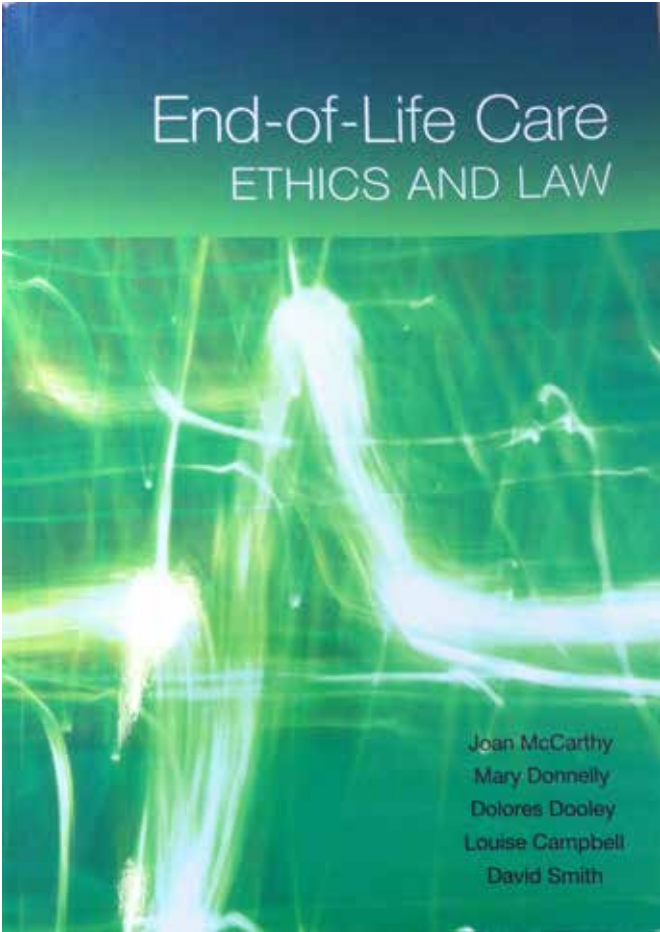
End-of-Life Care
ETHICS AND LAW

Joan McCarthy
Mary Donnelly
Dolores Dooley
Louise Campbell
David Smith

This book was launched in 2011 and is key text on UCC's Masters Degree in End-of-Life Ethics

5

Quality Standards for End of Life Care in Hospital

5. Quality Standards for End of Life Care in Hospital

The thing we have to be careful about in relation to the standards, [is] that we use language that is hospice friendly, so I'm anxious now, we don't use like 'evidence of compliance' we talk about 'how will we know if we're meeting the standard?' Those might seem small and semantic but they are kind of important[171].

The idea of developing a set of hospital-based standards for end of life care featured strongly as a work theme in the original grant application to the Atlantic Philanthropies. Daphne Doran was appointed Standards Development Project Manager in early 2007, and was joined the following month by Helen Donovan as Standards Development Co-ordinator. Working groups were set up in the Mater and Connolly hospitals as well as in the Royal Hospital, Donnybrook. They were then joined with a paediatric perspective from Our Lady's Children's Hospital, Crumlin. The first set of standards, to come from the team was ready by February 2008. As we have seen, it related mainly to issues of the physical environment and after consultation, came to be characterised as a set of Design and Dignity Guidelines for Physical Environments of Hospitals Supporting End of Life Care. Whilst there was representation from patient and lay groups of various kinds in the process of standards development, perhaps less in evidence were some of the professional and policy groups that would be the key to assessing and implementing the standards, once developed. Progress on the standards development was slower and more challenging than expected. There were meetings with the newly formed (2007) Health Information and Quality Authority (HIQA), in an attempt to align the HFH standards development process with that of the Authority. When the full draft standards went out to consultation, some 10 months later than originally planned, the response was huge – perhaps reflecting the lack of groundwork with professional groups. Notice of the public consultation was published in national newspapers. The HFH programme staff alerted stakeholders that the public consultation was underway through circulation of almost 4000 flyers. The consultation period was initially from 12th June 2009 until 31st July 2009. Due to the response volume, the deadline for receipt of submissions was extended until 14th August 2009. Consultation feedback was obtained either on line, by email or written response. The draft document yielded a total of 152 responses, including something from almost every major hospital in Ireland, as well as numerous professional, lay, patient and disability groups and stakeholder organisations of various kinds:

... broadly the responses were supportive. They wanted the standards to be more specific. The hospital responses wanted us to take hospitals as the actual reality on the ground, you know in terms of, particularly the issue that ... hospitals have difficulty with is we have designed dignity guidelines but a lot of the physical environment of hospitals doesn't support care in the way we would want to. And whilst people are very supportive of that, you know and want to do their very best, it is extremely difficult when you see the physical infrastructure of some of the places people are working at. The very relevant point that people made as well was that despite all the difficulties, people are providing very good care in lots of areas and also that should be acknowledged[172].

The volume of work involved in responding to the consultation was considerable and led to a full report entitled Response to the Public Consultation on Draft Quality Standards for End of Life Care in Hospitals, which appeared on 18th May 2010. The report set out the process of how the standards had been developed and summarised the responses at considerable length. Comments received ranged from feedback on the development process itself and who had been

involved, to detailed points about the language and layout used in the draft document. There was also much substantive comment on the key themes of integrated care, design and dignity, communication, and patient autonomy. Overall, the comments fell into three categories: those that were easily attended to and required minor amendments; those that could be attended to but required substantive amendments; those that could not be attended to, because they fell outside the remit of the HFH programme, or were in conflict with its objectives[173].

When they were completed, in May 2010, the standards were praised by President Mary McAleese in a foreword to the full publication

> *These 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[174].*

Developed to guide hospital staff who have responsibility for providing end-of-life care and to ensure that end-of-life care becomes central to the organization and management of hospital activities, the standards set out a shared vision of the end of life care that each person should have and what each hospital should aim to provide. The standards divided into four areas. The hospital – has systems in place to ensure that end of life care is central to the mission of the hospital and is organised around the needs of patients. The staff – are supported through training and development to ensure they are competent and compassionate in carrying out their roles in end of life care. The patient – receives quality end of life care that is appropriate to his/her needs and wishes. The family members are provided with compassionate support and, subject to the patient's consent, given information before, during and after the patient's death. The standards therefore seek to achieve in all hospitals:

- An acknowledgement of end-of-life care as a core quality service delivery component
- A hospital culture of compassionate end-of- life care
- Effective pain and symptom management
- Ongoing capacity development to ensure that the hospital can deal adequately with the different end-of-life scenarios that may arise
- Co-ordination and integration of care teams including out of hours and across various settings
- A hospital environment that supports personal dignity, privacy and confidentiality
- Education, training and supports for healthcare staff to enable them to be both competent and confident in dealing with the professional and personal challenges involved in delivering high quality care at end of life

The Quality Standards for End-of-Life Care in Hospitals published in 2010

There can be no doubt that the publication of the standards – for all the concerns about the process and the detail of the draft document, as well as the issue of the relationship to the Health Information Quality Authority (HIQA) - represented a major landmark for HFH. This piece of work had been key to the original grant application and it had been delivered in a document of quality and with significant public attention. The standards document also had a companion volume – representing the 'bookends' of phase one – and this was the work of the National Audit of End of Life Care in Irish Hospitals. Taken together these would point forwards - to the challenges of phase two and of standards implementation. As the Programme Manager put it:

> *We launched the standards and we launched the audit, two significant things. One was that the standards, which everybody had been asking for, once they were available, there was a certain amount of, a sense of, perhaps on some people's parts, of deflation-'oh, we have them, we've now delivered something, so what do we do with them?' And we did put a lot of effort into helping hospitals with a Memorandum of Understanding for Phase Two, to undertake a much more detailed arrangement so that they have nominated people for end of life care, as was requested in the standards. And that they would continue with structures like the standing committees, but they would also have development plans informed by the standards and the audit. And there was some success on that, but it became clear that the ability of hospitals to actually really focus on forming those evelopment plans, it was aspirational in some places. But nevertheless the idea that you have a nominated person and that you signed up to that; you had a nominated member of senior management team with responsibility for end of life issues; that you had a structure there that they worked with the standing committees and that you had a development plan or some even at it's simplest-to do list with some dates, which was linked to the standards, was, if you like, some progress in thinking[175].*

Nevertheless, by July 2010 the HFH Programme Manager could report to the NSC that the Quality Standards had now been posted to all acute hospital managers and also theDirectors of Nursing and Chairs of Standing Committees of hospitals linked to the programme. Similarly, a draft development plan for end-of-life care has been circulated to all hospitals participating

in the programme to guide them in developing their own plans for the implementation of the Standards. This work was being coordinated by the HFH Operations Manager Mary Bowen. In the same month a meeting with representatives of HIQA was organised to discuss how the HFH standards could link into the overall framework for HIQA standards then under development. As the Programme Manager commented in October 2011: **'if you like the standards didn't change anything overnight but they gave authority, moral authority, to engage with the process in a more structured and more sophisticated way**[176].

Subsequently, two things happened, one planned and one unexpected. The first was that HFH sought to renew its work with the Health Information and Quality Authority (HIQA) to build on interest (referred to by the Minister at the Clontarf conference on 19th May 2010) in the standards. The goal was to win a commitment from HIQA to include the Quality Standards as a key resource in its emerging National Standards for Safer Better Healthcare. By the NSC meeting of 5th December 2011, it was noted in a progress report that: 'Our understanding is that end-of-life care is referred to in the final document and that the Quality Standards for End-of-Life Care in Hospitals is listed amongst the recommended resources. The HIQA standards are currently with the Minister for Health for final approval'[177]. The long awaited National Standards document eventually appeared in June 2012[178]. In a list of available resources, although preceded by a heavy 'health warning'[179], it listed the HFH Standards document of 2010 (the Design and Dignity Guidelines were listed also). Beyond that the National Standards contained only two brief and rather general references to end of life care – one in a section on the promotion of a culture of kindness, consideration and respect and the other in a glossary of terms. As recognition of the considerable efforts and achievements of HFH in the standards area, it was considered significant by the HFH team. The second, was the unexpected interest in the Quality Standards for End of Life Care in Hospitals on the part of the National Economic and Social Council (NESC) – which sits with the Department of the Taoiseach. One of a series in a NESC project that examines how quality processes, standards and regulations contribute to continuous improvement in the delivery of services, the report was published in late Summer 2012.

This was a major commentary on the standards work within the HFH programme, produced by an independent body and running to over 100 pages in length, and one of a series of NESC reports that first originated in 1974. It explains how with almost 75 per cent of deaths taking place in hospitals and long-term care settings, the Irish Hospice Foundation set up the Hospice Friendly Hospitals programme to develop standards to improve end-of-life care in hospitals. It notes that the programme provides extensive supports to management and frontline staff to help them to implement the standards with Co-ordinators who work with hospital staff, providing training courses on end-of-life care, as well as resources such as relatives' handover bags (for taking home the deceased person's belongings), and information leaflets for bereaved persons. Providing such supports for front-line staff, the report observes, is an innovative way to improve quality in services. The report noted however that the end of life care standards are implemented only on a voluntary basis and that funding to employ some of the Co-ordinators who have assisted hospital staff to implement them was coming to an end. The report recommended a number of ways in which the HSE, HIQA and the Department of Health could support implementation of the standards into the future, so that the learning from the innovative Hospice Friendly Hospitals programme is not lost. The report posed two key questions:

- How convincing is the standards and quality improvement regime of HFH? It noted that whilst some standards are being implemented with success (particularly those related to staff development and provision of resources for day-to-day use by frontline staff) elsewhere, progress is mixed. Key examples here were how to recognise when patients are dying; how to talk to people who are dying; how to ensure there is adequate staff available; the training of staff not being recognised as a priority area; prioritising of single rooms for the dying; and the condition of mortuaries.
- Second, it asked to what extent do the standards (a) prevent the most serious harms/abuses and (b) promote quality improvement? It observed that the standards framework was developed to prevent harm, through promoting quality improvement. Through the National Audit of End-of-Life Care in Hospitals in Ireland, factors were identified that influenced the quality of end of life care, and HFH put in place a range of supports to increase the existence of these. It concluded that the extensive learning and monitoring approaches adopted by the programme also promoted continuous improvement.

The report expressed concern about the voluntary nature of involvement in the standards work and the fact that not all Irish hospitals were taking part in the endeavour. It acknowledged that individual hospitals could choose to fund the work themselves, but argued that 'front-line' enthusiasms must also be aided by 'a centre supportive of continuous improvement'. It is worth quoting the NESC report's more general observations at some length here, as they focus heavily on the dilemmas of HFH at the close of Phase Two. The report highlighted not only the specific challenges of standards implementation, but also the wider factors that come into play when third party organisations initiate programmes for change in the public sector that require effective partnership working – both strategic and operational – for their success:

Therefore, it is important for a central State body to support engagement with and implementation of the HFH standards. Specifically ... implementation of several of these standards would increase quality of care, and also reduce costs, but many of the supports that hospitals need to implement these standards lie outside their remit and are instead within the remit of a central government body ... A mandate to implement the standards is something that can most effectively be provided by a central government body ... In this regard, the role of the HSE, the key State partner in this programme, in sustaining the programme into the future in all hospitals is particularly important. However, there are a number of challenges to this. First, although the HFH programme has been championed by individuals in different regions and divisions of the HSE throughout its development and implementation to date, having a champion at national level has proved more challenging. While national managers have championed the programme, there have been many internal reorganisations of the HSE and changes in personnel since the HFH programme first started, with the result that the programme has had four different national leads in the HSE over the five-year period. This has made it difficult to sustain high-level engagement at a national level in the HSE. Second, the HSE is being dismantled into a series of independent hospital trusts, and the future shape of these organisations is not clear, so that it is difficult to know where the work developed by the HFH might fit in future. If the HFH work is to be maintained and developed by the successor body to the HSE, it would be

important for a focus on end-of-life care to be included in the service plan of this body, with related performance indicators so that improvements can be tracked.

Other central bodies may also be able to play a supportive role. For example, the Department of Health could support implementation of the end-of-life care standards is [sic] by grounding these standards in legislation. Such a legislative underpinning could ensure that non-participating hospitals become involved, or that more of the standards are successfully implemented. A quasi-legal approach could also be effective, with, for example, HSE (or Department of Health) service-level agreements with hospitals requiring a focus on such quality improvement standards in return for funding, as is currently the case with some organisations funded to provide home care on behalf of the HSE. HIQA may also be able to play a role in maintaining the work of the HFH programme, through, for example, recommending the standards as a guide to implement the requirements on end-of-life care in the standards frameworks that it oversees, such as Safer, Better Healthcare (HIQA, 2012), and the National Quality Standards for Residential Settings for Older People (HIQA, 2009) ...

It is also interesting to consider here the more general question of how standards and new approaches to quality and continuous improvement which are developed by actors outside the State standards and regulation regime, can be incorporated into existing mainstream public services. It seems from a range of services examined in this NESC project on standards and quality, that to promote continuous improvement, it may be necessary to have a combination of (a) standards and inspection led by a national organisation; (b) a range of other driver organisations; and (c) an appropriate connection between these two. The issue of an appropriate connection between those driving new types of standards (such as the Irish Hospice Foundation) and mainstream service deliverers (such as the HSE) is particularly pertinent for the HFH programme, to ensure that the learning from it is not lost. HIQA is the body empowered to set quality standards and drive continuous improvement in health and social services in Ireland, and so it may be particularly appropriate for HIQA to look at how it and related central organisations influencing health policy and funding can promote or officially recognise these standards, and indeed others that are developed by a third party[180].

The report was based on a small number of interviews and draws heavily on the voices of HFH staff members and those close to the programme. It urges caution on the generalisability of some of the statements. Also, it relied on just one Dublin hospital as a selected case study of implementation. Nevertheless, this is an important document, produced externally and apparently without prior lobbying, from a respected body. It provides a detailed insight into the development of the HFH standards and their subsequent implementation, and is particularly valuable for its wider commentary on the overall HFH approach and its relationship to state agencies and frameworks. It should be seen as a key marker of external recognition, coming at a significant point in the evolution of HFH.

6

The National Audit of End of Life Care in Hospitals

6. The National Audit
of End of Life Care in Hospitals

An audit, of necessity, has to tell it like it is, and, while there are many good things indicated in the audit, it is fair to say that there are many issues which will give us cause for concern[181].

From its earliest meetings, the National Steering Committee took an interest in how the HFH programme could be evaluated. A sub-committee was set up to take responsibility for these matters[182] and together with members of staff on the programme, ideas were explored which led to proposals for a national audit of end of life care in Irish hospitals. The NSC was wary of spending a large amount of money on an evaluation project. Over time therefore – and crucial to gaining support for it – the concept of an 'audit' of end of life care in the hospitals gained more saliency. This would provide a baseline of intelligence about the current delivery of end of life care in Irish hospitals and a measure against which to assess progress. But more crucially, it came to be seen as a crucial part of the intervention itself. To conduct the audit would be to accomplish a major piece of HFH business. This was less about an evaluation circling over the programme and more about a part of the programme itself. To that extent the audit was not only to capture significant programme resources, for a time at least it also sat at the centre of much of what the programme was doing across a large number of hospitals.
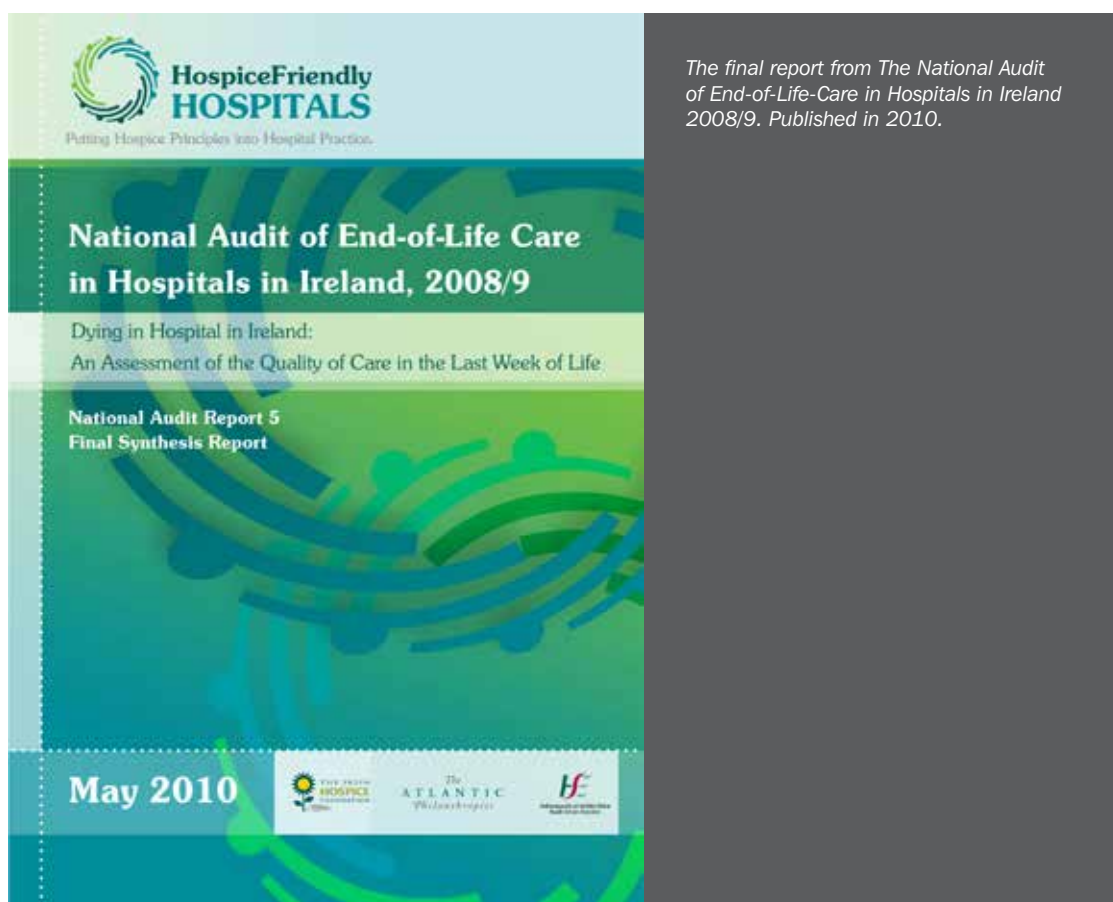
This work was taken forward and led by an experienced social and economic researcher, Dr Kieran McKeown. The challenges were enormous. There were questions about identifying a suitable method for the audit. There were issues in getting it approved by research ethics committees. There were huge logistical and practical difficulties in implementing it across so many settings. Yet once underway, conducting the national audit had huge benefits for the programme. It engaged a large number of people across many hospitals – going beyond those that had actually signed up to participate in the first phase of the programme itself. Producing quantitative data on numerous aspects of the care of dying people in the hospital context undoubtedly had an impact. Because of its wide engagement of personnel over so many hospitals, it also served as an identifier for those who would become involved in the 'champions for change' group, initiated in spring 2010. Linked to the standards document, it also produced considerable potential for raising awareness and taking the HFH programme forward into its second phase.

Nine hospitals were involved in the pilot phase of the audit during July and August 2008. This was followed by a series of road shows around the country in September 2008, when a much larger group of hospitals was given information about the audit and invited to take part. After much hard work and preparation, the full implementation of the audit was announced in November 2008. Data collection was carried out over most of the following year. Twenty four acute hospitals and 19 community hospitals participated, making a total of 43 audit sites. The process of obtaining ethical approval was a major undertaking because a separate application form was required for each committee. Many committees required an oral presentation and written clarification of specific issues was also sought in many cases. In total 14 local research ethics committees, mainly from the acute hospitals, scrutinised the audit protocol.

The audit was complex in design and challenging to administer. It was premised on an in-depth investigation of cases where known patients had died in the hospitals over a specific time period. It was 'retrospective' rather prospective in design. It proceeded from the deceased patient and then tried to capture the views and experiences of a wide range of people involved

in the person's care. It also collected some key structural data on all the hospitals taking part. It involved six separate questionnaires being administered to specific groups of staff and relatives of deceased patients.

The audit began on 1st November 2008. By September 2009 all data had been collected and the findings were launched in May 2010[183]. After the audit, each hospital received a confidential report on all aspects of its end of life services including comparative data with other hospitals. The final synthesis report is an impressive document, running to 246 pages and giving a comprehensive account of the entire audit process and outcomes, contextualised within the international literature. The audit incorporated an analysis of 999 deaths. The average age of the patients was 76. Their average stay in the acute hospitals was 24 days. Some 84% were admitted though A&E. It found significant differences in the assessment of quality of care outcomes by nurses, doctors and relatives, with the former giving the highest ratings and the latter the lowest. It showed that the proportion of 'unacceptable deaths', for example, is considerably higher in the assessment of relatives (21%), than nurses (13%) and doctors (3%). Multi-systems modelling was used to identify eight sets of influences on hospital care at the end of life. These were: cause of death; route of admission to hospital; team meetings; quality of staff discussion with patients and relatives; support for families to be with the patient; staff preparedness for the death of a patient; aspects of hospital governance. Doctor assessment of symptom management was 4.89% higher in hospitals with end of life care objectives in their service plan.

The final report from The National Audit of End-of-Life-Care in Hospitals in Ireland 2008/9. Published in 2010.

Eighteen ways to improve hospital care at the end of life were identified. One set of recommendations grouped around aspects of hospital organisation: include end of life objectives in the service plan; move from emergency to planned admissions; improve the physical environment and use of single rooms; improve documentation in the healthcare report; ensure sufficient ward staff; improve hospital information systems and facilitate patients to die at home. A second group of recommendations grouped around staff issues: develop skills to diagnose end of life and dying; improve end of life care decision making; hold team meetings; provide training in end of life care; prepare staff for the death of patients and build on staff experience. Patient focussed improvement objectives focussed on: extending the quality of care experienced by cancer patients, to those with all diagnoses; improving the quality of communication for patients; strengthening the role of specialist palliative care. Finally, a set of improvements was set out relating to family issues, including particular emphasis on those experiencing sudden deaths.

The audit report and standards were launched on 19th of May 2010, by that date a National Audit Sub-Committee had already met (on 29 April) and its terms of reference were agreed. The membership comprised senior staff from the HSE, some members of the National Steering Committee and some internationally recognised individuals from the world of palliative care development and research and was chaired by Dr Deirdre Madden, of University College, Cork and a barrister at law. Its terms of reference were to advise the National Steering Committee of the HFH Programme regarding the findings of the baseline National Audit of End-of-Life Care in Hospitals.

The committee provided feedback prior to the publication of the full audit report[184]. It developed an action plan relating to the 18 issues in the report identified as being salient to better end of life care in hospitals. There was praise for the achievement – a huge task had been accomplished and in so doing had addressed what had been a 'data free zone' 18 months earlier. There was agreement about the practical value of the results as a full illustration of prevailing patterns of end of life care in Irish hospitals. It was recognised that this material had significant power to assist with practice and system change.

By July 2010, the NSC could note the need to consider what form the next round of audit would take in 2012 and how it might best be organised, given that the HFH programme would be winding up in that year. Work on scoping a system for regular review of deaths at ward/unit level was to begin in September and a project team had been formed for this purpose[185]. Through this route an initiative was in development that would form part of a second audit, conducted through late 2012 and into 2013. This consisted initially of a project to develop a system and culture of regular review of deaths in key units and wards of acute hospitals[186]. A project advisory group[187] was also formed to guide the second audit – now entitled a System for Audit and Review of Care at End of Life.

Some key issues seem to have been captured in discussions with HIQA and HSE. From the perspectives of these organisations, the interest was in finding a mechanism wherein the work could provide a framework for clinical audit but there was also interest in stimulating review and reflective learning. Of course, clinical audit involves the setting of clear and agreed measureable criteria which can be examined over time. HIQA seem to have been concerned that the proposals for the new system were not clearly linked to specific criteria in order to create

a framework for clinical audit. If the linkage could be made, then opportunities to connect to wider national initiatives would arise – including articulation with the work of the National Clinical Effectiveness Committee, competence requirements for medical practitioners and the draft National Standards for Safer Better Healthcare. But as HIQA pointed out, for the work to fulfil the requirements of these initiatives, it would have to be robust and follow an evidence based methodology. By September 2012 the proposal had achieved a high level of support within the clinical programme and the HSE. The outcome seemed to be a partnership that combined 'outside the box' thinking from HFH with the requirements of the formal health care system. To this could also be added the very significant resources brought to the project by HFH – the like of which could not have been identified from the HSE. By such means it appeared that a circle had been squared – to combine essential elements of clinical audit, with more reflective, practice oriented enquiry.

The documentation for the second audit and associated review ran to 123 pages and over 32,000 words, it set out the proposal in enormous detail. The document described a system for auditing end of life care and included a set of instruments for doing the audit. Part 1 described the audit system in terms of its context, objectives, structure and governance and included the instruments for carrying out the audit. Part 2 described the pilot study which will test the audit system, including its specific objectives, methodology, and tasks to be undertaken at each study-site. The proposal drew on findings from a pre-pilot of the audit system, carried out in May-June 2011 at a site in each of four different settings – acute hospital, community hospital, nursing home, and home care team. The pre-pilot confirmed that the audit tool for healthcare staff was a useful format for reviewing a person's end of life care but also led to two additional components being added to the audit system: an independent assessment of care by a recognised expert in end-of-life care for the purpose of assessing the validity and reliability of the audit tool; and a survey of bereaved relatives / friends to give an additional perspective to the healthcare team. Subsequently, a fourth component was added to facilitate each site in recording the quality improvements taking place at the end of each year of the audit cycle.

The system was designed explicitly to support a process of continuous quality improvement in the care of persons at the end of life. It acknowledged that audit can be valuable as an enabler of change by producing knowledge and insight into the quality of care and its determinants and, by virtue of that, generating a motivation and momentum for change but took the view that 'audit alone is unlikely to produce either motivation or momentum for change if these are not already present, at least in embryonic form, since lack of knowledge and insight are rarely the biggest obstacles to improving quality'[188]. By late 2012 there were encouraging signs that the audit and review process was working well in hospital settings and generating new insights and learning. A key resource decision was to appoint a National Audit Co-ordinator, Dr Kathy McLoughlin, an experienced researcher in palliative care who had worked as Head of Education, Research and Professional Development at Milford Care Centre, in Limerick. It was anticipated that by March 2013, there would be 200-300 cases captured by the pilot and ready for analysis, across the various care settings. Dr McLaughlin would also lead on the production of papers for publication, drawing in particular on work from the 2010 audit report.

7

Practice Development Programme (End of Life Care)

7. Practice Development Programme (End of Life Care)

Practice development as a professional concept had its beginnings in nursing in Oxford, UK in the 1980s and emerged via Nursing Development Units through Practice Development Units (PDUs) with significance nationally and internationally[189]. Notwithstanding its nursing origins, Practice Development is usually characterised as multidisciplinary in nature, although the majority of research and development in the field has been within nursing.

In the period since the early 1990s, Practice Development as an approach to improving care, has continued to grow and mature, endeavouring to use its central approaches of reflection, critical enquiry and judicious use of evidence to hone effectiveness. **'Practice Development is messy'**[190] and recognises that clinical practice takes place in the equally 'messy' real world and attempts to produce improvement in practice in that context. Practice Development emphasises the importance of person centred care, a facilitated approach and leadership to improve the quality of care in a sustainable way (Box 4)[191].

Practice Development within the HFH programme became increasingly important from 2009 – towards the end of Phase One. Its emphasis on the importance of a patient centred approach and the relevance of the culture and context of care resonated with the aims and values of the HFH programme. Brendan McCormack, Professor of Nursing Research at the University of Ulster had been invited to become involved with the HFH programme by the HFH Programme Manager in 2008, following discussions about some work Professor McCormack had been leading on developing practice in residential homes in Ireland. An internationally recognised leader in Practice Development, he supported the creation of the post of National Practice Development Coordinator (End of Life Care), a joint position between HFH and – crucially - the HSE. This was advertised at the beginning of 2009 and by May Lorna Peelo-Kilroe had been appointed. A nurse by background, she had 10 years' experience in practice development education and planning but nevertheless had a daunting task ahead of her, initially organising meetings with Directors of Nursing of the key acute hospitals linked to the HFH programme, to inform and persuade them about the benefits of a practice development approach to end of life care. In this she was actively supported by Professor McCormack who provided supervision and mentorship and who, together with Michael Shannon, then Director of Dublin-Mid Leinster Nursing Midwifery Planning Development Unit, Mervyn Taylor HFH Programme Manager and herself, comprised the Project Group for Practice Development within HFH.
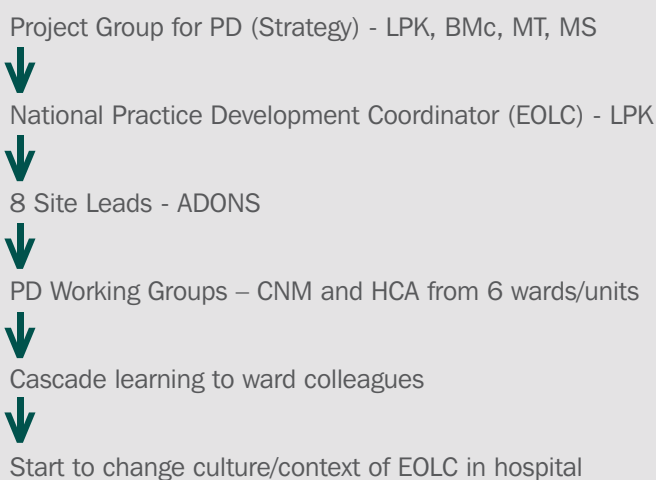
The first year of the Practice Development project within HFH was taken up by identifying key stakeholders and winning hearts and minds over to the importance of this particular approach to changing the culture and context of end of life care in Irish acute hospitals. By July 2010, Lorna Peelo-Kilroe was able to organise a workshop for the Directors of Nursing in all the major academic hospitals to further explain and clarify what involvement in practice development for end of life care would mean in terms of support structures, time allocation and so on. This proved very successful in providing a forum for these individuals to come together and discuss strategies, planning and challenges in a way that had not been done before. By September 2010 when the framework for Practice Development for End of Life Care was rolled out, eight out of nine of the major academic teaching hospitals were involved.

St James's Hospital, Dublin
Beaumont Hospital, Dublin
Cork University College Hospital
The Mater Hospital, Dublin
Mid-Western Regional Hospitals
University College Hospital, Galway
James Connolly Hospital, Dublin
The Adelaide and Meath National Children's Hospital, Tallaght

These eight hospitals represented the first phase of the Practice Development Programme for End of Life Care. Within each hospital an Assistant Director of Nursing (ADON) was identified as the Lead, or Site, Facilitator, and charged with establishing a Practice Development Working Group for End of Life Care. Six wards or units with the highest death rates had to identify a Clinical Nurse Manager and a Health Care Assistant who would be part of the working group.

Programme structure

Project Group for PD (Strategy) - LPK, BMc, MT, MS

↓

National Practice Development Coordinator (EOLC) - LPK

↓

8 Site Leads - ADONS

↓

PD Working Groups – CNM and HCA from 6 wards/units

↓

Cascade learning to ward colleagues

↓

Start to change culture/context of EOLC in hospital

From September 2010, the ADONs attended six weekly 'Programme Days' in Dublin with Lorna Peelo-Kilroe aimed at promoting facilitation and key practice development skills that they could then take back to their own hospitals and share with colleagues on the working group who, in turn, would cascade these new skills to their own ward team. By doing this it was hoped that not only would the practitioners involved develop reflective practice and facilitation skills to affect real change in the context and culture of care but that they would also assume ownership of the process, thus making it sustainable for the future when the HFH Practice Development Programme ended. The model of Practice Development used was emancipatory practice development (ePD) which is based on critical social theory and aims to develop individuals and teams in a realistic and sustainable way in the context and culture of care in which they work. At the end of each Programme Day the Site Facilitators were required to complete a reflection on an aspect of their recent learning in relation to Practice Development: this could be from the programme day or be about an aspect of Practice Development within their own hospital. Despite their experience and previous knowledge of development work it was clear that these practitioners found the approach used in the programme challenging. This was because they quickly became aware that, unlike traditional training where best practice is already defined, they had to find a way to define and clarify best practice in partnership with their Practice Development Working Group and try not to control the process too much. Soon, however, they realised that when this was done effectively, individuals and groups took ownership of the programme and the process gained momentum and sustainability. In addition, the Site facilitators found daunting the need to challenge colleagues in their group in order to progress the programme:

> *(I) felt a little apprehensive as if the group tend to close down…at the same time feel the facilitator, me, needs to be able to open up the discussion so that the unsaid can surface, to feel some responsibility-but need to balance it, not to control (Reflections of Programme Day attendee 2010)*

After nine months there were clear signs of the Site Facilitators growing and developing through the process itself. Initially, their reflections concentrated on the challenges of changing the culture of end of life care because of difficulties with others. Through using a structured reflection model they came to focus more on themselves and their own learning experience and the reflections improved in quality as a result. Evidence began to emerge of greater insight into the challenges of providing the highest quality end of life care and a lack of willingness to accept current practice in relation to it. Some themes began to emerge from these reflections that would clearly help the planning and approach to changing the culture of end of life care in their own organisations:

1. The importance of person centred and authentic communication
2. The need to challenge cultures of care and their consequences
3. Practitioner self-awareness
4. Dignity and respect for all
5. Real teams and real team work involving patients, family and staff
6. Time for person centred care
7. Developing skills in the diagnosis of dying

Lorna Peelo-Kilroe felt that progress was gratifyingly fast in a context where participants quickly understood and were sympathetic to the importance of high quality end of life care:

> *I mean there was very little of any kind of persuasion with the groups, of the significance of end of life care and having it and doing it right which is really good because that often is a battle in practice development that you have to deal with before you can move onto practice development processes[192].*

Whilst this work was going on with the eight academic teaching hospitals, plans were also being made for the practice development programme aimed at general acute and community hospitals. Progress was being made with engaging these hospitals and this culminated in July 2011 with a Practice Development Introductory Summer School[193]. The first of its kind in Ireland, this was linked in to the International Practice Development Collaborative[194] and involved Brendan McCormack plus an IPDC facilitator. It offered 25 places to staff from around the country and was quickly oversubscribed. Planned to give interested parties a flavour of the Practice Development approach it was also designed to allow these staff to start linking in with the processes and learning involved. In addition, attention was paid to the particular issues involved in the North West of the country where there was no major hospital involved in the first phase of the National Practice Development academic teaching hospital programme. This involved Donegal, Leitrim and Sligo undertaking a scaled down, but intensive, version of the first phase, given that they only had one year rather than two to complete it. Less than a year after the roll out of the framework and following a great deal of work, effort and persuasion to bring key stakeholders on board the mood of those leading the Practice Development programme for end of life care was buoyant:

> *But I think now, I feel a lot more positive about this work and it's really moving on since the last time we spoke[195].*

Part of this was surely due to the engagement of key stakeholders and the staff from each of the eight sites, but also to the perceived increase in involvement and understanding of staff from the HFH programme itself about the place of Practice Development in achieving the long term aim of changing the culture of care for the dying in Irish hospitals. This could be seen as significant, the recognition that:

> *… if you can truly bring about change in end of life practice then it's about culture change and really changing the way people view the world of end of life care and that these standards and protocols etc are merely tools for doing that and not an end in themselves and…a methodology like practice development engages people in…trying to change the world for themselves rather than another thing that's being imposed on them[196].*

Continuing to engage with the HFH staff, in particular the Programme Manager and Deputy, along with Development Co-ordinators, reiterating the importance of sustained facilitation and engagement with those involved in providing end of life care reaped rewards for those involved in the Practice Development programme. The HFH Operations Manager, Mary Bowen was invited by Lorna Peelo-Kilroe to become Co-facilitator of the National Practice Development Group. This allowed her to develop her knowledge and understanding of the Practice Development approach

and to link this in with other aspects of the HFH programme.
As a result of these developments confidence in the approach grew:

> *I had reservations (the previous year) about where Practice Development was seen as part of the HFH programme...but now I see it as quite integral...I think its seen as integral to the programme, I always saw it as being that but I think now people have come to understand it*[197]*.*

Originally planned for major acute hospitals, interest in the Practice Development Programme for End of Life Care was such that by the end of 2012 it was conceptualised as consisting of five different strands:

Strand 1 – Major Acute Hospitals

Strand 2 – Practice Development Programme in the North West

Strand 3 – Intellectual Disability Services

Strand 4 – Two Day Workshop on Practice Development and Facilitation Skills

Strand 5 – Introductory residential Practice Development School

Strand 1

All eight acute hospital sites had, by late 2012, completed the full two year programme with participants stating that they had become more confident in the field of end of life care and empowered to challenge areas of poor practice. This was considered to have been particularly marked with Health Care Assistants:

> *I feel much more confident as a Health Care Assistant and I know what my role is now. 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*[198]*.*

Participants described becoming more aware of the environment of care, with some using an 'environmental walkabout exercise'[199] to attempt to evaluate what their clinical work area might feel like for a dying patient and to better understand the role and needs of the families of the dying.

Strand 2

Seven sites had participated in the PD programme in the North West of Ireland: two acute hospitals, one hospice, one community hospital/hospice and three community hospitals. All sites completed the shorter 12 month programme together with an additional two programme days. Here the programme aim was to develop 'effectiveness in end of life care that

demonstrates principles of person centeredness within teams, individuals and workplaces' and a variety of activities such as a review of language used in relation to patients and families, as well as approaches used in Strand 1, were employed to achieve this.

Strand 3

A four day programme was held for 13 staff, from 13 sites across Ireland, involving stakeholders in Services for People with Intellectual Disabilities. The aim was to introduce the fundamentals of emancipatory Practice Development and facilitation using the same approaches as Strands 1 and 2. Action plans were developed by participants to be used to persuade managers in their own workplace of the benefits of continuing with Practice Development work.

Strand 4

Twenty six nurses from acute hospital, residential and community settings attended a two day workshop that provided an opportunity to plan for end of life care at a ward or unit level. Each produced an Action Plan to be implemented in their own setting.

Strand 5

As previously detailed, an Introductory Practice Development School was held in the summer of 2011 with two further days, enabling continued development of skills, provided at the request of participants.

A formal evaluation of the Practice Development Programme for End of Life Care, using internationally validated tools, was nearing completion by the end of 2012. Early indications suggested that key stakeholders had a very positive response to the programme. Should these initial results be borne out in the full evaluation, it would help strengthen the case for the continued commitment of wards, units and hospitals to the Practice Development Programme for End of Life Care, thus ensuring its sustainability and reinforcing the gains already achieved.

Practice Development as a concept can be difficult to grasp. It can be seen as too reflective and introspective and be dismissed as impractical. Its language and terminology might be considered too mired in the social sciences to be truly relevant to the 'real world' of clinical practice, particularly beyond the practice of nursing where it has found a home. A lack of 'hard evidence' and clear links to strategic outcomes make its impact difficult to measure. Yet when the approach is rigorous, well facilitated and clear about what it is aiming to achieve it can enable truly person centred care, reflective practitioners and effective, sustained change in the culture and context of care.

Achieving this is not easy. It requires a clear vision and a willingness to learn critical reflection and effective leadership skills; it requires engagement and commitment beyond knowledge of standards and protocols; it requires taking responsibility for change on oneself. If this happens, experienced practice development practitioners claim, not only does patient care improve - but also staff job satisfaction. The Practice Development programme for End of Life Care within the

HFH programme showed signs of being crucial to the success of HFH as a whole, particularly with respect to changing the culture of care. It was not an easy option, but an on-going commitment of the hospitals involved in the Practice Development Programme might reap benefits for those dying in Irish hospitals:

> *I was just talking to a Palliative Medicine Consultant last week who said that she can see things in the clinical area changing since the Practice Development Programme started, which was the intention...but she's saying it's become very real so it's actually the practical application there which is great because that's exactly what I was hoping for[200].*

8

Community Hospitals

8. Community Hospitals

It just wasn't on people's radar and it's almost like the forgotten generation[201].

From the beginning there was awareness within the Hospice Friendly Hospitals programme of the need to consider the work of the community hospitals in Ireland and their place in caring for the dying. Even before HFH was launched formally in May 2007 these institutions were part of the vision, with the Programme Manger including them in his presentation to the first National Steering Committee (NSC) in November 2006 on 'What we (HFH) are trying to achieve'. His points included:

- Development of a comprehensive framework of standards for all Irish hospitals regarding death, dying and bereavement
- Development of the capacity of acute and community hospitals to introduce and sustain these standards
- Change the overall culture of care and organisation in Irish hospitals
- Explore the potential to include nursing homes

In the same presentation he was at pains to point out that the programme needed to avoid some common pitfalls such as characterising hospice care as good and hospitals as bad and pitting acute against community hospitals. There were, however, practical difficulties relating to the community hospitals that made their involvement in the programme challenging. There are some 157 community hospitals in Ireland. They are a diverse set of institutions. Some are large organisations, such as St Mary's, Phoenix Park, with over 300 residents and consultant support from the Mater Hospital in Dublin. Others, such as the Meath Community Unit with residents, are much smaller and are dependent on a limited amount of clinical support from General Practitioners. Some are housed in modern units but many are in old buildings such as workhouses and TB hospitals, unsuited to health and social care in general and high quality end of life care in particular. With respect to education and staff development there is a perception, in some quarters, that community hospitals were sometimes on the periphery and their increasing dependence on healthcare assistants, often from overseas, has highlighted communication and cultural issues. These staff, in turn, have sometimes been marginalised with respect to training and personal development and any influence on the improvement of patient care. For the HFH programme, at the beginning of its life, it was clear that meaningful involvement with the community hospital sector was going to be challenging and would need careful, consistent management over time.

In 2006, 'Expressions of Interest' in involvement in the HFH programme were received from a significant number of community hospitals and in March 2007 a meeting was organised with staff from seven Dublin community hospitals (Box 7)to brief them on the programme. Áoife O'Neill was appointed as Development Coordinator with responsibility for them. With a background in Social Work she was quickly aware of the particular issues the community hospitals faced:

I suppose some of the things that had been developed or put in place or were being planned for through the programme might not necessarily have…fit completely with what the needs were of the community hospitals. So sometimes it was about…adapting to facilitate these hospitals through the programme[202]

Royal Hospital, Donnybrook
Peamount
St. Mary's Hospital, Phoenix Park
Leopardstown Park
Meath Community Unit
 Bellevilla
 Brú Chaoimhín

Her approach was to get to know each of the hospitals individually through close contact with staff and management and in so doing to identify what areas were in particular need of being addressed from the perspective of end of life care. Like other Development Coordinators, she oversaw the establishment of Standing Committees for End of Life Care and facilitated these. For example when developing a policy, in one community hospital, for care around the time of death, she helped ensure that major issues affecting the delivery of high quality care were tackled there so that by the time the policy was produced and adopted it actually reflected practice. In this way, in some instances, issues raised in individual community hospitals by the National Audit of End of Life Care had already been addressed by the time the results were published. At the same time the programme leadership was engaging with the HSE, together with other groups concerned with services for older people, to facilitate the development of a mentoring service for those in leadership roles in community hospitals and other residential facilities. To this end, Professor Brendan McCormack was asked to brief the HFH and IHF staff on his work (previously described) on Practice Development in Community Hospitals, which was considered highly relevant to the programme as a whole.

Despite a perception that, in general, the people of Ireland preferred to ignore the conditions of care in some community hospitals[203][204], by 2008 there was some success in raising their profile particularly with respect to the environment of care. A firm of health and safety consultants, NiFAST, was asked to review conditions at Leopardstown Park Hospital by the management of the hospital together with its Standing Committee for End of Life Care and with the support of HFH. The report highlighted serious problems in relation to fire safety:

> *The issue of greatest concern is that there is no possible way all patients could be evacuated from the wards into fresh air at night since both escape routes from the day wards are not capable of allowing beds to pass. Even if the escape routes were acceptable, it would take the 2/3 staff members working at night, a significant amount of time to push all forty beds from the wards into the fresh air – time they would not have if there was smoke in the wards[205].*

In addition there were more general health and safety concerns such as the risk of slips and falls because of the lack of storage space and poor lighting, together with risks related to manual handling activities and the effect that the general conditions might have on the ability of staff to provide appropriate care for patients.

Subsequently, at the request of the hospital management, Enda Kenny, then opposition party leader, visited the hospital and raised his concerns about conditions, at Leader's Question Time, in the Dáil Éireann. This was reported in the Irish Independent:

> *Taoiseach Bertie Ahern has defended himself against accusations that 80 patients in a hospital are being treated without "respect, dignity or integrity". The patients are being accommodated in wards which are almost 100 years old in the Leopardstown Park Hospital in Dublin with less than "the width of an A4 page" between each bed. During leaders' questions in the Dáil, Fine Gael leader Enda Kenny said he had visited the hospital and witnessed the conditions at first hand. "There are 10 to 15 commodes (mobile toilets) operating in each ward, where there is neither respect, dignity nor integrity. It has been stripped away by the physical limitations of the building," he said. The hospital has been seeking to build new wards at a cost of €12m but so far it has not secured any funding commitment from the HSE. Mr Ahern said he would obtain an update on the hospital's application for new facilities. "He (Mr Kenny) is acknowledging that the staffing and care is very adequate and that the infrastructure is the issue. I will get an update on that," he said.[206]*

Despite the best efforts both of the hospital itself, and the HFH programme in using this data to lobby for a commitment from the HSE to facilitate the necessary changes, little support was obtained. This was complicated by changes of staff and Ministers and, ultimately, by a change in government and by the 'Fair Deal'[207] plan, the HSE scheme for the financial support of those in need of long-term nursing home care. Under this scheme, people in the future would be more likely to be cared for in private nursing homes with a subsequent running down of government community hospitals.

Also during 2008, discussions continued with the HSE about the ambition to re-organise community hospital care around the 'Household' or 'Teaghlach' model[208], to ensure that HFH principles were central to the approach. In this internationally recognised model, services for the elderly are organised so that the lives of both the elderly person and the care-giver are improved and there is an integrated approach to organisation of services and physical design of facilities. Efforts also continued to encourage coordination and integration of the various other initiatives aimed at improving care in community hospitals in general. In addition, consideration was given by the HFH to developing a parallel strand of the programme focusing more specifically on community hospitals.

Mary Bowen, Operations Manager for HFH, undertook a project, 'End of Life Care in Community Hospitals' that she submitted to the National Steering Committee in October 2008 for input and comments. A challenging project, she found it difficult to find out even the most basic information about numbers of community hospital beds and the services provided as this data was not recorded centrally. She highlighted the wide range of fundamental factors that affected the experience of care within community hospitals, many of which would have to be addressed for high quality end of life care to be achievable:

> *It's very hard to encourage staff within one of these institutions to talk to residents about what they want at the end of life when they might not even ask residents what time they want to get up in the morning[209].*

Nevertheless she found a high level of commitment, from the community hospital managers, to improving the services provided, although many were struggling to do so. As a result, morale was decreasing with a significant numbers seeking other employment. In her conclusion she reflected that there was a clear need for strong leadership, management and governance with support at a strategic level if a project aimed at improving end of life care in community hospitals was to lead to sustainable improvements. She suggested the following options for the HFH programme.[210]

- Partnership with gerontological services
- Avoiding project (HFH) overload i.e. initiatives to improve EOLC in community hospitals would need to be fully embedded in HSE structures and aligned to existing initiatives such as the Teaghlach Model
- Supporting the roll out of the HIQA standards[211]
- Training programmes to support staff in initiating end of life care discussions with patients and families
- Involvement in the Irish Hospice Foundation (IHF) initiative to support education in long term care settings
- Opportunities within the IHF Extending Access Programme where dementia care was a focus

There was an acknowledgement that it was beyond the scope of the HFH programme to address all the issues related to care in community hospitals but that HFH could be an essential, enthusiastic and resourceful partner with a variety of other stakeholders whilst advocating for the best quality care for the dying and their families.

Building on the previous report, a detailed and thought-provoking presentation on End of Life Care in Community Hospitals was delivered by Mary Bowen to the NSC, in February 2009, asking members to reflect on the issues and options to enable a plan to be made for the approach that HFH should take in Phase 2 of the programme in relation to community hospitals. Possibly for the first time, figures were presented for the number of long term care units and beds and the numbers of deaths in these settings each year. Of particular interest was that 24% of Irish deaths each year occurred in community hospitals, emphasising again that these hospitals could not be ignored. The presentation set out the options for the involvement of HFH in community hospitals suggesting a variety of approaches:

- 'Hands on' i.e. capacity development, practice development and education
- 'Advisory' i.e. information, awareness, sign posting and dissemination
- 'Coordination' i.e. events and forums

It reflected on the programme's ability to work with other initiatives, thereby avoiding duplication. This strategic approach was essential to future planning in the context of available resources and also in addressing the perception that the HFH approach in community hospitals was rather piecemeal.[212] However, despite this growing knowledge in relation to the community hospitals and a realistic, planned approach, progress was frustratingly slow. Plans for an invited workshop to develop a common strategy for End of Life Care in Community Hospitals in relation to state and voluntary initiatives proved challenging, but finally came to fruition in February 2010. Unfortunately nothing tangible emerged from this. By October 2011, the HFH Programme Manager admitted to a 'sense of defeat' in relation to the community hospitals.[213]

One initiative, however, could be seen as having had some success. In May 2009, Áoife O'Neill was asked to use her experience and knowledge to develop a Network of Community Hospitals in the greater Dublin area, building on the original seven. This was envisaged as a regular forum to exchange information, learn from the experience of others and provide peer support.

The first meeting took place on the 25th November 2009 and was addressed by Áine Brady, then Minister for Older People and Health Promotion[214]. At the second meeting, in June 2010, Bryan Nolan, Communications Coordinator, gave a presentation on 'Final Journeys'[215], the HFH programme aimed at improving the quality of interactions between patients at the end of life, their families and staff. In addition, Helen Harnett from Meath Community Unit talked about communication and end of life care and their experience of 'Relating Well to Residents in End of Life Care', a pilot project developed by the HFH programme with the support of the National Partnership Programme[216].

The Network of Community Hospitals for the Greater Dublin Area

The third meeting featured a well-received presentation by Dr Brian Farrell, the Dublin City coroner[217] and the fourth considered advance care planning and death reviews. In July 2011, staff from The Royal Hospital, Donnybrook gave a presentation to the group about the hospital's progress in relation to end of life care provision:

> *The Royal would have been one of the original seven whereas there would be units that had only come on board since Phase 2, since the Network started, so they're at a very different place. So at the presentation, the Royal would have been acknowledging the work they'd done but it would also be a way of giving the other units an idea 'Oh, that's something we need to do', or, you know, we shared around the policy that the Royal had done because there was a lot of work put into it rather than people starting from scratch[218]*

In the presentation the staff from The Royal Hospital showed powerful images of the changes they had made to the journey from the ward to the mortuary facilities, as well as improvements to the mortuary itself, to relatives' rooms and the approach to introducing resources such as the belongings bags and end of life spiral. They also described the development of their policy on the care of patients and relatives around the time of death, their approach to audit, review and standards development, their forging of links with the Blackrock Hospice and their education and training developments. All this provided evidence that the aim of Áoife O'Neill and the HFH programme to facilitate the hospital staff themselves to take ownership of the Community Hospital Network, and thereby help ensure its sustainability after HFH itself had ended, was being fulfilled.

A further meeting took place in October 2011 where the 'Final Journeys 1 and 2' training programme was actually delivered for the Community Hospital Network members. Meetings of the Network continued and gained strength in 2012 (Appendix 1 – Community Hospital Network for the Greater Dublin Area November 2012).

The challenge of developing and improving care for the dying in Irish community hospitals was demanding for the HFH programme. For the HFH management team it involved constant efforts to raise the profile of the community hospitals with those in positions of power and to develop innovative ways of working in partnership with other key stakeholders aiming to improve care for the mainly elderly residents in these units. This proved frustrating with few tangible results. For those 'in the field' however, there were other problems: the diversity of the units, the need to improve care in general and the need to provide a suitable safe place of care. Some issues were beyond the scope of the HFH programme, for example the scale of the problems related to the condition of many of the buildings. Yet there were areas within this where the programme's expertise proved useful – such as providing advice on evidence based design and on small scale projects, like the work at The Royal Hospital, Donnybrook, to maximise impact. There does seem to have been some success, as a result of determination and facilitation, with the Community Hospitals Network in Dublin. A diverse programme of meetings was presented and well attended. If that was to continue beyond the end of the HFH programme itself, the Network would have the potential to act as a 'beacon', perhaps bringing in community hospitals from other regions to form a National Network or using members' experience to support the development of Networks of Community Hospitals in other areas. The challenge for the Dublin Community Hospitals Network is not only to survive but for leaders to emerge to continue the lobbying and profile raising work that will be essential to any fundamental, sustainable changes in the care of those dying in Irish community hospitals.

9
Conclusions

9. Conclusions

Hospice Friendly Hospitals was first conceptualised at a time of optimism and buoyancy in the Irish economy, and as plans were developed for its roll out the IHF was able to take advantage of major philanthropic investment in health and social care available at that time. In 2005 a study by the Economist declared Ireland to have the best quality of life in the world[219]. It was also a time when great hopes existed for a re-structured health care system and where the Health Act of 2004 had given rise to the new Health Service Executive, which came into being in January the following year. It was this HSE which formed a partnership with the Irish Hospice Foundation to deliver the Hospice Friendly Hospitals programme across Ireland. Within a short time however concerns about the state of the economy were unsettling Irish society and along with it the health system itself. Moreover, doubts quickly emerged about the ability of the HSE to provide the healthcare system with the management structures and leadership that it required in order to modernize and improve quality. By 2008, Ireland was the first European economy to officially enter recession. Personal debt had spiralled, the country's credit rating was progressively down-graded, the property market collapsed. In November 2010 the government published the National Recovery Plan for 2011-14, involving a budget adjustment of €15bn over four years. Healthcare cuts began to bite from January 2010 and at the start of 2012 further expenditure reductions on Irish health care were announced at the level of €750m[220]– to be achieved though hospital budget reductions, early retirement schemes, closure of nursing homes beds, a freeze on cancer budgets and other measures. By the close of 2012, further healthcare cuts could not be ruled out[210].

It is in this context that we must make sense of the achievements of HFH and offer some considerations about its future. In this final section of our report we offer answers to the five questions posed at the beginning of our study. We incorporate into these some considerations about sustainability and factors to consider, going forward.

The five key questions

1. How did the HFH programme come about, what factors shaped its initial development and how consequential were these for the programme over time?

The Hospice Friendly Hospitals (HFH) Programme had a gradual gestation, starting in the mid-1990s, when trustees of the Irish Hospice Foundation began to take an interest in how hospice principles could be fostered in the practice and organisation of acute hospitals. This led to an exploratory study in one Dublin hospital in 1999 and a scoping exercise conducted by the RCSI in 2002, which paved the way for a pilot project in Our Lady of Lourdes Hospital, Drogheda where the concept of a 'hospice friendly hospital' began to be tested out in practice from 2004. The years 2006-2007 saw reflection on the pilot and a planning phase for the full national HFH programme, leading to the launch and national roll out of Phase One of the programme – in partnership with the Health Service Executive – from 2007. Phase Two of the programme covered the years 2010-12, which culminated in the creation of a Network of Hospice Friendly Hospitals, with the view to a 'sustainable' approach to on-going delivery thereafter. HFH became a multi-centre intervention to develop end of life care capacity, advocate for patients and families and create systems level change in the delivery of hospital care at the end of life. The programme in the period 2007-12 had three aims:

- To develop comprehensive standards for all hospitals in relation to dying, death and bereavement

- To develop the capacity of acute and community hospitals to introduce and sustain these standards
- To change the overall culture in hospitals and care settings in relation to dying, death and bereavement

The HFH programme has been widely praised for the inventiveness, richness and imaginative qualities of its various components. Over time it developed into a varied tapestry of resources, interventions, and strategies. It also sought to forge a culture of optimism that change could be achieved and it was effective in finding local advocates for improved end of life care in hospitals who could support one another through the mechanisms that HFH provided. But the programme could also seem too complex and perhaps subject to too many changes in strategy and nomenclature.

Rich in metaphor and symbol, it was at times unclear in its main messages and too varied in content for some to readily understand and therefore engage with it. Within a five year programme it is difficult to see why the four main platforms of activity each required a change of name at the mid-point. Moreover, some of these elements had much higher recognition and face validity than others. 'Design and Dignity' could quickly resonate with a wide constituency, but even years into the programme there were those close to it who were unclear about 'Integrated Care/Planning and Co-ordination' or 'Patient Autonomy/An Ethical Approach'. In future careful consideration needs to be given to the main messages of HFH as well as to the 'sub-brands' within it - with clarity, consistency and stability being high priorities in the short to medium term.

As in the 2002 report, our study uncovered numerous examples where the inclusion of 'hospice' in the name of the initiative appeared to be a barrier and not a facilitator to progress. The name Hospice Friendly Hospitals focuses on a mode of working and sector of care (developed outside the formal health care system and still the subject of significant debate within the international literature) rather than upon the intended beneficiaries of the intervention. If little enthusiasm exists for changing the name, then sustained work in clarifying the purposes of HFH with partners and external stakeholders will remain a high priority.

It is also clear that the palliative medicine community found difficulty with the strong emphasis on the care of the dying within HFH[221]. This is in a context where the still new medical speciality has been seeking to carve out claims to expertise based not upon care at the very end of life but upon interventions that can be made throughout the trajectory of life limiting and chronic illness.

Perhaps paradoxically, palliative medicine has become nervous about too close an association with care for the dying – but this is not unique to Ireland and is certainly strongly in evidence in the United States among current leaders in the field, who have even offered a new definition of palliative care that includes no reference to death, dying or end of life care[222]. HFH must devise new ways to engage the interests of the palliative medicine community – and that interest will be a key determinant of further progress.

In this context, the IHF might consider an approach to engaging high level clinical (as well as management) involvement in each of the current HSE regions. Involvement in the Network of Hospice Friendly Hospitals is too reliant upon voluntaristic compliance and involves few palliative care/medicine specialists. The Network has the capacity to raise awareness and foster enthusiasm among those who do participate, but its goals are unclear and not measureable and its coverage is not complete. HSE regional nominees with specialist palliative care backgrounds could identify and sign up to realistic goals that could also be agreed with the Clinical and Strategy Programmes Directorate – thereby closing an important gap between national strategy and regional operations.

In turn, IHF could give attention to the boundaries of HFH and how these relate to other work streams within and aspects of the IHF strategy. Activities developed later in Phase Two point to a growing interest in the continuum of care at the end of life in different settings – home, care home, hospice, and hospital, articulated though the Cork Pathfinder Project. These are legitimate interests, but for HFH the focus should remain clearly upon the acute and community hospitals. Standard 1 of the Quality Standards, requires that 'The hospital has systems in place to ensure that end-of-life care is central to the mission of the hospital and is organised around the needs of patients'. It is not clear how many hospitals have achieved this standard, but much work remains to be done – for example, by July 2011 just over half of the 22 actively engaged acute hospitals had end of life care development plans. 'Mission drift' into the broader continuum of care settings should therefore be avoided by HFH, though clearly that continuum is a legitimate area of interest for the IHF as a whole.

2. What are the key factors and content of programme development and delivery, how did these change over time and with what consequences?

The programme had four major components, which were each re-named at the start of Phase Two. These involved considerable complexity and were not always readily understood by outsiders to HFH. It was not uncommon for those we interviewed about the strengths and weaknesses of the four programme areas to ask to be reminded of what they were, or in some instances to have no recall of their content. We highlight here some key areas of the programme which made a particular impact.

Standards

The development of quality standards for end of life care was central to the HFH programme and featured heavily in the overall aims. Grouped around four domains - the hospital, the staff, the patient and the family - the standards provide clear information on the requirements for high quality end of life care in Irish hospitals. The final Standards document was well presented and easy to understand. It was highly valued by the Development and End of Life Co-ordinators as a support to the work they were doing and something tangible to offer hospitals. The standards also helped Development and End of Life Co-ordinators set targets and timescales with the End of Year Review for their hospitals linked to them. In June 2012, the Health Information and Quality Authority (HIQA) listed the Quality Standards for End of Life Care in Hospitals in the list of resources of their document 'National Standards for Safer Better Healthcare' (along with the Design and Dignity Guidelines).

This could be seen as a significant development for the HFH programme, signalling the possible adoption of the standards into the mainstream. Indeed, some of the language in the HIQA document, particularly in relation to Person Centred Care and Support, echoes that of the HFH programme - thus emphasising the generalizability of some of the HFH principles as being at the core of high quality care. Much more significant was the endorsement of the entire portfolio of standards work in the Summer 2012 report of the National Economic and Social Council, which set out in detail what had been achieved but also gave a thoughtful and nuanced analysis of the barriers to and opportunities for further progress. This report must be regarded as a major marker of esteem for the programme as a whole and the work on standards in particular. The effort on standards should be maintained, with priorities being further implementation, review and evaluation and closer links with HIQA and the wider system of standards in use in the Irish healthcare system.

Audit

HFH was responsible for the first audit of end of life care in Irish hospitals and this was a significant achievement in its own right. It developed a National Audit System to provide a base-line of end of life care in hospital settings and to assist in evaluating the quality of hospital end of life care over time. The baseline audit of end of life care in Irish hospitals was conducted in 2008-9 and led to a follow up that was piloted in late 2012. The first audit incorporated an analysis of 999 deaths, some 84% of which were patients admitted though A&E. It found significant differences in the assessment of quality of care outcomes by nurses, doctors and relatives, with the former giving the highest ratings and the latter the lowest. Eight sets of influences on hospital care at the end of life were identified: cause of death; route of admission to hospital; team meetings; quality of staff discussion with patients and relatives; support for families to be with the patient; staff preparedness for the death of a patient; aspects of hospital governance. Doctor assessment of symptom management was 4.89% higher in hospitals with end of life care objectives in their service plan. Eighteen ways to improve hospital care at the end of life were identified.

The second audit was built around 1) healthcare staff review of a person's end of life care 2) an independent assessment of care by a recognised expert in end-of-life care for the purpose of assessing the validity and reliability of the audit tool 3) a survey of bereaved relatives / friends 4) recording of quality improvements taking place at the end of each year of the audit cycle.

By late 2012 there were encouraging signs from a pilot study that the new audit and review process was working well in hospital settings and generating insights and learning. It was anticipated that by March 2013, there would be 200-300 cases captured by the pilot and ready for analysis. A plan had also been developed for the production of papers for publication, drawing in particular on work from the 2010 audit report.

Final Journeys

This piece of work emerged from the communications training workstream. It benefitted from high quality, motivated staff with real commitment. It became a high profile piece of work that appears to have been well received with excellent feedback from participants. The evaluation study that focused on it however, was less convincing and failed to contextualize the work within

the literature on best evidence for practice. Final Journeys merits a more rigorous evaluation – especially now that it has been consolidated into the main IHF educational programme. Nevertheless, Final Journeys can be seen as a major success, involving hundreds of participants and has also served as a source of advocacy for staff, with some evidence of increased job satisfaction following the learning experience. With rigorous evaluation, Final Journeys could become a beacon within HFH, bringing hospital staff into contact with HFH in a relevant and accessible way. Final Journeys now appears to have a sustainable life of its own and to that extent has been 'mainstreamed' within the work of the IHF.

Design and Dignity Guidelines and Grants scheme

The early gains of this work included linkage to an external evidence base, endorsement from major international expertise and concrete results. The Design and Dignity Guidelines were produced quickly and demonstrated that HFH could move imaginatively to stake out new areas of interest and debate. The focus on material conditions and concrete examples seemed to capture external interest, going beyond the HFH programme and entering into the wider media. This was true also for the production of symbolic materials in the form of resources such as the mortuary cover, the ward altars, the spiral symbol, and the patient's belongings bags. These resources found favour in the hospitals and contributed to profile raising more generally, though there use was sometimes problematic in practice. Through the attention to design issues, HFH was taking on a huge challenge given the scale of improvement needed in the fabric of Irish hospitals. This inspiring, high ambition part of the programme seemed to lose momentum however in Phase Two, despite some success with the grant scheme (for example improvements in patients' rooms, family rooms and mortuaries). As Phase Two closed, the HFH architectural adviser remained highly committed to the work and could be a significant source of advocacy and re-invigoration, going forward.

Practice Development

HFH fostered a Practice Development approach to attend to the challenging issue of the culture of hospital end of life care and made excellent use of high calibre expertise in the field. The initiative captured the imagination of senior nurses in the hospitals, who met together to improve communication skills and strategies and then proceeded to implement specific projects at ward level, creating a 'cascade' effect. The emphasis was on culture change and challenging the things seen to be wrong. Eight teaching hospitals took part in the work. Practice Development was also an area in which good working collaboration with the HSE was demonstrated.

Ethical Framework

This was an ambitious development that resulted in a high quality and accessible piece of work in an area often perceived as difficult to access. The web-based material and resulting book were substantial achievements. Nevertheless, there was little evidence of consistent and sustained use (other than in the Cork area) or of a breakthrough to wider communities of users. The Ethical Framework is a significant resource that would merit further promotion and dissemination.

The Framework for End of Life Care

Efforts to develop a framework for end of life care were a significant feature of the early period of the HFH programme. Good progress was made in this area, the approach was thoughtful and reflective and did not simply adopt wholesale other interventions, such as integrated care pathways (notably the Liverpool Care Pathway). The ward-based resource folders and the end of life care map (introduced in late 2012) were useful and pragmatic and assisted in implementing part of the Framework. The Framework aspired to be truly patient-centred based on the patient's 'journey' through the hospital. Yet the momentum of work on the Framework seemed to dissipate in Phase Two, for reasons that are not entirely clear. The Framework would merit re-visiting, especially concentrating on the trajectory of care in the acute hospital. This would also have merits for trajectories of care in other settings and could lead to a national framework programme for end of life care. But this would be a responsibility for IHF overall and would go beyond the specific work of HFH.

The Network of Champions for Change (later the Network of Hospice Friendly Hospitals)

This was undoubtedly an enthusiastic and inclusive group, but there was a lack of consistency in who attended. It was subsequently identified as the key component of and central to the sustainability of the Hospice Friendly Hospitals concept. But there must be serious concerns about its ability to take on this task – for which significant support will be required from IHF, if its members are to be able to contribute effectively, and in the context of many competing demands upon their time.

Community Hospitals Network: This appeared to provide excellent support, led by an enthusiastic and committed Development Co-ordinator. In common with some other areas of the programme, this support seemed to go beyond specific issues of end of life care. The network may well have a life beyond HFH as it appears to resonate with concerns in this sector at a time of major change and uncertainty.

3. In what ways did HFH seek to bring about systems-change and to what extent – in the view of key stakeholders and in relation to the available audit data – was this achieved?

This is both a difficult question to answer and an even more demanding challenge for the HFH programme. Certainly HFH did seek to bring about system change. It explored the use of engineering models to look at patient flows though the hospital. It encouraged hospitals to see themselves as others see them – highlighting issues from car parking, to signage, to mortuary facilities, to communication with relatives after the death of a patient[223]. It also looked at the care system as a whole – where hospitals fitted into its culture and history, why they operate in the way they do, what is known about best models of practice internationally, and how lessons might be learned for the Irish context. It set up standing committees within the participating hospitals to provide leadership and direction to systems change. It supported these with the provision of dedicated Development Co-ordinators who could take forward new initiatives

and programmes of work and provide resources to the hospital community as a whole. The HFH team members endeavoured constantly to adopt a non-judgemental and supportive approach to the work of hospital staff, recognizing the challenges they faced – and by and large they succeeded. HFH developed an innovative programme based on the principles of Practice Development that found favour with its audience, involved practical 'on the ground' collaboration with the HSE and made use of significant international expertise.

HFH took the debate away from specialist palliative care to see the care of people at the end of life – and of those close to them – as forming part of the core business of the acute hospital. As one of its international advisers commented, it needed in fact to challenge the nomenclature of 'the acute hospital' and to emphasise that most hospital activity is now concerned with the management of **chronic** illness and co-morbidity.

It introduced standards to achieve structural change across the hospital system. It shed light on systems of care and the experiences of staff and relatives though a major baseline audit, the implementation of which as well as the results it delivered, also fostered systems thinking among hospital managers and clinical staff.

It went into partnership with the newly formed Health Service Executive, in the belief that this would be the best chance of gaining access to the heart of the health care system. This proved a major challenge. The system was new and complex. Its clinical priorities lay elsewhere – though in cognate areas, such as cancer care. End of life care did attract ministerial interest but never became a policy priority. There was a national plan for palliative care that pre-dated the HSE, but it never gave way to a national strategy for care at the end of life. The HSE did nominate leads to take responsibility for palliative care, but these changed continually during the five years of the HFH programme, frustrating progress and partnership. Certainly, colleagues within the HSE demonstrated strong support for HFH – both at the strategic level and also in direct engagement, for example on the practice development activities. Ultimately, HFH would outlive the HSE and would be required to find its place in a post-HSE Irish healthcare system. The views of stakeholders varied on how effectively HFH tackled this wider systems and policy agenda. One perspective was that HFH had been insufficiently attentive to policy linkage or to engagement with prevailing strategies and systems. Others considered that it had tried hard to engage but met with resistance and gate-keeping. The partnership was always asymmetrical in scale, but the inability of the system to find ways to engage with a dynamic, challenging and at times irritating third sector development initiative was also noticeable. The standards work and the audit were the key sites of engagement between the wider system and the HFH. Results were mixed but offered some encouragement. There remains the possibility that HIQA will give more support to the implementation of the standards. The endorsement of the NESC report for the standards must also be encouraging. The conduct and subsequent dissemination of audit findings drew attention to several system-wide issues, especially the high proportion of people dying in hospital following admission though Accident and Emergency departments and the detrimental effects of this on their subsequent care. There was wide publicity for the audit results when they first appeared and there was praise for the scale of the dataset. By the end of 2012, no results from the follow up audit and review project were available, but the research design had changed so much from the baseline audit as to severely limit possibilities for comparison over time. This was a trade off judged appropriate by HFH; it involved restricting comparability between the first audit and the second in the interests of improving the design and robustness of the second audit.

4. To what extent did HFH become a source of advocacy, both within hospital settings and beyond, and what forms did this take?

HFH had a high profile, especially at the end of Phase One and the beginning of Phase Two – and this had the effect of raising awareness about hospital end of life issues within the national media and within wider discussions taking place in Irish society. This was in part due to the involvement of high profile figures from the world of arts and culture and may have been linked also to the work of the IHF-led Forum on End of Life Care. This involvement of well-known figures on the Irish cultural scene seemed not to be sustained through Phase Two. The Development and End of Life Care Co-ordinators in general proved to be excellent advocates and facilitators for the goals of the programme. Some of the Design and Dignity initiatives – including improvements to mortuaries and family areas and also the use of symbolic objects – performed effective advocacy functions and were welcomed at local level. There was likewise evidence of excellent advocacy for hospital staff involved in end of life care, through supportive training and development opportunities provided by HFH. There were also parallels with other advocacy programmes within the public health tradition and these attracted interest - the incoming CEO to the IHF recognized this and clearly saw the potential to build on it, going forward. From the time of the pilot onwards, HFH gained further recognition by winning three awards for the merit of its activities: Public Sector Excellence Award (2006); Aramark Healthcare awards (2008); Irish Healthcare Awards (2010).

On the other hand, there was little evidence of the promotion of a 'social movement' or community of activists that could gather around the strength of the cause and lead to societal change in attitudes and expectations. Nor was there any move towards a stronger 'rights based' approach to advocacy for end of life care in hospitals. It is also difficult to see a concerted use of evidence from the programme being used to build an evidence-based case for end of life improvement in hospitals. At a more detailed level, there is a point to be made here about the composition of the National Steering Committee. This began with some very high level engagement from a wide range of senior academics, clinicians, policy makers and public interest representatives. These individuals could serve as strategic champions for the programme in subtle and perhaps unrecognized ways.

The rather deliberate move to re-fashion the membership to bring it closer to the day to day work of HFH was not a success. By the Spring of 2012 the distinction between the NSC and the membership of the Network of Hospice Friendly Hospitals (which were now meeting back to back on the same day) was becoming blurred. Operational matters had now come to dominate the NSC, and the space in which its members could give high level feedback, offer strategic direction and suggest new lines of development – in short advocate for HFH - appeared to have been lost.

5. What key lessons can be learned from the HFH programme that might i) inform future developments ii) be applied elsewhere?

i) Informing future HFH developments

We have explored how the idea of 'Hospice Friendly Hospitals' first started to be articulated in the mid-1990s, how it led to an exploratory study in one Dublin hospital in 1999, a planning document in 2002, a pilot in another hospital in County Louth in 2004-6 and then a roll

out across Ireland from 2007-12. Taking this longer view, it might be said with some validity, that the Hospice Friendly Hospitals concept is already showing signs of being something that is 'sustainable'. Moreover, in 2012, the Irish Hospice Foundation committed further support over three more years to the work of the Network of Hospice Friendly Hospitals, to work on the standards and to **Final Journey**s. The IHF states that it will 'continue to work with our service partners and the Network of Hospice Friendly Hospitals to improve the culture of care surrounding dying, death and bereavement in general hospitals ... We will sustain the work of the Hospice Friendly Hospitals Programme by supporting its National Steering Committee and the growing Network of Hospice Friendly Hospitals in implementing development plans based on the National Audit and Quality Standards for End-of-Life Care in Hospitals'[224]. By the time the 2012-15 IHF strategic plan concludes, the idea of the 'hospice friendly hospital' will have been in circulation in Ireland for nearly 20 years – testimony to its resilience and significance.

So recognising this notion of 'sustainability', what can be achieved, realistically, over the period to 2015, with an investment from the IHF of c€1m and taking into account the extremely bleak wider context within the health care system and the national economy? We are inclined to accept the view that a priority at this point must be to preserve what has been achieved, whilst at the same time nurturing bigger ideas that can be operationalised when the upside comes. Our considerations for action, listed here, are key to the sustainable development of HFH:

1 The Hospice Friendly Hospitals Network must be nurtured. Described as a 'delicate flower' by the outgoing Programme Manager[225], the Network is a different body to that to which IHF usually relates (i.e. the specialist world of hospice and palliative care). The Network will require strong support and leadership from the IHF, particularly in the short term when staffing issues within the former HFH programme are in a state of flux.

2 Potential sources of new philanthropic investment or partnership should be investigated. It is clear that reflective, development projects of the HFH kind are going to find no support within the straitened circumstance of the Irish public health economy in the next 3-5 years. Nevertheless, philanthropic partners may be drawn in – particularly if HFH could take on an international dimension. There is much that could be done (at low cost) to explore this in the next few years.

3 The HFH programme has produced a wealth of high quality publications and materials that have engaged interest and attention – and in some cases have been publically endorsed at ministerial level. A crucial ingredient remains absent however. Despite the very large sums expended on the audit in particular – and on Final Journeys and Practice Development also – there remains a complete dearth of peer reviewed, evidence based publications to shed light on the value of HFH and its activities. A concerted effort is now being made to gather up the 'evidence base' as it relates to HFH and to disseminate this through international meetings and in peer reviewed and professional journals. This could lead to some striking and clear messages; for example, the numbers of deaths occurring in the hospital coupled with the high proportion of cases revealed by the audit to have been admitted through Accident and Emergency, accounts for 10-15% of hospital costs. There might then be the possibility to advocate for improved care in these areas not only on a 'rights' and human dignity basis, but also on economic grounds. With this kind of focus, a high success rate in achieving editorials in national broadsheets on end of life issues could now be matched by similar

results with publications that are taken seriously by clinical leaders, managers, academics and key influencers in end of life care – and in particular those with the power to implement system change in Irish hospitals. This focus could be an extremely important one for IHF to support in the next three years – perhaps with the involvement of some new as well as existing academic partners.

ii) HFH application elsewhere

In general, Hospice Friendly Hospitals has not travelled much beyond Irish shores. At an early stage it did engage major international expertise to give advice and specialist input – from the USA, northern Europe, France and the United Kingdom. Some of the conferences have been well attended by interested individuals from the UK. Detailed discussions on specific aspects of the programme have also been taken forward in consultation with practitioners and policy makers from elsewhere. Work about the programme has been presented at conferences in Hungary, Canada, England and Scotland. But by 2012 there had been no indication of serious interest in replicating or transplanting aspects of the programme to other jurisdictions.

On the basis of the current evidence it would be hard to suggest that other jurisdictions should take up the format of HFH, **in toto**. The work in Ireland between 2007-12 remains exploratory, formative and unvalidated in many respect but, from the present work, it should be possible to identify areas that could be taken up and adapted in other contexts. Elements of the Design and Dignity work, the audit, the standards, **Final Journeys** and Practice Development might well serve needs and contexts elsewhere. The IHF should remain an active resource in this context and might even consider hosting a workshop on such matters – for example at a major international conference.

The completion of the present report coincided with the publication of an extensive evaluation concerned with the Atlantic Philanthropies' programme of support for hospice and palliative care in the Republic of Ireland.[226] This evaluation builds on the 'logic model' favoured by Atlantic Philanthropies (Appendix 2) and uses a 'RE-AIM' framework to set out the achievements of HFH and the other programmes it examined. Its findings accord with much of our own analysis. It viewed the Design and Dignity and Final Journeys initiatives along with the audit[227] and standards development as examples of particular success. It concluded that challenges remain in including end of life care in hospital and HSE service plans, in developing the work on autonomy and on integrated care and in achieving medical support for and engagement with HFH. Notably, it commended HFH as the one project of those examined that engaged successfully with a generalist audience.

We can be confident that HFH has contributed to the conditions required for better care of dying patients and their families. Many of its efforts were directed to framing an argument for the right to better hospital care at the end of life. It highlighted inequalities, poorly served groups, inadequate facilities, and inattention to dignity. It sought out public champions with wider appeal and recognition to help argue the case and to highlight injustice. There is no doubt HFH was a source of advocacy – for staff, for patients, for families and for the wider society. Its work must now continue under a new policy framework, with fewer resources – but in the face of continuing need and major challenges still to be overcome.

Appendices

10. Appendix 1

Community Hospital Network for the Greater Dublin Area

Beaumont Hospital

Blackrock Hospice

Claremount Complex

Community Medicine, Mater Hospital

Cuan Ross Community Unit

Health Information & Quality Authority

Leopardstown Park Hospital

Meath Community Unit

Peamount Hospital

St Colman's Wicklow

St John of Gods Services

St Vincent's Hospital, Athy

The Alzheimer Society of Ireland

TLC

Belvilla Community Unit

Cherry Orchard Hospital

Clonskeagh Hospital

Connolly Hospital

Dalkey Community Unit

HSE, Quality and Clinical Care Directorate

HSE, Local Health Managers

Our Lady's Hospice

Seanchara Community Unit

St Francis Hospice

St Mary's Hospital, Phoenix Park

St Vincent's University Hospital

The Royal Hospital, Donnybrook

11. Appendix 2

Logic Model

Inputs	Activities	Outputs	Short Term Outcomes Years 1-2	Medium Term Outcomes Years 3-4	Long Term Outcomes Year 5 and beyond
Skill & expertise of grantee Financial investment Research and feasibility study Outcomes of AP supported planning phase Experience gained from research and the Care for People Dying in Hospitals Project Financial Investment Expressions of Interest received from 18 hospitals (50% of hospitals with A&E)	Integrated Care Develop & implement a comprehensive framework of standards & training needs regarding dying, death & bereavement in hospitals Communications Develop & implement a standard approach to communicating around dying, death & bereavement Design & Dignity Develop & implement physical environment assessment tool to ensure privacy & dignity and to facilitate capital funding requests Patient Autonomy Develop& implement an ethical & legislative framework to underpin the concept of a 'good death'	Framework of standards and training needs regarding dying, death & bereavement Framework and training tested in three Dublin hospitals Standard approach to communicating about dying, death & bereavement Physical environment assessment tool to rate dignity & privacy Hospital applications for minor capital funding from the HSE to redesign environments to enhance dignity & privacy An ethical and legislative framework for a 'good death'	Framework & training is successfully implemented in a large-scale hospital setting Guidelines adopted & successfully rolled-out in participating hospitals Assessment tool successfully implemented in participating hospitals Capital funding for the specific redesign of physical environment to facilitate dying, death & bereavement Ethical & legislative framework tested in participating hospitals	Standards & training regarding dying, death & bereavement adopted by HIQA & HSE Guidelines adopted into professional, clinical and support staff training programmes in participating hospitals Awareness generated around design and dignity issues Awareness among health services providers of an ethical framework as a resource in their work	Standards & training become applicable for all hospital setting in Ireland Uptake evident across many care setting Training in communicating in difficult circumstances becomes central to training all frontline hospital staff and support staff Incorporation of key dignity enhancing measures into large scale developments & all existing care settings Widespread awareness & usage of methods for advance registration of preferences regarding place of care & end of life

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11. O'Shea D, Keegan O & McGee H (2002) End-of- Life-Care in General Hospitals. Developing a quality approach for the Irish setting. Dublin: Irish Hospice Foundation, p15 and 16.

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14. For example, the Bas Solais Conference at Dublin Castle, June 2000.

15. Interview 22, February 2010.

16. The HSE was established by the Health Act, 2004 and came into official operation on January 1, 2005.

17. http://www.4qconference.org/liitetiedostot/bp_long_descriptions/Ireland_A_long.pdf, accessed November 2010.

18. Interview 8, May 2010

19. Interview 22, February 2010.

20. It was also gaining recognition on the national stage. In 2006 the project was one of three winners of the Taoiseach's Public Service Excellence Awards to represent Ireland in Europe.

21. Interview 22, February 2010.

22. http://www.hospice-foundation.ie/index.php?option=com_content&task=view&id=264&Itemid=163, accessed
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23. Pat Cox speech at conference, 12 May 2005.

24. Finding a Better Way: Development of Care for People Dying in Hospitals. Planning grant application to Atlantic
Philanthropies, September 2005.

25. Hospice Friendly Hospitals Programme - Grant Proposal to the Atlantic Philanthropies. Dublin: The Irish Hospice
Foundation 2006

26. €1.75M was sought from the HSE but not realised in actual cash payments, though support in kind did materialise.

27. Membership at the first meeting consisted of: Pat McLoughlin, Chair of Steering Committee (Former Deputy - CEO Health
Service Executive); Denis Doherty, Chairman IHF; Eugene Murray, CEO IHF; Dr Mary Hynes, Assistant Director National

Hospitals Office - Quality, Risk and Customer Care; Brenda Power, Journalist / Broadcaster; Dr Doiminic Ó Brannagáin,
Consultant in Palliative Medicine, Dublin North East; Sheila Dickson, 1st Vice-President Irish Nurses Organisation; Julie Ling, Nurse Advisor Services for Older People and Palliative Care, Department of Health and Children; Orla Keegan, Education, Research and Development Manager, IHF; Professor David Clark, Director of International Observatory on End of Life Care, Lancaster University.

28. PowerPoint presentation, 22 November 2006: What are we trying to achieve?

29. These ideas were enshrined in a Memorandum of Understanding between the Irish Hospice Foundation and the Health Service Executive on the parameters of participation within Hospice Friendly Hospitals, dated April 2007. It read as follows:

The HFH Programme is committed to

The development of a comprehensive framework of standards for all Irish hospitals regarding dying, death and bereavement

The development of the capacity of acute & community hospitals to introduce and sustain these standards

Changing the overall culture of care and organisation in Irish hospitals & institutions of care regarding dying, death and bereavement

Working in partnership with the Health Service Executive and the Health Information and Quality Authority

By participating in the HFH Programme hospitals will have:

A dedicated resource in the form of a Development Co-ordinator to develop and support the work of the HFH Programme

Access to the standards framework, as it is developed and on completion

Access to and support from the office of the Hospice Friendly Hospitals Programme

Access to the Programme resources: educational material, publications, articles, DVDs and private section of the programme website

Access to and support from the programme's team of special advisers

Training opportunities/workshops across the four themes: Integrated Care, Communications, Design & Dignity and Patient Autonomy

Support from the National Steering Committee of the Hospice Friendly Hospitals Programme

Support for systems of local data collection, analysis and feedback detailing current activities around dying, death and bereavement

Opportunities to cross-fertilise learning and skills between hospitals nationally

Opportunities to engage in review and evaluation

30. The HFH Staff Team by the time of the launch in May 2007 comprised:

Standards Development Project Manager	*Daphne Doran*	*Mater, Connolly, RHD*
Standards Development Co-ordinator	*Helen Donovan*	*Mater, Connolly, RHD*
Development Co-ordinators	*Ann Hayes*	*Sligo*
	Shane Brennan	*Tallaght & Naas*
	Shelagh Twomey	*SE Acute*
	Paul Murray	*Crumlin*
	Bryan Nolan	*NE Acute*
	Katie Callaghan	*NE Community*
	Áoife O'Neill	*Dublin Community*
	Joanne Carr	*Dublin Community*
Champions for Change	*Mary Brodie*	*HSE - Communications*
Administrator	*Denise Robinson*	
Support Services	*Emma Meir*	
Manager	*Mervyn Taylor*	
Special Advisers& Consultants		
Medical	*Dr Max Watson*	
Mentoring & Coaching	*Dr Laraine Joyce & Hilary Maher*	
Integrated Care	*Tribal Consulting*	
Design & Dignity	*Rodd Bond*	
Intercultural Issues	*Helen Harnett*	

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39. Minutes of National Steering Committee, 5 December 2007.
40. Interview 22, February 2010
41. A reference to the sense conveyed by a portrait of Dame Cicely Saunders
42. This was a written comment in response to our interim report of January 2011.
43. Interview 22, February 2010.
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45. Clark, D – notes 'From the Margins to Mainstream' conference, Clontarf Castle, Dublin, 19th May 2010.
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56. Interview 4, March 2010
57. Interview 21, March 2010
58. Interview 14, March 2010
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Regional Lead DML, Brian Creedon - Regional Lead South, Feargal Twomey -Regional Lead West, Mary Devins - Paediatric Lead, Barry Cosgrove - GP lead, Ger Treacy - Nursing Lead, Lorna Peelo - Nursing representative, Mary Marsden - Nursing representative, Shirley Reale/Deirdre Rowe -AHP representatives, Valerie Keane - Social Work representative, Eileen O'Leary - HSE representative, Mo Flynn - Hospices CEO Group, Grainne Tipping - Pharmacy representative, Sheilagh Reaper Reynolds - HSE representative
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• *Review of international evidence regarding current best practice and development of draft standards*
• *Convening of Working Groups to develop and refine the draft standards*
• *Comments from the Working Groups, representing a wide range of opinions were integrated into the draft standards document.*
• *Draft standards were produced and reviewed by the Hospice Friendly Hospitals National Steering Committee and a Standards Reference Group*
• *Draft standards were revised in light of comments by the Hospice Friendly Hospitals National Steering Committee and Standards Reference Group*
A consultation copy of the "Draft Quality Standards for End of Life care in Hospitals" was available either to download on line on the Hospice Friendly Hospitals website or by request for hard copy. See: http://www.hospicefriendlyhospitals.net/images/stories/pdfs/Final_Pub_Con_Report_18_05_2010.pdf.

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THE IRISH
HOSPICE
FOUNDATION

The Irish Hospice Foundation
Morrison Chambers
32 Nassau Street
Dublin 2
Ireland

Telephone +353 (0) 1 6793188
Fax +353 (0) 6790040
www.hospicefoundation.ie

Charity No. CHY6830