

Northern Ireland Health & Social Care Services

Strategy for Bereavement Care

Contents

1. Executive Summary
2. Aims & Objectives
3. Need for a strategy in the HSC services
4. Development of the strategy
5. Standards for Bereavement Care
 - 5.1 Raising awareness
 - 5.2 Promoting safe and effective care
 - 5.3 Communication, information and resources
 - 5.4 Creating a supportive experience
 - 5.5 Knowledge and skills
 - 5.6 Working together
6. Evaluation of impact
7. Appendices

Northern Ireland Health & Social Care Services Strategy for Bereavement Care

1. Executive summary

- 1.1 A region wide multi-agency group from Health and Social Care (HSC) services has worked in partnership with other public and voluntary sector agencies to develop a strategy for bereavement care within the HSC services across Northern Ireland.
- 1.2 An HSC regional implementation group undertook the work following the appointment in 2006 of five Area Bereavement Co-ordinators funded by the Department of Health Social Services and Public Safety. This followed recommendations 9 and 10 of the 2002 O'Hara Inquiry into Human Organs.
- 1.3 Approximately 15,000 people die each year in Northern Ireland with the largest number dying in hospital, hospices and nursing homes (73%) and around 11% undergoing a consented hospital or non-consented Coroner's post mortem examination.
- 1.4 An audit was undertaken across the legacy HPSS Trusts and within all hospices across Northern Ireland to identify the profile of need and to map current services. The audit will be published in its entirety in 2009.
- 1.5 Many individuals in the Health and Social Care services come into contact with those who are dying and those affected by bereavement. The aim of the strategy is to build the capacity of all those who have such contact to respond in the most appropriate way according to their respective roles and the needs and preferences of those affected.
- 1.6 Working in partnership with a wide range of stakeholders six key standards were identified.
 1. Raising awareness
 2. Promoting safe and effective care
 3. Communication, information and resources
 4. Creating a supportive experience
 5. Knowledge and skills
 6. Working together
- 1.7 Specific criteria for action by Health and Social Care services were identified for each standard.

2 Aims and objectives

The **aim** of the NI Health and Social Care Strategy for Bereavement Care is to promote an integrated, consistent approach to all aspects of care across the public health and social care services in supporting individuals and families who have been bereaved and those that support them, appropriate to their individual needs and preferences.

The principal **objectives** of the strategy are:

1. to improve the understanding of bereavement by all Health and Social Care staff in contact with dying people and those affected by bereavement
2. to improve the quality of care delivered in the Health and Social Care services for family, friends and carers of people who are dying
3. to improve the information and support available within Health and Social Care to those affected by bereavement according to their individual needs and preferences
4. to ensure that systems are in place within the Health and Social Care services for the identification of those most likely to need specialist support
5. to work in partnership across the community, voluntary and statutory sector and with those who have been bereaved to assure and improve the quality of care provided
6. to provide a reference framework for other public strategies which address aspects of dying or bereavement care

3. Need for a Strategy in the Health & Social Care Services

Death and bereavement, at some time, affect everyone, with approximately 14,000-15,000 people dying in Northern Ireland every year. The majority of these deaths (73%) occur in hospitals, hospices and nursing homes, and over 1,600 (11%) undergo a hospital or Coroners' post mortem examination¹. It is estimated that for every death, at least four relatives and friends experience the loss, with over 56,000 people in Northern Ireland being affected by bereavement in any one year.

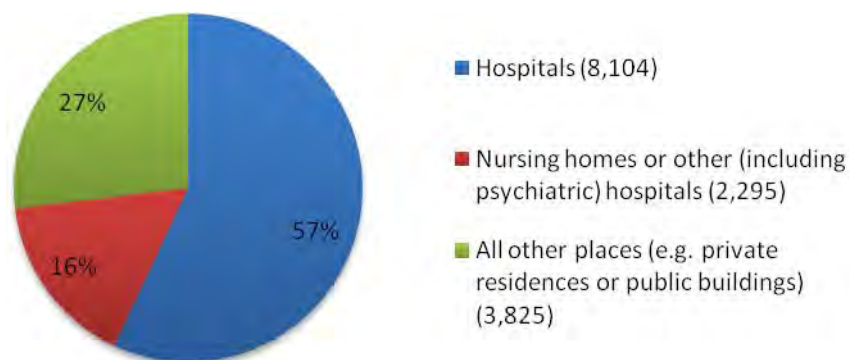


Figure 1: Number and location of deaths registered in Northern Ireland in 2005
(Registrar General statistics)

While the effects of bereavement can have a significant impact on the physical and mental health of many individuals, to the extent that specialist support services may be required, the majority of people cope with the experience with the care and support of family and friends so that some degree of healing and recovery occurs. It is recognised¹ that a compassionate and sensitive approach throughout all of the procedures and processes surrounding death can impact positively on the grieving process to facilitate such healing.

The NI Audit 2007 identified that the profile of deaths across Northern Ireland was closely aligned to the population distribution with the majority of deaths occurring in the Eastern area and fewest deaths within the Western area. At different times in this process a wide range of individuals in the Health and Social Care services come into contact with many of those directly affected by bereavement; this can happen either as a direct consequence of the death or incidentally as part of other care.

This strategy is aimed at those individuals and Health and Social Care organisations that come into contact with bereaved people, for whatever purpose, so that the quality of such contact is improved and that at least no harm is done to the healing and recovery process through the contact.

¹ NI Audit to Assess care after Death: Systems, Processes and Practices in Bereavement Care 2008

Consultation Version

An analysis of the number of certified deaths in hospitals and hospices showed that the majority (82%) were people of 65 years and older, with a smaller number in the 18-65 age range and the smallest for children of 28 days up to 18 years of age. A slightly larger number of stillbirths and neonatal deaths were identified (Figure 2).

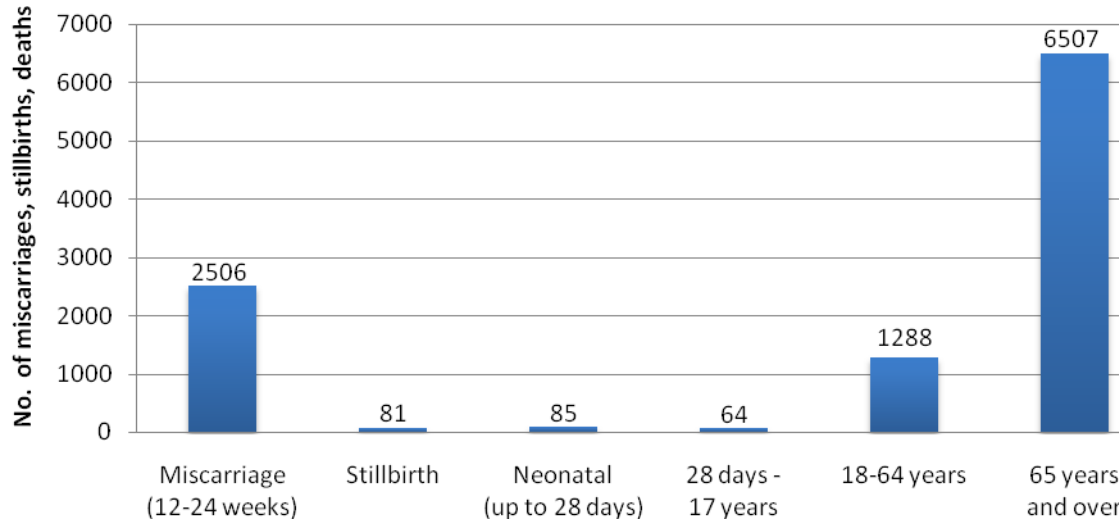


Figure 2: Miscarriages, stillbirths and certified deaths in all 35 hospitals and hospices in NI, 2005-2006

The profile of post mortem examinations (Figure 3) showed that, whereas the highest percentage of deaths occurred in the over-65 age group, there were relatively few post mortem examinations carried out on this population (i.e. as most deaths at that age are predicted to be from natural causes). The highest number of post mortem examinations was carried out on children under the age of 18 years. Indeed, almost half of all children who die in neonatal units undergo a hospital (consented) post mortem examination.

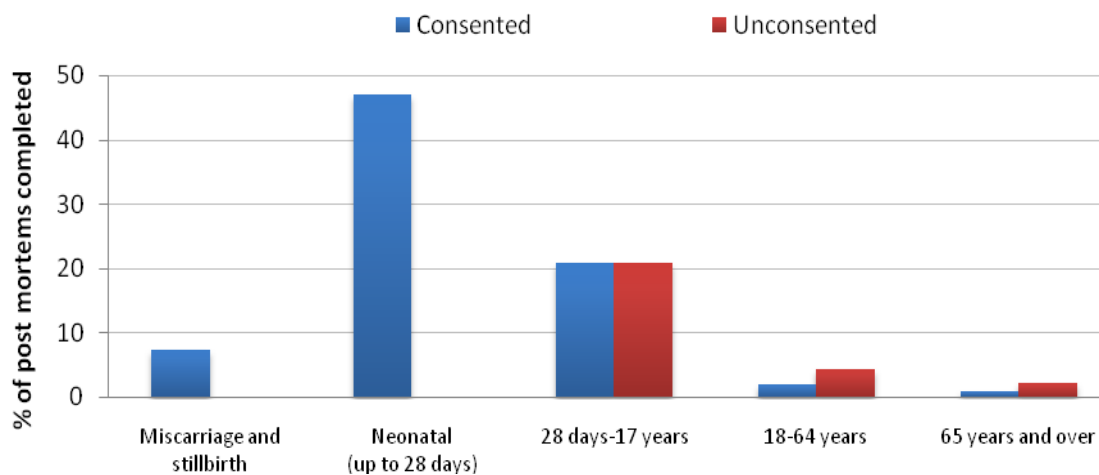


Figure 3: Post mortems completed in respect of miscarriages, stillbirths and deaths in all 35 hospitals in NI, 2005-2006

The recommendations from the O'Hara Inquiry into Human Organs 2002 identified the consent process for hospital post mortem examinations and the information process from the non-consented Coroners post mortem, including the deaths of children, as being particularly problematic in hospitals; this is reflected in the recommendations from the Human Organs Inquiry.

Following the O'Hara recommendations the Department of Health Social Services and Public Safety funded five Area Bereavement Co-ordinator (ABC) posts across Northern Ireland, based within the acute hospital sector where it had been identified that the greatest difficulties existed. The purpose of the ABC posts has been to work as a regional network team to develop standards for bereavement care and develop packages of training for bereavement related issues, including consent for post mortem examination. Although the focus of work in the initial stage has been in the acute sector, reflecting the greatest number of deaths and specific recommendations from the Human Organs Inquiry, it is intended to extend such work into the community care sector.

4. Development of the strategy

A number of public strategies have been developed to address different types of death and while bereavement care is often referred to in these strategies, there has not been an integrated approach to such care within the delivery of health and social care services. As a result, the physical, psychological, social, financial and spiritual needs of people who are dying may not always be met, and their families may not receive sufficient information and levels of support. A holistic, co-ordinated approach to bereavement care is needed, which applies:

- during the 'journey' of bereavement (i.e. prior to, at the time of, and following the death)
- in all circumstances (i.e. whether the death is sudden or expected)
- at all ages (i.e. miscarriage, stillbirth, children, young people, adults and older people)
- to all persons affected (e.g. patients, relatives, friends and staff)
- for all aspects of diversity² (i.e. religious belief, political opinion, race, age, marital status, sexual orientation, gender, disability, carers, social, economic, rural and urban needs)

The strategy seeks to promote a set of overarching standards for Health and Social Care and suggests assessment criteria assist which can be measured relevant to all aspects of bereavement care and staff coming into contact with bereaved people.

4.1 Human Organs Inquiry 2002

Recommendations 9 and 10 of the 2002 O'Hara³ Inquiry on Human Organs stated that improvements in bereavement care and the process of consent for post mortem examination within the Health and Social Care services were required in Northern

² Section 75 of the Northern Ireland Act 1998

³ O'Hara Report: The Human Organs Inquiry 2002 available at www.dhsspsni.gov.uk

Ireland, particularly within hospitals and to ensure compliance with the Codes of Practice of the Human Tissue Authority under the Human Tissue Act 2005. Following public consultation the DHSSPS established a regional bereavement network with the appointment in 2006 of five Area Bereavement Co-ordinators, one for each of the geographical areas now represented by the HSC Trusts created in April 2007 (appendix 2). The purpose of the network has been to work in partnership with HSC Trusts to improve the standards and training for bereavement care and consent for post mortem examination. A multi-agency Steering Group⁴ chaired by the Chief Nursing Officer has assured the delivery of an annual programme of work with a regional implementation group from the five HSC Trusts working with the Area Bereavement Co-ordinators undertaking operational responsibility.

4.2 Methodology

To develop the strategy a series of public workshops took place during 2007 using the “world café” and “open space” methodologies⁵. Such methods have also been used in the development of a Scottish model for bereavement care. Participants were drawn from across the statutory, voluntary, commercial, community sectors as well as individuals from a diverse range of faiths and interests⁶. The statutory sector included representatives from health, social care, coronial services, police, emergency services, critical care, Registrars, nurses, doctors, social workers, clinical psychologists, teachers, directors and managers of services, health boards and trauma advisory coordinators. Others represented a range of specialised bereavement and counselling services, support and befriending groups, funeral directors and nursing homes as well as individuals with particular interest or experience, including those who had been bereaved.

From the workshops a number of themes were identified which provided a framework for the regional strategy. A writing group largely comprised of the regional implementation group⁷ and workshop participants refined the themes to formulate the standards in the strategy. An agreed set of principles and values were identified.

In parallel a comprehensive baseline audit: NI Audit to Assess Care after Death: Systems, Processes, Practices in Bereavement Care 2007 reviewed care provision within all HPSS legacy Trusts and Hospices⁸ across the region. Services were audited against established standards and good practice guidelines drawn from the best validated sources, cited in appendix 1. The audit took place in acute, community hospitals and hospices including their links to primary care and key voluntary sector organisations using questionnaires, semi-structured interviews and management information in relation to service profiles and patient demographics. In 2009 it is intended to extend the audit to the remaining HSC community areas. It is recognised with a reorganised Health and Social Care Service that, while direct patient care may

⁴ Appendix 2 for membership of DHSSPS Steering Group & Regional Implementation Group

⁵ Appendix 3 for information on World Café & Open Space

⁶ Appendix 4 for a list of participants and agencies

⁷ Membership of Regional Implementation Group set out in Appendix 2

⁸ Northern Ireland Audit to Assess Care After Death: Systems, Processes & Practices in Bereavement Care Appendix 1

remain unaffected, arrangements for the management and governance of such services will be integrated into single services which offer opportunities for improvement.

Information from the workshops and NI Audit formed the basis of the strategy which was developed by the Area Bereavement network on behalf of the DHSSPS. It established the standards and assessment criteria for the HSC Services across Northern Ireland.

4.3 Principles and Values of the Northern Ireland HSC Bereavement Network

A number of key principles and values underpin the strategy which were identified in the consultative workshops and refined as follows:

- that the unique experience and diverse needs of every person and family affected by bereavement should be respected, ensuring that care is holistic, appropriate and timely
- that care delivered will be consistent with each individual and families needs and preferences
- that care of the dying, the deceased and those affected by bereavement should be recognised as an essential component of health and social care
- that all staff who come into contact with or offer support to those affected by bereavement should be appropriately trained
- that a supporting ethos with regard to death and bereavement should be fostered across all organisations
- that there should be a culture of continuous improvement for those coming into contact with individuals and families who have experienced a bereavement so that such contact is beneficial and not harmful
- that there is a partnership approach between those who have experienced bereavement, those with a special interest and those delivering care
- that the individual right to autonomy is respected such as in ensuring that systems for informed consent are in place

5. Standards for Bereavement Care

“People in receipt of services should be actively involved in all decisions affecting their lives and should fully contribute to any planning for, delivery and evaluation of services”
Quality Standards for Health and Social Care (2006)

A number of standards have been developed around key themes to assist Health and Social Care services in the delivery of services to people who are dying and their families, friends and carers and for those services coming into contact with them at other times. This has been done with the users as well as the providers of Health and Social Care services and those with a specialist interest. It is intended that these standards will inform regional guidelines and local policies and procedures where appropriate. Six principal standards were identified:

1. **Raising awareness:** That Health and Social Care staff will have an awareness and understanding of death, dying and bereavement, and of the fact that grief is a normal process following loss.
2. **Promoting safe and effective care:** That all Health and Social Care staff involved in the care of people who are dying and those who are affected by bereavement will deliver high quality, safe, sensitive and effective care before, at the time of and after death.
3. **Communication, information and resources:** That people who are dying and those who are affected by bereavement will have access to timely, accurate and consistent information in a format and language which will be helpful to their particular circumstances and consistent with their needs, abilities and preferences.
4. **Creating a supportive experience:** That those who are dying and their families will be afforded time, privacy, dignity and respect and, wherever possible, given the opportunity to die in their preferred environment with access to practical, emotional and spiritual support based on their individual needs and preferences.
5. **Knowledge and skills:** That Health and Social Care organisations recognise the value of a skilled workforce by ensuring that those coming into contact with, or caring for people who are dying and those affected by bereavement are competent to deliver care through continuing professional development; and by having systems in place to support them.
6. **Working together:** That good communication and co-ordination will take place within and between individuals, organisations and sectors, to ensure that resources are targeted efficiently and effectively and that there is integration of care to meet the needs of people who are dying and their families, friends and carers.

5.1 Standard: Raising awareness

"We need to create a context in which dying, death and bereavement can be developed as a matter of public concern and where the concept of a 'good death' is a valid aspect of social and public policy"
Pat Cox, Former President European Parliament (2006)

Standard

That Health and Social Care staff will have an awareness and understanding of death, dying and bereavement, and of the fact that grief is a normal process following loss.

Rationale

For HSC staff coming into contact with those affected by bereavement, understanding the impact of their behaviour may reduce the potential for harm and facilitate the healing process.

Assessment Criteria

1. Corporate induction arrangements should be in place in Trusts to ensure an appropriate level of awareness and understanding for all staff likely to have contact with people who are dying or bereaved.
2. Local induction for those with a more direct contact with dying and bereaved people (junior doctors, nurses and other clinical staff) should include awareness of the likely individual needs of specific patient groups.
3. Core content of corporate and local induction to be developed regionally through NI Bereavement Network.
4. Induction should include awareness of the cultural requirements and value of rituals such as viewing the body of the deceased.
5. The delivery of induction in Trusts should be monitored on an annual basis.
6. Ongoing awareness and training should be available to existing staff, identified through annual appraisal and planned through individual personal development contribution plans.

5.2 Standard: Promoting safe and effective care

Bereaved people greatly value the bereavement services and the professionals who provide them, at a particularly stressful, difficult time. Memories of the death and of the person who has died can be affected by the quality of these services in whatever form they take; and the experience around the time of death and afterwards can influence grieving and the longer term health of bereaved people.” When a Patient Dies (2005)

Standard

That all Health and Social Care staff involved in the care of people who are dying and those who are affected by bereavement will deliver high quality, safe, sensitive and effective care before, at the time of, and after death.

Rationale

Robust governance arrangements serve to benefit and protect people who are dying, those affected by bereavement, staff, and employers by ensuring optimum standards for the delivery of care. The nature of death and bereavement often means that those providing care and support only have one opportunity to ‘get it right’. There is evidence that an increasing number of complaints received by health service agencies are related to poor death and bereavement experiences, eg 54% in England.⁹ Safe and effective care is designed primarily to protect the people using services whilst at the same time ensuring that staff have the necessary resources, guidance, experience and support to provide the services required.

Assessment Criteria

1. Trusts should have in place systems for the proactive identification of risk and governance associated with end of life care and the care of bereaved people. Such systems should include audit and clinical supervision.
2. Core policies and procedures for the care of the dying, the deceased and those affected by bereavement should be in place within Trusts, these may include
 - Breaking bad news
 - Advance directives
 - Do not attempt to resuscitate
 - Chaplaincy/ spiritual care
 - Bereavement care and support including cultural and religious requirements
 - Information for relatives
 - Organ donation
 - Referral to Coroner
 - Consent for Post Mortem Examination
 - Death certification
 - Last offices
 - Transfer to mortuary/areas of repose

⁹ Healthcare Commission (2007)

- Release of body to undertakers
- 3. Interventions to support dying and bereaved people should be provided by individuals who have appropriate training and supervision
- 4. The use of the integrated care pathway for the dying should be used throughout all Trusts
- 5. A pathway for sudden death should be developed where this does not already exist
- 6. The implementation of all pathways should be monitored and audited
- 7. Trusts should ensure that an agreed minimum set of information is transferred with the body of the deceased
- 8. When transferring information the requirements of confidentiality should be balanced with the needs of safe practice
- 9. Sufficient information must be communicated to funeral directors to comply with Health and Safety requirements
- 10. Preference is given for the development and use of a regionally agreed mortuary form
- 11. Amendments should be made to Trust Patient Administration Systems (PAS) to ensure the removal of the name of the deceased patient from active patient records
- 12. Systems should be in place for monitoring services for care of the dying, the deceased and those affected by bereavement
 - Reporting and recording incidents and complaints
 - Variations from standards of end of life and bereavement care in line with the DHSSPS requirements
 - Learning lessons from such failures should be established and shared regionally
- 13. Systems should be in place for monitoring and regular audit of statutory requirements, such as death certificate and post mortem consent forms

5.3 Standard: Communication, information and resources

"We do not have much of a chance to learn about grieving - how it feels, what the right things to do are, what is 'normal' - or to come to terms with it. In spite of this we have to cope when we are finally faced with the death of someone we love." Royal College of Psychiatrists

Standard

That people who are dying and those who are affected by bereavement will have access to timely, accurate and consistent information in a format and language which will be helpful to their particular circumstances and consistent with their needs, abilities and preferences.

Rationale

Good communication and appropriate information can assist people to make informed choices and support bereaved families, reduce anxiety and strengthen coping mechanisms.

Assessment Criteria

1. Timely and accessible information pertaining to death, loss, and bereavement should be available to dying and bereaved people and staff who care for them
2. Information should be communicated verbally and reinforced/supported by written information
3. The format and content should be suitable to the needs, abilities and preferences of the individuals receiving the information
4. Core content of information to be sourced or developed regionally through the NI Bereavement Network
5. Care should be taken in communicating information during the grieving process. In particular support to parents of children who have died, individuals with special needs and those from different cultures should be available
6. Information on Consent for hospital post mortem examinations and the Coroners processes and services should be timely, clear and communicated sensitively and understood. Relatives have a right not to receive this information if this is their preference.
7. Compliance with the disclosure of information requirements for hospital and coroners post mortem examinations should be audited
8. A policy for chaplaincy services should be in place in Trusts

9. Interventions should be timely and accessible, and should be organised in advance where death is foreseen
10. Arrangements for immediate support should be in place when death is sudden or due to traumatic circumstances
11. Clear explanations should be given for treatment options and other complex processes such as death registration and post mortem procedures
12. A sufficient range of language intervention services should be available and audited for suitability
13. A directory of bereavement support services within the voluntary and statutory sectors should be developed for use by service users and staff
14. Information should be provided in a variety of formats and media including web-based services, to best meet the range of needs and preferences identified
15. Information should be regularly reviewed and updated

5.4 Standard: Creating a supportive experience

We never forget how we are treated after the death of someone close"

Bereavement Care in Practice 2004¹⁰

Standard

That those who are dying and their families will be afforded time, privacy, dignity and respect and, wherever possible, given the opportunity to die in their preferred environment with access to practical, emotional and spiritual support based on their individual needs, abilities and preferences.

Rationale

Dying people and their families have a right to be treated with dignity and respect, and to be cared for in an appropriate setting. As the way in which people who are dying and their families are cared for has an enduring impact, the provision of appropriate support not only benefits people who are dying and their families, but also provides support to those providing care.

Assessment Criteria

1. Dying and bereaved people should have access to a range of individuals within health and social care appropriate to their needs and preferences. This support should include chaplains, specialist nurses, social workers, clinical psychologists, counselling services and other clinical staff

¹⁰ Cruse Bereavement Care

2. Systems should be in place for the early identification of individuals requiring specialist support services
3. Dying and bereaved people should have opportunities for their religious and spiritual needs to be met
4. In recognition that such needs may change at various points in their journey, staff should ensure that this element of care is revisited at different times
5. Hospital chaplains' participation in multidisciplinary teams should be maximised
6. Minimum standards for facilities to care for dying and bereaved people should be identified
7. All new HSC buildings should take account of the requirements to respond to the personal needs of dying patients and the needs of those affected by bereavement
8. Trusts should ensure that the most effective use is being made of the facilities currently available to people who are dying and their families
9. Opportunities should be taken with existing HSC facilities to improve their ability to meet the needs of dying patients and those affected by bereavement

5.5 Standard: Knowledge and skills

It is essential that those involved in caring for people who are dying and for people who are bereaved are well informed so they feel confident about the care and support they give. They should have adequate opportunities to develop their knowledge, understanding, self-awareness and skills When a Patient Dies, 2005.

Standard

That Health and Social Care organisations recognise the value of a skilled workforce by ensuring that those coming into contact with, or caring for people who are dying and those affected by bereavement are competent to deliver care through continuing professional development and by having systems in place to support them.

Rationale

Ongoing training and education is necessary to ensure safe, sensitive and effective practice, and is required for the good governance of any service. Staff need sufficient awareness of the legal and practical requirements of care of the deceased such as death certification, the Coroners processes and last offices to enable compliance with standards and to advise relatives. There is a cost of caring in highly stressful areas of work such as end of life and bereavement care and HSC employers have a duty of care to ensure that appropriate support is in place to minimise the impact of such demanding experiences.

Assessment Criteria

1. All HSC staff, including hospital chaplains, should have opportunities for personal review and appraisal to ensure that individuals providing bereavement support and care are competent to do so. It is recognised that appraisal is a continuous process, but it is expected that formal appraisals should occur on at least an annual basis
2. Personal development/contribution plans should be informed by the appraisal process
3. Trusts should ensure that staff working with people who are dying and bereaved understand the importance of maintaining and developing appropriate skills through a variety of methods. Skills or practice development includes a wide range of methods for services, mentoring, observation, supervised practice, reading, experiential learning
4. Trusts should identify an accessible programme of accredited training for all individuals working with dying and bereaved people of a kind and to a level that is appropriate for their role, which should include training for chaplains
5. Specialist training should also be provided specifically within children's and maternity areas
6. Trusts should ensure that there is an ethos of life long learning which is reflected in staff members contract of employment
7. HSC organisations should have arrangements in place to ensure that individuals (consultants, doctors in training and staff grade doctors) who are taking consent for post mortem examination are competent to do so
8. Training for post mortem consent should comply with the requirements of the Human Tissue Authority
9. Regular audit of compliance with training should be undertaken
10. Health and Social Care Trusts should be aware of the impact bereavement can have on their employees
11. Trusts should have in place arrangements to ensure the psychological wellbeing of their employees through staff support or occupational health services
12. The needs of staff exposed to potentially traumatising or distressing situations should be considered against their individual needs or personal circumstances
13. Return to work interviews following personal bereavement should identify present circumstances or needs of staff

5.6 Standard: Working together

“Many people seemed genuinely staggered by the level of expertise, knowledge and experience in the room – and also the extent to which values, priorities and ideas were shared across the system. The question was – how can we make this more accessible and co-ordinated?”

NI Bereavement Strategy Workshop Discussions, 23 February 2007

Standard

That good communication and co-ordination will take place within and between individuals, organisations and sectors, to ensure that resources are targeted efficiently and effectively and that there is integration of care to meet the needs of people who are dying and their families, friends and carers.

Rationale

Just as the needs of people who are dying and their families may change over time, so too may those individuals and organisations (e.g. family, friends, community, voluntary and statutory organisations) who provide them with care and support. The probability of a person’s mental health being significantly adversely affected by bereavement can be reduced when there is consistency and continuity throughout the care and support process. A wide range of well evidenced sources of information on services and advice for bereaved relatives is available across the public and voluntary sectors but access by staff and relatives is more limited. There is an economy of effort in relying on these well developed resources rather than each service devoting resources to developing them independently.

Assessment Criteria

1. Trusts should develop more structured arrangements for public involvement in service reviews and developments in bereavement care
2. Systems for user engagement within bereavement care should be in place to assure the quality of service
3. The impact of user engagement should be audited
4. Each HSC Trust should provide multi-disciplinary and inter-agency opportunities for working together
5. A Trust wide bereavement forum should be developed and facilitated by the Area Bereavement Co-ordinators
6. Links should be established by Trusts to facilitate work in partnership with organisations supporting the needs of specific groups and individuals including mental health initiatives such as the Protect Life strategy, Northern Ireland

Cancer Network, the Critical Care Managed Network and other specific patient/client groups

7. Contact should be established by Trusts with those who provide support and information to minority groups with particular links to those agencies that support individuals with special needs and differing abilities.

6 Evaluation of impact

Following the launch of the HSC Bereavement strategy it is expected that standards and criteria for services will be issued to Health & Social Care services. As baseline data is now available through the 2007 NI Audit this enables a re-audit to determine the impact of progress against Trust implementation plans. A review of HSC Trusts annual reports on complaints, litigation and service user satisfaction would also serve as useful indices of improvement. It is expected that Trusts will be able to self assess against the criteria set out under each standard to facilitate the Regional Quality and Improvement Authority (RQIA) assessment of the quality of services provided for bereaved relatives in the Health and Social Care services.

7 Appendices

Appendix 1	Summary of the main findings of Northern Ireland Audit: Dying, Death and Bereavement
Appendix 2	Membership of DHSSPS Steering Group; Regional Implementation Group Area Bereavement Coordinators
Appendix 3	World Café & Open Space
Appendix 4	Workshop participants & writing group members
Appendix 5	References

APPENDIX 1 Summary of the findings of Northern Ireland Audit: Dying, Death and Bereavement

Audit Background

The audit was commissioned by the DHSSPS and funded through the Regional Multi-professional Audit Group (RMAG). It maps current services across the province and to identify the profile of need within the areas of care of the dying and bereavement care. It was undertaken by the Area Bereavement Coordinators in 2006-07, i.e. just prior to the amalgamation of the then 18 Health and Social Services (HSS) Trusts into the current five Health and Social Care (HSC) Trusts.

The audit targeted every hospice and all the main acute and local hospitals and a significant sample of minor and more specialist hospitals (specifically, in the areas of eldercare, mental health and learning disability) across Northern Ireland. A total of 5 hospices and 35 hospitals (including an inpatient mental health unit).

The audit was informed by national and regional standards alongside current legislation, core strategies, guidelines and literature, including the following:

- Births and Deaths Registration (Northern Ireland) Order (1976)
- Coroners Act (Northern Ireland) 1959 (Section 7)
- Human Tissue Act 2004
- DH (2003), NHS Chaplaincy: Meeting the Religious and Spiritual Needs of Patients and Staff
- DH (2005), When a Patient Dies: Advice on Developing Bereavement Services in the NHS
- DH (2006), Care and Respect in Death: Good Practice Guidance for NHS Mortuary Staff
- DHSSPS (2000), Partnerships in Caring: Standards for Service. A Review of Palliative Care
- DHSSPS (2003), Breaking Bad News: Regional Guidelines, Developed from Partnerships in Caring (2000)
- DHSSPS (2005), A Code of Good Practice on Post Mortem Examinations: A Careplan for Women who Experience a Miscarriage, Stillbirth or Neonatal Death
- DHSSPS (2005), Post Mortem Examinations - A Code of Good Practice: Rights of Patients and Relatives: Responsibilities of Professionals
- DHSSPS (2006), The Quality Standards for Health and Social Care: Supporting Good Governance and Best Practice in the HPSS
- DHSSPSNI, PSNI, Court Service NI and HSENI (2006), Memorandum of Understanding: Investigating Patient or Client Safety Incidents (Unexpected Death or Serious Untoward Harm)
- Equality Commission NI and DHSSPS (2003), Racial Equality in Health and Social Care - Good Practice Guide
- Human Tissue Authority (2006), Codes of Practice
- National Institute for Health and Clinical Excellence (2004), Improving Supportive and Palliative Care for Adults with Cancer

- NHS Executive (2000), Resuscitation Policy
- NHS Estates (2005), A Place to Die with Dignity: Creating a Supportive Environment

The chief executives with responsibility for each of the hospitals and hospices referred to in Table 1 were invited to take part in the audit, and all agreed and signed up to the project. Trust and audit leads were identified to assist the Area Bereavement Coordinators in the collection of information.

HSC Trust	Hospitals	Hospices
Belfast HSC Trust	Belfast City Hospital, Royal Victoria Hospital, Royal Jubilee Maternity Service, Royal Belfast Hospital for Sick Children, Mater Infirmorum Hospital, Musgrave Park Hospital, Forster Green Hospital, Muckamore Abbey Hospital, Knockbracken Healthcare Park.	Northern Ireland Hospice Care.
Northern HSC Trust	Antrim Area Hospital, Mid-Ulster Hospital, Whiteabbey Hospital, Causeway Hospital, Moyle Hospital, Braid Valley Hospital, Dalriada Hospital, Robinson Memorial Hospital, Holywell Hospital.	Northern Ireland Children's Hospice.
South Eastern HSC Trust	Ulster Hospital, Ards Hospital, Bangor Hospital, Lagan Valley Hospital, Downe Hospital, Downshire Hospital.	Marie Curie Hospice.
Southern HSC Trust	Craigavon Area Hospital, South Tyrone Hospital, Daisy Hill Hospital, Lurgan Hospital, Mullinure Hospital, Inpatient Psychiatry Unit, St Luke's Hospital, Longstone Hospital.	Southern Area Hospice Services.
Western HSC Trust	Altnagelvin Hospital, Tyrone County Hospital, Erne Hospital.	Foyle Hospice.

Table 1: Hospitals (n=35) and hospices (n=5) included in the audit

The audit comprised eight strands and used a mixed methodology of both quantitative and qualitative data collection. The strands are as detailed below:

1. Demographics – information on the profile of deaths.
2. Organisational – information on services provided and governance arrangements.
3. Ward visits – information from a sample of wards in different specialities, concerning policies, procedures and practices.
4. Mortuary services – information on facilities and practices.
5. Chaplaincy services – information on services provided and how patients' spiritual needs are met.
6. Palliative care services – information on the make-up of teams and services provided.
7. Porters and funeral directors services – information on the transfer and release of deceased patients.
8. Individual staff questionnaires – information on caring for dying patients and their families.

Sample of main audit findings

Demographics

Figure 1 shows the number of inpatient deaths recorded in each of the main specialist areas within the hospitals and hospices audited throughout the (financial) year 2005-06 with 7,944 recorded inpatient deaths in total: 7,359 in the 35 hospitals and 585 in the 5 hospices.

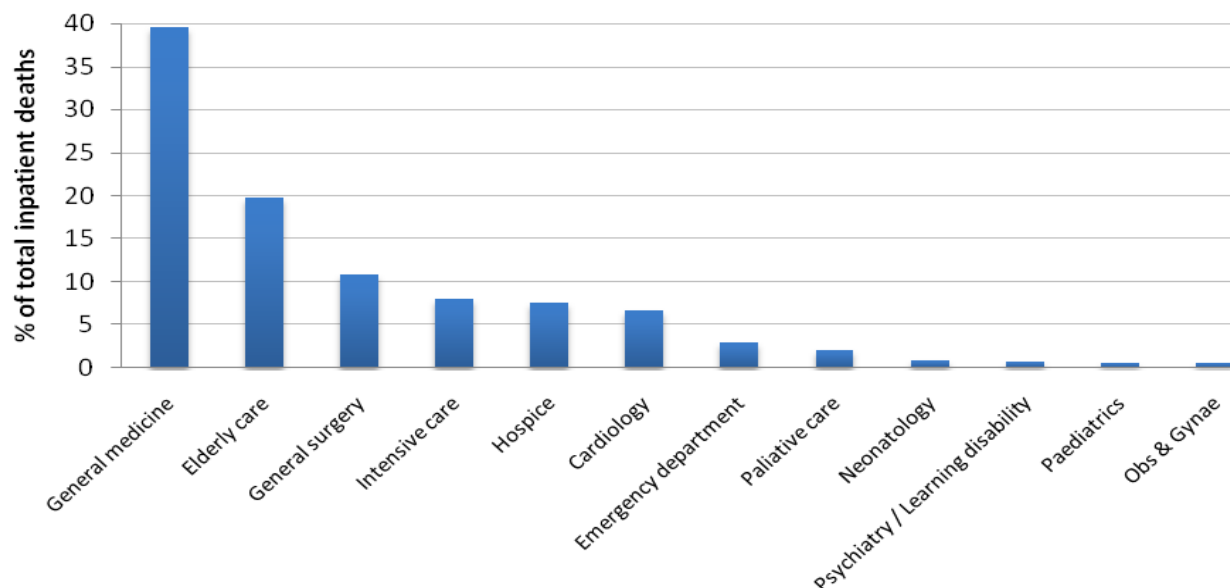


Figure 1: Inpatient deaths by specialist area (01 April 2005 to 31 March 2006)

General medicine (with almost 40% of all inpatient deaths) recorded the highest percentage, followed by elderly care (with almost 20%). It should be noted, however, that there will have been significant overlap between these two areas, since a high proportion of deaths in general medical wards occur amongst elderly patients. The areas recording the next-highest numbers of deaths were general surgery (11%), intensive care units (8.0%), hospices (7.5%) and cardiology wards (almost 7%). No other specialty accounted for more than 3% of the total recorded inpatient deaths for the year.

Figure 2 summarises the different types of mortuary facility available in the 40 hospitals and hospices included in the audit. A total of 18 organisations (45%) had access to a mortuary; 14 (35%) had designated areas where bodies could remain until collected by funeral directors; and in the remaining 8 (20%) it was practice for funeral directors to collect patients' bodies directly from wards.

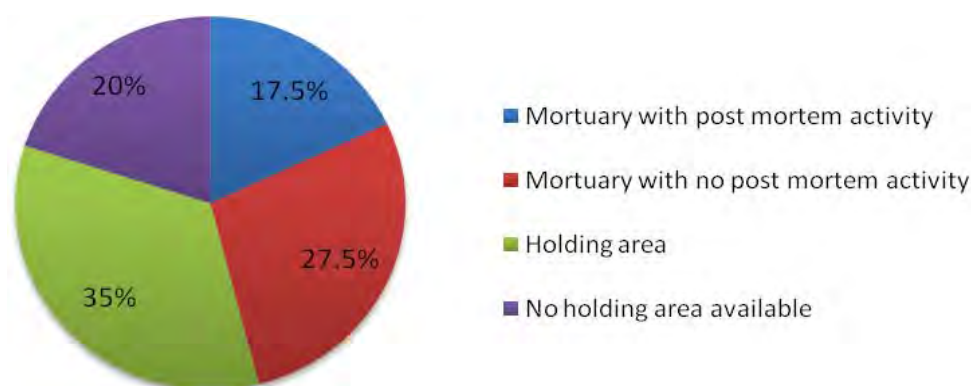


Figure 2: Types of mortuary facilities within the 35 hospitals and 5 hospices

Staff Groups

Questionnaires were issued to a variety of healthcare staff groups in an effort at securing information about their involvement and experience of caring for dying patients and their families. Staff were asked about the frequency of their contact with patients who are dying, their families or with other staff involved with the care of dying patients. Figure 3 shows about one-third of staff responded to the questionnaire

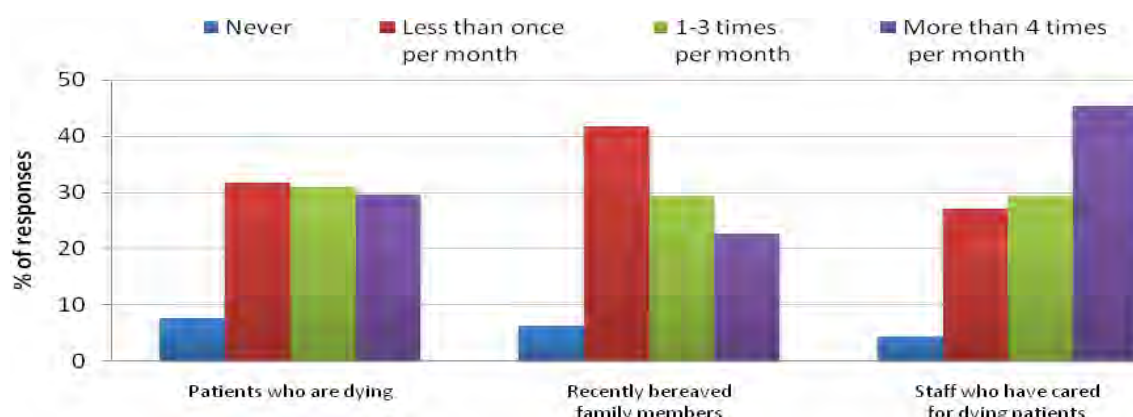


Figure 3: Frequency with which staff deal with issues of death and dying (n=1560)

often deal with dying patients or others directly affected by their deaths (i.e. at least weekly), with approximately similar numbers having at least monthly and rather less than monthly such experience respectively, and only just over 5% having no such contact at all.

The audit also sought to identify the profile of specialist palliative care services across the region. There are eleven such specialist teams within the acute sector regionally – three in the Belfast Trust, and two in each of the other four trusts – based in the Altnagelvin, Antrim, Belfast City, Causeway, Craigavon Area, Lagan Valley, Mater, Daisy Hill, Royal, Erne and Ulster Hospitals respectively. Some of these teams work across both hospital and community sites. Operational policies were in place for 60% of the teams in total.

Representatives of each palliative care service were asked to identify the different professions within their respective teams. The results are summarised in Figure 4, which shows that whilst all eleven teams comprised specialist nursing staff and 82% had a consultant physician, other professional groupings were much less likely to be included within such specialist services.

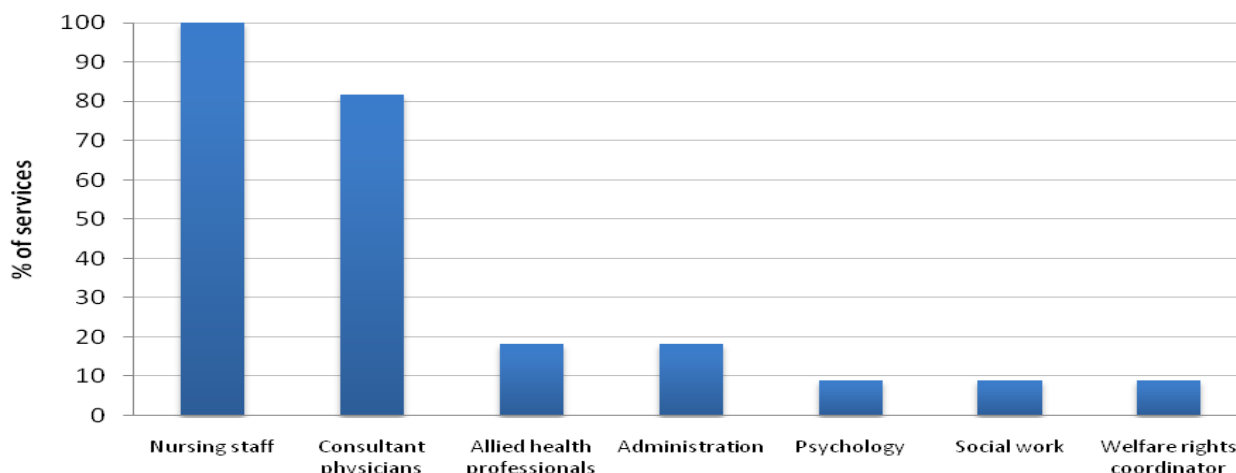


Figure 4: Professional membership of the specialist palliative care teams (n=11)

Consultation Version

Recent needs assessments carried out in the palliative care sector have led to the development and inclusion (limited numbers) of specialist practitioners from other disciplines as well, e.g. speech and language therapy, physiotherapy, occupational therapy, nutrition and dietetics, social work and psychology.

Figure 5 summarises the extent to which the main religious denominations are represented within the 27 chaplaincy teams which, between them, served 33 of the hospitals and hospices included in the audit. Most trusts employ a chaplain from each of the four main denominations, while it was widely reported that the Methodist chaplain liaises with other appropriate religious/spiritual representatives as required. Within the Northern Ireland Hospice, the spiritual needs of patients are attended to by two generic chaplains.

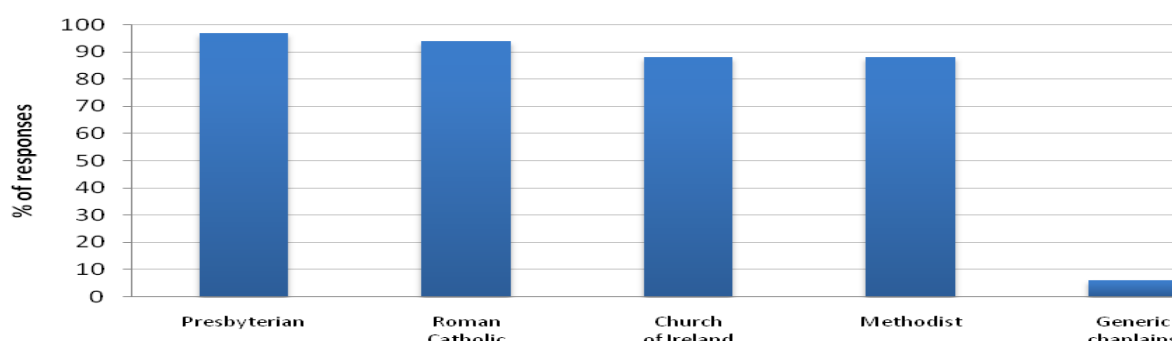


Figure 5: Religious denominations represented within chaplaincy services (n=33 hospitals and hospices)

Policies and guidelines

All 35 hospitals and 5 hospices were asked to provide information in respect of their policies, procedures and guidelines associated with end of life and bereavement care. This information was collected from the organisation leads and key individuals within the services audited.

A full list of the policies and procedures available is presented in Table 2, arranged in order of the extent to which those policies were reported as being complied with across the various organisations. (Note that not all organisations provided information in respect of every policy or procedure.)

Policy/Procedure Area	Hospitals	Hospices
Accessing translation services	94%	60%
Do not attempt resuscitation	94%	100%
Reporting cases to the coroner	91%	100%
Cultural and religious practices	88%	100%
Death certification	82%	100%
Breaking bad news	77%	100%
Care of the dying pathway	74%	100%
Care plan for miscarriage, stillbirth or neonatal death*	73%	(N/A)
Post mortem processes	71%	40%
Cremation	69%	80%
Memorandum of understanding	68%	100%
Information for relatives	62%	100%
Burial by hospital (if no next-of-kin)	61%	60%
Advance directives	51%	60%
Identification of the deceased	49%	60%
Bereavement care	46%	80%
Chaplaincy/Spiritual care	46%	100%
Sudden death protocols	42%	20%

Table 2: Hospitals (n=31-35) and hospices (n=3-5) reporting compliance with bereavement-related policies and procedures (*Note: applicable to 19 hospitals only)

Hospices had evidence of a higher level of written policies overall, as would be expected in services specialising in end of life care. And while organisations generally had in place policies, procedures and guidelines relating to statutory or legal obligations in end of life and after death care, those that bore no statutory obligation to direct or enhance supportive care tended to be less evident within the hospitals.

In Northern Ireland there is generally a short timeframe from death to burial and it is good practice for the MCCD to be given to the family as soon as practicable. However, the audit identified that it is issued at the time of death in only 50% of cases. Ward managers were asked to specify the reasons for the delay in the MCCD being issued. Their responses are presented in Figure 6.

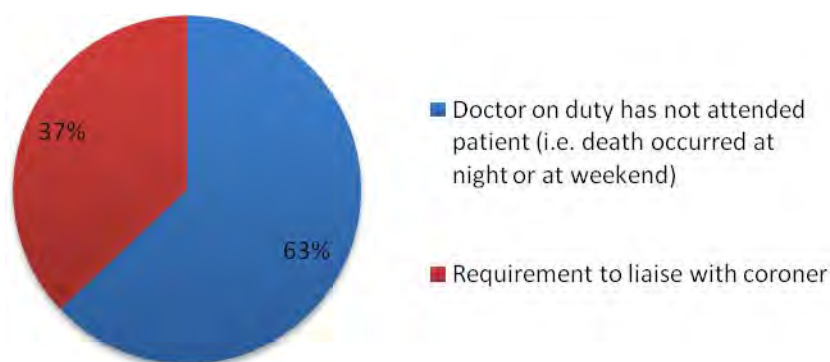


Figure 6: Reasons offered by ward managers (n=95) for a delay in issuing a death certificate

Two reasons were identified: the most common (accounting for 63% of cases) was that changes in junior doctors' working hours may mean that the duty doctor has not attended the patient personally, so that the issue of the certificate has to await the return of a doctor who has indeed treated the patient; and the second (accounting for the remaining 37% of cases) was that the circumstances of the death may require the doctor to discuss the case with a consultant and make contact with the Coroner for advice as to whether an MCCD can be issued or if further investigation is required.

Information and communication

Portering managers and those funeral directors carrying out portering and mortuary duties under service level agreements were asked about the information provided to them at the time of a deceased patient's transfer from a ward. Their responses are summarised in Figure 7, from which it can be seen that the nature of the information provided by ward staff varied considerably – especially that provided at the time a request for a body to be removed was being made.

Some of the porters and funeral directors were given information verbally and others through an attached mortuary identification form. Given the importance of effective communication on issues such as infection control, identification and release, these figures must be viewed as unacceptably low.

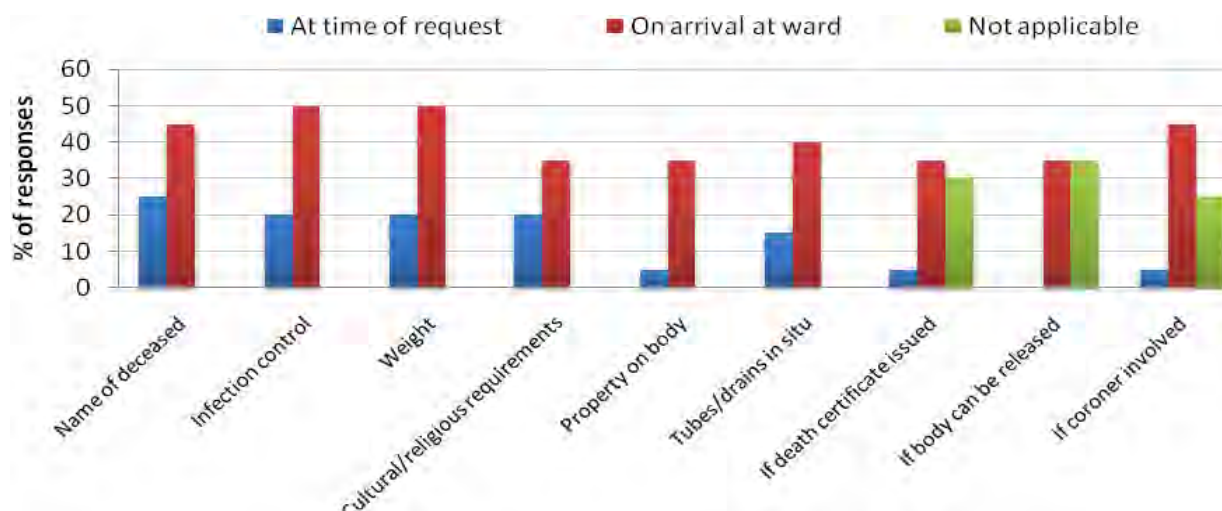


Figure 7: Information provided to porters and contracted funeral directors (n=20) when removing a body from a ward

Knowledge and skills

It is essential that those involved in the care of people who are dying and the bereaved are well informed, so they feel confident about the care and support they give. They should have adequate opportunities to develop their knowledge, understanding, self-awareness and skills (When a Patient Dies, DOH 2005).

In both the ward visits and the staff questionnaires, respondents were asked about the availability and uptake of training specific to end of life and bereavement care. Figure 8 details the various topics in which staff had received training. It was recognised that whilst staff may not have had formalised training, many have developed knowledge and skills in these subjects through experience and 'on-the-job' training.

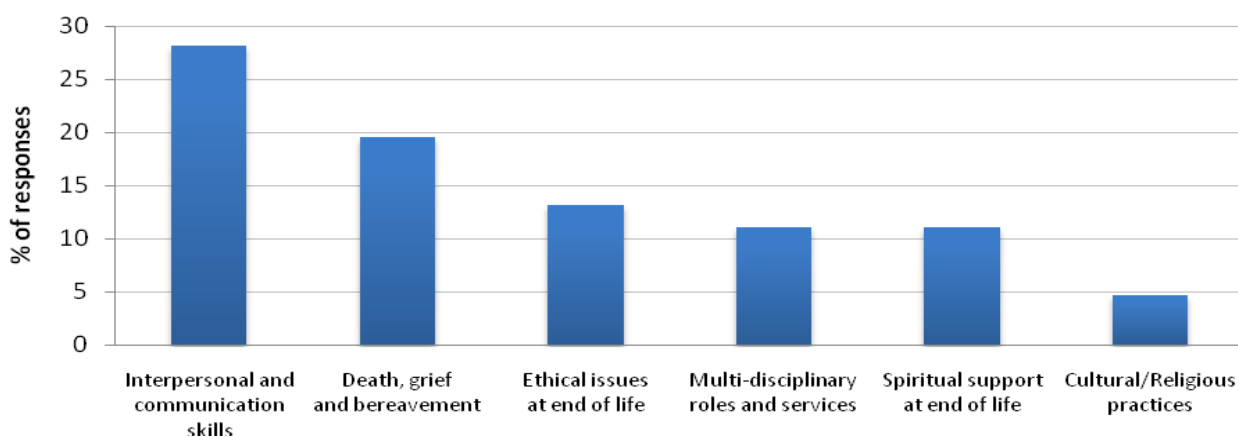


Figure 8: Percentage of staff responding to the questionnaires who had training in care of the dying and their relatives (n=1633)

Staff were also asked whether or not they felt confident in delivering end of life and bereavement care. The results are presented in Figure 9.

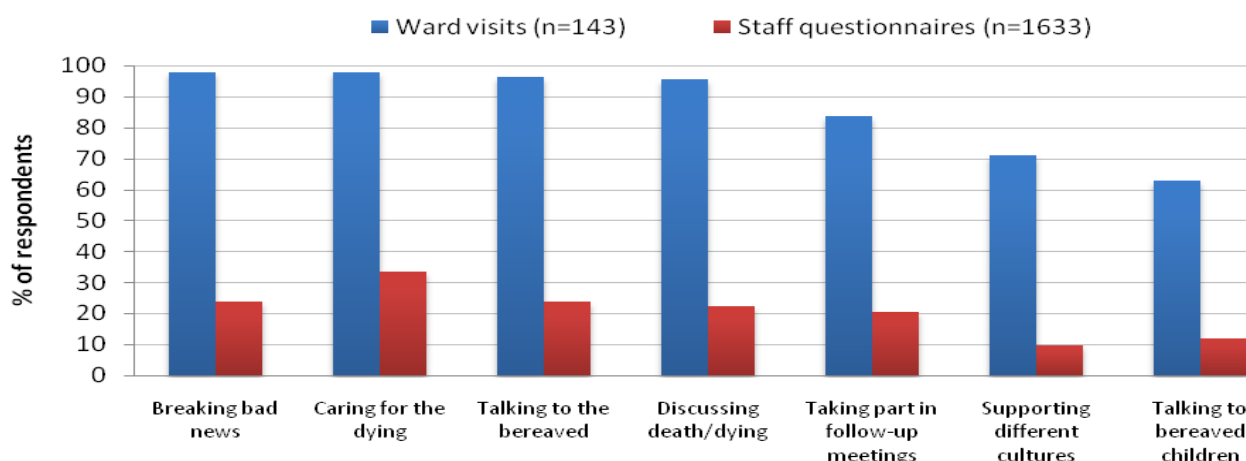


Figure 9: Percentages of staff expressing themselves confident in the delivery of end of life and bereavement care

The ward managers (who provided the information on the ward visits) reported themselves to be significantly more confident in the delivery of all aspects of end of life and bereavement care than did the staff who responded through staff questionnaires – a reflection, no doubt, of the high level of experience of the ward managers. Talking to bereaved children and supporting people from different cultures were the most difficult duties for all staff to perform.

Staff support

Staff participating in both the ward visits and the individual staff questionnaires were asked about the support systems in place throughout their organisations. Figure 10 summarises the responses of both groups.

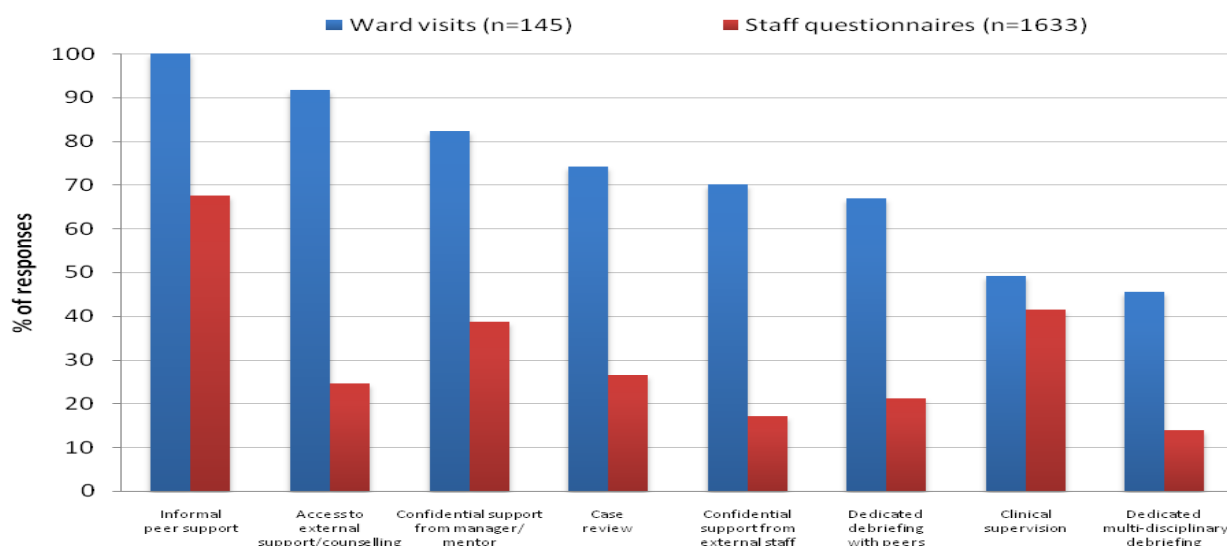


Figure 10: Staff support systems identified as being in place

The ward managers, as a reflection of their levels of experience, were much more aware than were the individual staff who responded to the questionnaires of the availability of appropriate staff support systems.

Environment and facilities

During the ward visits, staff were asked to rate the suitability of their ward environment to meet the needs of, and being supportive to, patients who are dying and their families with responses are in Figure 11.

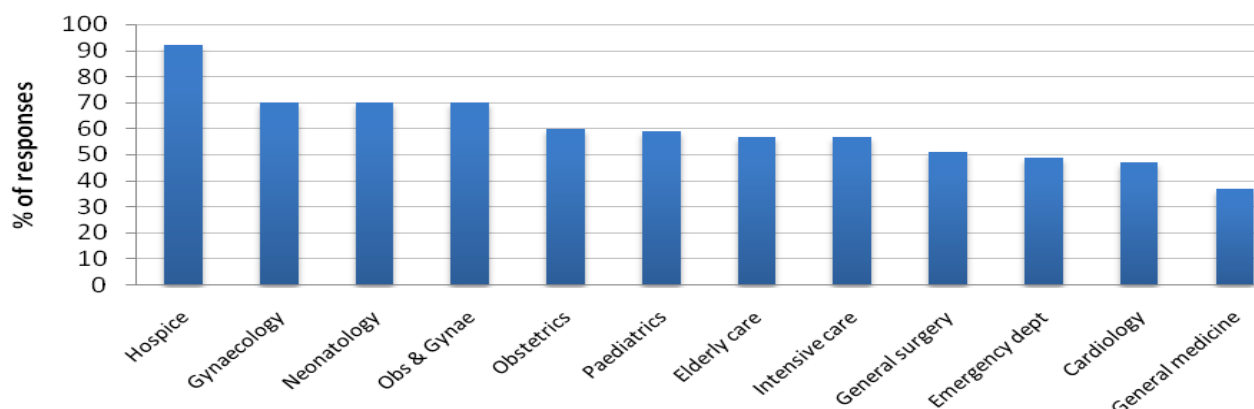


Figure 11: Percentage of wards and hospices rated 'excellent' or 'good' overall by their ward managers (n=145)

Hospices, as would be expected given their central focus on the care of dying patients, were rated the highest overall in terms of the suitability of their environment for the provision of care to those who are dying and their families, while general medical wards – the clinical area identified previously as having the highest death rate (see above, Figure 1), but also amongst the busiest within the hospital sector – were rated as the lowest.

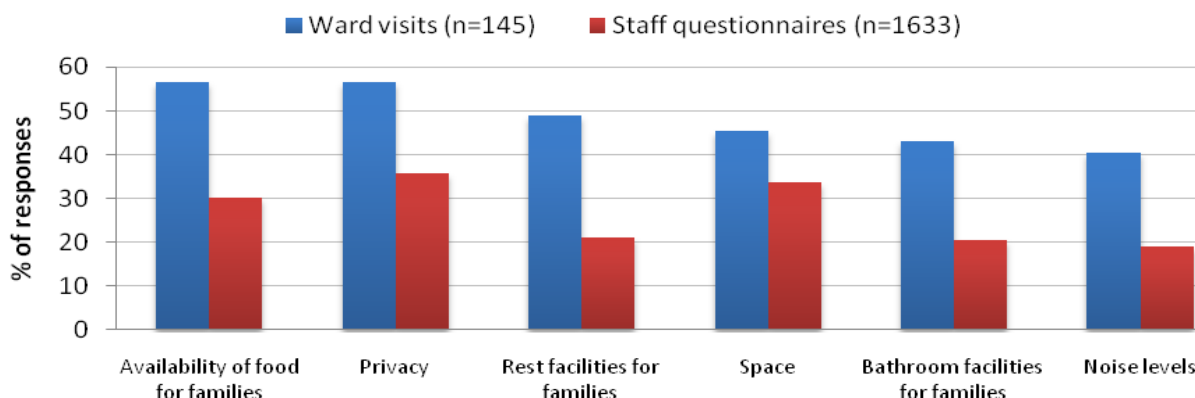


Figure 12: Environmental aspects of wards/facilities rated 'excellent' or 'good' by staff

Staff, both in ward visits and questionnaires, were asked to rate specific aspects of the environments. As Figure 12 clearly indicates, the ward managers consistently rated all aspects of their wards higher than did other members of staff. Indeed a significant number of staff in their individual questionnaire responses indicated a level of concern about the limitations of their respective environments for the provision of appropriate end of life care and bereavement support.

In response to a question about where exactly difficult discussions with families were likely to take place, staff identified six different locations (see Figure 13).

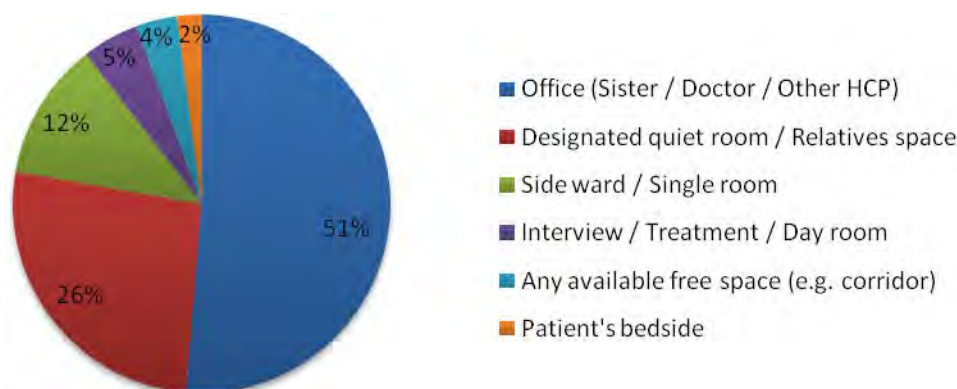


Figure 13: Locations where difficult discussions take place with relatives, as reported by ward managers (n=144)

Offices constituted by far the most common location for such discussions – those of the ward manager, a doctor or some other health care professional (51%) – with sizeable numbers taking place also in either designated quiet rooms or relatives’ spaces (26%) or in side wards or single rooms, if available (12%). Whilst staff clearly made efforts to find quiet areas in which to have such difficult discussions with family members, a small number identified that, due to ongoing pressures in acute wards in particular, it was not always possible to identify such locations. As a result, discussions did at times occur in wholly unsuitable places, including corridors and at patients’ bedsides.

Care and support

Given the importance of working in partnership with patients and families, ward managers were asked as part of the audit about whether they explore the wishes and feelings of patients who are dying. Figure 14 presents the results. Every manager from an elderly or a gynaecology ward reported routinely exploring the wishes and feelings of their dying patients, where appropriate. This contrasts sharply with over 30% of staff from emergency departments who reported doing so. The latter finding is predictable, however, given the number of sudden and unexpected deaths that occur in emergency departments. It is recognised that these types of discussions may need to be carried out by experienced staff who have advanced communication skills.

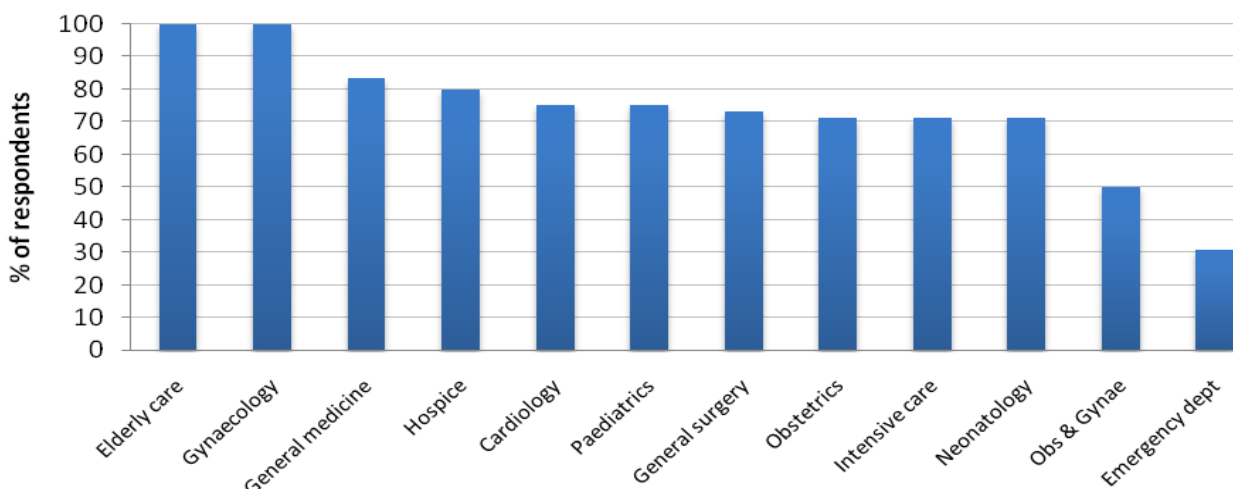


Figure 14: Ward managers from different specialist areas who reported that they routinely explore the wishes and feelings of dying patients (n=137)

All managers were asked during ward visits if a care of the dying pathway was operational in their particular units. Currently, only adult wards operate this system – the development of a separate care of the dying pathway for use within a number of children’s services is being considered – so only those responses from the managers of adult wards are reproduced here, in Figure 15.

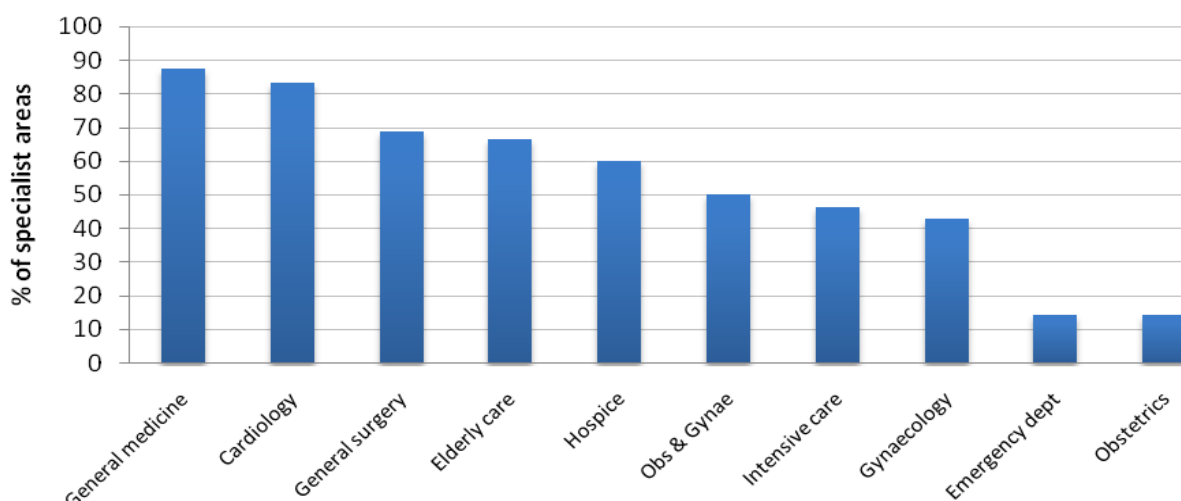


Figure 15: Areas where the care of the dying pathway is operational, as reported by ward managers (n=124)

As expected, general medicine, as the clinical area with the highest number of inpatient deaths, is also the area within which the care of the dying pathway is most frequently used. It is also used extensively in cardiology wards, but only rarely in obstetrics or emergency departments. Overall, staff comments were very positive about the benefits of the care of the dying pathway, which they felt helped to ensure a holistic approach to end of life care.

Senior staff were asked to identify those individuals and groups, whether from the statutory or the voluntary sector, with a remit within their respective organisations in the areas of care of the dying, after-death care and support for the bereaved. A total of 23 such organisations were identified, the most frequently cited of which are presented in Figure 16.

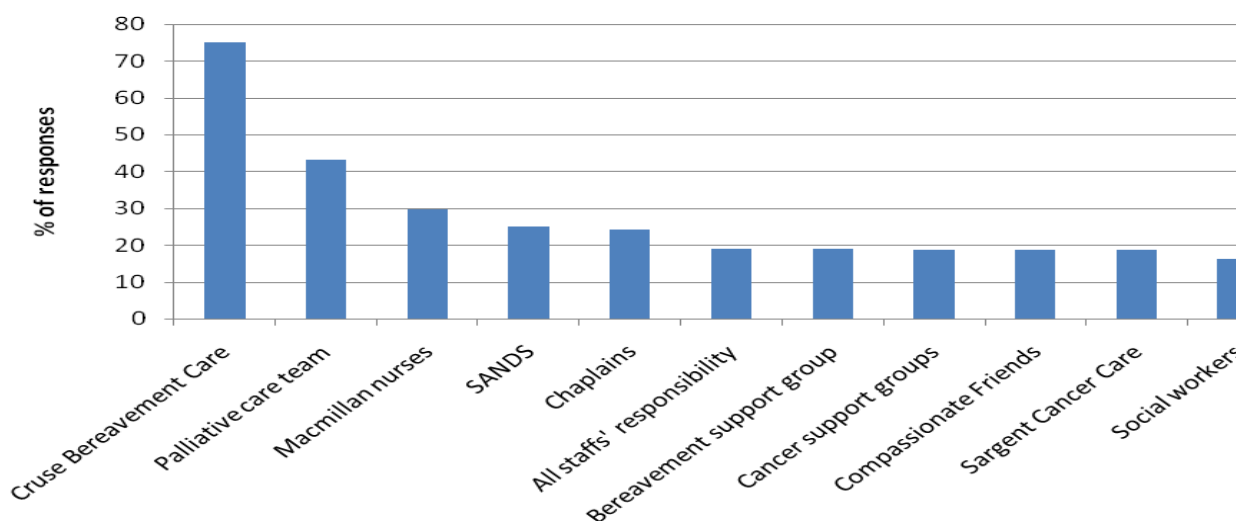


Figure 16: Services most frequently identified by senior managers (n=37) as having a link to bereavement care

Cruse Bereavement Care was by far the most frequently identified organisation, cited by over 70% of the managers. Of the rest, only those services provided by palliative care teams, Macmillan nurses, SANDS and hospital chaplains were identified by more than 20% of respondents. And of the 12 services not included within Figure 16 – care of the dying pathway coordinators, clinical psychologists, Marie Curie services, bereavement volunteers, Bliss for Babies, Child Bereavement Trust, Miscarriage Association, Ulster Cancer Foundation, area bereavement coordinators, community hospice nurses, occupational health services and PSNI Family liaison officers – each was identified by fewer than 10% of the managers.

Figure 17 indicates that symptom management, advice and support were the core services provided by all specialist palliative care teams, followed by education and training, including on the promotion of end of life care pathways (73%), referral on to community services (64%) and the provision of follow-up support (55%).

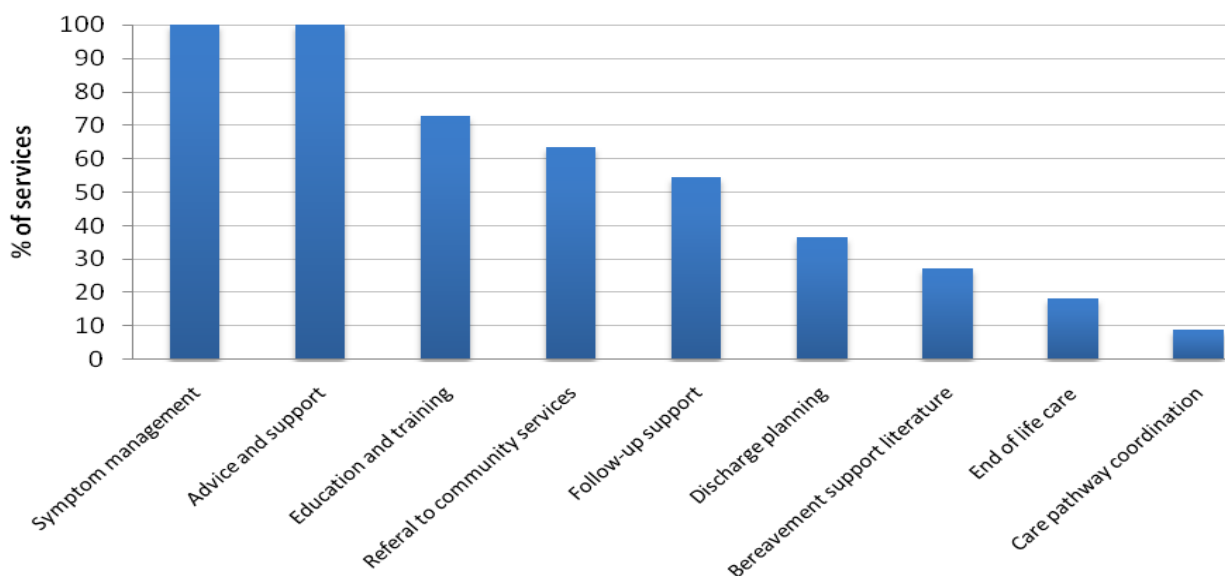


Figure 17: Services provided by specialist palliative care teams (n=11)

The various services which the chaplains provide are summarised in Figure 18.

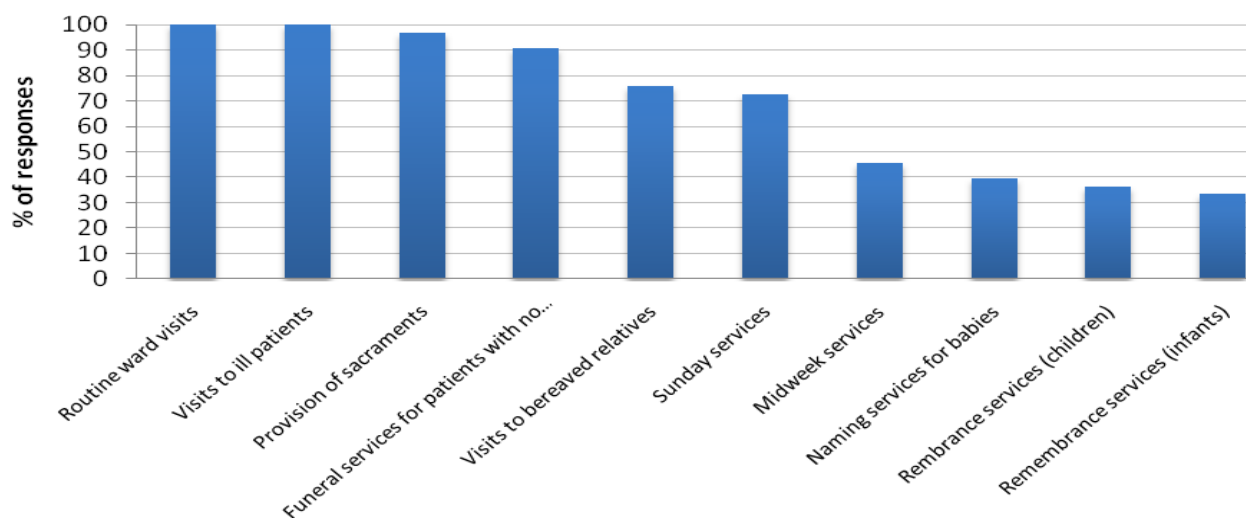


Figure 18: Services provided by chaplains (n=33) to patients and/or their families

Consultation Version

All chaplains carry out routine ward visits and visits to ill patients, and the vast majority (90%) provide the sacraments and undertake funeral services for patients without families. Some chaplains (40%) undertake a number of specifically child-related services, such as infants' or children's remembrance services or naming services for babies.

Information and communication

The audit identified a range of systems used by wards, departments and hospices to notify other professionals of a patient's death (Figure 19). The most common means was through a senior nurse on duty contacting the patient's GP directly (28%), although 5% of facilities had no recognised system at all in place for the notification of other professionals.

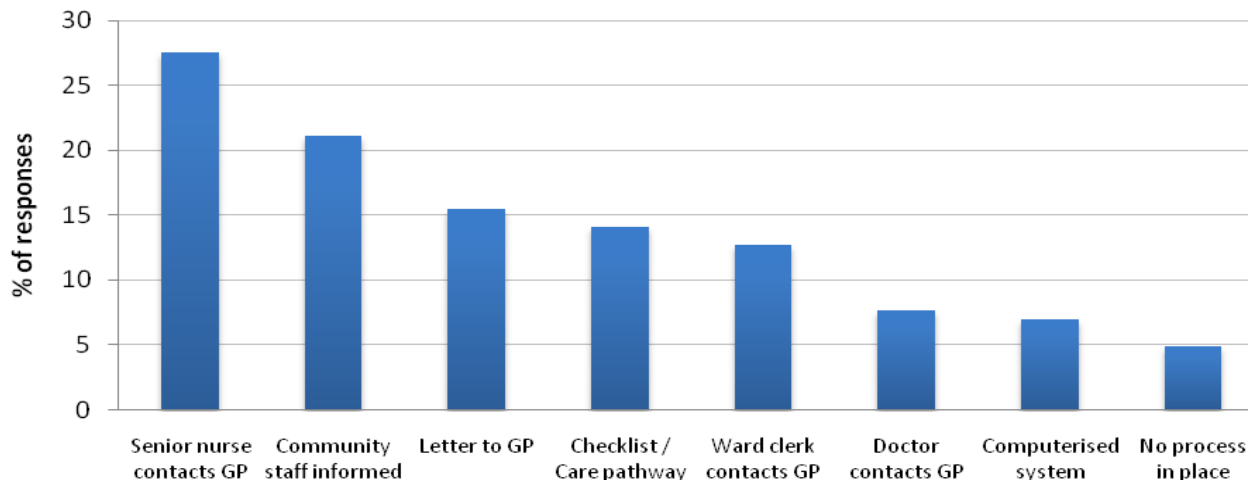


Figure 19: Systems in place for the notification of other professionals, as reported by ward managers (n=142)

No reporting system was identified as being entirely robust with the potential for communication to break down at times resulting in either a delay or the relevant professional not being informed at all of the patient's death. This has the potential to cause undue upset to bereaved families such as when they receive a letter offering an appointment to a person who has already died.

Figure 20 summarises the responses in the audit of ward managers when asked about the information provided to families when a post mortem examination is required.

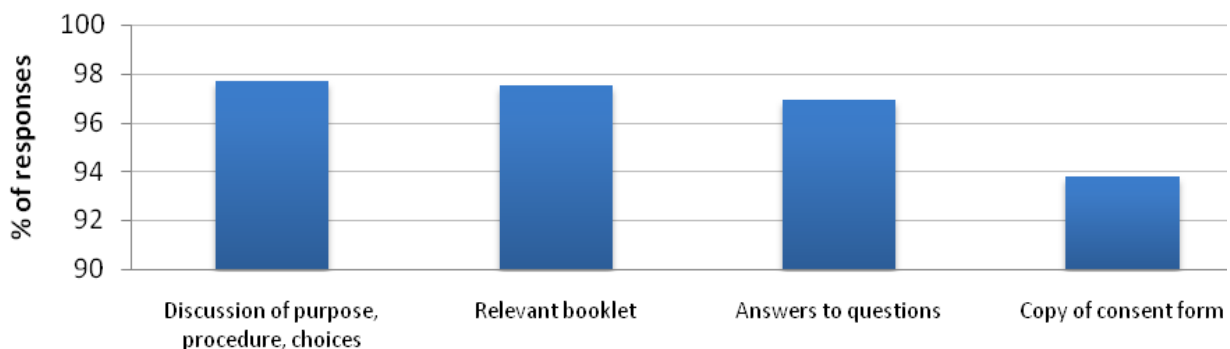


Figure 20: Information provided to families when a post mortem is required, as reported by ward managers (n=113-131)

Explanations and discussions with families, as well as answering their questions and providing them with relevant booklets were all identified practices within at least 97% of wards, although copies of consent forms were provided in only 94% of cases.

The nature of any written information provided to bereaved parents on those wards and departments which may be expected to experience the deaths of babies and/or children is summarised in Figure 21.

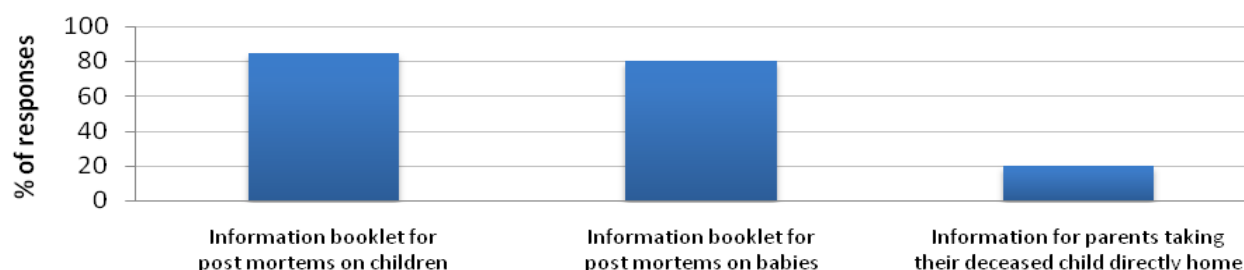


Figure 21: Written information provided to parents of deceased babies or children, as reported by ward managers (n=33-50)

Given that almost half of all children who die in a neonatal unit undergo a hospital post mortem, it is no surprise that information booklets in respect of post mortems on children and babies were the most commonly provided, in at least 80% each of the respective wards and departments. It is increasingly common for parents to take the bodies of their children directly home by car immediately following their deaths, where this was expected; only 20% of the relevant wards and departments had a written policy to support this practice.

Ward managers were asked what other information and resources they provided to bereaved families (see Figure 22). There was evidence of families being directed towards a number of voluntary organisations (in particular, Cruse Bereavement Care) in 78% of wards and departments; 74% provided families with forms to assist in registering the death; 62% provided booklets specifically designed to assist bereaved people; and 54% provided information in relation to the arranging of funerals.

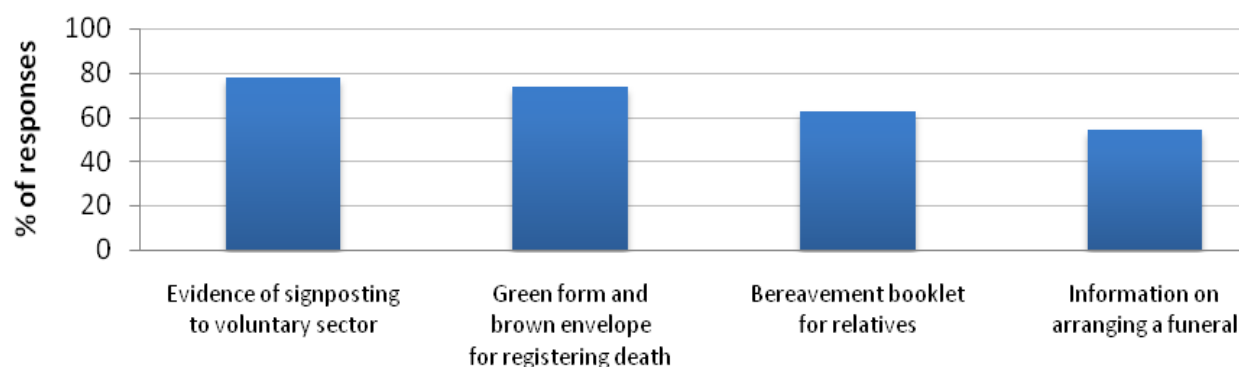


Figure 22: Other information and resources provided to bereaved relatives, as reported by ward managers (n=142)

Ward managers were asked whether or not follow-up meetings to discuss a patient's death were routinely offered to bereaved families. The percentages of units within each clinical area reporting that such follow-up meetings were *always* offered to families are presented in Figure 23.

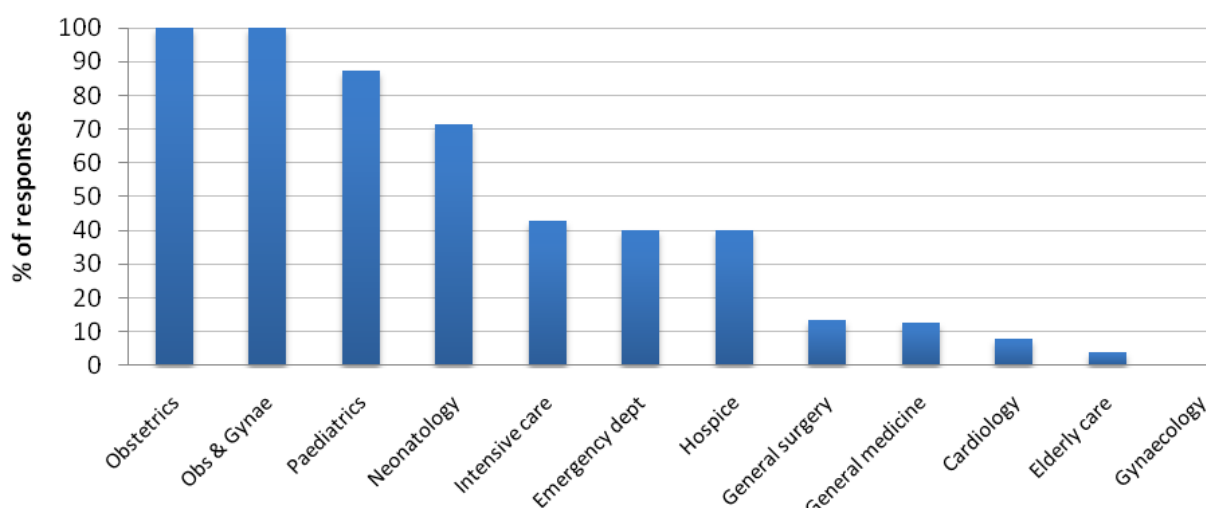


Figure 23: Wards and hospices offering follow-up meetings with bereaved families, as reported by ward managers (n=143)

There were only two clinical areas where every ward concerned provided routine follow-up meetings with families: obstetrics and joint obstetrics and gynaecology wards. Although follow-up meetings were not routinely offered in the majority of units, whether in the hospital or the hospice sector, such meetings were reported to take place at the request of families.

Ward and hospice managers were also asked to identify any methods they employed to obtain feedback from their service users. Their responses are summarised in Figure 24.

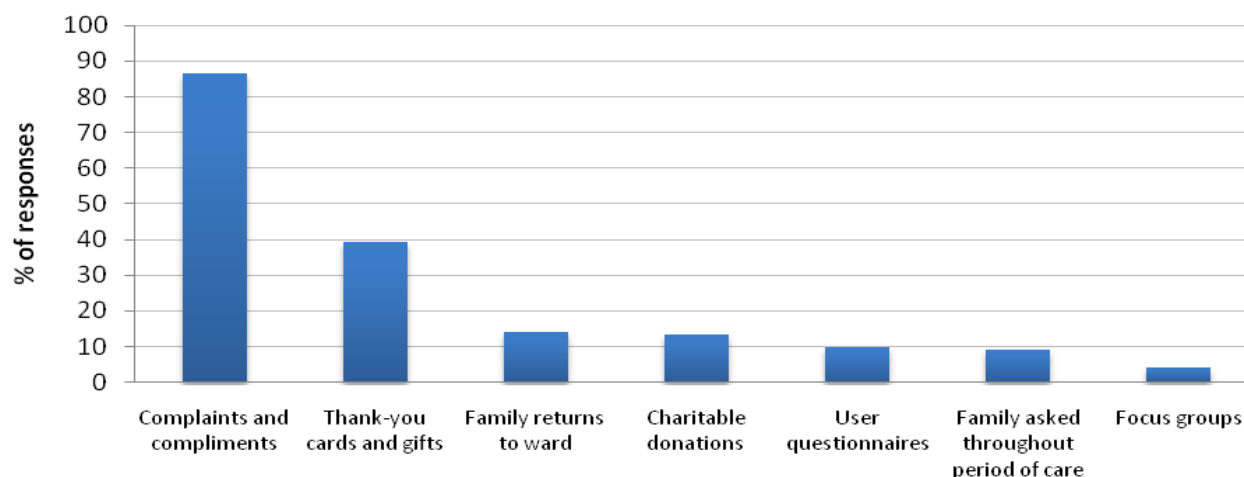


Figure 24: Methods employed by wards and hospices to secure user feedback, as reported by ward managers (n=143)

By far the most common method employed was through the receipt of complaints and compliments (reported by 87% of the managers audited). Thank you cards and gifts were reported by 39%, with families returning to the ward, charitable donations, and asking family members throughout their relative's stay in the unit each recorded by fewer than 15% of the managers.

Equally small percentages of the managers reported using more formal means of securing service user feedback, including user questionnaires (10%) or focus groups (4%).

APPENDIX 2 Membership

DHSSPS Steering Group

Martin Bradley	Chief Nursing Officer, DHSSPS (Chair)
Hazel Baird	Head of Governance & Patient Safety Northern H&SC Trust
Bob Brown	Asst. Director of Learning Development South Eastern H&SC Trust
Therese Brown	Head of Clinical Quality & Safety Western H&SC Trust
Andrew Browne	Secondary Care Directorate, DHSSPS
Dr Graeme Crawford	GP, Bangor Health Centre
Patricia Donnelly	Director of Clinical Services Belfast H&SC Trust
Irene Duddy	Director of Nursing Altnagelvin Hospitals HSS Trust
Ruth Fisher	Secondary Care Directorate, DHSSPS
Noel Graham	Chief Officer, Northern H&SS Council
Judith Hill	Chief Executive, NI Hospice
Liz McNair	Director of Nursing, NHSSB
Alice McParland	Deputy Director of Nursing United Hospitals Trust
Ann McVey	Asst. Director of Nursing Craigavon Area Hospital Group HSS Trust
John Mone	Director of Nursing & Quality Craigavon Area HSS Trust
Dr Heather Neagle	Medical Officer, DHSSPS
Ruth Smith	Directorate Manager Ulster Community & Hospitals HSS Trust
Christine Smyth	Social Services Inspectorate, DHSSPS
Eric Strain	Coroners' Policy Branch, NI Court Service
Anne Townsend	Regional Manager, Cruse Bereavement Care
Fiona Wright	Asst. Director Nursing Services Governance Southern H&SC Trust

Regional Implementation Group

Trust	Area Bereavement Co-ordinator	Manager
Belfast	Heather Russell	Patricia Donnelly (Chair)
Northern	Barbara Bankhead	Hazel Baird (from 29/10/07) Alice McParland (3/04/06- 29/10/07)
South Eastern	Paul McCloskey	Bob Brown (from 1/09/07) Ruth Smith (20/03/06-1/09/07)
Southern	Anne Coyle (from 17/09/07/07) Sharon McCloskey (31/01/06-22/06/07)	Fiona Wright (from 17/09/07) John Mone/ Anne McVey (to 17/09/07)
Western	Carole McKeeman	Therese Brown (from 1/11/06) Irene Duddy (1/2/06- 1/11/07)

Contact:

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APPENDIX 3 “World Café” and “Open Space”

World café

The “world café”¹¹, or conventional conference, is a useful, engaging and practical method for getting people to think together about issues that are important, such as the issues raised in the Bereavement Audit. It is a radical way of thinking about organisations as living systems and is based on an understanding of ‘whole systems working’¹². Information about setting up and running a World Café is readily available in an accessible and easy to follow format on The World Café website – <http://www.theworldcafe.com/> set up by World Café originators Juanita Brown and David Isaacs.

The approach is especially useful for sharing knowledge, stimulating innovative thinking and exploring possibilities for action with real life issues and questions. The approach is called a ‘café’ as groups are seated at café tables (usually of no more than 5-6 people) to enable easy conversations and sharing of ideas in an unthreatening environment.

In essence, the process involves setting a question, allowing a conversation to develop, encouraging people to capture what is said on paper tablecloths placed on the tables for that purpose, moving people to new tables with each new questions in order to get a cross pollination of ideas and occasionally sharing ideas in a whole group plenary to allow deeper, interlinking themes to emerge¹³.

Whole systems working

The way that human systems adapt and evolve is determined by the way the interconnected parts within the system relate to each other as well as the way individual parts behave. The NI Health and Social Care services are considered as a number of living systems and in relation to other parts of the public sector, voluntary and community systems as well as their service users.

Open Space

Open space working is a simple powerful way to catalyze effective working conversations. It can be used to synthesise thinking into action and identify key priorities for future work. The most useful website on Open Space working can be found at <http://www.openspaceworld.org/wiki/wiki/wiki.cgi?AboutOpenSpace>

Open space is effective for trying to find solutions for ‘wicked’ problems that change shape as you try to intervene. This works as a partner to the World Café methodology to identify issues that are important to people in the room. This follows a usual process of: identifying an agenda of items to be worked on – often derived from the Word Café conversations or may be brainstormed at the beginning of the session; workable priorities are negotiated from the brainstorming or conversations; each has a meeting for a defined period with a convenor; participants are free to move between debates; convenors report back to a plenary session where progress is reviewed and the agenda refined; meetings are re-convened as many times as necessary for an agreed set of actions to be identified.

¹¹ Brown Juanita (2002) *The World Café. A Resource Guide for Hosting Conventions that Matter*. California, Whole System Associates

¹² Pratt, Julian Gordan Pat and Pampling Diane (1999) *Working Whole Systems. Putting Theory into Practice in Organisations*. London, Kings Fund

¹³ Pippa Gough, Kings Fund 2007

APPENDIX 4 Workshop participants & writing group members

Adair	Carole	Educational Psychologist
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Barker	Grainne	Coroners Liaison Officer
Barr	Owen	Senior Lecturer, Nursing
Bolton	David	Director, NI Trauma Centre
Boyle	Una	Senior Social Worker
Bradley	Mandy	Macmillan Care Pathway nurse
Bradley	Martin	Chief Nursing Officer
Brogan	Paula	Counsellor, Psycho-oncology
Brown	Beverley	Funeral Director
Brown	Theresa	Risk Management Director
Browne	Andrew	Secondary Care, DHSSPS
Cairns	June	Sister, Care of Older People
Campbell	Sharon	Trauma Advisory Panel Co-ordinator, EHSSB
Carroll	Bridget	Irish Hospice Foundation
Carson	Ian	Chair, Regional Quality Improvement Authority
Chapman	Moreen	Sister, Paediatric Intensive Care Unit
Clarke	Jim	Funeral Director
Clements	Heather	Macmillan Nurse
Conway	Fidelma	Sister, Mater Maternity
Crawford	Graeme	General Practitioner
Crothers	Marie	Assistant Principal Social Worker
Daly	Kate	Sister, Emergency Department
Denvir	Bridget	Community Nursing Manager
Dilworth	Rosemary	
Donaghy	Eleanor	NI Transplant Co-ordinator
Donnelly	Patricia	Director, Clinical Services
Dornan	Kate	Child Bereavement Network
Drolka	Gen	Buddhist Teacher
Dunlop	Stephen	BPS
Elder	Ray	Senior Social Worker
Foden	Karen	Community Palliative Care
Gallagher	Claire	Care of Dying Pathway Co-ordinator
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Gilliland	Diane	Mortuary Technician
Glackin	Marie	Lecturer, School of Nursing
Gough	Pippa	Kings Fund
Grzmek	Brian	Criminal Justice Services
Guy	Steven	Chairperson, SANDS
Hawthorne	Mandy	Sister, Emergency Department
Healey	Arlene	Family Trauma Centre
Henderson	Mary	Relatives Association

Consultation Version

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Hume	Helen	Ward Manager
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Johnston	Derek	Chaplain
Johnston	Gail	Macmillan Lecturer
Kerr	Geraldine	Patient Liaison Officer
Lamont	Sam	Griefshare Co-ordinator
Levingston	Gail	Cruse Area Co-ordinator
MacFarlane	Marisa	Paediatric Macmillan Nurse
Mawhinney	Cathy	Dementia Team Leader
McBride	Michael	Chief Medical Officer
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McCloskey	Sharon	Area Bereavement Co-ordinator
McCloy	Sharon	Cemetery & Crematorium Manager
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McGarrigle	Ann	Bereaved Relative
McGurk	Rosemary	Bereaved Relative
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McKee	Mary	Independent Healthcare Provider
McKeeman	Carole	Area Bereavement Co-ordinator
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McSwiney	Theresa	Counsellor
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Moore	Helen	Capital Development Team
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Quinn	Ursula	Bereaved Relative
Riddell	Margaret	WAVE
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Schofield	Debbie	Audit Co-ordinator
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Slater	Alex	Fisherman's Mission

Consultation Version

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Sweet	David	Coroners Policy Branch
Taylor	Trevor	Consultant Neonatologist
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APPENDIX 5 References

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