



[First name(s)][Surname]
[Address Line 1]
[Address Line 2]
[Address Line 3]
[Address Line 4]
[Address Line 5]
[Address Line 6]

VOICES

VIEWS OF INFORMAL CARERS -
EVALUATION OF SERVICES

Dear [First name(s)] [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, or if English is not your first language and you would like interpreter services, please call our Survey Enquiry Line on 0800 298 5313

We are writing to you because you registered the death of [FIRST NAME(S) 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. 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 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 14th December 2012.

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.

If you have further questions about the study, please call our Survey Enquiry Line on 0800 298 5313, which is open Monday to Thursday 9am to 9pm, Friday 9am to 8pm, and Saturday 9am to 1pm.

Yours sincerely

Emma Gordon, Head of Health Analysis, Office for National Statistics

Study ID

1

How long had she been ill before she died?

Tick one only

☐

She was not ill - she 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 she died suddenly with no illness or time for care, please go to question 37. Otherwise, please continue with the questions below.

2

Did she spend any time at home during the last three months of life?

Tick one only

☐

Yes - go to question 3

☐

No - She was in a care home for the whole 3 months - go to question 12

☐

No - She was in hospital - go to question 24

Care at Home

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

3

When she was at home in the last three months of life, did she 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)

☐

She did not receive any care

☐

Don't know

☐

Something else - please write below



4 When she 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
- ☐ She 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 her?

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 her life, while she was at home, how well was her pain relieved?

Tick one only

- ☐ Does not apply - she 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 she was at home, did she 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 she contact, or who was contacted on her behalf?

Tick all that apply

- ☐ Her GP or the out-of-hours number
- ☐ NHS Direct
- ☐ District nurses
- ☐ Macmillan nurses
- ☐ She used her 'lifeline' pendant
- ☐ A hospice
- ☐ 999
- ☐ Someone else - please write in the space below

9 What happened as a result? Was she...
Tick one only

- ☐ Visited by her 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 she got when she needed care urgently in the evenings or weekends in the last three months of her life was:
Tick one only

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

District & Community Nurses

If she had care in the last 3 months from district and community nurses -
go to question 12.
If she 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 she 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 she 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 she see the GP she preferred to see?

Tick one only

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

16 How much of the time was she 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 her 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 her 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
- ☐ She 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 she 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 she live or stay in a care home at any time during her last three months of life?

Tick one only

Yes, she 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 she 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 her life, while she was in the care home, how well was her pain relieved?

Tick one only

Does not apply - she 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 she got from the care home in the last three months of her life was:

Tick one only

Excellent
Good
Fair
Poor
Don't know

Last Hospital Admission

24 Did she stay in hospital at any time during her last three months of life?

Tick one only

Yes - please write the name of the last hospital she stayed in below
Name:

Town:

No - go to question 29

Don't know - go to question 29

25 During her last hospital admission, how much of her time was she 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 her last hospital admission, how well was her pain relieved?

Tick one only

- ☐ Does not apply - she 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 her 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 she 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 she stay in a hospice at any time during her last three months of life?

Tick one only

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

Town:

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

30 How much of the time was she 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 her life, while she was in the hospice, how well was her pain relieved?

Tick one only

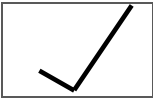
- ☐ Does not apply - she did not have any pain
- ☐ Completely, all of the time
- ☐ Completely, some of the time
- ☐ Partially
- ☐ Not at all
- ☐ Don't know

32 Overall, do you feel that the care she 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 her last two days of life was she:

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 she treated with respect and dignity in the last two days of her 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 she 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 her 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 her 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 her	<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 her?

Tick one box for each question (a-e)

- (a) Relief of pain
- (b) Relief of symptoms other than pain
- (c) Spiritual support
- (d) Emotional support
- (e) Support to stay where she wanted to be

Excellent	Good	Fair	Poor	Does not apply	Don't know
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Circumstances Surrounding Her Death

37 Did she know she 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 her she was likely to die break the news to her 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 she was dying
- ☐ Does not apply - they did not tell her she was dying

39 Were you contacted soon enough to give you time to be with her before she died?

Tick one only

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

40 Where did she die? (Continued overleaf)

Tick one only

- ☐ In her 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 she 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 she ever say where she 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 she say that she would like to die?
Tick one only
- ☐ At home
- ☐ In a hospice
- ☐ In a hospital
- ☐ In a care home
- ☐ She said she did not mind where she died
- ☐ She changed her mind about where she 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 she had enough choice about where she died?
Tick one only
- ☐ Yes
- ☐ No
- ☐ Not sure
- ☐ She died suddenly



45 On balance, do you think that she died in the right place?

Tick one only

☐ Yes

☐ No

☐ Not sure

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

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No, not at all

☐ Don't know

47 After she died, did staff deal with you or her 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 her life, was she involved in decisions about her care as much as she would have wanted?

Tick one only

☐ She was involved as much as she wanted to be

☐ She would have liked to be more involved

☐ She would have liked to be less involved

☐ Don't know

49 Looking back over the last three months of her life, were you involved in decisions about her 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 her care that she would not have wanted?

Tick one only

☐ Yes

☐ No

☐ Don't know

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

Tick one only

☐ Outstanding

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Don't know

52 Since she died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about her 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 her? Were you her:

Tick one only

- ☐ Husband / 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 she 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

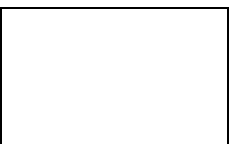
- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese
- ☐ Any other Asian background

Black / African / Caribbean / Black British

- ☐ African
- ☐ Caribbean
- ☐ Any other Black / African / Caribbean background

Other ethnic group

- ☐ Arab
- ☐ Any other ethnic group



58 What was her age when she died?

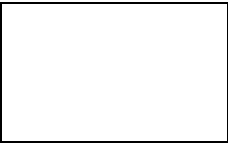
- ☐ 18 - 19
- ☐ 20 - 29
- ☐ 30 - 39
- ☐ 40 - 49
- ☐ 50 - 59
- ☐ 60 - 69
- ☐ 70 - 79
- ☐ 80 - 89
- ☐ 90 +

59 What was her 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[illegible]

Please continue on next page...

F

T

[illegible]

11

I do not wish to take part in the VOICES survey.

If you would like to tell us why, please write any comments below.

11/11/2019

L

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