Dear

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

We appreciate that this may be a very difficult time for you, but we would like to invite you to take part in the VOICES survey. VOICES gathers information on your experiences of health care services in the last months of life and is used by NHS England and other health care charities to monitor and improve the services they provide. For more information please read the information leaflet enclosed.

If you do wish to take part please complete the questionnaire and return it to ONS in the pre-paid envelope by Friday 11th December 2015.

If you do not wish to participate please tick the box on page 15 of the questionnaire and return it to ONS in the pre-paid envelope provided. This will ensure that you do not receive reminder letters.

Your views are important and will help improve health care for patients in England. We apologise if this enquiry has caused you any distress and hope that you feel able to take part in this study.

Yours sincerely

Neil Bannister
Head of End of Life Care Analysis
Office for National Statistics
Answer the questions by putting a tick in the most appropriate box or boxes. If you wish to change your answer, cross through the answer you do not want.

1. **How long had he been ill before he died?**
   - [ ] He was not ill - he died suddenly - go to question 38
   - [ ] 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

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

3. **Care at Home**
   These questions are about care at home - not in a care home
   - [ ] 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
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, in the last three months of care, 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 needed
   - Yes, we got some support but not as much as we needed
   - 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

Urgent Care Provided Out of Hours

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 three 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 111 (formerly NHS Direct)
   - District nurses
   - Macmillan nurses
   - He used his 'lifeline' pendant
   - A hospice
   - 999
   - Someone else
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 an Accident and Emergency Department at a hospital
- Advised to call 999
- Something else

10 Overall, on this last occasion, do you think that the health services responded in the right way?
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

District & Community Nurses

If he had care in the last three months from district and community nurses - go to question 12.
If he did not - go to question 15

12 How often, in the last three months of his life, 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 in the last three months of his life?
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

15 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 particular GP - go to question 20

16 How much of the time was he treated with respect and dignity by the GPs in the last three months of his life?
Tick one only
☐ Always
☐ Most of the time
☐ Some of the time
☐ Never
☐ Don't know

17 Were you able to discuss any worries and fears you may have had about his condition, treatment or tests with the GPs in the last three months of his life?
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

18 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

19 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
**Last Care Home**

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
- ☐ 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 last care home they stayed in?

*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 Stay**

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

*Tick one only*

- ☐ Yes
- ☐ 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
- ☐ Completely, some of the time
- ☐ Partially
- ☐ Not at all
- ☐ Don’t know

Nurses

- ☐ Always
- ☐ Most of the time
- ☐ Completely, some of the time
- ☐ Partially
- ☐ Not at all
- ☐ 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

Last Hospice Stay

29 Did he live or stay in a hospice at any time during his last three months of life? 
Tick one only
- Yes
- 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

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 in the last three months of his life was:

Tick one only

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

Experiences in the last two days of life

33 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

- 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

34 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)

<table>
<thead>
<tr>
<th>(a) There was enough help available to meet his personal care needs (such as toileting needs)</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Does not apply</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>(b) There was enough help with nursing care, such as giving medicine and helping him find a comfortable position in bed</td>
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<tr>
<td>(c) The bed area and surrounding environment had adequate privacy for him</td>
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</tbody>
</table>
As far as you are able to say, how much do you agree with the following statements about the overall level of care given by health and social care professionals to him in the last two days of life?

Tick only one response per statement

a) In the last two days of life he had sufficient pain relief
   - Strongly agree
   - Agree
   - Neither agree nor disagree
   - Disagree
   - Strongly disagree
   - Pain relief was not needed
   - Not sure

b) In the last two days of life he had support to eat or receive nutrition if he wished
   - Strongly agree
   - Agree
   - Neither agree nor disagree
   - Disagree
   - Strongly disagree
   - Food/nutrition was not needed
   - Not sure

c) In the last two days of life he had support to drink or receive fluid if he wished
   - Strongly agree
   - Agree
   - Neither agree nor disagree
   - Disagree
   - Strongly disagree
   - Drink/fluid was not needed
   - Not sure

d) In the last two days of life care and attention were given to problems apart from pain, thirst and hunger
   - Strongly agree
   - Agree
   - Neither agree nor disagree
   - Disagree
   - Strongly disagree
   - Does not apply
   - Not sure

e) In the last two days of life his emotional needs were considered and supported
   - Strongly agree
   - Agree
   - Neither agree nor disagree
   - Disagree
   - Strongly disagree
   - Does not apply
   - Not sure

f) In the last two days of life his spiritual and/or religious needs were considered and supported
   - Strongly agree
   - Agree
   - Neither agree nor disagree
   - Disagree
   - Strongly disagree
   - Does not apply
   - Not sure

This question continues overleaf
g) In the last two days of life efforts were made to make sure he was in the place he most wanted to be cared for

- [ ] Strongly agree
- [ ] Agree
- [ ] Neither agree nor disagree
- [ ] Disagree
- [ ] Strongly disagree
- [ ] Does not apply
- [ ] Not sure

36 Overall, how much do you agree with the following statements about communication between you and health care professionals in the last two days of his life?

Tick one box for each question (a-c)

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Don't know</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) I/we were kept informed on his condition and care</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) I/we had enough time with staff to ask questions and discuss his condition and care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) I/we understood information provided to us</td>
<td></td>
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</tr>
</tbody>
</table>

37 How much do you agree with the following statement?

In the last two days of his life you had a supportive relationship with the health care professionals.

Tick one only

- [ ] Strongly agree
- [ ] Agree
- [ ] Neither agree nor disagree
- [ ] Disagree
- [ ] Strongly disagree
- [ ] Does not apply
- [ ] Not sure
Circumstances Surrounding His Death

38 Did he know he was likely to die?
Tick one only
- Yes, certainly
- Yes, probably
- No, probably not
- No, definitely not
- Not sure

39 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
- Not sure
- Does not apply - they did not know he was dying
- Does not apply - they did not tell him he was dying

40 Were you contacted soon enough to give you time to be with him before he died?
Tick one only
- Yes
- No
- I was already there
- It was not clear that he was going to die soon
- I couldn't have got there anyway

41 Where did he die?
Tick one only
- In his own home
- In the home of another family member or friend
- In a hospital ward
- In a hospital Accident and Emergency Department
- In a hospital Intensive Care Unit
- In a hospice
- In a care home
- In an ambulance on the way to hospital or hospice
- Somewhere else

42 Did he ever say where he would like to die?
Tick one only
- Yes - go to question 43
- No - go to question 45
- Not sure - go to question 45

43 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
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>44 Did the health care staff have a record of this?</td>
<td>Tick one only</td>
</tr>
<tr>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Not sure</td>
<td></td>
</tr>
<tr>
<td>45 Do you think he had enough choice about where he died?</td>
<td>Tick one only</td>
</tr>
<tr>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
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<tr>
<td>Not sure</td>
<td></td>
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<tr>
<td>Not sure</td>
<td></td>
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<tr>
<td>46 On balance, do you think that he died in the right place?</td>
<td>Tick one only</td>
</tr>
<tr>
<td>Yes</td>
<td></td>
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<tr>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Not sure</td>
<td></td>
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<tr>
<td>47 Were you or his family given enough help and support by the healthcare team at the actual time of his death?</td>
<td>Tick one only</td>
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<tr>
<td>Yes, definitely</td>
<td></td>
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<tr>
<td>Yes, to some extent</td>
<td></td>
</tr>
<tr>
<td>No, not at all</td>
<td></td>
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<tr>
<td>Not sure</td>
<td></td>
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<tr>
<td>48 After he died, did staff deal with you or his family in a sensitive manner?</td>
<td>Tick one only</td>
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<tr>
<td>Yes</td>
<td></td>
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<tr>
<td>No</td>
<td></td>
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<tr>
<td>Not sure</td>
<td></td>
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<tr>
<td>Does not apply, I didn't have any contact with the staff</td>
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<tr>
<td>49 Looking back over the last three months of his life, was he involved in decisions about his care as much as he would have wanted?</td>
<td>Tick one only</td>
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<tr>
<td>He was involved as much as he wanted to be</td>
<td></td>
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<tr>
<td>He would have liked to be more involved</td>
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<tr>
<td>He would have liked to be less involved</td>
<td></td>
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<tr>
<td>He was not able to be involved</td>
<td></td>
</tr>
<tr>
<td>Not sure</td>
<td></td>
</tr>
<tr>
<td>50 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?</td>
<td>Tick one only</td>
</tr>
<tr>
<td>I was involved as much as I wanted to be</td>
<td></td>
</tr>
<tr>
<td>I would have liked to be more involved</td>
<td></td>
</tr>
<tr>
<td>I would have liked to be less involved</td>
<td></td>
</tr>
<tr>
<td>Not sure</td>
<td></td>
</tr>
<tr>
<td>51 Looking back over the last three months of his life, were any decisions made about his care that he would not have wanted?</td>
<td>Tick one only</td>
</tr>
<tr>
<td>Yes</td>
<td></td>
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<tr>
<td>No</td>
<td></td>
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<tr>
<td>Not sure</td>
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</tbody>
</table>
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
- Not sure

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

Information About You Both

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

What is your age?

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

Are you:
- Male
- Female

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Please could you indicate which ethnic group you belong to:

*Tick one only*

<table>
<thead>
<tr>
<th>White</th>
<th>Mixed / Multiple ethnic group</th>
</tr>
</thead>
<tbody>
<tr>
<td>English / Welsh / Scottish / Northern Irish / British</td>
<td>White and Black Caribbean</td>
</tr>
<tr>
<td>Irish</td>
<td>White and Black African</td>
</tr>
<tr>
<td>Gypsy or Irish Traveller</td>
<td>White and Asian</td>
</tr>
<tr>
<td>Any other white background</td>
<td>Any other mixed background</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Asian / Asian British</th>
<th>Any other Asian background</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indian</td>
<td>Black African / Caribbean / Black British</td>
</tr>
<tr>
<td>Pakistani</td>
<td>African</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>Caribbean</td>
</tr>
<tr>
<td>Chinese</td>
<td>Any other Black / African / Caribbean background</td>
</tr>
<tr>
<td>Any other Asian background</td>
<td>Other ethnic group</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other ethnic group</th>
<th>Arab</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any other ethnic group</td>
<td>Any other ethnic group</td>
</tr>
</tbody>
</table>
What was his age when he died?

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

What was his religion?

- No religion
- Christian (all denominations)
- Buddhist
- Hindu
- Jewish
- Muslim
- Sikh
- Any other religion

We would be grateful if you could return your questionnaire 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.

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 e-mail: helpline@cruse.org.uk

 DECLINE - Please tick this box if you decide not to complete this survey.

If you would like to tell us why, please write any comments below.
Please use the space below if there is anything you would like to say about the care provided. Information written here may be combined with information on other people’s experiences, and provided to NHS and ONS approved researchers, to inform studies on improving end of life care. All information provided to researchers will be anonymised. To help us ensure confidentiality please do not give names of people or places.

__________________________________________________________

__________________________________________________________

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__________________________________________________________

__________________________________________________________

Thank you for completing the VOICES survey, we will not ask you for any further information.