

VOICES

VIEWS OF INFORMAL CARERS -
EVALUATION OF SERVICES

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 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. NHS England 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. Your responses to the survey will be shared with NHS England 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 ticking the box on the back of the questionnaire and returning it to ONS in the pre-paid envelope provided. This will ensure that you do not receive reminder letters.

If you do wish to take part please complete the questionnaire and return it to ONS in the pre-paid envelope by Friday 13th December 2013.

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



Emma Gordon, Head of Life Events 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

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.

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

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

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 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
- Someone else - please write in the space below

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

District & Community Nurses

If he had care in the last 3 months from district and community nurses - go to question 12.

If he did not, go to question 15

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 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 GP - go to question 20

16 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

17 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

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

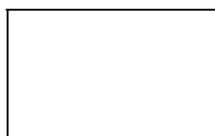
- Very easy
- Fairly easy
- Fairly difficult
- Very difficult
- He wanted the GPs to visit but they would not visit
- Does not apply - the GP did not need to visit
- Don't know

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

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

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

- | Doctors | Nurses |
|--------------------------|-------------------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> Excellent |
| <input type="checkbox"/> | <input type="checkbox"/> Good |
| <input type="checkbox"/> | <input type="checkbox"/> Fair |
| <input type="checkbox"/> | <input type="checkbox"/> Poor |
| <input type="checkbox"/> | <input type="checkbox"/> Don't know |

Last Hospice Admission

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

- | Doctors | Nurses |
|--------------------------|---|
| <input type="checkbox"/> | <input type="checkbox"/> Always |
| <input type="checkbox"/> | <input type="checkbox"/> Most of the time |
| <input type="checkbox"/> | <input type="checkbox"/> Some of the time |
| <input type="checkbox"/> | <input type="checkbox"/> Never |
| <input type="checkbox"/> | <input type="checkbox"/> Don't know |

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?

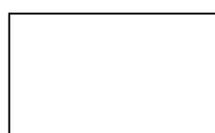
Please answer for both doctors and nurses

Doctors	Nurses
<input type="checkbox"/>	<input type="checkbox"/> Always
<input type="checkbox"/>	<input type="checkbox"/> Most of the time
<input type="checkbox"/>	<input type="checkbox"/> Some of the time
<input type="checkbox"/>	<input type="checkbox"/> Never
<input type="checkbox"/>	<input type="checkbox"/> 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)

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply	Don't know
(a) There was enough help available to meet his personal care needs (such as toileting needs)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) There was enough help with nursing care, such as giving medicine and helping him find a comfortable position in bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) The bed area and surrounding environment had adequate privacy for him	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



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)

	Excellent	Good	Fair	Poor	Does not apply	Don't know
(a) Relief of pain	<input type="checkbox"/>					
(b) Relief of symptoms other than pain	<input type="checkbox"/>					
(c) Spiritual support	<input type="checkbox"/>					
(d) Emotional support	<input type="checkbox"/>					
(e) Support to stay where he wanted to be	<input type="checkbox"/>					

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? (Continued overleaf)

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 next page...

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 e-mail:
helpline@cruse.org.uk

Information About You Both

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



56 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

57 Please could you indicate which ethnic group in your opinion 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



