



Note "Wordle" diagrams have been used on the front and back covers to illustrate the most frequently used words in the stories. The front cover highlights words from personal stories, the back cover from professional stories. Larger text identifies words used most often

## FOREWORD

The HSC Bereavement Network was established to facilitate continuous improvement in bereavement care: where death and dying are seen as part of life, where care of the dying is as important as care of the living and care after death for relatives, friends and professionals is a continuation of good practice.

This publication is the second phase of a regional audit into the experiences of those dying and bereaved within health and social care. The first audit, published in 2009, focused on statistical analysis of the profile of the 15000 deaths that occur every year in Northern Ireland; and the services available to support patients, relatives and staff around the time of death and bereavement. The audit also identified the significant pressures experienced by the services and the need for ongoing training and support. This second audit completes the picture by focusing more directly on individual bereaved people and professionals and gives us a very powerful view of their personal experiences.

Both audits underpin the aims of the HSC Bereavement Strategy, launched by the Minister in 2009, where six challenging standards were established in Health and Social Care for the improvement of bereavement services.

Sincere thanks is given to Trust Bereavement Coordinators for their central role in the audit but special thanks must be given to the many individuals who took the time and care to tell their personal, and at times painful, stories. The themes and issues identified remind us of the importance of undertaking this work, which has such a lasting effect on the lives of so many; and will form the basis of the improvement plans for our bereavement services.



Patricia Donnelly

**Health & Social Care Bereavement Network**





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## 1. EXECUTIVE SUMMARY

In 2006 a “Northern Ireland Audit on Dying, Death and Bereavement” was commissioned by the Department of Health, Social Services and Public Safety (DHSSPS). It was planned as a two phase audit.

Phase 1 mapped the policies, procedures and practices that related to death and bereavement in 35 hospitals in the Health and Personal Social Services (HPSS) legacy trusts and all five hospices in Northern Ireland. The findings of this first phase, combined with feedback from workshops which engaged bereaved people and representatives from statutory, primary, secondary, community and voluntary agencies, informed the development of six standards for bereavement care. These standards are central to the Northern Ireland Health and Social Care Services Strategy for Bereavement Care (DHSSPS June 2009).

Phase 2 of the audit, reported here, “The Experience of Bereaved People and Those Delivering Primary Care Services” was undertaken to capture experiences of care prior to, at the time of and following death, from bereaved people, and professionals who provide care and support in primary and community settings. The findings of this phase have complemented the information already gained in Phase 1 and provide a comprehensive overview of the impact of care given and received on the experiences of all involved around the time of death and bereavement.

As people often convey complex information through the relaying of stories, participants were offered the opportunity to describe their experience and indicate its impact on them using the “Cognitive Edge”© approach. This method allows both qualitative and quantitative data collection and analysis. Bereaved people were invited to tell the story of a death or bereavement from a personal perspective and professionals a story from their work experience. All respondents were asked to self-index their story by answering a number of questions.



The experiences were then analysed using SenseMaker™ software, which enabled the data collectors to identify main messages:

1. When healthcare professionals have identified that a patient is dying or has died, they have a responsibility to communicate this in a clear and supportive way to avoid misunderstanding or additional distress.

Professionals caring for patients and their families before, at the time of and after death can influence how a bereaved family copes following death by helping them come to terms with the diagnosis and prognosis, supporting them through the pre-bereavement stage, and giving them the information they need to help with the future.

2. Every effort should be made to support people to die in their preferred place, where at all possible, when death is expected. However, health care professionals can influence the experience at the time of death and bereavement in a positive or negative way, regardless of where death occurs. A supported experience can be achieved by treating the patient and their family with compassion, dignity and respect; and delivering care that meets their needs.
3. When care and decision making between the patient, family and professionals are viewed as a partnership, a positive experience for all is more likely. When the patient, family and professionals do not work together; or when treatments and actions are not explained or understood, this may lead to a negative experience.
4. When doctors do not complete medical certificates of cause of death accurately they are not accepted for death registration purposes. This causes additional distress and inconvenience to families at an already difficult and stressful time.
5. Those bereaved in a sudden and/or traumatic way will have additional issues to deal with which may complicate their grieving. They may therefore require specific information, guidance and support from healthcare professionals.





6. For many bereaved people the main sources of ongoing support are their family members and friends. Caring for someone who is dying, and death itself, can often bring a family closer or may put a strain on family relationships. Many people do not require help and support from outside their family, friends and community but some may benefit from external bereavement support, especially if the circumstances surrounding the death have been difficult.
7. When professionals identified that their training and experience helped them a lot, they were more likely to describe a positive experience. The experience of dying patients and their families is influenced positively or negatively by the skills of those caring for them. The death of a patient affects professionals and most rely on their peers to help deal with their feelings. Training and mentoring equip professionals to take care of their patients, themselves and each other.

The open approach used to capture the experiences, and the software used to analyse them, have provided very rich and compelling data which has allowed the effect of the delivery of care around the time of death and bereavement to be determined. This method has the potential to be used by other organisations and service groups who wish to evaluate the impact of care delivery on patients/clients, relatives and staff.

This audit emphasises the importance of the role of healthcare professionals who support people around the time of death and in bereavement. It has identified how the experience can be positively or adversely affected by the care the patient and/or bereaved people receive, which at times impacts on their well being and memory of the event. The findings also reflect the esteem in which skilled, supportive and compassionate professionals are held.

The commitment by Trusts to implement the six standards in the HSC Services Strategy for Bereavement Care (2009), aims to increase the capacity of all those who come into contact with dying and bereaved people. This will address the main messages and improve the experience of those providing and receiving care and support around the time of death.





## 2) INTRODUCTION

### BACKGROUND AND PURPOSE

Approximately 14,000 to 15,000 people die each year in Northern Ireland. Many health and social care (HSC) and primary care professionals coordinate and provide care and support for people who are dying and their families, both in hospital and community settings. In 2006 the HSC Bereavement Network was established with the appointment of five Trust Bereavement Coordinators who were given a remit to develop and coordinate bereavement care standards and training.

This regional audit is the second phase of the Northern Ireland Audit on Dying, Death and Bereavement, undertaken by the HSC Bereavement Network and commissioned by the Department of Health, Social Services and Public Safety (DHSSPS). The audit was funded initially by the Regional Multi-professional Audit Group (RMAG), and latterly by the Guidelines and Audit Implementation Network (GAIN).

The first phase of the audit, carried out in 2006-2007, mapped the policies, procedures and practices that related to death and bereavement in 35 hospitals in the HPSS legacy trusts and all five hospices in Northern Ireland. The findings of this audit, combined with feedback from workshops attended by bereaved people and representatives from statutory, primary, secondary, community and voluntary agencies, informed the development of six standards for bereavement care. These standards are central to the HSC Services Strategy for Bereavement Care (2009) and will be the yardstick against which the provision of bereavement care in Trusts will be measured. Links for these documents can be found in the reference section of this report.

Implementing the standards for bereavement care will be supported by governance structures in each HSC Trust and through the development of bereavement forums facilitated by the Trust Bereavement Coordinators.



This audit, Phase 2: “The Experience of Bereaved People and Those Delivering Primary Care Services”, was undertaken to capture the experience of care prior to, at the time of and following death of both bereaved people and professionals who provide care and support in primary and community settings. The findings of this audit will complement the knowledge and information already gained in Phase 1 and provide a comprehensive overview of the impact of practices and experiences of care for all involved around the time of death and bereavement. The findings will inform the ongoing implementation of the HSC Services Strategy for Bereavement Care (2009) across all settings and will contribute positively to the experience of patients, their families and the professionals who care for them.

## METHODOLOGY SELECTION

During Phase 1, as well as quantitative data, valuable qualitative information was provided by participants in the sections of the questionnaires that invited comment. This information was rich with the experiences of staff who provide care and support at the time of death and bereavement but proved difficult to analyse and report as quantitative methods were used for analysis.

It was acknowledged from the outset of Phase 2 that a different approach was required, one that would allow the analysis of both quantitative and qualitative data. Coincidentally the Beeches Management Centre was seeking applications from HSC Trusts to pilot the Cognitive Edge© approach, which, recognising that people often convey complex information through the relaying of stories, offers participants the opportunity to describe their experiences and indicate their impact (Appendix 8).

Dr Leslie Boydell, Associate Medical Director Public Health, Belfast HSC Trust (BHSCT), aware of the difficulties in reporting the qualitative element of Phase 1, recognised the potential in using Cognitive Edge© in capturing and analysing complex qualitative information. Dr Boydell advocated that BHSCT use this bereavement audit as a pilot project for the method. Following further explanation of the Cognitive Edge methodology, the Trust Bereavement Coordinators felt that this approach would be a suitable way of simultaneously collecting the experiences of both bereaved people and professionals.

This audit was accepted by The Beeches as one of their pilots and a project team was established which included the five Trust Bereavement Coordinators, an audit lead, an HSC associate medical director, a general practitioner and an expert by experience. Relevant local and national guidelines were reviewed to identify best practice associated with care around the time of death and bereavement and to select the criteria against which standards of care should be measured (Appendix 1). A funding application to GAIN was successful which enabled the pilot to be extended across Northern Ireland.

## AUDIT DESIGN

An audit tool was developed to capture professional and personal stories of care around the time of death and bereavement, which included prompts for storytelling and “signifiers” that would be used to filter the stories i.e. a story title, keywords to describe the experience and questions which would provide demographic details about the respondents (Appendices 5, 6 & 7).

The five Trust Chief Executives were informed of the audit and all agreed that professionals in community teams could be invited to participate. General Practitioners (GPs), the Northern Ireland Medical and Dental Training Agency (NIMDTA) and the HSC Patient and Client Council were informed of the audit; in addition a number of residential and nursing home staff were approached (Appendix 4).

Data collectors did not seek representation from people bereaved in specific circumstances; rather a broad cross-section of the experiences of individual bereaved people and professionals was sought. Fliers and posters were produced to publicise the audit and were widely circulated along with letters of invitation to participate (Appendices 2 & 3). Respondents had the option of accessing the tool online or requesting a hard copy from the Trust Bereavement Coordinators.

It was recognised that recalling and retelling the experience of a personal bereavement may have an impact on the people participating and it was therefore important that support could be accessed if required. For this reason personal stories



were invited from members of community and voluntary groups, where a supportive network was already in existence. In addition to this, the contact details of the Trust Bereavement Coordinators and organisations providing bereavement support were made available in the questionnaire.

As this was the first time the methodology was used in Northern Ireland, the project team was conscious of the need to ensure that the stories submitted would be interpreted in a reliable and valid way, thus maximising the value of the audit findings for health and social care. To this end project team members and their support staff attended training on data capture and analysis, which was delivered by Dave Snowden, Founder & Chief Scientific Officer, Cognitive Edge; and Anne McMurray, a Northern Ireland based training and registered Cognitive Edge consultant. Regular consultations with Dave Snowden and his team were also required during the development of the questionnaire. Data uploaded was held securely on a server managed by Cognitive Edge.

## DATA COLLECTION

A short pilot was carried out within BHSC to test the prompts, signifiers and other questions that would be used to filter the stories, using hard copies of the questionnaires. This identified that some refinements were required and, when these were made, the audit questionnaire was provided online via the SenseMaker website. Data was collected throughout Northern Ireland between November 2009 and March 2010.

Participants were assured of anonymity and were requested not to identify organisations or individuals by name within their story. Bereaved people were invited to relate their experience of a death or bereavement from a personal perspective and professionals a story from their work experience; they could also contribute a personal story if they wished. All respondents were asked to self-index their story by answering a number of questions.

The reflection and recording of stories was guided by the use of the prompt "Please write your story... You may wish to describe: the best and/or worst aspects about the

care provided for the person in the story...the best and/or worst aspects about the care you received when the person in the story died". Respondents were asked to give the story a title and indicate three words that best described their experience.

A number of questions were illustrated by triangles (triads) with a statement at each angle. To answer these questions, the participant had to place a mark within the triangle, on or between the statements that best represented their response. The mark placed in the triad was given a "link strength" by the software thus helping identify in analysis the strength of opinion and emotions linked to the respondents' story. The software also allowed identification of other stories that shared similar indexing. Finally a series of multiple choice questions were asked which allowed the collection of quantitative demographic and other descriptive data to further filter the stories, for example, "What is your relationship to the person in the story?"

When participating online the respondent had an opportunity, on the final screen, to submit or delete the story or to tell another if they wished. For those who completed a written questionnaire the information was uploaded to the website by the Trust Bereavement Coordinators and their secretaries.

## DATA ANALYSIS

At the end of the data collection period the information uploaded to the website was returned by Cognitive Edge to the Trust Bereavement Coordinators in the form of two databases, one containing personal responses and one containing professional responses, to be analysed and used to produce this report. The quantitative data was easily extracted and the stories were then filtered by using the responses to the questions. This allowed the data collectors to demonstrate the impact of the experiences on both personal and professional story tellers, and link the responses to the audit criteria.

On reading some of the stories the data collectors became aware of the value of participants giving meaning to their experience by self-indexing their own stories. This ensured that the interpretation of the experience was the respondent's own and not that of the data collectors.



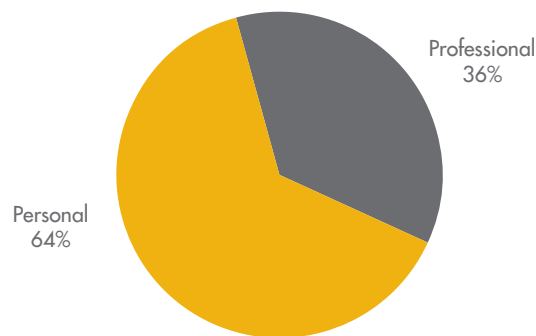
### 3) RESULTS

#### DEMOGRAPHIC INFORMATION

Participants were guided to tell either a personal or professional story. A professional could repeat the process so that they could tell a personal as well as a professional story. There was no limit to the number of stories a person could tell.

As participants did not always complete every section of the questionnaire, the results are presented by percentages of number of returns received for each question. Percentages were rounded up to the next percentage point.

**Figure 1: Number of personal and professional returns (n=260)**



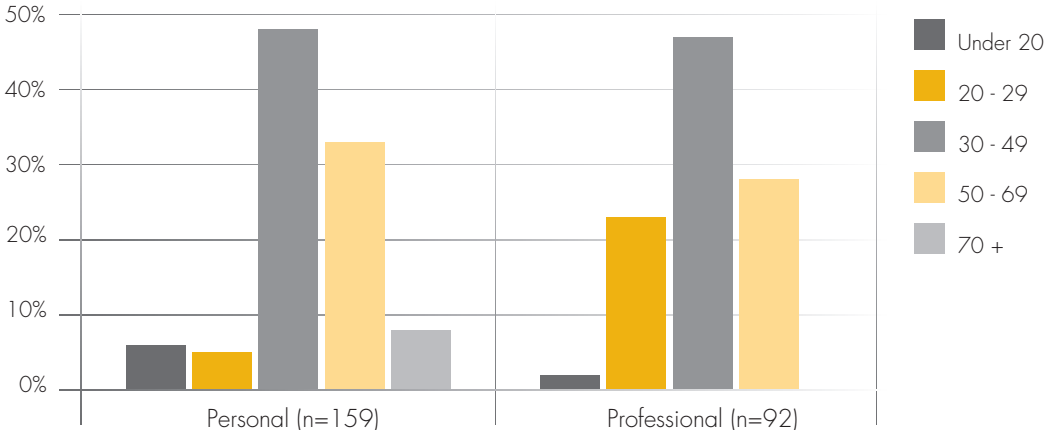
A total of 260 stories were submitted of which 64% (n=167) were personal and 36% (n=93) were professional. Of the 244 responses where gender was indicated, 217 (89%) were contributed by females and 27 (11%) by males.





Respondents were asked to indicate their age within a specified age band.

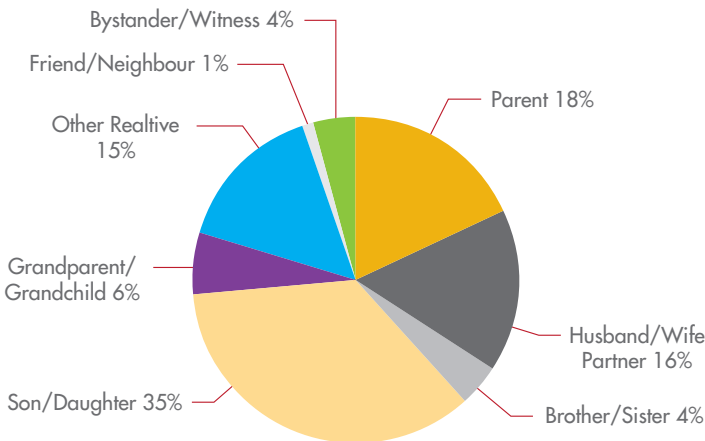
**Figure 2: Age profile of participants**



Stories were contributed by people from across a wide age range. As Figure 2 indicates, the largest group of both personal and professional respondents were in the 30-49 age band, with the second largest being in the 50-69 age band.

Personal respondents were asked to indicate their relationship to the person in the story.

**Figure 3: Personal relationship to person in the story (n=158)**

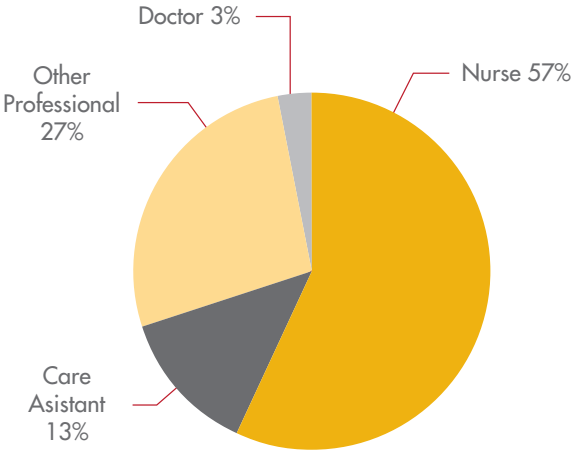


The largest group of respondents were sons and daughters (36%), followed by parents (18%) and husband/wife/partner (16%). A small number of stories were told by bystanders/witnesses (4%) and friends/neighbours (1%).



Professional respondents were asked to identify their role.

**Figure 4: Professional role to person in story (n=92)**

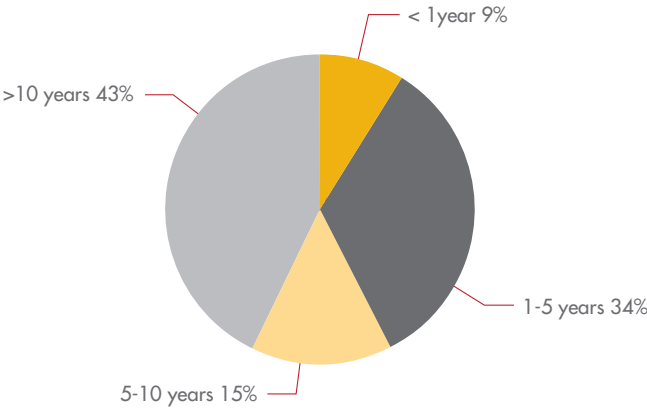


The largest group of respondents were nurses (57%), followed by other professionals (27%), care assistants (13%) and doctors (3%).

Most of the stories described a professional’s input before and at the time of death. A number were told by “other professionals”, for example complementary therapists and psychotherapists, who described their role in supporting bereaved people.

Professionals indicated how long they had been working in their area.

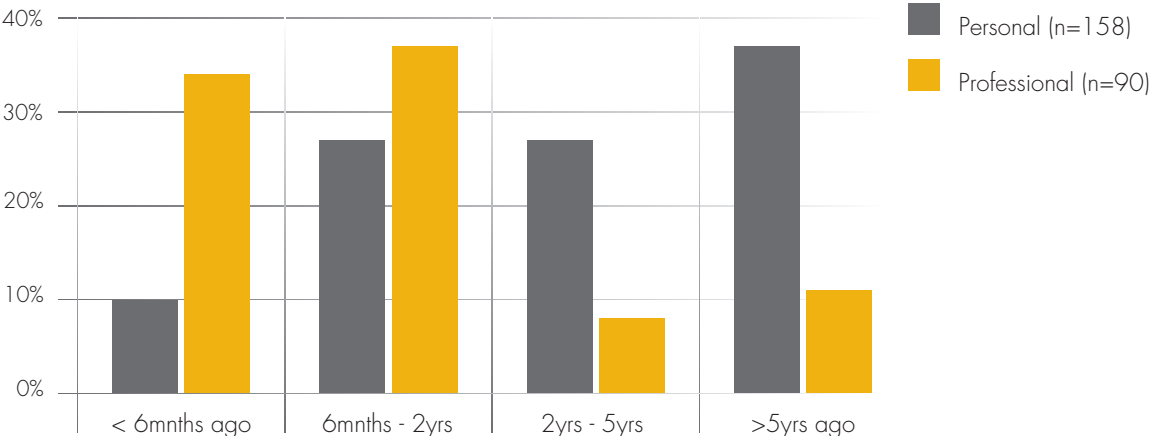
**Figure 5: Length of time professionals had worked in their area (n=89)**



A total of 57% of professional respondents had been working in their area for more than five years with 43% in post longer than 10 years. This finding corresponded with data collected in Phase 1 of the audit where 51% of participating staff had been in post more than 10 years. This indicates that the majority of professional respondents had many years of experience in health and social care.

In order to identify whether past or current practices were being described, participants were asked how long ago the person in the story died.

**Figure 6: How long ago the person died**

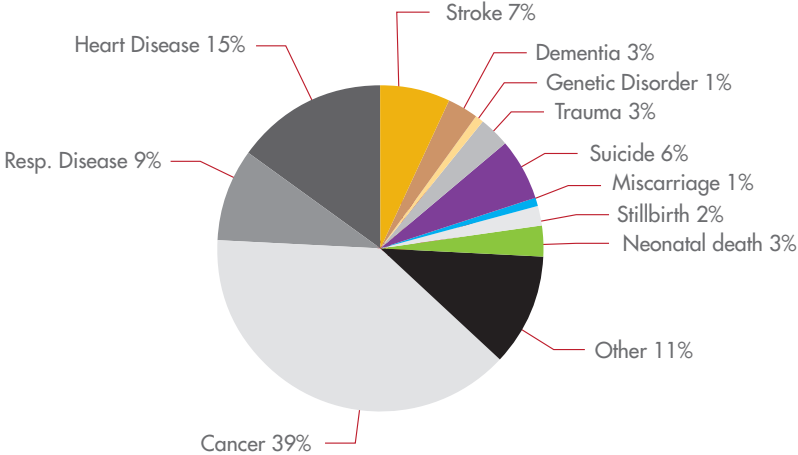


Most personal stories told by bereaved people described a death that occurred within the last five years (64%), most professional stories (71%) related to a death which occurred within the last two years; therefore much current and recent practice has been described.



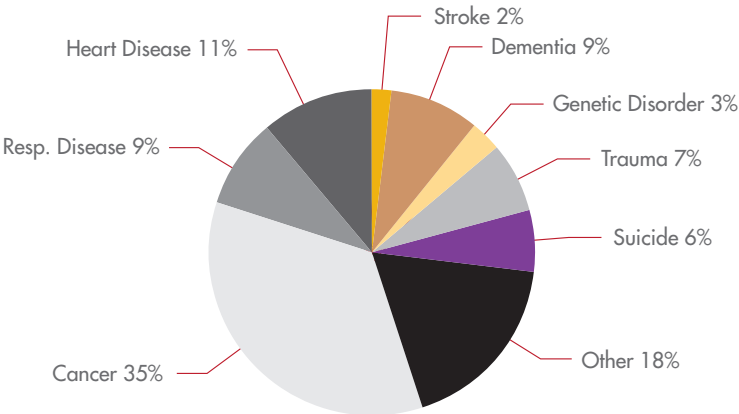
All respondents were asked to indicate the cause of death, if known.

**Figure 7: Breakdown of cause of death in personal stories (n=151)**



As indicated in Figure 7, personal stories were told about deaths due to a wide range of causes, the largest (39%) being cancer. Bereaved people recounted stories of baby deaths and miscarriages, which were not reported by community professionals as it is likely that these deaths are generally managed by hospital staff.

**Figure 8: Breakdown of cause of death in professional stories (n=89)**



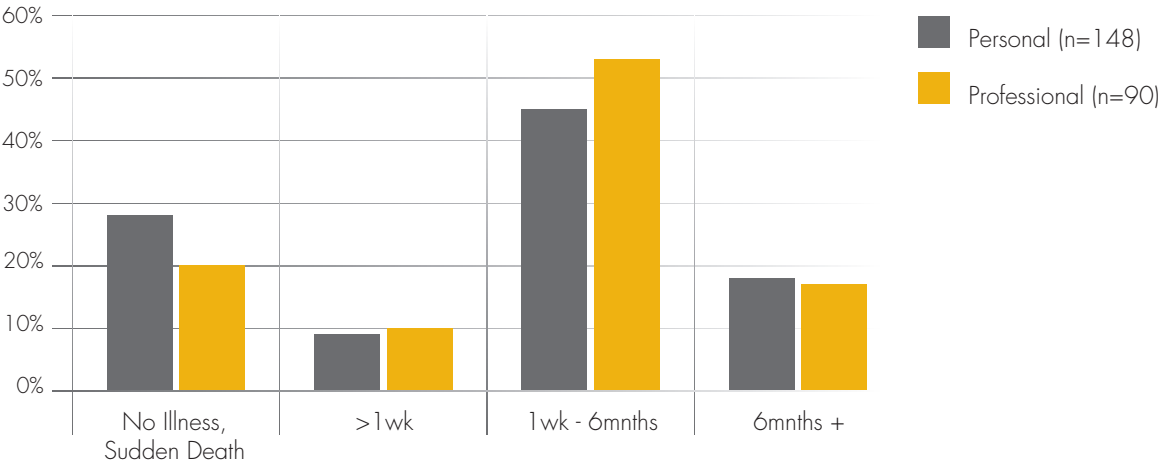
The most common cause of death described in professional stories was cancer (35%), followed by other chronic illnesses, which generally reflect statistical trends of cause of death in Northern Ireland. A number of respondents (18%) did not indicate a cause of death from the choices available.



The audit captured the experiences of professionals working and supporting people in circumstances where death was both expected and unexpected, therefore providing a range of perspectives of care delivered.

All participants were asked to indicate the length of the final illness.

**Figure 9: Length of final Illness**



The largest number of personal stories (45%) concerned a final illness of between one week and six months and 28% described a sudden death.

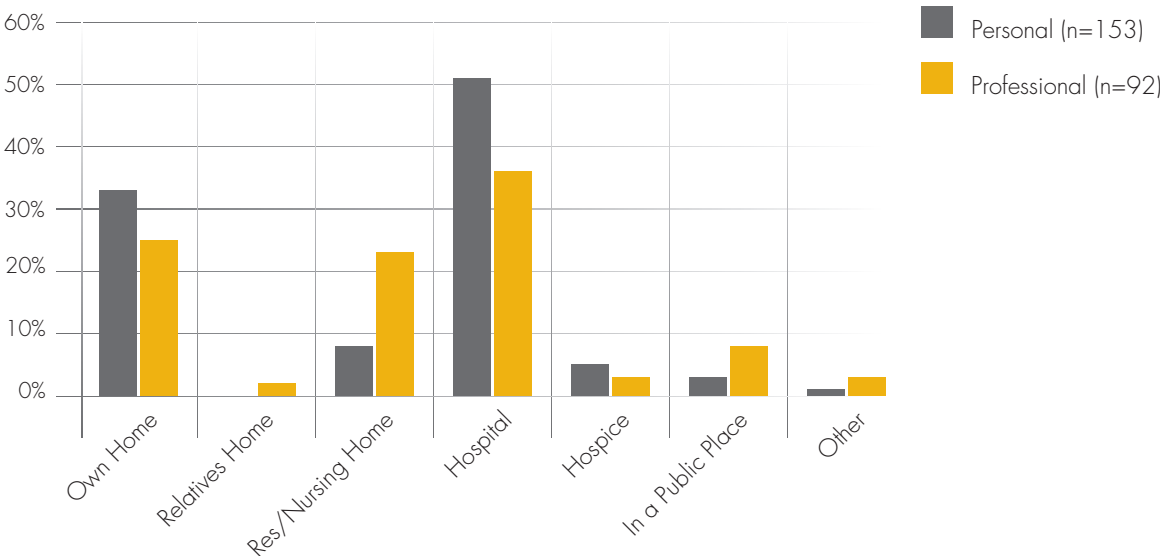
A similar pattern was found in the professional returns.

When stories relating to sudden deaths were analysed, it was evident that some related to an unexpected event during a chronic illness.



Respondents were asked to indicate where the person in the story died.

**Figure 10: Where the person died**



Personal stories described deaths in all settings with 51% relating to death in hospital, and 33% in the person’s own home.

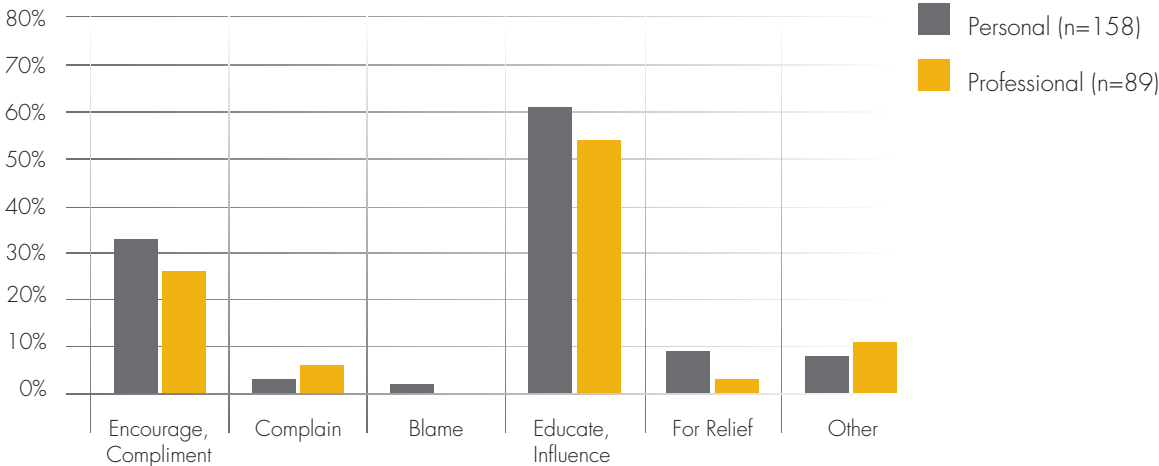
The most recent Registrar General Northern Ireland Annual Report (2008) states that 50% of deaths in Northern Ireland occurred in hospital, a further 16% in nursing homes and 33% in other areas.

The audit set out to capture the experiences of community staff and, while most described their experience of death and bereavement in community settings, some stories related to deaths in hospital. This, in part, is explained by the fact that a number of professionals had a role in supporting the bereaved relatives of people who died in hospital; also some professionals may have chosen to relate a significant experience, regardless of place of death.



Respondents were asked their main reason for telling the story

**Figure 11: Main reason for telling the story**



The majority of both personal (66%) and professional (54%) respondents indicated that their main reason for telling the story was to educate or influence, followed by to encourage and compliment. Smaller numbers were told for relief, to complain or blame.

When the three personal stories told to complain were reviewed, all involved sudden/traumatic circumstances. Two related to the death of a baby and one to a death by suicide. In the four told to blame, various issues including misdiagnosis, lack of guidance for family or lack of understanding and compassion close to the time of death, were described. The key words used by these respondents to describe their stories highlight their anguish and discontent as outlined in Table 1.

Table 1: Key words from personal stories told to complain or blame
• fighting, poor care and support in the community
• insensitivity, impractical, thoughtless
• sadness, suddenness and darkness
• helpless, anger, unanswered questions
• tragedy, heart-breaking and emotional
• indifference, incompetence, compassion
• sad, lonely, angry

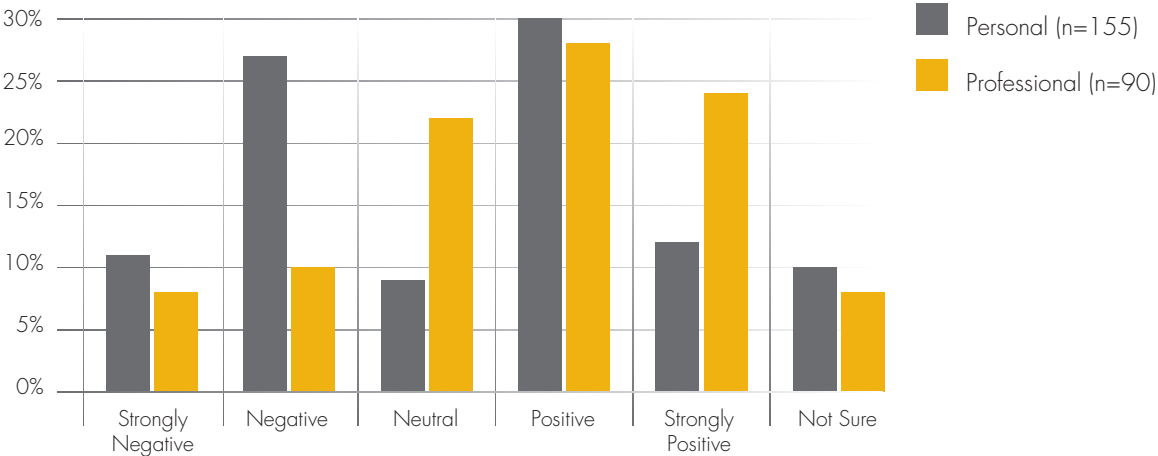


Of the 6% of professional stories told to complain most were contributed by student nurses. Their key words, outlined in Table 2, indicate that they found the situations they faced distressing.

<b>Table 2: Key words from professional stories told to complain</b>
• undignified, uncaring, lasting negative memory
• avoidable?, distressing, understating
• disrespectful, rough, undignified
• scared it might happen again, lack of time, oversight in the care of that patient’s relative

Respondents were asked to describe their overall feelings about the story on a scale ranging from strongly positive to strongly negative.

**Figure 12: Overall feeling about the story**



This was an important filter question as it allowed participants to indicate the emotional intensity rating of their story.

The responses show that, while professionals mainly told stories with a positive emotional intensity, bereaved people told positive and negative stories in almost equal numbers.





## QUALITATIVE ANALYSIS

Key questions were asked to determine compliance with the audit criteria. The responses with a greater than 75% link strength to an answer were used to identify experiences that could be measured against audit criteria. On analysis there was evidence in the stories to indicate compliance with most of the criteria, however for some, e.g. Criteria 5, the stories did not contain sufficient information to report compliance.

This section contains extracts from stories which have been reproduced verbatim. A number have been edited to maintain anonymity or reduce length. Each story is presented with some of the indexing given to it by the respondent and the question that connects it to the audit criteria.

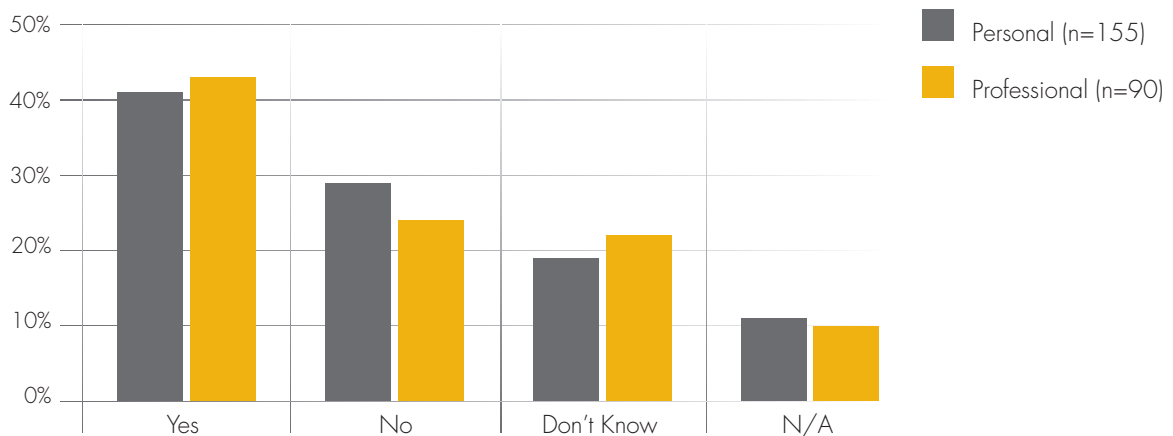
At the end of each section there is a main message which sums up key findings.



## Criteria 1: The patient is identified as dying

Respondents were asked if the person in the story knew they were dying.

**Figure 13: Did the person in the story know they were dying?**



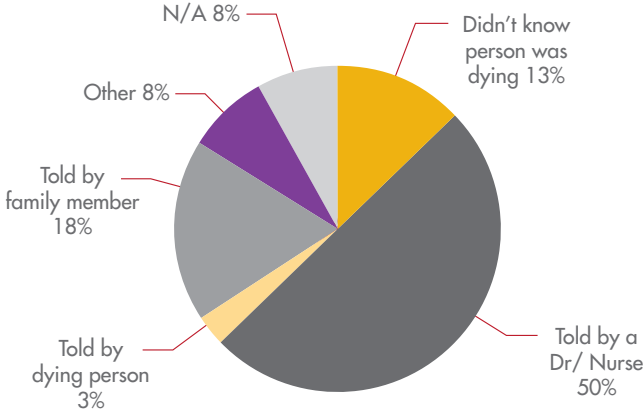
In the personal stories 41% indicated that the person in the story knew they were dying. Of the 29% where it was indicated that the person did not know, most described a sudden death and or the death of a child.

In the professional responses 43% indicated that the person in the story knew they were dying and 24% did not know.



Respondents were asked how they became aware that the person in the story was dying.

**Figure 14: How personal respondents became aware person was dying (n=157)**



Half of the personal respondents (50%) indicated that they were told by a doctor or nurse, 18% were told by a family member and 3% by the dying person.

The 13% of respondents who stated that they didn't know the person was dying described a short illness, sudden death, miscarriage or being bereaved when they were young.

This result illustrates the significant responsibility that health care professionals have when breaking bad news and the need for sensitive communication with patients and their families around the time of diagnosis and death. When there was good communication at this time a positive experience was reported; in contrast when communication was poor the impact of the experience was indicated as negative.



## Criteria 1: Story extracts

**Personal story 1**

**Title:** Bad news broken brilliantly

**Emotional intensity:** Strongly positive

**Reason for telling:** Encourage/compliment

*My father was in hospital for the last 6 weeks of his life. While he had been a sick man for many years we did not expect this to be his last illness. Medically all that could have been done to prolong his life was done and 2 weeks before he eventually died his consultant asked my mother and I how we thought he was doing. I will never forget the sensitive and compassionate way he confirmed that my father was indeed dying, which gave us all time to prepare and come to terms with this truth.*

**Key words:**

Compassion, professional, kind

**How did you feel at the time?**

In control

**How do you feel now?**

Accepting

**Did the person know they were dying?** Yes

**Personal story 2**

**Title:** Desperation

**Emotional intensity:** Strongly negative

**Reason for telling:** For relief

*Professionals would not listen when I said my mother was dying. They did not listen to how well she was prior to her short (undiagnosed until the last week) illness. The lack of communication was the worst for me. I did not know what they were thinking or did not get test results explained. Even a few hours before she died they told me she was ok. It was obvious she was dying a blood result finally convinced them. I had 6 hours of compassion before she died. That was the only care for me in over 2 weeks she was in hospital.*

*Best: Being left in private with her loved ones in her dying hours*

*Worst: Not listened to*



<b>Key words:</b>	Anger, sorrow, frustration
<b>How did you feel at the time?</b>	Frustrated/helpless
<b>How do you feel now?</b>	Angry
<b>Did the person know they were dying?</b>	Yes

### Criteria 1: Main message

When healthcare professionals have identified that a patient is dying or has died, they have a responsibility to communicate this in a clear and supportive way to avoid misunderstanding or additional distress.

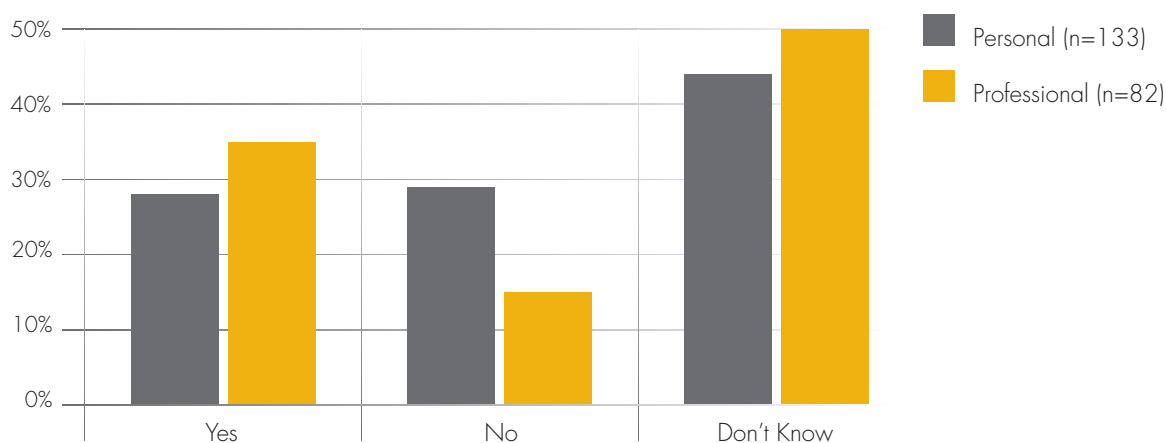
Professionals caring for patients and their families before, at the time of and after death, can influence how a bereaved family copes following death by helping them come to terms with the diagnosis and prognosis, supporting them through the pre-bereavement stage, and giving them the information they need to help with the future.



## Criteria 2: The preferred place of care and death is discussed with the patient and carers and measures taken to comply

Respondents were asked if the person in the story died in their preferred place.

**Figure 15: Death occurred in the preferred place**



A large number of personal (44%) and professional (50%) respondents did not know if the person died in their preferred place. This suggests that either the respondent was not involved in the conversation or that a conversation around preferred place of death did not take place.

Death occurred in the preferred place in 37 (28%) personal and 29 (35%) professional stories, and did not occur in the preferred place in 38 (29%) personal and 12 (15%) of professional stories.

When respondents reported that the person had died in their preferred place most personal (62%) and all professional (100%) stories described a strongly positive, positive or neutral experience. A number of personal respondents (22%) indexed their experience with negative or strongly negative emotional intensity.



## Criteria 2: Story extracts

### Personal story 3

**Title:** Dying gracefully

**Emotional intensity:** Strongly positive

**Reason for telling:** Encourage/compliment

*Mother diagnosed with cancer – lived over 4 years period in deteriorating health. Many admissions to hospital for various complications cared for by her family at home. Excellent support throughout from community nursing staff and GP*

**Key words:**

Loved, beautifully cared for, peace & tranquil

**How did you feel at the time?**

In control

**How do you feel now?**

Accepting

**Person died in their preferred place?**

Yes

### Personal story 4

**Title:** Inadequate communication and information increased patient and family's distress

**Emotional intensity:** Negative

**Reason for telling:** Educate/influence

*When my aunt was dying, there was a lack of accurate information as a number of doctors were involved in her management. Tests were cancelled and she was given confusing and contradictory information. Even when she was dying, her family were not sure why..... On a positive side, on the morning she deteriorated, the GP was very supportive, explaining her husband could choose if she was sent to A & E or allowed to die in her bed at home. Her husband, with no reservation, chose to keep her at home and her family was with her.*

**Key words:**

Frustrating, unsatisfactory, sad

**How did you feel at the time?**

Frustrated

**How do you feel now?**

Angry, sad, accepting

**Person died in their preferred place?**

Yes



**Professional story 1****Title: Pulling out the stops****Emotional intensity:** Positive**Reason for telling:** Educate/influence

*One of my first memories of caring for someone at the end of life and consequently the impact on the following bereavement for the family was when I first became a Macmillan nurse over 10 years ago. I was nursing a gentleman on one of the wards - he was obviously dying but it was his wish he should be at home to die. The consultant of the ward was not keen for him to be transported due to his ill condition but he was conscious and lucid and clearly expressed his wish to be at home. I stayed on late into the evening and escorted the man home in the ambulance as there were not enough nurses on the ward and the consultant had insisted on an escort. (I was enthusiastic and new then). Once home it was a bit makeshift but the relief and contentment on the man's face confirmed it was worth it. He died in the early hours of the morning very comfortably. I still see the family from time to time and they always refer to the fact that his wishes had been respected and every effort had been made, however makeshift, to support his decisions. I believe this made a difference.*

<b>Key words:</b>	Patient choice, human, control
<b>How did you feel at the time?</b>	In control
<b>How do you feel now?</b>	Accepting
<b>Person died in their preferred place?</b>	Yes

The stories where it was recorded that the person did not die in their preferred place were analysed to determine the reasons why. Some deaths were sudden or unexpected, therefore discussing or facilitating the preferred place was not possible; others described care needs which, at the time, could not be met in the preferred place.

The experience of dying in a setting other than that which was preferred by the patient and family was not always given a negative rating. When the person did not die in their preferred place 17 (45%) personal and four (33%) professional stories were rated negatively. However 11 (29%) personal and four (33%) professional stories were told with a positive emotional tone even though the person did not die in their preferred place.





**Personal story 5****Title: Supporting a single man in his last year of life****Emotional intensity:** Neutral**Reason for telling:** Educate/influence

*My brother in law died three years ago after a lengthy illness due to cancer. He had a 6 year remission but the last 18 months of his life he had intensive chemotherapy. As a bachelor he was dependent on me and my family. It was difficult but the support of the Cancer Centre and Macmillan was valued. Problems arose when he had stopped chemo, because if he felt unwell, accessing care through the local acute hospital was difficult and the continuity of care from one health setting to another was noticeable. His final 2 weeks in hospital were difficult and the limitation, even on family visits, in a general medical ward was distressing for all. More single rooms and less restriction for visits would have helped.*

**Key words:** Comfort, consistency, attitude  
**How did you feel at the time?** Frustrated  
**How do you feel now?** Sad  
**Person died in their preferred place?** No

**Personal story 6****Title: A peaceful setting to a distressing illness****Emotional intensity:** Strongly positive**Reason for telling:** Encourage/compliment

*My mother died several weeks ago after suffering from a very distressing form of dementia. She was transferred from the nursing home where she was well known and moved to a psycho-geriatric assessment centre. I was upset that she had to be moved. I knew she was dying and I wanted her to be where she was well known to staff. I worried that the unit would not be appropriate for her care needs, which had become palliative. I could not have been more wrong - she was cared for with total dignity and respect for the last few weeks of her life. The family were offered a high level of support. She had a calm and peaceful death. I could not have expected such care, even from a hospice setting.*

**Key words:** Support, caring, natural  
**How did you feel at the time?** In control  
**How do you feel now?** Sad, accepting  
**Person died in their preferred place?** No



**Professional story 2****Untitled****Emotional intensity:** Neutral**Reason for telling:** Other

*A patient with end stage Dementia was being cared for on the ward; it was early onset so the patient was only in their 60s. This fact made it quite a difficult experience for me. The care provided for the person was very good and the relatives stayed with him through the whole stay in hospital. They tried to encourage him to eat as he was refusing food most of the time, although because of the problems with his swallow and the problem of the food aspirating into the lungs, it was difficult.*

*The best aspect of the care provided to the patient was that members of the family were allowed to be with him constantly outside of visiting hours. Also the nurses provided good physical care.*

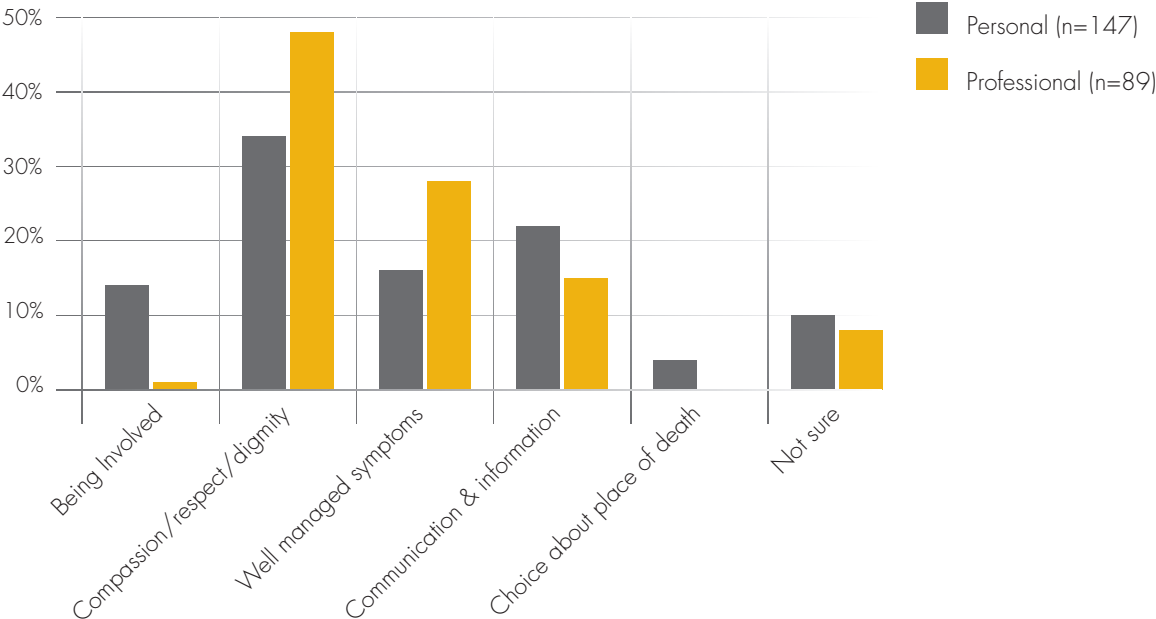
*The worst was the insensitivity of some of the nurses towards the relatives and their questioning; they could have been more understanding.*

<b>Key words:</b>	Not provided
<b>How did you feel at the time?</b>	Not provided
<b>How do you feel now?</b>	Sad
<b>Person died in their preferred place?</b>	No



Respondents were asked to indicate, from a list of options, the aspect of care which was most important to them.

**Figure 16: Aspect of care which was most important**



The largest proportion of bereaved people (34%) and professionals (48%) indicated that compassion/respect/ dignity was most important to them. Choice about place of death was rated most important by 4% of personal and 0% of professional respondents. On occasion more than one aspect of care was selected by those who completed a written questionnaire suggesting that more than one of the options given were considered to be important. However the online data collection tool allowed only one choice to be uploaded.

The delivery of care which met identified needs of dying people and their families may partly explain why respondents have rated as positive a death that did not occur in the person’s preferred place.



## Criteria 2: Main message

Every effort should be made to support people to die in their preferred place, where at all possible, when death is expected. However, health care professionals can influence the experience at the time of death and bereavement in a positive or negative way, regardless of where death occurs. A supported experience can be achieved by treating the patient and their family with compassion, dignity and respect; and delivering care that meets their needs.



### **Criteria 3: Carers are enabled and supported to care for the dying relative at home**

### **Criteria 4: Death is expected and care needs identified using an appropriate end of life tool**

Respondents were asked to indicate the statement that best described the decision making around the care prior to or after the person's death i.e. was it a partnership between the dying person/family and those providing care, was everything left up to the dying person/family or was everything taken out of the dying person/family's hands.

They were also asked to indicate what they believed determined the care provided i.e. needs/wishes of the dying person, family wishes or availability of services and working patterns of staff.

There was evidence within the stories that efforts had been made to plan and provide care that met the needs of the dying person and their family, although none of the personal and only three professional respondents mentioned the use of an end of life tool e.g. care pathway for the dying.

In the 47 personal stories where respondents strongly indicated that decision making was a partnership 32 (68%) were told with a strongly positive or positive emotional intensity and six (13%) were either negative or strongly negative.

Of the 45 stories where professionals strongly indicated that decision making was a partnership, 21 (47%) were strongly positive or positive, 14 (31%) were neutral and none were indexed with a negative or strongly negative emotional intensity.



## Criteria 3&4: Story extracts

### Personal story 7

**Emotional intensity:** Strongly positive

**Title:** Devotion without question!

**Reason for telling:** Encourage/compliment

*Sitting with my beloved grandmother in the last nine days of her life was comforting. Knowing that all staff were like family. It was home from home. Offers of tea, coffee, dinners, evening teas and breakfasts all there as we needed it. Staff going off shifts calling in to see her and us before they left for home, words of comfort, hugs when things got really bad. The care she received was outstanding and given with care and love. At the end, staff made the phone calls needed and we had no worry about what was next. My experience with our private nursing home was perfect.*

**Key words:**

Care, love, attention

**How did you feel at the time?**

In control

**How do you feel now?**

Not indicated

**Decision making?**

Partnership

**What determined the care provided?**

Availability of services/staff working patterns

### Professional story 3

**Emotional intensity:** Strongly positive

**Title:** A dignified death with potential for bad experiences

**Reason for telling:** Encourage/compliment

*Patient 60 years of age with CA bowel, CA Liver, managed at home, all equipment in place. 2 syringe drivers changed daily. Managed by family and district nursing. Haematemesis in last few hours of life, support for family with district nursing, evening service and Marie Curie.*

**Key words:**

Family orientated, anxious family, peaceful

**How did you feel at the time?**

Frustrated/helpless

**How do you feel now?**

Accepting

**Decision making?**

Partnership

**What determined the care provided?**

Family wishes



In eleven personal stories respondents indexed that everything was taken out of the dying person/family's hands; seven (64%) of these were strongly negative or negative and one was positive.

Of the nine stories where a professional strongly indicated that everything was taken out of the dying persons/families hands; none were positive or strongly positive and seven (78%) were told with a strongly negative or negative emotional intensity. None of these deaths occurred in the dying person's home, three described a sudden death and three were told by student nurses.

**Personal story 8**

**Title: A cavalier attitude by medical staff**

**Emotional intensity:** Strongly negative

**Reason for telling:** Educate/influence

*The consultant decided acute treatment for my father should stop, as he had a serious reaction to it. Nursing staff ordered an ambulance to transfer him back to a residential home where he was staying for a few weeks. The first thing the family knew of the decision to stop treatment and discharge him was when the manager of the residential home rang to say he had been sent back and was unwell, no longer mobile and needed a nursing care bed. The GP was contacted the following morning to say he was deteriorating further and he came after his surgery, which was some time after my father had actually died. On a positive note, the care staff in the home were excellent and did all they could to keep my father comfortable. When we made enquiries, the hospital apologised and assured us they would review their discharge procedures.*

**Key words:**

Unacceptable, distressing, thoughtless

**How did you feel at the time?**

Frustrated

**How do you feel now?**

Sad

**Decision making?**

Taken out of patient's/family's hands

**What determined the care provided?**

Availability of services/staff working patterns



**Personal story 9****Emotional intensity:** Positive**Title:** Poor death**Reason for telling:** Educate/influence

*Husband aged 45 – wife + 1 son aged 12. Husband ill 4/5 years. In hospital – 6 bedded bay on oxygen.*

*Obviously dying (wife, nurse) – felt staff unable to cope / unsure – sympathetic looks, but little communication. Except for 1 junior doctor who took time to talk to me one evening – showed me x-ray and explained reason for not intubating.*

**Key words:**

Frustrating, drawn out, long period to closure

**How did you feel at the time?**

Frustrated/helpless

**How do you feel now?**

Sad/accepting

**Decision making?**

Taken out of patient's/family's hands

**What determined the care provided?**

Availability of services/staff working patterns

**Personal story 10****Emotional intensity:** Negative**Title:** A sad end for a great person**Reason for telling:** Educate/influence

*Mrs Y was advised that her father was very poorly in hospital and she was aware that her father was probably nearing the end of his life.*

*The Consultant confirmed that Mr X required palliative care as opposed to curative care at a meeting with Mrs Y on the Monday, a week before his death. No one talked to Mrs Y about her needs (such as enabling her to carry out her father's wishes, asking what she herself wished or needed, such as information, support, involvement etc). There was no obvious sign from the nursing staff that end-of-life was close as they discussed Mr X's care with Mrs Y and they seemed to continue to take the approach that Mr X could get better during discussions with Mrs Y after the consultant's meeting. This lack of acknowledgement by staff that Mr X was nearing*





*end-of-life was confusing and uncomfortable for Mrs Y as she tried to prepare for her father's last days.*

<b>Key words:</b>	Not good enough
<b>How did you feel at the time?</b>	Frustrated
<b>How do you feel now?</b>	Sad
<b>Decision making?</b>	Taken out of patient's/family's hands
<b>What determined the care provided?</b>	Availability of services/family wishes

**Professional story 4**

**Title: A time to die**

**Emotional intensity:** Negative

**Reason for telling:** Educate/influence

*An elderly lady with end-stage illness and previous admissions - with each admission her condition was deteriorating. Her family accepted she was near death, but medical intervention was continued right up to the end.*

*Although she received good care, I felt that it was inappropriate to continue to actively and aggressively treat her with infusions etc and to continue taking blood samples etc when there was no hope of an improvement in her condition.*

<b>Key words:</b>	Frustration, sadness, medical treatment
<b>How did you feel at the time?</b>	Frustrated/angry
<b>How do you feel now?</b>	Sad
<b>Decision making?</b>	Taken out of patient's/family's hands
<b>What determined the care provided?</b>	Availability of services/staff working patterns

Of the 19 personal stories which strongly indicated that everything was left up to the dying person/ family 11 (58%) were strongly negative or negative, four (21%) were neutral and four (21%) were strongly positive or positive.



**Personal story 11**

**Title: How the system failed us.**

**Emotional intensity:** Strongly negative

**Reason for telling:** Educate/influence

*My wife was admitted to hospital (A) Informed she had suspected ovarian cancer and was being referred to another hospital (B), not expected to be admitted before Christmas and was being sent home. I was ill; my wife had been nursing me. Sent home without backup of any kind. Christmas came and went as did New Year and still no word of any kind. I rang the Gynaecologist concerned early January..... Rang a couple of days later.... rang couple of days later.... I spoke to this lady who told me to ring in a couple of days.... A couple of days later my wife received a letter of admission from other hospital (B) for end of January.*

*My wife commenced treatment end January - beginning February. I went to hospital (B) for my treatment a few days later..... My wife never returned home, she died in hospital (B) (Heart attack followed by a large clot) shortly after we arrived.*

**Key words:**

Uncared, unloved, forgotten

**How did you feel at the time?**

Helpless

**How do you feel now?**

Angry

**Decision making?**

Everything left up to dying patient/ family

**What determined the care provided?**

Family wishes

**Criteria 3&4: Main message**

**When care and decision making between the patient, family and professionals are viewed as a partnership, a positive experience for all is more likely. When the patient, family and professionals do not work together; or when treatments and actions are not explained or understood a negative experience may result.**



**Criteria 5: Death is reported to the patient's GP or Out of Hours service so that legal responsibilities in relation to death are coordinated e.g. death certification, reporting to coroner etc.**

The stories did not contain sufficient information around the legal processes at the time of death to measure practices against Criteria 5. This may be partly explained by the fact that, in community, general practitioners are the staff group responsible for completing death certificates and referring deaths to the Coroner, and only three stories were provided by GPs. A word search of both personal and professional data bases identified stories where post mortem (12), death certificates (5) and the Coroner (3) were mentioned.

An issue reported was the incorrect completion of a death certificate which had to be returned by a family member to the certifying doctor for amendment when inaccuracy was discovered by the Registrar of births, deaths and marriages.<sup>1</sup>

### Criteria 5: Story extracts

**Personal story 12**

**Emotional intensity:** Neutral

**Title:** Good bye daddy, God bless

**Reason for telling:** Educate/influence

*2 years ago my dad had a heart attack in the garden. He was moved to ICU and from there to theatre to repair his stomach which had been ruptured during resuscitation. Afterwards the Dr was very straight and told us there was no hope. I stayed with dad all night – we all did. He began to have wee fits and when I said to the nurse was this a bad sign she said the doctor would speak to us in the morning. He told us that the machine was keeping daddy alive and he would like our permission to switch it off. We were all there and all were in agreement.....The death certificate was incorrectly filled in and was rejected when my brother took it to the Registrar. He had to go back to the unit to have it corrected but the Dr who wrote it wasn't there....*

<sup>1</sup> The DHSSPS, Coroners Service NI and General Registrars Office have produced guidance to assist medical staff with the completion of MCCDs, Stillbirth and Cremation Certificates (See references).



**Key words:**

Heartache, shock, trance

**How did you feel at the time?**

Helpless

**How do you feel now?**

Sad/accepting

### **Criteria 5: Main message**

**When doctors do not complete medical certificates of cause of death accurately they are not accepted for death registration purposes. This causes additional distress and inconvenience to families at an already difficult and stressful time.**



## Criteria 6: Support/information is available for those bereaved suddenly or traumatically

A number of personal (28%) and professional (20%) stories concerned sudden deaths. These experiences were further explored against Criteria 6.

In a word search of the data, 11 (6.6%) personal stories mentioned 'counselling' and 12 (7.2%) 'support'. These stories included experiences where counselling and support were availed of, and stories where people stated that counselling and/or support were not offered. Most who required support recounted that they sought it themselves.

### Criteria 6: Story extracts

#### Personal story 13

Emotional intensity: Not indicated

Title: A Mother's story, bereaved by suicide

Reason for telling: For relief

*I was bereaved by suicide, over fourteen years ago. I lost my son he was twenty years old. We as a family had no prior warning that anything was wrong in his life. I would not have said he had mental health issues. Coming to terms that this loss was forever. At the time of the death my GP offered medication, which no one took rightly or wrongly. My two daughters were fourteen and eighteen. They were offered and just the younger girl took up the services of Counselling at our local Mental Health unit. This did help her return to her school. The worst aspects of my story would have been no support immediately at the time of his death, it was the loneliness the feelings of isolation, nobody knew how to access support. Employers tried to be supportive by giving time off, but really nothing out there. The only thing offered to us was medication, which was really not the thing we required. I now know with a lot of Statutory, Voluntary and work done through bereaved families things have changed. Feelings for those bereaved will never change guilt, stigma, shame to name just a few, feeling will I ever come through, whilst knowing life as it was will never be the same again that is forever. Bereaved people need immediate support when bereaved and then a backup at various stages on their grief journey.*



**Key words:** Mother, suicide, loss  
**How did you feel at the time?** Helpless/frustrated  
**How do you feel now?** Sad/accepting

**Personal story 14** **Title: The saddest day of our lives**  
**Emotional intensity:** Negative **Reason for telling:** Educate/influence

*I was 25 weeks pregnant when I thought I was going into labour having lost my mucous plug.....She died, we think of infection (we are unsure as I still do not have PM results) as I ended up seriously ill with septicaemia after her birth. The midwives who delivered my baby were amazing, so kind and just the right balance of being involved without being intrusive and the support after the baby's birth is something I am eternally grateful for - things like helping us bathe her, dress her, taking photos etc...things that you do not know if you should or should not do as this is not something you can ever be prepared for.*

**Key words:** Tragic, devastating, heartbreaking  
**How did you feel at the time?** Helpless/frustrated  
**How do you feel now?** Angry/sad

**Personal story 15** **Title: Unprepared**  
**Emotional intensity:** Positive **Reason for telling:** Educate/influence

*Best - best in terms of care with family having time together with dead mother at hospital.*

*Worst - it was breakfast time at the hospital so with only the hospital curtain around a large crowd around the 'death bed' with very little privacy and only a few short moments with my dead mother and together.*

*There was no information about any bereavement services that I do feel some family members (due to the sudden death) would have benefitted from, such as counseling*

service or how they might feel, short and long term, from a sudden death. For other family members returning to work they became ill and became depressed. For the latter more support from the GP would have been helpful in terms of recognising her symptoms equating the death. Being eventually given a sick note from her doctor for more time off work did help her come to terms more and to get over 'sleep deprivation' however it really 'medicalised' her condition to her employers instead of demonstrating that it was bereavement she was suffering from and not a 'sore throat'.

**Key words:** Sudden, impact, support  
**How did you feel at the time?** Helpless  
**How do you feel now?** Accepting

Stories told by both bereaved people and professionals, were analysed using the emotional intensity filter to identify what was helpful or unhelpful to those bereaved suddenly. Respondents described the value of sensitive and supportive staff and their practices at the time of death, which included being given information on appropriate sources of support. Conversely where there was insensitivity and lack of support, it impacted negatively on the experience.

**Personal story 16** Title: I didn't want him to die there  
**Emotional intensity:** Strongly positive Reason for telling: Educate/influence

*My dad passed away in intensive care after bypass surgery. Dad had a long history of cardiac problems. He had excellent care in ICU and we were involved as much as was possible. Staff were just so sensitive. Worst – told that dad was dying in a corridor, won't ever forget this. Best – sympathy card on anniversary, love and care from staff when dad died.*

**Key words:** Love, loss, never ending  
**How did you feel at the time?** Helpless  
**How do you feel now?** Sad/accepting



**Personal story 17****Title: Untitled 36****Emotional intensity:** Strongly negative**Reason for telling:** Educate/influence

*My husband took a heart attack and died 6 hours later in hospital. The staff were very good and sympathetic. The last thing the doctor said was do you have any questions but I was in Shock. The Nurse said that I could stay with the body for as long as I wanted. That was the last contact with the health service. No support from anywhere. Put in touch with Barnardos by child's Teacher otherwise would have had to search on my own.*

**Key words:**

Not indicated

**How did you feel at the time?**

Helpless

**How do you feel now?**

Sad

**Professional story 5****Title: Dismay****Emotional intensity:** Strongly negative**Reason for telling:** Educate/influence

*I worked with a family whose mother took her own life. She spent 35 hours in ICU before dying. Unfortunately the ICU staff were dismissive of the woman, they also seemed to have a poor policy on information given to her children. I had to spend extra time in my professional work with fears and misperceptions that the children had following the time their mum spent in hospital prior to her death.*

*During therapy with the family the remaining parent had wished for support in the immediate weeks, months post suicide.*

**Key words:**

Dismay, frustrating, harmful

**How did you feel at the time?**

Frustrated

**How do you feel now?**

Angry





Some stories describing sudden death have been indexed as having a negative emotional intensity, even when there is evidence in the story that supportive care was provided. This may possibly be due to the traumatic way in which the family was bereaved.

### **Criteria 6: Main message**

**Those bereaved in a sudden and/or traumatic way will have additional issues to deal with which may complicate their grieving. They may therefore require specific information, guidance and support from healthcare professionals.**



**Criteria 7: Systems in place to identify the individual needs of bereaved people and evidence of relevant support**

**Criteria 8: Evidence of links with the voluntary sector supporting bereaved people**

**Criteria 9: Ongoing bereavement support available for those who require it**

Personal respondents were asked who or what helped them most to deal with their grief.

Of the 158 who completed this triad, 75 (48%) strongly indexed that they were helped most by family and friends, eight (10%) by care and support from professionals and four (5%) by their community network. Analysis of the remaining responses demonstrated that bereaved people were helped to deal with their grief by more than one of these groups.

### **Criteria 7, 8 & 9: Story extracts**

**Personal story 18**

**Emotional intensity:** Positive

**Title:** Still got my memories

**Reason for telling:** For relief

*My first big experience of bereavement was when my father died 12 years ago. His health had been deteriorating but he only went into hospital a few days before he passed away.*

*Each of us comforted my mother in turn and then my thoughts turned to my 2 brothers who were on their way from America. My uncle and some of his lifelong friends were there also and we all took great strength from each other's company during those sad few hours.*



*We got back to the house and prepared for the customary wake. I have to say that the wake was an uplifting experience. It takes your mind away from the grief as friends, neighbours and relatives gather in the house relating funny stories and happy memories over cups of tea, iced buns and wee triangular sandwiches.*

This experience of bereavement overall was naturally sad but I was never overwhelmed by grief. I found that those tears I shed were in some way cathartic, they had to be shed rather than try to bottle up my feelings. I seemed to feel better afterwards. My brothers and sisters helped my mother and each other to cope.

**Key words:** Sad, family, strength  
**How did you feel at the time?** In control  
**How do you feel now?** Accepting  
**Who/what helped most deal with grief?** Family and friends

While most respondents looked to family and friends for support, some described situations where it appeared difficult for family members to provide the support their dependents needed.

**Personal story 19**

**Title:** My mum, 'Braveheart'

**Emotional intensity:** Not indicated

**Reason for telling:** For relief

*My mum was diagnosed with cancer in 2005.*

*The last two years of her life, until her death in 2007, was a roller-coaster of assorted emotions within and without our family. Our family nursed mum at home with initially a 15-minute morning and evening call for her personal hygiene needs by the community carers together with four calls per week by nurses in the monitoring and provision of pain control.*

*Eventually, I, along with one of my sisters, said we were unable to cope any more without getting more professional help from outside carers over a 24-hour period. Following our pressure, meetings were set up and support packages were put into place*



for mum from agencies like Marie Curie and Extra Care nurses at night. While this eased the pressure and the care provided was excellent, my dad and younger sister showed great resentment to our decision to reduce our night hours with Mum.

*The rift is still within our family.... I have serious concerns that my younger sister and dad have not been able to deal with mum's death in a healthy way, it is in this area that bereavement counselling, while not sought by any of the family, should have been offered. Maybe not all of us would have accepted, but I know I would have. Perhaps it would help me understand more about bereavement before and after the event and go some way in repairing the hurt and misunderstandings still festering in my family to this day.*

**Key words:** Sad, frustrated, relief  
**How did you feel at the time?** Helpless/frustrated  
**How do you feel now?** Sad/accepting  
**Who/what helped most deal with grief?** Family/friends

**Personal story 20**

**Title: Parents coping with grief by protecting children**

**Emotional intensity:** Negative

**Reason for telling:** Educate/influence

*My sister who was a twin died aged 2 months old when I was 9 years of age. She had been to the hospital for a check up and died following a blood transfusion.*

*My parents told my brother and I nothing about it and we stayed in my grandparents with my mother for a few days until my father had got rid of the second cot, the double pram, photographs and any evidence that she had ever lived. I don't know if there was a funeral - although presumably there must have been. No-one ever talked about her to us, nor did I ever hear my parents or grandparents talk to anyone else. No-one of them never talked to my youngest sister (her twin) about her twin that died. I remembered everything about her and would keep her memory alive with my brother and sister, telling them stories, making up songs and talking about what she would be like now if she'd lived. none of us told my parents about this as it would only have made them upset*

*Worst aspects - secrecy, adults trying to cope with their own grief by protecting children and preventing us from openly celebrating the short life that she had.*

**Key words:** Over-protection, communication  
**How did you feel at the time?** Helpless  
**How do you feel now?** Sad  
**Who/what helped most deal with grief?** Family/friends

The eight respondents who strongly indicated that professionals helped them most to deal with their grief, described the care and support provided by the professionals involved before and at the time of death. A word search identified that a small number accessed ongoing support from voluntary organisations to help them with their grieving.

### **Criteria 7, 8 & 9: Main message**

**For many bereaved people the main sources of ongoing support are their family members and friends. Caring for someone who is dying and death itself can often bring a family closer or may put a strain on family relationships. Many do not require help and support from outside their family, friends and community but some may benefit from external bereavement support especially if the circumstances surrounding the death have been difficult.**



## Criteria 10: That staff delivering care are competent, confident and supported to do so

Professionals were asked if they felt their training and experience in caring for dying and bereaved people helped them a lot, was just adequate or did not prepare them well enough; and who or what helped them most to deal with their feelings.

Of the 88 professionals who completed this triad, 42 (48%) indexed that their training and experience helped a lot. When their stories were further analysed, 30 (71%) of these were positive or strongly positive.

### Criteria 10: Story extracts

#### Professional story 6

**Title:** Peaceful end

**Emotional intensity:** Strongly positive

**Reason for telling:** Educate/influence

*... Best aspects for patient dying of heart failure: Family and GP definite in allowing patient to remain in nursing home bed and with familiar staff. Patient's family able to visit at will. Relaxed and peaceful atmosphere. Minister of religion in attendance. All done that could be done. Peaceful end. ... Worst aspects: Restlessness of patient, due to heart failure.*

**Key words:**

Interest of patient

**How did you feel at the time?**

In control

**How do you feel now?**

Accepting

**Training and experience?**

Helped them a lot

Six respondents (7%) strongly indicated that their training did not prepare them well enough; three were student nurses and one a care assistant. Four of these stories were indexed with strongly negative intensity.



**Professional story 7****Title: The Forgotten man****Emotional intensity:** Strongly negative**Reason for telling:** Other

*I have been involved with this patient for approximately three years. However, from September I noticed a change in his health. Spoke with GP who requested bloods and prescribed medication. Before Christmas, I wasn't happy with his condition and again I spoke with GP. Nothing appeared to be done. Within my skills and abilities, I did everything in my power to make the patient comfortable whilst informing the staff nurses.*

*Sadly, on my routine visit to the patient, I discovered him unresponsive and deceased on his bedroom floor. Cause of death was pneumonia. I was extremely upset about this and found that it has taken me weeks to come to terms with this patient's death. I have found the whole experience very difficult and testing, as I go about my daily routine at work. Somehow, it feels that I am to draw a line under this episode and get on with what I am paid to do, which I know is right, but I am only human and have feelings too.*

*My experience afterwards I feel is negative because I was asked to complete an incident form and that was as far as it went. No-one ever asked how I was feeling or if I needed someone to talk to at the time. Thankfully, my family supported me throughout this and understood the shock and sadness that I was feeling.*

**Key words:**

Sad, negative, preventable

**How did you feel at the time?**

Helpless/frustrated

**How do you feel now?**

Sad

**Training and experience?**

Didn't prepare me well enough

The stories told by the students suggested that they may have entered placements unprepared for the situations they met, and this had a negative impact on them. However, there was also evidence that mentoring and good example from role models can be an important source of support for students.



**Professional story 8****Title: Sad, undignified end to life****Emotional intensity:** Strongly negative**Reason for telling:** Complain

*Worst ... Family were not given time by the nurses to talk through explanation / difficulties. ... The patient and family were ignored by staff, as they sat at nursing station, before patient was put on dying pathway. ... The family was not given much privacy with their mother. ... Nothing was explained to student nurses about what was going on. ... Staff asked "is she not away yet?" i.e. dead, making me feel the patient was meaningless*

<b>Key words:</b>	Undignified, uncaring, lasting negative memory
<b>How did you feel at the time?</b>	Helpless
<b>How do you feel now?</b>	Angry/sad
<b>Training and experience?</b>	Didn't prepare me well enough

**Professional: 9****Title: Untitled 9****Emotional intensity:** Neutral**Reason for telling:** Educate/influence

*I was caring for a patient on a medical ward last year; the patient had severe learning difficulties so the family were greatly involved in day to day care and decision making. As the doctor took the family aside to tell them that their relative had not got long to live, the patient had died peacefully in her sleep. The staff were all very helpful and supportive of the family. I know this may not happen in all medical areas so I used it in learning about death, and I intend on using the compassion throughout my career.*

<b>Key words:</b>	Not indicated
<b>How did you feel at the time?</b>	Helpless
<b>How do you feel now?</b>	Accepting
<b>Training and experience?</b>	Just adequate/didn't prepare me well enough





Of the 83 professionals who indicated who or what helped them most to deal with their feelings, 27 (33%) strongly indexed that peer support helped them most, 17 (20%) family and friends, and five (6%) the services from employer or professionals. Analysis of the remaining responses demonstrated that professionals were helped to deal with their feelings by more than one of these groups.

Some professionals described a supportive working environment which helped them to be resilient in difficult circumstances. Others described strongly negative experiences due to a lack of support or thoughtlessness in their team; or the stress of meeting the varying needs of patients on their caseload.

**Professional story 10**

**Title: A wish fulfilled**

**Emotional intensity:** Strongly positive

**Reason for telling:** Educate/influence

*I was involved in the care of an elderly man who died at home about 9 months ago. He had chosen to be cared for at home and his family were supportive of his decision. I was responsible for co-ordinating his care involving GP, care agency, Marie Curie/ Hospice at home and family. He deteriorated quite rapidly and required to be nursed in bed at the end. I felt in control as a professional. I have studied a palliative care module in advanced symptom management and this certainly helped me to control all symptoms - working with the patients GP and the community hospice nurse. The patient died peacefully, with his family present. Worst aspect of providing palliative care and dealing with bereavement is that there is NO staff support. This is an issue when there are a number of patients deteriorating and dying around the same time.*

**Key words:**

Control, co-ordination, communication

**How did you feel at the time?**

Helpless

**How do you feel now?**

Angry/sad

**Training and experience?**

Just adequate



**Professional story 11****Title: Fighting to live against the odds****Emotional intensity:** Not indicated**Reason for telling:** For relief

*Best aspects - Gave care in the place where the person wanted to be when dying, therefore we granted that wish.*

*Worst aspects – Had to do routine nursing care in between trying to give this patient 100% palliative care.*

*The patient was only 25 dying of terminal ovarian cancer. She had terrible pain, difficult to manage needing 2 syringe drivers, IV paracetamol and even morphine gel applied to her sacral area regularly. This was the family's 2nd daughter to be dying from cancer.*

*It was very difficult to distance myself from feeling of being completely overwhelmed by this situation and sometimes knowing pain could not be completely resolved.*

*The day she died I was on duty alone and had to continue seeing patients when I felt I had been so traumatised. I felt physically sick with weeks of stress and exhaustion managing this palliative patient. It had even taken over my home life and affected my family.*

**Key words:**

Traumatic, stressful, experiential

**How did you feel at the time?**

Helpless

**How do you feel now?**

Angry/sad

**Training and experience?**

Didn't prepare me well enough



**Professional story 12****Title: My mummy left me here****Emotional intensity:** Strongly positive**Reason for telling:** Educate/influence

*Child 10, this mother hanged herself in front of the child, 2nd suicide in the family Worst - Lack of support structures, no family support  
Best - Regular supervision*

<b>Key words:</b>	Shock, anger, moving time
<b>How did you feel at the time?</b>	In control
<b>How do you feel now?</b>	Accepting
<b>Training and experience?</b>	Helped me a lot

**Professional story 13****Title: Caring professionals forget their own****Emotional intensity:** Strongly negative**Reason for telling:** Educate/influence

*This young person took their own life some months after discharge from inpatient treatment. They had moved to another country. They did not appear to truly connect in with inpatient treatment at the time. Following discharge and before moving country I maintained their outpatient treatment. When I returned from leave I found the young person's file in my in-tray with 'deceased' written over the top. Needless to say I felt upset, appalled, distressed and outraged once I caught my breath.*

<b>Key words:</b>	Disrespect, disconnection, sadness
<b>How did you feel at the time?</b>	Helpless
<b>How do you feel now?</b>	Angry/sad/accepting
<b>Training and experience?</b>	Helped me a lot

When professionals deliver care in a sensitive, competent and confident way the patient and family have a more positive experience. When professionals are not equipped to provide the care required this may have a detrimental effect on the experience of the patient and family.



There was evidence in the personal stories that some professionals provided care in a sensitive, competent and confident way and others did not demonstrate a competent knowledge of the care required. Some respondents described circumstances involving several professionals, where they experienced variations in practices and attitudes of individuals. This impacted on the family's perception of the standard of care they and their loved one received.

**Personal story 21**

**Title: Don't let efficiency get in the way of caring for the dying**

**Emotional intensity:** Negative

**Reason for telling:** Educate/influence

*Most of the staff were very nice but seemed to lack experience in dealing in a gentle and compassionate way with the patient e.g. when giving medication and helping him in and out of bed. I'm sure they were busy but it seemed like they felt giving medication and all the caring was "a bit of a waste of time since the person was going to die anyway" No one expressed this but it came across to the family in that way. One particular nurse on night duty was a gem and this was demonstrated by the caring way she spoke to the patient and took time to do whatever she had to do whilst not forgetting the relatives around the bed. However the nurse/sister in charge of the ward was loud and rough in handling the patient and we would almost squirm when she was on duty.....The family GP stood out, in that, over a holiday period he left his mobile number in case of an emergency, even though he was not on call but had been dealing with the patient and knew the complications so felt it would be better if he was called rather than someone who wasn't familiar with the case. We understood he had no need to do this but appreciated his concern for the terminally ill patient and also the family.*

**Key words:**

Lack of respect

**How did you feel at the time?**

Helpless

**How do you feel now?**

Angry



**Personal story 22****Title: Trusts have a lot to learn****Emotional intensity:** Not sure**Reason for telling:** Other

Person died of massive stroke within hours. Very hard to recall good practice. What is easiest to recall was the bad practice- i.e. person dying but told visiting was over?!

<b>Key words:</b>	One of the most challenging times in life
<b>How did you feel at the time?</b>	Helpless
<b>How do you feel now?</b>	Sad

**Personal story 23****Title: Untitled****Emotional intensity:** Strongly negative**Reason for telling:** Educate/influence

*My father suffered from Alzheimer's and when he was admitted to hospital it was apparent from day 1 that the nursing staff lacked knowledge and training on how to support Alzheimer's sufferers. Some examples are that he was left unsupervised enabling him to wander and in the last days of his life which were precious to us he fell twice, leaving him without speech, which devastated the family. Previous to that he would have been given verbal instructions which he (1). could not hold in his mind and (2). could not understand. There was also food left on the table for him to eat, unfortunately he did not know what to do with it and so at visiting times his family had to feed him. I could give many more examples, however, I feel the picture is clear, Alzheimer's sufferers are not given the care and understanding they deserve.*

<b>Key words:</b>	Not indicated
<b>How did you feel at the time?</b>	Not indicated
<b>How do you feel now?</b>	Angry/Sad



## Criteria 10: Main message

When professionals identified that their training and experience helped them a lot, they were more likely to describe a positive experience. The experience of dying patients and their families is influenced positively or negatively by the skills of those caring for them. The death of a patient affects professionals and most rely on their peers to help deal with their feelings. Training and mentoring equip professionals to take care of their patients, themselves and each other.



## 4) MESSAGES, RECOMMENDATIONS AND ACTIONS REQUIRED

### MAIN MESSAGES AND RECOMMENDATIONS

#### Message 1

When healthcare professionals have identified that a patient is dying or has died they have a responsibility to communicate this in a clear and supportive way to avoid misunderstanding or additional distress.

Professionals caring for patients and their families before, at the time of and after death, can influence how a bereaved family copes following death by helping them come to terms with the diagnosis and prognosis, supporting them through the pre bereavement stage, and giving them the information they need to help with the future.

#### Recommendation

*Healthcare professionals have a responsibility to share significant information with dying patients and their relatives. This information must be communicated in a clear and supportive way which reduces the potential for misunderstanding or additional distress and allows preparation for dying and bereavement.*

#### Message 2

Every effort should be made to support people to die in their preferred place, where at all possible, when death is expected. However, health care professionals can influence the experience at the time of death and bereavement in a positive or negative way, regardless of where death occurs. A supported experience can be achieved by treating the patient and their family with compassion, dignity and respect, and delivering care which meets their needs.



## **Recommendation**

*In all situations healthcare professionals should strive to create a supportive experience for dying people and their relatives by planning and delivering the practical, emotional and spiritual care that meets their individual needs.*

### **Message 3**

When care and decision-making between the patient, family and professionals are viewed as a partnership, a positive experience for all is more likely. When the patient, family and professionals do not work together; or when treatments and actions are not explained or understood, a negative experience may result.

## **Recommendation**

*Healthcare professionals must involve the patient, where circumstances allow, and family in decisions about care, treatment and what happens after death. A care pathway that identifies the needs of a dying person and their relatives may help staff deliver care that is consistent and has the patient and family at the centre.*

### **Message 4**

When doctors do not complete medical certificates of cause of death accurately they are not accepted for death registration purposes. This causes additional distress and inconvenience to families at an already difficult and stressful time.

## **Recommendation**

*Doctors must be trained in the completion of relevant documentation and ensure that all legally required documents are completed accurately, (in accordance with DHSSPSNI requirements,) so that families do not experience avoidable, additional distress because of a delay in processes.*



## Message 5

Those bereaved in a sudden and/or traumatic way will have additional issues to deal with which may complicate their grieving. They may therefore require specific information, guidance and support from healthcare professionals.

### Recommendation

*Healthcare professionals who provide care to people who are bereaved in a sudden way should provide them with the information they require to guide them through the additional processes they face e.g. information on the Coroner's Service and the support available for people bereaved traumatically. This information should be explained verbally and supplemented with up-to-date literature.*

## Message 6

For many bereaved people the main sources of ongoing support are their family members and friends. Caring for someone who is dying and death itself can often bring a family closer or sometimes put a strain on family relationships. Many do not require help and support from outside their family, friends and community but some may benefit from external bereavement support, especially if the circumstances surrounding the death have been difficult.

### Recommendation

*While it may not be the responsibility of the professionals providing care to the patient at the time of death to deliver ongoing support, it is important that they are aware of what help is available and be in a position to give this information to the family. Healthcare professionals should make information available to bereaved people that explains the normal grieving process, the immediate practical arrangements to be considered when someone dies, and where ongoing support can be accessed should they require it in the future.*



## Message 7

When professionals identified that their training and experience helped them a lot, they were more likely to describe a positive experience. The experience of dying patients and their families is influenced positively or negatively by the skills of those caring for them. The death of a patient affects professionals and most rely on their peers to help deal with their feelings. Training and mentoring equip professionals to take care of their patients, themselves and each other.

### Recommendation

*Health and Social Care and professional bodies should recognise the value to their organisations of a skilled workforce that is trained and supported to provide safe and effective care around the time of death and bereavement. Therefore they should provide opportunities for staff to access and undertake training, supervision and mentoring that enhances their knowledge, skills and personal resilience; thus enabling them to care, with competence, confidence and compassion, for dying and bereaved people.*

### ACTIONS REQUIRED

These audit findings underline the importance of the role of healthcare professionals who support people around the time of death and in bereavement. It has identified how the experience of bereaved people can be positively or adversely affected by the care they or their loved one received; and how the quality of the care can impact on the well being of bereaved people and their memory of the event.

The findings also reflect the esteem in which skilled, supportive, compassionate professionals are held, how much they can influence the experience of people at a difficult and distressing time; and the impact this can have on them personally.



The recommendations from this audit are reflected in the standards contained within the HSC Services Strategy for Bereavement Care (2009) and therefore will be addressed by action taken to implement those standards (Appendix 9). Trust Bereavement Coordinators, supported by the HSC Bereavement Network, are currently facilitating implementation of the bereavement standards in each HSC Trust, in partnership with bereaved people, and representatives from statutory, primary, secondary, community and voluntary agencies.

Whilst the HSC Services Strategy for Bereavement Care (2009) was developed to inform practices around the time of death for Health and Social Care staff, the standards contained within it are relevant to all who support dying people and their families, and would guide those who employ and train them.

The standards and actions contained in other regional strategies, for example “Living Matters: Dying Matters - A Palliative and End of Life Care Strategy for Adults in Northern Ireland” (DHSSPS 2010), “Improving the Patient and Client Experience” (DHSSPS 2008), “Protect Life: A Shared Vision - A Suicide Prevention Strategy and Action Plan” (DHSSPS 2006) will also contribute to the quality of the experience of bereaved people.

## SUSTAINING IMPROVEMENT AND RE-AUDIT

The implementation of the HSC Services Strategy for Bereavement Care (2009) will drive improvement in the delivery of care around the time of death. The standard of bereavement care provided by Trusts will be re-audited and the findings benchmarked against those from both phases of the Northern Ireland Audit: Dying, Death and Bereavement in 2012/2013.





## APPENDICES

- Appendix 1:      Audit standards**
- Appendix 2:      Specimen letter inviting participation**
- Appendix 3:      Promotional flyer for audit**
- Appendix 4:      Services and individuals invited to participate**
- Appendix 5:      Sample pages of online audit tool**
- Appendix 6:      Personal questionnaire – paper version**
- Appendix 7:      Professional questionnaire – paper version**
- Appendix 8:      Understanding SenseMaker™ - information about the  
Cognitive Edge© approach**
- Appendix 9:      HSC services standards for bereavement care**





## APPENDIX 1: AUDIT STANDARDS

Clinical & Social Care Audit measures care provided against criteria identified from evidence of best practice (often incorporated into local or national guidelines/protocols). You should ensure staff delivering this care agree that these audit standards represent best practice, to avoid later debate about what the results show and whether practice needs changing.

**If criteria refer to detail given in other standards (e.g. local protocols/guidelines), please attach a copy of these standards or provide a website reference**

Criteria	Target (%)	Exceptions	Source & Strength* of Evidence	Instructions for where to find data
1 The patient was identified as dying	100%	Death occurred unexpectedly	National Institute for Clinical Excellence (2004) Improving Supportive and Palliative Care for Adults with Cancer. (NICE) Key components of best practice in community care DHSSPS, (2003) Breaking Bad News Regional Guidelines	<a href="http://www.nice.org.uk">www.nice.org.uk</a> <a href="http://www.dhsspsni.gov.uk">www.dhsspsni.gov.uk</a>
2 The preferred place of care and death was discussed with patient and carer and measures taken to comply	100%	Death occurred unexpectedly	National Institute for Clinical Excellence (2004) Improving Supportive and Palliative Care for Adults with Cancer. (NICE) Key components of best practice in community care p111 DH (2006) Preferred Place of Death DH (2006) Our Health, Our Care, Our Say	<a href="http://www.nice.org.uk">www.nice.org.uk</a> <a href="http://www.doh.gov.uk">www.doh.gov.uk</a>

	Criteria	Target (%)	Exceptions	Source & Strength* of Evidence		Instructions for where to find data
3	Carers were enabled and supported to care for dying relative at home i.e. evidence of specific information, advice or support services available (if that was the dying person's wishes)	100%	Death occurred unexpectedly	National Institute for Clinical Excellence (2004) Improving Supportive and Palliative Care for Adults with Cancer. (NICE) Key components of best practice in community care p111	C	www.nice.org.uk
4	Death was expected and care needs identified using an appropriate end of life tool <ul style="list-style-type: none"> <li>• Liverpool Care Pathway for the Dying or similar</li> <li>• GP Contract; Quality and Outcomes Framework (QOF) Palliative Care Register</li> </ul>	100%	Death occurred unexpectedly	National Institute for Clinical Excellence (2004) Improving Supportive and Palliative Care for Adults with Cancer. (NICE) DHSSPS (NI) Quality and Outcomes Framework DHSSPS, (2006) The Quality Standards for Health and Social Care: Supporting good Governance and Best Practice in HPSS	C	www.nice.org.uk
5	Death was reported to the patients GP or Out of Hours Service so that legal responsibilities in relation to the death are coordinated (e.g. Death Certification, Reporting to Coroner etc)	100%	None Death in all circumstances in community to be reported to GP or service acting on their behalf (e.g. OOH service)	Deaths and Births Registration (NI) 1976 Coroners Act (NI) 1959 Section 7	C	www.coronersni.gov.uk www.gro.gov.uk





	Criteria	Target (%)	Exceptions	Source & Strength* of Evidence	Instructions for where to find data
6	Support/information was available for those bereaved suddenly or traumatically	100%	Death was expected	Promoting Mental Health: Strategy and Action Plan 2003-2008 Royal Hospitals, The, (2003) Sudden Death Information Pack	www.dhsspsni.gov.uk
7	Systems in place to identify the individual needs of bereaved people and evidence of the relevant support.	100%		Section 75 Northern Ireland Act 1998 Bamford Review of Mental Health and Learning Disability (NI) 2007 Equality Commission NI & DHSSPS, (2003) Racial Equality in Health and Social Care, A Good Practice Guide	www.nias.gov.uk www.dhsspsni.gov.uk
8	Evidence of links with the voluntary sector supporting bereaved people	100%		DOH (2005) when a patient Dies; advice on developing bereavement services in the NHS	www.doh.gov.uk
9	Ongoing bereavement support available for those who require it	100%		DOH (2005) when a patient Dies; advice on developing bereavement services in the NHS	www.doh.gov.uk
10	That staff delivering care are competent, confident and supported to do so.	100%		DOH (2005) when a patient Dies; advice on developing bereavement services in the NHS Professional Codes of Conduct e.g. NMC 2008 The Code	www.doh.gov.uk www.nmc-uk.org

**\*Strength of Evidence** **A** At least one randomised controlled trial as part of a body of literature of overall good quality and consistency addressing the specific recommendation  
**B** Availability of well-conducted clinical & social care studies but no randomised clinical trials on the topic of the recommendation  
**C** Expert committee reports or opinions and/or clinical experience of respected authorities. Absence of directly applicable clinical studies of good quality  
**D** Recommended good practice based on clinical & social care experience (local consensus)



## APPENDIX 2: SPECIMEN LETTER INVITING PARTICIPATION.

A variation of this letter was sent to GPs, Community healthcare professionals, community groups, agencies and individuals

### **Bereaved People and Community Groups/Service User Organisations**

26th October 2009

Dear

### **Northern Ireland Audit: Dying, Death and Bereavement:**

#### **Phase 2: The experiences of bereaved people and those delivering primary care services**

I am inviting you/members of your organisation to consider taking part in a unique audit which is being carried out by the Health and Social Care Bereavement Network.

As someone who may have experienced a personal bereavement, or as a key worker/member of a group or organisation providing advice, care and support for people in the community, your participation will help us improve care in the future.

#### **The purpose of the audit**

This audit aims to capture the experience of bereaved people and the experience of primary and community care professionals such as GP's and nurses, who provide care to dying and bereaved people. If you decide to take part you will be invited to provide an anecdote or story of your experience of care around the time of death and following bereavement. If you respond as a professional, you will also have the opportunity to contribute the story of a personal bereavement if you so wish.

These stories, combined with the key words you use to describe your experiences, will be analysed using a methodology developed by Cognitive Edge© which enables both qualitative and quantitative information to be analysed. The NI Bereavement Network, along with HSC Board and Trusts, will use the findings of this audit to inform and improve service delivery to dying and bereaved people.



## How to take part

The audit will run for 3 months from **2nd November 2009 to 1st February 2010**  
You can take part in 2 ways;

- The audit questionnaire can be accessed online from computers that have 'Flash Player' or similar software installed and is available at **<http://apps.sensemaker-suite.com/Bereavement>** (Most work based computers do not allow the use of interactive graphics so participants may be required to access the site from home).

Depending on typing speed and the length of the story or anecdote, the questionnaire should take around 15-20 minutes to complete. The information given will be anonymous and confidential. An explanation on how to consent and progress through the questionnaire is available when you go online.

- Alternatively the audit can be completed using a hard copy of the questionnaire. This can be done alone or, confidentially, at a group meeting set up by Trust staff facilitators. **If this option is preferable please contact me, or your local Trust Bereavement Coordinator, who will arrange the delivery of questionnaires, and/or dates for a group meeting.**

I hope that you will consider participating and share this information with your colleagues, relatives and friends. I have enclosed some flyers and posters for this purpose.

The Bereavement Coordinators, who have developed this audit, acknowledge that taking part may for some people evoke sad and painful memories.

If you would like further information on, or assistance with, participating, please do not hesitate to contact me or your local Bereavement Coordinator.

Yours sincerely

**Trust Bereavement Coordinator**



## APPENDIX 3: FLYER PROMOTING AUDIT

# EXPERIENCES OF BEREAVED PEOPLE AND COMMUNITY STAFF DELIVERING END OF LIFE CARE

(A regional audit of end of life and bereavement care)  
**WOULD YOU TELL YOUR STORY?**

Online at:


<http://apps.sensemaker-suite.com/Bereavement/>

or

at a local group or individual meeting

Trust	Name	Tel. Number
Northern	Barbara Bankhead	028 9442 4992
Southern	Anne Coyle	028 3861 3861
South Eastern	Paul McCloskey	0289048 4511X2398
Western	Carole McKeeman	0287134 5171X5545
Belfast	Heather Russell	0289063 3904

*The Bereavement Coordinators listed above can provide further information on taking part and the support available afterwards for those who require it.*

 Health and Social Care  
in Northern Ireland

 GAIN

GUIDELINES AND AUDIT  
IMPLEMENTATION NETWORK

## APPENDIX 4: SERVICES AND INDIVIDUALS INVITED TO PARTICIPATE IN EACH TRUST AND REGIONALLY

<b>Medical Directorate</b>		
• Out of Hours Lead	• General Practitioners	
<b>Nursing</b>		
• Community Lead (DN & MH, LD & SW, Dementia)	• Nursing Assistants	• Specialist Palliative Care Teams
• Health Visitors	• Midwives	• Children's Community Nurses
• Community Heart Failure Team	• Community Renal Failure Team	• Community Chronic Obstructive Pulmonary Disease Team
<b>Allied Health Professionals</b>		
• Community Allied Health Professionals		
<b>Social Care</b>		
• Social Workers	• Care Managers	• Domiciliary and Residential Care Teams
<b>Promoting Wellbeing Team (Where Applicable)</b>		
<b>Nursing/Residential Homes</b>		
• Statutory	• Private	

### LIST OF BEREAVED PEOPLE/SERVICE USERS AND SUPPORT ORGANISATIONS APPROACHED

<b>Miscarriage/Stillbirths</b>		
• Miscarriage Association	• SANDS Group	
<b>Children</b>		
• Compassionate Friends	• Barnardos including NOVA	• Remember our Child
<b>Adult/Older People</b>		
• Cruse Bereavement Care	• Age Concern	• Relatives Association
• Bereavement Support Groups (Locality Based)	• Alzheimer's Society	• Nursing/Residential Homes
<b>Suicide</b>		
• Suicide Support Groups		



### Trauma

- Trauma Advisory Panel (TAP)

### General Groups

- Belfast Carer Centre
- Care in Crisis
- Befrienders
- Clergy - Church Groups
- Funeral Directors with SLA
- MCCC Nurses
- Cultural/Ethnic Groups

### Teaching Establishments

- NIMDTA
- Beeches
- QUB
- NEDC
- UU

### Organisations Invited to Host Link to Audit

- NICaN
- Patient/Client Council



# APPENDIX 5: SAMPLE PAGES OF ONLINE AUDIT TOOL

1. This is the welcome page that introduces the project

**Bereavement - Personal**

Thank you for agreeing to take part, your name will not be requested and the information you provide will be anonymous. Please do not record the names of family members, carers or professionals in your story. The information you provide will not be identifiable or traceable back to you.

All information will be handled and stored in accordance with the Data Protection Act 1998.

When you have completed the questionnaire and before you leave the system, you will be given the opportunity to delete your entries if you change your mind about taking part.

If you have concerns about any aspect of the audit, you can contact one of the Trust Bereavement Coordinators who will try to answer your questions. If you remain dissatisfied and wish to make a complaint, you will be provided with the relevant information to enable you to do so. The contact details for the Trust Bereavement Coordinators are provided at the end of the questionnaire.

By completing the questionnaire you are consenting for your anonymous information to be used in the development of a report which will be presented to health and social care providers for the purpose of developing end of life and bereavement services.

2. On this page, the respondent types in an experience

**Bereavement - Personal**

Write your story in the box below. You may wish to describe:

- the best and/or worst aspects about the care provided for the person in the story?
- the best and/or worst aspects about the care YOU received when the person in the story was dying or died?



**B** **I** **U** **D** Arial

**If you were to give your story a title what would it be?**      **What three key words would best describe your story?**



3. Where the triangle below is applicable to an experience, the respondent places the bubble at the appropriate position in the triangle

**Bereavement - Professional**

<p><b>How did this experience make you feel at the time?</b></p> <p style="text-align: center;"><b>In Control</b> <input type="checkbox"/> N/A</p>  <p style="text-align: center;"><b>Helpless</b> <span style="margin-left: 150px;"><b>Frustrated</b></span></p>	<p><b>How do you feel about this experience now?</b></p> <p style="text-align: center;"><b>Angry</b> <input type="checkbox"/> N/A</p>  <p style="text-align: center;"><b>Accepting</b> <span style="margin-left: 150px;"><b>Sad</b></span></p>
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4. Further multi-choice questions are asked to gain an understanding of the demographics of the respondent

**Bereavement - Professional**

<p><b>What is your age?</b></p> <input type="text"/>	<p><b>Are you male or female?</b></p> <input type="text"/>
<p><b>What is your relationship/role to the person who died?</b></p> <input type="text"/>	<p><b>Was the person in the story able to speak English?</b></p> <input type="text"/>
<p><b>If you are telling a professional story, how long have you worked in your area?</b></p> <input type="text"/>	<p><b>What is the main reason for telling the story?</b></p> <input type="text"/>
<p><b>How would you describe your overall feeling about this story?</b></p> <input type="text"/>	<p><b>In your conversations with other people, how common would you say this type of story is?</b></p> <input type="text"/>



## APPENDIX 6: PERSONAL QUESTIONNAIRE

### **Northern Ireland Audit: Dying, Death and Bereavement:**

### **Phase 2: The experiences of bereaved people and those delivering primary care services**

## PERSONAL QUESTIONNAIRE



**INFORMATION FOR PARTICIPANTS  
REGIONAL AUDIT OF END OF LIFE  
AND BEREAVEMENT CARE**

Thank you for considering taking part in this audit. If you decide to complete the questionnaire, your name will not be requested and the information you provide will be anonymous and not traceable back to you. Please do not record the names of family members, carers or professionals in your story.

All information will be handled and stored in accordance with the Data Protection Act 1998.

By completing and returning the questionnaire you are consenting for your anonymous information to be used with that of others in the development of an audit report. The findings of the audit will be presented to health and social care providers for the purpose of developing or improving end of life and bereavement services.

If you have concerns about any aspect of the audit, you can contact one of the Trust Bereavement Coordinators, who will try to answer your questions. If you remain dissatisfied and wish to make a complaint, you will be provided with the relevant information to enable you to do so. The contact details for the Trust Bereavement Coordinators are provided at the end of the questionnaire.

**PROMPTS FOR STORYTELLING**

Please write your story in the box below. You may wish to describe:

- the best and/or worst aspects about the care provided for the person in the story?
- the best and/or worst aspects about the care YOU received when the person in the story was dying or died?



**Thank you for your story. Please continue with the following questions:**

If you were to give your story a title what would it be?

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What 3 key words would best describe your story?

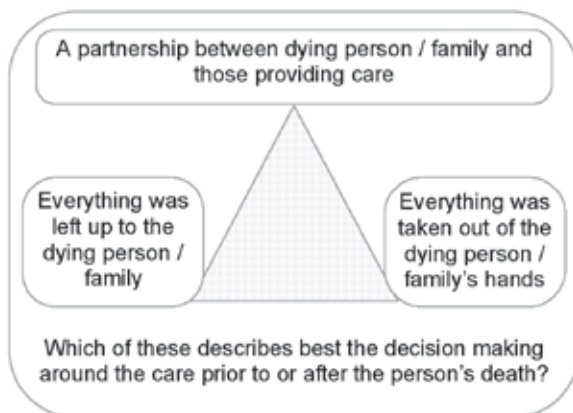
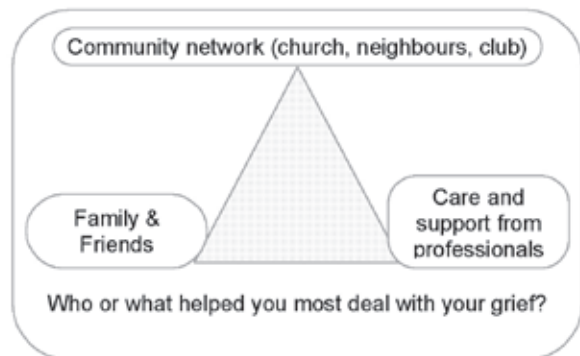
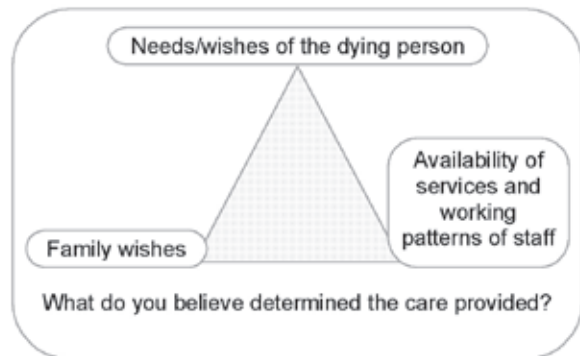
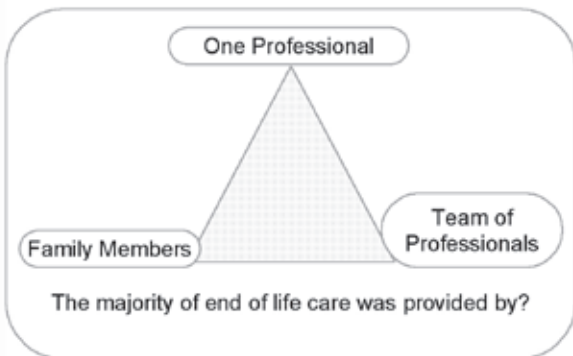
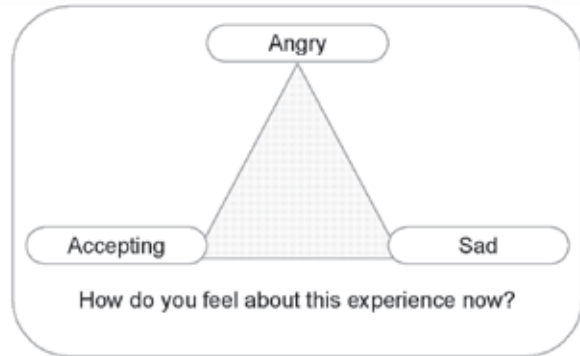
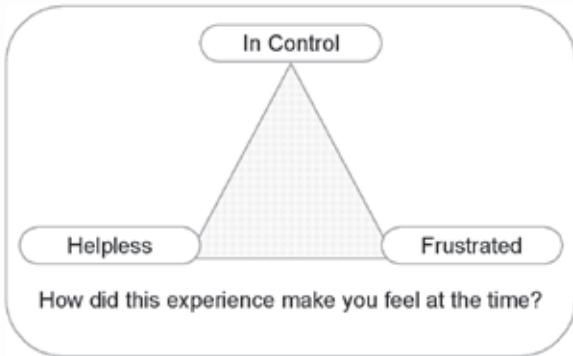
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### **Triangle Exercise** **Instructions for Completion**

On the following pages you will see seven triangles with a question below each. Please mark an **X** in the triangle at a place that best describes your answer, for example:

- If the answer at only one point of the triangle is relevant to you then mark the X there
- If two answers are relevant mark the X on the line between the two
- If all three answers are somewhat relevant mark the X at a suitable place within the triangle
- If the question is not relevant to your story write N/A in the box to the left of the triangle





Questions	Options
What is your age?	<input type="checkbox"/> under 20 <input type="checkbox"/> 20 – 29 <input type="checkbox"/> 30 – 49; <input type="checkbox"/> 50 – 69 <input type="checkbox"/> over 70
Are you male or female?	<input type="checkbox"/> Male <input type="checkbox"/> Female
What is your relationship to the person in the story?	<input type="checkbox"/> parent <input type="checkbox"/> husband/wife/partner <input type="checkbox"/> brother/sister <input type="checkbox"/> son/daughter <input type="checkbox"/> grandparent/grandchild <input type="checkbox"/> other relative <input type="checkbox"/> friend/neighbour <input type="checkbox"/> bystander/witness
Was the person in the story able to speak English?	<input type="checkbox"/> yes <input type="checkbox"/> no
What is the main reason for telling this story?	<input type="checkbox"/> To encourage/compliment <input type="checkbox"/> To complain <input type="checkbox"/> To educate/influence <input type="checkbox"/> for relief <input type="checkbox"/> other
How would you describe your overall feeling about this story?	<input type="checkbox"/> strongly positive <input type="checkbox"/> positive <input type="checkbox"/> neutral <input type="checkbox"/> negative <input type="checkbox"/> strongly negative <input type="checkbox"/> not sure
In your conversations with other people, how common would you say this type of story is?	<input type="checkbox"/> rare <input type="checkbox"/> common <input type="checkbox"/> not sure
How long ago did the person in this story die?	<input type="checkbox"/> < 6 months <input type="checkbox"/> 6 months – 2 years <input type="checkbox"/> 2 - 5 years <input type="checkbox"/> > 5 years
Did the person in the story know they were dying?	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> don't know <input type="checkbox"/> not applicable
How did you become aware that the person was dying?	<input type="checkbox"/> didn't know the person was dying <input type="checkbox"/> told by a doctor/nurse <input type="checkbox"/> told by the dying person <input type="checkbox"/> told by a family member <input type="checkbox"/> other <input type="checkbox"/> not applicable
Which of these things do you think was most important to the person in the story?	<input type="checkbox"/> being involved in decision making <input type="checkbox"/> compassion /respect /dignity <input type="checkbox"/> well managed symptoms <input type="checkbox"/> communication and information <input type="checkbox"/> choice about place of death <input type="checkbox"/> not sure/other
Which of these things was most important for you?	<input type="checkbox"/> being involved in decision making <input type="checkbox"/> compassion /respect /dignity <input type="checkbox"/> well managed symptoms <input type="checkbox"/> communication and information <input type="checkbox"/> choice about place of death <input type="checkbox"/> not sure
Where did the person in the story live?	<input type="checkbox"/> own home <input type="checkbox"/> relative's home <input type="checkbox"/> residential/nursing home <input type="checkbox"/> other
Where did the person in the story die?	<input type="checkbox"/> own home <input type="checkbox"/> relative's home <input type="checkbox"/> residential/nursing home <input type="checkbox"/> hospital <input type="checkbox"/> hospice <input type="checkbox"/> in a public place <input type="checkbox"/> other



If place of death was hospital/hospice/residential/nursing home, how long was the person there before they died?	<input type="checkbox"/> < 24 hours	<input type="checkbox"/> < 1 week	<input type="checkbox"/> 1 week - 1 month
	<input type="checkbox"/> 1 month - 6 months	<input type="checkbox"/> > 6 months	
Was this their preferred place of death?	<input type="checkbox"/> yes	<input type="checkbox"/> no	<input type="checkbox"/> don't know
If you know the cause of death, what was it?	<input type="checkbox"/> cancer	<input type="checkbox"/> respiratory disease	<input type="checkbox"/> heart disease
	<input type="checkbox"/> stroke	<input type="checkbox"/> alzheimers/dementia related	<input type="checkbox"/> genetic disorder
	<input type="checkbox"/> trauma eg accident	<input type="checkbox"/> suicide	<input type="checkbox"/> miscarriage
	<input type="checkbox"/> stillbirth	<input type="checkbox"/> neonatal death	<input type="checkbox"/> other
What length was the final illness?	<input type="checkbox"/> no illness, sudden death	<input type="checkbox"/> less than 1 week	
	<input type="checkbox"/> between 1 week - 6 months	<input type="checkbox"/> 6 months +	

### Thank you for sharing this story.

If you think you might need help with emotions experienced while telling your story, please contact the Bereavement Coordinator within your area who can advise you further about local support organisations.

### Please return Questionnaire by 28 February 2010

Trust Bereavement Coordinator	Contact details
<b>Northern Trust</b> Barbara Bankhead	028 94424992
<b>Southern Trust</b> Anne Coyle	028 38613861
<b>South Eastern Trust</b> Paul McCloskey	028 90484511 ext 2398
<b>Western Trust</b> Carole McKeeman	028 71345171 ext 5545
<b>Belfast Trust</b> Heather Russell	028 90633904



## APPENDIX 7: PROFESSIONAL QUESTIONNAIRE

### **Northern Ireland Audit: Dying, Death and Bereavement:**

### **Phase 2: The experiences of bereaved people and those delivering primary care services**

## PROFESSIONAL QUESTIONNAIRE

**INFORMATION FOR PARTICIPANTS  
REGIONAL AUDIT OF END OF LIFE  
AND BEREAVEMENT CARE**

Thank you for considering taking part in this audit. If you decide to complete the questionnaire, your name will not be requested and the information you provide will be anonymous and not traceable back to you. Please do not record the names of family members, carers or professionals in your story.

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**PROMPTS FOR STORYTELLING**

Please write your story in the box below. You may wish to describe:

- the best and/or worst aspects about the care provided for the person in the story?
- the best and/or worst aspects about the care YOU received when the person in the story was dying or died?



**Thank you for your story. Please continue with the following questions:**

If you were to give your story a title what would it be?

---

What 3 key words would best describe your story?

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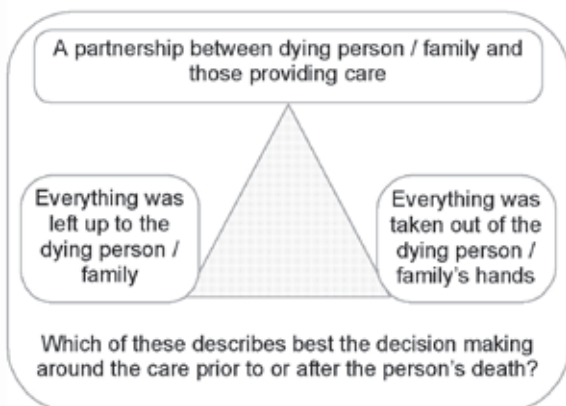
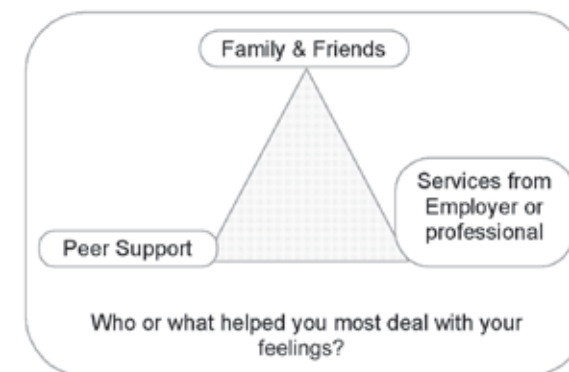
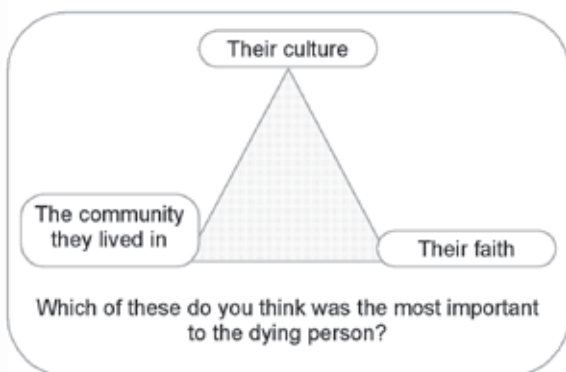
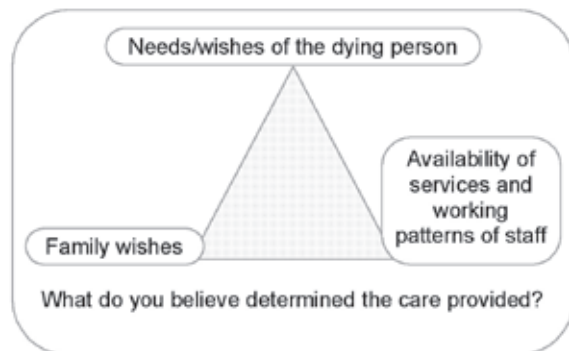
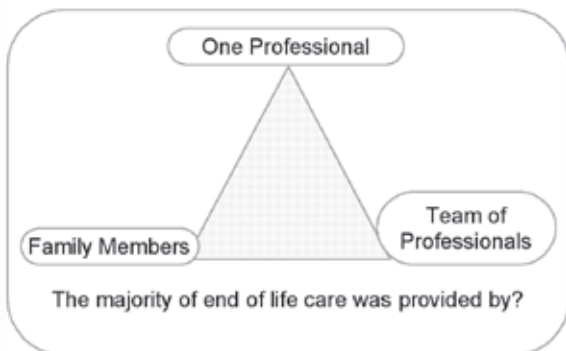
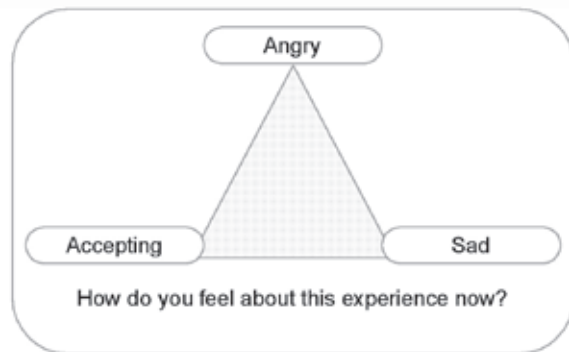
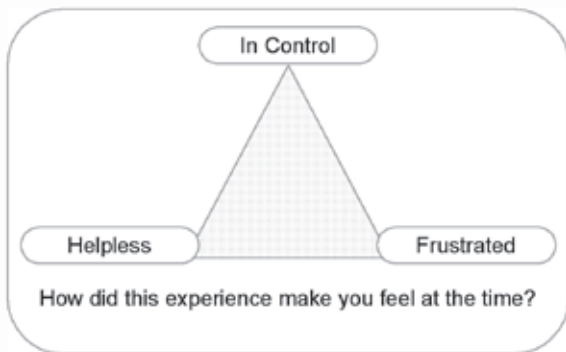
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Questions	Options
What is your age?	<input type="checkbox"/> under 20 <input type="checkbox"/> 20 – 29 <input type="checkbox"/> 30 – 49; <input type="checkbox"/> 50 – 69 <input type="checkbox"/> over 70
Are you male or female?	<input type="checkbox"/> Male <input type="checkbox"/> Female
What is your relationship/role to the person who has died?	<input type="checkbox"/> doctor <input type="checkbox"/> nurse <input type="checkbox"/> care assistant <input type="checkbox"/> other professional
Was the person in the story able to speak English?	<input type="checkbox"/> yes <input type="checkbox"/> no
What is the main reason for telling this story?	<input type="checkbox"/> To encourage/compliment <input type="checkbox"/> To complain <input type="checkbox"/> To educate/influence <input type="checkbox"/> for relief <input type="checkbox"/> other
How would you describe your overall feeling about this story?	<input type="checkbox"/> strongly positive <input type="checkbox"/> positive <input type="checkbox"/> neutral <input type="checkbox"/> negative <input type="checkbox"/> strongly negative <input type="checkbox"/> not sure
In your conversations with other people, how common would you say this type of story is?	<input type="checkbox"/> rare <input type="checkbox"/> common <input type="checkbox"/> not sure
How long ago did the person in this story die?	<input type="checkbox"/> < 6 months <input type="checkbox"/> 6 months – 2 years <input type="checkbox"/> 2 - 5 years <input type="checkbox"/> > 5 years
Did the person in the story know they were dying?	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> don't know <input type="checkbox"/> not applicable
How did you become aware that the person was dying?	<input type="checkbox"/> didn't know the person was dying <input type="checkbox"/> told by a doctor/nurse <input type="checkbox"/> told by the dying person <input type="checkbox"/> told by a family member <input type="checkbox"/> other <input type="checkbox"/> not applicable
Which of these things do you think was most important to the person in the story?	<input type="checkbox"/> being involved in decision making <input type="checkbox"/> compassion /respect /dignity <input type="checkbox"/> well managed symptoms <input type="checkbox"/> communication and information <input type="checkbox"/> choice about place of death <input type="checkbox"/> not sure/other
Which of these things was most important for you?	<input type="checkbox"/> being involved in decision making <input type="checkbox"/> compassion /respect /dignity <input type="checkbox"/> well managed symptoms <input type="checkbox"/> communication and information <input type="checkbox"/> choice about place of death <input type="checkbox"/> not sure
Where did the person in the story live?	<input type="checkbox"/> own home <input type="checkbox"/> relative's home <input type="checkbox"/> residential/nursing home <input type="checkbox"/> other
Where did the person in the story die?	<input type="checkbox"/> own home <input type="checkbox"/> relative's home <input type="checkbox"/> residential/nursing home <input type="checkbox"/> hospital <input type="checkbox"/> hospice <input type="checkbox"/> in a public place <input type="checkbox"/> other



If place of death was hospital/hospice/residential/nursing home, how long was the person there before they died?	<input type="checkbox"/> < 24 hours	<input type="checkbox"/> < 1 week	<input type="checkbox"/> 1 week - 1 month
	<input type="checkbox"/> 1 month - 6 months	<input type="checkbox"/> > 6 months	
Was this their preferred place of death?	<input type="checkbox"/> yes	<input type="checkbox"/> no	<input type="checkbox"/> don't know
If you know the cause of death, what was it?	<input type="checkbox"/> cancer	<input type="checkbox"/> respiratory disease	<input type="checkbox"/> heart disease
	<input type="checkbox"/> stroke	<input type="checkbox"/> alzheimers/dementia related	<input type="checkbox"/> genetic disorder
	<input type="checkbox"/> trauma eg accident	<input type="checkbox"/> suicide	<input type="checkbox"/> miscarriage
	<input type="checkbox"/> stillbirth	<input type="checkbox"/> neonatal death	<input type="checkbox"/> other
What length was the final illness?	<input type="checkbox"/> no illness, sudden death	<input type="checkbox"/> less than 1 week	
	<input type="checkbox"/> between 1 week - 6 months	<input type="checkbox"/> 6 months +	

### Thank you for sharing this story.

If you think you might need help with emotions experienced while telling your story, please contact the Bereavement Coordinator within your area who can advise you further about local support organisations.

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<b>Northern</b>	Barbara Bankhead	028 94424992
<b>Southern</b>	Anne Coyle	028 38613861
<b>South Eastern</b>	Paul McCloskey	028 90484511 ext 2398
<b>Western</b>	Carole McKeeman	028 71345171 ext 5545
<b>Belfast</b>	Heather Russell	028 90633904



## APPENDIX 8: UNDERSTANDING SENSEMAKER

This is a glossary of terms often mentioned in our report

<p><b>Sensemaking</b> How do we make sense of the world so we can act in it?</p>	<p><b>Narrative approaches</b> Collecting data in the form of narratives, as human tend to convey complex knowledge through their experiences (narratives)</p>	<p><b>Modulators</b> A force or factor which changes the property of a phenomenon</p>
<p><b>SenseMaker™ software</b> Analytical and interrogation suite of tools making extensive use of visualisations, allowing complex patterns and exceptions to be discovered</p>	<p><b>Prompting questions</b> A deliberately ambiguous question designed to elicit experiences from people, in the form of fragmented narrative</p>	<p><b>Fragments</b> An experience captured in or related as a narrative, a document, an anecdote, a video, digital recording or even an image</p>
<p><b>Signifiers</b> A semi-structured approach to tagging where additional layers of meaning are added to the original fragment</p>	<p><b>Filters</b> A measurement of a factor /value / modulator that is a feature of one's narrative</p>	<p><b>Multi-choice questions</b> Questions that cover a range of demographic details about the respondent, as well as details about narratives</p>



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### A comparison of approaches

Cognitive Edge Approach	Traditional Survey Methods
Numbers come with context of stories, the latter which can be accessed directly when needed	Numbers that do not inform of the context
Seeks narratives (experiences) from people, as humans convey complex knowledge through stories	Seeks opinions of people
Use of indirect prompting questions to elicit answers that tend to be more honest and revealing	Use of direct questions which people usually expect
Building understanding of context by collection of samples of data	Averages out someone's experience regardless of context
Cognitive Edge methods and tools ascertain patterns in these stories to obtain insights - visualisations in SenseMaker © present alternative and diverse points of view	Reliance on traditional statistical analysis which "drowns out" weak signals until they become significant, at which point it may be difficult and expensive to intervene



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## APPENDIX 9: HSC SERVICES STANDARDS FOR BEREAVEMENT CARE

- 1. Raising Awareness:** That Health and Social Care staff will be suitably trained to have an awareness and understanding of death, dying and bereavement. Staff should also acknowledge the fact that grief is a normal process following loss, and that needs vary according to an individual's background, community, beliefs, and abilities.
- 2. Promoting Safe and Effective Care:** That all Health and Social Care staff who have contact with people who are dying and/or with those affected by bereavement will deliver high quality, safe, sensitive and effective care before, at the time of and after death according to individuals' backgrounds, communities, beliefs and abilities.
- 3. Communication, Information and Resources:** That people who are dying and those who are affected by bereavement will have access to up-to-date, timely, accurate and consistent information in a format and language which is appropriate and will be helpful to their particular circumstances consistent with their needs, abilities and preferences. Staff will remember that the availability of written or other information does not negate their personal support role.
- 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, abilities 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.





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The HSC Bereavement Network and Trust Bereavement Coordinators would like to sincerely thank all those who contributed their experiences of bereavement by completing an on-line or paper copy of the questionnaire, or by attending a focus group. The wealth of data collected would not have been possible without your generous input.

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Thanks also to fellow audit project team members for your valuable support and contribution.

- Dr. Leslie Boydell, Associate Medical Director for Public Health, Belfast Trust
- Dr. Graeme Crawford, GP Representative
- Mrs Rose McGurk, Public Representative
- Mr. Simon Dunlop, Audit Lead, Belfast Trust

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Finally, we appreciate the encouragement of Dr. Patricia Donnelly, Chair HSC Bereavement Network, the Bereavement Network and the Trust Bereavement Coordinators Board who have supported us while undertaking this innovative project.



## TRUST BEREAVEMENT COORDINATOR CONTACT DETAILS

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<b>Barbara Bankhead Northern HSC Trust</b>	Bush House Bush Road Antrim BT41 2QB	Work 028 9442 4992 Trust mobile: 078 4146 8824	<b>Barbara.Bankhead@northerntrust.hscni.net</b>
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