HospiceFriendly HOSPITALS

Putting Hospice Principles into Hospital Practice.

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

2008/9

Dying in Hospital in Ireland: Nurse & Doctor Perspectives

National Audit Report 2

May 2010

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

THE IRISH HOSPICE FOUNDATION

Research Team

Kieran McKeown
Social & Economic Research Consultant,
16 Hollybank Rd., Drumcondra, Dublin 9, Ireland.
Email: kmckeown@iol.ie

Trutz Haase
Social & Economic Consultant,
17 Templeogue Rd., Terenure, Dublin 6W, Ireland.
Email: thaase@iol.ie

Shelagh Twomey
National Audit Manager of HFH Programme
Irish Hospice Foundation, Morrison Chambers,
32 Nassau St., Dublin 2, Ireland.
Email: shelagh.twomey@hospice-foundation.ie

How to cite this report

McKeown, K., Haase, T., and Twomey, S., 2010. Dying in Hospital in Ireland: Nurse and Doctor Perspectives, Report 2, Dublin: Irish Hospice Foundation. Available at http://www.hospicefriendlyhospitals.net

Ownership & Confidentiality

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

When Death Comes
by Mary Oliver [1]

When death comes
like the hungry bear in autumn;
when death comes and takes all the bright coins from his purse

to buy me, and snaps the purse shut;
when death comes
like the measle-pox;

when death comes
like an iceberg between the shoulder blades,

I want to step through the door full of curiosity, wondering:
what is it going to be like, that cottage of darkness?

And therefore I look upon everything
as a brotherhood and a sisterhood,
and I look upon time as no more than an idea,
and I consider eternity as another possibility,

and I think of each life as a flower, as common
as a field daisy, and as singular,

and each name a comfortable music in the mouth,
tending, as all music does, toward silence,

and each body a lion of courage, and something
precious to the earth.

When it's over, I want to say: all my life
I was a bride married to amazement.
I was the bridegroom; taking the world into my arms.

When it's over, I don't want to wonder
if I have made my life something particular, and real.
I don't want to find myself sighing and frightened,
or full of argument.

I don't want to end up simply having visited this world.

---

[1] Mary Oliver (1935 -) from New and Selected Poems. She is the author of several poetry books, winner of the Pulitzer Prize for Poetry and the National Book Award. She lives in Massachusetts, USA.

Table of Contents

Figures

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**
Cork University Hospital	Fionuala O'Gorman
Mid-Western Regional Hospital Limerick	Catherine Hand
Cavan General Hospital	Bridget Clarke
Monaghan General Hospital	Josephine O'Hagan
Our Lady of Lourdes Hospital, Drogheda	Mary McCrane
Our Lady's Hospital, Navan	Concepta Tallon
Louth County Hospital, Dundalk	Kathriona Campbell
Kerry General Hospital, Tralee	Richard Walsh
Wexford General Hospital	Bernard Finnegan
St. James's Hospital, Dublin 8	Paul Gallagher & Lucy Kielty
Sligo General Hospital, Sligo	Kate Bree
Mater Misericordiae University Hospital	Breda Doyle
Connolly Hospital	Catriona Higgins
Letterkenny General Hospital	Pauline McManus
St. Luke's Hospital, Rathgar	Wendy Fair
Portlaoise, Midland Regional Hospital	Emer McEvoy & Ann Sheerin
Beaumont Hospital	Mary Baggot
Waterford Regional Hospital	Cliona Rafter
South Tipperary General Hospital	Maria Barry
St. Luke's Hospital, Kilkenny	Debbie Kavanagh
Tallaght Hospital	Kathleen Flynn
Nenagh, Mid-Western Regional Hospital	Mary Clifford
Naas General Hospital	Breda Murphy
Tullamore, Midlands Regional Hospital	Claire O'Dea & Lorna Griffith

Community Hospitals	**Hospital Audit Managers**
St. Joseph's Hospital, Trim	Frances Flynn
Royal Hospital Donnybrook	Anne Dooley
Bru Chaoimhin	Muthu Saba
Bellvilla	Niamh Curran
Meath Community Unit	Karen Rowlett
St. Mary's Hospital, Phoenix Park	Michelle Russell
St John's Hospital, Sligo	Fran Butler
St. Mary's Castleblayney	Susan McGoldrick
Oriel House	Geraldine Smyth
Leopardstown Park Hospital	Elaine Flanagan
Peamount Hospital, Newcastle	Elaine Keane
Breffni	Ann Gaffney
Virginia	Bernardine Lynch

Lisdaran	Bernie McManus
Sullivan Centre, Cavan	Martha Adams
Boyne View Drogheda	Lena Varghese Ciara Cullen
Cottage Hospital, Drogheda	Karen McElaine (Unit 1) Mary Gallagher (Unit 2)
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.

At national level, HSE staff supplied us with data and datasets which were extremely useful. We particularly thank the following people:

Des Williams	HSE National Employment Monitoring Unit
Howard Johnson & Carmel Cullen	HSE Health Information Unit
Judy Cronin	HSE FactFile
Sean O'Cinnéide	HSE Consultant Appointments Unit
Mary Culliton and Deirdre McKeown	HSE Office of Consumer Affairs

Some hospitals participated in two pilot phases of the audit, one carried out by the HFH Programme itself and the other by the Royal College of Surgeons of Ireland (RCSI). We thank both groups of hospitals for helping us to break new ground by showing, through these pilot studies, that the audit was technically feasible and a potentially powerful instrument of change when embraced by the entire hospital community. The acute and community hospitals who participated in the pilot studies are:

HFH Pilot Study
Cork University Hospital
Mater M University Hospital
St. Mary's Phoenix Park
Leopardstown Park Hospital
St. Mary's Castleblayney
St. Columba's, Co. Kilkenny

RCSI Pilot Study
Midland Regional, Mullingar
Naas General Hospital
St. John's Hospital, Sligo
St. Columba's, Co. Kilkenny

Within the HFH programme, we acknowledge the contribution to the national audit of the staff team comprising:

Mervyn Taylor	Programme Manager

Shelagh Twomey	Deputy Programme Manager
Helen Donovan	Standards Development Coordinator
Mary Bowen	Operations Manager
Denise Connor	Project Development Coordinator
Róisín Clarke	Programme Administrator
Grace O'Sullivan	Programme Administrator & Development Support
Lorna Peelo-Kilroe	National Practice Development Coordinator End-of-Life Care
Paul Murray	Development Coordinator - Forum on End-of-Life Care
Joanne Carr	Development Coordinator
Amanda Manning	Development Coordinator
Fran McGovern	Development Coordinator
Bryan Nolan	Development Coordinator
Aoife O’Neil	Development Coordinator
Ruth Agar	Development Coordinator
Colette Cunningham	Development Coordinator
Mary Friel	Development Coordinator
Nuala Harmey	Development Support

The national audit was guided and supported by an Evaluation Sub-Committee and their contribution is gratefully acknowledged. The members of the Evaluation Sub-Committee are:

Prof. David Clark	Chair, Visiting Professor of Hospice Studies, TCD & UCD
Orla Keegan	Head of Education, Research & Bereavement Services, The Irish Hospice Foundation
Mervyn Taylor	Programme Manager, Hospice Friendly Hospitals Programme
Shelagh Twomey	Deputy Programme Manager, Hospice Friendly Hospitals Programme
Max Watson	Consultant in Palliative Medicine, Northern Ireland Hospice
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:

Prof. Cillian Twomey	Chair, Consultant Physician in geriatric medicine at Cork University Hospital and St. Finbarr’s Hospital, Cork
Prof. David Clark	Visiting Professor of Hospice Studies, TCD & UCD
Denis Doherty	Chairman, The Irish Hospice Foundation Chairman, and Chairman, Nursing Homes Ireland
Eugene Murray	Chief Executive Officer, The Irish Hospice Foundation
Prof. Brendan McCormack	Director of Nursing Research & Practice Development, Royal Group of Hospitals, Belfast and University of Ulster at Jordanstown

Orla Keegan	Head of Education, Research & Bereavement Services, Irish Hospice Foundation
Richard Dooley	Network Manager, South Eastern Hospitals Group, HSE
Ann Ryan	Inspector Manager, Health Information & Quality Authority
Brenda Power	Broadcaster and journalist
Geraldine Fitzpatrick	Principal Officer, Services for Older People & Palliative Care, Department of Health & Children
Sheila Dickson,	First Vice-President, Irish Nurses Organisation
Margaret Murphy	Patient Representative on the Council of the Irish Society for Quality and Safety in Healthcare
Dr. Doiminic Ó Brannagáin	Consultant in Palliative Medicine, Health Services Executive, North East
Barbara Fitzgerald	Director of Nursing, Naas General Hospital
Dr. Peter Lawlor	Consultant in Palliative Medicine, St. James's Hospital and Our Lady's Hospice
Dr. Emer Longley	General Practitioner, Inchicore Medical Centre, D8.
Noel Mulvihill,	Health Service Executive, Local Health Manager, LHO - Dublin North Central (HSE)

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.

All of the data were entered by Insight Statistical Consulting, under the direction of David Harmon. This work was carried out with meticulous attention to detail for which we are most grateful.

We express our thanks to the funding partners of the HFH programme without whom the audit would not have been possible: The Atlantic Philanthropies, the Health Service Executive, the Health Services National Partnership Forum and the Dormant Accounts Fund.

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 nurses and doctors, of 999 patients who died in hospitals in Ireland in 2008/9. Nearly nine out of ten of these patients died in acute hospitals - the remainder in community hospitals - and this constitutes a representative sample of 10% of annual deaths in those acute hospitals. These acute hospitals, in turn, represent three quarters of the acute sector in Ireland[2], so it is a reasonable inference that the report is broadly representative of the care offered at the end of life by acute hospitals in Ireland. Coverage of the community hospital sector is less extensive, covering just 20% of bed-capacity, and is therefore less representative. Throughout the report we use comparative data, wherever possible, to assess how the experience of dying in an Irish hospital compares to hospitals elsewhere.

Patient Characteristics

Patients are mainly 65 years and over and were admitted to hospital through Accident and Emergency Departments (A&E). The average length of stay in acute hospitals (24 days) is well above the national average[3], and well above international standards for patients who die in acute hospital[4]. 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%).

Ward and Room Characteristics

Less than half of all patients (44%) died in a single room, significantly less than the proportion of patients who die in single rooms in Northern Ireland (70%)[5]. In acute hospitals, these patients spent five days in a single room before death, compared to 3 days in a community hospital. Conversely, most patients died in multi-occupancy rooms and, in the acute sector, over a quarter (28%) of these are mixed gender. The room where patients died was rated at 5.7 out of 10 in terms of dignity, privacy, environment and control, and appears higher compared to the staff ratings of hospital facilities in Northern Ireland.

Assessment of Patient

The vast majority of patients (86%) were diagnosed as dying about 5-6 days before their death. This suggests that deaths in Irish hospitals are anticipated more frequently than in French hospitals[6] and earlier than in English hospitals[7]. About a

---

[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 national average for acute in-patients aged 65 and over is 11.5 days (Hospital In-Patient Enquiry, 2006:Table 3.9). In the HSE's 2009 National Service Plan, the target for average length of stay in acute hospitals is 5.9 days (HSE National Service Plan 2009, 2008:71)

[4] For example, the OECD average length of stay is 6.3 days (OECD, 2007:73). In the US, the average length of stay in the last six months of life varies from 4.87 to 19.67 days for the same diagnostic categories and independently of need and outcome (Wennberg, Fisher, Stukel, Skinner, Sharp, and Bronner, 2004). In the UK, the average length of stay before death is usually well below 20 weeks (Abel, Rich, Griffin and Purdy, 2009; and Addicott and Dewar, 2008).

[5] 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.

[6] Ferrand, Jabre, Vincent-Genod, et al, 2008:870 and Table 2. This study was based on 3,793 patients who died in 200 French hospitals in 2004.

fifth of patients could have died at home, in the opinion of nurses and doctors, if appropriate supports were available. Studies in the UK suggest that a similar pattern over-using acute hospitals for patients at the end of life[8].

Team Meetings about Patient

Two types of meetings - usually involving medical and nursing staff only, but sometimes involving the full multidisciplinary team of all health care professionals – are held to discuss the care of the patient in about seven out of ten cases. Significantly no meetings are held in nearly a third of cases. The responses of nurses and doctors agree, in about six out of ten cases only, that these meetings actually took place, which suggests that they are relatively informal and probably not documented in many cases. Meetings are more likely in community hospitals and, within acute hospitals, were more likely for patients with cancer and those in single rooms. The family attended these meetings in about two thirds of cases but where they did not, only half were told about their outcome.

Communication with Patients and Relatives

Hospital staff are much more likely to discuss end-of-life issues with relatives (96%) than with patients (55%). Equally, discussions with relatives are more likely to be documented (83%) compared to discussions with patients (76%). The quality of communication with relatives was assessed, using a 10-point scale, as being significantly better (8.5) compared to communication with patients (7.3). These findings are consistent with another Irish study which identified a tendency among health care professionals to 'speak with families of older people, as opposed to the older individuals themselves, regarding treatment and services'[9]. This pattern of communication is also similar to that found among English patients on the Liverpool Care Pathway (LCP)[10].

Meeting the Wishes of Patients and Relatives

Relatives expressed wishes more frequently than patients (88% compared to 32%) but also expressed a larger number of wishes (4.4 compared to 1.3). Although the wishes of patients were more likely to be documented (62% compared to 43%) the actual number of relatives' wishes which were documented would necessarily be much greater compared to patients. In the assessment of nurses, using a 10-point scale, the hospital was significantly more likely to meet the wishes and worries of relatives (8.3) compared to patients (6.8).

---

7 This is inferred from the audit of patients on the Liverpool Care Pathway (LCP), based on 3,893 patients in 155 hospitals who died between October and December 2008. Patients are placed on the LCP where there is a diagnosis of dying and the average length of time on LCP was 33 hours (Marie Curie Palliative Care Institute Liverpool, 2009:21; see also 2007:5). The audit estimates that 21% of all deaths in those hospitals were on the LCP (Marie Curie Palliative Care Institute Liverpool, 2009:24).

8 Abel, Rich, Griffin and Purdy, 2009; National Audit Office, 2008.

9 McGlone and Fitzgerald, 2005:72.

10 The results of a national audit of patients on the Liverpool Care Pathway LCP – based on 3,893 patients in 115 hospitals who died between October and December 2008 – showed that patients were less likely to be aware of their diagnosis (50%, compared to 79% of relatives), to recognise that they were dying (40%, compared to 76% of relatives), or to have their care plan explained to them (30%, compared to 72% of relatives). (Marie Curie Palliative Care Institute Liverpool, 2009:45-54).

Palliative Care Decisions about Patient

Nurses and doctors make about six end-of-life decisions for each patient. However, in a third of cases, the responses of nurses and doctors do not agree[11] on whether a decision was made, or on whether that decision was documented. Even when a patient has been diagnosed as dying, there seems to be a reluctance by nurses and doctors to make a decision to stop invasive monitoring, stop antibiotics, withhold or withdraw treatment. This contrasts with the LCP practice in English hospitals where, in the vast majority of cases, decisions are made to discontinue blood tests (91%), antibiotics (89%), IV fluids / medications (83%), do not resuscitate (94%) and inappropriate nursing interventions such as vital signs and blood sugar monitoring (75%)[12]. Similarly, decisions to withhold or withdraw life support are taken much less frequently in Irish hospitals compared to other European countries[13].

Quality of Palliative Care

Nurses and doctors have markedly different perceptions of the 5-6 key symptoms that many patients experience in the last days and hours of life such as pain, nausea, breathing difficulties, increased secretions, restlessness, and anxiety. Agreement is low between the responses of nurses and doctors on the frequency (50% agreement) and management (42% agreement) of these symptoms. This raises a question about the true quality of palliative care, and whether in fact patients are being kept comfortable and free of pain in the last week of life. Bearing this question in mind, nurses and doctors estimate that 80-90% of patients are kept relatively comfortable during the last week of life. In the national audit of patients on the LCP in English hospitals, about 75% were assessed as comfortable in these symptom areas[14].

Specialist Palliative Care Services

A majority of patients did not receive specialist palliative care. The proportion of patients who actually received it varies from 22% according to doctors to 32% according to nurses, which is a substantial 10-percentage point difference of opinion. This suggests that there may be some misunderstanding between – and within – nurses and doctors as to what exactly is specialist palliative care. Leaving aside these differences, the proportion of patients who received specialist palliative care is slightly higher compared to UK hospitals (19%)[15], but much higher compared to

---

[11] 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 than questions with four or two response categories. In view of that, we measured agreement using either two or four response categories, depending on the question (See Section 14.5 in the Technical Appendix).

[12] Marie Curie Palliative Care Institute Liverpool, 2009.

[13] Decisions to withhold and withdraw treatment were taken in less than half of all cases (47%) but more frequently in intensive care (53%). This is significantly lower than in the Ethicus study of 4,248 intensive care deaths in 17 European countries where both withholding and withdrawing life support – but not active life-ending procedures – occurred in 73% of patients (Sprung, Cohen, Sjokvist, et al., 2003). The Mater Hospital contributed to the Ethicus study and its results were published separately to show that 70% of patients who died in ICU in 1999/2000 had a decision made to withhold or withdraw life-sustaining therapy, but only 72% of these decisions were documented (Collins, Phelan, Marsh and Spring, 2006:317).

[14] Marie Curie Palliative Care Institute Liverpool, 2009:40-42.

[15] In a UK study carried out by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD), a sub-sample of deaths (1,478) was analysed and there was no involvement by a palliative care team in 81% of cases (National Confidential Enquiry into Patient Outcome and Death, 2009:94). Commenting on this, the report states: ‘While the sample of patients included in this study may not be representative of all who were admitted with palliative intent, the paucity of input from palliative care teams may be indicative of the lack of co-ordinated end of life care in acute hospitals’ (Ibid:94-95).

French hospitals where, according to one study, 'only 12.1% had a palliative care consultation'[16].

Quality of Life

The quality of living and dying in Irish hospitals, measured using the Quality of Dying and Death Instrument (QODD)[17], is reasonably good compared to similar studies in the US[18]. Relationship well-being is stronger than personal well-being, both physical and psychological, , possibly because many hospitals facilitate relatives to spend time with the patient in the last days. Some of the physical challenges facing dying patients are indicated by the high prevalence of those who, for most or all of the time, do not have the energy to do things (87%), show little or no sign of enjoyment (65%), and have breathing difficulties (31%). At the same time, patients appear to be greatly comforted by aspects of their relationship such as spending most or all of the time with children (79%) and friends (78%), or simply knowing that loved ones are there (88%).

Quality of Care

Quality of care was measured using a sub-scale from the Family Evaluation of Hospice Care (FEHC)[19]. As with palliative care, the responses of nurses and doctors do not always agree on what constitutes good quality of care for a patient (only 44% agreement), or what constitutes an acceptable death (only 40% agreement). Despite that, both rate the quality of care given to patients at over 8 out of 10, somewhat lower than the scores normally given by relatives for hospice care in the US, the main source of comparative data on the FEHC scale[20]. Both nurses and doctors gave their lowest rating for communication with the patient and their highest for communication with relatives. A minority of deaths are regarded as unacceptable (13% according to nurses and 5% according to doctors), a low figure by comparison with a French study where 58% of nurses found the deaths of their patients unacceptable[21].

Moment of Death and After

Relatives or friends are often present at the moment of death (65%), much higher than in a recent French study (24%)[22]. Hospital staff were present at three quarters of

---

[16] Ferrand, Jabre, Vincent-Genod, et al, 2008:870. This study was based on 3,793 patients who died in 200 French hospitals in 2004.

[17] 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).

[18] Levy, Ely, Payne, Engelberg, Patrick and Curtis, 2005; Hodde, Engelberg, Treece, Steinberg, and Curtis, 2004.

[19] 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).

[20] 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).

[21] Ferrand, Jabre, Vincent-Genod, et al, 2008:Table 4.

[22] Ferrand, Jabre, Vincent-Genod, et al, 2008:Table 3.

the deaths. However there is no evidence of anyone being present at a quarter of all deaths. The main ritual immediately following death is for hospital staff to offer sympathy (91%) and tea (87%) to the family; prayers are frequently said (81%), candles are usually lit (69%), and there is a moment of silence in over half the cases (53%).

Staff offered information and advice about moving the body to the mortuary (73%) and collecting the patient's personal belongings (73%), but were less likely to inform relatives about mortuary access and viewing times (39%), how the deceased patient may be taken home (43%), arranging the funeral (48%), or how to register the death (20%). The personal belongings of patients are usually handed over in a bag supplied by the patient or relative (43%), or in a hand-over bag supplied by the hospital (21%), but plastic bags are used in a significant minority of cases (21%).

Less than a third GPs are known to have been informed about the patient's death (32%), similar to the pattern found in English hospitals[23]. Most nurses were unable to state if the patient's death had been certified or if a death certificate had been issued by the hospital.

Reviewing Deaths and Supporting Staff

A ward-level review of the patient's death takes place in half of all cases (51%), and these seem to mainly involve an informal discussion with peers; a formal review facilitated by a senior member of ward staff is relatively rare (13%). A significant minority of staff felt very upset at the death of a patient (21%) but few of these (15%) are known to have had an opportunity to talk about how this affected them. This suggests a relatively low level of support for staff, similar to the situation in Northern Ireland24.

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 and reflection.

---

[23] Marie Curie Palliative Care Institute Liverpool, 2009:52.

[24] This emerges from an audit of dying, death and bereavement in Northern Ireland hospitals and hospices, which included a survey of 1,632 hospital staff. According to this survey, relatively few staff perceive that supports are in place for: case review / critical incident analysis (27%), de-briefing following traumatic situations with either peers (21%), or the multi-professional team (14%). (Northern Ireland Health and Social Care Bereavement Network, 2009:55).

1 Introduction

The experience of dying in hospital is unique to each patient and, in its fullest sense, can only be understood through that experience[25]. However this understanding is impossible once the patient has died and, even in circumstances where death is expected or sudden, it can be difficult to access the patient's direct experience[26]; even if accessed, this opens up questions about whether it is always in the patient's best interests to do so[27]. Faced with this predicament, but nevertheless committed to the primacy of the patient's experience at end-of-life, the audit relies on three people – the nurse, the doctor, and the relative - to provide an approximation of how the patient experienced dying and death in hospital. This approximation is usually as close as one gets to the actual experience[28].

This accepted and acceptable procedure has been used in numerous previous studies which have examined the patient experience 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[29] review of these studies has not been undertaken but some of their broad findings, of particular relevance to the audit, are:

there tends to be a 'moderate' level of agreement between the reports of patients and those of relatives[30], nurses and doctors[31].

by comparison with patients, nurses and doctors tend to under-estimate symptoms[32] - and doctors tend to under-estimate more than nurses[33] - while relatives tend to

---

[25] The uniqueness of the patient's experience is underlined by Daniel Gilbert as follows: 'If we want to know how a person feels, we must begin by acknowledging the fact that there is only one observer stationed at the critical point of view … she is the only person who has even the slightest chance of describing 'the view from in here', which is why her claims serve as the gold standard against which all other measures are measured' (Gilbert, 2006).

[26] 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).

[27] This does not imply that it is never appropriate to interview dying patients since the experience of the Picker Institute (2005) is that when interviewers are trained and sensitive to bereavement issues both patients and family members are usually willing to participate in surveys of this type. A team of researchers recently observed that 'some people facing death [however] may want to participate in research and should be allowed to do so. Ethics committees and clinical staff must balance understandable concern about non-maleficence with the right of people with advanced illness to participate in research. Despite the inherent difficulties, end of life research can be conducted with ethical and methodological rigour. Adequate psychological support must be provided for participants, researchers, and transcribers' (Kendall, et al, 2007)

[28] In acknowledging that the audit is based on the mediated experiences of nurses, doctors and relatives, we are also acknowledging that these experiences do not necessarily coincide with those of patients. 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).

[29] 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).

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

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

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

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

over-estimate symptoms[34]. 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[35].

the reports of nurses and doctors tend to show less agreement with patients when there is severe pain[36] while, for relatives, agreement tends to be less when symptoms are highly subjective and not directly observable[37].

nurses, doctors and other health professionals tend not use standardised procedures for assessing and recording pain[38], and this is likely to militate against the accurate diagnosis and treatment of pain.

Bearing these findings and limitations in mind, our approach is to use the remembered experiences of nurses, doctors and relatives - who knew and cared for the patient at the end of life – to reflect on the nature of dying, death and bereavement in hospital. In addition, these remembered experiences provide an opportunity, through the audit, for hospitals to reflect on the quality of care and the quality of life of patients who die in their care[39]. In this report, our focus is on the mediated experiences of nurses and doctors, and this is complemented by a separate report on the mediated experiences of relatives in Report Three.

Most people die in a hospital or similar setting, outside the home. In Ireland, at least half of all deaths occur 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%)[40]. The main focus of the audit is on patients who die in acute hospitals[41] but patients in one type of long-stay facility – community hospitals[42] – are also included.

This report is based on data collected using two questionnaires: Questionnaire 1 completed by the nurse(s) who gave most care during the last week of the patient's life, and Questionnaire 2 completed by the doctor who attended the patient prior to death. These questionnaires were completed on a sample of deaths in the four month period between November 2008 and February 2009; in a small number of cases, local circumstances dictated minor changes to the audit period and resulted in the audit beginning earlier or finishing later.

Larger hospitals with an annual average of 150 deaths or over – comprising 18 of the 24 acute hospitals – were required to complete these two questionnaires on a quota

---

34 Tang and McCorkle, 2002; McMillan and Moody, 2003; Bondestam, et al, 1987.

35 Seland, et al, 2005; Puntillo, et al, 2003; Weiner, et al, 1999; Grossman, et al, 1991.

36 Puntillo, et al, 2006; Grossman, et al, 1991.

37 Tang and McCorkle, 2002; McPherson and Addington-Hall, 2003.

38 Seland, et al, 2005; Chanvej, et al, 2004; Bruera, et al, 2005.

39 Significantly, the front cover of the UK End of Life Care Strategy (Department of Health, 2008) has the following quotation: 'How people die remains in the memory of those who live on', Dame Cicely Saunders, Founder of the Modern Hospice Movement, July 2008.

40 McKeown, Haase and Twomey, 2010a.

41 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.

42 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.

of 50 deaths. Smaller hospitals with an annual average of less 150 deaths - comprising all of the community hospitals - were required to complete the audit on every death which occurred within this four month period, since none could reach the quota of 50 within the period.

In order to facilitate completion of the audit in larger hospitals, the quota was evenly distributed over the four months. The quota for each month was also broken down to reflect the proportion of deaths in the previous year in: (i) A & E (ii) intensive care and (iii) other wards. The monthly quota in these hospitals was filled by talking all deaths from the beginning of the month until the monthly quota for that category was completed. This ensured that the audit was manageable in terms of the number of questionnaires to be completed each month, an important consideration in larger hospitals.

This sampling procedure is justified on a number of grounds. First, monthly variations in the number of deaths in Irish hospitals are relatively modest – varying no more than 15% above or below the mean for all hospitals in the HIPE system - so that no significant distortion arises from the selected four month audit period. Second, the risk of selection bias is excluded because hospitals were given no discretion as to which death to include in the audit; in larger hospitals, all deaths from the beginning of each month were to be selected until the quota for that month was filled; in the smaller hospitals, all deaths were included in the audit period without exception. Third, the statistical analysis of data, especially the separation of patient-level and hospital-level data, requires roughly 25 individual-level observations per hospital; given an anticipated response rate of 50% to the survey of bereaved relatives, this will allow that target to be met, subject to the grouping of smaller community hospitals.

The total number of deaths in the audit is 999. Most of these took place in acute hospitals (880, 88%) with the remainder (119, 12%) in community hospitals (Table 1.1). As a proportion of total deaths in 2008, the audit is a representative sample of 10% of acute hospital deaths and 29% of community hospital deaths. In sampling terms, this is a high sampling fraction and, other things being equal, provides a robust basis for drawing conclusions about the experience of dying in an Irish hospital. The estimated sampling error associated with this sample, at the 95% level of probability, is in the 2-3% 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 2-3% percentage points[43].

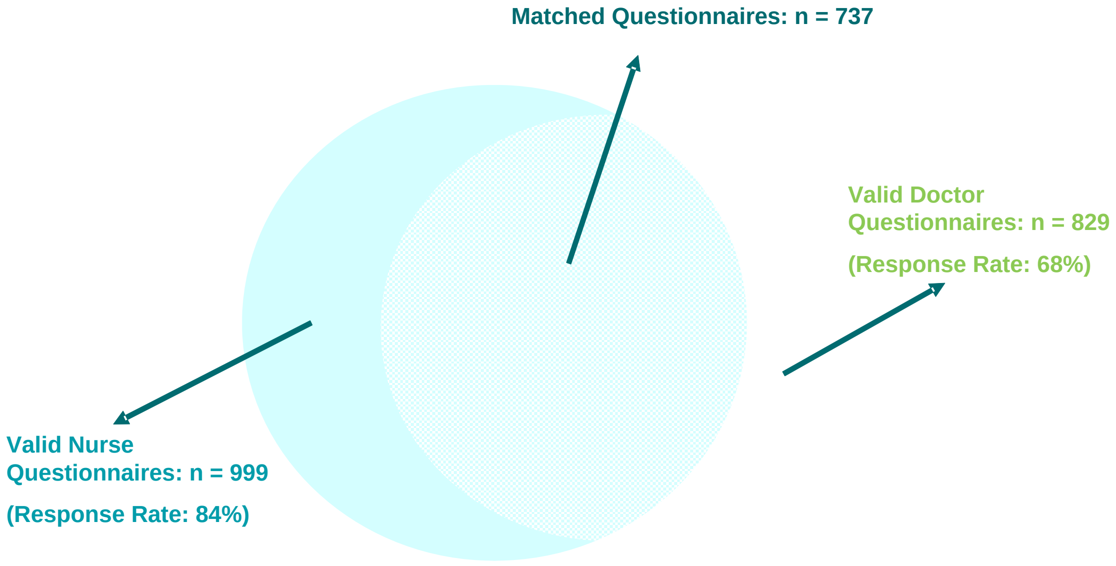
The quota achieved by nurses for Questionnaire 1 was 84%, yielding 999 valid questionnaires[44] (Tables 1.2 and 1.3). The quota achieved by doctors for Questionnaire 2 was 68%, yielding 737 valid questionnaires. In other words, of the 999 deaths in the audit, there are 737 deaths for which there is matching data from both nurses and doctors (Figure 1.1). A detailed patient-level analysis was undertaken to assess the level of agreement between nurses and doctors on all of the variables common to both Questionnaires 1 and 2 (Tables 1.4 to 1.7). The results of this analysis will be presented throughout the report as appropriate.

---

[43] More specifically, frequencies of 10% or 90% have a sampling error in the +/-2% range while frequencies of 50% to 70% have a sampling error in the +/-3% range. This implies that the statistical significance of any relationship between variables can only be determined on a case-by-case basis.

[44] Note that 5% of questionnaires had to be excluded because they contained almost no information.

Figure 1.1: Nurse and Doctor Questionnaires in Audit



As expected, there was some missing data for both Questionnaire 1 and 2, partly because this is inevitable with self-completion questionnaires, and partly because the scale of data collection involved over 500 variables covering 23 themes for both questionnaires combined. The problem with missing values is not so much reduced sample size as the possibility that the data set is biased because missing data may not be random. For this reason, we undertook missing value analysis and replaced missing values using maximum likelihood estimation, yielding complete data for all 999 cases (See Section 14.1 of the Technical Appendix below).

The data analysis involves reporting the results for each variable as well as more detailed analysis of selected variables that are expected to be sources of variation in the data including:

- type of hospital (acute or community)
- type of ward (A&E, intensive care, surgical, medical, oncology, geriatric, other)
- type of room (single or multi-occupancy)
- diagnostic category (cancer, circulatory/organs, respiratory, frailty/dementia, other)
- sex (male or female)
- age (under 45, 45 to 64, 65 to 84, 85+)
- length of stay (under 1 day, 1 day to 1 week, 1 week to 1 month, over one month)
- type of death (expected or sudden)

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).

The results are now presented, using the same format as the questionnaires, as follows:
Section 2: Patient Characteristics
Section 3: Ward and Room Characteristics
Section 4: Assessment of Patient
Section 5: Communication with Patient
Section 6: Communication with Relative
Section 7: Palliative Care
Section 8: Specialist Palliative Care Service
Section 9: Quality of Life
Section 10: Quality of Care

Section 11: Moment of Death and After
Section 12: Reviewing Deaths and Supporting Staff

In Section 13 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.

2 Patient Characteristics

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

2.1 Gender and age

The proportion of male and female patients in the audit is almost identical at 51% and 49% respectively (Table 2.1). This is similar to the proportion of males and females in the general population. However females constitute a higher proportion of hospital discharges (55% compared to 45%)45 suggesting that, of those admitted to hospital, males have a slightly greater likelihood of dying there.

The vast majority of patients who died are aged 65 years and over (79%) (Table 2.2a-c). This is identical to the corresponding proportion (79%)46 of deaths in this age range in the total population. The average age at death of males (73.4 years) is lower than females (78.0 years), and both are about three years lower than the average life expectancy in Ireland (76.8 years for males and 81.6 years for females)47, but higher than the OECD average (75.7 for males and 81.4 for females)48.

2.2 Marital status and living alone

Compared to the population aged 65 and over[49], patients in the audit are less likely to be 'ever married' (45% compared to 53%), and more likely to be single (20% compared to 16%) (Table 2.3). The proportion who are widowed (31%) is the same. However the proportion of patients who lived alone before being admitted to hospital (18%) is much less than in the population aged 65 years and over (32%)[50], which indicates that living alone is not a predictor of dying in hospital (Table 2.4). More than seven out of ten patients who died in hospital (72%) were living at home prior to being admitted to hospital and more than a fifth (22%) lived in a nursing home (Table 2.5).

2.3 Nationality, ethnicity and religion

The vast majority of patients in the audit are Irish by nationality (96%) and ethnicity (96%). This is higher than the corresponding proportions in the total population, at 89% and 87% respectively[51] (Tables 2.6-7). Similarly the proportion who are Catholic (88%) is higher than in the population (88%)[52] (Table 2.8). All of these characteristics reflect the older age range of hospital patients in the audit.

2.4 Public and private

---

45 Hospital In-Patient Enquiry, 2006:Table 3.1.

46 Vital Statistics, 2009.

47 Irish Life Tables, 2009:Table 1.1.

48 OECD, 2007:21.

49 Census 2006, 2007.

50 Census 2006, 2007.

51 Census 2006, 2007.

52 Census 2006, 2007.

The vast majority of patients in the audit are public (85%), higher than the proportion among patients generally (80%)[53] (Table 2.9). Community hospitals have a higher proportion of public patients (94%) than acute hospitals (84%). These rates are also higher than the target set by the HSE's 2009 National Service Plan[54] which requires that 80% of patients are public patients. This profile seems to reflect the older age of patients in the audit, many of whom would be entitled to a Medical Card[55].

2.5 Route of Admission

The majority of acute hospital patients in the audit were admitted through A&E (84%) (Table 2.10). As such, they were emergency rather than elective admissions although only a minority involved trauma or accident (7%) (Tables 2.11-12). This is considerably higher than the route of admission to a cross-section of UK hospitals (57%) in which patients died within 96 hours of admission[56].

2.6 Length of Stay

The average length of stay for patients in acute hospitals is 24 days; this compares to the national average of 6.7 days for all acute hospital in-patients, and 11.5 days for those aged 65 and over[57]. In the HSE's 2009 National Service Plan, the target average length of stay in acute hospitals is 5.9 days[58]. In the US the Institute for Healthcare Improvement has adopted 7.24 days as an indicator of an efficient length of stay[59]. It is clear that the average length of stay of patients who die in acute hospitals in Ireland is high by international standards[60], and by comparison with patients who die in acute hospitals in England[61].

---

[53] Public patients receive hospital services free of charge while private patients pay through either private health insurance or out-of-pocket payment. In HIPE, public / private status relates to whether the patient saw the consultant on a private or public basis. Private consultant care may be funded through private health insurance or out-of-pocket payment, although HIPE does not distinguish between these two methods of payment (Hospital In-Patient Enquiry, 2006:72).

See http://www.hse.ie/eng/Find_a_Service

[54] HSE National Service Plan 2009, 2008:54

[55] In 2001, the Medical Card was made available to all persons aged 70 years and over, irrespective of means. In 2009, this was restricted to those persons aged 70 years and over whose self-assessed income met the eligibility criteria.

[56] This study was carried out by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) and based on a sample of 3,153 deaths which occurred between October 2006 and March 2007. See National Confidential Enquiry into Patient Outcome and Death, 2009:Table 3.2.

[57] Hospital In-Patient Enquiry, 2006:Table 3.9.

[58] HSE National Service Plan 2009, 2008:71

[59] 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).

[60] For example, the OECD average length of stay is 6.3 days (OECD, 2007:73).

[61] 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).

Female patients in the audit had a significantly longer stay in acute hospitals compared to male patients (152 days compared to 87 days) (Tables 2.13a-c). This is much higher than the national average length of stay for males (7.0 days, rising to 11.1 days for males aged 65 and over) and females (6.1, rising to 11.9 days for females aged 65 and over)[62]. Understandably, the average length of stay for patients in community hospitals is high at 826 days.

Average length of stay in the audit varies substantially by the patient's diagnosis and type of ward in acute hospitals (Table 2.13d-e). Focusing on diagnosis, patients with frailty / dementia have the longest length of stay (55 days) while those with cancer (15 days) have the shortest, and considerably shorter than the national average length of stay for cancer patients in all acute hospitals in Ireland (26.6 days)[63]. Turning to wards in acute hospitals, the longest length of stay is in geriatric wards (136 days) with much shorter stays in surgical (35 days), medical (21 days), oncology (13 days), and intensive care (11 days).

2.7 Expected and Sudden Deaths

The majority of deaths in hospital are expected (76%) rather than sudden (Table 2.15). In acute hospitals, three quarters of deaths (74%) are expected compared to nearly nine out of ten in community hospitals (87%). The more likely time of death is 'am' (55%) rather than 'pm' (45%) but the difference is not great (Table 2.16).

2.8 Primary Diagnosis

In Ireland, the three main causes of death are circulatory system diseases (35%), cancer (28%) and respiratory system diseases (13%)64. These are also the three main causes of death among patients in the audit: circulatory (31%), cancer (23%) and respiratory (19%) (Table 2.17a-b).

The largest proportion of deaths occurred in medical wards (42%) but nearly one in five deaths (18%) occurred in intensive care (Table 2.18). A similar proportion of deaths occurred in geriatric (13%) and surgical (12%) wards.

2.9 Summary

Patients are evenly divided between men and women, most (89%) are aged 65 years and over, and their average life expectancy is about three years below the national average. Compared to the national population aged 65 and over, patients in the audit are more likely to be single and never married, though significantly less likely to live alone, and seven out of ten lived at home prior to hospitalisation. The vast majority of patients are Irish and Catholic and, as a consequence of their age profile, are less diverse than the population in general.

Most are public patients (85%) and were admitted to hospital through A&E, although only a minority of these involved trauma or accident. The average length of stay in acute hospitals (24 days) is well above the national average of 11.5 days for in-

---

62 Hospital In-Patient Enquiry, 2006:Table 3.9.

63 Hospital In-Patient Enquiry, 2006:Table 3.9.

64 Vital Statistics, 2009:49

patients aged 65 and over, and well above international standards for patients who die in acute hospital.

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%). In addition, 'frailty / dementia' was the diagnosed cause of death in less than a tenth of cases. The majority of deaths were expected (76%) rather than sudden and were slightly more likely to take place during 'am' rather than 'pm'.

Overall, a striking feature about this profile of patients is that their end-of-life journey takes place in a health system which does not operate a planned approach to their admission or discharge from acute hospital. Most patients who die in acute hospital are admitted through A&E, even though many would have been patients of the hospital already, with already-diagnosed conditions. This suggests a discontinuity in the health system between primary and acute care on the one hand, and between different episodes of acute care on the other. Similarly, the absence of a planned approach to discharge is clearly indicated by the fact that patients who die in acute hospitals in Ireland spend much longer there compared to patients who die in acute hospitals elsewhere in the US or the UK. In addition, as revealed below, both nurses and doctors estimate that about a fifth of patients in the audit could have died at home if appropriate supports were available. These considerations suggest that the end-of-life journeys of patients could be improved if admissions and discharges from acute hospital were planned in a more holistic manner. This would require a more person-centred approach to health care and a coordinated continuum of care options by public, private and voluntary providers – involving hospitals, hospices, nursing homes, community-based services, and home-based supports - that are managed by the HSE to facilitate the needs and preferences of patients[65].

---

[65] It is important to acknowledge that this is already part of the vision of the CEO of the HSE as outlined in the introduction to the 2009 National Service Plan: '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).

3 Ward and Room Characteristics

The physical characteristics of the ward and room where the patient died – and the hospital generally - are known to influence the quality of care and the quality of life. 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'[66]. In that light, this section reports on the ward and room where patients spent most of the last week of life, and the nurses' assessment of that room.

3.1 Ward where patients died

The total number of wards in the audit is 347, most of them in the acute sector (285, 82%) with the remainder in community hospitals (62, 18%) (Table 2.18). In acute hospitals, the average ward where patients died had about 23 beds, most of them in-patient beds (19.6) with a small number of day beds (3.7) (Table 3.1). Community hospital wards are broadly similar in size (22.3 beds) but with fewer day beds (0.8).

Nearly a fifth (19%) of beds in acute hospital wards are in single rooms, slightly higher than the proportion of 'side-rooms' in English hospitals (15%) which use the Liverpool Care Pathway[67]. In community hospitals just over a tenth (13%) of beds are in single rooms (Table 3.2). In practice this means that the average ward in an acute hospital, based on those where patients died, comprises 16 in-patient beds in multi-occupancy rooms and 4 beds in single rooms; these multi-occupancy rooms, in turn, tend to have about 5 beds each (Table 3.3). In the community sector, the breakdown of each ward is 16 beds in multi-occupancy rooms and 3 beds in single rooms and these multi-occupancy rooms, in turn, tend to have about 6 beds each. It is significant that, in acute hospitals, over a quarter (28%) of the beds in multi-occupancy rooms are mixed gender, much higher than in community hospitals (7%) (Table 3.4). Mixed gender rooms are most likely to be found in intensive care (74%), and A&E (59%) wards.

3.2 Room where patient died

Just under half of all patients (44%) died in a single room, higher in acute (46%) than in community (34%) hospitals (Table 3.5). This compares to about 70% of patients who die in single rooms in hospitals in Northern Ireland[68].

In acute hospitals, patients who die in a single room spend an average of 5.0 days there compared to 3.6 days in community hospitals (Table 3.6). Given that the average length of stay in hospital is much longer than this (24 days in acute and 826

---

[66] 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.

[67] Marie Curie Palliative Care Institute Liverpool, 2009:23.

[68] 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.

days in community), this implies that patients tend to be moved during their last week of life and this is confirmed by the fact that, on average, patients in both acute and community hospitals are moved about once (1.3 times) during their final stay in hospital (Table 3.7). It is also significant that the vast majority of patients who died in single rooms did not have a hospital acquired infection (89%) or did not receive immuno-suppression therapy (98%) (Table 3.8). This suggests that they were allocated a single room in order to facilitate a more dignified death, and this indicates an awareness of the special needs of patients at the end of life.

3.3 Appraisal of room where patient died

The audit asked each nurse 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). The response rate to this question was relatively poor, ranging from 33-54%, and invites some caution in interpreting the results.

The overall rating of the room where the patient spent most of the last week of life was 5.7 out of 10, with only a slight difference between acute (5.6) and community (6.3) hospitals (Table 3.9a-b). This overall score is almost identical (5.8) to the rating of hospital facilities by management during the audit of resources and facilities for end-of-life care (Report One)[69].
Further analysis reveals that a majority of the rooms were rated as good or very good in terms of dignity (72%) and privacy (63%), with much lower ratings for environment (45%) and control (31%). These ratings are higher than the overall rating of hospital and hospice facilities for end-of-life care in Northern Ireland by both managers (55%)[70] and staff (35%)[71].

Predictably, the rating of single rooms (7.1) is higher than multi-occupancy rooms (4.6) but the dimensions of multi-occupancy rooms which typically give rise to most concern – privacy (5.3) and dignity (6.3) – receive higher ratings compared to environment (4.6) and control (3.2) (Table 3.9b). In fact - across all hospitals, wards and rooms - dignity (7.1) and privacy (6.7) score consistently higher than environment (5.6) or control (4.4). This is surprising given that a majority of patients (66%) died in multi-occupancy rooms with at least five other patients, and a quarter of these rooms involved mixed gender. In terms of wards, the highest scores were given by nurses in oncology (6.9) and the lowest by nurses in A&E (3.4) and intensive care (4.8) (Table 3.9d).

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[72]. That study gave an overall score of 3.6 out of 10 for the physical environment of these hospitals, well below the

---

[69] McKeown, Haase and Twomey, 2010a:Section 7.

[70] 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).

[71] 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).

[72] Tribal, 2007.

self-assessed score of management in those hospitals (5.8)[73]. Similarly, the Tribal score for privacy (3.3) is also well below the self-assessed score of nurses in these hospitals for this dimension (6.7). This clearly suggests a tendency among hospital management and staff to over-rate the physical environment of their hospital, possibly due to the lack of awareness about what is possible and desirable in terms of evidence-based design in hospitals. 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'[74].

The issues here are not just methodological however; they are 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' [75].

3.4 Summary

The results in this section reveal that the average ward where patients died had about 23 beds. In acute hospitals, nearly a fifth (19%) of beds are in single rooms, slightly higher than the proportion of 'side-rooms' in English hospitals (15%) which use the Liverpool Care Pathway. Community hospitals have fewer single rooms (13%). In acute hospitals, over a quarter (28%) of all beds in multi-occupancy rooms are mixed gender, much higher than in community hospitals (7%).

Just under half of all patients (44%) died in a single room, compared to about 70% of patients who die in single rooms in hospitals in Northern Ireland. Those who die in a single room spend about 4-5 days there and the vast majority of these patients did not have a hospital acquired infection, which suggests that they were moved there to facilitate a more dignified death.

---

[73] McKeown, Haase and Twomey, 2010a:Section 7.

[74] Tribal, 2007:iii.

[75] Tribal, 2007:13.

The room where each patient died was rated at 5.7 out of 10, with only a slight difference between acute (5.6) and community (6.3) hospitals. The ratings for dignity and privacy were consistently higher than for environment and control, but the overall rating of the rooms where patients died appears to be higher compared to the staff ratings of hospital facilities in Northern Ireland. These ratings are almost identical (5.8) to those of hospital management but significantly above the ratings of independent healthcare consultants.

Overall, these results suggest that hospital staff make considerable efforts to facilitate patients to die in a single room despite competing demands for the limited stock of these rooms. Independent healthcare consultants have pointed out that the physical facilities in Irish hospitals are not always conducive to dignity, privacy or control of the environment, but staff and management consistently adopt a more positive view, and rate their end-of-life facilities highly, including more highly than their counterparts in Northern Ireland. This tendency to over-rate the physical environment of hospitals may be due to a lack of awareness about what is possible and desirable in terms of evidence-based design in hospitals. Whatever the reason, the results suggest that in order to build momentum for improving the physical environment of hospitals, it may be necessary to first raise awareness about how Irish hospitals compare with best practice elsewhere, so that opportunities for improvement can be identified and implemented.

4 Assessment of Patient

It is recognised by experts that assessing whether a patient is dying, and beginning the end-of-life journey generally, can be difficult and uncertain, except for certain conditions such as cancer where relatively accurate prognosis is possible[76]. Given that the diagnosis of dying is 'a clinical challenge'[77], one of the top ten 'quality markers' in the UK strategy for end-of-life is to 'institute effective mechanisms to identify those who are approaching the end of life'[78]. Faced with this situation, many clinical settings in the US have found it useful for doctors and nurses to ask the following 'no surprise' question: 'Is this person sick enough that it would be no surprise if he or she died within the coming year (or the coming few months)?'[79] Commenting on this approach to diagnosis, its author observed: 'This "no surprise" question has worked well for targeting clinical improvement activities, though it has not been tested in regulatory, financing, or more formal service delivery innovations. Some patients identified in this way will die quickly and some will live a long time, but all are sick enough that they would benefit from comprehensive services tailored to advanced illness and the last part of life'[80].

The diagnosis of dying – or end of life more generally - is an important first step in the process of assessing a patient's needs and providing the type of care that is appropriate to each at the end of life. The rationale for diagnosing dying is that when death is expected, the emphasis moves from care that is curative to care that is palliative, and the over-riding focus is the patient's comfort and quality of life. In this section we examine the extent to which hospital staff diagnosed that the patient was dying, whether this was documented, what meetings happened as a result of the diagnosis and whether, in retrospect, the patient could have died at home.

4.1 Diagnosis of dying

The audit collected data on the diagnosis of dying by asking the following question of both nurses and doctors: 'Had the medical team diagnosed that this patient was dying?'. The results indicate that a diagnosis of dying was made by the medical team in the vast majority of cases (86%), and occurred 5-6 days before the death of the patient (Tables 4.1N to 4.2D). There is a high level of agreement[81] between the responses of nurses and doctors (86%) on cases where a diagnosis of dying is made (Table 1.4 and Figure 4.1).

---

[76] Lynn, Schall, Milne, Nolan and Kabcenell, 2000; Lynn, Schuster and Kabcenell 2000.

[77] Marie Curie Palliative Care Institute Liverpool, 2007:10

[78] Department of Health, 2009:11. Similarly, the Australian palliative care standards notes that: 'Health care providers need to be experienced and skilled in recognising when the terminal phase of the life limiting illness has begun. This is important in order to facilitate appropriate care for the patient, their caregiver/s and family' (Palliative Care Australia, 2008:30).

[79] Lynn, 2004:43.

[80] Lynn, 2004:44.

[81] 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 using either two or four response categories, depending on the question (See Section 14.5 in the Technical Appendix).

Figure 4.1: Diagnosis of Dying

n = 737	Nurses	Doctors	Agreement (Scale 1-2)
Death diagnosed	86%	86%	86%
Diagnosis documented	89%	86%	73%

The rate of diagnosing death is high compared to a French study which found that 50% of deaths were anticipated by nurses 'for at least 3 days'[82]. It is also high compared to a UK study where, within the sampling period, 50% of deaths were expected[83]. Similarly, the duration between diagnosis and death would appear to be longer than in England where it averages 33 hours[84]. From this it would appear that deaths in Irish hospitals are anticipated more frequently than in French hospitals and earlier than in English hospitals.

Diagnosis of dying is more frequent in acute than in community hospitals but, where it occurs, the duration between diagnosis and death tends to be longer in community than in acute hospitals. Both nurses and doctors concur that diagnosis of dying is most likely for patients with cancer, for younger patients, for patients in single rooms, and where death is expected rather than sudden. The latter finding indicates that diagnosis does not imply any certainty about the time of death and this is exemplified by the finding that nearly half of all sudden deaths had been diagnosed as dying.

As expected, nursing staff are aware that a patient is dying when a medical diagnosis of dying has been made and documented. However, in a minority of cases (4%), nursing staff are aware of patients who were dying even if where there was no medical diagnosis or no documentation. This can be inferred from the fact that nursing staff were aware the patient was dying in 90% of cases even though there was a medical diagnosis of dying in only 86% of cases. This 'gap' is greatest in intensive care and geriatric wards, and for patients with frailty / dementia.

The medical diagnosis of dying is documented in the patient's hospital chart in nearly nine out of ten cases (86-89%), although the responses of nurses and doctors only agree on this in three quarters of cases (73%). Documenting the diagnosis of dying is more likely in acute hospitals, and most likely for patients with cancer (94%) and those in oncology wards (96%) and least likely in A&E (42%). Patients who died in single rooms were more likely to have their diagnosis of dying documented (82%) which suggests that documentation may increase a patient's chance of dying in a single room.

---

[82] Ferrand, Jabre, Vincent-Genod, et al, 2008:870 and Table 2. This study was based on 3,793 patients who died in 200 French hospitals in 2004.

[83] National Confidential Enquiry into Patient Outcome and Death, 2009: Table 8.1. This study was based on a sample of 3,153 deaths which occurred between October 2006 and March 2007.

[84] This is inferred from the audit of patients on the Liverpool Care Pathway (LCP), based on 3,893 patients in 155 hospitals who died between October and December 2008. Patients are placed on the LCP where there is a diagnosis of dying and the average length of time on LCP was 33 hours (Marie Curie Palliative Care Institute Liverpool, 2009:21; see also 2007:5). The audit estimates that 21% of all deaths in those hospitals were on the LCP (Marie Curie Palliative Care Institute Liverpool, 2009:24).

4.2 Team meetings about patient’s care

The audit explored the extent of team-work within the hospital, following the diagnosis of dying, by asking about the type of meetings which were held to ‘talk about and review the aims of the patient’s care’. Two types of meeting are distinguished in the audit: (i) a multidisciplinary team meeting of all health care professionals involved in the care of the patient and (ii) a meeting of medical and nursing staff involved in the care of the patient. Before reporting the results, it is worth noting that the responses of nurses and doctors agree, in about six out of ten cases only (Table 1.4 and Figure 4.2), that these meetings actually took place, which suggests that they are relatively informal and probably not documented in many cases.

Figure 4.2: Team Meetings About Patient

n = 737	Nurses	Doctors	Agreement (Scale 1-2)
Team Meeting (Nurses & Doctors)	70%	66%	66%
Team Meeting (Multidisciplinary)	46%	40%	60%
No Team Meeting	28%	31%	-
Family involved	70%	66%	67%

Meetings were held in about seven out of ten cases, with no meeting in a third of cases (Tables 4.3N and 4.3D). Cases where no meetings were held can be found throughout the hospital system but were more likely in A&E, if the patient spent less than a day in hospital, and if the death was sudden.

The most frequent type of meeting involved medical and nursing staff only – not including other health care professionals – and this was held in nearly seven out of ten cases (70% according to nurses, 66% according to doctors). Multidisciplinary team meetings were held in about four out of ten cases (46% according to nurses, 40% according to doctors). Both types of meeting was more likely in community hospitals and, within acute hospitals, were more likely for patients with cancer and those in single rooms.

These meetings were frequently attended by the family of the patient, in about two thirds of cases. However, where this did not happen, about half (56%) the patients / families were later told later about its outcome; by implication, the other half were not told.

4.3 Could the patient have died at home?

The question of whether a patient could, or should, die at home, depends on a number of factors including their condition and the level of home care support. Given this complexity, each nurse and doctor was asked the following question: ‘Depending on the patient’s condition during their last week of life, do you think the patient could have been allowed to die at home, if they got enough home care support?'. There is a relatively high level of agreement (74%) between the responses of nurses and doctors in their answers to this question (Table 1.4).

The results reveal that over a fifth (22%) of patients – in the opinion of nurses and doctors though not necessarily of patients - could have died at home. This is similar to the results of other studies in Ireland[85] and England[86], but lower than another UK study[87]. Patients who could have died at home were more likely to be in an acute hospital and were more likely to have cancer. Significantly, patients who died in a single room were more likely to be judged as suitable for a home death which suggests that level of functioning and dependency may not be an important influence on the allocation of single rooms.

4.4 Summary

Diagnosing dying, and the start to an end-of-life journey generally, is recognised as 'a clinical challenge' as well as an important first step in assessing the patient's needs and providing care that is appropriate. The audit reveals that a diagnosis of dying was made by the medical team in the vast majority of cases (86%), and occurred 5-6 days before the death of the patient. This suggests that deaths in Irish hospitals are anticipated more frequently than in French hospitals and earlier than in English hospitals. The rate of diagnosis is higher in acute hospitals and for patients with cancer, for younger patients, and patients in single rooms. The medical diagnosis of dying is documented in nearly nine out of ten cases (86-89%), although the responses of nurses and doctors only agree on this in three quarters of cases (73%). Documenting the diagnosis is more likely when patients have cancer (94%).

Two types of meetings - usually involving medical and nursing staff only, but sometimes involving the full multidisciplinary team of all health care professionals – are held to discuss the care of the patient in about seven out of ten cases. Significantly no meetings are held in nearly a third of cases. The responses of nurses and doctors agree, in about six out of ten cases only, that these meetings actually took place, which suggests that they are relatively informal and probably not

---

[85] This study, based on 191 patients who were referred to the home-care team based at Our Ladys Hospice in Dublin, estimated that 'Sixteen (18%) of the 89 patients admitted to either hospice or acute hospital could have remained at home with extra nursing support, as judged by the nurses and doctors caring for the patient. … . However, the conclusions that can be drawn from these statements are 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.' (Tiernan, Connor, Kearney, and Siorain, 2002:234).

[86] This study, based on 599 patients who died in an acute hospital in the south west of England, found that, in the opinion of two specialist palliative care consultants, 21% of these could definitely have died at home, with an additional 13% in the 'maybe' category (Abel, Rich, Griffin and Purdy, 2009:3 and Table 1).

[87] This study, based on 200 patients, reported the following: 'Our detailed examination of patient records in one PCT [Primary Care Trust] found that 40 per cent of patients who died in hospital in October 2007 did not have medical needs which required them to be treated in hospital, and nearly a quarter of these had been in hospital for over a month. Alternative places of care for these patients identified by our work were equally split between home based alternatives (in the patient's own home or a care home) and bed based care in a hospice. Local data suggest there was sufficient inpatient palliative care capacity to take many of the patients who died in hospital' '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, 2008:7). Significantly, the study adds 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' (National Audit Office, 2008:28).

documented in many cases. Meetings are more likely in community hospitals and, within acute hospitals, were more likely for patients with cancer and those in single rooms. The family attended these meetings in about two thirds of cases but where they did not, only half were told about their outcome.

About a fifth of patients could have died at home in the opinion of nurses and doctors. Studies in the UK suggest that a similar, and even higher, proportion of acute hospital deaths could take place elsewhere.

Overall, the audit provides impressive evidence, relative to experience elsewhere, about the capacity of doctors and nurses to diagnose dying well in advance of death. However it is less impressive about the practice of documenting this. Given the fundamental importance of this diagnosis for subsequent patient care, the uneven pattern of documentation could have negative consequences for the care of patients. This concern is suggested by the fact that patients whose diagnosis is undocumented are less likely to be offered a single room and these patients, in turn, are less likely to receive a specialist palliative service.

It is clear that considerable flexibility and informality exists around the holding of, and attendance at, team meetings in hospital, and there is clearly no standardised procedure for reporting the outcome of meetings to patients and relatives. The fact that the frequency of team meetings varies by ward (being more frequent in oncology and geriatric wards) and diagnostic category (being more frequent for cancer patients) suggests that a team approach to patient care, where it exists, may be more influenced by the work practices of different disciplines and wards than a standardised approach to planning the end-of-life needs of patients. This, in turn, invites reflection within hospitals on existing procedures for holding team meetings, particularly where a patient has been diagnosed as dying.

The substantial proportion of patients who could die at home if appropriate supports were available has significant implications in terms of meeting patient needs and preferences, and the cost of meeting those needs and preferences in different care settings. In terms of preferences, it is known that a majority of Irish people would prefer to die at home[88] and, interestingly, doctors and nurses also have a stronger preference to die at home compared to patients[89]. In addition, there is evidence 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[90].

In terms of cost, there is 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

---

[88] 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).

[89] 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.

[90] 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).

settings[91]. The audit suggests that the same applies to many patients who die in acute hospital but who could die just as well at home if appropriate supports were available. If this finding is extrapolated to the acute hospital sector in Ireland, we estimate that over €80 million[92] could be made available for end-of-life care in non-acute settings through more appropriate care for people approaching the end of their life. 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’[93.] This approach is consistent with the HSE’s five-year development framework for palliative care services (2009-2013) which acknowledges that: ‘identification of appropriate funding may be achieved through a combination of the following: reorientation and reconfiguration of existing resources, to be undertaken in partnership with all relevant stakeholders, including both the statutory and voluntary sectors; identification of additional resource requirements when further funding comes on-stream’[94].

---

[91] 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).

[92] 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 60,255 bed days by these patients. The cost of these bed days, in turn, is approximately €82.6 million.

[93] 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).

[94] HSE Palliative Care Services – Five Year Development Framework 2009-2013, 2009.

5 Communication with Patients and Relatives

There is a substantial evidence that effective and empathic communication influences the quality of care and the quality of life of patients who are dying, and an even larger body of evidence that this is an area where end-of-life care could be improved within hospitals[95]. 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'[96]. For this reason, quality standards for end-of-life care tend to place great importance on discussing and documenting the needs and preferences of patients and their relatives[97].

The closest relatives and friends of a patient are invaluable companions on the end-of-life journey. Indeed, as our analysis below reveals (Section 9), one of the main influences on the quality of living and dying of patients is their relationship with family and friends. From a care perspective therefore, it makes sense to regard the patient, along with his/her family, as a single unit of care. This fact, combined with the frailty of dying patients, is the main reason why communication with relatives is such an important aspect of end-of-life care.

The audit reveals that hospital staff are much more likely to discuss end-of-life issues with relatives (96%) than with patients (55%) (Figure 5.1; Tables 5.1 and 6.1). Where no discussion took place with patients, this was mainly because the patient was too ill (80%), but also because the patient died suddenly (27%), or had dementia (26%) (Table 5.2). It is noteworthy that some of the reasons which are commonly cited for hospital staff not discussing their patient's end-of-life issues – such as the patient did not want to talk about dying, relatives did not want the patient to be told, lack of privacy, hospital staff lacked experience in communication - were not significant influences.

In broad terms, the overall level of communication with patients and relatives is consistent with another Irish study which identified a tendency among health care professionals to 'speak with families of older people, as opposed to the older individuals themselves, regarding treatment and services'[98]. This pattern of communication is also similar to that found among English patients on the Liverpool Care Pathway (LCP)[99].

---

[95] Baker, et al., 2000; Edmonds and Rogers, 2003; Heyland, et al., 2005; Hodges, London and Lundstedt, 2006; Irvine, 1993; Murphy, et al., 2000; Pincombe, Brown, and McCutcheon, 2003.

[96] 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'.

[97] For example, two of the top ten quality markers in the UK end-of-life strategy are to: 'ensure that individuals' preferences and choices, when they wish to express them, are documented and communicated to appropriate professionals' and 'ensure that the needs of carers are appropriately assessed and recorded through a carer's assessment' (Department of Health, 2009:11). In the Australian standards for palliative care, the need to assess and document the needs and preferences of patients and relatives is also explicitly noted (Palliative Care Australia, 2008:24).

[98] McGlone and Fitzgerald, 2005:72.

[99] The results of a national audit of patients on the Liverpool Care Pathway LCP – based on 3,893 patients in 115 hospitals who died between October and December 2008 – showed that patients were less likely to be aware of their diagnosis (50%, compared to 79% of relatives), to recognise that they were dying (40%, compared to 76% of relatives), or to have their care plan explained to them (30%, compared to 72% of relatives). (Marie Curie Palliative Care Institute Liverpool, 2009:45-54).

Figure 5.1: Communication with Patients and Relatives

n = 737	Patients	Relatives
Discussion held	55%	96%
Discussion documented	76%	83%
Quality of discussion (Score 1- 10)	7.3	8.5

The topics most frequently discussed with patients and relatives were: the patient's situation and prognosis, whether the aim of care was curative or palliative; the benefit versus burden of current treatment; and active resuscitation of the patient. It is significant that the topics least likely to be discussed, with either relatives or patients, were the preferences of the patient about where they would like to be cared for, or where they would like to die. This is significant given the finding in the next sub-section that one of the wishes expressed by a significant minority of patients (14%) was to be cared for at home, a wish that was clearly not fulfilled. In the previous section we also found that over a fifth (22%) of patients, mostly in acute hospitals, could have died at home, if they got enough home care support.

Discussions with patients at the end of life are more likely in oncology wards (75%) and, understandably, least likely in A&E (31%) and intensive care (39%). They are also more likely for patients with cancer and in single rooms, possibly because the latter are more likely to have been diagnosed as dying (see Tables 4.1N and 4.1D). By contrast, there is relatively little variation in the pattern of communication with relatives since almost all relatives are involved in discussions with staff.

Discussions with relatives are more likely to be documented (83%) compared to discussions with patients (76%). Again, documentation of discussions with patients is more likely to occur in oncology wards (91%), for patients with cancer (84%) and in single rooms (80%).

When discussions take place with patients and relatives, these tend to be at the same time as the diagnosis of dying (Tables 5.3a and 5.3b, 6.4a and 6.4b). This is usually no more than a week before death, averaging 5-6 days (Tables 4.2N and 4.2D). In other words, there is generally no delay in discussing the implications of a diagnosis of dying.

Discussions about the patient's end-of-life are usually started by hospital staff – either singly or in combination – such as doctor or nurses (Tables 5.4 and 6.5). However in about four out of ten cases, relatives started the discussion, but it is relatively rare for patients to initiate these discussions. Accordingly, the main participants in these end-of-life discussions tend to be doctors, nurses and relatives.

Nurses were asked to assess how the patient and relative might have felt about these discussions. This involved rating the discussion on a 10-point scale, from 1 (poor) to 10 (excellent) on criteria such as sensitive, open & honest, reassuring, expressing concerns, expressing preferences, asking questions, and making decisions. The results indicate that the quality of communication is significantly better with relatives (8.5) compared to patients (7.3). Equally significant is the fact that there is relatively little variation in rating the different communication criteria, or little variation between hospitals, wards, rooms or diagnosis (Tables 5.5 and 6.6).

It is clear that hospital staff, particularly where there is a diagnosis of dying, attach high priority to the involvement of relatives, and rate highly their discussions with relatives. However it is noteworthy that discussions with relatives are more likely to be documented than discussions with patients, and to be rated more highly than discussions with patients. These findings give some ground for reflecting on whether there is an appropriate balance between the needs and rights of patients and relatives, the place of a patient-centred approach[100], and the importance of protecting the patient's autonomy as far as possible. Equally open for reflection is the question, particularly regarding end-of-life, of whether hospital staff may feel more comfortable with, and attach greater importance to, the views of relatives over patients, particularly since relatives have the power to complain which dying patients do not[101]. Further reflection is also suggested by the uniformly high staff-ratings for communication with relatives on the grounds that, given the huge variability of hospital circumstances under which these discussions take place, and the natural human variability in communication skills, a wider range of scores might have been expected. This in turn prompts the question, which only hospital staff can address, as to whether there is scope for being more self-critical about communication patterns and a greater ease in acknowledging weaknesses as well as strengths[102].

---

[100] Goodrich, 2009.

[101] These questions are also opened up by the results of the audit of the Liverpool Care Pathway (LCP) – based on 3,893 patients in 115 hospitals who died between October and December 2008 – which shows that relatives are much more likely than patients to be aware of the patient's diagnosis (79% compared to 50%), to recognise that the patient is dying (76% compared to 40%); and to have had the patient's care plan explained (72% compared to 30%) (Marie Curie Palliative Care Institute Liverpool, 2009: 45-51). The commentary on the first round of the LCP audit seems to acknowledge and endorse, perhaps unwittingly, that this result may indicate greater importance being attached to the views of relatives over patients: 'This suggests that healthcare professionals are more comfortable in assessing the insight of carers which is encouraging as the Healthcare Commission Report 'Spotlight on Complaints' (2007) illustrates that many complaints arise from carers being unprepared for the patient's death' (Marie Curie Palliative Care Institute Liverpool, 2007:43).

[102] This interpretation is supported by results from the Older Persons National Practice Development Programme in Ireland where nurses self-ratings of the 'practice context' were higher at baseline than midway through the programme, indicating a 'more realistic reflection of the existing practice context' (McCormack and Wright, 2009).

6 Meeting the Wishes of Patients and Relatives

The audit assessed the extent to which patients and relatives expressed specific wishes or worries. The results show that relatives expressed wishes more frequently than patients (88% compared to 32%) but also expressed a larger number of wishes (4.4 compared to 1.3) (Figure 6.1; Tables 5.6 and 6.7). Although the wishes of patients were more likely to be documented (62% compared to 43%), the actual number of relatives' wishes which were documented would necessarily be much greater compared to patients.

By far the most frequent wish expressed by patients (75%) was to have pain and other symptoms controlled, and nearly half (45%) wanted pastoral care or their own spiritual adviser. Significantly, over a third (34%) expressed the wish not to be actively resuscitated while a fifth (21%) wanted their relatives to be contacted. Very few spoke about changing a will, arranging the funeral, or donating organs. Cancer patients, and those aged 64 or less, were most likely to express wishes.

Figure 6.1: Meeting the Wishes of Patients and Relatives

n = 737	Patients	Relatives
Wishes expressed	32%	88%
Average Number of wishes expressed	1.3	4.4
Wishes documented	62%	43%
How well wishes were met (Score 1- 10)	6.8	8.3

In a separate question, the audit asked if the patient documented any preferences for their end-of-life care and this revealed that only 13 patients (1%) were known to have done so (Table 5.7). This is remarkably low by comparison with the US[103]. Equally striking is the fact that there was no response to this question in over a third of cases (34%) suggesting that hospital staff may not be aware if the patient has documented any end-of-life preferences. In addition, the fact that wishes expressed by patients to staff were documented in only 62% of cases suggests that the wishes of patients may not be given the priority they deserve.

By contrast, nearly all relatives expressed the wish to be kept informed if the patient's condition deteriorated (94%). Many wanted to be told if the patient might die soon (77%), and wanted to be at the patient's bedside (77%). A large proportion of relatives were also worried about the patient's pain and overall symptom

---

[103] A literature review on advance directives (AD) and advance care planning (ACP) concluded that: 'Despite the institutionalization of ADs in state and federal law and widespread public support for ACP from healthy and ill populations as well as the medical community, the accumulated evidence shows that adoption of ADs is low. Most of the literature suggests that between 18% and 30% of Americans have completed an AD. Acutely ill individuals, a group for which ADs are particularly relevant, complete ADs at rates only slightly higher than the healthy population. At most only one in three chronically ill individuals in the community have completed ADs (e.g., 35% in dialysis patients; 32% in chronic obstructive pulmonary disease (COPD) patients)' (Wilkinson, Wenger and Shugarman, 2007:10).

management (61%) and nearly as many asked for a religious service or prayers at the patient's bedside (58%). Significantly, a fifth (20%) asked for a single room for the patient.

It is worth noting here that relatives were offered a range of supports to assist spending time with the patient, including the facility to visit at any time (88%), free food and drink (78%), and stay overnight in the hospital (67%) (Table 6.9). However only a minority (19%) were offered preferential parking and fewer still (15%) were offered information leaflets on dying, death and bereavement. These supports were more likely to be offered to cancer patients, to patients in single rooms and, understandably, to those where death is expected.

As in the previous sub-section, nurses were asked to assess how the hospital dealt with the patient's and relative's wishes and worries on a 10-point scale, from 1 (not at all) to 10 (completely). The results indicate that the hospital was significantly more likely to meet the wishes and worries of relatives (8.3) compared to patients (6.8) (Figure 6.1; Tables 5.8 and 6.8). It is also significant that there is relatively little variation in the rating of different wishes and worries, or between the different contexts of care, except that the rating for patients with frailty / dementia (5.0) is well below that of any other patient group.

These results need to be interpreted with some care since they reflect not only the 'objective' qualities of the hospital's response to the wishes and worries of patients and relatives, but also the 'subjective' qualities of how nurses perceive that response. That is why it is essential to take the perceptions of bereaved relatives into account. That, in its turn, is also a salutary reminder that there is no possibility of taking the perceptions of these patients into account.

Nevertheless the results suggest that existing practices for documenting discussions with patients and relatives, including their wishes and worries, may fall short of HSE standards for the management of healthcare records, particularly the criteria that: 'all relevant communication with patients and families shall be documented in the relevant part of the healthcare record'[104] and 'the involvement of the patient in decisions about his or her care shall be documented in the record under 'patient wishes''[105]. Given that documentation is essential to supporting a consistent approach to patient care across the hospital team – and is itself an indicator of quality of care[106] - it is possible that if a patient's wishes are not documented they may not addressed, and this is particularly significant for the three main wishes expressed by patients: pain control, pastoral / spiritual care, and not to be resuscitated. This suggests the need for some strengthening of procedures for documenting the needs and preferences of patients[107].

---

104 HSE National Hospitals Office, 2008:30.

105 HSE National Hospitals Office, 2008:31. The overall standard on the content of the healthcare record states: 'The content of the healthcare record shall provide an accurate chronology of events and all significant consultations, assessments, observations, decisions, interventions and outcomes. The content of each record shall comply with clinical guidance provided by professional bodies and legal guidance provided by the Clinical Indemnity Scheme. This standard shall apply to both hardcopy and electronic documentation' (page 20).

106 One study - based on 3,793 patients who died in 200 French hospitals in 2004 – found that nurses were more likely to perceive a patient's death as acceptable if the patient's wishes about treatment were documented (Ferrand, Jabre, Vincent-Genod, et al, 2008:Table 4).

107 Similar problems with documentation were identified in a UK study carried out by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD), based on a sample of 3,153 deaths which occurred between October 2006 and March 2007. The study observed that 'Poor documentation remains commonplace. This hinders effective communication between team members and makes the subsequent assessment and audit of care difficult' (National

As in the previous section, it is difficult to avoid the impression that the wishes and worries of relatives may carry more weight than those of patients. Equally, it is striking that hospital staff feel more confident in meeting the wishes and worries of relatives compared to patients, given that the overt purpose of the hospital is to meet the needs of patients. It is true that the needs of patients and relatives are not necessarily in conflict – and ideally both form a single unit of care - but the apparent imbalance in how the hospital seems to respond to each invites further reflection on the underlying quality of care for patients. This is particularly important in the context of end-of-life care given the frailty of dying patients and the key mediating role of relatives in the care relationship.

Confidential Enquiry into Patient Outcome and Death, 2009:30). Elsewhere the report states: ‘Good documentation of clinical findings, clearly written management plans and robust systems for handover are all increasingly vital elements required to ensure that care is not jeopardised by poor communication. Communication is vital, not only between members of the same teams, but also between different professional groups, and where present, members of the hospital at night team. Advisors expressed concern that in a number of cases there was evidence of poor communication at all levels’ (Ibid:30).

7 Palliative Care of Patient

The aim of palliative care, and end-of-life care generally, is to reduce and, if possible, eliminate suffering, and improve the quality of living and dying[108]. Where patients have been diagnosed as beyond cure and entering the dying phase, hospital staff are expected to re-orient their care towards comfort and the control of symptoms. That is the clear guidance of the Irish Medical Council to its doctors: 'Where death is imminent, it is the responsibility of the doctor to take care that the sick person dies with dignity, in comfort, and with as little suffering as possible. In these circumstances a doctor is not obliged to initiate or maintain treatment which is futile or disproportionately burdensome'[109]. In order to meet this requirement, hospital staff need to have the skill and empathy[110] to diagnose and manage symptoms, and a clear understanding of the needs and preferences of the patient. This section details the decisions that were made about the patient during the last week of life, including whether those decisions were documented (7.1). The frequency of selected symptoms in the last week and their management by the hospital team is also analysed (7.2).

7.1 Palliative care decisions

The audit asked nurses and doctors whether a range of palliative care decisions had been taken and documented during the last week of life. A significant finding is that the responses of nurses and doctors do not always agree on whether a decision was made (67% agreement), or on whether it was documented (62% agreement) (Figure 7.1). For example, there is 77% agreement that a decision was made to optimise comfort but only 61% agreement that this was documented (Table 1.5). Similarly, there is only 61% agreement that a decision was made to stop invasive monitoring and only 67% agreement that this was documented. This result opens the question as to whether in fact decisions were made in those cases where there is no agreement between the responses of nurses and doctors as well as broader questions about how decisions are made and documented in hospital about the end-of-life needs of patients.

---

[108] Palliative care has been described as an 'interdisciplinary speciality that focuses on improving quality of life for patients with advanced illness and for their families through pain and symptom management, communication and support for medical decisions concordant with goals of care, and assurance of safe transitions between care settings' (Morrison, et al, 2008). According to the World Health Organisation, 'palliative care has the following characteristics: provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patients illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications'. Available at http://www.who.int/cancer/palliative/en/. Accessed 18 March 2009.

[109] Irish Medical Council, 2004:Paragraph 23.1. The Law Reform Commission considered this ethical guidance in the context of its report on advance care directives and made the following comment: 'The Commission considers that this guidance deals correctly with a difficult ethical matter in a manner that is also consistent with existing criminal law on euthanasia' (Law Reform Commission, 2009:Paragraph 1.78, page 34).

[110] 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).

Figure 7.1: Palliative Care Decisions

n = 737	Nurses	Doctors	Agreement on 10 Decisions (Scale 0-1)
Average number of decisions made	6.2	6.0	67%
Decisions documented	79%	73%	62%

Doctors reported that the following decisions were made in about three quarter of cases: to review whether the aim of care was curative or palliative, to optimise comfort, to stop non-essential medication, and to talk about resuscitation. About three quarters of nurses also reported that decisions were taken to optimise comfort, talk about resuscitation and assess skin integrity. However, both nurses and doctors report that, even when death is expected, no decisions were taken in the majority of cases to: stop antibiotics, stop invasive monitoring, or withhold treatment. In general, decisions about end-of-life care were more likely to be taken in oncology wards, involving cancer patients, where death is expected and, perhaps as a consequence of this, for patients in single rooms.

The extent to which end-of-life decisions are taken about dying patients in Irish hospitals is significantly less compared to patients dying in English hospitals[111], especially those on the Liverpool Care Pathway (LCP) where, in the vast majority of cases, decisions were made to discontinue blood tests (91%), antibiotics (89%), IV fluids / medications (83%), do not resuscitate (94%) and inappropriate nursing interventions such as vital signs and blood sugar monitoring (75%)[112]. None of the acute hospitals in the audit use the LCP although it is used by some hospitals who are not in the audit[113]. Similarly, although decisions to withhold or withdraw life support are taken more frequently in intensive care (53%) compared to other wards

---

[111] In a study of 3,153 deaths across acute hospitals in the UK, discussions about treatment withdrawal were held with patients or relatives in 83% of cases (National Confidential Enquiry into Patient Outcome and Death, 2009:89).

[112] This audit was based on 3,893 patients in 115 hospitals who died between October and December 2008 (Marie Curie Palliative Care Institute Liverpool, 2009:36-37).

[113] The Liverpool Care Pathway (LCP) is a multi-professional framework of care which is used during the dying phase and is based on standards of care found in the hospice environment. The goals of care are to ensure the physical comfort of the patient, psychosocial insight, spiritual care for patients and carers, as well as communication including information giving and receiving. This framework is one of three – the other two are Gold Standards Framework and Preferred Priorities for Care – that have been recommended by the UK Department of Health and by the UK National Institute for Health and Clinical Excellence (NICE). In a UK study carried out by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD), based on a sample of 3,153 deaths between October 2006 and March 2007, one third of those diagnosed as dying (33%, 1,505) were placed on an end-of-life care pathway. For those not on a pathway, the 'overall quality of care was less good than those who had such a pathway in place' (National Confidential Enquiry into Patient Outcome and Death, 2009:91). However this study also drew attention to some limitations of care pathways: 'While these [care pathways] may well be an aid to patient care by providing a common framework, good quality end of life care can equally well be provided by committed and compassionate individuals who are experienced in the care of the dying. Indeed consideration should be taken to prevent the act of dying becoming overly medicalised and process driven. Perhaps the greatest value of these care pathways may be in situations were health care professionals are less confident and experienced in providing end of life care' (National Confidential Enquiry into Patient Outcome and Death, 2009:90).

(47%), they are much less frequent compared to the practice in 17 European countries[114].

Decisions to withhold and withdraw treatment were taken in less than half of all cases but more frequently in intensive care. The audit also revealed that about three quarters of end-of-life decisions by nurses and doctors are documented (Table 7.1N and 7.1D). Documentation of decisions is more likely in oncology wards, involving cancer patients, where death is expected and, perhaps as a consequence of this, for patients in single rooms. From a comparative perspective, the practice of documenting medical decisions about end-of-life in Irish hospitals tends to be less frequent than for patients on the LCP in English hospitals, particularly in areas such as medication, blood tests, IV fluids, resuscitation - where over nine out of ten decisions are documented[115]. However decisions regarding the non-medical aspects of LCP are less likely to be documented[116], and may not be very different to practices in Irish hospitals.

7.2 Quality of Palliative Care

It is recognised that 5-6 key symptoms may occur for many patients in the last hours or days of life: pain, nausea, breathing difficulties, increased secretions, restlessness, and anxiety[117]. For this reason, the audit asked nurses and doctors to assess the frequency with which these symptoms were experienced in the last week of life on a four-point scale comprising: all of the time, most of the time, some of the time, and none of the time. The level of agreement between the responses of nurses and doctors on the frequency of symptoms is only 50%, on average, which indicates a substantial level of ambiguity and uncertainty about the incidence of patient symptoms and needs (Table 1.6). For example, there is only 48% response agreement on whether a patient was in pain all or most of the time (Figure 7.2). Equally significant is the fact that the proportion of patients identified as being in pain, all or most of the time during the last week of life, is much compared to studies elsewhere - including Europe[118], the US[119], and Canada[120] - where about 50% of

---

[114] In the Ethicus study of 4,248 intensive care deaths in 17 European countries, both withholding and withdrawing life support – but not active life-ending procedures – occurred in 73% of patients (Sprung, Cohen, Sjokvist, et al., 2003). The Mater Hospital contributed to the Ethicus study and its results were published separately to show that 70% of patients who died in ICU in 1999/2000 had a decision made to withhold or withdraw life-sustaining therapy, but only 72% of these decisions were documented (Collins, Phelan, Marsh and Spring, 2006:317).

[115] Marie Curie Palliative Care Institute Liverpool, 2009:34-37.

[116] For example, inappropriate nursing interventions such as vital signs and blood sugar monitoring are not documented in a quarter of cases (Marie Curie Palliative Care Institute Liverpool, 2009:37). In the case of a patient's psychosocial and spiritual aspects of care – such as awareness of diagnosis, recognition of dying, religious and spiritual needs assessed – the extent of non-documentation is closer to a third (Marie Curie Palliative Care Institute Liverpool, 2009:45-46); discussing the plan of care with the patient was not documented in half the cases compared to a quarter in the case of relatives (Marie Curie Palliative Care Institute Liverpool, 2009:51). Equally, the extent to which the family were given information about hospital procedures or about bereavement is not documented in about half the cases. Adherence to hospital procedures for at the time of death and after ('last offices') is not documented in about half of all cases (Marie Curie Palliative Care Institute Liverpool, 2009:56-58).

[117] Marie Curie Palliative Care Institute Liverpool, 2009:34; see also Klinkenberg, Willems, van der Wal, and Deeg, 2004.

[118] 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

patients in long-term care experienced pain in the last week and, in half of these cases, the pain was categorised as daily.

Figure 7.2: Quality of Palliative Care: Pain Management

n = 737	Nurses	Doctors	Agreement on Level of Pain (Scale 1-4)
Patient had pain all or most of the time	16%	10%	48%
Management of patient's pain (Score 1- 10)	8.3	7.8	43%

The audit also asked nurses and doctors to rate – on a 10-point scale from very badly (1) to excellent (10) - how well these symptoms were managed by the hospital team to keep the patient comfortable. The level of agreement between the responses of nurses and doctors on symptom management falls to 42%, on average, and indicates that, in the majority of cases, there is no agreement on whether the patient was kept comfortable (Figure 7.2 and Table 1.6). In practice, this means that, in the case of patients with pain all or most of the time, for example, there is a less than even chance of agreement that this was well managed.

If symptoms are experienced all or most of the time, it seems reasonable to infer that the patient is uncomfortable and that the symptoms are not being properly managed; the converse, where symptoms are experienced none or some of the time, is less clear cut but might be described as relatively comfortable. Using this standard, the results show that most patients are kept relatively comfortable, although nurses are somewhat less likely to rate patients as being relatively comfortable compared to doctors (Tables 7.2aN and 7.2aD). Most patients are kept relatively comfortable with respect to nausea (94-95%), pain (84-90%), anxiety (87-89%), restlessness (83-85%), and secretions (80-83%), but much fewer are kept relatively comfortable with breathing (60-65%). Further analysis reveals that cancer patients are more likely to experience pain, those diagnosed with a respiratory disease are, understandably, more likely to have breathing difficulties, and patients diagnosed with frailty / dementia are least likely to experience anxiety.

It is useful to compare how the symptoms of these patients are managed by comparison with those on the Liverpool Care Pathway (LCP) in England where 75% were assessed as comfortable in these symptom areas, falling to 62% in the case of

---

pain, but not necessarily lead to quantitative and qualitatively better (pharmacological) treatment' See also Finne-Soveri, et al, 2000.

[119] Sawyer, et al, 2007. This study, based on 27,628 Alabama nursing home residents found 45% had pain in the last week. See also Zyczkowska, et al, 2007.

[120] 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.

bowel care[121]. None of the acute hospitals in the audit use the LCP, but it is used by St. Vincent's University Hospital in Dublin. With the exception of breathing difficulties, these results suggest that patients who die in Irish hospitals may be kept as comfortable as patients who died in English hospitals using the Liverpool Care Pathway (LCP).

7.3 Summary

This section found that nurses and doctors make a substantial number of decisions, six on average, about the end-of-life care of their patients. However, in a significant minority of cases, the responses of nurses and doctors do not agree on whether a decision was made, or on whether it was documented. Decisions are made – and are more likely to be made if the patients have cancer or respiratory diseases - in areas such as reviewing whether the aim of care is curative or palliative, optimising comfort, stopping non-essential medication, and talking about resuscitation. By contrast, decisions are made in less than half of all cases to stop invasive monitoring, stop antibiotics, withhold or withdraw treatment, even when death is expected. This contrasts with the practice in English hospitals using the Liverpool Care Pathway (LCP) where, in the vast majority of cases, decisions are made to discontinue blood tests (91%), antibiotics (89%), IV fluids / medications (83%), do not resuscitate (94%) and inappropriate nursing interventions such as vital signs and blood sugar monitoring (75%). Similarly, although decisions to withhold or withdraw life support are taken more frequently in intensive care compared to other wards, they are much less frequent compared to the practice in other European countries.

Decisions by doctors and nurses tend to be documented in about three quarters of cases. This is lower than the rate of documenting medical decisions about patients on the LCP in English hospitals, but broadly similar to the rate for documenting non-medical decisions on the LCP.

The diagnosis and management of symptoms – particularly the 5-6 key symptoms that many patients experience in the last days and hours of life such as pain, nausea, breathing difficulties, increased secretions, restlessness, and anxiety – is central to palliative care. The average level of agreement between the responses of nurses and doctors on the frequency (50%) and management (42%) of these symptoms is low.
The audit reveals that, during the last week of life, 80-90% of patients are kept relatively comfortable – defined as experiencing a symptom some or none of the time - with respect to pain, nausea, anxiety, restlessness, and secretions, but fewer were kept comfortable with their breathing (60-65%). In the national audit of patients on the LCP in English hospitals, about 75% were assessed as comfortable in these symptom areas. In general, both nurses and doctors gave relatively high ratings to the hospital team for its management of these symptoms.

Overall, these results suggest that nurses and doctors are oriented to the end-of-life needs of patients and, as they perceive it, maintain a level of comfort for patients that is comparable to the experience of English patients on the LCP. However there is significant disagreement between the responses of nurses and doctors on what palliative care decisions were made and documented, and substantially more

---

[121] Marie Curie Palliative Care Institute Liverpool, 2009:40-42. Based on 3,893 patients in 115 English hospitals who died between October and December 2008. Note that the assessment of comfort in the LCP involved six assessments over a 24 hour period, one every four hours (Ibid:67), and is clearly a much more in-depth assessment compared to the retrospective assessment of doctors and nurses used in this audit.

disagreement on the frequency and management of the patient's symptoms. This inevitably raises a series of questions about the different standards – whether objective or subjective, explicit or implicit – being used to assess and treat patients, the extent of dialogue between nurses and doctors about these matters, the manner in which decisions are made and documented, the implications for treatment of diagnosing symptoms differently, and the true quality of care and comfort provided to patients where the level of agreement between nurses and doctors is less than the level of disagreement. More specific questions about palliative care are suggested by the apparent reluctance of doctors and nurses, relative to best practice elsewhere, to withhold or withdraw certain types of monitoring and treatment, and whether this may be due to the absence of clear practice guidelines. Finally, the documentation of medical decisions leaves considerable room for improvement in light of the importance of documentation for ensuring that all members of the hospital team have a clear and consistent approach to patient's end-of-life needs.

8 Specialist Palliative Care Services

The purpose of specialist palliative care, as defined by the National Advisory Committee on Palliative Care, is ‘the continuing active total care of patients and their families, at a time when the medical expectation is no longer cure. Palliative care responds to physical, psychological, social and spiritual needs, and extends to support in bereavement’[122]. The National Advisory Committee recommended that, in the acute hospital sector, ‘patients should be referred to the specialist palliative care team for advice on symptom control, psychosocial support and problems relating to quality of life. The function of the specialist palliative care team is to act as a role model, sharing its knowledge and skills with hospital teams, and not to de-skill members of the ward team by taking over care’[123]. A number of studies have documented how palliative care improves the quality of living and dying for patients with advanced disease[124].

The audit reveals that a majority of patients did not receive specialist palliative care. The proportion of patients who actually received it varies from 22% according to doctors to 32% according to nurses, which is a substantial 10-percentage point difference of opinion (Figure 8.1; Tables 1.7, 8.1N and 8.1D). This suggests that there may be some misunderstanding between – and within – nurses and doctors as to what exactly is specialist palliative care. Leaving aside these differences, the proportion of patients who received specialist palliative care is higher compared to UK hospitals (19%)[125], and much higher compared to French hospitals where, according to one study, ‘only 12.1% had a palliative care consultation‘[126]. The exception to this is A&E and ICU Departments, where the audit reveals that specialist palliative care services are consulted in only 3-6% of cases respectively.

Given that a specialist palliative care service is known to be available within the hospital for the vast majority of patients (87%), it is important to inquire why so few received it. The main reason is that between 29% and 35% of patients (according nurses and doctors respectively) would not have benefited from it. Equally significant is the fact that, in over a quarter of cases (26% according to nurses and 29% according to doctors), it is not known if the patient would have benefited. In a relatively small proportion of cases (14%), the patient would have benefited from specialist palliative care but did not receive it. However the responses of nurses and doctors agree in only 44% of these cases as to the reason why the patient did not receive specialist palliative care.

---

[122] National Advisory Committee on Palliative Care, 2001:20. This committee was set up by the Minister for Health and Children in 1999 and its report was published in 2001. This report, in turn, has been adopted as government policy. The committees recommendations on acute general hospitals are in Chapter Seven (pp.57-70) of the report while the recommendations on community hospitals are in Chapter Eight (pp.89-90).

[123] National Advisory Committee on Palliative Care, 2001:81.

[124] Casarett, Pickard, Bailey, et al, 2008; Ferrand, Jabre, Vincent-Genod, et al, 2008; Cohen, Boston, and Mount, 2001; Stromgren, Sjogren, Goldschmidt, et al, 2005.

[125] In a UK study carried out by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD), a sub-sample of deaths (1,478) was analysed and there was no involvement by a palliative care team in 81% of cases (National Confidential Enquiry into Patient Outcome and Death, 2009:94). Commenting on this, the report states: ‘While the sample of patients included in this study may not be representative of all who were admitted with palliative intent, the paucity of input from palliative care teams may be indicative of the lack of co-ordinated end of life care in acute hospitals’ (Ibid:94-95).

[126] Ferrand, Jabre, Vincent-Genod, et al, 2008:870. This study was based on 3,793 patients who died in 200 French hospitals in 2004.

Figure 8.1: Specialist Palliative Care (SPC) for Patient

n = 737	Nurses	Doctors	Agreement
Patient received SPC	32%	22%	(Scale 1-2) 82%
No SPC, but patient would have benefited	14%	14%	(Scale 1-3) 44% n = 469
No SPC, but patient would not have benefited	29%	35%	
No SPC, but don't know if patient would have benefited	26%	29%	

These findings are open to a variety of interpretations, some of which could include: that there is not a common understanding of what specialist palliative care actually means; that there is lack of information about the role of specialist palliative care; that the palliative care needs of these patients were not been properly assessed; that nurses and doctors have different perceptions of when a patient requires a specialist palliative care service; that there is no systematic procedure for calling upon the expertise of the specialist palliative care team when a diagnosis of dying is made. Further analysis and reflection is needed within each hospital on the reasons and implications of this finding.

Despite discrepancies in the perception of specialist palliative care services, there is consensus that it is more likely to be offered in acute hospitals, to cancer patients, to those whose death is expected, to patients under 65 years, to those who spend a week or more in hospital, and to patients in single rooms (Table 8.2aN and 8.2aD).

There is a time-lag between the diagnosis of dying and the introduction of specialist palliative care in up to half the patients who receive it (Tables 8.3a-bN to 8.3a-bD). This too is open to the range of possible interpretations suggested above. Given that the average length of time between the diagnosis of dying and death is relatively short – 5-6 days (Table 4.2N and 4.2D) – this delay means that some patients who might have benefited from specialist palliative care do not.

The input of specialist palliative care services tends to follow a 'bimodal' pattern with over half the patients receiving a relatively short input of less than a week and the remainder receiving an input of up to a month. However, the latter group of patients – mainly younger, long-stay, dying of cancer - absorb a substantial amount of time and account for the relatively high average duration of specialist palliative care input per patient, at 10-12 days.

These findings suggest that there is a lack of clarity and consensus about the role of specialist palliative care within hospitals. This is reflected in the different perceptions by nurses and doctors about what constitutes specialist palliative care, and the fact that it is not known if a substantial minority of patients could have benefited from this service. It is clear that the specialist palliative care service in hospital is not routinely consulted when a diagnosis of dying is made, and even when consulted, there is often a delay between the diagnosis of dying and the input of specialist palliative care. This lack of clarity may be organisational as well as conceptual, possibly indicating the need for additional guidelines about what should happen when a diagnosis of dying is made. It is clear that specialist palliative care services are not playing the full role envisaged within acute hospitals by the National Advisory Committee on Palliative Care[127], and its predominant focus is still on cancer patients[128].

---

[127] This is especially the case with the recommendation that: ‘patients should be referred to the specialist palliative care team for advice on symptom control, psychosocial support and problems relating to quality of life. The functions of the specialist palliative care team is to act as a role model, sharing its knowledge and skills with hospital teams, and not to de-skill members of the ward team by taking over care’ (National Advisory Committee on Palliative Care, 2001:81).

[128] It is increasingly recognised that the need for specialist palliative care arises for patients other than those with cancer. A recent report estimated that, when the needs of patients with heart failure, dementia and chronic obstructive pulmonary disease are added to those with cancer, the estimated number of patients requiring specialist palliative care ‘would increase by at least 50%’ (Health Service Executive and Irish Hospice Foundation, 2008:2).

9 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 as intrinsically valuable as life itself and, 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[129]. One of the established, and recommended[130], instruments for measuring this is the Quality of Dying and Death Instrument (QODD)[131]. 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 here), and a 22-item version was self-administered by bereaved relatives (and reported separately in report Three). 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.

The total QODD score, based on nurses assessment of 999 deaths, is 72.4 (SD 14.6)[132] (Tables 9.1-9.6). This falls within the range set by two US studies[133], based on nurses' assessment of deaths in ICU, which yielded total QODD scores of 66.9 (SD 16.3)[134] and 73.2 (SD 21.4)[135]. It is true that the sample of deaths in the audit is much larger than either of these studies (38 and 149 deaths respectively), but the standard deviation in the audit is smaller than either which may suggest a

---

[129] 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).

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

[131] 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).

[132] 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.

[133] 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.

[134] Levy, Ely, Payne, Engelberg, Patrick and Curtis, 2005.

[135] Hodde, Engelberg, Treece, Steinberg, and Curtis, 2004.

consistency in the quality of dying across Irish hospitals, or a consistency in now nurses perceive the quality of dying, or maybe both.

As indicated, QODD covers the physical and psychological symptoms of personal well-being as well as relationship well-being such as spending time with loved ones. When these two dimensions are separated, it emerges that the total QODD score for personal well-being (66.5; SD 17.8) is considerably less than the score for relationship well-being (77.8; SD 14.6) (Figure 9.1; Table 9.5-9.6). This suggests that the main challenges for Irish patients during the last week of life are physical and psychological. The converse is also true in that relationship well-being is a major source of comfort and support to these patients in their last week. This is consistent with the findings of one other QODD study[136]. It is also consistent with two other results of the audit. First, the weaker physical and psychological well-being of patients is consistent with the questions raised about the effectiveness of the hospital team in diagnosing and managing the 5-6 key symptoms associated with dying, reflected in the low levels of agreement between the responses of nurses and doctors on these symptoms and the absence of decisions that are normally associated with good palliative care (Section 7). Second, the higher relational well-being of patients is consistent with substantial supports offered by hospitals to facilitate the involvement of family and friends, including the greater ease which staff seem to have with relatives compared to patients (Sections 5 and 6).

Some the physical challenges facing dying patients are indicated by the high prevalence of patients who, for most or all of the time, do not have the energy to do things (87%), show little or no sign of enjoyment (65%), have breathing difficulties (31%), and have difficulty eating or drinking (16%). At the same time, patients appear to be greatly comforted by aspects of their relationship such spending most or all of the time with children (79%) and friends (78%), or simply knowing that loved ones are there (88%). 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 patient's quality of life does not seem to be influenced by either the number of treatment decisions made by hospital staff or the receipt of specialist palliative care.

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 the patient to spend as much time as they wish with family and friends in their last days. At the same time, the results suggest there is scope for improving personal well-being through a more skilful use of palliative care, drawing upon the resources of specialist palliative care. In line with other studies, the audit underlines the importance of a holistic approach to personal well-being which addresses psychological as well as physical symptoms[137].

---

[136] 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).

[137] 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

10 Quality of Care

The quality of care was measured using a five-item subscale taken from the Family Evaluation of Hospice Care (FEHC)[138]. Nurses and doctors were asked to assess how well the hospital team provided different aspects of care such as: communication with patient, providing respectful care to the patient, and managing the patient's symptoms; communication with the family, and giving emotional support to the family. Each of these five aspects were rated on a 10-point scale, from 1 (not well) to 10 (very well).

In addition, we borrowed a question from a study of dying in French hospitals[139] which involved asking nurses, doctors and relatives to rate the acceptability to them and their family or friends, of how the patient died in hospital. This too was based on a 10-point scale, from 1 (definitely not acceptable) to 10 (very acceptable).

We now report the results from both nurses and doctors. However the interpretation of these results poses particular challenges since, in the majority of cases, there is no agreement between the responses of nurses and doctors on either the quality of care provided to patients (only 44% agreement) or the acceptability of the how the patient died (only 40% agreement).

10.1 Quality of Care

The five-item subscale in the FEHC involved asking nurses, doctors and relatives to rate, on a scale from 1 to 10, how well the hospital team: (i) communicated with the patient (ii) provided care that respected the patient's wishes (iii) communicated with relatives (iv) managed the patient's symptoms and (v) gave emotional support to the family. The results of the audit reveal an average score of 8.1 out of 10 for nurses and 8.4 out of 10 for doctors (Figure 10.1; Tables 10.1N and 10.1D). 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, on these five items, averages 9.4 out of 10, with relatively little variation between items or hospices[140]. This suggests, as might be expected, that the quality of care in Irish

---

(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 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).

[138] 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).

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

[140] 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

hospitals is below that offered by hospices[141]. Given that hospices offer a recognised standard for end-of-life care, this result indicates the margin of improvement that hospitals need to make to reach that standard.

Figure 10.1: Quality of Care of Patients

n = 737	Nurses	Doctors	Agreement (Scale 1-4)
Total quality of care (Score of 1-10)	8.1	8.4	44%
Quality of communication with patient (Score of 1-10)	7.0	7.7	34%
Quality of communication with relative (Score of 1-10)	8.7	8.7	52%
An acceptable way to die? (Score of 1-2)	87%	95%	40%

Further analysis of the data reveals that the lowest rating, by both nurses and doctors, was given for communication with the patient (7.0 and 7.7 respectively) and the highest was for communication with relatives (8.7 for both nurses and doctors). This is consistent with the communication patterns described above (Sections 5 and 6 above) where hospital staff were – understandably in some cases given the condition of the patient - much more likely to discuss patient issues with relatives than with patients (96% compared to 55%) but - perhaps less understandably - were more likely to document discussions with relatives than with patients (83% compared to 76%), had better communication with relatives than with patients (rated 8.5 compared to 7.3 out of 10), and were more likely to meet the wishes of relatives than of patients (8.3 compared to 6.8 out of 10).

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 quality of care suggests that, when sampling error is taken into account, the patient's quality of life does not seem to be influenced by either the number of treatment decisions made by hospital staff or the receipt of specialist palliative care (Tables 10.2N and 10.2D). Similarly, there is little variation in quality of care between wards, rooms, diagnosis, or length of stay, or the patient's age and sex.

---

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).

[141] 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).

10.2 Acceptability of Way Patient Died

The audit asked nurses, doctors and relatives to rate the acceptability, to them and their family or friends, of how the patient died in hospital. As indicated above, the results are challenging to interpret since there is no agreement between the responses of nurses and doctors in 60% of cases.

Nurses and doctors respectively rated the acceptability of deaths in the audit, at 7.4 and 8.3 out of 10 respectively (Figure 10.1; Tables 10.3bN and 10.3bD). Conversely, nurses rated over a tenth (13%) of all deaths as unacceptable to them, nearly three times the rate of deaths that were unacceptable to doctors (5%) (Tables 10.3cN and 10.3cD). 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, over four times higher than the rate of unacceptable deaths in Ireland[142].

A significant finding is that deaths were much more likely to be judged, by both nurses and doctors, as being unacceptable, where the patient did not receive a specialist palliative care service but could have benefited from it (Tables 10.3cN and 10.3cD). 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[143].

10.3 Summary

The quality of care was measured by a subscale of the Family Evaluation of Hospice Care (FEHC) and indicates a relatively high self-assessed quality of care 8.1 and 8.4 out of 10 for nurses and doctors respectively. This is lower than the average score of 9.4 out of 10 for US hospices, the main source of comparative data, but consistent with the finding that end-of-life care is better in hospices than in hospitals. The audit found that the lowest rating was given for communication with the patient and the highest was for communication with relatives. The relatively high quality of care is also indicated by the fact that a minority of nurses (13%) and doctors (5%) found the death of their patients personally unacceptable, a low figure by comparison with a much larger French study where 58% of nurses found the deaths of their patients unacceptable.

Overall, the quality of care for patients who die in Irish hospital appears reasonably good. However, the fact that the responses of nurses and doctors are more likely to disagree than agree on what constitutes good quality care is sufficient to raise questions about the underlying standards of care – objective or subjective, explicit or implicit – which are being used to make these assessments. It also raises questions about the extent of dialogue between nurses and doctors on what constitutes good

---

[142] 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.

[143] '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 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).

quality end-of-life care and what is an acceptable death. As such, the findings could be seen as an invitation for nurses and doctors to collectively reflect on the quality of care being provided to dying patients by their ward and hospital. This reflection might also consider why communication with the patient - the core relationship of care within the hospital - is the weakest aspect of care, and consistently below the quality of communication with relatives, and whether staff are always 'seeing the person in the patient'[144]. Given that these assessments always have an 'objective' as well as a 'subjective' dimension, the results are also an invitation for deeper reflection on how nurses and doctors empathise[145] and interact[146] with patients, and the extent to which this relationship is informed by – or infused with – compassion[147]. Within the hospital generally, there is also an invitation in these findings to reflect on how specialist palliative care services can play a fuller role in the care of dying patients given that a minority of patients are dying in unacceptable ways because they did not receive this service. The high ratings given by nurses and doctors for the quality of care to patients may be a positive indicator of staff morale – reflecting the sense of a job well done - but they also contain a challenge to complacency since it is clear that substantial improvements are not only possible but desirable and even urgent.

---

144 Goodrich and Cornwell, 2008.

145 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).

146 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).

147 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'.

11 Moment of Death and After

The moment of death, and its immediate aftermath, is significant for those present, especially the patient's relatives. Some may feel the need to mark the moment in a ritual way, others may wish to spend time with their deceased relative, all are likely to need some information and advice about what happens next, and finally, all will probably want to collect the personal belongings of the deceased patients. Those aspects of the time immediately after death are explored in this section.

11.1 Presence of Relatives and Staff

The presence of family members at the time of death can be important for the dying patient as much as for the relatives[148]. The audit revealed that relatives or friends were present for two thirds of the deaths (65%), and possibly more since there is no information in nearly a fifth of cases (18%) (Table 11.1a-b). This is much higher compared to a study of dying in French hospitals where only a quarter had family or friends present[149]. Hospital staff were present at three quarters of the deaths (75%) while pastoral care tended to be present immediately after the death in about half the cases (47%), and possibly more since there is a large proportion with no information (22%).

Figure 11.1: Persons Present at Moment of Death

(n = 999)	Present
Relatives	65%
Staff	75%
Anyone	75%
Staff had time to be available for relatives	80%

Overall it is known that someone was present – either family or staff – for the moment of death in three quarters of cases (75%) but it is unknown who, if anyone, was present in the remaining one quarter. In the French study just cited, no one was present at the patient's death in 16% of cases[150].

11.2 Rituals

The audit asked if any rituals were held around the body immediately after death (Table 11.2a-b). The main ritual is that hospital staff offer sympathy (91%) and tea (87%) to the family in about nine out of ten cases; prayers are usually said (81%), candles are frequently lit (69%), and there is a moment of silence in over half the

---

[148] As noted above, a study of ICU patients based on the QODD 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).

[149] Ferrand, Jabre, Vincent-Genod, et al, 2008:Table 3.

[150] Ferrand, Jabre, Vincent-Genod, et al, 2008:Table 3.

cases (53%). Generally speaking, nurses are unaware of what rituals are held when the body is being taken away to the mortuary, possibly because this is usually done by a porter (89%) rather than nurses (15%) (Table 11.3).

11.3 Time with the patient

In the vast majority of cases (94%), relatives were given all the time they needed to be with the patient immediately after death (Table 11.4). However a significant minority of staff (20%) may not have had enough time to be available for the relatives immediately after death.

11.4 Information and advice

There are significant gaps in the type of information and advice offered to relatives at the time of the patient's death. In a substantial minority of cases, nurses seemed to be unaware about what types of information and advice were offered, possibly because there is not a standardised approach to this in the ward or hospital (Table 11.5a-b). The most frequent information offered to relatives was about moving the body to the mortuary (73%) and collecting the patient's personal belongings (73%). However only four in ten were told about mortuary access and viewing times (39%), and most were not advised about how the deceased patient may be taken home (43%), about arranging the funeral (48%), or how to register the death (20%). Similarly, less than a third of GPs were informed about the patient's death (32%) (Table 11.6), similar to the pattern found in English hospitals[151]. In general, community hospitals provide more information and advice than acute hospitals and, within acute hospitals, A&E tends to offer more than other wards, although the number of deaths there is relatively small compared to other wards (Table 11.5c).

11.5 Death Certificate

From a relative's perspective, the death notification form issued by the hospital, following certification of death by the doctor, is a formal public acknowledgement that the death has occurred[152]. The audit reveals that most nurses are not informed about this process, and only one in ten (10%) were able to indicate how much time elapsed between the patient's death and the issuing of a death notification form (Table 11.7). Those who know this information indicated that, on average, it takes 2.8 days for the hospital to issue a death notification form, but it could take up to a maximum of 18 days.

11.6 Personal belongings

Responsibility for gathering the patient's personal belongings usually falls to the nurse (63%) or healthcare assistant (13%) (Table 11.7). However, in nearly a fifth of cases (19%), the personal belongings were gathered by the relative. Personal belongings are usually held in a bag supplied by the patient or relative (43%), or in a hand-over bag supplied by the hospital (21%) (Table 11.8). However it is significant

---

[151] The results of an audit of the Liverpool Care Pathway (LCP) – based on 3,893 patients in 115 hospitals who died between October and December 2008 –shows that the GP was informed in 31% of cases (Marie Curie Palliative Care Institute Liverpool, 2009: 52).

[152] Note that the death notification form must be presented at the local General Register Office – usually referred to as the registrar for births, deaths and marriages - before a death certificate can be issued (see www.groireland.ie).

that plastic bags are used in over a fifth of cases (21%), given that some relatives and staff may find this lacks dignity and respect for the deceased patient.

11.7 Summary

This section examined what happens at the moment of death and its immediate aftermath. The audit found that relatives or friends were present for two thirds of the deaths (65%), much higher than in a recent French study where only a quarter of hospital deaths (24%) had a family or friends present. The main ritual immediately following death is for hospital staff to offer sympathy (91%) and tea (87%) to the family. In the vast majority of cases (94%), relatives are given all the time they need to be with the patient, but a significant minority of hospital staff (20%) may not have had enough time to be available for the relatives at this time.

There seem to be significant gaps in the type of information and advice offered to relatives at the time of the patient's death, reflecting the absence of a standardised approach. Most nurses were unable to state if the patient's death had been certified of if a death notification form had been issued by the hospital. The personal belongings of patients are usually handed over in a bag supplied by the patient or relative (43%) or in a hand-over bag supplied by the hospital (21%), but plastic bags are used in a significant minority of cases (21%).

Overall, the moment of death tends to take place in the presence of hospital staff and relatives and to be dignified by the ritual of prayers and the offer of sympathy and tea. However the reality of hospital life, especially in the acute sector, tends to make itself felt in the fact that a significant minority of staff do not have enough time to be available for relatives, and most relatives were not told about mortuary access and viewing times, how the deceased may be taken home, or how to register the death. This suggests that hospitals and wards could give more thought to the manner in which the moment of death and its aftermath is properly honoured and protected so that staff and relatives have adequate time to be present at that moment, and to address whatever personal and practical matters arise. This would require a clearer acknowledgement of the symbolic importance of the moment of death, and an encouragement for staff to see that time is available to be with relatives at this time. At a practical level, hospital staff, but especially nurses, could be supported by having an information pack that would answer all of the main queries that typically arise for relatives at this time.

The moment of death and its aftermath also reveals the workings of the hospital system in microcosm. This system needs to issue death certificates and inform GPs that their patient has died. However the system for tracking these processes does not seem to include nurses in the 'information-loop'. This provides an opportunity for hospitals – and the HSE more generally – to examine the requirements of an IT system which would simultaneously operate as a check that key tasks around the death of patients have been done, and that key staff have been informed that these tasks has been done.

12 Reviewing Deaths and Supporting Staff

It is recognised that opportunities for hospital staff to reflect regularly on their work can contribute to both quality improvement and self-care[153]. For this reason, the audit examined the extent to which staff in wards took, or were given, an opportunity to review how the patient's death was managed. The results indicate that a ward-level review of the patient's death takes place in half of all cases (51%), and these seem mainly to involve an informal discussion with peers (Figure 12.1; Table 12.1a-c). However there is a substantial level of 'no information' about whether the review was formal or informal (about 40%) and this leaves some doubt as to what type of review actually took place in many cases. Nevertheless it would appear that a formal review facilitated by a senior member of ward staff is relatively rare (13%).

A significant minority of staff felt very upset at the death of a patient (21%). However few of these staff (15%) are known to have had an opportunity to talk about how the patient's death affected them. This suggests a relatively low level of support for staff, similar to the situation in Northern Ireland[154]. This suggests that supports for staff – whether through peers, multidisciplinary teams, or management – are either not in place, or are not known to staff.

Figure 12.1: Ward Review of Death and Supports for Staff

n = 999	Staff
Any ward-level review	51%
Review type: informal discussion with peers	44%
Review type: formal discussion with senior staff	13%
Staff very upset at death	21%
Staff who were very upset had opportunity to talk	3%

Overall, the practice of reviewing how deaths are managed in wards is uneven and highly informal, with little evidence of senior staff taking a leadership role in facilitating these reviews. It is possible that the culture and practice in many wards does not include space for such ward-level reviews, and there may be no tradition or structure for reviewing how the ward managed the dying and death of a particular patient. Equally, the support structures for staff, particularly where a patient's death was very upsetting, are highly informal with little information about whether or not

---

[153] This is one of the thirteen standards in Australian palliative care : 'Staff and volunteers reflect on practice and initiate and maintain effective self-care strategies' (Palliative Care Australia, 2008:7). It is also one of the top ten quality markers in the UK end-of-life strategy: 'Monitor the quality and outputs of end of life care' (Department of Health, 2009:11).

[154] This emerges from an audit of dying, death and bereavement in Northern Ireland hospitals and hospices, which included a survey of 1,632 hospital staff. According to this survey, relatively few staff perceive that supports are in place for: case review / critical incident analysis (27%), de-briefing following traumatic situations with either peers (21%), or the multi-professional team (14%). (Northern Ireland Health and Social Care Bereavement Network, 2009:55).

staff find the support they need at these times. In view of this there is merit in further examining how a process for reviewing deaths in each ward could be of benefit to staff – and ultimately to patients and families - and how this might be structured to provide opportunities for staff support and learning.

13 Conclusions and Issues for Consideration

A key finding of the audit is that, in many respects, the quality of end-of-life care in Irish hospitals compares favourably with that reported by hospitals elsewhere. For example, the diagnosis of dying seems to be made more frequently here than in French hospitals and earlier than in English hospitals. Similarly, patients who die in Irish hospitals seem to be kept as comfortable as patients who die in English hospitals using the Liverpool Care Pathway (LCP). Also, deaths are more likely to be rated as acceptable by nurses and doctors compared to deaths in French hospitals. The quality of life of patients, and the quality of care offered to them and their relatives, are broadly comparable to that reported in other studies. In light of this, it is reasonable to infer that dying in an Irish hospital is probably not very different to dying in a comparable hospital in the US, the UK, or France, the main countries for which we have comparative data.

Despite this relatively positive picture, deeper analysis of the data – not usually found in other studies or audits - gives rise to more unsettling insights. This emerges when the responses of nurses and doctors are compared on a patient-by-patient basis rather than simply comparing averages. Equally, it emerges when comparisons are made between the different patterns of staff communication with patients and relatives.

Beginning with nurses and doctors, the results show that while both groups give relatively high ratings for their diagnosis and management of the main symptoms associated with dying - pain, nausea, breathlessness, secretions, restlessness, and anxiety - there is only 50% of agreement between their responses on the frequency of these symptoms, and only 40% agreement on how well they were managed. Equally worrying is the fact that, in their assessment of the quality of care offered to patients and relatives, their responses agree in 40% of cases only. The same applies to ratings on the acceptability of how the patient died.

These findings inevitably raise questions about the different standards – whether objective or subjective, explicit or implicit – which nurses and doctors are using to assess and treat patients, the extent of dialogue between them about these matters, the manner in which decisions are made and documented, the implications for treatment of diagnosing symptoms differently, and the true quality of care and comfort provided to patients.

Equally challenging are the findings on the different patterns of staff communication with patients and relatives. For example, hospital staff are – understandably in some cases given the condition of the patient - more likely to discuss issues with relatives than with patients. Perhaps less understandably, they were more likely to document their discussions with relatives than with patients, to rate the quality of communication with relatives as better than with patients, and more likely to meet the wishes of relatives than of patients. In their assessment of the quality of care, both nurses and doctors rate their communication with the patient - the core relationship of care within the hospital - as the weakest aspect of care, and consistently below the quality of communication with relatives.

These findings give ground for reflecting on whether Irish hospitals maintain an appropriate balance between the needs and rights of patients on the one hand and those of relatives on the other. Equally open for reflection is the question, particularly regarding end-of-life, of whether hospital staff may feel more comfortable with, and attach greater importance to, the views of relatives over patients, bearing in mind relatives have the power to complain which dying patients do not[155].

The findings of the audit therefore raise a wide range of issues that require reflection and attention at all levels of the hospitals from individual staff, wards, management, and the HSE more generally. Far from encouraging complacency, these results challenge and invite hospitals to engage in a deeper examination of the care that is offered to patients at the end of life, and to take action to improve it, as appropriate and possible. In order to facilitate this, we set out 14 of the most important issues that have emerged from the audit.

13.1 Admission and Discharge in Acute Hospitals

The end-of-life journey of patients who die in acute hospital takes place in a health system which, by and large, does not operate a planned approach to admission or discharge from acute hospital. Most patients who die in acute hospital are admitted through A&E, even though many would have been patients of the hospital already, with already-diagnosed conditions. This suggests that there is a discontinuity in the health system between primary and acute care on the one hand, and between different episodes of acute care on the other. Similarly, the absence of a planned approach to discharge is clearly indicated by the fact that, in the opinion of nurses and doctors, about a fifth of patients who die in acute hospitals could have died at home if appropriate supports were available. In addition, patients who die in acute hospitals in Ireland spend much longer there compared to patients who die in acute hospitals elsewhere in the US or the UK. These considerations suggest that the end-of-life journeys of patients could be improved if their needs and preferences were placed at the heart of the health system, and if admissions and discharges from acute hospital were planned in a more holistic manner. This would require a more person-centred approach to health care provision and a coordinated continuum of care options – involving hospitals, hospices, nursing homes, community services, and home-based supports - that are managed to facilitate the needs and preferences of patients[156].

---

155 These questions are also opened up by the results of the audit of the Liverpool Care Pathway (LCP) – based on 3,893 patients in 115 hospitals who died between October and December 2008 – which shows that relatives are much more likely than patients to be aware of the patient's diagnosis (79% compared to 50%), to recognise that the patient is dying (76% compared to 40%); and to have had the patient's care plan explained (72% compared to 30%) (Marie Curie Palliative Care Institute Liverpool, 2009: 45-51). The commentary on the first round of the LCP audit seems to acknowledge and endorse, perhaps unwittingly, that this result may indicate greater importance being attached to the views of relatives over patients: 'This suggests that healthcare professionals are more comfortable in assessing the insight of carers which is encouraging as the Healthcare Commission Report 'Spotlight on Complaints' (2007) illustrates that many complaints arise from carers being unprepared for the patient's death' (Marie Curie Palliative Care Institute Liverpool, 2007:43).

156 It is important to acknowledge that this is already part of the vision of the CEO of the HSE as outlined in the introduction to the 2009 National Service Plan: '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).

13.2 Alternatives to Dying in Acute Hospitals

The audit reveals that over a fifth of acute hospital patients, in the opinion of nurses and doctors, could have died at home if appropriate supports were available. This has significant implications in terms of meeting patient needs and preferences, and the associated cost. In terms of preferences, it is known that a majority of Irish people would prefer to die at home[157] and, interestingly, doctors and nurses also have a stronger preference to die at home compared to patients[158]. In addition, there is evidence 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[159].

In terms of cost, there is 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[160]. If our finding - that over a fifth of acute hospital patients could have died at home - is extrapolated to the acute hospital sector in Ireland, we estimate that over €80 million[161] could be made available for end-of-life care in non-acute settings through more appropriate care for people approaching the end of their life. 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

---

[157] 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).

[158] 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.

[159] 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).

[160] 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).

[161] 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 60,255 bed days by these patients. The cost of these bed days, in turn, is approximately €82.6 million.

cost more than the current pattern of hospital-based care’[162] This approach is consistent with the HSE’s five-year development framework for palliative care services (2009-2013) which acknowledges that: ‘identification of appropriate funding may be achieved through a combination of the following: reorientation and reconfiguration of existing resources, to be undertaken in partnership with all relevant stakeholders, including both the statutory and voluntary sectors; identification of additional resource requirements when further funding comes on-stream’[163].

13.3 Improving the Physical Environment of Hospitals

Hospital staff make considerable efforts to facilitate patients to die in a single room despite competing demands for the limited stock of these rooms. As a result, about four in ten patients die in a single room, considerably less than in Northern Ireland. Independent healthcare consultants have pointed out that physical facilities in Irish hospitals are not always conducive to dignity, privacy or control of the environment, but staff and management consistently adopt a more positive view, and rate their end-of-life facilities highly, including more highly than their counterparts in Northern Ireland. This tendency to over-rate the physical environment of hospitals may be due to a lack of awareness about what is possible and desirable in terms of evidence-based design in hospitals. Whatever the reason, the results suggest that in order to build momentum for improving the physical environment of hospitals, it may be necessary to first raise awareness among management and staff about how Irish hospitals compare to best practice elsewhere, so that the need for improvement becomes more obvious, and the motivation to make those improvements becomes stronger.

13.4 Addressing Inconsistencies in Care of Patients

The audit revealed significant inconsistencies in the care of patients that do not seem to be related to their end-of-life needs. For example, in cases where there is a diagnosis of dying, there are substantial inconsistencies in terms of whether this is documented which, in turn, affects the likelihood of subsequent care. Similarly, there are inconsistencies in holding team meetings, in making and documenting palliative care decisions, in making referrals to specialist palliative care, as well as inconsistencies in terms of involving and supporting relatives. Of potentially greater significance is the low level of agreement between the responses of nurses and doctors on the frequency and management of six key symptoms associated with end-

---

[162] 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).

[163] HSE Palliative Care Services – Five Year Development Framework 2009-2013, 2009.

of-life: pain, nausea, breathlessness, secretions, restlessness and anxiety. These inconsistencies suggest that the care of patients at the end of life is marked by the absence of agreed standards and procedures. By virtue of that, the audit also highlights the case for introducing standards and procedures as soon as possible. This is a major undertaking and will only be successful if accompanied by a process which changes existing practices, and actively promotes excellence in end-of-life care.

13.5 Documentation on Patients

The audit suggests that key information about patients – such as the diagnosis of dying, patient’s wishes and worries, decisions about palliative care – are documented in only three quarters of cases, at most. The uneven quality of documentation is further illustrated by the fact that, in a substantial minority of cases, the responses of nurses and doctors do not agree if a particular item of patient information has been documented. Given that the diagnosis of dying, and subsequent palliative care decisions, are fundamental to patient care, the uneven pattern of documentation should be seen in the context of other audit findings, notably that patients whose diagnosis is undocumented are less likely to be offered a single room and these patients, in turn, are less likely to receive a specialist palliative service. Similarly, staff communication with patients is documented less frequently compared to communication with relatives and, although patients express fewer wishes and worries compared to relatives, they also have less wishes and worries documented.

These results suggest that existing practices for documenting discussions with patients and relatives, including their wishes and worries, may fall short of the HSE’s standards for the management of healthcare records, particularly the criteria that: ‘all relevant communication with patients and families shall be documented in the relevant part of the healthcare record’[164] and ‘the involvement of the patient in decisions about his or her care shall be documented in the record under ‘patient wishes’’[165]. Given that documentation is essential to supporting a consistent approach to patient care across the hospital team – and is itself an indicator of quality of care[166] - it is possible that if a patient’s wishes are not documented they may not addressed, and this is particularly significant for the three main wishes expressed by patients: pain control, pastoral / spiritual care, and not to be resuscitated. This suggests the need for some strengthening of procedures for documenting the needs and preferences of patients.

13.6 Team Meetings about Patients

The audit reveals that considerable flexibility and informality exists around the holding of, and attendance at, team meetings in hospital, and there is clearly no standardised procedure for reporting the outcome of meetings to patients and

---

[164] HSE National Hospitals Office, 2008:30.

[165] HSE National Hospitals Office, 2008:31. The overall standard on the content of the healthcare record states: ‘The content of the healthcare record shall provide an accurate chronology of events and all significant consultations, assessments, observations, decisions, interventions and outcomes. The content of each record shall comply with clinical guidance provided by professional bodies and legal guidance provided by the Clinical Indemnity Scheme. This standard shall apply to both hardcopy and electronic documentation’ (page 20).

[166] One study - based on 3,793 patients who died in 200 French hospitals in 2004 – found that nurses were more likely to perceive a patient’s death as acceptable if the patient’s wishes about treatment were documented (Ferrand, Jabre, Vincent-Genod, et al, 2008:Table 4).

relatives. This is suggested not just by the responses of doctors and nurses but also by the fact that these responses disagree on whether the meeting actually took place in up to a third of cases. The fact that the frequency of team meetings varies by ward (being more frequent in oncology and geriatric wards) and diagnostic category (being more frequent for cancer patients) suggests that a team approach to patient care, where it exists, may be more influenced by the work practices of different disciplines and wards rather than by a standardised approach to planning the end-of-life care of patients. This, in turn, invites reflection within hospitals on existing procedures for holding team meetings, and the role of these meetings in planning for the end-of-life care of patients.

13.7 Communication with Patients

Hospital staff engage, wherever possible, in extensive discussions with patients about end-of-life and try to elicit their wishes and worries. It is reassuring that nurses give relatively high ratings to both the quality of staff communication with patients and the hospital's response to patients' wishes, though less reassuring that these ratings are consistently lower than for relatives. These results reflect the 'objective' qualities of the communication but also the 'subjective' qualities of how nurses perceive it, bearing in mind that these two aspects are not easy to separate. However, if one focuses on the 'subjective' aspect of these ratings, what is striking is their relative uniformity across different wards and patient types. Even the natural human variability in communication skills would suggest that a wider range of scores might have been expected[167]. This finding invites reflection on whether there is scope for hospital staff - nurses, doctors and other health care professionals - to be more self-critical about their communication with patients, and to recognise weaknesses as well as strengths since, paradoxically, there is more strength in acknowledging weakness than not. This process would also involve deeper reflection on how hospital staff empathise[168] and interact[169] with patients, and the extent to which this relationship is

---

[167] This interpretation is supported by results from the Older Persons National Practice Development Programme in Ireland where nurses self-ratings of the 'practice context' were higher at baseline than midway through the programme, indicating that as the programme unfolded there was a 'more realistic reflection of the existing practice context' (McCormack and Wright, 2009).

[168] 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).

[169] 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

informed by – or infused with – compassion[170]. From the perspective of end-of-life care, it might also involve reflection on the way staff communicate with patients which may itself be influenced by their fear of dying and death[171]. This in turn prompts the question as to whether hospitals can create more opportunities to allow staff – especially those in direct contact with patients - to reflect on their communication practices and how they respond to patient needs.

13.8 Balancing the Needs of Patients and Relatives

Hospital staff, particularly where there is a diagnosis of dying, attach high priority to the involvement of relatives, addressing their wishes, and facilitating their access to the patient. Nurses rate highly their discussions with relatives and efforts to meet their wishes, and this is a positive indication of family involvement. However, as already indicated, it is noteworthy that discussions with relatives are more likely to be documented than discussions with patients, staff rate their communication with relatives more highly than with patients, while also rating more highly their capacity to meet the wishes of relatives. Indeed, in their overall assessment of the quality of care, both nurses and doctors rate communication with the patient - the core relationship of care within the hospital - as the weakest aspect of care, and consistently below the quality of communication with relatives.

---

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).

[170] 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'.

[171] 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).

This pattern of communication has some similarities to that found in English hospitals which use the Liverpool Care Pathway (LCP)[172]. It is also consistent with another Irish study which identified a tendency among health care professionals to 'speak with families of older people, as opposed to the older individuals themselves, regarding treatment and services'[173]. These findings give ground for reflecting on how hospital staff balance the needs and rights of patients and relatives, the importance of protecting patient autonomy, and the overall place of a patient-centred approach in end-of-life care. Equally open for reflection, particularly regarding end-of-life, is the question of whether hospital staff may feel more comfortable with, and attach greater importance to, the views of relatives over patients, as indeed another Irish study has shown[174]. Is it even possible that these patterns of communication reflect, however unconsciously, the fact that relatives have a power to complain which dying patients do not[175].

13.9 Quality of Palliative Care

The audit suggest that nurses and doctors are oriented to the end-of-life needs of patients and, as they perceive it, maintain a level of comfort for patients that seems comparable to the experience of English patients on the LCP. However there is some disagreement between the responses of nurses and doctors on what palliative care decisions are actually made and documented, and substantial disagreement on the diagnosis and management of the patient's symptoms. This suggests that the self-assessed quality of palliative care offered by nurses and doctors may not match their actual behaviour, since this level of disagreement is scarcely compatible with an accurate assessment of patient needs, or with good quality palliative care[176].

---

[172] The results of a national audit of patients on the Liverpool Care Pathway LCP – based on 3,893 patients in 115 hospitals who died between October and December 2008 – showed that patients were less likely to be aware of their diagnosis (50%, compared to 79% of relatives), to recognise that they were dying (40%, compared to 76% of relatives), or to have their care plan explained to them (30%, compared to 72% of relatives). (Marie Curie Palliative Care Institute Liverpool, 2009:45-54).

[173] McGlone and Fitzgerald, 2005:72.

[174] This study identified a tendency among health care professionals to 'speak with families of older people, as opposed to the older individuals themselves, regarding treatment and services' (McGlone and Fitzgerald, 2005:72).

[175] These questions are also opened up by the results of the audit of the Liverpool Care Pathway (LCP) – based on 3,893 patients in 115 hospitals who died between October and December 2008 – which shows that relatives are much more likely than patients to be aware of the patient's diagnosis (79% compared to 50%), to recognise that the patient is dying (76% compared to 40%); and to have had the patient's care plan explained (72% compared to 30%) (Marie Curie Palliative Care Institute Liverpool, 2009: 45-51). The commentary on the first round of the LCP audit seems to acknowledge and endorse, perhaps unwittingly, that this result may indicate greater importance being attached to the views of relatives over patients: 'This suggests that healthcare professionals are more comfortable in assessing the insight of carers which is encouraging as the Healthcare Commission Report 'Spotlight on Complaints' (2007) illustrates that many complaints arise from carers being unprepared for the patient's death' (Marie Curie Palliative Care Institute Liverpool, 2007:43).

[176] Palliative care has been described as an 'interdisciplinary speciality that focuses on improving quality of life for patients with advanced illness and for their families through pain and symptom management, communication and support for medical decisions concordant with goals of care, and assurance of safe transitions between care settings' (Morrison, et al, 2008). According to the World Health Organisation, 'palliative care has the following characteristics: provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patients illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications'. Available at http://www.who.int/cancer/palliative/en/. Accessed 18 March 2009.

This inevitably raises a series of questions about the different standards – whether objective or subjective, explicit or implicit – being used to assess and treat patients, the manner in which decisions are made and documented, the implications for treatment of diagnosing symptoms differently, the extent of dialogue between nurses and patients about patients, and the true quality of care and comfort provided to patients. More specific questions about palliative care are also suggested by the apparent reluctance of doctors and nurses, relative to best practice elsewhere, to withhold or withdraw certain types of monitoring and treatment from patients who have been diagnosed as dying. It is a core principle of palliative care that, where patients have been diagnosed as beyond cure and entering the dying phase, hospital staff are expected to re-orient their care towards comfort and the control of symptoms. That is also the clear guidance of the Irish Medical Council to its doctors: 'Where death is imminent, it is the responsibility of the doctor to take care that the sick person dies with dignity, in comfort, and with as little suffering as possible. In these circumstances a doctor is not obliged to initiate or maintain treatment which is futile or disproportionately burdensome'[177].

Overall, these considerations suggest that nurses and doctors would benefit from having a much clearer set of standards-based procedures which outline precisely the steps to be taken and documented when a patient is diagnosed as dying, including the frequency of these steps until the patient has died. Naturally, these formal procedures cannot replace the intuitive and instinctual intelligence which is required to care for patents, or the sense of empathy and compassion which leads nurses and doctors to care for a 'person' and not just a 'patient'. For that reason, a standards-based approach to improving palliative care needs to be accompanied by an education programme which cultivates this natural awareness, intelligence and compassion of nurses and doctors, and which ensures that a more standardised approach to end-of-life care is also a more caring approach.

These considerations suggest that nurses and doctors would benefit from jointly participating in an education programme on all aspects of end-of-life care, particularly around the implementation of common standards and practices on how, and how frequently, to assess the 5-6 key symptoms associated with dying including: sensitively asking patients about their symptoms – especially pain - and listening carefully to what they have to say; documenting the patient experience using a common record as part of an integrated pathway for dying; improving mechanisms for team-working including regular reviews of how the patient's death is being handled; and understanding the role of specialist palliative care services in supporting nurses and doctors to deliver end-of-life care. Ideally, and as envisaged by the National Advisory Committee on Palliative Care, this type of education programme would be undertaken by the specialist palliative care team in each hospital[178].

---

177 Irish Medical Council, 2004:Paragraph 23.1. The Law Reform Commission considered this ethical guidance in the context of its report on advance care directives and made the following comment: 'The Commission considers that this guidance deals correctly with a difficult ethical matter in a manner that is also consistent with existing criminal law on euthanasia' (Law Reform Commission, 2009:Paragraph 1.78, page 34).

178 It is clear that this type of education programme needs to have a strong practical and professional dimension. However it is unlikely to succeed unless it also has a strong personal dimension which focuses on creating awareness among nurses and doctors of their own natural capacities to care, empathise, and interact with patients and how these has been influenced by their professional socialisation (See Janssen, Macleod and Walker, 2008).

13.10 Specialist Palliative Care Services

The purpose of specialist palliative care, as defined by the National Advisory Committee on Palliative Care, is ‘the continuing active total care of patients and their families, at a time when the medical expectation is no longer cure. Palliative care responds to physical, psychological, social and spiritual needs, and extends to support in bereavement’[179]. The National Advisory Committee recommended that, in the acute hospital sector, ‘patients should be referred to the specialist palliative care team for advice on symptom control, psychosocial support and problems relating to quality of life. The functions of the specialist palliative care team is to act as a role model, sharing its knowledge and skills with hospital teams, and not to de-skill members of the ward team by taking over care’[180]. A number of studies have documented how palliative care improves the quality of living and dying for patients with advanced disease[181].

The audit suggests that there is a lack of clarity and consensus about the role of specialist palliative care services within hospitals. This is reflected in different perceptions by nurses and doctors about whether some patients received specialist palliative care, and the fact that it is not known if a substantial minority of patients could have benefited from this service. It is clear that the specialist palliative care services are not routinely consulted when a diagnosis of dying is made, and even when consulted, there is often a delay between the diagnosis of dying and the input of specialist palliative care. In the case of A&E and ICU Departments, specialist palliative care services are rarely consulted. This lack of clarity may be organisational as well as conceptual, possibly indicating the need for additional guidelines about what should happen when a diagnosis of dying is made. It is clear from the audit that specialist palliative care services are not playing the full role envisaged within acute hospitals by the National Advisory Committee on Palliative Care, and its predominant focus is still on cancer patients.

13.11 Improving the Quality of Living and Dying

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[182]. The results of the audit – based on the Quality of Dying and Death Instrument (QODD) - suggest that the quality of dying in Irish hospitals is reasonably good and compares favourably with the limited number of QODD-based studies elsewhere. A significant finding is that relationship well-being (as measured by spending time with loved ones) 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

---

[179] National Advisory Committee on Palliative Care, 2001:20. This committee was set up by the Minister for Health and Children in 1999 and its report was published in 2001. This report, in turn, has been adopted as government policy. The committees recommendations on acute general hospitals are in Chapter Seven (pp.57-70) of the report while the recommendations on community hospitals are in Chapter Eight (pp.89-90).

[180] National Advisory Committee on Palliative Care, 2001:81.

[181] Casarett, Pickard, Bailey, et al, 2008; Ferrand, Jabre, Vincent-Genod, et al, 2008; Cohen, Boston, and Mount, 2001; Stromgren, Sjogren, Goldschmidt, et al, 2005.

[182] 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).

the patient in their last days. At the same time, the results also suggest there is scope for improving personal well-being (as measured by physical and psychological symptoms) by using the resources of specialist palliative care to assist decision-making and the overall responsiveness to patient needs. The audit, in line with other studies, underlines the importance of a holistic approach to personal well-being which addresses psychological as well as physical symptoms[183].

13.12 Honouring the Moment of Death and After

The moment of death tends to take place in the presence of hospital staff and relatives, and to be dignified by the ritual of prayers and the offer of sympathy and tea. However the reality for a significant minority of patients is that up to a quarter seem to die alone. Similarly up to a fifth of staff indicated that they did not have enough time to be available for relatives. There is also considerable scope for improving the information offered to relatives about things like mortuary access and viewing times, how the deceased may be taken home, or how to register the death. This suggests that hospitals and wards could give more thought to the manner in which the moment of death and its aftermath is properly honoured and protected so that staff and relatives have adequate time to be present at that moment, and to address whatever personal and practical matters arise. This would require a clearer acknowledgement of the symbolic importance of the moment of death, and an encouragement for staff to see that time is available to be with the patient and their family at this time. At a practical level, hospital staff, but especially nurses, could be supported by having an information pack that would answer all of the main queries that typically arise for relatives at this time.

13.13 Supporting Staff

The audit revealed that support structures for staff, particularly where a patient's death is very upsetting, are highly informal. Staff who are very upset at the death of a patient – comprising about a fifth of nurses – typically do not have an opportunity to talk about it within the hospital. This suggests that, whatever formal support structures may be in place within the hospital, they are not well known or used. This finding suggests that hospitals may need to look at their staff support systems, and their accessibility to staff at times of particular need.

13.14 Reviewing Deaths

The practice of reviewing how deaths are managed in wards is uneven and highly informal, with little evidence of senior staff taking a leadership role in facilitating these

---

[183] 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 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).

reviews. It is possible that the culture and practice in many wards does not include space for such ward-level reviews, and there appears to be no tradition or structure for reviewing how the ward managed the dying and death of a particular patient. In view of this there is merit in further examining how a process for reviewing deaths at ward level ward could be of benefit to staff – and ultimately to patients and families - and how this might be structured to provide opportunities for staff support and learning.

13.15 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, in many respects, the quality of end-of-life care in Irish hospitals compares favourably with that reported by hospitals elsewhere. Despite being as good as elsewhere, it is not nearly good enough since the audit has revealed significant and substantial inconsistencies in the care offered to patients which raise challenging questions about the standards of care, the day-to-day procedures for managing patient needs, and the true quality of care and comfort being experienced by patients. These questions are a challenge to any complacency since it is clear that substantial improvements are not only possible but desirable and even urgent.

14 Bibliography

Abel, J., Rich, A., Griffin, T., and Purdy, S.,2009. 'End-of-life care in hospital: a descriptive study of all inpatient deaths in 1 year', Palliative Medicine, 28 May.

Achterberg, WP., Gambassi, G., Finne-Soveri, H, Liperoti, R., Noro, A., Frijters, DHM., Cherubine, A., Dell'Aquila, G., and Ribbe, MW., 2009. 'Pain in European long-term care facilities: Cross-national study in Finland, Italy and the Netherlands', Pain, doi:10.1016/j.pain.2009.10.008.

Addicott, R., and Dewar, S., 2008. Improving choice at end of life: A descriptive analysis of the impact and costs of The Marie Curie Delivering Choice Programme in Lincolnshire, London: King's Fund. Available at www.kingsfund.org.ul/publications. Accessed on 14 October 2009.

Addington-Hall, JM., et al, 1992. 'Randomised Control Trial of effects of coordinating care for terminally ill caner patients', BMJ, Vol 305, pp.1317-1322.

Addington-Hall, J., and O'Callaghan, AC., 2009. 'A comparison of the quality of care provided to cancer patients in the UK in the last three months of life in in-patient hospices compared to hospitals, from the perspective of bereaved relatives: results from a survey using the VOICES questionnaire', Palliative Medicine, 23, pp.190-197.

Ainsworth, MDS., 1991. 'Attachments and other Affectional Bonds Across the Life Cycle', in Parkes, CM., Stevenson-Hindle, J., and Marris, P., (Editors), Attachment Across the Life Cycle, pp.33-51, New York: Tavistock/Routledge.

Angus, DC., Barnato, AE., Linde-Zwirble, WT., et al., 2004. 'Use of intensive care at the end of life in the United States: an epidemiologic study'. Crit Care Med, 32: 638-43.

Baker, R., Wu, A.W., Teno, J.M., Kreling, B., Damiano, A.M., Rubin, H.R., Roach, M.J., Wenger, N.S., Phillips, R.S., Desbiens, N.A., Connors, A.F., Jr., Knaus, W., & Lynn, J., 2000. 'Family satisfaction with end-of-life care in seriously ill hospitalized adults'. Journal of the American Geriatrics Society, 48(5 Suppl), S61-9.

Bate, P., Mendel, P., and Robert, G., 2008. Organizing for Quality: The Improvement Journeys of Leading Hospitals in Europe and the United States: Oxford: Radcliffe Publishing.

Bjornberg, A., Cebolla Garrofe, B., and Lindblad,A., 2009. European Healthcare Consumer Survey Index 2009: Report, Health Consumer Powerhouse. Available at www. healthpowerhouse.se. Accessed on 26 March 2010.

Bondestam, E., Hovgren, K., Gaston Johansson, F., Jern, S., Herlitz, J., and Holmberg, S., 1987. 'Pain assessment by patients and nurses in the early phase of acute myocardial infarction'. J Adv Nurs, Nov, 12(6):677-82.

Bowlby, J., 1979. The Making and Breaking of Affectional Bonds, London: Tavistock.

Bruera, E., Willey, JS., Ewert-Flannagan, PA., Cline, MK., Kaur, G, Shen, L., Zhang, T., and Palmer, JL., 2005. 'Pain intensity assessment by bedside nurses and palliative care consultants: a retrospective study'. Support Care Cancer, Apr, 13(4):228-31.

Budischewski, KM., de la Fuente, F., Nierhoff, CE., Mose, S., 2006. 'The burden of pain of inpatients undergoing radiotherapy – discrepancies in the ratings of physicians and nurses'. Onkologie, Oct, 29(10):431-5.

Casarett, D., Pickard, A., Bailey, FA., et al., 2008. 'Do palliative consultations improve patient outcomes?' Journal of American Geriatric Society, 56(4), 593-599.

Census 2006, 2007. Principal Demographic Results, March, Dublin: Stationery Office.

Chanvej, L., Petpichetchian, W., Kovitwanawong, N, Chaibandit, C., Vorakul, C., Khunthong, T., 2004. 'A chart audit of postoperative pain assessment and documentation: the first step to implement pain assessment as the fifth vital sign in a University Hospital in Thailand', J Med Assoc Thai, Dec, 87(12):1447-53.

Cohen, SR., Boston, P., and Mount, BM., 2001. 'Changes in quality of life following admission to palliative care units', Palliative Medicine, 15(5), 363-371.

Collins, N., Phelan, D., Marsh, B., and Sprung, CL., 2006. 'End-of-life care in the intensive care unit: the Irish Ethicus data', Critical Care and Resuscitation, Volume 8, Number 4, December, pp.315-320.

Commission on Patient Safety and Quality Assurance, 2008. Building a Culture of Patient Safety, July, Dublin: Stationery Office. Available at www.doh.ie

Connor, S. R., Teno, J., Spence, C., & Smith, N., 2005. 'Family evaluation of hospice care: results from voluntary submission of data via website'. Journal of Pain and Symptom Management, 30(1), 9-17.

Copeland, G., 2005. A Practical Handbook for Clinical Audit, March, Published at: http://www.evidence.nhs.uk

Cornwell, J., and Goodrich, J., 2009. 'Exploring how to enable compassionate care in hospital to improve patient experience', 21 April, www.nursing times.net.

Cornwell, J., 2009. 'Exploring how to improve patients' experience in hospital at both national and local levels', 6 July, www.nursing times.net.

Coulehan, J.L., Platt, F.W., Egener, B., et al., 2001. 'Words that help build empathy'. Annals of Internal Medicine, 135, 221–227.

Curtis, J. R., Patrick, D. L., Engelberg, R. A., Norris, K., Asp, C., & Byock, I., 2002. 'A measure of the quality of dying and death. Initial validation using after-death interviews with family members'. J Pain Symptom Manage, 24(1), 17-31.

Davoudi, N., Afsharzadeh, P., Mohammadalizadeh, S., and Haghdoost, AA., 2008. 'A comparison of patients' and nurses' assessment of pain intensity in patients with coronary artery disease', Int J Nurs Pract. October 14(5):347-56.

Department of Health, 2008. End of Life Care Strategy: Promoting high quality care for all adults at the end of life, July, January, London: Department of Health. Available at: **http://www.dh.gov.uk/en/Publicationsandstatistics/index.htm.** Accessed 30 May 2009.

Department of Health, 2009. End of Life Care Strategy: Quality Markers and measures for end of life care, June, January, London: Department of Health. Available at: **http://www.dh.gov.uk/en/Publicationsandstatistics/index.htm.** Accessed 30 May 2009.

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

Ferrand, E., Jabre, P., Vincent-Genod, C., et al, 2008. 'Circumstances of Death in Hospitalized Patients and Nurses' Perceptions', Arch Intern Med, 168(8), 28 April, 867-875.

Finne-Soveri, UH., Ljunggren, G., Schroll, M., Jonsson, P.V., Hjaltadottir, I., El Kholy, K., and Tilvis, RS., 2000. 'Pain and its association with disability in the institutional long-term care in four Nordic countries', Can J Aging 19, pp. S38–S49.

Firth-Cozens, J., and Cornwell, J., 2009. The Point of Care: Enabling compassionate care in acute hospital settings, April, London: The King's Fund. Available at: www.kingsfund.org.uk/publications.

Fries, BE., Simon, SE., Morris, JN., Flodstrom, C., and Bookstein, FL., 2001. 'Pain in U.S. nursing homes: validating a pain scale for the minimum data set', Gerontologist 41, pp. 73–179.

Edmonds, P., & Rogers, A., 2003. 'If only someone had told me . . .' A review of the care of patients dying in hospital'. Clinical Medicine, 3(2), 149-52.

Gilbert, D., 2006. Stumbling on Happiness, New York: Knopf.

Goodrich, J., and Cornwell, J., 2008. Seeing the Person in the Patient: The Point of Care review paper, November, London: The King's Fund. Available from: www.kingsfund.org.uk/publications Accessed on 8 September 2009.

Goodrich, J., 2009. 'Exploring the wide range of terminology used to describe care that is patient-centred'. Nursing Times.net, 19 May. Available at: http://www.nursingtimes.net/nursing-practice-clinical-research/acute-care/exploring-the-wide-range-of-terminology-used-to-describe-care-that-is-patient-centred/5001746.article. Accessed 24 August 2009.

Grossman, SA., Sheidler, VR., Swedeen, K., Mucenski, J., Piantadosi, S., 1991. 'Correlation of patient and caregiver ratings of cancer pain', J Pain Symptom Manage, Feb, 6(2):53-7.

Harvey, S., Liddell, A., and McMahon, L., 2009. Windmill 2009: NHS response to the financial storm, London: The King's Fund. Available from: www.kingsfund.org.uk/publications Accessed on 18 December 2009.

Health Service Executive and Irish Hospice Foundation, 2008. Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks, June, . Available at: http://www.hospice-foundation.ie and http://www.hse.ie Accessed on 8 June 2009.

HSE Audit of Palliative Care Service Provision, 2007, Dublin: Health Service Executive. Available at: http://www.hse.ie/eng/services/Publications/corporate/palframework.html Accessed on 5 October 2009.

HSE National Service Plan 2009, 2008. November. Dublin: Health Services Executive. Available at: http://www.hse.ie/eng/Publications/corporate/National_Service_Plan_2009.pdf Accessed on 5 October 2009.

HSE Palliative Care Services – Five Year Development Framework 2009-2013, 2009. Dublin: Health Service Executive. Available at: http://www.hse.ie/eng/services/Publications/corporate/palframework.html Accessed on 5 October 2009.

Hearn, J., and Higginson, IJ., - Palliative Care Audit Project Group, 1999. 'Development and validation of a core outcome measure for palliative care: The palliative care outcome scale', Quality in Health Care, Vol 8, pp.219-227.

Heyland, D.K., Groll, D., Rocker, G., Dodek, P., Gafni, A., Tranmer, J., Pichora, D., Lazar, N., Kutsogiannis, J., Shortt, S., & Lam, M., 2005. 'End-of-life care in acute care hospitals in Canada: a quality finish?' Journal of Palliative Care, 21(3), 142-50.

Hodges, M., London, M.R., & Lundstedt, J., 2006. 'Family-driven quality improvement in inpatient end-of-life care'. Journal for Healthcare Quality, 28(2), 20-6, 31.

Hodde, N. M., Engelberg, R. A., Treece, P. D., Steinberg, K. P., & Curtis, J. R., 2004. 'Factors associated with nurse assessment of the quality of dying and death in the intensive care unit'. Crit Care Med, 32(8), 1648-1653.

Hojat, M., Gonnella, J.S., Nasca, T.J., et al. 2002. 'Physician empathy: Definition, components, measurement, and relationship to gender and specialty'. American Journal of Psychiatry, 159, 1563–1569.

Horton, R., 2002. 'Differences in assessment of symptoms and quality of life between patients with advanced cancer and their specialist palliative care nurses in a home care setting', Palliative Medicine, Nov, 16(6):488-94.

Hospice Friendly Hospitals Programme, 2010. Quality Standards for End-of-Life Care in Hospitals, May, Dublin: Irish Hospice Foundation. Available at http://www.hospicefriendlyhospitals.net.

Hospice Friendly Hospitals Programme, 2008. Design and Dignity Guidelines for Physical Environments of Hospitals Supporting End-of-Life Care, June, Dublin: Irish Hospice Foundation. Available at http://www.hospicefriendlyhospitals.net.

Hospice Friendly Hospitals Programme, 2007. Design and Dignity Baseline Review, November, Dublin: Irish Hospice Foundation. Available at http://www.hospicefriendlyhospitals.net.

Hospital In-Patient Enquiry, 2006. December, Dublin: Economic and Social Research Institute.

HSE National Hospitals Office, 2008. Code of Practice for Healthcare Records Management, October, Available at www.hse.ie Accessed on 16 October 2009.

Irish Life Tables No. 15, 2009. 29 January, Dublin: Central Statistics Office. Available at: http://www.cso.ie/releasespublications/documents/births_d_m/current/irishlife.pdf. Accessed 24 August 2009.

Irish Medical Council, 2004. A Guide to Ethical Conduct and Behaviour, Dublin: Irish Medical Council.

Irvine, B., 1993. 'Developments in palliative nursing in and out of the hospital setting'. British Journal of Nursing, 2(4), 218-20, 222-4.

Janssen, AL., Macleod, RD., and Walker, ST., 2008. 'Recognition, reflection, and role models: Critical elements in education about care in medicine', Palliative and Supportive Care (), 6, 389–395.

Keegan, O., McGee, H., Brady, T., Kunin, H., Hogan, M., O'Brien, S., and O'Siorain, 1999. Care for the Dying – Experiences and Challenges. A study of quality of health service care during the last year of life of patients at Saint James's Hospital, Dublin, from their relatives' perspective, February, Dublin: Royal College of Surgeons of Ireland and the Irish Hospital Foundation, and St. James's Hospital.

Keegan, O., McGee, H., Hogan, M., Kunin, H., O'Brien, S., & O'Siorain, L. 2001. 'Relatives views of health care in the last year of life'. International Journal of Palliative Nursing, 7(9), 449-456.

Keller, JA., and Kronick, K., 2008. 'Transforming care in children's hospitals through environmental design: Literature Review', in Evidence for Innovation: Transforming Children's Health Through the Physical Environment, Alexandra VA: National Association of Children's Hospitals and Associated Institutions, pp.18-47. Available at http://www.childrenshospitals.net Accessed on 26 May 2009.

Kendall, M., Harris, F., Boyd, K., Sheik, A., Murray, S., Brown, D., Mallinson, I., Kearney, N., and Woth, A., 2007. 'Key challenges and ways forward in researching the 'good death': qualitative in-depth interview and focus group study', BMJ, 334:521 (10 March).

Klinkenberg, M., Willems, DL., van del Wal, G., Degg, DJ., 2004. 'Symptom burden in the last week of life', Journal of Pain and Symptom Management, 27(1):5-13.

Kubler-Ross, E., 2009. On Death and Dying. What the Dying have to Teach Doctors, Nurses, Clergy, and their own Families. Fortieth Anniversary Edition, Oxon: Routledge.

Law Reform Commission, 2009. Bioethics: Advance Care Directives, Report, September, Dublin: Law Reform Commission,

Levy, CR., Ely, EW., Payne, K., Engelberg, RA., Patrick, DL., and Curtis, JR., 2005. 'Quality of Dying and Death in Two Medical ICUs', Chest, 127, 5, May, pp.1775-1783. Available from www.chestjournal.org

Lorenz K., Lynn, J., Morton, SC., Dy S., Mularski, R., Shugarman, L., Sun, V., Wilkinson, A., Maglione, M., Shekelle, PG., 2004. End-of-Life Care and Outcomes. Evidence Report/Technology Assessment No. 110. (Prepared by the Southern California Evidence-based Practice Center, under Contract No. 290-02-0003.) AHRQ Publication No. 05-E004-2. Rockville, MD: Agency for Healthcare Research and Quality. December 2004. Available at www.ncbi.nlm.nih.gov

Lunney JR, Lynn J, Hogan C., 2002. 'Profiles of Older Medicare Decedents', J Am Geriatr Soc, Vol. 50, No. 6, pp. 1108-1112.

Lynn J., Schuster JL., Kabcenell A., 2000. Improving Care for the End of Life: A Sourcebook for Health Care Managers and Clinicians, RAND , 2000.

Lynn J., Schall M. W., Milne C., Nolan K. M., Kabcenell A., 2000. 'Quality improvements in end-of-life care: Insights from two collaboratives'. Journal of Quality Improvement 26: (5) 254-267.

Lynn J., 2004. Sick to Death and Not Going to Take it Anymore! Reforming Health Care for the Last Years of Life, California/Milbank Books on Health and the Public, University of California Press, Berkeley, CA: 2004.

Macleod, R., and McPherson, KM., 2007. 'Care and compassion: Part of person-centred rehabilitation, inappropriate response or a forgotten art?', Disability and Rehabilitation, Ocotber-November, 29(20-21):1589-1595.

Marie Curie Palliative Care Institute Liverpool, 2007. National Care of the Dying Audit – Hospitals (NCDAH): Generic Report, 2006/2007, December, Liverpool: Marie Curie Palliative Care Institute. Available from www.mcpcil.org.uk

Marie Curie Palliative Care Institute Liverpool, 2009. National Care of the Dying Audit – Hospitals (NCDAH): Round 2, Generic Report, 2008/2009, September, Liverpool: Marie Curie Palliative Care Institute. Available from www.mcpcil.org.uk

McCormack, B., and Wright, J., 2009. The Implementation of a Model of Person Centred Practice in Older Person Settings: Interim Report, July, Newtownabbey Co. Antrim: University of Ulster.

McCarthy, S., and O'Boyle, C., 2010. Family Views of End-of-Life Care in Acute and Community Hospitals, Dublin: Royal College of Surgeons of Ireland and the Irish Hospice Foundation.

McGlone, E., and Fitzgerald, F., 2005. Perceptions on Ageism in Health and Social Services in Ireland, Report No. 85, Dublin: National Council on Ageing and Older People.

McKeown, K., 2008. National Audit of End-of-Life Care in Hospitals in Ireland, The Manual, October, Dublin: Irish Hospice Foundation. Available at http://www.hospicefriendlyhospitals.net

McKeown, K., Haase, T., and Twomey, S., 2010a. Resources and Facilities for End-of-Life Care in Irish Hospitals, National Audit Report 1, May, Dublin: Irish Hospice Foundation. Available at http://www.hospicefriendlyhospitals.net

McKeown, K., Haase, T., and Twomey, S., 2010b. Dying in Hospital in Ireland: Nurse and Doctor Perspectives, National Audit Report 2, May, Dublin: Irish Hospice Foundation. Available at http://www.hospicefriendlyhospitals.net

McKeown, K., Haase, T., and Twomey, S., 2010c. Dying in Hospital in Ireland: Family Perspectives, National Audit Report 3, May, Dublin: Irish Hospice Foundation. Available at http://www.hospicefriendlyhospitals.net

McKeown, K., Haase, T., and Twomey, S., 2010d. The Culture of End-of-Life Care in Hospital in Ireland, National Audit Report 4, May, Dublin: Irish Hospice Foundation. Available at http://www.hospicefriendlyhospitals.net

McKeown, K., Haase, T., Pratschke, J., Twomey, S., Donovan, H., and Engling, F., 2010. Dying in Hospital in Ireland: An Assessment of the Quality of Care in the Last Week of Life, May, National Audit Report 5, Dublin: Irish Hospice Foundation. Available at: http://www.hospicefriendlyhospitals.net

McPherson, GJ., and Addington-Hall, JM., 2003. 'Judging the quality of care at the end of life: can proxies provide reliable information?', Social Science and Medicine, 56, pp.95-109.

Martin-Moreno, J., Harris, M., Gorgojo, L., Clark, D., Normand, C., Centeno, C., 2008. Palliative Care in the European Union, Strasburg: European Parliament.

Martin, LA., Nelson, EC., Lloyd, RC., and Nolan, TW., 2007. Whole System Measures, Innovation Series 2007, Cambridge Massachusetts: Institute for Healthcare Improvement. Available at www.ihi.org.

Morris, JN., Murphy K., and Nonemaker, S., 1995. Long term care facility Resident Assessment Instrument (RAI) user's manual version 2.0, HCFA, Baltimore.

Morrison, RS., Penrod, JD., Cassel, JB., Caust-Ellenbogen, M., Litke, A., Spragens, L., Meier, DE., 2008. 'Cost Savings Associated with US Hospital Palliative Care Consultation Programs', Arch Intern Med, Volume 168, Number 16, 8 September.

Mularski, RA., Heine, CE., Osborne, ML., Ganzini, L., & Curtis, JR., 2005. 'Quality of dying in the ICU: ratings by family members'. Chest, 128(1), 280-287.

Mularski, RA., Curtis, JR., Osborne, ML.,, Engleberg, RA., and Ganzini, L., 2004. 'Agreement among family members in their assessment of the Quality of Dying and Death', Journal of Pain and Symptom Management, Vol 28, No 4, October, pp.3.6-315.

Mularski, RA., et al., 2007. 'A Systematic Review of Measures of End-of-Life Care and Its Outcomes', HSE: Health Services Research 42:5, October, 1848-1870.

Murphy, P., Kreling, B., Kathryn, E., Stevens, M., Lynn, J., & Dulac, J., 2000. 'Description of the SUPPORT intervention. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments'. Journal of the American Geriatrics Society, 48(5 Suppl), S154-61.

National Advisory Committee on Palliative Care, 2001. Report, Dublin: Department of Health & Children.

Nolan, A., 2007. 'Productive Ward: releasing time to care', Health Service Journal, 117, 6052, S1-S19.

National Audit Office, 2008. End of Life Care, Report by the Comptroller and Auditor General, November, London: The Stationery Office.

Northern Ireland Health and Social Care Bereavement Network, 2009. Northern Ireland Audit: Dying, Death and Bereavement, Policies, procedures and practices in hospital and hospice settings, Belfast: Department of Health, Social Services and Public Safety.

OECD, 2007. Health at a Glance 2007, November. Paris: OECD.

O'Keeffe, S. T., Noone, I., & Pillay, I., 2000. 'Telling the truth about cancer: views of elderly patients and their relatives'. Irish Medical Journal, 93(4), 104-105.

O'Mahony, S., McHenry, J., Blank, AE., Snow, D., Karakas, SE., Santoro, G., Selwyn, P. and Kvetan, V., 2009. 'Preliminary report on the integration of a palliative care team into an intensive care unit', Palliat Med OnlineFirst, 13 October, 0(00) 1-12.

PA Consulting Group, 2007. Acute Hospital Bed Capacity Review: A Preferred Health System in Ireland to 2020: Detailed Report, September, Dublin: Health Services Executive. Available at: http://www.hse.ie/eng/Publications/Hospitals/PA_Consulting_Acute_Hospital_Bed_Capacity_Review_2008.html. Accessed 20 March 2009

PA Consulting Group and Balance of Care Group, 2007. Acute Hospital Bed Review: A review of acute hospital bed use in hospitals in the Republic of Ireland with an Emergency Department, June, Dublin: Health Services Executive.

Palliative Care Australia, 2008. Standards for Providing Quality Palliative Care for all Australians, http://pallcare.org.au

Parsley, K., and Corrigan, P., 1999. Quality Improvement in Healthcare: Putting Evidence into Practice, Cheltenham, UK: Nelson Thornes Ltd.

Patrick, D. L., Engelberg, R. A., & Curtis, J. R., 2001. 'Evaluating the quality of dying and death'. J Pain Symptom Manage, 22(3), 717-726.

Picker Institute, 2005. A guide to the NHS patient survey programme, Oxford: Picker Institute. Available at: http://www.pickerinstitute.org/publications.html Accessed 3 August 2009.

Pincombe, J., Brown, M., & McCutcheon, H., 2003. 'No time for dying: a study of the care of dying patients in two acute care Australian hospitals'. Journal of Palliative Care, 19(2), 77-86.

Proctor, WR., and Hirdes, JP., 2001. 'Pain and cognitive status among nursing home residents in Canada', Pain Res Manage 6, pp. 119–125.

Puntillo, K., Miaskowski, C., Kehrle, K., Stannard, D., Gleeson, S., and Nye, P., 1997. ‘Relationship between behavioural and physiological indicators of pain, critical care patients’ self-reports of pain, and opioid administration’, Crit Care Med. Jul, 25(7):1159-66.

Puntillo, K., Neighbor, M, O’Neill, N., and Nixon, R., 2003. ‘Accuracy of emergency nurses in assessment of patients’ pain’, Pain Manag Nurs. Dec, 4(4):171-5.

Puntillo, K., Neighbor, M, Chan, GK., and Garbez, R., 2006. ‘The influence of chief complaint on opioid use in the emergency department’, J Opioid Manag. Jul-Aug, 2(4):228-35.

Quinlan, C., and O’Neill, C., 2009. Practitioners’ Perspectives on patient Autonomy at End of Life, November, Dublin: Hospice Friendly Hospitals Programme.

Rhodes, RL., Mitchell, SL., Miller, SC., Connor, SR., and Teno, JM., 2008. ‘Bereaved Family Members’ Evaluation of Hospice Care: What Factors Influence Overall Satisfaciton with Services?’, Journal of Pain and Symptom Management, Vol. 35, No. 4, April, pp.365-371.

Reinertsen,JL., Bisognano, M., Pugh, MD., 2008. Seven Leadership Leverage Points for Organization-Level Improvement in Health Care (Second Edition). IHI Innovation Series white paper. Cambridge, MA: Institute for Healthcare Improvement. Available on www.IHI.org.

Reynolds,W.J. & Scott, B., 2000. ‘Do nurses and other professional helpers normally display much empathy?’ Journal of Advanced Nursing, 31, 226–234.

Roter, D.L., Stewart, M., Putnam, S.M., et al., 1997. ‘Communication patterns of primary care physicians’, JAMA, 277, 350–356.

Sadler, BL., Keller, JA., and Rostenberg, B., 2009. Using Evidence-Based Environmental Design to Enhance Safety and Quality. Institute for Healthcare Improvement Innovation Series White Paper, Cambridge, Massachusetts: Institute for Healthcare Improvement. Available at www.IHI.org Accessed on 26 May 2009.

Sawyer, P., Lillis, P., Bodner, BS., and Allman, RM., 2007. ‘Substantial daily pain among nursing home residents’, J Am Med Dir Assoc 8, pp. 158–165.

Scally, G., and Donaldson, L., 1998. ‘Clinical governance and the drive for quality improvement in the new NHS in England’, *British Medical Journal,* 4 July, 317(7150): 61-65.

Seland, M., Kaasa, S., and Klepstad, P., 2005. ‘Symptoms assessment in cancer patients on admission to hospital’, Tidsskr Nor Laegeforen, Sep 22, 125(18):2500-3. [Article in Norwegian].

Sprung, CL., Cohen, SL., Sjokvist, P., et al., 2003. ‘End-of-life practices in European intensive care units. The Ethicus study’. JAMA, 290: 790-7.

Sprung, CL., Carmel, S., Sjokvist, P., et al., 2007. ‘Attitudes of European doctors, nurses, patients and families regarding end of life decisions’. The ETHICATT Study. Intensive Care Medicine, 33:104-110.

Stromgren, AS., Sjogren, P., Goldschmidt, D., et al., 2005. ‘A longitudinal study of palliative care: patient-evaluated outcome and impact of attrition’, Cancer, 103(8), 1747-1755.

Tang, ST., and Corkle, R., 2002. ‘Use of family proxies in quality of life research for cancer patients at the end of life: A literature review’, Cancer Invest, 20, pp.1086-1104.

Teno, JM., 2005. ‘Measuring End-of-Life Outcomes retrospectively?’, Journal of Palliative Medicine, Volume 8, Supplement 1, pp.S42-S49.

Teno, J. M., Clarridge, B., Casey, V., Edgman-Levitan, S., & Fowler, J., 2001. 'Validation of Toolkit After-Death Bereaved Family Member Interview', Journal of Pain & Symptom Management, 22(3), 752-758.

Tiernan, E., Connor, MO., Kearney, PM., and Siorain, L., 2002. 'A Prospective Study of Preferred Versus Actual Place of Death Among Patients Referred to a Palliative Care Home-care Service', Irish Medical Journal, Vol 95, Issue 8, September, pp.232-235.

Turner, M., 2009. 'HealthStat: measuring the performance of the Irish public health service', Journal of the Statistical and Social Inquiry Society of Ireland, Vol.38, 2008/09, pp.178-204.

UCD and Lansdowne Market Research, 2007. Insight 07: Health and Social Serivces in Ireland – A Survey of Consumer Satisfaction, Dublin: Health Services Executive. Available at http://www.hse.ie/eng/Publications/Your_Service,_Your_Say_Consumer_Affairs/Reports/Insight_07.pdf Accessed on 27 May 2009.

Ulrich, R., 2008. 'Design and Dignity: The Case for Renewing our Hospitals', Public Lecture in St. Ann's Church, Dawson St. Dublin, June. Available at http://www.hospicefriendlyhospitals.net

Ulrich, R., Zimring, C., Zhu X, et al, 2008. 'A review of the research literature on evidence-based health-care design', Health Environments Research and Design Journal, 1(3):61-125.

Vital Statistics, 2009. Annual Report for 2006, July, Dublin: Stationery Office.

Walters, G., 2004. 'Is there such a thing as a good death?', Palliative Medicine, 18:404-408.

Weafer & Associates Research with TNS MRBI, 2004. A nationwide survey of public attitudes and experiences regarding death and dying, November, Dublin: Hospice Friendly Hospitals Programme.

Weafer, J., McCarthy, J., and Loughrey, M, 2009. Exploring Death and Dying: The views of the Irish public, November, Dublin: Hospice Friendly Hospitals Programme.

Weafer, J., 2009. A Qualitative Study of Public Perceptions of End-of-Life Issues, September, Dublin: Hospice Friendly Hospitals Programme.

Wennberg, JE., Fisher, ES., Stukel, TA, Skinner, JS., Sharp, SM., and Bronner, KK., 2004. 'Use of hospitals, physician visits, and hospice care during last six months of life among cohorts loyal to highly respected hospitals in the United States', British Medical Journal, Volume 328, 13 March, pp.607-610.

Zyczkowska, J., Szczerbinska, K., Jantzi, MR., and Hirdes, JP., 2007. Pain among the oldest old in community and institutional settings, Pain 129, pp. 167–176.

15 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, Q4A1 refers to Question A1 in Questionnaire 4, Q5B2 refers to Question B2 in Questionnaire 5, 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 purple measure the level of agreement between the responses from nurses and doctors 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 Hospital	63	130	373	566	47	8.3
A02	Acute Hospital	60	84	304	448	44	9.8
A03	Acute Hospital	4	39	194	237	19	8.0
A04	Acute Hospital	0	16	73	89	20	22.5
A05	Acute Hospital	23	52	198	273	46	16.8
A06	Acute Hospital	21	32	116	169	43	25.4
A07	Acute Hospital	35	50	145	230	45	19.6
A08	Acute Hospital	27	71	331	429	50	11.7
A09	Acute Hospital	22	34	234	290	24	8.3
A10	Acute Hospital	133	194	606	933	48	5.1
A11	Acute Hospital	22	59	264	345	37	10.7
A12	Acute Hospital	119	164	501	784	33	4.2
A13	Acute Hospital	82	72	310	464	35	7.5
A14	Acute Hospital	29	79	208	316	37	11.7
A15	Acute Hospital	0	0	44	44	9	20.5
A16	Acute Hospital	14	28	98	140	27	19.3
A17	Acute Hospital	156	212	637	1005	50	5.0
A18	Acute Hospital	46	90	418	554	49	8.8
A19	Acute Hospital	9	50	153	212	39	18.4
A20	Acute Hospital	23	64	181	268	26	9.7
A21	Acute Hospital	67	112	278	457	42	9.2
A22	Acute Hospital	8	17	100	125	22	17.6
A23	Acute Hospital	52	70	183	305	49	16.1
A24	Acute Hospital	26	46	181	253	39	15.4
C50	Community Hospital				42	8	19.0
C51	Community Hospital				30	7	23.3
C52	Community Hospital				5	5	100.0
C53	Community Hospital				9	5	55.6
C54	Community Hospital				5	1	20.0
C55	Community Hospital				124	34	27.4
C56	Community Hospital				86	23	26.7
C57	Community Hospital				41	8	19.5
C58	Community Hospital				2	1	50.0
C59	Community Hospital				23	8	34.8
C60	Community Hospital				13	4	30.8
C61	Community Hospital				5	0	0.0
C62	Community Hospital				10	2	20.0
C63	Community Hospital				13	2	15.4
C64	Community Hospital				3	0	0.0
C65	Community Hospital				5	4	80.0
C66	Community Hospital				12	3	25.0
C67	Community Hospital				0	0	
C68	Community Hospital				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 Hospital	4	8	35	47	50	94
A02	Acute Hospital	3	8	33	44	50	88
A03	Acute Hospital		3	16	19	50	38
A04	Acute Hospital		3	17	20		
A05	Acute Hospital	3	8	35	46	50	92
A06	Acute Hospital	2	10	31	43	50	86
A07	Acute Hospital	1	8	36	45	50	90
A08	Acute Hospital	3	6	41	50	50	100
A09	Acute Hospital		5	19	24		
A10	Acute Hospital	5	9	34	48	50	96
A11	Acute Hospital	2	9	26	37	50	74
A12	Acute Hospital	3	6	24	33	50	66
A13	Acute Hospital	1	7	27	35	50	70
A14	Acute Hospital		13	24	37	50	74
A15	Acute Hospital			9	9		
A16	Acute Hospital		10	17	27		
A17	Acute Hospital	7	10	33	50	50	100
A18	Acute Hospital	3	11	35	49	50	98
A19	Acute Hospital	1	7	31	39	50	78
A20	Acute Hospital		6	20	26		
A21	Acute Hospital		7	35	42	50	84
A22	Acute Hospital	1	5	16	22		
A23	Acute Hospital	1	13	35	49	50	98
A24	Acute Hospital	1	8	30	39	50	78
C55	Community Hospital				34		
C56	Community Hospital				26		
C70	Community Hospital				31		
C80	Community Hospital				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 ID	Hospital	Total Returns	Quota *	Quota achieved %	matched returns	unmatched returns
A01	Acute Hospital	39	50	78	37	2
A02	Acute Hospital	32	50	64	28	4
A03	Acute Hospital	24	50	48	16	8
A04	Acute Hospital	20			19	1
A05	Acute Hospital	46	50	92	43	3
A06	Acute Hospital	23	50	46	19	4
A07	Acute Hospital	38	50	76	37	1
A08	Acute Hospital	28	50	56	28	0
A09	Acute Hospital	16			15	1
A10	Acute Hospital	43	50	86	42	1
A11	Acute Hospital	32	50	64	24	8
A12	Acute Hospital	25	50	50	21	4
A13	Acute Hospital	37	50	74	26	11
A14	Acute Hospital	35	50	70	28	7
A15	Acute Hospital	8			7	1
A16	Acute Hospital	32			19	13
A17	Acute Hospital	51	50	102	50	1
A18	Acute Hospital	48	50	96	47	1
A19	Acute Hospital	24	50	48	23	1
A20	Acute Hospital	6			6	0
A21	Acute Hospital	22	50	44	20	2
A22	Acute Hospital	23			19	4
A23	Acute Hospital	49	50	98	47	2
A24	Acute Hospital	20	50	40	15	5
C55	Community Hospital	32			32	0
C56	Community Hospital	23			20	3
C70	Community Hospital	29			25	4
C80	Community Hospital	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: Level of Agreement between Nurses and Doctors Responses (Awareness)

	Item No.	C1	C2	C4		C5.1	C5.2	C5.3	C5.4	C6	
	Question	**Medical diagnosis of dying**	**Diagnosis documented**	**Nurses aware of dying**		**Multi-disciplinary Team Meeting**	**Medical & Nursing Team Meeting**	**Patient / Family at Meeting**	**Patient / Family told of Meeting**	**Patient could have died at home**	
	Category										
	In Agreement	**%**	**%**	**%**		**%**	**%**	**%**	**%**	**%**	**n**
A / C	Acute Hospitals	87	75	86		61	66	67	59	75	636
	Comm. Hospitals	83	58	84		56	69	68	63	67	101
Ward	A & E	66	62	62		76	62	66	76	93	29
	Intensive Care	85	77	86		56	67	71	65	90	124
	Surgical	91	71	91		64	64	63	60	74	88
	Medical	88	77	85		61	65	64	56	67	300
	Oncology	94	80	89		57	66	71	51	71	35
	Geriatric	84	61	86		55	70	70	66	69	115
	Other	85	74	87		65	70	74	54	76	46
Room	Single	90	75	91		60	70	67	60	71	336
	Multi-occupancy	83	71	80		60	63	67	60	76	401
MDC	Cancer	95	78	91		55	70	70	58	68	176
	Circulatory/Organs	85	73	81		65	66	68	61	75	220
	Respiratory	83	71	84		60	65	66	61	71	139
	Frailty/Dementia	76	67	83		53	64	69	57	72	56
	Other	87	72	88		62	63	64	60	83	146
Sex	Male	87	73	86		58	67	67	61	77	378
	Female	86	74	85		62	65	68	59	71	359
Age	under 45	83	67	96		54	67	88	71	83	24
	45 to 64	89	79	86		66	67	67	56	78	92
	65 to 84	87	75	86		60	68	67	59	74	448
	85 to 100	83	67	83		57	60	66	62	71	173
Stay	under 1 day	75	71	78		69	59	66	67	80	96
	1 day – 1 week	89	77	88		62	64	67	63	76	214
	1 week – 1 month	89	74	86		56	65	66	55	73	280
	over one month	85	68	84		61	76	70	59	69	147
Death	Expected	91	74	89		59	69	68	58	71	564
	Sudden	72	72	73		63	57	63	66	83	173
H99	**All HFH Hospitals**	**86**	**73**	**85**		**60**	**66**	**67**	**60**	**74**	**737**
H99	***kappa***	**0.44**	**0.29**	**0.39**		**0.19**	**0.23**	**0.25**	**0.20**	**0.23**	**737**

Table 1.5: Level of Agreement between Nurses and Doctors Responses (Treatment)

	Item No.	**F1.1**	**F1.2**	**F1.3**	**F1.4**	**F1.5**	**F1.6**	**F1.7**	**F1.8**	**F1.9**	**F1.10**	
	Question **Category**	**Aim curative v. palliative**	**Optimise Comfort**	**Stop non-essential Med.**	**Stop blood tests**	**Stop antibiotics**	**Review hydration**	**Stop invasive monitoring**	**Withhold treatment**	**Withdraw treatment**	**Talk about resuscitation**	
	In Agreement	%	%	%	%	%	%	%	%	%	%	**n**
A / C	Acute Hospitals	66	76	72	66	67	63	64	65	64	76	636
	Comm. Hospitals	63	78	68	53	62	62	47	47	74	60	101
Ward	A & E	83	93	97	90	93	90	93	86	76	69	29
	Intensive Care	65	67	61	57	59	57	66	62	67	74	124
	Surgical	63	76	71	56	63	62	56	58	63	82	88
	Medical	67	75	71	69	67	62	60	65	59	75	300
	Oncology	49	77	80	77	74	63	71	57	71	83	35
	Geriatric	66	82	75	61	65	63	47	51	70	66	115
	Other	63	87	72	57	67	65	78	70	78	65	46
Room	Single	67	81	75	67	66	65	61	62	64	78	336
	Multi-occupancy	64	73	68	63	67	61	62	63	66	70	401
MDC	Cancer	65	86	79	73	66	66	63	62	63	75	176
	Circulatory/Organs	66	75	69	65	66	68	64	60	64	73	220
	Respiratory	69	79	63	65	63	54	61	66	70	73	139
	Frailty/Dementia	57	69	69	50	67	60	47	47	59	57	56
	Other	66	67	75	60	69	60	63	69	67	80	146
Sex	Male	68	77	75	66	68	64	66	65	68	73	378
	Female	63	76	67	63	65	62	57	60	62	74	359
Age	under 45	88	75	71	58	67	71	88	79	71	88	24
	45 to 64	57	77	73	70	67	65	70	67	70	78	92
	65 to 84	66	76	72	65	66	63	61	61	62	74	448
	85 to 100	64	77	71	60	66	60	53	60	70	70	173
Stay	under 1 day	63	74	79	76	82	70	75	72	71	65	96
	1 day – 1 week	69	70	66	58	67	57	63	60	64	80	214
	1 week – 1 month	65	80	73	68	63	65	63	63	62	75	280
	over one month	64	81	72	59	61	63	46	59	67	67	147
Death	Expected	66	79	73	63	65	62	57	60	62	74	564
	Sudden	67	69	67	69	72	67	76	72	76	71	173
H99	**All HFH Hospitals**	**66**	**77**	**72**	**64**	**66**	**63**	**61**	**62**	**65**	**74**	**737**
H99	***kappa***	**0.25**	**0.33**	**0.31**	**0.30**	**0.31**	**0.24**	**0.20**	**0.26**	**0.27**	**0.33**	**737**
	Documentation											
H99	**All HFH Hospitals**	**59**	**61**	**58**	**63**	**63**	**61**	**67**	**62**	**64**	**63**	**737**
H99	***kappa***	**0.18**	**0.18**	**0.15**	**0.14**	**0.17**	**0.17**	**0.13**	**0.21**	**0.18**	**0.24**	**737**

Table 1.6: Level of Agreement between Nurses and Doctors Responses (Symptoms)

	Item No.	**F2. 1.1**	**F2. 2.1**	**F2. 3.1**	**F2. 4.1**	**F2. 5.1**	**F2. 6.1**	**F2. 1.2**	**F2. 2.2**	**F2. 3.2**	**F2. 4.2**	**F2. 5.2**	**F2. 6.2**
		Symptoms						**Management of Symptoms**					
	Question **Category**	**Pain**	**Nausea**	**Breathing**	**Secretions**	**Restlessness**	**Anxiety**	**Pain**	**Nausea**	**Breathing**	**Secretions**	**Restlessness**	**Anxiety**
	In Agreement	%	%	%	%	%	%	%	%	%	%	%	%
A / C	Acute Hospitals	48	65	38	47	51	50	42	46	43	41	38	13
	Comm. Hospitals	48	70	39	46	51	57	44	27	45	54	50	56
Ward	A & E	67	67	-	50	33	33	-	-	-	-	-	-
	Intensive Care	49	73	40	45	55	54	39	60	48	50	46	29
	Surgical	47	59	44	49	39	46	36	27	38	26	38	38
	Medical	48	65	35	45	53	52	45	48	38	38	36	35
	Oncology	56	63	52	52	47	43	40	50	38	40	35	31
	Geriatric	44	70	38	44	50	54	40	23	50	58	54	50
	Other	51	57	34	60	51	46	60	56	71	54	35	56
Room	Single	47	66	41	41	46	50	43	48	43	41	37	34
	Multi-occupancy	49	66	35	52	54	52	42	37	44	46	44	43
MDC	Cancer	47	58	38	51	47	42	37	48	45	40	39	38
	Circulatory/Organs	51	72	36	47	52	57	47	30	44	43	47	40
	Respiratory	47	69	41	34	48	48	46	42	44	46	36	34
	Frailty/Dementia	47	68	37	57	67	65	73	33	53	50	41	25
	Other	47	63	36	49	50	53	40	56	35	42	35	44
Sex	Male	49	66	35	44	48	48	44	43	43	44	39	35
	Female	47	66	40	50	53	54	41	44	44	42	41	42
Age	under 45	56	75	41	44	41	47	57	83	50	100	44	38
	45 to 64	42	57	45	37	49	44	38	54	42	30	36	33
	65 to 84	50	66	36	50	52	51	44	40	46	46	41	38
	85 to 100	46	69	39	44	50	54	41	33	37	43	38	41
Stay	under 1 day	52	52	18	49	52	64	44	43	45	25	36	44
	1 day – 1 week	50	69	43	47	57	57	44	47	44	42	42	37
	1 week – 1 month	47	66	36	45	48	46	41	50	40	40	41	41
	over one month	47	66	42	49	47	49	44	31	49	53	38	31
Death	Expected	48	66	37	44	49	51	40	43	41	43	40	36
	Sudden	48	63	41	59	57	50	56	46	62	44	38	50
H99	**All HFH Hospitals**	**48**	**66**	**38**	**47**	**51**	**51**	**43**	**43**	**44**	**43**	**40**	**38**
H99	***kappa***	**0.15**	**0.25**	**0.14**	**0.18**	**0.22**	**0.16**	**-**	**0.06**	**0.07**	**0.09**	**0.03**	**0.03**
	n	*575*	*558*	*606*	*581*	*588*	*557*	*254*	*93*	*317*	*195*	*235*	*150*

Management Scores have been recoded to form a 4-point scale.

Table 1.7: Level of Agreement between Nurses and Doctors Responses (SPC 1)

	Item No.	**G2**		**G4**	
Q1 D1	**Question** **Category**	**Patient received SPC Service**		**Patient would have benefited from SPC**	
	In Agreement	%	**n**	%	**n**
A / C	Acute Hospitals	83	636	40	396
	Comm. Hospitals	79	101	43	74
Ward	A & E	100	29	64	28
	Intensive Care	93	124	52	114
	Surgical	84	88	30	53
	Medical	80	300	41	160
	Oncology	71	35	44	9
	Geriatric	83	115	43	80
	Other	65	46	44	25
Room	Single	77	336	37	165
	Multi-occupancy	87	401	48	304
MDC	Cancer	69	176	44	48
	Circulatory/Organs	83	220	43	159
	Respiratory	89	139	44	106
	Frailty/Dementia	88	56	40	45
	Other	90	146	48	111
Sex	Male	83	378	45	239
	Female	82	359	44	230
Age	under 45	92	24	35	17
	45 to 64	74	92	53	43
	65 to 84	82	448	43	281
	85 to 100	86	173	45	128
Stay	under 1 day	89	96	46	80
	1 day – 1 week	86	214	51	150
	1 week – 1 month	78	280	39	147
	over one month	82	147	40	92
Death	Expected	79	564	44	317
	Sudden	93	173	45	152
H99	**All HFH Hospitals**	**82**	**737**	**44**	**469**
H99	***kappa***	**0.56**	**737**	**0.11**	**469**

With regard to Q1G1/Q2C1 there is a 88% agreement (kappa = 0.42) between nurses and doctors on whether a Specialist Palliative Service exists within the hospital.

Table 1.8: Level of Agreement between Nurses and Doctors Responses

	Item No.	J1	J2	J3	J4	J5	J8.1	J8.2	
Q1 D1	**Question** **Category**	**Communication with Patient**	**Respectful End-of-Life Care for Patient**	**Communication with Relatives or Friends**	**Managing Patient's Symptoms**	**Emotional Support to Relatives**	**Care was acceptable to you**	**Care was acceptable to your family or friends**	
	In Agreement	%	%	%	%	%	%	%	**n**
A / C	Acute Hospitals	38	43	50	47	42	37	38	636
	Comm. Hospitals	47	48	67	64	50	61	62	101
Ward	A & E	45	59	59	59	48	26	40	29
	Intensive Care	27	52	53	48	50	43	44	124
	Surgical	24	35	46	44	30	38	37	88
	Medical	32	40	50	44	39	33	33	300
	Oncology	37	40	37	60	43	43	43	35
	Geriatric	44	44	62	63	51	55	57	115
	Other	46	54	63	50	48	46	49	46
Room	Single	32	43	55	49	42	44	45	336
	Multi-occupancy	35	45	51	49	43	36	36	401
MDC	Cancer	39	40	51	50	44	43	44	176
	Circulatory/Organs	31	42	55	51	44	41	43	220
	Respiratory	30	42	49	45	44	37	36	139
	Frailty/Dementia	33	48	62	55	45	32	33	56
	Other	35	50	50	48	37	40	40	146
Sex	Male	34	45	50	48	42	39	39	378
	Female	33	43	55	51	44	41	42	359
Age	under 45	75	42	58	63	63	38	38	24
	45 to 64	34	52	54	50	47	39	41	92
	65 to 84	35	41	54	48	40	40	41	448
	85 to 100	31	47	49	51	44	40	40	173
Stay	under 1 day	37	50	52	54	38	27	29	96
	1 day – 1 week	33	38	48	43	38	40	42	214
	1 week – 1 month	30	43	51	47	43	40	39	280
	over one month	41	50	63	59	52	46	49	147
Death	Expected	34	43	53	48	43	39	40	564
	Sudden	32	45	51	53	43	41	42	173
H99	**All HFH Hospitals**	**34**	**44**	**52**	**49**	**43**	**40**	**40**	**737**
H99	***kappa***	**-0.03**	**0.03**	**0.02**	**0.03**	**-0.01**	**0.06**	**0.07**	**737**

Items J1 to J8 have been recoded to form a 4-point scale ranging from highly unacceptable to highly acceptable.

2 Patient Background Information (A)

Note 1: For the remainder of the Technical Appendix all tables refer to 999 cases, unless otherwise specified.

Note 2: All tables coloured blue refer to responses from nurses, whilst green tables are responses from doctors.

Table 2.1: 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**

Table 2.2a: 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**

Table 2.2b: 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
H99	**All Deaths***	**6**	**15**	**51**	**28**	**100**

**Source: Vital Statistics, 2006.*

Table 2.2c: 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**

Table 2.3: 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**
	2006 Census*	**16.5**	**52.7**			**30.8**		**100**

**Based on population aged 65 years and over.*

Table 2.4: 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**
	2006 Census*	**31.8**	**68.2**	

**Based on population aged 65 years and over.*

Table 2.5: 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**

Table 2.6: 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**
	2006 Census*	**88.8**	**6.6**	**4.6**	**100**

**Based on total population.*

Table 2.7: 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**
	2006 Census*	**87.3**			**100**

**Based on total population.*

Table 2.8: 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**
	2006 Census*	**88.2**	**3.0**				**2.5**	**100**

**Based on total population.*

Table 2.9: 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**
	HIPE 38 (2007)	**80.0**	**20.0**	**100**

Table 2.10: 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**
H99	**HIPE 38**					**n/a**	**100**

Table 2.11: Type of Admission

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

Table 2.12: 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**

Table 2.13a: 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**

Table 2.13b: 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**
	HIPE 2006 (OECD)	**6.7 (6.3)**			

Table 2.13c: 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**

Table 2.13d: 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	1490
	Respiratory	18	27	0	180
	Frailty/Dementia	55	130	0	718
	Other	33	231	0	2920
H98	**Comm. Hospitals**	**826**	**1,158**	**1**	**4,410**
	Cancer	476	965	2	3285
	Circulatory/Organs	928	1,245	1	4410
	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

Table 2.13e: 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	1490
	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**

Table 2.14a: 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**

Table 2.14b: 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
	Other Wards	0	0	0	0
H98	**Comm. Hospitals**	**nil**	**nil**	**nil**	**nil**
H99	**Total**	**1.2**	**4.7**	**0**	**90**

Table 2.15: 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**

Table 2.16: 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**

Table 2.17a: 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**	

Table 2.17b: 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**

Table 2.18: Ward in which Death Occurred

Q1A9	Hospital	A & E %	ICU %	Surgical %	Medical %	Oncology %	Geriatric %	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*

Table 2.19: 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**

3 Patient’s Place of Death in Hospital (B)

Table 3.1: Beds in the Ward where Patients Died

Q1B1	Hospital	In-patient beds		Day beds		Total beds	
		Mean	SD	Mean	SD	Mean	SD
H97	Acute Hospitals	19.6	10.9	3.7	9.4	23.2	15.7
H98	Comm. Hospitals	21.5	12.9	0.8	1.9	22.3	13.5
H99	**All HFH Hospitals**	**19.8**	**11.2**	**3.3**	**8.9**	**23.1**	**14.5**

Table 3.2: Beds in Single and Multi-occupancy Rooms

Q1B2	Hospital	Beds in single rooms		Beds in multi-occupancy rooms		In-patient beds	
		Mean	SD	Mean	SD	Mean	SD
H97	Acute Hospitals	3.8	3.8	16.4	9.6	20.2	11.1
H98	Comm. Hospitals	2.5	2.8	16.4	10.6	18.9	10.8
H99	**All HFH Hospitals**	**3.7**	**3.7**	**16.4**	**9.8**	**20.8**	**11.1**

Note: Tables 3.1 and 3.2 are not fully reconciled.

Table 3.3: Number of Beds in Multi-occupancy Rooms Where Patient Died

Q1B6	Hospital	Beds in multi-occupancy room		Beds occupied	
		Mean	SD	Mean	SD
H97	Acute Hospitals	5.2	2.5	4.6	2.8
H98	Comm. Hospitals	6.1	3.3	5.7	3.3
H99	**All HFH Hospitals**	**5.3**	**2.7**	**4.8**	**2.9**

Table 3.4: Gender Mix of Multi-occupancy Rooms by Type of Ward

Q1B6	Ward	Multi-occupancy Rooms			Single Room
		Male only %	Female only %	Mixed %	%
H97	**Acute Hospitals**	**13.5**	**13.0**	**28.1**	**45.5**
	A & E	9.8	7.3	58.5	22.8
	Intensive Care	2.2	0.6	74.4	22.8
	Surgical	24.4	12.2	10.6	52.8
	Medical	16.2	19.8	14.3	49.8
	Oncology	9.5	4.8	7.1	78.6
	Geriatric	17.2	20.7	10.3	51.7
	Other	9.8	9.8	21.6	58.8
H98	**Comm. Hospitals**	**19.3**	**40.3**	**6.7**	**33.6**
	Medical				100
	Oncology	50.0	50.0		
	Geriatric	21.0	41.0	6.7	31.4
	Other		36.4	9.1	54.5
H99	**All HFH Hospitals**	**14.2**	**16.2**	**25.5**	**44.0**

Table 3.5: Type of Room where Patient Died and spent most of Last Week

Q1B4	Hospital	Where Patient Died		Where Patient spent most time during last week	
		Single rooms %	Multi-occupancy rooms %	Single rooms %	Multi-occupancy rooms %
H97	Acute Hospitals	45.5	54.5	34.5	65.5
H98	Comm. Hospitals	33.6	66.4	18.5	81.5
H99	**All HFH Hospitals**	**44.0**	**56.0**	**32.6**	**67.4**

Table 3.6: Days Spent in Single Room by Patients who Died there

Q1B5	Hospital	Mean	Std. Deviation	Minimum	Maximum
H97	Acute Hospitals	5.0	7.3	0	7
H98	Comm. Hospitals	2.6	2.8	0	7
H99	**All HFH Hospitals**	**4.8**	**7.0**	**0**	**7**

Table 3.7: Moves within Hospital before Dying

Q1B3	Hospital	Mean	Std. Deviation	Minimum	Maximum
H97	Acute Hospitals	1.3	1.2	0	8
H98	Comm. Hospitals	1.4	1.3	0	5
H99	**All HFH Hospitals**	**1.3**	**1.2**	**0**	**8**

Table 3.8: Patients with Hospital Infections by Type of Room

Q1B5	Hospital	Hospital acquired infection		Immuno-suppression therapy	
		Yes	No	Yes	No
H97	**Acute Hospitals**	**11.6**	**88.4**	**2.5**	**97.5**
	single occupancy	22.8	77.3	5.0	95.0
	multi-occupancy	2.3	97.7	0.4	99.6
H98	**Comm. Hospitals**	**3.4**	**96.6**	**1.7**	**98.3**
	single occupancy	7.5	92.5	2.5	97.5
	multi-occupancy	1.3	98.7	1.3	98.7
H99	**All HFH Hospitals**	**10.6**	**89.4**	**2.4**	**97.6**

see Endnotes.

Table 3.9a: Nurses Perceptions of Room (5 categories)

Q1B7	Hospital	very poor	poor	middle	good	very good	n
		%	%	%	%	%	
	Acute Hospitals						
7.1	Privacy	10.4	14.8	11.7	16.7	46.5	480
7.2	Dignity	4.2	10.0	14.2	22.9	48.6	471
7.3	Environment	21.6	18.1	18.4	16.9	25.0	320
7.4	Control	46.6	13.9	9.8	9.5	20.3	296
	Comm. Hospitals						
7.1	Privacy	1.8	10.5	22.8	10.5	54.4	57
7.2	Dignity		1.7	22.4	31.0	44.8	58
7.3	Environment	2.3	9.1	22.7	20.5	45.5	44
7.4	Control	30.0	13.3	13.3	13.3	30.0	30
	All HFH Hospitals						
7.1	Privacy	9.5	14.3	12.8	16.0	47.3	537
7.2	Dignity	3.8	9.1	15.1	23.8	48.2	529
7.3	Environment	19.2	17.0	19.0	17.3	27.5	364
7.4	Control	45.1	13.8	10.1	9.8	21.2	326

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

Table 3.9b: Nurses Perceptions of Room

Q1B7	Hospital	Acute Hospitals		Community Hospitals		All HFH Hospitals	
		Mean	**SD**	**Mean**	**SD**	**Mean**	**SD**
7.1	Privacy – staff	6.0	3.2	6.2	2.9	6.0	3.2
7.2	Privacy – family	6.3	3.9	6.6	3.0	6.2	3.3
7.3	Privacy – stay	7.6	2.8	8.6	4.7	7.7	2.8
7.4	Dignity – care	8.2	2.4	8.8	1.9	8.3	2.4
7.5	Dignity – personal	6.6	3.3	7.1	2.7	6.7	3.2
7.6	Dignity – company	6.4	3.2	6.8	3.1	6.5	3.2
7.7	Environ – nature	4.4	3.2	6.6	3.0	4.6	3.2
7.8	Environ – daylight	6.9	2.9	8.5	1.8	7.1	2.9
7.9	Environ – quiet	5.4	3.2	6.1	2.9	5.5	3.2
7.10	Environ – TV radio	5.2	3.6	6.0	3.9	5.3	3.6
7.11	Control – space	5.5	3.3	6.9	2.9	5.7	3.3
7.12	Control – TV radio	5.3	3.5	5.3	3.4	5.3	3.7
7.13	Control – hot/cold	3.1	2.8	3.1	2.7	3.1	2.7
7.14	Control – light	4.5	3.4	4.3	3.2	4.4	3.4
7.15	Control - air	3.4	2.9	3.7	2.9	3.4	2.9
	Average Score	**5.6**	**2.3**	**6.3**	**1.9**	**5.7**	**2.3**

Table 3.9c: Nurses Perceptions of Room by Single/Multi-occupancy

Q1B7	Hospital	Privacy	Dignity	Environ	Control	Total
	Single	8.4	8.2	6.9	5.9	7.1
	Multi-occupancy	5.3	6.3	4.6	3.2	4.6
H99	**All Rooms**	**6.7**	**7.1**	**5.6**	**4.4**	**5.7**

Table 3.9d: Nurses Perceptions of Room by Type of Ward

Q1B7	Hospital	Privacy	Dignity	Environ	Control	Total
	A & E	5.6	4.9	2.5	2.0	3.4
	Intensive Care	6.5	6.5	4.5	3.2	4.8
	Surgical	6.5	7.1	5.8	4.8	5.8
	Medical	6.7	7.4	5.9	4.7	6.0
	Oncology	7.6	8.1	6.7	6.0	6.9
	Geriatric	6.8	7.4	6.6	4.6	6.1
	Other	7.5	7.5	6.0	4.8	6.2
H99	**All Wards**	**6.7**	**7.1**	**5.6**	**4.4**	**5.7**

4 Team Assessment of Patient (C)

Table 4.1N: Length of time Between Diagnosis of Dying and Death (Nurses)

Q1 C1-4	Hospital	no diagnosis %	less than 1 day %	1 day – 1 week %	1 week – 1 month %	more than 1 month %	Total
	Acute Hospitals	14.1	33.0	34.5	16.4	2.0	100
	Comm. Hospitals	23.5	26.9	18.5	22.7	8.4	100
H99	**All HFH Hospitals**	**15.2**	**32.2**	**32.6**	**17.1**	**2.8**	**100**

Table 4.2N: Diagnosis of Death (Nurses)

	Question	**C1**	**C2**	**C3**	**C4**	
Q1 C	**Category**	**Medical Diagnosis of dying**	**Medical Diagnosis documented**	**Time from Diagnosis to Death**	**Nursing Staff Awareness of dying**	
		Yes %	**Yes %**	**Mean (days)**	**Yes %**	**n**
A / C	Acute Hospitals	87.0	77.9	4.7	90.4	841
	Comm. Hospitals	76.6	64.0	11.2	87.4	111
Ward	A & E	78.1	50.0	1.1	81.3	32
	Intensive Care	83.9	75.0	1.5	91.7	168
	Surgical	82.6	79.3	7.2	85.1	121
	Medical	88.6	78.4	4.7	91.1	403
	Oncology	95.5	93.2	10.0	95.5	44
	Geriatric	78.6	65.9	10.5	88.1	126
	Other	91.4	82.8	6.4	93.1	58
Room	Single	91.1	83.1	6.4	92.7	425
	Multi-occupancy	81.6	70.8	4.8	87.9	527
MDC	Cancer	94.8	87.3	11.0	96.1	229
	Circulatory/Organs	83.7	71.9	3.0	86.4	295
	Respiratory	87.3	78.5	3.7	91.2	181
	Frailty/Dementia	78.1	67.1	6.8	89.0	73
	Other	79.3	70.7	3.8	87.4	174
Sex	Male	85.7	76.4	5.4	89.9	483
	Female	85.9	76.1	5.6	90.2	469
Age	under 45	85.7	78.6	4.2	89.3	28
	45 to 64	90.4	83.5	8.6	93.9	115
	65 to 84	85.7	74.4	4.4	89.9	574
	85 to 100	83.8	77.0	6.9	88.5	235
Stay	under 1 day	73.5	60.2	1.1	83.2	113
	1 day – 1 week	83.5	75.0	3.1	84.5	284
	1 week – 1 month	90.8	84.1	6.2	94.3	371
	over one month	87.0	72.3	10.5	94.0	184
Death	Expected	94.8	85.0	6.9	97.4	732
	Sudden	56.1	47.5	0.7	65.6	221
H99	**All HFH Hospitals**	**85.8**	**76.3**	**5.5**	**90.0**	**952**

Table 4.1D: Length of time Between Diagnosis of Dying and Death (Doctors)

Q2 A1-4	Hospital	no diagnosis %	less than 1 day %	1 day – 1 week %	1 week – 1 month %	more than 1 month %	Total
	Acute Hospitals	14.5	31.9	34.6	17.8	1.3	100
	Comm. Hospitals	10.9	25.7	16.8	37.6	8.9	100
H99	**All HFH Hospitals**	**14.0**	**31.1**	**32.2**	**20.5**	**2.3**	**100**

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

Table 4.2D: Diagnosis of Death (Doctors)

	Question	A1	A2	A3	A4	
Q2 A	**Category**	**Medical Diagnosis of dying**	**Medical Diagnosis documented**	**Time from Diagnosis to Death**	**Doctors Awareness of dying**	
		Yes %	**Yes %**	**Mean (days)**	**Yes %**	**n**
A / C	Acute Hospitals	85.5	74.2	4.2	81.8	636
	Comm. Hospitals	89.1	70.3	14.6	87.1	101
Ward	A & E	65.5	48.3	0.1	65.5	29
	Intensive Care	85.5	79.8	2.2	84.7	124
	Surgical	83.0	67.0	6.4	81.8	88
	Medical	86.0	75.3	4.6	80.3	300
	Oncology	94.3	80.0	6.1	88.6	35
	Geriatric	90.4	72.2	13.7	87.8	115
	Other	89.1	73.9	4.0	84.8	46
Room	Single	91.1	80.4	6.3	87.8	336
	Multi-occupancy	81.8	68.1	5.1	78.1	401
MDC	Cancer	93.8	80.1	10.7	89.8	176
	Circulatory/Organs	79.1	70.5	3.6	76.8	220
	Respiratory	88.5	74.8	3.3	84.2	139
	Frailty/Dementia	82.1	64.3	8.8	76.8	56
	Other	86.3	73.3	3.8	84.2	146
Sex	Male	86.0	72.8	5.1	82.3	378
	Female	86.1	74.7	6.2	82.7	359
Age	under 45	91.7	87.5	6.4	83.3	24
	45 to 64	88.0	73.9	4.5	84.8	92
	65 to 84	85.9	74.1	5.0	82.1	448
	85 to 100	84.4	70.5	7.9	82.1	173
Stay	under 1 day	76.0	66.7	2.4	74.0	96
	1 day – 1 week	83.6	72.4	2.3	80.4	214
	1 week – 1 month	89.3	75.7	5.0	84.6	280
	over one month	89.8	76.2	14.0	87.1	147
Death	Expected	92.6	81.0	6.9	89.0	564
	Sudden	63.6	49.7	1.5	61.3	173
H99	**All HFH Hospitals**	**86.0**	**73.7**	**5.7**	**82.5**	**737**

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

Table 4.3N: Staff Meetings About the Dying Patient (Nurses)

	Question	C5.1	C5.2	C5.1+2	C5.3	C5.4	C6	
Q1 C	**Category**	**Multi-disciplinary Team Meeting**	**Medical & Nursing Team Meeting**	**Neither**	**Patient / Family at Meeting**	**Patient / Family told of Meeting**	**Patient could have died at home**	
		Yes %	**Yes %**	**No %**	**Yes %**	**Yes %**	**Yes %**	**n**
A / C	Acute Hospitals	44.6	69.4	28.8	69.8	55.2	23.2	841
	Comm. Hospitals	56.8	77.5	21.6	68.5	64.9	15.3	111
Ward	A & E	31.3	53.1	46.9	43.1	37.5	12.5	32
	Intensive Care	41.1	75.6	23.2	76.2	60.7	6.5	168
	Surgical	33.9	62.8	34.7	62.0	47.1	25.6	121
	Medical	48.4	69.2	28.8	70.0	53.8	27.8	403
	Oncology	52.3	72.7	25.0	70.5	61.4	38.6	44
	Geriatric	56.3	76.2	23.0	68.3	65.1	18.3	126
	Other	50.0	74.1	24.1	75.9	67.2	24.1	58
Room	Single	52.2	73.4	24.2	74.1	57.4	26.4	425
	Multi-occupancy	41.0	67.9	30.9	66.0	55.4	19.0	527
MDC	Cancer	55.0	76.0	21.4	73.4	61.6	32.3	229
	Circulatory/Organs	41.7	67.5	30.8	69.2	55.3	16.6	295
	Respiratory	44.8	65.7	32.6	68.0	49.7	26.0	181
	Frailty/Dementia	45.2	76.7	23.3	71.2	64.4	20.5	73
	Other	43.1	70.1	28.7	66.7	54.6	15.5	174
Sex	Male	44.5	68.5	29.8	66.3	52.2	19.7	483
	Female	47.5	72.3	26.0	73.1	60.6	24.9	469
Age	under 45	60.7	75.0	17.9	82.1	67.9	10.7	28
	45 to 64	46.1	73.0	26.1	74.8	63.5	20.9	115
	65 to 84	45.5	69.3	29.1	67.8	55.1	21.8	574
	85 to 100	45.5	71.1	27.2	70.2	54.5	25.5	235
Stay	under 1 day	23.9	51.3	46.0	54.0	41.6	19.5	113
	1 day – 1 week	38.4	68.0	31.3	66.5	52.1	20.1	284
	1 week – 1 month	50.7	72.2	25.1	74.7	58.5	23.7	371
	over one month	62.0	82.1	16.8	73.9	67.4	24.5	184
Death	Expected	51.7	75.9	22.2	76.2	62.1	25.3	732
	Sudden	27.1	52.0	47.1	48.0	37.1	12.2	221
H99	**All HFH Hospitals**	**46.0**	**70.4**	**27.9**	**69.6**	**56.3**	**22.3**	**952**

Table shows 'Yes' Responses only. Don't know and missing coded 'No'.

Note: Q1C6 expresses nurse's opinion of whether patient could have been allowed to die at home.

Table 4.3D: Staff Meetings About the Dying Patient (Doctors)

	Question	A5.1	A5.2	A5.1+2	A5.3	A5.4	A6	
Q2 A	Category	Multi-discipli-nary Team Meeting	Medical & Nursing Team Meeting	Neither	Patient / Family at Meeting	Patient / Family told of Meeting	Patient could have died at home	
		Yes %	Yes %	No %	Yes %	Yes %	Yes %	n
A / C	Acute Hospitals	37.9	63.8	32.5	64.9	49.2	21.9	636
	Comm. Hospitals	55.4	76.2	22.8	75.2	55.4	24.8	101
Ward	A & E	6.9	20.7	79.3	31.0	27.6	6.9	29
	Intensive Care	43.5	66.9	28.2	69.4	56.5	12.1	124
	Surgical	34.1	65.9	33.0	73.9	52.3	25.0	88
	Medical	37.3	62.7	33.7	62.3	45.0	26.0	300
	Oncology	51.4	74.3	22.9	71.4	54.3	22.9	35
	Geriatric	51.3	78.3	20.0	73.0	60.0	26.1	115
	Other	47.8	69.6	23.9	71.7	47.8	19.6	46
Room	Single	46.7	71.1	25.9	72.3	54.5	25.0	336
	Multi-occupancy	34.9	60.8	35.7	61.3	46.4	20.0	401
MDC	Cancer	55.7	75.0	21.0	76.7	58.5	29.5	176
	Circulatory/Organs	31.8	63.2	34.1	60.0	45.9	20.9	220
	Respiratory	38.1	66.2	32.4	68.3	47.5	27.3	139
	Frailty/Dementia	35.7	58.9	39.3	67.9	48.2	17.9	56
	Other	38.4	59.6	34.9	61.0	49.3	12.3	146
Sex	Male	42.9	66.1	31.0	65.6	47.9	20.6	378
	Female	37.6	64.9	31.5	67.1	52.4	24.0	359
Age	under 45	54.2	75.0	25.0	79.2	50.0	16.7	24
	45 to 64	44.6	64.1	27.2	67.4	51.1	20.7	92
	65 to 84	39.5	66.1	31.3	66.1	52.0	21.4	448
	85 to 100	38.2	63.6	34.1	64.7	44.5	26.0	173
Stay	under 1 day	27.1	43.8	53.1	50.0	40.6	17.7	96
	1 day – 1 week	31.8	64.0	32.2	67.3	48.6	23.4	214
	1 week – 1 month	43.9	67.9	28.2	67.1	51.4	22.5	280
	over one month	54.4	77.6	21.1	74.1	55.8	23.1	147
Death	Expected	44.7	72.9	23.9	72.2	55.0	25.2	564
	Sudden	26.0	41.6	54.9	47.4	34.1	12.7	173
H99	**All HFH Hospitals**	**40.3**	**65.5**	**31.2**	**66.4**	**50.1**	**22.3**	**737**

Table shows 'Yes' Responses only. Don't know and missing coded 'No'.

Note: Q1A6 expresses doctor's opinion of whether patient could have been allowed to die at home.
Note: Based on matched cases only (n=737).

Table 4.4: Deaths in Acute Hospitals and Hospices in Ireland (HIPE38)

		Deaths in Hospital	Transfers to Hospice	Deaths in Hospitals and Hospices	Deaths in Hospices
ID	**Hospital**	**Number**	**Number**	**Number**	**%**
A01	Acute Hospital	527	164	691	**23.7**
A02	Acute Hospital	442	86	528	**16.3**
A03	Acute Hospital	259	5	264	**1.9**
A04	Acute Hospital	109	0	109	**0.0**
A05	Acute Hospital	269	2	271	**0.7**
A06	Acute Hospital	186	0	186	**0.0**
A07	Acute Hospital	182	0	182	**0.0**
A08	Acute Hospital	374	2	376	**0.5**
A09	Acute Hospital	255	0	255	**0.0**
A10	Acute Hospital	860	66	926	**7.1**
A11	Acute Hospital	278	57	335	**17.0**
A12	Acute Hospital	698	15	713	**2.1**
A13	Acute Hospital	313	2	315	**0.6**
A14	Acute Hospital	297	84	381	**22.0**
A15	Acute Hospital	55	18	73	**24.7**
A16	Acute Hospital	111	0	111	**0.0**
A17	Acute Hospital	824	45	869	**5.2**
A18	Acute Hospital	465	0	465	**0.0**
A19	Acute Hospital	216	0	216	**0.0**
A20	Acute Hospital	269	0	269	**0.0**
A21	Acute Hospital	423	32	455	**7.0**
A22	Acute Hospital	162	2	164	**1.2**
A23	Acute Hospital	231	2	233	**0.9**
A24	Acute Hospital	265	0	265	**0.0**
	Acute Hospital	307	2	309	**0.6**
	Acute Hospital	625	18	643	**2.8**
	Acute Hospital	94	2	96	**2.1**
	Acute Hospital	321	62	383	**16.2**
	Acute Hospital	200	23	223	**10.3**
	Acute Hospital	68	0	68	**0.0**
	Acute Hospital	55	2	57	**3.5**
	Acute Hospital	164	2	166	**1.2**
	Acute Hospital	164	0	164	**0.0**
	Acute Hospital	190	2	192	**1.0**
	Acute Hospital	515	31	546	**5.7**
	Acute Hospital	349	4	353	**1.1**
	Acute Hospital	128	2	130	**1.5**
	Acute Hospital	175	0	175	**0.0**
	HIPE 24 (2007)	**8,070**	**582**	**8,652**	**6.7**
	HIPE 38 (2007)	**11,425**	**732**	**12,157**	**6.0**

Note: Transfers to Hospice includes transfers to Harold's Cross Hospice (which is part of HIPE) and all other Hospices not in HIPE.

Table 4.5: Cancer Deaths in Acute Hospitals and Hospices in Ireland (HIPE38)

		Deaths in Hospital	**Transfers to Hospice**	**Deaths in Hospitals and Hospices**	**Deaths in Hospices**
ID	**Hospital**	**Number**	**Number**	**Number**	**%**
A01	Acute Hospital	149	158	307	**51.5**
A02	Acute Hospital	76	74	150	**49.3**
A03	Acute Hospital	70	2	72	**2.8**
A04	Acute Hospital	22	0	22	**0.0**
A05	Acute Hospital	89	0	89	**0.0**
A06	Acute Hospital	42	0	42	**0.0**
A07	Acute Hospital	47	0	47	**0.0**
A08	Acute Hospital	109	2	111	**1.8**
A09	Acute Hospital	64	0	64	**0.0**
A10	Acute Hospital	290	7	297	**2.4**
A11	Acute Hospital	79	47	126	**37.3**
A12	Acute Hospital	209	12	221	**5.4**
A13	Acute Hospital	68	2	70	**2.9**
A14	Acute Hospital	61	75	136	**55.1**
A15	Acute Hospital	55	8	63	**12.7**
A16	Acute Hospital	29	0	29	**0.0**
A17	Acute Hospital	264	41	305	**13.4**
A18	Acute Hospital	179	0	179	**0.0**
A19	Acute Hospital	57	0	57	**0.0**
A20	Acute Hospital	61	0	61	**0.0**
A21	Acute Hospital	145	2	147	**1.4**
A22	Acute Hospital	14	2	16	**12.5**
A23	Acute Hospital	53	2	55	**3.6**
A24	Acute Hospital	95	0	95	**0.0**
	Acute Hospital	42	2	44	**4.5**
	Acute Hospital	217	4	221	**1.8**
	Acute Hospital	26	2	28	**7.1**
	Acute Hospital	127	55	182	**30.2**
	Acute Hospital	56	23	79	**29.1**
	Acute Hospital	15	0	15	**0.0**
	Acute Hospital	11	2	13	**15.4**
	Acute Hospital	16	2	18	**11.1**
	Acute Hospital	45	0	45	**0.0**
	Acute Hospital	56	2	58	**3.4**
	Acute Hospital	264	27	291	**9.3**
	Acute Hospital	91	2	93	**2.2**
	Acute Hospital	32	2	34	**5.9**
	Acute Hospital	35	0	35	**0.0**
	HIPE 24 (2007)	**2,327**	**434**	**2,761**	**15.7**
	HIPE 38 (2007)	**3,360**	**557**	**3,917**	**14.2**

Note: Transfers to Hospice includes transfers to Harold's Cross Hospice (which is part of HIPE) and all other Hospices not in HIPE.

5 Communication with Patient (D)

Table 5.1: Discussion with the Patient

	Item No.	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**(9)**			
Q1 D1	**Question** / **Category**	**Situation and Prognosis**	**Aims of Care**	**Benefit versus Burden**	**Expectation**	**Patient's Concerns**	**Resuscitation**	**Place of Care**	**Location of Dying**	**Any Other Discussion**	**1+ Communication**	**1+ Comm. Documented**	
	Yes	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**n**
A / C	Acute Hospitals	30	30	28	17	27	27	14	8	7	**56**	**43**	841
	Comm. Hospitals	27	32	32	15	26	17	18	13	9	**52**	**37**	111
Ward	A & E	19	16	13	9	6	19	0	0	3	**31**	**22**	32
	Intensive Care	23	12	16	9	14	16	4	1	6	**39**	**30**	168
	Surgical	30	29	22	17	28	29	12	8	5	**57**	**45**	121
	Medical	30	35	31	19	30	30	16	8	8	**61**	**45**	403
	Oncology	55	55	50	34	50	39	43	30	7	**75**	**68**	44
	Geriatric	28	33	34	18	27	20	16	11	7	**55**	**44**	126
	Other	36	36	31	16	36	31	24	17	9	**62**	**45**	58
Room	Single	36	38	33	21	32	29	20	13	7	**61**	**49**	425
	Multi-occupancy	24	24	24	14	23	23	10	5	7	**51**	**37**	527
MDC	Cancer	49	51	42	29	42	40	28	19	9	**74**	**62**	229
	Circulatory/Organs	24	22	22	14	20	22	10	6	7	**49**	**35**	295
	Respiratory	27	29	29	15	27	24	12	6	7	**56**	**41**	181
	Frailty/Dementia	11	22	22	12	22	22	11	6	6	**44**	**29**	73
	Other	24	21	21	10	20	19	8	4	6	**45**	**37**	174
Sex	Male	30	30	27	16	26	23	14	8	8	**55**	**42**	483
	Female	29	30	29	18	27	29	15	9	6	**56**	**43**	469
Age	under 45	32	36	32	11	36	25	14	14	0	**50**	**43**	28
	45 to 64	40	37	32	23	31	36	18	14	9	**63**	**52**	115
	65 to 84	30	30	28	18	27	25	15	8	7	**55**	**42**	574
	85 to 100	24	26	26	14	24	23	12	7	8	**52**	**39**	235
Stay	under 1 day	17	20	14	7	10	22	5	3	7	**40**	**28**	113
	1 day – 1 week	26	24	24	15	23	22	11	5	6	**50**	**38**	284
	1 week – 1 month	37	36	34	22	33	32	18	12	7	**64**	**50**	371
	over one month	28	35	32	16	30	22	19	11	9	**57**	**43**	184
Death	Expected	31	33	30	19	29	28	17	11	8	**58**	**44**	732
	Sudden	26	20	20	12	21	20	7	1	5	**47**	**36**	221
H99	**All HFH Hospitals**	**30**	**30**	**28**	**17**	**27**	**26**	**14**	**9**	7	**55**	**42**	**952**

Table shows 'Yes' Responses only. Don't know, n/a and missing coded 'No'.
Last two column show where at least one type of communication and documentation took place.

Table 5.2: Reasons for No Discussion with Patient

Q1D2	**Reason**	**A&E %**	**Intensive Care %**	**Other Wards %**	**All Wards %**
1	Patient died suddenly	87.1	28.1	21.3	27.3
2	Patient had dementia	3.2	7.0	34.3	25.6
3	Patient too ill	67.7	88.6	78.1	80.0
4	No medical diagnosis or awareness of dying	12.9	9.6	10.2	10.2
5	Patient did not want to talk about dying	0.0	0.9	4.0	3.0
6	Relatives did not want patient to be told	3.2	2.6	6.2	5.1
7	Lack of privacy	6.5	2.6	5.6	4.9
8	Medical staff lacking experience in comm.	0.0	0.9	2.5	1.9
9	Nursing staff lacking experience in comm..	0.0	2.6	2.5	2.3
10	Other reason	9.7	17.5	7.1	9.8

Note: Table applies only to those cases where staff did not talk to patients; i.e. the 45% of cases which complement the second last column of Table 5.1 (n = 469).

Table 5.3a: Time between Diagnosis of Dying and Discussion with Patient

Q1D4 **Q1C3**	**Time of Discussion** **Diagnosis of Dying**	**no discuss-ion**	**under 1 day**	**1 day – 1 week**	**1 week – 1 month**	**over one month**	**Total**
	no diagnosis	22.2	2.0	2.5	2.7	0.1	**29.5**
	under 1 day	10.7	4.2	1.3	0.7	0.5	**17.4**
	1 day – 1 week	17.1	0.9	12.8	2.0	0.3	**33.1**
	1 week – 1 month	6.9	0.1	1.9	7.9	0.3	**17.1**
	over one month	1.6		0.1	0.3	0.8	**2.8**
	Total	**58.6**	**7.2**	**18.6**	**13.6**	**2.0**	**100**

Table 5.3b: Time between Diagnosis of Dying and Discussion with Patient

Q1D4 **Q1C3**	**Time of Discussion** **Diagnosis of Dying**	**no discuss-ion**	**under 1 day**	**1 day – 1 week**	**1 week – 1 month**	**over one month**	**Total**
	Acute Hospitals	57.5	7.8	20.0	13.1	1.6	**100**
	Comm. Hospitals	66.4	2.5	8.4	17.6	5.0	**100**
H99	**All HFH Hospitals**	**58.6**	**7.2**	**18.6**	**13.6**	**2.0**	**100**

Table 5.4: Person initiating or participating in any Discussion with Patient

Q1D3	Person	Initiating Discussion %	Participating in Discussion %
1+2	Doctor or specialist doctor	81.4	53.6
3+4	Nurse or specialist nurse	69.7	40.1
5	Patient	14.2	16.5
6	Relative or Friend	42.9	34.6

Note1: Table applies only to cases where it is known that a discussion with patient took place (Q1D1) and where information was provided with respect to who initiated it or took part (n = 478).
Note2: Sums may add up to more than 100%, as they may relate to different types of communications.
Note3: Participation of Patient may be understated as it is implied in the phrasing of the question.

Table 5.5: Staff Rating of Discussion with Patient

		1	2	3	4	5	6	7		
Q1D5	Question Category	Sensitive	Open and honest	Reassuring	Expressing Concerns	Expressing Preferences	Asking Questions	Making decisions	Mean Score	Number of Cases (n)
	Yes	M	M	M	M	M	M	M	M	
A / C	Acute Hospitals	7.4	7.8	7.0	7.0	6.8	7.2	6.4	**7.2**	318
	Comm. Hospitals	8.0	8.1	8.0	7.5	7.5	7.9	7.4	**8.1**	42
Ward	A & E	7.3	7.5	6.7	3.7	6.7	6.7	6.7	**6.9**	4
	Intensive Care	7.8	8.1	6.6	6.8	6.9	7.4	6.2	**7.4**	35
	Surgical	7.1	7.1	6.8	6.5	6.1	6.5	6.0	**6.6**	41
	Medical	7.3	7.7	7.0	7.0	6.7	7.0	6.3	**7.1**	175
	Oncology	7.9	8.4	7.8	8.1	7.8	8.2	7.3	**7.9**	28
	Geriatric	7.6	7.9	7.4	7.2	7.0	7.5	6.9	**7.6**	53
	Other	7.9	8.1	7.5	7.9	7.9	8.3	7.6	**8.1**	24
Room	Single	7.6	7.9	7.2	7.2	6.9	7.3	6.6	**7.3**	182
	Multi-occupancy	7.3	7.7	6.9	6.9	6.9	7.2	6.5	**7.2**	178
MDC	Cancer	7.9	8.1	7.5	7.7	7.3	7.9	7.2	**7.7**	132
	Circulatory/Organs	7.0	7.8	7.0	6.7	6.5	7.0	5.9	**7.2**	95
	Respiratory	7.2	7.4	6.8	6.5	6.5	6.7	6.0	**6.8**	74
	Frailty/Dementia	6.8	7.2	5.9	6.4	6.7	6.7	5.4	**6.5**	20
	Other	7.5	7.6	6.9	6.8	7.0	6.9	6.8	**7.4**	39
Sex	Male	7.5	7.7	7.2	7.1	6.9	7.3	6.6	**7.2**	179
	Female	7.5	8.0	7.0	7.0	6.8	7.2	6.5	**7.3**	181
Age	under 45	8.0	8.9	8.0	8.0	7.4	8.1	8.6	**8.1**	9
	45 to 64	8.1	8.3	7.7	7.8	7.4	7.9	7.4	**7.9**	48
	65 to 84	7.3	7.7	7.0	7.1	6.8	7.2	6.4	**7.2**	224
	85 to 100	7.3	7.6	6.9	6.4	6.5	6.8	6.1	**7.0**	79
Stay	under 1 day	7.6	8.4	7.4	6.5	6.9	7.6	6.9	**7.4**	24
	1 day – 1 week	7.3	7.5	7.2	6.9	6.7	7.1	6.3	**7.1**	89
	1 week – 1 month	7.2	7.6	6.8	7.0	6.7	7.1	6.2	**7.0**	170
	over one month	8.2	8.3	7.6	7.7	7.6	7.7	7.6	**7.9**	77
Death	Expected	7.5	7.9	7.2	7.1	6.9	7.3	6.6	**7.3**	300
	Sudden	7.1	7.5	6.6	6.6	6.5	7.2	6.0	**7.1**	60
H99	**All HFH Hospitals**	**7.5**	**7.8**	**7.1**	**7.1**	**6.9**	**7.3**	**6.5**	**7.3**	**360**

Table shows responses with regard to 360 out of 530 patients with whom at least some discussion took place (Q1D1.1).

Table 5.6: Patient's Wishes

		1	2	3	4	5	6	7	8	9	10	11	12			
Q1 D6	**Question** **Category**	**How long to live**	**Pain Control**	**No Resuscitation**	**Contacting Relatives**	**Asking for Single Room**	**Care at Home**	**Financial Burden**	**Pastoral/Spiritual Care**	**Changing Will**	**Arranging Funeral**	**Donating Organs**	**Other**	**Average No. of Wishes**	**Avg. No. Documented**	**Number of Cases (n)**
	Yes	%	%	%	%	%	%	%	%	%	%	%	%			
A / C	Acute Hospitals	9	74	33	21	12	16	1	45	3	3	1	3	**1.3**	**.8**	280
	Comm. Hospitals	9	84	40	21	7	2	2	44	2	7	2	0	**1.6**	**1.4**	43
Ward	A & E	50	50	0	0	0	50	0	0	0	0	0	0	**.3**	**.0**	2
	Intensive Care	3	74	26	26	0	9	0	43	0	3	3	6	**1.0**	**.5**	35
	Surgical	8	74	26	15	10	13	3	44	5	5	0	0	**1.1**	**.8**	39
	Medical	7	73	34	22	12	16	1	44	2	1	1	2	**1.3**	**.8**	151
	Oncology	15	81	27	23	27	31	0	46	0	4	0	12	**2.1**	**1.1**	26
	Geriatric	10	76	44	24	6	4	2	52	4	8	4	0	**1.7**	**1.5**	50
	Other	20	85	50	15	20	15	0	50	5	5	0	0	**1.5**	**.8**	20
Room	Single	11	77	31	20	18	20	1	46	3	2	1	4	**1.5**	**.9**	166
	Multi-occupancy	6	73	37	23	4	8	1	45	2	4	2	1	**1.2**	**.8**	157
MDC	Cancer	15	80	33	25	19	22	2	50	5	5	1	3	**2.1**	**1.2**	134
	Circulatory/Organs	1	67	33	19	7	12	0	49	0	0	0	1	**.9**	**.5**	69
	Respiratory	3	80	37	20	5	10	2	35	0	5	0	3	**1.2**	**.8**	60
	Frailty/Dementia	0	56	31	13	6	6	0	44	0	0	0	0	**.8**	**.8**	16
	Other	11	73	36	20	5	2	0	39	2	2	7	2	**1.1**	**.8**	44
Sex	Male	9	76	29	21	12	18	2	36	4	4	1	2	**1.4**	**.8**	169
	Female	8	74	40	22	10	10	1	55	1	3	3	3	**1.3**	**.9**	154
Age	under 45	10	70	10	50	40	20	10	20	0	0	0	10	**1.7**	**.6**	10
	45 to 64	22	76	41	31	22	24	2	53	8	6	0	4	**2.0**	**1.1**	49
	65 to 84	6	76	30	20	6	13	0	42	1	3	2	2	**1.2**	**.8**	195
	85 to 100	7	71	43	14	13	9	3	52	3	3	1	1	**1.2**	**.8**	69
Stay	under 1 day	6	76	24	12	12	24	0	35	0	0	0	6	**.7**	**.3**	17
	1 day – 1 week	8	78	37	24	9	9	1	49	1	1	1	3	**1.2**	**.8**	76
	1 week – 1 month	10	75	34	21	11	14	2	43	3	4	1	3	**1.5**	**.9**	159
	over one month	7	72	34	23	14	17	0	49	4	4	3	0	**1.5**	**1.1**	71
Death	Expected	9	75	35	21	11	16	1	47	3	4	2	2	**1.5**	**1.0**	281
	Sudden	5	76	26	24	10	5	0	33	0	0	0	5	**.7**	**.4**	42
H99	**All HFH Hospitals**	**9**	**75**	**34**	**21**	**11**	**14**	**1**	**45**	**2**	**3**	**2**	**2**	**1.3**	**.8**	**323**

Table shows responses with regard to 323 out of 530 patients with whom at least some discussion took place (Q1D1.1).

Table 5.7: Patient's Documented Preferences for End of Life Care

Q1D8	**Hospital**	Yes %	No %	Missing %	Total %
	Acute Hospitals	0.8	65.3	33.9	100
	Comm. Hospitals	5.0	56.3	38.7	100
H99	**All HFH Hospitals**	**1.3**	**64.3**	**34.4**	**100**

Table 5.8: Staff Rating of Hospital Response to Patient's Wishes

		1	2	3	4	5	6	7	8	9	10	11	12	
Q1 D7	**Question** / **Category**	**How long to live**	**Pain Management**	**Resuscitation**	**Contacting Relatives**	**Asking for Single Room**	**Care at Home**	**Financial Burden**	**Pastoral/Spiritual Care**	**Changing Will**	**Funeral Arrangements**	**Organ Donation**	**Other**	**Mean Score**
	Yes	**M**	**M**	**M**	**M**	**M**	**M**	**M**	**M**	**M**	**M**	**M**	**M**	**M**
A / C	Acute Hospitals	6.9	7.6	7.4	7.7	8.1	5.6	4.7	8.0	8.0	7.1	7.0	3.8	6.9
	Comm. Hospitals	2.3	6.5	7.9	7.8	8.7	5.0	7.0	7.1	9.0	8.0	10.0		6.3
Ward	A & E	10.0	10.0											7.5
	Intensive Care	5.0	7.6	8.0	8.3		9.3		8.5				5.0	6.9
	Surgical	5.0	7.7	5.3	9.3	9.0	3.8	7.0	7.9	8.5	10.0			6.7
	Medical	6.8	7.4	6.9	6.8	8.3	5.4	3.5	7.6	6.3	8.0	9.0	3.3	6.7
	Oncology	7.0	8.6	9.0	8.3	8.4	6.9		8.8		1.0		3.3	7.8
	Geriatric	3.8	7.1	8.4	8.2	8.7	7.5	7.0	7.5	9.5	8.5	10.0		7.0
	Other	7.3	6.6	8.9	10.0	5.5	3.0		9.1	10.0	10.0			6.3
Room	Single	6.4	7.4	7.9	7.5	8.9	5.7	7.0	8.1	7.2	5.3	9.0	5.0	6.9
	Multi-occupancy	5.9	7.5	7.1	7.9	4.0	5.3	3.5	7.7	9.7	8.6	6.7	.0	6.8
MDC	Cancer	6.6	7.9	8.7	8.7	8.3	5.5	7.0	8.3	7.9	7.9	10.0	2.5	7.3
	Circulatory/Organs	5.0	6.3	5.2	6.5	5.8	5.5		7.6					6.2
	Respiratory	3.5	7.4	7.4	7.5	9.7	7.0		7.9		5.3		5.0	6.9
	Frailty/Dementia		5.3	5.6	9.5	7.0	5.0		3.7					5.0
	Other	6.0	8.1	8.1	5.9	9.5	.0		8.7	10.0	10.0	6.0	10.0	6.9
Sex	Male	6.9	7.7	7.8	7.6	7.5	5.5	7.0	8.3	7.7	6.0	10.0	5.0	7.0
	Female	5.3	7.2	7.2	7.9	8.9	5.7		7.7	9.5	9.0	7.0	2.5	6.6
Age	under 45	9.0	9.7	10.0	5.4	9.8	5.0	7.0	10.0				10.0	8.2
	45 to 64	7.4	8.3	9.0	9.7	8.7	5.6	7.0	9.5	6.8	3.7		5.0	7.7
	65 to 84	5.9	7.5	7.4	7.6	7.3	5.6		7.6	9.5	8.5	7.0	2.5	6.9
	85 to 100	3.8	6.3	6.4	6.5	7.8	5.7	3.5	7.3	9.5	9.5	10.0		5.9
Stay	under 1 day	10.0	6.5	7.8	9.5	10.0	3.0		5.0				10.0	5.9
	1 day – 1 week	6.8	7.0	6.9	7.7	7.0	8.7		7.6	10.0	6.0	.0		6.5
	1 week – 1 month	5.9	7.7	7.3	7.9	8.2	4.8	7.0	8.5	6.8	7.3	9.0	4.0	6.9
	over one month	5.8	7.7	8.4	7.2	8.4	6.0		7.7	9.3	8.0	10.0		7.4
Death	Expected	6.0	7.6	7.7	7.8	8.5	5.6	5.3	8.0	8.1	7.4	7.6	3.3	6.9
	Sudden	9.0	6.6	5.3	7.0	5.3	4.0		7.0				5.0	6.4
H99	**All HFH Hospitals**	**6.2**	**7.4**	**7.5**	**7.7**	**8.1**	**5.6**	**5.3**	**7.9**	**8.1**	**7.4**	**7.6**	**3.8**	**6.8**
	Number of Cases	28	242	110	69	36	46	4	146	8	11	5	8	316

Note: Each cell has a different underlying number of cases (n). This can be computed out of the row percentages in Table 5.6, multiplied by the number of cases in the last column of that row. Note that, for many of the above figures, the underlying (n) is very small.

6 Communication with Relatives or Friends (E)

Table 6.1: Discussion with Relatives

	Item No.	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**(9)**			
Q1 E1	**Question** / **Category**	**Situation and Prognosis**	**Aims of Care**	**Benefit versus Burden**	**Expectation**	**Patient's Concerns**	**Resuscitation**	**Place of Care**	**Location of Dying**	**Any Other Discussion**	**1+ Communication**	**1+ Comm. Documented**	
	Yes	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**n**
A / C	Acute Hospitals	86	65	65	59	27	68	25	19	7	**96**	**80**	865
	Comm. Hospitals	76	65	59	45	33	39	42	25	15	**96**	**78**	114
Ward	A & E	68	23	38	38	8	43	5	5	15	**83**	**45**	40
	Intensive Care	93	60	71	63	17	74	9	5	6	**99**	**85**	179
	Surgical	82	61	54	53	27	63	24	18	9	**96**	**77**	119
	Medical	86	69	67	60	31	66	31	24	7	**96**	**80**	409
	Oncology	91	83	74	74	57	81	48	45	0	**100**	**93**	42
	Geriatric	77	69	60	47	31	44	41	26	12	**95**	**79**	131
	Other	84	70	75	58	27	75	36	22	10	**97**	**81**	59
Room	Single	90	75	72	64	34	71	35	27	5	**97**	**85**	433
	Multi-occupancy	82	57	59	52	23	59	21	15	11	**95**	**76**	546
MDC	Cancer	86	74	70	62	47	69	41	35	9	**97**	**86**	228
	Circulatory/Organs	86	63	64	56	22	66	23	16	6	**94**	**76**	305
	Respiratory	88	67	69	61	22	62	25	14	7	**97**	**84**	184
	Frailty/Dementia	85	64	68	51	23	63	28	21	9	**96**	**80**	75
	Other	81	55	55	52	21	59	20	14	11	**96**	**74**	187
Sex	Male	84	66	64	57	27	63	29	20	9	**96**	**78**	494
	Female	86	64	65	58	29	66	26	20	7	**97**	**82**	485
Age	under 45	97	69	66	59	38	72	38	24		**97**	**86**	29
	45 to 64	85	68	73	63	38	70	28	28	5	**96**	**83**	120
	65 to 84	85	65	63	57	26	63	26	18	9	**96**	**78**	592
	85 to 100	85	64	63	55	27	64	29	21	8	**96**	**82**	238
Stay	under 1 day	72	36	41	42	9	55	15	11	12	**87**	**55**	121
	1 day – 1 week	88	61	62	58	21	65	20	17	7	**97**	**82**	290
	1 week – 1 month	88	73	73	61	35	68	33	23	7	**98**	**85**	378
	over one month	84	73	68	57	36	62	36	24	9	**96**	**84**	190
Death	Expected	88	72	69	62	32	68	32	25	8	**98**	**84**	751
	Sudden	77	42	49	42	15	54	11	4	9	**89**	**65**	228
H99	**All HFH Hospitals**	**85**	**65**	**65**	**57**	**28**	**64**	**27**	**20**	**8**	**96**	**80**	**979**

Table shows 'Yes' Responses only. Don't know, n/a and missing coded 'No'.
Last two column show where at least one type of communication and documentation took place.

Table 6.2: Reasons for not Discussing with Relatives

Q1D2	Reason	A&E %	Intensive Care %	Other Wards %	All Wards %
1	Patient died suddenly	87.5	100.0	73.9	76.8
2	No medical diagnosis or awareness of dying	25.0	100.0	37.0	37.5
3	Patient did not want to talk about dying	0.0	0.0	0.0	0.0
4	Relatives did not want patient to be told	12.5			1.8
5	Lack of privacy	12.5		4.3	5.4
6	Medical staff lacking experience	0.0	0.0	0.0	0.0
7	Nursing staff lacking experience	0.0	0.0	0.0	0.0
8	Other reason	12.5		4.3	5.4

Note: Table applies only to those cases where staff did not talk to patients; i.e. the 4.0% of cases which complement the second last column of Table 6.1 (n = 56).

Table 6.3: Patient's Knowledge about Discussion with Relatives

Q1E2		Yes %	No %	Total %
1	Patient knows about Relative's discussion	17.2	82.8	100.0
2	Patient consents to Relative's discussion	12.5	87.5	100.0

Note: Table applies only to those cases where staff did communicate with relatives (n = 943).

Table 6.4a: Time between Diagnosis of Dying and Discussion with Relatives

Q1E5 **Q1C3**	**Time of Discussion** **Diagnosis of Dying**	**no discuss**	**under 1 day**	**1 day – 1 week**	**1 week – 1 month**	**over one month**	**Total**
	no diagnosis	18.2	3.5	4.1	3.1	.6	**29.5**
	under 1 day	4.7	9.7	2.0	.8	.2	**17.4**
	1 day – 1 week	5.7	1.9	22.0	3.2	.3	**33.1**
	1 week – 1 month	4.7	.1	2.8	9.3	.2	**17.1**
	over one month	.9	.2	.2	1.0	.5	**2.8**
	Total	**34.2**	**15.4**	**31.1**	**17.4**	**1.8**	**100.0**

Table 6.4b: Time before Dying and Discussion with Relatives

Q1D4 **Q1C3**	**Time of Discussion**	**no discuss-ion**	**under 1 day**	**1 day – 1 week**	**1 week – 1 month**	**over one month**	**Total**
	Acute Hospitals	32.4	16.9	33.5	15.9	1.3	**100**
	Comm. Hospitals	47.9	4.2	13.4	28.6	5.9	**100**
H99	**All HFH Hospitals**	**34.2**	**15.4**	**31.1**	**17.4**	**1.8**	**100**

Table 6.5: Persons initiating and participating in Discussion with Relative

Q1E4	Person	Initiating Discussion %	Participating in Discussion %
1+2	Doctor or specialist doctor	85.2	42.2
3+4	Nurse or specialist nurse	73.2	43.7
5	Patient	9.7	10.0
6	Relative or Friend	46.8	33.8

Note1: Table applies only to cases where it is known that a discussion with relative took place (Q1E1) and where information was provided with respect to who initiated it or took part (n = 890).
Note2: Sums may add up to more than 100%, as they may relate to different types of communications.
Note3: Participation of Relative may be understated as it is implied in the phrasing of the question.

Table 6.6: Staff Rating of Discussion with Relative

		1	2	3	4	5	6	7		
Q1 E6	**Category**	**Sensitive**	**Open and honest**	**Reassuring**	**Expressing Concerns**	**Expressing Preferences**	**Asking Questions**	**Making decisions**	**Mean Score**	**Number of Cases (n)**
	Yes	**M**	**M**	**M**	**M**	**M**	**M**	**M**	**M**	**M**
A / C	Acute Hospitals	8.3	8.7	8.1	8.6	8.3	8.8	8.5	8.5	755
	Comm. Hospitals	8.6	8.9	8.7	8.9	8.9	9.2	9.1	8.9	94
Ward	A & E	8.7	9.0	7.8	8.5	8.3	9.0	8.3	8.5	29
	Intensive Care	8.7	8.9	8.2	8.8	8.5	9.1	8.7	8.7	163
	Surgical	8.2	8.7	8.0	8.7	8.2	8.9	8.3	8.4	101
	Medical	8.2	8.5	8.1	8.4	8.2	8.6	8.3	8.3	355
	Oncology	8.8	8.9	8.5	9.0	9.0	9.1	8.7	8.9	39
	Geriatric	8.4	8.8	8.6	8.8	8.8	9.1	8.9	8.8	110
	Other	8.5	9.0	8.7	8.8	8.9	9.1	8.9	8.8	52
Room	Single	8.5	8.8	8.4	8.8	8.7	9.0	8.7	8.7	387
	Multi-occupancy	8.2	8.6	8.1	8.4	8.2	8.7	8.4	8.4	462
MDC	Cancer	8.4	8.7	8.2	8.7	8.7	8.9	8.6	8.6	204
	Circulatory/Organs	8.2	8.6	8.1	8.5	8.2	8.7	8.5	8.4	256
	Respiratory	8.4	8.7	8.3	8.6	8.4	8.8	8.5	8.5	164
	Frailty/Dementia	8.3	8.7	8.3	8.7	8.7	9.0	8.8	8.6	62
	Other	8.5	8.8	8.3	8.6	8.3	8.9	8.4	8.5	163
Sex	Male	8.3	8.6	8.1	8.6	8.3	8.8	8.4	8.4	427
	Female	8.5	8.8	8.3	8.7	8.5	8.9	8.7	8.6	422
Age	under 45	8.6	9.0	7.7	8.2	8.3	8.8	8.6	8.4	26
	45 to 64	8.7	9.1	8.4	9.0	8.9	9.2	8.8	8.9	108
	65 to 84	8.3	8.6	8.2	8.5	8.3	8.8	8.4	8.4	509
	85 to 100	8.3	8.7	8.3	8.6	8.5	8.8	8.7	8.5	206
Stay	under 1 day	8.4	8.7	7.8	8.3	8.0	8.8	8.4	8.3	87
	1 day – 1 week	8.4	8.7	8.2	8.5	8.2	8.8	8.3	8.4	257
	1 week – 1 month	8.3	8.7	8.2	8.7	8.5	8.8	8.6	8.5	338
	over one month	8.5	8.8	8.5	8.9	8.8	9.1	8.8	8.7	167
Death	Expected	8.4	8.7	8.3	8.7	8.5	8.9	8.6	8.6	677
	Sudden	8.4	8.7	8.0	8.4	8.1	8.7	8.2	8.4	172
H99	**All HFH Hospitals**	**8.4**	**8.7**	**8.2**	**8.6**	**8.4**	**8.8**	**8.5**	**8.5**	**849**

Table shows responses with regard to 849 out of 943 relative with whom at least some discussion took place (Q1E1.1).

Table 6.7: Relative's Wishes

		1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**			
Q1 E7	**Question** **Category**	**Asking for Single Room**	**Pain Control**	**Being kept informed**	**Knowing when dying**	**Knowing about dying**	**About Resuscitation**	**To stay by bedside**	**Religious Service**	**Donating Organs**	**Arranging Funeral**	**Help with Grief**	**Other**	**Mean No. of Wishes**	**Mean. No. Documented**	**Number of Cases (n)**
	Yes	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**			**n**
A / C	Acute Hospitals	21	62	94	76	21	20	79	59	2	27	8	2	**4.4**	**1.8**	777
	Comm. Hospitals	11	49	95	78	26	11	67	47	1	26	8	2	**4.0**	**2.4**	104
Ward	A & E	0	46	62	73	19	31	58	65	0	58	38	4	**3.6**	**1.1**	26
	Intensive Care	3	56	95	84	26	25	84	63	5	32	7	5	**4.5**	**1.6**	167
	Surgical	29	63	93	72	18	23	74	53	0	31	10	3	**4.4**	**1.7**	108
	Medical	27	64	95	74	19	16	78	57	2	24	7	1	**4.4**	**1.9**	368
	Oncology	23	74	92	77	26	13	87	54	0	15	5	3	**4.4**	**2.2**	39
	Geriatric	15	57	95	80	27	14	69	57	1	29	9	2	**4.3**	**2.4**	117
	Other	25	52	96	71	16	18	80	61	2	16	2	2	**4.3**	**2.4**	56
Room	Single	32	72	96	77	24	19	83	60	1	27	8	3	**4.7**	**2.1**	397
	Multi-occupancy	10	52	92	76	19	19	73	57	2	27	8	2	**4.0**	**1.7**	484
MDC	Cancer	29	73	95	81	23	16	81	56	1	25	8	4	**4.8**	**2.3**	216
	Circulatory/Organs	20	57	93	77	23	18	76	61	2	28	8	2	**4.2**	**1.6**	262
	Respiratory	16	57	95	74	19	24	76	55	2	21	7	1	**4.2**	**2.0**	168
	Frailty/Dementia	17	51	94	74	17	14	71	52	1	26	7	1	**4.1**	**1.9**	69
	Other	13	58	92	73	21	20	80	61	2	34	10	2	**4.3**	**1.8**	166
Sex	Male	19	62	92	77	19	16	78	57	2	28	8	3	**4.3**	**1.8**	443
	Female	21	60	95	76	24	21	76	59	2	26	8	2	**4.4**	**2.0**	438
Age	under 45	33	54	88	75	33	17	92	75	13	38	13	0	**4.5**	**2.3**	24
	45 to 64	19	58	88	78	27	17	80	53	3	30	8	5	**4.5**	**2.1**	111
	65 to 84	19	66	94	78	22	19	78	59	2	27	8	3	**4.4**	**1.8**	525
	85 to 100	21	49	96	73	16	18	73	57	0	23	8	1	**4.2**	**1.9**	221
Stay	under 1 day	10	53	83	72	15	24	71	59	1	36	15	1	**3.8**	**1.1**	92
	1 day – 1 week	19	58	93	75	20	17	77	55	2	30	9	3	**4.3**	**1.7**	264
	1 week – 1 month	23	66	97	79	24	22	81	61	2	24	5	3	**4.5**	**2.1**	347
	over one month	21	58	95	76	22	12	74	57	1	23	9	2	**4.4**	**2.3**	178
Death	Expected	22	62	95	79	22	18	79	59	2	25	7	2	**4.5**	**2.1**	707
	Sudden	10	55	87	67	18	22	69	52	3	34	13	2	**3.7**	**1.1**	174
H99	**All HFH Hospitals**	**20**	**61**	**94**	**77**	**21**	**19**	**77**	**58**	**2**	**27**	**8**	**2**	**4.4**	**1.9**	**881**

Table shows responses with regard to 881 out of 943 relatives with whom at least some discussion took place (Q1E1.1).

Table 6.8: Staff Rating of Hospital Response to Relative's Wishes

		1	2	3	4	5	6	7	8	9	10	11	12	
Q1 E8	**Category**	**Asking for Single Room**	**Pain Control**	**Being kept informed**	**Knowing when dying**	**Knowing about dying**	**About Resuscitation**	**To stay by bedside**	**Religious Service**	**Donating Organs**	**Arranging Funeral**	**Help with Grief**	**Other**	**Average Percentage**
	Yes	**M**	**M**	**M**	**M**	**M**	**M**	**M**	**M**	**M**	**M**	**M**	**M**	**M**
A / C	Acute Hospitals	8.0	8.3	8.9	8.6	8.0	7.9	9.2	9.0	7.7	7.9	7.5	5.0	**8.4**
	Comm. Hospitals	6.7	7.7	8.7	8.1	7.0	7.7	9.0	8.4	10.0	8.5	8.6	.0	**8.0**
Ward	A & E		6.1	8.5	7.3	7.6	9.0	8.9	8.5		6.7	6.7	.0	**6.6**
	Intensive Care	5.6	8.2	9.1	8.7	7.8	8.1	9.2	9.6	9.4	8.1	9.8	6.6	**8.7**
	Surgical	8.2	8.5	8.9	8.6	7.6	7.8	9.1	9.0		7.8	7.2	3.3	**8.5**
	Medical	8.1	8.2	8.7	8.5	7.8	7.9	9.2	8.8	5.2	8.2	7.3	5.2	**8.4**
	Oncology	8.9	8.4	9.0	8.9	9.2	4.2	9.4	8.8		6.2	5.5	6.0	**8.6**
	Geriatric	7.9	8.1	8.9	8.4	7.5	8.0	9.1	8.6	10.0	8.2	8.1	.0	**8.2**
	Other	6.7	8.4	8.5	8.6	8.9	8.7	8.9	7.9	9.0	7.3	6.0	.0	**8.0**
Room	Single	8.7	8.6	9.0	8.8	8.7	8.0	9.3	9.0	6.2	8.3	7.7	4.3	**8.6**
	Multi-occupancy	6.0	7.7	8.7	8.3	6.9	7.9	9.1	8.8	8.5	7.6	7.6	4.9	**8.1**
MDC	Cancer	8.5	8.3	8.7	8.6	8.7	6.9	9.0	8.8	5.0	8.1	7.3	2.3	**8.4**
	Circulatory/Organs	7.8	8.0	9.0	8.4	7.8	8.4	9.2	8.9	8.0	8.3	7.9	3.2	**8.4**
	Respiratory	7.6	8.2	8.6	8.3	7.3	8.3	9.2	8.9	6.3	8.2	7.8	10.0	**8.2**
	Frailty/Dementia	6.4	8.3	8.7	8.8	8.0	6.4	9.0	9.0	10.0	8.2	9.2	10.0	**8.2**
	Other	8.1	8.4	9.1	8.6	7.3	8.2	9.2	9.1	10.0	7.2	7.1	7.0	**8.4**
Sex	Male	7.7	8.2	8.8	8.5	7.6	7.8	9.1	8.7	9.4	7.6	7.5	3.6	**8.3**
	Female	8.2	8.2	8.9	8.6	8.0	8.0	9.3	9.1	5.7	8.4	7.8	6.0	**8.4**
Age	under 45	8.3	8.7	8.9	9.3	8.8	6.8	9.5	9.6	10.0	8.7	9.7		**8.6**
	45 to 64	8.0	9.1	9.4	8.8	8.2	8.6	9.2	9.4	8.7	8.0	8.7	8.8	**8.8**
	65 to 84	8.2	8.1	8.8	8.4	7.8	7.9	9.1	8.9	6.6	7.7	6.6	2.9	**8.3**
	85 to 100	7.3	8.1	8.7	8.5	7.5	7.7	9.1	8.7	10.0	8.5	9.2	5.0	**8.3**
Stay	under 1 day	8.3	7.9	8.5	8.1	6.4	8.0	9.0	9.1	10.0	7.4	7.3	.0	**7.9**
	1 day – 1 week	8.4	8.0	8.8	8.4	8.0	7.5	8.9	9.3	8.2	7.7	7.5	7.3	**8.3**
	1 week – 1 month	8.0	8.3	8.9	8.6	7.9	8.4	9.3	8.8	7.0	8.2	7.1	3.9	**8.4**
	over one month	7.2	8.4	9.0	8.7	8.1	7.2	9.4	8.7	10.0	8.4	8.8	2.3	**8.5**
Death	Expected	8.0	8.3	8.9	8.6	7.9	7.9	9.2	8.8	6.8	8.0	7.5	4.4	**8.4**
	Sudden	7.2	7.7	8.5	8.1	7.8	8.1	9.0	9.4	10.0	7.7	8.0	5.0	**8.0**
H99	**All HFH Hospitals**	**8.0**	**8.2**	**8.8**	**8.5**	**7.8**	**7.9**	**9.2**	**8.9**	**7.8**	**8.0**	**7.7**	**4.5**	**8.3**
	Number of Cases	176	535	826	674	189	165	682	511	16	237	72	21	878

Note: Each cell has a different underlying number of cases (n). This can be computed out of the respective percentages in Table 5.6, multiplied by the number of cases in the last column of the same table. Thus, for many of the above figures, the underlying (n) is very small!

Table 6.9: Special Supports for Relatives

		1	2	3	4	5	6
Q1 E9	**Category**	**Opportunity to stay overnight**	**Stay overnight**	**Free to visit any time**	**Offered free food and drink**	**Offered preferential car parking**	**Offered information on dying**
	Yes	**%**	**%**	**%**	**%**	**%**	**%**
A / C	Acute Hospitals	69	49	88	78	13	14
	Comm. Hospitals	66	32	90	82	66	23
Ward	A & E	17	7	63	81	12	29
	Intensive Care	74	49	88	78	8	18
	Surgical	60	42	87	79	7	12
	Medical	73	51	90	75	12	10
	Oncology	82	77	93	86	30	18
	Geriatric	69	34	90	81	61	23
	Other	69	53	90	86	26	23
Room	Single	78	60	93	83	19	16
	Multi-occupancy	62	37	85	75	19	15
MDC	Cancer	77	59	94	83	19	16
	Circulatory/Organs	70	47	87	78	17	17
	Respiratory	66	41	89	74	15	13
	Frailty/Dementia	67	41	90	76	34	16
	Other	60	42	84	78	29	15
Sex	Male	67	44	87	77	16	14
	Female	72	50	90	79	22	17
Age	under 45	65	61	81	77	13	23
	45 to 64	73	54	88	80	16	28
	65 to 84	69	47	88	78	17	12
	85 to 100	68	43	91	77	26	16
Stay	under 1 day	39	30	71	69	14	17
	1 day – 1 week	70	47	89	79	10	14
	1 week – 1 month	77	53	93	79	17	14
	over one month	72	47	90	82	41	18
Death	Expected	78	54	94	82	22	15
	Sudden	40	24	70	67	9	16
H99	**All HFH Hospitals**	**69**	**47**	**88**	**78**	**19**	**15**

7 Discussion about Treatment (F)

Table 7.1N: Decisions about Treatment (Nurses)

Q1 F1		1	2	3	4	5	6	7	8	9	10	11			
	Question **Category**	**Aim curative v. palliative**	**Optimise Comfort**	**Stop non-essential Med.**	**Stop blood tests**	**Stop antibiotics**	**Review hydration**	**Stop invasive monitoring**	**Withhold treatment**	**Withdraw treatment**	**Talk about resuscitation**	**Assess skin integrity**	**Mean No. of Decisions**	**Mean No. Documented**	**Number of Cases (n)**
	Yes	%	%	%	%	%	%	%	%	%	%	%			
A / C	Acute Hospitals	60	76	70	49	42	53	41	47	39	75	80	**6.3**	**4.9**	846
	Comm. Hospitals	64	79	78	36	31	62	34	28	18	55	83	**5.7**	**4.4**	118
Ward	A & E	7	7	3	7	3	7	10	7	17	27	3	**1.0**	**.6**	30
	Intensive Care	61	72	63	34	29	32	12	47	44	76	75	**5.4**	**4.1**	174
	Surgical	58	76	73	46	33	55	40	41	29	73	82	**6.1**	**4.4**	119
	Medical	62	79	75	54	49	60	50	49	39	78	85	**6.8**	**5.3**	408
	Oncology	56	91	84	67	60	67	65	58	42	88	93	**7.7**	**6.8**	43
	Geriatric	69	82	82	42	39	66	42	34	25	60	85	**6.3**	**5.0**	131
	Other	58	80	71	54	39	64	46	42	34	64	85	**6.4**	**5.3**	59
Room	Single	65	84	80	61	54	64	52	54	44	78	87	**7.2**	**5.8**	428
	Multi-occupancy	56	70	64	36	29	46	30	37	29	69	75	**5.4**	**4.1**	536
MDC	Cancer	67	87	84	61	54	68	57	55	42	80	92	**7.5**	**6.1**	228
	Circulatory/Organs	58	71	65	45	38	47	33	44	34	72	76	**5.8**	**4.4**	294
	Respiratory	65	81	73	45	36	53	37	40	37	75	83	**6.2**	**5.1**	183
	Frailty/Dementia	55	72	67	40	39	60	40	37	31	64	79	**5.8**	**4.5**	75
	Other	52	66	67	39	31	47	33	39	33	66	73	**5.5**	**3.9**	184
Sex	Male	59	75	72	46	39	52	39	43	34	71	81	**6.1**	**4.7**	482
	Female	61	77	71	48	42	56	41	46	38	74	80	**6.3**	**5.0**	482
Age	under 45	59	48	55	34	34	34	31	48	41	62	72	**5.2**	**4.7**	29
	45 to 64	60	81	71	51	41	49	39	53	42	73	78	**6.4**	**5.2**	116
	65 to 84	60	75	71	46	41	52	40	45	37	73	80	**6.2**	**4.9**	580
	85 to 100	60	78	76	48	38	63	43	39	31	73	84	**6.3**	**4.7**	239
Stay	under 1 day	33	43	35	25	15	29	24	28	20	53	47	**3.5**	**2.6**	106
	1 day – 1 week	61	73	68	41	32	46	35	44	37	76	82	**6.0**	**4.4**	291
	1 week – 1 month	65	83	80	55	50	62	47	49	41	79	87	**7.0**	**5.7**	377
	over one month	64	84	79	53	48	64	42	45	34	66	84	**6.6**	**5.2**	190
Death	Expected	68	85	82	56	49	63	48	50	39	80	89	**7.1**	**5.5**	745
	Sudden	33	47	37	16	12	22	14	24	25	48	52	**3.3**	**2.5**	219
H99	**All HFH Hospitals**	**60**	**76**	**71**	**47**	**40**	**54**	**40**	**44**	**36**	**73**	**81**	6.2	4.9	**964**

Note: Columns show 'Yes' percentages of all cases. 'n/a' is recoded to 'no' throughout.

Table 7.1D: Decisions about Treatment (Doctors)

Q1 B1		1	2	3	4	5	6	7	8	9	10			
	Question Category	Aim curative v. palliative	Optimise Comfort	Stop non-essential Med.	Stop blood tests	Stop antibiotics	Review hydration	Stop invasive monitoring	Withhold treatment	Withdraw treatment	Talk about resuscitation	Mean No. of Decisions	Mean No. Documented	Number of Cases (n)
	Yes	%	%	%	%	%	%	%	%	%	%			
A / C	Acute Hospitals	73	78	70	61	44	58	40	59	46	75	6.0	4.5	636
	Comm. Hospitals	78	88	80	63	45	66	50	49	19	70	6.1	3.4	101
Ward	A & E	24	14	7	17	3	10	7	21	17	21	1.4	1.0	29
	Intensive Care	70	73	64	51	38	48	29	58	45	73	5.5	4.3	124
	Surgical	76	86	73	64	47	58	38	55	44	78	6.2	4.4	88
	Medical	78	83	76	66	49	64	47	64	48	78	6.5	4.9	300
	Oncology	66	86	83	71	51	63	60	60	46	86	6.7	5.1	35
	Geriatric	80	88	81	69	50	70	50	52	27	76	6.4	3.9	115
	Other	72	80	67	59	35	54	37	54	41	70	5.7	3.8	46
Room	Single	78	87	79	71	54	67	48	65	48	81	6.8	5.0	336
	Multi-occupancy	70	74	65	54	36	52	36	51	37	69	5.4	3.9	401
MDC	Cancer	84	93	85	73	53	69	48	62	48	80	6.9	5.2	176
	Circulatory/Organs	68	73	65	55	40	56	38	55	35	71	5.6	3.8	220
	Respiratory	78	81	68	61	45	59	42	60	47	83	6.3	4.9	139
	Frailty/Dementia	70	73	73	63	45	68	39	55	34	61	5.8	3.7	56
	Other	67	74	68	56	40	47	39	54	43	71	5.6	3.9	146
Sex	Male	72	79	72	62	46	59	41	56	42	72	6.0	4.6	378
	Female	75	80	71	61	43	58	42	59	43	77	6.1	4.2	359
Age	under 45	67	71	71	54	42	50	25	71	54	71	5.8	5.2	24
	45 to 64	72	78	73	66	49	59	41	60	48	78	6.2	4.5	92
	65 to 84	74	79	70	59	43	58	42	56	42	74	6.0	4.4	448
	85 to 100	74	82	75	65	46	61	45	57	39	75	6.2	4.1	173
Stay	under 1 day	45	40	36	31	18	29	24	38	34	47	3.4	2.6	96
	1 day – 1 week	72	78	69	62	40	55	42	57	43	79	6.0	4.4	214
	1 week – 1 month	80	89	80	67	50	65	43	63	46	78	6.6	4.8	280
	over one month	81	90	82	69	57	71	50	60	37	79	6.8	4.6	147
Death	Expected	81	88	81	70	50	67	47	63	46	82	6.8	4.9	564
	Sudden	48	52	41	34	27	32	24	39	30	50	3.8	2.6	173
H99	**All HFH Hospitals**	**74**	**80**	**72**	**61**	**45**	**59**	**42**	**57**	**42**	**74**	**6.0**	**4.4**	**737**

Note: Columns show 'Yes' percentages of all cases. 'n/a' is recoded to 'no' throughout.
Note: Based on matched cases only (n=737).

Table 7.2aN: Symptoms during last Week of Life (Nurses)

		F2.1.1	F2.2.1	F2.3.1	F2.4.1	F2.5.1	F2.6.1	
Q1 F2	**Question** **Category**	**Pain**	**Nausea**	**Breathing**	**Secretions**	**Restlessness**	**Anxiety**	**Number of Cases (n)**
	% all / most of the time	**%**	**%**	**%**	**%**	**%**	**%**	
A / C	Acute Hospitals	15.4	6.1	41.7	20.1	16.9	13.7	846
	Comm. Hospitals	17.9	2.8	30.4	19.3	15.5	7.8	118
Ward	A & E	54.5	50.0	55.6	33.3	33.3	33.3	30
	Intensive Care	15.7	8.3	46.3	19.2	10.9	15.7	174
	Surgical	13.1	4.8	44.5	23.1	18.0	11.4	119
	Medical	14.0	4.7	37.8	17.3	17.4	12.9	408
	Oncology	14.6	5.3	52.5	31.6	17.9	12.8	43
	Geriatric	17.1	2.5	32.3	20.8	16.5	7.8	131
	Other	23.1	7.8	41.1	21.2	19.6	18.0	59
Room	Single	18.2	5.7	36.6	19.8	18.6	13.4	428
	Multi-occupancy	13.6	5.6	43.4	20.1	15.1	12.5	536
MDC	Cancer	20.5	7.8	41.0	20.5	17.9	15.6	228
	Circulatory/Organs	16.5	3.5	31.0	17.1	13.8	12.8	294
	Respiratory	10.6	3.9	61.0	23.1	20.4	13.3	183
	Frailty/Dementia	3.3	.0	20.3	12.9	13.8	4.8	75
	Other	18.3	10.1	39.1	23.4	16.9	12.4	184
Sex	Male	16.6	6.6	44.1	23.6	19.9	14.8	482
	Female	14.9	4.7	36.4	16.5	13.7	11.2	482
Age	under 45	25.0	15.0	35.0	10.5	30.0	26.3	29
	45 to 64	18.4	8.7	52.1	29.2	15.5	18.7	116
	65 to 84	16.4	5.9	42.6	19.6	18.3	14.2	580
	85 to 100	12.3	2.9	30.0	17.7	12.1	6.3	239
Stay	under 1 day	15.9	9.7	42.0	19.7	15.6	11.5	106
	1 day – 1 week	16.9	5.1	43.0	18.1	19.3	15.6	291
	1 week – 1 month	14.7	5.8	42.7	21.5	14.8	11.4	377
	over one month	16.3	4.5	31.1	19.8	17.2	12.7	190
Death	Expected	15.4	4.8	41.5	20.9	17.1	12.4	745
	Sudden	17.4	9.3	34.8	15.8	15.0	15.3	219
H99	**All HFH Hospitals**	**15.8**	**5.6**	**40.3**	**20.0**	**16.7**	**12.9**	**964**

Table 7.2aD: Symptoms during last Week of Life (Doctors)

		B2.1.1	B2.2.1	B2.3.1	B2.4.1	B2.5.1	B2.6.1	
Q1 B2	Question / Category	Pain	Nausea	Breathing	Secretions	Restlessness	Anxiety	Number of Cases (n)
	% all / most of the time	%	%	%	%	%	%	
A / C	Acute Hospitals	10.7	5.9	36.7	17.7	15.9	11.6	636
	Comm. Hospitals	8.4	2.1	23.5	11.3	8.3	4.2	101
Ward	A & E	16.7	33.3	.0	28.6	.0	.0	29
	Intensive Care	10.3	7.4	37.5	20.2	12.6	13.8	124
	Surgical	14.1	1.2	45.2	21.7	22.0	13.6	88
	Medical	8.5	4.6	37.3	16.4	14.4	11.2	300
	Oncology	17.1	12.1	40.0	17.1	17.6	14.7	35
	Geriatric	8.2	2.8	23.0	14.4	12.6	4.5	115
	Other	14.6	9.5	21.4	4.8	14.3	4.9	46
Room	Single	9.6	3.6	36.7	20.4	17.1	9.8	336
	Multi-occupancy	11.0	6.8	33.1	13.6	12.8	11.1	401
MDC	Cancer	17.2	9.1	36.7	18.9	19.0	15.7	176
	Circulatory/Organs	10.4	4.3	27.0	11.5	12.9	9.5	220
	Respiratory	4.0	1.6	53.4	18.3	12.3	11.8	139
	Frailty/Dementia	5.8	1.9	17.0	13.2	15.4	2.0	56
	Other	9.5	7.3	32.0	21.9	14.3	7.3	146
Sex	Male	9.7	6.9	37.3	19.2	17.9	10.9	378
	Female	11.0	3.7	32.1	14.3	11.7	10.0	359
Age	under 45	26.3	10.5	14.3	10.0	25.0	10.5	24
	45 to 64	15.2	9.2	47.6	28.8	20.0	17.7	92
	65 to 84	10.4	4.8	36.6	16.5	13.4	10.6	448
	85 to 100	6.1	4.3	26.6	12.7	14.5	6.7	173
Stay	under 1 day	17.7	15.0	27.0	10.2	18.0	6.6	96
	1 day – 1 week	8.1	3.6	46.8	19.2	13.9	11.9	214
	1 week – 1 month	11.4	6.1	34.4	17.2	17.3	12.9	280
	over one month	8.5	2.1	21.7	15.3	9.9	5.7	147
Death	Expected	9.7	4.3	36.7	17.4	15.6	10.2	564
	Sudden	13.0	9.4	26.9	14.3	11.4	11.5	173
H99	**All HFH Hospitals**	**10.4**	**5.3**	**34.8**	**16.8**	**14.8**	**10.5**	**737**

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

Table 7.2bN: Symptoms during last Week of Life (Nurses)

		F2.1.1	F2.2.1	F2.3.1	F2.4.1	F2.5.1	F2.6.1
Q1 F2	**Question** **Category**	**Pain**	**Nausea**	**Breathing**	**Secretions**	**Restlessness**	**Anxiety or fear**
		%	**%**	**%**	**%**	**%**	**%**
	all of the time	6.5	3.1	20.1	7.2	5.4	5.1
	most of the time	9.2	2.5	20.2	12.8	11.3	7.8
	some of the time	52.8	24.0	37.5	36.7	46.3	38.7
	none of the time	31.4	70.3	22.3	43.3	37.0	48.4
	Total	**100**	**100**	**100**	**100**	**100**	**100**
	n	827	799	857	821	838	804

Table 7.2bD: Symptoms during last Week of Life (Doctors)

		B2.1.1	B2.2.1	B2.3.1	B2.4.1	B2.5.1	B2.6.1
Q1 B2	**Question** **Category**	**Pain**	**Nausea**	**Breathing**	**Secretions**	**Restlessness**	**Anxiety or fear**
		%	**%**	**%**	**%**	**%**	**%**
	all of the time	3.0	1.8	13.8	4.9	3.6	2.9
	most of the time	7.4	3.5	20.9	11.9	11.2	7.6
	some of the time	43.2	26.3	37.3	37.3	39.6	30.7
	none of the time	46.5	68.4	28.0	45.9	45.7	58.8
	Total	**100**	**100**	**100**	**100**	**100**	**100**
	n	665	658	679	673	670	658

Table 7.3N: Staff Rating Response to Symptoms (Nurses)

Q1F2	Hospital	Mean	Std. Deviation	Minimum	Maximum	n
2.1.1	Pain	8.4	2.1	1	10	118
2.2.1	Nausea	7.2	2.5	1	10	33
2.3.1	Breathing	8.2	2.0	1	10	314
2.4.1	Secretions	8.0	2.2	1	10	144
2.5.1	Restlessness	7.5	2.5	1	10	127
2.6.1	Anxiety	7.5	2.3	1	10	95

Staff response rating to patients reporting symptoms either all or most of the time.

Table 7.3D: Staff Rating Response to Symptoms (Doctors)

Q1B2	Hospital	Mean	Std. Deviation	Minimum	Maximum	n
2.1.1	Pain	6.9	2.0	1	10	62
2.2.1	Nausea	7.0	2.2	3	10	25
2.3.1	Breathing	7.3	1.8	1	10	203
2.4.1	Secretions	7.5	2.0	1	10	91
2.5.1	Restlessness	7.1	2.2	1	10	81
2.6.1	Anxiety	6.7	2.1	2	10	54

Staff response rating to patients reporting symptoms either all or most of the time.

Table 7.4N: Management of Symptoms during last Week of Life (Nurses)

		F2.1.2	F2.2.2	F2.3.2	F2.4.2	F2.5.2	F2.6.2	
Q1 F2	**Question** **Category**	**Pain**	**Nausea**	**Breathing**	**Secretions**	**Restlessness**	**Anxiety**	**Number of Cases (n)**
		mean	**mean**	**mean**	**mean**	**mean**	**mean**	
A / C	Acute Hospitals	8.3	8.2	8.3	8.2	8.0	7.8	846
	Comm. Hospitals	8.5	8.6	8.8	8.8	8.8	8.6	118
Ward	A & E	8.3	7.0	8.4	8.0	7.6	8.3	30
	Intensive Care	8.6	8.1	8.6	8.7	8.1	8.4	174
	Surgical	8.1	8.7	8.5	8.4	8.2	8.0	119
	Medical	8.2	8.1	8.1	8.1	7.9	7.6	408
	Oncology	8.4	8.2	7.7	8.1	8.4	8.1	43
	Geriatric	8.5	8.2	8.7	8.6	8.6	8.1	131
	Other	8.8	8.8	8.5	8.4	8.4	7.9	59
Room	Single	8.5	8.3	8.4	8.5	8.4	8.1	428
	Multi-occupancy	8.2	8.2	8.2	8.1	7.9	7.7	536
MDC	Cancer	8.4	8.6	8.2	8.1	8.2	8.0	228
	Circulatory/Organs	8.4	8.1	8.3	8.4	8.0	7.9	294
	Respiratory	8.2	7.8	8.3	8.1	8.2	7.8	183
	Frailty/Dementia	8.3	8.4	8.6	8.5	7.9	7.4	75
	Other	8.3	8.3	8.5	8.6	8.2	7.9	184
Sex	Male	8.3	8.1	8.2	8.2	7.9	7.8	482
	Female	8.4	8.4	8.5	8.4	8.4	8.0	482
Age	under 45	7.7	8.2	8.7	9.4	6.8	7.0	29
	45 to 64	8.6	8.3	8.4	8.6	8.5	8.3	116
	65 to 84	8.3	8.2	8.3	8.3	8.0	7.8	580
	85 to 100	8.5	8.4	8.4	8.2	8.2	7.9	239
Stay	under 1 day	8.4	8.2	8.3	8.8	8.1	8.2	106
	1 day – 1 week	8.1	7.9	8.2	8.0	7.9	7.7	291
	1 week – 1 month	8.4	8.3	8.3	8.2	8.1	8.0	377
	over one month	8.7	8.5	8.6	8.7	8.4	7.8	190
Death	Expected	8.5	8.3	8.4	8.3	8.2	8.0	745
	Sudden	7.8	7.8	7.9	8.4	7.4	7.4	219
H99	**All HFH Hospitals**	**8.3**	**8.2**	**8.3**	**8.3**	**8.1**	**7.9**	**964**

Table 7.4D: Management of Symptoms during last Week of Life (Doctors)

		B2.1.2	B2.2.2	B2.3.2	B2.4.2	B2.5.2	B2.6.2	
Q1 B2	**Question** **Category**	**Pain**	**Nausea**	**Breathing**	**Secretions**	**Restlessness**	**Anxiety**	**Number of Cases (n)**
		mean	**mean**	**mean**	**mean**	**mean**	**mean**	
A / C	Acute Hospitals	7.6	7.7	7.6	7.6	7.5	7.3	636
	Comm. Hospitals	8.5	8.5	8.5	8.9	8.1	8.4	101
Ward	A & E	6.0	6.0	.	.	.	2.0	29
	Intensive Care	8.0	8.0	8.2	7.9	8.1	7.9	124
	Surgical	7.5	8.0	7.6	7.7	7.3	7.5	88
	Medical	7.4	7.5	7.4	7.4	7.3	7.0	300
	Oncology	8.2	8.3	7.9	7.7	7.8	7.9	35
	Geriatric	8.4	8.3	8.4	8.7	8.0	8.1	115
	Other	7.7	8.3	7.7	8.2	7.7	7.4	46
Room	Single	7.8	8.1	7.9	7.8	7.6	7.6	336
	Multi-occupancy	7.7	7.6	7.6	7.8	7.6	7.3	401
MDC	Cancer	7.7	8.0	7.5	7.7	7.6	7.3	176
	Circulatory/Organs	7.8	7.7	7.7	7.8	7.6	7.7	220
	Respiratory	7.9	7.5	7.7	7.6	7.6	7.5	139
	Frailty/Dementia	7.9	8.4	8.0	8.4	7.5	7.0	56
	Other	7.7	7.6	8.1	8.1	7.6	7.6	146
Sex	Male	7.9	7.9	7.8	7.9	7.7	7.6	378
	Female	7.6	7.8	7.7	7.7	7.5	7.3	359
Age	under 45	7.4	7.6	7.9	8.5	7.7	6.7	24
	45 to 64	8.1	8.1	7.9	7.4	7.9	7.7	92
	65 to 84	7.6	7.7	7.7	7.8	7.6	7.4	448
	85 to 100	8.0	8.1	7.9	8.0	7.4	7.5	173
Stay	under 1 day	7.2	7.4	7.8	7.5	7.8	7.0	96
	1 day – 1 week	8.1	8.2	7.6	7.5	7.7	7.8	214
	1 week – 1 month	7.6	7.7	7.7	7.8	7.5	7.2	280
	over one month	7.9	7.8	8.1	8.2	7.6	7.9	147
Death	Expected	7.8	7.9	7.7	7.9	7.6	7.5	564
	Sudden	7.5	7.3	7.9	7.6	7.2	6.9	173
H99	**All HFH Hospitals**	**7.8**	**7.8**	**7.8**	**7.8**	**7.6**	**7.5**	**737**

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

8 Specialist Palliative Care Service (G)

Table 8.1N: Specialist Palliative Care Service (SPC – Nurses)

Q1 G1-4		**Yes %**
G1	SPC was available in hospital	87.3
G2	Patient received SPC	31.8
G4	Patient would have benefited from SPC	13.5
G4	Patient would not have benefited from SPC	28.9
G4	Don't know	25.7
	Total	**100**

Table 8.1D: Specialist Palliative Care Service (SPC – Doctors)

Q1 G1-4		**Yes %**
G1	SPC was available in hospital	86.8
G2	Patient received SPC	22.4
G4	Patient would have benefited from SPC	13.7
G4	Patient would not have benefited from SPC	35.3
G4	Don't know	28.6
	Total	**100**

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

Table 8.2aN: Specialist Palliative Care Service (SPC) for Patients (Nurses)

		G2	G3	
Q1G	**Question** **Category**	**Patients Received Input from SPC Service**	**Average Length of SPC Input**	**Number of Cases**
	Yes	**%**	**Days**	
A / C	Acute Hospitals	33.5	7.5	880
	Comm. Hospitals	19.3	40.3	119
Ward	A & E	2.4	.5	41
	Intensive Care	6.1	2.4	180
	Surgical	40.7	5.3	123
	Medical	40.5	7.7	415
	Oncology	65.9	9.4	44
	Geriatric	24.6	31.0	134
	Other	41.9	10.3	62
Room	Single	46.4	12.2	440
	Multi-occupancy	20.4	5.8	559
MDC	Cancer	68.2	10.4	233
	Circulatory/Organs	21.2	12.4	312
	Respiratory	21.5	6.9	186
	Frailty/Dementia	19.7	10.0	76
	Other	19.8	6.6	192
Sex	Male	31.8	8.5	507
	Female	31.9	11.3	492
Age	under 45	19.4	15.2	31
	45 to 64	46.7	9.2	122
	65 to 84	33.4	9.1	604
	85 to 100	21.9	13.1	242
Stay	under 1 day	10.1	.4	129
	1 day – 1 week	25.4	1.8	295
	1 week – 1 month	41.8	7.7	383
	over one month	36.5	25.4	192
Death	Expected	39.6	10.4	755
	Sudden	7.8	2.2	244
H99	**All HFH Hospitals**	**31.8**	**9.9**	999

Table 8.2aD: Specialist Palliative Care Service (SPC) for Patients (Doctors)

		G2	G3	
Q1G	**Question** / **Category**	**Patients Received Input from SPC Service**	**Average Length of SPC Input**	**Number of Cases**
	Yes	**%**	**Days**	
A / C	Acute Hospitals	24.1	12.2	636
	Comm. Hospitals	11.9	13.4	101
Ward	A & E	3.4	0.3	29
	Intensive Care	4.0	6.7	124
	Surgical	25.0	14.2	88
	Medical	29.3	12.7	300
	Oncology	57.1	13.4	35
	Geriatric	16.5	10.8	115
	Other	21.7	9.8	46
Room	Single	31.3	12.6	336
	Multi-occupancy	15.0	11.9	401
MDC	Cancer	45.5	18.5	176
	Circulatory/Organs	17.3	5.5	220
	Respiratory	14.4	6.7	139
	Frailty/Dementia	10.7	4.2	56
	Other	14.4	8.7	146
Sex	Male	22.8	13.6	378
	Female	22.0	10.9	359
Age	under 45	25.0	39.2	24
	45 to 64	29.3	17.7	92
	65 to 84	23.0	10.8	448
	85 to 100	16.8	7.2	173
Stay	under 1 day	10.4	11.3	96
	1 day – 1 week	17.8	4.1	214
	1 week – 1 month	31.4	10.3	280
	over one month	19.7	29.5	147
Death	Expected	27.0	13.2	564
	Sudden	7.5	2.4	173
H99	**All HFH Hospitals**	**22.4**	**12.3**	**737**

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

Table 8.2bN: Specialist Palliative Care Service (SPC) for Patients (Nurses)

		1	2	3	4	5	6	7	8	9	10	11	
	Question **Category**	**Aim curative v. palliative**	**Optimise Comfort**	**Stop non-essential Med.**	**Stop blood tests**	**Stop antibiotics**	**Review hydration**	**Stop invasive monitoring**	**Withhold treatment**	**Withdraw treatment**	**Talk about resuscitation**	**Assess skin integrity**	**Number of Cases (n)**
	Acute Hospitals												
Q1F1	*% decisions made*	57	73	68	47	40	51	39	45	37	72	77	880
Q1G2	*% received palliative care*	44	42	44	52	53	48	57	46	44	39	40	295
	Comm Hospitals												
Q1F1	*% decisions made*	63	78	77	35	31	61	34	28	18	55	82	119
Q1G2	*% received palliative care*	24	23	25	33	32	19	30	27	33	23	24	23

Note: Rows 2 and 4 indicate the proportion of those for whom a decision was made who received SPC.

Table 8.2bD: Specialist Palliative Care Service (SPC) for Patients (Doctors)

		1	2	3	4	5	6	7	8	9	10		
	Question **Category**	**Aim curative v. palliative**	**Optimise Comfort**	**Stop non-essential Med.**	**Stop blood tests**	**Stop antibiotics**	**Review hydration**	**Stop invasive monitoring**	**Withhold treatment**	**Withdraw treatment**	**Talk about resuscitation**		**Number of Cases (n)**
	Acute Hospitals												
Q1F1	*% decisions made*	73	78	70	61	44	58	40	59	46	75		636
Q1G2	*% received palliative care*	29	30	31	30	35	31	34	29	31	29		153
	Comm Hospitals												
Q1F1	*% decisions made*	78	88	80	63	45	66	50	49	19	70		101
Q1G2	*% received palliative care*	13	14	14	13	9	13	14	18	16	16		12

Note: Rows 2 and 4 indicate the proportion of those for whom a decision was made who received SPC.
Note: Based on matched cases only (n=737).

Table 8.3aN: Duration of Patient receiving Specialist Palliative Care Service (Nurses)

Q1G3 Q1C3	Duration of SPC Duration from Diagnosis of Dying to Death	no SPC	under 1 day	1 day – 1 week	1 week – 1 month	more than 1 month	Total
	up to 1 day	11.6	1.1	0.2			**12.9**
	1 day – 1 week	22.0	2.2	5.2	0.1		**29.5**
	1 week – 1 month	22.3	0.7	7.4	7.7	0.2	**38.3**
	more than 1 month	12.2	0.2	1.5	4.0	1.3	**19.2**
	Total	**68.2**	**4.2**	**14.3**	**11.8**	**1.5**	**100.0**

Table 8.3bN: Duration of Patient receiving Specialist Palliative Care Service (Nurses)

Q1G3 Q1C3	Duration of SPC Duration from Diagnosis of Dying to Death	no SPC	under 1 day	1 day – 1 week	1 week – 1 month	over one month	Total
	Acute Hospitals	66.5	4.7	15.6	11.9	1.4	**100**
	Comm. Hospitals	80.7	0.8	5.0	10.9	2.5	**100**
H99	**All HFH Hospitals**	**68.2**	**4.2**	**14.3**	**11.8**	**1.5**	**100**

Table 8.3aD: Duration of Patient receiving Specialist Palliative Care Service (Doctors)

Q2G3 Q1C3	Duration of SPC Duration from Diagnosis of Dying to Death	no SPC	under 1 day	1 day – 1 week	1 week – 1 month	more than 1 month	Total
	up to 1 day	11.7	.4	.5	.3	.1	13.0
	1 day – 1 week	23.9	.4	4.1	.5	.1	29.0
	1 week – 1 month	26.1	1.5	4.7	5.2	.5	38.0
	more than 1 month	16.0	.3	.7	2.2	.8	19.9
	Total	**77.6**	**2.6**	**10.0**	**8.1**	**1.6**	**100.0**

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

Table 8.3bD: Duration of Patient receiving Specialist Palliative Care Service (Doctors)

Q2G3 Q1C3	Duration of SPC Duration from Diagnosis of Dying to Death	no SPC	under 1 day	1 day – 1 week	1 week – 1 month	over one month	Total
	Acute Hospitals	75.9	3.0	10.8	8.5	1.7	**100**
	Comm. Hospitals	88.1		5.0	5.9	1.0	**100**
H99	**All HFH Hospitals**	**77.6**	**2.6**	**10.0**	**8.1**	**1.6**	**100**

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

9 Quality of Life in the Last Week (H)

Table 9.1: Patient Experiences of Dying and Death (QODD - Part A)

H1		**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**	55.5	37.3	7.2	836
2	able to eat	**1 - 6**	60.9	23.3	15.8	943
3	difficulty breathing	**1 - 6**	35.1	33.5	31.4	940
4	comfortable	**1 - 6**	8.2	32.2	59.7	932
5	anxious	**1 - 6**	66.7	28.5	4.8	833
6	having enjoyment	**1 - 6**	65.0	28.2	6.8	834
7	having energy	**1 - 6**	86.7	10.9	2.4	865
8	toilet problems	**1 - 6**	75.1	12.7	12.2	885
9	worried	**1 - 6**	82.5	15.3	2.1	658
10	maintain dignity	**1 - 6**	0.7	4.5	94.7	949
11	time with partner	**1 - 6**	16.6	18.4	65.0	440
12	time with children	**1 - 6**	6.1	14.7	79.2	626
13	time with friends	**1 - 6**	5.0	17.4	77.6	795
14	time alone	**1 - 6**	21.9	30.1	48.0	611

			% no	**% yes**	**Number of cases**
15	meaning and purpose	**0 / 1**	55.2	44.8	511
16	knowledge of loved ones	**0 / 1**	11.6	88.4	730
17	monetary worries	**0 / 1**	96.4	3.6	361
18	said goodbye	**0 / 1**	57.0	43.0	716
19	had spiritual visit	**0 / 1**	5.7	94.3	910
20	had spiritual service	**0 / 1**	41.9	58.1	850
21	someone there on death	**0 / 1**	10.3	89.7	947

			% alert	**% semi-conscious**	**% unconscious**	**Number of cases**
22	condition prior to death	**1 - 3**	5.5	12.1	82.4	909

Table 9.2: Quality of Dying and Death (QODD - Part A, adjusted)

Q1 H (A)	Category	Personal well-being	Relationship well-being	Total	Number of Cases
A / C	Acute Hospitals	61	69	65	870
	Comm. Hospitals	65	72	69	119
Ward	A & E	59	67	63	38
	Intensive Care	60	68	64	175
	Surgical	61	70	66	123
	Medical	61	70	66	413
	Oncology	60	72	67	44
	Geriatric	64	71	68	134
	Other	62	71	67	62
Room	Single	61	71	66	439
	Multi-occupancy	62	68	65	550
MDC	Cancer	61	71	66	232
	Circulatory/Organs	62	70	66	308
	Respiratory	60	69	65	185
	Frailty/Dementia	63	69	66	76
	Other	60	69	65	188
Sex	Male	61	69	65	503
	Female	62	70	66	486
Age	under 45	61	70	66	29
	45 to 64	59	70	65	120
	65 to 84	61	69	66	599
	85 to 100	63	70	67	241
Stay	under 1 day	60	68	64	124
	1 day – 1 week	61	69	65	292
	1 week – 1 month	61	70	66	381
	over one month	62	71	67	192
Death	Expected	60	70	66	751
	Sudden	64	68	66	238
H99	**All HFH Hospitals**	**61**	**70**	**66**	**989**

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

Table 9.3aN: 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	65.1	18.2	65.8	12.2	65.2	10.0
	1 – 3 decisions	62.8	12.9	65.5	11.2	63.9	8.6
	4 – 6 decisions	60.2	10.4	68.1	10.3	63.8	7.8
	7 – 9 decisions	59.4	8.9	70.4	9.9	64.8	7.3
	10 or 11 decisions	58.7	9.2	70.4	9.3	64.4	7.4
	Total	**60.5**	**11.5**	**68.7**	**10.5**	**64.4**	**8.0**

Table 9.3bN: 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	59.6	9.4	70.8	9.2	65.1	7.4
	Patient would have benefited from SPC	58.0	9.7	68.8	9.2	63.4	7.5
	Patient would not have benefited from SPC	61.7	12.5	66.5	11.5	63.9	8.5
	Don't know	61.8	13.2	68.2	11.2	64.6	8.2
	Total	**60.5**	**11.5**	**68.7**	**10.5**	**64.4**	**8.0**

Table 9.4: Quality of Patient Experiences (QODD Part B)

Q1H (B)		**Quality of Patient Experience (QODD Part B)**			
		Scale	**Mean**	**Std. Deviation**	**n**
1	physical pain	**1 - 10**	7.1	2.5	715
2	taking food	**1 - 10**	6.6	2.6	737
3	breathing	**1 - 10**	6.7	2.7	768
4	being comfortable	**1 - 10**	7.4	2.3	838
5	being anxious	**1 - 10**	6.8	2.6	712
6	having enjoyment	**1 - 10**	6.1	2.8	621
7	having energy	**1 - 10**	4.8	2.9	633
8	bathroom	**1 - 10**	5.5	3.2	697
9	strain to loved ones	**1 - 10**	6.5	2.9	493
10	maintaining dignity	**1 - 10**	8.8	1.7	838
11	time with partner	**1 - 10**	8.2	2.1	348
12	time with children	**1 - 10**	8.4	1.9	546
13	time with friends	**1 - 10**	8.3	2.0	703
14	time alone	**1 - 10**	7.2	2.5	547
15	meaning and purpose	**1 - 10**	6.0	2.9	431
16	knowledge of loved ones	**1 - 10**	8.3	2.0	665
17	monetary worries	**1 - 10**	8.3	2.1	336
18	saying goodbye	**1 - 10**	6.2	3.3	519
19	spiritual visit	**1 - 10**	8.5	1.9	770
20	spiritual service	**1 - 10**	7.9	2.6	615
21	someone there on death	**1 - 10**	8.3	2.4	752
22	condition prior to death	**1 - 10**	7.8	2.4	619
23	quality at moment of death	**1 - 10**	7.8	2.4	818
24	quality of last week	**1 - 10**	6.4	2.8	793
25	overall quality of dying	**1 - 10**	7.2	2.4	762
	Average of 25 items		**7.3**		**651**

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

Table 9.5: Quality of Patient Experiences (QODD Part B, adjusted)

Q1 H (B)	Category	Personal well-being	Relationship well-being	Total	Number of Cases
A / C	Acute Hospitals	66	77	72	870
	Comm. Hospitals	73	83	79	119
Ward	A & E	66	76	71	38
	Intensive Care	67	79	73	175
	Surgical	66	77	71	123
	Medical	65	76	71	413
	Oncology	64	78	72	44
	Geriatric	70	81	76	134
	Other	71	80	76	62
Room	Single	67	80	74	439
	Multi-occupancy	66	76	71	550
MDC	Cancer	64	78	72	232
	Circulatory/Organs	68	78	73	308
	Respiratory	66	77	72	185
	Frailty/Dementia	68	79	73	76
	Other	67	78	72	188
Sex	Male	65	77	71	503
	Female	68	79	74	486
Age	under 45	65	76	70	29
	45 to 64	66	80	73	120
	65 to 84	65	76	71	599
	85 to 100	69	80	75	241
Stay	under 1 day	66	76	71	124
	1 day – 1 week	67	77	72	292
	1 week – 1 month	65	78	72	381
	over one month	68	80	75	192
Death	Expected	67	79	73	751
	Sudden	66	73	69	238
H99	**All HFH Hospitals**	**66**	**78**	**72**	**989**

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

Table 9.6a: Quality of Dying and Death (QODD Part B)

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	67.9	16.8	75.2	14.1	71.3	14.0
	1 – 3 decisions	65.5	18.1	73.7	16.0	69.4	16.0
	4 – 6 decisions	66.4	16.9	77.0	14.9	71.7	14.1
	7 – 9 decisions	65.8	18.2	79.7	14.0	73.2	14.6
	10 or 11 decisions	67.1	18.7	80.4	13.4	74.5	14.3
	Total	**66.5**	**17.8**	**77.8**	**14.6**	**72.4**	**14.6**

Table 9.6b: Quality of Dying and Death (QODD Part B)

Q1H (A)	Patient receiving SPC	Personal well-being		Relationship well-being		Total	
		Mean	**SD**	**Mean**	**SD**	**Mean**	**SD**
	Patient received SPC	65.2	19.4	79.6	14.6	73.0	15.1
	Patient would have benefited from SPC	62.2	17.6	75.4	14.2	69.1	14.3
	Patient would not have benefited from SPC	68.9	16.9	77.8	15.0	73.3	14.6
	Don't know	67.4	16.4	76.7	14.0	72.2	13.7
	Total	**66.5**	**17.8**	**77.8**	**14.6**	**72.4**	**14.6**

10 Quality of Care (J)

Table 10.1N: 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 10.1D: 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 10.2N: Quality of Care (Nurses)

		J1	J2	J3	J4	J5	J1-5
Q1H (A)	**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	7.4	8.0	8.8	8.5	8.4	8.2
	Patient would have benefited from SPC	6.4	7.1	8.1	7.8	7.8	7.4
	Patient would not have benefited from SPC	6.9	7.9	8.7	8.7	8.6	8.2
	Don't know	7.1	8.0	8.7	8.6	8.4	8.1
	Total	**7.0**	**7.9**	**8.6**	**8.5**	**8.4**	**8.1**

Table 10.2D: Quality of Care (Doctors)

		J1	J2	J3	J4	J5	J1-5
Q1H (A)	**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	7.8	8.5	8.8	8.4	8.1	8.3
	Patient would have benefited from SPC	6.9	7.9	8.4	7.9	7.5	7.7
	Patient would not have benefited from SPC	7.9	8.8	8.9	8.8	8.5	8.6
	Don't know	7.8	8.6	8.8	8.6	8.2	8.4
	Total	**7.7**	**8.6**	**8.8**	**8.6**	**8.2**	**8.4**

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

Table 10.3aN: Acceptability of Patient's Dying Experience (Nurses)

Q1J8	Hospital	not acceptable (scores 1-3)	acceptable (scores 4- 10)	Mean	SD	n
		%	%			
1	Acceptable for you	12.9	87.1	7.4	2.8	932
2	Acceptable for your family or friends	13.5	86.5	7.4	2.8	879

Table 10.3bN: Acceptability of Patient's Dying Experience (Nurses)

Q1J8	Category	Mean	n	% of experiences not acceptable
A / C	Acute Hospitals	7.2	817	14.1
	Comm. Hospitals	8.5	115	4.3
Ward	A & E	7.5	33	9.1
	Intensive Care	7.4	165	13.9
	Surgical	7.2	115	16.5
	Medical	7.0	392	14.5
	Oncology	7.5	43	11.6
	Geriatric	8.3	127	5.5
	Other	8.3	57	10.5
Room	Single	7.9	418	8.1
	Multi-occupancy	7.0	514	16.7
MDC	Cancer	7.3	224	13.8
	Circulatory/Organs	7.6	283	10.2
	Respiratory	7.1	175	13.1
	Frailty/Dementia	7.4	72	11.1
	Other	7.4	178	16.3
Sex	Male	7.2	470	15.1
	Female	7.5	462	10.6
Age	under 45	6.7	26	15.4
	45 to 64	7.4	114	14.9
	65 to 84	7.4	562	13.2
	85 to 100	7.5	230	10.9
Stay	under 1 day	7.3	109	14.7
	1 day – 1 week	7.2	276	15.6
	1 week – 1 month	7.2	359	12.8
	over one month	8.0	188	8.0
Death	Expected	7.5	724	11.2
	Sudden	6.8	208	18.8
H99	**All HFH Hospitals**	**7.4**	**932**	**12.9**

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

Q1J8	Hospital	not acceptable (scores 1-3)	acceptable (scores 4- 10)	Mean	SD	n
		%	%			
1	Acceptable for you	5.2	94.8	8.3	2.1	632
2	Acceptable for your family or friends	5.0	95.0	8.2	2.1	633

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

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

Q1J8	Category	Mean	n	% of experiences not acceptable
A / C	Acute Hospitals	8.2	560	5.6
	Comm. Hospitals	9.1	72	1.4
Ward	A & E	7.9	24	12.0
	Intensive Care	8.2	111	6.2
	Surgical	8.0	75	7.2
	Medical	8.1	263	5.5
	Oncology	8.3	31	3.0
	Geriatric	8.9	88	1.1
	Other	8.7	40	2.4
Room	Single	8.3	283	4.3
	Multi-occupancy	8.2	349	5.9
MDC	Cancer	8.1	158	5.5
	Circulatory/Organs	8.3	187	5.1
	Respiratory	8.4	126	3.8
	Frailty/Dementia	8.5	44	8.9
	Other	8.2	117	4.8
Sex	Male	8.3	323	5.0
	Female	8.3	309	5.3
Age	under 45	7.6	18	4.8
	45 to 64	7.7	79	8.1
	65 to 84	8.4	391	4.2
	85 to 100	8.4	144	6.1
Stay	under 1 day	8.2	80	9.5
	1 day – 1 week	8.5	186	2.1
	1 week – 1 month	7.9	252	7.2
	over one month	8.8	114	2.5
Death	Expected	8.3	487	4.9
	Sudden	8.2	145	5.9
H99	**All HFH Hospitals**	**8.3**	**632**	**5.2**

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

Table 10.3cN: Acceptability of Patient's Dying Experience (Nurses)

Q1J8	Category	Mean	n	% of experiences not acceptable
	Patient received SPC	7.5	305	12.1
	Patient would have benefited from SPC	6.5	132	17.4
	Patient would not have benefited from SPC	7.5	271	14.0
	Don't know	7.6	224	9.8
	Total	**7.4**	**932**	**12.9**

Table 10.3cD: Acceptability of Patient's Dying Experience (Doctors)

Q1J8	Category	Mean	n	% of experiences not acceptable
	Patient received SPC	8.3	147	3.2
	Patient would have benefited from SPC	7.5	93	8.3
	Patient would not have benefited from SPC	8.6	232	4.6
	Don't know	8.2	161	6.5
	Total	**8.3**	**633**	**5.3**

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

11 Moment of Death and After

Table 11.1a: Persons present at Death

Q1J6		Yes %	No %	Don't Know %	Total %
1	Relatives or friends	65.0	17.3	17.7	100.0
2	Hospital staff	74.6	8.4	17.0	100.0
3	Other	5.0	13.3	81.7	100.0
	At least one person present	**75.1**	**0.0**	**24.9**	**100.0**

Table 11.1b: Presence of Pastoral Care Team

Q1J7		At time of Death %	Immediately after Death %	No %	Don't Know %	Total %
1	Relatives or friends	12.3	46.7	19.0	21.9	100.0

Table 11.2a: Immediately after Death

Q1K1		Yes %	No %	Don't Know %	Total %
1	Prayers being said	81.1	9.2	9.7	100.0
2	Moment of silence	52.9	28.6	18.5	100.0
3	Candles lit	69.4	21.7	8.9	100.0
4	Sympathy offered	91.3	1.8	6.9	100.0
5	Tea offered	86.7	4.4	8.9	100.0
6	Other	7.3	4.2	88.5	100.0

Table 11.2b: When Body was being taken away

Q1K1		Yes %	No %	Don't Know %	Total %
1	Prayers being said	10.0	42.1	47.8	100.0
2	Moment of Silence	18.0	31.7	50.3	100.0
3	Candles lit	16.4	33.4	50.2	100.0
4	Sympathy offered	24.7	21.8	53.5	100.0
5	Tea offered	17.0	26.1	56.9	100.0
6	Other	1.9	10.5	87.6	100.0

Table 11.3: Accompanied Body to Mortuary

Q1K4		Yes %	No %	Don't Know %	Total %
1	Porter	88.8	1.5	9.7	100.0
2	Nurse	15.0	37.2	47.7	100.0
3	Other	8.9	29.1	62.0	100.0

Table 11.4: Time given to Relatives after Death

Q1K		Yes %	No %	Don't Know %	Total %
2	Relatives given all the time needed to be with patient	94.0	1.5	4.5	100.0
3	Staff had time to be available for relatives	79.9	14.6	5.5	100.0

Table 11.5a: Information and Advice to Relatives

Q1K5		Yes %	No %	Don't Know %	Total %
1	How moved to mortuary	73.1	9.3	17.6	100.0
2	How taken home	42.5	26.7	30.7	100.0
3	Access to mortuary	38.9	30.8	30.2	100.0
4	Arranging funeral	48.1	21.8	30.0	100.0
5	Collecting belongings	73.2	7.6	19.2	100.0
6	Registering the death	19.6	46.0	34.3	100.0
7	Post-mortems	8.1	43.5	48.3	100.0
8	Bereavement services	8.4	56.1	35.5	100.0
9	Other	2.4	18.6	79.0	100.0
K6	GP informed	31.8	35.3	32.8	100.0

Table 11.5b: Information and Advice to Relatives

Q1K5		Mean	Std. Deviation	Min	Max	n
1	Number of items of information & advice	3.1	2.1	0	9	999

Table 11.5c: Information and Advice to Relatives

	Q1K5 Category	Mean Number items of information & advice	Number of Cases
A / C	Acute Hospitals	3.0	880
	Comm. Hospitals	4.5	119
Ward	A & E	4.6	41
	Intensive Care	3.3	180
	Surgical	2.9	123
	Medical	2.7	415
	Oncology	2.8	44
	Geriatric	4.2	134
	Other	3.2	62
Room	Single	3.1	440
	Multi-occupancy	3.2	559
MDC	Cancer	2.9	233
	Circulatory/Organs	3.3	312
	Respiratory	3.0	186
	Frailty/Dementia	3.4	76
	Other	3.2	192
Sex	Male	3.1	507
	Female	3.2	492
Age	under 45	3.3	31
	45 to 64	3.3	122
	65 to 84	3.0	604
	85 to 100	3.3	242
Stay	under 1 day	3.3	129
	1 day – 1 week	2.9	295
	1 week – 1 month	3.0	383
	over one month	3.7	192
Death	Expected	3.1	755
	Sudden	3.3	244
H99	**All HFH Hospitals**	**3.1**	**999**

Table 11.6: Information on Death to GP

Q1K6		Yes %	No %	Don’t Know %	Total %
K6	GP informed	31.8	35.3	32.8	100.0

Table 11.7: Death Certificate

Q1K7		Mean (days)	Std. Deviation	Min	Max	n
1	Doctor certified the death	2.6	2.0	1	6	17
2	Hospital issued Death Certificate	2.8	3.2	1	18	98

Table 11.8: Gathering the Patient’s Personal Belongings

Q1L1		%
	Nurse	63.2
	Care Assistant	13.0
	Relative	19.1
	Other	4.6
	Total (n= 832)	**100.0**

Table 11.9: Packaging of Personal Belongings

Q1L2		%
	Patient’s own Bag	36.8
	Bag supplied by Relative	6.2
	Plastic Bag	21.1
	Family hand-over bag	21.1
	Other	14.8
	Total (n= 934)	**100.0**

12 Reviewing Deaths and Supporting Staff (M)

Table 12.1: Review at Ward Level

Q1M		Yes %	No %	Don’t Know %	Total %
1	Ward Level Review	51.0	39.5	9.5	100.0
2.1	- formal discussion	13.3	47.3	39.4	100.0
2.2	- informal discussion	43.8	20.5	35.6	100.0
3	Staff feeling upset	21.1	48.5	30.3	100.0
4	- opportunity to talk	14.5	6.6	n/a	n/a
5.1	- in hospital	14.5	6.6	n/a	n/a
5.2	- outside hospital	0.3			

Note: the opportunity to talk relates only to those members of staff who stated that they got upset by the patient’s death.

13 Endnotes:

Tables 1.2 and 1.3:

1. Completion rates are calculated only for those hospitals which have 150 deaths or more in a year and which could meet the target of completing the audit on 50 deaths in a four month period. Thus the overall completion rate for these hospitals is calculated as the number of deaths in the audit as a percent of 50 deaths. Completion rates were also calculated for A&E, Intensive Care, and Other Wards and expressed as the percent of audited deaths in each area of the hospital relative to their percentage share in total deaths.

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

- St. Mary's Phoenix Park
- St John's Hospital, Sligo
- 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

Table 3.8

The questionnaire only inquired about infections and IST with regard to those who died in a single room. However, the question was also answered with regard to most other patients and we thus computed the incidence for all patients.

14 Appendix:

14.1 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.

14.2 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 14.1: Distribution of QODD_A Personal Well-being, adjusted values

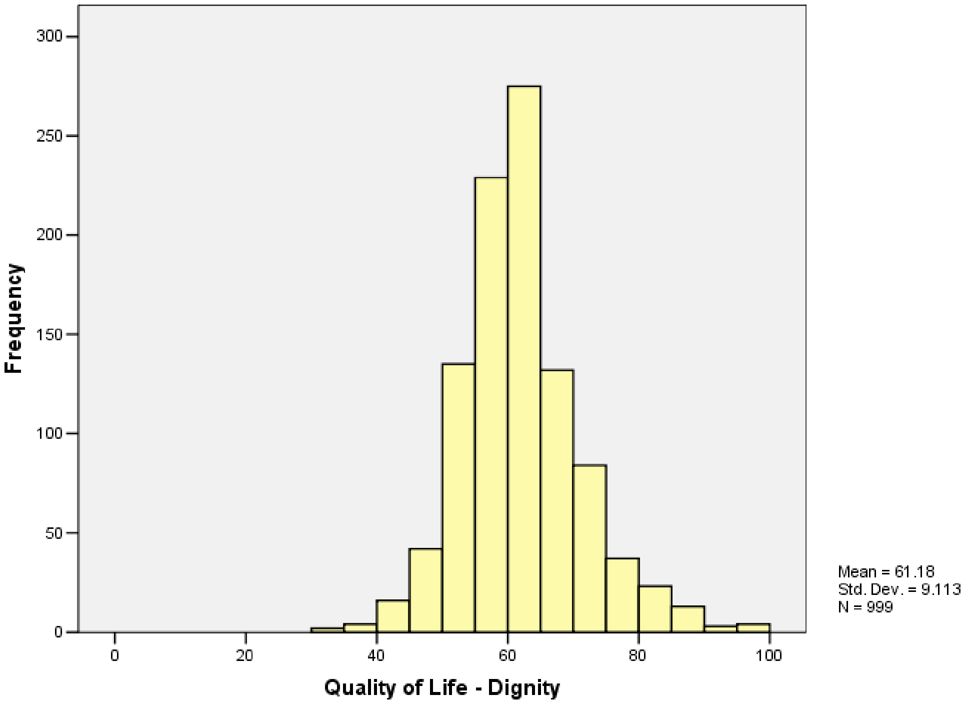


Figure 14.2: Distribution of QODD_A Relationship Well-being, adjusted values

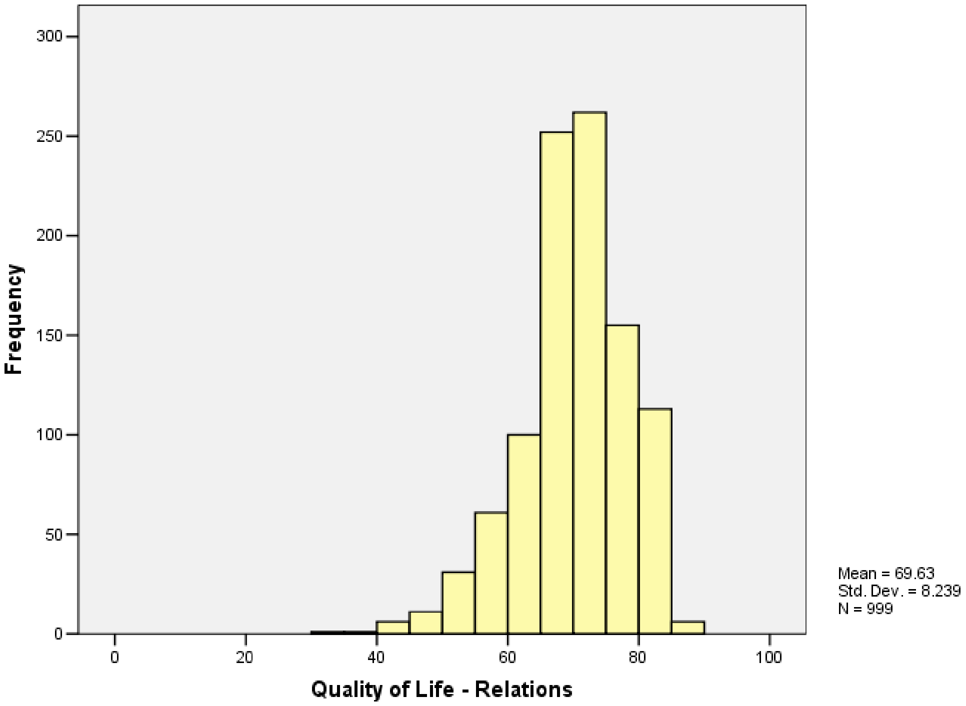
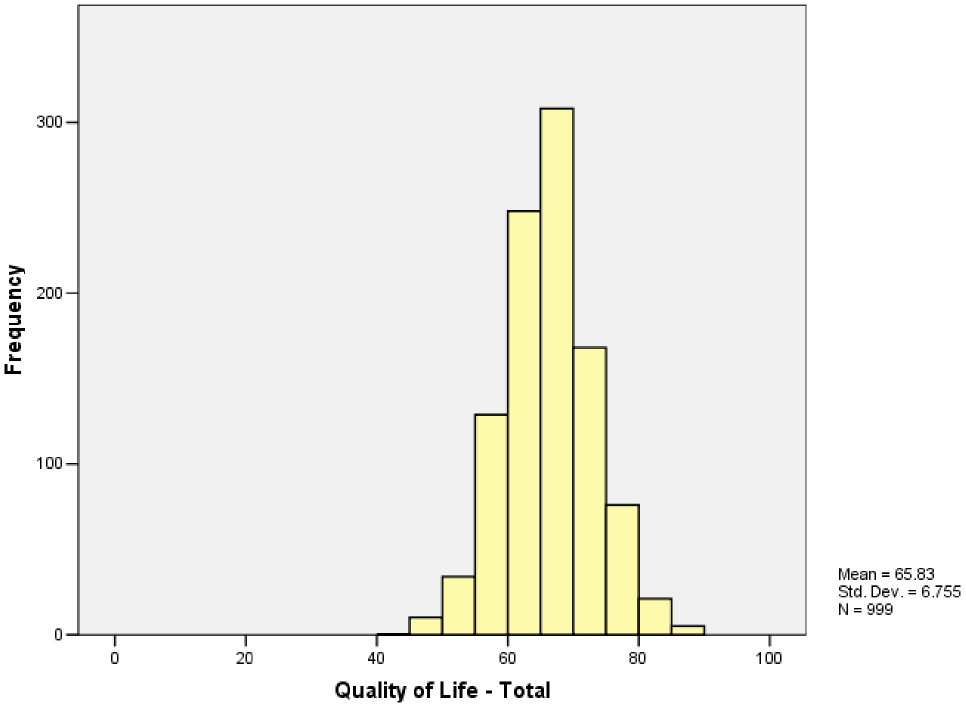


Figure 14.3: Distribution of QODD_A Total, adjusted values



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.

14.3 Imputation of Values for QODD (Part B)

Figure 14.4: Distribution of QODD_B, Raw Variables

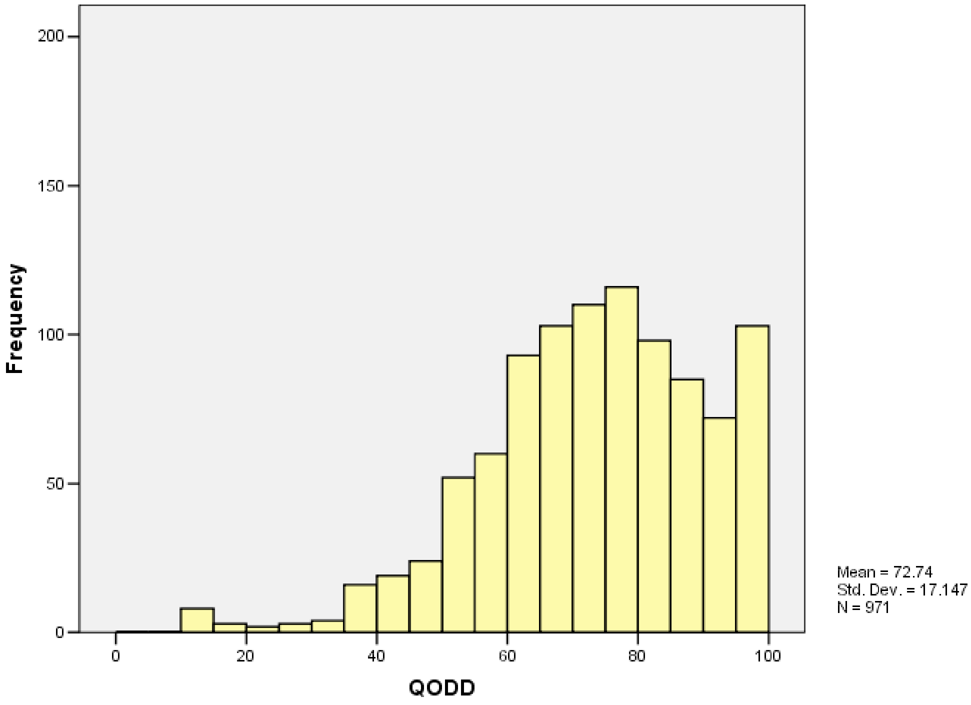
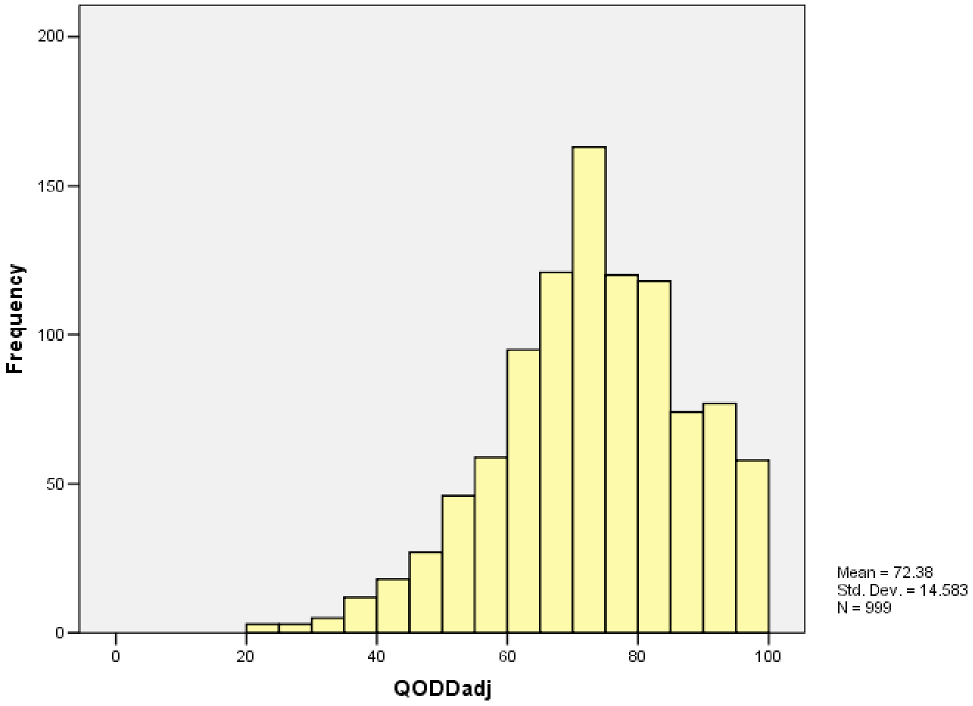


Figure 14.5: Distribution of QODD_B after Estimation of Missing Values (MVA – ML algorithm)



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.

14.4 Quality of Care Analysis

Figure 14.8: Distribution of QCare, raw values

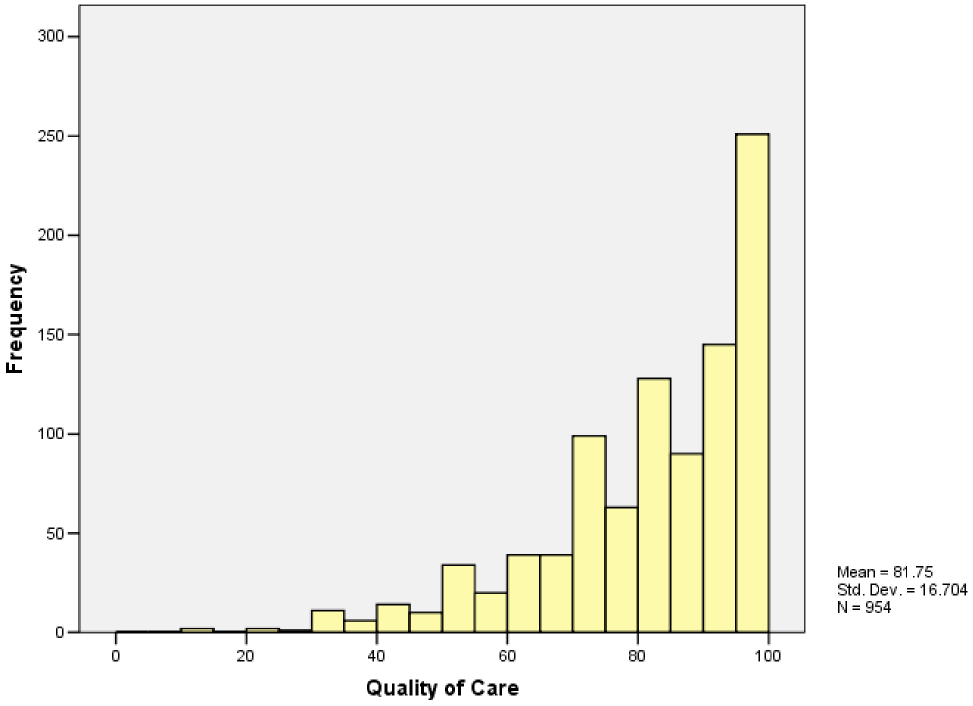
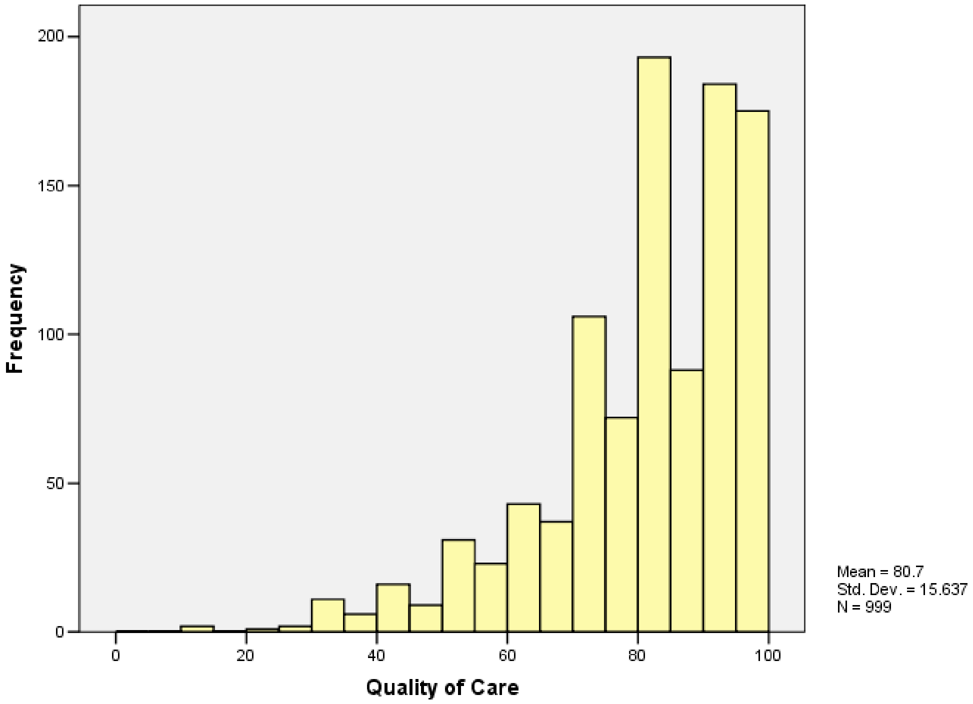


Figure 14.9: Distribution of QCare, adjusted values



14.5 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 14.10: 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 14.11: 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 14.12: 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 14.13 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 14.13: 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 14.14: Level of pain experienced – nurses' and doctors' responses

Column % *q1f2.1.1*	*q2f2.1.1*	**Pain experienced by patient – doctors' responses**				
		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%**				

Table14.15: Pain management – nurses’ and doctors’ responses (5 categories)

Column % *q1f2.1.2_grp1*	*q2f2.1.2_grp1*	**Pain management – doctors’ responses**					
		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 14.16: Pain management – nurses’ and doctors’ responses (4 categories)

Column % *q1f2.1.2_grp*	*q2f2.1.2_grp*	**Pain management – doctors’ responses**				
		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%**				