

Palliative and end of life care Priority Setting Partnership

Do you have questions about palliative and end of life care?
If you do please fill in this survey.

Why we need your help:

We are asking for your help so that we can identify priority areas for research in the treatment, care, and support of those who are in the last years of their life.

Who you are:

- A person with a long-term illness who might be within the last years of life
- Caring for a loved one or someone you know in the last years of life
- A bereaved carer or family member
- Health or social care professionals or volunteers working with people who are in the last years of life
- A member of the public who has an interest in palliative and end of life care.

Your experience and knowledge, as someone who has been directly affected by end of life care, will be essential in helping us identify the most important questions that need to be researched.

What we are asking you to do:

This is a unique opportunity to directly influence future research into palliative and end of life care.

Please think about your own experiences of palliative and end of life care and take part in our quick and simple survey over the page. It will take you approximately 10 minutes to complete. You can complete our survey on paper to be posted back to us at our freepost address, on-line or over the telephone.

What we mean by palliative care:

Besides helping those with advanced, progressive, incurable illness to live as well as possible until they die, palliative care is about supporting everyone involved in a person's life, such as family, friends and carers.

For patients, it includes management of pain and other symptoms and provision of psychological, emotional, social, spiritual and practical support.

For family, friends and carers it includes the support that can be provided as and when required to help the family cope during the person's illness and in their own bereavement.

What will happen to your question(s):

Your question(s) will be gathered together and examined with questions we receive from everyone else who takes part in this survey.

- The questions that haven't already been answered by research will be published (see below for more information).
- They will go through a process of prioritisation which you can be involved in if you like.
- This will result in a 'top ten' list of research topics which we will use to influence future research decisions.

SUPPORTED AND GUIDED BY



James
Lind
Alliance

Priority Setting Partnerships

IN PARTNERSHIP WITH



Survey – section 1:

Your questions about palliative and end of life care that you've been unable to find the answers to

Your question(s) can be about whatever you think is important and went unanswered for you. All you need to do is write a sentence or two about whatever it is. If your question(s) relate(s) to any particular condition or disease, please tell us which one. Send us as many questions as you like. If you run out of room you can add an additional sheet of paper with your survey or fill the survey in online.

What question(s) do you have about **the care, support and treatment** for people who are at the end of life that could help them **live** as well as possible?

This could also include question(s) about care and support for current or bereaved carers or families.

What question(s) would you like answered about **the care, support and treatment** for those rapidly approaching the end of life?

This could also include question(s) about care and support for current carers or families looking after someone at the end of life.

Which of the following categories best describes you? (please tick all that apply)

This question is essential in order for us to fully process your questions.

Your name or organisation will NOT be published in association with the question.

- | | |
|--|---|
| <input type="radio"/> I am approaching the end of my life | <input type="radio"/> I am a professional working with people at the end of life |
| <input type="radio"/> I am a carer or family member or partner or friend of someone at the end of their life | <input type="radio"/> I am a volunteer working with people at the end of life |
| <input type="radio"/> I am a bereaved carer or family member or friend | <input type="radio"/> I am a member of the public who has an interest in the subject. |

Other, please specify _____

Consent

By participating in this survey you are agreeing to allow us to anonymously publish your unanswered question(s) in an online tool for researchers called UK DUETs (UK Database of Uncertainties about the Effects of Treatments, www.library.nhs.uk/duets). UK DUETs also publishes research recommendations. This enables researchers to enhance existing research. Your name or organisation will not be published in association with your question(s).

By providing us with your unanswered question(s) you are consenting for us to enter them anonymously into SurveyMonkey for analysis. Data will be subject to SurveyMonkey's privacy policy which can be found at www.surveymonkey.com/mp/policy/privacy-policy/

If you do provide your personal contact details, we will keep them confidentially and securely, in accordance with the Data Protection Act.

Please note that there are circumstances under which the Palliative and end of life care Priority Setting Partnership will have a duty to share information provided in this survey with the relevant body, such as where abuse and/or criminal activity is disclosed, or where an individual is at risk to themselves or others (including children or vulnerable adults).

We regret that we are unable to respond to specific personal questions that you may have about your own, or another individual's care but if you need further support with any issues raised by filling out this survey this can be found at www.palliativecarepsp.org.uk

Need this in large print?

Contact us at PeolcPSP@mariecurie.org.uk or call 0207 091 4153

This survey is also available online at www.palliativecarepsp.org.uk

Survey - section 2:

Some questions about you

These questions will help us to understand the range of people who have responded to our survey.

1. Where do you live?

- England
- Scotland
- Wales
- Northern Ireland
- Ireland
- Other, please specify _____
- Prefer not to say

2. We would like to stay in touch with you throughout 2014 to keep you updated on the progress of the project and in early 2015 send you a report of the results. Please tick below if you would like to be kept up to date:

- Yes please. I would like to be kept up to date on the progress of the project and the results

Also, in autumn 2014 there may be an opportunity for you to be involved in prioritising the received questions through a series of workshops and focus groups. Please tick below if you are interested in taking part in a focus group. We are happy to talk to you about your access needs if applicable.

- Yes please. I am interested in taking part in a focus groups to prioritise the questions and would like to be invited

If you answered '**Yes please**' to the above question(s), please enter your contact details below. Your details will be treated with complete confidentiality.

Name: _____

Organisation (if applicable): _____

Address: _____

City/Town: _____

Post code: _____

Country: _____

Email address: _____

Phone number: _____

(We will detach this section so we can keep your contact details confidentially)

section 2 continues overleaf

section 2 continued

If you're happy for us to contact you, please indicate which method listed below you would prefer that we contact you by:

- Email Telephone Post

3. How did you complete this survey?

- On your own
 As part of a group (two or more people)

If you completed this as part of a group, how many were in your group? _____

ONLY for health and social care professionals working in palliative care and/or with people at the end of life

4. Which is your primary profession (*please tick one box only*)

- Palliative care doctor
 Other specialist doctor, please specify _____

- General Practitioner
 Specialist palliative care nurse
 Other specialist nurse, please specify _____

- Nurse
 Professional allied to medicine
 Social worker
 Care home, or home care, staff
 Chaplain
 Clinical researcher, please specify area of research _____

Other, please specify _____

- Prefer not to say

Thank you for taking the time to complete this survey

Please return your completed survey by 30th April 2014 by email to PeolcPSP@mariecurie.org.uk, or by freepost to:

FREEPOST RLUH-ATGY-BXSA

89 Albert Embankment
LONDON
SE1 7TP

If you need help with completing this form and/or if you would like to comment, please either email us on the above email address or call on **0207 091 4153**.

Please don't forget to support us further by passing details of this survey to others who might be interested.

You can tweet about us too [@PeolcPSP](https://twitter.com/PeolcPSP)