The Irish Longitudinal Study on Ageing

Appendix X: Wave 6 End-of-Life Questionnaire (Exit Interview)

Version 6.2.0.1

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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.

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: You should have received an information leaflet and consent form in the post. You were asked to read these to familiarise yourself with the study. Have you read the End of Life Information Leaflet for this study?

1. Yes
5 No (IWER: Ask R to read PIL and ICF and rearrange appointment once complete)

CS001b:
IWER: Do you have any questions about the study?
1. Yes (IWER: Answer questions.)
5. No (IWER move on)

IF CS001b = 1, go to CS001c; OTHERWISE go to CS001d

CS001c:
IWER: Record the questions

CS001d:
IWER: Are you happy to participate in this interview?
1. Yes
5. No (please inform TILDA- mark in database as such)

CS001e:IWER: Do you give TILDA permission to store your name and contact information as part of this study? TILDA will store this data securely and not share it with any **other research groups**.

1. Yes
5. No (IWER: End phone conversation explaining that contact details are required to take part in the study. Please inform TILDA.)

IWER: Do you agree to being contacted by TILDA to follow up on your participation as an End of Life interviewee in this study, if required?
1.Yes
5. No (Please inform TILDA.)

INSERT TICK BOX HERE: Interviewer to tick box to confirm they are happy that the R understands the study and any questions have been answered and the participant has provided freely given informed consent.

IWER: TILDA will post you a 20euro One4All gift card as a token of appreciation for your participation in this study. You can expect this in 2-3 weeks.

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. Stepchild
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
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?
IWER: Read out options

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,
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

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

XT_CS008: ILL BEFORE DEATH

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?
IWER: Read out options

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

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
10. Dementia
11. COVID-19
95. Other (Please specify...) **GO TO XT_CS010oth**
98. DK
99. RF
[ELSA/SHARE/HRS]

IF XT_CS010=95 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 (new additions re visitors at end of life etc)
And where did [Name of deceased] die?
IWER: Read out options

1. At home
2. At another person's home
3. In hospital
4. In a hospice
5. In a nursing 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 = 98, 99 GO TO XT_CS016
IF XT_CS012 = 95 GO TO XT_CS012oth
OTHERWISE GO TO XT_CS012a

XT_CS012oth: OTHER PLACE DIED
What was this other place?
IWER: Write in
GO TO XT_CS012a

XT_CS012a:
When [the person who died] died, was [he/she] with other people?
1. With family and/or friends
2. With a priest/chaplain/spiritual advisor
3. With a health service professional
4. Alone
5. Other (please specify)
98. DK
99. RF

XT_CS012b:
During the last week of life, how often did [Name of deceased] receive visitors?
1 Every day
2 Most days
3 Once or twice
4 Did not receive any visitors
98 DK
99 RF

IF XT_CS012 = 1 GO TO XT_CS016
IF XT_CS012 = 2 GO TO XT_CS013
OTHERWISE GO TO_CS014

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
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.
IWER: Read out options

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

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
IWER: Read out options

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**
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_CS037
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 = 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

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
IWER: Read out options

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 = 8 (In sheltered housing) GO TO XT_CS030
IF XT_CS016 = 95 (In other place) GO TO XT_CS032
OTHERWISE GO TO XT_CS037

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

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
IWER: Read out options

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 = 8 (In sheltered housing) GO TO XT_CS030
IF XT_CS016= 95 (In other place) GO TO XT_CS032
OTHERWISE GO TO XT_CS037

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

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
IWER: Read out options

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 = 8 (In sheltered housing) GO TO XT_CS030
IF XT_CS016= 95 (In other place) GO TO XT_CS032
OTHERWISE GO TO XT_CS037

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

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
IWER: Read out options

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 = 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_CS037

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

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*
IWER: Read out options

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_CS037

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)

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
IWER: Read out options

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_CS037: SPIRITUAL SUPPORTS

Did [Name of deceased] have enough access to spiritual care or religious supports in the last year of life?

1 Yes
5 No
96 Did not want spiritual care or religious supports
98 Don't know
99 RF

XT_AD006: ADVANCE CARE PLANNING (additions in this section to capture did C19 spure these decisions)

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**

IF XT_AD006_03 = 1 GO TO XT_AD006a, OTHERWISE GO TO XT_AD007

XT_AD006a: ADVANCE CARE PLANNING TIMING

When did [Name of deceased] first make this formal documentation?

1. In the last three months of his/her life **XT_AD006a_01**
2. More than three months, but less than a year before dying **XT_AD006a_02**
3. More than a year, but less than two years before dying **XT_AD006a_03**
4. More than two years, but less than five years before dying **XT_AD006a_04**
5. More than five years before dying **XT_AD006a_05**
96. None of these **XT_AD006a_96**
98. DK **XT_AD006a_98**
99. RF **XT_AD006a_99**

IF XT_ CS011m >= 2 & XT_CS011y == 2020 GO TO XT_AD006c, OTHERWISE GO TO XT_AD007

XT_AD006c: As far as you are aware, was COVID -19 the main reason for him/her to begin making these plans?

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

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

IF XT_AD007 = 1 GO TO XT_AD007a, OTHERWISE GO TO XT_ FL001

XT_AD007a: NOMINATED PROXY TIMING

When did [Name of deceased] first appoint this person to make these decisions?

1. In the last three months of his/her life **XT_AD007a_01**

2. More than three months, but less than a year before dying	**XT_AD007a_02**
3. More than a year, but less than two years before dying	**XT_AD007a_03**
4. More than two years, but less than five years before dying	**XT_AD007a_04**
5. More than five years before dying	**XT_AD007a_05**
96. None of these	**XT_AD007a_96**
98. DK	**XT_AD007a_98**
99. RF	**XT_AD007a_99**

IF XT_ CS011m >= 2 & XT_CS011y == 2020 GO TO XT_AD007c, OTHERWISE GO TO XT_ FL001

XT_AD007c: As far as you are aware, was COVID -19 the main reason for [him/her] to make this proxy appointment?

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

GO TO XT_ FL001

I(ADL) & HELPERS (FL)

XT_ FL001: (HELP WITH ADL (XT_FL001_01 – XT_FL001_06)

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.
IWER: Read out options

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. Stepchild
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. Stepchild
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.

XT_FL010: During the last three months of [his/her] life, did [Name of deceased] have difficulty doing any of the activities?
IWER: Read out options

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]**
7.	Communicating?	**[XT_FL010_07]**
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_07 = 1 (Communicating) GO TO XT_FL035
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
IF XT_FL010_07 = 1 (Communicating) GO TO XT_FL035

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
IF XT_FL010_07 = 1 (Communicating) GO TO XT_FL035
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
IF XT_FL010_07 = 1 (Communicating) GO TO XT_FL035
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_FL010_07 = 1 (Communicating) GO TO XT_FL035

OTHERWISE GO TO XT_FL015

XT_FL035: REASON HELPED WITH COMMUNICATING

You said earlier that during the last three months of [his/her] life [Name of deceased] received help with communicating. 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

XT_FL035_01: TIME HELPED WITH COMMUNICATING

In total, for how long when [he/she] died had [he/she] needed help with communicating?
IWER: Code how the answer is given.
1. In months and years
2. Since a specified age
98. DK
99. RF

{
(XT_FL035)
XT_FL035y: YEARS HELPED WITH ...
XT_FL035m: MONTHS HELPED WITH ...
XT_FL035a: 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/ communicating] 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]
***CAPI: 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. Stepchild
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. Stepchild
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. Stepchild
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. Stepchild
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_i = 1 - 14 ask XT_FL020c_i

XT_FL020c_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_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

PHYSICAL HEALTH

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?
IWER: Read out options

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)

XT_PH002: HEART CONDITIONS

Since we last talked to [him/her] did a doctor ever tell [him/her] that [he/she] had any of these conditions?
IWER: Read out options

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 (transient ischaemic attack)	**[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)

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 these conditions?
IWER: Read out options

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
What sort of treatments had [he/she] received for cancer?
IWER: Read out options

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

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

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_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_PH022
ELSE GO TO XT_PH020

XT_PH022: MEDICATIONS FOR PAIN

Was their pain managed by medications?
1. Yes
5. No
98. DK
99. RF

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 / _____ **[XT_BH004k]**
____ Stone / _____ Pounds **[XT_BH004s] [XT_BH004p]**
(HRS)

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?
IWER Note: 10 pounds = 4.5 kg

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 of more but less than ten years
4. Ten years or more
98. DK
99. RF

IF XT_PH117=1, USE WORDING 'B', ALL OTHERS, USE WORDING 'A'

IQCODE

IWER: INTRO

(A) "Now we want you to remember what [Name of Deceased] was 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 about 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".

(B) "Now we want you to remember what [Name of Deceased] was like when you first got to know him/her 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 when you first knew him/her. So if when you first knew [Rname] he/she always forgot where he/she had left things and still did, then this would be considered "Not much changed".

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)

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
(IQCODE /HRS in modified form)

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?
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)

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?
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)

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?
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)

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?
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
(HRS in modified form)

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?
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)

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?
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/ [Name of Deceased] didn't do the activity
98. DK
99. RF
(IQCODE/HRS in modified form)

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?
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)

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?
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)

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?
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)

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?
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)

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?
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)

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?
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)

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?
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)

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?
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)

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 **[XT_MH002m] [XT_MH002y]**
_____AGE_____ **[XT_MH002age]**

XT_MH005: TREATMENT FOR DEPRESSION

Was their depression managed by any treatment, medicine or support?

1 Yes
5 No
98 Don't know
99 Refused

XT_MH003: HOW OFTEN HAPPY

How often do you think [Name of Deceased] felt happy during [his/her] last year of life?
IWER: Read out options

1 Often
2 Sometimes
3 Rarely
4 Never
98 Don't know

99 Refused
(ELSA)

XT_MH004: HOW OFTEN FELT CONTENT

And how about the last three months of [his/her] life, how often do you think [Name of Deceased] felt content or at peace during this time?
IWER: Read out options

1 Often
2 Sometimes
3 Rarely
4 Never
5 Don't know
99 Refused
(ELSA)

XT_MH006: WORRIED ABOUT FINANCIAL BURDEN

Was [Name of Deceased] worried about the financial impact of their death on surviving family?
1 Yes
5 No
98 Don't know
99 Refused

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	**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. LAYA / BUPA / QUINN
2. VHI Healthcare
3. AVIVA / Hibernian Healthcare/VIVAS Health
4. GLO Health / Irish Life
95. Other
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

XT_HU076: PRIVATE HOME CARE DAYS
Let's think for a moment about the private home care [Name of deceased] received. On average per month, on about how many days did [he/she] receive private home care?
IWER NOTE: If the death occurred after COVID19 pandemic, ask the average prior to the outbreak. The COVID19 related impact will be ask in the specific section.
0… 31
-98. RF
-99. DK

XT_HU077: PRIVATE HOME CARE HOURS
On the days when [Name of deceased] received private home care, for about how many hours per day did [he/she] receive private home care?
1…24
-98. DK
-99. RF

XT_HU077a: PRIVATE HOME CARE SATISFACTION
Was [Name of deceased] satisfied with this private home care?
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_HU078: PRIVATE HOME CARE OUT OF POCKET PAYMENTS
About how much did [Name of deceased] [and [you/his/her] [husband/wife/partner]) pay for this private home care in the last month? (May be zero)
€0 … €10,000
-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?
IWER NOTE: If the death occurred after COVID19 pandemic, ask the average prior to the outbreak. The COVID19 related impact will be ask in the specific section.
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_HU022a: HOME HELP SATISFACTION
Was [Name of deceased] satisfied with this home help service?
IWER: Read out options
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_HU079

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?
IWER NOTE: If the death occurred after COVID19 pandemic, ask the average prior to the outbreak. The COVID19 related impact will be ask in the specific section.
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

XT_HU025a: PERSONAL CARE SATISFACTION
Was [Name of deceased] satisfied with this personal care service?
IWER: Read out options
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_HU079

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?
IWER NOTE: If the death occurred after COVID19 pandemic, ask the average prior to the outbreak. The COVID19 related impact will be ask in the specific section.

0… 31
-98. RF
-99. DK

XT_HU027a: MEALS SERVICES SATISFACTION
Was [Name of deceased] satisfied with this meals service?
IWER: Read out options
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_HU079

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?
IWER NOTE: If the death occurred after COVID19 pandemic, ask the average prior to the outbreak. The COVID19 related impact will be ask in the specific section.
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

XT_HU074a: HOME CARE PACKAGE SATISFACTION

Was [Name of deceased] satisfied with this home care package?
IWER: Read out options
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: READ OUT Palliative care, which is sometimes called "supportive care", focuses on providing relief from the symptoms and stress of a serious illness, with the goal to improve quality of life for both the patient and the family.

XT_HU079: PALLIATIVE CARE

In the last 12 months of [his/her] life, did [Name of the deceased] receive palliative care?
1 Yes
5 No
98 DK
99 RF
If XT_HU079=1, GO TO XT_HU080
IF XT_HU079≠1, GO TO XT_HU029
[HRS]

XT_HU080: PLACE RECEIVED PALLIATIVE CARE

When [Name of the deceased] received palliative care, was this in a
IWER: Read out options

IWER: CODE ALL THAT APPLY
1. Hospital as an inpatient
2. Hospital as an outpatient
3. Day care centre
4. At their home or place of residence
5. Inpatient hospice
98. DK
99. RF

XT_HU080a: PALLIATIVE CARE SATISFACTION

Was [Name of deceased] satisfied with the palliative care?
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_HU029: USE OF STATE SERVICES

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

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: Read out options
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

Do you feel that [Name of the deceased] and [his/her] family were satisfied with this service?
IWER: Read out options
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

Do you feel that [Name of the deceased] and [his/her] family were satisfied with this service?
IWER: Read out options
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

Do you feel that [Name of the deceased] and [his/her] family were satisfied with this service?
IWER: Read out options
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

Do you feel that [Name of the deceased] and [his/her] family were satisfied with this service?
IWER: Read out options
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

Do you feel that [Name of the deceased] and [his/her] family were satisfied with this service?
IWER: Read out options
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

Do you feel that [Name of the deceased] and [his/her] family were satisfied with this service?
IWER: Read out options
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

Do you feel that [Name of the deceased] and [his/her] family were satisfied with this service?
IWER: Read out options
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

Do you feel that [Name of the deceased] and [his/her] family were satisfied with this service?
IWER: Read out options
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

Do you feel that [Name of the deceased] and [his/her] family were satisfied with this service?
IWER: Read out options
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

Do you feel that [Name of the deceased] and [his/her] family were satisfied with this service?
IWER: Read out options
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

Do you feel that [Name of the deceased] and [his/her] family were satisfied with this service?
IWER: Read out options
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

Do you feel that [Name of the deceased] and [his/her] family were satisfied with this service?
IWER: Read out options
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: 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: Read out options
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**

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

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. No service in the area
08. COVID 19

95. Other
98. Don't Know
99. Refused

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

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

98. DK

99. RF

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			
PERSON i			

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. Stepchild

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_ie:
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			
PERSON i			

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. Stepchild
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_i:

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

IF XT_ CS011m >= 2 & XT_CS011y == 2020 GO TO XT_CV001 (COVID19 SECTION)
OTHERWISE GO TO NEXT SECTION XT_AD001 AS THE LAST SECTION

COVID19 IMPACT (Full section added mirroring C19 SCQ)

IWER: I'd now like to ask questions about the impact of COVID19 pandemic and how it changed the deceased life during this particular period of time. We hope that you will be able to answer the questions and do not find them too intrusive.

PREVENTATIVE / PRECAUTIONARY BEHAVIOURS

XT_CV001
IWER: SINCE THE OUTBREAK OF THE COVID-19 PANDEMIC, HOW OFTEN DID [HE/SHE] DO THE FOLLOWING ACTIVITIES, AS COMPARED TO BEFORE THE OUTBREAK? NOT AT ALL, LESS OFTEN, ABOUT THE SAME, OR MORE OFTEN?

XT_CV001a Leave the home
0. Not at all
1. Less often
2. About the same
3. More often
98. DK
99. RF

XT_CV001b Go grocery shopping
0. Not at all
1. Less often
2. About the same
3. More often
98. DK
99. RF

XT_CV001c Travel to visit family members
0. Not at all
1. Less often
2. About the same
3. More often
98. DK
99. RF

XT_CV001d Travel to visit friends
0. Not at all

1. Less often
2. About the same
3. More often
98. DK
99. RF

XT_CV001e Attend religious services outside home
0. Not at all
1. Less often
2. About the same
3. More often
98. DK
99. RF

XT_CV001f Exercise at home
0. Not at all
1. Less often
2. About the same
3. More often
98. DK
99. RF

XT_CV001g Walk outside home for more than 20 minutes
0. Not at all
1. Less often
2. About the same
3. More often
98. DK
99. RF

XT_CV001h Do hobbies, crafts, or puzzles
0. Not at all
1. Less often
2. About the same
3. More often
98. DK
99. RF

XT_CV001i Watch TV, Netflix, stream movies, or shows
0. Not at all
1. Less often
2. About the same
3. More often
98. DK
99. RF

XT_CV001j Volunteer
0. Not at all
1. Less often

2. About the same
3. More often
98. DK
99. RF

XT_CV001k Do garden work or home repairs

0. Not at all
1. Less often
2. About the same
3. More often
98. DK
99. RF

XT_CV001l Read books, magazines, or newspapers (in print or online)

0. Not at all
1. Less often
2. About the same
3. More often
98. DK
99. RF

XT_CV001m Meet with social groups on Zoom or other online video conference sites

0. Not at all
1. Less often
2. About the same
3. More often
98. DK
99. RF

XT_CV002

IWER: HOW MANY PEOPLE DID [HE/SHE] SHARE [HIS/HER] ACCOMMODATION WITH DURING THE COVID-19 PANDEMIC?

1. Number of people aged 18 years and older **[XT_CV002_01]**
2. Number of people aged less than 18 years **[XT_CV002_02]**
98. DK
99. RF

XT_CV003

IWER: DOES THE PROPERTY [HE/SHE] LIVED IN HAVE ANY OF THE FOLLOWING?

(PLEASE SELECT ALL THAT APPLY)

1. A garden **[XT_CV003_01]**
2. A roof terrace or large balcony **[XT_CV003_02]**

3. Other private outdoor space **[XT_CV003_03]**
4. Other shared outdoor space **[XT_CV003_04]**
5. None of these **[XT_CV003_05]**
98. DK **[XT_CV003_98]**
99. RF **[XT_CV003_99]**

XT_CV004

IWER: DID [HE/SHE] CHANGE WHERE [HE/SHE] LIVED BECAUSE OF THE COVID-19 PANDEMIC?

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

IF XT_CV004= 1 GO TO XT_CV005, OTHERWISE GO TO XT_CV006

XT_CV005

IWER: IF [HE/SHE] DID CHANGE WHERE [HE/SHE] LIVED BECAUSE OF THE COVID-19 PANDEMIC, WHERE DID [HE/SHE] MOVE TO? (PLEASE TICK ALL THAT APPLY)

1. To own home **[XT_CV005_01]**
2. To a child's / stepchild's home **[XT_CV005_02]**
3. To a home of some other family member **[XT_CV005_03]**
4. To a friend's home **[XT_CV005_04]**
5. To a health care facility (incl. nursing home or hospital) **[XT_CV005_05]**
95. Other (SPECIFY) **[XT_CV005_95]** **[XT_CV005oth]**
98. DK **[XT_CV005_98]**
99. RF **[XT_CV005_99]**

XT_CV005oth

Please specify.

XT_CV006

IWER: DID [HE/SHE] HAVE SOMEONE MOVE IN WITH [HIM/HER] BECAUSE OF THE COVID-19 PANDEMIC?

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

IF XT_CV006= 1 GO TO XT_CV007, OTHERWISE GO TO XT_CV008

XT_CV007

IWER: IF SOMEONE DID MOVE IN WITH [HIM/HER] BECAUSE OF THE COVID-19 PANDEMIC, WHAT WAS THE RELATIONSHIP OF THIS PERSON TO [HIM/HER]? PLEASE TICK ALL THAT APPLY.

1. Spouse / partner	**[XT_CV007_01]**
2. Parent(s)	**[XT_CV007_02]**
3. Sibling(s)	**[XT_CV007_03]**
4. Son(s) or daughter(s)	**[XT_CV007_04]**
5. Grandchild(ren)	**[XT_CV007_05]**
6. Other relative(s)	**[XT_CV007_06]**
7. Friend / neighbour(s)	**[XT_CV007_07]**
8. Carer	**[XT_CV007_08]**
95. Other (SPECIFY)	**[XT_CV007_95] [XT_CV007oth]**
98. DK	**[XT_CV007_98]**
99. RF	**[XT_CV007_99]**

XT_CV007oth

Please specify.

SOCIAL CONTACTS USUAL ACTIVITIES

XT_CV008

IWER: COMPARED TO BEFORE THE OUTBREAK OF THE COVID-19 PANDEMIC, HOW OFTEN DID [HE/SHE] HAVE PERSONAL CONTACT (THAT IS, FACE TO FACE) WITH THE FOLLOWING PEOPLE FROM OUTSIDE [HIS/HER] HOME?

XT_CV008a Children

0. Not at all
1. Less often
2. About the same
3. More often
96. No children
98. DK
99. RF

XT_CV008b Grandchildren

0. Not at all
1. Less often
2. About the same
3. More often
96. No grandchildren
98. DK
99. RF

XT_CV008c Other relatives/ friends/ neighbours

0. Not at all
1. Less often
2. About the same
3. More often
98. DK
99. RF

XT_CV009

IWER: SINCE THE OUTBREAK OF THE COVID-19 PANDEMIC, HOW OFTEN DID [HE/SHE] HAVE CONTACT BY PHONE, EMAIL OR ANY OTHER ELECTRONIC MEANS WITH THE FOLLOWING PEOPLE FROM OUTSIDE [HIS/HER] HOME?

XT_CV009a Children

0. Not at all
1. Less often
2. About the same
3. More often
96. No children
98. DK
99. RF

XT_CV009b Grandchildren

0. Not at all
1. Less often
2. About the same
3. More often
96. No grandchildren
98. DK
99. RF

XT_CV009c Other relatives / friends/ neighbours

0. Not at all
1. Less often
2. About the same
3. More often
96. No other relatives / friends/ neighbours
98. DK
99. RF

ECONOMIC WELLBEING

XT_CV010

IWER: WAS [HIS/HER] WORK AFFECTED BECAUSE OF THE COVID-19 PANDEMIC?

1. Yes
5. No

96. No, he/she was not working when it started
98. DK
99. RF

IF XT_CV010= 1 GO TO XT_CV011, OTHERWISE GO TO XT_CV013

XT_CV011

IWER: IF EMPLOYED OR SELF-EMPLOYED, HOW WAS [HIS/HER] WORK AFFECTED? (PLEASE SELECT ALL THAT APPLY)

1. Had to change workdays or hours. **[XT_CV011_01]**
2. Work became more risky or dangerous **[XT_CV011_02]**
3. Work became harder **[XT_CV011_03]**
4. Switched to working from home or working remotely **[XT_CV011_04]**
95. Other (SPECIFY) **[XT_CV011_95] [XT_CV011oth]**
98. DK **[XT_CV011_98]**
99. RF **[XT_CV011_99]**

XT_CV011oth

Please specify.

IF XT_CV011_01= 1 GO TO XT_CV011a, OTHERWISE GO TO XT_CV012

XT_CV011a

IWER: Did the total amount of work increase or decrease?

1. Increased
2. Decreased
98. DK
99. RF

XT_CV012

IWER: IF EMPLOYED OR SELF-EMPLOYED, DID [HE/SHE] LOSE [HIS/HER] JOB, WERE [HE/SHE] FURLOUGHED, DID [HE/SHE] QUIT, OR WHAT? (PLEASE SELECT ONE OPTION)

1. Lost job/laid off permanently **[XT_CV012_01]**
2. Furloughed/laid off temporarily **[XT_CV012_02]**
3. Quit **[XT_CV012_03]**
95. Other (SPECIFY) **[XT_CV012_95] [XT_CV012oth]**
98. DK **[XT_CV012_98]**
99. RF **[XT_CV012_99]**

XT_CV012oth

Please specify.

XT_CV013
IWER: WERE [HE/SHE] IN RECEIPT OF THE COVID-19 PANDEMIC UNEMPLOYMENT PAYMENT PER WEEK?

1. Yes
5. No
96. I do not know what this payment is
98. DK
99. RF

CARING

XT_CV014 STATE SERVICES
IWER: SINCE THE OUTBREAK OF THE COVID-19 PANDEMIC DID [HE/SHE] CONTINUE TO RECEIVE ANY OF THE FOLLOWING STATE SERVICES?

IF XT_HU020= 1 GO TO XT_CV014a
IF XT_HU020= 2 GO TO XT_CV014b
IF XT_HU020= 3 GO TO XT_CV014c
IF XT_HU020= 4 GO TO XT_CV014d
OTHERWISE GO TO XT_CV014e

XT_CV014a Home help (a person employed by State to help with household chores such as cleaning and cooking)

1. Yes, continued to receive at same frequency
2. Yes, but at reduced frequency
3. No longer received
98. DK
99. RF

XT_CV014b Personal care attendant (a person employed by the State to assist with bathing, showering, bodily care etc.)

1. Yes, continued to receive at same frequency
2. Yes, but at reduced frequency
3. No longer received
98. DK
99. RF

XT_CV014c Meals-on-Wheels

1. Yes, continued to receive at same frequency
2. Yes, but at reduced frequency
3. No longer received
98. DK
99. RF

XT_CV014d Home Care Package

1. Yes, continued to receive at same frequency
2. Yes, but at reduced frequency
3. No longer received
98. DK
99. RF

XT_CV014e Unpaid care from family and friends

1. Yes, continued to receive at same frequency
2. Yes, but at reduced frequency
3. No longer received
98. DK
99. RF

IF XT_HU072= 1 GO TO XT_CV031
OTHERWISE GO TO XT_CV015

XT_CV031 PRIVATE HOME CARE
IWER: SINCE THE OUTBREAK OF THE COVID-19 PANDEMIC DID [HE/SHE] CONTINUE TO RECEIVE ANY PRIVATE HOME CARE?

XT_CV031d: PRIVATE HOME CARE DAYS
Let's think for a moment about the private home care [Name of deceased] received. On average per month, after the covid19 outbreak, on about how many days did [he/she] receive private home care?
section.
0… 31
-98. RF
-99. DK

XT_ CV031h: PRIVATE HOME CARE HOURS
On the days when [Name of deceased] received private home care, for about how many hours per day did [he/she] receive private home care, after the covid19 outbreak?
1…24
-98. DK
-99. RF

XT_CV015

IWER: DURING THE COVID-19 PANDEMIC, DID ANYONE FROM OUTSIDE [HIS/HER] HOME HELPED [HIM/HER] WITH ANY OF THE FOLLOWING. Please tick all that apply

1. Paying bills		**[XT_CV015_01]**
2. Paying rent or mortgage		**[XT_CV015_02]**
3. Shopping for groceries (including online shopping)		**[XT_CV015_03]**
4. Getting in touch to check on wellbeing		**[XT_CV015_04]**
5. Delivering medicines		**[XT_CV015_05]**
6. Providing transport to appointments		**[XT_CV015_06]**
7. Household chores, including gardening		**[XT_CV015_07]**
95. Other (SPECIFY)	**[XT_CV015_95]**	**[XT_CV015oth]**
96. None		**[XT_CV015_96]**
98. DK		**[XT_CV015_98]**
99. RF		**[XT_CV015_99]**

XT_CV015oth

Please specify.

XT_CV016

IWER: DURING THE COVID-19 PANDEMIC, DID [HE/SHE] HELP ANYONE FROM OUTSIDE [HIS/HER] HOUSEHOLD WITH ANY OF THE FOLLOWING. (PLEASE TICK ALL THAT APPLY)

1. Paying bills		**[XT_CV016_01]**
2. Paying rent or mortgage		**[XT_CV016_02]**
3. Shopping for groceries (including online shopping)		**[XT_CV016_03]**
4. Getting in touch to check on wellbeing		**[XT_CV016_04]**
5. Delivering medicines		**[XT_CV016_05]**
6. Providing transport to appointments		**[XT_CV016_06]**
7. Household chores, including gardening		**[XT_CV016_07]**
8. Helped out with a community or charitable organisations efforts to support people		**[XT_CV016_08]**
95. Other (SPECIFY)	**[XT_CV016_95]**	**[XT_CV016oth]**
96. None		**[XT_CV016_96]**
98. DK		**[XT_CV016_98]**
99. RF		**[XT_CV016_99]**

XT_CV016oth

Please specify.

HEALTHCARE

XT_CV017

IWER: SINCE THE OUTBREAK OF THE COVID-19 PANDEMIC IN MARCH 2020, WAS THERE ANY TIME WHEN [HE/SHE] NEEDED MEDICAL (INCLUDING DENTAL) CARE, BUT DELAYED GETTING IT, OR DID NOT GET IT AT ALL?

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

IF XT_CV017= 1 GO TO XT_CV018 & XT_CV019, OTHERWISE GO TO XT_CV020

XT_CV018

IWER: WHY DID [HE/SHE] DELAY OR NOT GET THAT CARE? (PLEASE TICK ALL THAT APPLY)

1. Could not afford it		**[XT_CV018_01]**
2. Could not get an appointment		**[XT_CV018_02]**
3. The clinic/hospital/doctor's office cancelled		**[XT_CV018_03]**
4. The clinic/hospital/doctor's office rescheduled		**[XT_CV018_04]**
5. I decided it could wait		**[XT_CV018_05]**
6. He/She was afraid to go		**[XT_CV018_06]**
7. Issues with transport		**[XT_CV018_07]**
95. Other (SPECIFY)	**[XT_CV018_95]**	**[XT_CV018oth]**
98. DK		**[XT_CV018_98]**
99. RF		**[XT_CV018_99]**

XT_CV018oth

Please specify.

XT_CV019

IWER: WHAT TYPE(S) OF CARE OR HEALTH SERVICES WERE DELAYED/CANCELLED? (PLEASE TICK ALL THAT APPLY)

1. Major Surgery (requiring a hospital stay of one or more nights)	**[XT_CV019_01]**
2. Minor Surgery as an outpatient or day case	**[XT_CV019_02]**
3. Seeing his/her General Practitioner	**[XT_CV019_03]**
4. Getting a prescription filled	**[XT_CV019_04]**
5. Getting medications (including over-the-counter)	**[XT_CV019_05]**
6. Dental care	**[XT_CV019_06]**
7. Optician	**[XT_CV019_07]**
8. Public health or Community Nurse	**[XT_CV019_08]**
9. Occupational therapy	**[XT_CV019_09]**

10. Physiotherapy services **[XT_CV019_10]**
11. Psychological/counselling services **[XT_CV019_11]**
12. Hearing services **[XT_CV019_12]**
13. Respite services **[XT_CV019_13]**
95. Other (SPECIFY) **[XT_CV019_95] [XT_CV019oth]**
98. DK **[XT_CV019_98]**
99. RF **[XT_CV019_99]**

XT_CV019oth

Please specify.

XT_CV020

IWER: DID [HE/SHE] AVAIL OF A TELEPHONE OR ONLINE APPOINTMENT FROM ANY OF THE FOLLOWING? (PLEASE TICK ALL THAT APPLY)

1. General practitioner **[XT_CV020_01]**
2. Pharmacist **[XT_CV020_02]**
3. Hospital doctor **[XT_CV020_03]**
4. Any other health professional **[XT_CV020_04]**
95. Other (SPECIFY) **[XT_CV020_95] [XT_CV020oth]**
96. None **[XT_CV020_96]**
98. DK **[XT_CV020_98]**
99. RF **[XT_CV020_99]**

XT_CV020oth

Please specify.

XT_CV021

IWER: SINCE THE OUTBREAK OF THE COVID-19 PANDEMIC IN MARCH 2020, WAS THERE ANY TIME WHEN HE/SHE WANTED TO PURCHASE ANY OF THE FOLLOWING BUT WERE UNABLE TO DO SO. (PLEASE TICK ALL THAT APPLY)

1. Soap **[XT_CV021_01]**
2. Hand sanitizer **[XT_CV021_02]**
3. Protective face mask **[XT_CV021_03]**
4. Protective gloves **[XT_CV021_04]**
96. None **[XT_CV021_96]**
98. DK **[XT_CV021_98]**
99. RF **[XT_CV021_99]**

IF XT_CV021_01= 1 GO TO XT_CV021_01a

IF XT_CV021_02= 1 GO TO XT_CV021_01b

IF XT_CV021_03= 1 GO TO XT_CV021_01c
IF XT_CV021_04= 1 GO TO XT_CV021_01d
OTHERWISE GO TO XT_CV022

XT_CV021_01a If unable to purchase, what was the reason?
1. Too expensive
2. Not available in shops
3. Could not access shops
98. DK
99. RF

XT_CV021_01b If unable to purchase, what was the reason?
1. Too expensive
2. Not available in shops
3. Could not access shops
98. DK
99. RF

XT_CV021_01c If unable to purchase, what was the reason?
1. Too expensive
2. Not available in shops
3. Could not access shops
98. DK
99. RF

XT_CV021_01d If unable to purchase, what was the reason?
1. Too expensive
2. Not available in shops
3. Could not access shops
98. DK
99. RF

INFORMATION SOURCES

IWER: WE WOULD NOW LIKE TO ASK SOME SPECIFIC DETAILS ABOUT THE EXPERIENCE OF DEATH DURING COVID19. WE UNDERSTAND THESE QUESTIONS ARE DIFFICULT TO ANSWER AND APPRECIATE THEY MAY CAUSE SOME UPSET. WE HOPE BY EXAMINING THESE TOPICS, WE CAN LEARN HOW TO IMPROVE THIS DIFFICULT TIME FOR OTHER PEOPLE IN THE FUTURE.

XT_CV024
IWER: DID [HE/SHE] HAVE COVID-19?
1. Yes, confirmed by a positive test

2. Yes, suspected by a doctor but not tested
3. No, confirmed by a negative test
98. DK
99. RF

IF XT_CV024 = 1 GO TO XT_CV025, OTHERWISE GO TO XT_CV026

XT_CV025
IWER: YOU HAVE STATED R WAS DIAGNOSED WITH COVID-19. Was [HE/SHE] ADMITTED TO A HOSPITAL BECAUSE OF THE VIRUS?
1. Yes
5. No
98. DK
99. RF

IF XT_CV025 = 1 GO TO XT_CV025m & XT_CV025d & XT_CV025n & XT_CV025o, OTHERWISE GO TO XT_CV026

XT_CV025m Which month was that
IWER: Enter the number of the Month (Range 1…12)
98. DK
99. RF

XT_CV025d Which day was that
IWER: Enter the number of the Day (Range 1…31)
98. DK
99. RF

XT_CV025n How many nights did [he/she] spend in the hospital?
IWER: Enter the number of nights (Range 1…200)
98. DK
99. RF

XT_CV025a Was [he/she] allowed visitors during their hospital stay?
1. Yes
5. No
98. DK
99. RF

XT_CV025c How would you rate the communication between you/your family/friends and the hospital?
1. Excellent
2. Good
3. Fair
4. Poor
5. Very Poor
98. DK

99. RF

XT_CV025s Did [he/she] require any of the following while they were in the hospital?
(PLEASE SELECT ALL THAT APPLY)
1. Oxygen
2. ICU Admission
3.Ventilator
4.Palliative Care services
96. None
98. DK
99. RF

XT_CV026
IWER: HAS ANYONE IN [HIS/HER] HOUSEHOLD OTHER THAN [HIM/HER] BEEN DIAGNOSED WITH COVID-19? IF YES, WHAT IS THEIR RELATIONSHIP TO [HIM/HER]? (PLEASE SELECT ALL THAT APPLY)

1. Spouse / partner		**[XT_CV026_01]**
2. Parent(s)		**[XT_CV026_02]**
3. Sibling(s)		**[XT_CV026_03]**
4. Son(s) or daughter(s)		**[XT_CV026_04]**
5. Grandchild(ren)		**[XT_CV026_05]**
6. Other relative(s)		**[XT_CV026_06]**
7. Friend / neighbour(s)		**[XT_CV026_07]**
8. Carer		**[XT_CV026_08]**
95. Other (SPECIFY)	**[XT_CV026_95]**	**[XT_CV026oth]**
96. No, no one else		**[XT_CV026_96]**
98. DK		**[XT_CV026_98]**
99. RF		**[XT_CV026_99]**

XT_CV026oth
Please specify.

XT_CV028
IWER: HAS ANYONE ELSE CLOSE TO [HIM/HER], SUCH A FRIEND OR FAMILY MEMBER, DIED WITH COVID-19”?
1. Yes
5. No
98. DK
99. RF

IF XT_CV028 = 1 GO TO XT_CV029, OTHERWISE GO TO XT_CV030

XT_CV029
IWER: WHAT WAS THEIR RELATIONSHIP TO [HIM/HER]?

1. Spouse / partner		**[XT_CV029_01]**
2. Parent(s)		**[XT_CV029_02]**
3. Sibling(s)		**[XT_CV029_03]**
4. Son(s) or daughter(s)		**[XT_CV029_04]**
5. Grandchild(ren)		**[XT_CV029_05]**
6. Other relative(s)		**[XT_CV029_06]**
7. Friend / neighbour(s)		**[XT_CV029_07]**
8. Carer		**[XT_CV029_08]**
95. Other (SPECIFY)	**[XT_CV029_95]**	**[XT_CV029oth]**
98. DK		**[XT_CV029_98]**
99. RF		**[XT_CV029_99]**

XT_CV029oth

Please specify.

AFTER DEATH

IWER: 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

IWER: 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,
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

IWER: 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
IF XT_AD002==5 & (XT_ CS011m >= 2 & XT_CS011y == 2020) GO TO XT_AD003a
OTHERWISE, GO TO XT_AD004.

XT_AD003: LOCATION OF WAKE

IWER: 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
GO TO XT_AD004

XT_AD003a: REASON FOR NO WAKE
IWER: Was the decision not to hold a wake due to COVID19 restrictions?
1. Yes
5. No
98 DK
99 RF

XT_AD004: FUNERAL
IWER: Was a funeral held for [Name of deceased]?
1. Yes
5. No
98. DK
99. RF
IF XT_AD004==1 GO TO XT_AD004b
IF XT_AD004==5 & (XT_ CS011m >= 2 & XT_CS011y == 2020) GO TO XT_AD400a
OTHERWISE, GO TO XT_108.

XT_AD004a: REASON FOR NO FUNERAL
IWER: Was the decision not to hold a funeral due to COVID19 restrictions?
1. Yes
5. No
98 DK
99 RF

XT_AD004b: FUNERAL SERVICE
IWER: What type of funeral service was held for [Name of deceased] after [he/she] died?
1. Religious service
2. Non-religious service
98 DK
99 RF

XT_AD005: FUNERAL
Was [Name of deceased]
1. Buried
2. Cremated
98 DK
99 RF

IF XT_ CS011m >= 2 & XT_CS011y == 2020 GO TO XT_AD008
OTHERWISE, GO TO XT_108.

XT_AD008: FUNERAL SERVICE DISRUPTIONS

IWER: HOW DID COVID-19 AFFECT FUNERAL PLANS FOR HIM/HER?
IWER: Read out options
IWER: CODE ALL THAT APPLY.

1. Date of funeral affected
2. Location of funeral affected
3. Number of people in attendance limited
4. Some family/friends unable to travel
5. Will arrange memorial service at later date
6. Other (please specify)

96. None
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 _____

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