



An Chomhairle Náisiúnta Eacnamaíoch agus Shóisialta
National Economic & Social Council

Quality and Standards in Human Services in Ireland: 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.

