

VOICES Survey - Experiences of care in the last months of life

INFORMATION LEAFLET

If you would like to receive this information in large print, or if English is not your first language and you would like interpreter services, please call our Survey Enquiry Line on 0800 298 5313

The Survey Enquiry Line is open Monday to Thursday 9am to 9pm, Friday 9am to 8pm, and Saturday 9am to 1pm.

You are being invited to take part in a questionnaire-based research study of bereaved people called the VOICES Survey (Views Of Informal Carers - Evaluation of Services). Before you decide whether or not you would be willing to participate, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

We understand that coping with the loss of a loved one is not easy and we really appreciate you taking the time to read this information.

What is the purpose of the VOICES Survey?

VOICES is a survey of bereaved carers who provided support and care to a relative, partner or friend. It covers experiences in the last months of life and will be used nationally to monitor and improve services provided. Although participation in VOICES will not help you directly, we hope that the information you give us will enable us to improve people's experiences of care at the end of their lives and improve services provided to bereaved relatives and friends.

Why have I been chosen?

You have been chosen to take part because you registered a death in the past year. The Office for National Statistics (ONS) will not share any personal information about you with anyone. Your survey responses will be shared with the Department of Health and their approved researchers using only an anonymous Study ID number. This ensures that the information you provide is totally confidential, in accordance with the Data Protection Act 1998.

What will taking part involve?

We would like you to fill in a questionnaire which will take around 30 minutes. It asks about the care and support both you and your relative/friend received in the last months of their life and whether their needs were fully met. Your experiences are very important, so please feel free to be completely open and honest.

If you do not think you are the best person to complete the questionnaire, please pass it on to whoever you feel would be the best person to complete it. If you would like to complete the questionnaire with the help of your family or a group of friends, you are welcome to do so.

Most of the questions can be answered by ticking the most appropriate box. If you make a mistake or wish to change your answer, simply cross through the answer you do not want. If you would prefer not to answer a question, please go on to the next one. We would be very grateful for any additional comments that you would like to make in the spaces provided.

To return the completed questionnaire, please use the enclosed pre-paid envelope. You can request a replacement envelope by phoning the Survey Enquiry Line on 0800 298 5313. The closing date for returning completed questionnaires is Friday 14th December 2012.

Do I have to take part?

Taking part is completely voluntary. If you do decide to take part you may change your mind and choose not to continue in the research at any time, without having to give a reason for doing so. If you decide not to participate, you can let us know by ticking the box on the back of the questionnaire and returning it to ONS in the pre-paid envelope. This will ensure that you do not receive reminder letters.

What are the possible disadvantages of taking part?

Some people find it distressing to think about the care that their loved ones or close friends received during the last months of their lives. Answering questions about care at the end of life can bring back painful memories. If you find it distressing, you can stop completing the questionnaire at any time and choose not to continue.

We are working with Cruse Bereavement Care services, a charitable organisation that provides help and support to those who have lost loved ones. If you feel that you would like to talk about your feelings or discuss painful memories brought back by completing the questionnaire, please contact Cruse Bereavement Care by telephone on 0844 477 9400 or by e-mail at helpline@cruse.org.uk

How will the information I give be kept confidential?

ONS will not give personal information that identifies you to anyone else. Your survey responses will only be identified by an anonymous Study ID number. All the information collected will be kept strictly confidential and secured against unauthorised access. We would also like to make absolutely clear that no information that could identify you will be used in any reports or articles we write. If you add comments at the end of the questionnaire, you are asked for additional consent to share these comments in full with local organisations and providers. You will **not** be asked to include your name (or the name of your relative, partner or friend) on the questionnaire.

The information collected will be retained and securely stored for 10 years and will then be disposed of securely.

Who is funding and organising the study?

The VOICES study is funded by the Department of Health and run by the Office for National Statistics.

What will happen to the results of the study?

Information obtained from the questionnaire will be entered into a database and analysed by ONS, the Department of Health and their approved researchers. At the end of the project, the findings will be presented in reports and tables. Results from last year's survey can be found at the following links:

www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices-/2011/index.html

www.dh.gov.uk/health/2012/07/voices/

The information we get from this project will help to improve the quality of end of life care provided in England.

If you would like more information about the study, please call our Survey Enquiry Line on 0800 298 5313.

Thank you again for taking the time to read this information. We are confident that this study will make a difference to improving the way that care is delivered to people at the end of their lives.