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

Executive Summary

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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 hospitals[1] 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 hospital staff to further improve the quality of their end-of-life care. It provides

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[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.

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 HSE[2], 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.

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[2]   Or its successor.