



An Chomhairle Náisiúnta Eacnamaíoch agus Shóisialta
National Economic & Social Council

Quality and Standards in Human Services in Ireland: End-of-Life Care in Hospitals

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National Economic and Social Council

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Abbreviations

A&E

Accident and Emergency

CEO

Chief Executive Officer

FSC

Forest Stewardship Council

GPs

General Practitioners

HFH

Hospice Friendly Hospitals

HIQA

Health Information and Quality Authority

HSE

Health Service Executive

ICU

Intensive Care Unit

IHF

Irish Hospice Foundation

NESC

National Economic and Social Council

NGOs

Non Governmental Organisations

Quality and Standards in
End-of-Life Care in Hospitals -
Non-Technical Summary

This report is one of a series in a NESC project that examines how quality processes, standards and regulations contribute to continuous improvement in delivery of services. This report focuses on the standards in place to improve end-of-life care in hospitals.

Every year almost 30,000 people die in Ireland, with 75 per cent of all deaths now occurring in hospitals and long-term care settings, compared to 49 per cent in 1960. However, end-of-life care has not been seen as a core activity of hospitals, where ‘curing’ is often seen as the main focus. Due to this, in 2007 the Irish Hospice Foundation established the five-year Hospice Friendly Hospitals (HFH) programme in partnership with the HSE, and supported by the Atlantic Philanthropies, to improve the quality of end-of-life care in Irish hospitals. As part of the HFH programme, *Quality Standards for End-of-Life Care in Hospitals* were developed in consultation with doctors, nurses and families of the bereaved, and a range of supports for hospitals to implement these standards have been put in place. Twenty-seven acute hospitals and thirty community hospitals¹ across Ireland are currently striving to implement the standards, on a voluntary basis.

The HFH programme supports organisational change, by requiring each participating hospital to include improved end-of-life care in its service plan; to devise a development plan to implement the standards; and to set up a Standing Committee chaired by senior management to oversee this implementation. In return, the HFH programme provides a range of supports to hospitals, including an end-of-life care co-ordinator, training and development courses, practical resources, and access to specialised advice. The HFH works on the philosophy that it is ‘pushing an open door’ by supporting already motivated hospital staff to further improve the quality of their end-of-life care.

The HFH programme ran from 2007 to April 2012, and to build on its successes, the Irish Hospice Foundation has decided to continue to fund three key elements of the programme until 2014. These three are the Network of Hospice Friendly Hospitals, which brings together those working on the programme in different 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.

¹ There is no official definition of a ‘community hospital’ in Ireland but the convention is to differentiate it from an ‘acute hospital’ if it does not have an accident and emergency department. Community hospitals are effectively long-stay facilities but offer a higher level of medical support compared to the average nursing home.

Ten stakeholders interviewed as part of this research, representing HFH managers, and a case-study hospital implementing the standards, identified a number of strengths in the HFH programme, as follows:

- The extensive supports provided to hospital management and frontline staff by the programme (as outlined above).
- The strong focus on the service user – both the patient, and the bereaved family – in the standards.
- The Audit of end-of-life care commissioned by the HFH in 2008, of a random sample of 1000 deaths in Irish hospitals. This Audit identified key factors that improve the quality of end-of-life care, and these informed development of the standards. The Audit also provided each hospital participating in the programme with baseline data on how they scored on these key factors. As a result, each hospital has been able to monitor its progress on improving these aspects of end-of-life care.
- The practice development programme supported by HFH and the HSE, which facilitates staff to observe and question the detail of day-to-day work practices, so that they can change these to develop more person-centred end-of-life care, and change workplace culture on this.
- The network of key staff in all participating hospitals, which meets regularly to share learning and innovation on how to implement the standards.
- The fact that international evidence shows that implementing practices included in the standards (such as effective communication with the patient and their family, aligning treatment with patient preferences, and using multi-disciplinary ways of working) both improves quality of end-of-life care and reduces costs.

There are, however, a number of challenges faced in progressing implementation of the standards, as follows:

- As participation in the HFH programme is voluntary, not all hospitals have been implementing the standards, and not all standards have been progressed as much as desired.
- Reductions in staff numbers mean that it is difficult to release staff for training and development, or for them to spend time organising implementation of the standards.
- Cuts in overall health funding mean that it is difficult to see how infrastructural changes included in the standards (such as more single rooms for those at end-of-life, and family viewing rooms in mortuaries) can be implemented.
- As the main phases of the HFH programme have recently ended, there is a risk of some of the engagement in and innovation from its work being lost, if

mechanisms to maintain these are not put in place by central health policy and funding organisations.

- Despite the partnership of the HSE in the HFH programme, and the involvement of HIQA and the Department of Health in aspects of the programme, there is no mechanism to ensure that these central health policy, funding, delivery and regulatory organisations will sustain the work developed by the HFH programme into the future.
- Many staff changes in the HSE have meant that engagement with the programme by national lead staff there has been inconsistent, which weakens the prospect of the HSE sustaining implementation of the standards into the future.

Given these strengths and challenges, the following are pointers for future policy development:

- While individual hospitals have an important role to play, the support of the HSE, HIQA and the Department of Health will also be important to sustain the work developed by the HFH programme into the future.
- The *Quality Standards for End-of-Life Care in Hospitals* could be integrated by HIQA into other national health and social care standards.
- The HSE/Department of Health could link hospital funding allocations to implementation of the standards. The fact that implementing practices in the standards can reduce costs while improving quality provides support for such a move.
- A focus on quality end-of-life care could be included in the service plan of the HSE (or its successor body), with related performance indicators, to help sustain implementation of these standards.
- More generally, as HIQA is empowered to set quality standards and drive continuous improvement in health and social services in Ireland, it could look at how it and related central organisations influencing health policy and funding (such as the HSE and the Department of Health) can promote or officially recognise these standards, and indeed other quality standards that are developed by a third party.

Introduction

This report examines standards and quality improvement processes for end-of-life care in hospitals in Ireland. It is one of a series that make up the NESC project, *Quality and Standards in Human Services in Ireland*. This project assesses how quality processes, standards and regulations contribute to continuously improving human services.

End-of-life care in hospitals is defined as all care (clinical, administrative and support) provided by hospital staff in relation to death, dying and bereavement. Every year almost 30,000 people die in Ireland, with 75 per cent of all deaths occurring in hospitals and long-term care settings. However, end-of-life care has not been seen as a core activity of hospitals, where ‘curing’ is often seen as the main focus. Due to this, in 2007 the Irish Hospice Foundation, a not-for-profit organisation that supports the development of hospice and palliative care, established the five-year Hospice Friendly Hospitals (HFH) programme in partnership with the HSE, and with funding from the Atlantic Philanthropies, to improve the quality of end-of-life care in Irish hospitals. A key aspect of the HFH programme is the *Quality Standards for End-of-Life Care in Hospitals*.

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

These standards were developed in consultation with doctors, nurses, and families of the bereaved. They were also informed by an Audit of end-of-life care commissioned by the HFH in 2008, of a random sample of 1000 deaths in Irish hospitals. This Audit identified key factors that improve the quality of end-of-life care, and these factors were incorporated into the final standards, as issues to address within hospitals.

There are four high-level standards, focusing on the hospital, the staff, the patient and the family. More detailed actions are listed under each of the high-level standards.

Twenty-seven acute hospitals and thirty community hospitals² across Ireland are currently striving to implement the standards, on a voluntary basis. The HFH works on the philosophy that it is ‘pushing an open door’, by supporting already motivated

² There is no official definition of a ‘community hospital’ in Ireland but the convention is to differentiate it from an ‘acute hospital’ if it does not have an accident and emergency department. Community hospitals are effectively long-stay facilities but offer a higher level of medical support compared to the average nursing home.

hospital staff to further improve the quality of their end-of-life care. It provides supports for organisational change in the participating hospitals by requiring each to:

- Include improved end-of-life care in its service plan;
- Devise a development plan to implement the standards; and
- Set up a Standing Committee chaired by senior management to oversee this implementation.

In return, the HFH programme provides a range of supports to the hospitals. These include:

- An end-of-life care co-ordinator;
- Training and development courses;
- Practical resources such as a ward altar, sympathy cards, an end-of-life care resource folder, information leaflets for bereaved relatives, etc.; and
- Access to specialised advice.

The HFH programme consists of two phases, with the standards developed in Phase 1, between 2007 and 2010; and their implementation in hospitals supported in Phase 2, between 2010 and April 2012. With the programme now ended, the Irish Hospice Foundation has decided to continue to fund three key elements of it until 2014, in order to build on its successes. These three are – the Network of Hospice Friendly Hospitals, which brings together those working on the programme in key hospitals that took part in Phase 2; the new System of Audit and Review of End-of-Life Care to be used initially in acute hospitals, and in future in all care settings; and the *Final Journeys* staff training programme on end-of-life care.

Five Key Themes

The material referenced in this report was gained through documentary research, and interviews with ten stakeholders (representing HFH managers, policy-makers, and a case-study hospital implementing the standards). These sources of information were used to ascertain how implementation of the standards is relevant to the five key themes addressed in this NESC project. These five key themes are – responsive regulation (which is how implementation of quality standards is encouraged by a balance of sanctions and supports); involvement of the service user; monitoring and learning; devolution and accountability; and addressing costs while improving quality.

Responsive Regulation

In terms of responsive regulation, the HFH programme, proposed and developed by a voluntary organisation, albeit in partnership with the HSE, does not have any legal

power to require hospitals to implement the standards. Therefore, it has built up a comprehensive ‘strengths-based’ model of supports, which builds on pre-existing work and desire to promote better end-of-life care, by hospital management and frontline staff. It is an example of ‘smart regulation’, with a third party rather than the government developing this system to improve standards. The programme does have a number of ‘soft sanctions’, or pressures, which it can use to encourage compliance with the standards. These include a Memorandum of Understanding between participating hospitals and the HFH, which lays out the responsibilities of each, as well as data from the 2008/9 Audit, which provides each hospital with baseline data on how they scored on key aspects of end-of-life care, allowing them to measure their progress since then against top-scoring hospitals, thus providing an incentive for improvement.

Involvement of the Service User

The views of the service user are incorporated into the standards; both in general (as they focus on improving the experience of people who are dying, and their families), and in particular, through implementation of the standards. One of the four high-level standards focuses on the experience of the patient; in particular, communication with the patient, their preferences, and their pain and symptom management. Family members of the bereaved also become service users, and their needs are focused on a second high-level standard, and a range of supports have been put in place to meet these needs. The input of family members was also gained through their representation on working groups that devised early drafts of the standards.

Learning

The HFH programme has a particularly strong emphasis on learning, with regular monitoring and review of structures and tools to implement the standards. There are also a number of systems in place to encourage learning on implementation. In the hospitals, the Standing Committee, the working groups that support it, and staff development and education sessions all promote learning. The baseline Audit, and the benchmarking linked to it, form the basis for both the hospital end-of-life care development plan and monitoring of the extent to which benchmarks are reached by each individual hospital. Between hospitals, the Hospice Friendly Hospitals Network shares learning and innovation on standards’ implementation. At a national level, membership of the HFH National Steering Committee is drawn from the HFH programme implementers and wider policy-making bodies, which allows learning from the programme to feed into central policymaking and funding bodies in the health service.

Devolution and Accountability

The HFH ensures accountability of participating hospitals through use of a Memorandum of Understanding between the hospital and the HFH. However, external accountability, to e.g. a State organisation, is weak, despite the partnership of the HSE in the programme, as participation in the programme is voluntary.

Devolution and innovation are a strong part of the HFH ethos of building on existing strengths in end-of-life care, with a view to improving it. In line with this, the

mechanisms to support implementation of the *Quality Standards for End-of-Life Care in Hospitals* promote innovation in how the standards are implemented in each hospital.

Addressing Costs While Improving Quality

Implementation of some aspects of these standards, such as the purchase of low-cost supports, is not so strongly affected by recent funding cuts. However, reductions in staff numbers have a strong impact on the time that staff have available to attend training on, and implement improvements in, end-of-life care. Cuts in capital budgets are also likely to have a negative impact on the prospect of more single rooms in hospitals, or viewing rooms in mortuaries – both issues that need to be tackled to improve the quality of end-of-life care, and provide better experiences for the bereaved. Meanwhile, international evidence shows that implementation of several aspects of the standards (such as communicating effectively with patients and their families about end-of-life, providing treatment in line with patients' wishes, multi-disciplinary team-working in the hospital, and staff training on end-of-life care) helps to improve the quality of end-of-life care, while at the same time reducing the costs of that care. This provides strong arguments for implementing these standards.

Finally – Are There Things Which Need to Change to Ensure the Provision of This Quality Service?

Participation in the HFH programme is voluntary, and not all hospitals are involved. This reduces the extent to which the programme can promote quality improvement in all hospitals. Some standards are more successfully implemented than others, and literature on responsive regulation would suggest that a mix of supports and sanctions to promote continuous improvement might be more successful, both in engaging all hospitals, and in ensuring that as many standards as possible are implemented.

Looking to the future, the HFH programme is now at a crossroads, with Phases 1 and 2 complete. The difficulty currently faced is that some of the engagement in and innovation from the programme could be lost, if mechanisms to maintain the momentum and investment from it are not put in place.

Clearly, the role of individual hospitals is important in this. They can choose to continue implementing the standards, and/or to fund supports for their implementation within the hospital. However, this NESC study of standards in a range of public services shows that it is not only 'front-line' service providers who play an important role in improving quality, but also a policy centre which supports continuous improvement. Therefore the role of central State bodies such as the Department of Health, the HSE and HIQA, is important. The first two organisations have the strongest ability to alter funding lines to support more end-of-life care, and to alter the location in which this care can be received; both practices that have

been shown to increase quality while reducing cost. Central State bodies are also in the strongest position to ensure that the standards are mandatory, which could optimise increases in quality and reductions in costs. The HSE³, in particular, the key State partner in this programme, could play a central role in sustaining the programme in all hospitals into the future. However, due to internal reorganisations and staff moves, the HFH programme has had four different national leads in the HSE over the past five years. This has made it difficult to sustain high-level engagement at a national level in the HSE. A champion at national level would be helpful. It could also be useful for a focus on end-of-life care to be included in the annual service plan of the HSE (or its successor), with clear indicators to measure progress.

Greater integration of the HFH end-of-life care standards with other national standards overseen by HIQA, such as *Safer Better Healthcare* (HIQA, 2012); and the *National Quality Standards for Residential Care Settings for Older People* (HIQA, 2009); could also help maintain momentum. The HSE or the Department of Health could also support the standards by allocating increased funding to hospitals that provide a high standard of end-of-life care.

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's 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. As HIQA is empowered to set quality standards and to drive continuous improvement in health and social services in Ireland, it may be particularly appropriate for HIQA to look at how it and related 'central' organisations influencing health policy and funding (such as the HSE and the Department of Health) can promote or officially recognise these standards, and indeed others that are developed by a third party.

³ Or its successor.

Chapter 1

Introduction

This report examines standards and quality in relation to end-of-life care in hospitals in Ireland. It is one of a series of reports that make up the NESC project, *Quality and Standards in Human Services in Ireland*. This project assesses how quality processes, standards and regulation can best contribute to continuously improving human services. An earlier report, *Overview of Concepts and Practice* (NESC, 2011), set out the main approaches to quality, standards and regulation both in Ireland and internationally. Other reports from the project review quality and standards in the service areas of residential care for older people, home care for older people, disability services, the schools system, and policing. A synthesis report draws together the conclusions of the overview and the individual human services reports and includes suggestions for the way forward.

End-of-life care in hospitals is the focus of this report, and is defined as all care (clinical, administrative and support) that is provided by hospital staff in relation to death, dying and bereavement (Hospice Friendly Hospitals, 2010a).⁴ It provides an interesting case-study, as *Quality Standards for End-of-Life Care in Hospitals* have been developed and supported by a voluntary organisation, the Irish Hospice Foundation.⁵ Unlike standards in some of the other policy areas studied for this project, the Irish Hospice Foundation cannot provide a legislative underpinning to these standards, so instead it has developed strong supports to facilitate voluntary implementation of the standards. This provides interesting lessons on approaches taken to drive standards for continuous improvement, and so highlights areas of learning and good practice for implementation of standards in other human service areas.

The *Quality Standards for End-of-Life Care in Hospitals* (Hospice Friendly Hospitals, 2010a) are one part of the Hospital Friendly Hospitals (HFH) programme developed by the Irish Hospice Foundation, to put hospice principles of care into hospital practice. The HFH programme has three aims – to develop these standards, to develop the capacity of hospitals to implement them, and to change the culture of care and organisation in hospitals.

⁴ Such end-of-life care can also be termed ‘general palliative care’, and is provided by many different disciplines of staff (and not just clinical staff). Meanwhile, ‘specialist palliative care’ is provided by specialist palliative care consultants and nurse specialists who have particular training and expertise in pain management and symptom control, and in helping patients and their families cope with the many burdens of a serious illness.

⁵ The Irish Hospice Foundation is a not-for-profit organisation that promotes the hospice philosophy and supports the development of hospice and palliative care.

In Chapter 2 end-of-life care in Ireland, the HFH programme, and the *Quality Standards for End-of-Life Care in Hospitals* will be outlined, followed by a description in Chapter 3 of the supports provided for implementation of the standards. Chapter 4 then outlines how this standards framework and its implementation are relevant to the five key themes of the overall project, *Quality and Standards in Human Services in Ireland*, before addressing three key questions about the overall efficacy of these standards in improving end-of-life care in hospitals. These five themes and three questions are outlined in Box 1.1. Finally, in Chapter 5, a summary of this standards framework, and comment on its effectiveness, are provided.

Box 1.1 Quality and Standards in Human Services in Ireland: Key Themes and Questions

Five key themes:

1. Responsive Regulation and Standards

To what extent is the regulatory, standards and quality improvement regime driven from a command-and-control, self-regulatory, or responsive regulation perspective?

2. Involvement of Service Users

To what extent, and in what way, are service users involved in the provision and/or regulation of services?

3. Monitoring and Learning

What, if any, are the mechanisms for continuous learning?

4. Devolution with Accountability

Who are the main actors (State, local, private, voluntary providers) driving the regulatory, standards and quality improvement regime, and what are their respective roles?

5. Cost Effectiveness

Have attempts been made to improve quality, while reducing costs? If so, how?

What impact, if any, has this had on the quality of outcomes? Are there any barriers preventing implementation?

Three key questions:

1. How convincing is this regulatory, standards and quality assurance regime?

2. To what extent does this regime (a) prevent the most serious harms/abuses; and (b) promote quality improvement?

3. Are there things in this regime that need to change to ensure the provision of a quality service?

The first five themes outlined in Box 1.1 are key issues considered in this project (see NESCS, 2011) and addressed in this report with respect to end-of-life care in hospitals, so an explanation of them is provided in the following sections.

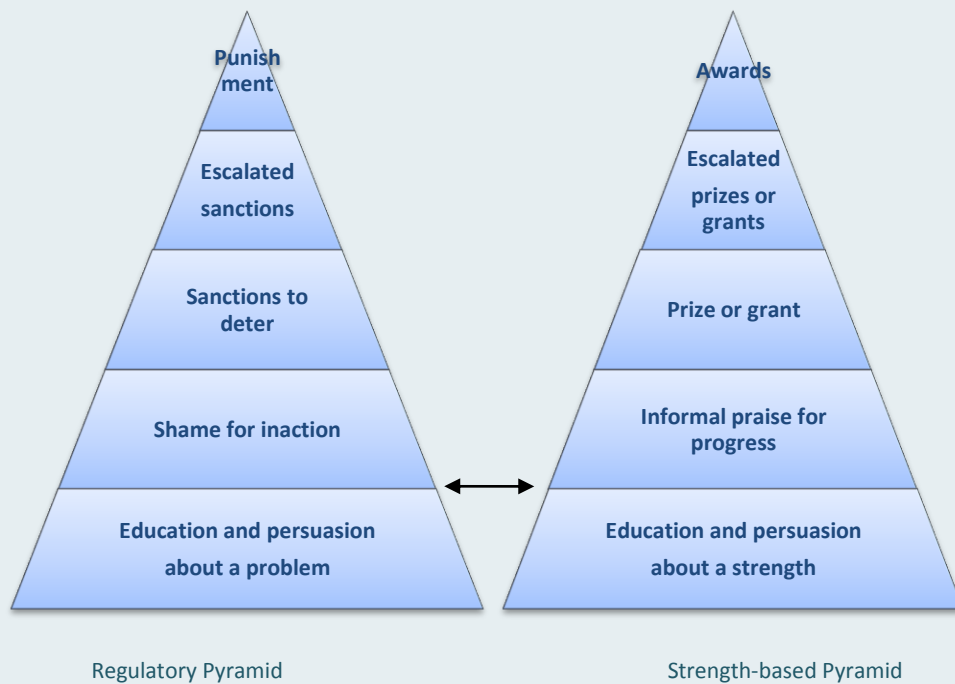
1.1 Responsive Regulation

Regulation, often defined as rule-making and rule enforcement, is one of a number of quality-enhancing mechanisms that can improve the quality of services. The concept of responsive regulation arises from studies indicating that regulation can be limited when it is one of two extremes, which are ‘command and control’ (with rules and regulations implemented through a top-down approach directed by a central regulator), or ‘self-regulation’ (a bottom-up approach where service providers and professionals self-regulate). Responsive regulation instead aims to combine both approaches, and is often depicted as a regulatory pyramid of approaches, with self-regulation and voluntary approaches at the base and sanctions at the top (Braithwaite *et al.*, 2007). To ensure standards are met, the regulator or oversight organisation begins at the bottom of the pyramid with information provision and persuasion, but with the capacity to escalate towards punishment if persuasion fails, sometimes referred to as ‘the gorilla in the closet’. Regulators will seek to persuade, but will act further if matters do not improve (NESCS, 2011).

This pyramid alone, however, does not capture sufficiently the importance of rewards to spur effective regulation. Therefore, Braithwaite has since developed a ‘strengths-based’ pyramid to complement the ‘regulatory’ pyramid. The strengths-based pyramid promotes ‘virtue’ while the regulatory pyramid restrains ‘vice’ (Braithwaite, 2008). Standards as a tool for regulation are used differently and rather than being pushed up through a floor as in the regulatory pyramid, are instead pulled up through a ceiling in the strengths-based model. This is similar to the distinction made by Seddon (2008), who focuses on increasing purpose and *performance* in services rather than on compliance with regulations, and who sees frontline staff heavily involved in driving improvements.

The complementary pyramids – regulatory and strengths-based – are illustrated in Figure 1.1.

Figure 1.1 An Example of a Strengths-Based Pyramid Complementing a Regulatory Pyramid



Source Braithwaite (2008: 116)

Overall, taking the two pyramids together, the focus is on continuous improvement, by identifying problems and fixing them, but also by identifying opportunities and developing them. The strength of this dual-pyramid approach is at the bottom, where they are interconnected. This is where most of the activity takes place within the service-delivery organisation, with limited support and/or intervention from external organisations, such as regulators and overseers (NESC, 2011).

A range of approaches can be taken within responsive regulation, one of which is particularly relevant to this study of end-of-life care standards. This is 'smart regulation' (Gunningham & Grabosky, 1998), where a range of non-State bodies are involved in supporting regulation, for example, professional organisations, trade unions and NGOs. These groups may be able to act as 'quasi-regulators', for example, NGOs that provide supports to implement standards, although it may be necessary for the State to enforce such standards with organisations that do not respond to the persuasive work of the NGO or other third parties.

1.2 Involvement of Service Users

An increasing trend in the provision of human services is a focus on how the *service user* receives the service. This has led to growing references to ‘person-centred’ services,⁶ ‘tailored services’,⁷ ‘money following the patient/client’, and so on. There is greater emphasis on taking into account the views of service users through consultation, ongoing engagement and, in some cases, the co-production of services and associated standards, for example, through student councils, patients’ committees, residents’ committees and joint policing committees. Associated with a greater emphasis on service users is an increasing focus on outcomes – for the service user, but also for the service providers, and the service system more widely (NESC, 2011). As will be shown in later chapters, this is a hallmark of the HFH approach.

1.3 Monitoring and Learning

Seeking feedback on the delivery and quality of services is a vital element of all quality-assurance systems and is key to continuous improvement. What is needed is a mechanism for practitioners to learn from their practice, and monitoring on an ongoing basis to ensure that review and learning, which can be described and demonstrated, are a constant feature of what people do at a local service-delivery level (NESC, 2011; Sabel, 1994). According to Kendrick, monitoring and evaluation can point to the need for changes in service models: ‘They [quality and monitoring] are not in themselves capable of assuring quality, unless they are subsequently combined with feasible measures to improve service practice and models’ (Kendrick, 2006: 3).

A key message from all the evidence reviewed by NESC in its *Overview of Concepts and Practices* (2011) is the need for a learning culture in the provision of quality human services. Ideally, learning should take place at a number of levels, an approach sometimes referred to as ‘triple-loop learning’. The first loop of learning occurs when practitioners monitor their achievements and make adjustments to gain improved outcomes. The second loop occurs when this kind of practical learning is noted by managers who subsequently adjust their systems and routines to take note of this. And the third loop occurs when regulators and oversight authorities learn from monitoring the organisation’s improved goals and revise their strategy for the entire field. Meanwhile, diagnostic monitoring⁸ and other service-

⁶ Person-centred services focus on the wishes of the service user in relation to the kind of services received and how they are delivered. This is the opposite of more ‘task-focused’ services that are often provided.

⁷ This refers to mainstream services that have supports specifically tailored to the needs of the person accessing them, so that the person can overcome obstacles arising from disadvantaged social circumstances. See also NESC’s *Developmental Welfare State* report (NESC, 2005).

⁸ Information from the monitoring of services is used to diagnose problems and find solutions.

review approaches focus on asking ‘Why?’, in a systematic way with a view to sharing learning, and changing systems at the highest level.

In this report on the *Quality Standards for End-of-Life Care in Hospitals*, some of the learning approaches outlined in NESC (2011) to drive continuous quality improvement are particularly relevant. These are quality improvement methods that take a systems approach, with continuous quality improvement built into work processes, rather than being an add-on. Such methods try to shift the culture of organisations towards trust and open disclosure, and seek to identify the root causes of problems and rectify them. These approaches view staff as motivated by pride in their work, and focus on organising work in order to improve performance, and involving frontline staff in driving improvements (Seddon, 2008).

A second author concerned with improving performance is Sparrow, who argues for ‘picking important problems and fixing them’ (Sparrow, 2000: viii). He suggests that qualitative changes in societal conditions can be achieved when the relevant resources come together with a clear purpose, which he calls ‘partnerships with a purpose’.

Another method referred to in NESC (2011) to achieve quality in human services is the use of checklists, which Gawande (2010) argues set out the minimum steps necessary in a process, help ensure consistency of approach, and help with memory recall. They are an aid in making systems work, although it is how the components of a system work that is most important in ensuring standards are met and outcomes improved.

1.4 Devolution with Accountability

There is some evidence from practice, and in the literature, that those delivering services directly to service users know well what is required. Devolving responsibility to service providers to maintain quality, but with clear accountability mechanisms to ‘the centre’,⁹ can be an effective part of a regulatory system. The evidence suggests that a fruitful approach is to set a broad regulatory framework or a small number of guiding principles ‘at the centre’ and then devolve their application to the local context. The centre continues to have an oversight role to ensure compliance but local providers have the opportunity, and, in some cases, the incentive, to improve quality and performance. The overriding priority is on achieving and improving outcomes for service users (NESC, 2011).

⁹ Depending on the context, ‘the centre’ can be government, a government department, a regulator, etc.. In this particular case, it is the HFH programme. The important point is that power (to varying degrees) is devolved from a central to the local or ‘frontline’ context.

1.5 Addressing Costs While Improving Quality

In the current economic climate, cost is to the forefront of any debate on providing public services. In this context, an emphasis on quality may seem like a luxury. Should emphasis instead be put on securing basic services and access to them? This is an understandable stance but care should be taken about creating a division between 'basic' and 'quality' human services, as if the latter is somehow superfluous. Quality should be seen as a basic expectation for all users of human services and not something that might supplement the delivery of services, if resources happen to be available. Rather, quality should be seen as intrinsic to the delivery of human services provided by the State, private sector, voluntary sector and communities (NESC, 2012d forthcoming). In this context, a corresponding perspective is that strategies are needed to ensure that quality is not jeopardised, i.e. that services do not deteriorate when there are budget reductions (NESC, 2011).

This raises the question of the costs and savings associated with quality improvement initiatives. A review by Ovretveit (2009) of a range of quality improvement initiatives in the health services found that few studies actually included all relevant costs, meaning that the evidence available to assess the costs of quality improvement was weak. Nonetheless, savings have been reported in some cases. There is strong evidence that quality improvement changes will improve outcomes for patients, but Ovretveit's review showed that savings depend on the type of improvement, on who pays for the cost of poor quality, and the intervention cost of the solution. For example, changes to reduce pressure ulcers can reduce extra treatments and admission rates to hospital. This is beneficial to patients, but will only save the provider money if the cost to the provider of implementing the change is lower than the losses made from the problem before the change. But it is not always the provider who saves through implementation of such initiatives. In some payment systems, longer stays in hospital due to infection are not a cost to the hospital, but extra income. A hospital can also spend time and money improving, for example, discharge information, but might not gain savings, because the next 'downstream' service will benefit instead from this information.

Another important influence on savings associated with quality improvement initiatives is how well they are implemented, which can vary considerably. External support, or previous experience with making changes effectively, will reduce the cost of implementation.

These findings show that addressing costs while improving quality is not a straightforward process. Nonetheless, the limited evidence available suggests that some quality approaches can reduce the cost of provision, for example, cutting out waste, changing the way services are provided to make them more efficient and effective (such as more care at home, or changes in staff skill-mix), and taking a person-centred approach. The challenge is to organise work systems and practices in such a way that staff resources can deliver the optimal quality service within the financial resources available, and that associated regulation, standards and quality improvement initiatives support this approach.

1.6 Methodology

The methods used to gather the information in this report include documentary research to outline the *Quality Standards for End-of-life Care in Hospitals*, and the supports devised for their implementation; interviews with key stakeholders in the HFH programme management and the Department of Health; and interviews with staff involved in implementing these standards in one general acute hospital in Dublin, which was selected as a case-study.¹⁰ These interviews were carried out to gain greater insight into how the standards were designed, and how they are operating in practice, from a number of viewpoints. A list of the ten people interviewed is outlined in Box 1.3.

To preserve anonymity, quotes and examples given by those interviewed are presented using the numeric identifiers R1 (Respondent 1) to R10.

A workshop was also held with thirteen key stakeholders representing those designing and implementing standards in the areas of end-of-life care, residential standards for older people and home care for older people.¹¹ The discussion in this workshop is also referenced in this report. The NESC would like to thank all of those interviewed for their interest and the time they gave to explain the design and implementation of the *Quality Standards for End-of-Life Care in Hospitals*.

To provide some context on the reasons for choosing those interviewed, a number of key elements of the HFH programme are briefly defined in Box 1.2.

¹⁰ A HFH programme manager [R4] indicated that the performance of this hospital in the implementation of the standards was average to above average.

¹¹ Standards for residential care and home care of older people are the subject of two other NESC reports (NESC, 2012c; 2012b).

Box 1.2 Definition of Key Elements of the HFH Programme

HFH (Hospice Friendly Hospitals) Programme – an initiative set up by the Irish Hospice Foundation to promote hospice principles of care in hospital practice.

Quality Standards for End-of-Life Care in Hospitals – the standards developed as part of the HFH programme, to improve end-of-life care in hospitals.

National Audit of End-of-Life Care in Hospitals in Ireland, 2008–9 (the Audit) – this Audit of 1000 deaths in hospitals, commissioned by the HFH programme, identifies key factors that promote a ‘good death’, and the *Quality Standards for End-of-Life Care in Hospitals* drew on this Audit data. Each hospital knows how they scored in the Audit, which allows benchmarking of progress.

National Steering Committee of the HFH programme – this group, with representation from various organisations and disciplines, steers the overall HFH programme.

Hospital Standing Committees – each hospital implementing the *Quality Standards for End-of-Life Care in Hospitals* has set up a Standing Committee, to oversee implementation of the standards in that hospital.

Hospital working groups – these groups support the hospital Standing Committee, focusing on implementation of specific standards, such as the Hospital, the Patient, the Family and the Staff.

End-of-life care co-ordinators – these individuals, employed as part of the HFH programme, work with hospitals to help co-ordinate implementation of the standards within them.

Hospice Friendly Hospitals Network (previously known as the Champions for Change network) – this group has been set up to share learning between different hospitals. Its members include the Chairs and Deputy Chairs of the Standing Committee of each hospital, end-of-life care co-ordinators, and other key champions.

Community Hospital network (Greater Dublin Area) on quality of life at end of life – this network has been set up to promote communication and collaboration on end-of-life care between community hospitals/units, specialist palliative care providers, acute hospitals, primary/community care services, and HSE managers in the greater Dublin area.

Practice development programme, and co-ordinator – practice development is a culture-improvement programme of facilitated learning that leads hospital staff to reflect on and alter their day-to-day working practices, so that these practices become more person-centred. The practice development co-ordinator works with a number of hospitals taking part in this programme.

Box 1.3 **Stakeholders Interviewed on *Quality Standards for End-of-life Care in Hospitals***

Organisation	Number Interviewed
Department of Health	One manager from the Services for Older People division.
HFH programme	Two managers of the programme.
Case-study hospital taking part in the HFH programme	The Chair of the hospital's Standing Committee on end-of-life care; Two other members of the Standing Committee; and The hospital's end-of-life care co-ordinator.
Various people working on practice development	The co-ordinator of practice development work in the HFH programme; The co-ordinator of a separate network on practice development; and An independent researcher on practice development.

As the number of people interviewed is not very large, it is difficult to give weight to some of the issues raised in terms of their representativeness, so some caution is advised in their interpretation. Nevertheless, the discussions held do begin to reveal key issues arising in the implementation of *Quality Standards for End-of-Life Care in Hospitals*.

Chapter 2

End-of-Life Care in Ireland, and the Hospice Friendly Hospitals Programme

2.1 End-of-Life Care in Ireland

Every year almost 30,000 people die in Ireland. A 2004 survey showed that two-thirds of Irish people would prefer to die at home, but 75 per cent of all deaths now take place in hospitals and long-stay centres, and 48 per cent of deaths occur in acute hospitals. Only 4 per cent of deaths occur in a hospice. This means that the majority of end-of-life care occurs in hospitals. This is a reversal of previous practice – up till 1960, more than half of deaths in Ireland occurred at home. This change has been linked to demographic issues such as longer life expectancy, accompanied by rising illness rates, particularly among older age groups, which is resulting in high rates of hospitalisation for older people. Cultural reasons for this change include the ‘medicalisation of everyday life’, which leads to medical treatment for normal life processes such as death, even though a ‘good death’ involves much more than medical treatment. For example, the UK end-of-life strategy defines a good death as: treating an individual with dignity and respect, being without pain and other symptoms, being in familiar surroundings, and being in the company of close family and/or friends.¹² Meanwhile, social reasons for the increase in the proportion of deaths in hospital include the decline in family size, and in other community supports. There are, however, variations by country. In Ireland, 25 per cent of people die at home, while in England and Wales 19 per cent of people do, compared to 30 per cent in Germany and the Netherlands (see McKeown *et al.*, 2010b).

Although the majority of deaths in Ireland occur in hospital, end-of-life care is not seen as a core activity of hospitals, where ‘curing’ is often seen as the main focus. Due to this, the Irish Hospice Foundation decided to establish the Hospice Friendly Hospitals programme, which aims to improve the quality of end-of-life care in hospitals in Ireland. This programme, and the *Quality Standards for End-of-Life Care in Hospitals* that were developed as part of it, are outlined in the following sections.

¹² See McKeown *et al.*, 2010b, footnote 6.

2.2 The Hospice Friendly Hospitals Programme

The Hospice Friendly Hospitals (HFH) programme is an initiative of the Irish Hospice Foundation, which is a charity founded in 1986 to improve services for people at end-of-life, regardless of illness, and whether death is sudden or expected. Over time, the services of the Irish Hospice Foundation have developed, from initial fund-raising and hospice building, to training, research and education, and since, 1998, have included a focus on end-of-life care in hospitals.¹³ The first foray into this area came when the Irish Hospice Foundation funded a research project in St James' Hospital in Dublin in 1998; and this was followed in 2001 by the commissioning of a feasibility study to inform the notion of a 'hospice friendly hospital'. The resulting document mapped out some core elements that were put into practice in a pilot project called *Care for People Dying in Hospitals* which was carried out between 2004 and 2006 in Our Lady of Lourdes Hospital in Drogheda, in association with the local health board. This project aimed to develop a culture of care for those facing death in hospital, drawing on the principles of hospice care. It explored means of supporting patients, their families, and medical, nursing and other clinical and non-clinical staff working with those with life-threatening illness and/or death.

Following successful conclusion of this pilot, it was decided to disseminate the learning gained to hospitals nationwide, and in May 2007 the five-year HFH programme was launched. It is run in partnership with the HSE, with funding of €10 million - €5.5 million from the Atlantic Philanthropies, €1.5 million from the Dormant Accounts Fund, over €1 million from the HSE and the Health Services National Partnership Forum, and €0.5 million from the Irish Hospice Foundation. The programme aims to promote a 'good death', by encouraging hospitals to adopt a hospice philosophy in caring for patients at end-of-life, and their families (McKeown *et al.*, 2010b). It has three main aims:

- i. To develop standards for end-of-life care in hospitals;
- ii. To develop the capacity of hospitals to implement these standards; and
- iii. To improve the overall culture of care and organisation in hospitals, regarding all aspects of end-of-life, dying, death and bereavement (Hospice Friendly Hospitals, 2010a).

The first of these aims was completed during Phase 1 of the programme, which ran from 2007 to 2010; while work on implementation the standards in hospitals is part of Phase 2, which ran from 2010 to April 2012. Phase 3 has recently been put in place, and will be outlined in Section 5.3 of this report.

¹³ For further information, see

http://www.hospice-foundation.ie/index.php?option=com_content&view=article&id=2&Itemid=6, accessed 15 June 2012.

To achieve the three aims, the programme is focused around four key themes, as follows:

- i. Competence and compassion (a focus on culture and skills);
- ii. Planning and co-ordination (a focus on systems and processes);
- iii. The physical environment (a focus on buildings and infrastructure); and
- iv. An ethical approach (outlining the ethics of end-of-life care) (Hospice Friendly Hospitals, 2010a).

As will be outlined below, the first two foci of the programme, competence and compassion, and planning and co-ordination, are addressed in the *Quality Standards for End-of-Life Care in Hospitals*. These standards are the main focus of this report, as they aim to improve the quality of care, as do standards in other reports in this NESC project, such as those on care of older people (NESC, 2012b; 2012c), and care of those with disabilities (NESC, 2012a). The third and fourth foci of the HFH programme, the physical environment and an ethical approach, are mainly addressed in a different way, and so are not addressed in this report.¹⁴

The three main aims of the programme, as listed above, show that the *Quality Standards for End-of-Life Care in Hospitals* are therefore a key element of the HFH programme. How these standards were developed, and what they contain, is outlined in the following sections, beginning with a description of the *National Audit of End-of-Life Care in Hospitals in 2008–9*, which informed their development.

2.2.1 The National Audit of End-of-Life Care in Hospitals in Ireland, 2008–9

To inform development of the standards on end-of-life care, in 2008 the HFH programme commissioned the National Audit of End-of-Life Care in Hospitals in Ireland, 2008–9, focusing on the end-of-life care of 1000 people in Ireland. The

¹⁴ Standard 1.1 of the *Quality Standards for End-of-Life Care in Hospitals* does focus on Clinical Ethics Support, and asks that hospital management ensure each staff member has access to this, as appropriate. The HFH has supported this by developing an ethical framework of eight study modules, produced by experts in ethics, law and theology, as well as clinicians. The study modules cover topics such as the ethics of breaking bad news, managing pain, and life-prolonging treatments, as well as the role of rights in healthcare decision making, patient autonomy in law and practice, and confidentiality (see <http://www.hospicefriendlyhospitals.net/ethical-framework>, accessed 14 March 2012). Meanwhile, Standard 1.5 is focused on the Hospital Environment, and looks for a physical environment which supports high-quality end-of-life care, dignity and privacy. Development of such an environment can be supported by applying the guidelines developed by the HFH on this, entitled *Design & Dignity Guidelines for Physical Environments of Hospitals Supporting End-of-Life Care* (see <http://www.hospicefriendlyhospitals.net/media/k2/attachments/DESIGN1.pdf> accessed 14 March 2012); through a small grants scheme for hospitals to develop design and dignity in their environments; and other reports and articles (see <http://www.hospicefriendlyhospitals.net/resources-and-courses/itemlist/category/15-resources-the-physical-environment>, accessed 14 March 2012).

Audit looked at a random sample of deaths in twenty four acute hospitals (representing 74 per cent of acute bed capacity), and in nineteen community hospitals¹⁵ (representing 20 per cent of community-hospital bed capacity) (see McKeown *et al.*, 2010b). This Audit used literature reviews, and existing sets of standards on end-of-life care, to define key care outcomes and care inputs that were likely to lead to a 'good death' for patients in Ireland. Questionnaires were designed to capture the patient's final journey from admission to discharge, from the perspective of a number of groups – the nurse and the doctor who provided most care to the dying person in their last week; a relative (as a proxy for the patient);¹⁶ and other hospital staff, including management. The data collected identified eighteen key factors which improve the quality of end-of-life care in Ireland. These are outlined in Box 2.1 below.

¹⁵ There is no official definition of a 'community hospital' in Ireland but the convention is to differentiate it from an 'acute hospital' if it does not have an accident and emergency department. Community hospitals are effectively long-stay facilities but offer a higher level of medical support compared to the average nursing home.

¹⁶ Internationally, there is relatively little research that draws on relative and patient perspectives as to what constitutes a 'good death', which has been attributed to practical, ethical, methodological and emotional difficulties associated with interviewing people who are dying (see O'Shea *et al.*, 2008).

Box 2.1 Eighteen Key Factors That Improve the Quality of End-of-Life Care in Hospitals in Ireland

- **The hospital's service plan contains end-of-life care objectives**
- **Admission is planned**
- **The patient is cared for in a single room**
- **The patient's health record contains good documentation**
- **There is sufficient ward staff**
- **There is good quality of information on deaths, at hospital level**
- **Patients are facilitated to die at home**
- **Patients close to death are diagnosed as such**
- **There is good decision-making on when to begin end-of-life care**
- **Team meetings are held, especially between nurses and doctors**
- **Training is provided in end-of-life care**
- **Staff are prepared for the death of patients**
- **There are experienced nurses on the ward**
- **The patient is suffering from cancer (cancer care services were rated as having the highest standard of end-of-life care, compared to other services such as dementia care)¹⁷**
- **There is high-quality communication with patients**
- **Specialist palliative care teams have a strong role**
- **There is support for families who are bereaved**
- **Families are supported following sudden death**

Source McKeown *et al.* (2010b)

¹⁷ This is partly because other factors that positively influence end-of-life care outcomes are more likely to apply to cancer patients, such as planned admission to hospital, death in a single room, being the object of more team meetings and better communication, and having relatives who stay overnight and are present at the time of death.

The audit compared the eighteen key factors influencing end-of-life care in Irish hospitals to studies from other countries, finding that in many cases the experience of these aspects of end-of-life care in Ireland was similar to the experience internationally.

The audit then looked at how the participating hospitals performed on the factors that improve end-of-life care, dividing performance into ‘good’, ‘average’ and ‘unsatisfactory’.¹⁸ A hospital’s rating may vary from one indicator to another, given that a hospital can have strengths in some areas and weaknesses in others, and so there is no composite score. Importantly, this information provides each hospital with baseline data on how it scored on the key factors influencing end-of-life care, which means that the hospital can monitor its progress by comparing later data against the original baseline data.

The baseline data also showed that two-thirds of acute hospitals were scored as ‘unsatisfactory’ on a number of factors influencing end-of-life care, including admissions through A&E, deaths in single rooms, nurses trained in end-of-life care, work experience of nurses, sufficient staff on wards, and end-of-life goals in the hospital’s service plan. As will be shown in Section 2.4, many of these issues are addressed in the *Quality Standards for End-of-Life Care in Hospitals*.

2.3 Development of the *Quality Standards for End-of-Life Care in Hospitals*

A number of sources of information were used to develop the *Quality Standards for End-of-Life Care in Hospitals*. First, international evidence on best practice and development of draft standards was gathered to feed into the standards design process. Working groups of healthcare staff and interested parties, including bereaved relatives, were also convened to develop and refine a set of draft standards. A final source of information that influenced drafting of the standards was the *National Audit of End-of-Life Care in Hospitals in Ireland, 2008–9* (McKeown *et al.*, 2010b).

The draft standards developed using these three sources of information were then reviewed, both by the HFH National Steering Committee¹⁹ and a standards reference group. The draft standards were then submitted for public consultation over a period of two months. The feedback from all these processes was used to

¹⁸ The data collected was grouped into thirty-six main care outcomes and care inputs. For each of these thirty-six pieces of data, a benchmark has been set, which is the mean score of the hospitals that scored in the top 25 per cent on this piece of data. A score of ‘good’ is 100 per cent of this benchmark, while ‘average’ is 80–99 per cent of the benchmark, and ‘unsatisfactory’ is less than 80 per cent of the benchmark.

¹⁹ This National Steering Committee was made up of private and public-sector representatives from Ireland and overseas, comprising hospital doctors, nurses, GPs, patients, HIQA, the HSE, the Department of Health and Children, the Irish Hospice Foundation and a journalist. See Section 4.3.11.

produce the final standards, the *Quality Standards for End-of-Life Care in Hospitals* (Hospice Friendly Hospitals, 2010a).

2.4 What is in the *Quality Standards for End-of-Life Care in Hospitals*?

The standards are divided into two main sections – standards around end-of-life care for adults, and end-of-life care for babies/children. However, both have similar foci. The standards for adult end-of-life care (which this report focuses on) are grouped into four high-level standards, as follows:

- the hospital,
- the staff,
- the patient, and
- the family.

The standards are ordered according to the group seen to have most responsibility for implementing the standards, with the hospital most important (although the patient is recognised as being at the heart of the service).

Box 2.2 provides some detail on what is to be put in place under each of these four high-level standards. The detail reflects the eighteen key factors that the Audit found needed to be in place for good end-of-life care.

Box 2.2 *The Quality Standards for End-of-Life Care in Hospitals*

Standard 1: The Hospital

- 1.1 A Culture of Compassionate End-of-Life Care
- 1.2 General Governance Policies and Guidelines
- 1.3 Effective Communication with Patients and their Families
- 1.4 The Healthcare Record
- 1.5 The Hospital Environment
- 1.6 Monitoring and Evaluating End-of-Life Care
- 1.7 Assessing and Responding to End-of-Life Care Needs of Patients
- 1.8 Clinical Responsibility and Multi-Disciplinary Working
- 1.9 Pain and Symptom Management
- 1.10 Clinical Ethics Support
- 1.11 Care after Death
- 1.12 Post Mortems
- 1.13 Bereavement Care

Standard 2: The Staff

- 2.1 Cultivating a Culture of Compassionate End-of-Life Care among Staff
- 2.2 Staff Induction
- 2.3 Staff Education and Development Needs
- 2.4 Staff Education and Training Programmes
- 2.5 Staff Support

Standard 3: The Patient

- 3.1 Communicating a Diagnosis of the Possibility of a Need for End-of-Life Care
- 3.2 Clear and Accurate Information
- 3.3 Patient Preferences
- 3.4 Pain and Symptom Management
- 3.5 Discharge Home/Out of the Hospital
- 3.6 The Dying Patient

Standard 4: The Family

- 4.1 Communication with Family Members
- 4.2 Communication with Family Members – Where death may be anticipated
- 4.3 Communication with Family Members – Sudden/unexpected death or sudden irreversible decline in health leading to death
- 4.4 Patient Discharge
- 4.5 Supporting Family Members
- 4.6 Responding to the Needs of Family Members after a Death

Source Hospice Friendly Hospitals (2010a)

Each standard has an outcomes statement that sets out in broad terms what is expected regarding the service provided to the patient and family. Under each standard, criteria are also set out, which explain how a service can be judged, to see whether or not the standard is being met. The example of Standard 2.1, *Cultivating a Culture of Compassionate End-of-Life Care Among Staff*, is given in Box 2.3.

Box 2.3 Standard 2.1: Cultivating a Culture of Compassionate End-of-Life Care Among Staff – Outcomes Statement and Criteria

All hospital staff have access to education and training opportunities in the delivery of compassionate end-of-life care in accordance with their roles and responsibilities.

How do we know that we are meeting this Standard?

The hospital manager ensures that there are education, training and staff mentorship programmes in end-of-life care for hospital staff in accordance with the size, complexity and specialties of the hospital.

The design of staff education and training programmes involves key stakeholders with relevant experience and knowledge.

A core group of clinical and non-clinical hospital staff with the required expertise in end-of-life care are facilitated and supported to deliver end-of-life care education and training to hospital staff.

The hospital facilitates staff, as appropriate, to undertake additional formal education and training in end-of-life care.

Source Hospice Friendly Hospitals (2010a: 59)

In the following chapter, the mechanisms and supports in place to implement the *Quality Standards for End-of-Life Care in Hospitals* are outlined.

Chapter 3

How Implementation of the
*Quality Standards for
End-of-Life Care in Hospitals*
is Promoted

3.1 What Hospitals Are Taking Part in Implementation of the *Quality Standards for End-of-Life Care in Hospitals*?

When the HFH programme began, the Irish Hospice Foundation advertised in national newspapers, seeking interested hospitals to apply to take part in the programme. For Phase 1, which comprised the audit of end-of-life care in Ireland, and development of the standards, 23 acute and 19 community hospitals took part; for Phase 2, which is implementation of the standards, 23 general acute hospitals have signed up (79 per cent of all general acute public hospitals²⁰), three specialist acute hospitals, and one children's hospital (Hospice Friendly Hospitals, 2012) as well as 30 community hospitals, equivalent to 20 per cent of the 150 community hospitals in Ireland²¹.

3.2 Supports Provided by the HFH Programme

The HFH programme provides a wide variety of supports to facilitate implementation of the standards. These can be divided into 'structural' supports, which are those that assist organisational change in the hospital, and 'tools', which are supports used on a day-to-day basis by frontline staff implementing the standards.

The main structural supports are those provided and agreed through a Memorandum of Understanding signed between each hospital implementing the *Quality Standards for End-of-Life Care in Hospitals*, and the HFH programme. Under the Memorandum of Understanding, the hospital commits to adopting an end-of-life care development plan to implement the standards, and to include the commitment to introduce and implement such a plan in the service plan of the hospital. The hospital also commits to establishing a Standing Committee on end-

²⁰ *Activity in Acute Public Hospitals in Ireland Annual Report 2010* (ESRI, 2011) shows that there were 29 acute general public hospitals in Ireland in that year.

²¹ Less community than acute hospitals are currently taking part, as the HFH programme was devised initially for acute hospitals, as almost half of all deaths occur there.

of-life care to drive implementation of the development plan. In return, the HFH programme provides supports such as an end-of-life care co-ordinator, training and development courses, resources, and access to specialised advice (Hospice Friendly Hospitals, undated-a).

Meanwhile, tools for all staff, particularly frontline staff, to use include a staff development programme on end-of-life care, called *Final Journeys*, and practical resources to be used in hospitals. The latter include a symbol that can be displayed to indicate that a patient is dying or has died in a ward; a ward altar; sympathy cards; an end-of-life care resource folder; and DVDs and booklets on care of the dying (for staff). Other booklets provide information for the bereaved.²²

Another important support is a practice development programme to reflect on and change the culture of end-of-life care in the hospital; a support that both assists organisational change and facilitates frontline staff to reflect on day-to-day work practices.

Each of these supports will be outlined in more detail in the following sections.

3.3 Structural Supports to Promote Improved End-of-Life Care in Hospitals – Memorandum of Understanding

All of the hospitals taking part in implementation of the standards have signed a Memorandum of Understanding with the HFH programme. The main commitments and supports in this are outlined in Box 3.1 below. On the hospital side, the Memorandum of Understanding is signed by the CEO or General Manager, the Director of Nursing, and the Clinical Director, thus aiming for buy-in at a high level in the hospital. The Memorandum is also signed by the HSE Regional Director of Operations over the hospital.

²² A booklet on the HFH website describes each of these supports, and provides details on suppliers and costs. See http://www.hospicefriendlyhospitals.net/media/k2/attachments/Practical_Resources_for_End_of_Life_Care.pdf accessed 2 May 2012.

Box 3.1 **Summary of Memorandum of Understanding Between Hospitals Implementing the *Quality Standards for End-of-Life Care in Hospitals*, and the HFH programme**

Hospitals commit to:	HFH commits to:
Introducing an end-of-life care development plan	An end-of-life care co-ordinator to work with hospitals
Assigning responsibility for this to a senior manager	Supports being provided by a national Practice Development Co-ordinator
Ensuring a functioning Standing Committee on end-of-life care development, and working groups that support this	Access to all HFH special advisers
Participating in ongoing auditing	Access to all HFH resources
Developing guidelines and policies on end-of-life care	Opportunities to take part in shared learning
Providing induction and awareness training on end-of-life care; ensuring that staff are enabled to attend these	Access to HFH audit and evaluation systems
Providing on-site facilities and administrative support to the end-of-life care co-ordinator	Information workshops from HFH
	Access to all HFH grant schemes

Source Hospice Friendly Hospitals (undated-a)

The key supports for structural change in the hospital are the Standing Committee, the end-of-life care development plan, and the end-of-life care co-ordinator. These are explained in greater detail below.

3.3.1 Standing Committees

Standing Committees are tasked with ensuring the development, implementation and monitoring of progress on the end-of-life care development plan, and the effective co-ordination of hospital resources on all end-of-life issues. They are required to be representative of all key hospital disciplines, perspectives and stakeholder groups, including independent representatives of the public interest (Hospice Friendly Hospitals, undated-a). The Memorandum of Understanding suggests an indicative membership of the Standing Committee, as follows:

Box 3.2 Suggested Membership of the Standing Committee on End-of-Life Care in Hospitals

Hospital Manager or Deputy Manager	Representative of pastoral care services
Director or Deputy Director of Nursing	Representative of allied health professionals
Operational Services Manager	University departments
HR Manager	Representative of public interest
Practice development nurse	Representative of nursing homes in the catchment area
Quality and audit manager	GP from the catchment area
Staff and trade union organisations	Public health nurse from catchment area
Centre for Nurse & Midwifery Education	Representative of community hospital in the catchment area
Representative of the medical board	Representative of local hospice organisations
Representatives of palliative care services	
Representative of administrative and support staff	

Source Hospice Friendly Hospitals (undated-a)

This is a large membership, but it aims to ensure buy-in from all key groups, clinical and non-clinical, from both inside and outside the hospital. Inclusion of the public health nurse, GP and local hospice organisations should also help to develop links between the hospital and those who can care for the dying in the community.

The Memorandum of Understanding specifies that the Standing Committee must operate under the authority of the hospital's senior management team. The member of the senior management team who is responsible for the end-of-life care development plan is to play a leading role in the functioning of the Standing Committee, and provide a two-way link with the senior management team. This person may, or may not, be the chair of the Committee.

Under the Standing Committee, smaller work groups and project teams can be established to co-ordinate work on specific aspects of the end-of-life care development plan and other relevant issues. Most hospitals have one working group for each high-level standard – i.e. one working group for the standards under the Hospital, one for those under the Staff, one for those under the Patient, and one for those under the Family. In the case-study hospital, four working groups are in operation. Each focuses on the standards which fit under their remit, and/or are

referred to it by the hospital Standing Committee, and prioritise which issues they will focus on over the next number of months in order to implement the standards.

The hospital Standing Committee is required to meet at least once a quarter (in the case-study hospital it meets once a month). The Memorandum of Understanding specifies that meeting minutes and action logs are to be circulated electronically within one week of the meeting, and action logs are to be updated prior to each meeting.

The case-study hospital reported that key items on the agenda of the Standing Committee are built around the end-of-life care development plan, and several agenda items are the same from month to month. The latter include reports from each of the working groups under the hospital Standing Committee, and a report from the practice development co-ordinator. The Committee also hears reports from the meetings of the Hospice Friendly Hospitals Network (see Section 4.3.9 for more detail). Three-monthly reports on how the hospital is meeting the various standards are also presented to the committee, by the end-of-life care co-ordinator. The Standing Committee helps to collate, and also reviews, these progress reports. Other agenda items refer to particular issues that have arisen – e.g. a policy on staff bereavement; essential maintenance of the mortuary, etc.

3.3.2 End-of-Life Care Development Plan

The end-of-life care development plan provides a framework for the development of end-of-life care in the hospital. It is a link between the results of the *National Audit of End-of-Life Care in Hospitals in Ireland, 2008–9* (McKeown *et al.*, 2010b), and the *Quality Standards for End-of-Life Care in Hospitals* (Hospice Friendly Hospitals, 2010a). The results of the Audit allow each hospital identify the areas where improvement is needed in their end-of-life care. The HFH has developed a template for hospitals on how to draw up a plan to implement each standard, based on the Audit results. This template is outlined in Box 3.3.

Box 3.3 Possible Template for Development Plan to Implement Each Standard

- Name and number of standard
- Existing performance against standard, based on Audit and other data
- Targets to achieve the standard, including timeframe
- Description of actions to achieve standard, including timeframe
- Name of responsible lead for actions
- Resources and supports needed to implement actions
- Verifiable data to be used in reports on implementation
- Explain how the action(s) are sustainable

Source Hospice Friendly Hospitals (2010b)

Together, the plans for improvement of each standard form the development plan. The template outlined in Box 3.3 shows that the development plan also emphasises timelines and accountability, to help ensure that the plan is implemented.

3.3.3 The End-of-Life Care Co-Ordinator

The role of the end-of-life care co-ordinator is to support hospitals in developing their capacity to meet and sustain the *Quality Standards for End-of-Life Care in Hospitals*, in accordance with their end-of-life care development plan. The co-ordinator is either funded solely by the HFH programme, solely by the hospital, or jointly by HFH and the hospital. Some end-of-life care co-ordinators work only with one hospital, while others work with a number. Some are full-time co-ordinators, while others are members of staff who have a part-time role as co-ordinator (e.g. one day per week). Currently 18 acute hospitals have an end-of-life care co-ordinator working with them. One end-of-life care co-ordinator also works half-time with community hospitals in the greater Dublin area.

The Memorandum of Understanding outlines the duties of the end-of-life care co-ordinator in more detail. Key tasks are the co-ordination of work on the end-of-life care development plan; supporting the development, implementation and evaluation of guidelines, policies and procedures on end-of-life care; and preparing three-monthly progress reports for review and use by the Standing Committee, the HFH programme, and other relevant groups. HFH programme staff also underlined the role of the co-ordinator in raising awareness, supporting training and development, and rolling out HFH resources in the hospital [R4].

One member of the hospital Standing Committee said that the co-ordinator is:

Someone to pull it together and someone to enact things ... I don't come out of the committee with loads of work from the committee [because she will take some of the work on] ...you can delegate to the person who's co-ordinating it too because that's their job and they've got the time. [R7]

3.4 Tools to Support End-of-Life Care in Hospitals

In the following sections, a number of the key tools used, mostly by frontline staff, to support end-of-life care in hospitals, are outlined.

Tools – Final Journeys Staff Development Programme

In September 2010, the HFH launched *Final Journeys*, a staff development programme to enhance the quality of interaction between patients at the end of life, their families and hospital staff. The programme consists of two three-hour modules. The first module enhances awareness of end-of-life care issues among all staff. The second module develops communication skills in end-of-life care for staff in direct contact with patients and their families. The programme is aimed at staff from various disciplines, and is designed to be run locally in each hospital, using local facilitators. Each hospital has a key co-ordinator of *Final Journeys* (either a HFH team member, or an appropriate staff member with whom a link may have already been forged through an earlier HFH initiative). This co-ordinator invites certain staff, who are potential facilitators for *Final Journeys*²³ to the first session. Those who are interested in becoming *Final Journeys* facilitators are given a facilitation pack with resources for, and a step-by-step guide to, running and facilitating the programme. Two facilitators run each course, which ideally has ten to fourteen participants, from different hospital staff disciplines.

By May 2011, 201 facilitators had been trained, and there had been a total of 824 participants, on 49 courses (Byrne & Murphy, 2011).

Tools – Practical Resources for Use on the Ward

A variety of practical resources have been developed for frontline staff to use on the ward to promote dignity in end-of-life care. Some key resources will be outlined here – a resource folder, the end-of-life spiral symbol, the family handover bag, and

²³ Those invited may have participated in previous HFH programmes, in particular the 'Train the Trainer' communication skills course or be tutors and facilitators already working in the health system.

the information leaflet for families. Other resources include a ward altar, and sympathy cards.²⁴

Resource Folder

The resource folder contains guidance and procedures on how to approach end-of-life care, which can be customised to the policies of each individual hospital. The folder contains sections on diagnosing dying, how to communicate this diagnosis, advance-care planning, resuscitation, caring for a dying patient, and care after death (see *Hospice Friendly Hospitals*, undated-b). As an example, the checklist of steps to take following the death of a patient are outlined in Box 3.4.

²⁴ For other resources developed by the HFH programme, see <http://www.hospicefriendlyhospitals.net/resources-and-courses/itemlist/category/17-resources-general> accessed on 15 March 2012.

Box 3.4 Sample Checklist Outlined in Care After Death Resource Guide

- | | |
|---|---|
| <ol style="list-style-type: none"> 1. Inform doctor to pronounce patient's death and document date and time of death in the patient's notes. 2. Notify next of kin and provide support to patient's family. 3. Inform spiritual designate/chaplain, if appropriate. 4. Doctor completes death notification form within 3 working days. 5. Place end-of-life symbol at nurses' station to notify staff a patient has died. 6. Offer support and reassurance to other patients who may be aware of the situation. 7. Contact bed manager and nursing administration to notify GP and out-of-hours doctor on call. 8. To allow for the preparation of the patient's body, bring family to a private room, provide refreshments, use of phone, etc. 9. Prepare and lay out deceased patient using an end-of-life drape, observing rituals as appropriate and in line with the deceased patient's wishes – all tubes and drains should be removed unless otherwise indicated, for example, in a coroner's case. 10. Prepare family once again for viewing and advise the family of any deterioration in the patient's physical condition or of equipment that must be left <i>in situ</i>. | <ol style="list-style-type: none"> 11. Allow time for spiritual care as appropriate. 12. At an appropriate time, return patient's valuables as per hospital guidelines. 13. Provide family with bereavement-information pack, drawing attention to mortuary viewing times and collection of death notification form. 14. Notify the mortuary porter to transfer deceased patient to mortuary. 15. Once porter arrives, accompany family into a private room/space and provide tea/coffee while porter prepares patient for transfer. 16. Porter transfers patient to mortuary using end-of-life drape. 17. Document date and time patient was transferred to the mortuary in patient's notes. 18. Notify patient's GP and any other relevant services in the community. 19. Send sympathy card to the family preferably within one week of patient's death. 20. Finance department delays hospital bill for at least 6 weeks after patient's death to avoid it arriving on the patient's month's mind. 21. Out-patient department notified to cancel any planned appointments. |
|---|---|

Source http://www.hospicefriendlyhospitals.net/media/k2/attachments/8Care_after_death.pdf

Such a checklist approach has also been advocated and used by Gawande (2010) to improve quality of care, as checklists can set out all minimum necessary steps in a process, establish a higher standard of baseline performance, and ensure consistency of approach.

End-of-Life Spiral Symbol

Another useful resource is the end-of-life spiral, which is displayed in a ward or other area when a person is very close to death or has died. It is a signal to all staff that this profound event is happening for the patient and their family. One member of nursing staff on the Standing Committee in the case-study hospital described its use, as follows:

When we have a death on the ward ... we place the [end-of-life Newgrange spiral] symbol on the desk [see Figure 3.1], and that's really good because when people approach the desk they know there's been a death, and lower their voices. Whereas before, you could be laughing, joking, talking about the weekend – and that's all fine – and then suddenly you realise, oh my God, there's grieving relatives around the corner, and you're all upset and you feel really bad So the symbol works really well. [R7]

Figure 3.1 End-of-Life Newgrange Spiral Symbol on Desk of Hospital Ward



Family Handover Bag

A family handover bag has also been developed. This allows a more dignified way of returning the deceased patient's belongings to the family, as described by one person interviewed:

When my dad died, everything was just thrown into a black sack which could have connotations of it being refuse, and we left the hospital carrying the black bag out ... but other than the large black sack there was nothing else to put it in. And nurses hated handing over stuff in those old refuse bags so we've been using the [HFH] bags ... they're just nice bags ... it makes life easier – i.e. we feel better - to be able to hand over belongings in a proper bag. [R7]

Figure 3.2 HFH Family Handover Bag (on right)



Information Leaflets for Families

A variety of leaflets have been developed to provide information to bereaved families. One person interviewed described them as follows:

We have some bereavement leaflets ... for [families] – it gives information, for example on how to get a death cert; if you need some bereavement support, how to access it; how to go about getting the bereavement grant, telling people that a bereavement grant is available for all, because most people don't know. And [it means the relatives] don't have to take it all in [when you speak to them about it after a death] ... it's information that's written down. [R7]

Another information leaflet outlines procedures around post mortems.

It explains why there is a post mortem, so that takes all the mystery out of it. So now if a patient ... must have a post mortem, you can explain to [the relatives] and also give them this to take away – and there's lots of information on organ retention and also the other issues which come up ... [for example] if somebody is having a post mortem the death certificate would be delayed, maybe. There's a lot of information covered in this booklet. [R7]

3.5 A Structural Support and Tool for Change – The Practice Development Programme

Another important support is the practice development programme that the HFH funds through the HSE.²⁵ Practice development is ‘an organised approach to changing and improving practice through the systematic transformation of care practices and culture’ (HSE *et al.*, 2010: 13). Using facilitation and emancipatory practice development methodology and processes, participating staff are encouraged to observe and question the detail of day-to-day work practices, and change these in order to develop more person-centred care. As it is the staff themselves who question and adapt the work practices, the interventions adopted to achieve a person-centred culture of care can then become deeply embedded in the organisation. In this way, the practice development support aims to change day-to-day work practices, and so develop a more person-centred workplace culture.

The programme provides an opportunity for hospitals to implement an emancipatory practice development approach to develop end-of-life care, through a work-based learning model. It employs a practice development co-ordinator,²⁶ on secondment from the HSE, as a joint appointment between the Irish Hospice Foundation and the HSE Office of Nursing and Midwifery Services Director. Every six weeks the key staff members nominated by each hospital taking part²⁷ meet together with the practice development co-ordinator for a full day, to develop facilitation and practice development skills to use themselves, and to bring these skills back to the hospitals.²⁸ Within each hospital the facilitation and practice development learning is initially shared with a designated practice development group of clinical nurse managers and healthcare assistants. The size of the group is dependent on the number of wards/units taking part in the programme, and this varies according to the size of the hospital.

The key to success with this approach to learning is the extent to which the practice development group engages with its colleagues in the workplace to share practice development activities and create a learning environment for change to happen. This necessitates the development of shared decision-making systems and processes that value the knowledge and skills of the whole team and allow non-clinical decisions to be made together. The workplace learning includes the development of a common vision for end-of-life care; the use of person-centred language; challenging agreed unacceptable practices not in keeping with the vision; addressing aspects of the care environment relating to noise, privacy and dignity; and respecting colleagues’ contribution to care. Feedback from patients and their

²⁵ The HSE has made substantial contributions to this initiative.

²⁶ This co-ordinator focuses solely on the practice development programme, and is separate to the end-of-life care co-ordinators who work with the hospitals on implementing the *Quality Standards for End-of-Life Care in Hospitals*.

²⁷ All but one acute hospital in the HFH programme is also taking part in the practice development programme.

²⁸ The HFH operations manager also supports these training days.

families as well as colleagues is part of a detailed evaluation structure used throughout the programme [R1].

One approach to discovering the impact of the environment on care is an activity known as ‘environmental walk-about’. In groups of two or more, staff walk through their ward/unit as though for the first time, paying attention to how they may be greeted by staff, how clear the signs are, how noisy the environment is for sick patients, how information about patients is shared and displayed, the lighting and bed positioning used when a person is in the terminal stages of their life and a single room is not available, and how and where private conversations are conducted. This exercise enables staff in their workplaces to develop a deeper understanding of how patients and their families, and visiting staff, may be impacted by the care environment.

Participants also develop skills in action-learning through their engagement in a process known as ‘triads’. Individuals work in groups of three to learn how to resolve a task, problem or issue, using a structured process that promotes empowerment. Based on principles of adult and work-based learning, participants take ownership of problem-solving and support each other to find solutions together.

Having outlined key aspects, and supports for implementation of the *Quality Standards for End-of-Life Care in Hospitals*, how these are relevant to the five key themes of this project will be outlined in the next chapter.

Chapter 4

How the *Quality Standards for End-of-Life Care in Hospitals* are Relevant to the Five Key Themes of this Project

In this chapter, how the *Quality Standards for End-of-Life Care in Hospitals* and their implementation are relevant to the five key themes of this project – responsive regulation; the role of the service user; learning; devolution and accountability; and addressing costs while improving quality – are explored.

4.1 Responsive Regulation

The first theme considered is that of ‘responsive regulation’. This is defined in the Overview report of this series (NESC, 2011) as ‘seeking to persuade, whilst letting the regulated know that more onerous action will be undertaken if matters do not improve’. So, to what extent does the end-of-life care standards framework display elements of this? What is the balance between ‘command and control’, self-regulation and supports?

The HFH programme is driven and run by the Irish Hospice Foundation, a voluntary organisation, rather than by the State, and so does not have legislative power behind it to act as ‘command and control’ in helping to implement its *Quality Standards for End-of-Life Care in Hospitals*. Therefore, the programme has concentrated on developing supports, and can be seen as developing the ‘strengths-based pyramid’ aspect of responsive regulation (see section 1.1). This approach focuses on performance in services rather than on compliance with regulations, and sees frontline staff as motivated to provide a quality service, and as heavily involved in driving improvements. The strong involvement of this voluntary body is also an example of ‘smart regulation’, where non-State bodies are involved in supporting regulation. In the following sections, ways in which the HFH programme builds on and supports the performance of staff in the participating hospitals will be considered, followed by a consideration of what could be called ‘soft sanctions’ that the programme draws on.

4.1.1 The Strengths-Based Pyramid – Supporting Frontline Staff

Seddon (2008), a proponent of the strengths-based pyramid, sees frontline staff as driving improvements and motivated by pride in their work. In line with this, interviews with stakeholders indicated that the *Quality Standards for End-of-Life Care in Hospitals* are seen as ‘pushing an open door’, as staff already want to provide the best care they can to dying patients. A number of hospitals had some supports in place before the HFH programme began, as there was awareness that a focus on certain aspects of end-of-life care could improve the experience for

patients, family and staff, as indicated by the experience of this member of the Standing Committee in the case-study hospital:

Before the HFH programme ever started, we were running teaching sessions on breaking bad news, dealing with difficult deaths, and symptom management ... [as] everybody wants to do it well and no-one wants to make a bad situation worse. [R7]

The fact that all the hospitals are voluntarily involved in the programme also shows that hospital management and staff are strongly motivated to provide better end-of-life care.

The end-of-life care co-ordinator stressed that it is very important for the programme to support staff.

It's not about knocking the staff, it's about encouraging, and supporting staff members to build upon the good work already in existence. My role is to review the standards and ask staff members how we can support the improvements identified. Staff members are very committed and there is a lot of good will to making improvements. [R8]

In fact, the standards help staff build on the positive work they are already doing (as Braithwaite *et al.*, 2007, also found in an international study):

We'd introduced these bags for patients' belongings years ago, and we were working on improving end-of-life care ourselves ... we certainly [had], even without any standards, been fostering it ... so we were delighted to buy into the whole [HFH] process and I suppose just bring everything together. [R7]

In line with this, the HFH programme has focused on supporting the motivation and goodwill of staff throughout the standards development and implementation. This is evident in several ways. First, the views of staff have been incorporated into the Audit and the standards. When the *National Audit of End-of-Life Care in Hospitals in Ireland, 2008–9* (see McKeown *et al.*, 2010b) was carried out, part of the information in it was gleaned from questionnaires circulated to the nurses and doctors who had cared most for the patient in their last week, as well as from questionnaires to hospital management. This information later influenced development of the standards. Second, staff were members of the working groups convened to develop and refine a set of draft standards. In both of these ways, the experience and needs of staff were drawn on to help develop the standards.

The standards themselves also focus strongly on staff, with 'Staff' one of the four high-level standards devised. The outcomes statement for this high-level standard is that '*Staff are supported through training and development to ensure they are competent and compassionate in carrying out their roles in end-of-life care.*' Several supports to be provided for staff are outlined, such as training for staff, preparing them for the death of patients, and helping them develop skills to diagnose the end-of-life stage (see also Box 2.2 outlining all the standards). These support staff to improve the quality of end-of-life care that they provide. And the tools outlined in

Sections 3.4 and 3.5 help this, such as the resource folder which includes a section on identifying end-of-life (standard 2.1); and the induction training and *Final Journeys* staff development programme on end-of-life care (standard 2.4) (Hospice Friendly Hospitals, 2010a).

One stakeholder interviewed outlined how such training supports staff in their jobs:

In intern staff induction ... we would have done a session on breaking bad news. That wouldn't just be about the patient, it's also about the doctor too ... as we are looking at people who are 22, 23 or 24, who maybe have lost no one in their lives as is ... they could be on their first week working in the hospital, first job in a hospital and somebody dies suddenly maybe of cardiac arrest and the poor doctor is being told he has to ring the family ... it's kind of supporting each other through that, like having someone sitting with the person telling the news, or just being around, because all of that can be very difficult. [R7]

Staff were reported to find the supports developed useful for their work, as follows:

[I asked nursing staff how the] whole Hospice Friendly Hospital Programme had changed their practice on a daily basis ... and they tell me that they love all these practical changes [i.e. handover bag, leaflets], because sometimes when standards are developed it just means more work, and it's not always very user-friendly and people aren't always asked about it. [R7]

Participant feedback forms from the *Final Journeys* staff development programme also show that module 1 of this programme was rated as excellent by 84 per cent, and module 2 as excellent by 85 per cent (Byrne & Murphy, 2011).

All of these supports provide a very good example of a 'strengths-based' pyramid of improving performance.

Most recently, the HFH programme has developed an award, the 'Hospice Friendly Hospital Project of the Year', for hospitals adopting the standards, through the *Irish Medical Times* as part of their annual healthcare awards [R4]. Awards for good practice are also typical of the strengths-based pyramid.

4.1.2 The Strengths-Based Pyramid – Supporting Management

As well as supporting frontline staff, the *Quality Standards for End-of-Life Care in Hospitals* provide a range of supports targeted at hospital management, to help them change existing organisational patterns of work, in order to improve end-of-life care. There are several such supports. First, the *National Audit of End-of-Life Care in Hospitals in Ireland, 2008–9* provided each participating hospital with baseline data on how staff and relatives judged the experience of dying in that hospital, as well as comparisons of where each individual hospital stands on each of the key factors affecting end-of-life care, compared to the scores of the top 25 per

cent of hospitals on the relevant factor (see McKeown *et al.*, 2010b). Second, the standards themselves provide a support, as one stakeholder put it:

[Before the HFH standards were put together] I'm sure people were practising it and doing their very best but ... they hadn't put together guidelines ... [So] it's good to have standards, to have something to aspire to. [R7]

Third, a range of supports are provided under the Memorandum of Understanding with the HFH programme to help managers to better incorporate end-of-life care into hospital strategy and subsequent work. These include the requirement to establish a governance structure to implement the standards (the Standing Committee and any working groups supporting it); the provision of an end-of-life care co-ordinator to help co-ordinate implementation of the standards; a range of advice and resources that can be drawn on, including advice on audit and evaluation; a variety of grants for research and development; and finally, support through learning networks such as the Hospice Friendly Hospitals Network. All of these provide supports for a hospital that is committed to promoting improvement in end-of-life care to develop this further, and so again are an example of a 'strengths-based pyramid' of supports to increase performance in end-of-life care.

4.1.3 'Soft Sanctions'

Although the HFH programme relies heavily on the 'strengths-based' aspect of responsive regulation, this does not mean that there are no pressures for the HFH to draw on where participating organisations do not meet the expectations of the programme.

First, the Memorandum of Understanding signed between the hospital, the HSE regional director of operations, and the HFH, outlines what is expected of the hospital and the HFH programme. Under this agreement, it is expected that the hospital will put in place various requirements, in return for the supports that it can draw on from HFH. The Memorandum of Understanding specifically states that this will be 'a wide-ranging change process ... [which may] involve challenges to the existing cultures and systems of hospitals which will need to be openly acknowledged and constructively managed'. The Memorandum of Understanding goes on to say that 'the hospital's understanding and acceptance of [this] is the basis of participating in the HFH Programme and its continued participation in the programme is dependent on being able to demonstrate this understanding'. (Hospice Friendly Hospitals, undated-a: Section 6.2, 6.3). This agreement therefore allows the HFH programme to withdraw its supports if necessary, although given the programme's focus on supporting hospitals and developing strengths within them, it is likely that this would only be acted on in a case of last resort.

The benchmarking aspect of the Audit can also provide a pressure to promote implementation of the standards. The end-of-life care co-ordinator described one way in which this works:

The Audit gave us concrete information on end-of-life-care and indicators of how it could be improved in our hospital. It provided detailed information on specific aspects of care which were not known to us. This data in turn allowed us as a hospital set targets and key performance indicators. One example of this centred on death in single rooms. In the Audit we achieved 45 per cent of our deaths in single rooms. The Audit and Quality Standards gave us a mandate to look at how we could increase the number of deaths in single rooms. Following discussion with the Senior Lead in End-of-life Care and the Standing Committee, it was agreed to increase the number of deaths in single rooms to 50 per cent. [R8]

Each hospital also reports every three months on their progress vis-à-vis their performance in 2008–9 in the Audit, and is able to benchmark this information against the results of the hospitals that scored in the top 25 per cent for the relevant standard.²⁹ In this way the Audit data provide an element of competition between hospitals, which motivates each hospital to push forward the standards.

Sharing good practice between hospitals in meetings of the Hospice Friendly Hospitals Network was also reported to spur an element of competition between hospitals [R5].

Overall, however, compared to other standards frameworks examined in this NESC project, the HFH programme is not in a strong position to impose sanctions if a hospital does not engage effectively with implementation of the standards. This means that only the strengths-based pyramid of responsive regulation exists, while the counter-balancing regulatory pyramid, which Braithwaite and others (see NESC, 2011) argue is also needed for full implementation of standards, is not in place. This is an issue that will be returned to in Section 4.4.

4.2 Involving the Service User

This section looks at how the *Quality Standards for End-of-Life Care in Hospitals* take into account the needs and voices of service users. In these standards, an issue evident in all the areas examined under this NESC project is particularly clear, which is that the apparently detached individual service user is not actually a detached individual, but involved in and connected to a web of family and others. This is particularly evident at the end-of-life, as death is a social event, and involves both the dying person and those being bereaved. In addition, for end-of-life care, the patient and their family are service users; with the family becoming the focus of care following the death of their relative. These standards aim to support both the

²⁹ Each hospital knows how it is performing against the benchmarks, but not how the other hospitals are performing.

patient and the family, but at times it proves difficult to separate out the needs of the patient and the family, and examples of this are outlined below.

This end-of-life care standards framework also displays the strong tendency in many of the human service areas studied in this NESC project to take into account the views of service user representatives, rather than those of the service user him or herself.³⁰ This seems to be particularly the case for vulnerable service users. For these standards, the views of patient representatives were taken into account in the Audit and standards development process, while the standards outline that the views of the patient him or herself are to be taken into account in the provision of end-of-life care. These processes will also be outlined in the following sections.

4.2.1 Involving the Service User – The Patient

The key reason for the existence of the *Quality Standards for End-of-Life Care in Hospitals* is to ensure that the patient's experience of end-of-life care in hospital is improved. There is a focus on the patient in the standards themselves, and supports provided by the HFH programme help ensure that these are implemented. In addition, aspects of the patient's experience will have been captured in the Audit, by proxy, through the input of the patient's family. How these processes have involved the service user will be outlined in more detail in the following sections.

Focus on the Service User in the Development of the Quality Standards for End-of-Life Care in Hospitals

To help develop the standards, relatives were asked about the patient's experience of end-of-life care, during the *National Audit of End-of-Life Care in Hospitals in Ireland, 2008–9*. This means that the experience of the patient was captured by proxy, as it is the patient's representatives, rather than the patient themselves, who were consulted.³¹ The views of the patient may differ from those of their relative, so while the Audit process does give some indication of the views of the patient, it does place a limit on the extent to which the views of the patient were obtained and so able to influence the development of the standards.

However, one of the four high-level standards does focus specifically on the patient, and this will be outlined in the next section.

Focus on the Service User in the Quality Standards for End-of-Life Care in Hospitals

High-level standard three focuses on the patient, as outlined in Box 4.1.

³⁰ A failing that the methodology of this NESC project also suffers from. This was not intended, but became more apparent as the project progressed its work on how service users are involved in quality improvement of services. It is one of the learning points of this project.

³¹ As outlined in footnote 16 earlier, this is common in international studies of death and dying.

Box 4.1 **Focus on the Patient in the *Quality Standards for End-of-Life Care in Hospitals***

Standard 3: The Patient

- 3.1** *Communicating a diagnosis of a need for end-of-life care*
There is timely, clear and sensitive communication with each person, as appropriate, in respect of a diagnosis that s/he may be approaching or at the end of life.
- 3.2** *Clear and accurate information*
Clear and accurate information is provided as appropriate to the patient about his/her condition, treatment options, prognosis and care plan in a timely and culturally appropriate manner and in accordance with the patient's needs and preferences.
- 3.3** *Patient preferences*
The patient receives care in a manner and care setting of choice.
- 3.4** *Pain and symptom management*
Pain and symptom management for each individual patient takes full account of the multifaceted nature and individual experience of pain.
- 3.5** *Discharge home/out of hospital*
The patient is actively involved in discussions and decisions regarding admission, discharge home, or transfer to another setting for end-of-life care.
- 3.6** *The dying patient*
The particular needs of a patient whose death is imminent are assessed and provided for in a sensitive and culturally appropriate manner.

Source Hospice Friendly Hospitals (2010a)

Examples of how some of these standards are implemented are given below.

Communication of diagnosis, and accurate information

On standards 3.1 and 3.2, training and information booklets and other resources provide information for staff on how they can communicate diagnoses as sensitively as possible (see Section 3.5 above). The need to communicate sensitively with the patient was stressed in the case-study interviews, as this interview excerpt shows:

We talked a lot [when developing the standards] about communicating diagnosis ... In the old days it wasn't uncommon for a consultant on rounds to tell a patient that there was nothing else he could do for him. And the man's on his own in the bed at seven thirty in the morning and everybody walks away ... but sadly that was the norm in those days.
[R7]

Now, however, staff try to be sensitive to the particular patient's wishes around information on an end-of-life diagnosis:

One of the questions we would often ask at the beginning of a meeting [is] – are you the sort of person who likes to know everything [about a diagnosis]? Or will we just tell you a little bit about what’s going on? [R7]

Staff also try to break bad news to patients when they are accompanied by a relative or a friend, but it depends on what the patient wishes:

We have had a patient recently who would allow us to speak to no one about her condition ... she was given her bad news on her own and we told her everything about her treatment which was very complex, on her own. But that was her choice and I wouldn’t have dared go behind her back and phone her sister because I asked her and she wasn’t happy for us to do that. [R7]

This is one of the ways in which the blending of patient and family in an end-of-life situation is evident. One stakeholder reported that:

I also can remember twenty odd years ago as a student when patients were never told that they were dying but their husbands were, or their wives were, and they were told that it was best not to tell them, because they would die quicker ... And thankfully that’s changing ... I’ve had elderly patients saying to me please do tell me what’s going on. I want to know on my own what’s going on. I don’t want my family to influence what I know ... quite frequently the patient would say I want to be told on my own, and we have to accept this.³² [R7]

To support these developments, the HFH programme has produced an Ethical Framework to provide information on values and principles that are important considerations in end-of-life decision making.³³ Some of the eight modules in this framework are particularly focused on issues around breaking bad news, and the status of the service user. One of these modules is *The Ethics of Breaking Bad News*, which looks at the extent to which patients are fully told of ‘bad news’, and the role that doctors and families play in this. A second module, *Patient Autonomy in Law and Practice*, explores what is involved in respecting patient autonomy, and the process of informed consent in making decisions about treatment and care. These modules, and the interview excerpts cited above, indicate a move towards more open communication with the patient about the prognosis of their illness.

³² Even though relatives are not always happy about this, as one excerpt from an interview for this project shows: *Within our standards [setting focus] groups, the people there who were relatives of patients would have felt quite differently and would’ve felt they [relatives] should be told first. So having groups of people working together has its challenges!* [R7]

³³ See <http://www.hospicefriendlyhospitals.net/ethical-framework/>, accessed on 4 April 2012.

Culturally sensitive care

For standard 3.6, information is provided for staff on appropriate end-of-life care for those of different religions and cultures, as one stakeholder outlined:

We have an information leaflet on caring for patients of different faiths. [R7]

The sympathy card ... there's no religious icon or anything on it so we can send it to anyone without offending them. [R7]

A number of the Ethical Framework modules also make reference to cultural differences, with module 2, *The Ethics of Breaking Bad News*, specifically outlining that in many cultures of southern Europe, Asia and Africa there is a stronger emphasis on the role of the doctor and family compared to that of the patient, than in Ireland.

Pain and symptom management

There has been an increase in palliative support,³⁴ and management of pain, as this quote shows:

We've had a palliative care team here at the hospital, for about seven or eight years, I think. We've a palliative care consultant and clinical nurse specialists, and pain management has improved dramatically and everybody would say, yes, that it has. [R7]

However, this support is in place due to resources from beyond the remit of the HFH programme.

And was that as a result of the standards or something else? That was something that could have been here for a long time but there just wasn't funding ... pain not being addressed as well as it should [in the past], it wasn't really anyone's fault - you just didn't have the experts in situ, you didn't have the experts to refer to ... everybody's very happy to get the advice from Palliative Care these days, it's just the resources weren't there [in the past]. [R7]

This shows how increased resources in the wider healthcare sector support better end-of-life care.

4.2.2 Involving the Service User – The Family

There are a number of ways in which the input of the family as a service user is included in the development and implementation of the *Quality Standards for End-of-Life Care in Hospitals*. These are: including the perspective of the family in the

³⁴ This has occurred particularly since the National Advisory Committee on Palliative Care reported in 2001.

National Audit of End-of-Life Care in Hospitals in Ireland, 2008–9; including family representatives on the working groups devising the standards; the focus on the family in the standards themselves; and the supports from the HFH programme to implement these family-focused standards. All of these will be outlined in more detail below.

Including the Views of the Family in the Development of the Quality Standards for End-of-Life Care in Hospitals

First, families were asked about their experience of the end-of-life care of their relative, as part of the *National Audit of End-of-Life Care in Hospitals in Ireland, 2008–9*. The results showed that nurses and doctors rate the level of care given to a patient more highly than do relatives (and doctors rate it highest of all). Internationally, this is a common finding in such studies. The benchmark scores which were calculated from the Audit data and which the hospitals now aim to meet, were calculated using the mean score for each care outcome and input, as seen from the perspective of nurses, doctors and relatives (see McKeown *et al.*, 2010b). In these ways, the views of the families were incorporated into the Audit, which influenced the standards' development.

Second, there were patient representatives, including family, on the working groups that devised the standards:

I was part of the standards setting group ... there was me and there was the social worker and one other nurse, and maybe the other 7 or 8 people at a meeting were non-medical, non-nursing, non-hospital people ... I hadn't been a member of a group where you had patients before, or patients' carers, or relatives. And that was really good. Sometimes, their expectations were a bit [different to those of staff] ... and yet – we should be aspiring to meeting these expectations. [R7]

The involvement of patient representatives in the standards-setting groups helped ensure that the views of the family were better known to healthcare staff, and also reflected in the final standards. The draft standards were also put out for public consultation before they were finalised, and many groups and members of the public did respond to this call, and the draft standards were changed in a number of ways to reflect these inputs (Hospice Friendly Hospitals, 2010c).

Focus on the Family in the Quality Standards for End-of-Life Care in Hospitals

Families are focused on particularly in the standards themselves, with one of the four high-level standards entitled 'the Family'. Key issues covered in this section include communication with family members, supporting them, and responding to their needs before and after death (see Box 2.2 for details of all the standards).

Supports developed as part of the standards help hospital staff implement them, with examples given below.

Communication with Family Members

Under standard 4.3, the issue of breaking bad news to a family where a death is sudden or unexpected, has been debated by staff in the case-study hospital, and a booklet with guidelines on this was put together:

We put together guidelines on breaking bad news [before the HFH programme started], based on our own experiences. How do you tell somebody that his mum has died in the middle of the night? and you have to phone him because it's two in the morning and how do you get him in? And it's kind of talking about that and having the discussion on – do you tell him mum is dead already, or do you tell him she's dying? And then you're worried that he would have an accident with the car on the way in trying to get in – or what do you say? And it's kind of thrashing out that stuff. [R7]

In intern staff induction ... we would have done a session on breaking bad news. In many of the sessions I have done with nurses, I would say ... who knew the patient best? Who's met the relatives? And so discuss who might be the best person to speak to the family. [R7]

The *Final Journeys* staff development programme, the Ethical Framework module, *The Ethics of Breaking Bad News*, and the staff resource folder, also provide training and guidance on this issue.

Responding to the needs of a family after a death

Information for families on specific aspects of bereavement has also been developed as part of the standards:

Before [we had an information leaflet to give to relatives after a death] I was getting phone calls where people would say – I can't do anything without the death cert, I can't access any money without the death cert. How do I get the death cert? And you may have told them – but they're going to have forgotten because there was so much going on, on that day. [Relatives now] don't have to take it all in [at the time of death] ... it's information that's written down... [and you can] give them this to take away ... so that's really good and I think with HFH certainly there's more of an awareness around the need for communication with the patient's relatives. [R7]

We also encourage the ward within two weeks of a death to send out a sympathy card ... I would send them to families of my patients, or if somebody has died at home ... and people are just really delighted to get it from the ward. [R7]

4.2.3 How the Service User is Not Focused On

While the standards aim to improve end-of-life care in hospitals, most people are not dying in the place they wish, with many more preferring to die at home (67 per

cent³⁵) than currently do (25 per cent³⁶). However, the standards do include criteria that aim to change this, over the medium to long term. Standard 3.4 outlines how the patient is to be actively involved in discussion and decisions regarding admission, discharge home or transfer to another setting for end-of-life care. References to this are also included in the Memorandum of Understanding, which specifies that hospitals should 'identify, document and facilitate, to the greatest extent possible, the preferred place of care at end-of-life... taking whatever measures are required to facilitate effective communication and teamwork with community-based healthcare professionals and teams' (Hospice Friendly Hospitals, undated-a: Section 6.2). It was estimated in the Audit that up to 25 per cent of those who died in hospital could have died at home if appropriate supports were available (McKeown *et al.*, 2010b: 125). Actions suggested to facilitate this are that links be made between hospitals and appropriate primary and community care services, and that processes for rapid discharge planning in partnership with these services be put in place.

The HFH programme is actively progressing work on this. In August 2011, the programme engaged a 'pathfinder project manager' in the Cork area, to develop a project to enable more people die in or closer to their homes, and also to develop a network of care providers in home, hospice and hospital environments. In addition, the Primary Palliative Care programme, a joint programme between the Irish Hospice Foundation, the HSE and the Irish College of General Practitioners, has been initiated by the Irish Hospice Foundation. This aims to identify palliative care initiatives for primary care teams³⁷ caring for adults with life-limiting diseases in the community. It is overseen by a steering committee, whose members represent the HFH programme, the HSE, GPs, palliative care consultants, pharmacists, and public health nurses. The first phase of the programme produced the report, *Primary Palliative Care in Ireland: Identifying improvements in primary care to support the care of those in their last year of life* (Irish Hospice Foundation *et al.*, 2011), and the second phase, which commenced in 2012, is based on implementing recommendations from the report. The prioritised recommendations are to develop and implement a palliative care summary³⁸ for communication with out-of-hours services, and to create a system to assist primary care teams to identify patients with palliative care needs and respond appropriately.³⁹

Such an initiative may also reduce healthcare costs in the future, as the high level of inappropriate admissions to acute care at end-of-life is very expensive, and costs

³⁵ See McKeown *et al.*, 2010b: 38, citing Weafer and Associates, 2004.

³⁶ See McKeown *et al.*, 2010b: 37.

³⁷ Primary care is the 'first line' of healthcare, available in the community, from GPs and public health nurses, for example.

³⁸ This is a summary of a patient and carer's current condition and needs, which is initiated in primary care to communicate to an Out-of-Hours service, should they need to have contact with the patient/carer.

³⁹ See

http://www.hospice-foundation.ie/index.php?option=com_content&task=view&id=539&Itemid=310 accessed 30 March 2012.

are being unnecessarily incurred by an over-hospitalisation of the dying, with a resultant loss of resources to enable more people to die in or closer to home [R3] (See Section 4.5.6 for more detail).

In this way, the developers of the standards for end-of-life care in hospitals would ideally like to see less cases in which the *Quality Standards for End-of-Life Care in Hospitals* need to be applied, due to less people dying in hospitals, and more end-of-life care taking place outside hospitals.⁴⁰ This initiative is also an example of a focus on the needs of service users rather than on healthcare institutions, which is quite rare in Ireland, where many standards frameworks focus on the organisation delivering the service, rather than the person receiving it.

4.3 Learning

4.3.1 Introduction

This section will outline specific ways in which learning is incorporated into the *Quality Standards for End-of-Life Care in Hospitals*. Systems have been set up by the HFH programme to ensure that learning from experience is incorporated into each individual hospital's work; is shared between hospitals; feeds back up to the HFH management; and links to other national decision-making bodies. There is also an emphasis on learning in the overall approach of the HFH programme, and this will be described.

4.3.2 What is in the *Quality Standards for End-of-Life Care in Hospitals* to Promote Learning?

First, several specific standards aim to promote learning. These include learning for hospital management, and learning for frontline staff. On the former, standard 1.6 requires that 'end-of-life care in the hospital is continuously evaluated' (Hospice Friendly Hospitals, 2010a: 47). This means using Audit data to benchmark and identify priorities for improvement, collecting data on end-of-life care and reporting on it, and each hospital department identifying key performance indicators for end-of-life care. This is currently done through the collation of progress reports to be fed back to HFH management, and consistent use of Audit data to incentivise progress, as outlined in Sections 3.3.1 and 4.1.3 above.

Learning for frontline staff is evident in a number of standards. For example, standard 2.2 requires new staff to be inducted on end-of-life care; standard 2.3

⁴⁰ However, even if more people are supported to die at home, the standards would continue to be relevant for those with significant life-limiting illnesses, who typically have multiple admissions to hospital in the last year of life; and also to support good practice in communicating diagnoses.

requires education and development needs of staff relative to their roles in end-of-life care; and standard 2.4 requires staff education and training programmes on the standards (Hospice Friendly Hospitals, 2010a). How these are implemented was outlined in Section 3.5, and will be considered more in Section 4.3.4 below.

4.3.3 Learning Within the Hospital – The Standing Committee

Clearly, each hospital's Standing Committee and working groups are engaged in a process of continual learning through their work, as outlined in Section 3.3.1 above. There are also a number of specific tasks carried out by hospital Standing Committees that aid learning. One is that the hospital Standing Committee is informed of all complaints about end-of-life care and how they were resolved, so that it can take the learning from these on board:

If we have a complaint that involves the end-of-life, then [the hospital Standing Committee] would hear about that complaint, and the person dealing with the complaint will actually come to the committee and talk it through and say what have we done about it ... and what lessons have been learned, and how they've responded. [R8]

This helps to implement standard 1.13, which outlines that families are to be offered the opportunity to feed back on services, to 'inform service development and provision' (Hospice Friendly Hospitals, 2010a: 55), and standard 4.1, that feedback from families be acknowledged and noted.

The hospital Standing Committee also evaluates itself every year, through each member filling in an evaluation form. The information in these forms is collated for discussion at the committee's next meeting [R5].

4.3.4 Learning Within the Hospital – Staff Training and Development

The *Final Journeys* staff development programme outlined in Section 3.5 promotes learning in the hospital. This programme was developed because the Audit of end-of-life care showed that only 13 per cent of staff had received training in end-of-life care, and as Standards 2.3 and 2.4 aim to educate staff on end-of-life care, and put staff education and training programmes on the standards in place, respectively. One member of staff described the programme as follows:

I did it [the *Final Journeys* programme] just recently ... I was curious to see what it was like and it's actually really good. And it's multidisciplinary. We had secretaries, care assistants, physios and all grades of staff ... They're encouraging kitchen staff to go on it, some doctors have done it. It's there for all the staff. [R7]

The evaluation noted that very few medical staff had taken part in the programme (four out of 623 participants [Byrne & Murphy, 2011: 51–2]), but this is now being addressed by a newly developed third module to the programme, which is specifically for doctors and other clinical staff who have a role in breaking bad news [R4]. However, nearly 40 per cent of facilitators noted that it was difficult for staff

to be released to take part in the training. 23 per cent of participants had attended in their own time – which shows a desire on behalf of staff (and indeed of the hospital managers, for the remaining 77 per cent) to promote this learning. Also, as a number of hospital staff are trained to become facilitators of the programme, this again promotes learning on the importance of end-of-life care in the hospital, as these members of staff are likely to be particularly engaged with the standards. In the case-study hospital, 24 staff had been trained as facilitators by May 2011 (Byrne & Murphy, 2011).

Standard 2.2 also requires newly recruited staff to be inducted in end-of-life care. This process had been put in place in the case-study hospital:

I approached the facilitator of the corporate induction programme requesting a slot in it. This request was based on the need to let staff members know from the very outset the role they and the hospital play in providing good end-of-life care. We now have a thirty-minute slot solely dealing with the issue of end-of-life care and an overview of what we're trying to achieve. There's now a recognition that we need to be telling people that end-of-life care is a core part of our hospital business; that we have two patients dying every day in this hospital; that for every two people there's ten people directly affected by that; and that it's everybody's role. [R8]

This ensures that all new staff are learning about the importance of end-of-life issues and care in their hospital.

4.3.5 Learning Within the Hospital – Practice Development

Another important learning mechanism is the practice development post that the HFH programme has funded. As outlined in Section 3.7, practice development stresses the importance of culture change, aiming to change day-to-day work practices so that a person-centred approach becomes more deeply embedded in the culture of care. Stakeholders described it as:

Staff themselves looking at themselves, at their own day-to-day practice, how they care for patients and families and what becomes the norm without having to take the time to think about it, and how am I, and what's my role ... there's also that element of challenging yourself and there's that reflective piece, which is great. I think that's a really positive part of awareness-raising and changing culture. [R8]

[Practice development is] not full of rocket science but ... making people think about how they speak to people ... how they address people, how they speak to people, that sort of thing. It's very subtle, very effective. [R5]

A number of those spoken to during this research [R3, R4, R1] said that the processes used in practice development are actually the core of what it means to improve standards, because these processes allow staff look at how the patient

experiences care, and so help to change the culture of care, so that it becomes more person-centred. Too often standards focus on reaching a ‘technical’ end goal, without looking at the existing patterns of work, or the ‘people side’. The ‘people side’ means looking at how people work together, how they share power, how they manage conflict, etc. These issues must be grappled with to achieve good quality services, but they are not often focused on. It was considered that new standards that are established without corresponding work on how staff relate to each other, and existing patterns of work, will not be implemented effectively.

Practice development promotes less separation of management from staff, as it deliberately involves all staff, from healthcare assistants to clinical nurse managers. This allows the perspectives of the different groups to be presented to each other, which aids learning, also. This is line with Gawande’s (2010) argument that communication that stimulates discussion among team members, and gives all team members the authority to raise questions, helps establish a higher standard of performance. These practice development methodologies also echo aspects of the Quality Service Review (QSR) process,⁴¹ where a range of stakeholders review provision of a service to a client, and outline their perspectives and the reasons why they made certain decisions, to each other. As the QSR stakeholders are drawn from diverse backgrounds, they often need to articulate assumptions that would remain unstated in more homogeneous settings (NESC, 2011).

However, it can be difficult to implement practice development across the hospital, as one interviewee said:

We haven’t got the complete structure that ideally we would like to have here in the hospital in terms of the number of wards engaged, the staff necessary, that the practice development programme would have stated should be engaged. [R5]

4.3.6 Learning Within the Hospital – Changes in the Culture of Care

Following on from some of the issues raised by practice development methods, one stakeholder [R4] described how implementing the standards is very much about changing attitudes and behaviours, and empowering staff, by giving them space to reflect on and change their work. And hospital staff spoken to did feel that the resources provided by the programme were helping to embed a culture of compassion and respect more strongly in the hospitals.

It’s about cultivating a culture of compassion in end-of-life care. We’ve all been trying to do that but it’s great to have the little extras like the signs, like the bags, all those practical things, that make it look like

⁴¹ Quality Service Review (QSR) is an in-depth case-review method involving multiple stakeholders, which uses a performance-appraisal process to assess how service recipients benefit from services and how well service systems address their needs. See NESC, (2011), Box 2.9.

there is true compassionate caring, and that there's been a bit of thought put into it. [R7]

It was felt that several of the practical tools produced by the HFH programme have allowed greater respect for the deceased person and their families, as one staff member outlined.

The [handover bags for the deceased person's belongings] also make people more aware of what they put in the bag, I think – like not half-eaten bars of chocolate or dirty laundry or whatever. There is a little cognisance about being respectful, of packing it properly.

[The symbol for a death on each ward] – it's just to warn people that there has been a death on the ward so that there is that little, respectful quiet. It's never totally quiet but just that it's a more respectful environment.

When I came to work here I thought that the trolley carrying the remains to the mortuary looked very disrespectful ... now it gets covered in the purple drape [produced by the HFH programme]. And it's funny because now when you meet one on the corridor people are generally more respectful and do just kind of stop in their tracks. [R7]

4.3.7 Learning Within the Hospital – The Co-ordinators

The end-of-life care co-ordinators, and the practice development co-ordinator, all play an important role in promoting learning in the hospital. The co-ordinator interviewed in the case-study hospital described her job as:

I kind of see myself as being a catalyst; you know a motivator – sometimes providing direction, sometimes a decision maker, as well as moving things on. [R8]

As an example, she outlined the process when looking at a specific standard and how it could be met:

Sometimes it's difficult to get staff focused on how they could meet the standard. My role is to get people thinking about what the possibilities are and how we can use the expertise of the group members to meet the standard. We recently developed an information leaflet as it was identified that bereaved families were looking for practical information about what happens next after a death has occurred. This then devolved to the communications group, who [then] developed an information leaflet for families. [R8]

This involves working with many different staff groups, and across divisions, in the hospital. This means that the role of the end-of-life care co-ordinators is akin to what Silbey *et al.* (2008) called the 'sociological citizen', an individual who sees their work and themselves as a link in a complex web of interactions and processes, and so sees and acts beyond their institutional boundaries or silos, as 'networking

individuals'. This enables them to work by trial and error, to try to connect different organisations and arrangements, and to adopt a problem-solving approach. They work alongside and in collaboration with existing conventional processes and institutions (see NESC, 2011). Such innovative approaches promote organisational learning.

4.3.8 Learning Within the Hospital – Pilot System of Audit and Review of End-of-Life Care

The HFH is also piloting a new system of Audit and Review of End-of-Life Care to promote learning and continuous improvement on end-of-life care, both within hospitals, and in other care settings (such as hospices, community hospitals, residential care centres, and the home) (McKeown & Bowen, 2011). The new System of Audit and Review of End-of-Life Care is underpinned by the *Quality Standards on End-of-Life Care in Hospitals*. It also builds on the baseline *National Audit of End-of-Life Care in Hospitals in Ireland, 2008–9*, and simplifies it, by identifying eight 'domains of care' that are particularly important aspects of quality in end-of-life care. These are:

- Care planning,
- Preferred place of care,
- Pain and symptom management,
- Single room,
- Team working,
- Facilitating relatives,
- Moment of death and after, and
- Staff training, development and support.

The System of Audit and Review of End of Life Care will look at the end-of-life care of a randomly selected person in a care setting, and ask a number of questions in relation to their care in the last week of life, under each of these eight domains. Each question will be put to staff and relatives. Questions to be asked include, for example, 'Did this person die in a single room?' and 'How well did the healthcare team manage the person's symptoms in the last week of life?' And 'Imagine if this person was you. Would you find it acceptable to be cared for the way this person was cared for at the end of life?' The answers to the questions will be recorded on

a computer system, with an anonymous identifier for each deceased person, so that the views of staff and relatives on the end-of-life care of that person can be compared.⁴² One randomly selected death each month in each participating care setting is to be audited in this way – for example, the first death in every month. An independent assessor will also assess a proportion of the audits conducted.

For learning within the hospital, a particularly important part of this system of audit and review is a meeting of relevant healthcare staff, open to all those who were involved in any aspect of the person’s care in the last week of life. This consists of doctors (including GPs), nurses (including public health nurses), healthcare assistants, therapists, pastoral care staff, catering staff, mortuary staff, etc. At this meeting, which is organised and facilitated by an experienced member of staff, the answers to each question are discussed and recorded. This meeting is expected to generate a process of quality improvement by providing an opportunity for healthcare staff to review and reflect on actual cases of care and to identify areas of good practice, as well as areas where improvements in care could be made. To assist this, the final question posed in the audit is – ‘Reflecting on this audit, are there any areas where improvements could be made?’ (McKeown & Bowen, 2011: 17).

This new system of audit and review will assist such learning, but, importantly, the manual outlining the process to be undertaken (McKeown & Bowen, 2011) also underlines the key role of leadership, both collective and individual, in mobilising stakeholders to continuously improve.

4.3.9 Learning – Links Between Hospitals

The Hospice Friendly Hospitals Network

The Hospice Friendly Hospitals Network (previously known as the Champions for Change Network) was set up to share learning and good practice on end-life care in acute hospitals, and to suggest to the HFH programme the type of supports that should be made available to those championing the programme in the hospitals. The establishment of the network was suggested by the Chair of the Standing Committee at one hospital. Its membership includes the Chairs and Deputy Chairs of the hospital Standing Committees, the public interest representatives of those committees, and the end-of-life care development co-ordinators in the hospitals.

It was described by interviewees as follows:

You’re looking at the chair of the Standing Committee [in this hospital] hearing what’s happening in Wexford General Hospital or Mayo General Hospital or the Mid West Regional Hospital and they’re hearing about the positive practices that are done there, and bringing that back

⁴² Demographic data, and other information such as length of stay in hospital, type of ward, etc., will also be recorded. It will be possible to compare all the data across different hospitals, allowing benchmarking.

to the Standing Committee [here] and saying – could we implement that here? – that’s the idea. [R8]

What is really useful is that you’ve got other hospitals engaged in the network, and you can say – this is the kind of information leaflet they’ve got, and [we can] use that information [for ours]. [R7]

The network meets at least three times a year, starting with a working dinner with a keynote speaker, and continuing on with a workshop the next day, and displays of literature on interesting practices. This format promotes both formal and informal sharing of learning.

The HFH programme funds the network, and to help it function effectively and remain relevant, has put a number of requirements in place. For example, a Network meeting cannot proceed unless at least eight hospitals are represented at it. If a chair or deputy chair is unable to attend a meeting, an alternative representative has to be agreed in advance with the Network convenor and the manager of the HFH programme. All discussion items must end with a decision, action or definite outcome, where appropriate (Hospice Friendly Hospitals, undated-c). The Network is seen as a very effective learning method:

[The Network] works a treat ... and for the sake of a few bob a year ... you gain such a lot, you know ... after they have a network meeting, there’s bits and pieces [of information] coming from all angles. [R5]

This process has helped people move from being very protective of their own work to sharing it.

The Irish Hospice Foundation has decided that the Network is one of the HFH supports that it will continue to fund now that Phase 2 of the programme has ended (see Section 5.3 for more).

Other Mechanisms That Share Learning Between Hospitals

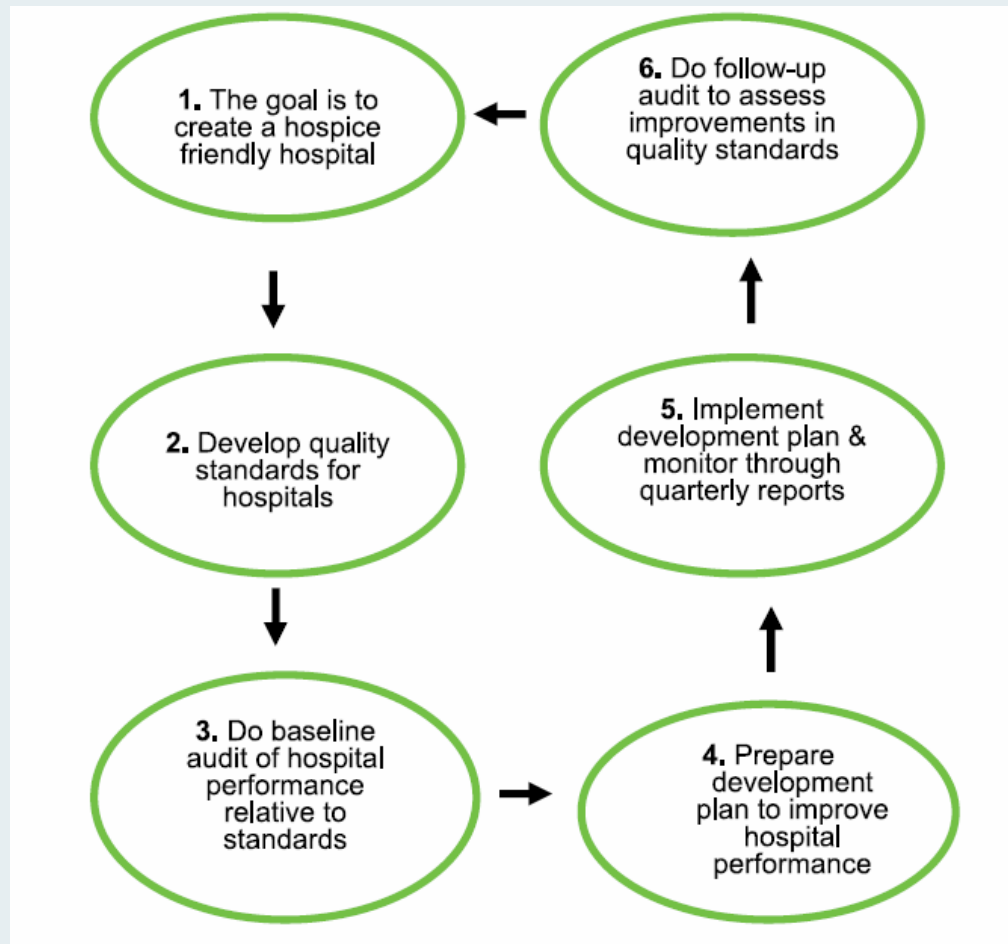
As outlined in Section 3.7 earlier, the key person working on practice development in each of the hospitals taking part in that programme meets every six weeks with their counterparts from the other participating hospitals, for a day of learning and reflection. This represents another way of sharing learning between hospitals. This process is assisted by the practice development co-ordinator, who works with a number of hospitals. Some of the end-of-life care co-ordinators also work with a number of hospitals, and this also assists sharing of learning between them. All of the end-of-life care co-ordinators also meet at least monthly [R4], which provides a mechanism for them to share learning with each other (see also Hospice Friendly Hospitals, undated-a).

4.3.10 The Focus on Learning in the HFH Programme

Overall, the HFH programme places a particularly strong emphasis on learning, monitoring and evaluation. A key way in which this is evident is the focus on the Audit in the programme. A diagram from McKeown *et al.* (2010b), which maps the

quality improvement process for end-of-life care, outlines this well. This diagram is reproduced below in Box 4.2.

Box 4.2 Map of the Quality improvement Process for End-of-Life Care



Source McKeown *et al.* (2010b:43)

The diagram shows the emphasis in the programme on using baseline data from the Audit to devise plans for improvement, and to monitor progress towards them. This allows a learning and diagnostic monitoring system to be put in place for the programme's implementation.

A second key learning element in the HFH approach is constant review of mechanisms used to implement the programme, to ensure that they are having the impacts hoped for. Examples can be seen in the Memorandum of Understanding (Hospice Friendly Hospitals, undated-a), where there are references to monitoring and review of the hospital Standing Committees, of the HFH National Steering Committee, and of progress in implementing the standards in each participating hospital. Similarly, the HFH plans to review progress of the practice development

project when the first phase of it is complete, and to produce a report with a baseline, interim and final assessment of the practice development process. The *Final Journeys* staff development programme has also recently been reviewed to ‘determine how well it met its stated goals and what additional modifications and developments were required’ (Byrne & Murphy, 2011: 6). These approaches are triple-loop learning and diagnostic monitoring in practice, as advocated by several researchers in order to improve performance (see NESC, 2011).

Finally, another key learning element is the emphasis in the programme on culture change, as outlined earlier in Sections 4.3.5 and 4.3.6.⁴³ This means challenges to the existing cultures and systems of hospitals (Hospice Friendly Hospitals, undated-a:5), which involves learning and change.

Some of these learning approaches may be influenced by one of the funders of the programme, Atlantic Philanthropies, which emphasises constant learning in its approach. Atlantic Philanthropies believes:

that a strategic approach to learning improves how we learn and how our grantees learn ... We are committed to learning from our grant making efforts: we want to know what is working, what isn’t, and we want to understand why. We develop a range of evaluation designs and methods that reflects the variety of approaches our grantees use to achieve their objectives ... we have a dedicated team that is focused on providing direct support to grantees by advising them on effective planning, strategy, organisational development and continuous evaluation.⁴⁴

Atlantic Philanthropies also want to ‘shar[e] useful, credible lessons that help other funders, policy makers and practitioners work effectively’, and in line with this, the HFH programme has published a wide range of reports, guidelines and booklets on the process of designing and implementing the standards, all of which are available on the programme’s website. Some of these publications are particularly focused on sharing learning and experience. For example, the process of designing the Audit has been written up (see McKeown, 2008), and several of the reasons for writing this manual are related to systemic learning, as its author outlines in the introduction.

In addition to this learning approach adopted by the management and funders of the HFH programme, there are a number of operational mechanisms set up to support learning within the HFH programme management.

First, the HFH programme is managed on a day-to-day basis by operations managers based in Dublin,⁴⁵ and co-ordinators at regional level. There is also a technical

⁴³ Indeed one of the five publications based on the Audit of end-of-life care is focused specifically on the culture of end-of-life care in hospitals (McKeown *et al.*, 2010a).

⁴⁴ See <http://www.atlanticphilanthropies.org/strategic-learning> accessed 30 March 2012.

⁴⁵ Following the end of Phase 2 of the programme in April 2012, it will be managed by one operations manager.

advisory team, with experts in palliative care, training, communication, evaluation, and the design of healthcare buildings. This all provides learning to management to support development and implementation of the programme.

Second, the end-of-life care co-ordinators provide three-monthly progress reports to the HFH management team. As one co-ordinator explained:

There's a standardised framework for the progress reports which has been set by the Programme Management Team in the HFH Programme. The progress report outlines in detail the developments that have taken place in the previous three-month period and specific information on how the *Quality Standards in End-of-Life Care* are being met. [R8]

The co-ordinator of practice development work in the acute hospitals also reports to the HFH.

These mechanisms therefore provide learning back to the HFH programme management.

4.3.11 Learning – Linking to National Organisations

National Council of the Forum on End of Life

The HFH links with national organisations in a variety of ways. First, at a very broad level, the Irish Hospice Foundation has established the National Council of the Forum on End of Life, which has a much broader remit than the HFH programme. This Council wants to improve healthcare, legal, ethical, financial, educational and administrative aspects of end-of-life in Ireland. It is currently engaged with a work plan involving ten main areas,⁴⁶ one of which is standards and regulation. Membership of the Council includes staff from the Department of Health and the HSE, and members of the HFH National Steering Committee and the Hospice Friendly Hospitals Network. This provides opportunities for learning from the HFH programme and the standards implementation process to be spread to this larger group at national level⁴⁷. The Council also considers the *Quality Standards for End-of-Life Care in Hospitals* and the Audit in carrying out its work.

HFH National Steering Committee

As noted in Chapter 1, at a macro level, the HFH is overseen by a National Steering Committee. The National Steering Committee of the HFH Programme was established in October 2006 to promote co-ordination of the work of the programme. Reviews of membership and functioning are undertaken at the end of

⁴⁶ The ten work plan areas are listed at <http://www.endoflife.ie/alist/work-plan.aspx> accessed 10 April 2012.

⁴⁷ See <http://www.endoflife.ie/alist/patrons-and-panel.aspx> accessed 4 April 2012.

each year. At first, membership of the National Steering Committee comprised representatives from a variety of public and private organisations, from Ireland and overseas, including hospital doctors, nurses, GPs, patients, HIQA,⁴⁸ the HSE, the Department of Health and Children, the Irish Hospice Foundation, and a journalist. This provided links between the HFH programme and a number of national organisations, and was useful in Phase 1 of the programme, when the standards were being developed. However, over time it was noted that there was a decline in participation by members. So in late 2010, the HFH programme decided to alter the composition of the National Steering Committee (see Taylor, 2011). The Committee has now been reformed with the Irish Hospice Foundation and the HSE as the stakeholder organisations, and with membership comprising four representatives from each of the four HSE regions, who are – a chair of a Standing Committee, a senior manager or end-of-life care co-ordinator, a public interest representative, and a member of the network of community hospitals (see below). This allows the Committee to better steer implementation of the standards.

The revised National Steering Committee membership more closely matches that of the Hospice Friendly Hospitals Network (which showed increased participation, whilst participation in the National Steering Committee declined). The work of the Network and of the National Steering Committee are now more strongly linked. Some of the members of the Hospice Friendly Hospitals Network are now also on the new National Steering Committee. The network also links into the National Steering Committee by having its meetings either directly before or after the meeting of the National Steering Committee [R5]. This allows the discussions of each group to be linked to the other, and provides another mechanism for learning.

Day-to-Day Links to the HSE

The HSE has been a partner of the HFH programme since its inception, part-funding it, and also being a signatory on the Memoranda of Understanding between the hospitals and the HFH. There are several operational links also. One is shared staff. For example, the practice development co-ordinator is a member of HSE staff seconded to work with the HFH programme, and she is also on the national group in the HSE that is starting to bring together examples of practice development with a view to developing a national focus for these. She also reports to both the HFH, and to senior staff in the HSE who are responsible for promoting practice development throughout the health sector [R1]. This helps to spread learning from this programme into the HSE.

Another example of how the HFH is increasingly working with the HSE is through their joint work on the Primary Palliative Care initiative (described in Section 4.2.3).

⁴⁸ HIQA, the Health Information and Quality Authority, is the independent authority established in May 2007 to drive continuous improvement in Ireland's health and social care services. It reports directly to the Minister for Health.

And similarly, the Network of Community Hospital in the Greater Dublin Area,⁴⁹ for quality of life at end-of-life, has been set up to facilitate collaboration for end-of-life care improvements at policy and planning level. The membership represents community hospitals/units, acute hospitals, HSE local health offices, HIQA, specialist palliative care services, primary care services, and voluntary organisations in the Dublin area (see Hospice Friendly Hospitals, undated-d). This helps spread learning at regional level.

4.4 Devolving Application of the *Quality Standards for End-of-Life Care in Hospitals* to Local Level

In this section, the key actors involved in driving the standards regime, and their respective roles, are outlined. This is followed by a consideration of accountability in the standards regime, and innovation within it.

4.4.1 Who Are The Key Actors, and How Are They Involved?

The key actors driving this standards regime are the hospitals, the HFH programme, and the HSE. The Department of Health and HIQA are, however, more peripherally involved.

The hospitals buy in to the vision and supports offered by the HFH, set up a Standing Committee to co-ordinate implementation of the *Quality Standards for End-of-Life Care* within the hospital, prepare a development plan on end-of-life care and link this to the hospital service plan, involve senior management, and support end-of-life care training and implementation. The commitment and work of hospital management and frontline staff are key in driving implementation of the standards at local level.

The HFH programme has developed and driven this programme on a purely voluntary basis, and has worked to ensure that key organisations who can promote its ethos in practice are facilitated to do so, and involved in the development and implementation of these standards. The HFH has worked with the HSE throughout, as well as many other key organisations and advisors. This approach is an example of Sparrow's (2000) 'partnerships with a purpose', whereby relevant resources come together with a clear purpose, to fix a problem. The HFH is the catalyst organisation in this process, and, drawing on the concept of the 'sociological citizen' (see NESC, 2011), it can be seen as a 'sociological organisation' – an organisation that sees its work and itself as a link in a complex web of interactions and processes, and so sees and acts beyond its institutional boundaries or silos, as a 'networking

⁴⁹ As there are a large number of community hospitals in Ireland, it was decided to focus resources in one area first, which is why the network is currently operating in Dublin only.

organisation'. This enables it to work by trial and error, to try to connect different organisations and arrangements, and to adopt a problem-solving approach. It works alongside and in collaboration with existing conventional processes and institutions (NESC, 2011). The HFH is very innovative in how it works, forming links, and learning and developing supports, to help it bypass the fact that it does not have 'hard power' to enforce its standards. This is a form of smart regulation, with this non-State body promoting and implementing a standards or regulation regime. The HFH seems similar in some way to the Forest Stewardship Council (FSC), which is establishing a global environmental standards setting system for forest products (see Overdevest & Zeitlin, 2011, for more on the FSC), based entirely on third-party initiative. The FSC relies on consumer sanctions and boycotts for its successful operation, with no government involvement. Gunningham and Sinclair (1997) do, however, note that governments could play a role in supporting the FSC, through e.g. formal endorsement, or the FSC being a factor to consider in government procurement policies.

This raises the issue of the involvement of State bodies in this end-of-life care standards regime. The HSE is a partner in the HFH programme, and is involved in many ways, through the sharing of staff, through being a signatory on the Memoranda of Understanding between the hospitals and the HFH, through its representation on the National Steering Committee, and through co-production of joint policies (e.g. that on primary palliative care). In this way, the standards regime is supported by, and familiar to, the HSE. This may help sustain the learning from the programme since funding for Phase 2 of the programme ceased in April 2012 (see Section 5.3 for further discussion on this issue).

However the Department of Health is not strongly involved. A representative from the Department was a member of the original HFH National steering committee, but the revised National Steering Committee does not include Departmental representation. One stakeholder [R10] suggested that the Department is happy for the HFH standards to be developed and progressed, but is not actively involved in this process. It was suggested that this was due to the pressures on the Department of Health to introduce standards already committed to by government (such as those drafted by HIQA for people with disabilities, children, etc.), and that it did not have adequate resources to devote to implementation of standards, such as these, which were not subject to a government commitment for implementation. This does reduce the strain on scarce regulatory resources, one of the benefits of smart regulation (see NESC, 2011). However, drawing on the suggestions of Gunningham and Sinclair (1997) the Department of Health could play a role in endorsing these standards, or rewarding hospitals that successfully adopt them through existing procurement and funding-allocation processes. Gunningham and Sinclair (1997) show that while the FSC is entirely third-party based, this is unusual, and they argue that government facilitation of second and third parties in regulation means their potential as quasi-regulators is most likely to be realised.

HIQA is involved in the HFH programme to some extent, as the standards were developed in consultation with them, and they were represented on the original steering group for the HFH programme. They were also heavily involved in the development of the pilot *National Audit of End-of-Life Care in Hospitals in Ireland*,

2008–9 (see Section 4.3.8). The *Quality Standards for End-of-Life Care in Hospitals* are also listed as a resource in HIQA's (2012) recently published *National Standards for Safer, Better Healthcare*, which apply to all healthcare settings. More specifically, Standard 1.7.3 in these requires service providers to put in place mechanisms to support service users during vulnerable stages of care, such as when approaching the end of life. In addition, the HFH end-of-life care standards complement the provisions on end-of-life care in HIQA's *National Quality Standards for Residential Care Settings for Older People*.⁵⁰ However as HIQA is empowered to set quality standards and drive continuous improvement in health and social services in Ireland, it may be in a particularly apt position to look at how the end-of-life care standards can be more comprehensively recognised by State bodies at national level.

So there are links at national level between the HFH programme and its participating hospitals, the HSE, HIQA, and the Department of Health – all the key organisations involved in developing and implementing national standards in healthcare, and in care for older people. This helps to promote the vision of the HFH *Quality Standards for End-of-Life Care in Hospitals*, and broaden knowledge of the development and implementation of these standards among the organisations that are in a position to promote their sustainability. However, given that Phase 2 of the HFH programme is now over, these national organisations may need to take stronger steps in future to ensure that the momentum and innovation of the HFH programme is sustained. This is an issue that will be returned to in the final chapter.

4.4.2 Accountability

In this section, two aspects of accountability in relation to implementation of these standards will be outlined. These are what could be termed 'internal accountability', which is accountability of the implementing hospitals to the HFH; and 'external accountability', which is accountability of implementing hospitals and the programme to external organisations representing society more widely, such as government bodies.

Internal accountability is required in a number of ways. Two key mechanisms are the Memorandum of Understanding, and requirements for the Hospice Friendly Hospitals Network.

'Internal Accountability' – The Memorandum of Understanding

The Memorandum of Understanding signed between the Irish Hospice Foundation and the hospital ensures that there is senior level buy-in to the standards in the hospital. As outlined in Section 3.3, senior management have to sign the Memorandum of Understanding with the HFH, and responsibility for implementing

⁵⁰ Standard 16 requires residents to receive end-of-life care that meets their physical, emotional, social and spiritual needs, and respects their dignity and autonomy (see HIQA, 2009).

the standards is to rest with a designated member of the hospital's senior management team. In the case-study hospital, the Director of Nursing is the chair of the Standing Committee, and the Memorandum of Understanding is signed by the CEO and a number of other senior managers of the hospital. This ensures that implementation of the standards is driven at management level. As the Director of Nursing is also on the hospital board, this provides a direct link between the standards and senior management discussions. The end-of-life care co-ordinator said:

I do think it's very important that there was that kind of top-down structure, that there was buy-in from the management ... so that those managers are kind of saying – this is what we're doing as a hospital ... that gives it an impetus and support. [R8]

The Memorandum of Understanding also specifies the broad conditions under which the hospital will continue to participate in the programme (see Section 4.1.3), which helps to ensure accountability.

Various other reporting arrangements to ensure accountability are also specified in the Memorandum of Understanding – for example, the end-of-life care co-ordinator in each hospital must regularly report to the hospital CEO or similar, and meet all members of hospital management teams who have responsibility for end-of-life care on a quarterly basis. The co-ordinator also must prepare three-monthly progress reports, to be made available to the HFH management and National Steering Committee, among others (see Hospice Friendly Hospitals, undated-a).

And, as outlined in Section 3.3.2, the HFH template for the development plan includes the name of the person responsible for implementing the action to implement each standard.

'Internal Accountability' – The Hospice Friendly Hospitals Network

Another area in which the HFH ensures there is accountability is in the operation of the Hospice Friendly Hospitals Network. As outlined in Section 4.3.9, the HFH stipulates that all discussion items at the Network meetings must end with a decision, action or definite outcome, as appropriate; and that if the chair or deputy chair of a Standing Committee is unable to attend a meeting, an alternative representative has to be agreed in advance with the Network convenor and the manager of the HFH programme.

External Accountability

While the HFH programme does ensure a level of internal accountability with hospitals receiving their support to implement the standards, there is no accountability for implementation with an external body, such as a government organisation, or regulation devised on behalf of government, which could provide a stronger degree of accountability [R4]. Participation in the programme is voluntary, and so some hospitals do not take part. While some may have decided not to take part in the programme as they already have similar processes in place, others may feel that they do not have enough time or financial resources to take part, even

though there may be a need to increase the quality of their end-of-life care. On the positive side, almost 80 per cent of public acute general hospitals are taking part in the programme, but the lack of external accountability means that the reach of the programme is not as wide as it could be.

Perhaps more importantly, not all standards are being progressed as much as hoped for. Some key issues that hospitals are having mixed success with include: how to recognise when patients are dying; how to talk to people who are dying; how to ensure there is adequate staff available; training of staff not being recognised as a priority area; prioritising of single rooms for the dying; the condition of mortuaries; and end-of-life care in A&E departments [R3, R4]. As will be outlined in Section 4.5 of this chapter, the pressures of government cutbacks in particular have an impact on the ability of hospitals to ensure staff availability, for both care and training; to increase the proportion of single rooms; and to upgrade mortuaries. For example:

The mortuary is in a bad state of repair ... [we're] pushing even to get funding to upgrade it ... it's been on the agenda for every meeting [of the Standing Committee] for the last two or three years, but unfortunately not a lot has happened to improve it. [R7]

It is possible that progress on these issues might be slower as the standards are not mandatory.

Mandatory or Voluntary?

Staff members in the case-study hospital wondered how useful it would be to have the *Quality Standards for End-of-Life Care in Hospitals* made mandatory, with a variety of opinions evident:

I prefer to see them voluntary. I think people would work better with them. Compulsory is like a stick to beat you with. I prefer people on board than not ... we need to bring people along with us and not impose the standards. [R5]

I don't think they should be mandatory because I think you will get people's backs up. [R7]

In contrast, another member of staff thought that both buy-in and a method to ensure focus on the standards (such as them being mandatory) would be helpful:

I have to say I'm kind of torn ... I like the voluntary nature of the standards and the kind of buy-in that this receives from staff. However, let's say that the standards were tied in with licensing or accreditation. I wonder would it focus minds a little more? Will people that are not necessarily engaging that maybe should be engaging more – be more focused or engaged? It may mean that their department would then be put under the spotlight by the CEO ... I do think having weight behind some standards would help. It would endorse the work and would probably focus minds somewhat. The challenge with the voluntary nature of the standards [is] that some things could be very much put

on the long finger. However, if it becomes mandatory then the response could be ...‘No we need that as there could be a financial penalty on the hospital in terms of the budget.’ This may mean that there would be a different incentive and it would be done. [R8]

While the views of staff differed on this, the literature on responsive regulation (NESC, 2011) suggests that a balance of regulatory requirements and strengths-based supports are most useful in progressing standards as far as possible.

4.4.3 How Much Scope and Innovation is Possible?

To move onto the issue of innovation and the scope for this in the *Quality Standards for End-of-Life Care in Hospitals*, it is clear that this standards framework encourages innovation. Some examples are provided here. First, the standards themselves are not prescriptive, with outcomes statements that do not specify how the standard should be reached. Instead it is left to each hospital to put in place mechanisms that they consider appropriate to their organisation, in order to implement each standard. This is valued by staff, as follows:

If you don't work in the area it's very difficult to tell people [what they should be doing] ... You do have to be sensitive in supporting those people doing that job ... when we brought out our own guidelines [on breaking bad news] we sent a copy to all the consultants, and we got some great feedback and I think that people were happy that we weren't telling them how to do it ... it's not meant to be prescriptive, merely a guideline on best practice. [R7]

This member of staff and of the hospital Standing Committee pointed out that it was important that a standard would allow for variation, depending on the context, taking the example of the standard to increase the proportion of people dying in single rooms.

I have mixed views on [the standard about people being allocated single rooms when they are dying]. There are some patients who hate to be in single rooms because ... [they] might feel vulnerable and frightened. And I'd have a number of patients with no family who might be very lonely. And some patients will beg you not to put them in a single room because they've seen a few people go into single rooms and not come out ... so each case is different. [R7]

A second example of how the HFH approach is not prescriptive is that while the HFH has drawn up a template to help hospitals develop their end-of-life development plan (see Section 3.3.2), the content of that plan and how it is implemented is left to each individual hospital. In fact, the Memorandum of Understanding is even more specific on the autonomy of the hospital, with each hospital responsible for developing and implementing policies and procedures to inform and guide the end-of-life and bereavement care (Hospice Friendly Hospitals, undated-a). This can be seen in the resource folder for end-of-life care in each hospital (see Section 3.4.2), which has space for both HFH material and hospital-specific material to be included

(HFH, undated). The comments of staff indicate that hospitals do develop their own guidance and procedures. For example:

The HFH Programme developed an end-of-life care resource folder which contained best practice guidelines and published research in different aspects like advanced care planning, breaking bad news – and then we as a hospital group are putting in our own policy and procedures. [R8]

The Standing Committee was also reported to allow innovation, as follows:

One of the things that we're looking at ... which is spearheaded by the Standing Committee is that we've written a policy on plaques and memorials, and we're having a sort of memorial garden. So that's ... innovation that comes from [the hospital Standing Committee]. People [on it] go off and they'll do some work and come back to you with the ideas. [R5]

A further way in which the HFH supports innovation is through the Hospice Friendly Hospitals Network, which specifically facilitates sharing of innovations developed by different hospitals.

4.5 Addressing Costs While Improving Quality

In this section, the issue of how to balance improvements in quality with cuts in resources will be considered.

The *Quality Standards for End-of-Life Care in Hospitals* draw on the issues that the Audit of end-of-life care (McKeown *et al.*, 2010b) identified as improving the quality of care and experience of the dying person and the bereaved. Therefore implementing the standards will improve the quality of end-of-life care. So it is useful to also consider to what extent implementing the standards can be associated with costs and/or savings. First, the key costs of implementing the standards will be outlined, followed by international evidence on the costs and quality of implementing practices that are advocated in the standards. Then, the impact of recent cuts in resources on implementation of the standards will be presented, before summarising these findings.

4.5.1 What Are the Costs Associated with Implementing These, and Other Such Standards?

The HFH programme has a budget of €10 million over five years, which has been used to develop the range of supports described in this report, such as the standards themselves, advisers and co-ordinators on end-of-life care, and other resources to implement the standards. Interviews with hospital management and staff show that staff time has also been contributed to the standards development and implementation, as well as other smaller amounts of funding sourced locally

(see Section 4.5.8). No figures are available quantifying either the value of this time or of local funding sources.

However, there are significant amounts of data from international studies on the cost and benefit of implementing aspects of the Irish *Quality Standards for End-of-Life Care in Hospitals*. Most of these international studies look at the cost and quality outcomes arising from provision of palliative care, and hospice care (both at home and in the community). These types of care are more specialist than the end-of-life care advocated by the Irish standards. Nevertheless, there are overlaps, as palliative care and the *Quality Standards for End-of-Life Care in Hospitals* both involve, for example, better communication with patients and their families at the end-of-life; discussion about the patient's preferred treatment; use of palliative care services; involvement of multi-disciplinary teams in care; etc. Due to this it is possible to assess costs and benefits of implementing some of the requirements in the Irish standards.⁵¹ Overall, it seems that implementation of several of the HFH standards would not only improve quality of care and service user satisfaction, but could also generate significant cost savings. Information on these findings will be outlined in the following sections, and summarised in Box 4.3, in section 4.5.7.

4.5.2 Better Communication and Discussion with Patients at End-of-Life

A number of studies show the value of communicating a diagnosis of end-of-life, and of facilitating discussions on what this means for treatment of the patient. For example, in a US study (Gilmer *et al.*, 2005), an ethics consultant facilitated discussions between a group of 552 patients⁵² and their clinicians on whether the patient would receive life-sustaining interventions, or comfort care only. The results were then documented and included in the patient's medical record, with a plan for future treatment.⁵³ Those who had undergone the ethics discussion had fewer days in hospital and lower hospital costs compared to the group who did not. These savings covered the costs of employing staff to facilitate such a discussion. Importantly, 80 per cent of patients (or their surrogates) agreed that they would seek such discussions again and recommend them to others, suggesting that they were seen as useful.

In another study of 145 patients with advanced cancer⁵⁴ in a range of US hospitals (Zhang *et al.*, 2009), it was found that the one-third who had had conversations with their physicians about their particular wishes for end-of-life care, had care in the

⁵¹ Data was not available on the costs and savings of all aspects of the standards.

⁵² 552 patients unlikely to survive to discharge were studied in seven hospitals, over a two-year period.

⁵³ Such plans for future treatment are also called Advanced Care Directives. There is no legislation in Ireland governing such documents and it is unclear whether they have any definitive legal standing. A Law Reform Commission report (Law Reform Commission, 2009) called for an appropriate legislative framework for advanced care directives.

⁵⁴ The 145 were drawn from a larger sample of 603, as they were exactly matched demographically, in acceptance of death, and in treatment preferences.

last week of life that cost 36 per cent less than those who did not have these discussions. In terms of quality, those who had had the end-of-life discussion also had less physical distress in the last week of life, although both the group of patients that had these discussions, and the group that had not, were similar in psychosocial distress, quality of death (as measured by caregivers and medical staff), and survival time.

Communication with the patient's family was also found to be helpful. Campbell & Guzman (2003) compared two groups of what they termed 'hopelessly ill' patients in an ICU in Detroit,⁵⁵ numbering 41 patients in total. For one group, the palliative care team communicated the prognosis to the family, discussed the patient's preferences for care, recommended comfort care, updated the family regularly, and consulted/educated the medical team regarding palliative care; while the second group received none of these interventions. Length of stay was decreased for the first group, and there was also a reduction in use of resources and costs of care for them when a switch was made to provide them with comfort care only.

Norton *et al.*'s (2007) year-long study of 191 patients in a New York intensive care unit had similar findings. They found that palliative care consultation, ethics consultation or communication-intensive family meetings on the care of patients most likely to die resulted in a shortened stay in the ICU, compared to a group who did not receive such interventions. The difference in stay in the ICU was statistically significant, being just under nine days for those receiving the palliative care consultation, compared to sixteen days for those who did not.

4.5.3 Use of Palliative Care Services in Hospital

Use of palliative care services in hospital was also associated with improved outcomes and reduced costs. In a review of several studies on this, Smith & Cassell (2009) found that palliative care in hospital reduced the costs of care of the terminally ill. Gade *et al.*'s (2008) study provides more detail. They looked at the type of palliative care interventions received by 275 patients over 18 months, in three US hospitals, and the outcomes for them and the hospital. Each palliative care team was made up of a palliative care doctor and nurse, as well as a hospital social worker and chaplain. The teams assessed the patient's need for symptom management, psychosocial and spiritual support, end-of-life planning, and post-hospital care. The team met before each consultation to share what was known about the patient from the medical record, and other sources. The entire team then met with the patient/family to address symptoms, diagnosis, prognosis and care goals. Advance directive forms were also discussed. After this meeting, the team put together a palliative care plan, and organised follow-up by team members. The team also provided consultation to the staff treating the patient. If the patient was being discharged, then the discharge plan was communicated to the primary care team through an electronic medical record.

⁵⁵ Those with multi-organ failure, and those who had experienced complete stoppage of blood flow to the brain.

The group of 275 patients receiving palliative care services reported higher satisfaction on a number of issues (place of care environment, communication with clinicians), than a matched group of 237 who did not receive these services. The authors argue that the higher patient satisfaction is due to the palliative care team addressing the patient's and family's need for information, and facilitating their active participation in decisions on their medical care. The costs of caring for those who received palliative care was also lower, even when the staffing cost of the palliative care team was taken into account.⁵⁶ The main savings were in ICU costs (if readmitted to hospital), with those receiving palliative care much less likely to be admitted to ICU.

4.5.4 What Other Practices Reduce Costs?

Other studies suggest end-of-life care programmes involving nurse practitioners in end-of-life care moderately reduce costs (Reb, 2003), as do programmes where staff are educated on end-of-life care issues (Byock *et al.*, 2006). A study of palliative care use in Spain also highlighted another reason for cost savings (although it may apply less in Ireland at this stage), which is that palliative care beds have a lower unit cost than conventional medical beds (Gomez-Batiste *et al.*, 2006).

4.5.5 Why Are There Cost Savings?

The savings that occur where there are discussions on preferred end-of-life care with patients and families, and where palliative care services are used, are due to two main factors – first, the length of stay of these patients in hospital is often reduced; and second, the patients spend less time receiving more aggressive treatment, which usually costs more.⁵⁷ In Zhang *et al.*'s study (2009), those who had had end-of-life treatment preference conversations with their doctor were less likely to receive mechanical ventilation, to be resuscitated, or to be in an intensive care unit, all of which reduced costs. Morrison *et al.* (2008) have carried out the most extensive research on this issue, looking at 5,354 patients who received palliative care consultation in eight US hospitals, matched to the remainder of patients in the hospitals who did not receive this consultation. The results showed that there was no significant difference in the length of time spent in the hospital between those who received palliative care and those who did not. However, the direct costs of care for those who received a palliative care consultation in the hospital and subsequently died there was \$4,908 less per admission than those who did not. The largest saving was in ICU costs, followed by pharmacy costs, and then laboratory test costs. The researchers found that the costs of care of those who received the palliative care consultation and those who did not were initially the same, but the costs of care began to fall for the former group 24–48 hours after the

⁵⁶ The costs were \$4,855 lower per patient, taking into account the costs of the palliative care team.

⁵⁷ It has also been suggested that savings (financial and non-financial) can be generated as the beds and treatments not used by terminally ill patients are then available for use by others who are ill and in need of treatment (Smith & Cassell, 2009).

palliative care consultation. Norton *et al.* (2007) argue that costs are saved as the palliative care team establishes clear treatment goals, reviews treatments given to ensure that they are in accordance with these goals, and recommends and legitimises discontinuation of treatments or tests that do not meet these goals. These treatments and tests that are discontinued are often those that are particularly expensive.

This literature therefore suggests that good communication on and discussion about end-of-life, and care treatment preferences at that time, with both patient and family, helps reduce use of aggressive treatment (which can be expensive), while also yielding higher patient and family care giver satisfaction.

4.5.6 Costs of End-of-Life Care at Home, Versus in Hospital

Another issue that the HFH is focusing on, that is, encouraging more end-of-life care at home, shows even larger cost savings. It is also associated with high satisfaction from patients, and their family caregivers.

One study that shows this well is from Spain, where a comprehensive range of palliative care services, including palliative care at home, from outpatient clinics and from the GP, had been put in place in the late 1990s (Gomez-Batiste, 2006). A study of 395 terminally ill cancer patients who received palliative care services in 2001 compared the costs of their care for the last six weeks of life to the costs of that care in 1992 (when there was little palliative care available at home) for patients with similar prognoses. There was a very significant reduction in costs, of 61 per cent. The authors argue that these savings are more than the costs of the palliative care teams. Looking at the treatments received, it is clear that much of that saving comes not only from moving patients from an acute hospital bed (which had a time-standardised cost of €272 per day) to a palliative care bed in an acute hospital (which cost €133 per day), but also from moving palliative care out of the hospital altogether (a home palliative care consultation cost €38). In 1992, the most common way to care for a terminally ill cancer patient was in a conventional acute hospital bed, with 1,836 stays by these patients in such a bed. But by 2001, this had been reduced to 371 stays, and the most common way to care for such a patient is now through home care. In 1992, this had been the least common place of care for these patients.

This Spanish study also showed that with the establishment of the various palliative care services there, there had been a reduction in admission of terminally ill cancer patients to hospital through A&E, which is positive, as the Irish end-of-life care Audit (McKeown *et al.*, 2010b) showed A&E admission to be associated with poorer quality end-of-life care.

A US study of 310 terminally ill patients (Brumley *et al.*, 2007), with 155 receiving standard end-of-life care, and 150 home palliative care, found that more of the palliative care group were satisfied with their care, both when allocated to this care, and at follow-up 30 and 90 days later. In fact, individuals in the palliative care group were three times as likely to report high levels of satisfaction at 30 and 90 days than those in the usual care group. These differences were statistically significant. Other

statistically significant findings were on use of services – 20 per cent of the home palliative group used A&E, compared to 33 per cent of the usual care group; and 36 per cent of the home palliative group were hospitalised, compared to 59 per cent of those receiving usual care. Some 71 per cent of the home palliative group did die at home, compared to 51 per cent of those receiving usual care. Not surprisingly, the costs of care were lower for those receiving home palliative care 33 per cent lower. One reason may be that those who received home palliative care died earlier, living on average 196 days after initiation of the care, compared to 242 days for the usual care group. However, Candy *et al* (2011) cite a study showing that patients receiving home hospice care used significantly less medical resources, including imaging tests, laboratory tests, and home medical equipment, than patients receiving conventional care.

A Canadian study also found cost savings where terminally ill patients received home and residential hospice care, rather than hospital care, at the end-of-life. This offset the costs associated with the introduction of palliative care services there (see Smith & Cassell, 2009).

Of course, moving the care of those at end-of-life to home means, as Dumont *et al.* (2009: 713) note, that ‘many of the costs previously incurred by the public health care system seem to be shifted to patients and their families’. Their study looked at the costs of caring for 248 terminally ill patients in Canada, calculating all the costs incurred, such as hospital care, medicine, medical aids, transportation – and the costs incurred by family caregivers. The latter was calculated as the amount of time the care giver spent on household chores, errands and personal care for the patient, and valued at \$13.47 per hour, which was the value of household work as calculated by the Bank of Canada in that year (2005–6). This showed that the public health care system assumed 71 per cent of the caring costs, and the family 27 per cent.

Dumont *et al.* (2009) did not look at the satisfaction of the terminally ill and their caregivers with such arrangements. However, in a review of eight studies of home hospice care in the US, UK and Israel, Candy *et al.* (2011) report that satisfaction is higher for bereaved relatives when home hospice care is used. A common theme was that family carers felt that with hospice home care services, the whole family was being cared for and that they would not have been able to cope with supporting their relative at home without this support. In one study, it was also reported that patients at home had better pain management than those in hospital. Altogether, in their review of 22 studies, Candy *et al.* (2011) found consistent evidence that hospice care (in a hospice, at home or in the community) supported increased patient and carer satisfaction with care, and reduced general healthcare use.

It is important in this case to ensure that home hospice/palliative care services to support end-of-life care at home are actually in place. Cartier (2003) notes that the last three decades have seen hospital care for many conditions decrease, without reliable provision for how care will take place at home. However, this can be balanced with the above findings showing high patient and care giver satisfaction with palliative care at home, suggesting that when good hospice home care is put in place, it is effective.

It has also been noted that for end-of-life care at home to work satisfactorily, there needs to be greater integration of care services. Systems that promote co-ordinated care have been shown to decrease costs (Reb, 2003); and co-ordinated care also yields better patient satisfaction at end-of-life (Byock *et al.*, 2006).

However, home hospice care is not suitable for all patients, as some have complex medical needs, which means that they need hospital care at the end-of-life. Therefore, there will continue to be a need for end-of-life care, and standards on this, within hospitals.

4.5.7 Summary of International Evidence, and Implications for Irish Practice

In summary, several of the pieces of research outlined in the above sections show a good outcome, in terms of cost and quality of care, from an end-of-life care practice that features in the Irish *Quality Standards for End-of-Life Care in Hospitals*. These practices are outlined in Box 4.3.

Box 4.3 Practices in the *Quality Standards for End-of-Life Care in Hospitals* that are Associated with Reduced Cost and Improved Outcomes at End-of-Life

Standard number	Practice	Evidence of improved quality and/or reduced costs
1.3	Effective communication with the patient and their families	Gilmer <i>et al.</i> , 2005; Zhang <i>et al.</i> , 2009; Norton <i>et al.</i> , 2007
1.4	[A good] healthcare record	Gilmer <i>et al.</i> , 2005; Gade <i>et al.</i> , 2008
1.7	Assessing and responding to the end-of-life care needs of patients	Gilmer <i>et al.</i> , 2005; Gade <i>et al.</i> , 2008; Norton <i>et al.</i> , 2007
1.8	Multi-disciplinary working [in the hospital]	Gade <i>et al.</i> , 2008; Norton <i>et al.</i> , 2007
1.10	Clinical ethics support	Norton <i>et al.</i> , 2007
2.2	Staff induction	Byock <i>et al.</i> , 2006
2.3, 2.4	Staff education	Byock <i>et al.</i> , 2006
3.1	Communicating a diagnosis of the possibility of a need for end-of-life care	Gilmer <i>et al.</i> , 2005; Zhang <i>et al.</i> , 2009; Campbell & Guzman, 2003
3.3	Patient preferences	Gilmer <i>et al.</i> , 2005; Campbell & Guzman, 2003; Gade <i>et al.</i> , 2008
3.5	Discharge home/out of the hospital	Gade <i>et al.</i> , 2008
4.1, 4.2	Communication with family members	Campbell & Guzman, 2003; Gade <i>et al.</i> , 2008; Norton <i>et al.</i> , 2007
4.4	Patient discharge [and the family]	Candy <i>et al.</i> , 2011

There may also be other practices in the standards that improve quality while reducing cost, for which such evidence does not yet exist, but the fact that those listed above meet both of these outcomes underlines the value of implementing the *Quality Standards for End-of-Life Care in Hospitals*. While implementing them has a number of costs, it seems that full implementation of many aspects of these

standards would reduce costs overall, while promoting greater satisfaction with end-of-life care.⁵⁸

4.5.8 How Have Recent Cuts Impacted on Implementation of These Standards?

Before leaving the issue of how to improve quality in a time of reduced resources, this section will consider the impact that recent cuts in resources have meant in practice for implementation of the standards in the case-study hospital. These cuts have given rise to difficulties in two key ways – reductions in staff time available, and reductions in financial allocations.

The Impact of Cuts on Staff Time

One of the biggest impacts of cuts in staff numbers is problems making time available to work on improving end-of-life care, as a number of comments showed. First, it was more difficult to release staff for training on end-of-life care (as noted in Section 3.5).

They'd like ... staff [to] have access to training days but it may not be possible to attend because there is no-one to do their job on that day. And you can't really hire in an agency nurse – in the old days you would have hired in an agency nurse for the day and people would have got to go [to the training day]. And now you can't. The funding is simply not there. [R7]

We've had a lot of issues trying to get [practice development] up and running ... how easy it is going to be to roll it out around the whole hospital is going to be the difficult bit, because of staff cutbacks. Because you have to release staff to go and talk about it. [R5]

This is constraining as the Audit showed that nurses with formal training in end-of-life care felt more prepared for the death of a patient, and were found by doctors to manage symptoms better than those without such training. Finding a mechanism to ensure that staff can be released for participation in training and development, and in practice development, is important to ensure that progress to date can be maintained.

Other impacts that cuts have had on available staff time, and continuous improvement in quality of end-of-life care, are as follows:

⁵⁸ Of course, some practices advocated by the standards are already being implemented, not just through the work of the standards, but also through the work of specialist palliative care teams. However, more extensive specialist palliative care is needed in Ireland, as well as more generalist palliative care - see the HSE policy briefing on this, at <http://www.hse.ie/eng/about/Who/clinical/natclinprog/briefingdoc.pdf>, accessed 24 July 2012.

We have less staff on the frontline. Whereas you might before have had time for a nurse to sit and hold a patient's hand for a couple of hours – it's not always possible now ... it's not all the high tech stuff you're talking about. You're talking somebody that's got time to sit down and talk to a patient. [R5]

People would like to spend more time with people who are dying ... It's just that there may not be enough staff to enable you to spend that time ... In the old days you could sit with somebody who was dying, do your charting and have a bit more time. Now it's just busier as there is less people. [R7]

This is a significant factor, as the Audit found that 'wards that have inadequate staffing levels have a significant negative effect on care outcomes' (McKeown *et al.*, 2010b: 26).

Some members of the hospital Standing Committee who have taken early retirement or voluntary redundancy have not been replaced, or were difficult to replace. As one interviewee put it:

Unfortunately there have been significant changes in the last nine months in terms of personnel within the acute hospitals, and I can say that [the chairs of three of the four working groups under the Standing Committee] have retired. They have either taken early retirement or they just came to that point. And that's a significant loss. Because they would have been motivating their own teams, their own staff and also driving these committees. **Who's taken over from them or have you been able to find people?** And that's just it – then you are going back to - who will take this on board on top of everything else? You know - on top of their jobs not being replaced.⁵⁹ [R8]

This did not mean that staff were unable to find ways around some of the time constraints arising from cutbacks.

People come in on their days off often to do [training] days like that because they know they might just be too short on the ward to give them a study day. [R7]

The *Final Journeys* evaluation showed that almost a quarter of staff undertook the training on their days off (Byrne & Murphy, 2011).

Another stakeholder reported that:

We have developed ... new documentation for nursing assessment, when a patient is admitted ... but we need to get the staff [to explain to them how it will work] ... [but] how are we going to release these staff

⁵⁹ R4 reported that in some hospitals *Final Journeys* facilitators have taken on such roles.

to get the half hour [for training in it]? ... So what we've done now is members of the committee have all got themselves a presentation and we do walkabout with the presentation and show it to staff that way. And it takes 15 minutes on a ward ... [but] we were an hour [in a meeting] trying to figure out how the hell we're going to do this. [R5]

However, on the other hand one person said that:

You can say – well [the cuts] encourage good teamwork ... [but] teams have lost numbers; we're down staff members in our team. So certainly the people who are there are more tired and more weary and under more pressure, and it's – you're working longer hours because you have to ... you're probably more tired and weary if you are dealing with relatives who decide to confront or challenge you. ... and I think there's a much greater risk of staff burnout. [R7]

She went on to say:

Due to staff shortages, we don't even have a social worker assigned to our team ... So someone who is dying today – they'll have gone home, with a note on the computer saying – due to no locum cover, no social worker was available. We all do our best, but staff shortages will ultimately impact on patient care. [R7]

In addition to this, all of those interviewed in the case-study hospital were specifically asked for positive examples of ways in which work was being reconfigured due to cutbacks, but none cited any.

The Impact of Cuts in Financial Allocations

Staff in the case-study hospital mentioned cuts in financial allocations much less often than cuts in staff numbers as problematic for implementation of the standards. This may be as the financial costs incurred to date in implementing the standards are quite low (€10 million over five years is low in comparison to healthcare budgets generally), and also as it seemed to be possible to find other sources of funding for some of these costs. It was reported that a range of fund-raising initiatives that support the standards are underway in different hospitals participating in the programme [R4]. Funding was still being found for HFH bags, drapes and leaflets in the case-study hospital, as these quotes suggest:

And what do you think is going to happen now [that the HFH programme is due to end] given all these things cost money? We'll probably end up holding coffee mornings if we have to! [Manager] is giving us money out of her fund for staff. We got money from the National Foundation, the Cancer Society, and from my study days and I had some left in the account and that paid for more *Breaking Bad News Booklets* to be printed, so we – you know you kind of just find it, really. [R7]

She noted how the existence of the standards can help to prevent cuts to end-of-life care resources:

What standards do is they say – hey it’s important, and we shouldn’t cut back on this; and it’s good if say our committee were getting upset because as you say resources were being cut and suddenly we can’t afford these ... essentials for dying people. At least we can say – there are standards. [R7]

However, a larger financial issue that probably impacts on the ability to meet a number of the standards, but was not mentioned by any of those spoken to, was the cost of e.g. building hospitals with more single rooms, and with more meeting rooms where bad news can be broken to relatives in private (there are very few of these). Similarly, mortuaries need to be refurbished. All of these are likely to incur higher financial costs, the like of which are usually paid for out of government funds. However, it is difficult to see how there could be much funding for such costs from this source in the foreseeable future.

Another issue of increasing importance is how progress on these standards will be sustained in future, as HFH funding ended in April 2012. This will be considered in more detail in Chapter 5.

4.5.9 Brief Summary of Evidence on Costs and Quality in End-of-Life Care

Overall, this consideration of costs and quality improvement in relation to end-of-life care suggests that in Ireland, the reduction in staff numbers is having a negative impact on the time available for management and frontline staff to work on implementing the standards to improve end-of-life care to the extent that they would like to. While relatively small amounts of funding have helped to develop the *Quality Standards for End-of-Life Care in Hospitals* and the supports to implement them locally, it is also important that funding is allocated at a ‘macro’ level to support this; for example, to ensure adequate specialist and generalist palliative care, adequate staff numbers to provide this care, and suitable environments in which to provide it. International literature suggests that provision of good end-of-life care not only improves quality of care, but also reduces costs, which provides a good argument for aligning funding to support these changes.

Chapter 5

Summary and Conclusions

5.1 Introduction

This final chapter summarises how the *Quality Standards for End-of-Life Care in Hospital* are relevant to the five key themes of this NESC project, which are: responsive regulation (i.e. how implementation of quality standards is encouraged by a balance of sanctions and supports); the role of the service user; learning; devolution and accountability; and addressing costs with the need to improve quality. The chapter concludes with a reflection on how this end-of-life care standards framework addresses the three overriding questions posed in the NESC *Overview Report* (2011). These are - how convincing is this standards framework? To what extent does it (a) prevent the most serious harms, and (b) promote quality? And, are there things in this standards framework that need to change to ensure the provision of quality services?

5.2 How the Five Key Issues Addressed in This Project are Reflected in the End-of-Life Care Standards

5.2.1 Responsive Regulation

In terms of responsive regulation, the HFH programme, proposed and developed by a voluntary organisation, does not have any legal power to require hospitals to implement the standards. Therefore, it has built up a comprehensive ‘strengths-based’ model of supports, which builds on pre-existing work and desire to promote better end-of-life care, by hospital management and frontline staff. In terms of supports, the HFH programme provides many – the end-of-life care co-ordinator, who acts as a catalyst and motivator to drive the standards forward within a hospital; the practical supports such as information leaflets, training modules, relatives’ bags, end-of-life symbols, mortuary trolley drapes, etc.; the networks that help staff swap experience of implementation between hospitals; and an overall governance, monitoring and support framework. A very important aspect of the programme is the *National Audit of End-of-Life Care in Hospitals in Ireland, 2008–9* (McKeown *et al.*, 2010b), which provides benchmark, outcome-based data, from the perspective of healthcare staff, and patients’ relatives. This Audit is well used to encourage, and to benchmark, progress. All of these supports build on the strong desire of hospital staff to provide the best end-of-life care they can.

Meanwhile, there are a number of ‘soft sanctions’, or pressures, which the HFH can make use of to encourage compliance with the standards. These include the Memoranda of Understanding between HFH management and the top managers of hospitals, which stipulate the terms on which the hospital receives resources from the HFH; the benchmarking of each hospital’s results against the top 25 per cent of hospitals, and regular monitoring of progress, which provide an element of competition to encourage hospitals to implement the standards; and the Hospice Friendly Hospitals Network which again encourages implementation.

5.2.2 Involvement of Service Users

The views of the service user are incorporated into the standards, both in general (as they focus on improving the experience of people who are dying, and their families), and in particular, through their design and implementation. The standards were informed by *the National Audit of End-of-Life Care in Hospitals in Ireland, 2008–9* (McKeown *et al.*, 2010b), with the views of staff and relatives incorporated into this; and through working groups made up of hospital staff and bereaved relatives. One of the four high-level standards also focuses particularly on the experience of the patient – in particular, communication with the patient, their preferences, and their pain and symptom management. Family members of the bereaved also become service users, and their needs are focused on in a second high-level standard, and a range of supports have been put in place to meet these needs.

5.2.3 Learning and Monitoring

The HFH programme has a particularly strong emphasis on learning, with regular monitoring and review of structures and tools to implement the standards. There are also a number of systems in place to encourage learning on implementation of the standards – within the individual hospitals, between hospitals, and within the national policy-making system. In the hospitals, the Standing Committee, the working groups that support it, staff development and education sessions, the new system of audit and review, and practice development projects, all promote learning. The baseline Audit, and the benchmarking linked to it, form the basis for both the hospital end-of-life care development plan and monitoring of the extent to which benchmarks are reached by each individual hospital. These are very important supports for learning. Between hospitals, the membership of the Hospice Friendly Hospitals Network, and increasingly of the National Steering Committee of the HFH programme, is drawn from several hospitals, and so provides learning links between these hospitals. The practice development programme also involves regular meetings between facilitators of practice development in different hospitals. Finally, members of the HFH National Steering Committee, and of the wider National Council of the Forum on End of Life set up by the Irish Hospice Foundation, are drawn from the HFH programme, and wider policy-making bodies. And the HFH managers monitor and learn from all of this. These processes show elements of single, double and triple-loop learning. Strictly speaking, single-loop learning involves staff on the frontline making adjustments to their work to improve outcomes, with these changes then noted by managers who adjust their systems to

incorporate them, which is double-loop learning. The final third loop of learning involves regulators and oversight authorities learning from these changes, and revising their strategy for the entire field (see NESC, 2011). In the HFH programme, however, the standards have been initiated by the HFH ‘oversight authority’, which has supported staff on the frontline to continue to make adjustments to their work to improve end-of-life care outcomes, and hospital management to adjust their systems to support this. However, the government oversight authorities (the HSE, Department of Health, and HIQA) have not yet adjusted their strategy for the entire field to incorporate the changes arising from the *Quality Standards for End-of-Life Care in Hospitals*, although the HFH has involved HIQA and the Department of Health in steering initial development of the standards. The HSE has been a partner with the HFH in this programme, and so the HSE (or its replacement) may be in a particularly appropriate position to implement this type of triple-loop learning in future.

5.2.4 Devolution and Accountability

The HFH ensures accountability of participating hospitals through use of a Memorandum of Understanding between the hospital and the HFH, including requirements for various reporting mechanisms, in return for HFH support. However, external accountability, to e.g. a State organisation, is weak, despite the partnership of the HSE.

Devolution and innovation are a strong part of the ethos of building on existing strengths in end-of-life care, with a view to improving it. In line with this, the framework to support the *Quality Standards for End-of-Life Care in Hospitals* supports and promotes innovation in how the standards are implemented in each hospital.

5.2.5 Addressing Costs While Improving Quality

The question of how to address costs while improving quality in services was considered. International evidence shows that implementation of several aspects of the standards, such as communicating effectively with patients and their families about end-of-life, providing treatment in line with patient wishes, multi-disciplinary working in the hospital, and staff training on end-of-life care, all help to improve the quality of end-of-life care, while at the same time reducing the costs of care. This provides strong arguments for implementing these standards (as well as continuing the implementation of specialist palliative care services in hospital and the community).

Meanwhile, the actual costs of implementing the standards to date are quite low, as it has cost €10 million to develop them and their implementation supports, although this has been supplemented by staff time and local funding sources. However, reductions in government resources to hospitals appear to be having a strong impact on the time staff have available to implement improvements in end-of-life care. For example, it is more difficult to release staff from day-to-day work to undertake training on end-of-life issues. Importantly, staff have less time to spend

with those who are dying. Cuts in capital budgets are likely to have a negative impact on the prospect of more single rooms in hospitals, or viewing rooms in mortuaries – both issues that need to be addressed to improve the quality of end-of-life care, and the experience of the bereaved.

In general, the international and Irish experience suggests that aligning overall government funding allocations to ensure provision of good end-of-life care would be practical, as it not only improves quality in care, but also reduces costs.

5.3 Overall Conclusions

First, a key question is – how convincing is this standards and quality improvement regime? Those interviewed for this report indicated that the *Quality Standards for End-of-Life Care in Hospitals* and their implementation framework are useful in improving the quality of end-of-life care in hospitals. However, while some standards are being successfully implemented, particularly those related to staff development, and provision of resources for day-to-day use by frontline staff, progress is mixed on others. As outlined in Section 4.4.2 earlier, key issues with which hospitals are having mixed success include – how to recognise when patients are dying; how to talk to people who are dying; how to ensure there is adequate staff available; training of staff not being recognised as a priority area; prioritising of single rooms for the dying; and the condition of mortuaries.

Second, to what extent do these standards (a) prevent the most serious harms/abuses; and (b) promote quality improvement? This standards framework was developed to prevent harm, through promoting quality improvement. Through the *National Audit of End-of-Life Care in Hospitals in Ireland, 2008–9* (McKeown *et al.*, 2010b), it has identified factors that influence the quality of end-of-life care, and put in place a range of supports to increase the existence of these. These aim to support patient, family and staff. The extensive learning and monitoring approaches adopted by the programme also promote continuous improvement.

Finally, are there things in this framework that need to change to ensure the provision of a quality service?

This standards framework, and in particular the supports for its implementation, are a very good example of a strengths-based approach to promoting continuous improvement. However, participation in the HFH programme is voluntary, and not all hospitals are involved. This reduces the extent to which the programme can promote quality improvement in all hospitals. Some standards are more successfully implemented than others, and literature on responsive regulation would suggest that a mix of supports and sanctions to promote continuous improvement might be more successful.

Looking to the future, the HFH programme is now at a crossroads, with the key phases, Phases 1 and 2, which developed the standards and supported their implementation in hospitals, complete. The difficulty now faced is that some of the

engagement in and innovation from the programme could be lost, if mechanisms to maintain the momentum and investment from it are not put in place.

The Irish Hospice Foundation has decided that it will support the HFH programme further, by funding three specific aspects of the programme for the next three years. These three supports are – continuation of the Hospice Friendly Hospitals Network; recruitment of an education co-ordinator to support continued roll-out of the *Final Journeys* staff development programme; and recruitment of a national audit co-ordinator, to roll out the new System of Audit and Review of End-of-Life Care, initially in acute hospitals, and, in time, in all care settings. These supports will be helpful in maintaining the momentum developed in hospitals, and also in promoting continuous learning in the future. They will complement the range of existing supports (such as practice development, the ethical framework, information and end-of-life care resources, design and dignity grants scheme, pathfinder projects, etc.), which will still be available. However, funding for the end-of-life care co-ordinators will formally end in 2013. A key task for 2012 will be to negotiate some form of ongoing support, whether full- or part-time, to enable the larger hospitals to continue to focus on implementing the *Quality Standards for End-of-Life Care in Hospitals*.

Individual hospitals can, of course, decide to continue implementing the standards, and to fund that implementation themselves, and a number are doing so. However, this NESC study of standards in a range of public services, and the means by which such standards can promote quality improvement, shows that it is not only the ‘front-line’ service providers who play an important role in this, but also ‘a centre supportive of continuous improvement’. Such a supportive policy centre has two main concerns, one being to improve the performance of individual organisations, while the second is to assess the efficacy of the overall field of practice. Such a supportive role can be carried out by a number of central policy organisations, for example, a regulator, a government department, or a government agency (see NESC, 2012d, forthcoming). Therefore, it is important for a central State body to support engagement with and implementation of the HFH standards. Specifically, as Section 4.5 shows, 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. For example, releasing staff for training in communication and end-of-life care is becoming increasingly difficult with staff cutbacks, which are decided on by central government bodies. Similarly, the increase in palliative care over the last decade, which is one of the standards and which international evidence shows both increases quality of care and reduces costs, is a decision that has been made and funded by central government bodies. Second, relying on a voluntary approach will not involve all hospitals, which will mean that increases in quality and reductions in costs will not be optimised. A mandate to implement the standards is something that can most effectively be provided by a central government body. A third point is that sharing useful learning on best practice implementation means that a group of hospitals needs to be implementing the standards, and that a mechanism be in place to share this learning. Again a central government body is well placed to facilitate this – either by carrying this work out itself, or mandating another body (such as the Irish Hospice

Foundation) to do this on its behalf. For all of these reasons, the involvement of central State bodies is very important. They are well placed to help support implementation of the standards into the future, and the sharing of learning and supports on this, so that the best-quality end-of-life care, which also reduces overall costs, can be provided to patients and their families.

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 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 Health⁶⁰) 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 (see NESC, 2012c). 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). (Some work has already begun on this – see Section 4.4.1.)

The HFH is also establishing an award system with the *Irish Medical Times* to promote quality end-of-life care. This will help maintain some of the momentum already generated by the HFH programme.

⁶⁰ As of the time of writing (July 2012), the HSE allocates funding to hospitals, but responsibility for health spending will shortly move back to the Department of Health.

Meanwhile, the overall goal is not just better end-of-life care in hospitals, but more end-of-life care in the community, so that more people are supported to die at home, as they wish. To that end, the HFH programme and the Irish Hospice Foundation are beginning work to look at how more people can be facilitated to be cared for and die at home, or nearer home. However, even though the number of deaths in hospital could decrease in the future, as hospitals will always be a key provider of end-of-life care, mechanisms will be needed to ensure that the work begun by the HFH to implement the *Quality Standards for End-of-Life Care in Hospitals* continues.

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.

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