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Date.....Interview No.....Interviewer initials.....

Enter start time of interview:.....

Enter end time of interview:.....

# VOICES-ESRD/Thai

Views of Informal Carers-Evaluation of Services<sup>(Female version)</sup>

## **Interviewer administered questionnaire**

This questionnaire is about the care and services provided in the last months of life to people with End Stage Renal Disease (ESRD).

We are interested in finding out the experiences of all older people with ESRD who were managed without dialysis, whether they died suddenly, after a short illness, or after a long illness.

The information you give will help us improve care for ESRD older people who are managing without dialysis in Thailand. Your views are, therefore, importance to us.

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

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

## **Content of questionnaire**

- Section 1: Information about the informant**
- Section 2: Information about the deceased**
- Section 3: Help at home**
- Section 4: Urgent Care (out of hours and in the week during office hours)**
- Section 5: Symptom experiences and treatment**
- Section 6: Provincial, district and community nurses**
- Section 7: General doctors& physicians**
- Section 8: Last hospital admission**
- Section 9: The last 3 days**
- Section 10: Circumstances surrounding the death**

**Section 1: Information about the informant**

1. What was your relationship to her?

Were you his:

Tick one only

- Husband/Partner
- Son/Daughter
- Brother/Sister
- Son-in-law/Daughter-in-law
- Parent
- Other relative
- Friend
- Neighbour
- Someone else

2. What is your age?

Tick one only

- 18-19
- 20-29
- 30-39
- 40-49
- 50-59

60-69

70-79

80-89

90+

3. Are you

Male

Female

4. What is your religion?

No religion

Buddhist

Muslim

Christian

Any other religion-please write in the space

below:.....

.....

.....

.....

.....

.....

.....

.....

## Section 2: Information about the deceased

5. What age was she when she died?

- 50-59
- 60-69
- 70-79
- 80-89
- 90+

6. What religion was she?

- No religion
- Buddhist
- Muslim
- Christian
- Any other religion-please write in the space below:

7. How long was it after she was diagnosed with ESRD and managed without dialysis until she died?

*Tick one only*

- She was not ill-she died suddenly
- Less than 24 hours
- One day or more, but less than one week
- One week or more, but less than one month
- One month or more, but less than three months
- Three months or more, but less than six months
- Six months or more, but less than one year
- One year or more

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

*Tick one only*

- Yes- go to Q 9
- No go to Q 54

---

## Section 3: Help at home

9. Did the patient receive any health services at home from any of the health care professionals listed below?

- A district, community nurse or provincial nurse

- Doctor
- Renal nurse specialist
- Community health volunteer
- Social worker/support worker

- Counsellor
- Religious leader (Not provide health service)
- Occupational therapist (OT)
- She did not receive any care
- Don't know
- Something else-please write in the space below:

.....

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.....

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.....

10. When she was at home in the last three months of life, did all these services work well together?

*Tick one only*

- Yes, definitely
- Yes, to some extent
- No, they did not work well together
- She did not receive any care
- Don't know

Please feel free to make comments in the space below:

.....

.....

.....

.....

.....

11. Did she have any special equipment, the equipment that the patient need at home to help her get better, (including types of oxygen support, i.e. a mask or tent), wheelchair etc.?

- Yes
- No
- Don't know

If Yes:

a) Please state what equipment she had

.....

.....

b) How often was this special equipment needed?

- Every day
- At least once a week
- At least once a month, but not every week
- Less than once a month

12. Was any equipment, the equipment apart from special equipments that the patient needed at home to help her get better from her symptoms, needed that she didn't have?

- Yes
- No
- Don't know

If Yes:

a) Please state what equipment was needed

.....  
 .....  
 .....

b) How often was this equipment needed?

- Every day
- At least once a week
- At least once a month, but not every week
- Less than once a month

13. Did she get help from family and friends (including yourself) with any of the following? (please tick one box for each type of help she got

Yes.....No.....Don't know

- |   |                          |                          |                          |
|---|--------------------------|--------------------------|--------------------------|
| Personal care (e.g. bathing, dressing)            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Household tasks (e.g. shopping, cleaning)         | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Night time care (e.g. caring at night; toilet)    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Taking of medicines (e.g. help to take medicines) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

If you answer YES in question 14:

a) How much time did family and friend (including yourself) spend on these tasks?

- Personal care (e.g. bathing, dressing)

- Less than 5 hours per week
- 5-10 hours per week

- 11-19 hours per week
- 20-39 hours per week
- 40 or more hours per week
- Household tasks (e.g. shopping, cleaning)
- Less than 5 hours per week
- 5-10 hours per week

- 11-19 hours per week
- 20-39 hours per week
- 40 or more hours per week
- Night time care (e.g. caring at night; toilet)
- Less than 5 hours per week
- 5-10 hours per week
- 11-19 hours per week
- 20-39 hours per week

- 40 or more hours per week
- Taking of medicines (e.g. help to take medicines)
- Less than 5 hours per week
- 5-10 hours per week
- 11-19 hours per week
- 20-39 hours per week
- 40 or more hours per week

14. Did you get help from health care professional with any of the following? (please tick one box for each type of help she got)

	Yes.....	No.....	Don't know
Personal care (e.g. bathing dressing)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Household tasks (e.g. shopping, cleaning)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Night time care (e.g. caring at night; toilet)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Taking of medicines (e.g. help to take medicines)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you answer YES in question 15:

a) How often did she or you get help from the “*health care professional*”?

- Personal care (e.g. bathing dressing)

- At least one a day
- At least one a week

- At least once a month, but not every week
- Less than once a month
- Household tasks (e.g. shopping, cleaning)
- At least one a day
- At least one a week





**Section 4: Urgent care (out of hours and in the week during office hours)**

**- Urgent care provided out of hours**

16. In the last three months of life, while she was at home, did she ever need to contact a health professional for “urgent care” in the evening or at the weekend? *Perception or need / or need for urgent / or they did go to look of original of VOICES*

Tick one only

Not at all in the last 3 months

If yes please tick one only

Once or twice

Three or four time

Five times or more

Don't know

17. The last time this happened, who (health care professional or health care staff who provided contact or urgent care to the patient out of hours) did she contact, or who was contacted on her behalf?

Tick all that apply

Out of hours hospital number

General doctor or physician

Provincial, District or community nurses

Nobody or can't contact

Something else-please write in the space below:.....

.....

18. What happened as a result? Was she...

Tick one only

Visited by a district nurse at home

Visited by a provincial nurse at home

Visited by district doctor or general physician at home

Visited by a provincial doctor at home

Advised to go to the Emergency department at a hospital

Advised to go to the renal unit at a hospital

Advised to go to the community health services

Something else-please write in the space below:

.....

.....

.....

.....

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

Tick one only

- Yes
- No
- Not sure

20. Overall, do you feel that the care she got when she needed care urgently in the evening or weekends in the last three months of life was:

Tick one only

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

**Urgent care provided in the week during office hours**

21. In the last three months of life, while she was at home, did she ever need to contact a health professional for something urgent during office hours?

Tick one only

- Not at all in the last 3 months
- Yes please tick one only

- Once or twice
- Three or four time
- Five times or more
- Don't know

22. The last time this happened, who did she contact, or who was contacted on his/her behalf?

Tick all that apply

- General doctor or physician or the out-of -hours number
- Provincial, District or community nurses
- Nobody or can't contact
- Something else-please write in the space below:

.....  
.....  
.....

23. What happened as a result? Was she...

Tick one only

- Visited by a district nurse at home
- Visited by a provincial nurse at home
- Visited by district doctor or general physician at home

- Visited by a provincial doctor at home
- Advised to go to the Emergency department at a hospital
- Advised to go to the renal unit at a hospital
- Advised to go to the community health services
- Something else-please write in the space below:

.....

.....

.....

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.....

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.....

.....

.....

.....

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

Tick one only

- Yes
- No
- Not sure

25. Overall, do you feel that the care she got when she needed care urgently during office hours in the last three months of life was:

Tick one only

- Excellent
- Good
- Fair
- Poor
- Don't like to rate

## Section 5: Symptom experiences and treatment

### Physical symptoms

#### Breathlessness

26. Was she feel hard to catch her breath?

	In the last 3-12 months before death	In the last 3 months before death
Yes, all the time	<input type="checkbox"/>	<input type="checkbox"/>
Yes, sometimes	<input type="checkbox"/>	<input type="checkbox"/>

Yes, rarely

Not at all

Don't know

If you ticked 'yes, all the time', 'Yes, sometimes' or 'Yes, rarely'

a) Did she receive any treatment for her breathing problem?

In the last 3-12 months before death      In the last 3 months before death

Yes, all the time

Yes, sometimes

Yes, rarely

Not at all

Don't know

b) Did the treatment relieve her breathing problem?

In the last 3-12 months before death      In the last 3 months before death

Yes, all the time

Yes, sometimes

Yes, rarely

Not at all

Don't know

c) Did she have physical weakness because she got the breathing problem?

In the last 3-12 months before death      In the last 3 months before death

Yes, all the time

Yes, sometimes

Yes, rarely

Not at all

Don't know

d) Did she find it hard to sleep at night because she got the breathing problem?

In the last 3-12 months before death    In the last 3 months before death

Yes, all the time

Yes, sometimes

Yes, rarely

Not at all

Don't know

## Itching

27. Did she suffer with itching?

In the last 3-12 months before death    In the last 3 months before death

Yes, all the time

Yes, sometimes

Yes, rarely

Not at all

Don't know

If you ticked 'yes, at all time', 'Yes, sometimes' or 'Yes, rarely'

a) Did he/she receive any treatment for her itching?

In the last 3-12 months before death    In the last 3 months before death

Yes, all the time

Yes, sometimes

Yes, rarely

Not at all

Don't know

b) Did the treatment help to relieve her itching?

	In the last 3-12 months before death	In the last 3 months before death
Yes, all the time	<input type="checkbox"/>	<input type="checkbox"/>
Yes, sometimes	<input type="checkbox"/>	<input type="checkbox"/>
Yes, rarely	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	<input type="checkbox"/>
Don't know	<input type="checkbox"/>	<input type="checkbox"/>

## Pain

28. Did she suffer with pain?

	In the last 3-12 months before death	In the last 3 months before death
Yes, all the time	<input type="checkbox"/>	<input type="checkbox"/>
Yes, sometimes	<input type="checkbox"/>	<input type="checkbox"/>
Yes, rarely	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	<input type="checkbox"/>
Don't know	<input type="checkbox"/>	<input type="checkbox"/>

If you ticked 'yes, at all time', 'Yes, sometimes' or 'Yes, rarely'

a) Did he receive any treatment for her pain?

	In the last 3-12 months before death	In the last 3 months before death
Yes, all the time	<input type="checkbox"/>	<input type="checkbox"/>
Yes, sometimes	<input type="checkbox"/>	<input type="checkbox"/>
Yes, rarely	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	<input type="checkbox"/>
Don't know	<input type="checkbox"/>	<input type="checkbox"/>

b) Did the treatment help to relieve her pain?

	In the last 3-12 months before death	In the last 3 months before death
Yes, all the time	<input type="checkbox"/>	<input type="checkbox"/>
Yes, sometimes	<input type="checkbox"/>	<input type="checkbox"/>
Yes, rarely	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	<input type="checkbox"/>
Don't know	<input type="checkbox"/>	<input type="checkbox"/>

...**Oedema**

29. Did she have oedema?

	In the last 3-12 months before death	In the last 3 months before death
Yes, all the time	<input type="checkbox"/>	<input type="checkbox"/>
Yes, sometimes	<input type="checkbox"/>	<input type="checkbox"/>
Yes, rarely	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	<input type="checkbox"/>
Don't know	<input type="checkbox"/>	<input type="checkbox"/>

If you ticked 'yes, at all time', 'Yes, sometimes' or 'Yes, rarely'

a) Did he/she receive any treatment for her oedema?

	In the last 3-12 months before death	In the last 3 months before death
Yes, all the time	<input type="checkbox"/>	<input type="checkbox"/>
Yes, sometimes	<input type="checkbox"/>	<input type="checkbox"/>
Yes, rarely	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	<input type="checkbox"/>
Don't know	<input type="checkbox"/>	<input type="checkbox"/>



b) Did the treatment help to reduce oedema?

	In the last 3-12 months before death	In the last 3 months before death
Yes, all the time	<input type="checkbox"/>	<input type="checkbox"/>
Yes, sometimes	<input type="checkbox"/>	<input type="checkbox"/>
Yes, rarely	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	<input type="checkbox"/>
Don't know	<input type="checkbox"/>	<input type="checkbox"/>

...Nausea/vomiting

30. Did she suffer with nausea/vomiting?

	In the last 3-12 months before death	In the last 3 months before death
Yes, all the time	<input type="checkbox"/>	<input type="checkbox"/>
Yes, sometimes	<input type="checkbox"/>	<input type="checkbox"/>
Yes, rarely	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	<input type="checkbox"/>
Don't know	<input type="checkbox"/>	<input type="checkbox"/>

If you ticked 'yes, at all time', 'Yes, sometimes' or 'Yes, rarely'

a) Did she receive any treatment for her nausea/vomiting?

	In the last 3-12 months before death	In the last 3 months before death
Yes, all the time	<input type="checkbox"/>	<input type="checkbox"/>
Yes, sometimes	<input type="checkbox"/>	<input type="checkbox"/>
Yes, rarely	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	<input type="checkbox"/>
Don't know	<input type="checkbox"/>	<input type="checkbox"/>

b) Did the treatment help to relieve her nausea/vomiting?

	In the last 3-12 months before death	In the last 3 months before death
Yes, all the time	<input type="checkbox"/>	<input type="checkbox"/>
Yes, sometimes	<input type="checkbox"/>	<input type="checkbox"/>
Yes, rarely	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	<input type="checkbox"/>
Don't know	<input type="checkbox"/>	<input type="checkbox"/>

**...Poor appetite**

31. Did she suffer with poor appetite?

	In the last 3-12 months before death	In the last 3 months before death
Yes, all the time	<input type="checkbox"/>	<input type="checkbox"/>
Yes, sometimes	<input type="checkbox"/>	<input type="checkbox"/>
Yes, rarely	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	<input type="checkbox"/>
Don't know	<input type="checkbox"/>	<input type="checkbox"/>

If you ticked 'yes, at all time', 'Yes, sometimes' or 'Yes, rarely'

a) Did she receive any treatment for her poor appetite?

	In the last 3-12 months before death	In the last 3 months before death
Yes, all the time	<input type="checkbox"/>	<input type="checkbox"/>
Yes, sometimes	<input type="checkbox"/>	<input type="checkbox"/>
Yes, rarely	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	<input type="checkbox"/>
Don't know	<input type="checkbox"/>	<input type="checkbox"/>

b) Did the treatment help to relieve her poor appetite?

	In the last 3-12 months before death	In the last 3 months before death
Yes, all the time	<input type="checkbox"/>	<input type="checkbox"/>
Yes, sometimes	<input type="checkbox"/>	<input type="checkbox"/>
Yes, rarely	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	<input type="checkbox"/>
Don't know	<input type="checkbox"/>	<input type="checkbox"/>

### Psychological symptoms

#### Worry

32. Did she have worry?

	In the last 3-12 months before death	In the last 3 months before death
Yes, all the time	<input type="checkbox"/>	<input type="checkbox"/>
Yes, sometimes	<input type="checkbox"/>	<input type="checkbox"/>
Yes, rarely	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	<input type="checkbox"/>
Don't know	<input type="checkbox"/>	<input type="checkbox"/>

If you ticked 'yes, at all time', 'Yes, sometimes' or 'Yes, rarely'

a) Did she receive any treatment for her worry

	In the last 3-12 months before death	In the last 3 months before death
Yes, all the time	<input type="checkbox"/>	<input type="checkbox"/>
Yes, sometimes	<input type="checkbox"/>	<input type="checkbox"/>
Yes, rarely	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	<input type="checkbox"/>
Don't know	<input type="checkbox"/>	<input type="checkbox"/>

b) Did the treatment help the worry?

	In the last 3-12 months before death	In the last 3 months before death
Yes, all the time	<input type="checkbox"/>	<input type="checkbox"/>
Yes, sometimes	<input type="checkbox"/>	<input type="checkbox"/>
Yes, rarely	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	<input type="checkbox"/>
Don't know	<input type="checkbox"/>	<input type="checkbox"/>

### Low mood

33. Did she suffer with low mood related to the health problems?

	In the last 3-12 months before death	In the last 3 months before death
Yes, all the time	<input type="checkbox"/>	<input type="checkbox"/>
Yes, sometimes	<input type="checkbox"/>	<input type="checkbox"/>
Yes, rarely	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	<input type="checkbox"/>
Don't know	<input type="checkbox"/>	<input type="checkbox"/>

If you ticked 'yes, at all time', 'Yes, sometimes' or 'Yes, rarely'

a) Did she receive any treatment or support for his/her low mood?

	In the last 3-12 months before death	In the last 3 months before death
Yes, all the time	<input type="checkbox"/>	<input type="checkbox"/>
Yes, sometimes	<input type="checkbox"/>	<input type="checkbox"/>
Yes, rarely	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	<input type="checkbox"/>
Don't know	<input type="checkbox"/>	<input type="checkbox"/>

b) Did the treatment or support help the low mood?

	In the last 3-12 months before death	In the last 3 months before death
Yes, all the time	<input type="checkbox"/>	<input type="checkbox"/>
Yes, sometimes	<input type="checkbox"/>	<input type="checkbox"/>
Yes, rarely	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	<input type="checkbox"/>
Don't know	<input type="checkbox"/>	<input type="checkbox"/>

---

**Section 6: Provincial, district and community nurses**

34. Did a nurse(s) visit her at home?

If yes, which type of nurse(s) visited he/she?

- Provincial nurse
- District nurse
- Community nurse
- Others.....

- If provincial, district or community nurses came to visit her at home

35. Did she receive help at home for her renal trouble from the nurses?

- Yes
- No
- Not sure

a) If yes, how often did the 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

36. How much of the time was she treated with respect by the nurse?

Tick one only

- Always
- Most of the time

Some of the time

Never

Don't know

37. Overall, do you feel that the care she got from the nurses in the last three months of life was:

Tick one only

Excellent

Good

Fair

Poor

Don't know

Didn't receive any care

38. How far is it from the provincial, district or community hospital to her home?

.....

.....

---

**Section 7: General doctors/ physicians**

39. What services did the doctor provide for her and you?

*Please tick all the boxes which apply*

Emergency care

Repeat prescriptions

Changing his/her medication

Emotional support

Arranging extra help at home

Providing information about his/her health conditions

Regular check-ups for his/her health condition.....

Referral to outpatients

40. How much did the doctor understand about her renal problems (breathlessness, pain, oedema, worry and depress etc.)

The doctor understood him/her very well

The doctor understood him/her quite well

The doctor did not know him/her well at all

Don't know

41. Do you feel that her doctor had time to listen and discuss things? *Please tick the most suitable box*

Always

- Sometimes
- Rarely
- Never
- Not applicable

42. In the last 3 months, how often did she see the doctor she preferred to see?

- Always or almost always
- A lot of the time
- Some of the times
- Never or almost never
- He/she didn't try to see a particular doctor
- He/she did not need to see any doctor

43. How much of the time was she treated with respect by the doctor?

Tick one only

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

44. If the doctor visited her at home in the last three months, how easy or difficult was it to get her to visit ?

- Very easy
- Fairly easy
- Fairly difficult
- Very difficult
- Don't know
- She/he wanted the doctor to visit but they would not visit
- Does not apply-the GP did not need to visit
- Don't know

Please feel free to make comments in the space below:

.....  
 .....

45. Overall, do you feel that the care she got from doctor in the last three months of life was

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

Please feel free to make comments in the space below:.....

**Section 8: Last Hospital Admission**

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

Tick one only

Yes-please write the name of the last hospital she stayed in, in the space below:.....  
 .....  
 .....

- No
- Don't know

47 Did the hospital services work well together with her doctor and other services outside of the hospital?

- Yes, definitely
- Yes, to some extent

No, they did not work well together

Don't know

48 Over all, do you feel that the care she got from the staff in the hospital on that admission was:

Doctors    Nurses

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

**Section 9: The Last 3 Days**

49 During her last three days of life was he

Tick one only

- At home all the time
- In a hospital all the time
- Others-please write in the space

50 How much of the time was she treated with respect in the last three days of life?

Please answer for both doctors and nurses

Doctors    Nurses

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



51 Your opinion about the help she received in the last three days of life

51 Your opinion about the help she received in the last three days of life	Yes, always	Yes, most of the time	Yes, some of the time	No	Don't know
(a) Was 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) Was 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) Did the bed area and surrounding environment have adequate privacy for him?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

52 During the last three days,

	Yes, always	Yes, most of the time	Yes, some of the time	No	Don't know
(a) How well were her symptoms relieved?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Did she received spiritual support?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Did she received emotional support?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Did she received financial support?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Did she received any support to stay where she/he wanted to be?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Section 10: Circumstances surrounding the death**

53 Did he/she know she was likely to die?

Tick one only

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

54 In your opinion, did the person who told her she was likely to die break the news to her in a sensitive and caring way?

Tick one only

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

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

Tick one only

- Yes
- No
- I was there already
- It was not clear that she was going to die soon
- I couldn't have got there anyway
- I didn't have contact as she died at home

56 Where did she die?

Tick one only

- In her own home
- In the home of another family member or friend
- In hospital ward-please write the name of the hospital in the space below:.....  
.....  
.....
- In hospital accident and emergency department-please write the name of the hospital in the space below:.....  
.....  
.....

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

In an ambulance on the way to  
hospital

Somewhere-please write in the  
space  
below:.....  
.....

57 Did she ever say where he/she would  
like to die?

Tick one only

Yes

No

Not sure

58 Where did she say that she would  
like to die?

At home

In a hospital

She said she did not mind where  
she died

She changed her mind about  
where she wanted to die

Somewhere else-please write in  
the space  
below:.....  
.....  
.....

59 Did the health care staff have a  
record or know of this?

Tick one only

Yes

No

Not sure

60 Do you think she had enough choice  
about where he/she died?

Tick one only

Yes

No

Not sure

She died suddenly

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

Tick one only

Yes

No

Not sure

62 Do you feel that her religious, beliefs or faith in God were taken into consideration by those caring for her?

Tick one only

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

Please feel free to make comments below:.....  
.....  
.....

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

Tick one only

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

64 After she died did staff deal with you or her family in a sensitive manner?

Tick one only

- Yes

- No
- Not sure
- Does not apply, I didn't have any contact with the staff

Please feel free to make comments in the space below:.....  
.....

65 Looking back over the last three months of her life, was she involved in decision about her care as much as she would have wanted?

Tick one only

- She was involved as much as she wanted to be
- She would have liked to be more involved
- She would have liked to be less involved
- Don't know

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

Tick one only

- I was involved as much as I wanted to be

- I would have liked to be more involved
- I would have liked to be less involved
- Don't know

67 Were any decision made about his/her care that she would not have wanted?

Tick one only

- Yes
- No
- Not sure

Please feel free to make comments in the space below:.....  
.....

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

Tick one only

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

69 Since she died have you talked to any health care professionals (nurses, doctors etc.) about your feeling, help and support after the patients' death?

Tick one only

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

What, if anything, was good about the care?

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