



The **Irish** Longitudinal Study on Ageing

End-of-Life Questionnaire (Exit Interview)

Version 4.1.0.8

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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: CONSENT

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_CS002n: PROXY RESPONDENT NAME

What is the proxy's name?

Text: Up to 60 characters

XT_CS002: PROXY RESPONDENT'S SEX

IWER: Code proxy respondent's sex.

1. Male

2. Female

[SHARE]

XT_CS002a: PROXY RESPONDENT AGE

What is the age of the proxy respondent?

0-120

-98 Don't know

-99 Refused

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

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. Grandchild
 12. Other relative (specify) **XT_CS003othr**
 13. Non-relative (specify) **XT_CS003othnr**
- [ELSA/SHARE]

IF XT_CS003 = 12 (Other Relative) GO TO XT_CS003othr

XT_CS003othr: SPECIFY RELATIVE

Please specify how you are related to the deceased?

IF XT_CS003 = 13 (Non-relative) GO TO XT_CS003othnr

XT_CS003othnr: SPECIFY HOW KNOW THE DECEASED

Please specify how you know the deceased?

IF XT_CS003 = 13 (Non-relative) GO TO XT_CS004

XT_CS004: HOW LONG PROXY KNEW DECEASED

How long had you known [him/her]?

IWER: *Code how the question is answered.*

1 Number of years and/or months (*Enter the number of years and months the respondent has known the deceased.*)

2 Since specific age of deceased (*Enter the age of deceased when they met, if known since birth enter 0.*)

3 Date they met (*month and year*)

[ELSA]

IF XT_CS003 ≠ 1 (not Spouse/Partner) Ask XT_CS005

XT_CS005: HOW OFTEN IN CONTACT

IWER: SHOW CARD CS1 [page #]

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_DM001: MAIN RESIDENCE

In the year prior to [Name of deceased]'s death, where was [his/her] primary residence?

1. In their own home **XT_DM002**
2. At another 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
95. At some other place (Please Specify) **XT_DM001oth**
98. DK
99. RF

IF XT_DM001=1 GO TO XT_DM002

IF XT_DM001=95 GO TO XT_DM001oth

ELSE GO TO XT_CS006

XT_DM001oth: Other principal residence

What was this other place?

IWER: Write in

XT_DM002: LIVING WITH OTHERS

Excluding [Name of deceased], did anyone else live in this household?

1. Yes
5. No

XT_CS006: DECEASED MARRIED AT TIME OF DEATH

IWER: SHOW CARD CS2 [page #]

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

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

IF XT_CS006 = 4, 5 GO TO XT_CS007

ELSE go to XT_CS008

XT_CS007: WHEN STOPPED LIVING TOGETHER

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

_____ MONTH (XT_CS007m)

_____ YEAR (XT_CS007y)

-98 DK

-99 RF

XT_CS008: ILL BEFORE DEATH

IWER: SHOW CARD CS3 [page #]

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 **(Please specify...) GO TO CS009oth**
 98. DK
 99. RF
- [ELSA/HRS]

XT_CS009oth:

IWER: Write in

.....

XT_CS010: THE MAIN CAUSE OF DEATH

IWER: SHOW CARD CS4 [page #]

Please look at card CS4. What was the main cause of [his/her] death?

IWER: Read out if necessary

1. Cancer
2. A heart attack
3. A stroke
4. Other cardiovascular related illness such as heart failure, arrhythmia
5. Respiratory disease
6. Disease of the digestive system such as gastrointestinal ulcer, inflammatory bowel disease
7. Severe infectious disease such as pneumonia, septicaemia or flu
8. Accident
9. Suicide
95. Other (Please specify...) **GO TO XT_CS010oth**
98. DK
99. RF

[ELSA/SHARE/HRS]

IF XT_CS010=10 GO TO XT_CS010oth

XT_CS010oth: OTHER MAIN CAUSE OF DEATH

What was the cause of death?

IWER: Write in

.....

XT_CS011: DATE OF DEATH

What was the date on which [Name of deceased] died?

(HRS)

XT_CS011m: What was the month in which [Name of deceased] died?

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
 - 99. RF
- (HRS)

XT_CS011y: What was the year in which [Name of deceased] died?

YEAR _ _ _ _

[HRS, ELSA]

XT_CS012: WHERE DIED

IWER: SHOW CARD CS5 [page #]

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,
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]

IF XT_CS012 = 1, 9, 98, 99 GO TO XT_CS016

IF XT_CS012 = 95 GO TO XT_CS012oth

IF XT_CS012 = 2 GO TO XT_CS013

OTHERWISE GO TO XT_CS014

XT_CS012oth: OTHER PLACE DIED

What was this other place?

IWER: Write in

GO TO XT_CS014

[ELSA]

XT_CS013: WHOSE HOME DIED

In whose home did [Name of deceased] die?

- 1 Relative
- 2 Non-relative

[ELSA]

XT_CS014: OCCASIONS STAYED IN PLACE OF DEATH

On how many different occasions did [Name of deceased] stay in XT_CS012/XT_CS012oth in the last two years before [he/she] died?

IWER: If appropriate include more than one person's home and specify the number of times.

Range: 1...95

-98 DK

-99 RF

XT_CS015: LENGTH OF TIME IN PLACE BEFORE DIED

IWER: SHOW CARD CS6 [page #]

In total, how long did [Name of deceased] stay in [XT_CS012 / XT_CS012oth (if XT_CS012=95)] in the last two years before [he/she] died?

IWER: 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 DK

99 RF

[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- MULT RESPONSE

IWER: SHOW CARD CS7 [page #]

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

IWER: Include HSE and privately-owned establishments CODE ALL THAT APPLY

- | | |
|---|-------------|
| 1. At home | XT_CS016_01 |
| 2. Other person's home | XT_CS016_02 |
| 3. In hospital | XT_CS016_03 |
| 4. In a hospice | XT_CS016_04 |
| 5. In a nursing home | XT_CS016_05 |
| 6. In a residential home | XT_CS016_06 |
| 7. In a mixed nursing /residential home | XT_CS016_07 |
| 8. In sheltered housing | XT_CS016_08 |
| 9. Stayed at no other places | XT_CS016_09 |
| 95. Other place (Specify) | XT_CS016_95 |
| 98. DK | XT_CS016_98 |
| 99. RF | XT_CS016_99 |
- [ELSA]

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

IF XT_CS016 = 2 (Another'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?

IWER: Enter the number of times

Range: 1...95

-98 DK

-99 RF

[ELSA]

XT_CS019: TIME STAYED IN ANOTHER'S HOME

IWER: SHOW CARD CS6 [page #]

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

IWER: 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 DK

99 RF

[ELSA]

IF XT_CS016 = 3 (In hospital) & XT_CS012 ≠ 3 GO TO XT_CS020

IF XT_CS016 = 3 (In hospital) & XT_CS012 = 3 GO TO XT_CS022

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?

IWER: Enter the number of times

Range: 1...95

-98 DK

-99 RF

[ELSA]

XT_CS021: TIME STAYED IN HOSPITAL

IWER: SHOW CARD CS6 [page #]

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

IWER: 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 DK

99 RF

[ELSA]

IF XT_CS016 = 4 (In a hospice) & XT_CS012 ≠ 4 GO TO XT_CS022

IF XT_CS016 = 4 (In a hospice) & XT_CS012 = 4 GO TO XT_CS024

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?

IWER: Enter the number of times

Range: 1...95

-98 DK

-99 RF

[ELSA]

XT_CS023: TIME STAYED IN HOSPICE

IWER: SHOW CARD CS6 [page #]

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

IWER: 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 DK

99 RF

[ELSA]

IF XT_CS016 = 5 (In a nursing home) & XT_CS012 ≠ 5 GO TO XT_CS024

IF XT_CS016 = 5 (In a nursing home) & XT_CS012 = 5 GO TO XT_CS026

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?

IWER: Enter the number of times

Range: 1...95

-98 DK

-99 RF

[ELSA]

XT_CS025: TIME STAYED IN NURSING HOME

IWER: SHOW CARD CS6 [page #]

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

IWER: 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 DK

99 RF

[ELSA]

IF XT_CS016 = 6 (In a residential home) & XT_CS012 ≠ 6 GO TO XT_CS026
IF XT_CS016 =6 (In a residential home) & XT_CS012 = 6 GO TO XT_CS028
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?

IWER: Enter the number of times

Range: 1...95

-98 DK

-99 RF

[ELSA]

XT_CS027: TIME STAYED IN RESIDENTIAL HOME**IWER: SHOW CARD CS6 [page #]**

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

IWER: 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 DK
- 99 RF
- [ELSA]

IF XT_CS016 = 7 (In a mixed nursing/residential home) & XT_CS012 ≠ 7 GO TO XT_CS028

IF XT_CS016 = 7 (In a mixed nursing/residential home) & XT_CS012 = 7 GO TO XT_CS030

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?

IWER: Enter the number of times

Range: 1...95

- 98 DK
- 99 RF
- [ELSA]

XT_CS029: TIME STAYED IN MIXED NURSING/RESIDENTIAL HOME

IWER: SHOW CARD CS6 [page #]

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

IWER: 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) & XT_CS012 ≠ 8 GO TO XT_CS030

IF XT_CS016 =8 (In sheltered housing) & XT_CS012 = 8 GO TO XT_CS032

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

OTHERWISE GO TO XT_ FL001

XT_CS030: TIMES STAYED IN MIXED SHELTERED HOUSING

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

IWER: Enter the number of times

Range: 1...95

- 98 DK
- 99 RF
- [ELSA]

XT_CS031: TIME STAYED IN MIXED SHELTERED HOUSING

IWER: SHOW CARD CS6 [page #]

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

IWER: *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) & XT_CS012 ≠ 95 GO TO XT_CS032
OTHERWISE GO TO XT_FL001**

XT_CS032: TYPES OF MIXED OTHER PLACE

How many other types of places did [he/she] stay in during the two years before [he/she] died?

IWER: *If more than one other place, record each place as a separate question. If more than 5 places, ask for 5 places stayed in most frequently.*

Range: 1...5

- 98 DK
- 99 RF
- [ELSA]

FOR XT_CS032 = 1 to 5

XT_CS033_01 – XT_CS033_05 Loop WHAT OTHER PLACE

What was this other place?

IWER: *Write in the other place*

STRING 100

[ELSA]

XT_CS034_01 – XT_CS034_05 Loop TIMES IN OTHER PLACE

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

IWER: *Enter the number of times*

Range: 1...95

- 98 DK
- 99 RF
- [ELSA]

XT_CS035_01 – XT_CS035_05 Loop TIME IN OTHER PLACE (#I)

IWER: SHOW CARD CS6 [page #]

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

IWER: 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]

GO TO XT_FL001

I(ADL) & HELPERS (FL)

XT_FL001: (HELP WITH ADL (XT_FL001_01 – XT_FL001_06)

IWER: SHOW CARD FL1 [page #]

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, such as cutting up food | [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) 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

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?

IWER: Code how the answer is given.

1 In months and years

2 Since a specified age

98 Don't know

[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 getting across a room?

IWER: Code how the answer is given.

1 In months and years

2 Since a specified age

98 Don't know

[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?

IWER: Code how the answer is given.

1 In months and years

2 Since a specified age

98 Don't know

[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?

IWER: Code how the answer is given.

1 In months and years

2 Since a specified age

98 Don't know

[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?

IWER: Code how the answer is given.

1 In months and years

2 Since a specified age

98 Don't know

[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?

IWER: Code how the answer is given.

- 1 In months and years
 - 2 Since a specified age
 - 3 Don't know
- [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:

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?

Note: Please begin by providing the name of the person who provided most help to [Name of deceased].

XT_FL008n_01:

What is her/his first name?

XT_FL008a_01:

Is this helper male or female?

1. Male
2. Female
98. DK
99. RF

XT_FL008b_01:

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
- 95: Paid helper [Paid by {name of deceased} or by other sources]
- 96: Employee of Nursing home
- 98: DK
- 99: RF

IF XT_FL008b_01 = 1 - 14 ask XT_FL008c_01

XT_FL008c_01: How old is [Helper]?

- 0...120
- 98. DK
- 99. RF

XT_FL009:

Did anyone else help with this activity/these activities?

REPEAT XT_FL009 FOR UP TO 3 HELPERS

- 1. Yes [Go to XT_FL009_i]
- 5. No GO TO XT_FL010
- 98. DK GO TO XT_FL010
- 99. RF GO TO XT_FL010

XT_FL009n_i: Helper # Name

What is her/his first name?

XT_FL009a_i: HELPER # GENDER

Is <helper > male or female?

- 1. Male
- 2. Female

XT_FL009b_i: HELPER # RELATION TO THE DECEASED

What was 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
- 95: Paid helper [Paid by {name of deceased} or by other sources]
- 96: Employee of Nursing home

98: DK
99: RF

IF FL009b_i = 1 - 14 ask XT_FL009c_i

XT_FL009c_i: How old is [Helper]? 0...120

-98. DK
-99. RF

**CAPI: TOTAL NUMBER OF HELPERS FOR THIS SECTION CAN EQUAL 4 (I.E. INITIAL PERSON NOMINATED AT XT_FL008 AND UP TO 3 REPEATS AT XT_FL009.
FOR EXAMPLE:**

Person	Name	Sex	Relationship	Age
1.	XT_FL008_01	XT_FL008a_01	XT_FL008b_01	XT_FL008c_01
2.	XT_FL009_01	XT_FL009a_01	XT_FL009b_01	XT_FL009c_01
3.	XT_FL009_02	XT_FL009a_02	XT_FL009b_02	XT_FL009c_02
4	XT_FL009_03	XT_FL009a_03	XT_FL009b_03	XT_FL009c_03

Helper name(s)

Note: all subsequent lists will also include the name of any helper(s) previously named.

IWER: SHOW CARD FL2 [page #]

XT_FL010: 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_FL001_01/_02/_03/_04/_05/_06 =1 AND XT_FL010_96/_98/_99 =1 GO TO XT_FL021
 IF XT_FL001_96/_98/_99 = 1 AND XT_FL010_96/_98/_99 = 1 GO TO XT_PH001

XT_FL011: REASON HELPED WITH PREPARING HOT MEALS/ HOUSEHOLD CHORES/ SHOPPING

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?

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

- 1. Yes
- 5. No
- 98. DK
- 99. RF
- [ELSA]

XT_FL011_01: TIME HELPED WITH PREPARING HOT MEALS/ HOUSEHOLD CHORES/SHOPPING

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?

IWER: Code how the answer is given.

- 1. In months and years
- 2. Since a specified age
- 98. DK
- 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?

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

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

IWER: Code how the answer is given.

- 1. In months and years
- 2. Since a specified age
- 98. DK
- 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?

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

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

IWER: Code how the answer is given.

- 1. In months and years
- 2. Since a specified age

98. DK
 99. RF
 [ELSA]
 {
 (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?

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

1. Yes
 5. No
 98. DK
 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?

IWER: Code how the answer is given.

1. In months and years
 2. Since a specified age
 98. DK
 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= 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?

Note: Please begin by providing the name of the person who provided most help to [Name of deceased]

[SHOW LIST OF HELPERS COMPILED FROM QUESTIONS FL008_01, FL009_01, FL009_02, FL009_03]

CAP: IF XT_FL015 "Other Person" GO TO XT_FL015n_01:

XT_FL015n_01:

What is her/his first name?

XT_FL015a_01:

Is this helper male or female?

- 1. Male
- 2. Female
- 98. DK
- 99. RF

XT_FL015b_01:

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
- 95: Paid helper [Paid by {name of deceased} or by other sources]
- 96: Employee of Nursing home
- 98: DK
- 99: RF

IF FL015b_01 = 1 - 14 ask XT_FL015c_01

XT_FL015c_01: How old is [Helper]?

0...120

-98. DK

-99. RF

XT_FL016: 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_95]

1. Yes **Go to XT_FL017n_i**

5. No **GO TO XT_FL018**

98. DK **GO TO XT_FL018**

99. RF **GO TO XT_FL018**

(HRS)

XT_FL017n_i: Helper # Name

What is her/his first name?

XT_FL017a_i: HELPER # GENDER

Is <helper > male or female?

1. Male

2. Female

XT_FL017b_i: HELPER # RELATION TO THE DECEASED

What was 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

95: Paid helper [Paid by {name of deceased} or by other sources]

96: Employee of Nursing home

98: DK

99: RF

IF FL017b_i = 1 - 14 ask XT_FL017c_i

XT_FL017c_i: How old is [Helper]?

0...120

-98. DK

-99. RF

CAPI: TOTAL NUMBER OF HELPERS FOR THIS SECTION CAN EQUAL 4 (I.E. INITIAL PERSON NOMINATED AT XT_FL015 AND UP TO 3 REPEATS AT XT_FL017.

Person	Name	Sex	Relationship	Age
1.	XT_FL015n_01	XT_FL015a_01	XT_FL015b_01	XT_FL015c_01
2.	XT_FL017n_01	XT_FL017a_01	XT_FL017b_01	XT_FL017c_01
3.	XT_FL017n_02	XT_FL017a_02	XT_FL017b_02	XT_FL017c_02
4.	XT_FL017n_03	XT_FL017a_03	XT_FL017b_03	XT_FL017c_03

Helper name(s)

Note: all subsequent lists will also include the name of any helper(s) previously named.

IF XT_FL014 = 1 GO TO XT_FL018

ELSE GO TO XT_FL021

XT_FL018:

Who most often helped [Name of deceased] to manage their money?

CAPI: SHOW LIST OF HELPERS COMPILED FROM QUESTIONS FL008_01, FL009_01, FL009_02 FL009_03 AND FL015, FL017_01, FL017_02, FL017_03

CAPI: IF XT_FL018 "NOT ON LIST" GO TO XT_FL018n_01:

Note: Please begin by providing the name of the person who provided most help to [Name of deceased]

XT_FL018n_01:

What is her/his first name?

XT_FL018a_01:

Is this helper male or female?

1. Male

2. Female

98. DK

99. RF

XT_FL018b_01:

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
- 95: Paid helper [Paid by {name of deceased} or by other sources]
- 96: Employee of Nursing home
- 98: DK
- 99: RF

IF FL018b_01 = 1 - 14 ask XT_FL018c_01

XT_FL018c_01: How old is [Helper]?

0...120

-98. DK

-99. RF

XT_FL019: ANYONE ELSE HELPER

Did anyone else help with this activity/these activities?

REPEAT XT_FL019_01-XT_FL019_95 TO FOR UP TO 3 HELPERS

1. Yes [Go to XT_FL020_i]

5. No **GO TO XT_FL021**

98. DK **GO TO XT_FL021**

99. RF **GO TO XT_FL021**

(HRS)

XT_FL020n_i: Helper # Name

What is her/his first name?

XT_FL020a_i: HELPER # GENDER

Is <helper > male or female?

1. Male

2. Female

XT_FL020b_i: HELPER # RELATION TO THE DECEASED

What was 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
- 95: Paid helper [Paid by {name of deceased} or by other sources]
- 96: Employee of Nursing home
- 98: DK
- 99: RF

IF FL020b_j = 1 - 14 ask XT_FL020c_j

XT_FL020c_j: How old is [Helper]?

- 0...120
- 98. DK
- 99. RF

CAPI: TOTAL NUMBER OF HELPERS FOR THIS SECTION CAN EQUAL 4 (I.E. INITIAL PERSON NOMINATED AT XT_FL018 AND UP TO 3 REPEATS AT XT_FL020.

Person	Name	Sex	Relationship	Age
1.	XT_FL018_01	XT_FL018a_01	XT_FL018b_01	XT_FL018c_01
2.	XT_FL020n_01	XT_FL020a_01	XT_FL020b_01	XT_FL020c_01
3.	XT_FL020n_02	XT_FL020a_02	XT_FL020b_02	XT_FL020c_02
4.	XT_FL020n_03	XT_FL020a_03	XT_FL020b_03	XT_FL020c_03

IF XT_FL001_01/_02/_03/_04/_05/_06 = 1 GO TO XT_FL021

IF XT_FL011/12/13/14= 1 GO TO XT_FL021

ELSE GO TO XT_PH001

HELPER ROSTER

Note: at this point a list is compiled by CAPI of all helpers mentioned in this section. The list will compile up to 12 names, excluding employees of facilities [i.e. exclude if code = 96].

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

IWER: IF HELPER IS FULL-TIME CARER CODE 24.

1...24

-98. DK

-99. RF

(HRS)

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

CAPI: DO NOT ASK QUESTIONS XT_FL024_i to XT_FL032_i IF THE HELPER IS THE SPOUSE/PARTNER OF THE DECEASED, CONTINUE TO NEXT HELPER ON LIST

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 [Name of deceased]?

1. Yes

GO TO XT_FL025

5. No

GO TO XT_FL021 (next helper)

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

(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 XT_FL021 (next helper)**

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_FL030**

2. Other relative **GO TO XT_FL021 (next helper)**

3. Someone else **GO TO XT_FL021 (next helper)**

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 XT_FL021 (next helper)**

IF XT_FL031_i = Yes Ask XT_FL032

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

END OF LOOP QUESTION

IF XT_FL001_01/_02/_03/_04/_05/_06 = 1 ASK XT_FL033

IF XT_FL011/12/13/14= 1 ASK XT_FL033

ELSE 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

IF XT_FL033 > 0 ASK XT_FL034

ELSE GO TO XT_PH001

XT_FL034: HOW MANY IRISH PAID HELPERS

How many of the paid helpers were Irish?

- 0... 10
- 98. DK
- 99. RF
- (TILDA)

PHYSICAL HEALTH

IWER: SHOW CARD PH1 [page #]

XT_PH001: DESCRIPTION OF PHYSICAL HEALTH

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 DK
- 99 RF
- (ELSA)

IWER: SHOW CARD PH2 [page #]

XT_PH002: HEART CONDITIONS

Since we last talked to [him/her] did a doctor ever tell [him/her] that [he/she] had any of the conditions on this card?

PROBE: What others? CODE ALL THAT APPLY.

- | | |
|--|-----------------------------|
| 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] |
| 9. Ministroke or TIA | [XT_PH002_09] |
| 10. High Cholesterol | [XT_PH002_10] |
| 11. Atrial Fibrillation | [XT_PH002_11] |
| 95 Any other heart trouble (SPECIFY) | [XT_PH002_95] [XT_PH002oth] |
| 96 None of these | [XT_PH002_96] |
| 98 DK | [XT_PH002_98] |
| 99 RF | [XT_PH002_99] |
| (ELSA) | |

XT_PH002oth

Please specify.

(ELSA)

IF XT_PH002_01/02/03/04/05/06/08/09/10/11/95 = 1, ASK XT_PH003 to XT_PH005
ELSE GO TO XT_PH006

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 such as

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]

96. None of these

[XT_PH004_96]

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?

1. Yes

5. No

98. DK

99. RF

(HRS)

IWER: SHOW CARD PH3 [page #]

XT_PH006: OTHER CONDITIONS

Since we last talked to [Name of Deceased] did a doctor ever tell [him/her] that [he/she] had any of the conditions on this card?

INTERVIEWER PROBE - 'What others?' CODE ALL THAT APPLY.

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]

10 Cirrhosis or serious liver damage

[XT_PH006_10]

11 Thyroid problems

[XT_PH006_11]

12 Chronic kidney disease

[XT_PH006_12]

95 Any other condition (SPECIFY)

[XT_PH006_95] [XT_PH006oth]

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_PH006oth

Please specify.

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 [page #]

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] [XT_PH008oth]

96. None of these

[XT_PH008_96]

98. DK

[XT_PH008_98]

99. RF

[XT_PH008_99]

XT_PH008oth

Please specify.

XT_PH009: ORGAN CANCER STARTED

IWER: SHOW CARD PH5 [page #]

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.....2016

-98. DK

-99. RF

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

ELSE GO TO XT_PH014

XT_PH011: EMOTIONAL, NERVOUS OR PSYCHIATRIC TYPE

IWER: SHOW CARD PH6 [page #]

What type of emotional, nervous or psychiatric problems did [Name of deceased] 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 deceased] received psychiatric treatment for [his/her] 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 [his/her] problems, such as counselling?

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

XT_PH014: FALLS

Had [name of deceased] fallen down in the last year?

- 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 in the last year?
(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 [name of deceased] fracture [his/her] hip in the last two years?

- 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 in the last two years?

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

IF XT_PH020 = 1 (Yes) GO TO XT_PH021
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 [Name of Deceased] 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?

IWER: Code how the answer is given.

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

____ Cigarettes **[XT_BH002c]**
____ Packs **[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?

IWER: Code how the answer is given.

- 1. KILOGRAMS
- 2. STONES AND POUNDS
- 98. DK
- 99. RF

_____ Kilograms / _____
_____ Stone / _____ Pounds
(HRS)

[XT_BH004k]
[XT_BH004s] [XT_BH004p]

XT_BH005: LOSE OR GAIN 10 POUNDS

Did [Name of Deceased] gain or lose ten or more pounds in the last 2 years of [his/her] life?

- 1. Yes, gained
 - 2. Yes, lost
 - 3. Yes, gained and lost
 - 5. No
 - 98. DK
 - 99. RF
- (HRS)

COGNITIVE FUNCTION

XT_PH117: How long have you known (Name of Deceased)?

IWER: CODE THE ONE THAT APPLIES

1. Less than two years
2. Two years or more but less than five years
3. Five years or more but less than ten years
4. Ten years or more

98. DK

99. RF

IQCODE

IWER: INTRO "Now we want you to remember what [Name of Deceased] was like like 2 years ago and to compare it to what he/she was like about 3 months before they died . Below are situations where he/she had to use his/her memory or intelligence and we want you to indicate whether this had improved, stayed the same, or gotten worse in that situation over this period.

Note the importance of comparing his/her performance 3 months before he/she died with 2 years ago. So if 2 years ago he/she always forgot where he/she had left things and he/she still did, then this would be considered "Not much changed".

IWER: SHOW CARD PH7 [page #]

XT_PH118: Compared with 2 years ago, 2 years ago, about 3 months before [he/she] died how was [he/she] at: Remembering things about family and friends, such as occupations, birthdays, and addresses.

Was this much improved, a bit improved, not much changed, a bit worse or much worse?

IWER: CODE THE ONE THAT APPLIES

1. Much improved
2. A bit improved
3. Not much changed
4. A bit worse
5. Much worse
6. Does not apply/ 98. DK

99. RF

(IQCODE/HRS in modified form)

IWER: SHOW CARD PH7 [page #]

XT_PH119: Compared with 2 years ago, how was [he/she] at:: Remembering things that had happened recently?

Was this much improved, a bit improved, not much changed, a bit worse or much worse?

IWER: CODE THE ONE THAT APPLIES

1. Much improved
2. A bit improved
3. Not much changed
4. A bit worse
5. Much worse
6. Does not apply

98. DK

99. RF

(IQC CODE /HRS in modified form)

IWER: SHOW CARD PH7 [page #]

XT_PH120: Compared with 2 years ago how was [he/she] at: Recalling conversations a few days later?

Was this much improved, a bit improved, not much changed, a bit worse or much worse?

1. Much improved
2. A bit improved
3. Not much changed
4. A bit worse
5. Much worse
6. Does not apply
98. DK
99. RF

(IQC CODE/HRS in modified form)

IWER: SHOW CARD PH7 [page #]

XT_PH121: Compared with 2 years ago, how was [he/she] at: Remembering [his/her] address and telephone number?

Was this much improved, a bit improved, not much changed, a bit worse or much worse?

1. Much improved
2. A bit improved
3. Not much changed
4. A bit worse
5. Much worse
6. Does not apply
98. DK
99. RF

(IQC CODE/HRS in modified form)

IWER: SHOW CARD PH7 [page #]

XT_PH122: (Compared with 2 years ago), how was [he/she] at: Remembering what day and month it is?

Was this much improved, a bit improved, not much changed, a bit worse or much worse?

1. Much improved
2. A bit improved
3. Not much changed
4. A bit worse
5. Much worse
6. Does not apply
98. DK
99. RF

(IQC CODE/HRS in modified form)

IWER: SHOW CARD PH7 [page #]

XT_PH123: Compared with [(IF XT_PH117=4) 10 years ago/ (IF XT_PH117=1,2,3,98,99) when you first got to know Name of Deceased], in the last 3 months of his/her life how was [he/she] at:

Remembering where things are usually kept?

Was this much improved, a bit improved, not much changed, a bit worse or much worse?

1. Much improved
 2. A bit improved
 3. Not much changed
 4. A bit worse
 5. Much worse
 6. Does not apply
 98. DK
 99. RF
- (HRS in modified form)

IWER: SHOW CARD PH7 [page #]

XT_PH124: Compared with [2 years ago], how was [he/she] at: Remembering where to find things which have been put in a different place than usual?

Was this much improved, a bit improved, not much changed, a bit worse or much worse?

1. Much improved
 2. A bit improved
 3. Not much changed
 4. A bit worse
 5. Much worse
 6. Does not apply
 98. DK
 99. RF
- (IQC CODE/HRS in modified form)

IWER: SHOW CARD PH7 [page #]

XT_PH125: Compared with [(IF XT_PH117=4) 10 years ago/ (IF XT_PH117=1,2,3,98,99) when you first got to know Name of Deceased], in the last 3 months of his/her life how was [he/she] at: Knowing how to work familiar machines around the house?

Was this much improved, a bit improved, not much changed, a bit worse or much worse?

1. Much improved
 2. A bit improved
 3. Not much changed
 4. A bit worse
 5. Much worse
 6. Does not apply/ [Name of Deceased] didn't do the activity
 98. DK
 99. RF
- (IQC CODE/HRS in modified form)

IWER: SHOW CARD PH7 [page #]

XT_PH126: Compared with [2 years ago], how was [he/she] at: Learning to use a new gadget or machine around the house?

Was this much improved, a bit improved, not much changed, a bit worse or much worse?

1. Much improved
2. A bit improved
3. Not much changed
4. A bit worse
5. Much worse
6. Does not apply

98. DK

99. RF

(IQC CODE/HRS in modified form)

IWER: SHOW CARD PH7 [page #]

XT_PH127: Compared with [2 years ago], how was [he/she] at: Learning new things in general?

Was this much improved, a bit improved, not much changed, a bit worse or much worse?

1. Much improved
2. A bit improved
3. Not much changed
4. A bit worse
5. Much worse
6. Does not apply

98. DK

99. RF

(IQC CODE/HRS in modified form)

IWER: SHOW CARD PH7 [page #]

XT_PH128: Compared with [2 years ago], how was [he/she] at: Following a story in a book or on TV?

Was this much improved, a bit improved, not much changed, a bit worse or much worse?

1. Much improved
2. A bit improved
3. Not much changed
4. A bit worse
5. Much worse
6. Does not apply

98. DK

99. RF

(IQC CODE/HRS in modified form)

IWER: SHOW CARD PH7 [page #]

XT_PH129: Compared with [2 years ago], how was [he/she] at: Making decisions on everyday matters?

Was this much improved, a bit improved, not much changed, a bit worse or much worse?

1. Much improved
2. A bit improved
3. Not much changed

- 4. A bit worse
 - 5. Much worse
 - 6. Does not apply
 - 98. DK
 - 99. RF
- (IQC CODE/HRS in modified form)

IWER: SHOW CARD PH7 [page #]

XT_PH130: Compared with [2 years ago], how was [he/she] at: Handling money for shopping?

Was this much improved, a bit improved, not much changed, a bit worse or much worse?

- 1. Much improved
 - 2. A bit improved
 - 3. Not much changed
 - 4. A bit worse
 - 5. Much worse
 - 6. Does not apply
 - 98. DK
 - 99. RF
- (IQC CODE/HRS in modified form)

IWER: SHOW CARD PH7 [page #]

XT_PH131: Compared with [2 years ago], how was [he/she] at: Handling financial matters, that is, [his/her] pension or dealing with the bank?

Was this much improved, a bit improved, not much changed, a bit worse or much worse?

- 1. Much improved
 - 2. A bit improved
 - 3. Not much changed
 - 4. A bit worse
 - 5. Much worse
 - 6. Does not apply
 - 98. DK
 - 99. RF
- (IQC CODE/HRS in modified form)

IWER: SHOW CARD PH7 [page #]

XT_PH132: Compared with [2 years ago], how was [he/she] at: Handling other everyday arithmetic problems, such as, knowing how much food to buy, knowing how long between visits from family or friends?

Was this much improved, a bit improved, not much changed, a bit worse or much worse?

- 1. Much improved
- 2. A bit improved
- 3. Not much changed
- 4. A bit worse
- 5. Much worse
- 6. Does not apply

98. DK

99. RF

(IQCODE/HRS in modified form)

IWER: SHOW CARD PH7 [page #]

XT_PH133: Compared with [2 years ago], how was [he/she] at: Using [his/her] intelligence to understand what's going on and to reason things through?

Was this much improved, a bit improved, not much changed, a bit worse or much worse?

1. Much improved

2. A bit improved

3. Not much changed

4. A bit worse

5. Much worse

6. Does not apply

98. DK

99. RF

(IQCODE/HRS in modified form)

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 [Name of Deceased] was depressed during [his/her] last year of life?

IWER: 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](#)

99 Refused

(ELSA)

[IF XT_MH001 = 2, 3 GO TO XT_MH002](#)

XT_MH002: HOW LONG DEPRESSED

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

IWER: Code how the answer is given.

1. In months and years

2. Since a specified age

98 Don't know

99 Refused

(ELSA)

____ MONTHS / ____ YEARS
____ AGE ____

[XT_MH002m] [XT_MH002y]
[XT_MH002age]

[SHOW CARD MH1 \[page #\]](#)

XT_MH003: HOW OFTEN HAPPY

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

99 Refused

(ELSA)

[SHOW CARD MH1 \[page #\]](#)

XT_MH004: HOW OFTEN FELT CONTENTED

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
5 Don't know
99 Refused
(ELSA)

HEALTHCARE UTILISATION

INTRO: I'd now like to ask you some questions about any health care services which [Name of Deceased] used 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?
- 2. GP Visit Card?
- 96. Neither of these
- 98. DK
- 99. RF

Note: This question is asked even of those covered by private medical insurance (EU-SILC)

XT_HU070: LONG TERM ILLNESS SCHEME HEALTH ACT AMENDMENT CARD

Was [Name of deceased] covered by?

- 1 The Long term illness scheme
- 2 A Health Act Amendment card
- 96 Neither of these
- 98 DK
- 99 RF

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
- 2. Yes, as the spouse of a subscriber
- 3. Yes, as the relative of a subscriber
- 5. No
- 98. DK
- 99. RF

GO TO XT_HU003
GO TO XT_HU003
GO TO XT_HU003
GO TO XT_HU005
GO TO XT_HU005
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. LAYA / BUPA / QUINN
- 2. VHI Healthcare
- 3. AVIVA / Hibernian Healthcare/VIVAS Health
- 4. GLO Health
- 95. Other
- 98. DK
- 99. RF

GO TO XT_HU005
GO TO XT_HU005
GO TO XT_HU005
GO TO XT_HU005
GO TO XT_HU004
GO TO XT_HU005
GO TO XT_HU005

(HEALTH INSURANCE AUTHORITY 2005 SURVEY)

XT_HU004: WHAT OTHER PRIVATE INSURANCE COMPANY

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

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_HU071**

-99. RF **GO TO XT_HU071**

(SHARE)

IF XT_HU005=0 GO TO XT_HU071

IF XT_HU005>0 AND XT_HU001=1, 2 GO TO XT_HU071

IF XT_HU005>0 AND XT_HU070= 2 GO TO XT_HU071

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

IF XT_HU005>0 AND XT_HU070≠2 GO TO XT_HU006

XT_HU006: GP OUT-OF-POCKET PAYMENT

About how much did [Name of deceased] pay for each visit to the GP, 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_HU071: CONSULTANT VISITS

Did [Name of deceased] visit a consultant in the last 12 months?

IWER: Code the one that applies

1 Yes

5 No

98 DK

99 RF

IF XT_HU071=1 GO TO XT_HU071a

ELSE GO TO XT_HU010

XT_HU071a: CONSULTANT OUT OF POCKET PAYMENT

In total, how much did [Name of deceased] pay for [his/her] visit(s) to consultant(s) in the last 12 months, after any health insurance reimbursement?’

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

€0 ... €20,000

-98. DK

-99. RF

XT_HU010: A&E VISITS

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) in the last 12 months?

IWER: IF RESPONDENT HAD NOT VISITED AN A&E DEPARTMENT IN THE LAST 12 MONTHS, CODE 0

0... 50

-98. DK

-99. RF

(HARP)

IF (XT_HU010>0 AND XT_HU001==1) GO TO XT_HU011

IF (XT_HU010>0 AND XT_HU070==2) GO TO XT_HU011

IF (XT_HU010>0 AND XT_HU001≠1) GO TO XT_HU010a

IF (XT_HU010>0 AND XT_HU070≠2) GO TO XT_HU010a

IF (XT_HU010=0, -98, -99) GO TO XT_HU011

XT_HU010a: A&E OUT OF POCKET PAYMENT

In total, how much did [Name of deceased] pay for [his/her] visit(s) to A&E in the last 12 months, after any health insurance reimbursement?’

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

€0 ... €20,000

-98. DK

-99. RF

XT_HU011: OUTPATIENT/ DAY PATIENT VISITS

In the last 12 months, about how many visits did [Name of the deceased] make to a hospital as an out-patient/day patient? (Include all types of consultations, tests, operations, procedures or treatments, including chemotherapy and kidney dialysis)

IWER: IF RESPONDENT HAS NOT MADE ANY OUT-PATIENT VISITS/DAY PATIENT VISITS, CODE 0
0...50

-98. DK GO TO XT_HU013

-99. RF GO TO XT_HU013

IF XT_HU011>0 GO TO XT_HU012

ELSE GO TO HU013

XT_HU012: NUMBER OF SUBSTANTIAL PROCEDURES AS OUTPATIENT/DAY PATIENT

On how many of these visits as on outpatient/ day patient 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 OUTPATIENT DAY-CASE PROCEDURES CODE 0

0... 50

-98. DK

-99. RF

XT_HU012a: OUTPATIENT/DAY PATIENT OUT OF POCKET PAYMENTS

In total, how much did [Name of deceased] pay for [his/her] outpatient/day patient visits in the last 12 months, after any health insurance reimbursement?

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

€0 ... €20,000

-98. DK

-99. RF

XT_HU013: ADMITTED TO HOSPITAL OVERNIGHT

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

Note: These are sometimes called in-patient admissions.

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

CODE 0

0...50

-98. DK [GO TO XT_HU072](#)

-99. RF [GO TO XT_HU072](#)

XT_HU013a: NIGHTS SPENT IN HOSPITAL

In total, about how many nights did [Name of deceased] spend in hospital in the last 12 months?

1 ... 365

-98. DK

-99. RF

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_HU016a: INPATIENT OUT OF POCKET PAYMENTS

In total, how much did [Name of deceased] pay for [his/her] overnight hospital stay (s) in the last 12 months, after any health insurance reimbursement?'

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

€0 ... €20,000

-98. DK

-99. RF

HOME CARE

XT_HU072: PRIVATE HOME CARE

In the last 12 months of [his/her] life, did [Name of the deceased] pay an individual or private company to provide home help or personal care

1 Yes

5 No

98 DK

99 RF

STATE HOME CARE

XT_HU020: STATE HOME CARE

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

IWER: CODE ALL THAT APPLY

1. Home help (a person employed by State to help [him/her] with household chores such as cleaning and cooking) [GO TO XT_HU021/HU022/HU022a/XT_HU023](#)
2. Personal care attendant (a person employed by the State to assist [him/her] with bathing, showering, bodily care etc.) [GO TO XT_HU024 / XT_HU025/ XT_HU025a/ XT_HU026](#)
3. Meals-on-Wheels [GO TO XT_HU027/ XT_HU027a/ XT_HU028](#)
4. Home Care Package (a package of state services which may include nurses, home help and various therapies tailored to the person) [HU073/ XT_HU074/ XT_HU074a/ XT_HU075](#)
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

Let's 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

IWER SHOW CARD HU1 [page #]

XT_HU022a: HOME HELP SATISFACTION

Please look at show card HU1. Was [Name of deceased] satisfied with this home help 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_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 [Name of deceased] 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

IWER SHOW CARD HU1 [page #]

XT_HU025a: PERSONAL CARE SATISFACTION

Please look at show card HU1. Was [Name of deceased] satisfied with this personal care 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_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 SERVICES 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

IWER SHOW CARD HU1 [page #]

XT_HU027a: MEALS SERVICES SATISFACTION

Please look at show card HU1. Was [Name of deceased] satisfied with this meals 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_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

GO TO XT_HU029

XT_HU073: HOME CARE PACKAGE DAYS

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

0... 31

-98. RF

-99. DK

XT_HU074: HOME CARE PACKAGE HOURS

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

1...24

-98. DK

-99. RF

IWER SHOW CARD HU1 [page #]

XT_HU074a: HOME CARE PACKAGE SATISFACTION

Please look at show card HU1. Was [Name of deceased] satisfied with this home care package?

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_HU075: HOME CARE PACKAGE OUT OF POCKET EXPENSES

Not counting costs paid by the HSE/health board, about how much did [Name of deceased] (and [your/his/her] [husband/wife/partner]) pay for this Home Care Package per month? (May be zero) €0 ... €10,000

- 98. DK
-99. RF

IWER: SHOW CARD HU2 [page #]

XT_HU029: USE OF STATE SERVICES

Please look at card HU2

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/ XT_HU031 |
| 02. Occupational therapy | GO TO XT_HU032/ XT_HU033 |
| 03. Chiropody services | GO TO XT_HU034/ XT_HU035 |
| 04. Physiotherapy services | GO TO XT_HU036/ XT_HU037 |
| 05. Speech & Language Therapist | GO TO XT_HU054/ XT_HU055 |
| 06. Social work services | GO TO XT_HU038/ XT_HU039 |
| 07. Psychological/counselling services | GO TO XT_HU040/ XT_HU041 |
| 08. Day centre services | GO TO XT_HU042/ XT_HU043 |
| 09. Optician service | GO TO XT_HU044/ XT_HU045 |
| 10. Dental services | GO TO XT_HU046/ XT_HU047 |
| 11. Hearing services | GO TO XT_HU048/ XT_HU049 |
| 12. Dietician services | GO TO XT_HU050/ XT_HU051 |
| 13. Respite services | GO TO XT_HU052/ XT_HU053 |
| 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

IWER: SHOW CARD HU1 [page #]

XT_HU031: SATISFACTION WITH PUBLIC HEALTH OR COMMUNITY NURSE

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

IWER: SHOW CARD HU1 [page #]

XT_HU033: SATISFACTION WITH OCCUPATIONAL THERAPY

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

IWER: SHOW CARD HU1 [page #]

XT_HU035: SATISFACTION WITH CHIROPODY SERVICES

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

IWER: SHOW CARD HU1 [page #]

XT_HU037: SATISFACTION WITH PHYSIOTHERAPY SERVICES

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

IWER: SHOW CARD HU1 [page #]

XT_HU055: SATISFACTION WITH SPEECH & LANGUAGE THERAPIST

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

IWER: SHOW CARD HU1 [page #]

XT_HU039: SATISFACTION WITH SOCIAL WORK SERVICES

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

IWER: SHOW CARD HU1 [page #]

XT_HU041: SATISFACTION WITH PSYCHOLOGICAL/COUNSELLING SERVICES

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

IWER: SHOW CARD HU1 [page #]

XT_HU043: SATISFACTION WITH DAY CENTRE SERVICES

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

IWER: SHOW CARD HU1 [page #]

XT_HU045: SATISFACTION WITH OPTICIAN SERVICE

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

IWER: SHOW CARD HU1 [page #]

XT_HU047: SATISFACTION WITH DENTAL SERVICES

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

IWER: SHOW CARD HU1 [page #]

XT_HU049: SATISFACTION WITH HEARING SERVICES

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

IWER: SHOW CARD HU1 [page #]

XT_HU051: SATISFACTION WITH DIETICIAN SERVICES

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

IWER: SHOW CARD HU1 [page #]

XT_HU053: SATISFACTION WITH RESPITE SERVICES

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

IWER: SHOW CARD HU2 [page #]

XT_HU056: COMMUNITY SERVICES DECEASED NEEDED BUT NOT PROVIDED

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 |
| 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. Don't Know | XT_HU056_98 |
| 99. Refused | XT_HU056_99 |

CAP: FOR EACH XT_HU056_01-16 ASK XT_HU057_i (i = 01 to 16)

IWER: SHOW CARD HU3 [page #]

XT_HU057: BARRIERS TO COMMUNITY SERVICES ACCESS

You have said [Name of deceased] didn't receive ... but would like to. Could you say what the main thing is that prevented [him/her] from receiving it?

IWER: Code main reason not receiving for each service selected in XT_HU056.

01. Never heard of service
02. Did not know it was available
03. Did not have suitable transport
04. It was too costly
05. He/she was reluctant to apply/ [he/she] didn't have time to apply
06. He/she was not eligible for it
07. Other
98. Don't Know
99. Refused

**IF XT_CS016 = 5 (Nursing Home) GO TO XT_HU058
ELSE GO TO XT_HU067**

IWER SHOW CARD HU4 [page #]

XT_HU058: NURSING HOME STAY COSTS

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

How was [Name of deceased]'s 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 scheme (or its replacement)
4. By Children or Relatives
5. Paid for in another way

98 DK

99 RF

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

Now we wish to ask you about any other medical expenses which the deceased may have had but which we have not asked you about....'

XT_HU067: HOW PAID FOR MEDICAL EXPENSES

How did [Name of Deceased] pay their medical expenses?

(Tick all boxes that apply)

1. Paid using savings/earnings
2. Took out a loan
3. Have not yet paid
95. Other (specify)
96. None of these
98. Don't know
99. Refused

XT_HU067: HOW PAID FOR MEDICAL EXPENSES

How else did [Name of Deceased] pay their medical expenses?

IWER: Write in

XT_HU068: RECEIVE ANY FINANCIAL HELP WITH MEDICAL EXPENSES

Did [Name of the deceased] receive any financial help to pay any of these medical expenses?

- 1. Yes
- 5. No
- 98. DK
- 99. RF
- [ELSA]

IF XT_HU068 = 1 GO TO XT_HU068_i
ELSE GO TO XT_HU062

XT_HU068_i: WHO HELPED WITH MEDICAL EXPENSES (ROSTER)

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

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

- 1....
- 2....
- 95. Other not on List
- 98. RF

IF XT_HU068_i=95: please specify other

XT_HU069_i: HOW MUCH MONEY

How much money in total did [Name of deceased] receive from [helper's name] to pay these medical expenses?

IWER: Enter amount to the nearest €.

Range: 0...9999997

- 98 DK
- 99 RF

XT_HU062: HOME MODIFICATIONS

Did [Name of deceased] ever add 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 grab bars, railings or ramps or larger modifications including remodelling existing buildings to make it easier or safer for an older person to live there.

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

IF XT_HU062=1 GO TO XT_HU063
IF XT_HU062≠1 GO TO XT_AS001

XT_HU063: HOME MODIFICATIONS COST

Were any of the costs of the modifications to [Name of deceased]'s home covered by the State?

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

IF XT_HU063=2,3 GO TO XT_HU064

XT_HU064: HOME MODIFICATIONS OUT OF POCKET PAYMENTS

How much did [Name of deceased] pay for the home modifications?

IWER: Enter amount to the nearest €

0-500,000

-98. DK

-99. RF

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 deceased] have a will?

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

**IF XT_AS001 = 1 and spouse/child is answering on behalf of deceased Ask XT_AS002_i
ELSE GO TO XT_AS004**

XT_AS002: BENEFICIARIES OF ESTATE

CAPI: [REPEAT XT_AS002_i through XT_AS002d_i for each beneficiary of the estate]

Who were the beneficiaries of the estate, including yourself?	Name	Sex	RELATIONSHIP TO THE DECEASED?
PERSON 1			
PERSON 2			
PERSON 3			
PERSONi			

XT_AS002a_i: What is her/his first name?

XT_AS002b_i:

Is this person male or female?

- 1. Male
- 2. Female
- 98. DK
- 99. RF

XT_AS002c_i:

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
98. DK
99. RF

XT_AS002d_i:

Age of Beneficiaries

- 98. DK
- 99. RF

XT_AS002_e:

Was anyone else a beneficiary of the estate?

- | | |
|--------|-----------------------|
| 1. Yes | [loop] |
| 5. No | GO TO XT_AS004 |
| 98. DK | GO TO XT_AS004 |
| 99. RF | GO TO XT_AS004 |

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
- 5. No
- 98 DK
- 99 RF

**IF XT_AS004 = Yes and spouse/child is answering on behalf of deceased- Ask XT_AS005
ELSE GO TO NEXT SECTION**

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 _____ (0..50000000)

- 98 DK
- 99 RF

XT_AS006: BENEFICIARIES OF INSURANCE

[CAPI: Display list of beneficiaries declared at XT_AS002_i]

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

CAPI: [REPEAT XT_AS006_i through XTAS006d_i for each beneficiary of the estate if not already listed]

Who were the beneficiaries of the life insurance policy, including yourself?	Name	Sex	RELATIONSHIP TO THE DECEASED?
PERSON 1			
PERSON 2			
PERSON 3			
PERSONi			

XT_AS006a_i: What is her/his first name?

XT_AS006b_i:

Is this person male or female?

1. Male
2. Female
98. DK
99. RF

XT_AS006c_i:

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
98. DK
99. RF

XT_AS006d_i:

Age of Beneficiaries

-98. DK

-99. RF

XT_AS006e_j:

Was anyone else a beneficiary of the life insurance policy?

1. Yes **[loop]**

5. No **GO TO next section**

98. DK **GO TO next section**

99. RF **GO TO next section**

GO TO Next Section

AFTER DEATH

The following questions will help us to learn about the preferred place of death of adults in Ireland and how Ireland is changing in terms of funeral traditions and practices. We hope that you will be able to answer the questions and do not find them too intrusive.

XT_AD001: PLACE OF DEATH PREFERENCE

Where did [Name of deceased] wish to die?

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,
7. In a mixed nursing /residential home,
8. In sheltered housing
95. At some other place (Please Specify)
- 98 DK
- 99 RF

IF XT_AD001==95 (At some other place) GO TO XT_AD001oth

XT_AD001oth: OTHER PLACE WISHED TO DIE

What was this other place?

IWER: Write in

XT_AD002: WAKE

Was a wake held for [Name of deceased]?

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

Note: A wake is a gathering of family and friends of the deceased usually with the body of the deceased present

IF XT_AD002==1 GO TO XT_AD003

XT_AD003: LOCATION OF WAKE

Where was the wake held?

1. At the home of [Name of deceased]
2. At the home of a relative of [Name of deceased]
3. At a funeral home
4. At another location
- 98 DK
- 99 RF

XT_AD004: FUNERAL SERVICE

What type of funeral service was held for [Name of deceased] after [he/she] died?

- 1. Religious service
- 2. Non-religious service
- 3. No service
- 98. DK
- 99. RF

XT_AD005: FUNERAL

Was [Name of deceased]

- 1. Buried
- 2. Cremated
- 98 DK
- 99 RF

XT_AD006: ADVANCE CARE PLANNING

Did [Name of deceased] make [his/her] wishes/preferences known about the kind of care that [he/she] would like to receive in the event of serious illness?

(Tick all boxes that apply)

IWER NOTE: A Living Will, Advance Care/Healthcare Directive and Think Ahead documents are written documents in which a person specifies what actions should be taken for their health or in the event of their death if they are no longer able to make decisions for themselves because of illness or incapacity.

- | | |
|---|--------------------|
| 1. Informally (by conversations with relatives/ significant others) | XT_AD006_01 |
| 2. Informally (by conversations with medical professionals) | XT_AD006_02 |
| 3. Formally by documenting in writing [his/her] wishes for example completing a "Living Will", "Advance Care/Healthcare Directive" or "Think Ahead" document? | XT_AD006_03 |
| 96. None of these | XT_AD006_96 |
| 98. DK | XT_AD006_98 |
| 99. RF | XT_AD006_99 |

XT_AD007:

Did [Name of deceased] appoint a person to take actions or make decisions on [his/her] behalf in the event that [he/she] became incapable of making decisions [himself/herself]?

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

XT_108: ANYTHING ELSE TO SAY ABOUT THE DECEASED

We have asked you many questions about numerous aspects of [Name of the deceased]'s life, health service use, need for help 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 _____

XT_Qxx3

INTERVIEWER:

Now complete a promissory note by writing on the 5 character Tilda serial number (<Tilda_Serial>) and hand it over to the person completing the interview

1. Continue with promissory note details [GO TO XT_Qxx5]
2. Person completing interview does not want to receive cheque [GO TO XT042]

XT_Qxx5:

As we are going to be sending you out a cheque for the 20 Euros, can I just confirm the name that you want the cheque made payable to?

NAME - Text: Up to 60 characters

XT_Qxx6:

Can I also confirm the address that you want the cheque sent to?

ADDRESS - Text: Up to 100 characters

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