

**Survey Participant Information Sheet for
Experiences of Palliative and End of Life Care in the East of England Survey
Conducted by Marie Curie in Partnership with NHS England**

Title of Survey	Experiences of Palliative and End of Life Care in the East of England
Key Question	What is the experience of care for people living with or supporting people with terminal illness in the East of England – what is working well and what are priority areas for improvement?
Invitation	You are being invited to take part in an online survey . Before you decide, it is important for you to understand why the survey is being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish and to decide whether you wish to take part. Thank you for reading this.

1. Who is organising and funding the survey?

This survey is being organised and funded by Marie Curie East of England Team with direction and financial contribution from NHS England's East of England Palliative and End of Life Care Strategic Clinical Network.

2. What is the purpose of the survey?

The purpose is to understand experiences of people over the age of 18 living with or supporting others with terminal illness in the East of England in order to ensure everybody gets the best possible experience of care at the end of life.

3. Who is the survey aimed at?

We are inviting people over the age of 18 who have been affected by terminal illness to take part in this survey. This includes people that are:

- currently **living with a terminal illness** who may or may not be receiving palliative or end of life care
- **supporting and/or caring for someone** living with a terminal illness – whether family, friends, volunteers or health or social care professionals
- **bereaved family or friends** of someone who has died from a terminal illness in the last 2 years.

We are really interested to hear the views of people from all of these groups.

4. Do I have to take part?

No, your participation is entirely voluntary. Deciding not to take part will involve no repercussions for you. You may discontinue participation at any time, without giving a reason. Any data that you have entered in the survey up until that point will be included.

5. What will the survey involve?

The survey comprises approximately 20 questions and should take no more than 15 minutes to complete. The questions are primarily structured to give you a range of options to select from, with a couple of open questions for you to share more about your experience. The questions focus on your personal experience of terminal illness, the care you have received and what you think can be done to improve care for those approaching the end of their life and those supporting them. Although a response to all questions is required, all include the option 'Prefer not to say'.

6. Support available?

If you need help completing the online survey, prefer a paper version, or would like guidance over the telephone – including in different languages, please send an email to eastofenglandinfo@mariecurie.org.uk or call our East of England Hub on 0121 752 9305.

7. What are the benefits of taking part?

Your input will help to highlight what is working well as well as priority areas for improvement. As such it will enable us to inform and provide recommendations to those who are responsible for shaping and making decisions about palliative and end of life care for people in the East of England. Ultimately you will be helping to ensure that more people get the best possible care and support at the end of life, reflecting what's most important to them.

8. What are the possible disadvantages and risks of taking part?

Completing the survey requires you to reflect on your own experiences of living with terminal illness and accessing care – or in the case that you are sharing experiences of someone who has died, a bereavement. This may bring up experiences that may be upsetting. If you need any support after completing the survey, you can contact **Marie Curie's Support Line on 0800 0902309**. It is open from Monday to Friday 8am-6pm, and Saturday 11am-5pm. Our trained team of professionals and volunteers will be there to listen and signpost you in the right direction.

9. What will happen to the results of the survey?

The results of this survey will be used to identify key issues and priorities for future palliative and end of life care in the East of England. We will be sharing the findings – which may include individual responses, data and quotes (which will all be anonymised) with those responsible for the provision of palliative and end of life care in the East of England, including the local ICBs (Integrated Care Boards), calling on them to incorporate a set of recommendations into their strategies, plans and service offering. We will also be publishing a summary report available to the public.

10. Do I need to share my personal details?

This is an anonymous survey and at no point will you be required to share your name and contact details.

However, as part of the survey we will ask you to share some personal information about you, and in the case that you are supporting someone, the person you are looking after. This includes:

- The area and first part of the postcode of the person who is ill. This will enable us to provide more targeted recommendations to healthcare leaders in different parts of the East of England.
- Demographic information of the person completing the survey, including age, ethnicity, language, length of time in the UK, religion, gender, sexuality and disability. We're asking these questions because we'd like to understand how people's experiences differ across the East of England.

At the close of the survey, you will also be asked whether you would be willing to share more about your experiences by participating in a one-to-one interview or group discussion. To 'opt in' to this, we will ask you to complete a separate online form or send an email to eastofenglandinfo@mariecurie.org.uk This will ensure that your responses in the survey are not linked to your contact information.

11. Will my responses be anonymous?

Yes. As we are not collecting your name or contact details, the information that we collect about you during the course of the survey will be anonymous and can not be identified or attributed to you. We ask that you do not include any information in the survey that could identify you or anyone else (e.g. name of your doctor or local hospice). Please note that due to the anonymous nature of the survey, we will not be able to respond to you on any specific issues or questions that you may raise in completing the survey. Should you wish to contact us directly, please email eastofenglandinfo@mariecurie.org.uk

12. How will data be shared?

Marie Curie will publish a report presenting consolidated data from the survey that will be shared with healthcare leaders in the East of England.

13. Local Data Protection Privacy Notice

You can access Marie Curie's privacy policy here: <https://www.mariecurie.org.uk/privacy> If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact Marie Curie in the first instance at DPO@MarieCurie.org.uk.

14. What if something goes wrong?

If you would like to make a complaint about the project or have any concerns please contact Marie Curie's East of England Team by email at eastofenglandinfo@mariecurie.org.uk Should you feel that your complaint has not been handled to your satisfaction, you can contact Marie Curie's central Complaints Team by email at complaints@mariecurie.org.uk

15. Who are the team for this project?

Marie Curie – East of England

Jonathan Clemo	Associate Director Strategic Partnerships & Services
Kate Vernon	Deputy Head of Operations
Tracey Allan	Community Engagement & Development Manager
Kim Bonnar	Head of Impact & Evaluation
Briony Hudson	Associate Director Internal Research Development

NHS England – East of England Palliative and End of Life Care Strategic Clinical Network

Beverley Pickett	Manager
Jo Tonkin	Lead Nurse
Kim Clark	Patient Experience Manager

16. Contact for further information

If you have any questions about this project, please get in touch the Project Lead, Kate Vernon, Deputy Head of Operations by email at kate.vernon@mariecurie.org.uk

Thank you for reading this Survey Participant Information Sheet and for considering to take part in this survey.