First national VOICES survey of bereaved people: key findings report

Appendix B: Survey questionnaire
### Appendix B: Copy of questionnaire, reminder letter, information leaflet and reply slips (3 versions)

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Dear [title] [surname]

Invitation to help with the VOICES survey of experiences of care in the last months of life.

If you would like to receive this information in large print please call our Survey Enquiry Line on 0800 298 5313

We are writing to you because you registered the death of [TITLE] [FIRST NAME AND SURNAME OF DECEASED].

We appreciate that this may be a very difficult time but we would like to invite you to take part in the VOICES survey of experiences of care in the last months of life. The results will be used to improve care and services for people and their families at the end of life. The Department of Health is funding this survey which the Office for National Statistics (ONS) is undertaking on their behalf. ONS will not release your personal details to anyone else. Your responses to the survey will be shared with the Department of Health and their approved researchers using only your Study ID Number to ensure that total confidentiality is maintained.

Taking part in the VOICES survey involves completing a questionnaire which asks about experiences in the last months of life, care received from health and social services and whether care needs were fully met. This takes about 30 minutes. 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 do not wish to participate you can let us know by completing and returning the reply slip in the pre-paid envelope provided. This will ensure that you do not receive reminder letters.

If you do decide to take part we ask that you complete this questionnaire and return it in the pre-paid envelope to the Office for National Statistics. Alternatively, you can complete the questionnaire online on our secure website at: www.ons.gov.uk/VOICEsonline. This facility is available until 31st January 2012. After clicking on ‘Begin Survey Now’, you will be asked to log in using your Study ID Number (see the box at the bottom of the page) and your unique password:
Password: [REDACTED]

Your views are important and will help improve future care for patients and families in England. We apologise if this enquiry has caused you any distress and hope this letter does not bring back too many painful memories. We are aware that some local surveys of the bereaved have been undertaken and we apologise if this means you have been approached twice. Thank you for taking the time to read this letter and we very much hope that you feel able to take part in this study.

Yours sincerely

Myer Glickman, Head of Health Analysis, Office for National Statistics
1. How long had he been ill before he died?

   Tick one only  
   [✓] He was not ill - he died suddenly
   [ ] Less than 24 hours
   [ ] One day or more but less than one week
   [ ] One week or more but less than one month
   [ ] One month or more but less than six months
   [ ] Six months or more but less than one year
   [ ] One year or more
   
   If he died suddenly with no illness or time for care, please go to question 37.
   Otherwise, please continue with the questions below.

2. Did he spend any time at home during the last three months of life?

   Tick one only
   [ ] Yes - go to question 3
   [ ] No - He was in a care home for the whole 3 months - go to question 12
   [ ] No - He was in hospital - go to question 24

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**Care at Home**

These questions are about care at home - not in a care home

3. When he was at home in the last three months of life, did he get any help at home from any of the services listed below?

   These may be provided by different organisations, such as voluntary organisations, a private agency or social services.

   Tick all that apply

   [ ] A district or community nurse (a nurse in uniform who comes to the house)
   [ ] A Macmillan nurse, hospice home care nurse or specialist (a care nurse who visits or telephones to talk and advise on medications and other aspects of care. Not in uniform)
   [ ] A Marie Curie nurse (someone who comes to the house for a few hours or overnight to care for the patient)
   [ ] Any other nurse at home
   [ ] Home care worker, home care aide or home help
   [ ] Social worker / support worker
   [ ] Counsellor
   [ ] Religious leader
   [ ] Meals-on-wheels or other home delivered meals
   [ ] Hospice at home
   [ ] Occupational therapist (OT)
   [ ] Rapid response team (team of nurses and home care workers who provide care over the short term to allow someone to remain at home and prevent hospital admission)
   [ ] He did not receive any care
   [ ] Don’t know
   [ ] Something else - please write below
4 When he was at home in the last three months of life, did all these services work well together?

   Tick one only
   ☐ Yes, definitely
   ☐ Yes, to some extent
   ☐ No, they did not work well together
   ☐ He did not receive any care
   ☐ Don't know

5 Overall, do you feel that you and your family got as much help and support from health and social services as you needed when caring for him?

   Tick one only
   ☐ Yes, we got as much support as we wanted
   ☐ Yes, we got some support but not as much as we wanted
   ☐ No, although we tried to get more help
   ☐ No, but we did not ask for more help
   ☐ We did not need help

6 During the last three months of his life, while he was at home, how well was his pain relieved?

   Tick one only
   ☐ Does not apply - he did not have any pain
   ☐ Completely, all of the time
   ☐ Completely, some of the time
   ☐ Partially
   ☐ Not at all
   ☐ Don't know

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7 In the last three months of life, while he was at home, did he ever need to contact a health professional for something urgent in the evening or at the weekend?

   Tick one only
   ☐ Not at all in the last 3 months - go to question 12
   ☐ Once or twice - go to question 8
   ☐ Three or four times - go to question 8
   ☐ Five times or more - go to question 8
   ☐ Don't know - go to question 12

8 The last time this happened, who did he contact, or who was contacted on his behalf?

   Tick all that apply
   ☐ His GP or the out-of-hours number
   ☐ NHS Direct
   ☐ District nurses
   ☐ Macmillan nurses
   ☐ He used his 'lifeline' pendant
   ☐ A hospice
   ☐ 999
   ☐ Something else - please write in the space below

   [Space for writing]
9 What happened as a result? Was he...
Tick one only

☐ Visited by his GP at home
☐ Visited by another GP at home
☐ Visited by a nurse at home
☐ Visited by a hospice doctor at home
☐ Given medical advice over the phone
☐ Given another number to ring to get medical advice
☐ Advised to go to an out-of-hours GP surgery
☐ Advised to go to the GP surgery when it opened
☐ Advised to go to an Accident and Emergency Department at a hospital
☐ Advised to call 999
☐ Something else - please write below

10 In your opinion, was this the right thing for them to do?
Tick one only

☐ Yes
☐ No
☐ Not sure

11 Overall, do you feel that the care he got when he needed care urgently in the evenings or weekends in the last three months of his life was:
Tick one only

☐ Excellent
☐ Good
☐ Fair
☐ Poor
☐ Don't know

12 How often did the district or community nurse visit (at the most frequent time)?
Tick one only

☐ More than once a day
☐ Every day
☐ 2-6 times a week
☐ Once a week
☐ 2 - 3 times a month
☐ Less often
☐ Don't know

13 How much of the time was he treated with respect and dignity by the district and community nurses?
Tick one only

☐ Always
☐ Most of the time
☐ Some of the time
☐ Never
☐ Don't know

14 Overall, do you feel that the care he got from the district and community nurses in the last three months of his life was:
Tick one only

☐ Excellent
☐ Good
☐ Fair
☐ Poor
☐ Don't know
Care from the GP

In the last three months, how often did he see the GP he preferred to see?

Tick one only

☐ Always or almost always
☐ A lot of the time
☐ Some of the time
☐ Never or almost never
☐ He didn’t try to see a particular GP
☐ He did not need to see a GP - go to question 20

How much of the time was he treated with respect and dignity by the GPs?

Tick one only

☐ Always
☐ Most of the time
☐ Some of the time
☐ Never
☐ Don’t know

Were you able to discuss any worries and fears you may have had about his condition, treatment or tests with the GPs?

Tick one only

☐ I had no worries or fears to discuss
☐ Yes, I discussed them as much as I wanted
☐ Yes, I discussed them, but not as much as I wanted
☐ No, although I tried to discuss them
☐ No, but I did not try to discuss them

Overall, if the GP visited him at home in the last three months, how easy or difficult was it to get him / her to visit?

Tick one only

☐ Very easy
☐ Fairly easy
☐ Fairly difficult
☐ Very difficult
☐ He wanted the GPs to visit but they would not visit
☐ Does not apply - the GP did not need to visit
☐ Don’t know

Overall, do you feel that the care he got from the GP in the last three months of life was:

Tick one only

☐ Excellent
☐ Good
☐ Fair
☐ Poor
☐ Don’t know

Please feel free to make comments in the space below

__________________________________________________________

__________________________________________________________
Care Homes

20 Did he live or stay in a care home at any time during his last three months of life?

Tick one only

☐ Yes, he was in a care home - please write the name of the care home in the space below:
   Name:
   Town:

☐ No - go to question 24

☐ Don't know - go to question 24

21 How much of the time was he treated with respect and dignity by the staff at the care home?

Tick one only

☐ Always
☐ Most of the time
☐ Some of the time
☐ Never
☐ Don't know

22 During the last three months of his life, while he was in the care home, how well was his pain relieved?

Tick one only

☐ Does not apply - he did not have any pain
☐ Completely, all of the time
☐ Completely, some of the time
☐ Partially
☐ Not at all
☐ Don't know

23 Overall, do you feel that the care he got from the care home in the last three months of his life was:

Tick one only

☐ Excellent
☐ Good
☐ Fair
☐ Poor
☐ Don't know

Last Hospital Admission

24 Did he stay in hospital at any time during his last three months of life?

Tick one only

☐ Yes - please write the name of the last hospital he stayed in below
   Name:
   Town:

☐ No - go to question 29

☐ Don't know - go to question 29

25 During his last hospital admission, how much of his time was he treated with respect and dignity by the hospital doctors and nurses?

Please answer for both doctors and nurses

Doctors
☐ Always
☐ Most of the time
☐ Some of the time
☐ Never
☐ Don't know

Nurses
☐ Always
☐ Most of the time
☐ Some of the time
☐ Never
☐ Don't know
26 During his last hospital admission, how well was his pain relieved?

**Tick one only**

- ☐ Does not apply - he did not have any pain
- ☐ Completely, all of the time
- ☐ Completely, some of the time
- ☐ Partially
- ☐ Not at all
- ☐ Don't know

27 Did the hospital services work well together with his GP and other services outside of the hospital?

**Tick one only**

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No, they did not work well together
- ☐ Don't know

28 Overall, do you feel that the care he got from the staff in the hospital on that admission was:

**Please answer for both doctors and nurses**

<table>
<thead>
<tr>
<th>Doctors</th>
<th>Nurses</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐ Excellent</td>
</tr>
<tr>
<td>☐</td>
<td>☐ Good</td>
</tr>
<tr>
<td>☐</td>
<td>☐ Fair</td>
</tr>
<tr>
<td>☐</td>
<td>☐ Poor</td>
</tr>
<tr>
<td>☐</td>
<td>☐ Don't know</td>
</tr>
</tbody>
</table>

29 Did he stay in a hospice at any time during his last three months of life?

**Tick one only**

- ☐ Yes - please write the name of the last hospice he stayed in below:
  - Name:
  - Town:

- ☐ No - go to question 33
- ☐ Don't know - go to question 33

30 How much of the time was he treated with respect and dignity by the hospice doctors and nurses?

**Please answer for both doctors and nurses**

<table>
<thead>
<tr>
<th>Doctors</th>
<th>Nurses</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐ Always</td>
</tr>
<tr>
<td>☐</td>
<td>☐ Most of the time</td>
</tr>
<tr>
<td>☐</td>
<td>☐ Some of the time</td>
</tr>
<tr>
<td>☐</td>
<td>☐ Never</td>
</tr>
<tr>
<td>☐</td>
<td>☐ Don't know</td>
</tr>
</tbody>
</table>

31 During the last three months of his life, while he was in the hospice, how well was his pain relieved?

**Tick one only**

- ☐ Does not apply - he did not have any pain
- ☐ Completely, all of the time
- ☐ Completely, some of the time
- ☐ Partially
- ☐ Not at all
- ☐ Don't know
32 Overall, do you feel that the care he got from the staff in the hospice was:

Tick one only

☐ Excellent
☐ Good
☐ Fair
☐ Poor
☐ Don't know

Please remember to answer the questions by ticking the most appropriate box or boxes like this:

If you make a mistake or wish to change your answer, cross through the answer you do not want.

Experiences in the last two days of life

33 During his last two days of life was he:

Tick one only

☐ At home all the time
☐ In a care home all the time
☐ In a hospital all the time
☐ In a hospice all the time
☐ Other - please write in the space below:

34 How much of the time was he treated with respect and dignity in the last two days of his life?

Please answer for both doctors and nurses

Doctors Nurses
☐ ☐ Always
☐ ☐ Most of the time
☐ ☐ Some of the time
☐ ☐ Never
☐ ☐ Don't know

35 Please look at the following statements and tick the answer box that corresponds most with your opinion about the help he received in the last two days of life

Tick one box for each question (a-c)

| (a) There was enough help available to meet his personal care needs (such as toileting needs) |
|---|---|---|---|---|---|
| Strongly Agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree | Does not apply | Don't know |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

| (b) There was enough help with nursing care, such as giving medicine and helping him find a comfortable position in bed |
|---|---|---|---|---|
| Strongly Agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |
| ☐ | ☐ | ☐ | ☐ |

| (c) The bed area and surrounding environment had adequate privacy for him |
|---|---|---|---|---|
| Strongly Agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |
| ☐ | ☐ | ☐ | ☐ |

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36. During the last two days, how do you assess the overall level of support given in the following areas from those caring for him?

**Tick one box for each question (a-e)**

<table>
<thead>
<tr>
<th></th>
<th>Excellent</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
<th>Does not apply</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Relief of pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(b) Relief of symptoms other than pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(c) Spiritual support</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(d) Emotional support</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(e) Support to stay where he wanted to be</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

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**Circumstances Surrounding His Death**

37. Did he know he was likely to die?

**Tick one only**

- Yes, certainly
- Yes, probably
- Probably not
- No, definitely
- Not sure

38. In your opinion, did the person who told him he was likely to die break the news to him in a sensitive and caring way?

**Tick one only**

- Yes, definitely
- Yes, to some extent
- No, not at all
- Don't know
- Does not apply - they did not know he was dying
- Does not apply - they did not tell him he was dying

39. Were you contacted soon enough to give you time to be with him before he died?

**Tick one only**

- Yes
- No
- I was there already
- It was not clear that he was going to die soon
- I couldn’t have got there anyway

40. Where did he die?

**Tick one only**

- In his own home
- In the home of another family member or friend
- In a hospital ward - please write the name of the hospital below

Name:

Town:

*Continued on page 10*
Please continue with question 40 about 'Where did he die?'

Tick one only

☐ In a hospital Accident and Emergency Department - please write the name of the hospital below
   Name:

   Town:

☐ In a hospital Intensive Care Unit - please write the name of the hospital below
   Name:

   Town:

☐ In a hospice - please write the name of the hospice below
   Name:

   Town:

☐ In a care home - please write the name of the care home below
   Name:

   Town:

☐ In an ambulance on the way to hospital or hospice

☐ Somewhere else - please write below

41 Did he ever say where he would like to die?

Tick one only

☐ Yes - go to question 42
☐ No - go to question 44
☐ Not sure - go to question 44

42 Where did he say that he would like to die?

Tick one only

☐ At home
☐ In a hospice
☐ In a hospital
☐ In a care home

☐ He said he did not mind where he died

☐ He changed his mind about where he wanted to die

☐ Somewhere else - please write below

43 Did the health care staff have a record of this?

Tick one only

☐ Yes
☐ No
☐ Not sure

44 Do you think he had enough choice about where he died?

Tick one only

☐ Yes
☐ No
☐ Not sure

☐ He died suddenly
45 On balance, do you think that he died in the right place?

Tick one only

☑ Yes
☐ No
☐ Not sure

46 Were you or his family given enough help and support by the healthcare team at the actual time of his death?

Tick one only

☐ Yes, definitely
☐ Yes, to some extent
☐ No, not at all
☐ Don't know

47 After he died, did staff deal with you or his family in a sensitive manner?

Tick one only

☐ Yes
☐ No
☐ Don't know
☐ Does not apply, I didn't have any contact with the staff

48 Looking back over the last 3 months of his life, was he involved in decisions about his care as much as he would have wanted?

Tick one only

☐ He was involved as much as he wanted to be
☐ He would have liked to be more involved
☐ He would have liked to be less involved
☐ Don't know

49 Looking back over the last three months of his life, were you involved in decisions about his care as much as you would have wanted?

Tick one only

☐ I was involved as much as I wanted to be
☐ I would have liked to be more involved
☐ I would have liked to be less involved
☐ Don't know

50 Were any decisions made about his care that he would not have wanted?

Tick one only

☐ Yes
☐ No
☐ Don't know

51 Overall, and taking all services into account, how would you rate his care in the last three months of life?

Tick one only

☐ Outstanding
☐ Excellent
☐ Good
☐ Fair
☐ Poor
☐ Don't know
52 Since he died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about his illness and death?

Tick one only

☐ Yes

☐ No, but I would have liked to

☐ No, but I did not want to anyway

☐ Not sure

If you feel that you would like to talk about your feelings or discuss painful memories brought back by completing this questionnaire, please call:

Cruse Bereavement Care
0844 477 9400

or by email on:
helpline@cruse.org.uk

53 What was your relationship to him? Were you his:

Tick one only

☐ Wife / Partner

☐ Son / Daughter

☐ Brother / Sister

☐ Son-in-law / Daughter-in-law

☐ Parent

☐ Other relative

☐ Friend

☐ Neighbour

☐ Staff in care home

☐ Warden (sheltered accommodation)

☐ Other official

☐ Someone else - please write below

54 What is your age?

☐ 18-19

☐ 20-29

☐ 30-39

☐ 40-49

☐ 50-59

☐ 60-69

☐ 70-79

☐ 80-89

☐ 90+

55 Are you:

☐ Male

☐ Female
Please could you indicate which ethnic group you belong to:

*Tick one only*

**White**
- [] English / Welsh / Scottish / Northern Irish / British
- [] Irish
- [] Gypsy or Irish Traveller
- [] Any other white background

**Mixed / Multiple ethnic group**
- [] White and Black Caribbean
- [] White and Black African
- [] White and Asian
- [] Any other mixed background

**Asian / Asian British**
- [] Indian
- [] Pakistani
- [] Bangladeshi
- [] Chinese
- [] Any other Asian background

**Black / African / Caribbean / Black British**
- [] African
- [] Caribbean
- [] Any other Black / African / Caribbean background

**Other ethnic group**
- [] Arab
- [] Any other ethnic group

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Please could you indicate which ethnic group he belonged to:

*Tick one only*

**White**
- [] English / Welsh / Scottish / Northern Irish / British
- [] Irish
- [] Gypsy or Irish Traveller
- [] Any other white background

**Mixed / Multiple ethnic group**
- [] White and Black Caribbean
- [] White and Black African
- [] White and Asian
- [] Any other mixed background

**Asian / Asian British**
- [] Indian
- [] Pakistani
- [] Bangladeshi
- [] Chinese
- [] Any other Asian background

**Black / African / Caribbean / Black British**
- [] African
- [] Caribbean
- [] Any other Black / African / Caribbean background

**Other ethnic group**
- [] Arab
- [] Any other ethnic group
58. What was his age when he died?

- [ ] 18-19
- [ ] 20-29
- [ ] 30-39
- [ ] 40-49
- [ ] 50-59
- [ ] 60-69
- [ ] 70-79
- [ ] 80-89
- [ ] 90+

59. What was his religion?

- [ ] No religion
- [ ] Christian (all denominations)
- [ ] Buddhist
- [ ] Hindu
- [ ] Jewish
- [ ] Muslim
- [ ] Sikh
- [ ] Any other religion: please write below

Thank you for taking the time to complete this questionnaire

We would be grateful if you could return it to us in the pre-paid envelope provided

If you require a replacement envelope or if you have any other questions please phone the Survey Enquiry Line on 0800 298 5313
Please use the space below if there is anything you would like to say about the care provided. What, if anything, was good about the care? What, if anything, was bad about the care?

Please indicate if you are willing for us to share these comments with local care organisations and providers. (Your name and address will not be shared with them)

☐ Yes  ☐ No
Dear [firstname(s)] [surname]

Invitation to help with the VOICES survey of experiences of care in the last months of life.

You may remember that we wrote to you a few weeks ago asking for your help with a survey we are currently conducting on behalf of the Department of Health. As our records show that we have not heard back from you, we are writing again to check whether or not you are willing to take part in this study.

If you have responded recently, please accept our apologies for having bothered you. Some reply slips were returned without the Study ID number entered in the box and we were unable to remove these respondents from the mailing list. We have made every effort to remove everyone who has responded from the list.

We would be grateful if you could complete the questionnaire and return it to the Office for National Statistics in the pre-paid envelope provided. If you do not feel you are the best person to complete the questionnaire, please pass it on to whoever you think may be the best person to take part. If you require another copy of the questionnaire please phone the Survey Enquiry Line on the number below.

Your views are important and will help improve future care for patients and families in England. We apologise if this enquiry has caused you any distress and hope this letter does not bring back too many painful memories.
You can complete the questionnaire online if you would prefer. To do this, go to our secure website at: www.ons.gov.uk/ons/index.html. Click on the ‘About ONS’ tab, then select ‘A-Z of Surveys’ and go to the letter N for ‘National Bereavement Survey’. After clicking on ‘Begin Survey Now’, you will be asked to log in using

your Study ID Number (username) [XXXXXXXXXX]

your unique password: [XXXXXXXXXX]

If you do not wish to take part in this study please complete the ‘REPLY SLIP’ and return it in the pre-paid envelope provided. This will ensure that you do not receive any further reminder letters from us. It is important to enter your Study ID number on the slip so that we can remove you from our mailing list.

Thank you for taking the time to read this letter and we very much hope that you feel able to take part in this study.

Yours sincerely

Myer Glickman, Head of Health Analysis, Office for National Statistics

If you would like to receive this information in large print please call our Survey Enquiry Line on 0800 298 5313
You are being invited to take part in a questionnaire-based research study called The VOICES Survey (Views Of Informal Carers – Evaluation of Services). Before you decide 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.

If you would like more information or you have any questions, please phone our Survey Enquiry number on 0800 298 5313 (Monday to Thursday - 9 am to 9 pm; Friday - 9 am to 8 pm and Saturday - 9 am to 1 pm).

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 will not share any personal information about you with anyone else. Your survey responses will be shared with the Department of Health but only identified by an anonymous ID number. This ensures that the information you provide is totally confidential, in accordance with the Data Protection Act.

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 your relative / friend’s needs were fully met. Your experiences are very important, so please feel free to be completely open and honest. If you do not think that 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.

Most of the questions can be answered by simply ticking the most appropriate box. 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, simply use the enclosed pre-paid envelope. You can request a replacement envelope by phoning the Survey Enquiry Line number 0800 298 5313.

If you prefer, you can complete the questionnaire online (until 31st January 2012) on our secure website at: www.ons.gov.uk/ons/index.html. Click on the ‘About ONS’ tab, then select ‘A-Z of Surveys’ and go to the letter N for ‘National Bereavement Survey’. After clicking on ‘Begin Survey Now’, you will be asked to log in using your Study ID Number (see the box at the bottom of the questionnaire page) and your unique password:
Do I have to take part?

Taking part is completely voluntary. If you do decide to take part you may change your mind or choose not to continue in the research at any time, without having to give a reason for doing so. However, if you decide not to complete the questionnaire, please return the reply slip so that the Office for National Statistics does not contact you again about this survey.

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 year 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 this questionnaire, please call Cruse Bereavement Care on 0844 477 9400 or by email at helpline@cruse.org.uk

How will the information I give be kept confidential?

The Office for National Statistics (ONS) will not give personal information which identifies you to anyone else. Your survey responses will only be identified by an anonymous ID number. All the information collected will be kept strictly confidential within the approved researchers 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 journal 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 care 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 organising and funding 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 the Office for National Statistics, the Department of Health and their approved researchers. At the end of the project, the findings will be written up into a report that will be submitted to the Department of Health. The results will be available to the public. The information we get from this project will help improve the quality of end of life care provided in England.

If you have further questions about the study, or if English is not your first language and you would like interpreter services, you can call our Survey Enquiry Line on 0800 298 5313 which is open Monday to Thursday - 9 am to 9 pm; Friday - 9 am to 8 pm and Saturday - 9 am to 1 pm.

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. 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.

Many thanks again.

National Bereavement Survey (VOICES), Office for National Statistics, Room 1364, Government Buildings, Cardiff Road, NEWPORT NP10 8XG
VOICES Survey
Views Of Informal Carers - Evaluation of Services

REPLY SLIP

Please enter your Study ID number (you can find it in the box at the bottom of the questionnaire pages)

Study ID Number: 

If you would prefer NOT to take part in the VOICES study, (Please tick)
please return this form in the pre-paid envelope,
so that the Office for National Statistics does not contact you again about this survey.

You do not have to give a reason, but if you feel able to tell us why, it will help us to understand why some people choose not to take part in this type of research.

Thank you for taking the time to complete and return this form

Please return in the pre-paid envelope
VOICES Survey
Views Of Informal Carers - Evaluation of Services

REPLY SLIP

If you would prefer NOT to take part in the VOICES study, please return this form in the pre-paid envelope.

This will ensure the Office for National Statistics does not contact you again about this survey.

Please enter your Study ID number so that we can remove you from the mailing list
(you can find the Study ID number on the second page of the letter)

Fill in Study ID Number here:  

You do not have to give a reason, but if you feel able to tell us why, it will help us to understand why some people choose not to take part in this type of research.

Thank you for taking the time to complete and return this form

Please return in the pre-paid envelope
If you would prefer NOT to take part in the VOICES study, please return this form in the pre-paid envelope.

Please note that the Office for National Statistics will not contact you again about this survey.

Please enter your Study ID number
(you can find the Study ID number on the questionnaire, in the box at the bottom of the page)

Fill in Study ID Number here: ______________________

You do not have to give a reason, but if you feel able to tell us why, it will help us to understand why some people choose not to take part in this type of research.

Thank you for taking the time to complete and return this form

Please return in the pre-paid envelope