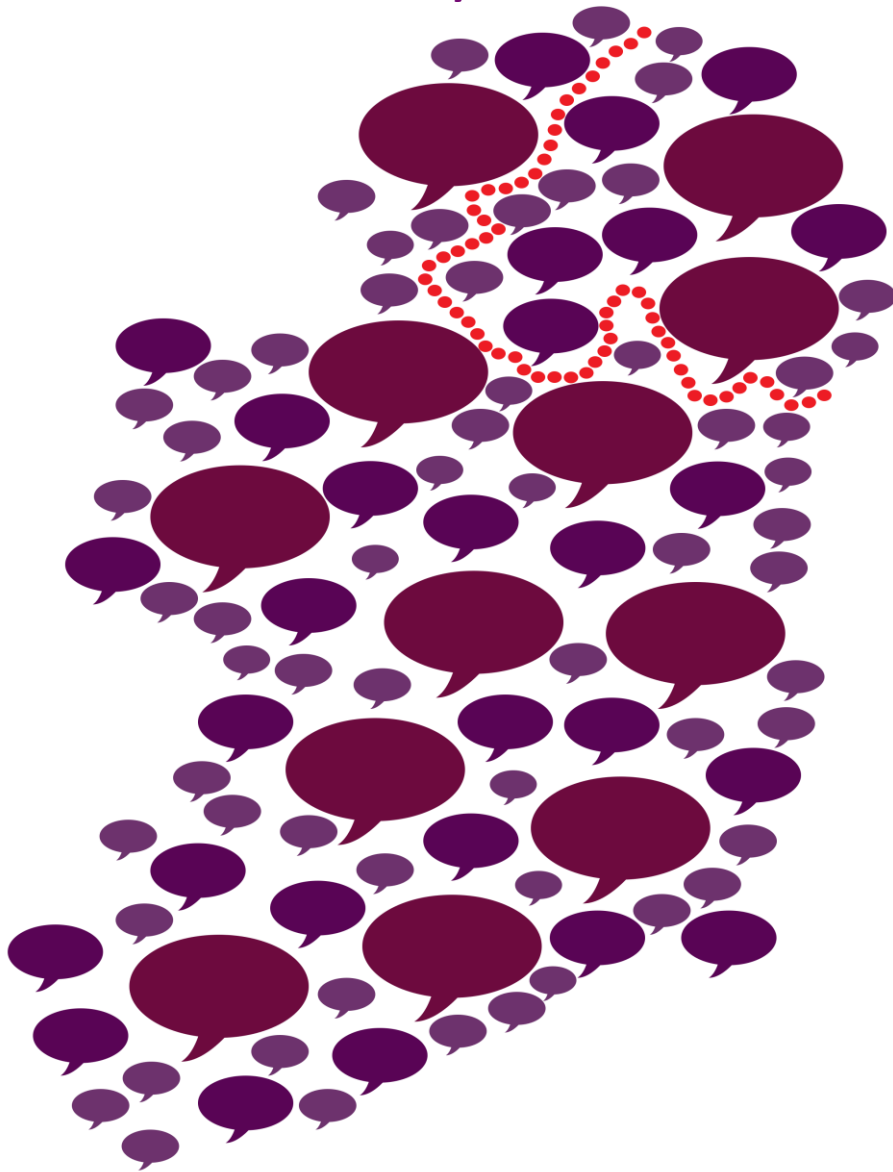


let's talk about survey



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](http://www.letstalk-about.org)



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.

*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*

### 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.***

**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 in 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 that 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:***

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## Understanding the Experience

This next section will ask you eight questions about this experience as well as asking you to tick some background information. The eight questions are in the form of triangles. Please place **one** mark at any point **inside** each triangle question to show what best fits your experience. You may mark the spot anywhere **within** the triangle.

### Examples of triangle questions about the weather

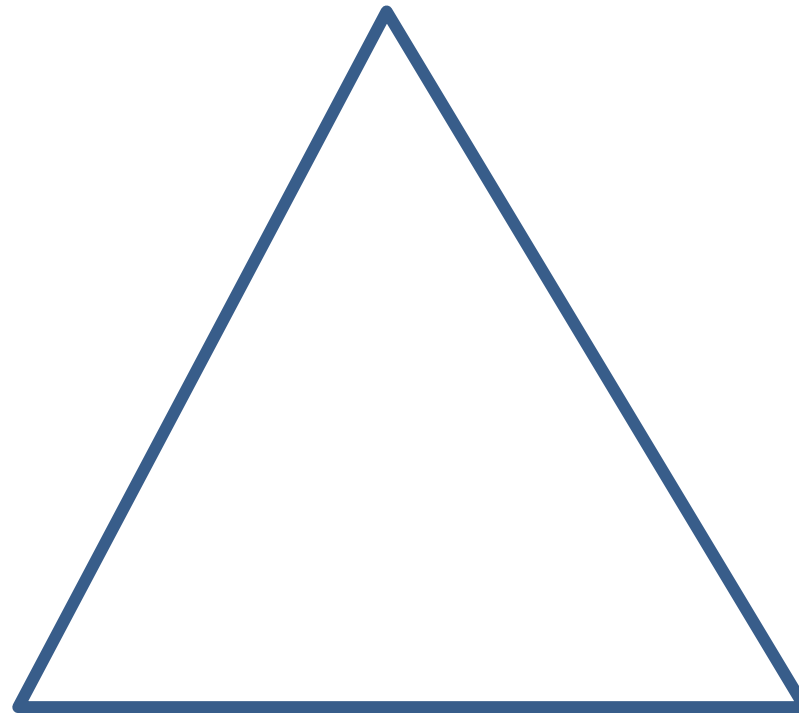
The image shows three examples of weather-related triangle questions, each enclosed in a rounded rectangular box. Each example consists of a question, a response, and a triangle with an 'X' mark.

- Example 1:**  
Question: What is the weather like today?  
Response: *It's sunny.*  
Triangle vertices: SUNNY (top), DULL AND CLOUDY (bottom-left), RAINY (bottom-right).  
Mark: An 'X' is placed in the upper-left area of the triangle.
- Example 2:**  
Question: What is the weather like today?  
Response: *It's a mixture of sunny and rainy.*  
Triangle vertices: SUNNY (top), DULL AND CLOUDY (bottom-left), RAINY (bottom-right).  
Mark: An 'X' is placed in the center of the triangle.
- Example 3:**  
Question: What is the weather like today?  
Response: *It's a mixture of sunny, rainy, dull & cloudy*  
Triangle vertices: SUNNY (top), DULL AND CLOUDY (bottom-left), RAINY (bottom-right).  
Mark: An 'X' is placed in the center of the triangle.

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.

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

**Finance or cost of living**



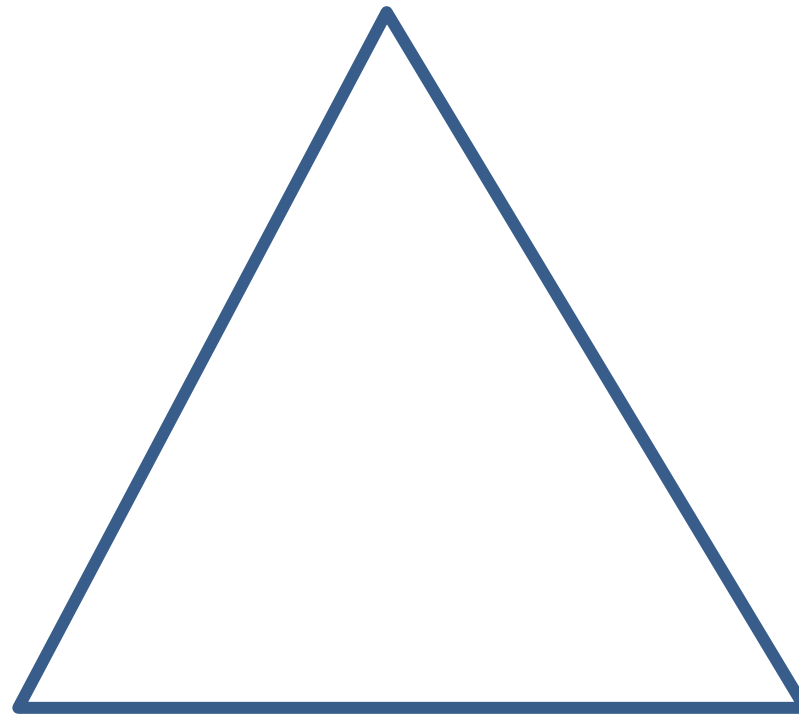
**Planning for the future**

**Travel or transport**

N/A

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

**Supported**



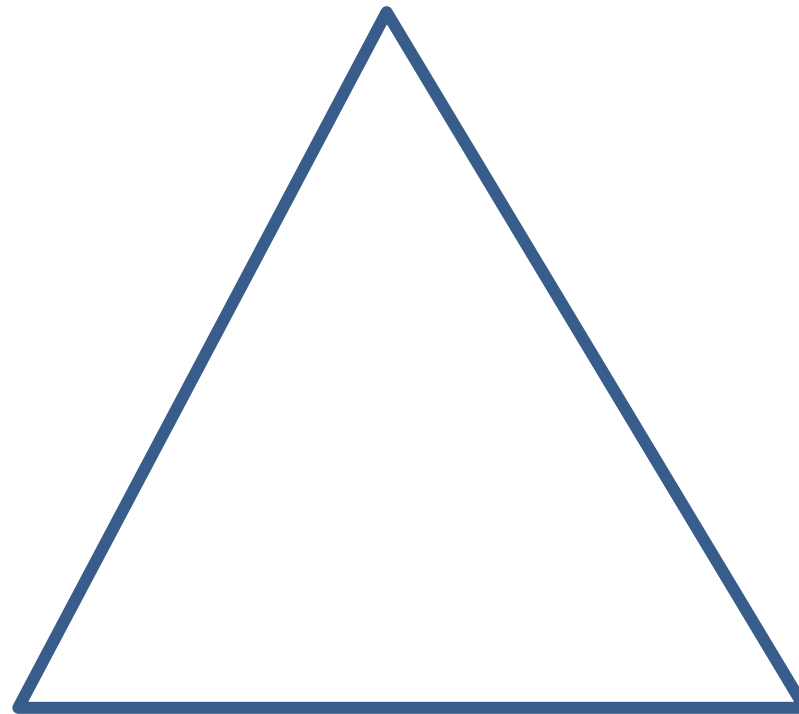
**Frustrated**

**Helpless**

N/A

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

**Clearly or sensitively**



**Avoided completely**

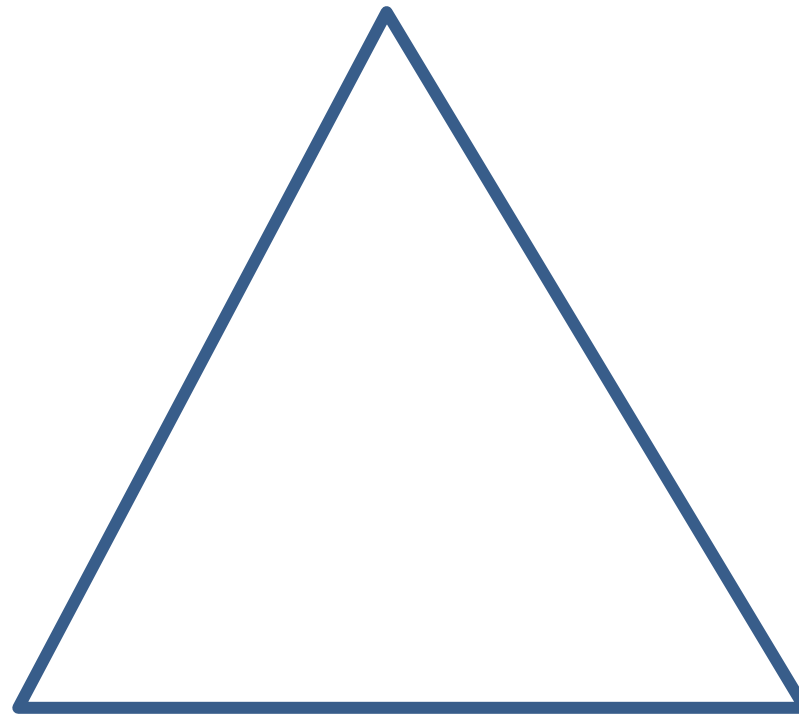
**Used jargon**

N/A



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

**Timely or appropriately**



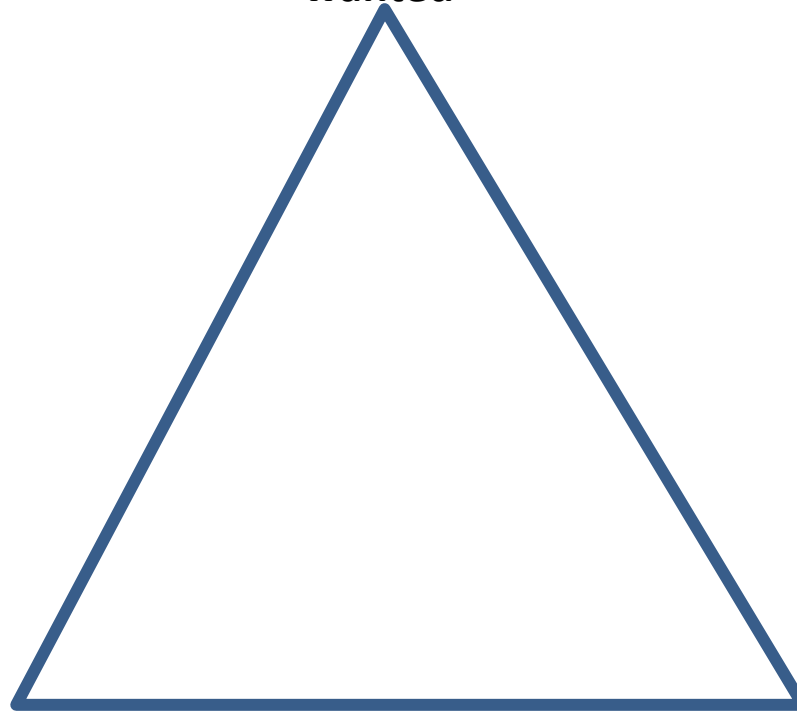
**Too much, too soon**

**Too little, too late**

**N/A**

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

**Able to make the choices  
wanted**



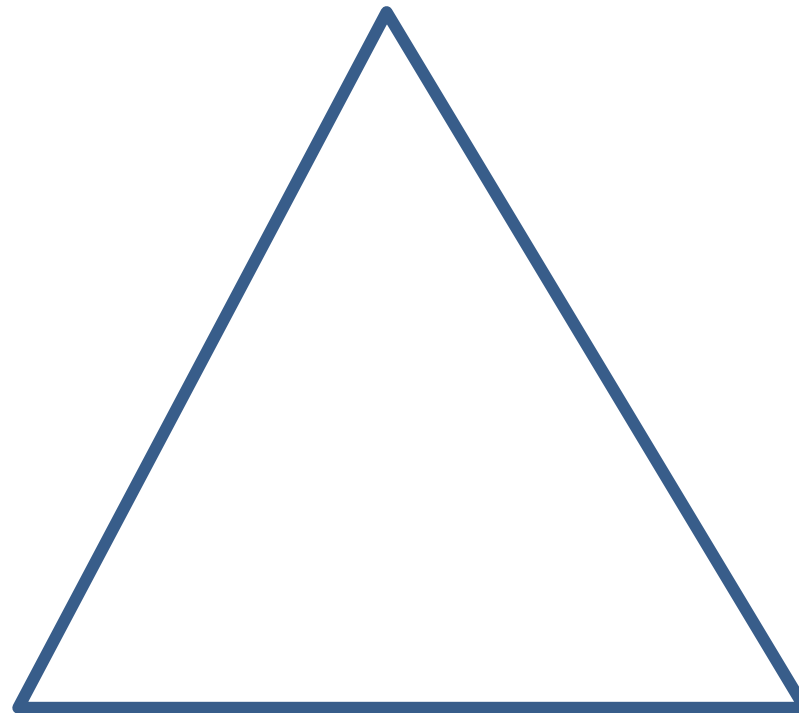
**Choices were limited**

N/A

**Control was in someone  
else's hands**

6) Which needs were least well met in this experience?

Emotional or Psychological



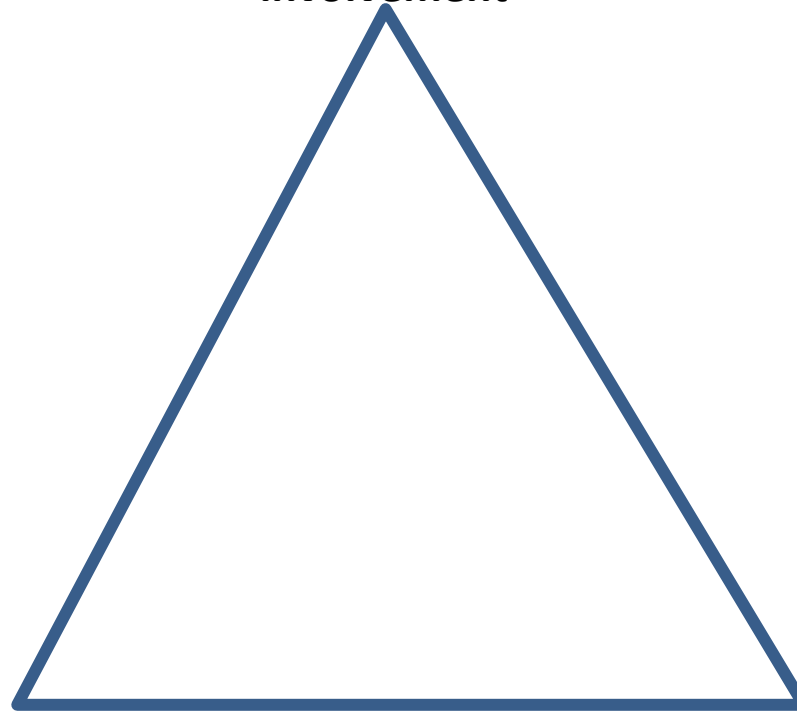
Cultural or Spiritual

Physical symptoms

N/A

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

**Better information or  
involvement**



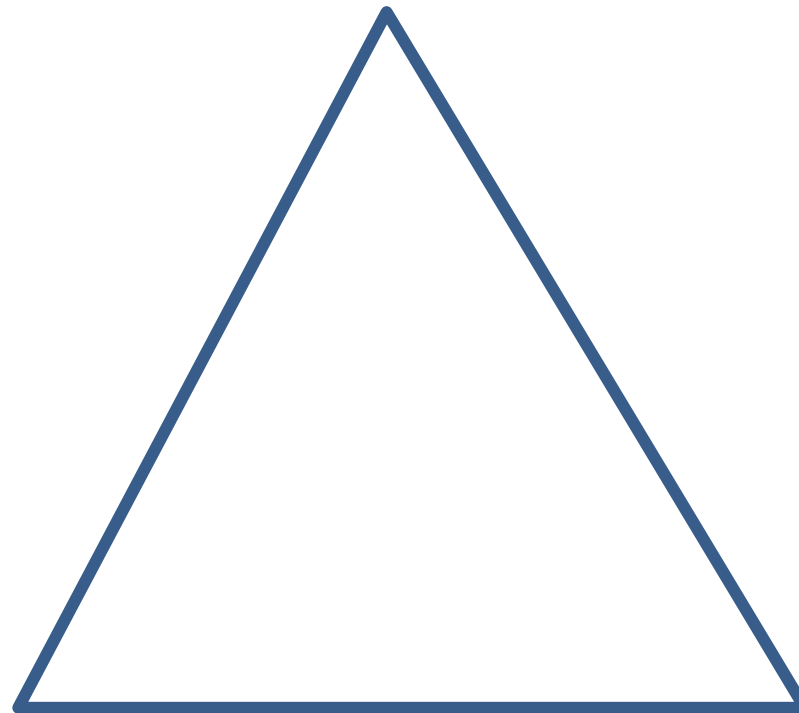
**Better co-ordination of care  
or treatment**

**Better emotional support**

N/A

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

**Involved or respected**



**Forgotten about or excluded**

**Put under too much pressure**

N/A

**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

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

LOCATION (ROI) or (NI)		v
Antrim	(NI)	<input type="checkbox"/>
Armagh	(NI)	<input type="checkbox"/>
Carlow	(ROI)	<input type="checkbox"/>
Cavan	(ROI)	<input type="checkbox"/>
Clare	(ROI)	<input type="checkbox"/>
Cork	(ROI)	<input type="checkbox"/>
Donegal	(ROI)	<input type="checkbox"/>
Down	(NI)	<input type="checkbox"/>
Dublin	(ROI)	<input type="checkbox"/>
Fermanagh	(NI)	<input type="checkbox"/>
Galway	(ROI)	<input type="checkbox"/>
Kerry	(ROI)	<input type="checkbox"/>
Kildare	(ROI)	<input type="checkbox"/>
Kilkenny	(ROI)	<input type="checkbox"/>
Laois	(ROI)	<input type="checkbox"/>
Leitrim	(ROI)	<input type="checkbox"/>
Limerick	(ROI)	<input type="checkbox"/>
Longford	(ROI)	<input type="checkbox"/>
Londonderry	(NI)	<input type="checkbox"/>
Louth	(ROI)	<input type="checkbox"/>
Mayo	(ROI)	<input type="checkbox"/>
Meath	(ROI)	<input type="checkbox"/>
Monaghan	(ROI)	<input type="checkbox"/>
Offaly	(ROI)	<input type="checkbox"/>
Roscommon	(ROI)	<input type="checkbox"/>
Sligo	(ROI)	<input type="checkbox"/>
Tipperary	(ROI)	<input type="checkbox"/>
Tyrone	(NI)	<input type="checkbox"/>
Waterford	(ROI)	<input type="checkbox"/>
Westmeath	(ROI)	<input type="checkbox"/>
Wexford	(ROI)	<input type="checkbox"/>
Wicklow	(ROI)	<input type="checkbox"/>

<b>Age:</b>	✓
18 – 29 years	<input type="checkbox"/>
30 - 39 years	<input type="checkbox"/>
40 – 49 years	<input type="checkbox"/>
50 – 59 years	<input type="checkbox"/>
60 - 69 years	<input type="checkbox"/>
70 – 79 years	<input type="checkbox"/>
80 – 89 years	<input type="checkbox"/>
90 +	<input type="checkbox"/>

<b>Gender:</b>	✓
Male	<input type="checkbox"/>
Female	<input type="checkbox"/>
Transgender	<input type="checkbox"/>
Prefer not to comment	<input type="checkbox"/>

<b>Ethnic or Cultural Background:</b>	✓
<b>White</b>	
➤ White	<input type="checkbox"/>
➤ Traveller	<input type="checkbox"/>
➤ Any other White background	<input type="checkbox"/>
<b>Black</b>	
➤ Black	<input type="checkbox"/>
➤ African	<input type="checkbox"/>
➤ Any other Black background	<input type="checkbox"/>
<b>Asian</b>	
➤ Asian	<input type="checkbox"/>
➤ Chinese	<input type="checkbox"/>
➤ Any other Asian background	<input type="checkbox"/>
<b>Any other Background</b>	<input type="checkbox"/>

<b>Where was the person living at the time of this experience</b>	✓
In their own or family members home	<input type="checkbox"/>
In Hospital	<input type="checkbox"/>
In Nursing home	<input type="checkbox"/>
In Residential home	<input type="checkbox"/>
In Hospice	<input type="checkbox"/>
Any Other	<input type="checkbox"/>



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 ( <i>such as COPD, Emphysema, pulmonary fibrosis and cystic fibrosis</i> )		
Cancer		
Haematological Malignancy		
Chronic Kidney Disease		
Dementia		
Frailty		
Heart Failure		
Parkinson's Disease		
Progressive Neurological Disorders ( <i>such as Motor Neurone Disease, Multiple Sclerosis, Huntington's Disease, Neurological Palsy</i> )		
<b>Other (please specify):</b>		

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		<b>Other (please specify) :</b>	
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](http://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 (AIHPC) is to improve the experience of care – more information at [www.aiihpc.org](http://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](mailto:info@aiihpc.org)



**AIHPC**

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.)