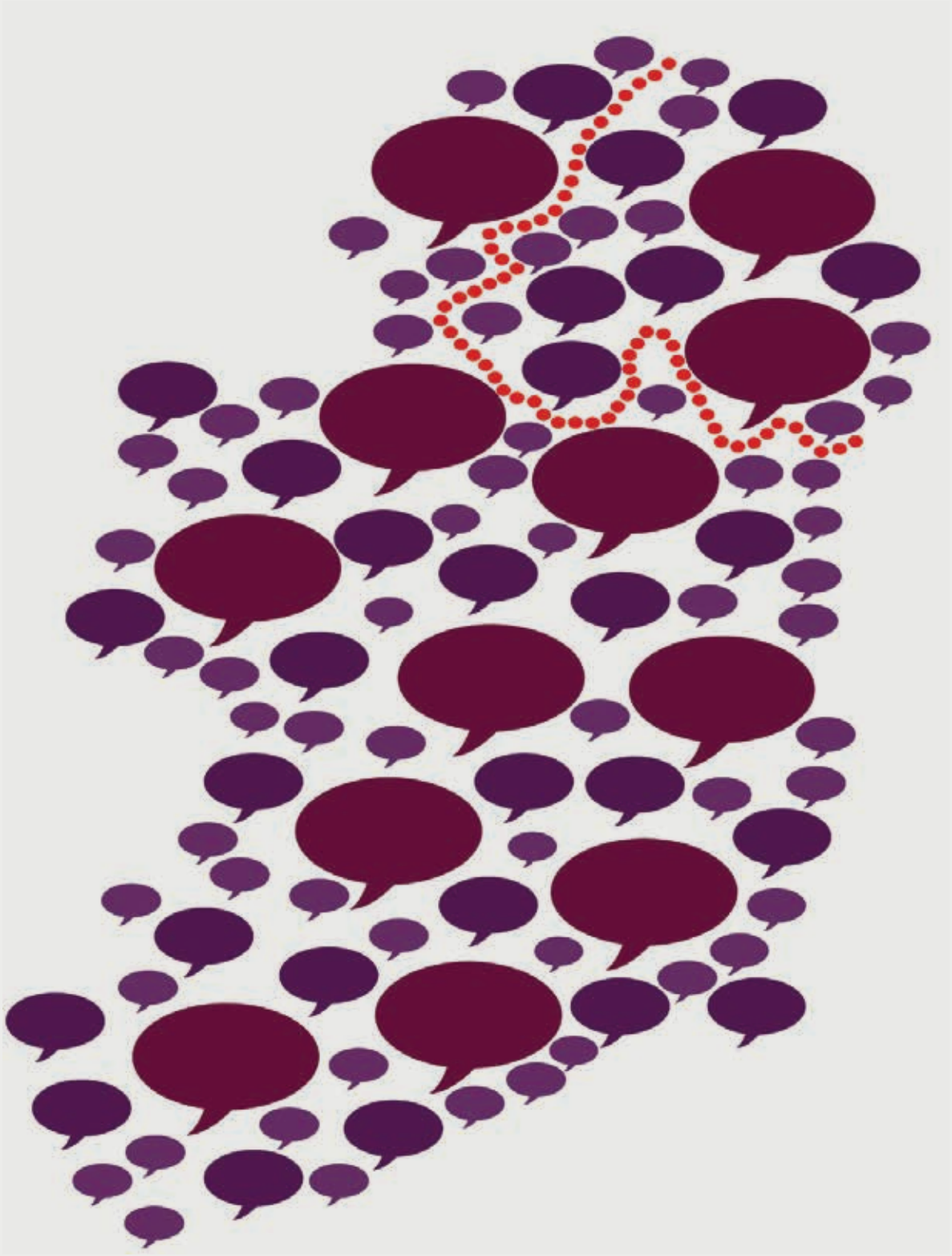
Let's Talk About

Palliative Care Survey Report

Each story is valuable. Hundreds of stories are powerful!

AIIHPC
All Ireland Institute of
Hospice and Palliative Care



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All Ireland Institute of Hospice and Palliative Care (AIIHPC) are indebted to the many people across the Republic of Ireland and Northern Ireland who made the considerable effort to take part in the *Let's Talk About* survey.

This initiative was led by AIIHPC with part funding from the Public Health Agency (PHA) in Northern Ireland and the Health Service Executive (HSE) in the Republic of Ireland.

This project was led by Paddie Blaney, AIIHPC Director 2011-2015. The project was supported by Cathleen Mulholland, AIIHPC Programme Manager, who played a lead role in generating analysis for this report, and by Brendan O'Hara, AIIHPC Programme Manager, who supported initiating the project and finalizing this report.

We are also indebted to Anne Molloy, Voices4Care member working on a consultancy basis with the Institute on specific aspects of the Let's Talk About initiative.

Foreword

I am delighted to present the complete report on the *Let's Talk About* initiative undertaken by All Ireland Institute of Hospice and Palliative Care (AIIHPC) in 2014 and 2015.

Let's Talk About was developed in the context of the overall aim of AIIHPC to improve the experience of palliative and end-of-life care on the island of Ireland by enhancing capacity, developing knowledge, promoting learning, influencing policy and shaping practice.

The title of the *Let's Talk About* survey conveys the importance of beginning a conversation about a topic considered too difficult and too frightening to discuss: the reality of living with a long term progressive condition which cannot be cured. Making planning for the future normal might help to remove fear of the unknown and increase public awareness of the issues to be decided by the person and their family or friends. I am mindful that this is a very personal issue and individuals must decide for themselves what they want to discuss.

A study conducted in the Republic of Ireland found that 80% of the total deaths are associated with conditions with palliative care needs. This same study also found that Ireland has the most rapidly rising need for palliative care in Europe.[1] Similarly another recent study has estimated that there are approximately 3,000 people in Northern Ireland who are currently not accessing the palliative care they need. This is coupled with an expected increase of 28% in the death rate by 2037 in Northern Ireland.[2] These figures indicate that unmet need will increase dramatically unless we take action to address related issues now.

Specifically, *Let's Talk About* was devised to address AIIHPC's commitment to the meaningful involvement of users, carers and communities in the development and delivery of palliative care which is recognised as a major contributing factor to the delivery of safe, accessible, high quality services.

The issues around living with a long-term progressive condition are complex and multi-faceted. By finding out about a high number of people's diverse experiences it is possible to build a picture of current reality from a range of perspectives.

I would like to take this opportunity to thank everyone who completed the *Let's Talk About* survey. To everyone who shared their story and experience - their contribution has been invaluable. These contributions have collectively allowed us to analyse a significant number of narratives helping reveal patterns and trends. These have and will continue to inform palliative care practice and policy development across the Republic of Ireland and Northern Ireland.

Karen Charnley
Head of AIIHPC
April 2016

1 Kane, Pauline M et al., "The Need for Palliative Care in Ireland: A Population-Based Estimate of Palliative Care Using Routine Mortality Data, Inclusive of Non-malignant Conditions," *Journal of pain and symptom management* 49, no. 4 (2015): 726-733: p.729

2 Dixon, Josie et al., *Equity in the provision of palliative care in the UK: review of evidence.* (London: London School of Economics, 2015): p.24

Executive Summary

During the two phases of data collection during 2014 and 2015, a total of 528 people completed the *Let's Talk About* survey. Of these, 419 surveys came from the Republic of Ireland, and 109 surveys came from Northern Ireland. Surveys were completed from all 26 counties in the Republic of Ireland and six counties in Northern Ireland.

Respondents were asked to identify the primary long-term condition(s) of the individuals who had the experience of palliative care. Cancer was the most frequently experienced condition equating to almost half of all conditions identified. Neurological disorders including Dementia and Parkinson's disease were the next biggest grouping. Taken collectively, it has been possible to identify two discreet groupings, people who had cancer and people who did not, which provided the opportunity for further analysis (See Section 4).

The main analysis of the survey is detailed in Section 3 of the report, presenting the results from the eight triangle questions showing how the 528 respondents signified their experiences. Further detail of the survey tool used is included in Section 1 of the report.

In Section 3, results are provided for each of the eight questions followed by a broad interpretation highlighting key themes. Stories submitted by the respondents are included by way of illustration, relating to each of the eight questions for which a summary statistical overview is provided on page 6.

Readers are encouraged to take time to read the extracts from the moving personal narratives contained in Section 3 and Section 5 of this report.

Further research into the complexity of the information available will be required to maximize this resource. In particular it would be useful to explore the marked contrast of those in the non-cancer group being more likely to experience feelings of frustration compared to the experience of the cancer group (See Section 4).

Section 5 sets out a thematic analysis of the stories contributed through the survey.

This analysis resulted in three broad thematic categories (each with a number of sub-themes): The differences good care makes; Poor experience of care; and Poor communication. Exemplar stories allow readers to understand the theme/sub-theme from the perspective of the people who went through the experience.

The most common theme emerging from the stories is the difference good care makes to people's lives, care ranging from specialised medical interventions to everyday personal care. From the stories, it is very clear that people's understanding of care is not just about caring for an illness and its physical symptoms. Good care puts the person at the centre of care and takes into account how the person's illness or condition affects them physically, socially and psychologically.

Respondents to the Let's Talk About survey recount both good and bad experiences of palliative care from health and social care services. User experience must continue to be the benchmark against which policy makers and commissioners approach the future of palliative care services and policy development across the Republic of Ireland and Northern Ireland.

The stories and sharing of personal experience provide a unique insight into the experience of living and dying with a life-limiting condition; the richness of the responses informed the formulation and initial exploration of the following key themes:

- People need help to plan for the future
- People experience too little autonomy
- People feel helpless and frustrated
- People value clear and sensitive communication
- People value timely and appropriate information
- There are emotional and psychological needs that are not met
- People would like their family and friends more involved

Statistical summary of responses to survey questions*

1 In this experience, what was the biggest practical worry?

68% of respondents signified that planning for the future was their biggest practical worry.

2 What describes how you or the person felt by the care provided in this experience?

52% indicated that they felt Frustrated or Helpless or a combination of both, while **27%** felt supported.

3 In this experience, how were any issues talked about by those who provided the care?

48% of respondents felt they were communicated with clearly or sensitively while **22%** indicated that issues were avoided completely.

4 In this experience, how timely was the information that was given?

34% of respondents experienced information being communicated timely or appropriately while **37%** felt they received information too little, too late.

5 In this experience, how in control were you or the person?

24% of respondents felt they were able to make the choices wanted; **34%** felt control was in someone else's hands and **21%** felt that choices were limited.

6 Which needs were least well met in this experience?

51% felt that their emotional or psychological needs were least well met. Notably psychologists and counsellors were the lowest number of professionals identified as being involved in the care of those reporting their experience.

7 What would you have liked more of in this experience?

42% of respondents indicated they would have preferred better coordination of care or treatment; **20%** signified that better emotional support could have been provided.

8 How were the family or close friends treated in this experience?

50% of people felt that family and friends were involved or respected; **20%** felt family and friends were forgotten about or excluded and **18%** felt they were put under too much pressure.

* Statistical summaries and percentages throughout this report must be considered cautiously as respondents were not responding only to yes/no or either/or choices. For example, for the first question, of the 68% of people who said that planning for the future was their biggest practical worry, this did not mean that the other choices for this question, 'finance or cost of living' or 'travel or transport' were not also practical worries for them. Or of the 51% responding to question 6 who said their emotional or psychological needs were least well met, it cannot be inferred that the other 49% of respondents did not have concerns about how their emotional and psychological needs were met. People were asked to make a choice on what best fitted their experience and this enabled patterns and trends to be identified, as reflected in this report.

Recommendations

Based on the results of the survey, the following recommendations are proposed which are aimed at a wide range of audiences including policymakers, commissioners, statutory, voluntary and private agencies, including AIIHPC, involved in the delivery of palliative care:

1. Develop practice models which (a) better coordinate care and treatment options and (b) reflect the emotional and psychological needs of the individual, their families and or carers and support their needs to plan for the future.
2. Build the capacity of professionals to respond to the needs of individuals through the development of competences (physical, psychological, social and spiritual) and communications skills and through access to ongoing and appropriate personal supports.
3. Deliver an information and awareness raising campaign targeted at professionals: GPs, community-based nurses and hospital-based consultant teams who are key to the identification of patients' palliative care needs.
4. Enable individuals to exercise personal choice where possible through the timely provision of accessible and appropriate information on palliative care.
5. Develop principles for involvement and formalise support for family, friends or others where appropriate, in order to encourage participation in supporting an individual.
6. Promote a wider societal normalisation of planning for the future.
7. Promote public awareness and access to a palliative approach to care for all individuals with a serious or progressive condition from which they are unlikely to be cured and which may limit or shorten life.

These recommendations have implications for policy makers, for professionals and for society.

As AIIHPC embarks on the implementation of their second strategic phase in 2016-2020 the findings from *Let's Talk About* will be widely disseminated and used to inform future work.

There will be a continued commitment to user / carer feedback to improve services and to reassure people that their 'stories' were listened to and as claimed in the survey – Each story is valuable. Hundreds of stories are powerful!

1. Introduction

The *Let's Talk About* survey was an innovative approach to find out about the views and experiences of service users and carers of palliative care services in the Republic of Ireland and Northern Ireland. *Let's Talk About* was a two stage survey initiative begun in February 2014 and completed in June 2015.

The *Let's Talk About* survey and subsequent analysis has been completed on the premise of the World Health Organisation definition that:

> "Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." [3]

The concept of 'experience-based design'[4] which uses the experiences of users and carers to shape commissioning and delivery of human services is a well-accepted approach to policy development in the Republic of Ireland and in Northern Ireland.[5] This 'evidence from experience' is an important input which can be used to inform future service commissioning, design and delivery.

In Northern Ireland, the Health and Social Care system has a commitment to Personal and Public Involvement (PPI), involving people in plans and decisions about their own care or treatment and learning from their experiences to improve service delivery. In the Republic of Ireland, one of the guiding principles of the National Strategy for Service User Involvement in the Irish Health Service 2008-2015[6] is that service users have a right to be involved in the development of the health and social services that they use; this is a key element in the delivery of patient-centred care.

The *Let's Talk About* report is divided into four main sections:

1. A demographic profile of the people whose experience was shared
2. A statistical analysis of eight interpretative questions (Main Analysis and a separate Cancer and Non-Cancer Analysis)
3. Thematic analysis of the content of the stories
4. Conclusions and recommendations

The findings from these surveys have assisted in highlighting key themes and identifying priorities for service users forming the basis for recommendations for health and social care improvements.

3 "WHO Definition of Palliative Care," World Health Organization. Accessed 30 November 2015. http://www.who.int/cancer/palliative/definition/en/

4 NHS Institute for Innovation and Improvement: Patient Experience. Accessed 15 September 2015. http://www.institute.nhs.uk/quality_and_value/experienced_based_design/the_ebd_approach_%28experience_based_design%29.html

5 *'Speak out for Change' – Neurological Conditions Network survey 2012.* Public Health Agency. Accessed 25 November 2015. http://www.publichealth.hscni.net/speak-out-change; GAIN. *'Your Story Can Change Lives' - Users and Carers Experience of Mental Health Services in Northern Ireland* (GAIN, 2010). Accessed 30 November 2015: http://www.gain-ni.org/images/Uploads/Audit/Dying_Death_Bereavement.pdf; Public Health Agency (NI) *10,000 Voices Annual Report* (PHA, 2014).

6 Health Service Executive, *National Strategy for Service User Involvement in the Irish Health Service 2008-2015* (Dublin, HSE 2008).

1.1 Methodology

The *Let's Talk About* survey asked a person who cares (or cared) for someone who has a long-term progressive medical condition that is unlikely to be cured, to describe a recent good or bad experience of palliative care services in the Republic of Ireland or Northern Ireland. The survey invited respondents to share a 'story' that had an impact on them, through answering a number of interpretative questions (See Appendices I and II : *Let's Talk About* Survey Information Leaflet and Survey).

1.1.1 Design of Survey Tool

SenseMaker™ Software was used to collect, store, and analyse a high volume of qualitative "narratives" about people's experiences. Two stakeholder workshops were held in October 2013 to plan the design of the SenseMaker™ survey tool. The first workshop drew on the knowledge and experience of users, carers and citizens with an interest.[7] The second workshop drew on the knowledge and experience of both specialist and generalist palliative care professionals and service providers.

The output from these workshops, combined with desk-based research on international quality standards on palliative care[8] and expert input on good practice, informed the design of the *Let's Talk About* survey. A draft survey was finalised and piloted during December 2013. Feedback from the pilot[9] was incorporated into the final design. (See Appendix II Let's Talk About survey tool).

The design of the survey had three sections: respondents were asked to write about an experience; to give their experience a title; and to provide three words or phrases that sum up the key themes about their experience.

The second section asked respondents to interpret the significance of their particular experience, using eight questions in the form of triangles. Each triangle related to an issue which was deemed to be important based on research related to palliative care services.

Each triangle question had three 'signifier labels' that is, labels for the experience. These signifier labels reflected what service users and professionals had identified as important, and also incorporated what is known from current research and quality guidelines. By design, some signifier labels did not have a direct relationship to each other but related to different aspects of experience, so as to capture as much understanding of the experience as possible. Where signifier labels were related, they reflected the graduation of the range of experiences.

In the last section, respondents were asked a series of demographic and profile questions to build a better picture of the person who had the experience and to enable further interpretation of the data.

1.1.2 Data Collection

Phase I of the *Let's Talk About* survey ran from mid-February to early June 2014 with a total of 367 surveys being completed in this time. An extensive postal and media campaign accompanied Phase I. An initial report on Phase I of the *Let's Talk About* survey was published.[10]

Data collection in Phase II ran concurrently from June 2014 to the beginning of June 2015 with a total of 161 surveys giving a total of 528 from the two phases. Targeted awareness campaigns with Radio adverts were also run to promote engagement during the second phase.

1.1.3 Results Interpretation

Following the collation of the initial results from Phase I of the survey, a Results Interpretation Workshop was held in June 2014 with a mix of Voices4Care members and the professionals from the original groups of participants. Workshop participants assisted with the interpretation of the results and identification of the main themes. As initial results from Phase II indicated only minor statistical differences, a further interpretation exercise was not considered necessary. Both datasets were then merged for analysis.

7 Voices4Care is an AIIHPC initiative involving people receiving palliative care (service users), carers and the wider community in the work of the Institute. The perspectives of Voices4Care members inform and influence AIIHPC's work in palliative care education, research, policy and practice, in a collaborative and supportive manner. http://aiihpc.org/policy-practice/voices4care/

8 NICE, *End of life care for adults: Quality standard* (London: NICE, 2011); Palliative Care Australia, *Standards for Providing Palliative Care for All Australians;* (Canberra, Palliative Care Australia, 2005)

9 AIIHPC. *My Story, My experience* (Dublin: AIIHPC, 2014), accessed 30 November 2015: http://aiihpc.org/wp-content/uploads/2015/03/Final_Pilot_Report.pdf

10 AIIHPC, *Let's Talk About: Phase I.* (Dublin: AIIHPC, 2015). Accessed 30 November 2015: http://aiihpc.org/wp-content/uploads/2015/02/Lets-Talk-About-Final-Report.pdf

2. Profile of Respondents

During the two phases of data collection, a total of 528 people completed the *Let's Talk About* survey. Of these, 419 surveys came from the Republic of Ireland, and 109 surveys came from Northern Ireland. Surveys were completed from all 26 counties in the Republic of Ireland and six counties in Northern Ireland. Table 1 reflects the percentage distribution of surveys between the two jurisdictions as compared with the populations.

Table 1

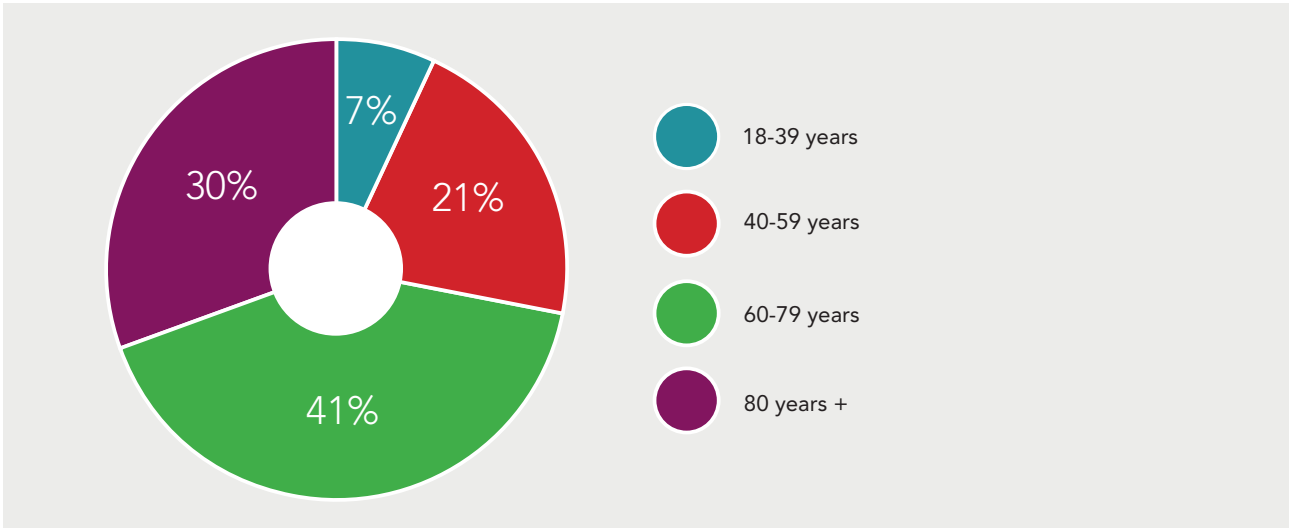
	Phase 1	Phase II	Total	Population (2011)[11]
Republic of Ireland	281 (77%)	138 (86%)	419 (79%)	4.6m (72%)
Northern Ireland	86 (23%)	23 (14%)	109 (21%)	1.8m (28%)
	367	161	528	6.4m (100%)

Respondents were asked to complete the survey from the perspective of the individual living with a long-term progressive condition. Table 2 below shows the breakdown of how respondents described themselves.

Table 2

62 (12%)	Someone living with a long term progressive condition
161(31%)	Caring for someone with a long term progressive condition
303 (57%)	Caring for someone with a long term progressive condition who had died in the last 2 years

2.1.2 Age



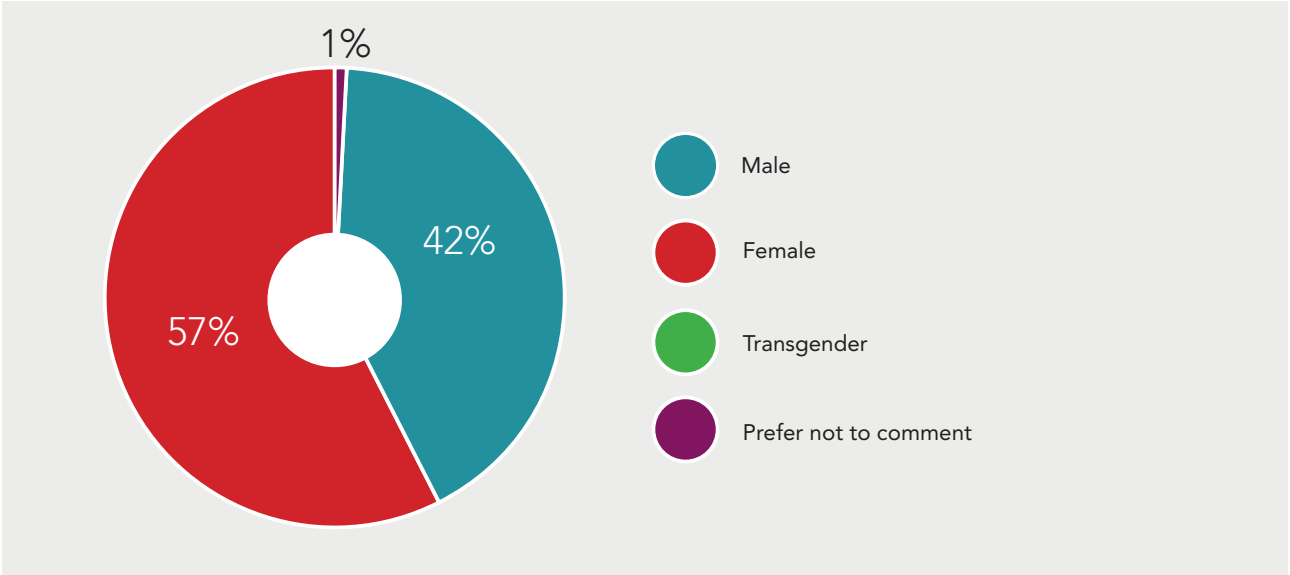
The experiences reported were represented by those from across the adult age range from 18 to over 90 years. The majority were in the 60-79 years age range.

Please note, percentages are rounded to the nearest whole number which means totals will not always reflect exactly 100% in the charts.

11 CSO/NISRA, *Census 2011: Ireland and Northern Ireland* (Dublin, Government of Ireland, 2014).

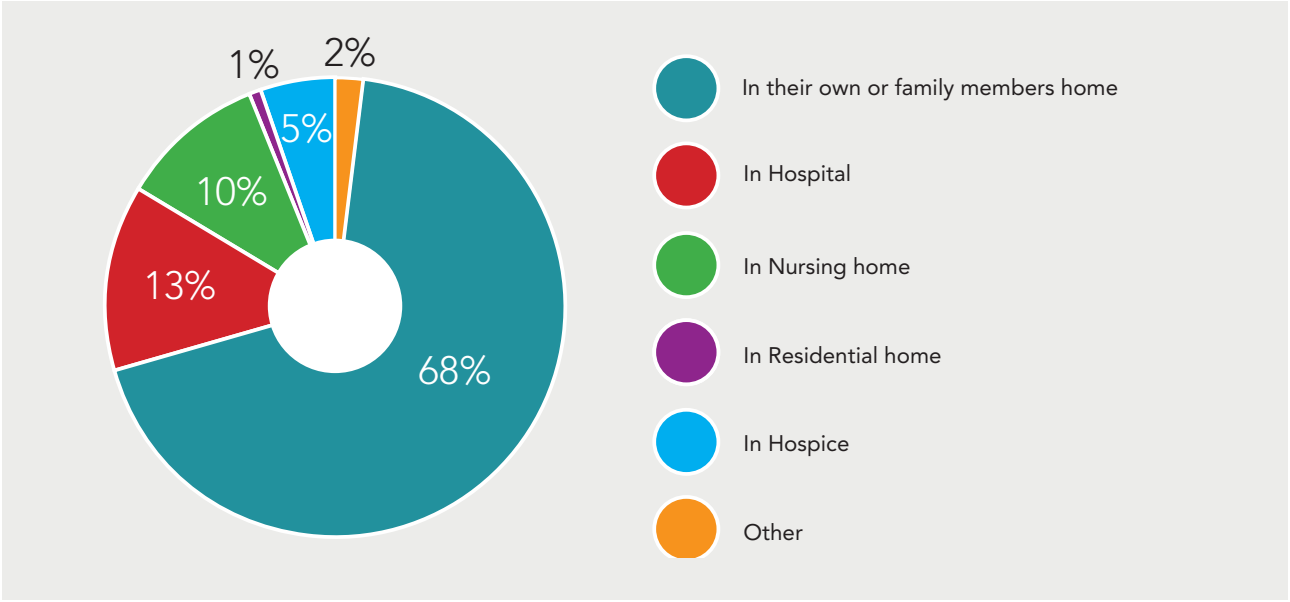
2.1.3 Gender

The majority of the experiences recorded were about females.



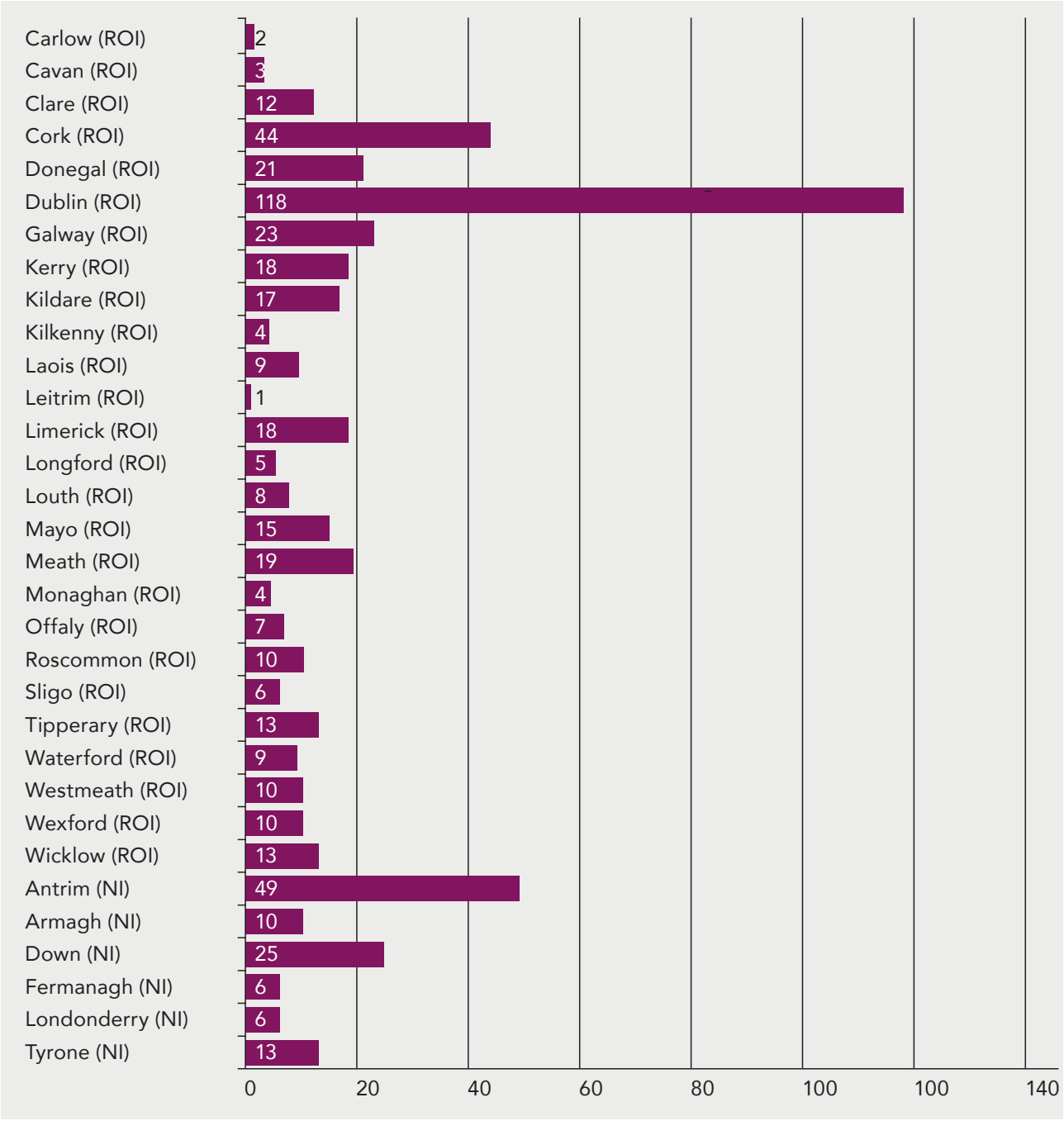
2.1.4 Setting of care

Respondents were asked to identify where the person was living at the time of the experience.



The majority of respondents (68%) identified that they had the experience while living in their home setting. Although it is not clear that this is where the experience happened.

2.1.5 Location*

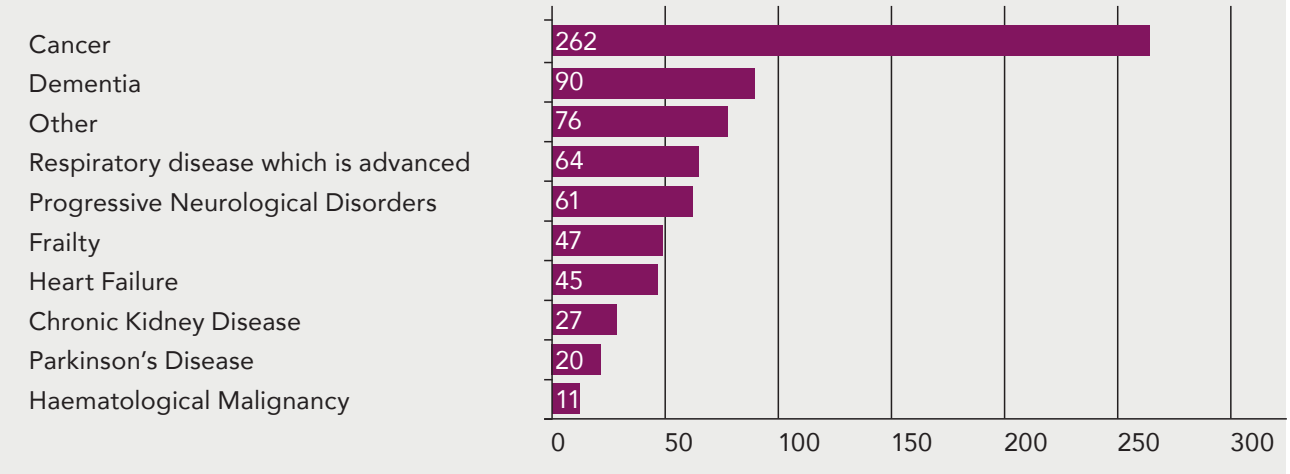


Out of a total of 528 responses, 419 were from the Republic of Ireland and 109 were from Northern Ireland. There were responses from all counties. 14% (74) of the surveys completed were from County Antrim and County Down (i.e. the greater Belfast area) and 22% (118) of responses were from Dublin.

*** Respondents were asked to note the county of residence of the person whose experience was shared – this does not necessarily relate to the county in which they had the experience.**

2.1.6 Illness or Condition

Respondents were asked to identify the primary long-term condition(s) of the individuals who had the experience. In view of the fact that some individuals may have had more than one condition, respondents were asked to tick all that applied.

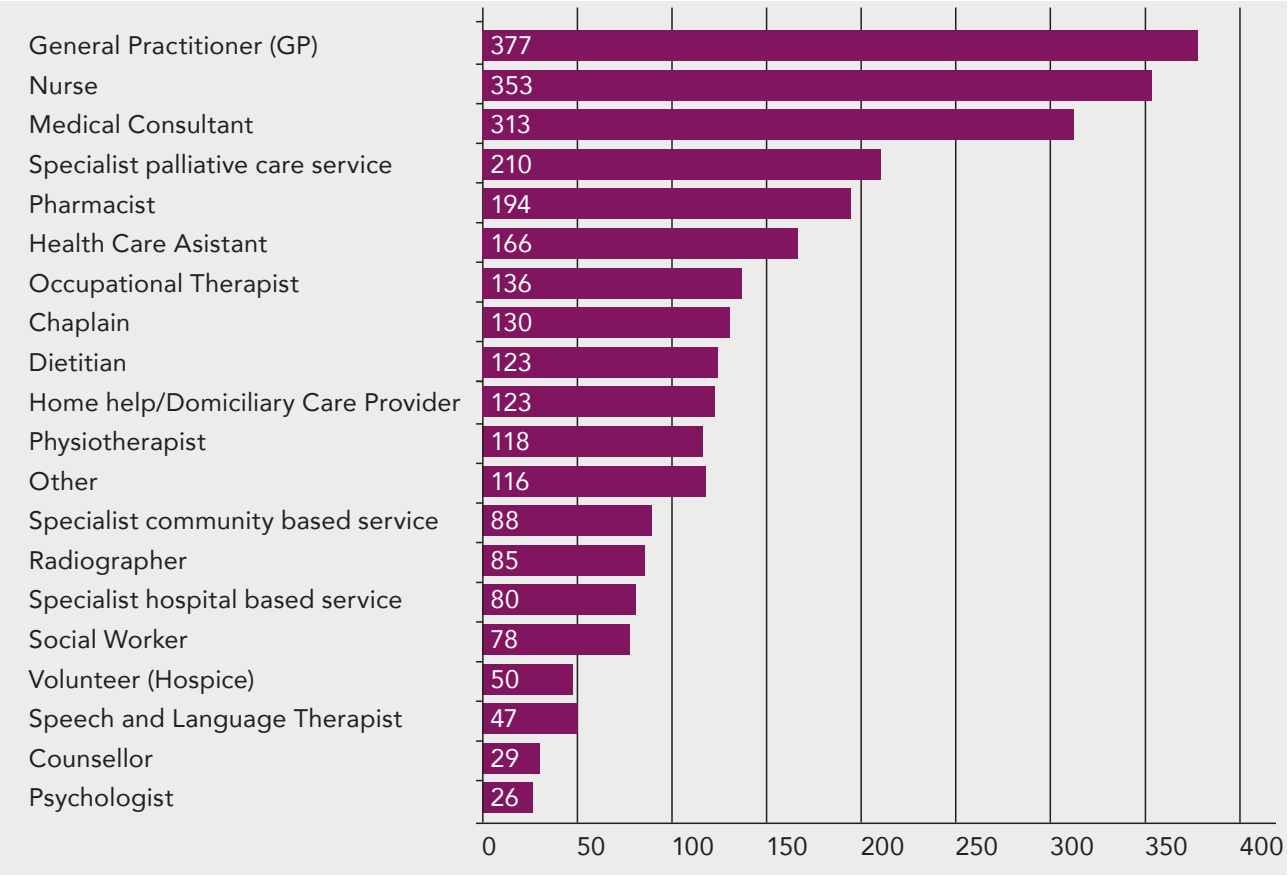


Cancer was the most frequently experienced condition equating to almost half of all conditions identified. Neurological disorders including Dementia and Parkinson's disease were the next biggest grouping.

Taken collectively, it has been possible to identify two discreet groupings, people who had cancer and people who did not, which provided the opportunity for further analysis (See section 4).

2.1.7 Care Providers

The table below shows the range of care providers who were identified as being involved. Again, individuals may have had more than one care provider involved and could tick all that applied.



This shows that GPs, Medical Consultants and Nurses were the care providers that respondents had most contact with. They had the least contacts with Psychologists and Counsellors.

3. Main Analysis

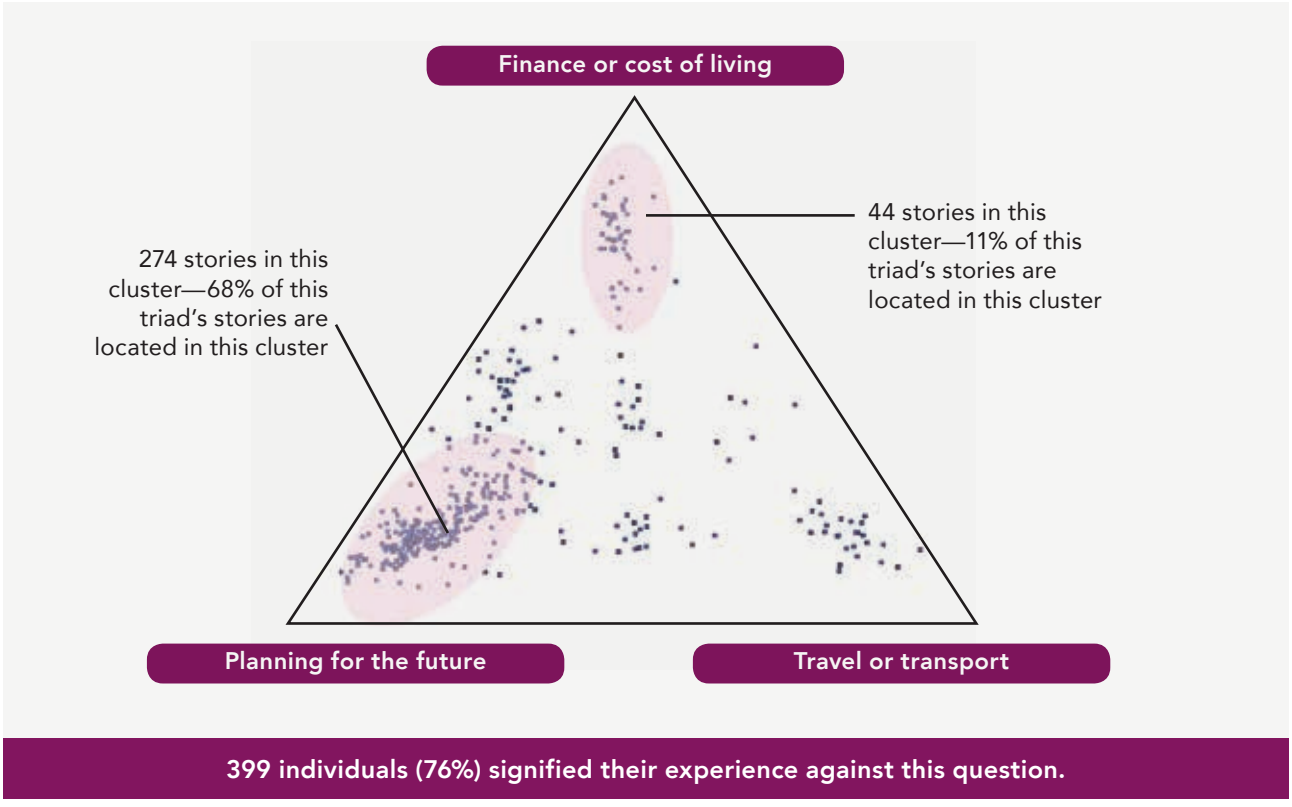
This section will present the results from the eight triangle questions showing how the 528 respondents signified their experiences. Results are provided for each of the eight questions and their signifiers followed by a broad interpretation highlighting key themes. Stories submitted by the respondents follow by way of illustration.

3.1 Triangle Question Analysis

Respondents made their choice based on a combination of the three factors provided, or if none of the factors appeared relevant, the respondents could select 'not applicable'. The results for each question are presented in the form of a triangle 'heat map' consisting of patterns and clusters of dots. Each dot in the triangle represents a story and the location correlates to where the person who provided that story chose to place it. The pattern of responses forms a heat map where the clusters of dots were plotted. For the purpose of this report, the overall 'heat map' is presented.

It should be noted that the percentage results represent the cluster responses at each of the corners of the triangle only and do not account for the responses distributed throughout the triangle.

Question 1: In this experience, what was the biggest practical worry?



399 individuals (76%) signified their experience against this question.

Analysis and Commentary

In the first question, respondents were asked to signify between *Finance or cost of living, Planning for the future* and *Travel or transport* as their biggest practical worry in the experience. This question had the lowest response rate overall with only 76% (399) of respondents choosing to signify their experience against this question.

Overall most people tagged somewhere between Planning for the future and Finance or cost of living with 68% of respondents choosing Planning for the future. 11% of respondents signified Finance or cost of living as their biggest practical worry.

Planning for the future is an umbrella term which covers many issues, one aspect of which concerns planning for end of life. The significance of issues related to *Planning for the future* resonated strongly with participants in the Interpretation Workshop similar to findings in recent studies. One such study, conducted in the Republic of Ireland, found that between 2004 and 2014 people are increasingly seriously considering or actively planning for end-of-life. However most people did not have arrangements in place and those that did were least likely to have included advance care directives or sharing information with regard to their preferred place of death.[12]

The findings appear to signify the need to 'normalise' the task of planning ahead linked to the more general need to promote public awareness and understanding of issues related to palliative care.[13] Given that GPs, medical consultants and nurses are the most likely professionals that patients encounter, it is important that these groups of professionals recognise when someone needs a palliative approach to care that embraces *Planning for the future*. Ongoing initiatives which promote advance care planning like the Your Life and Your Choices: Plan Ahead[14] in Northern Ireland and the Think Ahead[15] project in the Republic of Ireland need further dissemination and ongoing support in this regard.

12 Weafer, John. *Irish attitudes to death, dying and bereavement 2004-2014* (Dublin: Irish Hospice Foundation, 2014) p. 31-33.

13 McIlfatrick, Sonja, et al., "Public awareness and attitudes toward palliative care in Northern Ireland" BMC palliative care 12, no. 1 (2013)p.34; McCarthy, Joan et. al, "Irish views on death and dying: a national survey" *Journal of Medical Ethics* 36, no. 8 (2010): 454-458.

14 MacMillan Cancer Support Your Life and Your Choices: Plan Ahead in Northern Ireland

15 Irish Hospice Foundation's Think Ahead project (www.thinkahead.ie)

Exemplars of stories from each corner are presented below.

Finance or cost of living

"Has been a serious financial impact as they had to give up work, had to move house as not able to afford house we lived in."

TITLE: DESPERATE, LONELY
CONTRIBUTED BY: CURRENT CARER

Travel or transport

"I am suffering from Non-Hodgkin's Lymphoma. I also have asthma. I am some distance from the nearest hospital and it was a weekend. No GP available. Fortunately I was just about able to make it to [local town] in the morning to see the doctor on call. I drove myself. I was very short of breath. I am 79 years old."

TITLE: BRONCHOSPASM/ASTHMA ATTACK
CONTRIBUTED BY: PERSON LIVING WITH CONDITION

Planning for the future

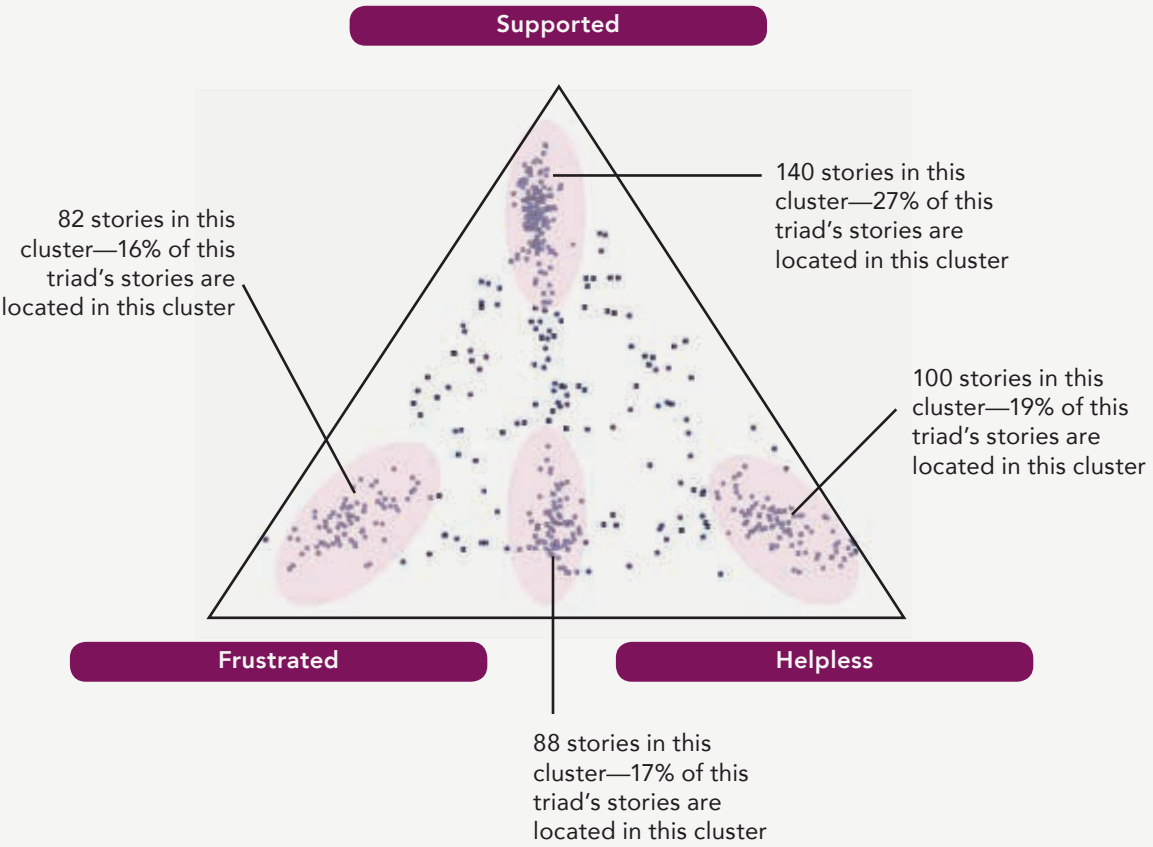
"I cared for my Mum who got a late diagnoses for Vascular dementia, her affairs were not in order and because of the diagnosis she was deemed unfit to make decisions, her wishes or requests were completely ignored."

TITLE: ALONE AND IGNORED
CONTRIBUTED BY: FORMER CARER

"I am a nurse in a residential care home .... Within the last 16 months an 87 year old resident with late stage dementia was given a peg tube … It had become very apparent to staff that Mrs S wanted to die and had endured enough but sadly her family insisted that Mrs S be transferred to hospital in which they insisted a peg-feed was inserted. Sadly again poor Mrs S had no say in this and with no pre-planned future healthcare in place, it was left to her family to decide."

TITLE: WHY CAN'T I HAVE A VOICE
CONTRIBUTED BY: CURRENT CARER

Question 2: What describes how you or the person felt by the care provided in this experience?



518 individuals (98%) signified their experience against this question.

Analysis and Commentary

When respondents were asked to describe how they felt about the care provided in their experience, 27% of people signified that they felt *Supported* by the care that was being provided while 52% indicated that they felt *Frustrated* or *Helpless* or a combination of both. This question had the highest response rate possibly indicating the immediate relevancy and or significance of the question to respondents.

These findings suggest that more than one in two people that professionals meet in their care providing role could be assumed to be coping with feelings of frustration and/or helplessness. A recent study by Brick et. al. also found that there is a need to focus on communication and support to reduce anxiety and worry experienced by families during the last week of their relative's life.[16] The challenge is for professionals to respond in a way that alleviates the negative feelings and builds up a sense of support.

The factors that help people feel supported based on the stories in the top corner included: being listened to, being given time, being informed, being included, access to appropriate home supports and being shown compassion to improve quality of life and ensure a good death. A significant correlation to emerge from statistical interpretation of the data is how clear and sensitive communication increases feelings of being supported. This question provided particular relevance in identifying both positive and negative correlations in the data (See Section 3.2).

16 Brick, Aoife, et al., *Economic Evaluation of Palliative Care in Ireland* (2015) Report prepared for The Atlantic Philanthropies. http://www.medicine. tcd.ie/health_policy_management/assets/pdf/Final-report-July-2015.pdf. p.xvi

Exemplars of stories from each corner are presented below.

Supported

"My wife had been diagnosed with terminal cancer in late 2012. She managed very well until last summer when pain began to become something of a problem. Palliative care team in hospital responded during a brief stay for a scan and got her on to a successful pain-control regime. They had also contacted a local care team in … [local area] who made immediate contact when she returned home. This team also put in place a daily care visit and also made contact with …[name of local Hospice]."

TITLE: EXCELLENT
CONTRIBUTED BY: FORMER CARER

Helpless

"…Looking back, I can see that we were all so worried and preoccupied with Mum that we just accepted everything as it was. I don't think I had the strength to challenge what seemed to me like the 'experts' or dig deeper to find out what help we were entitled to or could ask for. It felt like "this is how it is"… after the diagnosis and short discussion about palliative care, the hospital had washed their hands off us (all). I had no one (from the medical profession) to ring to ask for help…."

TITLE: I NEEDED HELP/ADVICE 24/7 – MY MUMS ILLNESS WAS NOT 9-5
CONTRIBUTED BY: FORMER CARER

Frustrated

"While there were individual examples of kindness and competence there were serious shortcomings in terms of communication across services, which commenced at diagnostic stage leading to a significant delay in correct diagnosis leading to poor outcome of immediate surgery and chemotherapy.

The GP was probably the weakest link in the chain rather than the leader in the community and did not advocate for support in her home, which left friends/relatives under huge stress much as they were willing to do everything they could. The practice of a hospital prescription having to be brought to the GP to be transcribed was a major stressor when person had no transport. It also involved a delay as person was never seen on time in the doctor's surgery and she usually had to prompt the GP what had happened, as notes had not been consulted. Frequently the chemist did not have the drugs and this involved further stress as person had to organise a further visit.

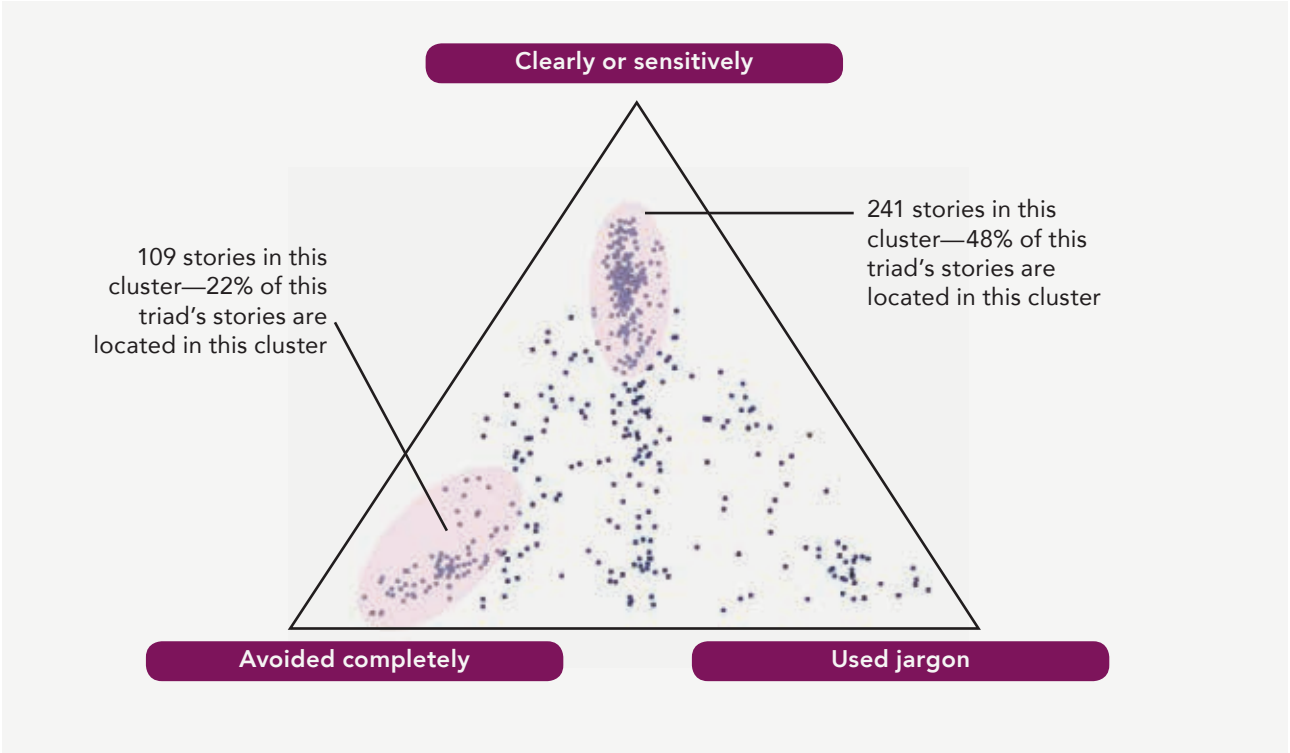
With the allied health professionals the practice of cancelling/changing appointments at the last minute was very distressing to the patient as that was the focal point of a day and they would be psyched up to ask questions. The meaning of this for the person was huge and it consolidated a view that she was not important or respected. There were a lot of promises and assurances without action.

Waiting times in hospital clinics became an ordeal with 3 hours being an average time waiting to see the doctor. The single biggest and simple remedy here would be if files were maintained in order of check in- they were placed on a ledge and they often fell and when they were picked up they were in a different order…

The scheduling of appointments was not user friendly with x rays, scans, blood tests, clinic visits & physiotherapy appointments usually all on separate days which meant a huge stress on carers and client …."

TITLE: PATIENT CARE/GOVERNANCE
CONTRIBUTED BY: CURRENT CARER

Question 3: In this experience, how were any issues talked about by those who provided the care?



499 individuals (95%) signified their experience against this question.

Analysis and Commentary

When asked about how issues were talked about by those who provided the care, almost half (48%) of respondents felt they were communicated with *Clearly or sensitively*. More than one in five (22%) of respondents felt issues were *Avoided completely*. When looking at the correlations in the data, good communication is seen to increase the feeling of being supported when issues are not avoided and are discussed in a clear and sensitive manner. A substantial percentage of the experiences were signified as *Avoided completely* or *Used jargon* indicating that there is still more focus on communication required.

In a recent survey on health literacy in the Republic of Ireland, foremost among the headline findings was that 39% of patients called on healthcare professionals to use less medical jargon and to communicate more clearly.[17] Similarly, a recent UK study was highlighted in the media and referenced low levels of health literacy. The article urged medics to avoid the use of words such as 'chronic', 'palliative' and 'hospice', and warns that describing a diagnosis of cancer as 'positive' can be misinterpreted as good news. The article went on to explain that: "Doctors, having spent many years immersed in the biology of human health and disease, may overestimate the health literacy of their patients".[18]

Participants in the Interpretation Workshop also highlighted that a technical word can sound like jargon the first time it is used and perhaps part of educating care professionals on how to communicate with patients is to develop skills which enable them to provide lay interpretation of technical terms. This was echoed in a recent review of bereaved carers in the UK which found that professionals still employed language which was incomprehensible, lacked the skills to deliver bad news and were often viewed as being too busy to be available to talk.[19]

17 https://www.nala.ie/news/irish-people-calling-healthcare-professionals-use-less-medical-jargon

18 Campbell, Denis, "Doctors told to dispense with confusing medical jargon" *The Guardian*, 18 June, 2014. Accessed 30 November 2015. http://www.theguardian.com/society/2014/jun/18/doctors-dispense-with-medical-jargon-patients; Royal College of General practitioners, "Health Literacy Report from an RCGP-led health literacy workshop.". Accessed 30 November: http://www. rcgp. org. uk/clinical-and-research/clinical-resources/~/media/Files/CIRC/Health% 20Literacy% 20Report/Health% 20Literacy% 20Final% 2029, no. 20 (2014): 07.

19 Royal College of Physicians, *National care of the dying audit for hospitals* (London: RCPI, 2014).

Exemplars of stories from each corner are presented below.

Used jargon

"After weeks of wishing we finally had a meeting with the consultant in charge of my father's care. He knew nothing about our father except the diagnosis, which was not shared with us. He used jargon and obfuscation and avoided direct answers. He used inappropriate humour and was neither caring or compassionate. Except that one of our family is a doctor and could read between the lines it was utterly frustrating and upsetting."

TITLE: DREADFUL
CONTRIBUTED BY: FORMER CARER

Avoided completely

"I care for an aunt (age 83) who is at the palliative stage of her cancer illness. The scenario is very challenging for her, mostly in relation to understanding exactly her situation, terminology, future expected lifetime, meaning of different type of services and reluctance of professionals to be open and frank in relation to her condition.

In the absence of forthright information I have had to spend much time informing her in a non-clinical way on her present circumstances and de-briefing her after clinical appointments that I attend with her. She is currently in denial of the extent of her illness and believes that the clinician's read from a different person's scan etc..."

TITLE: LIVING WITH THE DYING?
CONTRIBUTED BY: CARER

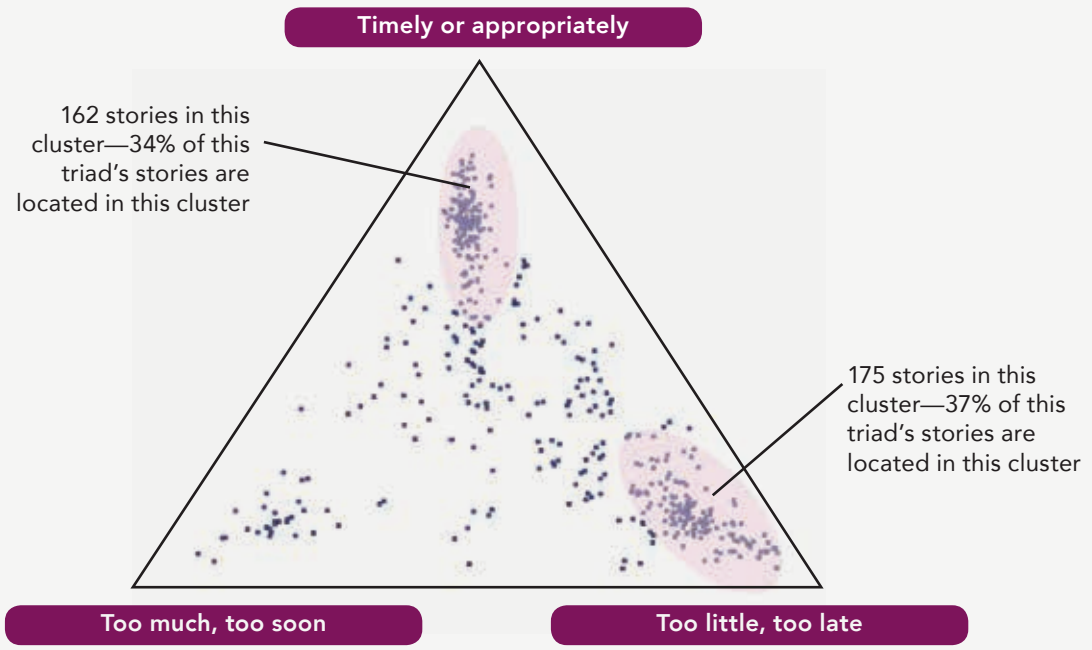
Clearly and sensitively

"With the exception of Palliative Care, who involved the family every step of the way they showed the ultimate respect for mum always speaking with her and not at or about her, affording her the opportunity to have a greater understanding of her condition. Giving us as a family confidence in the level of care mum was receiving. Affording her a quality of life to enjoy the time she had left with her family in particular her grandchildren who she loved dearly.

When it came to the time of Mum's passing it was peaceful and dignified thanks to the unwavering commitment and dedication of the palliative care team."

TITLE: IN SUPPORT OF PALLIATIVE CARE
CONTRIBUTED BY: FORMER CARER

Question 4: In this experience, how timely was the information that was given?



476 individuals (90%) signified their experience against this question.

Analysis and Commentary

When respondents were asked how timely the information was received in the experience, it was encouraging that approximately one third (34%) of respondents experienced information being communicated *Timely or appropriately*, however 37% overall felt they received information *Too Little, too late*.

Timely communication is important for a number of reasons. Early referral to palliative care services has been found to be beneficial in ensuring better quality of life outcomes, increasing survival time,[20] as well as resulting in significantly lower treatment costs.[21]

Participants in the Interpretation Workshop also highlighted the importance of recognising from the stories that individuals also have different needs for information. It is very important for professionals to check out at the start what the person wants to know, how much information is to be shared, at what stage and with whom.

Some people actively choose not to be told certain information. How information is best provided, to whom and when are critical issues to agree between care providers and individuals at the outset. The stories also point to the need for individuals to have a key contact person to whom they can ask questions that may come up after the formal meeting when they have had time to reflect on what they have been told.

20 Temel, Jennifer S., et. al., "Early palliative care for patients with metastatic non–small-cell lung cancer." *New England Journal of Medicine* 363, no. 8 (2010): 733-742.

21 Brick, Aoife, et al., *Economic Evaluation of Palliative Care in Ireland* (2015) Report prepared for The Atlantic Philanthropies. http://www.medicine. tcd.ie/health_policy_management/assets/pdf/Final-report-July-2015.pdf. p.xvi

Exemplars of stories from each corner are presented below.

Timely or appropriately

"I am a community outreach coordinator. I have been dealing with a young man suffering with a rare degenerative disorder. Two other brothers are also sufferers but in the early stages. As there is very little known about the disorder he was referred to the palliative care unit to get information. I found the team caring, patient and had a lovely way of giving such sad news to a family. He attended OT and Physio also within the unit. Although discharged he still attends on a maintenance programme of complimentary therapies. He loves this and it gives his family a break."

TITLE: EXCELLENT
CONTRIBUTED BY: CARER

Too much, too soon

"I asked my doctor what was my prognosis. He told me that the average age of survival with my type of cancer was 6 to 12 months. I was 40 with two young children. I know he answered my question but he gave me no hope. Two and a half years later I am still here."

TITLE: HOPELESS
CONTRIBUTED BY: PERSON LIVING WITH CONDITION

"When my relative collapsed initially, the hospital consultant informed me the following morning to hope that the results of his cat scan showed a tumour not a stroke. I did not understand at the time, that he was obviously looking at the long term affect as my relative was in his early forties. I found this statement to be both brutal and callous and have never forgotten it."

TITLE: CRUEL INDIFFERENCE BY A CONSULTANT
CONTRIBUTED BY: FORMER CARER

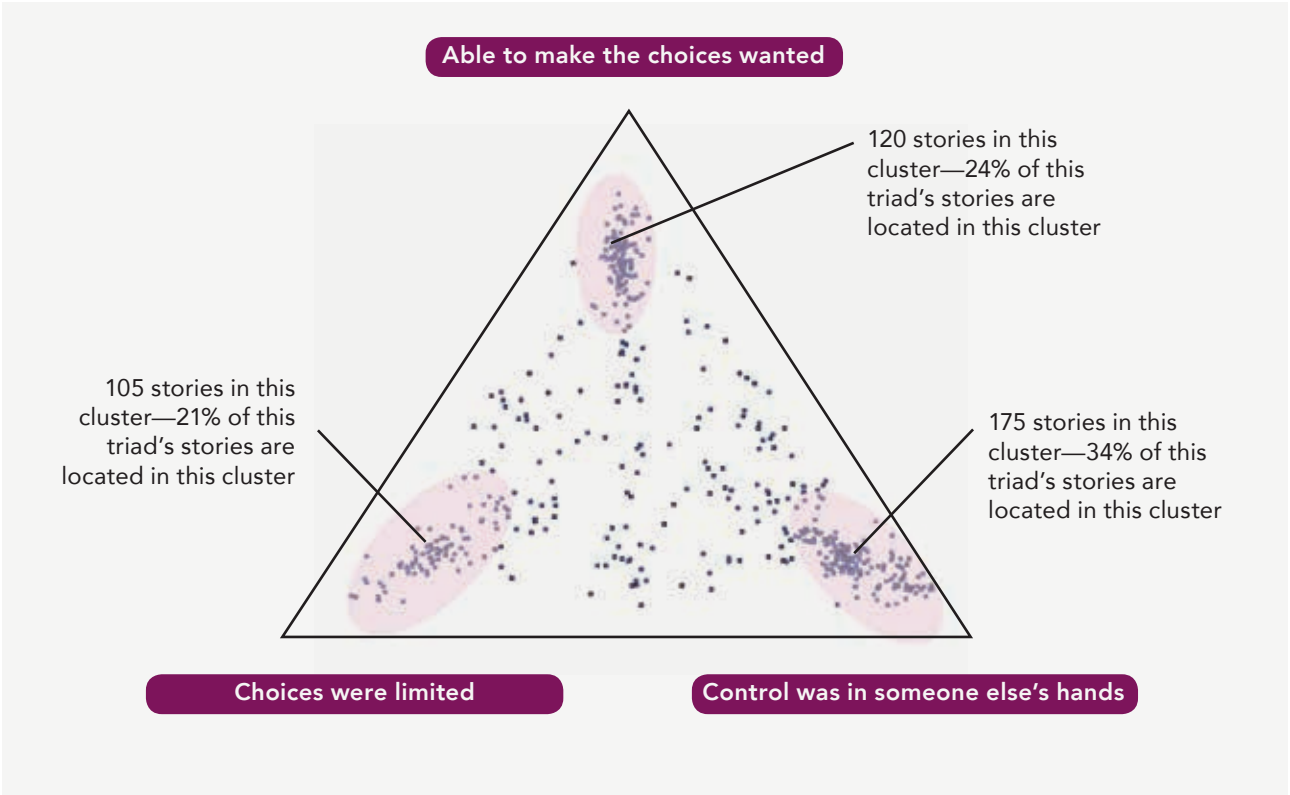
Too little, too late

"…Having seen mums anxiety levels rise and her suffer so unnecessarily and despite me informing the staff and being ignored. I demanded Palliative care be called as I knew they would understand and see mum would be put back on her proper medication. I was informed there was no palliative care in the hospital. Knowing this was a blatant lie as my sister in law had passed away in the same hospital under the care of Palliative Care.

I had no alternative but to call the palliative care team office and speak with one of the team that looked after mum, and ask them to intervene. It was only after this the hospital listened…."

TITLE: NIGHTMARE
CONTRIBUTED BY: FORMER CARER

Question 5: In this experience, how in control were you or the person?



510 individuals (97%) signified their experience against this question.

Analysis and Commentary

Nearly a quarter (24%) of respondents felt they were *Able to make the choices wanted*. Just over a third (34%) of respondents felt that *Control was in someone else's hands* whereas one in five (21%) felt that their *Choices were limited*. Comparative analysis between the experiences show where people felt *Control was in someone else's hands* they were more likely to have felt *Helpless* and *Frustrated*.

Participants in the Interpretation Workshop also highlighted that while disease conditions may dictate the level of control and choice an individual feels they have, it is also important for professionals to enable individuals to exercise as much choice and control as possible over the matters they still can influence, within the constraints of the system and their condition.

The analysis of the stories emphasises the importance of access to services and appropriate personal and care supports; access is instrumental in helping to preserve an individual's dignity and sense of autonomy for as long as possible.

Exemplars of stories from each corner are presented below.

Able to make decisions

"Helped care for my aunt last year who was diagnosed with an advanced type of lymphoma. She was initially cared for in an acute hospital, then went to live with her sister and was cared for by many family members. Due to assistance given by various nurses who contributed to her care it was possible to keep her at home to the very end. Their assistance was invaluable ensuring that she was kept comfortable and pain free and a great reassurance to her family members."

TITLE: HOME NURSING CARE
CONTRIBUTED BY: FORMER CARER

Control was in someone else's hands

"My partner had HIV since 1997 and died in 2013. In the last months he could not get access to a hospice, and it was on a day when the hospice worker came over after two months of trying to gain access for assessment, and said 'oh he must come over', and although my partner had at this stage lost his voice, the very last words I ever heard him say was "we won" - referring to being accepted in the hospice. He never actually got to the hospice because he died two days later."

TITLE: SOME DEATHS ARE LESS EQUAL THAN OTHERS
CONTRIBUTED BY: FORMER CARER

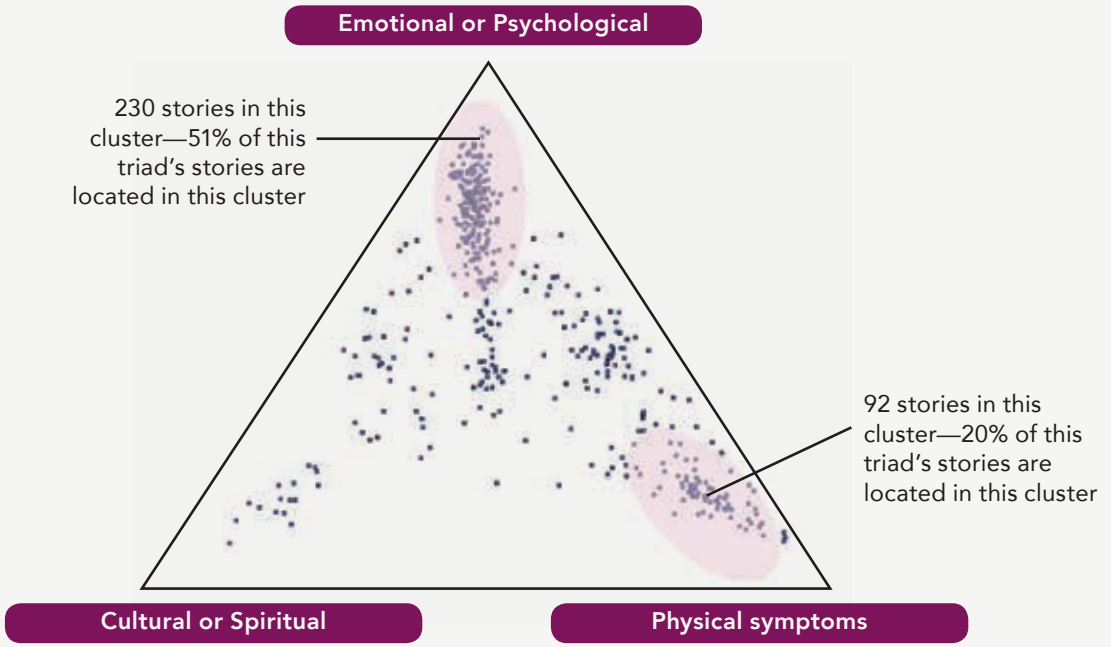
Choices were limited

"Constantly looking for support to care for a family member with Dementia, and been sent from service to service, each one passing you on. Finally being told that you can get 1 hour a week but not at weekends and the maximum being 15 hours over five days, if you are extremely lucky.

Having to work full time to cover a mortgage and cover nights with my parent, suffering from Dementia. Paying privately for nursing support and then after years having to put an otherwise healthy parent into a nursing home[…]"

TITLE: FRUSTRATING
CONTRIBUTED BY: CURRENT CARER

Question 6: Which needs were least well met in this experience?



453 individuals (86%) signified their experience against this question.

Analysis and Commentary

In response to this question, just over half (51%) of respondents felt that their *Emotional or Psychological* needs were least well met in the experience. Notably psychologists and counsellors were the lowest number of professionals identified as being involved in the care of those reporting their experience. To ensure a holistic palliative approach to care is realised, assessments of psychological and emotional needs and appropriate referrals should be made where required.

For one in five of all respondents, the least well met need was *Physical symptoms.* In a recent study conducted in the Republic of Ireland, symptom management ranked second after being surrounded by loved ones, on the list of priorities for individuals following diagnosis of a life-limiting condition.[22]

A study conducted in the UK found that the most important concern for individuals at the end of their lives is to have control over pain.[23]
Another similar study has also found that: "pain management and symptom control were the aspects of their overall wellbeing that mattered to them most. Respondents also valued holistic support, emotional support and spiritual care".[24]

Participants in the Interpretation Workshop similarly identified that all three sets of needs are interconnected. Yet research indicates that unless there is access to symptom management, ease of access to care and no undue pressure on family and friends only then does any other issue become important.[25]

22 Weafer, John. Irish attitudes to death, dying and bereavement 2004-2014 (Dublin: Irish Hospice Foundation, 2014) p.8

23 "Marie Curie survey highlights top concerns of public when it comes to caring for a terminally ill loved one." Marie Curie. Last modified 2 February, 2015. http://www2.mariecurie.org.uk/ImageVaultFiles/id_2122/cf_100/Marie_Curie_survey_highlights_top_concerns_of_publ.PDF; The Choice in End of Life Care Programme Board, *What the evidence tells us? A Review of Choice in End of Life Care* (London: Department of Health 2015), p.15

24 The Choice in End of Life Care Programme Board, *What the evidence tells us? A Review of Choice in End of Life Care* (London: Department of Health 2015), p.22

25 Irish Hospice Foundation *A nationwide survey of public attitudes and experiences regarding death and dying.*" (Dublin: Irish Hospice Foundation, 2004).

Exemplars of stories from each corner are presented below.

Emotional or Psychological

"[…]…In brief I have little positive to say about the behaviour of the primary medical care he received. Not in medical terms - they always did the best they could in the circumstances - but I have very negative feelings about the way they behaved and communicated to him and his family…[…]"

TITLE: MEDICAL CARE OF AN ADVANCED RCC PATIENT
CONTRIBUTED BY: FORMER CARER

"The experience of going through Chemo (when really there was no hope) and then after a few months being told it was palliative care from here on. Such a feeling of hopelessness and distress and nobody in the professional field being available to you."

TITLE: ALMOST DESPAIR
CONTRIBUTED BY: FORMER CARER

Cultural or Spiritual

"She has Dementia. It is hard to walk now. In the past she was a wonderful dancer. She doesn't know anyone anymore. She makes little contact with you. She has a big family who she doesn't know. But put on music and she will dance very well and have all the right steps. Smiling and laughing and having fun. So good for her and so for the family."

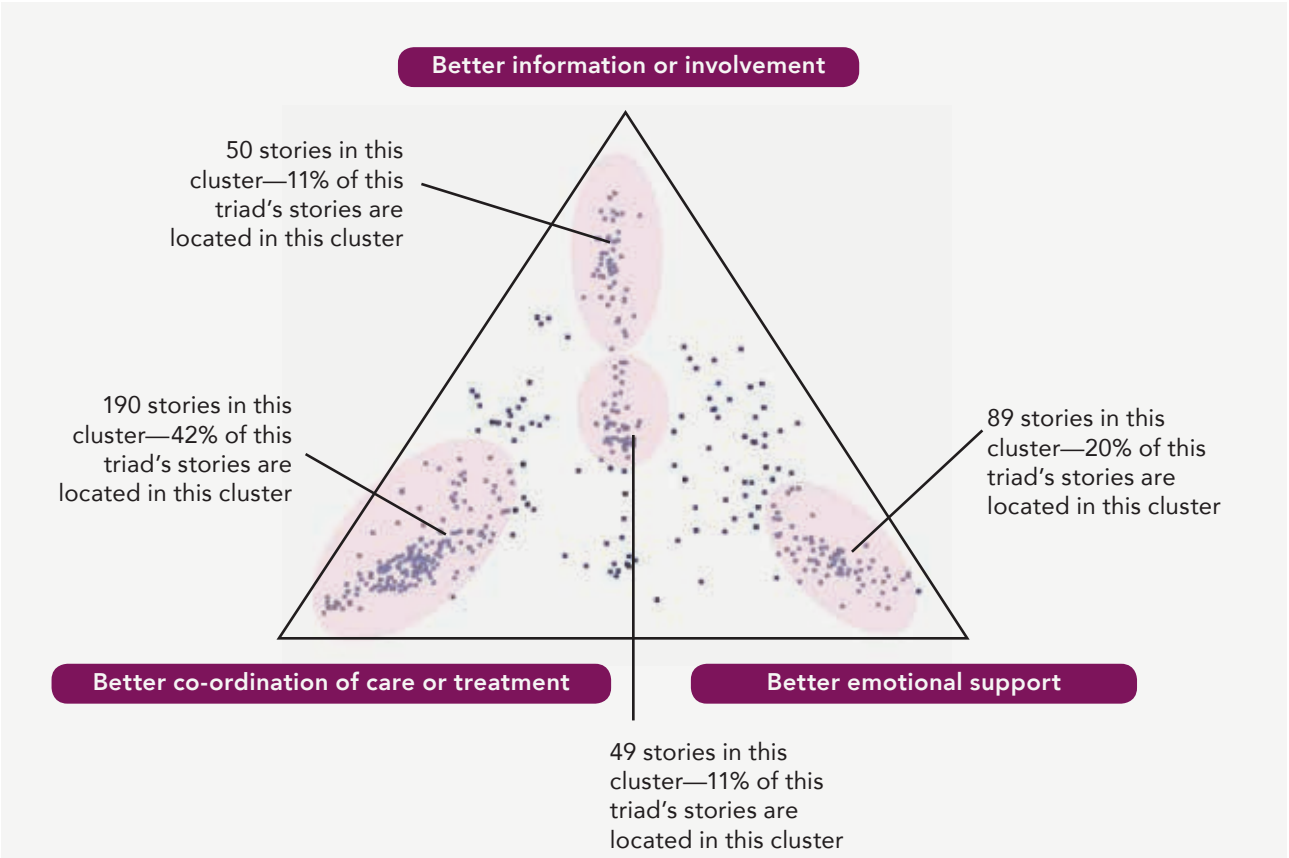
TITLE: THE ONLY THING I REMEMBER IS HOW TO DANCE
CONTRIBUTED BY: CARER

Physical symptoms

"My sister died from a terminal cancer related illness. She was a young sixty three year old. She spent her final two weeks of her life in a hospice hoping that she would meet her end in comfort without pain. She was willing to sleep away as she said herself. Her pain increased on the Friday morning and eventually a second pump was erected. The night nurse at the hospice had exhausted all the pain relief prescribed for her and rang the hospital for further guidance. There was nowhere to avail of the pain relief prescribed. The DOC refused to call out to the hospice with this pain relief medicine. My sister groaned out all night until morning when she breathed her last. This memory for my family was horrendous. She was cachexic and possibly couldn't absorb her medication."

TITLE: DISAPPOINTING
CONTRIBUTED BY: FORMER CARER

Question 7: What would you have liked more of in this experience?



449 individuals (85%) signified their experience against this question.

Analysis and Commentary

In this question respondents indicate they would have preferred *Better co-ordination of care or treatment* (42%). This is important given the range of care professionals that respondents reported encountering in the course of their care.

For 20% of the respondents they signified that *Better emotional support* could have been provided with an additional 11% preferring combination of *Better co-ordination of care or treatment, Better emotional support,* and *Better information or involvement.* Through further analysis of the data, a relationship emerged between wanting *Better emotional support* in this question and *Physical symptoms* being least well met in question 6.

Physical symptoms being least well met also correlated positively with needing *Better co-ordination of care and treatment.* Effective coordination of care should facilitate both access to services and ensure support is delivered by a primary healthcare or a specialist team. Epiphaniou, Eleni, et al. in a study of patients' experiences on end of life care coordination in the UK found the remarkably positive role care coordinators can play in patients with a serious illness. Interestingly, in this study, experiences of patients with COPD in the UK compared less favourably to those with lung cancer who often had more routine access to a care coordinator.[26] The need for better co-ordination of care within the system must continue to be a priority for palliative care policy and to ensure effective service delivery.

26 Epiphaniou, Eleni, et al., "Coordination of end-of-life care for patients with lung cancer and those with advanced COPD: are there transferable lessons? A longitudinal qualitative study." Primary Care Respiratory Journal 23, no. 1 (2014): 46-51.

Exemplars of stories from each corner are presented below

Better information or involvement

"I am three years caring for my Mum who has Dementia and last year I was at a talk given by a nurse about end of life care and the penny dropped that I am doing exactly that for Mum. I would have associated end of life care and palliative care with Cancer. It was my Eureka moment. Since that day everything has become so much easier now we are both preparing for Mum's end of life but we are happy and content doing the best and giving Mum the best possible life quality."

TITLE: UNDERSTANDING LIFE CYCLE
CONTRIBUTED BY: CURRENT CARER

Better emotional support

"The fear engendered by receiving a terminal diagnosis is one thing however it is quite another when one does not understand what is being said and what it means. I feel that the shock and trauma suffered by the individual and the family results in an inability to comprehend what is being said. I feel that this initial stage and how it is dealt with lays the foundation for either a positive or negative attitude towards dealing with the diagnosis for both the individual and the family.

All I remember after the initial news was complete terror and I know that was my mother's first and foremost feeling and this never left her. She continued petrified and terrified throughout the experience and I don't believe it has to be like this."

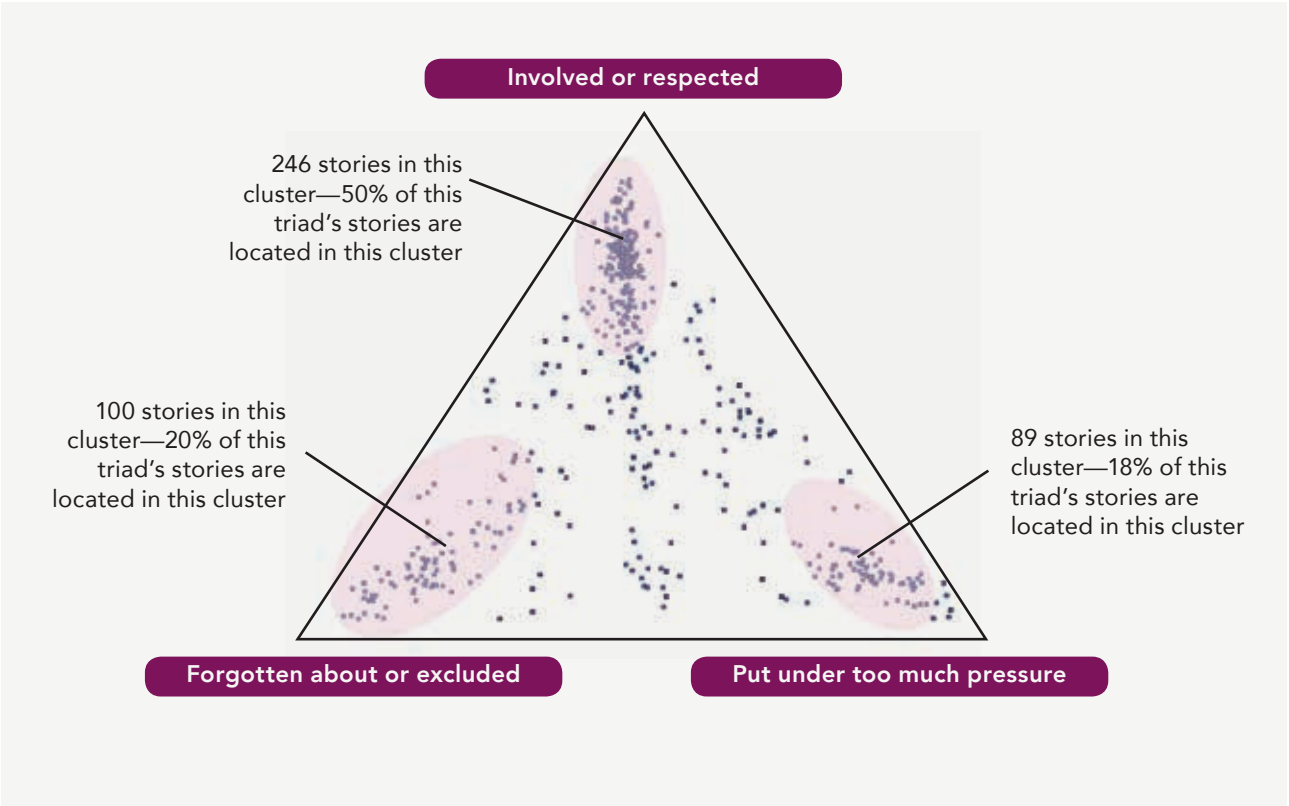
TITLE: IT COULD HAVE BEEN SO DIFFERENT
CONTRIBUTED BY: FORMER CARER

Better co-ordination of care or treatment

"Before transferring to an adult hospice, my wife received palliative care at home via community care workers. Although the individual nurses were very helpful, both myself and my wife found the range of service providers rather confusing and uncoordinated. It was also difficult to have issues dealt with quickly. When a new medicine was needed, we had to wait until we could contact the GP to get a prescription, then check around the pharmacies to see who had the medicine and then go and collect it. This problem was exacerbated if help was needed at night time. My wife found the delays very distressing at times."

TITLE: UNCOORDINATED AND DISTRESSING
CONTRIBUTED BY: FORMER CARER

Question 8: How were the family or close friends treated in this experience?



492 individuals (93%) signified their experience against this question.

Analysis and Commentary

In this triad which sought to find out how family or close friends were treated in the experience, the most significant cluster was that 50% of respondents felt that family and friends were *Involved or respected.*

This is a positive indication but more is evidently required given that being surrounded by your loved ones[27] and ensuring they would be under no undue pressure have been identified in recent studies as top priorities if someone was to receive a diagnosis of a life-limiting condition.[28, 29]

Timely ease of access to appropriate services and improved communications are required to ensure family and close friends feel more *Involved or respected* and to counter the 20% who felt *Forgotten about or excluded* or the 18% who signified that they were *Put under too much pressure* in the experience. Certainly this has been the focus of initiatives designed to improve and promote effective communication from health and social care professionals.

27 Weafer, John. *Irish attitudes to death, dying and bereavement 2004-2014* (Dublin: Irish Hospice Foundation, 2014) p.30)

28 Wood, Claudia and Jo. Salter. *A time and a place: what people want at the end of life.* (Sue Ryder/Demos, 2013).; Weafer, John. *Irish attitudes to death, dying and bereavement 2004-2014* (Dublin: Irish Hospice Foundation, 2014) p.30; Demos 2013)

29 Weafer, John. *Irish attitudes to death, dying and bereavement 2004-2014* (Dublin: Irish Hospice Foundation, 2014) p. 30

Exemplars of stories from each corner are presented below.

Involved or respected

"I will never forget being taken into the side room in the outpatients department with my grandfather and him being told they had found something sinister on his oesophagus. Our worlds were shattered that very instant but the nurse and the doctor who delivered the news showed amazing compassion towards us. From then on in for 6 months it was constant treks to the hospital and to … [city] but every professional we met on the journey were amazing and helped us through the most horrible experience of our lives."

TITLE: THE HEALTHCARE PROFESSIONALS WERE BASICALLY FAMILY
CONTRIBUTED BY: FORMER CARER

Put under too much pressure

"….The nursing and pastoral staff were amazing and extremely kind in all possible ways….However - there was one experience that was not very pleasant: my mom was admitted for assessment and during that period went downhill rapidly - she died 6 weeks to the day that she was admitted into the hospice - however we were called to a family meeting with her consultant and nursing team about 2 weeks into her stay at the hospice - the consultant told us that she was not actively dying and that we would have to find an alternative place for my mom to go i.e. a nursing home. It caused huge stress on us at a time when we should just have been thinking of my mom's needs and spending as much time with her as possible.

The consultant was not very sensitive in her delivery of this news either. As a family we had to argue our case, which we did so very strongly and in the end, my mom was allowed to stay … but I really feel that the pressure put on us as a family (already in a vulnerable place) was very unfair and insensitive. We were aware that there is great pressure on the allocation of beds but surely there is a more sensitive way to deal with issues like this. And I would question the procedures around this whole issue."

TITLE: FAMILY MEETINGS
CONTRIBUTED BY: FORMER CARER

Forgotten about or excluded

"My father was diagnosed with a brain tumour after just over coming lymphoma. When he was diagnosed he lived with my invalided mother his wish was to go home and die at home. I work in the HSE and I had to make all the relevant arrangements for him to go home with beds home help and palliative nurse. … both my sister and I knew what we were dealing with even though we are not nurses but for a family that didn't you are left all alone. It is not a nice place to be in. We saw the public health nurse three times in that three weeks. I feel it's like dealing with the mafia trying to find out what you can get what is available and where and how to get it. People taking care of people need a back up they don't need to feel alone."

TITLE: A PRIVILEGE
CONTRIBUTED BY: FORMER CARER

3.2 Correlations

The SenseMaker software enables an exploration of relationships between responses in the different triangle questions. The Let's Talk About data was tested for significant correlations (See Appendix III for fuller detail and diagrams).

The strongest correlations were between Question 2 and Questions 3, 4 and 5. A relationship was also found between responses to Questions 6 and 7.

Questions 2 and 3 - quality of care and communication

Question 2 tested for the individual's feelings about the care they received: What describes how you or the person felt by the care provided in this experience? The answer choices were *Frustrated, Supported, Helpless and N/A (where none of the triangle statements related to the story)*.

Question 3 tested for communication: In this experience, how were any issues talked about by those who provided the care? The answer choices were *Avoided completely, Clearly and sensitively, Used jargon and N/A*.

The responses to Question 2 and Question 3 show that where issues were avoided completely there was a higher likelihood of feeling frustrated and helpless. Likewise, there was also a higher likelihood of these feelings being experienced when jargon was used. Survey respondents indicated less likelihood of feeling supported where issues were avoided completely.

The correlations suggest that communication increases the feeling of being supported when issues are not avoided and are discussed with the person in a clear and sensitive manner.

Questions 2 and 4 - quality of care and timeliness and quality of information

Question 4 in the survey tests for the timeliness and quality of information being provided: In this experience, how timely was the information that was given? The answer choices were *Too much, too soon, Timely or appropriately, Too little, too late and N/A*.

When information was given timely or appropriately, survey respondents indicated a higher likelihood of feeling supported and where information is given too little, too late they were more likely to feel frustrated and helpless.

Questions 2 and 5 - quality of care and autonomy

Question 5 in the survey tests for the degree of choice and control the individual experienced in the situation: In this experience, how in control were you or the person? The answer choices were C*hoices were limited, Able to make the choices wanted; Control was in someone else's hands and N/A*.

Where survey respondents indicated being able to make the choices wanted, they were more likely to have felt supported, and where control was in someone else's hands they were more likely to feel helpless and frustrated.

Questions 6 and 7 - needs and experiences

Finally there is a correlation between Question 6: Which needs were least well met in this experience? The answer choices were: *Cultural or Spiritual; Emotional or Psychological; Physical Symptoms and N/A*; and Question 7: What would you have liked more of in this experience? The answer choices were: *Better co-ordination of care or treatment; Better Information or involvement; Better emotional support and N/A*.

Where survey respondents indicated the need for better co-ordination of care and treatment there was more likelihood of their physical symptoms being least well met. Where physical symptoms were least well met there was more likelihood of needing better emotional support.

Key Messages

In summary, the analysis of the correlations between the 528 responses highlights particular aspects which can improve the experience of the individual living with a life-limiting condition.

The resultant key messages are that:

- Avoidance of talking about the issues increases frustration and helplessness,
- Information given too little, too late increases frustration and helplessness,
- Clear and sensitive communication increases the feeling of being supported,
- Ability to make choices increases the feeling of being supported,
- Better co-ordination of care and treatment helps with physical symptom management.

4. A comparison of cancer and non-cancer responses in Let's Talk About

This section provides a comparison of survey responses according to two distinct groups – those whose condition(s) included cancer and those whose condition(s) didn't include cancer.

People who completed the survey were asked to select the illness or condition that related to the experience of the person involved. They were provided with a list of nine illnesses or conditions, with an option of adding an 'other' illness/ condition if required. In view of the fact that some individuals may have had more than one condition, respondents were asked to tick all that applied. The *Let's Talk About* data provides an opportunity to see if people's experiences of palliative care varied according to their condition or illness.

4.1 Methodology

Of the 528 stories that people contributed to the *Let's Talk About* survey, 262 described experiences where Cancer was ***at least one*** of the illnesses/ conditions involved (the Cancer Experiences Group) and 265 described experiences where Cancer was ***not one*** of the illnesses/conditions (the Non-Cancer Experiences Group).

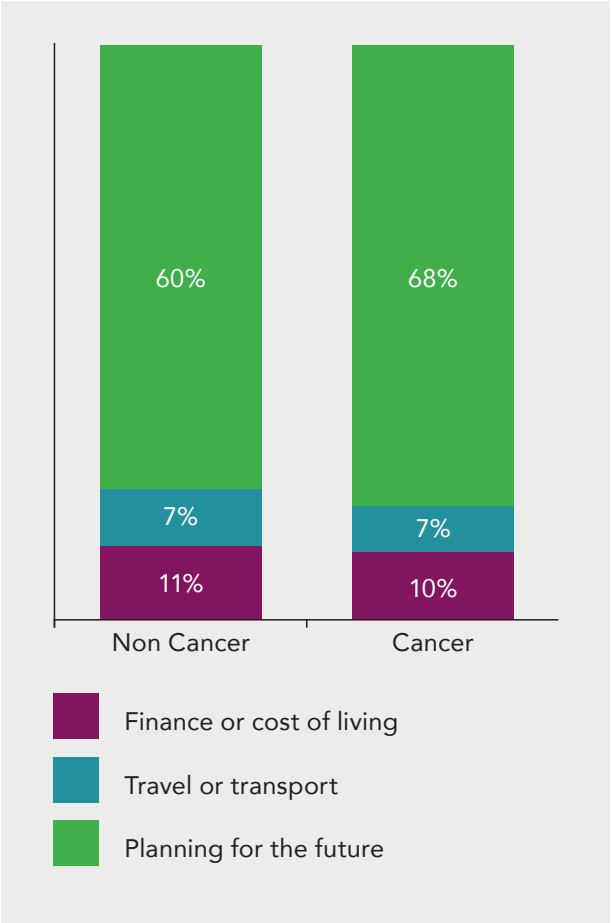
For the purposes of comparison between the Cancer and Non-Cancer groups the triangle 'heatmap' was re-produced to show how each group answered each survey question. The percentage of each answer, as represented by dots on the triangle heat map, was calculated and entered onto an Excel spreadsheet to enable analysis.

4.2 Triangle Questions Analysis

The analysis of how survey questions were answered across the Cancer and Non-cancer experience groups is presented in a stacked column format. This allows for a visual comparison between where clusters occurred and how the questions were answered across different conditions.

Percentages used reflect where survey participants indicated what best fitted their experience. Percentages not detailed is where people signified their experience as a combination of two or three of the data labels.

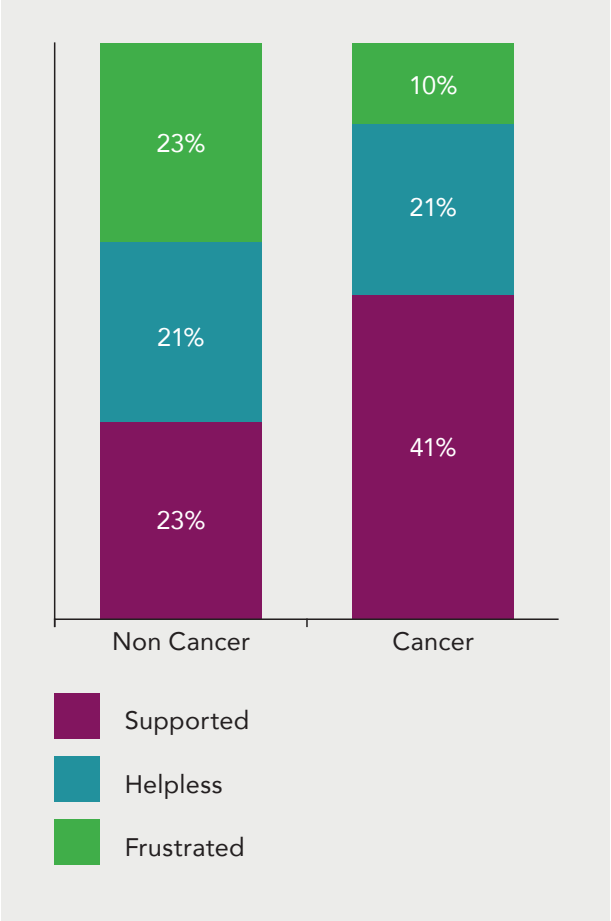
Question 1: In this experience, what was the biggest practical worry?



399 individuals signified their experience against this question, representing 188 cancer experiences and 211 non-cancer experiences

Question 1 in both the cancer and non-cancer experiences *Planning for the future* came across as the biggest practical worry. There are however some differences in how the question was answered; *Planning for the future* was more of an issue in cancer experiences.

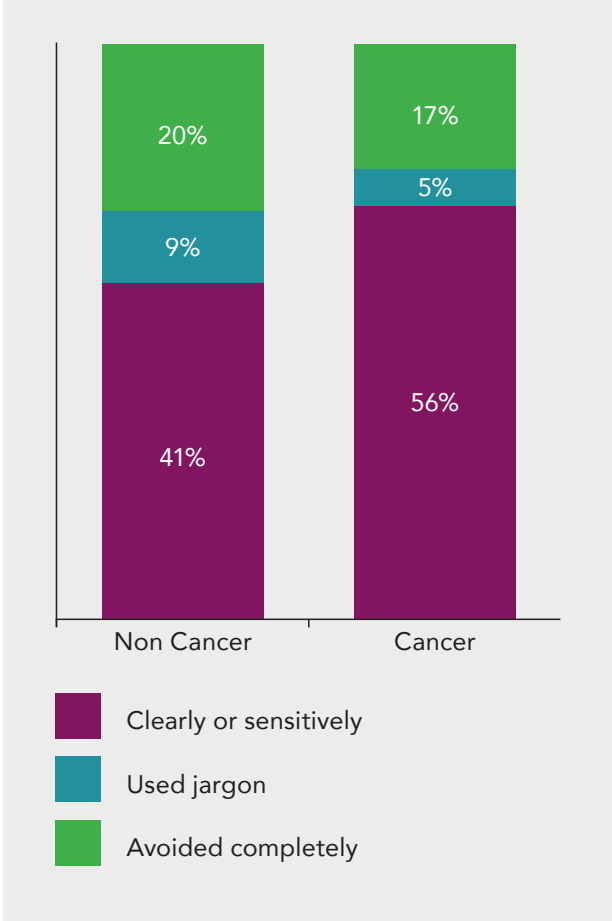
Question 2: What describes how you or the person felt by the care provided in this experience?



518 individuals signified their experience against this question, representing 260 cancer experiences and 258 non-cancer experiences

For this question, where people were asked about how they felt about the care provided, there is a difference in how cancer and non-cancer experiences were signified. The non-cancer experiences were less likely to report that they felt supported and indicated feeling more frustrated. This is a marked contrast between the cancer and non-cancer groups which suggests that there is scope for a further analysis in terms of how non-cancer patients experience care.

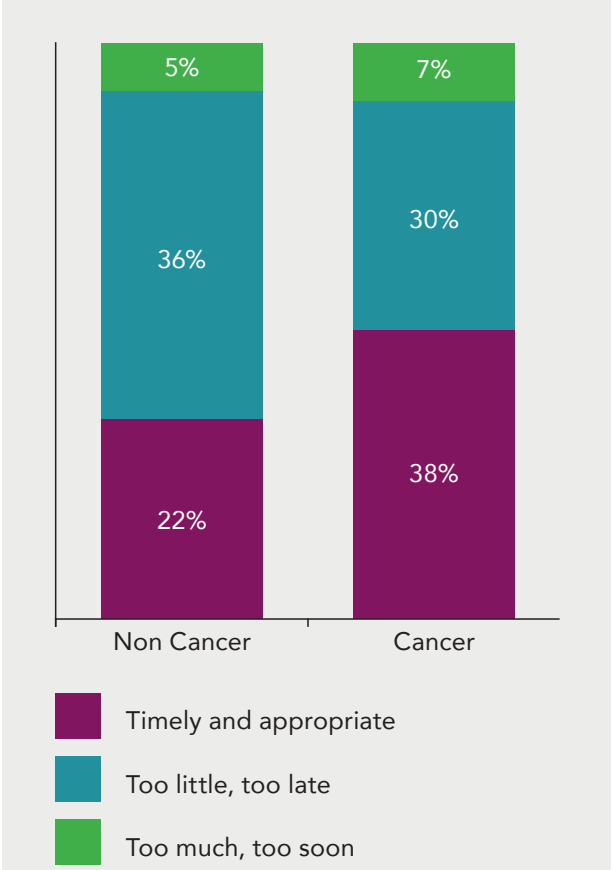
Question 3: In this experience, how were any issues talked about by those who provided the care?



499 individuals signified their experience against this question, representing 255 cancer experiences and 244 non-cancer experiences

For this question there was broad consistency in how issues were talked about, with both cancer and non-cancer groups mostly reporting that they were talked to *Clearly or sensitively*. Though, in cancer experiences, they were more likely to report that this was the case. In non-cancer experiences, they were more likely to signify that issues were either *Avoided completely* or *Used jargon.*

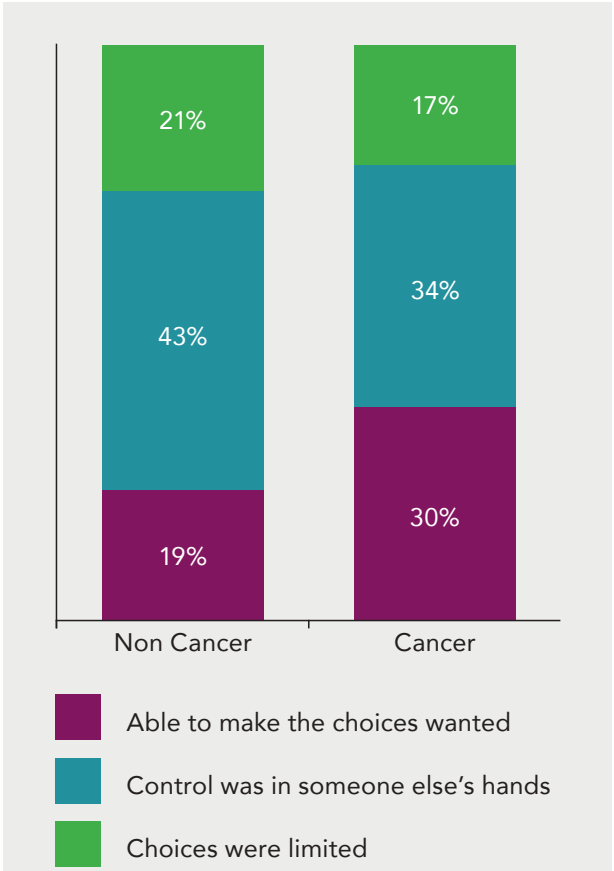
Question 4: In this experience, how timely was the information that was given?



476 individuals signified their experience against this question, representing 251 cancer experiences and 225 non-cancer experiences

For this question, there was a clear difference in perception of how people in the non-cancer group felt that information was given to them. The non-cancer experiences were more likely to report that the information provided was *Too little, too late*. Whereas the cancer group felt that they were more likely to get information in a timely and appropriate manner.

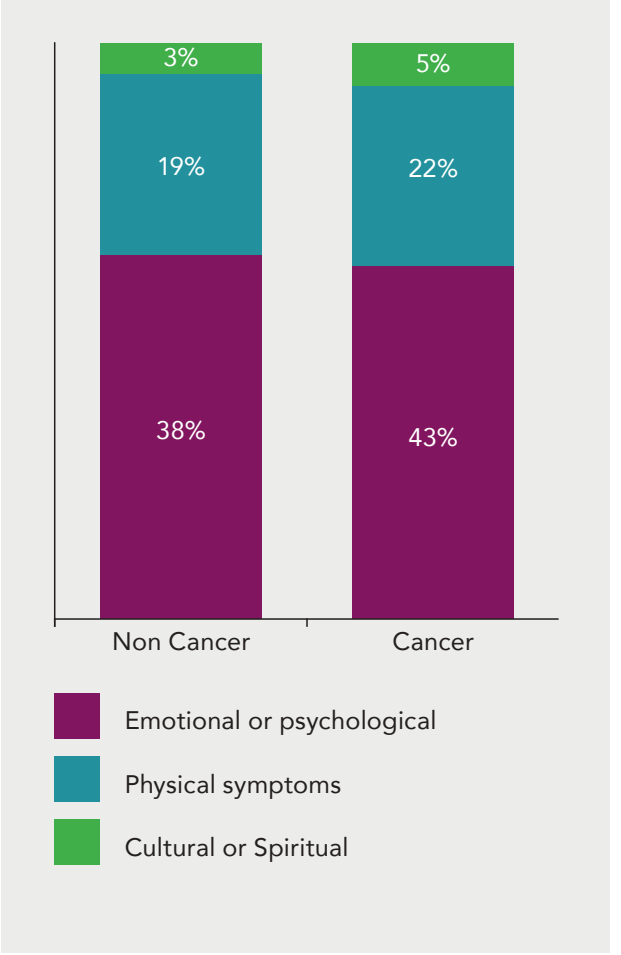
Question 5: In this experience, how in control were you or the person?



510 individuals signified their experience against this question, representing 257 cancer experiences and 253 non-cancer experiences

For this question where people were asked about how in control they felt about the experience they described, there is a marked difference between cancer and non-cancer groups. The non-cancer group was more likely to feel that *Control was in someone else's hands* and that their *Choices were limited*. For cancer experiences, they were more likely to report that they were *Able to make the choices they wanted.*

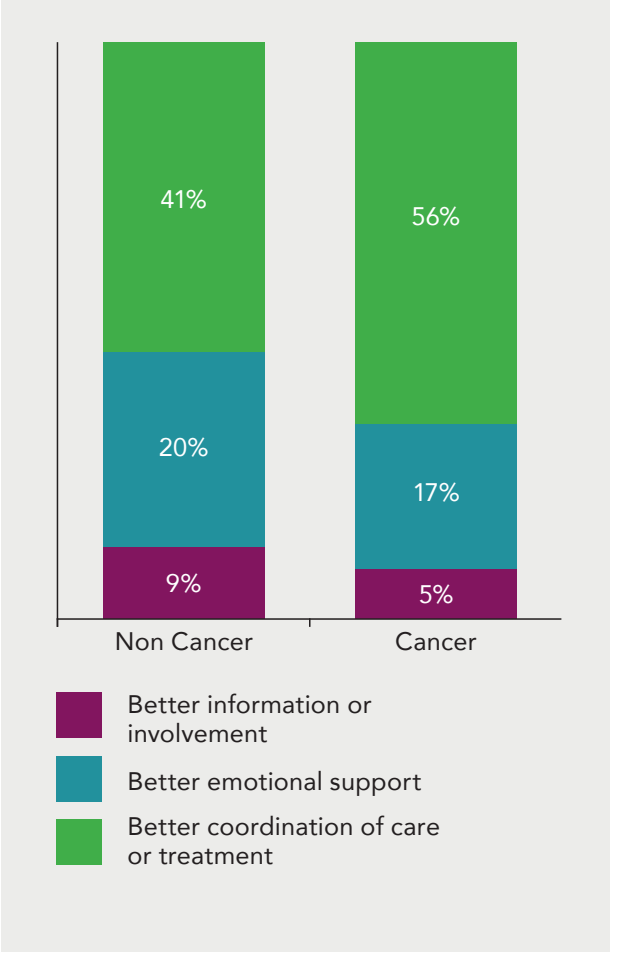
Question 6: Which needs were least well met in this experience?



453 individuals signified their experience against this question, representing 218 cancer experiences and 235 non-cancer experiences

For this question there is broad consistency across both cancer and non-cancer groups in identifying needs that were least well met. For both groups there is a strong indication of the need to give more focus to *Emotional or psychological* needs.

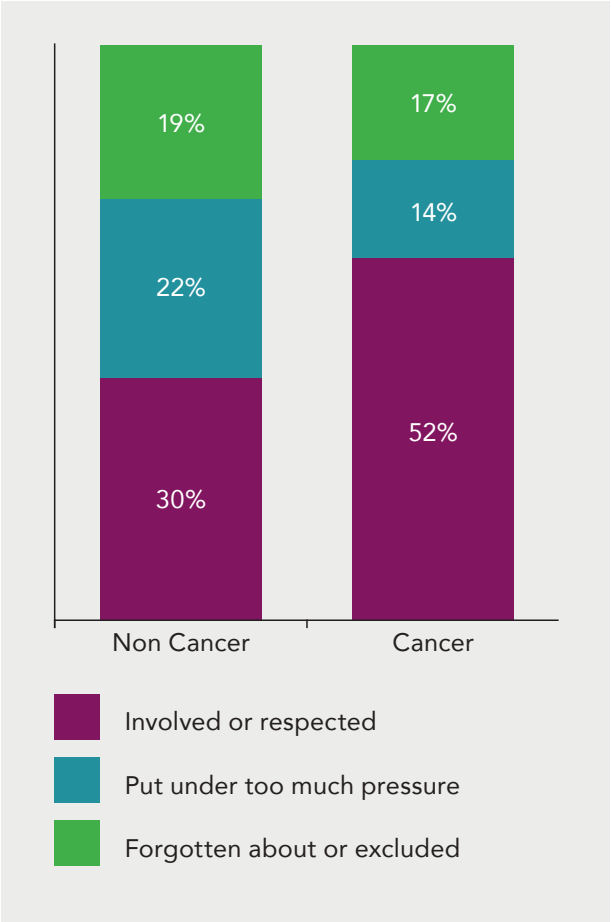
Question 7: What would you have liked more of in this experience?



449 individuals signified their experience against this question, representing 214 cancer experiences and 235 non-cancer experiences

For this question, there was a broad consistency across the two groups, with the majority of respondents indicating the need for *Better coordination of care or treatment, though this was more marked for cancer patients.*

Question 8: How were the family or close friends treated in this experience?



492 individuals signified their experience against this question, representing 249 cancer experiences and 243 non-cancer experiences.

In this question about how family and close friends were treated, some of the most marked differences occurred between how the different groups responded. The cancer group was significantly more likely to report that their family and close friends were *Involved or respected*. The non-cancer group was much more likely to indicate that their family and close friends had either been *Put under too much pressure* and were slightly more likely to be *Forgotten about or excluded*. These differences point to an issue of how family and friends perceived how they were treated in the non-cancer group.

4.3 Conclusion

The tentative picture that emerges from these findings is a sense that people with non-cancer illnesses/conditions report a lower level of support than people with cancer as one of their conditions. One of the most marked findings is that non-cancer experiences are significantly less likely to report that they felt supported in the experience that they described in the survey. This is coupled with the finding that they are less likely to report that they received information in a timely and appropriate way and that they were less likely to report that they were able to make the choices they needed.

There are also two significant findings which relate to how the family or close friends are treated in non-cancer group. In these stories, family and close friends were less likely to be involved or respected and more likely to report that they felt that they were put under too much pressure. This suggests that a feeling of lack of support extends to the family and close friends of the non-cancer group.

While these are tentative findings, they do suggest a strong basis for further investigation into how people with life limiting conditions/ illnesses other than cancer experience palliative care and support. A survey of specialist palliative care service providers highlighted a number of perceived barriers for non-cancer patients in accessing palliative care. The top three barriers were the unpredictability of the non-cancer disease trajectory, the resultant difficulties with developing referral criteria and the lack of non-cancer disease specific expertise. These perceived barriers may explain why people with non-cancer conditions report they felt less supported in the experiences they described in the survey.[30]

30 O'Leary, Norma, and Eoin Tiernan. "Survey of specialist palliative care services for non-cancer patients in Ireland and perceived barriers." Palliative Medicine 22, no. 1 (2008): 77-83.

5. Thematic Analysis

Introduction/Rationale

The 528 people who contributed to the *Let's Talk About* survey provided a unique insight into a very difficult time in their lives. They gave us the privilege of accessing complex and often deeply personal stories about their experience of care, both good and bad, and the impact it had on their lives. They are a valuable source of information on the experience of palliative care from the perspective of people with life-limiting illnesses and their carers.

The main analysis, Section 3 of this report, has focused on how people signified their experience against the eight *Let's Talk About* survey questions. The personal stories encompass a wide range of experiences and additional level of detail. People's stories range in their level of detail from short statements to detailed overviews of the challenges of living with a particular condition or descriptions of a palliative or end of life experience. They highlight what matters to people in how care and support are provided.

To ensure this richness and level of detail is captured and the full value is realised, a thematic analysis of the stories was carried out. This, thematic analysis, looks at the 'experience bank' of stories and pulls out the common issues that people bring up about their experiences of palliative care. It provides an additional layer of analysis by capturing the issues that fall outside the main survey questions yet come up as important aspects of people's experience of palliative care.

Methodology

This thematic analysis looks at the stories in *Let's Talk About* and identifies the common issues that recur.[31] The people who contributed to the *Let's Talk About* survey had the choice to share a detailed account or short statement describing their experience.

The stories were initially read and annotated. The next step developed recurring themes across people's experience of palliative care. These themes were coded and then gathered to develop a list of all the themes that the stories were coded against. The codes were grouped, cross checked and agreed with a second reviewer. The agreed codes were then applied to all of the stories. A draft summary of the findings was then written, pulling out exemplar stories to illustrate the themes. Two other reviewers commented on this draft and a final version was agreed.

While there is an inherent subjectivity to any thematic analysis, the methodology used was designed to develop broad categories. The intention was not to reduce the experiences to single factors, but rather to categorise the stories in a meaningful way. The extensive use of exemplar stories allows the reader to draw their own conclusions.

Anne Molloy was invited to write this thematic analysis to research the range of themes in the stories people contributed in the survey. Anne is a member of Voices4Care, AIIHPC's panel of service users, carers, former carers and interested citizens, which informs the work of the Institute. She is a member of the HSE's Palliative Care Programme Working Group and currently works as an education and evaluation consultant.

31 For the purpose of the thematic report, the dataset includes stories that provided detail on the experience and/or impact of palliative care. For example, a story that is a short description of the diagnosis or of symptoms was not included in the dataset for analysis as they did not provide sufficient information on the type of care provided. This resulted in a combined data set of 356 stories - taken from 234 of the Phase I stories and 122 of the Phase II stories.

Thematic Analysis

The thematic analysis uses the stories people contributed to the *Let's Talk About* survey and the themes have been developed inductively, through an analysis of the stories. The themes are a means of categorising the data in a way that highlights common issues reported by people with life limiting illnesses/conditions or their carers, on their behalf.

The first stage of analysis was the identification and refinement of three broad thematic categories. Within each category, there are a number of sub themes that highlight a specific aspect of people's experience. These thematic categories and sub themes are:

5.1 The difference good care makes,
including the sub-themes:

a. Talking about death and dying

b. Including the family

c. Home support

d. Improved quality of life

e. A good death

5.2 Poor experience of care,
including the subthemes:

a. Personal care needs not met

b. Lack of home support

c. Lack of coordination

d. Issues with managing symptoms

e. Transition

5.3 Poor communication,
including the sub-themes:

a. Lack of communication with family members

b. Lack of clarity in communication

c. Mixed messages

d. Isolation

e. Lack of information

Exemplar stories are used to illustrate each theme and allow readers to understand the theme or sub-theme from the perspective of the people who went through the experience. A number of stories have been edited to preserve anonymity, obvious typographic errors were corrected and in some cases the length of the story has been shortened.

5.1 The difference good care makes to people's lives

"That time was so precious to me, I have great memories"

Overview

The most common theme emerging from the stories is the difference good care makes to people's lives. The care provided in the stories ranges from specialised medical interventions to help with everyday personal care. The stories show the positive impact on people when they are cared for in a comfortable environment, with the appropriate supports and when symptoms are effectively managed, when there is sensitive, clear communication with the patient and their family and there is time to listen and to address concerns.

From the stories, it is very clear that people's understanding of care is not just about caring for an illness and its physical symptoms. Good care puts the person at the centre of care and takes into account how the person's illness or condition affects them physically, socially and psychologically.

5.1a Talking about death and dying

"I knew I wasn't on my own and no fear was taboo"

In situations where people are approaching end of life, there can be trepidation about how the illness will progress and anxiety about how they will manage the final stages. When people in this situation are given time to ask questions and are listened to in a sensitive, caring manner, it can relieve this stress and allow them to focus on making the most of the time they have left. An open conversation may ensure that people know what their options are, so they can access care required to meet their needs. In some cases a single conversation where they could ask questions was seen to relieve anxiety and stress. The examples selected demonstrate how good care puts the person at the centre and takes into account how people have different ways of dealing with their illness.

"I was consumed with anxiety about how we were going to get through the next 6 months (following diagnosis). I really wanted to respect my mother's wishes to die at home and was so unsure that I could support her properly. I met with the doctor from the hospice homecare team and she changed everything. Her interaction with my mother was so caring, reassuring, and most importantly, she removed the anxiety and fear of talking about what the next months had. Then she answered all my questions. I knew I wasn't on my own and no fear was taboo. When she left I felt empowered and safe. And so did my Mam (we ordered a Chinese takeaway!)"

TITLE: NOTHING FOR YOU, WITHOUT YOU, AND NOTHING YOU DON'T WANT
CONTRIBUTED BY: CARER

"The palliative care consultant visited. My Aunt was able to openly talk to him about her physical symptoms, her prognosis and what her options were. She moved to the hospice where she started to live again. She got a hair piece and a wheelchair. She spent hours in the gardens. She entertained her son, daughter and grandchildren as well as her sisters and nieces and nephews. She arranged her funeral. On the day she died she attended an "indoor" family picnic and died that afternoon with everyone close to her present."

TITLE: DELIVERANCE
CONTRIBUTED BY: FORMER CARER

5.1b Including the family

"They gave us valuable time together as a family"

Many of the stories illustrate the importance of including family members in the care of their loved ones. The stories highlight the difficulties and distress families experience when their loved one has a life-limiting condition. In many cases, family members have a primary caring role, and the stories show how good communication can support them in their role as carer, and increase feelings of being able to cope.

Many stories identified how it is also important to recognise that during the last few months, weeks or days of someone's life, opportunities to focus on spending quality time with loved ones are very valuable. Many of the stories express gratitude for having had the time to spend with their loved one, and to say goodbye.

"…My views on hospice changed completely when I understood and realised fully the care that is given there. My husband and my baby were cared for impeccably at a very difficult time in our lives. The hospice staff moved my husband to the relatives' room and allowed us to effectively move into the room with him. They gave us valuable time together as a family….something that would not have been possible in an acute hospital…"

TITLE: HOSPITAL VS HOSPICE CARE
CONTRIBUTED BY: FORMER CARER

"My husband had lung cancer, went through chemo in 2013 and 2014 but we always knew it could not be cured the aim was just to contain it. In June 2014 it all got more serious as complications set in and breathing became worse. During a long spell in hospital at the beginning of July 2014 the palliative care team at the hospital visited & discussed how we could move forward to getting home. The home care team were then put in place. We knew what it meant that palliative care were being brought in and it was good for us to discuss how things would go including his funeral and my life afterwards. This was positive for us and a great comfort to me now in the aftermath."

TITLE: RELIEF SHOULD HAVE COME SOONER
CONTRIBUTED BY: FORMER CARER

"A fall in the residential unit, meant Mam attending a local A & E service. On the first visit, the experience was not great as not all the hospital staff involved seemed to have an understanding of how to communicate effectively with people with Alzheimer's. However, when we asked about 2 family members to come in to be with Mam, things improved as we could explain what was happening and reassure Mam - we had more time to do this. This really helped communication and meant that Mam could be reassured by somewhat familiar faces. The learning from this was that A & Es are busy places and people with Alzheimer's disease may find this a challenging, distressing and confusing, environment - a little bit of knowledge and training for staff as well as willingness to engage with families here can help hugely in managing and treating the person with Alzheimer's disease when they have an emergency situation. It also means that carers, whether family or other, can be actively involved in ensuring an easier time for the person with Alzheimer's and also potentially A & E staff."

TITLE: ALZHEIMER'S AND A & E EXPERIENCE
CONTRIBUTED BY: CURRENT CARER

5.1c Home support

"We got him home, the man was so happy, you have no idea"

Many of the stories bring out the difference it makes to people's lives when they are supported to make choices about their care and preferred place of death. The stories illustrate the benefits for the patient and their family of being in an environment they have been able to choose, with the necessary supports in place, in particular when they are supported to stay in their home.

"…My Father hated hospital so [I] fought for him to be moved to nursing home. As he started to get stronger he wanted to go home (he was a farmer and hated being cooped up). I fought tooth and nail to get him out, had to make supports in place and house up to standard. We got him home, the man was so happy, you have no idea, we had great support from home help, someone used to sleep the night and we all took turns at weekend. That time was so precious to me, I have great memories, he survived 9 months..."

TITLE: SO IMPORTANT THAT ALL OF THE FAMILY INFORMED ABOUT A LOVED ONE'S ILLNESS
CONTRIBUTED BY: FORMER CARER

"the final weeks of my father in laws life were difficult in that different family members were at different stages of acceptance ... The staff involved in his care recognised this and treated us all with sensitivity and care and always kept him and his best interests uppermost. He got home the day before he passed away as this was his wish and all the stops were pulled out to make this happen on a Saturday - it was all much appreciated."

TITLE: THE FINAL JOURNEY
CONTRIBUTED BY: FORMER CARER

5.1d Improved quality of life

"She was even able to have a hot toddy before she went to bed"

The stories show how good palliative care can have a positive impact on people's quality of life, at any stage of their illness. People with life-limiting conditions can experience a range of uncomfortable symptoms or side effects that can have a significant impact on their quality of life. Palliative care that deals with a particularly troubling symptom allows a person to enjoy simple pleasures and time with loved ones.

"…Palliative care became involved in mum's life twelve months prior with their unwavering support and care they gave mum a quality of life that enabled her to enjoy her grandchildren which she held so dear. They strived to get mum on suitable medication to deal with the anxiety caused by COPD. Giving mum a sense of feeling safe and being able to cope. As an entire family we could enjoy quality time with her. Palliative care fully involved the family with her care plan affording us the opportunity to fully understand the effects of COPD on mum…"

TITLE: NIGHTMARE
CONTRIBUTED BY: FORMER CARER

"…Mam said she had not slept well for the past couple of nights and she was very tired. The Nurse explained she would help her with that. She began on Oromorph that day and because I was at work the Nurse took the prescription to the chemist and they had it ready for me to collect on that evening. Mam also had a sore mouth and throat and the Nurse said this was Thrush from the Steroids she had been on the previous week and she got her medication for that which also gave her great relief. Mam was so much more at ease. She was able to get up and sit by the fire that evening eat a bit of her birthday cake and watch television. She was even able to have a hot toddy before she went to bed…."

TITLE: OUR ANGEL
CONTRIBUTED BY: FORMER CARER

5.1e A good death

"We each had time alone with him to say our private goodbyes and to sing the songs one last time, together as a family"

It is striking to read stories where words generally not associated with death are used to describe the last few days of a loved one's life; words such as "wonderful", "graceful" and "happy". These stories show how good palliative care can bring comfort and solace to the person dying and their family members at a difficult time.

"My mother passed away three weeks ago after a 19 month battle with stage 4 lung cancer at 59 years of age. The care and support that she received as a cancer patient and we received as her family was absolutely fantastic. The nurses were in contact constantly either calling to see her or checking in via phone. There were so many queries in relation to the cocktail of medication she was on which could essentially cause terrible worry and frustration we were spared that worry thanks to the Palliative Care nurses that were assigned to my mother. They gave so much support and help all throughout her sickness and towards the end mostly. The night nurse that was provided ensured that my mother's wishes were made possible i.e. to be at home for her final couple of days and to pass away peacefully and most importantly pain free. This gives us a family a great comfort something that is very hard to come by at a time like this."

TITLE: UNABLE TO GIVE THIS A TITLE
CONTRIBUTED BY: FORMER CARER

"I don't think I will ever get over losing my Dad, but being able to say goodbye in the privacy and comfort of the Hospice gave him dignity in these final hours and gave us time to accept that he was ready to and this was how it should be. I will be eternally grateful for the kindness and warmth we received and for time we had with Dad, it was really special. Once admitted to the Hospice, Dad found peace and I think being there allowed him to give himself permission to leave us, his passing was very peaceful and we each had time alone with him to say our private goodbyes and to sing the songs one last time, together as a family."

TITLE: PEACEFUL PASSING
CONTRIBUTED BY: FORMER CARER

"My mother died peacefully at home. She had a number of medical conditions and needed full time care for the last two years of her life. She had the service of the palliative care team from the local hospice for the last 10 days of her life and this was a wonderful service for her and for all our family She had the night nurse service for one night and this was the night she passed away peacefully and I was with her. We feel we were really blessed to have both services and it was really good at the time and since she died to know that our beloved mother was getting the best possible service and didn't experience any pain or distress in the last days of her life."

TITLE: SUPPORT OF HOSPICE HOME CARE TEAM AND NIGHT NURSE SERVICE
CONTRIBUTED BY: FORMER CARER

5.2 Poor experience of care

"They were too busy fine tuning medication rather than looking at her individual circumstances and needs"

Overview

Many of the stories describe situations where people felt the care they received was not appropriate to their needs. The reasons for this are varied. The stories cited highlight a lack of access to the right supports to have a good quality of life, a lack of access to effective symptom management or to care in an environment that meets their needs. For others, it can be a lack of information or support to manage their condition or illness. This can result in isolation and add to the distress of the person with the condition as well as their carers.

5.2a Personal care needs not met

"She needed to be treated in an unhurried and gentle manner "

A recurring feature of experiences described every day activities and personal care that people needed help with because of their illness. These are activities which need to be addressed several times a day that most of us take for granted - washing, eating, going to the toilet. In situations where personal care needs were not met, the stories describe the discomfort, distress and a loss of dignity that this can bring.

"Overall Mam could have been treated better, much, much better if only the management treated her as an individual, they were too busy fine tuning medication rather than looking at her individual circumstances and needs. She needed to be treated in an unhurried and gentle manner (quite often the opposite was the norm). Incontinence was a huge issue, mainly due to Mam quite often not 'performing' when she was brought to the toilet after her tea. Quite often she would need to go maybe an hour later and no staff were available but I made sure she would not suffer such an indignity and 90 odd percent of the times would source a member of staff to help her to the toilet."

TITLE: DEMENTIA LATER DIAGNOSED AS AGGRESSIVE DEMENTIA
CONTRIBUTED BY: FORMER CARER

"My elderly father suffers from Alzheimer's and vascular dementia and was transferred by ambulance to hospital for an acute urinary tract infection. Although a private patient it was necessary to request transfer to a public ward in order to ensure some supervision. He had been very distressed in the private room and had fallen when trying to climb out over the side rails of bed. He was not found for some time. In addition he had to be strapped into a chair with his feet immobilised to prevent him getting up. Nobody ensured he had eaten his meals and he was left unsupervised for long periods. His personal care was over looked. There is no specialist unit to facilitate his care. He may as well have been invisible. Carers had to be paid to go into the hospital to ensure his safety and ensure basic needs were being met. It was distressing for my father and those around him."

TITLE: INADEQUATE SPECIALIST SERVICES
CONTRIBUTED BY: CURRENT CARER

"I sat with the patient for almost an hour and she had a very strong smell of excrement (she had soiled herself) and she wasn't cleaned up in the hour I was there. The patient's dirty washing was left in bags. Her family lived far away so washing was left in locker beside the bed for days."

TITLE: OUTSIDE LOOKING IN
CONTRIBUTED BY: CURRENT CARER

5.2b Lack of home support

"For the rest of the day she was totally on her own"

There are many instances which describe the challenges of managing a life-limiting condition at home. In many cases this was because they felt that the support provided did not adequately meet their care needs. The reasons cited include insufficient time or frequency of allocated home supports. In other examples people did have access to care, but there was a mismatch between the care required and the care that was provided.

"… She was granted home help for one hour a day. The carer called to her at 9 a.m. and left at 10 a.m. Monday to Friday. For the rest of the day she was totally on her own and due to her declining dementia, she would take off to the city centre and wander around all day. Finally she would call in a distressed state because she wouldn't know where she was and we would have to get her to describe the area around her so we could go and get her and take her home. Many times she would have serious falls while walking around and we would get a call from the hospital and due to her age she would have broken bones which meant weeks in hospital for her."

TITLE: DESCENT INTO DEMENTIA
CONTRIBUTED BY: CURRENT CARER

"Carers were introduced to help look after my dad. My sister, mum and I had privately got extension built with level access shower. We showered dad several times a week but carers were not able to do this -without training - not able to get training and enough staff to help with this, so we continued to do it willingly. They were not permitted to transfer dad from wheelchair to toilet for bowel movements due to moving and handling issues for him - the recommendation by the managers of the carer was to 'pad dad up' (with incontinence pads) even though he was aware of when he needed to have his bowels move. As a palliative care nurse I feel that this would have been very undignified for dad. Carers when carrying out personal care didn't brush Dad's teeth or shave him and often my mum had to wash him when they left."

TITLE: LACK OF COORDINATED SERVICES CAUSING FAMILIAL STRESS
CONTRIBUTED BY: FORMER CARER

5.2c Lack of coordination

"Passed from pillar to post at times when you are at your most vulnerable"

People with a progressive or terminal illness often have complex medical needs that need the attention of a range of medical professionals. The experience recounted by many people is that dealing with multiple appointments and services could be confusing, stressful and time consuming. The lack of coordination causes difficulties for people, in particular there is uncertainty about who is responsible for providing different supports and a lack of knowledge on where to find support. A lack of coordination can also mean a lack of information on people's conditions.

"I have cancer that is incurable, had allergic reaction to chemo after I'd been on it 18 months, now managed by intermittent surgeries. Also have other chronic stuff eg Gastro Oesophageal Reflux Disease; Diabetes; Asthma, etc all of which were exacerbated by the numerous surgeries and the chemo. Needless to say this was/is a personal disaster but this was majorly compounded by the sheer nightmare that is the administration part of being seriously ill. The amount of form filling and rounds of begging that has to be done to get a basic service, at a time when you can't think straight, or even get your head around your situation is just horrendous."

TITLE: CANCER IS AN ADMINISTRATIVE NIGHTMARE
CONTRIBUTED BY: PERSON LIVING WITH CONDITION

"My mother is living with cancer that cannot be cured and has been in and out of hospital over the past 5 years. Due to the complexity of her cancer and as she is from the country but being treated in a Dublin Hospital it has been very difficult for her as she does need to go to the local hospital for care also. She is caught between the two systems and appears to have no direct person who will take overall responsibility for her care as a result."

TITLE: NOBODY DIRECTLY RESPONSIBLE FOR CARE
CONTRIBUTED BY: CURRENT CARER

"None of the support is coordinated or appears to be. Passed from pillar to post at times when you are at your most vulnerable… no literature given on what to expect from each person involved and who to contact for what. It appears to have been lost in translation somewhere that at the time things are very raw and being told things verbally is not enough as you are not always fully receptive to the information."

TITLE: FIRST IMPRESSIONS COUNT
CONTRIBUTED BY: CURRENT CARER

"When admitted to hospital in the last weeks of life it was a weekend. My relative was admitted through Emergency Department and eventually got a bed on a Medical Assessment Unit medical notes did not appear to be available. A Junior Doctor told some family members that he needed to biopsy the tumour which was now fungating on my relatives neck he did not seem to understand that this cancer had been diagnosed one year earlier and had been treated both surgically and with radiotherapy. My relative was not asked for consent and options were not discussed. My family were quite distressed by the medical and nursing staff not understanding my relative was at the end of life stage it appeared none of the staff had read the GP and Macmillan Community Nurses letters. I had to advise staff that biopsy was unwise that my relative was at end of life and that a biopsy was likely to result in haemorrhage pain and great distress. Why a biopsy was considered when an end of life cancer diagnosis was already made we will never know but luckily I was able to avert this situation. While the staff were very pleasant I feel if medical notes had been available and read this distressing situation could have been avoided."

TITLE: ADMISSION TO HOSPITAL AT END OF LIFE
CONTRIBUTED BY: FORMER CARER

5.2d Issues with managing symptoms

"We later discovered that this is mainly preventable"

The symptoms associated with a life limiting illness can be very difficult to deal with. They often require specialist treatment, or medication. Many of the stories described difficulties accessing the right medication or treatment to manage symptoms, in particular pain. There were various reasons identified from a lack of specialist medical care to a lack of out of hours access to medication and care.

"…he was being cared for on a very busy medical ward the only time he saw a nurse was for medications. He started palliative radiotherapy. During his radiotherapy he got a very common side effect - sore mouth and oesophagitis and was unable to eat and started losing weight, had a lot of pain and discomfort - we later discovered that this is mainly preventable but as he was not under the oncology team it was not spotted. What was very obvious to us was the lack of regard for the patient experience - the ego of the oncology team seemed to be more important than the dying people in the hospital: while we could understand the nurses being busy - the hospital was obviously understaffed, but the nurses on the general medical ward were under-skilled and unable to identify a very serious/distressing and preventable side effect of radiotherapy."

TITLE: APPALLING
CONTRIBUTED BY: FORMER CARER

"… palliative care was provided in the home following discharge from hospital. In this instance, where there was acute pain experienced by the now deceased, there was no direct way of addressing this pain, other than taking the palliative team's advice and phoning, (out of hours). They would answer the phone, ask for the patient's details and by the time a nurse even phoned back, the now deceased was in excruciating pain and nobody was able to administer any medication. This was a let down."

TITLE: A MUDDLED EXPERIENCE
CONTRIBUTED BY: FORMER CARER

"…The following experience happened at a weekend. My mother's subcutaneous line for morphine became dislodged during the night. I contacted the local hospice helpline for advice as I was concerned about her not having enough pain relief. They advised me to contact the GP out of hours service. Initially the GP on call refused to come out to see my mother and wanted us to wait until the nurse visited some 7 hours later. I refused to accept this. Eventually, the GP came out to the house but clearly had no idea as to how to refit the subcutaneous line as he contacted the hospice for instruction. He then proceeded to replace it. It stayed in situ until the nurse arrived, but had not been placed correctly leading to swelling and bruising to my mother's arm. When I relayed the above to the specialist palliative care nurse who had been involved with my mum from the start, she said that if this occurred again that we should drive my mum to the hospice (30 mins away by car) to get the line resited. I personally do not think that this was an appropriate option for my mother who was in such a terminal stage - a car journey in the middle of the night would have caused more stress."

TITLE: LACK OF COORDINATED SERVICES CAUSING FAMILIAL STRESS
CONTRIBUTED BY: FORMER CARER

5.2e Transition

"Coming home from hospital with terminal cancer to my home was dreadful"

The transition between any combination of home, hospital, nursing home and hospice was often described in stories as a stressful experience. It also appeared to be a particular fault line in the provision of care. There were repeated experiences of difficulties when someone with a life-limiting condition transitions from one care setting to another. The difficulties described generally highlight a lack of care and supports in these situations.

"…Feeling of failure needing admission for family member with dementia who was distressed/out of home environment in A&E. Family member has NEVER been admitted to hospital for respite or care. Experience; family upset and distressed at family member who had long period on trolley being uncomfortable, shouting out, loss of dignity. Junior doctor assessing patient implied to his wife (full time carer) that this was not an opportunity for a social admission over Christmas and that patient would have to be taken home again. Experience; upset, guilt, anger that implied not looking after family member, worry about family member, needing end of life, palliative guidance."

TITLE: NEVER MAKE ASSUMPTIONS; TREAT EVERYONE THE WAY YOU YOURSELF WANT TO BE TREATED
CONTRIBUTED BY: FORMER CARER

"Coming home from hospital with terminal cancer to my home was dreadful. Until the services were set up (which was almost two weeks later) my husband and son had to do everything for me. The pain became unbearable and was uncontrolled. The palliative care team then started to visit and could not have done more for me. They worked with me in every way to alleviate my symptoms. However, I am often angry and afraid and unfortunately my husband and son take the brunt of my anger."

TITLE: COMING HOME FROM HOSPITAL TO DIE
CONTRIBUTED BY: PERSON WITH CONDITION

5.3 Poor communication

"That approach towards me following the loss of my wife was shocking"

The stories of poor communication could also be categorised under the theme of 'poor experience of care'. However the number of stories that include examples of poor communication means that it is included as a separate category. Poor communication is reported throughout people's experience of palliative care, from initial diagnosis to treatment in the last days of people's lives. The examples highlight a complete lack of communication, insensitive, or rushed communication. The stories not only describe situations of poor communication, they also show the negative impact and hurt it can cause for people with life-limiting conditions and their families.

5.3a Lack of communication with family members

"I will never forget until I die myself, the expression of sheer distress on her face and how upset she was"

Family members are involved in the care of their loved ones and poor communication has an impact on how they can provide for care. Many of the stories highlight the negative impact on both the person being cared for and their loved ones when communication difficulties arise between family members and medical professionals.

"I care for an aunt (age 83) who is at the palliative stage of her cancer illness. The scenario is very challenging for her mostly in relation to understanding exactly her situation terminology future expected lifetime meaning of different type of services and reluctance of professionals to be open and frank in relation to her condition. In the absence of forthright information I have had to spend much time informing her in a non-clinical way on her present circumstances and de-briefing her after clinical appointments that I attend with her. She is currently in denial of the extent of her illness and believes that the clinicans read from a different person's scan etc. The Hospice service visit her regularly at her home and she goes on weekly outings to the hospice centre which she enjoys. I am her next of kin but I do not have any feedback from the hospice etc. not afforded an opportunity to do so I feel that this is a gap as a partnership approach should be taken between my aunt the hospice GP and I to managing her care and other needs."

TITLE: LIVING WITH THE DYING?
CONTRIBUTED BY: CURRENT CARER

"When my wife passed away and after relatives had left I was on my own. I came out of the inner room within the 8 bed Intensive Care Unit (ICU), no member of staff offered me any sympathy or even a cup of tea. I was broken, a lovely part of my life gone. I went to the nurses' station and took the liberty of opening my wife's large file looking at charts, consultants' reports, GP letters, etc. A nurse standing in a stripped uniform whom I assume was a head dept nurse said to me that file will go into archive and will be destroyed after a number of years. That approach towards me following the loss of my wife was shocking. I said nothing and just left. Leaving the ICU I went back up to the specialist ward."

TITLE: UNPROFESSIONAL AND INSENSITIVE
CONTRIBUTED BY: FORMER CARER

"My mother was told that she had terminal cancer on a public ward by the consultant and his team without any family members present. She had been in hospital having tests and because I had a medical background as an occupational therapist myself, prior to the consultant telling her the news, I had concerns about the outcome of the tests after having a conversation with our GP. I had therefore requested that I be allowed to be present if any bad news was to be given to my Mum. I had made this request formally to both the junior doctor on the team and the nursing staff in the days before the above event. The ward round occurred early in the morning, and I got a call from one of the other patients on the ward who had got to know my mother. She just said that my mother was upset about what the results might show & could I come down to hospital (she did not tell me directly that my mother had been told the news in case it upset me too much). When I got to the ward, I asked the nurses if my mother was upset, they were unaware that she was. The junior doctor was present at the desk when I arrived and he asked to talk to me. He informed me that the consultant had proceeded in telling my mother at the ward round. It took me some time to absorb the news myself, before I was able to go into see my mother. I will never forget until I die myself, the expression of sheer distress on her face and how upset she was. I was so angry about the manner in which she had been treated but also about how the nurses and doctors failed to contact me directly as next of kin even after the event to tell me what had occurred."

TITLE: LACK OF HUMANITY AND EMPATHY
CONTRIBUTED BY: FORMER CARER

5.3b Lack of clarity in communication

"Trying to interpret the news initially was, and remained the main difficulty"

When people are absorbing complex or difficult information a lack of clear information can be an issue. At these times, the shock of hearing difficult news can affect their ability to understand what they are being told. This can have a lasting negative impact on how people deal with the diagnosis.

"She was being looked after by the respiratory doctor who came to us when I was visiting and told us they had seen 'a funny lump' on her lung and left. At this stage I have to tell you I'm a nurse so funny lump is not how I would describe cancer. My mum however thought nothing of it, who wouldn't if it's 'funny'. I started asking the nurses to please give me more information, but they said they were not allowed. Two days later an oncology doctor came to talk to us. She explained everything and told mum it was cancer. That is all we wanted to be told."

TITLE: THE WORD IS CANCER
CONTRIBUTED BY: CURRENT CARER

The issue of communicating a terminal diagnosis can be a very difficult one for medical professionals. There are variations in people's perspective on what level of information about their diagnosis is either desirable or acceptable. Several stories highlight the challenges in finding the right line between the responsibility to inform and someone's preference not to receive information.

"… The level of care required was extraordinary but more importantly trying to interpret the news initially was, and remained the main difficulty. When my mother received the news, and for the following visits my sister who is an A&E nurse accompanied her and could interpret what was being said for my mother and the rest of the family. This for me was the biggest issue and, as I noted, we were lucky because we had someone in the family who could explain in 'lay man's' terms what was being said. I often think of the vulnerable individuals especially the elderly who have no one to do this for them. The fear engendered by receiving a terminal diagnosis is one thing, however it is quite another when one does not understand what is being said and what it means. I feel that the shock and trauma suffered by the individual and the family results in an inability to comprehend what is being said. I feel that this initial stage and how it is dealt with lays the foundation for either a positive or negative attitude towards dealing with the diagnosis for both the individual and the family. All I remember after the initial news was complete terror and I know that was my mother's first and foremost feeling and this never left her. She continued to be petrified and terrified throughout the experience and I don't believe it has to be like this…"

TITLE: IT COULD HAVE BEEN SO DIFFERENT
CONTRIBUTED BY: FORMER CARER

"The worst experience was trying to keep my mother's inevitable death from her (she was dying of lung cancer) in her final weeks. The Hospice staff appeared to be of the opinion that she should know clearly she was dying, but this was not my mother's wishes, as she was a very positive, outgoing person, and had indicated before she became ill that if she was ever dying she didn't want to know. Even the first day after the diagnosis from her consultant that the cancer had returned, the person in charge of palliative care in the hospital where she was attending made an issue of the fact that she was not going to get any further treatment and proceeded to ask her questions about death and dying and even asked her if she was afraid of dying, which was an extremely intrusive question posed to a woman who had just learned, having been four years free of cancer, that the cancer had returned. At that stage my mother did not know what the prognosis was, and was certainly not willing, and chose not to contemplate death. So to have members of the palliative care team endeavouring to entice her into the realm of those who are going to die shortly was extremely distressing. This was also the case with some of the nurses who visited her at home during her final two weeks. I accept that they were wonderful in relieving her pain, but do not believe they should have been so intrusive in relation to my mother's pending death, unless, of course, if she asked, which is completely different, and for the reasons already outlined she chose not to ask questions."

TITLE: DISTRESSING
CONTRIBUTED BY: FORMER CARER

5.3c Mixed Messages

"The stress of the conflicting advice and the feeling that you were responsible for coordinating services was profound"

A particular aspect of poor communication is where people get mixed messages from different medical professionals. Conflicting medical opinion can result in a significant burden at a very stressful time. The stories report the confusion and sense of isolation in these situations, but also the impact on quality of life for people with life limiting conditions.

"…The ward that my mother was in was quite dark, it had no day room, and only a small garden area that was difficult to physically access. There was also a lot of sick people in the ward, so the whole atmosphere was quite oppressive. ..There was no way of escaping the ward scenario unless you left the ward… I was present for one of the doctor's ward rounds and requested that she [my mother] be allowed to go home during the day while she waited for the biopsy results. They agreed to this verbally and the nurses that my mum could go home during the following day for day release. We did this and this enabled my mother to be with her family and also to see her garden which was one of her favourite things. However, when I arrived the following day to take her out again, the nurses refused as the doctors had not written their consent in the notes and failed to tell the ward sister that it was to be an ongoing thing until the results came back. On this particular day, the doctors were rotating and so members of the team were in a meeting all day and the ward sister was unable to get in contact with them. So, after much discussion and distress for me, I was unable to take my mum out home because of hospital procedure. I think that there should have been much more emphasis on the quality of life given to the person facing such a diagnosis as my mother. The days left are precious and should be spent as much as possible enjoying every moment enabling you to have a quality of life. Instead, it is so much a medical approach that the opportunities can be lost."

TITLE: LIMITED EMPATHY AND LACK OF EMPHASIS ON QUALITY OF LIFE

CONTRIBUTED BY: FORMER CARER

"My mother was diagnosed late in her illness with terminal cancer and lived one month after diagnosis… The stress of the conflicting advice and the feeling that you were responsible for coordinating services was profound on us as a family, especially as we knew that my mother was soon to die… I think we, as a family, had too much of the responsibility for coordination of different professionals involved and the stress of this was an added burden at a very difficult time."

TITLE: CONFLICTING ADVICE AND TOO MUCH RESPONSIBILITY ON FAMILY

CONTRIBUTED MY: FORMER CARER

"My uncle was discharged home from hospital to die on a bank holiday weekend a few years ago. He had a rectal cancer and following rectal surgery developed a chest infection. Each day his condition became weaker and had a cardiac arrest. He never regained renal function and required renal dialysis 3/week. A 65 year old farmer he eventually found ways to resume farming activities despite having a stoma and requiring dialysis. He had a good quality of life for one year when his cancer started to progress."

5.3d Isolation

"To this day I feel that I am basically left to die"

A lack of communication can cause or add to a sense of isolation for people who have to deal with life changing situations. In particular, isolation can arise when someone learns that they have a serious illness and do not get follow up communication or when there is a lack of communication on how to manage their condition.

"I have terminal cancer and I have found that the health service are not geared to deal with end of life. I was told when I was on my own and had to drive two hours home by myself. I waited for three weeks for anyone from the oncology unit to contact me with regards to my recent diagnosis. No one contacted me, in the end I lost the head and rang my doctor who contacted oncology. When I was first diagnosed I was surrounded with info, nurses and doctors. Still to this day I feel that I am basically left to die. I just have to go through the stages without anyone letting you know what you may have to face."

TITLE: APPALLING
CONTRIBUTED BY: PERSON WITH THE CONDITION

5.3e Lack of information

"We did not know whom to contact for advice or support"

The selected stories highlight the importance of being given relevant information on the symptoms and trajectory of an illness for patients and their carers. Many of these stories emphasise the challenge of finding out how to manage symptoms but also how to access supplementary information and support.

I cared for my mother for the last 3 years, Mum was diagnosed with vascular dementia in 2010. It was very difficult at stages as we had no idea what was happening, whether we could reverse a stage or was it getting worse. There was no advice or enlightenment from the medical team, the local GP was very ignorant of the whole process of Dementia, he kept reminding me Mum was old and it was the ageing process, not much help!!!... The simplistic piece of information or piece of equipment such as a recliner can make an unbelievable difference to the life of the "sufferer" and the "carer"

TITLE: THE LONG GOOD BYE
CONTRIBUTED BY: FORMER CARER

"My husband had motor neurone disease and passed away just 8 months after diagnosis, though he had been showing symptoms for a year before diagnosis. We had no idea what illness he had and had virtually no help until he was diagnosed. After diagnosis help was available in some areas, but not in all, and we did not know whom to contact for advice or support."

TITLE: TERMINAL ILLNESS WE HAD TO DEAL WITH MOSTLY BY OURSELVES
CONTRIBUTED BY: FORMER CARER

"I was recently diagnosed with COPD. This was all I could hear the consultant say and I spent the next two months reeling from the diagnosis and being dismayed at how little information there is about this disease. I consumed every piece of information available online and, eventually, found a support group, which has helped me greatly. The information that is publicly available focuses almost exclusively on explaining what the disease is and how one is affected; but very little on what one can do to help oneself, apart from quitting smoking. So, I've really had to learn by trial and error about issues such as, how far can I push myself in terms of exercise. And I've no idea about how quickly the disease will progress or when I will need palliative care …. I would dearly love to have some signposts along the way, someone who truly understands to talk to. Friends are great but they don't really appreciate what my reality is."

TITLE: REELING FROM THE DIAGNOSIS AND DEARTH OF INFORMATION AND SUPPORT FOR COPD SUFFERERS

CONTRIBUTED BY: PERSON LIVING WITH CONDITION/ILLNESS

Conclusion

"Dying is an intimate experience"

One contributor's words expressing that 'dying is an intimate experience' resonate strongly. The words and phrases people use to describe their experience of palliative care capture the nub of an issue.

With the range of services and care environments that a person with a life limiting illness will experience it can be hard to preserve this intimacy. It is also clear that health and social care professionals who care for people with life limiting illnesses often work in a very challenging environment, which can make it difficult to provide the level of care they themselves would like to provide.

Yet, ultimately these stories show that despite these challenges, good palliative care can be provided in a way that supports, and ultimately provides comfort for people and their loved ones at the most difficult time in their lives. These stories show how this is possible.

6. Recommendations and Report Conclusion

6.1 Recommendations

Based on the results of the survey, the following recommendations are proposed which are aimed at a wide range of audiences including policymakers, commissioners, statutory, voluntary and private agencies, including AIIHPC, involved in the delivery of palliative care:

1. Develop practice models which (a) better coordinate care and treatment options and (b) reflect the emotional and psychological needs of the individual, their families and or carers and support their needs to plan for the future.
2. Build the capacity of professionals to respond to the needs of individuals through the development of competences (physical, psychological, social and spiritual) and communications skills and through access to ongoing and appropriate personal supports.
3. Deliver an information and awareness raising campaign targeted at professionals: GPs, community-based nurses and hospital-based consultant teams who are key to the identification of patients' palliative care needs.
4. Enable individuals to exercise personal choice where possible through the timely provision of accessible and appropriate information on palliative care.
5. Develop principles for involvement and formalise support for family, friends or others where appropriate, in order to encourage participation in supporting an individual.
6. Promote a wider societal normalisation of planning for the future.
7. Promote public awareness and access to a palliative approach to care for all individuals with a serious or progressive condition from which they are unlikely to be cured and which may limit or shorten life.

6.2 Report Conclusion

Respondents to the *Let's Talk About* survey recount both good and bad experiences of palliative care from health and social care services. User experience must continue to be the benchmark against which policy makers and commissioners approach the future of palliative care services and policy development across the two jurisdictions.

The stories and sharing of personal experience provide a unique insight into the experience of living and dying with a life-limiting condition; the richness of the responses informed the formulation and initial exploration of key themes:

- People need help to plan for the future
- People experience too little autonomy
- People feel helpless and frustrated
- People value clear and sensitive communication
- People value timely and appropriate information
- There are emotional and psychological needs that are not met
- People would like their family and friends more involved

Further research into the complexity of the information available will be required to maximize this resource. In particular it would be useful to explore the marked contrast of those in the non-cancer group being more likely to experience feelings of frustration compared to the experience of the cancer group.

As AIIHPC embarks on the implementation of their second strategic phase in 2016-2020 the findings from Let's Talk About will be widely disseminated and used to inform future work. There will be a continued commitment to user /carer feedback to improve services and to reassure people that their 'stories' were listened to and as claimed in the survey –

Each story is valuable. Hundreds of stories are powerful!

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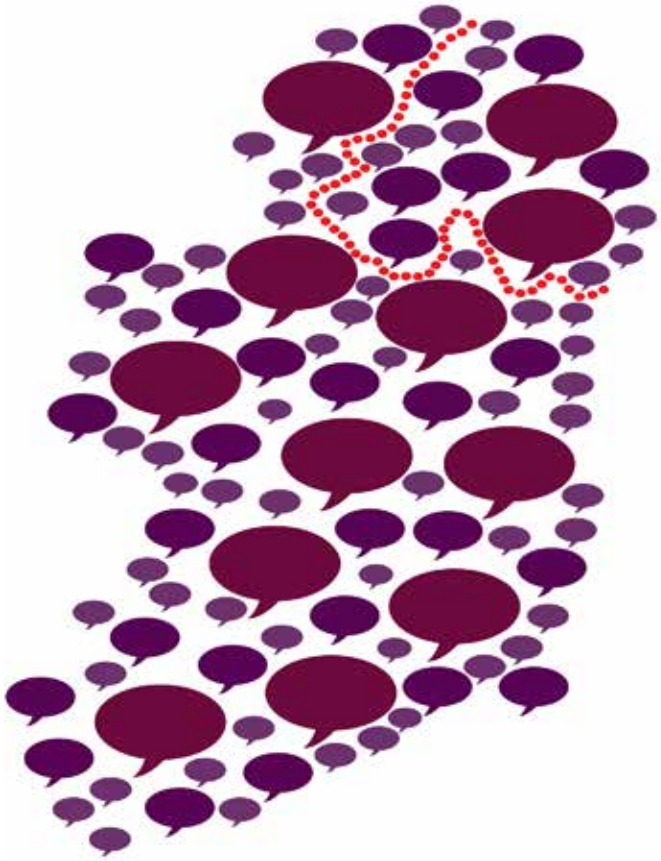
Appendices

Appendix I: *Let's Talk About* Information Leaflet

let's talk about survey

let's talk about... an experience of someone with a serious or progressive medical condition that is unlikely to be cured. Talk about yourself, someone you know or someone you knew.



Help improve policy and services for people by sharing experiences in this **survey**

www.letstalk-about.org

Appendix II: *Let's Talk About* survey

Take part in the *Let's Talk About* survey and help us improve people's experience

Who is this survey for?

Are you living with a **serious or progressive medical condition** from which you are unlikely to be cured? Or do you know or care for someone living with such a condition? Or did you know or care for someone who had such a condition within the past two years?

If so, we want to hear from you about any aspect of these experiences, good or bad by completing this short survey. If you are answering on someone else's behalf, please do so from their point of view as best you can.

Confidentiality

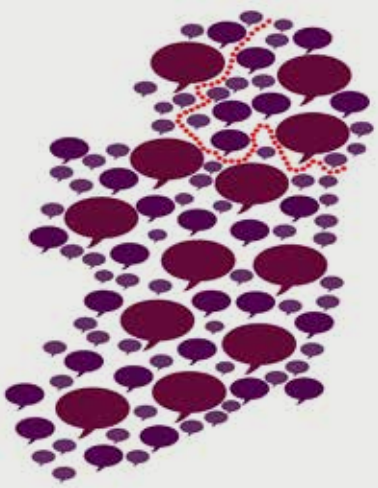
As this survey does not require your name, the information you provide will be anonymous and not traceable back to you. Please do not record the names of family members, carers, professionals, institutions or organisations in your story. By completing the survey you are consenting for your anonymous information to be used with that of others in the development of a report.

We really appreciate the time and effort in telling these stories. You may find that it helps to have someone to talk to about your responses to the questions – a friend or family member, or someone who provides you with support.

This survey uses a new way to collect a large volume of information on a nation-wide basis. We are sorry we are unable to deal with any specific or individual issues raised. If you have a concern we would urge you to raise it directly with the care provider involved.

Each story is valuable. Hundreds of stories will be powerful.

Let's Talk About survey



let's talk about ...

an experience of someone with a serious or progressive medical condition that is unlikely to be cured. Talk about yourself, someone you know or someone you knew.

Serious or progressive medical condition *such as an advanced respiratory disease, cancer, chronic kidney disease, heart failure, a disease such as dementia, or another illness which is unlikely to be cured*

Firstly, please tick which of the following best describes you ✓

I live with a serious or progressive medical condition that is unlikely to be cured.	
I am caring for, or know someone who has a serious or progressive medical condition that is unlikely to be cured. I am answering from their point of view as best I can.	
I knew or cared for someone who had a serious or progressive medical condition within the past two years. I am answering from their point of view as best I can.	

Please describe **an experience that made an impact** and happened within the last two years which shows what it is like to live with a serious or progressive medical condition that is unlikely to be cured.

Write as little or as much as you wish. Do not worry about spelling or grammar. We just want to know about an experience. Please do not provide the names of family members, caregivers, professionals, institutions or organisations.

What title would you give this experience?

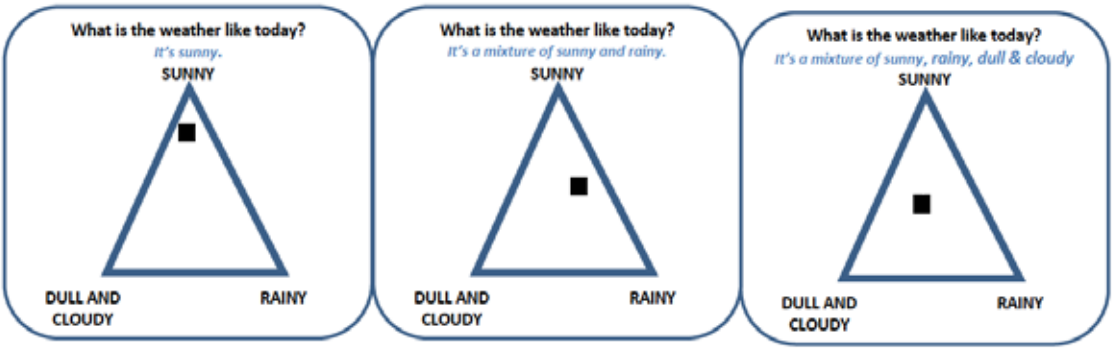
Title: _____

Understanding the Experience

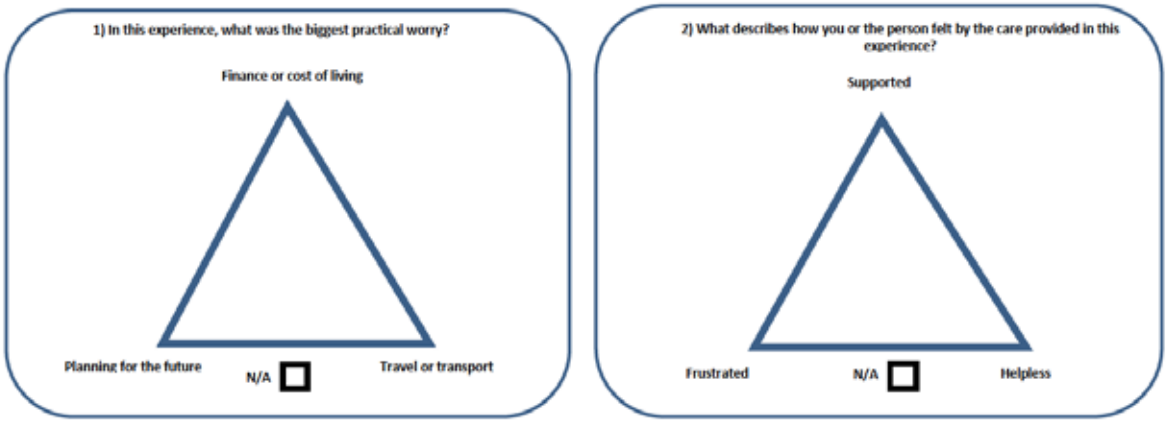
This next section will ask you eight questions about this experience as well as asking you to tick some background information.

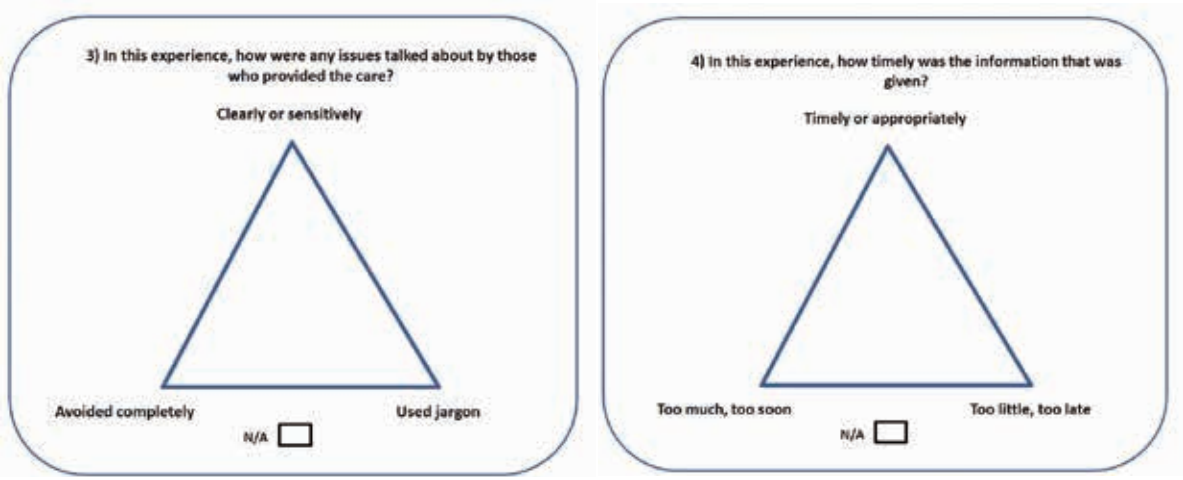
Please mark each triangle question to show what best fits your experience. You may mark the spot anywhere on the triangle.

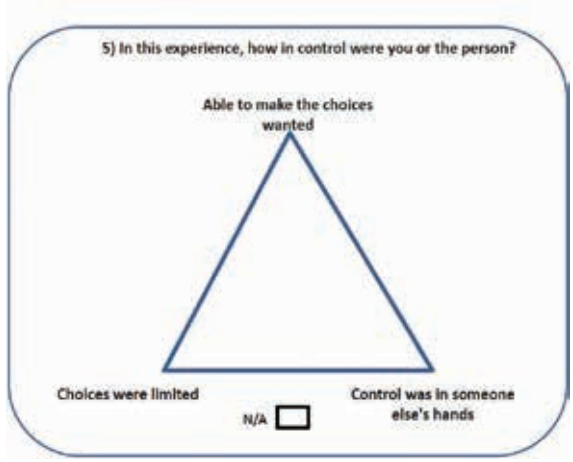
Examples of triangle questions about the weather

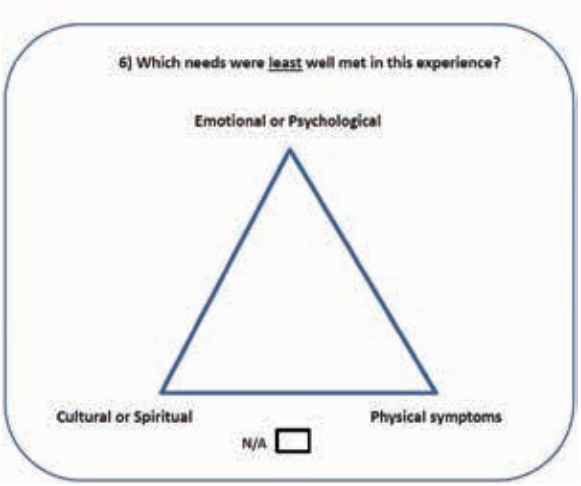


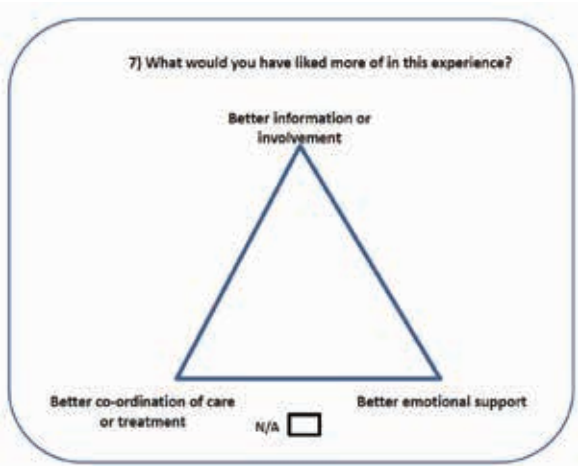
Put your mark within each triangle statement to where you feel it best describes your story. The closer the mark to any one statement, the stronger that statement is in the context of the story. If none of the statements apply to your experience, then please tick the N/A (not applicable) box.

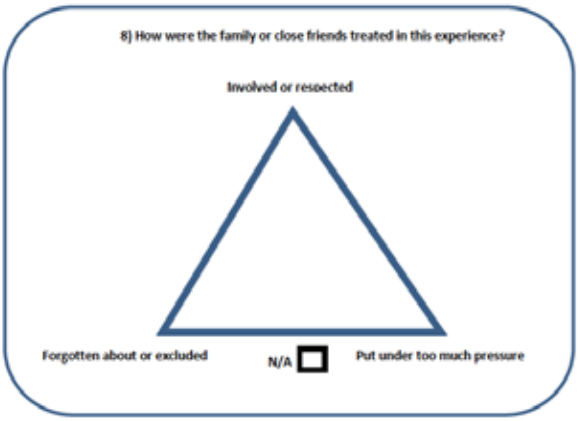












If you would like to, list up to 3 *words or phrases* that describe the key themes in this experience:

1 _____

2 _____

3 _____

Background Questions about the Person with the Medical Condition

Background Questions about the Person with the Medical Condition

Location: Please tick where the person with the condition lives or lived:
ROI Republic of Ireland
NI Northern Ireland

LOCATION (ROI) or (NI)		√
Antrim	(NI)	
Armagh	(NI)	
Carlow	(ROI)	
Cavan	(ROI)	
Clare	(ROI)	
Cork	(ROI)	
Donegal	(ROI)	
Down	(NI)	
Dublin	(ROI)	
Fermanagh	(NI)	
Galway	(ROI)	
Kerry	(ROI)	
Kildare	(ROI)	
Kilkenny	(ROI)	
Laois	(ROI)	
Leitrim	(ROI)	
Limerick	(ROI)	
Longford	(ROI)	
Londonderry	(NI)	
Louth	(ROI)	
Mayo	(ROI)	
Meath	(ROI)	
Monaghan	(ROI)	
Offaly	(ROI)	
Roscommon	(ROI)	
Sligo	(ROI)	
Tipperary	(ROI)	
Tyrone	(NI)	
Waterford	(ROI)	
Westmeath	(ROI)	
Wexford	(ROI)	
Wicklow	(ROI)	

Age:	✓
18 – 29 years	
30 - 39 years	
40 – 49 years	
50 – 59 years	
60 - 69 years	
70 – 79 years	
80 – 89 years	
90 +	

Gender:	✓
Male	
Female	
Transgender	
Prefer not to comment	

Ethnic or Cultural Background:	✓
White	
➢ White	
➢ Traveller	
➢ Any other White background	
Black	
➢ Black	
➢ African	
➢ Any other Black background	
Asian	
➢ Asian	
➢ Chinese	
➢ Any other Asian background	
Any other Background	

Where was the person living at the time of this experience	✓
In their own or family members home	
In Hospital	
In Nursing home	
In Residential home	
In Hospice	
Any Other	

To the best of your knowledge, please tick the box or boxes below which best describes the illness/condition that relates to the experience of the person involved (you can tick more than one box, if applicable)

ILLNESS/CONDITION	✓
Respiratory disease which is advanced *(such as COPD, Emphysema, pulmonary fibrosis and cystic fibrosis)*	
Cancer	
Haematological Malignancy	
Chronic Kidney Disease	
Dementia	
Frailty	
Heart Failure	
Parkinson's Disease	
Progressive Neurological Disorders *(such as Motor Neurone Disease, Multiple Sclerosis, Huntington's Disease, Neurological Palsy)*	
Other (please specify):	

People who were involved in providing care (please tick all that apply)

PEOPLE PROVIDING CARE	✓		✓
Chaplain		Psychologist	
Counsellor		Radiographer	
Dietitian		Social Worker	
General Practitioner (GP)		Specialist hospital based service	
Health Care Assistant		Specialist palliative care service	
Home help/Domiciliary Care Provider		Specialist community based service	
Medical Consultant		Speech and Language Therapist	
Nurse		Volunteer (Hospice)	
Occupational Therapist		**Other (please specify) :**	
Pharmacist			
Physiotherapist			

Thank you for sharing your experience. Your experience along with others will be used to help improve services.

Each story is valuable. Hundreds of stories will be powerful.

Write about as many experiences as you wish, but please use a new survey for each experience. You can complete the survey from February to the end of May either online at www.letstalk-about.org or on this paper copy with the Freepost envelope supplied. If you need extra paper copies of this survey, please email or phone us at the contact details below and provide your name and address (these details will be used for mailing purposes only).

The role of All Ireland Institute of Hospice and Palliative Care (AIIHPC) is to improve the experience of care – more information at www.aiihpc.org. The ***let's talk about survey*** will provide evidence of what matters to individuals living with a serious or progressive medical condition that is unlikely to be cured. If you have a query please contact us at +353 1 491 2948 or email us at info@aiihpc.org

AIIHPC
All Ireland Institute of Hospice and Palliative Care

We comply with all relevant legislation in accordance with the Data Protection (Amendment) Act 2003 (Ireland) and the Data Protection Act 1998 (U.K.)

Appendix III: Correlations[32]

The SenseMaker software enables an exploration of relationships between responses in the different triangle questions. The Let's Talk About data was tested for significant correlations.

The strongest correlation relationships were between Question 2 and Questions 3, 4 and 5. A relationship was also found between responses to Questions 6 and 7.

Questions 2 and 3

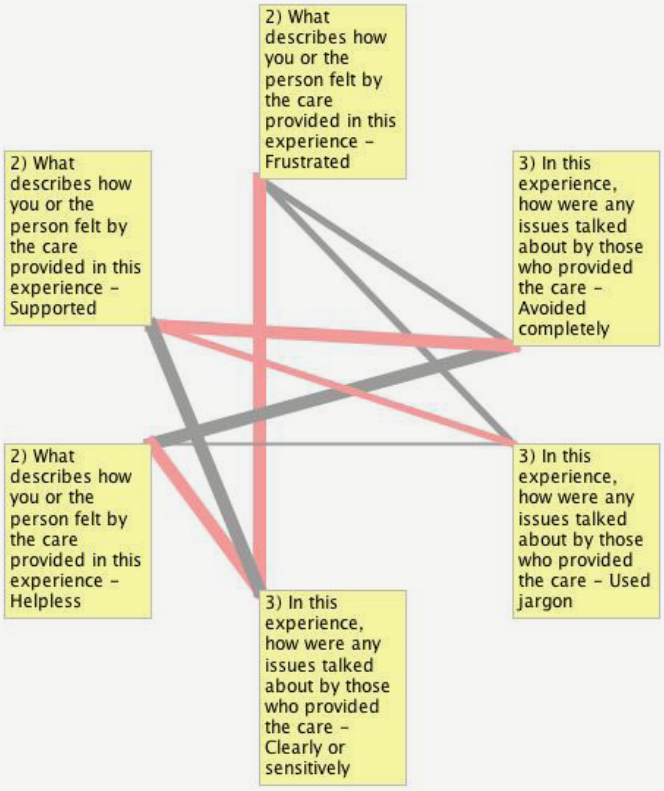
Question 2 tested for the individual's feelings about the care they received: What describes how you or the person felt by the care provided in this experience? The answer choices were *Frustrated, Supported, Helpless and N/A*.

Question 3 tested for communication: In this experience, how were any issues talked about by those who provided the care? The answer choices were *Avoided completely, Clearly and sensitively, Used jargon and N/A*.

The responses to Question 2 and Question 3 show that where issues were avoided completely there was a higher likelihood of feeling frustrated and helpless. Likewise, there was also a higher likelihood of these feelings being experienced when jargon was used. Survey respondents indicated less likelihood of feeling supported where issues were avoided completely.

The correlations suggest that communication increases the feeling of being supported when issues are not avoided and are discussed with the person in a clear and sensitive manner.

The positive correlation between responses to Question 2 and Question 3 is shown in the visual relationships map in the diagram below.



The grey lines show a positive correlation, i.e. if this behaviour is present then it is more likely that certain other behaviours are present.

The pink lines show a negative correlation i.e. if this behaviour is present, then is less likely that the other factors are present.

The thicker the line visually, the stronger the relationship.

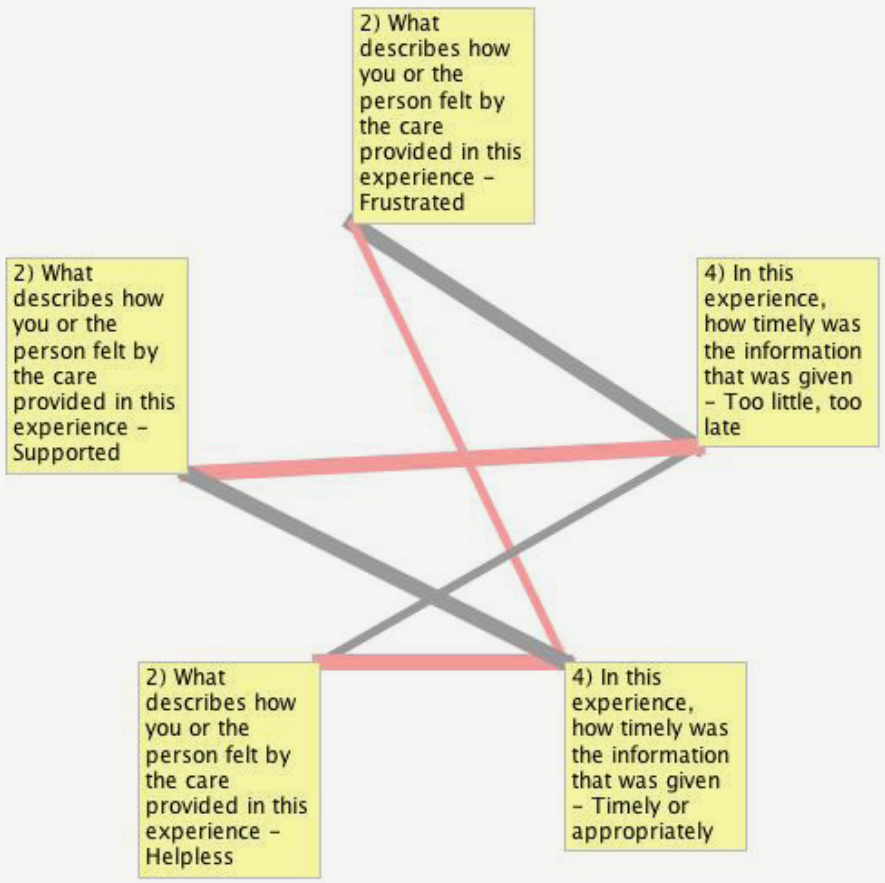
32 This information detailing correlations between the data was prepared by Ms Anne McMurray, Director, Anne McMurray Development Ltd (www.annemcmurray.com).

Questions 2 and 4

Question 4 in the survey tests for the timeliness and quality of information being provided: In this experience, how timely was the information that was given? The answer choices were *Too much, too soon, Timely or appropriately, Too little, too late and N/A*.

When information was given timely or appropriately, survey respondents indicated a higher likelihood of feeling supported and where information is given too little, too late they were more likely to feel frustrated and helpless.

There are correlations between responses to Question 2 and Question 4 shown in the diagram below.



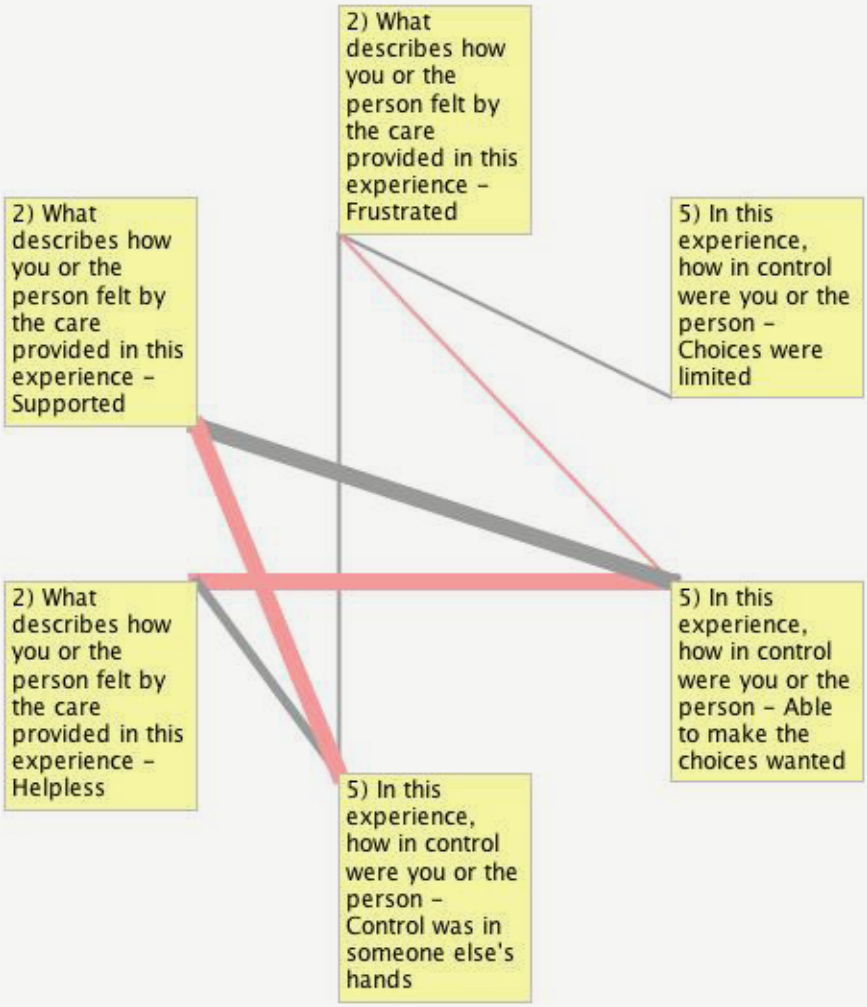
There is a positive correlation between information being *Timely or appropriately* with feeling *Supported* (0.667).

There is a positive correlation between information given *Too little, too late* and feeling *Frustrated* (0.423) and *Helpless* (0.423).

Questions 2 and 5

Question 5 in the survey tests for the degree of choice and control the individual experienced in the situation: In this experience, how in control were you or the person? The answer choices were *Choices were limited, Able to make the choices wanted; Control was in someone else's hands and N/A*.

Where survey respondents indicated being able to make the choices wanted, they were more likely to have felt supported, and where control was in someone else's hands they were more likely to feel helpless and frustrated.



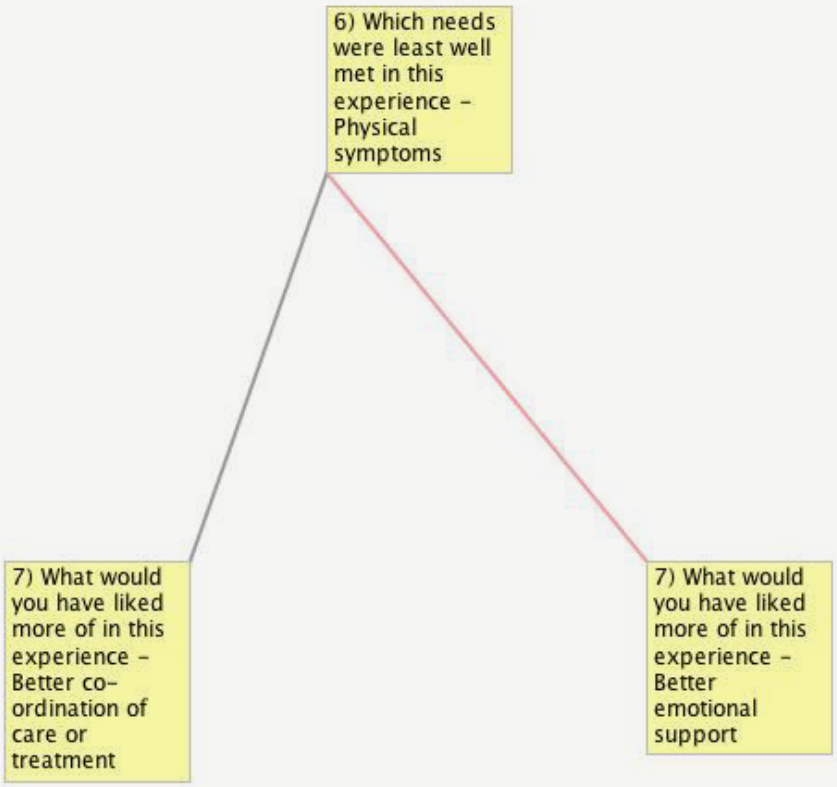
The correlations between Question 2 and Question 5 show a positive correlation between being *Able to make the choices I wanted* with feeling *Supported* (0.599).

There is also a positive correlation between feeling *Control was in someone else's hands* with feeling *Helpless* (0.354) and *Frustrated* (0.384).

Questions 6 and 7

Finally there is a correlation between Question 6: Which needs were least well met in this experience? The answer choices were: *Cultural or Spiritual; Emotional or Psychological; Physical Symptoms and N/A*; and Question 7: What would you have liked more of in this experience? The answer choices were: *Better co-ordination of care or treatment; Better Information or involvement; Better emotional support and N/A*.

Where survey respondents indicated the need for better co-ordination of care and treatment there was more likelihood of their physical symptoms being least well met. Where physical symptoms were least well met there was more likelihood of needing better emotional support.



There is a positive correlation in Question 6 between needing *Better co-ordination of care and treatment* (0.314) and *Physical Symptoms* being least well met. There is a negative correlation between *Physical symptoms* and needing *Better emotional support.*

Key Messages

In summary, the analysis of the correlations between the 528 responses highlights particular aspects which can improve the experience of the individual living with a life-limiting condition.

The resultant key messages are that:

- Avoidance of talking about the issues increases frustration and helplessness,
- Information given too little, too late increases frustration and helplessness,
- Clear and sensitive communication increases the feeling of being supported,
- Ability to make choices increases the feeling of being supported,
- Better co-ordination of care and treatment helps with physical symptom management.

AIIHPC

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