



# AIHPC

All Ireland Institute of  
Hospice and Palliative Care

## Public Awareness Campaign 2016

*6 December 2016*



Report on Public Awareness Raising  
**Palliative Care Week 2016, October 3-8.**

Prepared by Ronan Cavanagh, Cavanagh Communications, and Karen Charnley,  
Gareth Wescott and Brendan O'Hara, AIHPC

## TABLE OF CONTENTS

1. Summary.....	3
2. Campaign Overview.....	4
3. Campaign Development.....	6
4. Campaign Impact.....	9
5. Commentary.....	11

## APPENDICES

Appendix A: Reference Group Members.....	12
Appendix B: Information Materials.....	14
Appendix C: News Releases.....	16
Appendix D: Media coverage.....	22
Appendix E: Public Awareness Survey Findings.....	24



## 1. SUMMARY

All Ireland Institute of Hospice and Palliative Care (AIHPC) ran the third annual Palliative Care Week, a dedicated campaign to raise greater public awareness and understanding of palliative care, across the island of Ireland from 3-8 October 2016.

Building on the success and learning of the campaigns in 2014 and 2015, a decision was made to place a special emphasis in the 2016 campaign on social media and engagement with the palliative care sector.

The campaign was developed with guidance and input from a Campaign Reference Group that was representative of the sector across the Republic of Ireland and Northern Ireland.

### Top line Outcomes

- The campaign had by far its most successful year to date on social media in 2016.
  - The campaign hashtag #pallcareweek was repeatedly the top trending item on social media on the island of Ireland during the week.
  - #pallcareweek was the second most used hashtag overall over the entire week.
  - Twitter activity included 720 posts, 255 users, 535,000 reach and 4.24m impressions.
  - A Thunderclap used to kick off the week had a social reach of 195,485.
- The campaign had its most successful year to date in terms of information events hosted by partners or stakeholders. The Institute supported four major conferences as well as providing Palliative Care Week information packs to approximately 400 organisations. Additional promotional materials were provided to 25 contacts to support awareness raising events and activities across the island.
- 30 newspaper articles were published, 29 radio interviews broadcast and 19 articles published online – a significant increase on 2014.
- There were 1,923 page views on the campaign website which was housed on [www.thepalliativehub.com](http://www.thepalliativehub.com), including 839 unique users.
- The goodwill and support built up by the campaign in previous years was significantly grown among the sector and secured for future campaigns.

Palliative Care Week 2016 was delivered for a cost of €30,300 / £26,300.





## Audiences

- The General Public (inc. patients, families and carers)
- Partners, stakeholders, health and social care professionals, hospices, hospitals, Foundations, Trusts, the Health Service Executive (HSE) and the Public Health Agency (PHA) etc.

## Reference Group

To develop and agree the Key Messages, AllHPC established a Reference Group which was representative of the sector north and south. The Terms of Reference for the Group were to advise on a campaign which:

- Identifies messages and content which are representative of thinking across the sector
- Is reflective of patient perspectives
- Integrates harmoniously with messages and activities of other stakeholders in the sector.

Engagement with the group included email circulars at two critical points:

- Feedback on first set of campaign Key Messages and Design proofs
- Feedback on revised / second set of campaign Key Messages and Design Proofs.

The members of the Reference Group, which was significantly expanded on previous years, are in **Appendix A**.

## Key Messages

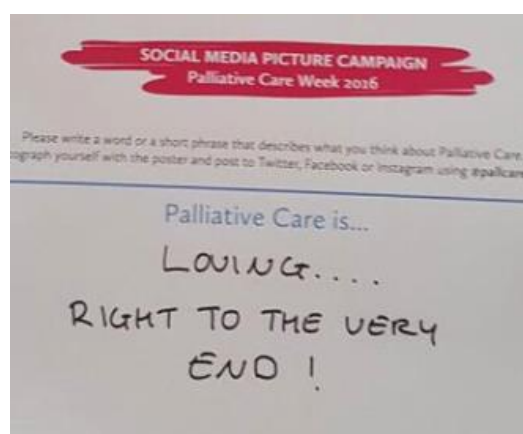
Following consultation with the Reference Group, the Key Messages for the campaign were:

### *Palliative Care...*

- Ensures best possible quality of life for a person with a serious and progressive condition, regardless of age or condition
- Involves the person and those close to them
- Supports planning for the future
- May be appropriate for a number of years, not just the weeks and days at the end of life
- Puts the person at the centre of care whether it is provided at home, in a nursing home, hospital or hospice.

### *Find out more...*

- Palliative Care Week takes place from **October 3-8** across the Republic of Ireland and Northern Ireland
- Go to [www.thepalliativehub.com](http://www.thepalliativehub.com)



### 3. CAMPAIGN DEVELOPMENT

#### Resourcing

##### Communications Consultant

AllHPC recruited Communications Consultant Ronan Cavanagh, Cavanagh Communications, for the third consecutive year, to support Palliative Care Week, working with an AllHPC team including Karen Charnley, Gareth Wescott and Brendan O'Hara.

Regular Team Meetings were held and a Work Plan agreed and regularly updated and revised.

##### Design & Print

Dublin based agency *Engage Communications* was recruited to design and print the materials.

##### @Ireland Social Media Account

The @Ireland Social Media Account was secured by the campaign for the week for the first time. Resourcing the considerable time required to do this was mainly delivered internally by Gareth Wescott with additional input from Rebecca Lloyd of Milford Care Centre and John Kenny of Culture Head.

(The @Ireland Account is a curated twitter account which has been set up voluntarily to promote and represent Ireland through the thoughts and experiences of others. It has 45K followers and rotates to different people each week.)

#### Information Materials

The following information materials were designed:

- A campaign logo
- A 'Communications Toolkit' cover letter
- A leaflet (A5)
- 3 vignette story A4 Posters
- 3 vignette story web banners
- A social media campaign picture frame sheet
- Web friendly formats of each of the above.

Approximately 400 hardcopy packs of printed materials were posted to a range of partners, organisations supporting people with specific conditions, and supportive organisations across the community and voluntary sector. The packs included:

- Communications Toolkit
- 3 Information Leaflets
- 3 posters
- 2 Social Media Campaign Photo Sheets

In addition to the packs, more than 1,500 leaflets were provided to 25 contacts across the island to support various awareness raising activities, for example, for conferences, and at stands in health care buildings, universities and other facilities during Palliative Care Week.

The information materials can be viewed in **Appendix B**, or at [www.thepalliativehub.com](http://www.thepalliativehub.com).

## Campaign Briefings

Four 'Campaign Briefing' emails were issued via Mailchimp to AllHPC's email database of 1,300.

## Media

Two campaign news releases were issued to all relevant media – print, radio, TV and online. Tailored versions of the releases were prepared and issued for media north and south.

The first news release, issued three weeks in advance of the campaign, announced that it was coming up and used findings from the Public Awareness Survey drawing attention to the fact that more than 50% of respondents in both jurisdictions said that they had a basic or minimal understanding of Palliative Care.

The second news release, issued the day before the campaign began, also drew from the Public Awareness survey and highlighted a need for a greater understanding of the holistic nature of Palliative Care.

The news releases incorporated comments from the Health Service Executive and the Public Health Agency and the second releases included endorsement of the Palliative Care Week Campaign and a comment from the Health Minister in the north and the Minister of State for Mental Health and Older People in the south.

The campaign news releases can be viewed in **Appendix C**.

## Website

The Public Awareness website pages at [www.thepalliativehub.com](http://www.thepalliativehub.com) were populated to include new content and messaging for the 2016 campaign including:

- All of the campaign materials
- 5 new 40 second videos tackling myths in understanding of palliative care ([Link](#))
- A new three minute videoscribe titled 'Understanding Palliative Care' was developed by AllHPC and the Northern Health and Social Care Trust ([Link](#))
- A podcast comprising a 30 minute interview on Highland Radio, which took place as part of Palliative Care Week 2015, and was shortlisted for an Irish Broadcasting Award ([Link](#))
- Updated 'Introduction to Palliative Care' e-Learning course targeted at the general public ([Link](#))

## Social Media

All campaign materials and activity promoted use of the hashtag #pallcareweek.

### Tweets

Tweets using the key messages of the campaign were prepared in advance and issued by AllHPC in the lead into and during the week. These Tweets were also issued to the campaign database by email and included in the Communications Toolkit and were Tweeted by many supporters.

A particular focus was placed on social media activity in 2016. This included the following new activities:

### A Thunderclap

A thunderclap gets as many followers as possible to sign up to having an agreed message sent out from their account at an agreed time which creates a mass of activity and focus on social media.

## A Word Cloud

We invited followers and the campaign database via social media and email to submit electronically two or three words that described their opinion on what palliative care is. These answers were collected to create a Word Cloud over the week.

## Social Media Photo Campaign

We supplied a picture frame sheet in both hardcopy and online and asked people to write a word or phrase to describe what they think about palliative care. We then encouraged people to photograph themselves with the frame and post to Twitter, Facebook or Instagram using #pallcareweek

New campaign content and activities such as the videos, the Thunderclap, the Word Cloud and the Photo Campaign also created useful reasons to Tweet campaign information.

## Events

To encourage more information events in 2016, AIIHPC flagged the Week early to partners and key stakeholders. AIIHPC offered small amounts of financial support to partners to support events, for which the Institute invested a total of almost €2,900.

## Costs

The total campaign cost for 2016 was €30,300/£26,300.

This breaks down into:

- Creative Concepts, Design, Production and Print = €7,400
- Communications Consultant = €13,000
- Survey costs = €4,300
- Support for Partner events = €2,900
- Media monitoring and social media = €1,500
- Distribution (Postage etc) = €1,200

Additional time and support was provided by AIIHPC staff and this was absorbed within the Institute's ongoing running costs.



## 4. CAMPAIGN IMPACT

### Information Materials

The campaign Key Messages and Designs were very well received and supported across the sector. In particular, the tone and graphics used were universally received warmly.

### Social Media

#pallcareweek 2016 – The numbers

- 720 individual posts
- 255 people posted
- 535,000 reach – number of accounts who potentially saw #pallcareweek
- 4.2m impressions – number of times #pallcareweek was potentially seen.

For 3 to 9 October 2016 #pallcareweek was the second highest trending item in Ireland:

1. #SpaceWeek16
2. #pallcareweek
3. #HWCH16 (hard working class heroes)
4. #727TourDublin (fifth harmony tour)
5. #COYBIG (Irish Football)

One week after Palliative Care Week 2016 a follow up random sample poll was conducted on Twitter with an unaffiliated, unbiased account and randomly promoted across Twitter in Ireland to ascertain the impact of the campaign on the Twitter population. The active daily user population of Twitter across Ireland is 700,000.

**Question:** Last week was #pallcareweek 2016. We are trying to find out if you heard about it and if it helped you to understand palliative care?

- 8% (56,000) - Yes, I heard about it
- 4% (28,000) - Yes & it helped me learn
- 88% (616,000) - No, I did not hear

Sample Size: 838, Confidence Level 95%, Margin of Error 3.4%

The @ireland account was also used to help promote the Irish Hospice Foundation's campaign "Have your say" and helped to collect over 200 completed surveys.

### Media Profile

- 30 newspaper articles were published, 29 radio interviews broadcast and 19 articles published online (See **Appendix D**).
- There was very strong media coverage in ROI, the highest of any campaign to date, with some high quality content including an Editorial in a national newspaper, Opinion Editorials, case studies and features.
- There was equal effort in media engagement in NI. Some key pieces such as a feature in the *Irish News* and an interview on *BBC Good Morning Ulster* were agreed and set up but unfortunately did not make it to print or air at the final step due to breaking news. Despite the media engagement there was less media coverage in NI.

## Website

During the week The Palliative Hub had the following traffic:

- Total number of sessions - 1,024
- Total number of unique users - 839
- Total number of pageviews - 1,923
- Avg. Session Duration - 00:02:06

The source of this traffic was:

- Direct (Typed in URL) – 323 (31.54%)
- Social (Redirected from social media site) – 315 (30.76%)
- Referral (Linked to from another website/newsletter etc)- 283 (27.64%)
- Organic Search (Google or other search engine) – 103 (10.06%)

## Events

A range of events took place surrounding the week. Many of these occurred at a local level and involved AllHPC's 23 partner organisations. Events with which the Institute was directly involved and/or provided additional promotional materials included:

- Ulster University exhibition and stand on Jordanstown Campus on 3 October 2016 involving the Institute of Nursing & Health Research
- Southern Health and Social Care Trust – ‘Palliative Care: New Approaches Conference’, 5 October 2016, Lough Neagh Discovery Centre, Oxford Island, Craigavon, Co Armagh
- Milford Care Centre, Limerick, hosted events on 6 & 7 October 2016, Castletroy Park Hotel, Limerick:
  - “Making a difference, measuring the difference - International models of quality in palliative care and the Irish context” - 6 October 2016
  - Compassionate Cities International Summit - 7 October 2016.
- Foyle Hospice (Derry/Londonderry) engaged with local students and with the public through a coffee morning on 8 October
- Western Health and Social Care Trust - ‘Choice and Planning with a Life Limiting Illness - what matters?’ – Wednesday 12 October 2016, Silver Birch Hotel, Omagh
- Northern Health and Social Care Trust - Palliative Care Speed Network Event - Wednesday 12 October 2016, The Sandel Centre, Coleraine
- Our Lady’s Children’s Hospital Crumlin, Dublin, had information events throughout the week
- Other organisations for which Palliative Care Week materials were provided for promotional events included: Marymount University Hospital and Hospice, Cork; Mayo General Hospital; St James Hospital, Dublin; North West Regional College, Derry/Londonderry; South Eastern Health and Social Care Trust; Sligo University Hospital; Galway Hospice; Naas General Hospital, Kildare; Dungloe Community Hospital, Donegal; Donegal Hospice; Health Centre, Glenties, Donegal; Midlands Regional Hospital; Marie Curie, Belfast; Our Lady’s Hospice, Dublin; Home Instead Senior Care.

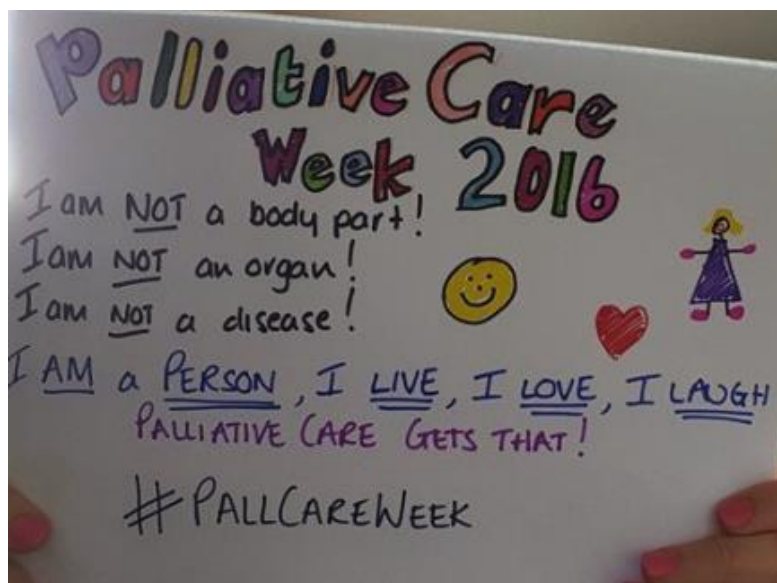
#### 4. COMMENTARY

Palliative Care Week 2016 was a success and delivered strong impact and return for the level of investment.

The progress made in 2016 puts the campaign in a strong position to move forward into future years.

Some learning from the campaign and elements to consider for future development include:

- Social media is a very strong tool through which to communicate with the sector;
- Strong media profiling links have been developed in the Republic of Ireland, but this needs to be grown in Northern Ireland;
- The timing of the week should be considered carefully. In 2016 it came shortly after Hospice Week in the RoI and the same week as UK Hospice Week in NI. However, the link with WH&PCD worked well. The timing did not pose any overt problem for the campaign in 2016, but future scheduling should be made in awareness of the other initiatives;
- A physical 'flag' prop for the campaign could be considered such as the 'pink ribbon' for breast cancer, daffodil for cancer or heart pin for heart disease. This may assist the campaign in developing its presence as a strong long term identity and branding with a distinct annual presence;
- A specific public facing activity such as an art, poetry, or photography competition or travelling exhibition on the theme of palliative care could be considered for future years, though this may raise resource issues.



## 5. APPENDICES

### Appendix A: Reference Group Members

#### Communication contacts from Council of Partner Organisations

Anne-Marie Hayes	Milford Care Centre
Jane Flynn	Irish Hospice Foundation
Claire Bradshaw	Northern Ireland Hospice
Dee Kinane	St Francis Hospice
Eleanor Flew	Our Lady's Hospice and Care Services
Michael Craig	Galway Hospice Foundation
Sarah Meagher	Lauralynn Ireland's Children's Hospice
Terri Sythes	Foyle Hospice
Irene Hegarty	Marymount University Hospital & Hospice
Gareth Colhoun	Marie Curie
Jeanne McDonagh	Our Lady's Hospice and Care Services

#### Council of Partners

Alan Corry Finn	Western Health and Social Care Trust
Angela McVeigh	Southern Health and Social Care Trust
Anne Molloy	Voices4Care
Anthony Staines	Dublin City University
Audrey Houlihan	Our Lady's Hospice and Care Services
Brenda Creaney	Belfast Health and Social Care Trust
Catherine Sweeney	University College Cork
Charles Normand	University of Dublin Trinity College
Donall Henderson	Foyle Hospice
Eamon O'Kane	Marie Curie
Eithne Frost	Voices4Care
Heather Weir	Northern Ireland Hospice
Karen Ryan	St Francis Hospice
Laura Dempsey	National University of Ireland Galway
Marian Traynor	Queen's University Belfast
Mary Nash	Galway Hospice Foundation
Pat Quinlan	Milford Care Centre
Philip Larkin	University College Dublin School of Nursing & Midwifery
Sharon Foley	Irish Hospice Foundation
Sharon Morrow	LauraLynn Ireland's Children's Hospice
Siobhan McCarthy	Royal College of Surgeons in Ireland
Sonja McIlfratrick	Ulster University
Tony O'Brien	Marymount University Hospital & Hospice
Una Cuning	Northern Health and Social Care Trust

#### Service Improvement Leads

Aileen Mulligan	Southern Health and Social Care Trust
Louise Hagan	Belfast Health and Social Care Trust
Emma King	Western Health and Social Care Trust
Fiona Gilmour	Northern Health and Social Care Trust
Ray Elder	South Eastern Health and Social Care Trust

#### Other contacts

Fidelma Browne	Health Service Executive
Corrina Grimes	Public Health Agency
Helen Mallen	Patient and Client Council
Maeve Hully	Patient and Client Council
Megan Perry	Public Health Agency

Una Daly	Northern Ireland Hospice
Sheilagh Reaper-Reynolds	Health Service Executive
Paul Turley	Health and Social Care Board
Greg Price	Health Service Executive
Diane Walker	Marie Curie
Carmel Geoghegan	Voices4Care
Paul McIvor	Foyle Hospice
Kiran Kaur	Belfast Health and Social Care Trust and Northern Ireland Hospice
Sarah McCloskey	Marymount University Hospital & Hospice
Kathy McLoughlin	Milford Care Centre
Regina McQuillan	St Francis Hospice
Eileen Wright	Voices4Care

## Appendix B: Information Materials

The Campaign Information Materials can be downloaded and viewed in full quality at [www.thepalliativehub.com](http://www.thepalliativehub.com)

### INFORMATION LEAFLET

### COMMUNICATIONS TOOLKIT

## POSTERS



## SOCIAL MEDIA PICTUREFRAME



## WEB BANNERS



## Appendix C: News Releases

### Release 1 - Rol Version

Issued by All Ireland Institute of Hospice and Palliative Care  
Sunday, September 11, 2016

#### **Palliative Care is Still Largely Misunderstood by the Public**

##### **Survey highlights need for greater understanding of the benefits of Palliative Care**

More than half of adults surveyed in Ireland (55%) report that they have a basic or minimal understanding of what palliative care involves.

Eighty-five percent of respondents did not believe that there is sufficient public understanding of palliative care.

The results of the survey, commissioned by All Ireland Institute of Hospice and Palliative Care (AIHPC) earlier this month, were announced today at the launch of Palliative Care Week which will take place across the island of Ireland from October 3-8.

Head of Institute at AIHPC Karen Charnley said the survey showed the need for greater public education on the benefits of palliative care and when it is appropriate.

“By focussing on meeting people with life limiting condition’s physical, social, emotional and spiritual needs and involving friends and family, palliative care helps maintain quality of life.

“We want to raise awareness that palliative care can benefit the quality of life of any person with a life-limiting or life-shortening illness. Palliative care puts the individual at the centre of every decision, helping them to make choices and supporting their families and carers.

“It is very important that the public are well informed and feel comfortable to discuss their concerns beyond the diagnosis of illness that cannot be cured.”

Among the 55% with a low level of understanding, 27% identified a basic understanding, 12% a low level and 16% said that they did not understand what palliative care involves at all. Young people (18-34) were more likely to know little about palliative care as 29% reported no level of understanding compared to 12% for 35-54 year olds and 4% among over 55s.

Palliative Care Week is being widely supported by health and social services in the Republic of Ireland.

HSE National Lead for Palliative Care, Sheilagh Reaper-Reynolds encouraged the public to take the opportunity to find out more and to talk about palliative care within families and also with health professionals.

“Through our National Clinical Programme for Palliative Care and by supporting initiatives such as Palliative Care Week, our aim is to alleviate fears and anxieties surrounding palliative care services. This will help ensure that people with life-limiting conditions and their families can easily access the type of palliative care services that best meet their needs.”

Many information events will take place during Palliative Care Week.

Publically focused information about palliative care and Palliative Care Week is available at [www.thepalliativehub.com](http://www.thepalliativehub.com) where a new section for health and social care professionals has been added.

### **Further Information**

Ronan Cavanagh, Cavanagh Communications: 00353 (0) 86 317 9731.  
[www.thepalliativehub.com](http://www.thepalliativehub.com) / [www.aiihpc.org](http://www.aiihpc.org)

### **NOTES to the Editor**

The research was carried out as part of an omnibus survey by iReach Insights on a representative sample of 1000 adults across Ireland.

#### *AIHPC*

The All Ireland Institute of Hospice and Palliative Care (AIHPC) aims to improve end-of-life care and experience on the island of Ireland by enhancing capacity, developing knowledge, promoting learning, influencing policy and shaping practice. AIHPC is comprised of a consortium of Health Agencies and Universities in the North and South of Ireland and its work is focused on three areas – policy & practice, research and education.

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### **Release 1 – NI Version**

Issued by All Ireland Institute of Hospice and Palliative Care  
Monday, September 12, 2016

#### **Palliative Care is Still Largely Misunderstood by the Public**

##### **Survey highlights need for greater understanding of the benefits of Palliative Care**

More than half of adults recently surveyed in Northern Ireland (51%) report that they have a basic or minimal understanding of what palliative care involves.

Eighty-three percent of respondents did not believe that there is sufficient public understanding of palliative care.

The results of the survey, commissioned by All Ireland Institute of Hospice and Palliative Care (AIHPC) earlier this month, were announced today at the launch of Palliative Care Week which will take place across the island of Ireland from October 3-8.

Head of Institute at AIHPC Karen Charnley said the survey showed the need for greater public education on the benefits of palliative care and when it is appropriate.

“By focussing on meeting people with life limiting condition’s physical, social, emotional and spiritual needs and involving friends and family, palliative care helps maintain quality of life.

“We want to raise awareness that palliative care can benefit the quality of life of any person with a life-limiting, or life-shortening illness. Palliative care puts the individual at the centre of every decision, helping them to make choices and supporting their families and carers.

“It is very important that the public are well informed and feel comfortable to discuss their concerns beyond the diagnosis of illness that cannot be cured.”

Among the 51% with a low level of understanding, 29% identified a basic understanding, 4% a low level and 18% said that they did not understand what palliative care involves at all. Young people (18-34) were more likely to know little about palliative care as 28% reporting no level of understanding compared to 13% among over 35s.

Palliative Care Week is being widely supported by health and social services in Northern Ireland.

Public Health Agency (PHA) Allied Health Professions Consultant and Regional Palliative Care Lead, Corrina Grimes encouraged the public to take the opportunity to find out more and to talk about palliative care with those important to them and also with health professionals.

“The Regional Palliative Care Board – ‘Palliative Care in Partnership’ support initiatives such as Palliative Care Week with the aim to help people improve their understanding of what palliative care is and alleviate fears and anxieties which may surround palliative care.

“We hope that people with progressive, advanced or life-limiting conditions and those important to them can have improved quality of life and a positive experience through a palliative care approach and services.”

Many information events will take place during Palliative Care Week.

Publically focused information about palliative care and Palliative Care Week is available at [www.thepalliativehub.com](http://www.thepalliativehub.com) where a new section for health and social care professionals has been added.

#### **Further Information**

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#### **NOTES to the Editor**

The research was carried out as part of an omnibus survey by iReach Insights on a representative sample of 450 adults across Northern Ireland.

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#### **Release 2 – Rol version**

Issued by All Ireland Institute of Hospice and Palliative Care  
Sunday, October 2, 2016

#### **Call for greater understanding of ‘holistic’ nature of Palliative Care**

#### **Public urged to find out more about palliative care during awareness week**

Greater public understanding of how palliative care addresses all needs of the person – physical, social, emotional and spiritual – has been called for, as Palliative Care Week begins today.

A survey of public understanding of palliative care found that the overwhelming majority of people (70%) identified ‘pain management’ as the most important part of a good experience of palliative care.

The survey also found that 35% of people were not aware that palliative care may be suitable for a number of years and 21% were not aware that the approach supports family, friends and carers during an illness and afterwards.

The results of the survey, commissioned by All Ireland Institute of Hospice and Palliative Care (AIHPC), were announced today at the start of Palliative Care Week (October 3-8).

AIHPC, Head of Institute, Karen Charnley said the survey showed the need for greater public understanding of the holistic approach of palliative care and of when it is appropriate.

“We are encouraging a greater understanding of how palliative care encompasses the full human needs of each person – physical, social, emotional and spiritual – to enable the best possible quality of life.

“Palliative care also supports clear and timely communication between patients and health and social care professionals. It places the person at the centre of every decision, helping them to plan for the future and make choices – and works together in these choices with families and carers.

“It is very important that pain management is available and effective, but a good palliative care experience integrates all of these elements of care. Palliative care may be beneficial for a number of years and responds appropriately to the differing needs of people as these change.

“We are urging the public to be informed, to discuss and to plan for all of the needs which a child, adult or older person has following diagnosis of an illness that will shorten or limit their life.”

The survey also found that more than half of adults surveyed in Ireland (55%) reported that they have a basic or minimal understanding of what palliative care involves. Eighty-five percent of respondents did not believe that there is sufficient public understanding of palliative care.

The Minister of State for Mental Health and Older People, Helen McEntee, said she is supporting Palliative Care Week.

“Through our National Clinical Programme for Palliative Care, and by supporting Palliative Care Week, our aim is to alleviate fears and anxieties surrounding palliative care services. This will help ensure that people with life-limiting conditions and their families can access palliative care services that best meet their needs.”

HSE National Lead for Palliative Care, Sheilagh Reaper-Reynolds encouraged the public to find out more and to talk about palliative care within families and with health and social care professionals.

Many information events will take place during the week. Details of these as well as videos, leaflets and other information resources are available at [www.thepalliativehub.com](http://www.thepalliativehub.com).

#### **Further Information**

[www.thepalliativehub.com](http://www.thepalliativehub.com)

Ronan Cavanagh, Cavanagh Communications: (086) 317 9731.

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## Release 2 – NI Version

Issued by All Ireland Institute of Hospice and Palliative Care  
Monday, October 3, 2016

### **Call for greater understanding of ‘holistic’ nature of Palliative Care**

#### **Public urged to find out more about palliative care during awareness week**

Greater public understanding of how palliative care addresses all needs of the person – physical, social, emotional and spiritual – has been called for, as Palliative Care Week begins today.

A survey of public understanding of palliative care in Northern Ireland found that the majority of people (52%) identified ‘pain management’ as the most important part of a good experience of palliative care.

The survey also found that 34% of people were not aware that palliative care may be suitable for a number of years and 20% were not aware that the approach supports family, friends and carers during an illness and afterwards.

The results of the survey, commissioned by All Ireland Institute of Hospice and Palliative Care (AIHPC), were announced today at the start of Palliative Care Week (October 3-8).

AIHPC, Head of Institute, Karen Charnley said the survey showed the need for greater public understanding of the holistic approach of palliative care and of when it is appropriate.

“We are encouraging a greater understanding of how palliative care encompasses the full human needs of each person – physical, social, emotional and spiritual – to enable the best possible quality of life. This year the focus of our campaign is ‘enabling living’.

“Palliative care puts the person at the centre of every decision, helping them to plan for the future and make choices. It is essential that pain management is available and effective. Palliative care integrates all of the person’s needs - physical, social, emotional and spiritual – into their care. Palliative care may be beneficial for weeks, months and years and responds appropriately to the differing needs of people as these needs change.

“We are urging the public to be informed, to discuss, and to plan for all of the needs which a child, adult or older person has following diagnosis of an illness that will shorten or limit their life.”

The survey also found that more than half of adults surveyed in Northern Ireland (52%) reported that they have a basic or minimal understanding of what palliative care involves. 83% percent of respondents did not believe that there is sufficient public understanding of palliative care.

Health Minister Michelle O’Neill said: “Palliative Care Week is an excellent opportunity to increase awareness and understanding about what palliative care is. The focus this year on ‘Enabling Living’ highlights the positive role that an holistic approach to palliative care plays in supporting people living with progressive, advanced or life-limiting conditions, and those important to them, to have improved quality of life, with care that is planned around them and with them. I very much welcome and commend the work that is being taken forward across the island of Ireland to raise awareness of palliative care.”

Public Health Agency (PHA) Allied Health Professions Consultant and Regional Palliative Care Lead, Corrina Grimes encouraged the public to take the opportunity to find out more and to talk about palliative care with those important to them and also with health professionals.

“The Regional Palliative Care Board – ‘Palliative Care in Partnership’ supports Palliative Care Week with the aim of helping people improve their understanding of what palliative care is and how it enables living and supports quality of life to the end of life.”

Many information events will take place during the week. Details of these as well as videos, leaflets and other information resources are available at [www.thepalliativehub.com](http://www.thepalliativehub.com).

**Further Information**

Ronan Cavanagh, Cavanagh Communications: 00353 (0) 86 317 9731.

[www.thepalliativehub.com](http://www.thepalliativehub.com)

**NOTES to the Editor**

The research was carried out as part of an omnibus survey by iReach Insights on a representative sample of 450 adults across Northern Ireland.

**All Ireland Institute of Hospice and Palliative Care (AIHPC)**

All Ireland Institute of Hospice and Palliative Care (AIHPC) is a collaborative of hospices, health and social care organisations and universities on the island of Ireland. AIHPC advances education, research and practice to improve the palliative care experience of people with life limiting conditions and their families.

## Appendix D: Media Coverage

### PRINT

#### Launch

- Irish Independent: Public 'has little knowledge of palliative care'
- Irish Examiner: Call for education on palliative care
- The Herald: Most adults only have 'basic' knowledge of palliative care
- Evening Echo: Palliative care poorly understood by many adults
- Weekly Observer: Palliative Care is Still Largely Misunderstood by the Public
- Irish Catholic: Poor understanding of end-of-life care unsurprising - Bishop Doran
- Limerick Post: Palliative care

#### Palliative Care Week

- Limerick Leader: Palliative care to be focus of week
- Weekly Observer: Public encouraged to find out more about palliative care
- Vale Star: Public encouraged to find out more about palliative care
- Northern Standard: Palliative Care is Still Largely Misunderstood by the Public
- Letterkenny Post: Fundraising drive to top €100k mark
- Clare Champion: Gaining an understanding of palliative care
- Donegal News: 'Causeway' to top €100,000 mark
- Connacht Tribune: Open Evening at Galway Hospice
- Nenagh Guardian: Find out more about palliative care
- IPU Review: Dates for your Diary
- Limerick Post: Palliative care
- Limerick Leader County Edition: Patrickswell
- IPU Review: Survey highlights need for greater understanding of Palliative Care
- Irish Examiner: Life goes on as usual in hospice
- Irish Examiner: Issues we all need to discuss
- Irish Examiner: Public unaware of what palliative care entails
- Irish Independent Tabloid-Health & Living supplement: Last words
- Daily Mirror Eire: Palliative care week begins
- Irish Times: Health and Family Health board
- Evening Echo: Marymount plays big part in palliative care in Cork
- Galway Independent Galway Hospice 'Open Evening'
- Tuam Herald Galway Hospice host open evening
- Anglo Celt: Local News
- Letterkenny Post: Call for greater understanding of 'holistic' nature of Palliative Care

### RADIO

#### Launch

- Newstalk News (nationwide local radio distribution to 27 stations in ROI)
- Q Radio Network (broadcast on six local stations in NI)
  
- Connemara Community Radio
- Dublin City FM
- LMFM
- Midwest Radio
- Near FM
- Youghal Community Radio

### **Palliative Care Week**

- Q Radio Network (broadcast on six local stations in NI)
- Clare FM
- Connemara Community Radio
- Downtown Radio (Belfast)
- Dundalk FM
- East Coast Radio
- Galway Bay FM
- Kildare FM
- Phoenix FM
- Radio Corca Baiscin (Clare)
- South East Radio
- Tipp FM

### **ONLINE**

#### **Launch**

- Irish Independent
- Irishhealth.com
- InTallaght

### **Palliative Care Week**

- Irish Examiner #1
- Irish Examiner #2
- Irishhealth.com
- ehospice
- Journal.ie #1
- Journal.ie #2
- Journal.ie #3
- Clare Champion
- Derry Now
- LymphIreland
- Care Appointments NI
- Irish Medical Directory News
- Activelink x 2
- HSE website Home Page
- PHA website Home Page

## Appendix E: Awareness Survey






For more information, contact Oisín Byrne, Managing Director  
Phone: 01-214-3741 Email: oisín.byrne@ireach.ie

### Palliative Care Study (August 2016 v1.3)




www.ireachinsights.com

### Republic of Ireland



### Palliative Care Study STUDY HIGHLIGHTS (Republic of Ireland)



ROI

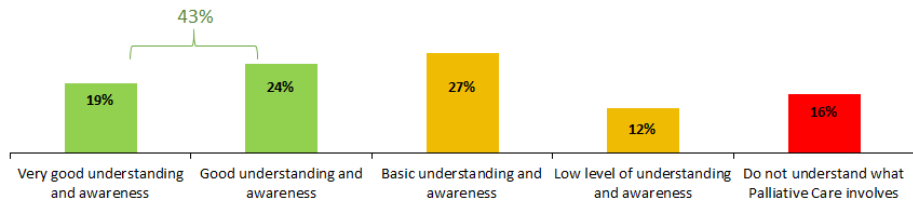
<b>Palliative Care Awareness</b>	Over 4 in 10 (43%) adults (living in Republic of Ireland) have a good (or very good) awareness of Palliative Care. Mature adults 55+ (59%), females (49%) and RoI region (50%) show highest awareness levels of this type of care.
<b>PC - Public Understanding</b>	Only 1 in 6 (15%) think there is sufficient public understanding of Palliative Care, lowest amongst 35-54 year olds in Ireland (12%).
<b>PC - Personal Understanding</b>	Suitable for people of any age (86%); Cares for all aspects of the person (84%); Is beneficial for anyone with a life limiting illness (83%); Should be considered as early as possible (80%); are the statements that the vast majority of respondents recognise as being true.
<b>PC – Factors Determining Good Experience</b>	“Pain relief and physical symptom management” is perceived to be the most important factor (70% choose it over other factors) that would help a person have a good experience of palliative care. “Care for the emotional, social and spiritual needs of the person” is perceived as the second most important factor (13%).

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Over 4 in 10 (43%) adults (living in Republic of Ireland) have a good (or very good) awareness of Palliative Care. Mature adults 55+ (59%), females (49%) and RoL region (50%) show highest awareness levels of this type of care.



### Palliative Care - Awareness



	Male	Female	18-34	35-54	55+	ABC1	C2DE	Dublin	RoL	Munster	C/U
Very good understanding and awareness	19%	19%	17%	19%	25%	19%	19%	22%	21%	12%	25%
Good understanding and awareness	19%	30%	18%	26%	34%	26%	23%	20%	29%	31%	19%
Basic understanding and awareness	24%	31%	26%	28%	28%	32%	22%	28%	29%	28%	23%
Low level of understanding and awareness	16%	9%	10%	15%	9%	12%	14%	12%	11%	15%	8%
Do not understand what Palliative Care involves	22%	11%	29%	12%	4%	11%	22%	18%	10%	14%	25%

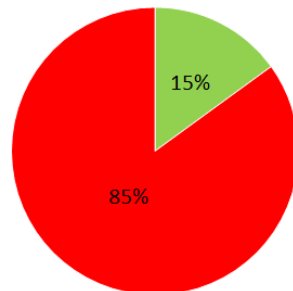
Q: Which of the following best describes your level of understanding and awareness of Palliative Care? (Single select, n = 1,013)

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Only 1 in 6 (15%) think there is sufficient public understanding of Palliative Care, lowest amongst 35-54 year olds in Ireland (12%).



### Palliative Care – Public Understanding



■ YES ■ NO

Male	Female	18-34	35-54	55+	ABC1	C2DE	Dublin	RoL	Munster	C/U
13%	16%	16%	12%	20%	17%	13%	13%	19%	16%	12%
87%	84%	84%	88%	80%	83%	87%	87%	81%	84%	88%

Q: Do you think there is sufficient general public understanding of Palliative Care? (Single select, n = 1,013)

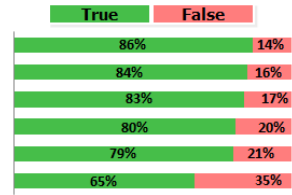
www.ireachinsights.com

Suitable for people of any age (86%); Cares for all aspects of the person (84%); Is beneficial for anyone with a life limiting illness (83%); Should be considered as early as possible (80%); are the statements ranked strongly.



**Palliative Care – Personal Understanding**

Is suitable for people of any age  
 Cares for all aspects of the person – physical, social, emotional and spiritual  
 Is beneficial for anyone with a life limiting illness  
 Should be considered as early as possible when diagnosed with a life limiting illness  
 Supports family, friends and carers during an illness and afterwards  
 May be suitable for a number of years



	Male	Female	18-34	35-54	55+	ABC1	C2DE	Dublin	RoL	Munster	C/U
Is suitable for people of any age	81% 19%	92% 8%	80% 20%	89% 11%	92% 8%	88% 12%	85% 15%	85% 15%	90% 10%	89% 11%	79% 21%
Cares for all aspects of the person – physical, social, emotional and spiritual	81% 19%	86% 14%	78% 22%	85% 15%	91% 9%	86% 14%	81% 19%	83% 17%	84% 16%	84% 16%	85% 15%
Is beneficial for anyone with a life limiting illness	79% 21%	87% 13%	72% 28%	88% 12%	91% 9%	83% 17%	83% 17%	77% 23%	85% 15%	89% 11%	84% 16%
Should be considered as early as possible when diagnosed with a life limiting illness	79% 21%	80% 20%	74% 26%	82% 18%	85% 15%	79% 21%	81% 19%	77% 23%	82% 18%	82% 12%	81% 19%
Supports family, friends and carers during an illness and afterwards	73% 27%	85% 15%	68% 32%	83% 17%	91% 9%	83% 17%	75% 25%	75% 25%	81% 19%	82% 18%	80% 20%
May be suitable for a number of years	66% 34%	63% 37%	65% 35%	64% 36%	66% 34%	63% 37%	67% 33%	64% 36%	63% 37%	66% 34%	67% 33%

Q: Are the following statements either true or false about Palliative Care? (Multiple select, n = 1,013)

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“Pain relief and physical symptom management” is perceived to be the most important factor (70% choose it over other factors) that would help a person have a good experience of palliative care. “Care for the emotional, social and spiritual needs of the person” is perceived as the second most important factor (13%).



**Factors Determining Good Experience of Palliative Care**

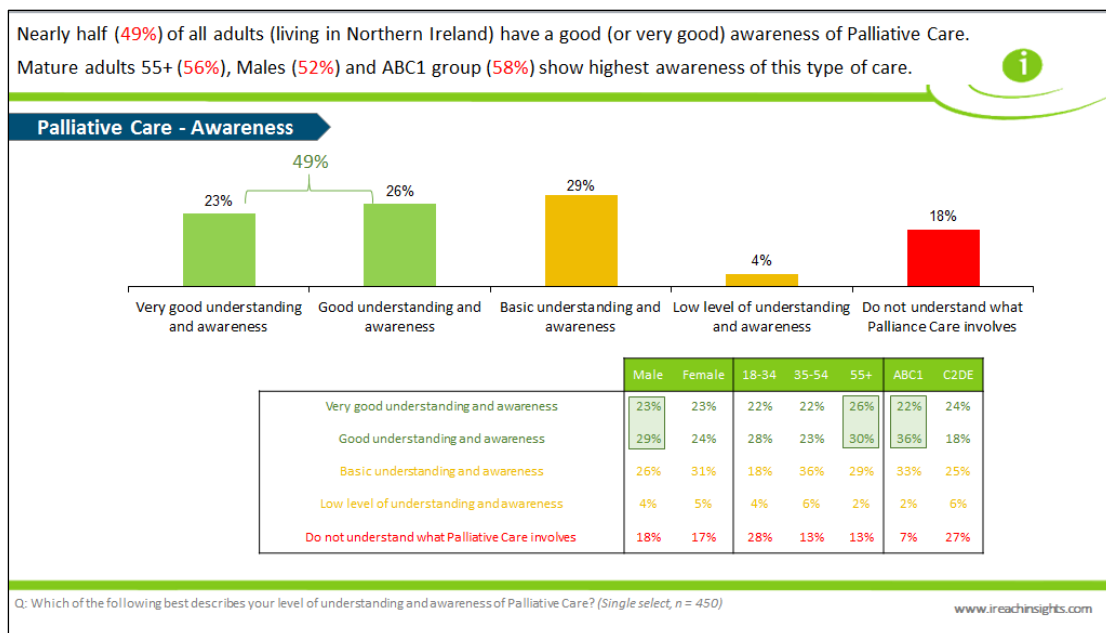
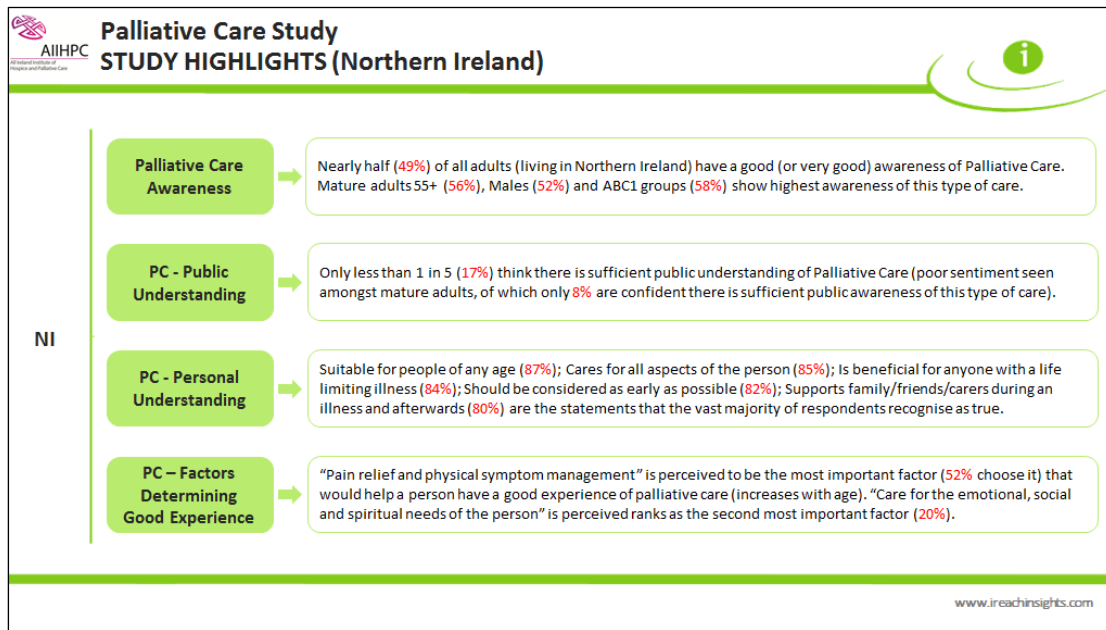


	Male	Female	18-34	35-54	55+	ABC1	C2DE	Dublin	RoL	Munster	C/U
Pain relief and physical symptom management	70%	70%	70%	70%	68%	73%	66%	69%	67%	67%	78%
Care for the emotional, social and spiritual needs of the person	11%	16%	14%	14%	10%	15%	11%	15%	14%	14%	9%
Support for patients to plan for the future and to make their own choices	4%	6%	2%	7%	9%	5%	6%	4%	3%	8%	6%
Regular communication with health professionals	8%	3%	5%	5%	6%	3%	8%	6%	5%	6%	2%
Co-ordination of health and social care services	4%	3%	5%	3%	4%	3%	5%	5%	5%	4%	1%
Support and guidance for family and carers	3%	2%	4%	1%	3%	1%	4%	1%	6%	1%	4%

Q: Can you rank in order of importance what you think would help a person have a good experience of palliative care. Please rank (drag and drop) between 1 = most important and 5 = least important. (Ranking = 1,013)

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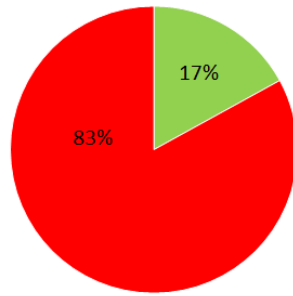
## Northern Ireland



Less than 1 in 5 (17%) think there is sufficient public understanding of Palliative Care (poor sentiment seen amongst mature adults, of which only 8% are confident there is sufficient public awareness of this type of care).



### Palliative Care – Public Understanding



■ YES ■ NO

Male	Female	18-34	35-54	55+	ABC1	C2DE
17%	16%	20%	20%	8%	20%	14%
83%	84%	80%	80%	92%	80%	86%

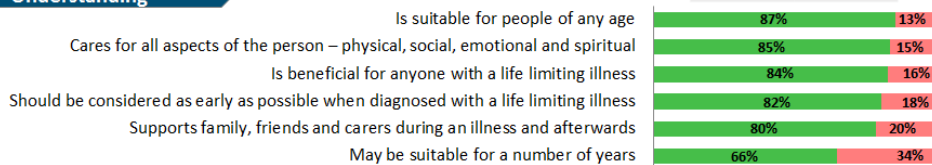
Q: Do you think there is sufficient general public understanding of Palliative Care? (Single select, n = 450)

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Suitable for people of any age (87%); Cares for all aspects of the person (85%); Is beneficial for anyone with a life limiting illness (84%); Should be considered as early as possible (82%); Supports family/friends/carers during an illness and afterwards (80%) are the statements that the vast majority of respondents recognise as true.



### Palliative Care – Personal Understanding



	Male	Female	18-34	35-54	55+	ABC1	C2DE
Is suitable for people of any age	83% 17%	94% 6%	82% 18%	91% 9%	94% 6%	89% 11%	84% 16%
Cares for all aspects of the person – physical, social, emotional and spiritual	83% 17%	88% 12%	80% 20%	82% 18%	92% 8%	87% 13%	79% 21%
Is beneficial for anyone with a life limiting illness	81% 19%	89% 11%	78% 22%	85% 15%	91% 9%	83% 17%	86% 14%
Should be considered as early as possible when diagnosed with a life limiting illness	81% 19%	84% 16%	77% 22%	80% 20%	84% 16%	84% 16%	80% 20%
Supports family, friends and carers during an illness and afterwards	74% 26%	86% 14%	72% 28%	87% 13%	89% 11%	84% 16%	76% 24%
May be suitable for a number of years	68% 32%	64% 36%	69% 31%	61% 39%	69% 31%	64% 36%	67% 33%

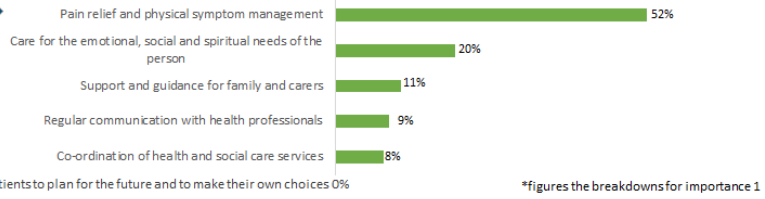
Q: Are the following statements either true or false about Palliative Care? (Multiple select, n = 1,013)

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“Pain relief and physical symptom management” is perceived to be the most important factor (52% choose it) that would help a person have a good experience of palliative care (increases with age). “Care for the emotional, social and spiritual needs of the person” is perceived ranks as the second most important factor (20%).



**Factors Determining Good Experience of Palliative Care**



\*figures the breakdowns for importance 1

	Male	Female	18-34	35-54	55+	ABC1	C2DE
Pain relief and physical symptom management	51%	54%	38%	57%	61%	54%	51%
Care for the emotional, social and spiritual needs of the person	18%	21%	29%	16%	16%	20%	20%
Support and guidance for family and carers	15%	7%	13%	11%	7%	10%	11%
Regular communication with health professionals	13%	6%	12%	7%	10%	9%	10%
Co-ordination of health and social care services	3%	12%	8%	9%	6%	7%	8%
Support for patients to plan for the future and to make their own choices	0%	1%	0%	0%	1%	1%	0%

Q: Can you rank in order of importance what you think would help a person have a good experience of palliative care. Please rank (drag and drop) between 1 = most important and 6 = least important. (Ranking, n = 450)

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