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National Audit of End-of-Life Care in Hospitals in Ireland

2008/9

Dying in Hospital in Ireland: Family Perspectives

National Audit Report 3

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Feidhmeannacht na Seirbhíse Sláinte
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THE IRISH HOSPICE FOUNDATION

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This report is the joint property of the hospitals who contributed to the national audit of end-of-life care in 2008/9, and the Irish Hospice Foundation. Information about any individual hospital is confidential to that hospital.

List of National Audit Reports

Report One	Resources and Facilities for End-of-Life Care in Hospitals in Ireland
Report Two	Dying in Hospital in Ireland: Nurse and Doctor Perspectives
Report Three	Dying in Hospital in Ireland: Family Perspectives
Report Four	The Culture of End-of-Life Care in Hospitals in Ireland
Report Five	Dying in Hospital in Ireland: An Assessment of the Quality of Care in the Last Week of Life

The Well of Grief

by David Whyte [1]

Those who will not slip beneath

the still surface of the well of grief

turning downward through its black water

to the place we cannot breathe

will never know the source from which we drink,

the secret water,

cold and clear,

nor find in the darkness

glimmering the small round coins thrown away

by those who wished for something else.

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[1] David Whyte (1955 -), published in 1990 in Where Rivers Meet, Washington: Many Rivers Press. He is the author of six books of poetry and three books of prose. He was born in England but lives in Washington State, USA.

Table of Contents

Figures and Tables

Acknowledgements

This audit is about hospitals and the quality of their care for patients at the end of life. Without the participation and support of these hospitals, the audit would not have been possible. We are thus enormously grateful to the 43 participating hospitals - 24 acute and 19 community – which had the vision to see this audit as an opportunity to examine and improve their end-of-life care. We would like to thank the management and staff of each hospital, and especially the hospital audit managers who were responsible for data collection. The acute and community hospitals which participated in the audit are:

Acute Hospitals	**Hospital Audit Managers**
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St. Mary's Hospital, Drogheda	Myrna Guay (Unit 1) Ann Keane (Unit 2)
St. Joseph's Hospital, Ardee	Eileen Dullaghan Bernie Murphy & Patricia Barry

In addition to the audit managers, many hospital staff members contributed to the audit. Nurses and doctors completed detailed questionnaires on a sample of patients who died in their care. Nurses and healthcare assistants completed a questionnaire on the culture of care in their ward, while a similar questionnaire was completed by a sample of staff drawn from throughout the hospital.

The families of the aforementioned patients made a huge contribution to the audit, and this is gratefully acknowledged. Their perspective is irreplaceable in helping us to understand how patients and their relatives experience hospital care at the end of life.

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HFH Pilot Study	**RCSI Pilot Study**
Cork University Hospital	Midland Regional, Mullingar
Mater M University Hospital	Naas General Hospital
St. Mary's Phoenix Park	St. John's Hospital, Sligo
Leopardstown Park Hospital	St. Columba's, Co. Kilkenny
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Gail Birkbeck	The Atlantic Philanthropies (in attendance)

The HFH Programme is overseen by a National Steering Committee and its input to the audit is also acknowledged. Its membership currently comprises:

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The research design for the audit, including questionnaires, is published in a separate Manual (McKeown, 2008). In addition to those listed above, many people contributed to the Manual. Siobhán McCarthy and Professor Ciarán O'Boyle, at the Royal College of Surgeons of Ireland (RCSI), prepared a literature review on the instruments used in the survey of bereaved relatives. Dr. Karen Ryan, Consultant in Palliative Medicine at the Mater Hospital and St. Francis Hospice, made helpful comments on earlier drafts of some of the questionnaires. Similarly, Professor Phil Larkin, Chair of Palliative Care Studies at University College Dublin, made constructive suggestions on all the questionnaires. The Manual was reviewed by a number of external experts – including Dr. Patricia Ricker from Harvard University, Dr. Joanne Lynn from the US Office of Clinical Standards and Quality at the Centers for Medicare and Medicaid Services, and Dr. Mark Dynarski from Mathematica Policy Research, NY – and their comments are gratefully acknowledged.

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Finally, in acknowledging everyone's contribution to the national audit of end-of-life care, we wish to emphasise that responsibility for this report, and any errors it may contain, rests entirely with the Research Team.

Dr. Kieran McKeown, on behalf of the Research Team.
May 2010.

Executive Summary

This report describes the experiences, as perceived by family members, of 461 patients who died in hospitals in Ireland in 2008/9. Nearly nine out of ten (87%) of these patients died in acute hospitals, the remainder in community hospitals. This sample constitutes 5% of annual deaths in these acute hospitals[2] and 14% of annual deaths in these community hospitals[3]. The response rate to the survey is 46% which is within the range found in similar surveys of relatives, both in Ireland[4] and elsewhere[5].

It is recognised that the patient's experience is not the same as that reported by the relative, or indeed by the nurse or doctor. Nevertheless, given the frailty of patients during their last week of life, the accepted and acceptable method of study is to rely on reports about the patient from family and friends, since there is considerable evidence that these reports tend to be a reasonable approximation of the patient's experience[6].

Characteristics of Relatives

Two thirds of relatives are female (65%) with an average age of 57. A majority are either the child (41%) or partner (24%) of the patient. This profile is broadly similar to two other studies of bereaved relatives in Ireland[7]. In terms of attitudes, respondents are positive about the quality of end-of-life care in Irish hospitals. They regard 'being free from pain' as by far the most important thing about care when dying, which contrasts to the findings of a national survey which rated the presence of loved ones as the most important thing about care when dying[8]. Significantly, relatives rated the least important things about dying as: to be in a private space (6% compared to 11% in national survey), to have spiritual support (6% compared to 19% in national survey), and to be at home (6% compared to 34% in national survey).

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2 The 24 acute hospitals in the audit represent a major part of that sector in Ireland in terms of bed-capacity (74%), number of patients (72%), deaths (71%), and staff (73%). See McKeown, Haase, and Twomey, 2010a.

3 The 19 community hospitals in the audit constitute 12% of the 156 community hospitals in Ireland, equivalent to just 20% of all community hospital beds in Ireland although these hospitals tend to be larger (averaging 110 beds each) compared to community hospitals generally (averaging 68 beds each). See McKeown, Haase, and Twomey, 2010a.

4 In Ireland, one survey achieved a response rate of 57% (Keegan, et al, 1999) while a more recent survey had a response rate of 32% (McCarthy and O'Boyle, 2010).

5 In the US, four studies which have used either the QODD or the FEHC, both used in the audit, had response rates of 27% (Curtis, et al, 2002), 38% (Mularski, et al, 2004), 45% (Teno, et al, 2007), and 55% (Levy, et al, 2005).

6 Three substantial reviews (Tang and McCorkle, 2002; McPherson and Addington-Hall, 2003; Teno, 2005) have examined the extent of agreement between direct patient reports and the reports of their relatives, referred to as 'patient-proxy agreement'. The first review examined 25 patient-proxy studies and concluded that 'this review highlights that the majority of terminal cancer patients and their family caregivers agreed at least moderately well (0.60) on the patients' QOL. Family caregivers can act as a reliable alternative source of data for terminal cancer patients who are no longer able to speak for themselves. The bias introduced by the use of family respondents is generally of a modest magnitude. When discrepancies existed, without exception, family caregivers held a more negative view of patients' QOL than did patients. The degree of agreement between patients' and family caregivers' assessments varies as a function of the dimensions of QOL being measured. Caregivers were least reliable in evaluating the aspects of QOL that lack observable clues and require subjective judgments, as well as psychological reactions and social/spiritual concerns of patients. Family caregivers were best able to assess physical and functional aspects. As patients' health deteriorates, family caregivers become less effective in assessing and reporting patient QOL.' (Tang and McCorkle, 2002:1101). The second review examined 23 studies and concluded: 'This review provides encouraging evidence for the use of proxies at the end of life, for some aspects of the patient's experience, most notably for service provision and evaluation, and for symptoms that are more observable in nature. However, care must be taken when using proxies to report on aspects of the patient's experience that are more subjective, such as pain and affective states' (McPherson and Addington-Hall, 2003:106). The third review, while acknowledging the need for care in the use of proxy data, concluded that: 'It is important to recognise that bereaved families' perceptions of the quality of care delivered to them during the final illness of loved ones are important indicators of the quality of care' (Teno, 2005:S-47). Overall, these reviews suggest that relatives are a reasonably good proxy for the experiences of patients.

7 Keegan, et al, 1999; McCarthy and O'Boyle, 2010.

8 Weafer & Associates Research, 2004.

Characteristics of Patients

There is no significant difference between the patients on whom relatives completed Questionnaire 3 (461) – on which this report is based - and the larger sample of patients on whom nurses completed Questionnaire 1 (999), on which Report Two[9] is based. Both samples are virtually identical in terms of gender, age, marital status, living alone, nationality, ethnicity, religion, public / private status, route of admission to and length of stay in hospital, expected / sudden deaths, and primary diagnosis. This means that we can have confidence that the sample is broadly representative of the entire population of patients and relatives. In summary form, these patients are generally 65 years and over and were admitted to hospital through Accident and Emergency Departments (A&E). They are mainly public patients with average length of stay in acute hospitals of 24 days. The three main causes of death reflect the national pattern in terms of their order of priority: circulatory system diseases (31%), cancer (23%), and respiratory system diseases (19%).

Characteristics of Ward

About 15% of beds in acute and community hospitals are in single rooms[10]. Despite this, nearly half the patients (48%) died in a single room, which is lower than the 70% of patients who die in single rooms in hospitals in Northern Ireland[11]; the remainder (52%) in a shared room with at least five other patients, some of them mixed-gender rooms. On a 10-point scale, relatives gave a higher rating to the room where the patient died rated (6.2) compared to nurses (5.7) and hospital management (5.8), and much higher than independent healthcare consultants (3.6)[12]. In terms of organisation, nine out of ten relatives believe the ward where the patient died was either very well organised (54%) or relatively well organised (35%). However, one third (33%) believed the ward's end-of-life care was either average, poor or very poor.

Preferences for dying in a single room

Nearly half of all patients who died in a shared room would have preferred a single room (45%). This suggests that there is a substantial unmet preference for patients to die in a single room which, given the high proportion of patients who did not express a preference, could range from 24-40% of all deaths.

Preferences for dying at home

Just over a tenth of patients indicated to relatives (14%), during the last week of life, that they would like to die at home. In the assessment of relatives, nearly a quarter of all patients (24%) could have died at home if there was enough support, similar to the overall assessments made by nurses (22%) and doctors (22%)[13]. However a case-by-case comparison of these assessments indicates that relatives, nurses and doctors agree in only 29% of cases, while nurses and doctors agree in only 48% of cases. This suggests that each has a different approach to making these assessments. Further analysis reveals that relatives are more likely to assess a patient as suitable to die at home when they rate the responsiveness of staff to

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[9] McKeown, Haase and Twomey, 2010b.

[10] McKeown, Haase and Twomey, 2010a.

[11] This estimate is taken from the audit of dying, death and bereavement in Northern Ireland. Most deaths were in the three areas of general medicine (40%), elderly care (20%) and general surgery (10%) where the proportion 'cared for in a single room on more than 75% of occasions' is 65%, 75% and 80% respectively (Northern Ireland Health and Social Care Bereavement Network, 2009:6 and 28). From this it is a reasonable inference that around 70% of deaths are in single rooms.

[12] Tribal, 2007.

[13] McKeown, Haase and Twomey, 2010b.

requests as average or poor, and when the quality of end-of-life care on the ward, and in Irish hospitals generally, is rated as average or poor.

Quality of staff

Relatives gave high ratings for the quality of all staff – nursing, medical, other - in both acute and community hospitals. Over eight out of ten relatives (83%) rated the responsiveness of staff - the way staff responded to requests - as good or very good. Nearly nine out of ten relatives rated the quality of staff - what do you think of the quality of staff - as good or very good. However, a quarter of relatives felt there was not enough nursing and medical staff in acute hospitals, and this may be due to their experience that staff do not have – and are not given – enough time to be with patients and relatives. Nevertheless, these results paint a positive picture of staff quality and responsiveness, and are consistent with other findings which show relatively high levels of satisfaction among people who have direct experience of Irish hospitals[14].

Quality of life

The quality of life of patients during their last week is simultaneously a measure of their living and dying. It is therefore an important indicator of a hospital's end-of-life care, since quality of life is as intrinsically valuable as life itself. Reflecting this, it is the preference of the majority of Irish people that, if they were ill with no hope of recovery, the quality of life would be more important than how long it lasted[15]. Overall, the quality of living and dying in Irish hospitals, as measured by the Quality of Dying and Death Instrument (QODD)[16], is comparable to that found in other QODD-based studies of hospital deaths[17]. During their last week of life, patients are more challenged by their physical and psychological symptoms, but their relationship

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14 In 2007, HSE's Office of Consumer Affairs commissioned a study, comprising a random sample of 3,517 Irish people, on experiences of public health and social care services. A sub-sample of these (344, 10%) had experience of hospital services in the last year and reported high overall levels of satisfaction on dimensions such as: effective treatment by a trusted professional (78%), involvement in decisions and respect for own preferences (75%), clear and comprehensive information (80%), emotional support, empathy and respect (83%), easy to get around the hospital (74%). However there was a marked dip in satisfaction on dimensions such as cleanliness of hospital toilets (62%), contact with the hospital by phone (69%), and car-parking facilities (46%) (UCD and Lansdowne Market Research, 2007). Similarly, a majority of people (75%) who had someone close die in an Irish hospital in the past two years or so reported that end-of-life care in Irish hospitals was good or very good (Weafer & Associates Research, 2004: Figure 15, page 19).

15 This is based on a national survey of 667 adults who were interviewed by telephone in September 2007. In response to the statement - if I were ill with no hope of recovery, the quality of my life would be more important than how long it lasted - 63% agreed strongly and 18% agreed somewhat (Weafer, McCarthy and Loughrey, 2009:35).

16 Developed by, and available from, the University of Washington End of Life Care Research Program at: http://depts.washington.edu/eolcare/instruments/index.html. The Quality of Dying and Death Instrument (QODD) was developed by Donald Patrick, Ruth Engleberg and Randall Curtis (Patrick, Engleberg and Curtis 2001) and has been used in four studies (Curtis, Patrick, Engleberg, Norris, Asp, and Byock, 2002; Hodde, Engelberg, Treece, Steinberg, and Curtis, 2004; Mularski, Heine, Osborne, Ganzini, and Curtis, 2005; Levy, Ely, Payne, Engelberg, Patrick and Curtis, 2005).

17 The main QODD-based studies, and their scores, are as follows:

Study	Sample	Completed by Relatives		Completed by Nurses		Completed by Doctors	
		M	SD	M	SD	M	SD
US Deaths in hospital and home (Curtis, et al, 2002)	252	67.4	15.1	-	-	-	-
US Deaths in ICU (Hodde, et al, 2004)	149	-	-	73.1	21.4	-	-
US Deaths in ICU (Levy, et al, 2005)	38	77.7	9.3	66.9	16.3	67.8* 82.5**	22.5* 17.3**
US Deaths in ICU (Mularski, et al, 2004)	38	60.0	14.0	-	-	-	-

Notes: *resident physicians or registrars. *attending physicians or primary doctor.

well-being seems to be a major source of comfort and support, consistent with the findings of an other QODD study[18].

Compared to nurses, relatives report that patients have more frequent negative experiences of some physical and psychological symptoms such as being in pain, uncomfortable, anxious, or worried. The prevalence of pain among patients, for all or most of the time during the last week of life, varies significantly between relatives (34%), nurses (16%) and doctors (11%). Significantly, all of these ratings suggest a lower level of pain compared to previous studies in Ireland[19] and to studies of elderly patients in long-term care in Europe[20], the US[21], and Canada[22].

The patient's quality of life seems to improve in line with staff responsiveness to requests, and the perceived quality of end-of-life care in the ward and hospital. Conversely, it seems to decrease in line with the patient's pain and anxiety, while the number of treatment decisions made by hospital staff, and the receipt of specialist palliative care does not seem to have any direct effect on QODD scores.

Quality of care

The quality of care for patients who die in Irish hospital appears reasonably good, reflected in the fact that a substantial majority of relatives (78%) rate it as 'good or very good'. This however is lower than the corresponding ratings by nurses (91%) and doctors (95%) indicating that, from the perspective of relatives, the quality of care is not as good as nurses and doctors believe.

The concept of 'quality of care' is far from clear-cut, and the different perceptions of relatives, nurses and doctors are underlined by the fact that there is only 30% agreement between them. The fact that communication with patients is consistently assessed by relatives, nurses and doctors as the weakest aspect of care is a challenging finding. Equally challenging is the fact that there is least agreement (10%) in their three assessments on this aspect of care. Relatives perceive the quality of care to be better when staff are responsive to requests, when relatives perceive that end-of-life care in the ward and hospital is good or very good, and when patients are free from pain and anxiety.

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[18] Hodde, Engelberg, Treece, Steinberg, and Curtis, 2004. This study, based on 178 patients who died in ICU, found that: 'Nurses in our study perceived patients with family members or others present at the time of death and those without CPR performed in the 8 hrs before their death as having higher quality deaths' (Hodde, Engelberg, Treece, Steinberg, and Curtis, 2004:1652).

[19] Keegan et al, 1999. This study, based on 155 relatives, found that during the last week, 64% of patients had pain (58% of it very distressing), 83% had trouble breathing (47% of it very distressing), and 50% had anxiety (61% of it very distressing) (Ibid:19, Table 3.1).

[20] Achterberg, et al, 2010. This study, based on 10,015 residents in long-term care in Finland, Netherlands and Italy, found 49% had pain in the last week, leading the authors to conclude: 'The prevalence of pain that we found is indeed alarming, especially because estimates do not show any improvement compared to earlier studies, despite increased attention to its assessment and treatment worldwide. The adoption of a common instrument such as the MDS [Minimum Data Set] allows, for the first time, to compare prevalence rates and to document clinical correlates of pain that are basically identical near the north pole as well as at the borders of Africa. A more widespread adoption of a tool such as the MDS instrument might represent a way to improve the situation, by cross-national benchmarking, and by the exchange of best practices. Implementation of verbal and non-verbal pain scales will help increase recognition of pain, but not necessarily lead to quantitative and qualitatively better (pharmacological) treatment' See also Finne-Soveri, et al, 2000.

[21] Sawyer, et al, 2007. This study, based on 27,628 Alabama nursing home residents found 45% had pain in the last week. Other studies, using different instruments, also indicate 'a pain prevalence of 70-100% among cancer patients' (Lorenz, et al, 2004:2).

[22] Proctor and Hirdes, 2001. This study, based on 3195 nursing home residents in Ontario, Manitoba and Saskatchewan found 50% had pain in the last week. See also Zyczkowska, et al, 2007.

An Acceptable Death

The rate of unacceptable deaths in Irish hospitals is not inconsiderable (21%) and, although much lower compared to French hospitals (58%), it is significantly higher compared to the assessments of nurses (13%) or doctors (3%). This is an important finding given that an acceptable death would appear to be a good indicator of a 'good death' which is one of the core outcomes of the HFH programme, as articulated in the original grant proposal: 'The single most important outcome is the development of a widespread understanding of what constitutes a good death, how that is best achieved and how constraints in achieving it can be addressed'[23].

Post-Mortems

Just under a tenth of all deaths (9%) were followed by a post-mortem, all of them in acute hospitals. This suggests that the sample of relatives under-estimates the true extent of post-mortems since about a fifth of all acute hospital deaths are followed by a post-mortem[24]. Whenever a post-mortem took place, about two thirds of relatives were made aware of the reasons for it in a sensitive, timely, and clear manner. However a third of relatives do not seem to have been properly informed about the reasons for the post-mortem, and were less than satisfied with the information provided by the hospital.

Conclusions and issues for consideration

These findings raise a number of issues which merit further consideration by each individual hospital and their staff, and the HSE generally. In the final section of the report, we outline these issues in detail in order to facilitate discussion, reflection and a considered response.

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[23] Irish Hospice Foundation, 2006, Grant Proposal to Atlantic Philanthropies, 19 July.
[24] McKeown, Haase, and Twomey, 2010a.

1 Introduction

The rationale for studying end-of-life is that, through greater understanding of the journey towards death, it may be possible to respond with greater empathy and compassion to each person at this important threshold of life. This type of study is not a simple undertaking however, since a patient's journey towards death is marked by physical and psychological frailty and decline[25] and that makes it difficult, often impossible, to access the patient's direct experience[26]. Faced with this challenge, the accepted and acceptable method of study is to rely on the patient's reported experience, based on the views of nurses, doctors, and relatives.

The audit follows the procedure used in numerous previous studies where the patient experience is examined through the eyes of nurses, doctors and relatives. Inevitably, these studies raise questions about the correspondence between the patient's actual experience and the patient's reported experience – sometimes referred to as 'patient-proxy agreement'. A full meta-analytic[27] review of these studies has not been undertaken but some of the broad findings, of particular relevance to the audit, are worth noting at the beginning of this report:

1) there tends to be a 'moderate' level of agreement between the reports of patients and those of their relatives[28], nurses and doctors[29].
2) by comparison with patients, nurses and doctors tend to under-estimate symptoms[30] - and doctors tend to under-estimate more than nurses[31] - while relatives tend to over-estimate symptoms[32]. As a consequence of this, there is a general acknowledgement that patient symptoms such as pain may be under-diagnosed and under-treated by hospital staff[33].
3) the reports of nurses and doctors tend to show less agreement with patients when there is severe pain[34] while, for relatives, agreement tends to be less when symptoms are highly subjective and not directly observable[35].
4) nurses, doctors and other health professionals tend not use standardised procedures for assessing and recording pain[36], and this is likely to militate against the accurate diagnosis and treatment of pain.

These findings point to limitations in terms of using the perceptions of relatives, nurses and doctors for understanding the experience of patients. At the same time, however, they are integral to the patient experience since it is the perceptions of

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[25] For example, one study conducted in the UK found that approximately two thirds of palliative care patients could not complete a brief survey (Hearn and Higginson, 1999). Another study found that a similar proportion of cancer patients in a London hospital could not be interviewed (Addington-Hall, et al, 1992).

[26] The patient's experience in hospital, as one review has pointed out, 'is such that no one else can know how it works from one moment to the next, how the different aspects of the experience (the process of care, the manner in which it is delivered, the environment in which it occurs, the physical sense of place) come together, or what they mean for this particular person at this particular moment in their life' (Goodrich and Cornwell, 2008:7).

[27] Meta-analysis is a statistical technique for synthesising individual quantitative studies. Results from these individual studies are entered into a database, and this "meta-data" is "meta-analyzed", using statistical methods similar to those used in primary data analysis. The result is an integrated review of findings that is more objective and exact than a narrative review, as here. The appeal of meta-analysis is that it in effect combines all the research on one topic into one large study with many participants. The danger is that in amalgamating a large set of different studies the construct definitions can sometimes become imprecise and the results may be difficult to interpret meaningfully. The term 'meta-analysis' was first used by Gene Glass in 1976 (Glass, 1976; 2000).

[28] Tang and McCorkle, 2002; McPherson and Addington-Hall, 2003; Teno, 2005.

[29] Horton, 2002; Hearn and Higginson, 1999; Davoudi, et al, 2008.

[30] Davoudi, et al, 2008; Puntillo, et al, 2003; Puntillo, et al, 1997; Bondestam, et al, 1987.

[31] Budischewski, et al, 2006; Nekolaichuk, et al, 1999.

[32] Tang and McCorkle, 2002; McMillan and Moody, 2003; Bondestam, et al, 1987.

[33] Seland, et al, 2005; Puntillo, et al, 2003; Weiner, et al, 1999; Grossman, et al, 1991.

[34] Puntillo, et al, 2006; Grossman, et al, 1991.

[35] Tang and McCorkle, 2002; McPherson and Addington-Hall, 2003.

[36] Seland, et al, 2005; Chanvej, et al, 2004; Bruera, et al, 2005.

nurses, doctors and relatives that have a major influence on the quality of care, and therefore the quality of life, of the patient. In this report, we focus on the perceptions of family and friends and, wherever possible, compare these with the corresponding perceptions of nurses and doctors. Discrepancies in these perceptions pose significant challenges not just in terms of understanding the authentic patient experience but also, as we have seen in the second audit report, because they raise questions about what is the true standard of care offered to patients in their last days and hours. For that reason, this method of auditing end-of-life care provides an important opportunity for hospitals to reflect on the quality of care offered to patients, and the respective weights to be attached to the views of relatives, nurses and doctors.

The focus of the audit is on patients who die in acute hospitals[37] and community hospitals[38]. This, in turn, reflects the fact that most people die outside the home with at least half of all deaths occurring in acute hospitals (48%) or hospices (4%); deaths at home still constitute a quarter of the total (25%), and a fifth die in long-stay facilities (20%); the remainder are deaths from suicide and traffic accidents (3%)[39].

This third audit report is based on data collected using a postal questionnaire sent to the bereaved relatives of patients who died in hospital, and on whom a corresponding questionnaire had already been completed by the nurse, the doctor, or both. A period of three months elapsed between the death of the patient (typically between November 2008 and February 2009) and sending out the postal questionnaire (typically between February and June 2009). This is similar to the 'bereavement period' adopted in other surveys of bereaved relatives[40]. Full ethical approval was granted by each hospital, or network of hospitals, to carry out this survey as well as the other parts of the audit.

Prior to sending out the questionnaire, a designated member of staff in each hospital phoned the bereaved relatives to ask for their consent to send out the questionnaire. There were very few refusals and these were mostly from relatives who were dissatisfied with the experience of the hospital; as a result, this may underestimate the true range of responses among relatives but, in view of the relatively low refusal rate, the extent is probably not great.

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[37] Twenty four (24) acute hospitals participated in the audit. These represent a major part of the sector in Ireland in terms of bed-capacity (74%), number of patients (72%), deaths (71%), and staff (73%); see McKeown, Haase and Twomey, 2010a.

[38] 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. Audit coverage of the community hospital sector is less extensive, comprising just 20% of bed-capacity although the average size of the audited hospitals (110 beds) is considerably higher than the average for all community hospitals (68 beds); see McKeown, Haase and Twomey, 2010a.

[39] McKeown, Haase and Twomey, 2010a.

[40] Similar surveys are those which have used, as in this audit, the Quality of Dying and Death Scale (QODD), or the Family Evaluation of Hospice Care Scale (FEHC). The bereavement periods before contacting the family are as follows:

Study	Achieved sample of relatives	Bereavement period	Response rate
QODD:US Deaths in hospital and home (Curtis, et al, 2002)	252	1-3 years	27%
QODD: US Deaths in ICU (Levy, et al, 2005)	50	1 month	55%
QODD: US Deaths in ICU (Mularski, et al, 2004)	38	4-12 months	38%
FEHC: US Deaths in hospice (Teno, et al, 2007)	106,514	1-3 months	45%

The materials sent to each relative included: a letter of invitation about the survey; the questionnaire; a leaflet on bereavement; and a stamped addressed envelope to return the completed questionnaire. Each questionnaire had a unique ID number, corresponding to the ID on the questionnaire completed by the nurse and doctor on this patient. A national help-line was set up to assist relatives who, on foot of being contacted by the hospital, expressed a need for bereavement support; however only two phone calls were received.

The total number of completed questionnaires returned by relatives was 461, equivalent to a response rate of 46% (Table 1.4). This response rate is within the range found in similar surveys of relatives, both in Ireland[41] and elsewhere[42]. The response rate was somewhat higher where the patient died in a community hospital (52%) than in an acute hospital (45%).

The 461 questionnaires returned by relatives had a corresponding match with a nurse's questionnaire in 86% of cases (398) and with a doctor's questionnaire in 68% of cases (312) (Figure 1.1). This allows detailed analysis on the level of agreement between all three questionnaires.

Figure 1.1: Nurse, Doctor, and Relative Questionnaires in Audit

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[41] In Ireland, one survey achieved a response rate of 57% (Keegan, et al, 1999) while a more recent survey had a response rate of 32% (McCarthy and O'Boyle, 2010).

[42] In the US, four studies which have used either the QODD or the FEHC had response rates of 27% (Curtis, et al, 2002), 38% (Mularski, et al, 2004), 45% (Teno, et al, 2007), and 55% (Levy, et al, 2005).

The sampling error associated with this sample, at the 95% level of probability, is in the 3-4% range for each statistic generated from the sample. In other words, each statistic is likely to be correct for the entire population of audited hospitals to within 3-4% percentage points[43].

The data analysis involves reporting the results for each variable as well as cross-tabulations of selected variables. It is acknowledged that more detailed analysis of the dataset is possible and desirable and this will be presented in the fifth and final audit report (Report Five) [44].

The results are now presented, broadly using the same format as the questionnaires, as follows:
Section 2: Respondent Characteristics
Section 3: Patient Characteristics
Section 4: Ward and Hospital Characteristics
Section 5: Preferences to Die in Single Room
Section 6: Preferences to Die at Home
Section 7: Quality of Staff
Section 8: Quality of Life
Section 9: Quality of Care
Section 10: Acceptability of Way Patient Died
Section 11: Post Mortem

In Section 12 of the report we present our conclusions and raise issues for further consideration. All of the statistical tables are in a Technical Appendix at the end of the report.

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[43] More specifically, frequencies of 10% or 90% have a sampling error in the +/-3% range while frequencies of 50% to 70% have a sampling error in the +/-4% range. This implies that the statistical significance of any relationship between variables can only be determined on a case-by-case basis.
[44] McKeown, Haase and Twomey, 2010e.

2 Respondent Characteristics

This section describes some of the salient characteristics of respondents. Where possible and appropriate, comparative data is used to identify the uniqueness of these respondents.

2.1 Gender and age

The gender breakdown of respondents is approximately two thirds female (65%), and one third male (35%) (Table 2.1). The average age is 57, but one male respondent was aged 82 and one female respondent was aged 89 (Table 2.2a-c).

2.2 Relationship to Patient

A majority of the questionnaires were completed by either a child (41%) or partner (24%) of the patient (Table 2.3). A minority of respondents (24%) were carers of the patient before they entered hospital (Table 2.4). This was more likely where the patient entered a community hospital.

2.3 Attitudes to End-of-Life Care in Hospital

A substantial majority of respondents (68%) believe that end-of-life care in Irish hospitals was good or very good. This should be seen in the context of a national survey of the population, carried out in 2004, which showed that a small majority (57%) reported that end-of-life care in Irish hospitals was good or very good[45]. However, among a sub-sample of that national sample - defined as those who had someone close who died in an Irish hospital in the past two years or so - a much larger majority (75%) reported that end-of-life care in Irish hospitals was good or very good[46]. This suggests that people's experience of hospitals tends to be quite positive[47] and, perhaps more significantly, tends to be more positive among those who speak from direct experience of hospital services. The attitudes of relatives in the audit are also consistent with this result.

Relatives were asked to list the most important things about care when dying. The two most important things, by a wide margin, are: to be free from pain (57%), and to be surrounded by loved ones (20%) (Table 2.6). This contrasts with the results of the national survey referred to in the previous paragraph where the order of priorities is reversed: (i) to be surrounded by loved ones (68%) and (ii) to be free from pain (55%). Equally significant are the perceptions of relatives on the least important things about care when dying: to be in a private space (6% compared to 11% in the national survey); to have spiritual support (6% compared to 19% in the national survey); to be at home (6% compared to 34% in the national survey).

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[45] Weafer & Associates Research, 2004: Figure 12, page 16.

[46] Weafer & Associates Research, 2004: Figure 15, page 19.

[47] In 2007, HSE's Office of Consumer Affairs commissioned a study, comprising a random sample of 3,517 Irish people, on experiences of public health and social care services. A sub-sample of these (344, 10%) had experience of hospital services in the last year and reported high overall levels of satisfaction on dimensions such as: effective treatment by a trusted professional (78%), involvement in decisions and respect for own preferences (75%), clear and comprehensive information (80%), emotional support, empathy and respect (83%), easy to get around the hospital (74%). However there was a marked dip in satisfaction on dimensions such as cleanliness of hospital toilets (62%), contact with the hospital by phone (69%), and car-parking facilities (46%) (UCD and Lansdowne Market Research, 2007).

2.4 Summary

This section has shown that two thirds of respondents are female (65%) with an average age of 57. A majority are either the child (41%) or the partner (24%) of the patient. This profile is broadly similar to two other studies of bereaved relatives in Ireland[48]. In terms of attitudes, respondents are positive about the quality of end-of-life care in Irish hospitals – with two thirds believing it to be good or very good. This suggests, as other studies have done[49], that people's experience of hospitals tends to be more positive among those who speak from direct experience. Respondents regard 'being free from pain' as by far the most important thing about care when dying, in contrast to the findings of a national survey which rated the presence of loved ones as the most important thing about care when dying[50]. The least important things about care when dying, according to relatives, are: to be in a private space, to have spiritual support, and to be at home.

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[48] Keegan, et al, 1999; McCarthy and O'Boyle, 2010.

[49] Weafer & Associates Research, 2004; see also UCD and Lansdowne Market Research, 2007.

[50] Weafer & Associates Research, 2004.

3 Patient Characteristics

This section analyses the main differences between patients on whom relatives completed Questionnaire 3 (461) – on which this report is based - and the larger sample of patients on whom nurses completed Questionnaire 1 (999), on which Report Two is based. Matched data is available for a sub-sample of 398 patients (Questionnaires 1 and 3) and these are compared to the total sample of 999 patients (Questionnaire 1). For 63 patients about whom relatives completed Questionnaire 3, there is no matching data from Questionnaire 1.

The analysis yields the quite remarkable result that, when the sampling error of 3-4% is taken into account, there is no statistically significant difference between patients on whom relatives completed Questionnaire 3 and those who did not. This does not imply that there may not be other unmeasured differences between these two groups of patients, and we have already suggested that some bias may have been introduced by the refusal of some who were least satisfied with the care of their relative, to complete Questionnaire 3. Nevertheless, we can have considerable confidence that the sample of patients on whom relatives completed Questionnaire 3 (461) may be broadly representative of the entire population if patients and relatives.

Given the remarkable similarity between these two groups of patients, it is worth listing the variables on which this is based:

- gender and age
- marital status and living alone
- nationality, ethnicity and religion
- public and private status
- route of admission to hospital
- length of stay in hospital
- expected and sudden deaths
- primary diagnosis.

In summary, these patients are generally 65 years and over and were admitted to hospital through Accident and Emergency Departments (A&E). They are mainly public patients with average length of stay in acute hospitals of 24 days. The three main causes of death reflect the national pattern in terms of their order of priority: circulatory system diseases (31%), cancer (23%), and respiratory system diseases (19%).

4 Ward Characteristics

There is substantial evidence that the physical characteristics of a hospital, especially its wards and rooms, influence the quality of care and the quality of life of patients. This was highlighted in a recent review of research on the use of evidence-based design in health care settings: ‘Compared to 2004, the body of evidence has grown rapidly and substantially … It is now widely recognised that well designed physical settings play an important role in making hospitals less risky and stressful, promoting more healing for patients, and providing better places for staff to work’[51]. In view of that, this section reports on the ward and room where patients spent most of the last week of life, and the relatives’ assessment of that ward and room. We report first on the physical characteristics (Section 4.1) and then on the quality of the ward in terms of both organisation and end-of-life care (Section 4.2).

4.1 Physical Characteristics of Ward where Patient died

In the first audit report we found that 15% of beds in hospitals are in single rooms. Despite this, the second audit report found that a third of patients (33%) spent most of the last week of life in a single room, and more than four in ten (44%) died in a single room. This suggests that hospital staff try to allocate single rooms to patients in order to facilitate a more dignified death, itself indicating an awareness of the importance of single rooms at the end of life. The results from the survey of relatives in this report are consistent with this pattern which again suggests that this sub-sample of patients is broadly representative of the total population of patients (Tables 4.1 and 4.2).

Each relative was asked to rate, on a scale from 1 (very poor) to 10 (excellent), the room where the patient spent most of the time during the last week of life. This involved rating 15 aspects of the room covering privacy (such as allowing conversations with family and staff), dignity (such as facilitating personal care and access to toilet), environment (such as experiencing nature, daylight and quiet), and control (such as altering the temperature, light or air in the room or turn on/off the TV).

Relatives rated the room where the patient spent most of the last week of life at 6.2, with only a slight difference between acute (6.1) and community (6.5) hospitals (Tables 4.3a-d). This overall score is higher than the rating of nurses (5.7) and hospital management (5.8) for these hospital facilities. In percentage terms, relatives either agreed with the scores of nurses (32%) or gave a higher rating (38%) (Tables 4.4a-b).

Further analysis reveals that a majority of the rooms were rated as good or very good in terms of dignity (70%) and privacy (67%), with much lower ratings for environment (46%) and control (30%). These ratings are broadly similar to the ratings of nurses for these facilities but higher than the overall rating of hospital and hospice facilities for end-of-life care in Northern Ireland by both managers (55%)[52] and staff (35%)[53].

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[51] Ulrich, Zimring, Zhu, et al, 2008; Keller and Kronick, 2008; Sadler, Keller and Rostenberg, 2009. The practical implications of this research for improving the design of existing and new hospital facilities are spelt out in Sadler, Keller and Rostenberg, 2009.

[52] In a survey of 143 managers, about 55% of the facilities were rated as good / excellent (Northern Ireland Health and Social Care Bereavement Network, 2009:50).

[53] In a survey of 1,632 staff, about 35% of the facilities were rated as good / excellent (Northern Ireland Health and Social Care Bereavement Network, 2009:53).

Predictably, the rating of single rooms (7.3) is higher than multi-occupancy rooms (5.3). However, given that a majority of patients died in multi-occupancy rooms with at least five other patients and a quarter of these rooms involved mixed gender, it is a little surprising that dignity (7.5) and privacy (7.4) score consistently higher than environment (6.1) or control (4.9). However it is consistent with the fact that relatives gave the lowest priority to 'a private space' when asked to list the most important things about care when dying.

The ratings of relatives are similar for each type of ward. This is broadly similar to the ratings of nurses with the exception of intensive care which they rated as lower than other wards in terms of the quality of the physical environment.

This pattern of results is at variance with an independent observation of 15 acute and 5 community hospitals – all included in this audit - carried out for the HFH programme in 2007 by Tribal healthcare consultants[54]. That study gave an overall score of 3.6 out of 10 for the physical environment of these hospitals, well below the self-assessed score of management (5.8), staff (5.7), and relatives (6.2) in those hospitals. Similarly, the Tribal score for privacy (3.3) is also well below the self-assessed score of relatives (7.4) or nurses (6.7) for this dimension. This clearly suggests that healthcare consultants, possibly because they are more aware of what is available and desirable in terms of evidence-based design in hospitals, are considerably more critical of hospital facilities compared to management, staff and relatives. This in turn underlines the vagaries of self-assessment as a method of auditing a hospital's physical environment and, as the authors of the Tribal study who pointed out, there is 'no recognised structured approach which can be used to assess these conditions [the physical conditions of hospitals] and to compare one hospital with another'[55].

The issue here are not just methodological however; it is also substantive because the physical environment of hospitals directly affects the quality of care. This is underlined by the authors of the Tribal report in their commentary on privacy and confidentiality in the 20 Irish hospitals which they observed: 'Throughout the review, a general finding was that the lack of single rooms and use of multiple bed bays means that patients and relatives are not afforded the dignity that they deserve. Although generally the wards allowed for a degree of gender separation, this was not always the case with there being several examples of mixed gender wards and bed bays. It is recognised best practice to separate male and female patients into different wards, or areas. This is clearly to provide each with dignity, privacy and respect. Where this is not possible, it completely breaches privacy and dignity issues, which may become heightened where a person is nearing the end of life and may require more levels of personal support and intervention. The ward layouts did not tend to allow for any significant level of privacy for patients or visitors from an acoustic or visual perspective given that the main bed complement of the wards is based on multiple bed bays. This was particularly apparent in the older estate facilities where there were poor ward layouts and not enough space between each bed on the ward. … Noise levels where often high in many of the wards visited. … In general, there was a lack of quiet spaces, interview or relatives' rooms across all sites, preventing opportunities for confidential discussion and/or quiet reflection' [56].

4.2 Quality of Ward

The audit asked relatives two questions to determine the quality of the ward:

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[54] Tribal, 2007.
[55] Tribal, 2007:iii.
[56] Tribal, 2007:13.

(i) do you think the ward was well-organised?
(ii) overall, how would you rate this ward as a place for someone to get care at the end of their life?

In response to the first question, nine out of ten relatives indicated that the ward was either very well organised (54%) or relatively well organised (35%) (Table 4.6). Differences between acute and community hospitals are slight and unlikely to be statistically significant.

In response to the second question, two thirds of relatives (66%) believe the wards to be good or very good at end-of-life care, but one third (33%) are either average, poor or very poor (Table 4.7). Community hospitals are seen as being significantly better at providing good or very good end-of-life care (79%) compared to acute hospitals (64%). The pattern of results to this question suggests that it captures some significant sources of variation in the experiences of relatives, and that is confirmed in the subsequent analysis in this report (see Sections 6-10 below).

4.3 Summary

This section examined how relatives perceived the ward and room where the patient spent most of the last week of life, given that this is known to influence the quality of care and the quality of life[57]. Relatives rated this room at 6.2 out of 10, higher than the corresponding rating of nurses (5.7) and hospital management (5.8). By contrast, independent healthcare consultants gave an overall score of 3.6 out of 10 for the physical environment of 15 acute and 5 community hospitals – all included in this audit – in 2007[58].
Predictably, relatives rated single rooms (7.3) higher than multi-occupancy rooms (5.3). However, given that a majority of patients died in multi-occupancy rooms with at least five other patients and a quarter of these rooms involved mixed gender, it is a little surprising that dignity (7.5) and privacy (7.4) scored consistently higher than environment (6.1) or control (4.9). However it is consistent with the fact that relatives gave the lowest priority to 'a private space' when asked to list the most important things about care when dying.

Relatives were also asked to rate the quality of the ward in terms of its organisation and the its end-of-life care. In terms of organisation, nine out of ten relatives believe the ward is either very well organised (54%) or relatively well organised (35%). However, much greater variation was revealed in terms of relatives' perceptions of the ward's end-of-life care with two thirds (66%) believing the ward to be good or very good, but one third (33%) believing it to be either average, poor or very poor.

Overall, these results suggest that relatives see the physical environment of wards in a positive light, much like nurses and hospital managers. Given that these perceptions are at variance with independent healthcare consultants – and with the standards that are increasingly being prescribed for new hospitals - this suggest a lack of awareness among hospital staff and relatives about what is possible and desirable in terms of evidence-based design in hospitals. At the same time, relatives see beyond the physical context of the ward and seem to be more discriminating in rating the quality of end-of-life care provided by wards.

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[57] Ulrich, Zimring, Zhu, et al, 2008; Keller and Kronick, 2008; Sadler, Keller and Rostenberg, 2009. The practical implications of this research for improving the design of existing and new hospital facilities are spelt out in Sadler, Keller and Rostenberg, 2009.
[58] Tribal, 2007.

5 Preference to Die in Single Room

It is a core principle of the HFH programme that a patient should be facilitated to die in peaceful and dignified surroundings within the hospital and, where possible, their preference to die in a single room should be respected. These are value-based principles but they are also evidence-based given the importance of well-designed hospital spaces to the well-being of patients[59]. Against this background, we asked relatives to report on the patient's preference for a single room, including the relative's own preferences for the patient, and the extent to which those preferences were met.

Just under half of all patients (48%) died in a single room, higher in acute (49%) than in community (39%) hospitals (Table 5.1a-b). This compares to about 70% of patients who die in single rooms in hospitals in Northern Ireland[60]. However it also needs to be seen in the context that only about 15% of beds in Irish acute and community hospitals are in single rooms[61].

Nearly half of all patients who died in a shared room would have preferred a single room (45%), while two thirds of their relatives would have preferred a single room for the patient (64%) (Tables 5.2a-b). This suggests that there is a substantial unmet preference for patients to die in a single room which, given the high proportion of patients who did not express a preference, could range from 24-40% of all deaths.

These findings, as they relate to acute hospitals, are consistent with a previous study of bereaved relatives in Ireland which noted that 'the issue of lack of privacy and not having a room at the time of death was frequently raised as a dissatisfying incident'[62]. Similarly, a study of hospital practitioners found that 'the inadequacies of … hospital space in terms of providing a place for dying patients and their relatives was highlighted over and over again in the research'[63]. At the same time, it should also be borne in mind that relatives gave the lowest priority to 'a private space' when asked to list the most important things about care when dying.

Overall, the limited stock of single rooms (15%) in acute and community hospitals, and the competing demands for those rooms, effectively means that the end-of-life wishes of a significant minority of patients (ranging from 24-40% of all deaths) cannot be met. This is a significant challenge for hospitals. At present, the stock of single rooms in Irish hospitals, both acute and community, falls way below all standards for this type of accommodation. In the US, 100% single rooms have now been adopted as the standard for all new hospital accommodation[64], while in the UK a minimum of 50% of single rooms is now the standard[65]. In Ireland, a draft of the infection control building guidelines recommends that 100% of in-patient accommodation in newly

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[59] Ulrich, Zimring, Zhu, et al, 2008; Keller and Kronick, 2008; Sadler, Keller and Rostenberg, 2009.

[60] This estimate is taken from the audit of dying, death and bereavement in Northern Ireland. Most deaths were in the three areas of general medicine (40%), elderly care (20%) and general surgery (10%) where the proportion 'cared for in a single room on more than 75% of occasions' is 65%, 75% and 80% respectively (Northern Ireland Health and Social Care Bereavement Network, 2009:6 and 28). From this it is a reasonable inference that around 70% of deaths are in single rooms.

[61] McKeown, Haase, and Twomey, 2010a.

[62] Keegan, et al, 1999:15.

[63] Quinlan and O'Neill, 2009:4. This study, based on practitioners who manage end-of-life in hospitals in Ireland, consisted of 102 written narratives, 57 interviews, and 14 focus groups with 104 practitioners.

[64] Facility Guidelines Institute and the AIA Academy of Architecture for Health, 2006. Available at: http://www.fgiguidelines.org/guidelines.html. Accessed 20 March 2009.

[65] Cited in Fitzpatrick, Roche, Cunney and Humphreys, 2009:278. Significantly, the proportion of 'side-rooms' in English hospitals (15%) which use the Liverpool Care Pathway, similar to the proportion in Ireland (Marie Curie Palliative Care Institute Liverpool, 2009:23).

built acute care hospitals should be single-patient rooms[66]. Significantly, the HIQA standard for residential care facilities for older people in Ireland, requires that there must be 80% single rooms for 'the newly built residential care setting, new extension or first time registration'[67].

These standards are a national challenge for the hospital system not just because of the importance of meeting patient preferences – bearing in mind that the preference for single rooms is not confined to patients at the end of life[68] – but also because of the need to control hospital-acquired infections[69], and the need to ensure equal access to single rooms for patients on the basis of need[70]. The consequences of inadequate hospital accommodation for patients at the end of life was underlined in an earlier study of 20 hospitals in Ireland which concluded that the lack of single rooms 'does not provide flexibility or choice on the ward for staff to support a dying patient and their family in privacy, if required. Where single rooms were available they were predominantly used for isolation purposes in respect of infection control policies and MRSA management. At certain sites there was also the added demand for the use of single rooms for private patients'[71].

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[66] Cited in Fitzpatrick, Roche, Cunney and Humphreys, 2009:278-9

[67] Health Information and Quality Authority, 2008:45

[68] There is a growing body of research which shows that patients and their families prefer single rooms for a variety of reasons including: visual and auditory confidentiality and privacy; reduced noise levels; control over personal information; opportunity to rest; and peacefulness of the dying process. For a review of the research, see Hugodot, 2007; Ulrich, 2008; see also Hugodot, A., and Normand, C., 2007.

[69] A key concern with hospital accommodation is that the control of infection is increasingly hindered by the absence of single rooms where infected patients can be isolated (See Fitzpatrick, Roche, Cunney and Humphreys, 2009; see also Dowdeswell, Erskine and Heasman, 2004).

[70] It has also been observed that 'a significant proportion of the existing single rooms in public hospitals are private patient beds' (PA Consulting Group, 2007:71).

[71] Tribal, 2007:11

6 Preference to Die at Home

The preference to die at home is an aspect of patient autonomy. Autonomy is a core concept of the HFH Programme and is defined as the capacity for self-determination, which is manifested in the person's ability to make choices about their life. The moral principle of autonomy requires that, in a healthcare context, health professionals recognize and support the values, priorities and preferences of patients. This means that the needs and wishes of the dying person - and not just their family - must be taken into account. However, autonomy is not an absolute right: the right to autonomy is limited by the legitimate autonomy and welfare claims of others. Health professionals may constrain autonomous choices by deciding to limit treatment options where they might pose a harm or disadvantage to others, or where a patient is insisting on a treatment which is deemed futile.

The importance of dying at home is also underlined by studies which show that patients who die at home, and who die in the place they prefer, have a better quality of dying compared to those who do not[72]. In addition, it is known that a majority of Irish people would prefer to die at home[73] and even doctors and nurses have a stronger preference to die at home compared to patients[74]. Dying at home is also relevant in the context of a growing realisation that many patients who are treated in acute hospitals in Ireland could be treated as well, and more cost effectively, in other settings[75]. We saw in the second audit report[76] that patients who die in Ireland's acute hospitals spend at least twice as long there before dying compared to other countries such as the UK[77], the US[78] and the OECD[79], and this inevitably raises

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[72] Curtis, Patrick, Engleberg, Norris, Asp, and Byock, 2002. This study, based on the Quality of Dying and Death (QODD) instrument completed by relatives on 252 patients who died at home or in hospital found that: 'Decedents who died at home had a significantly higher QODD score than those dying in other settings (P=0.006). Decedents who died in the setting where the respondent told us they died in the setting where the respondent told us they wanted to die also had higher QODD scores that approached our definition of statistical significance (P=0.013)' (Curtis, Patrick, Engleberg, Norris, Asp, and Byock, 2002:25).

[73] In a survey of 1,000 adults aged 15+ in the Republic of Ireland, carried out in 2004, 67% indicated that they would like to be cared for at home if they were dying (Weafer and Associates, 2004:10-11).

[74] This is based on a survey of 1,899 ICU doctors, nurses and patients in six European countries, who were asked where they would rather be if they had a terminal illness with only a short time to live; the results showed that more doctors and nurses would prefer to be at home or in a hospice and more patients and families preferred to be in an ICU (Sprung, Carmel, Sjokvist, et al., 2007). The same study also revealed that physicians provide more extensive treatment to seriously ill patients than they would choose for themselves, possibly indicating a public demand for life-prolonging interventions that may have little prospect of success.

[75] In Ireland, a random sample of 3,035 medical and surgical in-patients across 37 acute hospitals were reviewed between November 2006 and February 2007 by PA Consulting Group and Balance of Care Group (2007) for the HSE. The results of this study, though not focused on end-of-life, showed that 13% could have been treated outside an acute setting, 75% of elective survey patients were admitted earlier than necessary, 39% of day patients could have been treated in an alternative setting, and discharge planning was in evidence from the notes of 40% of patients. In the UK, the National audit office found that 'forty per cent of the 200 patients who died in hospital were found not to have had medical needs which required them to be in hospital at the point of admission, and could have been cared for elsewhere' (National Audit Office, 2008:28). Significantly, the study also found that: 'These patients used 1,500 bed days in acute hospitals. Assuming the cost of an inpatient day in an acute hospital to be £250 … this suggests that over the course of a year up to £4.5 million could be made available for end of life care in the community in Sheffield through more appropriate use of hospital care for people approaching the end of their life' (Ibid).

[76] McKeown, Haase and Twomey, 2010b.

[77] A study of 599 deaths in an acute hospital in the south west of England found that the average length of stay before death was 12 days (Abel, Rich, Griffin and Purdy, 2009:3 and Table 6). A study of 314 cancer deaths in Boston Lincolnshire between September 2006 and March 2007 found that the average length of stay before death was 16.6 days (Addicott and Dewar, 2008:Tables 4 and 7).

[78] Martin, Nelson, Lloyd, and Nolan, 2007:6; see also Wennberg, et al, 2004. This target was set following research published by Dartmouth Atlas which showed that length of stay in the last six months of life varied across the US from 4.87 to 19.67 days for the same diagnostic categories and independently of need and outcome albeit with significant variations in cost (Wennberg, Fisher, Stukel, Skinner, Sharp, and Bronner, 2004). At the same time, setting targets for average lengths of stay, also needs to recognise that short lengths of stay combined with high occupancy levels can put pressure on the quality of care. A recent study of the factors enabling compassionate care in acute hospital settings noted that: 'The factor that has arisen again and again in terms of producing stress and reducing compassion is the heightened bed occupancy within hospitals. As hospitals cope with increasing patient

questions about whether this reflects the case-mix of patients or, more likely[80], the overall management of hospitals and health services generally. In line with this, the HSE's five-year development framework for palliative care services acknowledges the need for some 'reorientation and reconfiguration of existing resources' within the sector[81].

Against this background, the audit used three questions to measure preferences for dying at home. The first question asked: During the last week of life, did your relative or friend say that they would like to die at home? The results indicate that, during the last week of life, very few - just over a tenth of patients (14%) - would like to die at home (Table 6.1). Most indicated that they would not like to die at home (76%) with no information on the remainder.

The second question asked: Depending on your relative's or friend's condition during their last week of life, do you think they could have been allowed to die at home if there was enough support? The responses to this question indicate that nearly a quarter of patients (24%) were assessed by relatives as being able to die at home. This is almost identical to the proportion of patients, in the second audit report, who were assessed by nurses (22%) and doctors (22%) as capable of dying at home, which is somewhat similar to another study where doctors and nurses assessed that 18% of patients who died in a hospice or hospital could have died at home[82]. However when the assessments of relatives, nurses and doctors are compared on a case-by-case basis, it reveals that all three agree in only 29% of cases, while nurses and doctors agree in only 48% of cases (Table 6.2). This suggests a modest level of agreement on how to assess the suitability of patients for dying at home, either among professionals, or in consultation with relatives.

The third question asked: During their last week of life, would you have liked your relative or friend to be cared for at home? The responses indicated that four out of ten relatives (40%) would have liked the patient to die at home. It is clear from this, given the relatives' assessment that only 25% of patients could have died at home, that the preferences of some relatives may be 'unrealistic'. In these cases, the

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demand and higher levels of throughput, it becomes even more important to address humanity within the process, dealing compassionately with staff so that they in turn can do the same for patients. There is of course noting wrong per se with technically focused, rapid treatment, high-turnover, and short lengths of hospital stay – only a minority of patients would willingly prolong their stay in hospital – but it is important for compassion to be seen and valued as essential to the delivery of care, not an option or add-on' (Firth-Cozens and Cornwell, 2009:12).

[79] The OECD average length of stay is 6.3 days (OECD, 2007:73).

[80] In the introduction to the 2009 HSE National Service Plan, the CEO observed that: 'There is no acceptable reason why people in Ireland should have to spend longer in an acute hospital than those in comparable countries for the same conditions and procedures. To address this issue and improve on our ability to deliver consistently high quality patient experiences, we will continue to modernise many front line services in keeping with our overall strategic direction as set out in our Corporate Plan 2008-2011. … . Our focus on making services more easily available through enhanced community services is now widely accepted and, as a result of the continued commitment to community based care from Government, more new developments will be rolled out during 2009. We will also continue to integrate hospital and community based services so we can provide more seamless and streamlined services, support more direct clinical involvement in management and at the same time devolve more responsibility and authority locally within defined national parameters' (Health Services Executive, 2009:iv).

[81] HSE Palliative Care Services – Five Year Development Framework 2009-2013, 2009. A review of evidence on the cost of end-of-life care concluded that: 'hospice care saves money at all levels of analysis when compared with the alternatives. Sustained support for hospice care will ensure the integration of a cost-effective and desirable alternative in the health service' (Murray, 2009:103). An exception to this is a recent study on the impact and costs of The Marie Curie 'Delivering Choice Programme' in Lincolnshire, England. This programme, whose aim is to develop services for people who choose to die at home, found that 'the project in Lincolnshire has significantly increased the proportion of deaths at home and decreased the proportion of deaths in hospital, while keeping the overall combined cost of acute and community care stable for patients receiving palliative care in the last eight weeks of life ….. As such, we can conclude that the findings presented here demonstrate that the programme has successfully achieved its objective while not incurring any additional costs on the health care system or indeed incurring any significant overall shifts in costs between the acute and community sectors.' (Addicott and Dewar, 2008:33).

[82] Tiernan, Connor, Kearney, and Siorain, 2002.

responses of relatives, which were three months after the death, may be influenced by a sense of grief and loss for the patient, and the belief that greater intimacy with the patient during their last week might have been possible at home. At the same time, relatives rated dying at home as one of least important things about care when dying (6% compared to 34% in national survey).

Further analysis was carried out to see what factors might influence relatives when they assess a patient as being able to die at home, given enough supports. This revealed that the assessment of relatives is strongly influenced by how relatives perceive the quality of care in the ward and hospital. For example, relatives are more likely to assess a patient as suitable to die at home when the responsiveness of staff to their requests is rated as average or poor (Table 6.3). Similarly, relatives are more likely to assess a patient as suitable to die at home when the quality of end-of-life care on the ward, and in Irish hospitals generally, is rated as average or poor. In addition, patients who are perceived by relatives, nurses and doctors as being anxious or afraid are also deemed suitable to die at home (Table 6.4). Taken together, these findings suggest that the assessments of relatives on whether a patient could die at home are influenced by both the psychological well-being of the patient and the quality of end-of-life care in the ward and hospital. In other words, the way a relative assesses a patient as being able to die at home may indicate more about their experience of how the hospital is caring for the patient rather than a more objective assessment of the most suitable place to die.

Overall, the audit reveals that just over a tenth of patients indicated to relatives (14%), during the last week of life, that they would like to die at home. In the assessment of relatives, nearly a quarter of all patients (24%) could have died at home if there was enough support, similar to the overall assessments made by nurses (22%) and doctors (22%). However a case-by-case comparison of these assessments indicated that relatives, nurses and doctors agree in only 29% of cases, while nurses and doctors agree in only 48% of cases. This suggests that each has a different approach to making these assessments. Further analysis reveals that the assessments of relatives are more indicative of the quality of end-of-life care in the ward and hospital rather than the physical or psychological condition of the patient. In other words, relatives are more likely to assess a patient as being able to die at home if the quality of hospital care is not satisfactory. This is an important finding and suggests that hospital staff should be aware that, for relatives at least, the suitability of dying at home may be more indicative of an unsatisfactory service rather than a more appropriate response to patient needs.

A further implication of these findings, particularly in view of the modest level of agreement between nurses and doctors, is that hospital staff may not have an agreed methodology to make these assessments accurately and consistently. This limitation is clearly acknowledged in another Irish study involving assessments by nurses and doctors on the feasibility of dying at home which were deemed to be limited 'not least because of the lack of standardisation and objectivity in the judgements of the doctors and nurses with respect to the feasibility of care at home with adequate nursing support. Adequate nursing support was not defined in this study, nor was it possible to state accurately the quantity or quality of care that would have been required to allow a patient be cared for at home'[83]. Clearly, any measures to facilitate patients to die at home must first involve a proper assessment of their needs, using protocols that have been tried and tested elsewhere. In order to facilitate the planning of services therefore, the assessment of a patient's suitability to

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[83] Tiernan, Connor, Kearney, and Siorain, 2002:234.

die at home, would need to be carried out and peer reviewed, in order to establish the likely scale of alternative support services needed[84].

In the second audit report, we estimated that over €80 million could be made available for end-of-life care if 22% of patients died at home rather than in acute hospitals[85]. This is something worth investigating further but would need to be done as part of a whole-system approach to end-of-life care and the creation of a network of services which support patients to die at home, in nursing homes, and in hospices as their needs and preferences require. The rationale for a whole-system approach is that 'It is no good taking care out of hospitals if it leaves behind 'stranded costs' – both from staffing and infrastructure. If these are not removed from the system and savings passed back … for maintaining the supply of other services, care closer to home will cost more than the current pattern of hospital-based care'[86.]

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84 Some of the alternative supports could include adequate nursing care, night sitting service, good symptom control, confident and committed general practitioners, access to specialist palliative care, effective co-ordination of care, financial support, and terminal care education.

85 This calculation is based on a number parameters. There were 11,412 deaths in the 38 acute hospitals in Ireland's HIPE system in 2007 (the latest data available). The average cost of an inpatient day varies from €825 in a major regional hospital to €1,917 in a major teaching hospital, equivalent to an overall average of €1,371 per day (PA Consulting Group, 2007:155). The audit reveals that 22% of deaths could have taken place at home, and the average length of stay for deaths in acute hospitals is 24 days. This results in the usage of 60,203 bed days by these patients. The cost of these bed days, in turn, is approximately €82.5 million.

86 Harvey, Liddell and McMahon, 2009:41. Significantly, these authors add: 'At the moment, there is little firm evidence that care closer to home is cheaper than hospital-based care (although there may be some quality benefits). It would be useful if an authoritative study were undertaken to show how the benefits – including the reduction of costs in acute hospitals – could be derived. This would need to recognise that changes in the way care is delivered should be system-wide' (Harvey, Liddell and McMahon, 2009:42). A recent study on the impact and costs of The Marie Curie 'Delivering Choice Programme' in Lincolnshire, England found that 'the project in Lincolnshire has significantly increased the proportion of deaths at home and decreased the proportion of deaths in hospital, while keeping the overall combined cost of acute and community care stable for patients receiving palliative care in the last eight weeks of life ….. As such, we can conclude that the findings presented here demonstrate that the programme has successfully achieved its objective while not incurring any additional costs on the health care system or indeed incurring any significant overall shifts in costs between the acute and community sectors.' (Addicott and Dewar, 2008:33). However, a review of evidence on the cost of hospice care concluded that: 'hospice care saves money at all levels of analysis when compared with the alternatives. Sustained support for hospice care will ensure the integration of a cost-effective and desirable alternative in the health service' (Murray, 2009:103).

7 Quality of Staff

The audit measured the quality of staff by asking relatives three questions. The first question asked: During the last week of life of your relative or friend, how would you rate the way the staff responded to your requests? The results show that over eight out of ten relatives (83%) rated the responsiveness of staff as good or very good (Table 7.1). Relatives experienced staff in community hospitals as slightly more responsive compared to staff in acute hospitals (94% compared to 82%).

The second question asked: What did you think of the quality of the staff – nursing, medical, other - on the ward where your relative or friend died? The results also show that nearly nine out of ten relatives rated the quality of all staff as good or very good, with no difference between staff or between acute and community hospitals (Table 7.2).

The third question asked: Were there enough staff – nursing, medical, other - on the ward where your relative or friend died? The responses indicate that a quarter of relatives found there were not enough nursing and medical staff in acute hospitals (Table 7.3). Relatives were much less likely to report that there were not enough 'other staff', or not enough staff in community hospitals.

Overall, relatives give a high rating for the quality of all staff – nursing, medical, other - in both acute and community hospitals. The responsiveness of staff is also highly rated, especially in community hospitals. These results paint a positive picture of staff quality and responsiveness, and are consistent with other findings which show relatively high levels of satisfaction among people who have direct experience of Irish hospitals[87].

It is significant that a quarter of relatives felt there was not enough nursing and medical staff in acute hospitals. This may be due to their experience that staff do not have – and are not given – enough time to be with patients and relatives. It is increasingly recognised that the amount of time spent by staff with patients is a subtle and important determinant of quality of care[88], and we will test this further in Report Five. Equally, it is recognised that 'time for the patient' is shaped by organisational and human factors within the ward and hospital. For example, evidence from the UK has shown that ward-based nurses spend up to 40% of their time on so-called 'non-productive' activities such as: paperwork; fetching, carrying, searching for missing items; and shift handovers[89]. This suggests that reducing the amount of time nurses spend on non-productive work is a necessary condition for increasing the time spent with patients. However, the sufficient condition is that hospital and ward management must ensure that the additional time created through re-structuring activities is spent with patients. This will involve positive reinforcement and support for nurses, and other caregivers, to be more physically and emotionally

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[87] See, for example, Keegan et al, 2009. In 2007, HSE's Office of Consumer Affairs commissioned a study, comprising a random sample of 3,517 Irish people, on experiences of public health and social care services. A sub-sample of these (344, 10%) had experience of hospital services in the last year and reported high overall levels of satisfaction on dimensions such as: effective treatment by a trusted professional (78%), involvement in decisions and respect for own preferences (75%), clear and comprehensive information (80%), emotional support, empathy and respect (83%), easy to get around the hospital (74%). However there was a marked dip in satisfaction on dimensions such as cleanliness of hospital toilets (62%), contact with the hospital by phone (69%), and car-parking facilities (46%) (UCD and Lansdowne Market Research, 2007). Similarly, a majority of people (75%) who had someone close die in an Irish hospital in the past two years or so reported that end-of-life care in Irish hospitals was good or very good (Weafer & Associates Research, 2004: Figure 15, page 19).

[88] Cornwell, 2009:4.

[89] Nolan, 2007.

present to the people they care for. This is the challenge for hospital management which is implicit in these findings.

8 Quality of Life

The quality of life of patients during their last week is simultaneously a measure of their living and dying. It is therefore an important indicator of a hospital's end-of-life care since quality of life is as intrinsically valuable as life itself. Reflecting this, it is the preference of the majority of Irish people that, if they were ill with no hope of recovery, the quality of life would be more important than how long it lasted[90].

One of the established, and recommended[91], instruments for measuring this is the Quality of Dying and Death Instrument (QODD)[92]. This is a multi-item questionnaire in two parts: Part A records the frequency of the patient's experience (covering physical and psychological symptoms of personal well-being, and relationship well-being such as spending time with loved ones) and Part B rates the quality of that experience for the patient on a scale from 1 ('terrible' which we re-labelled 'unsatisfactory') to 10 ('perfect' which we re-labelled 'satisfactory'). The questionnaire is usually self-administered by doctors, nurses and family members, but can also be interviewer-administered. In the audit, a 25-item version of the QODD was self-administered by nurses (and the results reported in the second audit report[93]). A 22-item version was self-administered by bereaved relatives and is reported here. The total QODD score is derived by adding the scores from each individual item, dividing the result by the total number of items, and multiplying that by 100 to yield a score range from 0 to 100. We now report the results for Part A (frequency of patient experience) and Part B (quality of patient experience).

8.1 Frequency of Patient Experience

The patient experience can be summarised into two broad domains covering personal well-being and relationship well-being. Personal well-being comprises both physical symptoms (such as pain, difficulties eating or breathing, not having energy) and psychological symptoms (such as anxious, worried, maintaining dignity). Relationship well-being comprises experiences such as spending time with partner, children, friends including having someone there at the time of death.

These experiences have the natural qualities of being either desirable and attractive (such as spending time with partner, children, friends) or undesirable and aversive (such as pain, difficulties eating, being anxious or worried). In view of this, we re-scaled all of the experiences so that the least frequency also corresponds with undesirable and aversive experiences and the most frequency corresponds with desirable and attractive experiences. We also standardised each score to a common scale (1-6) and then re-scaled everything to 100, in line with the procedure for Part B of the QODD[94].

The results show that, in the opinion of relatives, patients experience relationship well-being (69 out of 100) more frequently than personal well-being (55 out of 100)

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[90] This is based on a national survey of 667 adults who were interviewed by telephone in September 2007. In response to the statement - if I were ill with no hope of recovery, the quality of my life would be more important than how long it lasted - 63% agreed strongly and 18% agreed somewhat (Weafer, McCarthy and Loughrey, 2009:35).

[91] Mularski, et al, 2007:1855.

[92] Developed by, and available from, the University of Washington End of Life Care Research Program at: http://depts.washington.edu/eolcare/instruments/index.html. The Quality of Dying and Death Instrument (QODD) was developed by Donald Patrick, Ruth Engleberg and Randall Curtis (Patrick, Engleberg and Curtis 2001) and has been used in four studies (Curtis, Patrick, Engleberg, Norris, Asp, and Byock, 2002; Hodde, Engelberg, Treece, Steinberg, and Curtis, 2004; Mularski, Heine, Osborne, Ganzini, and Curtis, 2005; Levy, Ely, Payne, Engelberg, Patrick and Curtis, 2005).

[93] McKeown, Haase and Twomey, 2010b.

[94] A detailed description of the methodology is outlined in the technical appendix.

(Tables 8.1a-b). This implies that, during their last week of life, patients are more challenged by their physical and psychological symptoms than by their relationships with family and friends. Significantly, these challenges do not vary by type of hospital, ward, or room, or by the patient's age, sex, illness, or length of stay in hospital.

Given that the QODD was completed by nurses as well as relatives, it is useful to compare the level of agreement between them on the frequency of each item (Table 8.2) The results reveals two important results. First, relatives are likely to report that patients have more negative experiences compared to nurses, especially for some physical and psychological symptoms such as pain, uncomfortable, anxious, worried. By implication, these are the areas of least agreement - averaging 46% - between relatives and nurses. This finding is consistent with another QODD-based study which found that relatives report a higher frequency of symptoms, and a more negative impact of symptoms on the quality of life of patients[95].

Second, relatives and nurses are more likely to agree on experiences related to relationship well-being such as spending time with partner, children, friends including having someone there at the time of death. By implication, these are the areas of most agreement - averaging 71% - between relatives and nurses.

The audit collected data on three symptoms associated with end-of-life - pain, breathing difficulties, anxiety - from nurses, doctors and relatives. This data allows us to compare these symptoms from these three different perspectives and the results highlight four important findings (Tables 8.3a-b):
(i) relatives report a higher frequency of all three symptoms compared to nurses and doctors.
(ii) nurses report either the same or higher frequency of symptoms as doctors, but never lower.
(iii) nurses and doctors have a higher level of agreement[96] on symptoms (78%) compared to either relatives and nurses (67%) or relatives and doctors (70%).
(iv) the prevalence of symptoms for all or most of the time during the last week of life is much higher for breathing difficulties than for pain, or anxiety.

The 'true' prevalence rate for these symptoms cannot be inferred from this data, since it is heavily influenced by the perspective of each. However if, to take one of these symptoms, the prevalence for pain is set in comparative perspective, then it would appear to be lower compared to previous studies in Ireland[97] and to studies elsewhere of elderly patients in long-term care where a common and validated assessment instrument was used and completed by nurses[98]. The broad consensus

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[95] In a small study using the QODD in a New York hospital, family members (10) give significantly more negative ratings for the patient's quality of life compared to nurses (9) for the following symptoms: able to feed himself / herself; appear to breathe comfortably, appear to feel at peace with dying, say goodbye to loved ones (O'Mahony, et al, 2009:Table 2).

[96] Note that the measurement of agreement is sensitive to the number of response categories for each question and the level of agreement tends to fall as the number of response categories increases. For example, questions with 10 response categories will show a much lower level of agreement, other things being equal, than questions with four or two response categories. In view of that, we measured agreement on these three symptoms - pain, breathing difficulties, anxiety - using two response categories (See Section 13.5 in the Technical Appendix).

[97] Keegan et al, 1999. This study, based on 155 relatives, found that during the last week, 64% of patients had pain (58% of it very distressing), 83% had trouble breathing (47% of it very distressing), and 50% had anxiety (61% of it very distressing) (Ibid:19, Table 3.1).

[98] The instrument is referred to as the Minimum Data Set (MDS) and is part of the interRAI Long Term Care Facility Resident Assessment Instrument (interRAI LTCF). It is designed to assess the needs, strengths, and preferences of those in long-term care settings (www.interrai.org). The MDS assessment combines a physical examination, patient history, observation, consultation with other caregivers, and information abstracted from medical records. Where used, a full MDS assessment is performed within 7 days of admission to the facility, after 30 days, and quarterly thereafter. In the 1990's, the MDS instrument was mandated for all nursing homes in the US, and several European countries have since tested and progressively introduced it into routine practice, notably Netherlands, Italy, Sweden,

of these studies - in Europe[99], the US[100], and Canada[101] - is that about 50% of patients experienced pain in the last week and, in half of these cases, the pain was categorised as daily. These results suggest three possibilities regarding Irish patients who die in acute and community hospitals: (i) their pain is correctly-assessed and correctly-treated; (ii) their pain is under-assessed and under-treated; or (iii) some combination of both depending on the practice and protocols in each setting. None of these possibilities can be proven from the data available. Nevertheless, the divergence of views between relatives, nurses and doctors raises questions about the diagnosis and treatment of pain among patients who die in Irish hospitals, particularly when viewed from the perspective that, by far the single most important thing about care when dying, in the opinion of relatives, nurses and doctors, is to be free from pain (see Section 2 above and Report 4).

The analysis in this report is purely descriptive since detailed statistical analysis will be presented in the final report (Report Five). However a cross-tabulation of selected variables with QODD scores suggests that, when sampling error is taken into account, the frequency of a patient's positive experiences is influenced by the responsiveness of staff to requests and the quality of end-of-life care in the ward and hospital (Table 8.6). In addition, there is equally strong evidence from the cross-tabulations that the presence of pain and anxiety – but not breathing difficulties – have a significantly reduce the patient's positive experiences (Table 7.7). By contrast, neither the number of treatment decisions made by hospital staff nor the receipt of specialist palliative care seem to have a direct influence on QODD scores (Tables 8.4 and 8.5). These findings, though consistent with other studies[102], remain indicative pending a full statistical analysis in Report Five.

Norway, Finland and Denmark. Currently, the EU commission is funding an eight-country study to assess and validate the MDS for use in nursing homes in Europe; referred to as the SHELTER Study at (www.shelter-elderly.eu), it includes Italy, Czech Republic, Germany, Finland, France, Israel, The Netherlands, Spain, and the United Kingdom. The MDS assessment is filled out primarily by nurses who know the resident well. Pain is measured in terms of frequency (coded as no pain; less than daily pain; and daily pain in the last 7 days) and intensity (code as no pain; mild pain; moderate pain; and severe pain). The validity and precision of the MDS for measuring pain has been established against the Visual Analogue Scale in a study involving 95 US nursing home residents (Fires, et al, 2003). The definition of pain in the MDS is: "Pain refers to any type of physical pain or discomfort of the body. Pain may be localized to one area, or be more generalized. It may be acute or chronic, continuous or intermittent (comes and goes), or occur at rest with movement. The pain experience is very subjective; pain is whatever the resident says it is." [Morris, et al, 1995]. Coding instructions are: "Code for the highest level of pain present in the last seven days." [Ibid].

[99] Achterberg, et al, 2010. This study, based on 10,015 residents in long-term care in Finland, Netherlands and Italy, found 49% had pain in the last week, leading the authors to conclude: 'The prevalence of pain that we found is indeed alarming, especially because estimates do not show any improvement compared to earlier studies, despite increased attention to its assessment and treatment worldwide. The adoption of a common instrument such as the MDS [Minimum Data Set] allows, for the first time, to compare prevalence rates and to document clinical correlates of pain that are basically identical near the north pole as well as at the borders of Africa. A more widespread adoption of a tool such as the MDS instrument might represent a way to improve the situation, by cross-national benchmarking, and by the exchange of best practices. Implementation of verbal and non-verbal pain scales will help increase recognition of pain, but not necessarily lead to quantitative and qualitatively better (pharmacological) treatment' (See also Finne-Soveri, et al, 2000).

[100] Sawyer, et al, 2007. This study, based on 27,628 Alabama nursing home residents found 45% had pain in the last week. Other studies, using different instruments, also indicate 'a pain prevalence of 70-100% among cancer patients' (Lorenz, et al, 2004:2).

[101] Proctor and Hirdes, 2001. This study, based on 3195 nursing home residents in Ontario, Manitoba and Saskatchewan found 50% had pain in the last week. See also Zyczkowska, et al, 2007.

[102] Mularski, Heine, Osborne, Ganzini, and Curtis, 2005. This study, based on a sample of 38 ICU patients, found that the overall quality of dying, as measured by family members' rating on ICU QODD, was influenced by four factors: (i) how often the patient appeared to have his or her pain under control (ii) how often the patient appeared to have control over what was going on around him or her (iii) how often the patient appeared to feel at peace with dying and (iv) how often the patient appeared to keep his or her dignity and self-respect. Commenting on this finding, the authors draw out the following implication: 'Although prior studies indicate that better symptom assessment and management can improve the quality of care for those dying in ICU, our study suggests caution in focusing solely on these measures for the assessment of the quality of dying and the improvement of end-of-life care. If our findings are confirmed in subsequent studies, our results suggest that, even in the ICU, assessment and improvement of whole-person concern and preparation-for-death aspects of the dying experience are important to the quality of dying' (Mularski, Heine, Osborne, Ganzini, and Curtis, 2005:286). In another study, the main finding was that: 'Nurses in our

8.2 Quality of Patient Experience

The total QODD score, based on relatives' assessment of 461 patients in the last week of life, is 68.8 (SD[103] 20.0) (Table 8.8). This falls within the range set by three US studies[104], based on relatives' assessment of deaths in hospital, which yielded total QODD scores of 60 (SD 14.0)[105], 67.4 (SD 15.1)[106], 77.7 (SD 9.3)[107]. It is true that the sample of deaths in the audit is much larger than any of these studies (38, 252, and 38 deaths respectively), but the standard deviation in the audit is higher than the other studies, reflecting both the larger sample size and the greater range of experiences across the different hospitals.

As indicated, QODD covers personal and relationship well-being. When these two dimensions are separated, it emerges that the QODD score for personal well-being (61.3; SD 24.1) is considerably less than the score for relationship well-being (76.1; SD 18.7) (Tables 8.8 and 8.9). This is similar to the frequency of experiences in the previous section and suggests that the main challenges for Irish patients during the last week of life are their physical and psychological symptoms. The converse is also true in that relationship well-being is a major source of comfort and support to these patients. This is consistent with the findings of one other QODD study[108].

We cross-tabulated QODD scores (Part B) with selected variables and this produced similar results to the preceding analysis on the frequency of patient experiences (Tables 8.10 to 8.13). In other words, the patient's quality of life seems to increase with staff responsiveness to requests and the quality of end-of-life care in the ward and hospital, while decreasing with the presence of pain and anxiety. However, the number of treatment decisions made by hospital staff, the receipt of specialist palliative care, and having breathing difficulties seems to have no direct effect on QODD scores.

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study perceived patients with family members or others present at the time of death and those without CPR performed in the 8 hrs before their death as having higher quality deaths' (Hodde, Engelberg, Treece, Steinberg, and Curtis, 2004:1652).

[103] SD = Standard Deviation. SD measures the spread of scores by calculating the average amount of scores that deviate from the mean. The more widely scores are spread out the larger the SD, and *vice versa*.

[104] The main QODD-based studies, and their scores, are as follows:

Study	Sample	Completed by Relatives		Completed by Nurses		Completed by Doctors	
		M	SD	M	SD	M	SD
US Deaths in hospital and home (Curtis, et al, 2002)	252	67.4	15.1	-	-	-	-
US Deaths in ICU (Hodde, et al, 2004)	149	-	-	73.1	21.4	-	-
US Deaths in ICU (Levy, et al, 2005)	38	77.7	9.3	66.9	16.3	67.8* 82.5**	22.5* 17.3**
US Deaths in ICU (Mularski, et al, 2004)	38	60.0	14.0	-	-	-	-

Notes: *resident physicians or registrars. *attending physicians or primary doctor.

[105] Mularski, et al, 2004.

[106] Curtis, et al, 2002.

[107] Levy, et al, 2005.

[108] Hodde, Engelberg, Treece, Steinberg, and Curtis, 2004. This study, based on 178 patients who died in ICU, found that: 'Nurses in our study perceived patients with family members or others present at the time of death and those without CPR performed in the 8 hrs before their death as having higher quality deaths' (Hodde, Engelberg, Treece, Steinberg, and Curtis, 2004:1652).

8.3 Summary

The quality of life of the patient during the last week of life was measured using the Quality of Dying and Death Instrument (QODD)[109]. This is a multi-item questionnaire in two parts: Part A records the frequency of the patient's experience (covering physical and psychological symptoms of personal well-being, and relationship well-being such as spending time with loved ones) and Part B rates the quality of that experience for the patient on a scale from 1 ('terrible' which we re-labelled 'unsatisfactory') to 10 ('perfect' which we re-labelled 'satisfactory').

The total QODD score, based on relatives' assessment of 461 patients in the last week of life, is 69. This is within the range set by three US studies[110] of deaths in hospital which yielded QODD scores of 60, 67 and 78. The results also show that patients are more likely to experience relationship well-being compared to personal well-being. This implies that, during their last week of life, patients are more challenged by their physical and psychological symptoms, and these challenges do not vary by type of hospital, ward, or room, or by the patient's age, sex, illness, or length of stay in hospital. The converse is also true in that relationship well-being seems to be a major source of comfort and support to patients, which is consistent with the findings of another QODD study[111].

Compared to nurses, relatives report that patients have more frequent negative experiences of some physical and psychological symptoms such as being in pain, uncomfortable, anxious, or worried. This is consistent with another QODD-based study which found that relatives report a higher frequency of symptoms, and a more negative impact of those symptoms on patients[112].

Three symptoms associated with end-of-life - pain, breathing difficulties, anxiety – were compared from the perspectives of nurses, doctors and relatives. This revealed that:

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[109] Developed by, and available from, the University of Washington End of Life Care Research Program at: http://depts.washington.edu/eolcare/instruments/index.html. The Quality of Dying and Death Instrument (QODD) was developed by Donald Patrick, Ruth Engleberg and Randall Curtis (Patrick, Engleberg and Curtis 2001) and has been used in four studies (Curtis, Patrick, Engleberg, Norris, Asp, and Byock, 2002; Hodde, Engelberg, Treece, Steinberg, and Curtis, 2004; Mularski, Heine, Osborne, Ganzini, and Curtis, 2005; Levy, Ely, Payne, Engelberg, Patrick and Curtis, 2005).

[110] The main QODD-based studies, and their scores, are as follows:

Study	Sample	Completed by Relatives		Completed by Nurses		Completed by Doctors	
		M	SD	M	SD	M	SD
US Deaths in hospital and home (Curtis, et al, 2002)	252	67.4	15.1	-	-	-	-
US Deaths in ICU (Hodde, et al, 2004)	149	-	-	73.1	21.4	-	-
US Deaths in ICU (Levy, et al, 2005)	38	77.7	9.3	66.9	16.3	67.8* 82.5**	22.5* 17.3**
US Deaths in ICU (Mularski, et al, 2004)	38	60.0	14.0	-	-	-	-

Notes: *resident physicians or registrars. *attending physicians or primary doctor.

[111] Hodde, Engelberg, Treece, Steinberg, and Curtis, 2004. This study, based on 178 patients who died in ICU, found that: 'Nurses in our study perceived patients with family members or others present at the time of death and those without CPR performed in the 8 hrs before their death as having higher quality deaths' (Hodde, Engelberg, Treece, Steinberg, and Curtis, 2004:1652).

[112] In a small study using the QODD in a New York hospital, family members (10) give significantly more negative ratings for the patient's quality of life compared to nurses (9) for the following symptoms: able to feed himself / herself; appear to breathe comfortably, appear to feel at peace with dying, say goodbye to loved ones (O'Mahony, et al, 2009:Table 2.)

(i) relatives report a higher frequency of all three symptoms compared to nurses and doctors.
(ii) nurses report either the same or higher frequency of symptoms compared to doctors, but never lower.
(iii) nurses and doctors have a higher level of agreement on symptoms compared to either relatives and nurses, or relatives and doctors.
(iv) the prevalence of symptoms, for all or most of the time during the last week of life, is much higher for breathing difficulties (39%) than for pain (16%), or anxiety (9%), based on the assessment of nurses.

The audit's findings on the prevalence of pain – which is lower compared to previous studies in Ireland[113] and to studies of elderly patients in long-term care in Europe[114], the US[115], and Canada[116] - suggest three possibilities regarding Irish patients who die in acute and community hospitals: (i) their pain is correctly-assessed and correctly-treated; or (ii) their pain is under-assessed and under-treated; or (iii) some combination of both depending on the practice and protocols in each setting. None of these possibilities can be proven from the data available. Nevertheless, the divergence of views between relatives, nurses and doctors raises questions about the diagnosis and treatment of pain among patients who die in Irish hospitals, particularly when viewed from the perspective that, by far the single most important thing about care when dying, in the opinion of relatives, nurses and doctors, is to be free from pain (see Section 2 above and Report 4[117]).

The analysis in this report is purely descriptive since detailed statistical analysis will be presented in the final report (Report Five). However the results of cross-tabulating QODD scores with selected variables suggests that a patient's quality of life increases with staff responsiveness to requests, and the perceived quality of end-of-life care in the ward and hospital. Conversely, it seems to decrease in line with the patient's pain and anxiety, while the number of treatment decisions made by hospital staff, the receipt of specialist palliative care, and having breathing difficulties, does not seem to have any direct effect on QODD scores.

Overall, the quality of living and dying in Irish hospitals, as measured by the QODD, is comparable to that found in other QODD-based studies of hospital deaths. A significant finding is that relationship well-being is particularly important for the quality of life of dying patients and this reinforces the importance, already recognised by many hospitals, of supporting relatives to spend as much time as they wish with the patient in their last days.

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[113] Keegan et al, 1999. This study, based on 155 relatives, found that during the last week, 64% of patients had pain (58% of it very distressing), 83% had trouble breathing (47% of it very distressing), and 50% had anxiety (61% of it very distressing) (Ibid:19, Table 3.1).

[114] Achterberg, et al, 2010. This study, based on 10,015 residents in long-term care in Finland, Netherlands and Italy, found 49% had pain in the last week, leading the authors to conclude: 'The prevalence of pain that we found is indeed alarming, especially because estimates do not show any improvement compared to earlier studies, despite increased attention to its assessment and treatment worldwide. The adoption of a common instrument such as the MDS allows, for the first time, to compare prevalence rates and to document clinical correlates of pain that are basically identical near the north pole as well as at the borders of Africa. A more widespread adoption of a tool such as the MDS instrument might represent a way to improve the situation, by cross-national benchmarking, and by the exchange of best practices. Implementation of verbal and non-verbal pain scales will help increase recognition of pain, but not necessarily lead to quantitative and qualitatively better (pharmacological) treatment' See also Finne-Soveri, et al, 2000.

[115] Sawyer, et al, 2007. This study, based on 27,628 Alabama nursing home residents found 45% had pain in the last week. Other studies, using different instruments, also indicate 'a pain prevalence of 70-100% among cancer patients' (Lorenz, et al, 2004:2).

[116] Proctor and Hirdes, 2001. This study, based on 3195 nursing home residents in Ontario, Manitoba and Saskatchewan found 50% had pain in the last week. See also Zyczkowska, et al, 2007.

[117] McKeown, Haase and Twomey, 2010d.

A full statistical analysis of the factors which influence the quality of life of patients during their last week will be carried out in the final report but our preliminary findings suggest that the following may be among the key drivers for improving the quality of life of patients: (i) controlling the level of pain and anxiety experienced by patients and (ii) improving the overall quality of end-of-life care in the ward and hospital, including the responsiveness of staff to requests from patients and relatives. These are just preliminary findings and further statistical analysis is required to establish the full set of influences, both direct and indirect, on the factors which influence the quality of life of patients during their last week.

9 Quality of Care

The quality of care was measured using a five-item subscale taken from the Family Evaluation of Hospice Care (FEHC)[118]. Relatives were asked, like nurses and doctors in the second audit report[119], to assess on a scale from 1 to 10, how well the hospital team did the following: (i) communicated with the patient (ii) managed the patient's symptoms (iii) provided care that respected the patient's wishes (iv) communicated with relatives and (v) gave emotional support to the family. The results reveal the average score for relatives was 7.4 out of 10 (Table 9.1). The main comparative data, albeit pertaining to hospices rather than hospitals, is provided by the US National Hospice and Palliative Care Organisation which uses the FEHC to evaluate hospice performance. This indicates that the quality of care, based on the relatives' evaluation of these same five items, averages 9.4 out of 10, with relatively little variation between items or hospices[120]. This suggests, as might be expected[121], that the quality of care in Irish hospitals is below that offered by hospices.

The two domains of care that received the highest rating from relatives, and were deemed to be 'good or very good' by nearly eight out of ten respondents, were: providing care that respected the patient's wishes (79%), and managing patient symptoms (79%) (Table 9.2). By contrast, the lowest ratings were reserved for three areas, and deemed to be poor or very poor by about a fifth of respondents: communication with the patient (20%), communication with relatives (16%), and giving emotional support to relatives (18%). This suggests that hospital staff are perceived by relatives to be better at the physical aspects of care and weaker at its communicative and emotional aspects, similar to the findings of another Irish study[122]. Significantly, a study based on hospital practitioners also found that 'the emotional needs of the dying were … generally overlooked in the hustle and bustle of busy hospitals'[123].

The audit allows us to compare how the quality of care is perceived by relatives, nurses, and doctors. The results highlight five key findings (Tables 9.1-9.3):
(i) relatives report, on a 10-point scale, a lower overall quality of care (7.4) compared to nurses (8.1) and doctors (8.4).
(ii) highest ratings are consistently given by doctors and lowest ratings by relatives, with nurses holding an intermediate position.
(iii) one area of care - communication with the patient - is consistently rated as the lowest by relatives (6.9), nurses (7.0), and doctors (7.7).

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[118] Developed by, and available from, the National Hospice and Palliative Care Organisation (NHPCO), based in Virginia in the US at: http://www.nhpco.org/i4a/pages/Index.cfm?pageid=4397. The Family Evaluation of Hospice Care (FEHC) was developed by Joan Teno and Stephen Connor at Brown University in the US (Connor, Teno, Spence and Smith, 2005) based on a previously validated scale, Toolkit After-Death Bereaved Family Member Interview (Teno, Clarridge, Casey, Edgman-Levitan and Fowler, 2001).

[119] McKeown, Haase and Twomey, 2010b.

[120] Connor, Teno, Spence and Smith, 2005:Table 3. This was based on a survey of 29,292 relatives whose family members died in 352 hospices in the US during 2004. Another, much larger sample using the full Family Evaluation of Hospice Care – based on 116,974 relatives whose family members died in 819 hospices throughout the US - found that a high level of satisfaction with the quality of care was associated with four key processes of care: (i) being regularly informed by the hospice team about their loved one's condition (ii) the hospice team providing the right amount of emotional support to them (iii) the hospice team providing them with accurate information about the patient's medical treatment and (iv) identifying one nurse as being in charge of their loved one's care (Rhodes, Mitchell, Miller, Connor, and Teno, 2008).

[121] A recent study, based on a sample of 40 respondents who had the experience of a relative dying of cancer in both a hospital and a hospice in England found that: 'In comparison to hospital care, from the perspective of bereaved relatives, hospice in-patient care provided better pain control, better communication with patients and families, and better medical, nursing and personal care, which treated the patient with more dignity' (Addington-Hall and O'Callaghan, 2009:190) .

[122] McCarthy and O'Boyle, 2010.

[123] Quinlan and O'Neill, 2009:4. This study, based on practitioners who manage end-of-life in hospitals in Ireland, consisted of 102 written narratives, 57 interviews, and 14 focus groups with 104 practitioners.

(iv) The overall level of agreement between relatives, nurses, and doctors is almost identical at around 50%.
(v) The one area where there is least agreement between relatives, nurses, and doctors is communication with the patient (10% agreement); this is closely followed by giving emotional support to relatives (16% agreement).

We analysed further the possible influence of selected variables - number of treatment decisions made by hospital staff, receipt of specialist palliative care, staff responsiveness to requests, quality of end-of-life care in the ward and hospital, frequency of pain, breathing difficulties and anxiety - on the quality of care. This is a preliminary analysis only, using cross-tabulations, since detailed statistical analysis is presented in the final report (Report Five).

The results of this analysis suggest that, when sampling error is taken into account, the quality of care is influenced by staff responsiveness to requests, and the quality of end-of-life care in the ward and hospital, but it is not influenced by either the number of treatment decisions made by hospital staff, or the receipt of specialist palliative care (Tables 9.4 to 9.6). In addition, the cross-tabulations suggest that the presence of pain and anxiety – but not breathing difficulties – have a significant effect on the quality of care (Table 9.7). The latter finding is inevitably ambiguous in terms of its causation since it is not possible to confirm if: (i) the quality of care is better when patients are pain-free because measures are taken to control their pain, or (ii) pain-free patients perceive the quality of care to be better because these patients are more likely to have positive perceptions than those who are in pain. This ambiguity cannot be clarified within the confines of this analysis – since the findings are consistent with both sets of causes – but will be addressed in the full statistical analysis in Report Five. Pending that analysis, these results indicate that relatives perceive the quality of care to be better when staff are responsive to requests, when end-of-life care in the ward and hospital is good or very good, and when patients are free from pain and anxiety.

Overall, the quality of care for patients who die in Irish hospital appears reasonably good, reflected in the fact that a substantial majority of relatives (78%) rate it as ‘good or very good’. This however is lower than the corresponding ratings by nurses (91%) and doctors (95%), indicating that, from the perspective of relatives, the quality of care is not as good as nurses and doctors think it is.

The concept of ‘quality of care’ is far from clear-cut, and the different perceptions of relatives, nurses and doctors are underlined by the fact that there is only 30% agreement between them. This raises questions about the underlying standards – objective or subjective, explicit or implicit – which are being used to assess the quality of care. Equally, it provides the basis for further dialogue between these different stakeholders – including patients wherever possible – on the key ingredients of good quality care. This has important implications for how standards of care are implemented since it is desirable to have a common set of criteria by which quality of care could be measured and monitored unambiguously by all stakeholders.

The fact that communication with patients is consistently assessed by relatives, nurses and doctors as the weakest aspect of care is a challenging finding. Equally challenging is the fact that there is least agreement (10%) in the three assessments on this aspect of care. We do not know if this is unique to end-of-life care in hospitals – possibly associated with the difficulties which many people, including hospital practitioners[124], have about talking openly, simply, and gently about dying and death - or is more generic to the culture of hospitals. It would seem that the issue here is not just about communication skills in the ordinary sense – such as speaking simply and listening attentively - but about feeling at ease when communicating with patients and relatives when life is approaching its end. This suggests that any intervention to improve end-of-life communication with patients must also address the fears that many people have about dying and death including ultimately, their own fear of dying and death[125]. This implies that communication skills, particularly in the context of end of life, have a personal and not just a professional dimension, thereby inviting nurses and doctors into some deeper reflection on how they empathise[126] and interact[127] with patients, including the extent to which their relationships with

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124 Quinlan and O'Neill, 2009:5, in their study of hospital practitioners, report that: 'The practice, in general, among clinicians in terms of communication around dying and death is to follow the patient's lead, to answer any direct questions. This means that clinicians seldom volunteer information. Also highlighted as problematic were euphemisms that are used by clinicians when talking to patients about dying and death. Consultants were said to be very cautions and deliberately oblique with the language they use with patients'.

125 The link between the fear of dying and death, and the quality of care offered to dying patients was articulated over 40 years ago by Elisabeth Kubler-Ross – herself a medical doctor - in her pioneering work on dying and death where she writes: 'When a patient is severely ill, he is often treated as a person with no right to an opinion. … He may cry out for rest, peace, dignity, but he will get infusions, transfusions, a heart machine, or a tracheostomy. He may want one single person to stop for one single moment so that he can ask one single question – but he will get a dozen people round the clock, all busily preoccupied with his heart rate, pulse, electrocardiogram or pulmonary functions, his secretions or excretions, but not with him as a human being. … Is the reason for this increasingly mechanical, depersonalised approach our own defensiveness? Is this approach our own way to cope with and repress the anxieties that a terminally or critically ill patient evokes in us? Is our concentration on equipment, on blood pressure, our desperate attempt to deny the impending end, which is so frightening and disquieting to us that we displace all our knowledge onto machines, since they are less close to us than the suffering face of another human being, which would remind us once more of our lack of omnipotence, our own limitations and fallibility and, last but not least perhaps, our own mortality?' (Kubler-Ross, 2009:7-8). There is a large body of literature on the fear of dying and death - by philosophers, poets, religious teachers, etc – of which a key theme is that a person's response to this fear determines their likelihood of a 'good death' as well as a 'good life'. The life and work of Socrates (469-399BC) is often cited as an example of this. When condemned to death for allegedly corrupting the youth of Athens, Socrates observed that he had no fear of dying since he had been practicing death all his life because he regarded death as no more than release and separation of the soul from the limitations of the body which is also the state of wisdom sought by the true philosopher; 'If a man has trained himself throughout his life to live in a state as close as possible to death, would it not be ridiculous for him to be distressed when death comes to him? … True philosophers make dying their profession' (Plato, 2003:129). In more recent times, under the influence of Kierkegaard (1983), the American cultural anthropologist, Ernest Becker, has argued that human conditioning and culture is shaped by the need to deny death but this can be transcended through a process of self-realisation where the person 'opens himself up to infinity … links his secret inner self, his authentic talent, his deepest feelings of uniqueness to the very ground of creation' (Becker, 1974:90). A core theme in these writings is the invitation provided by dying and death to reflect on the true nature of the self, and the reality of existence which is unaffected by dying and death. This is also a central theme in eastern philosophies, articulated in the life and work of Ramana Maharshi: 'If a man considers he is born he cannot avoid the fear of death. Let him find out if he has been born or if the Self has any birth. He will discover that the Self always exists, that the body which is born resolves itself into thought and that the emergence of thought is the root of all mischief. Find wherefrom thoughts emerge. Then you will abide in the ever-present inmost Self and be free from the idea of birth or the fear of death' (Ramana Maharshi, 1989:82).

126 Empathy has been described as 'the key to a caring patient-doctor relationship – the art of medicine' (Janssen, Macleod and Walker, 2008:390). Empathy has an affective component which, like sympathy, has the capacity to feel as the other person is thought to feel. However, unlike sympathy, empathy also has a cognitive component which is the capacity to reflect and understand why the other person feels as they do. The importance of empathy is underlined by the fact that it is associated with reduced symptoms and improved satisfaction for patients (Reynolds and Scott, 2000), and is a good predictor of clinical competence (Hojat, Gonnella, Nessa, et al, 2002), diagnostic accuracy and patient compliance (Roter, Stewart, Putnam, et al, 1997; Coulehan, Platt, Egener, et al, 2001).

127 There are numerous ways of characterising styles of interaction depending on the underlying psychological theory. One of the most respected – and which underpins most behavioural and cognitive approaches – is attachment theory which explains a person's style of interaction by the way they 'attach' or connect with people, itself influenced by their early life experience of significant others, especially parents (Bowlby, 1979; Ainsworth, 1991). Depending on those formative experiences in early life, three main types of attachment and interaction style emerge: secure attachment, insecure-avoidant attachment, and insecure-anxious attachment. A secure style is where others are regarded as reliable and available and is associated with a warm, positive and reassuring style of interaction. An insecure-avoidant style is where others are regarded as uninterested or unavailable and is associated with an interaction style that is cold, competitive and controlled. An insecure-anxious style is where others are seen as unreliable or difficult and leads to an interaction style characterised by anxiety, stress and lack of confidence. The significance of this for doctors has been explored in a recent article on medical education: 'Attachment theory can provide valuable insight into situations where caring is paramount. In an institutional setting, patients are typically vulnerable and searching for security. Stresses to heighten a patient's vulnerability and need for attachment include their role as an ill person, the uncertainty of their well-being, the requirement placed upon them to trust strangers,

patients are informed by – and infused with – compassion[128]. Inescapably, this caring relationship has a personal as well as a professional dimension and, in their practical manifestation, these dimensions are inseparable[129].

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their separation from loved and reliable people, and the novel context. …… Clinicians need far more than a diagnosis in order to understand the perceptions, experiences, and resulting behavior of the person who is ill . …. . A doctor's experiences of care, his or her resulting attachment style, and the levels of support that colleagues and senior figures provide the doctor can make an important difference to the experiences and outcomes of a person under that doctor's care. …. A secure clinician is unlikely to become overwhelmed or controlling when faced with the clingy or anxious behavior typical of insecure-anxious patients.' (Janssen, Macleod and Walker, 2008:391-392).

128 It is recognised that compassionate care involves more than attending to the patient's physical needs; it also involves a dialogue between patient and caregiver where communication is 'human to human rather than clinician to patient. … In short, for healthcare professionals, compassion means seeing the person in the patient at all times and at all points of care' (Cornwell and Goodrich, 2009). According to Macleod and McPherson (2007:1591): 'The virtue of compassion is a trait combining an attitude of active regard for another's welfare with an imaginative awareness and emotional response of deep understanding, tenderness and discomfort at the other person's misfortune or suffering. It is expressed in acts of beneficence that attempt to prevent and alleviate the suffering of the other person'.

129 This is consistent with a recent review of the factors that shape the patient's experience in hospital: 'For patients in hospital, every detail of every interaction shapes the unique quality of the experience. From listening to patients, it is apparent that contact with the hospital as an organisation and with hospital personnel is shaped to a large degree by the actions, attitudes and behaviours of individual members of staff. In turn, these are shaped by their own personal experience, attitudes and values (including professional values), and by relationships between colleagues. The quality of the patient experience is also subtly shaped by the dynamics of the wider healthcare system and the political and social climate. … Moreover, because providing care exposes nurses to patients' distress, to human suffering, disability, pain, terminal illness and death, their natural human defences against psychological and emotional disturbance will, if the feelings do not receive attention, gradually and inevitably create ways of delivering care that protect nurses but are insensitive to patients. … While patients are perhaps less at risk of insensitive treatment when they are outpatients or day patients, all institutional clinical and care settings have the potential to depersonalise and dehumanise patients and caregivers. If we are concerned about the quality of patients' experience in hospital, then we need to find out how, practically, we can:

- Protect patients who are particularly at risk of insensitive treatment;
- Foster and promote compassion and empathy;
- Select staff who have the capacity to see the person in the patient;
- Support staff;
- Define behaviours that are and are not admissible;
- Give staff the courage to speak up on patients' behalf when and if the quality of care declines.' (Cornwell, 2009:1).

10 Acceptability of Way Patient Died

The audit borrowed a question from a study of dying in French hospitals[130] and asked relatives – as well as nurses and doctors - to rate the acceptability to them and their family or friends, of how the patient died in hospital. This was based on a 10-point scale, from 1 (definitely not acceptable) to 10 (very acceptable). Given that there is virtually no difference between acceptability to 'you' and to 'your family or friends', we report on acceptability to 'you' only.

The results reveal that a fifth (21%) of relatives found the patient's death to be unacceptable, where this is defined as a score of 3 or less out of 10 (Table 10.1). In comparative context, this suggests that the acceptability of dying in an Irish hospital seems to be much higher compared to French hospitals where 58% of nurses found the deaths of their patients unacceptable to them or their family / friends[131].

The audit allows us to compare the level of agreement between relatives, nurses, and doctors on the acceptability of the patient's death (Tables 10.2a-d). The results highlight three key findings:
(i) relatives report a higher proportion of unacceptable deaths (21%) compared to nurses (13%) and doctors (3%).
(ii) relatives report the same rates of unacceptable deaths in acute and community hospitals, but both nurses and doctors report a much higher rates in acute hospitals.
(iii) the overall level of agreement between relatives, nurses, and doctors is quite high, ranging from 73-82%.

Further analysis of the data reveals that the judgement by a relative on the acceptability of a death is influenced by characteristics of the patient and characteristics of the care received (Tables 10.3-10.7). The patient characteristics associated with an unacceptable death, in their order of importance are: being anxious or afraid all or most of the time (67% unacceptable), being in pain all or most of the time (40% unacceptable), having a sudden rather than an expected death (39% unacceptable), and being under the age of 45 (33% unacceptable). The care characteristics associated with an unacceptable death are: poor or very poor staff responsiveness (83% unacceptable), poor or very poor end-of-life care being in the ward (69% unacceptable) and hospital (72% unacceptable), and dying in a shared rather than a single room (29% unacceptable).

These findings highlight the multi-faceted nature of judgements by relatives about what constitutes an acceptable or unacceptable death. In Report Five we will systematically compare how relatives, nurses and doctors make these judgements, but some preliminary results, from a comparison of data with Report Two[132], suggest that there are important differences in their perspectives. For example, nurses and doctors are not influenced by some patient characteristics – such as the age and suddenness of death – but are more influenced than relatives by some care characteristics such as dying in an acute hospital, and whether patients who could have benefited from specialist palliative care but did not receive it[133], both of which

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[130] Ferrand, Jabre, Vincent-Genod, et al, 2008.

[131] Ferrand, Jabre, Vincent-Genod, et al, 2008:Table 4. This study was based on 3,793 patients who died in 200 French hospitals in 2004. The 'yes/no' response format in the French study was converted to a 10-point scale to give comparability with the audit results.

[132] McKeown, Haase and Twomey, 2010b.

[133] This is consistent with the findings of the French study which found that the absence of palliative care, in terms of both procedures and practices, was the major influence on unacceptable deaths: 'Variables significantly associated with the perception by the nurses of an acceptable death were the availability of a written protocol for end-of-life care in the department, a higher ratio of nurses to patients, anticipation of death by the nurse, designation by

are associated with higher rates of unacceptable deaths. Equally, nurses and doctors differ on aspects of the care setting such as dying in a shared room which is associated with unacceptable deaths for nurses but not for doctors.

Overall, the results indicate that the rate of unacceptable deaths in Irish hospitals (21%) is much lower compared to French hospitals (58%)[134]. However, a case-by-case comparison of deaths in Irish hospitals reveals that relatives report a higher rate of unacceptable deaths (21%) compared to nurses (13%) or doctors (3%). In judging whether a death is acceptable, relatives are influenced by characteristics of the patient (such as the relative youth and suddenness of the death, and the level of anxiety and pain), and by care characteristics (such as the responsiveness of staff, the quality of care in ward and hospital, and dying in a shared room). The findings also suggest that relatives, nurses and doctors take different sets of factors into account in making a judgement about the acceptability of a death.

A significant implication of these results is that the idea of an acceptable death as we have measured it – 'was the way the patient died acceptable to you?' - seems to draw together a wide range of disparate elements that shape the overall experience of dying in hospital. As such, it would appear to be a good indicator for the concept of a 'good death' which is one of the core outcomes of the HFH programme, as articulated in the original grant proposal: 'The single most important outcome is the development of a widespread understanding of what constitutes a good death, how that is best achieved and how constraints in achieving it can be addressed'[135].

The continued relevance of this outcome was highlighted in a recent a qualitative study of hospital practitioners in Ireland which found evidence that 'clearly establishes that there are good and bad deaths in Irish hospitals. The good deaths have a number of features in common: patient autonomy, the patient choosing what they want, articulating or communicating those choices, and those choices being respected and acted upon; the patient having access to all the resources and supports available; the patient having the support of palliative services, among them good pain and symptom management; and the establishment of good relationships between patient, family and practitioners'[136]. In light of this, our analysis in Report

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the patient of a surrogate decision-maker, an NTBR order or treatment-limitation decision recorded in the patient's medical record, adequate control of pain before death, information from the family that death was imminent, the presence of family or friends at the time of death, and a staff meeting with the family after death' (Ferrand, Jabre, Vincent-Genod, et al, 2008:870). Based on this analysis, the authors concluded: 'The major finding of our study is the frequent failure to adopt a palliative care approach at the time of death' (Ibid).

134 Ferrand, Jabre, Vincent-Genod, et al, 2008:Table 4. This study was based on 3,793 patients who died in 200 French hospitals in 2004. The 'yes/no' response format in the French study was converted to a 10-point scale to give comparability with the audit results.

135 Irish Hospice Foundation, 2006, Grant Proposal to Atlantic Philanthropies, 19 July. The proposal states: 'The Hospice Friendly Hospitals programme aims to put hospice principles into hospital practice and to ensure that a systematic quality approach exists within the public health services to facilitate, in so far as is humanly possible, a good death when it is expected, or can be predicted, and supportive systems when death occurs unexpectedly. The concept of 'a good death' is now widely recognised in the international literature and there is increasing awareness that the needs and wishes of the dying person, and not just of their family, need to be taken into account. To underpin the concept of 'a good death', hospitals need to identify the rights and responsibilities of patients, clinicians and families and provide a means for addressing advocacy issues. The patient's right to choose how and where they are treated is likely to become more of an issue as service users become increasingly more informed and assertive, and end-of-life care is addressed by legislative frameworks'. A previous study of bereaved relatives also recommended 'promoting the concept of a good death [since] the central tenet of palliative care is facilitation of a good death' (Keegan, et al, 2009:ix)

136 Quinlan and O'Neill, 2009:3-4. This study, based on practitioners who manage end-of-life in hospitals in Ireland, consisted of 102 written narratives, 57 interviews, and 14 focus groups with 104 practitioners. In addition to profiling a good death, the study also profiled a 'bad death' as follows: 'Bad deaths in hospital are often associated with inappropriate and, arguably, unethical active or aggressive treatments, investigations, resuscitations, and the administration of invasive, unwarranted, unnecessary and / or inefficacious procedures. Patients in Irish hospitals do not, as a rule, plan for their end-of-life experience. They do not anywhere or at anytime indicate in any way what it that they would want in terms of treatment or supports when they are dying. As a result of this, most deaths in hospital are managed through a moment-by-moment, event-by-event, decision-making process which is embedded in an oblique or certainly less than frank communication process which is negotiated between distressed and grieving

Five will contribute to identifying the statistically significant determinants of a good or acceptable death. This, in turn, may facilitate a broader agreement on what constitutes an acceptable journey into dying and death and with that, a common framework of standards for promoting it, including an appropriate set of indicators by which it can be monitored and evaluated on a regular basis.

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relatives and under-resourced and commonly over-stretched carers and clinicians' (Ibid:4). Outside of the hospital setting, a small qualitative study, based on two focus groups with the general public, revealed the following features of a good death:

- 'Fast and peaceful/ To die in your sleep (although this may be more painful for your family).
- To have your family with you when you die.
- To have control over the time and circumstances of your death.
- Cared for at home, with adequate medical support.
- No pain or suffering involved.
- To die with dignity and all that entails.
- Your children to be reared and independent.
- When you are old; in accordance with the natural life-cycle.
- With enough time to get your affairs in order.
- Emotional reassurance for the dying person.
- To stay alive as long as possible.
- To have time to do what you always wanted to do.
- With a pint of Guinness in one hand and a model (female) in the other!' (Weafer, 2009:16).

11 Post Mortem

A post-mortem is an examination of the body to determine the exact cause of death and is usually carried out by the hospital's pathologist. A post-mortem may be carried out at the request of either the hospital or the coroner[137]. The audit findings in Report One revealed that about a fifth (21%) of all acute hospital deaths are followed a post-mortem, with relatively few post-mortems in community hospitals[138]. Significantly, the rate of post-mortems in acute hospitals varies from a low of 2% to a high of 44%, suggesting considerable variation in post-mortem practices.

The survey of relatives revealed that just under a tenth of all deaths (9%) were followed by a post-mortem, and all of these were in acute hospitals (Table 11.1). In this respect therefore, the sample of relatives under-estimates the true extent of post-mortems.

Half of the post-mortems (50%) were requested by the hospital but a third of relatives (33%) did not know whether it was at the request of the hospital or the coroner (Table 11.2). Consistent with this, relatives indicated that the reason for the post-mortem was not explained to them by the hospital (25%) or they did not recall if an explanation had been given (11%) (Table 10.3). Relatives who received information about the post-mortem tended to find it good or excellent in terms of being sensitive (78%), given without delay (66%), clear and simple (63%) (Table 10.4).

Overall, these results suggest that, whenever a post-mortem took place, about two thirds of relatives were made aware of the reasons for it in a sensitive, timely, and clear manner. However a third of relatives did not seem to have been properly informed about the reasons for the post-mortem, and were less than satisfied with the information provided by the hospital. Given that the proportion of relatives affected by a post-mortem is substantially less than the true prevalence of post-mortems, some caution is needed in extrapolating from these findings. Nevertheless, they suggest that there is a good deal of variation in how information is communicated to relatives, and this points to opportunities for improving the way that relatives are informed about the reasons and outcomes of post-mortems.

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[137] The role of the coroner is to enquire into the circumstances of sudden, unexplained, violent or unnatural deaths. The coroner's purpose is simply to establish the facts and this may require a post-mortem examination which is carried out by a pathologist, who acts as the coroner's agent for this purpose. This may be followed by an inquest. The coroner is not permitted to consider civil or criminal liability. In a hospital setting, deaths are reported to the coroner in circumstances such as: an accident, suicide or homicide; negligence or misadventure; deaths occurring before a diagnosis is made; whilst a patient was undergoing an operation or was under the effect of an anaesthetic; neglect or lack of care, including self-neglect; and where the death resulted from any industrial disease. In historical perspective, an increasing proportion of deaths have become the subject of post-mortems and inquests over the past century. In 1885, for example, only 2% of deaths in Ireland involved a post-mortem / inquiry but, 120 years later in 2005, nearly a fifth (18%) of all deaths were investigated by a coroner (McKeown, Haase and Twomey, 2010a).

[138] McKeown, Haase and Twomey, 2010a.

12 Conclusions and Issues for Consideration

One of the main challenges in this audit is to hear the authentic voice of the patient in their last week of life. Due to their frailty at this time, the patient's voice is necessarily mediated through the reports of relatives, nurses and doctors.

Previous studies suggest that while there tends to be a 'moderate' level of agreement between the reports of patients and those of their relatives[139], nurses and doctors[140], there are also limitations with this approach, particularly where there are significant discrepancies between these perceptions. At the same time, however, these perceptions are integral to the patient experience since it they have a major influence on the quality of care, and therefore the quality of life, of the patient. Discrepancies in reports about the patient pose significant challenges not just in terms of understanding the authentic patient experience but also, as we have seen throughout this audit, because they raise questions about what is the true standard of care offered to patients in their last days and hours. For that reason, this method of auditing end-of-life care provides an important opportunity for hospitals to reflect on the quality of care offered to patients, and the respective weights to be attached to the views of relatives, nurses and doctors.

The overall finding of this audit report is that the quality of life and the quality of care experienced by patients in their last week of life is good, and similar to that reported in other studies. For example, nearly eight out of ten rate the quality of care as 'good or very good'. However there is significant variation in the experiences of patients, and these variations are influenced by the symptoms of the patient (such as whether they are anxious or in pain), and by the characteristics of care provided (such as the responsiveness of staff and the quality of end-of-life care at ward and hospital level). These influences also shape how relatives judge that the acceptability of the patient's dying and death.

The rate of unacceptable deaths in Irish hospitals is not inconsiderable (21%) and, although much lower compared to French hospitals (58%), it is significantly higher compared to the assessments of nurses (13%) or doctors (3%). This is an important finding given that an acceptable death would appear to be a good indicator of a 'good death' which is one of the core outcomes of the HFH programme, as articulated in the original grant proposal: 'The single most important outcome is the development of a widespread understanding of what constitutes a good death, how that is best achieved and how constraints in achieving it can be addressed'[141].

One aspect of a good death is to die without pain or anxiety. Relatives estimate that the prevalence of pain among patients, for all or most of the time during the last week of life (34%), is twice the rate reported by nurses (16%), and three times the rate reported doctors (11%). Significantly, all of these ratings suggest a lower level of pain compared to previous studies in Ireland[142] and to studies of elderly patients in long-term care in Europe[143], the US[144], and Canada[145]. As regards anxiety, relatives report much higher rates (25%) compared to nurses (9%) and doctors (9%).

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[139] Tang and McCorkle, 2002; McPherson and Addington-Hall, 2003; Teno, 2005.
[140] Horton, 2002; Hearn and Higginson, 1999; Davoudi, et al, 2008.
[141] Irish Hospice Foundation, 2006, Grant Proposal to Atlantic Philanthropies, 19 July.
[142] Keegan et al, 1999.
[143] Achterberg, et al, 2010.
[144] Sawyer, et al, 2007.
[145] Proctor and Hirdes, 2001.

An encouraging finding is the high ratings given by relatives for the quality of all hospital staff – nursing, medical, and other. For example, over eight out of ten relatives (83%) rated the responsiveness of staff as good or very good. However, a quarter of relatives felt there was not enough nursing and medical staff in acute hospitals, and this may be due to their experience that staff do not have – and are not given – enough time to be with patients and relatives.

A consistently challenging finding in the audit is that communication with patients is assessed by relatives, nurses and doctors as the weakest aspect of care. In addition, there is least agreement in the three assessments on this aspect of care.

One aspect of a good death in hospital is facilitating the patient, wherever possible, to die in a room of their choosing. This is not always easy when the preference is to die in a single room since only about 15% of beds in acute and community hospitals are in single rooms. Given this constraint, it is significant that nearly half of all patients died in a single room (48%). Equally significant is the fact that, of those who died in a shared room, nearly half would have preferred a single room (45%), and two thirds of their relatives would have preferred a single room (64%). This suggests that there is a substantial unmet preference for patients to die in a single room which, given the high proportion of patients who did not express a preference, could range from 24-40% of all deaths.

The audit offers some support for the view that more patients could die at home if there were sufficient supports. In the assessment of relatives, nearly a quarter of all patients (24%) could have died at home if there was enough support, similar to the overall assessments made by nurses (22%) and doctors (22%). However the interpretation of this finding requires some caution since agreement on a case-by-case basis is quite low. Also, our analysis revealed that relatives are more likely to assess a patient as suitable to die at home when the responsiveness of staff to their requests is rated as average or poor, and when the quality of end-of-life care on the ward, and in Irish hospitals generally, is rated as average or poor. This suggests that some care is needed when interpreting the assessments of relatives since they could simply mean that relatives are dissatisfied with the hospital care offered to the patient.

These findings provide reassurance that a majority of deaths in Irish hospitals, in the opinion of relatives, are acceptable and could be described as ‘good deaths’. Equally reassuring is the perception that most hospital staff are responsive to the needs of patients and relatives. However the findings also contain a series of challenges which invite a considered response and remedy from hospitals. We now outline eight separate issues which arise from this part of the audit.

12.1 Ward Characteristics

Overall, these results suggest that relatives see the physical environment of wards in a positive light, much like nurses and hospital managers. This is consistent with the fact that relatives gave the lowest priority to ‘a private space’ when asked to list the most important things about care when dying. However their perception of wards is at variance with independent healthcare consultants – and with the standards that are increasingly being prescribed for new hospitals[146] - which suggests that there is a

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[146] In the US, 100% single rooms have now been adopted as the standard for all new hospital accommodation (Facility Guidelines Institute and the AIA Academy of Architecture for Health, 2006). In the UK, a minimum of 50% of single rooms is now the standard (cited in Fitzpatrick, Roche, Cunney and Humphreys, 2009:278). In Ireland, a draft of the infection control building guidelines recommends that 100% of in-patient accommodation in newly built acute

lack of awareness among relatives – and hospital staff generally - about what is possible and desirable in terms of evidence-based design in hospitals. At the same time, relatives see beyond the physical context of the ward and seem to be more discriminating in rating the quality of end-of-life care provided by wards, since this is associated with significant variations in the patient's quality of care and quality of life.

12.2 Patient Preferences for a Single Room

The audit revealed that just under half of all patients (48%) died in a single room, which is lower than the 70% of patients who die in single rooms in hospitals in Northern Ireland[147]. Nearly half of all patients who died in a shared room would have preferred a single room (45%). This suggests that there is a substantial unmet preference for patients to die in a single room which, given the high proportion of patients who did not express a preference, could range from 24-40% of all deaths.

The limited stock of single rooms (15%) in acute and community hospitals, and the competing demands for those rooms, effectively means that the end-of-life wishes of many patients cannot be met. This is a significant challenge to hospitals which can only be addressed by the provision of additional single rooms. At present, the stock of single rooms in Irish hospitals, both acute and community, falls below all standards for this type of hospital accommodation[148]. These standards pose a significant national challenge for the hospital system not just because of the importance of meeting patient preferences – bearing in mind that the preference for a single rooms is not confined to patients at the end of life[149] – but also because of the need to control hospital-acquired infections[150], and the need to ensure equal access to single rooms for patients on the basis of need[151]. The consequences of inadequate hospital accommodation for patients at the end of life was underlined in an earlier study of 20 hospitals in Ireland which concluded that the lack of single rooms 'does not provide flexibility or choice on the ward for staff to support a dying patient and their family in privacy, if required. Where single rooms were available they were predominantly used for isolation purposes in respect of infection control policies and MRSA management. At certain sites there was also the added demand for the use of single rooms for private patients'[152].

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care hospitals should be single-patient rooms (cited in Fitzpatrick, Roche, Cunney and Humphreys, 2009:278). Significantly, the HIQA standard for residential care facilities for older people in Ireland, requires that there must be 80% single rooms for 'the newly built residential care setting, new extension or first time registration' (Health Information and Quality Authority, 2008:45).

[147] This estimate is taken from the audit of dying, death and bereavement in Northern Ireland. Most deaths were in the three areas of general medicine (40%), elderly care (20%) and general surgery (10%) where the proportion 'cared for in a single room on more than 75% of occasions' is 65%, 75% and 80% respectively (Northern Ireland Health and Social Care Bereavement Network, 2009:6 and 28). From this it is a reasonable inference that around 70% of deaths are in single rooms.

[148] In the US, 100% single rooms have now been adopted as the standard for all new hospital accommodation (Facility Guidelines Institute and the AIA Academy of Architecture for Health, 2006). In the UK, a minimum of 50% of single rooms is now the standard (cited in Fitzpatrick, Roche, Cunney and Humphreys, 2009:278). In Ireland, a draft of the infection control building guidelines recommends that 100% of in-patient accommodation in newly built acute care hospitals should be single-patient rooms (cited in Fitzpatrick, Roche, Cunney and Humphreys, 2009:278). Significantly, the HIQA standard for residential care facilities for older people in Ireland, requires that there must be 80% single rooms for 'the newly built residential care setting, new extension or first time registration' (Health Information and Quality Authority, 2008:45).

[149] There is a growing body of research which shows that patients and their families prefer single rooms for a variety of reasons including: visual and auditory confidentiality and privacy; reduced noise levels; control over personal information; opportunity to rest; and peacefulness of the dying process. For a review of the research, see Hugodot, 2007; Ulrich, 2008; see also Hugodot, A., and Normand, C., 2007.

[150] A key concern with hospital accommodation is that the control of infection is increasingly hindered by the absence of single rooms where infected patients can be isolated (See Fitzpatrick, Roche, Cunney and Humphreys, 2009; see also Dowdeswell, Erskine and Heasman, 2004).

[151] It has also been observed that 'a significant proportion of the existing single rooms in public hospitals are private patient beds' (PA Consulting Group, 2007:71).

[152] Tribal, 2007:11

12.3 Patient Preferences for Dying at Home

Facilitating patients to die at home, where there are appropriate supports, is an important aspect of patient autonomy. It is also consistent with good quality care since some studies have shown patients who die at home, and who die in the place they prefer, have a better quality of dying compared to those who do not[153]. In addition, it is known that a majority of Irish people would prefer to die at home[154] and even doctors and nurses have a stronger preference to die at home compared to patients[155].

The issue of dying at home also needs to be seen in the context that many patients who are treated in acute hospitals in Ireland could be treated as well, and more cost effectively, in other settings[156]. We saw in the second audit report[157] that patients who die in Ireland's acute hospitals spend at least twice as long there before dying compared to other countries such as the UK[158], the US[159] and the OECD[160], and this inevitably raises questions about whether this reflects the case-mix of patients or, more likely[161], the overall management of hospitals and health services generally. In

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[153] Curtis, Patrick, Engleberg, Norris, Asp, and Byock, 2002. This study, based on the Quality of Dying and Death (QODD) instrument completed by relatives on 252 patients who died at home or in hospital found that: 'Decedents who died at home had a significantly higher QODD score than those dying in other settings (P=0.006). Decedents who died in the setting where the respondent told us they died in the setting where the respondent told us they wanted to die also had higher QODD scores that approached our definition of statistical significance (P=0.013)' (Curtis, Patrick, Engleberg, Norris, Asp, and Byock, 2002:25).

[154] In a survey of 1,000 adults aged 15+ in the Republic of Ireland, carried out in 2004, 67% indicated that they would like to be cared for at home if they were dying (Weafer and Associates, 2004:10-11).

[155] This is based on a survey of 1,899 ICU doctors, nurses and patients in six European countries, who were asked where they would rather be if they had a terminal illness with only a short time to live; the results showed that more doctors and nurses would prefer to be at home or in a hospice and more patients and families preferred to be in an ICU (Sprung, Carmel, Sjokvist, et al., 2007). The same study also revealed that physicians provide more extensive treatment to seriously ill patients than they would choose for themselves, possibly indicating a public demand for life-prolonging interventions that may have little prospect of success.

[156] In Ireland, a random sample of 3,035 medical and surgical in-patients across 37 acute hospitals were reviewed between November 2006 and February 2007 by PA Consulting Group and Balance of Care Group (2007) for the HSE. The results of this study, though not focused on end-of-life, showed that 13% could have been treated outside an acute setting, 75% of elective survey patients were admitted earlier than necessary, 39% of day patients could have been treated in an alternative setting, and discharge planning was in evidence from the notes of 40% of patients. In the UK, the National audit office found that 'forty per cent of the 200 patients who died in hospital were found not to have had medical needs which required them to be in hospital at the point of admission, and could have been cared for elsewhere' (National Audit Office, 2008:28). Significantly, the study also found that: 'These patients used 1,500 bed days in acute hospitals. Assuming the cost of an inpatient day in an acute hospital to be £250 … this suggests that over the course of a year up to £4.5 million could be made available for end of life care in the community in Sheffield through more appropriate use of hospital care for people approaching the end of their life' (Ibid).

[157] McKeown, Haase and Twomey, 2010b.

[158] A study of 599 deaths in an acute hospital in the south west of England found that the average length of stay before death was 12 days (Abel, Rich, Griffin and Purdy, 2009:3 and Table 6). A study of 314 cancer deaths in Boston Lincolnshire between September 2006 and March 2007 found that the average length of stay before death was 16.6 days (Addicott and Dewar, 2008:Tables 4 and 7).

[159] Martin, Nelson, Lloyd, and Nolan, 2007:6; see also Wennberg, et al, 2004. This target was set following research published by Dartmouth Atlas which showed that length of stay in the last six months of life varied across the US from 4.87 to 19.67 days for the same diagnostic categories and independently of need and outcome albeit with significant variations in cost (Wennberg, Fisher, Stukel, Skinner, Sharp, and Bronner, 2004). At the same time, setting targets for average lengths of stay, also needs to recognise that short lengths of stay combined with high occupancy levels can put pressure on the quality of care. A recent study of the factors enabling compassionate care in acute hospital settings noted that: 'The factor that has arisen again and again in terms of producing stress and reducing compassion is the heightened bed occupancy within hospitals. As hospitals cope with increasing patient demand and higher levels of throughput, it becomes even more important to address humanity within the process, dealing compassionately with staff so that they in turn can do the same for patients. There is of course noting wrong per se with technically focused, rapid treatment, high-turnover, and short lengths of hospital stay – only a minority of patients would willingly prolong their stay in hospital – but it is important for compassion to be seen and valued as essential to the delivery of care, not an option or add-on' (Firth-Cozens and Cornwell, 2009:12).

[160] The OECD average length of stay is 6.3 days (OECD, 2007:73).

[161] In the introduction to the 2009 HSE National Service Plan, the CEO observed that: 'There is no acceptable reason why people in Ireland should have to spend longer in an acute hospital than those in comparable countries for the same conditions and procedures. To address this issue and improve on our ability to deliver consistently high quality patient experiences, we will continue to modernise many front line services in keeping with our overall

line with this, the HSE's five-year development framework for palliative care services acknowledges the need for some 'reorientation and reconfiguration of existing resources' within the sector[162].

It is significant that nearly a quarter of patients, in the assessment of relatives, could die at home if there was enough support, similar to the overall assessment of nurses and doctors. While this suggests that a substantial proportion of patients could die at home with appropriate supports, a case-by-case analysis of these assessments reveals only modest levels of agreement on which patients could actually die at home. This suggests that different criteria and considerations are being used to assess the suitability of patients for dying at home, even among nurses and doctors. Our analysis also indicated that, when relatives assessed a patient as being suitable to die at home, they were in effect indicating that the quality of end-of-life care in the ward and hospital is not satisfactory. This is an important finding and suggests that hospital staff should be aware that, for relatives at least, the suitability of dying at home may also be an indicator of an unsatisfactory service rather than a more appropriate response to patient needs.

A further implication of these findings, particularly in view of the modest level of agreement between nurses and doctors, is that hospital staff may not have an agreed methodology to make these assessments accurately and consistently. This limitation is clearly acknowledged in another Irish study involving assessments by nurses and doctors on the feasibility of dying at home which were deemed to be limited 'not least because of the lack of standardisation and objectivity in the judgements of the doctors and nurses with respect to the feasibility of care at home with adequate nursing support. Adequate nursing support was not defined in this study, nor was it possible to state accurately the quantity or quality of care that would have been required to allow a patient be cared for at home'[163]. Clearly, any measures to facilitate patients to die at home must first involve a proper assessment of their needs, using protocols that have been tried and tested elsewhere. In order to facilitate the planning of services therefore, the assessment of a patient's suitability to die at home, would need to be carried out and peer reviewed, in order to establish the likely scale of alternative support services needed[164].

In the second audit report, we estimated that over €80 million could be made available for end-of-life care if 22% of patients died at home rather than in acute

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strategic direction as set out in our Corporate Plan 2008-2011. … . Our focus on making services more easily available through enhanced community services is now widely accepted and, as a result of the continued commitment to community based care from Government, more new developments will be rolled out during 2009. We will also continue to integrate hospital and community based services so we can provide more seamless and streamlined services, support more direct clinical involvement in management and at the same time devolve more responsibility and authority locally within defined national parameters' (Health Services Executive, 2009:iv).

[162] HSE Palliative Care Services – Five Year Development Framework 2009-2013, 2009. A review of evidence on the cost of end-of-life care concluded that: 'hospice care saves money at all levels of analysis when compared with the alternatives. Sustained support for hospice care will ensure the integration of a cost-effective and desirable alternative in the health service' (Murray, 2009:103). An exception to this is a recent study on the impact and costs of The Marie Curie 'Delivering Choice Programme' in Lincolnshire, England. This programme, whose aim is to develop services for people who choose to die at home, found that 'the project in Lincolnshire has significantly increased the proportion of deaths at home and decreased the proportion of deaths in hospital, while keeping the overall combined cost of acute and community care stable for patients receiving palliative care in the last eight weeks of life ….. As such, we can conclude that the findings presented here demonstrate that the programme has successfully achieved its objective while not incurring any additional costs on the health care system or indeed incurring any significant overall shifts in costs between the acute and community sectors.' (Addicott and Dewar, 2008:33).

[163] Tiernan, Connor, Kearney, and Siorain, 2002:234.

[164] Some of the alternative supports could include adequate nursing care, night sitting service, good symptom control, confident and committed general practitioners, access to specialist palliative care, effective co-ordination of care, financial support, and terminal care education.

hospitals[165]. This is something worth investigating further but would need to be done as part of a whole-system approach to end-of-life care and the creation of a network of services which support patients to die at home, in nursing homes, and in hospices as their needs and preferences require. The rationale for a whole-system approach is that ‘It is no good taking care out of hospitals if it leaves behind ‘stranded costs’ – both from staffing and infrastructure. If these are not removed from the system and savings passed back … for maintaining the supply of other services, care closer to home will cost more than the current pattern of hospital-based care’[166.]

12.4 Quality of Staff

Overall, relatives give a high rating for the quality of all staff – nursing, medical, other - in both acute and community hospitals. The responsiveness of staff is also highly rated, especially in community hospitals. However a quarter of relatives felt there was not enough nursing and medical staff in acute hospitals, and this may be due to their experience that staff do not have – and are not given – enough time to be with patients and relatives. It is increasingly recognised that the amount of time spent by staff with patients is a subtle and important determinant of quality of care[167], and we will test this further in Report Five. Equally, it is recognised that ‘time for the patient’ is shaped by organisational and human factors within the ward and hospital. For example, evidence from the UK has shown that ward-based nurses spend up to 40% of their time on so-called ‘non-productive’ activities such as: paperwork, fetching, carrying, searching for missing items; and shift handovers[168]. This suggests that reducing the amount of time nurses spend on non-productive work is a necessary condition for increasing time spent with patients. However, the sufficient condition is that hospital and ward management must ensure that additional time created through re-structuring activities is spent with patients. This will involve positive reinforcement and support for nurses and other caregivers to be more physically and emotionally present to the people they care for. This is the challenge for hospital management which is implicit in these findings.

12.5 Quality of Life

The quality of life of a patient during the last week of life is simultaneously a measure of the patient’s living and dying. From the perspective of end-of-life care, quality of life is an important outcome measure because it is the preference of the majority of Irish people that, if they were ill with no hope of recovery, the quality of life would be more important than how long it lasted[169]. Overall, the quality of living and dying in Irish hospitals, as measured by the QODD, is comparable to that found in other QODD-based studies of hospital deaths. A significant finding is that relationship well-being is particularly important for the quality of life of dying patients and this

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[165] This calculation is based on a number parameters. There were 11,412 deaths in the 38 acute hospitals in Ireland’s HIPE system in 2007 (the latest data available). The average cost of an inpatient day varies from €825 in a major regional hospital to €1,917 in a major teaching hospital, equivalent to an overall average of €1,371 per day (PA Consulting Group, 2007:155). The audit reveals that 22% of deaths could have taken place at home, and the average length of stay for deaths in acute hospitals is 24 days. This results in the usage of 60,203 bed days by these patients. The cost of these bed days, in turn, is approximately €82.5 million.

[166] Harvey, Liddell and McMahon, 2009:41. Significantly, these authors add: ‘At the moment, there is little firm evidence that care closer to home is cheaper than hospital-based care (although there may be some quality benefits). It would be useful if an authoritative study were undertaken to show how the benefits – including the reduction of costs in acute hospitals – could be derived. This would need to recognise that changes in the way care is delivered should be system-wide’ (Harvey, Liddell and McMahon, 2009:42).

[167] Cornwell, 2009:4.

[168] Nolan, 2007.

[169] This is based on a national survey of 667 adults who were interviewed by telephone in September 2007. In response to the statement - if I were ill with no hope of recovery, the quality of my life would be more important than how long it lasted - 63% agreed strongly and 18% agreed somewhat (Weafer, McCarthy and Loughrey, 2009:35).

reinforces the importance, already recognised by many hospitals, of supporting relatives to spend as much time as they wish with the patient in their last days. However, patients are more challenged by their physical and psychological symptoms, and these challenges do not vary by type of hospital, ward, or room, or by the patient's age, sex, illness, or length of stay in hospital.

The 'true' prevalence of physical and psychological symptoms – such as pain, breathlessness, anxiety - cannot be inferred from the data since there is a wide divergence of views between relatives, nurses and doctors. However if the prevalence for pain is set in comparative perspective, then it would appear to be lower compared to previous studies in Ireland[170] and to studies elsewhere of elderly patients in long-term care where a common and validated assessment instrument was used and completed by nurses[171]. The broad consensus of these studies - in Europe[172], the US[173], and Canada[174] - is that about 50% of patients experienced pain in the last week and, in half of these cases, the pain was categorised as daily. These results suggest three possibilities regarding Irish patients who die in acute and community hospitals: (i) their pain is correctly-assessed and correctly-treated; (ii) their pain is under-assessed and under-treated; or (iii) some combination of both depending on the practice and protocols in each setting. None of these possibilities can be proven from the data available. Nevertheless, the divergence of views between relatives, nurses and doctors raises questions about the diagnosis and treatment of pain among patients who die in Irish hospitals, particularly when viewed from the perspective that, by far the single most important thing about care when dying, in the opinion of relatives, nurses and doctors, is to be free from pain (see Section 2 above and Report 4).

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[170] Keegan et al, 1999. This study, based on 155 relatives, found that during the last week, 64% of patients had pain (58% of it very distressing), 83% had trouble breathing (47% of it very distressing), and 50% had anxiety (61% of it very distressing) (Ibid:19, Table 3.1).

[171] The instrument is referred to as the Minimum Data Set (MDS) and is part of the interRAI Long Term Care Facility Resident Assessment Instrument (interRAI LTCF). It is designed to assess the needs, strengths, and preferences of those in long-term care settings (www.interrai.org). The MDS assessment combines a physical examination, patient history, observation, consultation with other caregivers, and information abstracted from medical records. Where used, a full MDS assessment is performed within 7 days of admission to the facility, after 30 days, and quarterly thereafter. In the 1990's, the MDS instrument was mandated for all nursing homes in the US, and several European countries have since tested and progressively introduced it into routine practice, notably Netherlands, Italy, Sweden, Norway, Finland and Denmark. Currently, the EU commission is funding an eight-country study to assess and validate the MDS for use in nursing homes in Europe; referred to as the SHELTER Study at (www.shelter-elderly.eu), it includes Italy, Czech Republic, Germany, Finland, France, Israel, The Netherlands, Spain, and the United Kingdom. The MDS assessment is filled out primarily by nurses who know the resident well. Pain is measured in terms of frequency (coded as no pain; less than daily pain; and daily pain in the last 7 days) and intensity (code as no pain; mild pain; moderate pain; and severe pain). The validity and precision of the MDS for measuring pain has been established against the Visual Analogue Scale in a study involving 95 US nursing home residents (Fires, et al, 2003). The definition of pain in the MDS is: "Pain refers to any type of physical pain or discomfort of the body. Pain may be localized to one area, or be more generalized. It may be acute or chronic, continuous or intermittent (comes and goes), or occur at rest with movement. The pain experience is very subjective; pain is whatever the resident says it is." [Morris, et al, 1995]. Coding instructions are: "Code for the highest level of pain present in the last seven days." [Ibid].

[172] Achterberg, et al, 2010. This study, based on 10,015 residents in long-term care in Finland, Netherlands and Italy, found 49% had pain in the last week, leading the authors to conclude: 'The prevalence of pain that we found is indeed alarming, especially because estimates do not show any improvement compared to earlier studies, despite increased attention to its assessment and treatment worldwide. The adoption of a common instrument such as the MDS [Minimum Data Set] allows, for the first time, to compare prevalence rates and to document clinical correlates of pain that are basically identical near the north pole as well as at the borders of Africa. A more widespread adoption of a tool such as the MDS instrument might represent a way to improve the situation, by cross-national benchmarking, and by the exchange of best practices. Implementation of verbal and non-verbal pain scales will help increase recognition of pain, but not necessarily lead to quantitative and qualitatively better (pharmacological) treatment' (See also Finne-Soveri, et al, 2000).

[173] Sawyer, et al, 2007. This study, based on 27,628 Alabama nursing home residents found 45% had pain in the last week. Other studies, using different instruments, also indicate 'a pain prevalence of 70-100% among cancer patients' (Lorenz, et al, 2004:2).

[174] Proctor and Hirdes, 2001. This study, based on 3195 nursing home residents in Ontario, Manitoba and Saskatchewan found 50% had pain in the last week. See also Zyczkowska, et al, 2007.

A full statistical analysis of the factors which influence the quality of life of patients during their last week will be carried out in the final report but our preliminary findings suggest that the following may be among the key drivers for improving quality of life: (i) controlling the level of pain and anxiety experienced by patients and (ii) improving the overall quality of end-of-life care in the ward and hospital, including the responsiveness of staff to requests from patients and relatives. These are just preliminary findings and further statistical analysis is required to establish the full set of influences, both direct and indirect, on the factors which influence the quality of life of patients during their last week.

12.6 Quality of Care

Overall, the quality of care for patients who die in Irish hospital appears reasonably good, reflected in the fact that a substantial majority of relatives (78%) rate it as 'good or very good'. However, the concept of 'quality of care' is far from clear-cut, and the different perceptions of relatives, nurses and doctors are underlined by the fact that there is only 30% agreement between them. This raises questions about the underlying standards – objective or subjective, explicit or implicit – which are being used to assess the quality of care. Equally, it provides the basis for further dialogue between these different stakeholders – including patients wherever possible – on the key ingredients of good quality care. This has important implications for how standards of care are implemented since it is desirable to have a common set of criteria by which quality of care could be measured and monitored unambiguously by all stakeholders.

The fact that communication with patients is consistently assessed by relatives, nurses and doctors as the weakest aspect of care is a challenging finding. Equally challenging is the fact that there is least agreement (10%) in the three assessments on this aspect of care. We do not know if this is unique to end-of-life care in hospitals – possibly associated with the difficulties which many people, including hospital practitioners[175], have about talking openly, simply, and gently about dying and death - or is more generic to the culture of hospitals. It would seem that the issue here is not just about communication skills in the ordinary sense – such as speaking simply and listening attentively - but about feeling at ease when communicating with patients and relatives when life is approaching its end. This suggests that any intervention to improve end-of-life communication with patients must also address the fears that many people have about dying and death including, ultimately, their own fear of dying and death[176]. This implies that communication skills, particularly in the

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[175] Quinlan and O'Neill, 2009:5, in their study of hospital practitioners, report that: 'The practice, in general, among clinicians in terms of communication around dying and death is to follow the patient's lead, to answer any direct questions. This means that clinicians seldom volunteer information. Also highlighted as problematic were euphemisms that are used by clinicians when talking to patients about dying and death. Consultants were said to be very cautions and deliberately oblique with the language they use with patients'.

[176] The link between the fear of dying and death, and the quality of care offered to dying patients was articulated over 40 years ago by Elisabeth Kubler-Ross in her pioneering work on dying and death where she writes: 'When a patient is severely ill, he is often treated as a person with no right to an opinion. … He may cry out for rest, peace, dignity, but he will get infusions, transfusions, a heart machine, or a tracheostomy. He may want one single person to stop for one single moment so that he can ask one single question – but he will get a dozen people round the clock, all busily preoccupied with his heart rate, pulse, electrocardiogram or pulmonary functions, his secretions or excretions, but not with him as a human being. … Is the reason for this increasingly mechanical, depersonalised approach our own defensiveness? Is this approach our own way to cope with and repress the anxieties that a terminally or critically ill patient evokes in us? Is our concentration on equipment, on blood pressure, our desperate attempt to deny the impending end, which is so frightening and disquieting to us that we displace all our knowledge onto machines, since they are less close to us than the suffering face of another human being, which would remind us once more of our lack of omnipotence, our own limitations and fallibility and, last but not least perhaps, our own mortality?' (Kubler-Ross, 2009:7-8). It is true that the fear of dying and death is common, and most people experience it, at some stage and to some degree. There is a large body of literature on the fear of dying and death - by philosophers, poets, religious teachers, etc – of which a key theme is that a person's response to this fear

context of end of life, have a personal and not just a professional dimension, thereby inviting nurses and doctors into some deeper reflection on how they empathise[177] and interact[178] with patients, including the extent to which their relationships with patients are informed by – and infused with – compassion[179]. Inescapably, the caring relationship is a relationship between persons, both the person in the patient and the person in the professional[180].

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determines their likelihood of a ‘good death’ as well as a ‘good life’. The life and work of Socrates (469-399BC) is a notable example of this. When condemned to death for allegedly corrupting the youth of Athens, Socrates observed that he had no fear of dying since he had been practicing death all his life because he regarded death as no more than release and separation of the soul from the limitations of the body which is also the state of wisdom sought by the true philosopher; ‘If a man has trained himself throughout his life to live in a state as close as possible to death, would it not be ridiculous for him to be distressed when death comes to him? … True philosophers make dying their profession’ (Plato, 2003:129). In more recent times, under the influence of Kierkegaard (1983), the American cultural anthropologist, Ernest Becker, has argued that human conditioning and culture is shaped by the need to deny death but this can be transcended through a process of self-realisation where the person ‘opens himself up to infinity … links his secret inner self, his authentic talent, his deepest feelings of uniqueness to the very ground of creation’ (Becker, 1974:90). A core theme in these writings is the invitation provided by dying and death to reflect on the true nature of the self, and the reality of existence which is unaffected by dying and death. This is also a central theme in eastern philosophies, articulated in the life and work of Ramana Maharshi: ‘If a man considers he is born he cannot avoid the fear of death. Let him find out if he has been born or if the Self has any birth. He will discover that the Self always exists, that the body which is born resolves itself into thought and that the emergence of thought is the root of all mischief. Find wherefrom thoughts emerge. Then you will abide in the ever-present inmost Self and be free from the idea of birth or the fear of death’ (Ramana Maharshi, 1989:82).

[177] Empathy has been described as ‘the key to a caring patient-doctor relationship – the art of medicine’ (Janssen, Macleod and Walker, 2008:390). Empathy has an affective component which, like sympathy, has the capacity to feel as the other person is thought to feel. However, unlike sympathy, empathy also has a cognitive component which is the capacity to reflect and understand why the other person feels as they do. The importance of empathy is underlined by the fact that it is associated with reduced symptoms and improved satisfaction for patients (Reynolds and Scott, 2000), and is a good predictor of clinical competence (Hojat, Gonnella, Nessa, et al, 2002),diagnostic accuracy and patient compliance (Roter, Stewart, Putnam, et al, 1997; Coulehan, Platt, Egener, et al, 2001).

[178] There are numerous ways of characterising styles of interaction depending on the underlying psychological theory. One of the most respected – and which underpins most behavioural and cognitive approaches – is attachment theory which explains a person’s style of interaction by the way they ‘attach’ or connect with people, itself influenced by their early life experience of significant others, especially parents (Bowlby, 1979; Ainsworth, 1991). Depending on those formative experiences in early life, three main types of attachment and interaction style emerge: secure attachment, insecure-avoidant attachment, and insecure-anxious attachment. A secure style is where others are regarded as reliable and available and is associated with a warm, positive and reassuring style of interaction. An insecure-avoidant style is where others are regarded as uninterested or unavailable and is associated with an interaction style that is cold, competitive and controlled. An insecure-anxious style is where others are seen as unreliable or difficult and leads to an interaction style characterised by anxiety, stress and lack of confidence. The significance of this for doctors has been explored in a recent article on medical education: ‘Attachment theory can provide valuable insight into situations where caring is paramount. In an institutional setting, patients are typically vulnerable and searching for security. Stresses to heighten a patient’s vulnerability and need for attachment include their role as an ill person, the uncertainty of their well-being, the requirement placed upon them to trust strangers, their separation from loved and reliable people, and the novel context. …… Clinicians need far more than a diagnosis in order to understand the perceptions, experiences, and resulting behavior of the person who is ill . …. . A doctor’s experiences of care, his or her resulting attachment style, and the levels of support that colleagues and senior figures provide the doctor can make an important difference to the experiences and outcomes of a person under that doctor’s care. …. A secure clinician is unlikely to become overwhelmed or controlling when faced with the clingy or anxious behavior typical of insecure-anxious patients.’ (Janssen, Macleod and Walker, 2008:391-392).

[179] It is recognised that compassionate care involves more than attending to the patient’s physical needs; it also involves a dialogue between patient and caregiver where communication is ‘human to human rather than clinician to patient. … In short, for healthcare professionals, compassion means seeing the person in the patient at all times and at all points of care’ (Cornwell and Goodrich, 2009). According to Macleod and McPherson (2007:1591): ‘The virtue of compassion is a trait combining an attitude of active regard for another’s welfare with an imaginative awareness and emotional response of deep understanding, tenderness and discomfort at the other person’s misfortune or suffering. It is expressed in acts of beneficence that attempt to prevent and alleviate the suffering of the other person’.

[180] This is consistent with a recent review of the factors that shape the patient’s experience in hospital: ‘For patients in hospital, every detail of every interaction shapes the unique quality of the experience. From listening to patients, it is apparent that contact with the hospital as an organisation and with hospital personnel is shaped to a large degree by the actions, attitudes and behaviours of individual members of staff. In turn, these are shaped by their own personal experience, attitudes and values (including professional values), and by relationships between colleagues. The quality of the patient experience is also subtly shaped by the dynamics of the wider healthcare system and the political and social climate. … Moreover, because providing care exposes nurses to patients’ distress, to human suffering, disability, pain, terminal illness and death, their natural human defences against psychological and emotional disturbance will, if the feelings do not receive attention, gradually and inevitably create ways of delivering care that protect nurses but are insensitive to patients. … While patients are perhaps less at risk of insensitive treatment when they are outpatients or day patients, all institutional clinical and care settings have the potential to depersonalise and dehumanise patients and caregivers. If we are concerned about the quality of patients’ experience in hospital, then we need to find out how, practically, we can:

12.7 An Acceptable Death

The rate of unacceptable deaths in Irish hospitals (21%) is much lower compared to French hospitals (58%)[181]. However, a case-by-case comparison of deaths in Irish hospitals reveals that relatives report a higher rate of unacceptable deaths (21%) compared to nurses (13%) or doctors (3%).

These findings suggest that the concept of an acceptable death may be a useful outcome measure for measuring the overall experience of dying in hospital. This is because the concept seems to draw together a wide range of disparate elements that shape the overall experience of dying in hospital. The concept is akin to a 'good death' which is one of the core outcomes of the HFH programme, as articulated in the original grant proposal: 'The single most important outcome is the development of a widespread understanding of what constitutes a good death, how that is best achieved and how constraints in achieving it can be addressed'[182].
A previous study of bereaved relatives also recommended 'promoting the concept of a good death [since] the central tenet of palliative care is facilitation of a good death'[183]. More recently, a qualitative study of hospital practitioners in Ireland found evidence which 'clearly establishes that there are good and bad deaths in Irish hospitals. The good deaths have a number of features in common: patient autonomy, the patient choosing what they want, articulating or communicating those choices, and those choices being respected and acted upon; the patient having access to all the resources and supports available; the patient having the support of palliative services, among them good pain and symptom management; and the establishment of good relationships between patient, family and practitioners'[184]. In light of these

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- Protect patients who are particularly at risk of insensitive treatment;
- Foster and promote compassion and empathy;
- Select staff who have the capacity to see the person in the patient;
- Support staff;
- Define behaviours that are and are not admissible;
- Give staff the courage to speak up on patients' behalf when and if the quality of care declines.' (Cornwell, 2009:1).

[181] Ferrand, Jabre, Vincent-Genod, et al, 2008:Table 4. This study was based on 3,793 patients who died in 200 French hospitals in 2004. The 'yes/no' response format in the French study was converted to a 10-point scale to give comparability with the audit results.

[182] Irish Hospice Foundation, 2006, Grant Proposal to Atlantic Philanthropies, 19 July. The proposal states: 'The Hospice Friendly Hospitals programme aims to put hospice principles into hospital practice and to ensure that a systematic quality approach exists within the public health services to facilitate, in so far as is humanly possible, a good death when it is expected, or can be predicted, and supportive systems when death occurs unexpectedly. The concept of 'a good death' is now widely recognised in the international literature and there is increasing awareness that the needs and wishes of the dying person and not just of their family need to be taken into account. To underpin the concept of 'a good death' hospitals need to identify the rights and responsibilities of patients, clinicians and families and provide a means for addressing advocacy issues. The patient's right to choose how and where they are treated is likely to become more of an issue as service users become increasingly more informed and assertive and end-of-life care is addressed by legislative frameworks'.

[183] Keegan, et al, 2009:ix. This study, based on a sample of 155 bereaved relatives, found that 84% of patients had a 'good death'.(Ibid:vii).

[184] Quinlan and O'Neill, 2009:3-4. This study, based on practitioners who manage end-of-life in hospitals in Ireland, consisted of 102 written narratives, 57 interviews, and 14 focus groups with 104 practitioners. In addition to profiling a good death, the study also profiled a 'bad death' as follows: 'Bad deaths in hospital are often associated with inappropriate and, arguably, unethical active or aggressive treatments, investigations, resuscitations, and the administration of invasive, unwarranted, unnecessary and / or inefficacious procedures. Patients in Irish hospitals do not, as a rule, plan for their end-of-life experience. They do not anywhere or at anytime indicate in any way what it that they would want in terms of treatment or supports when they are dying. As a result of this, most deaths in hospital are managed through a moment-by-moment, event-by-event, decision-making process which is embedded in an oblique or certainly less than frank communication process which is negotiated between distressed and grieving relatives and under-resourced and commonly over-stretched carers and clinicians' (Ibid:4). Outside of the hospital setting, a small qualitative study, based on two focus groups with the general public, revealed the following features of a good death:

- 'Fast and peaceful/ To die in your sleep (although this may be more painful for your family).
- To have your family with you when you die.
- To have control over the time and circumstances of your death.
- Cared for at home, with adequate medical support.

findings, our analysis in Report Five, will contribute further to identifying the statistically significant determinants of a good or acceptable death. This, in turn, may facilitate a broader agreement on what constitutes an acceptable journey into dying and death, and help create a common framework of standards for promoting it, including an appropriate set of indicators by which it can be monitored and evaluated on a regular basis.

12.8 Post-Mortems

Just under a tenth of all deaths (9%) were followed by a post-mortem, all of them in acute hospitals. This suggests that the sample of relatives under-estimates the true extent of post-mortems since about a fifth of all acute hospital deaths are followed by a post-mortem. Whenever a post-mortem took place, about two thirds of relatives were made aware of the reasons for it in a sensitive, timely, and clear manner. However a third of relatives do not seem to have been properly informed about the reasons for the post-mortem, and were less than satisfied with the information provided by the hospital. These results suggest that there is a good deal of variation in how information is communicated to relatives about post-mortems, and this points to opportunities for improving the way relatives are informed about the reasons and outcomes of post-mortems.

12.9 Concluding Comment

Audit is part of a learning cycle designed to assist hospitals and their staff to reflect on the quality of care offered to patients so that improvements can be made in areas where performance falls below acceptable standards. This audit shows that relatives, nurses and doctors hold quite different perspectives and assessments on the quality of the end-of-life care provided by hospitals. While this creates a basis for dialogue between these different stakeholders – and other stakeholders, including patients – it raises a significant challenge in terms of the relative weights to be accorded these different perspectives. Thus, in addition to the substantive issues raised in the audit, hospitals are also challenged by the need for a framework which will allow these different perspectives to be taken into account in the quality improvement process. This report is an invitation to hospitals to respond with insight and action to these challenges.

- No pain or suffering involved.
- To die with dignity and all that entails.
- Your children to be reared and independent.
- When you are old; in accordance with the natural life-cycle.
- With enough time to get your affairs in order.
- Emotional reassurance for the dying person.
- To stay alive as long as possible.
- To have time to do what you always wanted to do.
- With a pint of Guinness in one hand and a model (female) in the other!' (Weafer, 2009:16).

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14 Data Appendix

A note on how the querstionnaires are references in each table in the Appendix.

Note 1: Each table in this appendix contains a reference to one of the six questionnaires on which the data is based (Q1, Q2, Q3, Q4, Q5, or Q6). It also contains a reference to the question number within each questionnaire (A1, B2, C3, etc). Thus, Q1A1 refers to Question A1 in Questionnaire 1, Q2B2 refers to Question B2 in Questionnaire 2, etc.

Note 2: All tables are colour-coded. Tables coloured blue refer to responses from nurses in Questionnaire 1 and are numbered with the additional letter 'N'. Tables coloured green are responses from doctors in Questionnaire 2 and are numbered with the additional letter 'D'. Tables coloured yellow are responses from relatives in Questionnaire 3 and are numbered with the additional letter 'R'. Tables coloured purple measure the level of agreement between the responses from nurses, doctors, and relatives in Questionnaires 1, 2, and 3, respectively.

1 Data Coverage

Table 1.1: Number of Deaths in Each Hospital in 2008 and in HFH Audit 2008/9

Q6 C1.1		A & E	Intensive Care	Other Wards	Total	Deaths in Audit	
ID	**Hospital**	**No.**	**No.**	**No.**	**No.**	**No.**	**%**
A01	Acute	63	130	373	566	47	8.3
A02	Acute	60	84	304	448	44	9.8
A03	Acute	4	39	194	237	19	8.0
A04	Acute	0	16	73	89	20	22.5
A05	Acute	23	52	198	273	46	16.8
A06	Acute	21	32	116	169	43	25.4
A07	Acute	35	50	145	230	45	19.6
A08	Acute	27	71	331	429	50	11.7
A09	Acute	22	34	234	290	24	8.3
A10	Acute	133	194	606	933	48	5.1
A11	Acute	22	59	264	345	37	10.7
A12	Acute	119	164	501	784	33	4.2
A13	Acute	82	72	310	464	35	7.5
A14	Acute	29	79	208	316	37	11.7
A15	Acute	0	0	44	44	9	20.5
A16	Acute	14	28	98	140	27	19.3
A17	Acute	156	212	637	1005	50	5.0
A18	Acute	46	90	418	554	49	8.8
A19	Acute	9	50	153	212	39	18.4
A20	Acute	23	64	181	268	26	9.7
A21	Acute	67	112	278	457	42	9.2
A22	Acute	8	17	100	125	22	17.6
A23	Acute	52	70	183	305	49	16.1
A24	Acute	26	46	181	253	39	15.4
C50	Community				42	8	19.0
C51	Community				30	7	23.3
C52	Community				5	5	100.0
C53	Community				9	5	55.6
C54	Community				5	1	20.0
C55	Community				124	34	27.4
C56	Community				86	23	26.7
C57	Community				41	8	19.5
C58	Community				2	1	50.0
C59	Community				23	8	34.8
C60	Community				13	4	30.8
C61	Community				5	0	0.0
C62	Community				10	2	20.0
C63	Community				13	2	15.4
C64	Community				3	0	0.0
C65	Community				5	4	80.0
C66	Community				12	3	25.0
C67	Community				0	0	
C68	Community				16	4	25.0
H87	**HFH Acute Hospital**	**1,041**	**1,765**	**6,130**	**8,936**	**880**	**9.8**
H88	**HFH Community Hosp**			**444**	**444**	**119**	**28.7**
H89	**All HFH Hospitals (N)**	**1,041**	**1,765**	**6,574**	**9,380**	**999**	**10.7**
H89	**All HFH Hospitals (%)**	**11.1**	**18.8**	**70.1**	**100.0**	**10.7**	

Table 1.2: Number of Valid Questionnaires Returned by Nurses in HFH Audit

Q6 C1.1		**A & E**	**Intensive Care**	**Other Wards**	**Total**	**Quota ***	**Quota achieved**
ID	**Hospital**						**%**
A01	Acute	4	8	35	47	50	94
A02	Acute	3	8	33	44	50	88
A03	Acute		3	16	19	50	38
A04	Acute		3	17	20		
A05	Acute	3	8	35	46	50	92
A06	Acute	2	10	31	43	50	86
A07	Acute	1	8	36	45	50	90
A08	Acute	3	6	41	50	50	100
A09	Acute		5	19	24		
A10	Acute	5	9	34	48	50	96
A11	Acute	2	9	26	37	50	74
A12	Acute	3	6	24	33	50	66
A13	Acute	1	7	27	35	50	70
A14	Acute		13	24	37	50	74
A15	Acute			9	9		
A16	Acute		10	17	27		
A17	Acute	7	10	33	50	50	100
A18	Acute	3	11	35	49	50	98
A19	Acute	1	7	31	39	50	78
A20	Acute		6	20	26		
A21	Acute		7	35	42	50	84
A22	Acute	1	5	16	22		
A23	Acute	1	13	35	49	50	98
A24	Acute	1	8	30	39	50	78
C55	Community				34		
C56	Community				26		
C70	Dublin Group				31		
C80	North East Group				32		
H87	**HFH Acute Hospital (N)**	**41**	**180**	**659**	**880**	**900**	**84**
H87	**HFH Acute (%)**	**4.7**	**20.4**	**74.9**	**100**		
H88	**HFH Community**	**0**	**0**	**119**	**119**		
H89	**All HFH Hospitals (N)**	**41**	**180**	**778**	**999**		
H89	**All HFH Hospitals (%)**	**4.1**	**18.0**	**77.8**	**100**		

**See endnotes.*

Table 1.3: Number of Valid Questionnaires Returned by Doctors in HFH Audit

Q6 C1.1		**Total Returns**	**Quota ***	**Quota achieved**	**matched returns**	**unmatched returns**
ID	**Hospital**			**%**		
A01	Acute	39	50	78	37	2
A02	Acute	32	50	64	28	4
A03	Acute	24	50	48	16	8
A04	Acute	20			19	1
A05	Acute	46	50	92	43	3
A06	Acute	23	50	46	19	4
A07	Acute	38	50	76	37	1
A08	Acute	28	50	56	28	0
A09	Acute	16			15	1
A10	Acute	43	50	86	42	1
A11	Acute	32	50	64	24	8
A12	Acute	25	50	50	21	4
A13	Acute	37	50	74	26	11
A14	Acute	35	50	70	28	7
A15	Acute	8			7	1
A16	Acute	32			19	13
A17	Acute	51	50	102	50	1
A18	Acute	48	50	96	47	1
A19	Acute	24	50	48	23	1
A20	Acute	6			6	0
A21	Acute	22	50	44	20	2
A22	Acute	23			19	4
A23	Acute	49	50	98	47	2
A24	Acute	20	50	40	15	5
C55	Community	32			32	0
C56	Community	23			20	3
C70	Dublin Group	29			25	4
C80	North East Group	24			24	0
H87	**HFH Acute Hospital**	**721**	**900**	**68**	**636**	**85**
H88	**HFH Community**	**108**			**101**	**7**
H89	**All HFH Hospitals**	**829**			**737**	**92**

**See endnotes*

Matched and unmatched returns refer to the number of questionnaires returned by doctors (Questionnaire 2) which either match or do not match those returned by nurses (Questionnaire 1).

Table 1.4: Number of Valid Questionnaires Returned by Relatives in HFH Audit

Q3 Q1 Q2		Total Returns	matched returns with Q1	unmatched returns with Q1	matched returns with Q2	unmatched returns with Q2
ID	**Hospital**					
A01	Acute	21	18	3	14	7
A02	Acute	21	20	1	13	8
A03	Acute	2	1	1	1	1
A04	Acute	8	8	0	8	0
A05	Acute	27	26	1	24	3
A06	Acute	3	3	0	2	1
A07	Acute	26	22	4	18	8
A08	Acute	29	29	0	16	13
A09	Acute	16	8	8	5	11
A10	Acute	20	20	0	17	3
A11	Acute	16	10	6	8	8
A12	Acute	13	10	3	6	7
A13	Acute	18	14	4	11	7
A14	Acute	22	18	4	13	9
A15	Acute	5	4	1	3	2
A16	Acute	18	11	7	8	10
A17	Acute	23	23	0	23	0
A18	Acute	28	28	0	28	0
A19	Acute	15	11	4	5	10
A20	Acute	8	5	3	0	8
A21	Acute	6	5	1	2	4
A22	Acute	5	5	0	5	0
A23	Acute	24	22	2	22	2
A24	Acute	25	19	6	8	17
C55	Community	26	26	0	25	1
C56	Community	12	10	2	8	4
C70	Dublin Group	14	13	1	11	3
C80	North East Group	10	9	1	8	2
H87	**HFH Acute Hospital**	**399**	**340**	**59**	**260**	**139**
H88	**HFH Community**	**62**	**58**	**4**	**52**	**10**
H89	**All HFH Hospitals**	**461**	**398**	**63**	**312**	**149**

Matched and unmatched returns refer to the number of questionnaires returned by relatives (Q3) which either match or do not match those returned by nurses (Q1) or doctors (Q2).

Table 1.5: Number of Valid Questionnaires Returned by Relatives in HFH Audit

Q3 Q1 Q2		**Total Returns**	**matched returns with Q1&Q2 N**	**unmatched returns with Q1&Q2 N**	**matched returns with Q1&Q2 %**	**unmatched returns with Q1&Q2 %**
ID	**Hospital**					
A01	Acute	21	14	7	67	33
A02	Acute	21	13	8	62	38
A03	Acute	2	1	1	50	50
A04	Acute	8	8	0	100	0
A05	Acute	27	24	3	89	11
A06	Acute	3	2	1	67	33
A07	Acute	26	18	8	69	31
A08	Acute	29	16	13	55	45
A09	Acute	16	5	11	31	69
A10	Acute	20	17	3	85	15
A11	Acute	16	8	8	50	50
A12	Acute	13	6	7	46	54
A13	Acute	18	11	7	61	39
A14	Acute	22	13	9	59	41
A15	Acute	5	3	2	60	40
A16	Acute	18	8	10	44	56
A17	Acute	23	23	0	100	0
A18	Acute	28	28	0	100	0
A19	Acute	15	5	10	33	67
A20	Acute	8	0	8	0	100
A21	Acute	6	2	4	33	67
A22	Acute	5	5	0	100	0
A23	Acute	24	22	2	92	8
A24	Acute	25	8	17	32	68
C55	Community	26	25	1	96	4
C56	Community	12	8	4	67	33
C70	Dublin Group	14	11	3	79	21
C80	North East Group	10	8	2	80	20
H87	**HFH Acute Hospital**	**399**	**260**	**139**	**65**	**35**
H88	**HFH Community**	**62**	**52**	**10**	**84**	**16**
H89	**All HFH Hospitals**	**461**	**312**	**149**	**68**	**32**

Matched and unmatched returns refer to the number of questionnaires returned by relatives (Q3) which either match or do not match those returned by nurses (Q1) or doctors (Q2).

2 Relatives Background Information (A)

Note: For the remainder of the Technical Appendix all tables refer to 461 cases, unless otherwise specified.

Table 2.1: Respondent's Gender

Q3A2	Hospital	Male %	Female %	Total %
H87	HFH Acute	36.8	63.2	100
H88	HFH Community	26.2	73.8	100
H99	**All HFH Hospitals**	**35.4**	**64.6**	**100**

Table 2.2a: Respondent's Age

Q3A3	Hospital	Mean	Std. Deviation	Minimum	Maximum
H87	HFH Acute	56	13	13	89
H88	HFH Community	60	13	30	86
H99	**All HFH Hospitals**	**57**	**14**	**13**	**89**

Table 2.2b: Respondent's Age Group

Q3A3	Hospital	Under 45 %	45-64 %	65-84 %	85+ %	Not stated %	Total %
H87	HFH Acute	17.3	49.6	27.6	1.0	4.5	100
H88	HFH Community	11.3	51.6	29.0	1.6	6.5	100
H99	**All HFH Hospitals**	**16.5**	**49.9**	**27.8**	**1.1**	**4.8**	**100**

Table 2.2c: Respondent's Age by Gender

Q3A3	Hospital	Mean	Std. Deviation	Minimum	Maximum
H99	Male	57	12	32	82
H99	Female	57	14	13	89
H99	**Total**	**57**	**14**	**13**	**89**

Table 2.3: Relationship to Patient

Q3A1	Hospital	Husband Wife Partner %	Child %	Parent %	Brother Sister %	Other Relative %	Friend %	Total %
H97	Acute Hospitals	24.8	41.2	4.1	13.6	12.8	3.6	100
H98	Comm. Hospitals	16.6	38.3	8.3	8.3	18.3	10.0	100
H99	**All HFH Hospitals**	**23.7**	**40.8**	**4.7**	**12.9**	**13.5**	**4.5**	**100**

Table 2.4: Respondent was Care Provider prior to Hospital Admission

Q3A4	Hospital	Yes %	No %	Total %
H87	HFH Acute	22.0	78.0	100
H88	HFH Community	33.9	66.1	100
H99	**All HFH Hospitals**	**23.5**	**76.5**	**100**

Table 2.5: Respondent's Perception of Quality of End-of-Life Care in Irish Hospitals

Q3G 1	Hospital	very poor	poor	average	good	very good	n
		%	%	%	%	%	
	Acute Hospitals	3.8	8.2	20.9	28.5	38.6	**316**
	Comm. Hospitals	2.6	10.3	12.8	35.9	38.5	39
	All HFH Hospitals	**3.7**	**8.5**	**20.0**	**29.3**	**38.6**	**355**

	National Survey*	Don't know	poor	average	good	very good	n
		%	%	%	%	%	
	Total sample	6	13	24	44	13	**1,000**
	Sub-sample of respondents with someone close who died in an Irish hospital in past two years or so	2	9	14	34	41	**287**

Source: Weafer & Associates with TNS MRBI, 2004.

Table 2.6: Respondent's Perception of Most Important Things About Care When Dying

Q3G2	Aspect	most important	national sample*
1	being free from pain	57.3	55
3	to be surrounded by loved ones	20.4	68
5	having medical support	6.9	32
2	being able to communicate	6.3	35
4	to be at home	6.3	34
7	to be in private space	5.9	11
6	having spiritual support	5.9	19

*Source: Weafer & Associates with TNS MRBI, 2004.

3 Patient Characteristics

Note 1:
Throughout Section 3, first part of the table (the blue part) refers to the sample of 999 patients on whom nurses completed Questionnaire 1. The second part of the table (the yellow part) refers to the sample of 398 patients on whom families completed Questionnaire 3 and which can be matched to Questionnaire 3. For 63 patients (13.7%) this information cannot be matched.

Table 3.1: Gender

Q1A1	Hospital	Male %	Female %	Total %
H87	HFH Acute	52.4	47.6	100
H88	HFH Community	38.7	61.3	100
H99	**All HFH Hospitals**	**50.8**	**49.2**	**100**
H87	HFH Acute	51.2	48.8	100
H88	HFH Community	37.9	62.1	100
H99	**All HFH Hospitals**	**49.2**	**50.8**	**100**

Table 3.2a: Age

Q1A2	Hospital	Mean	Std. Deviation	Minimum	Maximum
H87	HFH Acute	74.5	13.0	18	100
H88	HFH Community	84.5	7.5	63	100
H99	**All HFH Hospitals**	**75.7**	**12.9**	**18**	**100**
H87	HFH Acute	75.7	11.3	30	99
H88	HFH Community	83.6	7.9	63	99
H99	**All HFH Hospitals**	**76.8**	**11.2**	**30**	**99**

Table 3.2b: Age Group

Q1A2	Hospital	Under 45 %	45-64 %	65-84 %	85+ %	Total %
H87	HFH Acute	3.5	13.8	62.6	20.1	100
H88	HFH Community		0.8	44.5	54.6	100
H99	**All HFH Hospitals**	**3.1**	**12.2**	**60.5**	**24.2**	**100**
H87	HFH Acute	2.1	12.1	65.6	20.3	100
H88	HFH Community		1.7	48.3	50.0	100
H99	**All HFH Hospitals**	**1.8**	**10.6**	**63.1**	**24.6**	**100**

Table 3.2c: Age by Gender

Q1A2	Hospital	Mean	Std. Deviation	Minimum	Maximum
H99	Male	73.4	13.1	18	94
H99	Female	78.0	12.2	26	100
H99	**Total**	**75.7**	**12.9**	**18**	**100**
H99	Male	74.9	11.3	30	92
H99	Female	78.7	10.9	40	99
H99	**Total**	**76.8**	**11.2**	**30**	**99**

Table 3.3: Marital Status

Q1A17	Hospital	Single %	Married %	Cohab-itating %	Separ. / Divorce %	Widow (er) %	Other %	Total %
H97	Acute Hospitals	19.0	41.5	4.2	4.8	28.6	1.0	100
H98	Comm. Hospitals	27.7	22.7	-	1.7	46.2	0.8	100
H99	**All HFH Hospitals**	**20.0**	**39.2**	**3.7**	**5.4**	**30.7**	**0.9**	**100**
H97	Acute Hospitals	17.9	42.4	2.4	5.3	31.5	0.6	100
H98	Comm. Hospitals	25.9	25.9		5.1	43.1		100
H99	**All HFH Hospitals**	**19.1**	**39.9**	**2.0**	**5.3**	**33.2**	**0.5**	**100**

Table 3.4: Living Arrangements prior to Hospital Admission

Q1A8	Hospital	Living Alone %	Living with Others %	Total %
H87	HFH Acute	16.6	83.4	100
H88	HFH Community	26.9	73.1	100
H99	**All HFH Hospitals**	**17.8**	**82.2**	**100**
H87	HFH Acute	18.5	81.5	100
H88	HFH Community	24.1	75.9	100
H99	**All HFH Hospitals**	**19.3**	**80.7**	**100**

Table 3.5: Place of Living prior to Admission

Q1A7	Hospital	Home %	Nursing Home %	Acute Hospital %	Non-acute Hospital %	Psych-iatric Unit %	Other %	Total %
H87	HFH Acute	77.2	17.5	0.9	1.9	0.3	2.2	100
H88	HFH Community	29.4	56.3	10.9	1.7	0.8	0.8	100
H99	**All HFH Hospitals**	**71.5**	**22.1**	**2.1**	**1.9**	**0.4**	**2.0**	**100**
H87	HFH Acute	80.0	15.0	0.6	2.4	0.3	1.8	100
H88	HFH Community	32.8	51.7	13.8	1.7			100
H99	**All HFH Hospitals**	**73.1**	**20.4**	**2.5**	**2.3**	**0.3**	**1.5**	**100**

Table 3.6: Nationality

Q1A18	Hospital	Irish %	Other EU %	Other %	Total %
H87	HFH Acute	95.7	2.2	2.2	100
H88	HFH Community	97.5	0.8	1.7	100
H99	**All HFH Hospitals**	**95.9**	**2.0**	**2.1**	**100**
H87	HFH Acute	97.1	1.5	1.5	100
H88	HFH Community	94.8	1.7	3.4	100
H99	**All HFH Hospitals**	**96.7**	**1.5**	**1.8**	**100**

Table 3.7: Ethnicity

Q1A19	Hospital	Irish %	Other White %	Other %	Total %
H87	HFH Acute	95.7	2.3	2.0	100
H88	HFH Community	97.5	0.8	1.7	100
H99	**All HFH Hospitals**	**95.9**	**2.1**	**2.0**	**100**
H87	HFH Acute	97.9	1.2	0.9	100
H88	HFH Community	98.3	1.7		100
H99	**All HFH Hospitals**	**98.0**	**1.3**	**0.8**	**100**

Table 3.8: Religion

Q1A20	Hospital	Roman Catholic %	Church of Ireland %	Other Christ. %	Muslim %	Other %	None / don’t know %	Total %
H87	HFH Acute	93.9	2.4	0.8	0.3	0.6	2.0	100
H88	HFH Community	97.5	2.5					100
H99	**All HFH Hospitals**	**94.3**	**2.4**	**0.7**	**0.3**	**0.5**	**1.8**	**100**
H87	HFH Acute	94.4	2.4	0.9	0.0	0.6	1.8	100
H88	HFH Community	96.6	3.4					100
H99	**All HFH Hospitals**	**94.7**	**2.5**	**0.8**	**0.0**	**0.5**	**1.8**	**100**

Table 3.9: Public v. Private Healthcare

Q1A16	Hospital	Public %	Private %	Total %
H97	Acute Hospitals	83.5	16.5	100
H98	Comm. Hospitals	94.1	5.9	100
H99	**All HFH Hospitals**	**84.8**	**15.2**	**100**
H97	Acute Hospitals	80.6	19.4	100
H98	Comm. Hospitals	93.1	6.9	100
H99	**All HFH Hospitals**	**82.4**	**17.6**	**100**

Table 3.10: Route of Admission to Hospital

Q1A5	Hospital	Out-patient %	A & E %	Day Services %	Medical Admission Unit %	Comm-unity Hospital %	Total %
H97	Acute Hospitals	3.4	83.5	5.0	8.1	n/a	100
H98	Comm. Hospitals	n/a	n/a	n/a	n/a	100	100
H99	**HFH Hospitals**	**3.0**	**73.6**	**4.4**	**7.1**	**11.9**	**100**
H97	Acute Hospitals	3.5	82.4	6.8	7.4	n/a	100
H98	Comm. Hospitals	n/a	n/a	n/a	n/a	100	100
H99	**HFH Hospitals**	**3.0**	**70.4**	**5.8**	**6.3**	**14.6**	**100**

Table 3.11: Type of Admission

Q1A6	Hospital	Elective %	Emergency %	Other %	Community Hospital %	Total %
H99	All HFH Hospitals	4.3	77.9	5.9	11.9	100
H99	All HFH Hospitals	5.3	73.6	6.5	14.6	100

Table 3.12: Trauma or Accident

Q1A12	Hospital	Yes %	No %	Total %
H97	Acute Hospitals	7.2	92.8	100
H98	Comm. Hospitals	4.2	95.8	100
H99	**All HFH Hospitals**	**6.8**	**93.2**	**100**
H97	Acute Hospitals	4.7	95.3	100
H98	Comm. Hospitals	1.7	98.3	100
H99	**All HFH Hospitals**	**4.3**	**95.7**	**100**

Table 3.13a: Length of Hospital Stay (days)

Q1A3	Hospital	up to one day %	more than one day to one week %	more than one week to one month %	over one month %	Total %
H97	Acute Hospitals	14.1	32.3	40.5	13.2	100
H98	Comm. Hospitals	4.2	9.2	22.7	63.9	100
H99	**All HFH Hospitals**	**12.9**	**29.5**	**38.3**	**19.2**	**100**
H97	Acute Hospitals	8.2	30.9	43.8	17.1	100
H98	Comm. Hospitals	5.2	12.1	24.1	58.6	100
H99	**All HFH Hospitals**	**7.8**	**28.1**	**41.0**	**23.1**	**100**

Table 3.13b: Mean Length of Stay (days)

Q1A3	Hospital	Mean	Std. Deviation	Minimum	Maximum
H97	Acute Hospitals	24	120	0	2,920
H98	Comm. Hospitals	826	1,158	1	4,410
H99	**All HFH Hospitals**	**119**	**489**	**0**	**4,410**
H97	Acute Hospitals	34	181	0	2,920
H98	Comm. Hospitals	584	989	1	4,015
H99	**All HFH Hospitals**	**114**	**454**	**0**	**4,015**

Table 3.13c: Mean Length of Stay by Gender (days)

Q1A3	Gender	Mean	Std. Deviation	Minimum	Maximum
H99	Male	87	397	0	4,225
H99	Female	152	567	0	4,410
H99	**Total**	**119**	**489**	**0**	**4,410**
H99	Male	114	485	0	4,015
H99	Female	114	423	0	2,920
H99	**Total**	**114**	**454**	**0**	**4,015**

Table 3.13d: Mean Length of Stay by Primary Diagnosis (days)

Q1A11	Diagnosis	Mean	Std. Deviation	Minimum	Maximum
H97	**Acute Hospitals**	**24**	**120**	**0**	**2,920**
	Cancer	15	16	0	100
	Circulatory/Organs	23	100	0	1,490
	Respiratory	18	27	0	180
	Frailty/Dementia	55	130	0	718
	Other	33	231	0	2,920
H98	**Comm. Hospitals**	**826**	**1,158**	**1**	**4,410**
	Cancer	476	965	2	3,285
	Circulatory/Organs	928	1,245	1	4,410
	Respiratory	80	141	7	387
	Frailty/Dementia	1,309	1,237	1	4,225
	Other	805	1,158	1	4,015
H99	**All HFH Hospitals**	**119**	**489**	**0**	**4,410**
	Cancer	55	305	0	3,285
	Circulatory/Organs	121	503	0	4,410
	Respiratory	22	46	0	387
	Frailty/Dementia	501	952	0	4,225
	Other	138	540	0	4,015

H97	**Acute Hospitals**	**34**	**181**	**0**	**2,920**
	Cancer	17	16	0	71
	Circulatory/Organs	42	163	0	1,490
	Respiratory	16	25	0	180
	Frailty/Dementia	57	69	2	240
	Other	70	407	0	2,920
H98	**Comm. Hospitals**	**584**	**989**	**1**	**4,015**
	Cancer	437	949	2	3,285
	Circulatory/Organs	451	808	6	2,929
	Respiratory	114	166	7	387
	Frailty/Dementia	953	1,134	1	2,920
	Other	831	1,240	1	4,015
H99	**All HFH Hospitals**	**114**	**454**	**0**	**4,015**
	Cancer	60	318	0	3,285
	Circulatory/Organs	89	333	0	2,929
	Respiratory	27	63	0	387
	Frailty/Dementia	408	819	1	2,920
	Other	252	763	0	4,015

Table 3.13e: Length of Stay in Hospital by Ward in which Death occurred (days)

Q1A3	Ward	Mean	Std. Deviation	Minimum	Maximum
H97	**Acute Hospitals**	**24**	**120**	**0**	**2,920**
	A & E	<1	1	0	8
	Intensive Care	11	16	0	120
	Surgical	35	263	0	2,920
	Medical	21	42	0	661
	Oncology	13	14	0	60
	Geriatric	136	1,090	0	1,490
	Other	27	44	0	240
H98	**Comm. Hospitals**	**826**	**1,158**	**1**	**4,410**
	Oncology	17	6	13	21
	Geriatric	846	1,175	1	4,410
	Other	860	1,123	6	3,465
H99	**Total**	**119**	**489**	**0**	**4,410**

H97	**Acute Hospitals**	**34**	**181**	**0**	**2,920**
	A & E	<1	<1	0	<1
	Intensive Care	10	12	0	53
	Surgical	73	42	0	2,920
	Medical	27	59	0	661
	Oncology	19	16	1	60
	Geriatric	131	392	1	1,490
	Other	32	55	0	240
H98	**Comm. Hospitals**	**584**	**989**	**1**	**4,015**
	Oncology	-	-	-	-
	Geriatric	654	1,035	1	4,015
	Other	89	143	6	375
H99	**Total**	**114**	**454**	**0**	**4,015**

Table 3.14a: Days Spent in A&E or Intensive Care before Death

Q1A10	Hospital	A & E %	Intensive Care Unit %	Surgical Medical Oncology Geriatric & Other %	Total %
H97	**Acute Hospitals**	**100**	**100**	**100**	**100**
	None			100	74.9
	less than half day	39.0	12.2		4.3
	half to full day	4.9	14.4		3.2
	1 to 2 days	2.4	17.2		3.6
	2 to 5 days	51.2	25.6		7.6
	5 to 10 days	2.4	13.9		3.0
	more than 10 days		16.7		3.4
H98	**Comm. Hospitals**	**nil**	**nil**	**100**	**100**
H99	**All HFH Hospitals**	**100**	**100**	**100**	**100**
H97	**Acute Hospitals**	**100**	**100**	**100**	**100**
	None			100	82.2
	less than half day	50.0	15.4		3.3
	half to full day	-	12.3		2.0
	1 to 2 days	-	16.9		2.8
	2 to 5 days	50.0	24.6		4.8
	5 to 10 days	-	13.8		2.3
	more than 10 days	-	16.9		2.8
H98	**Comm. Hospitals**	**nil**	**nil**	**100**	**100**
H99	**All HFH Hospitals**	**100**	**100**	**100**	**100**

Table 3.14b: Days Spent in A&E or Intensive Care before Death

Q1A3	Hospital	Mean	Std. Deviation	Minimum	Maximum
H97	**Acute Hospitals**	**1.3**	**4.9**	**0**	**90**
	A & E	2.3	2.0	0	6
	Intensive Care	6.0	9.5	0	90
H98	**Comm. Hospitals**	**nil**	**nil**	**nil**	**nil**
H99	**Total**	**1.2**	**4.7**	**0**	**90**
H97	**Acute Hospitals**	**1.0**	**3.4**	**0**	**32**
	A & E	2.1	2.2	0	5
	Intensive Care	5.3	6.3	0	32
H98	**Comm. Hospitals**	**nil**	**nil**	**nil**	**nil**
H99	**Total**	**0.9**	**3.2**	**0**	**32**

Table 3.15: Expected Death

Q1A13	Hospital	Expected %	Sudden %	Total %
H97	**Acute Hospitals**	**74.0**	**26.0**	**100**
	A & E	12.2	87.8	100
	Intensive Care	60.0	40.0	100
	Other Wards	81.6	18.4	100
H98	**Comm. Hospitals**	**87.4**	**12.6**	**100**
H99	**Total**	**75.6**	**24.4**	**100**
H97	**Acute Hospitals**	**80.0**	**20.0**	**100**
	A & E	16.7	83.3	100
	Intensive Care	60.0	40.0	100
	Other Wards	86.2	13.8	100
H98	**Comm. Hospitals**	**86.2**	**13.8**	**100**
H99	**Total**	**80.9**	**19.1**	**100**

Table 3.16: Time of Death

Q1A4	Hospital	1am – 4am %	4am – 8am %	8am – 12am %	12am – 4pm %	4pm – 8pm %	8pm – 12pm %	Total %
H97	Acute Hospitals	17.4	16.5	19.5	16.4	16.3	14.0	100
H98	Comm. Hospitals	19.3	21.0	26.1	11.8	12.6	9.2	100
H99	**All HFH Hospitals**	**17.6**	**17.0**	**20.3**	**15.8**	**15.8**	**13.4**	**100**
H97	Acute Hospitals	16.2	14.4	20.0	18.2	17.9	13.2	100
H98	Comm. Hospitals	25.9	19.0	22.4	15.5	10.3	6.9	100
H99	**All HFH Hospitals**	**17.6**	**15.1**	**20.4**	**17.8**	**16.8**	**12.3**	**100**

Table 3.17a: Primary and Secondary Diagnosis

Q1A11	Hospital	Primary Diagnosis HFH Audit %	CSO Vital Stats 2007 %	Secondary Diagnosis HFH Audit %
	Cancer	23.3	28	6.8
	Circulatory/Organs	31.2	35	23.8
	Respiratory	18.6	13	16.1
	Frailty/Dementia	7.6		12.0
	Other	19.2	30	13.9
	no secondary	n/a		27.3
H99	**All HFH Hospitals**	**100.0**	**100.0**	**100.0**
	Cancer	29.6	28	7.8
	Circulatory/Organs	28.4	35	26.4
	Respiratory	19.3	13	14.3
	Frailty/Dementia	5.8	30	12.8
	Other	16.8		11.6
	no secondary	n/a	n/a	27.1
H99	**All HFH Hospitals**	**100.0**	**100.0**	**100.0**

Table 3.17b: Dementia by Age Group

Q1A14	Hospital	under 41 %	41 to 60 %	61 to 80 %	81 to 100 %	Total %
H97	Acute Hospitals	-	1.1	9.5	26.7	14.8
H98	Comm. Hospitals	-	-	31.4	56.0	48.7
H99	**All HFH Hospitals**	**-**	**1.1**	**11.1**	**32.7**	**18.8**
H97	Acute Hospitals	-	-	8.8	27.6	15.0
H98	Comm. Hospitals	-	-	36.8	48.7	44.8
H99	**All HFH Hospitals**	**-**	**-**	**11.4**	**32.5**	**19.3**

Table 3.18: Ward in which Death Occurred

Q1A9	Hospital	A & E %	ICU %	Surgi-cal %	Medi-cal %	Oncol-ogy %	Geria-tric %	Other %	Total %
H97	Acute Hospitals	4.7	20.5	14.0	47.0	4.8	3.3	5.8	100
H97	*No. wards (acute)*	*16*	*49*	*57*	*99*	*16*	*15*	*33*	*285*
H98	Comm. Hospitals	-	-	-	0.8	1.7	88.2	9.2	100
H98	*No. wards (comm)*	*-*	*-*	*-*	*1*	*2*	*48*	*11*	*62*
H99	**All HFH Hospitals**	**4.1**	**18.0**	**12.3**	**41.5**	**4.4**	**13.4**	**6.2**	**100**
H99	*No. wards (All HfH)*	*16*	*49*	*57*	*100*	*18*	*63*	*44*	*347*
H97	Acute Hospitals	1.8	19.1	14.1	48.8	6.2	4.1	5.9	100
H97	*No. wards (acute)*	*5*	*31*	*31*	*67*	*13*	*9*	*17*	*173*
H98	Comm. Hospitals	-	-	-	1.7		87.9	10.3	100
H98	*No. wards (comm)*	*-*	*-*	*-*	*1*	*-*	*32*	*6*	*39*
H99	**All HFH Hospitals**	**1.5**	**16.3**	**12.1**	**42.0**	**5.3**	**16.3**	**6.5**	**100**
H99	*No. wards (All HfH)*	*5*	*31*	*31*	*68*	*13*	*41*	*23*	*212*

Table 3.19: Post-Mortem (PM)

Q1A15	Hospital	PM requested by Hospital %	PM carried out by Hospital %	PM requested by Coroner %	PM carried out by Coroner %
	No	72.5	44.9	62.7	38.5
	Yes	8.7	4.5	6.7	3.8
	Don't know	18.8	50.6	30.6	57.7
H99	**Total**	**100**	**100**	**100**	**100**
	No	77.4	46.0	67.3	41.0
	Yes	6.5	3.0	2.8	2.3
	Don't know	16.1	51.0	29.9	56.8
H99	**Total**	**100**	**100**	**100**	**100**

4 Experience of the Hospital and Ward (B)

Table 4.1: Type of Room where Patients spent most Time during last Week

Q3B4	Hospital	Single Room %	Shared Room %	Total %	n
H87	HFH Acute	34.5	65.5	100	880
H88	HFH Community	18.5	81.5	100	119
H99	**All HFH Hospitals**	**32.6**	**67.4**	**100**	**999**
H87	HFH Acute	39.4	60.6	100	378
H88	HFH Community	28.3	71.7	100	60
H99	**All HFH Hospitals**	**37.9**	**62.1**	**100**	**438**

Table 4.2: Type of Room where Patients Died

Q3B1	Hospital	Single Room %	Shared Room %	Total %	n
H87	HFH Acute	45.5	54.5	100	880
H88	HFH Community	33.6	66.4	100	119
H99	**All HFH Hospitals**	**44.0**	**56.0**	**100**	**999**
H87	HFH Acute	48.7	51.3	100	390
H88	HFH Community	39.3	60.7	100	61
H99	**All HFH Hospitals**	**47.5**	**52.5**	**100**	**451**

Table 4.3a Relatives Perceptions of Room (5 categories)

Q3B5	Hospital	very poor %	poor %	middle %	good %	very good %	n
	Acute Hospitals	**6.0**	**20.3**	**27.8**	**25.6**	**20.3**	**399**
5. 1- 3	Privacy	4.3	15.3	15.5	22.6	42.4	399
5. 4- 6	Dignity	4.8	10.5	15.3	25.6	43.9	399
5. 7-10	Environment	8.8	20.3	26.1	24.6	20.3	399
5.11-15	Control	26.8	22.8	21.3	14.8	14.3	399
	Comm. Hospitals		**16.1**	**33.9**	**27.4**	**22.6**	**62**
5. 1- 3	Privacy		6.5	12.9	24.2	56.5	62
5. 4- 6	Dignity	3.2	8.1	16.1	30.6	41.9	62
5. 7-10	Environment	3.2	14.5	29.0	16.1	37.1	62
5.11-15	Control	29.0	17.7	21.0	16.1	16.1	62
	All HFH Hospitals	**5.2**	**19.7**	**28.6**	**25.8**	**20.6**	**461**
5. 1- 3	Privacy	3.7	14.1	15.2	22.8	44.3	461
5. 4- 6	Dignity	4.6	10.2	15.4	26.2	43.6	461
5. 7-10	Environment	8.0	19.5	26.5	23.4	22.6	461
5.11-15	Control	27.1	22.1	21.3	15.0	14.5	461

Scores 1 or 2 = very poor; 3 or 4 = poor; 5 or 6 = middle; 7 or 8 = good; 9 or 10 = very good.
Ranges: 0-2.49 = very poor; 2.5-4.49 = poor; 4.5-6.49 = middle; 6.5-8.49 = good; 8.5-10 = very good.

Table 4.3b Relatives Perceptions of Room

Q3B5	Hospital	Acute Hospitals		Community Hospitals		All HFH Hospitals	
		Mean	**SD**	**Mean**	**SD**	**Mean**	**SD**
5.1	Privacy – staff	6.8	3.0	7.6	2.7	6.9	3.0
5.2	Privacy – family	6.8	3.1	7.2	3.0	6.9	3.1
5.3	Privacy – stay	8.2	2.7	9.5	1.1	8.4	.5
5.4	Dignity – care	7.6	2.8	8.2	2.2	7.6	2.7
5.5	Dignity – personal	7.7	2.8	7.8	2.7	7.7	2.8
5.6	Dignity – company	7.1	3.1	6.8	3.1	7.0	3.1
5.7	Environ – nature	4.7	3.2	6.3	3.2	4.9	3.3
5.8	Environ – daylight	7.6	2.6	8.4	2.2	7.7	2.6
5.9	Environ – quiet	6.0	3.3	6.5	3.0	6.0	3.3
5.10	Environ – TV radio	5.7	3.5	5.7	3.6	5.7	3.5
5.11	Control – space	5.8	3.3	6.2	3.2	5.9	3.2
5.12	Control – TV radio	5.4	3.4	5.1	3.6	5.3	3.5
5.13	Control – hot/cold	3.9	3.1	4.0	3.3	4.0	3.1
5.14	Control – light	4.9	3.3	4.5	3.3	4.8	3.3
5.15	Control - air	4.2	3.1	4.2	3.3	4.2	3.1
	Average Score	**6.1**	**2.3**	**6.5**	**2.1**	**6.2**	**2.3**

Table 4.3c: Relatives Perceptions of Room by Single/Multi-occupancy

Q3B5	Hospital	Privacy	Dignity	Environ	Control	Total
	Single	8.3	8.3	7.2	6.2	7.3
	Multi-occupancy	6.5	6.8	5.3	3.7	5.3
H99	**All Rooms**	**7.4**	**7.5**	**6.1**	**4.9**	**6.2**

Table 4.3d: Relatives Perceptions of Room by Type of Ward

Q3B5	Hospital	Privacy	Dignity	Environ	Control	Total
	A & E	8.8	8.7	7.9	8.2	8.3
	Intensive Care	7.2	7.6	6.3	4.9	6.3
	Surgical	6.7	7.2	5.3	4.3	5.6
	Medical	7.2	7.5	6.0	4.8	6.1
	Oncology	7.8	7.9	6.6	5.6	6.7
	Geriatric	7.8	7.4	6.6	4.7	6.4
	Other	8.3	8.0	6.7	6.0	7.0
H99	**All Wards**	**7.4**	**7.5**	**6.1**	**4.9**	**6.2**

Table 4.4a Comparison of Nurses and Relatives Perceptions of Room (5 categories)

Q3B5 & Q1B7	Category	Scale	Nurses indicate higher scores %	Agreement %	Relatives indicate higher scores %	Number of Cases
1	**privacy**	**1 - 5**	30	33	37	398
2	**dignity**	**1 - 5**	32	33	35	398
3	**environment**	**1 - 5**	33	28	39	398
4	**control**	**1 - 5**	34	27	39	398
5	**Singe rooms**	**1 - 5**	29	38	33	398
5	**Shared rooms**	**1 - 5**	29	27	44	398
5	**Acute**	**1 - 5**	27	33	40	398
5	**Community**	**1 - 5**	41	28	31	398
5	**Total**	**1 - 5**	**30**	**32**	**38**	**398**

Note: The methodology for measuring agreement is outlined in the Technical Appendix to Report Two.

Table 4.4b Comparison of Nurses and Relatives Perceptions of Room (5 categories)

Q3B5 & Q1B7		Relatives Perceptions of Quality of Room					
		very poor	**poor**	**middle**	**good**	**very good**	**Total**
Nurses Perception	**very poor**	.8	2.0	1.5	1.3	.5	**6.0**
	poor	2.0	7.3	8.0	4.5	3.0	**24.9**
	middle	.5	6.0	8.5	5.0	5.3	**25.4**
	good	.8	3.3	6.8	9.8	7.3	**27.9**
	very good	.8	1.0	3.5	4.8	5.8	**15.8**
	Total	**4.8**	**19.6**	**28.4**	**25.4**	**21.9**	**100.0**

Scores 1 or 2 = very poor; 3 or 4 = poor; 5 or 6 = middle; 7 or 8 = good; 9 or 10 = very good (n = 398).

Table 4.5a: Rating of Hospital Facilities

Q3B6	Hospital	not available %	poor %	fair %	good %	very good %	excellent %	n
B6.1	Adequate visitor car-parking	.7	12.5	16.1	27.5	22.4	20.8	447
B6.2	Easy finding way around	1.1		5.9	26.4	36.1	30.4	454
B6.3	Private meeting room on ward	3.6	20.1	15.4	16.7	16.5	27.7	448
B6.4	Quiet sitting room on each ward	6.7	21.5	15.7	17.6	14.5	24.0	433
B6.5	Child-friendly TV lounge on ward	22.1	38.5	7.8	14.1	6.3	11.2	348
B6.6	Relative's room close to ward	24.6	42.4	7.3	8.6	8.4	8.6	370
B6.7	Storage for personal items	5.4	15.2	21.3	23.4	17.6	17.1	427
B6.8	Multi-faith space in hospital	16.2	13.4	10.3	21.5	18.4	20.2	321
B6.9	Snacks and beverages nearby	4.1	10.2	14.1	24.5	19.5	27.7	441
B6.10	Visitor toilets on each ward	3.8	5.2	15.8	25.8	21.0	28.3	442
	Average of 10 items		**3.7**	**34.1**	**31.4**	**20.1**	**10.7**	**458**

Table 4.5b: Average Rating of Hospital Facilities (10 Items)

Q3B6	Hospital	poor %	fair %	good %	very good %	excellent %	n
	Acute Hospitals	4.0	33.8	33.6	19.7	8.8	396
	Comm. Hospitals	1.6	35.5	17.7	22.6	22.6	62
	All HFH Hospitals	**3.7**	**34.1**	**31.4**	**20.1**	**10.7**	**458**

Table 4.6: Organisation of Ward

Q3B11	Hospital	very disorganised %	fairly disorganised %	relatively organised %	very well organised %	don't know %
	Acute Hospitals	2.5	5.3	36.3	52.6	3.3
	Comm. Hospitals		1.6	29.0	66.1	3.2
	All HFH Hospitals	2.2	4.8	35.4	54.4	3.3

Table 4.7: Quality of Ward for End-of-Life Care

Q3B12	Hospital	very poor %	poor %	average %	good %	very good %	don't know %
	Acute Hospitals	9.0	6.8	18.3	21.8	42.6	1.5
	Comm. Hospitals	3.2	6.5	8.1	24.2	54.8	3.2
	All HFH Hospitals	8.2	6.7	16.9	22.1	44.3	1.7

5 Preferences of Where to Die (B)

Table 5.1a: Room in which Patient Died

Q3B1	Place of Death	Single room %	Shared room %	Total %	n
H87	HFH Acute	48.7	51.3	100	390
H88	HFH Community	39.3	60.7	100	61
H99	**All HFH Hospitals**	**47.5**	**52.5**	**100**	**451**

Table 5.1b: Room in which Patient spent most of last week

Q3B1	Place of Death	Single room %	Shared room %	Total %	n
H87	HFH Acute	39.4	60.6	100	378
H88	HFH Community	28.3	71.7	100	60
H99	**All HFH Hospitals**	**37.9**	**62.1**	**100**	**438**

Table 5.2a: Preference of Patient who died in Shared Room to die in Single Room

Q3B2	Place of Death	Yes %	No %	Don’t know %	Total %	n
H87	HFH Acute	48.2	19.3	32.5	100	197
H88	HFH Community	29.7	37.8	32.4	100	37
H99	**All HFH Hospitals**	**45.3**	**22.2**	**32.5**	**100**	**234**

Based on patients who died in a shared room.

Table 5.2b: Preference of Relative for Patient who died in Shared Room to die in Single Room

Q3B3	Place of Death	Yes %	No %	Don’t know %	Total %	n
H87	HFH Acute	68.3	22.8	9.0	100	189
H88	HFH Community	40.5	48.6	10.8	100	37
H99	**All HFH Hospitals**	**63.7**	**27.0**	**9.3**	**100**	**226**

Based on patients who died in a shared room.

6 Preferences to Die at Home (B)

Table 6.1: Preferences for Dying at Home

Q3C		Yes %	No %	Don't know %	Total %	n
26	Patient could have died at home	23.6	62.7	13.7	100	461
27	Patient would have liked to die at home	14.1	75.5	10.4	100	461
28	Relative would have liked if patient had died at home	39.7	47.3	13.0	100	461

Table 6.2: Patient Could Have Died at Home (Relatives)

Q3 C26	Category	Relatives Agree with Nurses Q1C6	Relatives Agree with Doctors Q2A6	Nurses and Doctors Agree	Relatives Agree with Nurses and Doctors	Number of Cases
		%	%	%	%	
A / C	Acute Hospitals	43.9	35.8	47.1	27.3	399
	Comm. Hospitals	64.5	50.0	54.8	40.3	62
H99	**All HFH Hospitals**	**46.6**	**37.7**	**48.2**	**29.1**	461

Table 6.3: Patient Could Have Died at Home by various Reference Groups

Q3C26	Reference Group	Patient could have died at home	Patient could not have died at home	Total	n
		%	%	%	
Q3B7	**Staff Responsiveness**	**25.2**	**74.8**	**100**	**341**
	Very poor / poor	40.0	60.0	100	15
	Average	44.8	55.2	100	29
	Good / very good	22.6	77.4	100	338
Q3B12	**Quality of Ward**	**25.7**	**74.3**	**100**	**338**
	Very poor / poor	42.6	57.4	100	47
	Average	39.0	61.0	100	59
	Good / very good	19.0	81.0	100	232
Q3G1	**Quality of End-of-Life Care in Irish Hospitals**	**26.2**	**73.8**	**100**	**271**
	Very poor / poor	42.4	57.6	100	33
	Average	36.5	63.5	100	52
	Good / very good	20.4	79.6	100	186
Q3G2.1	**Being free of pain is the most important thing about care when dying**	**25.6**	**74.4**	**100**	**344**
	Yes	24.0	76.0	100	192
	No	27.6	72.4	100	152

Based on maximum of 398 matched records only.

Table 6.4: Patient Could Have Died at Home by Main Symptoms

Q3C (A)	Agreement on Symptoms by Nurses, Doctors and Relatives	Patient could have died at home	Patient could not have died at home	Total	n
		%	%	%	
	Pain	**28.3**	**71.7**	**100**	**219**
	all agree	33.3	66.7	100	6
	disagree	28.1	71.9	100	96
	all agree on not	28.2	71.8	100	117
	Breathing Difficulty	**27.6**	**72.4**	**100**	**254**
	all agree	31.6	68.4	100	38
	disagree	25.6	74.4	100	133
	all agree on not	28.9	71.1	100	83
	Anxious or afraid	**27.1**	**72.9**	**100**	**225**
	all agree	66.7	33.3	100	3
	disagree	28.2	71.8	100	78
	all agree on not	25.7	74.3	100	144

Based on maximum of 312 matched records only.

7 Quality of Staff (B)

Table 7.1: Quality of Staff Response and Overall Quality of Ward

Q3B7	Hospital	very poor %	poor %	average %	good %	very good %	don't know %
	Acute Hospitals	3.5	3.8	10.3	13.3	68.4	.8
	Comm. Hospitals			4.8	11.3	82.3	1.6
	All HFH Hospitals	3.0	3.3	9.5	13.0	70.3	.9

Table 7.2: Quality of Hospital Staff

Q3B	Hospital	very poor %	poor %	average %	good %	don't know %
	Acute Hospitals					
B8.2	Medical Staff	3.5	3.3	14.3	77.4	1.5
B9.2	Nursing Staff	1.5	2.5	12.0	82.5	1.5
B10.2	Other Staff	1.0	1.8	17.8	69.9	9.5
	Comm. Hospitals					
B8.2	Medical Staff	1.6	1.6	4.8	88.7	3.2
B9.2	Nursing Staff	3.2	1.6	6.5	85.5	3.2
B10.2	Other Staff			11.3	80.6	8.1
	All HFH Hospitals					
B8.2	Medical Staff	3.3	3.0	13.0	79.0	1.7
B9.2	Nursing Staff	1.7	2.4	11.3	82.9	1.7
B10.2	Other Staff	.9	1.5	16.9	71.4	9.3

Table 7.3: Sufficiency of Hospital Staff

Q3B	Hospital	definitely not enough %	not enough %	enough %	definitely enough %	don't know %
	Acute Hospitals					
B8.1	Medical Staff	9.5	14.5	42.6	27.6	5.8
B9.1	Nursing Staff	8.8	17.8	46.4	22.3	4.8
B10.1	Other Staff	3.8	9.8	55.6	20.1	10.8
	Comm. Hospitals					
B8.1	Medical Staff	4.8	9.7	48.4	29.0	8.1
B9.1	Nursing Staff	4.8	9.7	50.0	27.4	8.1
B10.1	Other Staff	3.2	9.7	51.6	24.2	11.3
	All HFH Hospitals					
B8.1	Medical Staff	8.9	13.9	43.4	27.8	6.1
B9.1	Nursing Staff	8.2	16.7	46.9	23.0	5.2
B10.1	Other Staff	3.7	9.8	55.1	20.6	10.8

8 Quality of Life in the Last Week (C)

Note: The methodology for measuring QODD scores is outlined in the Technical Appendix to Report Two.

Table 8.1a: Patient Experiences of Dying and Death (QODD - Part A)

Q3H1		Scale	% none / a little of the time	% some / good bit of the time	% most / all of the time	Number of Cases
1	physical pain	**1 - 6**	40.2	36.8	23.0	413
2	able to eat	**1 - 6**	64.8	21.2	13.9	452
3	difficulty breathing	**1 - 6**	29.6	34.4	36.0	442
4	comfortable	**1 - 6**	21.7	34.4	43.9	451
5	anxious	**1 - 6**	49.1	35.2	15.7	426
6	having enjoyment	**1 - 6**	67.5	23.3	9.3	443
7	having energy	**1 - 6**	87.2	9.5	3.4	444
8	no toilet problems	**1 - 6**	69.5	14.4	16.0	430
9	worried	**1 - 6**	52.0	33.2	14.8	358
10	maintain dignity	**1 - 6**	8.0	20.6	71.4	451
11	time with partner	**1 - 6**	12.0	18.2	69.7	274
12	time with children	**1 - 6**	12.7	19.1	68.2	299
13	time with friends	**1 - 6**	12.0	16.8	71.2	393
14	time alone	**1 - 6**	23.4	25.3	51.3	316

			% no	% yes	Number of cases
15	meaning and purpose	**0 / 1**	58.6	41.4	362
16	knowledge of loved ones	**0 / 1**	2.3	97.7	433
17	monetary worries	**0 / 1**	94.1	5.9	439
18	said goodbye	**0 / 1**	70.2	29.8	409
19	had spiritual visit	**0 / 1**	5.8	94.2	430
20	had spiritual service	**0 / 1**	33.7	66.3	418
21	someone there on death	**0 / 1**	15.5	66.3	445

			% alert	% semi-conscious	% unconscious	Number of cases
22	condition prior to death	**1 - 3**	7.5	13.8	78.8	400

Table 8.1b: Quality of Dying and Death (QODD - Part A, adjusted)

Q3 C	**Category**	**Personal well-being**	**Relationship well-being**	**Total**	**Number of Cases**
A / C	Acute Hospitals	54	69	62	399
	Comm. Hospitals	58	70	65	62
Ward	A & E	70	72	71	6
	Intensive Care	55	69	63	65
	Surgical	54	69	62	48
	Medical	54	69	62	167
	Oncology	56	71	64	21
	Geriatric	56	70	64	65
	Other	57	71	65	26
Room	Single	56	72	64	190
	Multi-occupancy	54	67	61	208
MDC	Cancer	55	70	63	118
	Circulatory/Organs	56	70	64	113
	Respiratory	51	68	60	77
	Frailty/Dementia	59	72	66	23
	Other	55	67	62	67
Sex	Male	54	69	62	196
	Female	56	70	63	202
Age	under 45	44	68	57	4
	45 to 64	54	70	63	27
	65 to 84	55	69	63	201
	85 to 100	55	70	63	166
Stay	under 1 day	59	68	64	31
	1 day – 1 week	56	70	63	112
	1 week – 1 month	53	69	62	163
	over one month	56	70	63	92
Death	Expected	54	70	63	322
	Sudden	59	68	64	76
	Unmatched	54	67	61	63
H99	**All HFH Hospitals**	**55**	**69**	**63**	**461**

Mirroring the original QODD, all results are scaled to a maximum of 100.

Table 8.2: Comparison of Patient Experiences of Dying and Death (QODD - Part A)

H1		Scale	Nurses indicate higher discomfort %	Agreement %	Relatives indicate higher discomfort %	Number of Cases
1	physical pain	**1 - 6**	17.4	41.1	41.1	316
2	able to eat ®	**1 - 6**	17.8	56.0	26.3	377
3	difficulty breathing	**1 - 6**	20.3	46.9	32.8	369
4	comfortable ®	**1 - 6**	16.3	45.6	38.1	375
5	anxious	**1 - 6**	12.1	48.3	39.6	321
6	having enjoyment ®	**1 - 6**	20.5	57.2	22.3	346
7	having energy ®	**1 - 6**	8.9	78.3	12.9	350
8	no toilet problems ®	**1 - 6**	19.7	61.2	19.1	345
9	worried	**1 - 6**	8.4	50.7	40.9	215
10	maintain dignity ®	**1 - 6**	3.2	71.3	25.5	376
11	time with partner ®	**1 - 6**	26.2	55.0	18.8	149
12	time with children ®	**1 - 6**	8.2	67.6	24.2	219
13	time with friends ®	**1 - 6**	12.2	65.5	22.3	287
14	time alone ®	**1 - 6**	28.5	43.6	27.9	179
15	meaning and purpose ®	**0 / 1**	14.0	64.6	21.3	164
16	knowledge of loved ones ®	**0 / 1**	9.2	90.1	0.7	292
17	monetary worries	**0 / 1**	1.3	91.4	7.2	152
18	said goodbye ®	**0 / 1**	11.0	59.8	29.1	254
19	had spiritual visit ®	**0 / 1**	3.5	92.5	4.0	347
20	had spiritual service ®	**0 / 1**	26.5	57.9	15.6	321
21	someone there on death ®	**0 / 1**	2.9	87.7	9.4	373
22	condition prior to death	**1 - 3**	14.5	76.1	9.4	330

® indicates that the scales have been reversed such as to display the agreement columns in identical order with respect to the patient’s well-being.

Table 8.3a: Comparing Frequency of Symptoms (Relatives, Nurses and Doctors)

		Relatives %	Nurses %	Nurses %	Doctors %
	Physical Pain	**Q3C1a (rescaled)**	**Q1H1a (rescaled)**	**Q1F2.1.1**	**Q2B2.1.1**
	All or most of the time	34.2	17.0	14.4	10.9
	Some or none of the time	65.8	83.0	85.6	81.9
	Total	**100**	**100**	**100**	**100**

	Breathing difficulties	**Q3C3a (rescaled)**	**Q1H3a (rescaled)**	**Q1F2.3.1**	**Q2B2.3.1**
	All or most of the time	48.7	38.7	39.4	33.7
	Some or none of the time	51.3	61.3	60.6	66.3
	Total	**100**	**100**	**100**	**100**

	Anxious or afraid	**Q3C5a (rescaled)**	**Q1H5a (rescaled)**	**Q1F2.6.1**	**Q2B2.6.1**
	All or most of the time	25.3	7.7	10.9	9.3
	Some or none of the time	74.7	92.3	89.1	90.7
	Total	**100**	**100**	**100**	**100**

Note: QODD items in the relatives and nurses questionnaire have been rescaled from 6 to 4 categories. Comparisons are based on the maximum of 312 cases which are common across the relatives, nurses and doctors questionnaires.

Table 8.3b: Comparing Frequency of Symptoms (Nurses and Relatives)

Q3 D	Category Q1J	Scale	Nurses indicate higher level of symptoms %	Agreement %	Relatives indicate higher level of symptoms %	Number of Cases
D1	Physical Pain	**0 / 1**	8.1	65.6	26.3	247
D2	Breathing difficulties	**0 / 1**	14.2	62.1	23.6	288
D3	Anxious or afraid	**0 / 1**	4.4	72.7	23.0	252

based on a maximum of 312 matched cases

Table 8.3c: Comparing Frequency of Symptoms (Doctors and Relatives)

Q3 D	Category Q2D	Scale	Doctors indicate higher level of symptoms %	Agreement %	Relatives indicate higher level of symptoms %	Number of Cases
D1	Physical Pain	**0 / 1**	4.3	68.4	27.4	281
D2	Breathing difficulties	**0 / 1**	7.4	70.5	22.1	298
D3	Anxious or afraid	**0 / 1**	6.2	72.0	21.8	289

based on a maximum of 312 matched cases

Table 8.3d: Comparing Frequency of Symptoms (Nurses and Doctors)

Q3 D	Category Q2D	Scale	Nurses indicate higher level of symptoms %	Agreement %	Doctors indicate higher level of symptoms %	Number of Cases
D1	Physical Pain	**0 / 1**	11.2	81.1	7.7	312
D2	Breathing difficulties	**0 / 1**	20.5	64.7	14.7	312
D3	Anxious or afraid	**0 / 1**	7.1	87.5	5.4	312

based on a maximum of 312 matched cases

Table 8.3e: Comparing Frequency of Symptoms (Relatives, Nurses and Doctors)

Q3 D	Category Q2D	Scale	Relatives, Nurses and Doctors Agree %	At least one Disagreement %	Number of Cases
D1	Physical Pain	**0 / 1**	51.4	48.6	247
D2	Breathing difficulties	**0 / 1**	43.8	56.3	288
D3	Anxious or afraid	**0 / 1**	61.9	38.1	252

based on a maximum of 312 matched cases

Table 8.4R: Quality of Dying and Death (QODD Part A - Relatives)

Q3C (A)	Number of Decisions on Treatment	Personal well-being		Relationship well-being		Total	
		Mean	**SD**	**Mean**	**SD**	**Mean**	**SD**
	none / na / don't know	61.7	17.3	67.7	11.9	64.9	13.4
	1 – 3 decisions	58.6	14.7	66.8	9.8	63.1	10.7
	4 – 6 decisions	53.7	13.7	68.0	10.1	61.5	10.3
	7 – 9 decisions	54.1	11.6	70.2	9.6	62.9	9.2
	10 or 11 decisions	53.5	10.9	71.2	9.5	63.2	8.9
	Total	**55.0**	**13.1**	**69.3**	**10.0**	**62.9**	**10.0**

Based on matched records only. n = 398

Table 8.4N: Quality of Dying and Death (QODD Part A - Nurses)

Q1H (A)	Number of Decisions on Treatment	Personal well-being		Relationship well-being		Total	
		Mean	**SD**	**Mean**	**SD**	**Mean**	**SD**
	none / na / don't know	66.4	12.9	68.0	8.7	67.2	8.0
	1 – 3 decisions	64.4	10.0	67.2	8.8	66.0	7.7
	4 – 6 decisions	61.9	9.9	69.6	8.3	66.2	7.2
	7 – 9 decisions	60.8	8.3	71.7	7.5	66.8	6.3
	10 or 11 decisions	60.7	7.0	71.7	7.7	66.8	6.1
	Total	**62.0**	**9.2**	**70.3**	**8.2**	**66.6**	**6.8**

Based on matched records only. n = 398

Table 8.5R: Quality of Dying and Death (QODD Part A – Relatives)

Q3C (A)	Patient receiving SPC	Personal well-being		Relationship well-being		Total	
		Mean	**SD**	**Mean**	**SD**	**Mean**	**SD**
	Patient received SPC	54.8	12.6	70.4	9.5	63.3	9.4
	Patient would have benefited from SPC	53.6	13.5	68.3	11.7	61.7	11.7
	Patient would not have benefited from SPC	56.1	13.9	69.5	9.8	63.4	10.3
	Don't know	55.1	13.0	68.1	10.0	62.2	9.5
	Total	**55.0**	**13.1**	**69.3**	**10.0**	**62.9**	**10.0**

Based on matched records only. n = 398

Table 8.5N: Quality of Dying and Death (QODD Part A - Nurses)

Q1H (A)	Patient receiving SPC	Personal well-being		Relationship well-being		Total	
		Mean	**SD**	**Mean**	**SD**	**Mean**	**SD**
	Patient received SPC	61.5	8.7	72.0	8.0	67.3	6.8
	Patient would have benefited from SPC	59.7	8.7	70.0	6.6	65.4	6.3
	Patient would not have benefited from SPC	63.0	8.7	67.9	9.3	65.7	7.0
	Don't know	63.1	10.6	70.5	7.4	67.1	6.7
	Total	**62.0**	**9.2**	**70.3**	**8.2**	**66.6**	**6.8**

Based on matched records only. n = 398

Table 8.6: Experiences of Dying and Death by Reference Group (QODD Part A)

Q3C (A)		Personal well-being		Relationship well-being		Total		
		Mean	SD	Mean	SD	Mean	SD	n
Q3B7	**Staff Responsiveness**	**54.9**	**13.0**	**69.3**	**10.1**	**62.8**	**10.0**	**394**
	Very poor / poor	42.6	12.9	60.5	12.0	52.5	10.4	24
	Average	45.2	10.6	60.9	9.6	53.8	8.1	35
	Good / very good	56.8	12.3	70.8	9.2	64.5	9.2	335
Q3B12	**Quality of Ward**	**55.1**	**13.2**	**69.4**	**10.0**	**69.3**	**10.0**	**390**
	Very poor / poor	43.4	10.5	60.4	9.9	52.7	7.9	60
	Average	50.9	11.9	64.2	10.3	58.2	9.3	67
	Good / very good	58.8	12.2	72.8	8.0	66.5	8.4	263
Q3G1	**Quality of End-of-Life Care**	**54.8**	**13.2**	**68.9**	**10.2**	**62.5**	**10.1**	**310**
	Very poor / poor	46.4	15.3	62.2	10.2	55.1	10.9	39
	Average	51.6	11.3	63.5	10.3	58.1	9.0	60
	Good / very good	57.3	12.5	71.6	8.9	65.2	9.1	211
Q3G2.1	**Being free of pain is the most important thing when dying**	**55.0**	**13.1**	**69.3**	**10.0**	**62.9**	**10.0**	**398**
	Yes	54.5	13.2	69.2	9.8	62.6	9.9	172
	No	55.8	13.1	69.5	10.3	63.3	10.2	226

Based on maximum of 398 matched records only.

Table 8.7: Experiences of Dying and Death (QODD Part A) by Main Symptoms

Q3C (A)	Agreement on Symptoms by Nurses, Doctors and Relatives	Personal well-being		Relationship well-being		Total		
		Mean	SD	Mean	SD	Mean	SD	n
	Pain	**54.6**	**13.5**	**69.4**	**10.1**	**62.7**	**10.2**	**247**
	all agree	39.6	12.3	60.7	8.2	51.1	8.4	7
	disagree	47.8	12.6	67.5	10.5	58.6	10.1	108
	all agree on not	61.0	10.6	71.4	9.3	66.7	8.5	132
	Breathing Difficulty	**55.0**	**13.6**	**69.5**	**10.3**	**63.0**	**10.4**	**288**
	all agree	50.7	13.6	70.1	9.1	61.4	9.6	43
	disagree	52.8	12.7	68.8	10.4	61.6	9.9	147
	all agree on not	60.0	14.1	70.4	10.7	65.7	10.9	98
	Anxious or afraid	**54.8**	**13.6**	**69.6**	**10.5**	**62.9**	**10.4**	**252**
	all agree	28.7	2.9	56.7	11.9	44.0	6.0	3
	disagree	47.0	13.3	66.3	11.1	57.6	10.6	89
	all agree on not	59.7	11.1	71.6	9.5	66.2	8.6	160

Based on maximum of 312 matched records only.

Table 8.8: Quality of Patient Experiences (QODD Part B, adjusted) - Relative

Q1 C	Category	Personal well-being	Relationship well-being	Total	Number of Cases
A / C	Acute Hospitals	60	76	68	399
	Comm. Hospitals	68	78	73	62
Ward	A & E	74	82	77	6
	Intensive Care	64	79	72	65
	Surgical	57	75	66	48
	Medical	59	75	67	167
	Oncology	60	77	68	21
	Geriatric	65	75	70	65
	Other	67	79	73	26
Room	Single	65	80	73	190
	Multi-occupancy	58	72	65	208
MDC	Cancer	62	78	70	118
	Circulatory/Organs	63	77	70	113
	Respiratory	57	72	65	77
	Frailty/Dementia	69	82	76	23
	Other	60	73	66	67
Sex	Male	61	75	68	196
	Female	62	77	69	202
Age	under 45	62	72	67	4
	45 to 64	57	76	67	27
	65 to 84	63	76	69	201
	85 to 100	60	76	68	166
Stay	under 1 day	64	77	70	31
	1 day – 1 week	64	77	70	112
	1 week – 1 month	59	76	67	163
	over one month	62	75	69	92
Death	Expected	62	77	70	322
	Sudden	59	71	65	76
	unmatched	63	74	68	63
H99	**All HFH Hospitals**	**62**	**76**	**69**	**461**

Mirroring the original QODD, all results are scaled to a maximum of 100.

Table 8.9: Quality of Patient Experiences (QODD Part B)

Q1H (B)			**Relatives Rating**		**Nurses Rating**	
		Scale	**Mean**	**Std. Deviation**	**Mean**	**Std. Deviation**
1	physical pain	**1 - 10**	6.7	2.8	7.2	2.2
2	taking food	**1 - 10**	6.2	2.8	6.9	2.4
3	breathing	**1 - 10**	6.4	2.8	6.8	2.3
4	being comfortable	**1 - 10**	6.2	3.0	7.5	2.1
5	being anxious	**1 - 10**	6.0	3.0	7.0	2.3
6	having enjoyment	**1 - 10**	5.7	2.9	6.2	2.4
7	having energy	**1 - 10**	4.7	2.9	5.0	2.6
8	bathroom	**1 - 10**	5.5	2.9	5.7	2.9
9	strain to loved ones	**1 - 10**	6.7	2.4	6.4	2.4
10	maintaining dignity	**1 - 10**	7.2	2.9	8.8	1.5
11	time with partner	**1 - 10**	7.7	2.6	8.4	1.6
12	time with children	**1 - 10**	7.8	2.6	8.5	1.7
13	time with friends	**1 - 10**	7.7	2.6	8.4	1.7
14	time alone	**1 - 10**	7.0	2.8	7.4	2.1
15	meaning and purpose	**1 - 10**	6.1	3.0	6.2	2.4
16	knowledge of loved ones	**1 - 10**	8.7	2.0	8.3	1.8
17	monetary worries	**1 - 10**	8.4	2.1	8.2	1.6
18	saying goodbye	**1 - 10**	6.4	3.1	6.2	2.7
19	spiritual visit	**1 - 10**	8.4	2.2	8.6	1.8
20	spiritual service	**1 - 10**	7.8	2.7	7.7	2.3
21	someone there on death	**1 - 10**	8.1	2.7	8.4	2.1
22	condition prior to death	**1 - 10**	7.2	2.8	7.8	2.0
23	quality at moment of death	**1 - 10**	7.5	2.9	7.9	2.2
24	quality of last week	**1 - 10**	5.4	3.1	6.6	2.6
25	overall quality of dying	**1 - 10**	6.5	3.0	7.3	2.2
	Average of 25 items	**1 - 10**	**6.9**	**2.0**	**7.3**	**1.5**

Scale 1 – 10: 1 = unsatisfactory, 10 = satisfactory n = 398

Table 8.10R: Quality of Dying and Death (QODD Part B - Relatives)

Q3C (B)	Number of Decisions on Treatment Q1F1(A)	Personal well-being (Items 1-10)		Relationship well-being (Items 11-22)		Total	
		Mean	**SD**	**Mean**	**SD**	**Mean**	**SD**
	none / na / don’t know	67.1	26.1	76.4	21.5	71.3	22.9
	1 – 3 decisions	60.1	24.4	71.1	21.0	65.0	21.9
	4 – 6 decisions	60.4	24.3	73.2	19.5	67.1	20.6
	7 – 9 decisions	62.6	24.4	77.5	17.5	70.1	19.5
	10 or 11 decisions	59.4	22.6	79.4	16.5	69.7	17.9
	Total	**61.3**	**24.1**	**76.1**	**18.7**	**68.8**	**20.0**

Based on matched records only. n = 398

Table 8.10N: Quality of Dying and Death (QODD Part B - Nurses)

Q1H (B)	Number of Decisions on Treatment Q1F1(A)	Personal well-being (Items 1-10)		Relationship well-being (Items 11-22)		Total	
		Mean	**SD**	**Mean**	**SD**	**Mean**	**SD**
	none / na / don’t know	69.3	16.8	75.7	15.1	72.4	14.2
	1 – 3 decisions	69.2	17.0	75.3	16.3	71.9	16.1
	4 – 6 decisions	67.3	17.2	76.5	16.0	72.0	15.4
	7 – 9 decisions	65.3	18.3	80.5	12.4	73.6	13.7
	10 or 11 decisions	68.2	18.3	80.8	13.3	75.2	14.3
	Total	**67.4**	**17.7**	**78.6**	**14.4**	**73.3**	**14.6**

Based on matched records only. n = 398

Table 8.11R: Quality of Dying and Death (QODD Part B – Relatives)

Q3C (B)	Patient receiving SPC Q1G	Personal well-being (Items 1-10)		Relationship well-being (Items 11-22)		Total	
		Mean	**SD**	**Mean**	**SD**	**Mean**	**SD**
	Patient received SPC	61.0	23.1	79.2	16.1	70.4	18.0
	Patient would have benefited from SPC	58.5	26.7	71.1	22.6	64.9	23.8
	Patient would not have benefited from SPC	62.4	25.0	75.6	20.2	69.0	21.4
	Don’t know	62.4	22.9	74.8	17.5	68.5	18.7
	Total	**61.3**	**24.1**	**76.1**	**18.7**	**68.8**	**20.0**

Based on matched records only. n = 398

Table 8.11N: Quality of Dying and Death (QODD Part B - Nurses)

Q1H (B)	Patient receiving SPC Q1G	Personal well-being (Items 1-10)		Relationship well-being (Items 11-22)		Total	
		Mean	**SD**	**Mean**	**SD**	**Mean**	**SD**
	Patient received SPC	66.3	18.8	79.2	15.3	73.3	15.5
	Patient would have benefited from SPC	66.1	19.1	76.9	13.6	71.8	15.2
	Patient would not have benefited from SPC	68.4	16.5	79.0	14.0	73.9	14.1
	Don’t know	68.6	16.3	78.1	13.9	73.7	13.5
	Total	**67.4**	**17.7**	**78.6**	**14.4**	**73.3**	**14.6**

Based on matched records only. n = 398

Table 8.12: Quality of Dying and Death by Reference Group (QODD Part B)

Q3C (B)		Personal well-being		Relationship well-being		Total		
		Mean	SD	Mean	SD	Mean	SD	n
Q3B7	**Staff Responsiveness**	**61.3**	**24.0**	**76.1**	**18.7**	**68.8**	**20.0**	**394**
	Very poor / poor	30.7	19.2	53.3	19.2	42.0	17.6	24
	Average	37.0	15.2	56.6	16.9	46.1	13.3	35
	Good / very good	66.0	21.8	79.8	16.3	73.0	17.5	335
Q3B12	**Quality of Ward**	**61.4**	**24.0**	**76.1**	**18.7**	**68.8**	**20.0**	**390**
	Very poor / poor	34.9	18.7	57.2	18.5	45.6	16.0	60
	Average	49.9	19.3	66.3	18.3	58.3	17.0	67
	Good / very good	70.4	20.2	82.9	14.3	76.8	15.7	263
Q3G1	**Quality of End-of-Life Care**	**61.9**	**24.0**	**76.0**	**18.7**	**68.9**	**20.0**	**310**
	Very poor / poor	39.7	24.6	59.1	20.4	48.3	20.3	39
	Average	50.1	18.0	65.7	16.6	58.0	15.8	60
	Good / very good	69.3	21.5	82.0	15.6	75.8	16.9	211
Q3G2.1	**Being free of pain is the most important thing when dying**	**61.3**	**24.1**	**76.1**	**18.7**	**68.8**	**20.0**	**398**
	Yes	63.1	24.2	77.5	17.6	70.3	19.5	226
	No	59.0	23.8	74.3	20.0	66.7	20.6	172

Based on maximum of 398 matched records only.

Table 8.13: Quality of Dying and Death (QODD Part B) by Main Symptoms

Q3C (B)	Agreement on Symptoms by Nurses, Doctors and Relatives	Personal well-being		Relationship well-being		Total		
		Mean	SD	Mean	SD	Mean	SD	n
	Pain	**60.6**	**24.7**	**75.4**	**19.1**	**68.1**	**20.5**	**247**
	all agree	44.7	28.4	63.6	21.4	55.1	23.9	7
	disagree	50.2	25.3	69.7	20.1	60.1	21.1	108
	all agree on not	70.0	19.9	80.7	16.4	75.4	16.4	132
	Breathing Difficulty	**60.9**	**24.3**	**75.8**	**18.9**	**68.4**	**20.2**	**288**
	all agree	58.7	24.0	73.4	18.2	66.2	19.0	43
	disagree	61.2	23.9	75.7	18.9	68.4	20.1	147
	all agree on not	61.4	25.2	76.8	19.2	69.2	20.8	98
	Anxious or afraid	**60.9**	**24.5**	**76.1**	**18.9**	**68.6**	**20.1**	**252**
	all agree	20.7	7.6	47.3	5.5	35.7	0.6	3
	disagree	49.2	25.2	69.3	20.9	59.6	21.7	89
	all agree on not	68.2	20.8	80.5	16.1	74.3	16.8	160

Based on maximum of 312 matched records only.

9 Quality of Care (D)

Table 9.1R: Quality of Care (Relatives)

		D1	D3	D2	D4	D5	D1-5	
Q3 D1-5	**Category**	**Communication with Patient**	**Respectful End-of-Life Care for Patient**	**Communication with Relatives or Friends**	**Managing Patient's Symptoms**	**Emotional Support to Relatives**	**Quality of Care**	**Number of Cases**
		Mean	**Mean**	**Mean**	**Mean**	**Mean**	**Mean**	
A / C	Acute Hospitals	6.8	7.8	7.2	7.9	7.0	7.3	399
	Comm. Hospitals	7.5	8.3	8.1	8.2	8.4	8.1	62
Ward	A & E	8.3	9.3	9.2	9.0	9.2	9.0	6
	Intensive Care	7.2	8.1	7.3	8.1	7.4	7.6	65
	Surgical	6.9	7.9	7.1	7.9	6.8	7.3	48
	Medical	6.7	7.6	7.3	7.9	7.0	7.3	167
	Oncology	7.0	7.8	6.8	7.1	6.6	7.0	21
	Geriatric	7.0	8.0	7.8	7.9	7.9	7.7	65
	Other	7.1	7.9	7.6	8.1	7.5	7.6	26
Room	Single	7.3	8.3	7.7	8.1	7.4	7.8	190
	Multi-occupancy	6.6	7.4	7.1	7.7	7.0	7.2	208
MDC	Cancer	7.1	7.9	7.3	7.8	7.1	7.4	118
	Circulatory/Organs	7.2	7.9	7.8	8.1	7.6	7.7	113
	Respiratory	6.6	7.6	7.2	7.8	6.8	7.2	77
	Frailty/Dementia	7.8	8.5	8.3	8.4	8.3	8.3	23
	Other	6.3	7.6	6.6	7.7	6.7	7.0	67
Sex	Male	6.7	7.7	7.1	7.8	7.0	7.3	196
	Female	7.1	8.0	7.6	8.0	7.4	7.6	202
Age	under 45	7.7	8.0	8.1	7.7	8.0	7.9	7
	45 to 64	6.5	7.6	6.6	7.5	6.6	7.0	42
	65 to 84	6.9	7.8	7.3	7.8	7.1	7.4	251
	85 to 100	7.2	8.1	7.7	8.3	7.6	7.8	98
Stay	under 1 day	7.4	8.7	7.9	8.4	8.2	8.1	31
	1 day – 1 week	6.8	7.8	7.3	8.1	7.2	7.4	112
	1 week – 1 month	6.8	7.6	7.2	7.6	7.0	7.2	163
	over one month	7.1	8.1	7.6	8.1	7.3	7.6	92
Death	Expected	7.1	8.1	7.6	8.1	7.4	7.7	322
	Sudden	6.1	6.8	6.3	7.1	6.5	6.5	76
	unmatched	6.7	7.9	7.1	7.9	7.3	7.4	63
H99	**All HFH Hospitals**	**6.9**	**7.8**	**7.3**	**7.9**	**7.2**	**7.4**	**461**

Note: The methodology for calculating quality of care scores, based on the Family Evaluation of Hospice Care (FEHC), is outlined in the Technical Appendix.

Table 9.1N: Quality of Care (Nurses)

		J1	J2	J3	J4	J5	J1-5	
Q1 J1-5	**Category**	**Communication with Patient**	**Respectful End-of-Life Care for Patient**	**Communication with Relatives or Friends**	**Managing Patient's Symptoms**	**Emotional Support to Relatives**	**Quality of Care**	**Number of Cases**
		Mean	**Mean**	**Mean**	**Mean**	**Mean**	**Mean**	
A / C	Acute Hospitals	7.0	7.8	8.6	8.4	8.2	**8.0**	873
	Comm. Hospitals	7.6	8.5	9.0	8.9	9.1	**8.6**	119
Ward	A & E	7.3	8.0	9.1	8.3	8.5	**8.2**	41
	Intensive Care	6.8	7.9	8.8	8.7	8.6	**8.2**	179
	Surgical	6.5	7.6	8.6	8.2	8.1	**7.8**	122
	Medical	7.0	7.7	8.4	8.3	8.0	**7.9**	411
	Oncology	7.6	8.1	8.4	8.3	8.2	**8.1**	44
	Geriatric	7.5	8.4	8.9	8.8	8.9	**8.5**	133
	Other	7.5	8.3	9.0	8.6	8.8	**8.4**	62
Room	Single	7.1	7.9	8.7	8.5	8.4	**8.1**	439
	Multi-occupancy	6.9	7.8	8.6	8.4	8.3	**8.0**	553
MDC	Cancer	7.3	8.0	8.7	8.4	8.3	**8.1**	231
	Circulatory/Organs	7.1	7.9	8.7	8.5	8.5	**8.1**	311
	Respiratory	6.7	7.6	8.4	8.4	8.1	**7.8**	184
	Frailty/Dementia	6.7	7.7	8.6	8.4	8.5	**8.0**	75
	Other	7.1	8.0	8.8	8.5	8.4	**8.1**	191
Sex	Male	7.0	7.8	8.6	8.3	8.2	**8.0**	506
	Female	7.1	8.0	8.7	8.6	8.4	**8.2**	486
Age	under 45	6.9	7.8	8.4	8.3	8.3	**7.9**	30
	45 to 64	7.4	8.3	9.0	8.6	8.6	**8.4**	122
	65 to 84	6.9	7.8	8.5	8.4	8.3	**8.0**	600
	85 to 100	7.1	8.0	8.8	8.6	8.4	**8.2**	240
Stay	under 1 day	7.2	8.1	8.8	8.6	8.4	**8.2**	128
	1 day – 1 week	6.7	7.5	8.5	8.2	8.2	**7.8**	292
	1 week – 1 month	7.1	7.8	8.6	8.4	8.2	**8.0**	380
	over one month	7.3	8.4	8.9	8.8	8.7	**8.4**	192
Death	Expected	7.1	8.0	8.8	8.6	8.5	**8.2**	750
	Sudden	6.7	7.5	8.2	8.0	8.0	**7.7**	242
H99	**All HFH Hospitals**	**7.0**	**7.9**	**8.7**	**8.4**	**8.3**	**8.1**	**992**

Table 9.1D: Quality of Care (Doctors)

		D1	D2	D3	D4	D5	D1-5	
Q2 D1-5	**Category**	**Communication with Patient**	**Respectful End-of-Life Care for Patient**	**Communication with Relatives or Friends**	**Managing Patient's Symptoms**	**Emotional Support to Relatives**	**Quality of Care**	**Number of Cases**
		Mean	**Mean**	**Mean**	**Mean**	**Mean**	**Mean**	
A / C	Acute Hospitals	7.7	8.5	8.7	8.5	8.1	8.3	636
	Comm. Hospitals	8.2	9.0	8.8	8.9	8.7	8.7	101
Ward	A & E	7.1	9.0	8.8	8.6	7.6	8.2	29
	Intensive Care	8.0	8.8	9.0	8.8	8.6	8.6	124
	Surgical	7.4	8.2	8.5	8.4	7.6	8.0	88
	Medical	7.5	8.4	8.6	8.5	8.1	8.2	300
	Oncology	8.2	8.7	8.9	8.6	8.3	8.5	35
	Geriatric	8.0	8.8	8.7	8.8	8.5	8.6	115
	Other	8.4	9.1	9.2	8.9	8.7	8.9	46
Room	Single	7.7	8.6	8.8	8.5	8.2	8.3	336
	Multi-occupancy	7.8	8.6	8.7	8.7	8.2	8.4	401
MDC	Cancer	8.3	8.7	8.8	8.5	8.2	8.5	176
	Circulatory/Organs	7.8	8.6	8.7	8.6	8.2	8.4	220
	Respiratory	7.5	8.8	8.9	8.6	8.3	8.4	139
	Frailty/Dementia	7.2	8.4	8.7	8.9	8.5	8.3	56
	Other	7.4	8.4	8.4	8.6	7.9	8.2	146
Sex	Male	7.9	8.7	8.8	8.6	8.2	8.4	378
	Female	7.6	8.5	8.7	8.6	8.2	8.3	359
Age	under 45	8.2	9.2	8.9	8.6	8.8	8.7	24
	45 to 64	7.8	8.4	8.4	8.3	7.8	8.1	92
	65 to 84	7.8	8.6	8.7	8.6	8.2	8.4	448
	85 to 100	7.5	8.6	8.8	8.8	8.3	8.4	173
Stay	under 1 day	7.9	8.9	8.9	8.9	8.3	8.6	96
	1 day – 1 week	7.8	8.5	8.8	8.6	8.1	8.4	214
	1 week – 1 month	7.6	8.4	8.6	8.4	8.1	8.2	280
	over one month	7.8	8.8	8.8	8.7	8.5	8.5	147
Death	Expected	7.7	8.6	8.7	8.6	8.1	8.4	564
	Sudden	7.8	8.6	8.7	8.7	8.4	8.4	173
H99	**All HFH Hospitals**	**7.7**	**8.6**	**8.7**	**8.6**	**8.2**	**8.4**	**737**

Note: Based on matched cases only (n=737).

Table 9.2R: Quality of Care (Relatives)

Q3 D1-5	Category	D1 Communication with Patient %	D3 Respectful End-of-Life Care for Patient %	D2 Communication with Relatives or Friends %	D4 Managing Patient's Symptoms %	D5 Emotional Support to Relatives %	D1-5 Quality of Care %
H97	**Acute Hospitals**						
	Very poor	10.8	7.3	10.0	7.3	11.9	4.8
	Poor	9.2	4.2	5.8	5.8	6.2	8.3
	Middle	16.2	9.6	14.2	8.5	14.6	10.0
	Good	26.5	28.5	26.9	25.4	27.7	27.8
	Very good	37.3	50.4	43.1	53.1	39.6	49.1
H98	**Comm. Hospitals**						
	Very poor	11.5	5.8	7.7	1.9	7.7	3.2
	Poor	3.8	3.8	3.8	5.8	3.8	6.5
	Middle	9.6	9.6	7.7	15.4	1.9	4.8
	Good	34.6	21.2	25.0	25.0	30.8	14.5
	Very good	40.4	59.6	55.8	51.9	55.8	71.0
H99	**All HfH Hospitals**						
	Very poor	10.9	7.1	9.6	6.4	11.2	4.6
	Poor	8.3	4.2	5.4	5.8	5.8	8.0
	Middle	15.1	9.6	13.1	9.6	12.5	9.3
	Good	27.9	27.2	26.6	25.3	28.2	26.0
	Very good	37.8	51.9	45.2	52.9	42.3	52.1
	Total	**100**	**100**	**100**	**100**	**100**	**100**

Based on 312 matched records only. Scale converted from 10 point to 5 point scale.

Table 9.2N: Quality of Care (Nurses)

Q1 J1-5	Category	J1 Communication with Patient	J2 Respectful End-of-Life Care for Patient	J3 Communication with Relatives or Friends	J4 Managing Patient's Symptoms	J5 Emotional Support to Relatives	J1-5 Quality of Care
		%	%	%	%	%	%
H97	**Acute Hospitals**						
	Very poor	5.0	1.5	.8	1.5	1.2	
	Poor	11.9	5.8	5.4	5.4	4.2	3.5
	Middle	18.5	13.5	3.1	6.2	10.0	6.2
	Good	40.8	35.0	22.7	32.3	31.9	30.0
	Very good	23.8	44.2	68.1	54.6	52.7	60.4
H98	**Comm. Hospitals**						
	Very poor	5.8		3.8	1.9		
	Poor	1.9	3.8				
	Middle	7.7	5.8	3.8	5.8	1.9	5.8
	Good	46.2	32.7	17.3	19.2	25.0	15.4
	Very good	38.5	57.7	75.0	73.1	73.1	78.8
H99	**All HfH Hospitals**						
	Very poor	5.1	1.3	1.3	1.6	1.0	
	Poor	10.3	5.4	4.5	4.5	3.5	2.9
	Middle	16.7	12.2	3.2	6.1	8.7	6.1
	Good	41.7	34.6	21.8	30.1	30.8	27.6
	Very good	26.3	46.5	69.2	57.7	56.1	63.5
	Total	**100**	**100**	**100**	**100**	**100**	**100**

Based on 312 matched records only. Scale converted from 10 point to 5 point scale.

Table 9.2D: Quality of Care (Doctors)

		D1	D2	D3	D4	D5	D1-5
Q2 **D1-5**	**Category**	**Communication with Patient**	**Respectful End-of-Life Care for Patient**	**Communication with Relatives or Friends**	**Managing Patient's Symptoms**	**Emotional Support to Relatives**	**Quality of Care**
		%	**%**	**%**	**%**	**%**	**%**
H97	**Acute Hospitals**						
	Very poor	3.1	1.5	1.5	.4	.8	
	Poor	6.9	1.9	1.9	1.2	5.4	1.5
	Middle	11.5	4.2	5.0	5.8	10.8	3.8
	Good	30.8	24.2	19.6	30.4	35.0	21.2
	Very good	47.7	68.1	71.9	62.3	48.1	73.5
H98	**Comm. Hospitals**						
	Very poor			1.5			
	Poor	1.9	1.9	3.8	1.9		
	Middle	3.8	1.9	5.0	3.8	1.9	1.9
	Good	50.0	9.6	34.6	9.6	48.1	9.6
	Very good	44.2	86.5	61.5	84.6	50.0	88.5
H99	**All HfH Hospitals**						
	Very poor	2.6	1.3	1.3	.3	.6	
	Poor	6.1	1.9	2.2	1.3	4.5	1.3
	Middle	10.3	3.8	4.2	5.4	9.3	3.5
	Good	34.0	21.8	22.1	26.9	37.2	19.2
	Very good	47.1	71.2	70.2	66.0	48.4	76.0
	Total	**100**	**100**	**100**	**100**	**100**	**100**

Based on 312 matched records only. Scale converted from 10 point to 5 point scale.

Table 9.3a: Comparing Quality of Care (Relatives and Nurses)

Q3 D	Category Q1J	Scale	Nurses indicate higher quality of care %	Agreement %	Relatives indicate higher quality of care %	Number of Cases
D1	Communication with Patient	**1-5**	32.7	26.6	40.7	312
D3	Respectful End-of-Life Care for Patient	**1-5**	32.4	34.9	32.7	312
D2	Communication with Relatives or Friends	**1-5**	43.6	40.7	15.7	312
D4	Managing Patient’s Symptoms	**1-5**	32.7	43.6	23.7	312
D5	Emotional Support to Relatives	**1-5**	39.7	40.1	20.2	312
D1-5	**Quality of Care**	**1-5**	**31.7**	**49.4**	**18.9**	**312**

Based on 312 matched records only. Scale converted from 10 point to 5 point scale.

Table 9.3b: Comparing Quality of Care (Relatives and Doctors)

Q3 D	Category Q2D	Scale	Doctors indicate higher quality of care %	Agreement %	Relatives indicate higher quality of care %	Number of Cases
D1	Communication with Patient	**1-5**	24.4	29.2	46.5	312
D3	Respectful End-of-Life Care for Patient	**1-5**	15.4	44.2	40.4	312
D2	Communication with Relatives or Friends	**1-5**	23.4	53.2	23.4	312
D4	Managing Patient’s Symptoms	**1-5**	22.4	44.9	32.7	312
D5	Emotional Support to Relatives	**1-5**	36.2	38.1	25.6	312
D1-5	**Quality of Care**	**1-5**	**39.4**	**47.4**	**13.1**	**312**

Based on 312 matched records only. Scale converted from 10 point to 5 point scale.

Table 9.3c: Comparing Quality of Care (Nurses and Doctors)

Q3 D	Category Q2D	Scale	Nurses indicate higher quality of care %	Agreement %	Doctors indicate higher quality of care %	Number of Cases
D1	Communication with Patient	**1-5**	24.4	29.2	46.5	312
D3	Respectful End-of-Life Care for Patient	**1-5**	15.4	44.2	40.4	312
D2	Communication with Relatives or Friends	**1-5**	23.4	53.2	23.4	312
D4	Managing Patient’s Symptoms	**1-5**	22.4	44.9	32.7	312
D5	Emotional Support to Relatives	**1-5**	36.2	38.1	25.6	312
D1-5	**Quality of Care**	**1-5**	**31.7**	**49.4**	**18.9**	**312**

Based on 312 matched records only. Scale converted from 10 point to 5 point scale.

Table 9.3d: Comparing Quality of Care (Relatives, Nurses and Doctors)

Q3 D	Category Q2D	Scale	Relatives, Nurses and Doctors Agree %	Relatives, Nurses and Doctors Disagree %	Number of Cases
D1	Communication with Patient	**1-5**	9.6	90.4	312
D3	Respectful End-of-Life Care for Patient	**1-5**	21.8	78.6	312
D2	Communication with Relatives or Friends	**1-5**	23.4	76.6	312
D4	Managing Patient’s Symptoms	**1-5**	26.6	73.4	312
D5	Emotional Support to Relatives	**1-5**	15.7	84.3	312
D1-5	**Quality of Care**	**1-5**	**30.4**	**69.6**	**312**

Based on 312 matched records only. Scale converted from 10 point to 5 point scale.

Table 9.4R: Quality of Care (Relatives)

		D1	D3	D2	D4	D5	D1-5
Q3D	**Number of Decisions on Treatment Q1F1(A)**	**Communication with Patient**	**Respectful End-of-Life Care for Patient**	**Communication with Relatives or Friends**	**Managing Patient's Symptoms**	**Emotional Support to Relatives**	**Quality of Care**
		Mean	**Mean**	**Mean**	**Mean**	**Mean**	**Mean**
	none / na / don't know	7.1	7.9	7.5	8.7	7.9	7.8
	1 – 3 decisions	6.2	7.0	6.6	7.7	6.9	6.8
	4 – 6 decisions	6.8	7.7	7.4	7.6	6.8	7.2
	7 – 9 decisions	7.2	8.2	7.7	8.0	7.7	7.7
	10 or 11 decisions	7.3	8.2	7.8	8.1	7.4	7.8
	Total	**7.0**	**7.9**	**7.5**	**7.9**	**7.3**	**7.5**

Based on 312 matched records only.

Table 9.4N: Quality of Care (Nurses)

		J1	J2	J3	J4	J5	J1-5
Q2J	**Number of Decisions on Treatment Q2B1**	**Communication with Patient**	**Respectful End-of-Life Care for Patient**	**Communication with Relatives or Friends**	**Managing Patient's Symptoms**	**Emotional Support to Relatives**	**Quality of Care**
		Mean	**Mean**	**Mean**	**Mean**	**Mean**	**Mean**
	none / na / don't know	6.9	7.8	8.3	8.5	8.5	8.0
	1 – 3 decisions	6.3	7.5	7.6	7.8	7.9	7.4
	4 – 6 decisions	6.6	7.6	8.7	8.2	8.4	7.9
	7 – 9 decisions	7.4	8.2	9.0	8.6	8.6	8.4
	10 or 11 decisions	7.4	8.3	9.1	8.8	8.6	8.4
	Total	**7.0**	**8.0**	**8.7**	**8.4**	**8.5**	**8.1**

Based on 312 matched records only.

Table 9.4D: Quality of Care (Doctors)

		D1	D2	D3	D4	D5	D1-5
Q2D	**Number of Decisions on Treatment Q2B1**	**Communication with Patient**	**Respectful End-of-Life Care for Patient**	**Communication with Relatives or Friends**	**Managing Patient's Symptoms**	**Emotional Support to Relatives**	**Quality of Care**
		Mean	**Mean**	**Mean**	**Mean**	**Mean**	**Mean**
	none / na / don't know	8.1	9.2	8.7	9.0	8.5	8.7
	1 – 3 decisions	7.7	8.2	8.3	8.8	7.8	8.2
	4 – 6 decisions	7.6	8.7	8.7	8.7	8.1	8.4
	7 – 9 decisions	8.4	8.9	9.0	8.7	8.5	8.7
	10 or 11 decisions	7.9	8.8	9.2	8.7	8.2	8.5
	Total	**8.0**	**8.8**	**8.9**	**8.8**	**8.2**	**8.5**

Based on 312 matched records only.

Table 9.5R: Quality of Care (Relatives)

		J1	J2	J3	J4	J5	J1-5
Q1D	**Patient receiving SPC**	**Communication with Patient**	**Respectful End-of-Life Care for Patient**	**Communication with Relatives or Friends**	**Managing Patient's Symptoms**	**Emotional Support to Relatives**	**Quality of Care**
		Mean	**Mean**	**Mean**	**Mean**	**Mean**	**Mean**
	Patient received SPC	7.2	8.0	7.7	7.8	7.1	7.6
	Patient would have benefited from SPC	7.0	7.9	7.4	8.1	7.2	7.5
	Patient would not have benefited from SPC	6.6	7.6	7.0	7.8	7.4	7.3
	Don't know	7.0	8.1	7.7	8.2	7.6	7.7
	Total	**7.0**	**7.9**	**7.5**	**7.9**	**7.3**	**7.5**

Based on 312 matched records only.

Table 9.5N: Quality of Care (Nurses)

		J1	J2	J3	J4	J5	J1-5
Q1H	**Patient receiving SPC**	**Communication with Patient**	**Respectful End-of-Life Care for Patient**	**Communication with Relatives or Friends**	**Managing Patient's Symptoms**	**Emotional Support to Relatives**	**Quality of Care**
		Mean	**Mean**	**Mean**	**Mean**	**Mean**	**Mean**
	Patient received SPC	7.1	8.1	8.8	8.3	8.4	8.2
	Patient would have benefited from SPC	6.4	7.2	8.3	7.9	7.9	7.5
	Patient would not have benefited from SPC	7.1	8.3	8.7	8.8	8.8	8.3
	Don't know	7.2	8.1	8.8	8.5	8.6	8.3
	Total	**7.0**	**8.0**	**8.7**	**8.4**	**8.5**	**8.1**

Based on 312 matched records only.

Table 9.5D: Quality of Care (Doctors)

		J1	J2	J3	J4	J5	J1-5
Q1D	**Patient receiving SPC**	**Communication with Patient**	**Respectful End-of-Life Care for Patient**	**Communication with Relatives or Friends**	**Managing Patient's Symptoms**	**Emotional Support to Relatives**	**Quality of Care**
		Mean	**Mean**	**Mean**	**Mean**	**Mean**	**Mean**
	Patient received SPC	8.1	8.6	8.8	8.6	8.1	8.4
	Patient would have benefited from SPC	7.5	8.5	8.5	8.7	7.8	8.2
	Patient would not have benefited from SPC	8.0	9.2	9.1	8.9	8.5	8.7
	Don't know	8.1	8.8	9.0	8.9	8.4	8.6
	Total	**8.0**	**8.8**	**8.9**	**8.8**	**8.2**	**8.5**

Based on 312 matched records only.

Table 9.6: Quality of Care for various Reference Groups (Relatives)

		J1	J2	J3	J4	J5	J1-5	
Q3D		Communication with Patient	Respectful End-of-Life Care for Patient	Communication with Relatives or Friends	Managing Patient's Symptoms	Emotional Support to Relatives	Quality of Care	
		Mean	Mean	Mean	Mean	Mean	Mean	n
Q3B7	**Staff Responsiveness**	**6.9**	**7.9**	**7.4**	**7.9**	**7.2**	**7.5**	**394**
	Very poor / poor	3.1	3.3	3.2	4.0	3.0	3.3	24
	Average	4.1	4.9	4.4	5.2	4.5	4.6	35
	Good / very good	7.5	8.5	8.0	8.5	7.8	8.0	335
Q3B12	**Quality of Ward**	**6.9**	**7.9**	**7.4**	**7.9**	**7.2**	**7.5**	**390**
	Very poor / poor	4.4	5.1	5.1	5.3	4.7	4.9	60
	Average	6.1	7.0	6.6	7.3	6.1	6.6	67
	Good / very good	7.7	8.7	8.1	8.7	8.1	8.3	263
Q3G1	**Quality of End-of-Life Care**	**7.0**	**7.9**	**7.4**	**8.0**	**7.2**	**7.5**	**310**
	Very poor / poor	4.4	5.0	4.5	5.0	4.2	4.6	39
	Average	5.3	6.4	5.7	6.8	5.3	5.9	60
	Good / very good	8.0	8.9	8.4	8.8	8.2	8.4	211
Q3G2.1	**Being free of pain is the most important thing when dying**	**6.9**	**7.8**	**7.4**	**7.9**	**7.2**	**7.5**	**398**
	Yes	7.1	8.0	7.5	8.1	7.4	7.6	226
	No	6.7	7.6	7.2	7.7	7.0	7.2	172

Based on maximum of 398 matched records only.

Table 9.7: Quality of Care by Main Symptoms

Q3D	Agreement on Symptoms by Nurses, Doctors and Relatives	J1	J2	J3	J4	J5	J1-5	n
		Labels as in Table 8.6 above						
	Pain	**6.8**	**7.7**	**7.3**	**7.8**	**7.1**	**7.3**	**247**
	all agree	7.3	7.4	7.6	6.3	5.1	6.7	7
	disagree	6.2	7.1	6.8	6.8	6.4	6.7	108
	all agree on not	7.1	8.2	7.7	8.7	7.8	7.9	132
	Breathing Difficulty	**6.9**	**7.8**	**7.4**	**7.9**	**7.3**	**7.5**	**288**
	all agree	6.7	7.8	7.1	8.0	7.1	7.3	43
	disagree	6.9	7.9	7.5	7.9	7.4	7.5	147
	all agree on not	6.9	7.7	7.4	7.8	7.2	7.4	98
	Anxious or afraid	**7.0**	**7.9**	**7.5**	**7.9**	**7.4**	**7.5**	**252**
	all agree	6.3	6.3	6.7	3.7	3.0	5.2	3
	disagree	6.0	7.2	6.6	7.0	6.6	6.7	89
	all agree on not	7.6	8.3	8.0	8.5	7.9	8.0	160

Based on 312 matched records only.

10 Acceptability of Way Patient Died (D)

Table 10.1R: Acceptability of Patient's Dying Experience (Relatives)

Q1D	Hospital	Mean	SD	% not acceptable (scores 1-3)	n
	Acute Hospitals				
6	Acceptable for you	6.9	3.2	21.3	240
7	Acceptable for your family	6.9	3.2	20.1	234
	Community Hospitals				
6	Acceptable for you	7.4	3.2	20.8	48
7	Acceptable for your family	7.3	3.2	21.3	47
	All HfH Hospitals				
6	Acceptable for you	7.0	3.2	21.2	288
7	Acceptable for your family	7.0	3.2	20.3	281

Based on maximum of 312 matched cases.

Table 10.1N: Acceptability of Patient's Dying Experience (Nurses)

Q1J8	Hospital	Mean	SD	% not acceptable (scores 1-3)	n
	Acute Hospitals				
1	Acceptable for you	7.2	2.8	14.6	247
2	Acceptable for your family	7.1	2.9	17.2	239
	Community Hospitals				
1	Acceptable for you	8.7	2.3	6.0	50
2	Acceptable for your family	8.9	2.1	4.5	44
	All HfH Hospitals				
1	Acceptable for you	7.5	2.8	13.1	297
2	Acceptable for your family	7.4	2.9	15.2	283

Based on maximum of 312 matched cases.

Table 10.1D: Acceptability of Patient's Dying Experience (Doctors)

Q1D6	Hospital	Mean	SD	% not acceptable (scores 1-3)	n
	Acute Hospitals				
1	Acceptable for you	8.3	2.1	3.6	221
2	Acceptable for your family	8.2	2.2	4.3	232
	Community Hospitals				
1	Acceptable for you	9.1	1.4	-	39
2	Acceptable for your family	9.1	1.4	-	37
	All HfH Hospitals				
1	Acceptable for you	8.4	2.0	3.1	260
2	Acceptable for your family	8.3	2.1	3.7	269

Based on maximum of 312 matched cases.

Table 10.2a: Comparing Acceptability of Way Patient Died (Nurses and Relatives)

Q3 D	Category Q1J8	Scale	Nurses indicate higher acceptability %	Agreement %	Relatives indicate higher acceptability %	Number of Cases
D6	Acceptable to you	0 / 1	17.9	71.8	10.3	273
D7	Acceptable to your family	0 / 1	16.1	72.8	11.0	254

Items 1-3 of 10 point scale coded not acceptable. Based on maximum of 312 matched cases.

Table 10.2b: Comparing Acceptability of Way Patient Died (Doctors and Relatives)

Q3 D	Category Q2D6	Scale	Doctors indicate higher acceptability %	Agreement %	Relatives indicate higher acceptability %	Number of Cases
D6	Acceptable to you	0 / 1	18.6	79.7	1.7	242
D7	Acceptable to your family	0 / 1	17.6	80.8	1.6	245

Items 1-3 of 10 point scale coded not acceptable. Based on maximum of 312 matched cases.

Table 10.2c: Comparing Acceptability of Way Patient Died (Nurses and Doctors)

Q3 D	Category Q2D6	Scale	Nurses indicate higher acceptability %	Agreement %	Doctors indicate higher acceptability %	Number of Cases
D6	Acceptable to you	0 / 1	2.4	84.5	13.1	251
D7	Acceptable to your family	0 / 1	3.2	81.9	14.9	249

Items 1-3 of 10 point scale coded not acceptable. Based on maximum of 312 matched cases.

Table 10.2d: Comparing Acceptability of Way Patient Died (Relatives, Nurses and Doctors)

Q3 D	Category Q2D	Scale	Relatives, Nurses and Doctors Agree %	Relatives, Nurses and Doctors Disagree %	Number of Cases
D6	Acceptable to you	0 / 1	68.7	31.3	233
D7	Acceptable to your family	0 / 1	68.1	31.9	226

Items 1-3 of 10 point scale coded not acceptable. Based on maximum of 312 matched cases.

Table 10.3: Acceptability of Patient’s Dying Experience (Relatives)

Q3D6	Category	Mean	Std. Deviation	% of experiences not acceptable	n
A / C	Acute Hospitals	6.9	3.2	21.1	313
	Comm. Hospitals	7.6	3.1	18.5	54
Ward	A & E	9.0	1.0	0.0	5
	Intensive Care	7.4	3.1	15.5	58
	Surgical	6.7	3.3	19.5	41
	Medical	6.6	3.4	23.7	156
	Oncology	6.9	3.3	23.8	21
	Geriatric	7.3	3.2	22.6	62
	Other	7.3	2.9	12.5	24
Room	Single	7.6	2.9	12.5	184
	Multi-occupancy	6.3	3.5	29.0	183
MDC	Cancer	7.1	3.2	20.9	110
	Circulatory/Organs	7.5	3.1	15.4	104
	Respiratory	6.3	3.2	23.6	72
	Frailty/Dementia	8.1	2.6	8.7	23
	Other	6.3	3.5	31.0	58
Sex	Male	6.7	3.4	24.3	181
	Female	7.2	3.1	17.2	186
Age	under 45	6.7	4.2	33.3	6
	45 to 64	6.4	3.4	25.6	39
	65 to 84	7.0	3.2	20.3	232
	85 to 100	7.2	3.1	18.9	90
Stay	under 1 day	7.5	3.0	13.3	30
	1 day – 1 week	7.0	3.4	22.0	100
	1 week – 1 month	6.7	3.2	21.5	149
	over one month	7.3	3.1	20.5	88
Death	Expected	7.3	3.0	16.5	297
	Sudden	5.5	3.8	38.6	70
H99	**All HFH Hospitals**	**7.0**	**3.2**	**20.7**	**367**

Based on maximum of 398 matched cases.

Table 10.4R: Acceptability to You of Way Patient Died (Relatives)

Q1J8	Number of Decisions on Treatment Q1F1(A)	Mean	Std. Deviation	% not acceptable (scores 1-3)	n
	none / na / don't know	6.8	3.4	21.4	28
	1 – 3 decisions	6.4	3.9	34.3	35
	4 – 6 decisions	6.8	3.3	21.1	71
	7 – 9 decisions	7.2	3.0	17.1	82
	10 or 11 decisions	7.2	3.1	19.4	72
	Total	**7.0**	**3.2**	**21.2**	**288**

Based on max of 312 matched records.

Table 10.4N: Acceptability to You of Way Patient Died (Nurses)

Q1J8	Number of Decisions on Treatment Q1F1(A)	Mean	Std. Deviation	% not acceptable (scores 1-3)	n
	none / na / don't know	7.3	3.0	11.5	26
	1 – 3 decisions	6.7	3.4	25.7	35
	4 – 6 decisions	7.3	2.9	13.3	75
	7 – 9 decisions	7.9	2.3	7.1	84
	10 or 11 decisions	7.5	2.8	14.3	77
	Total	**7.5**	**2.8**	**13.1**	**297**

Based on max of 312 matched records.

Table 10.4D: Acceptability to You of Way Patient Died (Doctors)

Q2D6	Number of Decisions on Treatment Q2B1(A)	Mean	Std. Deviation	% not acceptable (scores 1-3)	n
	none / na / don't know	8.4	2.5	4.5	22
	1 – 3 decisions	8.7	1.8	0.0	28
	4 – 6 decisions	8.5	1.9	3.0	66
	7 – 9 decisions	8.5	1.6	1.4	72
	10 or 11 decisions	8.1	2.3	5.6	72
	Total	**8.4**	**2.0**	**3.1**	**260**

Based on max of 312 matched records.

Table 10.5R: Acceptability of Patient’s Dying Experience (Relatives)

Q3D6	Category	Mean	Std. Deviation	% not acceptable (scores 1-3)	n
	Patient received SPC	7.1	3.2	21.0	105
	Patient would have benefited from SPC	7.2	3.1	18.8	48
	Patient would not have benefited from SPC	6.8	3.3	22.5	71
	Don’t know	6.8	3.3	21.9	64
	Total	**7.0**	**3.2**	**21.2**	**288**

Based on max of 312 matched records.

Table 10.5N: Acceptability of Patient’s Dying Experience (Nurses)

Q3D6	Category	Mean	Std. Deviation	% not acceptable (scores 1-3)	n
	Patient received SPC	7.5	2.8	12.8	109
	Patient would have benefited from SPC	6.3	3.0	21.6	51
	Patient would not have benefited from SPC	8.0	2.6	11.0	73
	Don’t know	7.8	2.8	9.4	64
	Total	**7.5**	**2.8**	**13.1**	**297**

Based on max of 312 matched records.

Table 10.5D: Acceptability of Patient’s Dying Experience (Doctors)

Q3D6	Category	Mean	Std. Deviation	% not acceptable (scores 1-3)	n
	Patient received SPC	8.2	2.0	3.1	96
	Patient would have benefited from SPC	8.3	2.4	6.7	45
	Patient would not have benefited from SPC	8.8	1.8	1.7	60
	Don’t know	8.4	1.9	1.7	59
	Total	**8.4**	**2.0**	**3.1**	**260**

Based on max of 312 matched records.

Table 10.6: Acceptability to You of Way Patient Died (Relatives)

Q3D		Mean	Std. Deviation	% not acceptable (scores 1-3)	n
Q3B7	**Staff Responsiveness**	**7.0**	**3.2**	**20.4**	**363**
	Very poor / poor	2.2	2.2	82.6	23
	Average	3.3	2.6	56.3	32
	Good / very good	7.7	2.7	12.0	308
Q3B12	**Quality of Ward**	**7.0**	**3.2**	**20.3**	**360**
	Very poor / poor	3.0	2.9	69.0	58
	Average	5.4	2.8	31.1	61
	Good / very good	8.4	2.2	5.8	241
Q3G1	**Quality of End-of-Life Care**	**7.0**	**3.2**	**20.1**	**293**
	Very poor / poor	2.9	3.1	75.7	37
	Average	5.0	2.9	36.4	55
	Good / very good	8.3	2.2	5.5	201
Q3G2.1	**Being free of pain is the most important thing when dying**	**7.0**	**3.2**	**20.7**	**367**
	Yes	7.3	3.2	17.4	213
	No	6.6	3.3	25.3	154

Based on maximum of 398 matched cases

Table 10.7: Acceptability to You of Way Patient Died by Main Symptoms

Q3D	Agreement on Symptoms by Nurses, Doctors and Relatives	Mean	Std. Deviation	% not acceptable (scores 1-3)	n
	Pain	6.7	3.3	23.5	230
	all agree	4.0	3.7	40.0	5
	disagree	6.0	3.5	32.0	103
	all agree on not	7.5	8.6	15.6	122
	Breathing Difficulty	6.9	3.3	22.0	268
	all agree	6.5	3.4	23.8	42
	disagree	7.1	3.2	19.7	137
	all agree on not	6.8	3.3	24.7	89
	Anxious or afraid	7.0	3.2	21.4	234
	all agree	2.0	1.7	66.7	3
	disagree	5.6	3.6	35.7	84
	all agree on not	7.8	2.7	12.2	147

Based on maximum of 312 matched cases

11 Post Mortem

Table 11.1: Post Mortem

Q3E1	Hospital	Yes %	No %	Don't know %	Total %
H87	HFH Acute	9.0	82.2	8.8	100
H88	HFH Community		87.1	12.9	100
H99	**All HFH Hospitals**	**7.8**	**82.9**	**9.3**	**100**

n = 461

Table 11.2: Post Mortem by Request

Q3E2	Hospital	Hospital %	Coroner %	Don't know %	Total %
H87	HFH Acute	50.0	16.7	33.3	100
H88	HFH Community	-	-	-	-
H99	**All HFH Hospitals**	**50.0**	**16.7**	**33.3**	**100**

n = 36

Table 11.3: Reason for Post Mortem communicated

Q3E3	Hospital	Yes %	No %	Don't know %	Total %
H87	HFH Acute	63.9	25.0	11.1	100
H88	HFH Community	-	-	-	-
H99	**All HFH Hospitals**	**63.9**	**25.0**	**11.1**	**100**

n = 36

Table 11.4: Satisfaction with Communication of Post Mortem (5 categories)

Q1e4	Hospital	very poor	poor	fair	good	excellent
		%	%	%	%	%
	Acute Hospitals					
4.1	Clear	10.5	-	26.3	15.8	47.4
4.2	Sensitive	5.6	-	16.7	27.8	50.0
4.3	Timely	10.5	-	21.1	26.3	42.1

n = 23

Scores 1 or 2 = very poor; 3 or 4 = poor; 5 or 6 = fair; 7 or 8 = good; 9 or 10 = excellent.

12 Endnotes:

Tables 1.2 to 1.6:

Due to the small number of deaths in some community hospitals, the analysis reclassified these hospitals as follows:

- Dublin Group comprising:
    - ✓ Royal Hospital Donnybrook
    - ✓ Bru Chaoimhin
    - ✓ Bellvilla
    - ✓ Meath Community Unit
    - ✓ Leopardstown Park Hospital
    - ✓ Peamount Hospital, Newcastle
    - ✓
- North East Group comprising:
    - ✓ St. Joseph's Hospital, Trim
    - ✓ St. Mary's, Castleblayney
    - ✓ Oriel House, Monaghan Town
    - ✓ Breffni Care Unit, Ballyconnell, Co. Cavan
    - ✓ Virginia Healthcare Unit, Cavan
    - ✓ Lisdaran Unit, Cavan
    - ✓ Boyne View, Drogheda
    - ✓ Cottage Hospital, Drogheda
    - ✓ St. Mary's Hospital, Drogheda
    - ✓ Sullivan Centre, Cavan
    - ✓ St. Joseph's Hospital, Ardee

13 Appendix:

13.1 Data Imputation for Missing Values

The combined Questionnaires 1 and 2 comprise just over 500 variables covering 23 sections or themes. It is thus inevitable that there are a significant number of cases where either individual variables, or even full sections of data are missing. Improper handling of missing values will distort analysis because, until proven otherwise, the researcher must assume that missing cases differ in analytically important ways from cases where values are present. That is, the problem with missing values is not so much reduced sample size as it is the possibility that the remaining data set is biased.

There are a number of strategies available to the researcher in dealing with missing values which range from listwise or pairwise deletion, mean substitution, multiple regression and maximum likelihood estimation (MLE).

Listwise or pairwise deletion would lead to a significant loss in the number of cases available for analysis. More importantly, as missing data may not be random, it would result in a biased sample after the deletion of cases and is therefore ruled out, except for those cases where a very significant amount of data (a minimum of three full sections) is missing.

Mean substitution was once the most common method of imputation of missing values but is no longer preferred. Substitution of the simple (grand) mean will reduce the variance of the variable. Reduced variance can bias correlation downward (attenuation) or, if the same cases are missing for two variables and means are substituted, correlation can be inflated. That is, this method creates a spiked distribution at the mean in frequency distributions and causes attenuation in correlation of the item with others, and underestimates variance.

Multiple regression may be used for data imputation simply by using non-missing data to predict the values of missing data. However, this may "over-correct", introducing unrealistically low levels of noise in the data. The regression method has the problem that all cases with the same values on the independent variables will be imputed with the same value on the missing variable, thus overemphasising correlations. A preferred method is *stochastic substitution*, which uses the regression technique but adds a random value to the predicted result.

Maximum likelihood estimation (MLE) makes the least demands of the data in terms of statistical assumptions and is generally considered superior to imputation by multiple regression. This is now the most common method of imputation. The MLE method assumes missing values are *missing at random* (MAR as opposed to missing completely at random, MCAR) but shares with multiple regression the problem of over-correction and possible modelling of noise.

Throughout this study, we rely significantly on the imputation of missing values using MLE. We do, however, believe this to be the best approach to derive robust estimates from the data.

13.2 Constructing a Quality of Dying and Death Index (QODD - Part A)

The QODD is an established scale of how to measure the Quality of Dying and Death and is represented in the HfH Survey as QODD – Part B.

The analysis of QODD Part A utilises the information provided in Part A of the questions in Section H of Questionnaire 1 and is modelled on the construction of the QODD – Part B.

The following points outline the steps undertaken in the analysis:

1) Firstly, the 22 items have been split into two groups (i) QODD_A Personal Well-being, comprising items 1 to 10 and (ii) QODD_A Relationship Well-being, comprising items 11-22. after that a QODD_A Total is calculated, comprising all 22 items

2) Unlike the QODD_B, where all items ran from left to right, from unsatisfactory to satisfactory, the A parts of the questions had partly to be reversed in order. Doing this, and in tandem with the QODD_B, all items run from left (worst condition) to right (best condition).

3) Rescaling: To give each question the same weighting, scales are adjusted as follows:

    - 6 point items are running from 1 to 6.

    - 2 point items are recoded 2 and 5 respectively; 2 being the mid-point of 1,2 and 3 and 5 being the midpoint of 4,5 and 6.

    - 3 point items are recoded 1.5, 3.5 and 5.5, representing the respective midpoints of the 6 point scale.

4) This is followed by the computation of the means for the two subscales and the total scale. To gain, similar to the QODD_B, a scale ranging from 1 to 100, each of the sub-scale and total scale is divided by 6 and multiplied by 100.

5) MVA is done on the re-scaled raw scores and point 4) is repeated to gain a full set of data.

Figure 13.1: Distribution of QODD_A Personal Well-being, adjusted values

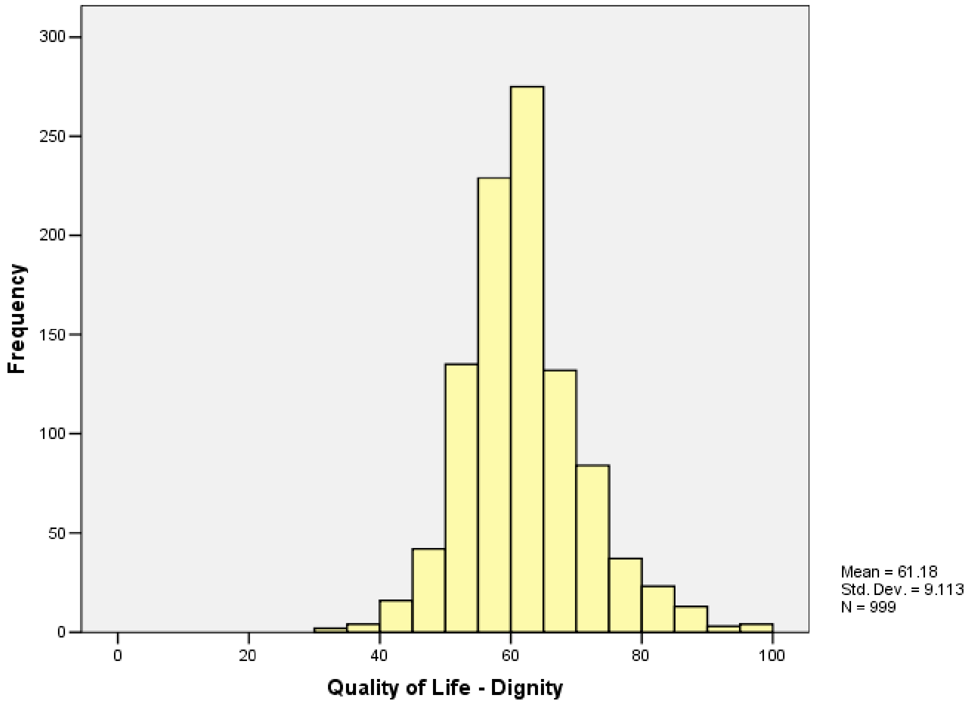


Figure 13.2: Distribution of QODD_A Relationship Well-being, adjusted values

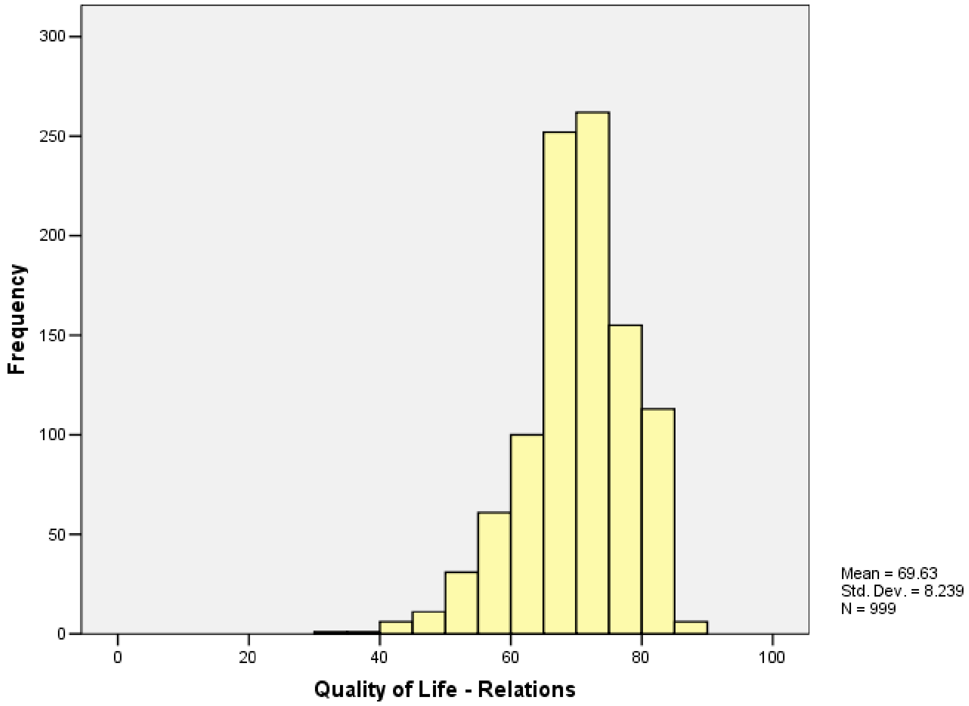
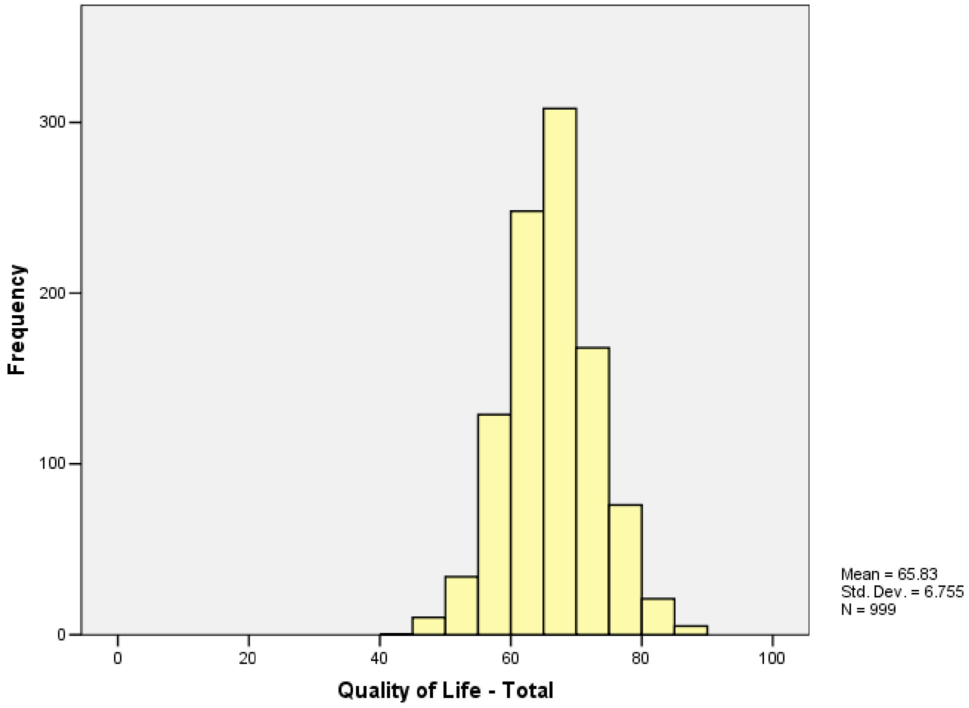


Figure 13.3: Distribution of QODD_A Total, adjusted values



6) The QODD_A Total scale comes out nearly 5 points below the QODD_B, which appears to be a more realistic level and is also more in line with the QODD mean (68) in the original reference study.

13.3 Imputation of Values for QODD (Part B)

Figure 13.4: Distribution of QODD_B, Raw Variables

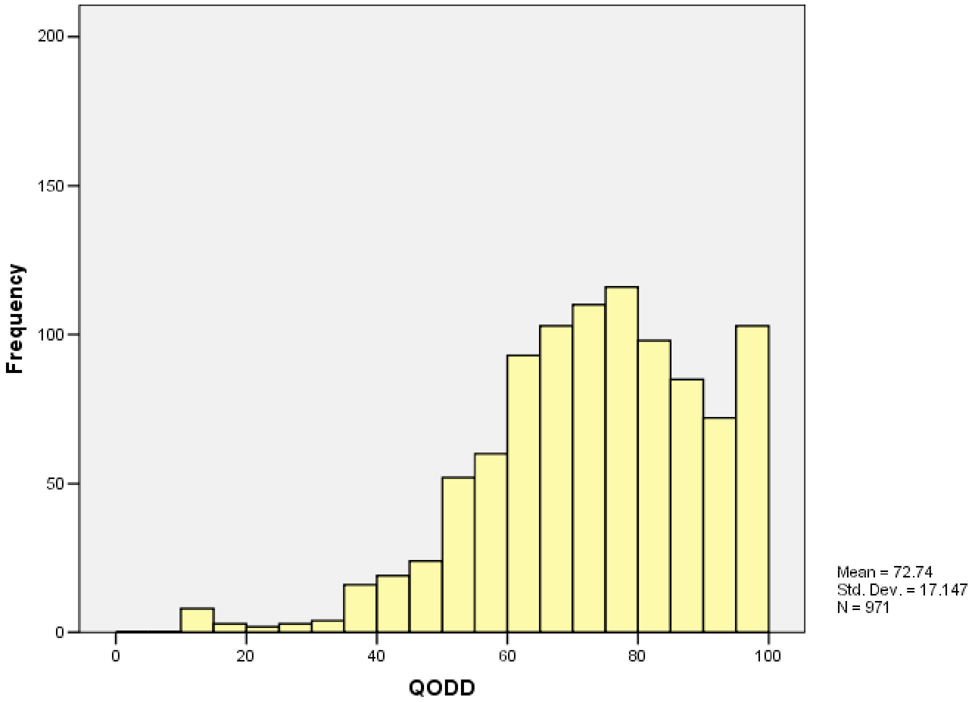
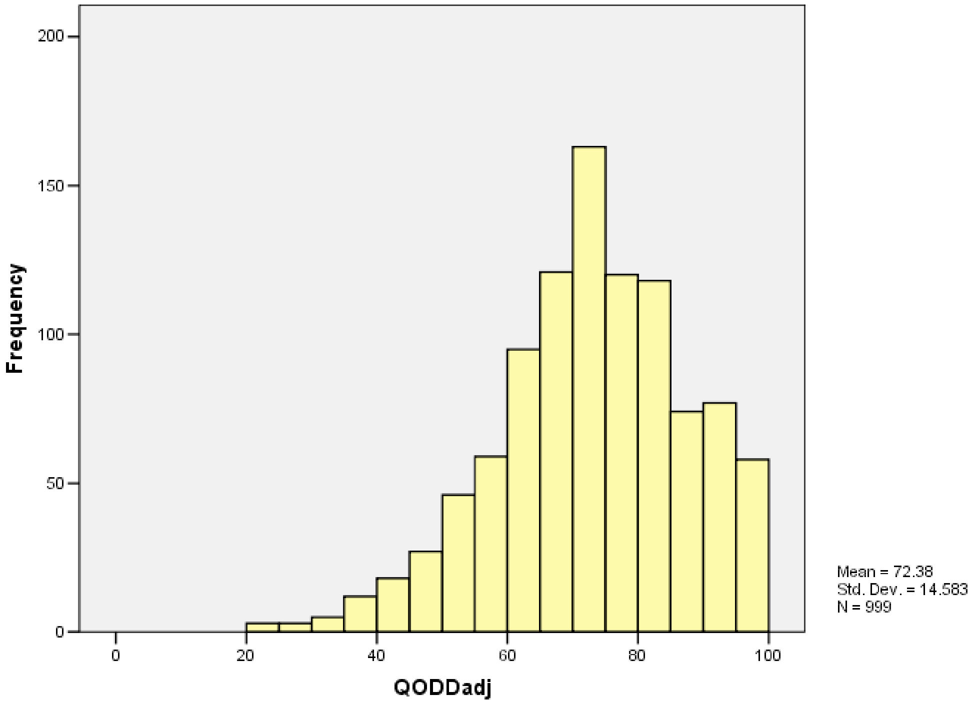


Figure 13.5: Distribution of QODD_B after Estimation of Missing Values (MVA – ML algorithm)



Note: The high number of cases just below 100 in Figure 14.4 results from a number of cases where a score of 10 was allocated to a set number of items, with all other items missing.

13.4 Quality of Care Analysis

Figure 13.8: Distribution of QCare, raw values

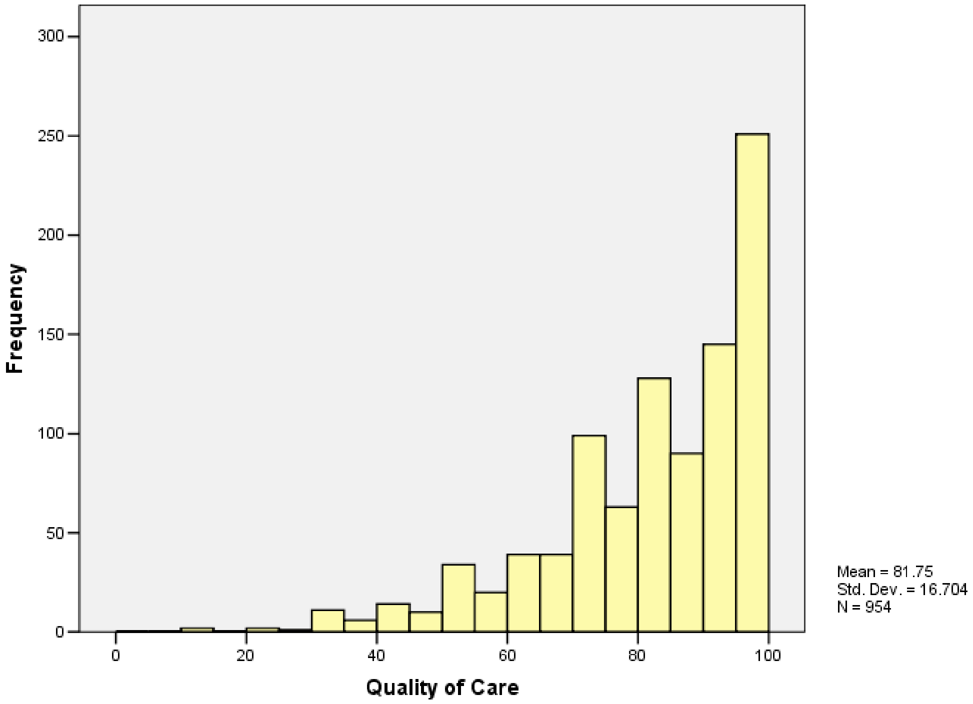
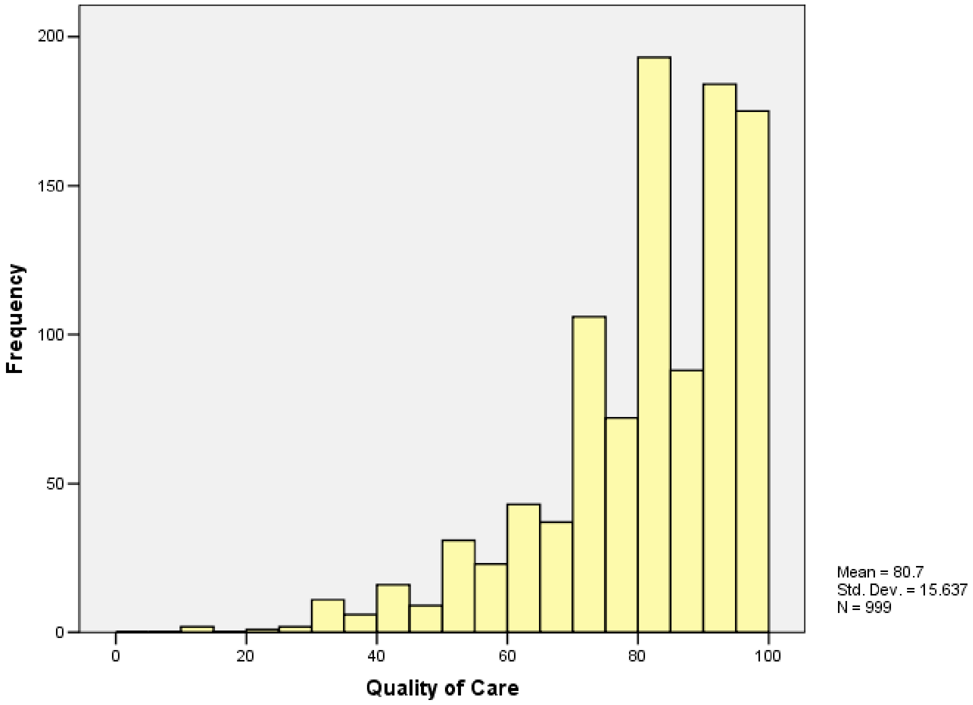


Figure 13.9: Distribution of QCare, adjusted values



13.5 Measurement of Agreement

In most studies, the level of agreement between the evaluations of two observers is measured using Cohen's *kappa.* A value of 1 indicates perfect agreement, a value of -1 perfect disagreement, whilst a value of 0 indicates that agreement is no better than chance. Landis and Koch (1977) provide the following table for interpreting values of kappa, based on personal opinion, although we should note that kappa will tend to be higher when there are fewer categories.

Table 13.10: Interpretation of Kappa Values

Kappa value	Interpretation
< 0	No agreement
0.0 — 0.20	Slight agreement
0.21 — 0.40	Some agreement
0.41 — 0.60	Moderate agreement
0.61 — 0.80	Substantial agreement
0.81 — 1.00	Almost perfect agreement

For research purposes, there seems to be general agreement that the kappa should be at least .60 or .70. However, the use of this statistic in the present context poses a number of difficulties. The tables below illustrate this, as they reveal a high level of agreement between doctors and nurses about the medical diagnosis, but with a low value for kappa, due to the relatively small number of cases in certain cells of the table. Despite the risks of overestimating the extent of agreement, we will therefore give precedence to a simpler measure, the percentage of cases classified in the same way by doctors and nurses. In the first table, we can see that in almost 85% of cases, both doctors and nurses were aware of the medical diagnosis, whilst coefficient kappa is equal to 0.14 ("slight agreement"), due to the responses of 4 nurses who thought that the medical team had diagnosed that the patient was dying, when in fact this was not the case, at least according to the doctors' responses.

At the same time, we need to point out a major drawback of the measure of agreement in terms of the percentage of observers agreeing, that is the vulnerability of this measure to the number of categories. If, for example, we use a ten point scale ranging from very bad to excellent, there will be comparatively few identical ratings between nurses and doctors. If, however, we reduce the number of categories to four, as we have done in this study, the proportion of ratings which are in agreement will rise accordingly. Thus the level of agreement has to be viewed in the context of the number categories and the distribution of ratings across these.

Table 13.11: Diagnosis of Death by Doctors and Nurses: Ward = "Other"

Column %	*q2c1*	**Had the medical team diagnosed that the patient was dying? (Doctors)**	
q1c1		No	Yes
Had the medical team diagnosed that the patient was dying? (Nurses)	No	1 (20.0%)	3 (7.3%)
	Yes	4 (80.0%)	38 (92.7%)
	Total	*5 (100.0%)*	*41 (100.0%)*
Agreement	Coeff. kappa	**0.14**	
	% agreement	**84.80%**	

Note: Based on matched cases only (n=736).

Table 13.12: Responses of Doctors and Nurses: Death = "Expected",

Column %	*q2c1*	**Had the medical team diagnosed that the patient was dying? (Doctors)**	
q1c1		No	Yes
Had the medical team diagnosed that the patient was dying? (Nurses)	No	8 (20.0%)	20 (3.8%)
	Yes	32 (80.0%)	503 (96.2%)
	Total	*40 (100.0%)*	*523 (100.0%)*
Agreement	Coeff. kappa	**0.19**	
	% agreement	**90.76%**	

Note: Based on matched cases only (n=736).

Table 13.13 demonstrates how the number of categories of a table influences the measures of agreement. To this end we choose the level of agreement on the quality of service in response to the underlying conditions for all HfH hospitals as shown in Table 1.6. We start with the values for the full 10 point scale, followed by the values after reducing the categories to a 5 point, 4 point and 2 point scale. The scale used for the management scores of Tables 1.6 and 1.7 are the 4 point scales.

Table 13.13: Effect of the Number of Categories on the Measures of Agreement

Item No.	**F2 1.2**	**F2 2.2**	**F2 3.2**	**F2 4.2**	**F2 5.2**	**F2 6.2**	**F2 1.2**	**F2 2.2**	**F2 3.2**	**F2 4.2**	**F2 5.2**	**F2 6.2**
	Cohen's kappa						**% Agreement**					
Question												
Category	**Pain**	**Nausea**	**Breathing**	**Secretions**	**Restlessness**	**Anxiety**	**Pain**	**Nausea**	**Breathing**	**Secretions**	**Restlessness**	**Anxiety**
10 point scale	**-**	**.04**	**-**	**-**	**.04**	**-**	**23**	**22**	**19**	**21**	**20**	**13**
5 point scale	**-**	**.07**	**.06**	**.09**	**.03**	**.02**	**37**	**39**	**38**	**41**	**35**	**32**
4 point scale	**-**	**.06**	**.07**	**.09**	**.03**	**.03**	**43**	**43**	**44**	**43**	**40**	**38**
2 point scale	**.11**	**.02**	**.08**	**.02**	**.09**	**-.11**	**86**	**83**	**82**	**80**	**80**	**69**

Table 13.14: Level of pain experienced – nurses' and doctors' responses

Column %	*q2f2.1.1*	**Pain experienced by patient – doctors' responses**				
q1f2.1.1		None of the time	Some of the time	Most of the time	All of the time	*Total*
Pain experienced by patient – nurses' responses	None of the time	115 (45%)	61 (24%)	3 (6%)	3 (18%)	*182*
	Some of the time	114 (45%)	152 (60%)	34 (72%)	7 (41%)	*307*
	Most of the time	11 (4%)	26 (10%)	6 (13%)	4 (24%)	*47*
	All of the time	16 (6%)	16 (6%)	5 (9%)	3 (18%)	*39*
	Total	*100%*	*100%*	*100%*	*100%*	*100%*
	N	*256*	*255*	*47*	*17*	*575*
Agreement	Coeff. kappa	**.15**				
	% agreement	**48%**				

Table13.15: Pain management – nurses' and doctors' responses (5 categories)

Column %	*q2f2.1.2_grp1*	**Pain management – doctors' responses**					
q1f2.1.2_grp1		Very bad	Bad	Average	Good	Very good	*Total*
Pain management – nurses' responses	Very bad	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (1%)	*1* *(0%)*
	Bad	0 (0%)	0 (0%)	4 (9%)	0 (0%)	3 (3%)	*7* *(3%)*
	Average	0 (0%)	2 (20%)	5 (11%)	7 (6%)	9 (10%)	*23* *(9%)*
	Good	0 (0%)	4 (40%)	9 (20%)	44 (40%)	30 (34%)	*87* *(34%)*
	Very good	0 (0%)	4 (40%)	28 (61%)	59 (54%)	45 (51%)	*136* *(54%)*
	Total	*100%*	*100%*	*100%*	*100%*	*100%*	*100%*
	N	*0*	*10*	*46*	*110*	*88*	*254*
Agreement	Coeff. kappa	**-**					
	% agreement	**37%**					

Table 13.16: Pain management – nurses' and doctors' responses (4 categories)

Column %	*q2f2.1.2_grp*	**Pain management – doctors' responses**				
q1f2.1.2_grp		Very bad	Bad	Good	Very good	*Total*
Pain management – nurses' responses	Very bad	0 (0%)	0 (0%)	0 (0%)	1 (1%)	*1* *(0%)*
	Bad	0 (0%)	4 (15%)	4 (3%)	8 (9%)	*16* *(6%)*
	Good	0 (0%)	8 (30%)	59 (42%)	34 (39%)	*101* *(40%)*
	Very good	0 (0%)	15 (56%)	76 (55%)	45 (51%)	*136* *(54%)*
	Total	*100%*	*100%*	*100%*	*100%*	*100%*
	N	*0*	*27*	*139*	*88*	*254*
Agreement	Coeff. kappa	**-**				
	% agreement	**42.5%**				