

Share w2 Exit Questionnaire version 2.7 2006-09-21

XT001_ INTRODUCTION TO EXIT INTERVIEW

[{Name of deceased}] has participated in the SHARE study before [his/her] death. [His/Her] contribution was very valuable. 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 strictly confidential, and will be held anonymously.

1. Continue

XT006_ PROXY RESPONDENT'S SEX

IWER:CODE PROXY RESPONDENT'S SEX

1. Male
2. Female

XT002_ RELATIONSHIP TO THE DECEASED

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

1. Husband or wife or partner
2. Son or Daughter
3. Son- or Daughter-in-law
4. Son or Daughter of husband, wife or partner
5. Grandchild
6. Sibling
7. Other relative (specify)
8. Other non-relative (specify)

IF XT002_ (RELATIONSHIP TO THE DECEASED) = 7. Other relative (specify)

|
| **XT003_ OTHER RELATIVE**
|
| IWER:SPEFICY OTHER RELATIVE

| _____

|
ENDIF

IF XT002_ (RELATIONSHIP TO THE DECEASED) = 8. Other non-relative (specify)

|
| **XT004_ OTHER NO-RELATIVE**
|
| IWER:SPEFICY OTHER NON-RELATIVE

| _____

|
ENDIF

XT005_ HOW OFTEN CONTACT LAST TWELVE MONTHS

During the last twelve months of [his/her] life, how often did you have contact with [{Name of

deceased}}, either personally, by phone, mail or email?

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

XT007_ YEAR OF BIRTH PROXY

Can you tell me your year of birth?

_____ (1900..1990)

XT008_ MONTH OF DECEASE

Let us now talk about the deceased. In what month and year did [he/she] pass away?MONTH:
YEAR:

IWER:MONTH

1. January
2. February
3. March
4. April
5. May
6. June
7. July
8. August
9. September
10. October
11. November
12. December

XT009_ YEAR OF DECEASE

In what month and YEAR did [he/she] pass away?MONTH: [XT008_MonthDiedYEAR]:

IWER:YEAR

1. 2004
2. 2005
3. 2006
4. 2007

XT010_ AGE AT THE MOMENT OF DECEASE

How old was [{Name of deceased}] when [he/she] passed away?

IWER:AGE IN YEARS

_____ (20..120)

XT011_ 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, septicemia or flu
- 8. Accident
- 9. Other (Please specify)

IF XT011_ (THE MAIN CAUSE OF DEATH) = 9. Other (Please specify)

|
 | **XT012_ OTHER CAUSE OF DEATH**
 |
 | IWER:SPEFICY OTHER CAUSE OF DEATH
 | _____
 |
 | *ENDIF*

IF XT011_ (THE MAIN CAUSE OF DEATH) <> 8. Accident

|
 | **XT013_ HOW LONG BEEN ILL BEFORE DECEASE**
 | How long had [{Name of deceased}] been ill before [he/she] died?
 | IWER:READ OUT
 | 1. Less than one month
 | 2. One month or more but less than 6 months
 | 3. 6 months or more but less than a year
 | 4. One year or more

| **XT014_ PLACE OF DYING**
 | Did [he/she] die ...
 | IWER:READ OUT
 | 1. at [his/her] own home
 | 2. at another person's home
 | 3. in a hospital
 | 4. in a nursing home, residential home or sheltered housing
 | 5. in a hospice
 | 6. at some other place (Please specify)

IF XT014_ (PLACE OF DYING) = 6. at some other place (Please specify)

|
 | **XT045_ OTHER PLACE OF DYING**
 |
 | IWER:SPECIFY OTHER PLACE OF DEATH
 | _____
 |
 | *ENDIF*

| **XT015_ TIMES IN HOSPITAL LAST YEAR BEFORE DYING**
 | In the last year before [he/she] died, on how many different occasions did [{Name of deceased}] stay in a hospital, hospice or nursing home?
 | IWER:DO NOT READ OUT
 | 1. Not at all
 | 2. 1 to 2 times
 | 3. 3 to 5 times
 | 4. More than 5 times

|
| *IF XT015_ (TIMES IN HOSPITAL LAST YEAR BEFORE DYING) > 1. Not at all*
||
|| **XT016_ TOTAL TIME IN HOSPITAL LAST YEAR BEFORE DYING**
|| During the last year of [his/her] life, for how long altogether did [{Name of deceased}] stay at hospitals, hospices or nursing homes?
|| IWER:DO NOT READ OUT
|| 1. Less than one week
|| 2. One week or more but less than one month
|| 3. One month or more but less than 3 months
|| 4. 3 months or more but less than 6 months
|| 5. 6 months or more but less than a year
|| 6. A full year
||
| *ENDIF*
|
ENDIF

XT017_ INTRODUCTION EXPENSES MEDICAL CARE

We would now like to ask you some questions about any expenses which [{Name of deceased}] incurred as a result of the medical care [he/she] received in the last 12 months before [he/she] died. For each of the types of care I will now read out, please indicate whether the deceased received the care and, if so, give your best estimate of the costs incurred from that care. Please include only costs not paid or reimbursed by the health insurance or the employer.

1. Continue

LOOP cnt:= 1 TO 8

|
| *IF cnt < 3 OR cnt > 5 OR XT015_ (TIMES IN HOSPITAL LAST YEAR BEFORE DYING) <> 1. Not at all*
||

|| **XT018_ HAD TYPE OF MEDICAL CARE IN THE LAST TWELVE MONTHS**
|| Has [{Name of deceased}] had any [care from a general practitioner/care from specialist physicians/hospital stays/care in a nursing home/hospice stays/medication/aids and appliances/home care or home help due to disability] (in the last 12 months of [his/her] life)?

|| 1. Yes
|| 5. No

||
|| *IF XT018_ (HAD TYPE OF MEDICAL CARE IN THE LAST TWELVE MONTHS) = 1. Yes*
|||

||| **XT019_ COSTS OF TYPE OF MEDICAL CARE IN THE LAST TWELVE MONTHS**

||| About how much did [his/her] [care from a general practitioner/care from specialist physicians/hospital stays/care in a nursing home/hospice stays/medication/aids and appliances/home care or home help due to disability] cost (in the last 12 months of [his/her] life)?

||| IWER:IF A TYPE OF CARE WAS RECEIVED AND ALL COSTS WERE PAID OR REIMBURSED BY THE HEALTH INSURANCE, FILL IN "0" AS AMOUNT INCURRED; ENTER AN AMOUNT IN

```
||| [local currency]
||| _____ (0.980000)
|||
|| ENDIF
||
| ENDIF
|
ENDLOOP
```

XT020_ INTRODUCTION DIFFICULTIES DOING ACTIVITIES

Because of a physical, mental, emotional or memory problem, did [Name of deceased] have difficulty doing any of the following activities during the last twelve months of [his/her] life? Please name only difficulties that lasted at least three months. IWER:READ OUT. CODE ALL THAT APPLY.

1. Dressing, including putting on shoes and socks
2. Walking across a room
3. Bathing or showering
4. Eating, such as cutting up your food
5. Getting in or out of bed
6. Using the toilet, including getting up or down
7. Preparing a hot meal
8. Shopping for groceries
9. Making telephone calls
10. Taking medication
97. None of these

IF XT020_IntroDiffADL.CARDINAL > 0 AND NOT 97. None of these IN XT020_(INTRODUCTION DIFFICULTIES DOING ACTIVITIES)

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|
| XT022_ ANYONE HELPED WITH ADL
| Thinking about the activities that the deceased had problems with during the last twelve months of
| [his/her] life, has anyone helped regularly with
| these activities?
| 1. Yes
| 5. No
```

IF XT022_(ANYONE HELPED WITH ADL) = 1. Yes

XT023_ WHO HAS HELPED WITH ADL

Who, including yourself, has helped mainly with these activities? Please name at most three persons.

IWER:AT MOST THREE ANSWERS!CODE RELATIONSHIP TO DECEASED!

- ```
|| 1. Yourself
|| 2. Husband or wife or partner
|| 3. Mother or father
|| 4. Son
|| 5. Son-in-law
|| 6. Daughter
|| 7. Daughter-in-law
|| 8. Grandson
|| 9. Granddaughter
```

- || 10. Sister
- || 11. Brother
- || 12. Other relative
- || 13. Unpaid volunteer
- || 14. Professional helper (e.g. nurse)
- || 15. Friend or neighbor
- || 16. Other person

|| **XT024\_ TIME THE DECEASED RECEIVED HELP**

|| Overall, during the last twelve months of [his/her] life, for how long did the deceased receive help?

|| IWER:READ OUT

- || 1. Less than one month
- || 2. One month or more but less than 3 months
- || 3. 3 months or more but less than 6 months
- || 4. 6 months or more but less than a year
- || 5. A full year

|| **XT025\_ HOURS OF HELP NECESSARY DURING TYPICAL DAY**

|| And about how many hours of help were necessary during a typical day?

|| \_\_\_\_\_ (0..24)

| *ENDIF*

| *ENDIF*

**XT026\_ THE DECEASED HAD A WILL**

The next questions are about the assets and life insurance policies the deceased may have owned when [he/she] died. Did the deceased have a will?

- 1. Yes
- 5. No

**XT027\_ THE BENEFICIARIES OF THE ESTATE**

Who were the beneficiaries of the estate, including yourself?

IWER:CODE ALL THAT APPLYCODE RELATIONSHIP TO DECEASED!

- 1. Yourself
- 2. Husband or wife or partner
- 3. Children
- 4. Grandchildren
- 5. Siblings
- 6. Other relatives (specify)
- 7. Other non-relatives (specify)
- 8. Church, foundation or charitable organization
- 9. Deceased did not leave anything at all (SPONTANEOUS)

*IF 6. Other relatives (specify) IN XT027\_(THE BENEFICIARIES OF THE ESTATE)*

| **XT028\_ OTHER RELATIVE BENEFICIARY**

| IWER:SPEFICY OTHER RELATIVE

| \_\_\_\_\_

|  
*ENDIF*

*IF 7. Other non-relatives (specify) IN XT027\_(THE BENEFICIARIES OF THE ESTATE)*

|  
| **XT029\_ OTHER NON-RELATIVE BENEFICIARY**

|  
| IWER:SPEFICY OTHER NON-RELATIVE

| \_\_\_\_\_

|  
*ENDIF*

**XT030\_ THE DECEASED OWNED HOME**

Did the deceased own [his/her] home or apartment - either in total or a share of it?

1. Yes
5. No

*IF XT030\_ (THE DECEASED OWNED HOME) = 1. Yes*

|  
| **XT031\_ VALUE HOME AFTER MORTGAGES**

| After any outstanding mortgages, what was the value of the home or apartment or the share of it owned by the deceased?

| IWER:ENTER AN AMOUNT IN [{{local currency}}]

| \_\_\_\_\_ (1000..50000000)

|  
| **XT032\_ WHO INHERITED THE HOME OF THE DECEASED**

| Who inherited the deceased's home or apartment, including yourself?

| IWER:CODE RELATIONSHIP TO DECEASED, ALL THAT APPLY

1. Yourself
2. Husband or wife or partner
3. Sons or daughters (ASK FOR FIRST NAMES)
4. Grandchildren
5. Siblings
6. Other relatives (specify)
7. Other non-relatives (specify)

|  
*IF 6. Other relatives (specify) IN XT032\_(WHO INHERITED THE HOME OF THE DECEASED)*

||  
|| **XT051\_ OTHER RELATIVE**

||  
|| IWER:SPEFICY OTHER RELATIVE

|| \_\_\_\_\_

||  
*ENDIF*

|  
*IF 7. Other non-relatives (specify) IN XT032\_(WHO INHERITED THE HOME OF THE DECEASED)*

||  
|| **XT052\_ OTHER NO-RELATIVE**

||  
|| IWER:SPEFICY OTHER NON-RELATIVE

|| \_\_\_\_\_

||

| *ENDIF*

|

| *IF 3. Sons or daughters (ASK FOR FIRST NAMES) IN XT032\_(WHO INHERITED THE HOME OF THE DECEASED)*

||

|| **XT053\_ FIRST NAMES CHILDREN**

||

|| IWER:FIRST NAMES OF CHILDREN WHO INHERITED HOME

|| \_\_\_\_\_

||

| *ENDIF*

|

*ENDIF*

**XT033\_ THE DECEASED OWNED ANY LIFE INSURANCE POLICIES**

Did the deceased own any life insurance policies?

1. Yes

5. No

*IF XT033\_ (THE DECEASED OWNED ANY LIFE INSURANCE POLICIES) = 1. Yes*

|

| **XT034\_ 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 [{local currency}]

| \_\_\_\_\_ (1000..50000000)

|

| **XT035\_ BENEFICIARIES OF THE LIFE INSURANCE POLICIES**

| Who were the beneficiaries of the life insurance policies, including yourself.

| IWER:CODE RELATIONSHIP TO DECEASED, ALL THAT APPLY

| 1. Yourself

| 2. Husband or wife or partner

| 3. Sons or daughters (ASK FOR FIRST NAMES)

| 4. Grandchildren

| 5. Siblings

| 6. Other relatives (specify)

| 7. Other non-relatives (specify)

|

| *IF 6. Other relatives (specify) IN XT035\_(BENEFICIARIES OF THE LIFE INSURANCE POLICIES)*

||

|| **XT054\_ OTHER RELATIVE**

||

|| IWER:SPECIFY OTHER RELATIVE

|| \_\_\_\_\_

||

| *ENDIF*

|

| *IF 7. Other non-relatives (specify) IN XT035\_(BENEFICIARIES OF THE LIFE INSURANCE POLICIES)*



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||
|| XT055_ OTHER NO-RELATIVE
||
|| IWER:SPEFICY OTHER NON-RELATIVE
|| _____
||
| ENDIF
|
| IF 3. Sons or daughters (ASK FOR FIRST NAMES) IN XT035_(BENEFICIARIES OF THE LIFE
| INSURANCE POLICIES)
||
|| XT056_ FIRST NAMES CHILDREN
||
|| IWER:FIRST NAMES OF CHILDREN WHO WERE BENEFICIARIES
|| _____
||
| ENDIF
|
| ENDIF

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**XT036\_ INTRODUCTION TYPES OF ASSETS**

I will now read out a few types of assets people may have. For each item, please tell me whether the deceased owned them at the time of [his/her] death and, if so, please give your best estimate of their value after any outstanding debts.

1. Continue

*LOOP cnt:= 1 TO 5*

```

|
| XT037_ THE DECEASED OWNED TYPE OF ASSETS
| Did [he/she] own any [businesses, including land or premises/other real estate/cars/financial assets,
| e.g. cash, money or stocks/jewelry or
| antiques]?
| 1. Yes
| 5. No
|
| IF XT037_ (THE DECEASED OWNED TYPE OF ASSETS) = 1. Yes
||
|| XT038_ VALUE TYPE OF ASSETS
|| About what was the value of the [businesses, including land or premises/other real
|| estate/cars/financial assets, e.g. cash, money or stocks/jewelry
|| or antiques] owned by [{Name of deceased}] at the time of [his/her] death?
|| IWER:ENTER AN AMOUNT IN [{local currency}]
|| _____ (100..50000000)
||
| ENDIF
|
| ENDLOOP

```

**XT039\_ NUMBER OF CHILDREN THE DECEASED HAD AT THE END**

How many children did [{Name of deceased}] have that were still alive at the time of [his/her] death? Please include foster and adopted children.

---

*IF XT039\_ (NUMBER OF CHILDREN THE DECEASED HAD AT THE END) > 1 AND NOT 9.  
Deceased did not leave anything at all (SPONTANEOUS) IN XT027\_(THE  
BENEFICIARIES OF THE ESTATE)*

| **XT040\_ TOTAL ESTATE DIVIDED AMONG THE CHILDREN**

| What would you say: how was the total estate divided among the deceased's children?

| IWER:READ OUT

- | 1. The estate was divided about equally among all children
- | 2. Some children received more than others to make up for previous gifts
- | 3. Some children received more than others to give them financial support
- | 4. Some children received more than others because they helped or cared for the deceased towards the end of his/her life
- | 5. Some children received more than others because of other reasons
- | 6. Children have not received anything

|  
*ENDIF*

**XT041\_ THE FUNERAL WAS ACCOMPANIED BY A RELIGIOUS CEREMONY**

Finally, we would like to know about the deceased's funeral. Was the funeral accompanied by a religious ceremony?

- 1. Yes
- 5. No

**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

- 1. Continue

**XT043\_ INTERVIEW MODE**

IWER:PLEASE STATE MODE OF INTERVIEW

- 1. Face-to-face
- 2. Telephone

**XT044\_ INTERVIEWER ID**

IWER:YOUR INTERVIEWER ID

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