

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

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 (AIHPC) in 2014 and 2015.

Let's Talk About was developed in the context of the overall aim of AIHPC 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 AIHPC'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.



A handwritten signature in black ink, appearing to read 'K. Charnley', written over a horizontal line.

Karen Charnley
Head of AIHPC
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 difference 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!



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