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Appendix A

VOICES

POSTAL QUESTIONNAIRE

This questionnaire is about the care and services received by people in the last months of life and by their family and friends. The information you give us will be used to help improve care for people who die, and for their family and friends. Your views are, therefore, important to us.

We are interested in finding out the experiences of all people who have died whether suddenly, after a short illness, or after a long illness. We also think it is important to find out about the care you and the family received at the time of death and in the months since then. Some of the questions may therefore not be relevant to you. Please fill in as much of the questionnaire as you can.

We realise this questionnaire may bring back strong memories. If you feel upset or distressed, you do not have to continue with the questionnaire and can stop at any time.

Your answers to these questions will, of course, be treated as strictly confidential. No names will be used in the reports we write.

We do not know the name of the person whose death you registered. We have, therefore, referred to him as s/he in the questionnaire.

Instructions

- As you go through the questionnaire, please follow the instructions and answer the questions by ticking the most appropriate box or boxes, like this: ✓
- If you would rather not answer one of the questions, please go on to the next one.
- We are very interested in what you have to say. Please continue on extra sheets if necessary.

Q1. How long had s/he been ill before s/he died?

Tick one only

- S/he was not ill – s/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

*If s/he died suddenly with no illness or time for care, please go to Section I (page 48)
Otherwise, please continue with the questions below.*

Q2. Did s/he spend any time at home during the last three months of life?

- Yes
- No

If **‘Yes’** please answer the questions in Part A on page 3 before going on to part B.

If **‘No’** please go straight to Part B on page 11

Part A: Care at home

The following questions are about the care s/he received at home during the last three months of life.

A1. In the last three months of life, did s/he get any help at home from any of the services listed below?

Please tick all that apply

A district or community nurse (a nurse in uniform who comes to the house)

A Macmillan nurse, hospice homecare nurse or specialist palliative care nurse (a palliative care nurse who visits or telephones to talk and advise on medications and other aspects of care. They do not wear a uniform)

A Marie Curie nurse (someone who comes to the house for a few hours or overnight to care for the patient)

Home care worker, home care aide, or home help

Meals on wheels

None of the above

Something else **PLEASE WRITE IN THE BOX BELOW**

Do not know

A2. When s/he was at home in the last three months of life did the doctors or nurses caring for him/her carry out an assessment of his/her needs? They may, for example, have asked about any physical, practical, social or emotional problems s/he had.

Tick one only

Yes, they assessed his/her needs once

Yes, they assessed his/her needs more than once

No

Don't know

A3. When s/he was at home in the last three months of life, did the doctors or nurses caring for him/her carry out an assessment of your needs, or those of your family?

Tick one only

Yes, they assessed our needs once

Yes, they assessed our needs more than once

No

Don't know

A4. When s/he was at home in the last three months of life, did all the health and social services involved in his/her care work well together?

Tick one only

Yes, definitely

Yes, to some extent

No, they did not work well together

S/he did not receive any care

Don't know

A5. In the last three months of his life, did s/he get enough help at home to meet his/her personal care needs? We're thinking of things like bathing, dressing, help with eating and going to the bathroom.

Tick one only

Yes, definitely

Yes, to some extent

No, s/he did not get enough help and support

S/he did not need any help with personal care

A6. During the last three months of his/her life while she was at home (not a nursing or residential home), did s/he have any pain?

Tick one only

Yes

No

Don't know

A7. Did s/he have any treatment for his/her pain?

Tick one only

Yes

No

Don't know

Not applicable, s/he did not have any pain

A8. Did the treatment relieve his/her pain?

Tick one only

Completely all of the time

Completely some of the time

Partially

Not at all

Don't know

Not applicable: s/he did not have any pain

Not applicable: s/he did not have any treatment for pain

A9. Did s/he know s/he was likely to die?

Tick one only

Yes, certainly **Go to question A10**

Yes, probably **Go to question A10**

Probably not **Go to question A12**

No, definitely **Go to question A12**

Not sure

Go to question A12

A10. Who had told him/her that s/he was likely to die?

Tick one only

Hospital doctor

Hospital nurse

GP

District nurse

Macmillan or specialist palliative care or hospice home care nurse

Hospice doctor

Hospice nurse

A family member

No-one

Don't know

A11. In your opinion, did the person who told him/her s/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

A12. During the last three months of his life, did s/he get any advice about state benefits s/he might be entitled to?

Tick one only

Yes

No

Don't know

A13. During the last three months of his life, did s/he receive an attendance allowance?

Tick one only

Yes

No

Don't know

A14. How difficult was it for him/her and his/her family to cover the cost of his/her care in the last three months of life?

Tick one only

Very difficult

Fairly difficult

Fairly easy

Very easy

Don't know

A15. 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/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 any help

A16. Overall, do you feel that the help and support you and your family received from health and social services when caring for him/her was:

Tick one only

Excellent

Good

Fairly good

Poor

Not applicable: we did not need any help

Part B: District and community nurses

These questions are about care from district and community nurses.

If s/he had care in the last three months of life from a district or community nurse **Go to question B1.**

If s/he did not **Go to question C1 on page 15**

(You may find it helpful to check your answer to question A1 on page 3)

B1. In your opinion, did the district and community nurses caring for him/her know enough about his/her condition or treatment?

Tick one only

All the nurses knew enough

Most of the nurses knew enough

Some of the nurses knew enough

None of the nurses knew enough

Don't know

B2. Did you have confidence and trust in the nurses who were caring for him/her?

Tick one only

Yes, in all of them

Yes, in some of them

No, not in any of them

Don't know

B3. Do you feel that his/her nurses had time to listen and discuss things?

Tick one only

Yes, definitely

Yes, to some extent

No

Don't know

B4. Were you able to discuss with the nurses any worries or fears you may have had about his/her condition, treatment or tests?

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

Don't know

B5. How much of the time was s/he treated with respect and dignity by the nurses?

Tick one only

Always

Most of the time

Some of the time

Never

Don't know

B6. How frequently did the district and community nurses visit him/her in the last three months? (if this varied, please tell us about when they were coming most often)

Tick one only

More than once a day

Once a day

Two to six times a week

Once a week

Two to three times a month

Once a month

Less than once a month

B7. Overall, do you feel that the care s/he got from the district and community nurses in the last three months of life was as:

Tick one only

Excellent

Good

Fair

- Poor
- Don't know

Part C: Care from GP

This part of the questionnaire concerns his general practitioners (GPs or family doctors) and any other doctor who visited him at home, or in a nursing or residential home, in the last three months of his life.

C1. Did s/he have any contact with his/her GP in last 3 months of life?

Tick one only

- Yes Go to question C2
- No Go to question D1
on page 19
- Not sure Go to question D1
on page 19

C2. In your opinion, did the GPs know enough about his/her condition or treatment?

Tick one only

- All the GPs knew enough
- Most of the GPs knew enough
- Only some of GPs knew enough
- None of the GPs knew enough
- Don't know

C3. Did you have confidence and trust in the GPs who were caring for him/her?
Tick one only

Yes, in all of them

Yes, in some of them

No, not in any of them

Don't know

C4. Do you feel that his/her GPs had time to listen and discuss things?
Tick one only

Yes, definitely

Yes, to some extent

No

Don't know

C5. Were you able to discuss with the GPs any worries or fears you may have had about his/her condition, treatment or tests?
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

Don't know

C6. How much of the time was he/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

C7. How often did the GP visit him/her at home during the last three months of his/her life?

Tick one only

The GP did not visit at home, and no visits were needed

The GP did not visit at home, but s/he wanted the GP to visit

The GP visited once

The GP visited 2-5 times

The GP visited 6-10 times

The GP visited 11-15 times

The GP visited 16-20 times

The GP visited more than 21 times

C8. Overall, do you feel that the care s/he got from his GP in the last three months of life was:

Tick one only

Excellent

Good

Fair

Poor

Don't know

Section D: 'Out of hours' medical care

D1. In the last three months of life, when s/he was at home, did s/he ever need to contact a doctor for something urgent in the evening or at a weekend?

Tick one only

Not at all in the last 3 months

Go to question E1 on page 22

Once or twice

Go to question D2

Three or four times

Go to question D2

Five times or more

Go to question D2

D2. The last time this happened, who did s/he contact (or who was contacted on his/her behalf?)

Tick one only

His/her GP, or the GP out-of-hours number

NHS Direct

District Nurses

Macmillan Nurses

A hospice

999

D3. What happened as a result? Was s/he...

Tick one only

Visited by his/her own 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 telephone

Given another number to ring to get medical advice

Advised to go to the GP surgery when it opened

Advised to go to an out-of-hours GP surgery

Advised to go to Accident and Emergency
at a hospital

advised to call 999

or something else PLEASE WRITE IN THE BOX BELOW

D4. In your opinion, was this the right thing for them to do, or not?

Tick one only

Yes

No

Not sure

D5. Altogether, what do you think about the care s/he got when he needed care urgently in the evenings or at weekends in the last three months of his life? Would you describe the care as:

Tick one only

Excellent

Good

Fair

Poor

Don't know

Part E: Nursing and residential care

E1. Did s/he live or stay in a nursing or residential home at any time during his/her last three months of life?

Tick all that apply

Yes, s/he was in a nursing home

Yes, s/he was in a residential home

No

Don't know

If she was in a nursing home, a residential home or both go to question E1.

If she was not in a nursing or residential home go to question F1 on page

<p>Please note that Part G of this questionnaire is about in-patient hospice care. Please do not fill in Part E about a stay in a hospice. Hospices provide care from multi-professional teams for people who are dying and their families.</p>
--

E2. In your opinion, did the staff know enough about his/her condition or treatment?

Tick one only

All the staff knew enough

Most of the staff know enough

Some of the staff knew enough

None of the staff knew enough

E3. Did you have confidence and trust in the staff who were caring for him/her?

Tick one only

- Yes, in all of them
- Yes in some of them
- No, not in any of them

E4. Did you feel that the staff had time to listen and discuss things?

Tick one only

- Yes, definitely
- Yes, to some extent
- No
- Don't know

E5. Were you able to discuss with the staff any worries or fears you may have had about his/her condition, treatment or tests?

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
- Don't know

E6. How much of the time was he treated with respect and dignity by the staff at the nursing or residential home?

Tick one only

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

E7. In your opinion, were there enough staff on duty to care for him/her while s/he was in the nursing or residential home?

Tick one only

- There were always or nearly always enough staff on duty
- There were sometimes enough staff on duty
- There were rarely or never enough staff on duty
- Don't know

E8. When s/he was in the home, did s/he get enough help to meet his /her personal care needs? We're thinking of things like bathing, dressing, help with eating, and going to the bathroom.

Tick one only

- Yes, definitely
- Yes, to some extent
- No, s/he did get enough help and support
- S/he did not need help with personal care

E9. During the last three months of her life, while she was in the nursing or residential home, did she have any pain?

Tick one only

- Yes
- No
- Don't know

E10. Did s/he have any treatment for her pain?

Tick one only

- Yes
- No
- Don't know
- Not applicable: s/he did not have any pain

E11. Did the treatment relieve her pain?

Tick one only

- Completely all of the time
- Completely some of the time
- Partially
- Not at all
- Don't know
- Not applicable: s/he did not have any pain
- Not applicable: s/he did not have any treatment for his/her pain

E12. Overall, do you feel that the care s/he got from the staff in the home was:

Tick one only

Excellent

Good

Fair

Poor

Don't know

Section F: Last hospital admission

These questions are about his last admission to hospital. If his last admission was for less than 24 hours, please answer these questions about a previous admission which was for more than 24 hours.

F1. Did s/he stay in hospital at any time during his/her last three months of life for more than 24 hours?

Tick one only

Yes

Go to question F2

No, not for more than 24 hours

Go to question G1 on Page 34

Don't know

Go to question G1 on Page 34

F2. What was the name of hospital? PLEASE WRITE IN THE BOX BELOW

F3. In your opinion, did the hospital doctors know enough about his/her condition or treatment?

Tick one only

All the doctors knew enough

Most of the doctors knew enough

Some of the doctors knew enough

None of the doctors knew enough

F4. Did you have confidence and trust in the hospital doctors who were caring for him?

Tick one only

Yes, in all of them

Yes, in some of them

No, not in any of the doctors

F5. Do you feel that his/her hospital doctors had time to listen and discuss things?

Tick one only

Yes, definitely

Yes, to some extent

No

Don't know

F6. How much of the time was s/he treated with respect and dignity by the hospital doctors?

Tick one only

Always

Most of the time

Some of the time

Never

Don't know

F7. In your opinion, did the hospital nurses know enough about his/her condition or treatment?

Tick one only

All the nurses knew enough

Most of the nurses knew enough

Some of the nurses knew enough

None of the nurses knew enough

F8. Did you have confidence and trust in the hospital nurses who were caring for him/her?

Tick one only

Yes, in all of them

Yes, in some of them

No, not in any of the nurses

F9. Do you feel that his/her hospital nurses had time to listen and discuss things?

Tick one only

Yes, definitely

Yes, to some extent

No

Don't know

F10. How much of the time was s/he treated with respect and dignity by the hospital nurses?

Tick one only

Always

Most of the time

Some of the time

Never

Don't know

F11. In your opinion, were there enough nurses on duty to care for him/her in hospital?

Tick one only

There were always or nearly always enough nurses on duty

There were sometimes enough nurses on duty

There were rarely or never enough nurses on duty

Don't know

F12. During this hospital stay, did s/he get enough help to meet his/her personal care needs? We're thinking of things like bathing, dressing, help with eating, and going to the bathroom.

Tick one only

Yes, definitely

Yes, to some extent

No

S/he did not need any help with personal care

Don't know

F13. Were you able to discuss with the hospital doctors, nurses or other staff any worries or fears you may have had about his/her condition, treatment or tests?

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

Don't know

F14. During this hospital stay, were you involved in decisions about his treatment and care as much as you wanted?

Tick one only

I was involved as much as I wanted to be

I would have liked to be more involved

Don't know

Not applicable

F15. During this hospital stay, did s/he have any pain?

Tick one only

Yes

No

Don't know

F16. During this hospital stay, did s/he have any treatment for his/her pain?

Tick one only

Yes

No

Don't know

Not applicable. s/he did not have any pain

F17. Did the treatment relieve his/her pain?

Tick one only

Completely all of the time

Completely some of the time

Partially

Not at all

Don't know

Not applicable: he did not have any pain

Not applicable: he did not have any treatment for his/her pain

F18. Overall, do you feel that the care she got from the doctors in the hospital was:

Tick one only

Excellent

Good

Fair

Poor

Don't know

F19. Overall, do you feel that the care she got from nurses in the hospital was:

Tick one only

Excellent

- Good
- Fair
- Poor
- Don't know

F20. Altogether do you think that the care she got from the hospital was:

Tick one only

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

Section G: Last hospice admission

These questions are about his last admission to hospice. If his last admission was for less than 24 hours, please answer these questions about a previous admission which was for more than 24 hours.

G1. Did s/he stay in a hospice at any time during his/her last three months of life for more than 24 hours?

Tick one only

Yes

Go to question G2

No, not for more than 24 hours

Go to question H1 on Page 41

Don't know

Go to question H1 on Page 41

G2. What was the name of the hospice? PLEASE WRITE IN THE BOX BELOW

G3. In your opinion, did the hospice doctors know enough about his/her condition or treatment?

Tick one only

All the doctors knew enough

Most of the doctors knew enough

Some of the doctors knew enough

None of the doctors knew enough

G4. Did you have confidence and trust in the hospice doctors who were caring for him?

Tick one only

Yes, in all of them

Yes, in some of them

No, not in any of the doctors

G5. Do you feel that his/her hospice doctors had time to listen and discuss things?

Tick one only

Yes, definitely

Yes, to some extent

No

Don't know

G6. How much of the time was s/he treated with respect and dignity by the hospice doctors?

Tick one only

Always

Most of the time

Some of the time

Never

Don't know

G7. In your opinion, did the hospice nurses know enough about his/her condition or treatment?

Tick one only

All the nurses knew enough

Most of the nurses knew enough

Some of the nurses knew enough

None of the nurses knew enough

G8. Did you have confidence and trust in the hospice nurses who were caring for him/her?

Tick one only

Yes, in all of them

Yes, in some of them

No, not in any of the nurses

G9. Do you feel that his/her hospice nurses had time to listen and discuss things?

Tick one only

Yes, definitely

Yes, to some extent

No

Don't know

G10. How much of the time was s/he treated with respect and dignity by the hospice nurses?

Tick one only

Always

Most of the time

Some of the time

Never

Don't know

G11. In your opinion, were there enough nurses on duty to care for him/her in hospice?

Tick one only

There were always or nearly always enough nurses on duty

There were sometimes enough nurses on duty

There were rarely or never enough nurses on duty

Don't know

G12. During this hospice stay, did s/he get enough help to meet his/her personal care needs? We're thinking of things like bathing, dressing, help with eating, and going to the bathroom.

Tick one only

Yes, definitely

Yes, to some extent

No

S/he did not need any help with personal care

Don't know

G13. Were you able to discuss with the hospice doctors, nurses or other staff any worries or fears you may have had about his/her condition, treatment or tests?

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

Don't know

G14. During this hospice stay, were you involved in decisions about his treatment and care as much as you wanted?

Tick one only

I was involved as much as I wanted to be

I would have liked to be more involved

Don't know

Not applicable

G15. During this hospice stay, did s/he have any pain?

Tick one only

Yes

No

Don't know

G16. During this hospice stay, did s/he have any treatment for his/her pain?

Tick one only

Yes

No

Don't know

Not applicable: s/he did not have any pain

G17. Did the treatment relieve his/her pain?

Tick one only

- Completely all of the time
- Completely some of the time
- Partially
- Not at all
- Don't know
- Not applicable: he did not have any pain
- Not applicable: he did not have any treatment for his/her pain

G18. Overall, do you feel that the care she got from the doctors in the hospice was:

Tick one only

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

G19. Overall, do you feel that the care she got from nurses in the hospice was:

Tick one only

- Excellent

Good

Fair

Poor

Don't know

G20. Altogether do you think that the care she got from the hospice was:

Tick one only

Excellent

Good

Fair

Poor

Don't know

PART H: Last 3 days

The questions are about his experiences in the last three days of his life and the care he received.

H1. During his last three days was s/he

Tick one only

At home all the time

Go to question H3

In a nursing or residential home all the time

Go to question H3

In hospital all the time

Go to question H3

In a hospice all the time

Go to question H3

At home to begin with and then in hospital

Go to question H2

At home to begin with and then in a hospice

Go to question H2

In a nursing or residential home first and then in a hospital

Go to question H2

In a nursing or residential home first and then in a hospice

Go to question H2

In hospital first and then at home

Go to question H2

In a hospice first and then at home

Go to question H2

Something else PLEASE WRITE IN THE BOX **Go to question H2**

BELOW

H2. Where did s/he spend most time in his/her last three days?

Tick one only

Home

Please answer part
H about where he

Nursing or residential home

spent the most
time

Hospital

Somewhere else PLEASE WRITE IN THE
BELOW

H3. How much of the time was s/he treated with respect and dignity by the doctors, nurses and other staff caring for him/her?

Tick one only

Always

Most of the time

Some of the time

Never

Don't know

H4. During these last three days, did she get enough help to meet his personal care needs? We're thinking of things such as bathing, dressing, help with eating and going to the bathroom?

Tick one only

Yes definitely

Yes to some extent

No

He did not need any help with personal care

Don't know

H5. During these last three days, did s/he get enough help with nursing care? We're thinking of things like getting dressings changed, and help with medication.

Tick one only

Yes definitely

Yes to some extent

No

He did not need any help with personal care

Don't know

H6. During these last three days, do you feel that his religious or spiritual beliefs were taken into consideration by those caring for him/her.

Tick one only

Yes, always

Yes, most of the time

Yes, some of the time

Never

Don't know

H7. Were you involved in decisions about his/her treatment and care as much as you wanted?

Tick one only

Involved as much as I wanted

Would have liked to be more involved

Don't know

Not applicable

H8. During these last three days, was there any decision made about his/her care or treatment that he would not have wanted?

Tick one only

Yes

No

Don't know

H9. During these last three days, did it seem likely that s/he would die very soon?

Tick one only

Yes

No

Don't know

H10. At anytime during the last three days, was s/he fed by a tube in her nose (nasogastric tube) or his/her stomach (PEG tube)?

Tick one only

Yes

No

Don't know

H11. If his/her heart stopped, was anything done to try and restart it?

Tick one only

Yes

No

Don't know

**H12.
(resp**

chine.

Tick one only

Yes

No

Don't know

H13. Did s/he have any pain in his/her last three days of life?

Tick one only

Yes

No

Don't know

H14. Did s/he have any treatment for his/his pain?

Tick one only

Yes

No

Don't know

Not applicable s/he did not have any pain

H15. Did the treatment relieve his/her pain:

Tick one only

Completely all of the time

Completely some of the time

Partially

Not at all

Don't know

Not applicable, s/he did not have any pain

Not applicable, s/he did not have any treatment for the pain

H16. Overall, do you think the care s/he received in the last three days of life was:

Tick one only

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

Part I: Events around his/her death

The following questions are about the events around his/her death, and your feelings about the way in which the health and social services treated you both at the time.

I1. Where did s/he die?

Tick one only

- In her own home
- In the home of another family member or friend
- In a hospital ward
- In a hospital Accident and Emergency Department
- In a hospice
- In a residential or nursing home
- In an ambulance on the way to hospital/hospice
- Somewhere else PLEASE WRITE IN THE BOX BELOW

I2. Did s/he ever say where s/he would like to die?

Tick one only

- Yes Go to question I3
- No Go to question I4
- Not sure Go to question I4

I3. Where did s/he say that s/he would like to die?

Tick one only

- At home
- In a hospice
- In hospital
- In a nursing or residential home
- S/he said s/he did not mind where s/he died
- Somewhere else PLEASE WRITE IN THE BOX BELOW

I4. Do you think s/he had enough choice about where s/he died?

Tick one only

- Yes
- No
- Not sure

I5. Do you think you had enough choice about where s/he died?

Tick one only

- Yes
- No
- Not sure

I6. On balance, do you feel that s/he died in the right place?

Tick one only

Yes, it was the right place

No, it was not the right place

Not sure

Don't know

17. Were you told that s/he was likely to die shortly?

Tick one only

Yes

No

18. Were you given a chance to talk about your feelings about this at the time?

Tick one only

Yes, definitely

Yes, to some extent

No, not as much as I needed to

I did not need to talk about it

Don't know

I did not know s/he was likely to die soon

19. Did you know what to expect when s/he was dying?

Tick one only

- Yes
- Yes, partially
- No
- Don't know

I10. This question is about how satisfied you are with the way in which the death was handled by health professionals and other officials.

For example, if you think the way you were given his property by the hospital was good, you should put a tick in the 'good' box next to this question. If you are less satisfied with how this was handled, you should put a tick in the 'fair' box or 'poor' box.

Some questions may not apply to you, perhaps because he died at home rather than in hospital. For each question which does not apply, please tick 'does not apply to me'.

Tick one box on each line (a) – (g)

	Excellent	Good	Fair	Poor	Does not	Don't know
(a) The way in which you were told about the death.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) The way in which you were given his property back by the hospital, hospice or nursing home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) The opportunities you were given to view the body.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) The place where you viewed the body.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) The way in which the need for a post-mortem examination was explained to you.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(f) The way in which the post-mortem examination was carried out.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(g) The way in which you were told the results of the post-mortem examination.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I11. Since s/he died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about his/her illness and death?

Tick one only

Yes

Go to question J1

No

Go to question I12

Not sure

Go to question I12

I12. Would you have liked to have talked to someone about your feelings about his/her illness and death?

Tick one only

Yes

Go to question J1

No

Go to question J1

Not sure

Go to question J1

Part J

In this section, we would like to know a little more about you both. This will help us make more use of the information you have given us.

**J1. What was your relationship to him?
Were you his:**

Wife/Partner

Son/daughter

Brother/Sister

Son-in-law/daughter-in-law

Parent

Other relative

Friend

Neighbour

Staff in nursing or residential home

Warden (*sheltered accommodation*)

Other official

Someone else PLEASE WRITE IN BOX

J2. What is your age?

J3. Are you:

Male

Female

J4. Please could you indicate to which ethnic group you belong:

White

Bangladeshi

Black African

Black Caribbean

Black other (*please specify below*)

Chinese

Indian

Pakistani

Other Asian

Something else **PLEASE WRITE IN BOX**

J5. What was his age at death?

J6. Was he:

Male

Female

J7. Please could you indicate to which ethnic group he belonged:

White

Bangladeshi

Black African

Black Caribbean

Black other (*please specify below*)

Chinese

Indian

Pakistani

Other Asian

Something else **PLEASE WRITE IN BOX**

J8. This question is about the illnesses he may have had in the last 3 months of life. It is also about what you think caused his death. Here is a list of illnesses which often affect people towards the end of life. In the first column, please tick all the illnesses he had in the last 3 months of life (if any). In the second column please tick the illness (or illnesses) which you think caused his death. Please tick 'don't know' if you do not know what caused his death.

	He had this illness in last 3 months of life (please tick all that apply)	This illness caused his death (please tick all that apply)
Cancer	<input type="checkbox"/>	<input type="checkbox"/>
Leukemia	<input type="checkbox"/>	<input type="checkbox"/>
Heart Failure	<input type="checkbox"/>	<input type="checkbox"/>
Lymphoma	<input type="checkbox"/>	<input type="checkbox"/>
Heart attack	<input type="checkbox"/>	<input type="checkbox"/>
Other type of heart disease	<input type="checkbox"/>	<input type="checkbox"/>
High blood pressure	<input type="checkbox"/>	<input type="checkbox"/>
Stroke (cerebrovascular disease)	<input type="checkbox"/>	<input type="checkbox"/>
Peripheral vascular disease	<input type="checkbox"/>	<input type="checkbox"/>
COPD (chronic obstructive pulmonary disease)	<input type="checkbox"/>	<input type="checkbox"/>
Other types of lung disease	<input type="checkbox"/>	<input type="checkbox"/>
End-stage renal disease	<input type="checkbox"/>	<input type="checkbox"/>
Liver Failure	<input type="checkbox"/>	<input type="checkbox"/>
Rheumatoid arthritis	<input type="checkbox"/>	<input type="checkbox"/>
Dementia	<input type="checkbox"/>	<input type="checkbox"/>
Multiple Sclerosis	<input type="checkbox"/>	<input type="checkbox"/>
Parkinson's Disease	<input type="checkbox"/>	<input type="checkbox"/>
Motor Neurone Disease	<input type="checkbox"/>	<input type="checkbox"/>
Cystic Fibrosis	<input type="checkbox"/>	<input type="checkbox"/>
Something else	PLEASE WRITE IN THE BOX BELOW	

Appendix B

VOICES Re-development

Over the last decade there have been six versions of VOICES, adapted for specific patient groups (heart failure, stroke) and for different care settings (hospice). The last version (DH VOICES) had 144 items (see Appendix A). In order to develop a more contemporary and shorter version that meets the requirements of the DH End of Life Care Strategy (thus reflecting changes in care planning and delivery priorities), a number of different procedures were employed:

- a) Addition of new questions to reflect the focus of the Strategy
- b) Gathering the views of professionals, patients and relatives
- c) Analysis of existing VOICES datasets
- d) Input from other experts and surveys
- e) Consultation with the Project Steering Group
- f) Gathering the views of specialist palliative care professionals and survey researchers

a) Addition of questions to meet the needs of the Strategy

Initially, DH VOICES was expanded to include questions that address the key issues within the DH End of Life Care Strategy. These additional questions focused on:

1. Preferred place of death
2. Whether preferred place of death was discussed with the healthcare team
3. Choices surrounding place of death
4. Breaking bad news
5. Co-ordination of care
6. Assessment of family and carer needs.

b) Gathering the views of professionals, patients and relatives

Discussions were held between specialist palliative care nurses and eight members of patient and relatives user groups. These discussion groups were used to ascertain priority issues at the end of life and to discuss the content, format, flow and length of the expanded DH VOICES questionnaire.

Members of these groups highlighted the key issues that should be represented in the questionnaire. Feedback was that the questionnaire was too long and that more comments boxes were required, and participants suggested a series of additional questions that focused on the following areas:

1. Emotional and spiritual support

2. The relief of symptoms other than pain
3. Maintenance of comfort
4. Whether healthcare staff have a record of preferred place of care.

Patients and carers were particularly concerned that participants should be given practical help to complete the questionnaire as well as emotional support in the event it provoked distress and suggested the use of a telephone helpline to achieve this. They also highlighted the need for help and advice for those wishing to make a complaint about the care their relative received.

c) Analysis of existing VOICES datasets

In order to identify questions which could be excluded from VOICES and therefore reduce its length, analysis of previous VOICES datasets was conducted to assess patterns of redundancy between questions. Questions suitable for exclusion were identified using the following methods:

1. Assessment of correlations between variables – questions could potentially be removed if they were very highly correlated with another question (However, questions about ‘dignity and respect’ and ‘overall satisfaction’ remained despite collinearity. This is because of their central role in any assessment of the quality of care at the end of life)
2. Assessment of maximum endorsement frequencies - questions where this was greater than 80% were potentially redundant
3. Analysis of missing data – questions with more than 10% missing data were also considered for exclusion

d) Input from other experts and surveys

Another major questionnaire about care quality at the end of life was used to inform the redesign of VOICES. The ‘Care in the last three days’ section was amended to ‘Last two days’ to align with the recently validated Care of the Dying Evaluation (CODE) questionnaire. Two questions from this questionnaire were also incorporated into VOICES to enable comparison.

Cruse Bereavement Care played a role in ensuring that the language and structure of the questionnaire was sufficiently sensitive and appropriate for bereaved relatives. Several changes to the wording and ordering of questions were made following discussion.

e) Consultation with the Project Steering Group

The project Steering group had further input into the design, content and format of the questionnaire, recommending:

1. A large space for additional comments at end of questionnaire
2. Removal of the ‘cause of death’ question (because these data are available from death

certificates)

3. Rewording of 'preferred place of care' to 'support to stay where she wanted to be'
4. The addition of a question on whether bereavement support was offered
5. A section on out-of-hours care
6. Questions asking whether the deceased and the informant were involved in decisions about the care as much as they would have wanted
7. A question about the religion of the decedent.

f) Gathering the views of specialist palliative care professionals and survey researchers

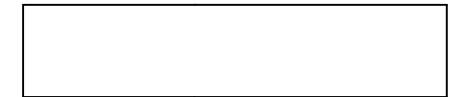
VOICES was amended to take account of all the above recommendations and then reviewed by twelve healthcare professionals and researchers working in palliative care. The only content amendment that resulted from this review was the addition of 'Intensive Care Unit' to the list of response options on place of death. Other comments were directed at the format and presentation of the questionnaire.

The Cognitive Interviews

The procedures involved and findings from the cognitive interviews and the finalisation of VOICES-SF are discussed in Section 3.1 of the Report.

Appendix C

VOICES



Thank you for taking the time to complete this questionnaire.
We would be very grateful if you could return it to us in the
Freepost envelope provided, or post to:

Faculty of Health Sciences
FREEPOST NAT 7537
Southampton
SO17 1BJ

VIEWS OF INFORMAL CARERS - EVALUATION OF SERVICES

This questionnaire is about the care and services received by you and your friend/relative in the last months of his life. The information you give will help us improve care for people who die, and for their family and friends. Your views are, therefore, important to us.

We realise this questionnaire may bring back strong memories. If you feel upset or distressed, you do not have to continue with the questionnaire and can stop at any time. If you would like to talk to someone about your experiences, you can call Cruse Bereavement Care on 01344 411919 (weekdays 10am-5pm).

We are interested in finding out the experiences of all people who have died whether suddenly, after a short illness, or after a long illness. We also think it is important to find out about the care you and the family received at the time of death and in the months since then. Some of the questions may therefore not be relevant to you. Please fill in as much of the questionnaire as you can. If you would like help and advice in filling in the questionnaire you can call us on 023 8059 8278 (weekdays 10am-6pm).

Your answers to these questions will, of course, be treated as strictly confidential. No names will be used in the reports we write.

Instructions

As you go through the questionnaire, please follow the instructions and 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, like this

If you would rather not answer one of the questions, please go on to the next one.

We are very interested in what you have to say. Please continue on extra sheets if necessary.

What, if anything, was good about the care?

Horizontal lines for text entry.

What, if anything, was bad about the care?

Horizontal lines for text entry.

Q1 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

If he died suddenly with no illness or time for care, please go to Q38. Otherwise, please continue with the questions below.

Q2 Did he spend any time at home during the last three months of life?

- Yes - go to Q3
He was in a care home for the whole 3 months - go to Q12
No - go to Q24

CARE AT HOME

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

Q3 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 homecare nurse or specialist (a palliative care nurse who visits or telephones to talk and advise on medications and other aspects of care. They do not wear a 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
Hospice at home
Occupational therapist (OT)
Rapid discharge scheme
He did not receive any care
Don't know
Something else - please write in the space below

Q4 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

Please feel free to make comments in the space below:

Q5 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?

- 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

Please feel free to make comments in the space below:

Q6 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

Q7 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?

- Not at all in the last 3 months - go to Q12
- Once or twice - go to Q8
- Three or four times - go to Q8
- Five times or more - go to Q8
- Don't know - go to Q12

Q8 The last time this happened, who did he contact, or who was contacted on his behalf?

- His GP or the out-of-hours number
- NHS Direct
- District nurses
- Macmillan nurses
- A hospice
- 999

Q9 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 telephone
- Given another number to ring to get medical advice
- Advised to go to the GP surgery when it opened
- Advised to go to an out-of-hours GP surgery
- Advised to go to an Accident and Emergency at a hospital
- Advised to call 999
- Something else - please write in the space below

Please use the space below if there is anything more you would like to say about the care provided:

Q54 Are you:

- Male
- Female

Q55 Please could you indicate to which ethnic group you belong:

- White
 - Bangladeshi
 - Black African
 - Black Caribbean
 - Black other (please specify below)
 - Chinese
 - Indian
 - Pakistani
 - Other Asian
 - Other - Please write in the space below
-

Q56 Please could you indicate to which ethnic group he belonged

- White
 - Bangladeshi
 - Black African
 - Black Caribbean
 - Black other (please specify below)
 - Chinese
 - Indian
 - Pakistani
 - Other Asian
 - Other - Please write in the space below
-

Q57 What was his age when he died?

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

Q58 What was his religion, if any?

- No religion
 - Christian, no denomination
 - Roman Catholic
 - Church of England (Anglican)
 - URC/congregational
 - Baptist
 - Methodist
 - Other Christian
 - Hindu
 - Jew
 - Muslim/Islam
 - Sikh
 - Buddhist
 - Other non Christian (Please write below)
-

Q10 In your opinion, was this the right thing for them to do, or not?

- Yes
- No
- Not sure

Q11 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 life was:

- Tick one only***
- Excellent
 - Good
 - Fair
 - Poor
 - Don't know

DISTRICT AND COMMUNITY NURSES

If he had care in the last 3 months from district and community nurses go to Q12. If he did not; go to Q15.

Q12 How often did the district or community nurses visit (at the most frequent time)?

- Tick one only***
- More than once a day
 - Every day
 - 2-6 times a week
 - Once a week
 - 2-6 times a month
 - Less often
 - Don't know

Q13 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

Q14 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

Q15 In the last 3 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 Q20

Q16 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

Q17 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

Q18 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
- The GP did not visit in the last three months, they were not wanted
- Does not apply - the GP did not need to visit
- Don't know

Q19 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

CARE HOMES

Q20 Did he live or stay in a care home at any time during his last three months of life?

Please tick all that apply

- Yes, he was in a care home

PLEASE WRITE THE NAME OF THE CARE HOME IN THE SPACE BELOW

- No - go to Q24
- Don't know - go to Q24

Q21 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

Q22 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

Q23 Overall, do you feel that the care he got from the care home in the last three months of life was:

Tick one only

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

LAST HOSPITAL ADMISSION

Q24 Did he stay in hospital at any time during his last three months of life?

- Yes

What was the name of the last hospital he stayed in?

- No - go to Q29
- Don't know - go to Q29

Q46 Were you or his family given enough help and support by the healthcare team at the actual time of his death?

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

Q47 After he died, did staff deal with you or his family in a sensitive manner?

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

Q48 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?

- 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

Q49 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?

- 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

Q50 Were any decisions made about his care that he would not have wanted?

- Yes
- No
- Don't know

Q51 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
- No, but I would have liked to
- No, but I did not want to anyway
- Not sure

INFORMATION ABOUT YOU BOTH

Q52 What was your relationship to him? Were you his:

- 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

Q53 What is your age?

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

Q40 Where did he die?

Tick one only

- In his own home
- In the home of another family member or friend
- In a hospital ward

What was the name of the hospital?

- In a hospital Accident and Emergency Department

What was the name of the hospital?

- In a hospital Intensive Care Unit

What was the name of the hospital?

- In a hospice

What was the name of the hospice?

- In a care home

What was the name of the care home?

- In an ambulance on the way to hospital/hospice

- Somewhere else (please write below)

Q41 Did he ever say where he would like to die?

Tick one only

- Yes - **go to Q42**
- No - **go to Q44**
- Not sure - **go to Q44**

Q42 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 (detail below)

Q43 Did the health care staff have a record of this?

Tick one only

- Yes
- No
- Not sure

Q44 Do you think he had enough choice about where he died?

- Yes
- No
- Not sure

Q45 On balance, do you think that he died in the right place?

- Yes
- No
- Not sure

Q25 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

- | | | |
|--------------------------|--------------------------|------------------|
| <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 |

Q26 During this 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

Q27 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

Q28 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

Examples of hospices in your area are:

Thames Hospicecare

Sue Ryder Hospice

Duchess of Kent Hospice

Phyllis Tuckwell Hospice

South Bucks Hospice

Princess Alice Hospice

Q29 Did he stay in a hospice at any time during his last three months of life?

Tick one only

- Yes - **go to Q30**

What was the name of the last hospice he stayed in?

- No - **go to Q33**

- Don't know - **go to Q33**

Q30 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 |

Q31 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

Q32 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

Q35 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

Tick one box for each question (a - c)

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
(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"/>
(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"/>
(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"/>

EXPERIENCES IN LAST 2 DAYS OF LIFE

Q33 During his last two days was he:

Tick one only

- At home all the time
- In a care home all the time
- In hospital all the time
- In a hospice all the time
- Other (Write in the space below:)

Q34 How much of the time was he treated with respect and dignity in the last two days of 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 |

Q36 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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Relief of symptoms other than pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Spiritual support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Emotional support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Support to stay where he wanted to be	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q37 During these last two days, were there any decisions made about his care or treatment that he would not have wanted?

Tick one only

- Yes
- No
- Don't know

Please feel free to make comments in the space below:

CIRCUMSTANCES SURROUNDING HIS DEATH

Q38 Did he know he was likely to die?

Tick one only

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

Q39 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, probably 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

Appendix D

VOICES

Views Of Informal Carers - Evaluation of Services

This questionnaire is about the care and services received by you and your friend/relative in the last months of his life. The information you give will help us improve care for people who are dying, and for their family and friends. Your views are, therefore, important to us.

We realise this questionnaire may bring back strong memories. If you feel upset or distressed, you do not have to continue with the questionnaire and can stop at any time.

We are interested in finding out the experiences of all people who have died whether suddenly, after a short illness, or after a long illness. We also think it is important to find out about the care you and the family received at the time of death and in the months since then. Some of the questions may not be relevant to you. Please fill in as much of the questionnaire as you can.

Your answers to these questions will be treated as strictly confidential. No names will be used in the reports we write.

Instructions

As you go through the questionnaire, please follow the instructions and 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, like this .

If you would rather not answer one of the questions, please go on to the next one.

We are very interested in what you have to say. Please continue on extra sheets if necessary.

Q1 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 Q38**. Otherwise, please continue with the questions below.

Q2 Did he spend any time at home during the last three months of life?

Tick one only

- Yes – **go to Q3**
- He was in a care home for the whole 3 months – **go to Q12**
- No – **go to Q24**

Care at Home

These questions are about care at home – not in a care home.

Q3 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 palliative care nurse who visits or telephones to talk and advise on medications and other aspects of care. They do not wear a 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 (a 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 in the space below:

Q4 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

Please feel free to make comments in the space below:

Q5 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?

- 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

Please feel free to make comments in the space below:

Q6 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

Please feel free to make comments in the space below:

Urgent Care Provided Out of Hours

Q7 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 Q12**
- Once or twice – **go to Q8**
- Three or four times – **go to Q8**
- Five times or more – **go to Q8**
- Don't know – **go to Q12**

Q8 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:

Q9 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 telephone
- 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 in the space below:

Q10 In your opinion, was this the right thing for them to do, or not?

Tick one only

- Yes
- No
- Not sure

Q11 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 life was:

Tick one only

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

District and Community Nurses

If he had care in the last 3 months from district and community nurses, **go to Q12.**

If he did not, **go to Q15.**

Q12 How often did the district or community nurses 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

Q13 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

Q14 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

Q15 In the last 3 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 Q20**

Q16 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

Q17 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

Q18 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
- Don't know
- He wanted the GPs to visit but they would not visit
- Does not apply – the GP did not need to visit
- Don't know

Q19 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

Q20 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:

-
- No – **go to Q24**
 - Don't know – **go to Q24**

Q21 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

Q22 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

Q23 Overall, do you feel that the care he got from the care home in the last three months of life was:

Tick one only

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

Last Hospital Admission

Q24 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, in the space below:

- No – **go to Q29**
- Don't know – **go to Q29**

Q25 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 | |
|--------------------------|--------------------------|------------------|
| <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 |

Q26 During this 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

Q27 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

Q28 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

Q29 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, in the space below:

- No – **go to Q33**
 Don't know – **go to Q33**

Q30 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 |

Q31 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

Q32 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

Experiences in the Last 2 Days of Life

Q33 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:

Q34 How much of the time was he treated with respect and dignity in the last two days of 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 |

Q35 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"/>

Q36 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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Relief of symptoms other than pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Spiritual support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Emotional support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Support to stay where he wanted to be	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Circumstances Surrounding His Death

Q37 Did he know he was likely to die?

Tick one only

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

Q38 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

Q39 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

Q40 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 in the space below:

- In a hospital Accident and Emergency Department – please write the name of the hospital in the space below:

- In a hospital Intensive Care Unit – please write the name of the hospital in the space below:

- In a hospice – please write the name of the hospice in the space below:

- In a care home – please write the name of the care home in the space below:

- In an ambulance on the way to hospital/hospice

- Somewhere else – please write in the space below:

Q41 Did he ever say where he would like to die?

Tick one only

- Yes – **go to Q42**
- No – **go to Q44**
- Not sure – **go to Q44**

Q42 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 in the space below:

Q43 Did the health care staff have a record of this?

Tick one only

- Yes
- No
- Not sure

Q44 Do you think he had enough choice about where he died?

Tick one only

- Yes
- No
- Not sure
- He died suddenly

Q45 On balance, do you think that he died in the right place?

Tick one only

- Yes
- No
- Not sure

Q46 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

Q47 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

Please feel free to make comments in the space below:

Q48 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?

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

Q49 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

Q50 Were any decisions made about his care that he would not have wanted?

Tick one only

- Yes
- No
- Don't know

Please feel free to make comments in the space below:

Q51 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

Q52 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

Q53 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

Q54 What is your age?

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

Q55 Are you:

- Male
- Female

Q56 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 & Black Caribbean
- White & Black African
- White & Asian
- Any other mixed background

Asian/Asian British

- Bangladeshi
- Chinese
- Indian
- Pakistani
- 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

Q57 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 & Black Caribbean
- White & Black African
- White & Asian
- Any other mixed background

Asian/Asian British

- Bangladeshi
- Chinese
- Indian
- Pakistani
- 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

Q58 What was his age when he died?

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

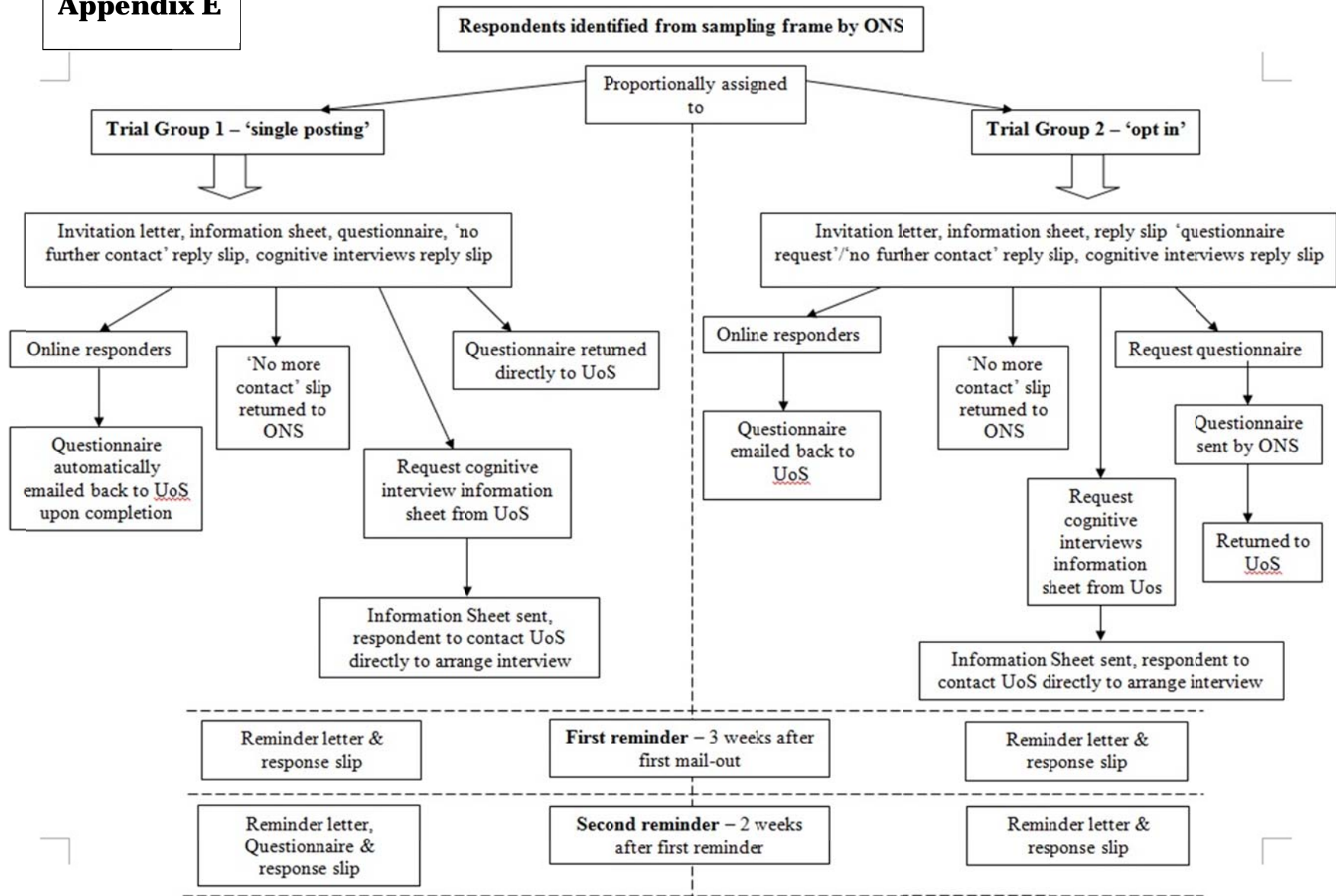
Q59 What was his religion?

- No religion
- Christian (all denominations)
- Buddhist
- Hindu
- Jewish
- Muslim
- Sikh
- Any other religion – please write in the space below:

Thank you for taking the time to complete this questionnaire.

We would be very grateful if you could return it to us in the Freepost envelope provided.

Appendix E



Appendix F

Study ID Number:

Date

[ADDRESS TO FIT IN ENVELOPE WINDOW]

Dear [title] [surname],

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

If you would like to receive this information in large print please call 023 8059 8278 (weekdays 10am-6pm)

We are writing to you because you registered the death of [title] [first name and surname of the deceased]. We appreciate that this may be a very difficult time but we would like to invite you to take part in the IMPROVE (Improving Methods and Piloting Recruitment for the VOICES End of life Survey) study 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 the IMPROVE study and our research team at the University of Southampton is working alongside the Department of Health and the NHS to carry out this study. The Office for National Statistics is managing the administrative side of the project and identified you from their deaths database. They are contacting you on our behalf and will not release any of your personal details to us.

Taking part in the IMPROVE Survey involves completing a questionnaire called VOICES (Views of Informal Carers – Evaluation of Services) 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.

It is up to you whether you would like to take part in the project. We have enclosed the VOICES questionnaire and an information sheet about the study so you can read more about the project. This will help you to make an informed decision about whether you want to get involved. Further details can be obtained by calling Katherine Hunt (one of the researchers) on 023 8059 8278 (weekdays 10am-6pm) or by looking on the study website at: www.southampton.ac.uk/voices

If you do decide to take part we ask that you complete the enclosed VOICES questionnaire and then return it in the FREEPOST envelope to the University of Southampton (no stamp is needed).

Alternatively, you can complete the questionnaire online by going to www.southampton.ac.uk/voices, clicking on the link 'Complete VOICES online' and entering the following user name and password:

User name:

Password:

You will then be asked to enter your unique and anonymous ID number, this is:

Online ID number

When you have finished completing the questionnaire online, it will be automatically emailed back to the researchers at the University of Southampton. The researchers will not be able to identify you from the questionnaire.

If you do not think that you are the best person to complete the questionnaire, please pass this on to whoever you feel would be the best person to complete it.

If you do not wish to participate you can let the Office for National Statistics know by filling in and returning the FREEPOST reply slip and envelope enclosed. This will ensure that you do not receive reminder letters.

Your views are very important and will help to 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. 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 at ONS

Professor Julia Addington-Hall

IMPROVE Survey

Experiences of care in the last months of life

INFORMATION LEAFLET

You are being invited to take part in a questionnaire-based research study called The IMPROVE Survey (Improving Methods and Piloting Recruitment for the VOICES End of life Survey).

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 talk to a member of the research team on 023 8059 8278 (weekdays 10am-6pm). Alternatively, you can visit the study website at www.southampton.ac.uk/voices.

Thank you for taking the time to read this. Your views are very important and will be used to help us to provide better care for patients and families in the future. We very much hope you will feel able to contribute.

Contact us at:
VOICES Study team
School of Health Sciences
University of Southampton
Southampton SO17 1BJ

What is the purpose of the IMPROVE Survey?

IMPROVE is a survey of bereaved relatives that uses VOICES, a questionnaire about experiences in the last months of life. The VOICES questionnaire will be used nationally to monitor and improve services provided but in the IMPROVE survey we are only sending it to people who registered the death of someone who died in East Berkshire and the Isle of Wight. You are one of 1400 people we are contacting who has recently registered the death of a relative or friend and we would like your help. If you decide to help by completing the VOICES questionnaire, your responses will be used to improve local services for people in the last months of life and to compare care and bereavement services in the Isle of Wight to other parts of the country. The IMPROVE Survey will also test the VOICES questionnaire to make sure that it asks the right questions and investigate the best way to give people the questionnaire. Half of the 1400 people we have contacted have received the VOICES questionnaire alongside this information sheet and the other half have been given a reply slip to request a copy of the questionnaire. As you will have noticed, you have been given the VOICES questionnaire with this information sheet.

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 Isle of Wight in the past year. We asked The Office for National Statistics (a government department that processes information on the UK population) to select death certificates from their database. To protect your privacy, the Office for National Statistics has contacted you on our behalf.

The Office for National Statistics has not given us any personal information about you. We do not know your name or your address. They have given each person who has been invited to take part, a unique identification number (written on the top left corner of the invitation letter addressed to you). 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 called VOICES. This 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.

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 or on the back page.

- Returning the completed questionnaire. We have enclosed a large FREEPOST envelope to be posted back to the research team in the University of Southampton. If you lose this envelope you can still return the questionnaire with no charge by posting it to FREEPOST NAT 7537.
- If you prefer, you can complete an electronic version of the questionnaire on the internet. If you would like to do so, please go to www.southampton.ac.uk/voices. When you have loaded the webpage, you will need to click on the link 'Complete VOICES online'. Then enter the user name and password found on the second page of the letter of invitation you received with this information sheet. You will then be asked to enter your unique and anonymous ID number also found on the second page of the invitation letter. The research team will not be able to identify you from this ID number. Any information you provide us or comments that you write in the questionnaire will remain entirely confidential. When you have finished completing the questionnaire online, it will be automatically emailed back to the research team at the University of Southampton.
- We are also keen to get your feedback on the VOICES questionnaire and would like to talk to you to understand your experiences of completing it. This will help us to make sure that the questionnaire really asks the right questions and is designed in the most appropriate and sensitive way.

If you think you might be interested in talking to us about the questionnaire, we ask that you return the slip titled 'Interviews about the VOICES questionnaire'. We will then send you more information about what it will involve so that you can make an informed decision about whether you would like to take part in an interview.

The research team are more than happy to provide extra help and support in completing the questionnaire. If you would like help, or if you have any questions, please call us on 023 8059 8278 (weekdays 10am-6pm).

If English is not your first language and you would like interpreter services, we have a language telephone line you can call on 023 8059 8278. We can then arrange for an interpreter to call you back.

What should I do if I want to take part?

If you would like to take part, please complete the questionnaire and then return it to the University of Southampton using the FREEPOST envelope enclosed. You do not need a stamp. Alternatively, complete the questionnaire online (at www.southampton.ac.uk/voices) and then it will automatically be emailed back to the research team when you have finished.

If you would like to take part in the interviews about the questionnaire, please return the slip titled 'Interviews about the VOICES questionnaire' and we will send you more information.

If you would like more information about the study to help you to decide whether you would like to get involved, you can call the research team on 023 8059 8278 (weekdays 10am-6pm) or go to the study website at www.southampton.ac.uk/voices.

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.

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. Please feel free to discuss the research with your family and friends before you make a decision. If you would like to take part, please complete the questionnaire and return it in the FREEPOST envelope.

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.

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 01344 411919 (weekdays 10am-5pm. 24 hour 7 day answerphone) and say that you have seen the VOICES questionnaire.

How will the information I give be kept confidential?

The Office for National Statistics (ONS) will not give us (the research team) any information which identifies you. You will only be identified by a number that the ONS provided.

All the information collected will be kept strictly confidential within the research team and secured against unauthorised access. We would also like to make absolutely clear that no names, or other information that could identify you, will be used in any reports we write. You will **not** be asked to include your name on the questionnaire;

instead an identification number will be assigned to ensure that you remain anonymous in any reports about the results.

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

What if there is a problem or I have a complaint?

If you have a concern or a complaint about this study you should contact Susan Rogers, Head of Research & Enterprise Services, at the School of Health Sciences:

University of Southampton
Building 67
Southampton
SO17 1BJ
Tel: +44 (0)23 8059 7942
Email: S.J.S.Rogers@southampton.ac.uk.

If you remain unhappy and wish to complain formally Susan Rogers can provide you with details of the University of Southampton Complaints Procedure.

Who is organising and funding the study?

The VOICES study has been set up by the University of Southampton, the National Health Service (NHS) and the Department of Health. The Office for National Statistics are organising the study and recruiting participants and the study has been funded by the Department of Health.

What will happen to the results of the study?

Information obtained from the questionnaire will be entered into a database and analysed by the researchers. At the end of the project, the findings will be written up into a report, which will be submitted, to the Department of Health and your local NHS Primary Care Trust. The results will be available to the public. We cannot promise the project will help you but the information we get from this project will help improve the quality of end of life care provided in England.

The results will be published in journal articles and presented at relevant conferences. However, no identifying information about you will be included in the report or any articles about this study.

If you would like to see the results of this study, you can visit the study website at www.southampton.ac.uk/voices Alternatively, you can complete the response slip at the bottom of this information sheet and we will send you a copy of the results to the address you give us.

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.

Yes please, I would like to receive feedback on the results of the study. My contact details are:

Your Name (please print clearly)

Your address

THANK YOU

Study ID Number:

Date

[ADDRESS TO FIT IN ENVELOPE WINDOW]

Dear [title] [surname],

Invitation to help with the IMPROVE survey about 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 some work we are currently conducting with the Department of Health. As 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.

We would be grateful if you could complete the enclosed questionnaire and return it to the University of Southampton 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.

You can complete the questionnaire online if you would prefer. To do this, go to www.southampton.ac.uk/voices, click on the link 'Complete VOICES online' and enter the following user name and password:

User name:

Password:

You will then be asked to enter your unique and anonymous ID number, this is:

Online ID number

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.

We apologise for any distress caused by this enquiry and hope that this letter does not bring back too many painful memories. We would like to take the opportunity to thank you for taking the time to read this letter and very much hope you will feel able to take part.

Should you have any questions, please do not hesitate to contact one of the research team, Katherine Hunt on 023 8059 8278 (weekdays 10-6pm).

We hope you will be happy to take part in this project.

Yours sincerely,

Myer Glickman at ONS

Professor Julia Addington-Hall

Study ID Number:

Date

[ADDRESS TO FIT IN ENVELOPE WINDOW]

Dear [title] [surname],

Invitation to help with the IMPROVE survey about experiences of care in the last months of life

You may remember that we wrote to you a couple of weeks ago to remind you about the study we are conducting with the Department of Health. As we have not heard back from you we are writing again to check whether or not you would like to take part in this study. If you have responded recently, please accept our apologies for having bothered you.

It is important to get people's views of care provided at the end of life in order to improve services. The results of this survey will be used to develop services that are designed around the needs and desires of the people who use them. We would therefore be grateful for your participation and ask if you could complete the enclosed questionnaire and return it to the University of Southampton 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.

You can complete the questionnaire online if you would prefer. To do this, go to www.southampton.ac.uk/voices, click on the link 'Complete VOICES online' and enter the following user name and password:

User name:

Password:

You will then be asked to enter your unique and anonymous ID number, this is:

Online ID number

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.

We apologise for any distress caused by this enquiry and hope that this letter does not bring back too many painful memories. We would like to take the opportunity to thank you for taking the time to read this letter and very much hope you will feel able to take part.

Should you have any questions, please do not hesitate to contact one of the research team, Katherine Hunt on 023 8059 8278 (weekdays 10-6pm).

We hope you will be happy to take part in this project.

Yours sincerely,

Myer Glickman at ONS

Professor Julia Addington-Hall

Language Support

English	For help in English, please call us on 023 8059 8278
Arabic	للمساعدة باللغة العربية، يُرجى الاتصال بنا على الرقم 023 8059 8278
Bengali	বাংলায় সাহায্যের জন্য অনুগ্রহ করে আমাদেরকে 023 8059 8278 নম্বরে ফোন করুন
Czech	Jestliže potřebujete pomoc v češtině, zavolejte nám na číslo 023 8059 8278
French	Pour une assistance en français, appelez-nous au 023 8059 8278
Gujarati	ગુજરાતી માં સહાયતા માટે, કૃપયા કરીને અમને 023 8059 8278 ઉપર ફોન કરો.
Hindi	हिन्दी में मदद के लिए, कृपया 023 8059 8278 पर फोन करें।
Simplified Chinese	寻求简体中文帮助，请致电023 8059 8278
Traditional Chinese	尋求繁體中文援助，請致電023 8059 8278
Polish	Aby uzyskać pomoc w języku polskim, zadzwoń do nas pod numer 023 8059 8278
Portuguese	Para obter ajuda em Português, contacte-nos pelo 023 8059 8278
Punjabi	ਪੰਜਾਬੀ ਵਿਚ ਮਦਦ ਮੰਗਣ ਲਈ ਕਿਰਪਾ ਕਰਕੇ ਸਾਨੂੰ 023 8059 8278 ਉੱਤੇ ਕਾਲ ਕਰੋ
Slovak	Pre pomoc v slovenčine volajte číslo 023 8059 8278
Somali	Haddii aad caawimo ku rabtid Af-Soomaali fadlan nagala soo xiriir 023 8059 8278
Spanish	Para obtener ayuda en español, llámenos al número 023 8059 8278
Turkish	Türkçe dilinde yardım almak için, lütfen 023 8059 8278 numaralı telefondan bizi arayınız.
Urdu	اردو میں مدد کے لئے، براہ کرم ہمیں 023 8059 8278 پر کال کریں

IMPROVE Survey

Experiences of care in the last months of life

REPLY SLIP

ID Number:

If you would prefer NOT to take part in the above study, please return this form in the pre-paid envelope, so that we do not contact you again.

(Please tick)

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

Appendix G

The BME Strategy

A combination of the following methods was employed to attempt to increase participation in members of minority ethnic groups:

1. Interpretation and translation
2. Awareness-raising and advertising
3. A BME boost sample

1. Interpreting and translations

Exploration of the factors affecting this low response through consultation with BME groups (refs) suggested that written questionnaires were part of the problem. Indeed, former VOICES surveys have demonstrated that translated versions of the questionnaire do not increase response (Hughes et al 2005). Suggested solutions to this problem were the use of face-to-face/telephone interviews, rather than questionnaires, as well as endorsement from community leaders and local advertising.

Using this experience, translated versions of VOICES-SF were not produced for the survey. However, all respondents were signposted to a telephone interpreting service (provided by Southampton City PCT Access to Communication) through a Language Support Document (translated into the 14 predominant languages used at the data collection sites) enclosed with each survey invitation letter.

Interpreters were briefed about the survey and provided with a glossary of nomenclature included in the questionnaire.

2. Awareness-raising and advertising

A targeted local advertising and awareness-raising campaign was used to raise the profile of the survey among BME communities. Relationships were developed between the research team and BME communities by establishing links with local organisations and places of worship. Slough Inequalities Commission sent out information about the survey to all members of their mailing lists and initiated meetings between the research team and other key community bodies. This was an important step in gaining access to the local communities and in identifying key organisations with which to build firm links.

As a result of these initial meetings, the Pakistan Welfare Association (PWA), a prominent organisation in East Berkshire that offers support and advice to the Asian community as well as providing a community space for groups to meet, became a key collaborator. The PWA organised lunches with the research team and community members to raise the profile of the survey as well as acting as a medium to enable the researchers to meet distinguished religious leaders in the Slough area. These were important sessions designed to generate links between the Asian community and the research team, build trust and understanding in the work carried out, increase the profile of the project, and better understand the community.

In addition, the research team attended Asian Carers Support Group and Asian Age Concern meetings to further broadcast the survey and to better understand the perceived barriers to participation among those communities. Although these sessions were not designed to recruit individuals into the survey, but aimed at encouraging community engagement and participation and were again instrumental in our understanding of perceptions of end of life and death in those societies.

To supplement these awareness-raising activities, posters were displayed in key locations. Posters advertising the survey were translated into the five most common languages in the study sites (Urdu, Polish, Punjabi, Arabic and Hindi) using forward translation, back translation and reconciliation. Posters provided a brief information about the survey and reiterated the importance of gathering the views of people from different communities. Posters included a telephone number for the interpreting service and for further information about the survey. Posters were placed in the PWA, places of worship, the Polish Association and Age Concern Berkshire premises.

In addition to poster-based advertisements, a media campaign was initiated with attempts to broadcast a feature on local Asian radio and local Asian newspapers.

3. A BME boost sample

Given that it is not possible to over-sample members of minority ethnic groups in the main survey because death certificates do not detail ethnicity, a boost sample was selected as a means to increase representation of these groups. However, because the post-bereavement method uses proxies to collect data on healthcare utilisation and satisfaction, the sampled unit is not the respondent. This means that identification of the deceased does not necessarily aid identification of the ideal respondent. Although recruitment of a self-selecting sample was initiated with the use of advertising posters, a sampling frame was sought to facilitate recruitment using pre-defined criteria.

Advice was sought from specialist palliative care staff, researchers who specialise in survey design and

the Steering Group and this suggested that recruitment of relatives from BME groups through funeral directors was a potential method to reach this group. Records held by Berkshire based Funeral Directors could be used as the sampling frame to recruit based on ethnicity and pursued as part of the trial.

The amendment to the project was reviewed by the University of Southampton, Faculty of Health Sciences Ethics Committee. However, the Committee expressed concerns about the recruitment methods (which have not been used in any other study to date), discussed the project at two further meetings and concluded that the study with this approach incorporated should not go ahead.

A further recruitment approach (suggested by the Steering Group) that would involve recruitment through Registrars was also considered by the Committee (without a full protocol) and was also dismissed as unethical.

Appendix H

End of Life Care: *It's Okay to Talk!*

Some say we're good at talking about the football results; last night's telly; our favourite singer or group, or something exciting that's happening at the weekend.

Whilst others say we excel at talking about the things or people who matter to us most. Sadly, what we don't do is talk about care; in particular End of Life Care... and especially our own!

For most of us, the idea of confronting things head-on and not letting things stand in our way, soon evaporates when the conversation in hand turns to a subject that, whilst affecting us all, is one that in most instances we would run a country mile to avoid.

But avoiding issues or putting them off has a tendency to make things worse, often to our regret, and - just like school homework - the actual thought of doing something we'd rather not do is far worse than actually doing it.

When was the last time you spoke to anyone about the care you might want to receive towards the end of your life? Does your partner, family or friend have an idea of what you might want? Have you ever had these conversations, if so you're doing well, if not, then you might like to consider doing so.

Commenting on this thorny subject, Lucy Sutton, Associate Director of End of Life Care across the NHS South Central region said, "It is only by knowing people's wishes that we can put in place the services to ensure they are met. It is better for all, the person themselves, their loved ones, and health and social care professionals if there is clarity around issues such as organ donation or where the person would like to be cared for."

The NHS provides a system of care that looks after us at every stage of our life, and has developed into a modern efficient health care system envied throughout the world. End of life Care is a significant element of our health service, but its one that the public need also to take more notice of and perhaps learn more about. The reason is simple. We have more choice than ever before and options now exist that might not have existed even a few years ago.

NHS South Central, on behalf of the Department of Health is to pilot a survey which will seek the views of 1400 people who have recently lost a loved one or close friend. The Voices Survey will provide important information relating to End of Life Care and Service currently being received in the region.

Speaking about this important work, Lucy Sutton said “To be able to put services in place we need to understand people’s wishes regarding care but just as important is then hearing about their experiences of the care they and their loved one receive. This enables us to praise good services and develop these further whilst addressing any improvements that are required. There is no more powerful voice in this than the person themselves and their carer they are the only people able to give us truly valuable insight into the services we provide.”

To begin with, make some enquiries yourself and get an idea of the sort of choices that now exist. You don’t have to be dying to do this, in fact you don’t even have to be ill. Just take a few minutes to explore what the options might be, think about them and decide what you would want to happen when that time draws nearer. Then share those thoughts with those closest to you – it might lead to a healthy discussion, and remove any potential worries or troublesome thoughts.

We look after those closest to us whilst we are alive so why do we so often leave them to make difficult decisions when we’re dying? *It’s Okay to Talk !*

Ends

NOTES:

1. Around half a million people die in England each year, of whom almost two thirds are aged over 75. The large majority of deaths at the start of the 21st century follow a period of chronic illness such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia. Most deaths (58%) occur in NHS hospitals, with around 18% occurring at home, 17% in care homes, 4% in hospices and 3% elsewhere.
2. The demographics of death in relation to age profile, cause of death and place of death have changed radically over the course of the past century. During the early 1900s most people died in their own homes. At that time acute infections were a much more common cause of death and a far higher proportion of all deaths occurred in childhood or early adult life. With these changes, familiarity with death within society as a whole has decreased. Many people nowadays do not experience the death of someone close to them until they are well into midlife. Many have not seen a dead body, except on television. As a society we do not discuss death and dying openly.
3. How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and it is a litmus test for health and social care services.
4. NHS South Central, in collaboration with the Department of Health and Southampton University is to pilot a survey in East Berkshire and the Isle of Wight, where individuals who have recent experience of a bereavement and dealing with End of Life Care services, will receive an invitation to take part in a survey in which they can provide information relating to the care and services experienced by their relative or friend. The confidential VOICES (Views Of Informal Carers – Evaluation of Services) survey is being conducted by Prof Julia Addington-Hall and Dr Katherine Hunt from the Faculty of Health Sciences based at the University of Southampton, further details on the VOICES Survey can be obtained via calling 023 8059 8278 or by visiting the study website at www.southampton.ac.uk/voices
5. In the past, the profile of end of life care within the NHS and social care services has been relatively low. Reflecting this, the quality of care delivered has been very variable. Implementation of this strategy will make a step change in access to high quality care for all people approaching the end of life. This should be irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic deprivation. High quality care should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere.
6. Media enquiries and requests for interviews with End of Life Care specialists and clinicians to Graham Groves, Communications Manager, South Central Strategic Health Authority 01635 275657
7. www.nhssouthcentral.nhs.uk The NHS South Central region covers the Isle of Wight, Hampshire, Berkshire, Oxfordshire, Buckinghamshire and Milton Keynes

End of Life Care Experience Isle of Wight Carers Views Sought

Relatives or carers who live on the Isle of Wight who have lost loved ones in recent months, are being invited to contribute towards a major survey about their experiences of End of Life Care services.

Isle of Wight and east Berkshire are the two areas within the NHS South Central region that have been selected for the pilot survey, ahead of a larger national survey, both commissioned by the Department of Health. Questionnaires have been sent to 1,400 relatives.

Individuals who have recently experienced bereavement have been sent an invitation to take part in the survey which seeks information relating to the care and services experienced by their relative or friend. The confidential IMPROVE Survey, which uses the VOICES (Views Of Informal Carers – Evaluation of Services) questionnaire, is being conducted by Prof Julia Addington-Hall and Dr Katherine Hunt from the Faculty of Health Sciences based at the University of Southampton. Further details on the survey can be obtained by calling 023 8059 8278 or by visiting the study website at www.southampton.ac.uk/voices. Dr Katherine Hunt said, “This survey is an important step towards understanding and improving end of life care in England. It is a great opportunity for people to have their voice heard and play a role in the way that health care is designed and delivered.”

Lucy Sutton, Associate Director of End of Life Care across the NHS South Central region said, “It is only by knowing people’s wishes that we can put in place the services to ensure they are met. It is better for all, the person themselves, their loved ones, and health and social care professionals, if there is clarity around a person’s wishes towards the end of life for example where they wish to be cared for.”

Around half a million people die in England each year, almost two thirds are aged over 75. The large majority of deaths at the start of the 21st century follow a period of chronic illness such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia.

Most deaths (58%) occur in NHS hospitals, with around 18% occurring at home, 17% in care homes, 4% in hospices and 3% elsewhere.

Lucy Sutton added, "To put services in place we need to understand people's wishes regarding care, but just as important is their experiences of care they and their loved ones have received. This enables us to praise good services and develop these further, whilst addressing any areas that need to be improved"

ENDS

Notes to Editor

For further information or to request an interview please call Sarah Eastman on 01635 275613. You can also call 02380 598278 for further details about the survey.

Don't forget to make your 'VOICES' heard

The IMPROVE Survey is a pilot survey currently being conducted by the University of Southampton in the South Central Strategic Health Authority (SCSHA). The survey uses the View Of Informal Carers – Evaluation of Services (VOICES) questionnaire to gather experiences of End of Life care from bereaved relatives.

Two regions have been chosen within the SCSHA region: Berkshire East and the Isle of Wight.

A total of 1400 questionnaires have been sent to relatives and carers to find out how they felt about the range of services received. The questions cover care delivery across a range of settings, bereavement support received by friends and family and whether peoples wishes were followed.

The closing date for this survey is 12th December 2010 yet a large proportion have still not completed the questionnaire. Dr Katherine Hunt from the Faculty of Health Sciences at the University of Southampton says, "we understand that we are asking people to reflect upon a really difficult time in their lives and so are immensely grateful to all those who have taken part. However, we still need more people to tell us their experiences so that our health service can be shaped around the needs of those who use it.". Once evaluated, the data obtained will be used to shape end of life care services and form the basis of a national survey which will be run next year by the Department of Health.

"We are extremely aware of the importance of End of Life care and by running this pilot scheme it allows us to determine the needs that both carers and/or relatives and the patient require," said Lucy Sutton, SCSHA Associate Director of End of Life care.

If you live in the East Berkshire or Isle of Wight and have received a questionnaire, please spend time answering the questions so that your views can be considered.

For further information on the survey, please visit the study website at:
www.southampton.ac.uk/voices and you will discover how important VOICES are.

-ends-

Notes to Editor

For further information or to request an interview please call Sarah Eastman on 01635 275613. You can also call 02380 598278 for further details about the survey.

Appendix I

Press organisations sent the press releases

Asian Star Radio

BBC Radio Solent

BBC Radio Berkshire

Time 1066 FM

Isle of Wight Radio

Express FM

The Breeze 107 fm

Slough Express

Maidenhead News

Maidenhead Advertiser

Wokingham Times

Bracknell News

Isle of Wight County Press

Appendix J

Sample size calculation formulae

According to Cochran, 1977, pp. 75-76, the formula for determining the net sample size for a proportion of 0.5 is the following:

$$n_o = \frac{\frac{0.25t^2}{d^2}}{1 + \frac{1}{N} \left(\frac{0.25t^2}{d^2} - 1 \right)}$$

where N is the population size in the sub-group, t is the Z-score for the desired confidence interval, i.e. 1.96 for the 95% percentile of the Normal Distribution, and d is the margin of error.

To adjust the sample size with the finite population correction factor:

$$n = \frac{n_o}{1 + (n_o - 1) / N}$$