



The **Irish** Longitudinal Study on Ageing

Wave 2

End-of-Life Questionnaire (Exit Interview)

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TILDA End-of-life interview

COVER-SCREEN

INTRODUCTION TO EXIT INTERVIEW

You may be aware that [Name of deceased] generously participated in the TILDA (The Irish Longitudinal Study on Ageing) study before [his/her] death. [His/her] contribution was very valuable. I appreciate that this may upset or distress you, but we would find it extremely helpful to have some information about the final year of [{Name of deceased}]'s life. All the information collected is completely confidential, and will be held anonymously.

This interview is completely voluntary. If we should come to any question that you don't want to answer, just let me know and I will go on to the next question.

[ELSA/SHARE/HRS]

XT_CS001: IWER: Has the proxy signed the End of life interview consent form?

1. Yes

5. No (IWER: Ask respondent to sign consent form and tick 'Yes')

XT_CS002: PROXY RESPONDENT'S SEX IWER:

Code proxy respondent's sex.

1. Male

2. Female

[SHARE]

XT_CS003: RELATIONSHIP TO THE DECEASED

Before we start asking questions about [{Name of deceased}]'s last year of life, would you please tell me what your relationship was to him/her?

1. Spouse/Partner

GO TO XT_CS006

2. Child/adopted child

GO TO XT_CS005

3. Step Child

GO TO XT_CS005

4. Child-in-law (daughter-in-law, son-in-law)

GO TO XT_CS005

5. Parent

GO TO XT_CS005

6. Parent-in-law

GO TO XT_CS005

7. Brother or sister

GO TO XT_CS005

8. Brother-in-law/Sister-in-law

GO TO XT_CS005

9. Grandparent

GO TO XT_CS005

10. Grandparent-in-law

GO TO XT_CS005

11. Grandchild

GO TO XT_CS005

12. Other relative (specify)

GO TO XT_CS003othr

13. Non-relative (specify)

GO TO XT_CS003othnr

[ELSA/SHARE]

XT_CS003othr: SPECIFY RELATIVE

Please specify how you are related to the deceased?

[GO TO XT_CS005](#)

XT_CS003othnr: SPECIFY HOW KNOW THE DECEASED

Please specify how you know the deceased?

XT_CS004: HOW LONG PROXY KNEW DECEASED

How long had you known [him/her]?

INTERVIEWER: *Code how the question is answered.*

1. Number of years and/or months
2. Since specific age of deceased
3. Date they met

[ELSA]

[XT_CS004y, XT_CS004m]: _____ Years / _____ Months (*Enter the number of years and months the respondent has known the deceased.*)

[XT_CS004dm] [XT_CS004dy]: _____ Month / _____ Year (*Enter date they met*)

[XT_CS004age]: _____ Age (*Enter the age of deceased when they met, if known since birth enter 0.*)

XT_CS005: HOW OFTEN IN CONTACT**IWER: SHOW CARD CS1**

Please look at card CS1. During the last twelve months of [his/her] life, how often did you have contact with [{Name of deceased}], either personally, by phone, mail or email?

1. Daily
2. Several times a week
3. About once a week
4. About every two weeks
5. About once a month
6. Less than once a month
7. Never

[SHARE]

XT_CS006: DECEASED MARRIED AT TIME OF DEATH**IWER: SHOW CARD CS2**

At the time [he/she] died, was [he/she]...?

- | | |
|--|---------------------------|
| 1. Married | GO TO XT_CS008 |
| 2. Living with a partner as if married | GO TO XT_CS008 |
| 3. Single (never married) | GO TO XT_CS008 |
| 4. Separated | GO TO XT_CS007m XT_CS007y |
| 5. Divorced | GO TO XT_CS007m XT_CS007y |
| 6. Widowed | GO TO XT_CS008 |

XT_CS007: WHEN STOP LIVING TOGETHER

In what month and year did [you/they] stop living together?

[XT_CS007y]:

(YYYY)

-98. DK

-99. RF

[XT_CS007m]

(mm)

98. DK

99. RF

XT_CS008: ILL BEFORE DEATH**IWER: SHOW CARD CS3**

I would now like to ask you a few questions about things that happened at the time of [{Name of deceased}]]'s death. How long had [he/she] been ill before [he/she] died?

1. Was not ill, died suddenly
2. One or two hours
3. Less than 24 hours
4. One day or more, but less than one week
5. One week or more but less than one month
6. One month or more but less than 6 months
7. 6 months or more but less than a year
8. One year or more

98. DK

99. RF

[ELSA/HRS]

XT_CS009: DEATH UNEXPECTED

Was the death expected at about the time it occurred, or was it unexpected?

1. Expected
2. Unexpected
95. Other

98. DK

99. RF

[ELSA/HRS]

XT_CS010: THE MAIN CAUSE OF DEATH**IWER: SHOW CARD CS4**

Please look at card CS4. What was the main cause of [his/her] death? (*IWER: Read out if necessary*)

- | | |
|---|-----------------------|
| 1. Cancer | GO TO XT_CS012 |
| 2. A heart attack | GO TO XT_CS012 |
| 3. A stroke | GO TO XT_CS012 |
| 4. Other cardiovascular related illness such as heart failure, arrhythmia | GO TO XT_CS012 |
| 5. Respiratory disease | GO TO XT_CS012 |
| 6. Disease of the digestive system such as gastrointestinal ulcer, inflammatory bowel disease | GO TO XT_CS012 |
| 7. Severe infectious disease such as pneumonia, septicaemia or flu | GO TO XT_CS012 |

- 8. Accident
- 9. Suicide
- 95. Other (Please specify...)
- 98. DK
- 99. RF

GO TO XT_CS012
 GO TO XT_CS012
 GO TO XT_CS010oth
 GO TO XT_CS012
 GO TO XT_CS012

[ELSA/SHARE/HRS: *Open string question*]

XT_CS010oth: Specify main cause of death

XT_CS011: DATE OF DEATH

What was the date on which [R's FIRST NAME] died?
 [HRS]

XT_CS011m:

ENTER MONTH:

- 01. JAN
- 02. FEB
- 03. MAR
- 04. APR
- 05. MAY
- 06. JUN
- 07. JUL
- 08. AUG
- 09. SEP
- 10. OCT
- 11. NOV
- 12. DEC
- 98. DK
- [HRS]

XT_CS011y:

ENTER YEAR:

- 98. DK
- 99. RF

[HRS, ELSA]

XT_CS012: WHERE DIED

IWER: SHOW CARD CS5

Please look at card CS5. And where did [{Name of deceased}] die? Was it ...READ OUT...

- 1. At home
- 2. At another person's home
- 3. In hospital
- 4. In a hospice
- 5. In a nursing home
- 6. In a residential home

GO TO XT_CS016
 GO TO XT_CS013
 GO TO XT_CS015
 GO TO XT_CS015
 GO TO XT_CS015
 GO TO XT_CS015

- 7. In a mixed nursing /residential home
 - 8. In sheltered housing
 - 9. In an ambulance/en route to hospital/en route to hospice etc?
 - 95. At some other place (Please Specify)
 - 98. DK
 - 99. RF
- [HRS/ELSA/SHARE]

GO TO XT_CS015
 GO TO XT_CS014
 GO TO XT_CS016
 GO TO XT_CS012oth
 GO TO XT_CS016
 GO TO XT_CS016

XT_CS012oth: OTHER PLACE DIED

What was this other place?

(INTERVIEWER: Write in.)

[ELSA]

GO TO XT_CS014

XT_CS013: WHOSE HOME DIED

In whose home did [{Name of deceased}] die?

- 1 Relative
 - 2 Non-relative
- [ELSA]

XT_CS014: OCCASIONS STAYED OTHERS HOME/SHELTERED HOME/ OTHER PLACE

On how many different occasions did [{Name of deceased}] stay in [XT_CS012] in the last two years before [he/she] died?

(INTERVIEWER: If appropriate include more than one person's home. Specify the number of times.

Range: 1..95

[ELSA]

XT_CS015: LENGTH OF TIME IN PLACE BEFORE DIED

In total, how long did [{Name of deceased}] stay in [XT_CS012] in the last two years before [he/she] died?

INTERVIEWER: If stayed on more than one occasion add the times together.

- 1. Less than 24 hours
 - 2. One day or more, but less than one week
 - 3. One week or more but less than one month
 - 4. One month or more but less than 3 months
 - 5. 3 months or more but less than 6 months
 - 6. 6 months or more but less than a year
 - 7. A year or more
 - 98. Don't know
 - 99. Refused
- [ELSA]

I would now like to ask you some questions about where [{Name of deceased}] lived or stayed overnight as a result of [his/her] health in the two years before [he/she] died.

XT_CS016: WHERE LIVED BEFORE DIED- MULTIPLE RESPONSE

IWER: SHOW CARD CS6

Did [he/she] live or stay in any of these places at any stage in the two years before [he/she] died?

(INTERVIEWER: Include HSE and privately-owned establishments

CODE ALL THAT APPLY.)

1. At home
 2. Other person's home
 3. In hospital
 4. In a hospice
 5. In a nursing home
 6. In a residential home
 7. In a mixed nursing /residential home
 8. In sheltered housing
 9. Stayed at no other places
 95. Other place (Specify)
 98. DK
 99. RF
- [ELSA]

IF XT_CS016 = 1, 9, 98, 99 GO TO XT_FL001

IF XT_CS016 = 2 (Other person's home) GO TO XT_CS017

IF XT_CS016 = 3 (In hospital) GO TO XT_CS020

IF XT_CS016 = 4 (In a hospice) GO TO XT_CS022

IF XT_CS016 = 5 (In a nursing home) GO TO XT_CS024

IF XT_CS016 = 6 (In a residential home) GO TO XT_CS026

IF XT_CS016 = 7 (In a mixed nursing/residential home) GO TO XT_CS028

IF XT_CS016 = 8 (In sheltered housing) GO TO XT_CS030

IF XT_CS016 = 95 (In other place) GO TO XT_CS032

XT_CS017: WHOSE HOME

In whose home did [{Name of deceased}] stay?

1. Relative
2. Non-relative

[ELSA]

XT_CS018: TIMES STAYED IN ANOTHER'S HOME

On how many different occasions did [{Name of deceased}] stay in another person's home in the last two years before [he/she] died?

(INTERVIEWER: Enter the number of times.)

Range: 1..95

[ELSA]

XT_CS019: TIME STAYED IN ANOTHER'S HOME

IWER: SHOW CARD CS7

In total, how long did [{Name of deceased}] stay in another person's home in the last two years before [he/she] died?

(INTERVIEWER: If stayed on more than one occasion add the times together.)

- 1 Less than 24 hours
 - 2 One day or more, but less than one week
 - 3 One week or more but less than one month
 - 4 One month or more but less than 3 months
 - 5 3 months or more but less than 6 months
 - 6 6 months or more but less than a year
 - 7 A year or more
 - 98 Don't know
- [ELSA]

IF XT_CS016 = 3 (In hospital) GO TO XT_CS020

IF XT_CS016 = 4 (In a hospice) GO TO XT_CS022

IF XT_CS016 = 5 (In a nursing home) GO TO XT_CS024

IF XT_CS016 = 6 (In a residential home) GO TO XT_CS026

IF XT_CS016 = 7 (In a mixed nursing/residential home) GO TO XT_CS028

IF XT_CS016 = 8 (In sheltered housing) GO TO XT_CS030

IF XT_CS016 = 95 (In other place) GO TO XT_CS032

OTHERWISE GO TO XT_FL001

XT_CS020: TIMES STAYED IN HOSPITAL

On how many different occasions did [{Name of deceased}] stay in a hospital in the last two years before [he/she] died?

(INTERVIEWER: Enter the number of times.)

Range: 1..95

[ELSA]

XT_CS021: TIME STAYED IN HOSPITAL

IWER: SHOW CARD CS7

In total, how long did [{Name of deceased}] stay in a hospital in the last two years before [he/she] died?

(INTERVIEWER: If stayed on more than one occasion add the times together.)

1. Less than 24 hours
 2. One day or more, but less than one week
 3. One week or more but less than one month
 4. One month or more but less than 3 months
 5. 3 months or more but less than 6 months
 6. 6 months or more but less than a year
 7. A year or more
 98. Don't know
 99. RF
- [ELSA]

IF XT_CS016 = 4 (In a hospice) GO TO XT_CS022

IF XT_CS016 = 5 (In a nursing home) GO TO XT_CS024

IF XT_CS016 = 6 (In a residential home) GO TO XT_CS026
IF XT_CS016 = 7 (In a mixed nursing/residential home) GO TO XT_CS028
IF XT_CS016 = 8 (In sheltered housing) GO TO XT_CS030
IF XT_CS016 = 95 (In other place) GO TO XT_CS032
OTHERWISE GO TO XT_FL001

XT_CS022: TIMES STAYED IN HOSPICE

On how many different occasions did [{Name of deceased}] stay in a hospice in the last two years before [he/she] died?

(INTERVIEWER: Enter the number of times.)

Range: 1..95

[ELSA]

XT_CS023: TIME STAYED IN HOSPICE

IWER: SHOW CARD CS7

In total, how long did [{Name of deceased}] stay in a hospice in the last two years before [he/she] died?

(INTERVIEWER: If stayed on more than one occasion add the times together.)

1. Less than 24 hours
2. One day or more, but less than one week
3. One week or more but less than one month
4. One month or more but less than 3 months
5. 3 months or more but less than 6 months
6. 6 months or more but less than a year
7. A year or more
98. Don't know
99. RF

[ELSA]

IF XT_CS016 = 5 (In a nursing home) GO TO XT_CS024
IF XT_CS016 = 6 (In a residential home) GO TO XT_CS026
IF XT_CS016 = 7 (In a mixed nursing/residential home) GO TO XT_CS028
IF XT_CS016 = 8 (In sheltered housing) GO TO XT_CS030
IF XT_CS016 = 95 (In other place) GO TO XT_CS032
OTHERWISE GO TO XT_FL001

XT_CS024: TIMES STAYED IN NURSING HOME

On how many different occasions did [{Name of deceased}] stay in a nursing home in the last two years before [he/she] died?

(INTERVIEWER: Enter the number of times)

Range: 1..95

[ELSA]

XT_CS025: TIME STAYED IN NURSING HOME

IWER: SHOW CARD CS7

In total, how long did [{Name of deceased}] stay in a nursing home in the last two years before [he/she] died?

(INTERVIEWER: If stayed on more than one occasion add the times together.)

1. Less than 24 hours
2. One day or more, but less than one week
3. One week or more but less than one month
4. One month or more but less than 3 months
5. 3 months or more but less than 6 months
6. 6 months or more but less than a year
7. A year or more
98. Don't know
99. RF

[ELSA]

IF XT_CS016 = 6 (In a residential home) GO TO XT_CS026

IF XT_CS016 = 7 (In a mixed nursing/residential home) GO TO XT_CS028

IF XT_CS016 = 8 (In sheltered housing) GO TO XT_CS030

IF XT_CS016 = 95 (In other place) GO TO XT_CS032

OTHERWISE GO TO XT_FL001

XT_CS026: TIMES STAYED IN RESIDENTIAL HOME

On how many different occasions did [{Name of deceased}] stay in a residential home in the last two years before [he/she] died?

(INTERVIEWER: Enter the number of times.)

Range: 1..95

[ELSA]

XT_CS027: TIME STAYED IN RESIDENTIAL HOME

IWER: SHOW CARD CS7

In total, how long did [{Name of deceased}] stay in a residential home in the last two years before [he/she] died?

(INTERVIEWER: If stayed on more than one occasion add the times together.)

1. Less than 24 hours
2. One day or more, but less than one week
3. One week or more but less than one month
4. One month or more but less than 3 months
5. 3 months or more but less than 6 months
6. 6 months or more but less than a year
7. A year or more
98. Don't know
99. RF

[ELSA]

IF XT_CS016 = 7 (In a mixed nursing/residential home) GO TO XT_CS028

IF XT_CS016 = 8 (In sheltered housing) GO TO XT_CS030

IF XT_CS016 = 95 (In other place) GO TO XT_CS032

OTHERWISE GO TO XT_FL001

XT_CS028: TIMES STAYED IN MIXED NURSING/RESIDENTIAL HOME

On how many different occasions did [{Name of deceased}] stay in mixed nursing/residential home in the last two years before [he/she] died?

(INTERVIEWER: Enter the number of times.)

Range: 1..95

[ELSA]

XT_CS029: TIME STAYED IN MIXED NURSING/RESIDENTIAL HOME

IWER: SHOW CARD CS7

In total, how long did [{Name of deceased}] stay in mixed nursing/residential home in the last two years before [he/she] died?

(INTERVIEWER: If stayed on more than one occasion add the times together.)

1. Less than 24 hours
 2. One day or more, but less than one week
 3. One week or more but less than one month
 4. One month or more but less than 3 months
 5. 3 months or more but less than 6 months
 6. 6 months or more but less than a year
 7. A year or more
 98. Don't know
 99. RF
- [ELSA]

IF XT_CS016 = 8 (In sheltered housing) GO TO XT_CS030

IF XT_CS016= 95 (In other place) GO TO XT_CS032

OTHERWISE GO TO XT_FL001

XT_CS030: TIMES STAYED IN SHELTERED HOUSING

On how many different occasions did [{Name of deceased}] stay in sheltered housing in the last two years before [he/she] died?

(INTERVIEWER: Enter the number of times.)

Range: 1..95

[ELSA]

XT_CS031: TIME STAYED IN SHELTERED HOUSING

IWER: SHOW CARD CS7

In total, how long did [{Name of deceased}] stay in sheltered housing in the last two years before [he/she] died?

(INTERVIEWER: If stayed on more than one occasion add the times together.)

1. Less than 24 hours
 2. One day or more, but less than one week
 3. One week or more but less than one month
 4. One month or more but less than 3 months
 5. 3 months or more but less than 6 months
 6. 6 months or more but less than a year
 7. A year or more
 98. Don't know
 99. RF
- [ELSA]

IF XT_CS016= 95 (In other place) GO TO XT_CS032

OTHERWISE GO TO XT_FL001

XT_CS032: TIMES STAYED IN MIXED OTHER PLACE

How many other types of places did [he/she] stay in during the two years before [he/she] died?
(INTERVIEWER: *If more than one other place, record each place at a separate question.*)

Range: 1..5

[ELSA]

FOR XT_CS032 = 1 to 5, LOOP THROUGH XT_CS033 TO XT_CS035

XT_CS033: Loop WHAT OTHER PLACE

What was this other place?

[XT_CS033_01 to XT_CS033_05]

(INTERVIEWER: *Write in the other place.*)

STRING 100

[ELSA]

XT_CS034: Loop TIMES IN OTHER PLACE (#I)

On how many different occasions did [{Name of deceased}] stay in this place in the last two years before [he/she] died?

[XT_CS034_01 TO XT_CS034_05]

(INTERVIEWER: *Enter the number of times.*)

Range: 1..95

[ELSA]

XT_CS035: Loop TIME IN OTHER PLACE (#I)

IWER: SHOW CARD CS7

In total, how long did [{Name of deceased}] stay in this place in the last two years before [he/she] died?

[XT_CS035_01 TO XT_CS035_05]

(INTERVIEWER: *If stayed on more than one occasion add the times together.*)

1. Less than 24 hours
2. One day or more, but less than one week
3. One week or more but less than one month
4. One month or more but less than 3 months
5. 3 months or more but less than 6 months
6. 6 months or more but less than a year
7. A year or more
98. Don't know
99. RF

[ELSA]

XT_CS036m: MONTH DECEASED BORN

In which month was [{Name of deceased}] born?

_____ MONTH [XT_CS036m]

XT_CS036y: YEAR DECEASED BORN

In which year was [{Name of deceased}] born?

_____ YEAR [XT_CS036y]

COVER-SCREEN FEEDFORWARD

There are a number of variables in the End of Life Wave 2 dataset which are taken from the Wave 1 Questionnaire. Below are a list of those within the Cover-Screen section of the dataset along with an explanation of how they were asked in the Wave 1 Questionnaire.

XT CS006ff

CS006:

Are you...

1. Married
2. Living with a partner as if married
3. Single (never married)
4. Separated
5. Divorced
6. Widowed
(HRS)

Note:

Married includes those living temporarily apart due to illness, work, etc...

Living with a partner is a situation where there is no formal marriage but R is living in a marriage-like relationship.

Separated is a situation where R is not living with partner and there is no marriage-like relationship anymore.

(HRS/MHAS/SHARE/ELSA)

XT DM017ff

DM017:

Have you ever lived abroad (outside of Republic of Ireland) for more than six months?

1. Yes
5. No
98. DK
99. RF

XT_CS034ff

CS034:

In total, then, how many living children do you have? (including step, foster and adoptive children)

0 ... 20

(HRS/ELSA/SHARE)

XT_TC008ff

XT_TC008:

In the last ten years, have you (or your spouse/partner) given the deeds of a house, business, property, or a large amount of money of €5,000 or more to any of your children (or grandchildren)?

IWER: INCLUDE LARGE TRANSFERS IN MONEY AND GIFTS SUCH AS IMMOVABLE PROPERTY (LAND, HOUSE), AND MOVABLE PROPERTY (CAR, JEWELLERY).

1. Yes

5. No

98. DK

99. RF

(HRS/MHAS/SHARE)

I(ADL) & HELPERS (FL)

XT_FL001 (01 to 06): HELP WITH ADL

IWER: SHOW CARD FL1

I would now like to ask you about problems [{Name of deceased}] might have had in [his/her] everyday life, in the three months before [he/she] died. Because of a health or memory problem, did [{Name of Deceased}] have difficulty doing any of the activities on this card:

- | | |
|---|---------------|
| 1. Dressing | [XT_FL001_01] |
| 2. Getting across a room | [XT_FL001_02] |
| 3. Bathing or showering | [XT_FL001_03] |
| 4. Eating their food or preparing the food to be eaten (e.g. cutting it up) | [XT_FL001_04] |
| 5. Getting in or out of bed | [XT_FL001_05] |
| 6. Using the toilet, including getting up and down | [XT_FL001_06] |
| 96. None of these | [XT_FL001_96] |
| 98. DK | [XT_FL001_98] |
| 99. RF | [XT_FL001_99] |

IF XT_FL001_01 = 1 (Dressing) GO TO XT_FL002

IF XT_FL001_02 = 1 (Getting across a room) GO TO XT_FL003

IF XT_FL001_03 = 1 (Bathing or showering) GO TO XT_FL004

IF XT_FL001_04 = 1 (Eating) GO TO XT_FL005

IF XT_FL001_05 = 1 (Getting in or out of bed) GO TO XT_FL006

IF XT_FL001_06 = 1 (Using the toilet) GO TO XT_FL007

IF XT_FL001 = 96, 98, 99 GO TO XT_FL010

XT_FL002: TIME HELPED WITH DRESSING

In total, for how long had [he/she] needed help with dressing?

INTERVIEWER: Code how the answer is given.

1. In months and years
2. Since a specified age
98. Don't know
99. RF

[ELSA]

(XT_FL002)

XT_FL002y: YEARS HELPED WITH ... *INTERVIEWER: Enter the number of years.*

Range: 0..110

XT_FL002m: MONTHS HELPED WITH ...

INTERVIEWER: Enter the number of months.

XT_FL002a: AGE SINCE HELPED WITH ...

INTERVIEWER: Enter the age.

[ELSA]

IF XT_FL001_02 = 1 (Getting across a room) GO TO XT_FL003
IF XT_FL001_03 = 1 (Bathing) GO TO XT_FL004
IF XT_FL001_04 = 1 (Eating) GO TO XT_FL005
IF XT_FL001_05 = 1 (Getting in and out of bed) GO TO XT_FL006
IF XT_FL001_06= 1 (Using the toilet) GO TO XT_FL007
OTHERWISE GO TO XT_FL008

XT_FL003: TIME HELPED WITH WALKING

For how long had [he/she] needed help with walking?

INTERVIEWER: Code how the answer is given.

1. In months and years
 2. Since a specified age
 98. Don't know
 99. RF
- [ELSA]

```

{
(XT_FL003)
XT_FL003y YEARS HELPED WITH ...
XT_FL003m MONTHS HELPED WITH ...
XT_FL003a AGE SINCE HELPED WITH ...
}

```

IF XT_FL001_03 = 1 (Bathing) GO TO XT_FL004
IF XT_FL001_04 = 1 (Eating) GO TO XT_FL005
IF XT_FL001_05 = 1 (Getting in and out of bed) GO TO XT_FL006
IF XT_FL001_06= 1 (Using the toilet) GO TO XT_FL007
OTHERWISE GO TO XT_FL008

XT_FL004: TIME HELPED WITH BATHING

In total, for how long had [he/she] needed help with bathing or showering?

INTERVIEWER: Code how the answer is given.

1. In months and years
 2. Since a specified age
 98. Don't know
 99. RF
- [ELSA]

```

{
(XT_FL004)
XT_FL004y YEARS HELPED WITH ...
XT_FL004m MONTHS HELPED WITH ...
XT_FL004a AGE SINCE HELPED WITH ...
}

```

IF XT_FL001_04 = 1 (Eating) GO TO XT_FL005

IF XT_FL001_05 = 1 (Getting in and out of bed) GO TO XT_FL006

IF XT_FL001_06 = 1 (Using the toilet) GO TO XT_FL007

OTHERWISE GO TO XT_FL008

XT_FL005: TIME HELPED WITH EATING

In total, for how long had [he/she] needed help with eating?

INTERVIEWER: Code how the answer is given.

1. In months and years

2. Since a specified age

98. Don't know

99. RF

[ELSA]

{

(XT_FL005)

XT_FL005y YEARS HELPED WITH ...

XT_FL005m MONTHS HELPED WITH ...

XT_FL005a AGE SINCE HELPED WITH ...

}

IF XT_FL001_05 = 1 (Getting in and out of bed) GO TO XT_FL006

IF XT_FL001_06 = 1 (Using the toilet) GO TO XT_FL007

OTHERWISE GO TO XT_FL008

XT_FL006: TIME HELPED WITH GETTING INTO BED

In total, for how long had [he/she] needed help getting in or out of bed?

INTERVIEWER: Code how the answer is given.

1. In months and years

2. Since a specified age

98. Don't know

99. RF

[ELSA]

{

(XT_FL006)

XT_FL006y YEARS HELPED WITH ...

XT_FL006m MONTHS HELPED WITH ...

XT_FL006a AGE SINCE HELPED WITH ...

}

IF XT_FL001_06 = 1 (Using the toilet) GO TO XT_FL007

OTHERWISE GO TO XT_FL008

XT_FL007: TIME HELPED WITH USING TOILET

In total, for how long had [he/she] needed help with using the toilet?

INTERVIEWER: Code how the answer is given. 1. In months and years

2. Since a specified age
 98. Don't know
 99. RF
 [ELSA]

```
{
(XT_FL007)
XT_FL007y YEARS HELPED WITH ...
XT_FL007m MONTHS HELPED WITH ...
XT_FL007a AGE SINCE HELPED WITH ...
}
```

IF XT_FL001_01/02/03/04/05/06 = 1 GO TO XT_FL008
ELSE GO TO XT_FL010

XT_FL008: WHO USUALLY HELPED

Thinking about the activities [getting across a room/ dressing/ bathing/ eating/ getting in/ out of bed/ using the toilet] that [{Name of deceased}] had problems with, who usually helped [{Name of deceased}] with these activities?

[DISPLAY BY CAPI Possible Helper name(s) (per wave 1 data)]

	Name	Relationship
1		Spouse/partner name
2	Through N_children's name	Children
	[ROW PROVIDED BY CAPI AS NECESSARY]	
95	PAID HELPER	
96	EMPLOYEE(S) OF NURSING HOME	
97	OTHER NOT IN THE LIST_SPECIFY	SPECIFY:
98	DK	
99	RF	

XT_FL008n_01: WHAT IS HER/HIS FIRST NAME?

Helper name(s) [displayed by capi (ROSTER) from previous responses]

1. R's spouse/partner name	[GO TO XT_FL023]
2. Children	[GO TO XT_FL023]
<i>[rows provided by CAPI as necessary]</i>	
96. Employee(s) of facility	[GO TO XT_FL023]
97. Other - not on list	[GO TO XT_FL021]
98. DK	[GO TO XT_FL023]
99. RF	[GO TO XT_FL023]

Note: "helpers" appearing on this list are all living persons in contact associated with the r, including current and/or ex-spouse/partner(s), children, their current and former spouses/partners, hhms, parents(-in-law) and siblings(-in-law). Note: all subsequent lists will also include the name of any helper(s) previously named following the selection of "not on list" (code 97); this applies for any list from which 97 is selected.

XT_FL008a_01: HELPER GENDER:

Male or Female?

1. Male
2. Female

XT_FL008b_01: HELPER # RELATION TO THE DECEASED

What was that person's relationship to {[Name of the deceased]}?

1. Spouse
2. Child/ adopted child
3. Step Child
4. Child-in-law (daughter-in-law, son-in-law)
5. Parent
6. Parent-in-law
7. Brother or sister
8. Brother-in-law/Sister-in-law
9. Grandparent
10. Grandparent-in-law
11. Other blood relative
12. Other in-law
13. Grandchild
14. Non-relative

XT_FL009o: ANYONE ELSE HELPER

Did anyone else help with this activity/these activities?

BL: REPEAT XT_FL009o_i TO XT_FL009o_03 FOR UP TO 3 NAMES

- | | |
|--------|------------------|
| 1. Yes | [GO TO XT_FL024] |
| 5. No | [GO TO XT_FL027] |
| 98. DK | [GO TO XT_FL027] |
| 99. RF | [GO TO XT_FL027] |
- (HRS)

XT_FL009: HELPER # NAME

Who was that? [XT_FL009t_01 to XT_FL009t_03]

	Name	Relationship
1.		Spouse/partner name
2	Through N_children's name	Children
	[ROW PROVIDED BY CAPI AS NECESSARY]	
95	PAID HELPER	
96	EMPLOYEE(S) OF NURSING HOME	
97	OTHER NOT IN THE LIST_SPECIFY	SPECIFY:
98	DK	
99	RF	

XT_FL009t_i: Helper name(s) [displayed by capi from previous responses]

2. R's spouse/partner name

Possible Helper name(s) (per wave 1 data)

[rows provided by CAPI as necessary]

96. Employee(s) of facility

97. Other - not on list

98. DK

99. RF

Note: "helpers" appearing on this list are all living persons in contact associated with the r, including current and/or ex-spouse/partner(s), children, their current and former spouses/partners, hhms, parents(-in-law) and siblings(-in-law). Note: all subsequent lists will also include the name of any helper(s) previously named following the selection of "not on list" (code 97); this applies for any list from which 97 is selected.

(HRS)

IF XT_FL009o_i = 97 (Not on the list) Ask XT_FL009n_i

XT_FL009n_01 Name of the helper?

XT_FL009a_i: HELPER # GENDER

Is <XT_FL009t_i> male or female?

1. Male

2. Female

XT_FL009b_i: HELPER # RELATION TO THE DECEASED

What is that person's relationship to [{name of deceased}]?

1. Spouse

2. Child/ adopted child

3. Step Child

4. Child-in-law (daughter-in-law, son-in-law)

5. Parent

6. Parent-in-law

7. Brother or sister

8. Brother-in-law/Sister-in-law

9. Grandparent

10. Grandparent-in-law

11. Other blood relative

12. Other in-law

13. Grandchild

14. Non-relative

NOTE: This repeats for:

(XT_FL009o_01 ... 03, XT_FL009t_01 ... 03, XT_FL009a_01 ... 03 and XT_FL009b_01 ... 03)

XT_FL010

IWER: SHOW CARD FL2

Please look at card FL2. Because of a health or memory problem during the last three months of [his/her] life, did [{Name of deceased}] have difficulty doing any of the activities on this card?

1. Preparing hot meals?

[XT_FL010_01]

2. Doing household chores (laundry, cleaning)

[XT_FL010_02]

3. Shopping for groceries?

[XT_FL010_03]

4. Making Telephone calls?

[XT_FL010_04]

5. Taking medication?

[XT_FL010_05]

- | | |
|---|---------------|
| 6. Managing money, such as paying bills and keeping track of expenses | [XT_FL010_06] |
| 96. None of these | [XT_FL010_96] |
| 98. DK | [XT_FL010_98] |
| 99. RF | [XT_FL010_99] |

IF XT_FL010_01 = 1 (Preparing Meals) GO TO XT_FL011
IF XT_FL010_02 = 1 (Doing household chores) GO TO XT_FL011
IF XT_FL010_03 = 1 (Shopping for groceries) GO TO XT_FL011
IF XT_FL010_04 = 1 (Making Telephone calls) GO TO XT_FL012
IF XT_FL010_05 = 1 (Taking medication) GO TO XT_FL013
IF XT_FL010_06 = 1 (Managing money) GO TO XT_FL014
IF XT_FL010 = 95, 98, 99 GO TO XT_PH001

XT_FL011 REASON HELPED WITH PREPARING HOT MEALS

(You said earlier that during the last three months of [his/her] life [{Name of deceased}] received help to prepare hot meals, doing household chores or shopping for groceries.) Was that because of a health or memory problem?

INTERVIEWER: If the respondent gives an actual reason, decide whether this was a problem with either their health or memory.

- 1. Yes
- 5. No
- 98. Don't know
- 99. RF
- [ELSA]

XT_FL011_01 TIME HELPED WITH PREPARING HOT MEALS

In total, for how long had [he/she] needed help with preparing hot meals, doing household chores or shopping for groceries up until [he/she] died?

INTERVIEWER: Code how the answer is given.

- 1. In months and years
- 2. Since a specified age
- 98. Don't know
- 99. RF
- [ELSA]

```

{
(XT_FL011)
XT_FL011y YEARS HELPED WITH ...
XT_FL011m MONTHS HELPED WITH ...
XT_FL011a AGE SINCE HELPED WITH ...
}

```

IF XT_FL010_04 = 1 (Making Telephone calls) GO TO XT_FL012
IF XT_FL010_05 = 1 (Taking medication) GO TO XT_FL013
IF XT_FL010_06 = 1 (Managing money) GO TO XT_FL014
OTHERWISE GO TO XT_FL015

XT_FL012 REASON HELPED WITH PHONE CALLS

(You said earlier that during the last three months of [his/her] life [{Name of deceased}] received help to make phone calls.) Was that because of a health or memory problem?

INTERVIEWER: If the respondent gives an actual reason, decide whether this was a problem with either their health or memory.

- 1. Yes
- 5. No
- 98. Don't know
- 99. RF

[ELSA]

XT_FL012_01 TIME HELPED WITH PHONE CALLS

In total, for how long had [he/she] needed help making telephone calls, when [he/she] died?

INTERVIEWER: Code how the answer is given.

- 1. In months and years
- 2. Since a specified age
- 98. Don't know
- 99. RF

[ELSA]

{

(XT_FL012)

XT_FL012y YEARS HELPED WITH ...

XT_FL012m MONTHS HELPED WITH ...

XT_FL012a AGE SINCE HELPED WITH ...

}

IF XT_FL010_05 = 1 (Taking medication) GO TO XT_FL013

IF XT_FL010_06 = 1 (Managing money) GO TO XT_FL014

OTHERWISE GO TO XT_FL015

XT_FL013 REASON HELPED WITH TAKING MEDICATION

(You said earlier that during the last three months of [his/her] life [{Name of deceased}] received help with taking medication.) Was that because of a health or memory problem?

INTERVIEWER: If the respondent gives an actual reason, decide whether this was a problem with either their health or memory.

- 1. Yes
- 5. No
- 98. Don't know
- 99. RF

[ELSA]

XT_FL013_01 TIME HELPED WITH TAKING MEDICATION

In total, for how long when [he/she] died had [he/she] needed help when taking medication?

INTERVIEWER: Code how the answer is given.

- 1. In months and years
- 2. Since a specified age
- 98. Don't know
- 99. RF
- [ELSA]

Years helped with taking medication [XT_FL015y]

Months helped with taking medication [XT_FL015m]

Age since helped with taking medication [XT_FL015a]

```
{  
(XT_FL013)  
XT_FL013y YEARS HELPED WITH ...  
XT_FL013m MONTHS HELPED WITH ...  
XT_FL013a AGE SINCE HELPED WITH ...  
}
```

IF XT_FL010_06 = 1 (Managing money) GO TO XT_FL014

OTHERWISE GO TO XT_FL015

XT_FL014 REASON HELPED WITH MANAGING MONEY

(You said earlier that during the last three months of [his/her] life [{Name of deceased}] received help with managing money, such as paying bills and keeping track of expenses.) Was that because of a health or memory problem?

INTERVIEWER: If the respondent gives an actual reason, decide whether this was a problem with either their health or memory.

- 1. Yes
- 5. No
- 98. Don't know
- 99. RF
- [ELSA]

XT_FL014_01 TIME HELPED WITH TAKING MANAGING MONEY

In total, for how long when [he/she] died had [he/she] needed help with managing money?

INTERVIEWER: Code how the answer is given.

- 1. In months and years
- 2. Since a specified age
- 98. Don't know
- 99. RF
- [ELSA]


```

{
(XT_FL014)
XT_FL014y YEARS HELPED WITH ...
XT_FL014m MONTHS HELPED WITH ...
XT_FL014a AGE SINCE HELPED WITH ...
}

```

IF XT_FL011/12/13/14/= 1 GO TO XT_FL015
ELSE GO TO XT_FL018

XT_FL015

Thinking about the activities [preparing meals/doing household chores/shopping for groceries/making telephone calls/ medications] that [{Name of deceased}] had problems with, who usually helped [{Name of deceased}] with these activities?

HELPER # NAME

	Name	Relationship
1.		Spouse/partner name
2	Through N_children's name	Children
	[ROW PROVIDED BY CAPI AS NECESSARY]	
95	PAID HELPER	
96	EMPLOYEE(S) OF NURSING HOME	
97	OTHER NOT IN THE LIST_SPECIFY	SPECIFY:
98	DK	
99	RF	

IF XT_FL015 = 97 (Not on list) GO TO XT_FL015n_01
ELSE GO TO XT_FL015a_01

XT_FL015n_01 Helper name(s) [displayed by capi from previous responses]

Note: "helpers" appearing on this list are all living persons in contact associated with the r, including current and/or ex-spouse/partner(s), children, their current and former spouses/partners, hhms, parents(-in-law) and siblings(-in-law). Note: all subsequent lists will also include the name of any helper(s) previously named following the selection of "not on list" (code 97); this applies for any list from which 97 is selected.

(HRS)

XT_FL015a_01 HELPER # NUMBER

Male or Female?

1.Male

2.Female

XT_FL015b_01: HELPER # RELATIONSHIP TO THE DECEASED

What was that person's relationship to {[Name of the deceased]}?

1. Spouse
2. Child/ adopted child
3. Step Child
4. Child-in-law (daughter-in-law, son-in-law)
5. Parent
6. Parent-in-law
7. Brother or sister
8. Brother-in-law/Sister-in-law
9. Grandparent
10. Grandparent-in-law
11. Other blood relative
12. Other in-law
13. Grandchild
14. Non-relative

XT_FL016_i: ANYONE ELSE HELPER

Did anyone else help with this activity/these activities?

REPEAT XT_FL016 TO FOR UP TO 3 HELPERS [XT_FL016_01 – XT_FL016_03]

1. Yes [Go to XT_FL017t_i]

5. No **GO TO XT_FL021**

98. DK **GO TO XT_FL021**

99. RF **GO TO XT_FL021**

(HRS)

XT_FL017_i (loop 1 to 3)

Who was that?

[XT_fl017t_01 to XT_fl017t_03]

	Name	Relationship
1.		Spouse/partner name
2	Through N_children's name	Children
	[ROW PROVIDED BY CAPI AS NECESSARY]	
95	PAID HELPER	
96	EMPLOYEE(S) OF NURSING HOME	
97	OTHER NOT IN THE LIST_SPECIFY	SPECIFY:
98	DK	
99	RF	

XT_FL017n_i Helper name(s) [displayed by capi from previous responses]

Note: "helpers" appearing on this list are all living persons in contact associated with the r, including current and/or ex-spouse/partner(s), children, their current and former spouses/partners, hhms, parents(-in-law) and siblings(-in-law). Note: all subsequent lists will also include the name of any helper(s) previously named following the selection of "not on list" (code 97); this applies for any list from which 97 is selected.

(HRS)

IF XT_FL017 = 97 (Not on list)

ELSE GO TO XT_FL017a_i

XT_FL017a_i HELPER # GENDER

Is <XT_FL017t_i> male or female?

1. Male
2. Female

XT_FL017b_i: HELPER # RELATION TO THE DECEASED

What is that person's relationship to {name of deceased}}?

1. Spouse
2. Child/ adopted child
3. Step Child
4. Child-in-law (daughter-in-law, son-in-law)
5. Parent
6. Parent-in-law
7. Brother or sister
8. Brother-in-law/Sister-in-law
9. Grandparent
10. Grandparent-in-law
11. Other blood relative
12. Other in-law
13. Grandchild
14. Non-relative

XT_FL021_i: HOW MANY DAYS DID HELPER'S NAME HELP

Let's think for a moment about the help [{name of deceased}] received with the difficulties that we just talked about. During his/her last three months, on average about how many days did HELPER's NAME help [him/her] per month?

0... 31

-98. DK

-99. RF

(HRS)

XT_FL022_i: HOW MANY HOURS PER DAY DID HELPER'S NAME HELP

On the days when HELPER's NAME helped [{name of deceased}], about how many hours per day was that?

IWER: IF HELPER PROVIDES LESS THAN AN HOUR PER DAY CODE 1

1...24

-98. DK

-99. RF

(HRS)

BL: IF HELPER IS A SPOUSE GO TO FL045 THEN GO TO LOOP FL042 (NEXT HELPER)

XT_FL023_i: HELPER NAME RECEIVED ALLOWANCE

Did HELPER's NAME receive the State Carer's Allowance or Carer's Benefit?

1. Yes

5. No

98. DK

99. RF

XT_FL024_i: HELPER NAME RECEIVED PAYMENT FROM DECEASED

Did HELPER's NAME receive regular payment from [{name of deceased}] or from you, your family or from an agency or organisation to help care for you?

- 1. Yes **GO TO XT_FL046**
- 5. No **GO TO XT_FL042 (next helper)**
- 98. DK
- 99. RF

XT_FL025_i: HELPER NAME ORIGIN

Is this person [helper's name]:

- 1. From a private agency
- 2. From a non-profit organization (such as the Irish Wheelchair Association, the Alzheimer's Society of Ireland, etc)
- 3. From the HSE (local health board)
- 4. Family or Friend who is paid to help
- 5. Other
- 98. DK
- 99. RF
- (SHARE)

XT_FL026_i: PERCENTAGE COST PAID BY HSE/HEALTHBOARD

Thinking now about the cost of this paid help, about what percentage of this cost did the HSE/health board cover per month?

- 0...100
- 98. DK
- 99. RF

XT_FL027_i: AMOUNT PAID TO HELPER BY DECEASED

Not counting costs paid by the HSE/health board, about how much did [{name of deceased}] (and you/their Husband/wife/partner) end up paying HELPER's NAME per month?

€0.00 ... €99,999.99

- 98. DK
- 99. RF
- (TILDA)

XT_FL028_i: DID OTHER PAY FOR HELP COST

Did any other person help [{name of deceased}] (and you/their [Husband/wife/partner]) pay for this cost?

- 1. Yes
- 5. No **GO TO FL042**
- 98. DK
- 99. RF
- (TILDA)

XT_FL029_i: DID CHILD HELP #

Is that a (child or other) relative of [{name of deceased}] (and you/their [Husband/ wife/ partner]), or is that someone else?

1. Child/child in-law/grandchild

GO TO XT_FL051

2. Other relative

LOOP XT_FL042

3. Someone else

LOOP XT_FL042

98. DK

99. RF

(TILDA)

XT_FL030_i: WHICH CHILD HELPED? (CHILD ROSTER)

Which child is that?

IF Grandchild

Which of [his/her] children is the parent of that grandchild?

Child name(s) [displayed by CAPI from previous responses]

3. Through 52. Child (& spouse/partner) name(s)

[Rows provided by CAPI as necessary]

92. Deceased child

98. DK

99. RF

IWER: ENTER NAME OF CHILD

Text: up to 60 characters

(HRS)

XT_FL031_i: OTHER CHILD HELPED_#

Any other child?

1. Yes

5. No GO TO THE NEXT HELPER

IF XT_FL031_i = Yes Ask XT_FL032_i

XT_FL032_i: WHICH CHILD HELPED? (CHILD ROSTER)

What is her/his name?

Child name(s) [displayed by CAPI from previous responses]

3. Through 52. Child (& spouse/partner) name(s)

[Rows provided by CAPI as necessary]

92. Deceased child

98. DK

99. RF

BL: END OF LOOP QUESTION

IF (XT_FL001 = None of these, DK or RF) AND (XT_FL010 = None of these, DK or RF) then skip over XT_FL033 (and XT_FL034) and go to XT_PH001

XT_FL033: HOW MANY DIFFERENT PAID HELPERS

How many different paid helpers – in total - were involved in taking care of [{Name of Deceased}] in the last two years? (If all helpers are unpaid relatives or friends code 0)

0... 10

-98. DK

-99. RF

XT_FL034: HOW MANY IRISH PAID HELPERS

How many of the paid helpers were Irish?

0... 10

-98. DK

-99. RF

(TILDA)

PHYSICAL HEALTH

XT_PH001: DESCRIPTION OF PHYSICAL HEALTH

IWER: SHOW CARD PH1

We'd like to ask you about [{Name of Deceased}]'s physical health and activity. During [his/her] last year, which of these descriptions fits [his/her] experience best?

- 1 [he/she] was active and disability free, and died suddenly
- 2 [he/she] was mostly active and disability free, but declined during the last few months before [he/she] died
- 3 [he/she] had times of being seriously disabled, mixed with times of being active
- 4 [he/she] gradually become more and more disabled, without times of being active
- 96 None of these
- 98 Don't know
- 99 RF
- (ELSA)

Our records (from [his/her] interview in R's LAST IW MONTH, YEAR) show that R's FIRST NAME hadxxxxxxx (Name cardiovascular conditions) xxxx

XT_PH002: HEART CONDITIONS

IWER: SHOW CARD PH2

Since we last talked to [him/her] did a doctor ever tell [him/her] that [he/she] had any [other_] of the conditions on this card? PROBE : What others? CODE ALL THAT APPLY. [Add1]

- | | |
|--|---------------|
| 1. High blood pressure or hypertension | [XT_PH002_01] |
| 2. Angina | [XT_PH002_02] |
| 3. A heart attack (including myocardial infarction or coronary thrombosis) | [XT_PH002_03] |
| 4. Congestive heart failure | [XT_PH002_04] |
| 5. A heart murmur | [XT_PH002_05] |
| 6. An abnormal heart rhythm | [XT_PH002_06] |
| 7. Diabetes or high blood sugar | [XT_PH002_07] |
| 8. A stroke (cerebral vascular disease) | [XT_PH002_08] |
| 95 Any other heart trouble (SPECIFY) | [XT_PH002_95] |
| 96 None of these | [XT_PH002_96] |
| 98 DK | [XT_PH002_98] |
| 99 RF | [XT_PH002_99] |
| (ELSA) | |

IF XT_PH002_01/02/03/04/05/06/08/95= 1, ASK XT_PH003 to XT_PH005, ELSE GO TO XT_PH006

XT_PH002oth

Please specify.

XT_PH003: MEDICATION FOR HEART

Was [he/she] taking medication for [his/her] heart problem?
(HRS)

- 1. Yes
- 5. No
- 98. DK

99. RF

XT_PH004: HEART PROCEDURES

In the last two years before [his/her] death, did [he/she] have a special test or treatment of [his/her] heart where tubes were inserted into [his/her] veins or arteries (cardiac catheterization, coronary angiogram, angioplasty, or bypass graft notation)?

1. Yes

5. No

98. DK

99. RF

Record what procedures?

1. Cardiac catheterization

[XT_PH004_01]

2. Coronary angiogram

[XT_PH004_02]

3. Angioplasty

[XT_PH004_03]

4. Bypass graft notation

[XT_PH004_04]

95. Other (specify)

[XT_PH004_95] [XT_PH004oth]

98. DK

[XT_PH004_98]

99. RF

[XT_PH004_99]

(HRS)

XT_PH004oth

Please specify.

XT_PH005: HEART SURGERY

In the last two years before [his/her] death, did [he/she] have surgery on [his/her] heart?
(HRS)

1. Yes

5. No

98. DK

99. RF

Our records (from [his/her] interview in R's LAST IW MONTH, YEAR) show
that R's FIRST NAME had axxxxxxx (Name non-cardiovascular conditions) xxxx

XT_PH006: OTHER CONDITIONS

IWER: SHOW CARD PH3

Since we last talked to [him/her] did a doctor ever tell [him/her] that [he/she] had any [other_] of
the conditions on this card? PROBE : What others? CODE ALL THAT APPLY. [Add1]

INTERVIEWER PROBE - 'What others?'•••CODE ALL THAT APPLY. [Add1]

01 Chronic lung disease such as chronic bronchitis or emphysema

[XT_PH006_01]

02 Asthma

[XT_PH006_02]

03 Arthritis (including osteoarthritis , or rheumatism)

[XT_PH006_03]

04 Osteoporosis, sometimes called thin or brittle bones

[XT_PH006_04]

05 Cancer or a malignant tumour (excluding minor skin cancers)

[XT_PH006_05]

06 Parkinson's disease

[XT_PH006_06]

07 Any emotional, nervous or psychiatric problems

[XT_PH006_07]

08 Alzheimer's disease

[XT_PH006_08]

09 Dementia, organic brain syndrome, senility or any other serious memory impairment

[XT_PH006_09]

96 None of these	[XT_PH006_96]
98 DK	[XT_PH006_98]
99 RF	[XT_PH006_99]
(ELSA)	

IF XT_PH006_05 =1 (Cancer) GO TO XT_PH007

IF XT_PH006_07 =1 (Any emotional, nervous or psychiatric) GO TO XT_PH011

ELSE GO TO XT_PH014

XT_PH007: CANCER TREATMENTS

In the last two years before [his/her] death], had [he/she] received any treatment for cancer?

- | | |
|--------|-----------------------|
| 1. Yes | |
| 5. No | GO TO XT_PH009 |
| 98. DK | GO TO XT_PH009 |
| 99. RF | GO TO XT_PH009 |

XT_PH008: CANCER TREATMENT TYPES

IWER: SHOW CARD PH4

Please look at this card. What sort of treatments had [he/she] received for cancer?

- | | |
|--|---------------|
| 1. Chemotherapy | [XT_PH008_01] |
| 2. Medication | [XT_PH008_02] |
| 3. Surgery | [XT_PH008_03] |
| 4. Biopsy | [XT_PH008_04] |
| 5. Radiation/X-Ray | [XT_PH008_05] |
| 6. Treatment for symptoms (pain, nausea, rashes) | [XT_PH008_06] |
| 95. Other (specify) | [XT_PH008_95] |
| 98. DK | [XT_PH008_98] |
| 99. RF | [XT_PH008_99] |

XT_PH008oth

Please specify

IF XT_PH008_01/02/03/04/05/06/95 = 1, ASK XT_PH009 to XT_PH009-XT_PH010

XT_PH009: ORGAN CANCER STARTED

IWER: SHOW CARD PH5

In which organ or part of [his/her] body did [his/her] cancer(s) start?

- | | |
|--------------------|---------------|
| 1. Lung | [XT_PH009_01] |
| 2. Breast | [XT_PH009_02] |
| 3. Colon or rectum | [XT_PH009_03] |
| 4. Stomach | [XT_PH009_04] |
| 5. Oesophagus | [XT_PH009_05] |
| 6. Prostate | [XT_PH009_06] |
| 7. Bladder | [XT_PH009_07] |
| 8. Liver | [XT_PH009_08] |
| 9. Brain | [XT_PH009_09] |

10. Ovary	[XT_PH009_10]
11. Cervix	[XT_PH009_11]
12. Endometrium	[XT_PH009_12]
13. Thyroid	[XT_PH009_13]
14. Kidney	[XT_PH009_14]
15. Testicle	[XT_PH009_15]
16. Pancreas	[XT_PH009_16]
17. Malignant melanoma (skin)	[XT_PH009_17]
18. Oral cavity	[XT_PH009_18]
19. Larynx	[XT_PH009_19]
20. Other pharynx (including nasopharynx, oropharynx, laryngopharynx or hypopharynx)	[XT_PH009_20]
21. Non-Hodgkin Lymphoma	[XT_PH009_21]
22. Leukaemia	[XT_PH009_22]
95. Other organ	[XT_PH009_95]
98. DK	[XT_PH009_98]
99. RF	[XT_PH009_99]

XT_PH010: YEAR CANCER DIAGNOSED

In what year was [his/her] (most recent) cancer diagnosed?

Range 1900.....2011

IF XT_PH006_07 =1 (Any emotional, nervous or psychiatric) GO TO XT_PH011, ELSE GO TO XT_PH014

SHOW CARD EI6

XT_PH011: EMOTIONAL, NERVOUS OR PSYCHIATRIC TYPE

IWER: SHOW CARD PH6

What type of emotional, nervous or psychiatric problems did [he/she] have? PROBE:
What others? CODE ALL THAT APPLY.

1. Hallucinations	[XT_PH011_01]
2. Anxiety	[XT_PH011_02]
3. Depression	[XT_PH011_03]
4. Emotional problems	[XT_PH011_04]
5. Schizophrenia	[XT_PH011_05]
6. Psychosis	[XT_PH011_06]
7. Mood swings	[XT_PH011_07]
8. Manic depression	[XT_PH011_08]
95. Something else	[XT_PH011_95]
98. DK	[XT_PH011_98]
99. RF	[XT_PH011_99]
(ELSA)	

XT_PH012: PSYCHIATRIC TREATMENT

In the last two years before [his/her] death], had [{name of decease}] received psychiatric treatment for their problems, such as attending a psychiatrist?

1. Yes

- 5. No
- 98. DK
- 99. RF

XT_PH013: PSYCHOLOGICAL TREATMENT

In the last two years before [his/her] death, had [he/she] received psychological treatment for their problems, such as counselling?

- 1. Yes
- 5. No
- 98. DK
- 99. RF

XT_PH014: FALLS

Had [he/she] fallen down [since R's LAST IW MONTH, YEAR/in the last two years]?

- 1. Yes
- 5. No
- 98. DK
- 99. RF

IF XT_PH014 = 1 (Yes) Ask XT_PH015

ELSE GO TO XT_PH017

XT_PH015: TIMES FALLEN

How many times had [he/she] fallen [since R's LAST IW MONTH, YEAR/in the last two years]? (HRS)

-
- 98. DK
 - 99. RF

XT_PH016: INJURED FALLING

[In that fall/In any of those falls], did [he/she] injure [himself/herself] seriously enough to need medical treatment?

- 1. Yes
- 5. No
- 98. DK
- 99. RF

(HRS)

XT_PH017: FRACTURED HIP

Did [he/she] fracture [his/her] hip (since R's LAST IW MONTH, YEAR)?

- 1. Yes
- 5. No
- 98. DK
- 99. RF

(HRS)

XT_PH018: TROUBLED BY PAIN

Was [he/she] often troubled with pain?

- 1. Yes

5. No
98. DK
99. RF
(HRS)

*IF XT_PH018 = Yes Ask XT_PH019
ELSE GO TO XT_PH020*

XT_PH019: HOW BAD WAS PAIN

How bad was the pain most of the time: mild, moderate or severe?

1. MILD
2. MODERATE
3. SEVERE
98. DK
99. RF
(HRS)

XT_PH020: OTHER MAJOR ILLNESSES

Did [he/she] have any (other) major illnesses [since the time of our interview in R'S LAST IW MONTH, YEAR/in the two years preceding [his/her] death]?

1. Yes
5. No
98. DK
99. RF
(HRS)

*IF XT_PH020 = 1 (Yes)
ELSE GO TO XT_BH001*

XT_PH021: WHAT OTHER ILLNESS

What illness was that?

-
98. DK
99. RF
(HRS)

BEHAVIOURAL HEALTH

XT_BH001: SMOKE CIGARETTES

Did [he/she] ever smoke cigarettes in the last two years of [his/her] life?

- 1. Yes **GO TO XT_BH002**
- 5. No **GO TO XT_BH003**
- 98. DK **GO TO XT_BH003**
- 99. RF **GO TO XT_BH003**

(HRS)

XT_BH002: HOW MANY CIGARETTES

About how many cigarettes or packs did [he/she] usually smoke in a day?

INTERVIEWER: Code how the answer is given.

- 1. Cigarettes
- 2. Packs
- 98. DK
- 99. RF

_____ Cigarettes
_____ Packs

[XT_BH002c]

[XT_BH002p]

(HRS)

XT_BH003: DRINK ALCOHOL

In the last two years before [his/her] death, did [he/she] ever drink any alcoholic beverages such as beer, wine, or liquor?

- 1. Yes
- 5. No
- 98. DK
- 99. RF

(HRS)

XT_BH004: WHAT WEIGHT

About how much did [he/she] weigh at the time of [his/her] death?

INTERVIEWER: Code how the answer is given.

- 1. Kilograms
- 2. Stones and pounds
- 98. DK
- 99. RF

_____ Kilograms
_____ Stones
_____ Pounds

[XT_BH004k]

[XT_BH004s]

[XT_BH004p]

(HRS)

XT_BH005: LOSE OR GAIN 10 POUNDS

Did R's FIRST NAME gain or lose ten or more pounds in the last 2 years of [his/her] life?

1. Yes

5. No

98. DK

99. RF

(HRS)

COGNITIVE FUNCTION

Now I would like to ask you some questions about [{Name of Deceased}]'s memory and concentration during [his/her] last year of life.

1 Continue

XT_PH100: HAVE MEMORY PROBLEMS

Did R's FIRST NAME have memory problems as of three months before [he/she] died?

- 1. Yes **GO TO XT_PH101**
- 5. No **GO TO XT_MH001**
- 98. DK **GO TO XT_MH001**
- 99. RF **GO TO XT_MH001**

XT_PH101: REMEMBERING THINGS ABOUT FRIENDS AND FAMILY

Did [{Name of Deceased}] have difficulty remembering things about [his/her] family and friends, like occupations, birthdays or addresses? Did he have ... READ OUT...

- 1 ...no difficulty,
- 2 slight difficulty,
- 3 or, great difficulty?
- 4 SPONTANEOUS: Don't know
(ELSA)

XT_PH102: REMEMBERING THINGS THAT HAPPENED RECENTLY

Did [he/she] have difficulty remembering things that had happened recently? Did he have ... READ OUT ...

- 1 ...no difficulty,
- 2 slight difficulty,
- 3 or, great difficulty?
- 4 SPONTANEOUS: Don't know
(ELSA)

XT_PH103: RECALLING CONVERSATIONS

Did [he/she] have difficulty recalling conversations a few days after they had taken place? Did he have ... READ OUT ...

- 1 ...no difficulty,
- 2 slight difficulty,
- 3 or, great difficulty?
- 4 SPONTANEOUS: Don't know
(ELSA)

XT_PH104: RECALLING ADDRESSES AND TELEPHONE

Did [he/she] have difficulty remembering [his/her] address and telephone number? Did he have ... READ OUT ...

- 1 ...no difficulty,
- 2 slight difficulty,
- 3 or, great difficulty?
- 4 SPONTANEOUS: Don't know
(ELSA)

XT_PH105: RECALLING DATE

Did [he/she] have difficulty remembering what day and month it was? Did he have ...

READ OUT ...

1 ...no difficulty,

2 slight difficulty,

3 or, great difficulty?

4 SPONTANEOUS: Don't know
(ELSA)

XT_PH106: REMEMBERING WHERE THINGS KEPT

Did [{Name of Deceased}] have difficulty remembering where things were usually kept? Did he have ... READ OUT ...

1 ...no difficulty,

2 slight difficulty,

3 or, great difficulty?

4 SPONTANEOUS: Don't know
(ELSA)

XT_PH107: DIFFICULTY FOLLOWING A STORY

Did [he/she] have difficulty following a story in a book, on the radio or on the TV? Did he have ... READ OUT ...

1 ...no difficulty,

2 slight difficulty,

3 or, great difficulty?

4 SPONTANEOUS: Don't know
(ELSA)

XT_PH108: DIFFICULTY MAKING DECISIONS

Did [he/she] have difficulty making decisions on everyday matters? Did he have ...

READ OUT ...

1 ...no difficulty,

2 slight difficulty,

3 or, great difficulty?

4 SPONTANEOUS: Don't know
(ELSA)

XT_PH109: DIFFICULTY HANDLING FINANCIAL MATTERS

Did [he/she] have difficulty handling financial matters, like [his/her] pension or dealing with the bank? Did he have ... READ OUT ...

1 ...no difficulty,

2 slight difficulty,

3 or, great difficulty?

4 SPONTANEOUS: Don't know
(ELSA)

XT_PH110: REPEAT THE SAME QUESTION

Did [he/she] ever forget what had been said and repeat the same question again and again? IF YES, PROBE: Did [he/she] do this occasionally or frequently?

1 No

2 Occasionally

3 Frequently

98 Don't know
(ELSA)

XT_PH111: DIFFICULTY INTERPRETING SURROUNDINGS

Did [{Name of Deceased}] have difficulty in interpreting surroundings, such as knowing where [he/she] was, or distinguishing between different types of people, such as doctors, visitors and relatives? Did he have ... READ OUT ...

- 1 ...no difficulty,
- 2 slight difficulty,
- 3 or, great difficulty?
- 4 SPONTANEOUS: Don't know
(ELSA)

XT_PH112: DIFFICULTY FINDING THE WAY

Did [he/she] have difficulty finding the way about [the_home] or finding the toilet? Did he have ... READ OUT ...

- 1 ...no difficulty,
- 2 slight difficulty,
- 3 great difficulty,
- 4 Not applicable
- 98 Don't know
(ELSA)

XT_PH113: DIFFICULTY FINDING THE RIGHT WORD

When speaking, did [he/she] sometimes have difficulty finding the right word, or sometimes use the wrong words? IF YES, PROBE: Did [he/she] do this occasionally or frequently?

- 1 No
- 2 Yes, occasionally
- 3 Yes, frequently
- 98 Don't know
(ELSA)

XT_PH114: REPEAT THE SAME WORD

Did [{Name of Deceased}] sometimes repeat the same word or phrase over and over again?

- 1. Yes
- 5. No
- 98 Don't know
(ELSA)

XT_PH115: THINKING SEEM MUDDLED

Did [his/her] thinking seem muddled at times?

- 1. Yes
- 5. No
- 98 Don't know

*IF XT_PH101-115 EQUAL YES GO TO XT_PH116
ELSE GO TO XT_MH001*

XT_PH116: HOW LONG WERE COGNITIVE DIFFICULTIES PRESENT

How long were these changes or difficulties with memory and concentration present?

PROBE: From about how long before [he/she] died?

INTERVIEWER: Code how the answer is given.

1. In months and years
2. Since a specified age
98. Don't know
(ELSA)

PHYSICAL HEALTH FEEDFORWARD

There are a number of variables in the End of Life Wave 2 dataset which are taken from the Wave 1 Questionnaire. Below are a list of those within the Physical Health section of the dataset along with an explanation of how they were asked in the Wave 1 Questionnaire.

XT PH105ff 01 – XT PH105ff 04

PH105:

Has a doctor ever told you that you have any of the following eye diseases?

IWER: CODE ALL THAT APPLY

- | | |
|-------------------------------------|-----------------|
| 1. Cataracts | [XT_PH105ff_01] |
| 2. Glaucoma | [XT_PH105ff_02] |
| 3. Age related macular degeneration | [XT_PH105ff_03] |
| 4. Other
(ELSA) | [XT_PH105ff_04] |

XT PH201ff 01-XT PH201ff 10

PH201:

Please look at card PH1. Has a doctor ever told you that you have any of the conditions on this card?

IWER: SHOW CARD PH1

INTERVIEWER: PROBE - 'WHAT OTHERS?' CODE ALL THAT APPLY.

- | | |
|--|-----------------|
| 1. High blood pressure or hypertension | [XT_PH201ff_01] |
| 2. Angina | [XT_PH201ff_02] |
| 3. A heart attack (including myocardial infarction or coronary thrombosis) | [XT_PH201ff_03] |
| 4. Congestive heart failure | [XT_PH201ff_04] |
| 5. Diabetes or high blood sugar | [XT_PH201ff_05] |
| 6. A stroke (cerebral vascular disease) | [XT_PH201ff_06] |
| 7. Ministroke or TIA | [XT_PH201ff_07] |
| 8. High cholesterol | [XT_PH201ff_08] |
| 9. A heart murmur | [XT_PH201ff_09] |
| 10. An abnormal heart rhythm | [XT_PH201ff_10] |

XT PH301ff 01 – XT PH301ff 14

PH301:

Please look at card PH2. Has a doctor ever told you that you have any of the following conditions?

IWER: SHOW CARD PH2

IWER: PROBE - 'WHAT OTHERS?' CODE ALL THAT APPLY.

- | | |
|---|-----------------|
| 1. Chronic lung disease such as chronic bronchitis or emphysema | [XT_PH301ff_01] |
| 2. Asthma | [XT_PH301ff_02] |
| 3. Arthritis (including osteoarthritis, or rheumatism) | [XT_PH301ff_03] |
| 4. Osteoporosis, sometimes called thin or brittle bones | [XT_PH301ff_04] |

5. Cancer or a malignant tumour (including leukaemia or lymphoma but excluding minor skin cancers)	[XT_PH301ff_05]
6. Parkinson's disease	[XT_PH301ff_06]
7. Any emotional, nervous or psychiatric problems, such as depression or anxiety	[XT_PH301ff_07]
8. Alcohol or substance abuse	[XT_PH301ff_08]
9. Alzheimer's disease	[XT_PH301ff_09]
10. Dementia, organic brain syndrome, senility	[XT_PH301ff_10]
11. Serious memory impairment	[XT_PH301ff_11]
12. Stomach ulcers	[XT_PH301ff_12]
13. Varicose Ulcers (an ulcer due to varicose veins)	[XT_PH301ff_13]
14. Cirrhosis, or serious liver damage (ELSA/similar question HRS/NSHAP)	[XT_PH301ff_14]

MOOD

I would now like to ask you a few questions about [{Name of Deceased}]'s mood during the last year of [his/her] life.

(ELSA)

XT_MH001: DEPRESSED IN LAST YEAR

Do you think [he/she] was depressed during [his/her] last year of life? IF YES, PROBE:

Was [he/she] depressed sometimes or frequently?

1 No **GO TO XT_MH003**

2 Yes, sometimes **GO TO XT_MH002**

3 Yes, frequently **GO TO XT_MH002**

98 Don't know **GO TO XT_MH003**

(ELSA)

IF XT_MH001 NOT EQUAL 2, 3 (Depressed) Ask XT_MH002

XT_MH002: HOW LONG DEPRESSED

How long had [he/she] felt like this, when [he/she] died?

INTERVIEWER: Code how the answer is given.

1. In months and years

2. Since a specified age

98. Don't know

99. Refused

____ MONTHS / ____ YEARS

[XT_MH002m] [XT_MH002y]

____ AGE ____

[XT_MH002age]

(ELSA)

XT_MH003: HOW OFTEN HAPPY

SHOW CARD MH1

How often do you think [{Name of Deceased}] felt happy during [his/her] last year of life?

1 Often

2 Sometimes

3 Rarely

4 Never

98 Don't know

(ELSA)

XT_MH004: HOW OFTEN FELT CONTENTED

SHOW CARD EI3

And how about the last three months of [his/her] life, how often do you think [{Name of Deceased}] felt contented or at peace during this time?

1 Often

2 Sometimes

3 Rarely

4 Never

98 Don't know

(ELSA)

HEALTHCARE UTILISATION

INTRO: I'd now like to ask you some questions about any expenses which [{Name of Deceased}] incurred as a result of the medical care [he/she] received in the year before [he/she] died. Before I do that, though, I'd like to assure you again that everything you have already told me and anything else you tell me will be kept completely confidential.

XT_HU001: MEDICAL CARD

Was [{Name of deceased}] covered by...

IWER: CODE THE ONE THAT APPLIES

- | | |
|-------------------------------------|---------------|
| 1. Full Medical Card or equivalent? | [XT_HU001_01] |
| 2. GP Visit Card? | [XT_HU001_02] |
| 96. Neither of these | [XT_HU001_96] |
| 98. DK | [XT_HU001_98] |
| 99. RF | [XT_HU001_99] |

Note: This question is asked even of those covered by private medical insurance. Most over 70s are entitled to medical cards.

(EU-SILC)

XT_HU002: PRIVATE MEDICAL INSURANCE

Did [{Name of the deceased}] have private medical insurance cover (VHI etc.) in their own name or through another family member?

- | | |
|---|----------------|
| 1. Yes, in their own name | GO TO XT_HU003 |
| 2. Yes, as the spouse of a subscriber | GO TO XT_HU003 |
| 3. Yes, as the relative of a subscriber | GO TO XT_HU003 |
| 5. No | GO TO XT_HU005 |
| 98. DK | GO TO XT_HU005 |
| 99. RF | GO TO XT_HU005 |

(HEALTH INSURANCE AUTHORITY 2005 SURVEY)

XT_HU003: WHICH PRIVATE INSURANCE

Which company was [{Name of the deceased}] insured with?

IWER: CODE THE ONE THAT APPLIES

- | | |
|------------------------------------|----------------|
| 1. QUINN Healthcare (BUPA Ireland) | GO TO XT_HU005 |
| 2. VHI Healthcare | GO TO XT_HU005 |
| 3. AVIVA / Hibernian Healthcare | GO TO XT_HU005 |
| 95. Other | GO TO XT_HU004 |
| 98. DK | GO TO XT_HU005 |
| 99. RF | GO TO XT_HU005 |

(HEALTH INSURANCE AUTHORITY 2005 SURVEY)

XT_HU004: WHAT MEDICAL INSURANCE SCHEME

Which medical insurance scheme/plan was [{Name of the deceased}] covered by?

Text: Up to 60 Characters

98. DK

99. RF

(HEALTH INSURANCE AUTHORITY 2005 SURVEY)

XT_HU005: NUMBER OF GP VISITS

In the last 12 months, about how often did [{Name of the deceased}] visit [his/her] GP?

IWER: IF RESPONDENT HAD NOT VISITED GP IN THE LAST 12 MONTHS CODE 0

0...200

-98. DK

GO TO XT_HU010

-99. RF

GO TO XT_HU010

BL:

IF XT_HU005=0 GO TO XT_HU007

IF XT_HU005>0 AND XT_HU001=1, 2 GO TO XT_HU010

IF XT_HU005>0 AND XT_HU001~=1, 2 GO TO XT_HU006

(SHARE)

XT_HU006: GP OUT-OF-POCKET PAYMENT

About how much did [he/she] pay for each visit to the GP out-of-pocket, after any health insurance reimbursement?'

IWER: IF R CANNOT GIVE EXACT VALUE, ACCEPT APPROXIMATE VALUE

€0.00 ... €9,999.99

-98. DK

-99. RF

XT_HU007: SPECIAL HEALTH SERVICES

In the last 12 months did [he/she] use any special facility or service which we haven't talked about, such as: an adult care center, a social worker, an outpatient rehabilitation program, physical therapy, or transportation for the elderly or disabled?

1. Yes

5. No

98. DK

99. RF

IF XT_HU007 = 1 & IF XT_HU002 = 1, 2 or 3 GO TO XT_HU008

IF XT_HU007 = 1 & IF XT_HU002 ~= 1, 2 or 3 GO TO XT_HU009

IF XT_HU007= 1 & IF XT_CS016_03 = 1 GO TO XT_HU010

IF XT_HU007= 1 & IF XT_CS016_03 ~= 1 GO TO XT_HU029

XT_HU008: SPECIAL HEALTH SERVICES COSTS COVERED BY HI

Were any of these costs covered by [VHI/Quinn-Bupa/AVIVA-Hibernian]?

1. Yes, all of the costs

2. Yes, some of the costs

3. No, none of the costs

4. No costs

XT_HU009: SPECIAL HEALTH SERVICES OUT-OF-POCKET

How much did [{Name of the deceased}] and you pay out-of-pocket [yourselves] for use of special facilities or services?

INTERVIEWER: Enter amount to the nearest €.

Range: 0..9999997

If XT_HU009 = Don't Know, ask XT_HU009a

XT_HU009a: Was it..... (Unfolding brackets)
BRACKETS (250, 1000, 5000, 10000)

1. Less than €250
 2. More than €2500 but less than €1,000
 3. More than €1,000 but less than €5,000
 4. More than €5,000 but less than €10,000
 5. More than €10,000
98. Don't know
99. Refused

IF XT_CS016_03 = 1 (Hospital) Ask XT_HU010 to XT_HU019

You told me earlier that [{Name of Deceased}] had stayed in a hospital in the 12 months before [his/her] death...

XT_HU010: TIMES VISIT A&E

Can you tell me how many times did [{Name of the deceased}] visit a hospital Emergency Department (sometimes called A&E or Accident and Emergency) as a patient?
IWER: IF RESPONDENT HAD NOT VISITED AN A&E DEPARTMENT IN THE LAST 12 MONTHS CODE 0
0... 50
-98. DK
-99. RF
(HARP)

XT_HU011: TIMES VISIT AS OUTPATIENT

In the last 12 months, about how many visits did [{Name of the deceased}] make to a hospital as an out-patient? (Include all types of consultations, tests, operations, procedures or treatments)
IWER: IF RESPONDENT HAS NOT MADE ANY OUT-PATIENT VISITS, CODE 0
0...50
-98. DK **GO TO XT_HU013**
-99. RF **GO TO XT_HU013**
BL:
IF XT_HU011=0 - GO TO XT_HU013
IF XT_HU011>0 - GO TO XT_HU012

XT_HU012: NUMBER OF SUBSTANTIAL PROCEDURES

On how many of these visits did [{Name of the deceased}] have a substantial procedure, operation or test i.e. one which took a considerable amount of time to perform?

Note: These are sometimes called day-case procedures.

IWER: IF RESPONDENT HAS NOT UNDERGONE ANY DAY-CASE PROCEDURES CODE 0

- 0... 50
-98. DK
-99. RF

XT_HU013: ADMITTED TO HOSPITAL OVERNIGHT

In the 12 months before [he/she] died, on how many occasions was [{Name of the deceased}] admitted to hospital overnight?

IWER: IF RESPONDENT WAS NOT ADMITTED TO HOSPITAL OVERNIGHT IN THE LAST 12 MONTHS
CODE 0

0...50

-98. DK **GO TO XT_HU029**

-99. RF **GO TO XT_HU029**

Note: These are sometimes called in-patient admissions.

BL:

IF XT_HU013=0 - GO TO XT_HU029

IF XT_HU013>0 - GO TO XT_HU011

XT_HU014: NUMBER OF FULL ANAESTHETIC OPERATIONS

During these hospital stays in the last 12 months of [{Name of the deceased}]’s life, about how many operations (procedures) involving a full anaesthetic did [he/she] have?

IWER: IF RESPONDENT DID NOT HAVE ANY OPERATIONS (PROCEDURES) INVOLVING A FULL ANAESTHETIC IN THE LAST 12 MONTHS OF LIFE CODE 0

0...50

-98. DK

-99. RF

XT_HU015: OVERNIGHT PRIVATE OR PUBLIC PATIENT

When [{Name of the deceased}] stayed overnight in hospital, was this

IWER: IF THE RESPONDENT HAS HAD INPATIENT ADMISSIONS AS BOTH A PUBLIC AND A PRIVATE PATIENT PLEASE CODE THE MOST USUAL

1. As a public patient

2. As a private patient

98. DK

99. RF

XT_HU016: OVERNIGHT PRIVATE OR PUBLIC HOSPITAL

When [{Name of the deceased}] stayed overnight in hospital, was this in a

IWER: IF THE RESPONDENT HAS HAD INPATIENT ADMISSIONS AS BOTH A PUBLIC AND A PRIVATE HOSPITAL PLEASE CODE THE MOST USUAL

1. Public Hospital

2. Private Hospital

98. DK

99. RF

XT_HU017: TREATMENTS NOT COVERED BY PUBLIC

Did [{Name of the deceased}] receive any treatments that were not covered by the public health care system (HSE)

1. Yes

5. No

-98. DK

-99. RF

[ELSA]

IF XT_HU017 = 1 & IF XT_HU002 = 1, 2 or 3 GO TO XT_HU018

IF XT_HU017 = 1 & IF XT_HU002 ~= 1, 2 or 3 GO TO XT_HU019
IF XT_HU017= 1 GO TO XT_HU_new015

XT_HU018: HOSPITAL TREATMENT COSTS COVERED BY HI

Were any of these costs covered by [VHI/Quinn-Bupa/AVIVA-Hibernian]?

1. Yes, all of the costs
2. Yes, some of the costs
3. No, none of the costs
4. No costs

-98. DK

-99. RF

[ELSA]

XT_HU019: HOSPITAL TREATMENTS OUT-OF-POCKET

How much did [{Name of the deceased}] [and you] pay out-of-pocket for the treatment [yourselves]?

INTERVIEWER: Enter amount to the nearest €.

Range: 0..9999997

If XT_HU019 = Don't Know, ask XT_HU019a

XT_HU019a: Was it..... (Unfolding brackets)

BRACKETS (250, 1000, 5000, 10000)

1. Less than €250
 2. More than €2500 but less than €1,000
 3. More than €1,000 but less than €5,000
 4. More than €5,000 but less than €10,000
 5. More than €10,000
98. Don't know
99. Refused

XT_HU020: STATE SERVICES

In the last 12 months of [his/her] life, did [{Name of the deceased}] receive any of the following State services?

CODE ALL THAT APPLY

1. Home help (a person employed by State to help [him/her] with household chores such as cleaning and cooking) **XT_HU021 through XT_HU023**
 2. Personal care attendant (a person employed by the State to assist [him/her] with bathing, showering, bodily care etc.) **XT_HU024 through XT_HU026**
 3. Meals-on-Wheels **XT_HU027 through XT_HU028**
96. None of these **GO TO XT_HU029**
98. DK **GO TO XT_HU029**
99. RF **GO TO XT_HU029**

XT_HU021: HOME HELP DAYS

Lets think for a moment about the home help [Name of deceased] received. On average per month, on about how many days did [he/she] receive home help?

0... 31

-98. RF

-99. DK

XT_HU022: HOME HELP HOURS

On the days when [Name of deceased] received home help, for about how many hours per day did [he/she] receive help?

1...24

-98. DK

--99. RF

XT_HU023: HOME HELP OUT OF POCKET PAYMENTS

Not counting costs paid by the HSE/health board, about how much did [Name of deceased] [and [you/his/her] [husband/wife/partner]] pay for this home help in the last month? (May be zero)

€0 ... €10,000

-98. DK

-99. RF

GO TO XT_HU029**XT_HU024: PERSONAL CARE DAYS**

Let's think for a moment about the help [Name of deceased] received from a personal care attendant. On average per month, on about how many days did [he/she] receive this service?

0... 31

-98. RF

-99. DK

XT_HU025: PERSONAL CARE HOURS

On the days when [he/she] received help from a personal care attendant, for about how many hours per day did [he/she] receive help?

1...24

- 98. DK

- 99. RF

XT_HU026: PERSONAL CARE OUT OF POCKET PAYMENTS

Not counting costs paid by the HSE/health board, about how much did [Name of deceased] (and [you/his/her] [husband/wife/partner]] pay this personal care attendant per month? (May be zero)

€0 ... €10,000

-98. DK

-99. RF

GO TO XT_HU029**XT_HU027: MEALS SERVICE DAYS**

Let's think for a moment about Meals-on-Wheels [Name of deceased] received. On average per month, on about how many days did [he/she] receive Meals-on-Wheels?

0... 31

-98. RF

-99. DK

XT_HU028: MEALS SERVICES OUT OF POCKET PAYMENTS

Not counting costs paid by the HSE/health board, about how much did [Name of deceased] (and [you/his/her] [husband/wife/partner]] pay for Meals-on-Wheels per month?

€0 ... €10,000

- 98. DK
- 99. RF

XT_HU029: USE OF STATE SERVICES

IWER: SHOW CARD HU1

Please look at card HU1

In the last 12 months of [his/her] life, did [{Name of the deceased}] receive any of the following State services?

Exclude any services that [{Name of the deceased}] paid for.

IWER: READ OUT AND CODE ALL THAT APPLY

- | | |
|--|-----------------------|
| 01. Public Health or Community Nurse | GO TO XT_HU030 |
| 02. Occupational therapy | GO TO XT_HU032 |
| 03. Chiropody services | GO TO XT_HU034 |
| 04. Physiotherapy services | GO TO XT_HU036 |
| 05. Speech & Language Therapist | GO TO XT_HU054 |
| 06. Social work services | GO TO XT_HU038 |
| 07. Psychological/counselling services | GO TO XT_HU040 |
| 08. Day centre services | GO TO XT_HU042 |
| 09. Optician service | GO TO XT_HU044 |
| 10. Dental services | GO TO XT_HU046 |
| 11. Hearing services | GO TO XT_HU048 |
| 12. Dietician services | GO TO XT_HU050 |
| 13. Respite services | GO TO XT_HU052 |
| 96. None of these | GO TO XT_HU056 |
| 98. DK | GO TO XT_HU056 |
| 99. REF | GO TO XT_HU056 |

IWER: Category 1 includes Public Health Nurses, Community RGNs, Community Mental Health Nurses, Clinical Nurse Specialists and Advanced Nurse Practitioners

XT_HU030: NUMBER OF TIMES WITH PUBLIC HEALTH OR COMMUNITY NURSE

In the last 12 months of [his/her] life how many times did [he/she] use this service

Please write number

XT_HU031: SATISFACTION WITH PUBLIC HEALTH OR COMMUNITY NURSE

IWER: SHOW CARD HU2

Do you feel that [{Name of the deceased}] and [his/her] family were satisfied with this service?

IWER: CODE THE ONE THAT APPLIES

- 1. Yes- satisfied
- 2. No – dissatisfied because service was not supplied frequently enough
- 3. No – dissatisfied because service was hard to access
- 4 No – dissatisfied for other reason
- 98. DK
- 99. RF

XT_HU032: NUMBER OF TIMES WITH OCCUPATIONAL THERAPY

In the last 12 months of [his/her] life how many times did [he/she] use this service

Please write number

XT_HU033: SATISFACTION WITH OCCUPATIONAL THERAPY

IWER: SHOW CARD HU2

Do you feel that [{Name of the deceased}] and [his/her] family were satisfied with this service?

IWER: CODE THE ONE THAT APPLIES

- 1. Yes- satisfied
- 2. No – dissatisfied because service was not supplied frequently enough
- 3. No – dissatisfied because service was hard to access
- 4 No – dissatisfied for other reason
- 98. DK
- 99. RF

XT_HU034 NUMBER OF TIMES WITH CHIROPODY SERVICES

In the last 12 months of [his/her] life how many times did [he/she] use this service

Please write number

XT_HU035: SATISFACTION WITH CHIROPODY SERVICES

IWER: SHOW CARD HU2

Do you feel that [{Name of the deceased}] and [his/her] family were satisfied with this service?

IWER: CODE THE ONE THAT APPLIES

- 1. Yes- satisfied
- 2. No – dissatisfied because service was not supplied frequently enough
- 3. No – dissatisfied because service was hard to access
- 4 No – dissatisfied for other reason
- 98. DK
- 99. RF

XT_HU036: NUMBER OF TIMES WITH PHYSIOTHERAPY SERVICES

In the last 12 months of [his/her] life how many times did [he/she] use this service

Please write number

XT_HU037: SATISFACTION WITH PHYSIOTHERAPY SERVICES

IWER: SHOW CARD HU2

Do you feel that [{Name of the deceased}] and [his/her] family were satisfied with this service?

IWER: CODE THE ONE THAT APPLIES

- 1. Yes- satisfied
- 2. No – dissatisfied because service was not supplied frequently enough
- 3. No – dissatisfied because service was hard to access
- 4 No – dissatisfied for other reason
- 98. DK
- 99. RF

XT_HU038: NUMBER OF TIMES WITH SOCIAL WORK SERVICES

In the last 12 months of [his/her] life how many times did [he/she] use this service

Please write number

XT_HU039: SATISFACTION WITH SOCIAL WORK SERVICES

IWER: SHOW CARD HU2

Do you feel that [{Name of the deceased}] and [his/her] family were satisfied with this service?

IWER: CODE THE ONE THAT APPLIES

- 1. Yes- satisfied
- 2. No – dissatisfied because service was not supplied frequently enough
- 3. No – dissatisfied because service was hard to access
- 4 No – dissatisfied for other reason
- 98. DK
- 99. RF

XT_HU040: NUMBER OF TIMES WITH PSYCHOLOGICAL/COUNSELLING SERVICES

In the last 12 months of [his/her] life how many times did [he/she] use this service

Please write number

XT_HU041: SATISFACTION WITH PSYCHOLOGICAL/COUNSELLING SERVICES

IWER: SHOW CARD HU2

Do you feel that [{Name of the deceased}] and [his/her] family were satisfied with this service?

IWER: CODE THE ONE THAT APPLIES

- 1. Yes- satisfied
- 2. No – dissatisfied because service was not supplied frequently enough
- 3. No – dissatisfied because service was hard to access
- 4 No – dissatisfied for other reason
- 98. DK
- 99. RF

XT_HU042: NUMBER OF TIMES WITH DAY CENTRE SERVICES

In the last 12 months of [his/her] life how many times did [he/she] use this service

Please write number

XT_HU043: SATISFACTION WITH DAY CENTRE SERVICES

IWER: SHOW CARD HU2

Do you feel that [{Name of the deceased}] and [his/her] family were satisfied with this service?

IWER: CODE THE ONE THAT APPLIES

- 1. Yes- satisfied
- 2. No – dissatisfied because service was not supplied frequently enough

- 3. No – dissatisfied because service was hard to access
- 4 No – dissatisfied for other reason
- 98. DK
- 99. RF

XT_HU044: NUMBER OF TIMES WITH OPTICIAN SERVICE

In the last 12 months of [his/her] life how many times did [he/she] use this service

Please write number

XT_HU045: SATISFACTION WITH OPTICIAN SERVICE

IWER: SHOW CARD HU2

Do you feel that [{Name of the deceased}] and [his/her] family were satisfied with this service?

IWER: CODE THE ONE THAT APPLIES

- 1. Yes- satisfied
- 2. No – dissatisfied because service was not supplied frequently enough
- 3. No – dissatisfied because service was hard to access
- 4 No – dissatisfied for other reason
- 98. DK
- 99. RF

XT_HU046: NUMBER OF TIMES WITH DENTAL SERVICES

In the last 12 months of [his/her] life how many times did [he/she] use this service

Please write number

XT_HU047: SATISFACTION WITH DENTAL SERVICES

IWER: SHOW CARD HU2

Do you feel that [{Name of the deceased}] and [his/her] family were satisfied with this service?

IWER: CODE THE ONE THAT APPLIES

- 1. Yes- satisfied
- 2. No – dissatisfied because service was not supplied frequently enough
- 3. No – dissatisfied because service was hard to access
- 4 No – dissatisfied for other reason
- 98. DK
- 99. RF

XT_HU048: NUMBER OF TIMES WITH HEARING SERVICES

In the last 12 months of [his/her] life how many times did [he/she] use this service

Please write number

XT_HU049: SATISFACTION WITH HEARING SERVICES

IWER: SHOW CARD HU2

Do you feel that [{Name of the deceased}] and [his/her] family were satisfied with this service?

IWER: CODE THE ONE THAT APPLIES

1. Yes- satisfied
2. No – dissatisfied because service was not supplied frequently enough
3. No – dissatisfied because service was hard to access
- 4 No – dissatisfied for other reason
98. DK
99. RF

XT_HU050: NUMBER OF TIMES WITH DIETICIAN SERVICES

In the last 12 months of [his/her] life how many times did [he/she] use this service

Please write number

XT_HU051: SATISFACTION WITH DIETICIAN SERVICES

IWER: SHOW CARD HU2

Do you feel that [{Name of the deceased}] and [his/her] family were satisfied with this service?

IWER: CODE THE ONE THAT APPLIES

1. Yes- satisfied
2. No – dissatisfied because service was not supplied frequently enough
3. No – dissatisfied because service was hard to access
- 4 No – dissatisfied for other reason
98. DK
99. RF

XT_HU052: NUMBER OF TIMES WITH RESPITE SERVICES

In the last 12 months of [his/her] life how many times did [he/she] use this service

Please write number

XT_HU053: SATISFACTION WITH RESPITE SERVICES

IWER: SHOW CARD HU2

Do you feel that [{Name of the deceased}] and [his/her] family were satisfied with this service?

IWER: CODE THE ONE THAT APPLIES

1. Yes- satisfied
2. No – dissatisfied because service was not supplied frequently enough
3. No – dissatisfied because service was hard to access
- 4 No – dissatisfied for other reason
98. DK
99. RF

XT_HU054: NUMBER OF TIMES WITH SPEECH & LANGUAGE THERAPIST

In the last 12 months of [his/her] life how many times did [he/she] use this service

Please write number

XT_HU055: SATISFACTION WITH SPEECH & LANGUAGE THERAPIST**IWER: SHOW CARD HU2**

Do you feel that [{Name of the deceased}] and [his/her] family were satisfied with this service?

IWER: CODE THE ONE THAT APPLIES

1. Yes- satisfied
2. No – dissatisfied because service was not supplied frequently enough
3. No – dissatisfied because service was hard to access
4. No – dissatisfied for other reason
98. DK
99. RF

XT_HU056: SERVICES DECEASED NEEDED BUT NOT PROVIDED**IWER: SHOW CARD HU1A**

Thinking of all these services, are there any that [{Name of deceased}] did not receive which you feel [he/she] had a need for?

IWER: CODE ALL THAT APPLY

- | | |
|---------------------------------------|---------------|
| 1. Public health or Community Nurse | [XT_HU056_01] |
| 2. Occupational therapy | [XT_HU056_02] |
| 3. Chiropody services | [XT_HU056_03] |
| 4. Physiotherapy services | [XT_HU056_04] |
| 5. Speech and Language Therapy | [XT_HU056_05] |
| 6. Social work services | [XT_HU056_06] |
| 7. Psychological/counselling services | [XT_HU056_07] |
| 8. Home help | [XT_HU056_08] |
| 9. Personal care attendant | [XT_HU056_09] |
| 10. Meals-on-Wheels | [XT_HU056_10] |
| 11. Day centre services | [XT_HU056_11] |
| 12. Optician service | [XT_HU056_12] |
| 13. Dental services | [XT_HU056_13] |
| 14. Hearing services | [XT_HU056_14] |
| 15. Dietician services | [XT_HU056_15] |
| 16. Respite services | [XT_HU056_16] |
| 96. None of these | [XT_HU056_96] |
| 98. DK | [XT_HU056_98] |
| 99. REF | [XT_HU056_99] |

XT_HU057: BARRIERS TO COMMUNITY SERVICES ACCESS**IWER: SHOW CARD HU3**

You have said [{Name of deceased}] didn't receive but would like to. Could you say what is the main thing that prevented [him/her] from receiving it? IWER: Code main reason not receiving for each service selected in XT_HU056

1. Never heard of service
2. Did not know it was available
3. Did not have suitable transport
4. It was too costly
5. He/she was reluctant to apply/ [he/she] didn't have time to apply
6. He/she was not eligible for it
7. Other

98. DK
99. RF

***IF XT_CS016_05 = 1 (Nursing Home) GO TO XT_HU058
ELSE GO TO XT_HU060***

You told me earlier that [{Name of Deceased}] had stayed in a Nursing Home in the 12 months before [his/her] death...

XT_HU058: NURSING HOME STAY COSTS

IWER: SHOW CARD 3A

How was his/her nursing home care paid for?

(Tick all boxes that apply)

1. Out of [his/her] own resources
2. By Health Insurance
3. By the government Fair Deal type scheme (or its replacement)
4. By Children or Relatives
5. Paid for in another way

98. DK
99. REF

XT_HU059: NURSING HOME OUT-OF-POCKET COSTS

Not counting health insurance refunds, about how much did [{ Name of Deceased}] pay out-of-pocket for the time [he/she] spent in a nursing home in the last 12 months of [his/her] life?

IWER: IF RESPONDENT CANNOT GIVE EXACT VALUE, ACCEPT APPROXIMATE VALUE

€0 ... and €50,000

- 98. DK
-99. RF

XT_HU059a Did it amount to a total of less than XXXXX, more than YYYYY?

BRACKETS (250, 1000, 5000, 10000)

1. Less than €250
2. More than €2500 but less than €1,000
3. More than €1,000 but less than €5,000
4. More than €5,000 but less than €10,000
5. More than €10,000

98. Don't know
99. Refused

Unfolding Brackets

(SHARE)

XT_HU060: PRESCRIPTION COSTS

IWER: SHOW CARD HU4

Please look at card HU4. Think of [{ Name of Deceased}]'s last prescription. Was [he/she] charged for this?

IWER: CODE THE ONE THAT APPLIES

1. No. [He/She] was covered by the Long Term Illness scheme or by the High Tech Drugs Scheme

GO TO XT_HU061

2. Yes, but [he/she] had a Medical Card and paid only the 50 cent per prescribed item charge

GO TO XT_HU062

3. Yes, but [he/she] only paid part of the cost. The rest was paid through the Drug Payment Scheme.

GO TO XT_HU062

4. Yes, but [he/she] claimed back part of it from [his/her] health insurance

GO TO XT_HU061

5. Yes, and [he/she] has not claimed anything back from [his/her] health insurance

GO TO XT_HU061

6. Yes, but [he/she] paid the full payment out of pocket

GO TO XT_HU062

98. DK **GO TO XT_HU061**

99. RF **GO TO XT_HU061**

HT_HU061: PRESCRIBED DRUGS OUT-OF-POCKET

In the last 12 months of [{Name of deceased}] life, not counting health insurance refunds, on average about how much did [Name of deceased] pay out-of-pocket for his/her prescribed drugs per month on average?

IWER: IF RESPONDENT DOES NOT PURCHASE PRESCRIBED DRUGS REGULARLY, ASK FOR TOTAL SPENT IN THE LAST 12 MONTHS IN PRESCRIBED DRUGS AND DIVIDE BY 12.

IWER: IF R CANNOT GIVE EXACT VALUE, ACCEPT APPROXIMATE VALUE

€0 ... €5,000

-98. DK

-99. RF

NOTE: do not consider expenses for self-medication or drugs not prescribed

NOTE: By 'out of pocket' expenses we mean everything that is not paid by the insurance company. If you first pay but later get it refunded, this is not out of pocket expenses.

(SHARE)

XT_HU062: HOME MODIFICATIONS

Did [{Name of Deceased}] have any out-of-pocket expenses for adding features to [his/her] home to make it easier or safer for an older person to live there?

This includes changes to the home to make it easier to get around like a ramp, railings, or modifications for a wheelchair and features that make it safer such as grab bars, a shower seat, or a call device to get help when needed.

1. Yes

5. No

98. DK

88. RF

IF XT_HU062 = 1 & IF XT_HU002 = 1, 2 or 3 GO TO XT_HU063

IF XT_HU062 = 1 & IF XT_HU002 ~= 1, 2 or 3 GO TO XT_HU064

IF XT_HU062 ~= 1 GO TO XT_HU066

XT_HU063: HOME MODIFICATIONS COVERED BY HEALTH INSURANCE

Were any of the home modification costs covered by [Health insurance]??

1. Yes, all of the costs
2. Yes, some of the costs
3. No, none of the costs
4. No costs

XT_HU064: HOME MODIFICATIONS OUT-OF-POCKET

How much did [{Name of the deceased}] [and yourself] pay for the home modifications?

INTERVIEWER: Enter amount to the nearest €.

Range: 0..9999997

If XT_HU064 = Don't Know, ask XT_HU064a

XT_HU064a: Did it amount to a total of less than XXXXX, more than YYYYY?

BRACKETS (250, 1000, 5000, 10000)

1. Less than €250
2. More than €250 but less than €1,000
3. More than €1,000 but less than €5,000
4. More than €5,000 but less than €10,000
5. More than €10,000
98. Don't know
99. Refused

Unfolding Brackets

XT_HU065: IN THE LAST 12 MONTHS, DID [he/she] GET NEW...

IWER: SHOWCARD HU5

- | | |
|---|-----------------------------|
| 1. Crutches, walking stick, rollator (tray with wheels on front)? | [XT_HU065_01] |
| 2. Wheelchair | [XT_HU065_02] |
| 3. Oxygen equipment | [XT_HU065_03] |
| 4. Feeding pump (gastrostomy) | [XT_HU065_04] |
| 5. Commode | [XT_HU065_05] |
| 6. Special bed | [XT_HU065_06] |
| 7. Bathroom or toilets adapted | [XT_HU065_07] |
| 95. Other equipment (specify) | [XT_HU065_95] [XT_HU065oth] |
| 96. None | [XT_HU065_96] |
| 98. DK | [XT_HU065_98] |
| 99. REF | [XT_HU065_99] |

XT_HU065oth: Please specify

XT_HU066: ANY OTHER OUT-OF-POCKET HEALTH EXPENSES

Not counting any refunds from [{Name of deceased}]'s health insurance, about how much did he/she pay (out-of-pocket) for any other health expenses he/she had in the last 12 months?

€0 ... and €20,000

-98. DK

-99. RF

Note:

By other health expenses we mean non-prescription drugs, private physiotherapy, preventive rehabilitative services such as occupational therapy etc..

By 'out of pocket' expenses we mean everything that is not paid by the insurance company. If you first pay but later get it refunded, this is not out of pocket expenses. Prescription drugs should be included in ? and not here.

(SHARE)

XT_HU067: HOW PAID FOR MEDICAL EXPENSES

How did [{Name of Deceased}] pay for this/these treatment(s)

1 Paid using savings/earnings

2 Took out a loan

3 Have not yet paid

95 Other (specify)

98 Don't know

XT_HU067oth: Please specify

XT_HU068: RECEIVE ANY FINANCIAL HELP WITH MEDICAL

Did [{Name of the deceased}] receive any financial help to pay for any of these medical treatments?

1. Yes

GO TO XT_HU068_i

5. No

98. Don't know

99. RF

[ELSA]

XT_HU068_i: WHO HELPED WITH MEDICAL EXPENCES (ROSTER)

Who [else] did [{Name of the deceased}] receive financial help from? CODE ALL THAT APPLY.

[Household roster is presented to the interviewer to select names]

1.

2.

...

97. IF not on List

98. DK

99. RF

XT_HU68othr Specify the name of the relative

XT_HU68othnr Specify the name of the Non-relative

IF respondent did receive financial help, ask XT_HU069

XT_HU069 HOW MUCH MONEY

How much money in total did [{Name of deceased}] receive from others to pay for these treatments?

INTERVIEWER: Enter amount to the nearest €.

Range: 0...9999997

IF XT_HU069= Don't Know, ask XT_HU069a

XT_HU069a Was it..... (Unfolding brackets)

BRACKETS (250, 1000, 5000, 10000)

1. Less than €250
2. More than €2500 but less than €1,000
3. More than €1,000 but less than €5,000
4. More than €5,000 but less than €10,000
5. More than €10,000
98. Don't know
99. Refused

Unfolding Brackets

ASSETS AND LIFE INSURANCE

The next questions are about the assets and life insurance policies the deceased may have owned and what happened to those assets after [he/she] died. I appreciate that this may upset or distress you, but we would find it very helpful to have some information about the financial issues surrounding death. Before I continue, though, I'd like to assure you again that everything you have already told me and anything else you tell me will be kept completely confidential.
[SHARE]

XT_AS001: THE DECEASED HAD A WILL

Some people make a will to determine who receives what parts of the estate. Did [{name of the deceased}] have a will?

- 1. Yes **Go To XT_AS002**
- 5. No **Go To XT_AS004**
- 98. DK
- 99. RF

XT_AS002_i: BENEFICIARIES OF ESTATE

Who were the beneficiaries of the estate, including yourself?
[Household roster is presented to the interviewer to select names]

...

IF XT_AS002_35 or XT_AS002_36 = 1 Ask XT_AS002othr or XT_AS002othnr

XT_AS002p_i: PERCENTAGE OF ESTATE [For each beneficiary]

About what percentage of the estate did <beneficiary_i> receive?

- 1...100
- 98. DK
- 99. RF

XT_AS003othr_i: Specify the name of the relative
XT_AS003othnr_i: Specify the name of the Non-relative

XT_AS003othra_i: (About what percentage of the estate did this relative receive?)

XT_AS003othnra_i: (About what percentage of the estate did this non relative receive?)

XT_AS004: THE DECEASED OWNED ANY LIFE INSURANCE POLICIES

Did the [{Name of deceased}] own any life insurance policies that were paid out on [his/her] death?

- 1. Yes **Go to XT_AS005**
- 5. No **Go to XT_AS008**
- 98. DK
- 99. RF

XT_AS005: VALUE OF ALL LIFE INSURANCE POLICIES

In total, about what was the value of all life insurance policies owned by the deceased?

IWER: Enter an amount in [Euro] _____ (0..50000000)

-98. DK

-99. REF

XT_AS006_i BENEFICIARIES OF INSURANCE

Who were the beneficiaries of the life insurance policies, including yourself?

[Household roster is presented to the interviewer to select names]

...

IF not on List Specify the relative/Non relative

XT_AS006a_i PERCENTAGE OF INSURANCE [For each beneficiary]

About what percentage of the life insurance payment did <beneficiary_i> receive?

1...100

-98. DK

-99. RF

XT_AS007othr_i: Specify the name of the relative

XT_AS007othnr_i: Specify the name of the non-relative

XT_AS007othra_i: (About what percentage of the life insurance did this relative receive?)

XT_AS007othnra_i: (About what percentage of the life insurance did this non relative receive?)

XT_AS008: TOTAL ESTATE DIVIDED AMONG THE CHILDREN

IWER: SHOW CARD AS1

How would you say was the total estate divided among the deceased's children?

IWER: Please read out

1. Some children received more than others

GO TO XT_AS009

2. The estate was divided about equally among all children

3. The estate was distributed exactly equally among the children

4. The children have not received anything

95. Other

GO TO XT_AS008oth

98. DK

99. RF

XT_AS008oth: How else would you say the total estate was divided?

Please specify

XT_AS009: SOME CHILDREN RECEIVED MORE FOR PREVIOUS GIFTS

Would you say that some children received more than others to make up for previous gifts?

1. Yes

5. No

98. DK

99. RF

XT_AS010: SOME CHILDREN RECEIVED MORE TO GIVE THEM FINANCIAL SUPPORT

Would you say that some children received more than others to give them financial support?

- 1. Yes
- 5. No
- 98. DK
- 99. RF

XT_AS011: SOME CHILDREN RECEIVED MORE FOR CARING

Would you say that some children received more than others because they helped or cared for the deceased towards the end of [his/her] life?

- 1. Yes
- 5. No
- 98. DK
- 99. RF

XT_AS012: SOME CHILDREN RECEIVED MORE FOR OTHER REASONS

Would you say that some children received more than others because of other reasons?

- 1. Yes
- 5. No
- 98. DK
- 99. RF

XT_AS013: REASONS SOME CHILDREN RECEIVED MORE

What other reasons do you mean? _____

XT_108: ANYTHING ELSE TO SAY ABOUT THE DECEASED

We have asked you many questions about numerous aspects of [{name of the deceased}]]'s health and finances, and we want to thank you very much for your assistance with them. Is there anything else you would like to add about the life circumstances of [{name of the deceased}] in [his/her] last year of life?

IWER: If nothing to say, type none and press enter _____

XT042_ : THANKS FOR THE INFORMATION

This is the end of the interview. Thank you once again for all the information you have given us. It will prove extremely useful in helping us to understand how people fare at the end of their lives

Thank You