

**HEALTH AND LIFESTYLES OF PEOPLE
AGED 50 AND OVER
(ELSA)**

**P2896
ELSA WAVE 4
END OF LIFE INTERVIEW**

**INTERVIEWER
PROJECT INSTRUCTIONS**

CONTENTS

1.	END OF LIFE INTERVIEW	3
1.1	Background	3
1.2	Eligibility	3
1.3	Mode of interview	4
1.4	Addresses issued to interviewers.....	4
1.5	Who will act as an informant?	5
	How do I establish the best person to do the End of Life interview?.....	5
1.6	Advance letter	6
1.7	End of Life interview Record Form (ERF)	6
1.8	End of Life interview program	9
	Content of End of Life interview	10

1. END OF LIFE INTERVIEW

1.1 Background

The End of Life interview (previously known as the 'Exit interview') was introduced at ELSA Wave 2. As at Waves 2 and 3, we will be approaching a close friend/relative of eligible ELSA respondents who have died.

The Health and Retirement Study (HRS) in the United States successfully adopted an End of Life interview, and the content of this interview has been revised for use in ELSA.

The aim of the End of Life interview is to complete the information collected at previous waves of ELSA. We can link the answers given by the late respondent to those given in their End of Life interview to find out how their lives may have changed in the two years preceding their death. We are interested in their health, social circumstances, and financial situation over this time, and what happened to their assets after they died.

If for any reason you do not want to carry out the End of Life interview, please contact your project supervisor so that the interview can be reallocated to another interviewer.

1.2 Eligibility

We will only be conducting an End of Life interview for respondents who are core members (CMs). To be a CM, they must have taken part in at least one wave of the ELSA interview.

Cases identified as having died before the End of Life interview is launched

When the End of Life interview is launched in November 2008, we will be issuing around 200 core members who have been identified as having died and have not yet had an End of Life interview. These cases will have been identified as having died from one of the following sources:

- Wave 4 main interview (batch 1),
- Wave 3 Life history interview,
- Wave 3 main interview,
- Sample updates in the field or between waves,
- Mortality data from the NHS Central Register database.

Such information regarding how we found out about the death will be provided on the sample coversheet.

Please note that seven cases being issued in November were also previously issued for the Wave 3 End of Life interview. We have only included such cases who died **after** the beginning of Wave 3 fieldwork. The cases were selected to be issued again because they were meant to have the End of Life interview by telephone but this was not carried out, they were not ready to be interviewed at Wave 3 because they were still upset about the death, or the case was meant to be reallocated but this did not happen.

Cases identified as having died after the End of Life interview is launched

If you discover that an existing sample core member in the ELSA main Wave 4 sample has died then they will also be eligible for an End of Life interview.

At Wave 2 we only conducted End of Life interviews if the respondent had died more than six months ago. The main reason for this was that it can take a few months for people's finances to be sorted out after they die. However, from Wave 3 onwards we have been carrying out End of Life interviews with respondents who have died at any time. There is a screening question at the beginning of the End of Life program to find out if their finances have been sorted out, and if they haven't, then the financial questions will not be included in the interview.

1.3 Mode of interview

In this wave, all End of Life interviews will be carried out face-to-face. You should conduct the End of Life interview face-to-face if the respondent lives in your area. If the respondent lives out of your area, please give a 615 outcome code on the ERF (see section 1.7 for further details) and enter it in the admin block of the CAPI. When you transmit this back to the office, the interview can be reallocated to a different interviewer who lives in the area. Please also contact the office to let them know this case needs to be reallocated

1.4 Addresses issued to interviewers

We will be issuing cases to interviewers for those ELSA core members who we know have died and who have not yet had an End of Life interview done for them. We have attempted to identify a potential End of Life respondent by prioritising possible interviewees in the following order:

(1) Potential respondent identified by interviewer

Some of the sample members were identified as having died during the fieldwork for Wave 3, Life History or Wave 4. In these cases, the interviewer would have attempted to identify someone who could be an informant for the End of Life interview and if someone was found, the contact details of this person will be pre-printed on the front of the ERF.

(2) Another ELSA sample member in the household

For cases where there was another ELSA sample member in the household, this person will be identified as the potential End of Life respondent.

(3) Proxy nomination/stable contact

If the deceased gave details for a proxy nomination or stable address contact then this person would be provided to you as the potential End of Life respondent. The priority would be given to the proxy nomination over the stable address contact.

(4) No potential respondent identified

If none of the previous three options are possible then we will have issued the case with the deceased respondent's last known address. If possible try and identify a potential End of Life interview respondent (see next section).

You do not need to carry out the interview with the person who we have identified as being the potential End of Life respondent. If they are not willing and you find a different person who is, or you find someone more appropriate, then you may carry out the interview with them instead.

If you discover that one of your issued Wave 4 main sample cases has died you will also need to identify a potential End of Life respondent. If other household members are eligible for the ELSA interview, information about the deceased will be collected in the CAPI interview and recorded in the Final Questions module (FQ). However, if no other household members are eligible for the ELSA interview you will need to record the information about the deceased directly in the admin block, and if possible try and identify a potential End of Life interview respondent (see next section).

1.5 Who will act as an informant?

Any close relative/friend or carer of the deceased can complete the End of Life interview. It is up to interviewers to identify who is best placed to answer the questions.

How do I establish the best person to do the End of Life interview?

1. The most common way of identifying an End of Life interview respondent is during the main ELSA interview (if at least one eligible household member has agreed to the ELSA interview). After the household grid, you are prompted to establish who is the best person to speak to about the deceased, and then during their FQ module ask whether they would be willing to be the End of Life interview respondent. If they are not willing, they are then asked to nominate another person who they think would do the interview (living in or outside their household).

Questions relating to the End of Life interview will only appear in the ELSA CAPI program if the deceased agreed to be recontacted at previous waves of ELSA.

2. If no other members of the household (that lived with the deceased) are eligible for an ELSA interview, you could still approach them and ask for consent to do the End of Life interview. Details of a potential End of Life interview respondent would need to be recorded on the ERF, because no FQ module would be completed.

If you identify an ELSA member who lived alone who has died, you could ask a neighbour for information about a potential End of Life interview respondent. You can also approach a proxy nomination or a stable contact. However, if this proves difficult please give an unproductive outcome code of 331 stating the reasons.

1.6 Advance letter

You will not get an advance letter to send out if the deceased was issued at this wave of ELSA. However, if the deceased died before Wave 4 then they will get an advance letter. There are three types of advanced letter (with minor differences between them):

Another ELSA respondent in the household (ELSA_{amp})

If the End of Life respondent is also an ELSA respondent themselves, they will be getting this type of letter.

Respondent identified by interviewer (Intid)

You will be provided with this type of letter if a previous interviewer identified a potential End of life respondent but the End of Life interview has not yet been carried out.

Proxy/Stable (StaPro)

A letter has been provided for End of Life respondents who we were chosen by the deceased as a proxy nomination or stable address contact.

1.7 End of Life interview Record Form (ERF)

There is one ERF (A).

It is crucial that all information you put on the ERF is then put into the Admin block in the End of Life CAPI program, because the ERFs will **NOT** be looked at but shredded once they are sent back to the office. The Admin block follows a similar layout as the ERF.

If we have identified someone to be the potential End of Life respondent, their details will be printed on the left label (information about potential end of life respondent) on the front of the ERF including their name, address, telephone number, relationship to the deceased, and the type of contact they are (e.g. proxy nom). The deceased's name will be printed on the right ERF label.

If you have found out about a death during Wave 4 after the End of Life interview is launched, you will need to fill in the information on the front of the ERF instead. We would like you to record the serial number of the deceased and their full name on the front of the ERF. You will also need to enter the contact details for the (potential) End of Life interview respondent (if you have identified one) in the box above the interviewer's (your) name.

A Contact Information

If the date of death is not given on the coversheet, please enter this at the top of page 3 of the ERF, before proceeding to question A1.

A1 Identify whether a name of a potential End of Life respondent is given on the label on the front of the ERF. If it is not given, proceed to Section C.

- A2 If there is a potential End of Life respondent printed on the label on the front of the ERF, code whether the potential End of Life interview respondent lived in the same household as the deceased or not. Proceed to Section B if they lived at a different address to the deceased.
- A3 This question checks whether you were able to make contact with the nominated/potential End of Life respondent.
- A4 If you were not able to do so, record details in this question before proceeding to Section C.
- A5 If you were able to make contact with the nominated/potential End of Life respondent, code whether this person is willing and able to do the End of Life interview.
- A6 If this person is not willing and able to do the interview, code whether they are unwilling for anyone to answer the End of Life interview. If this is the case, complete Section D before giving an outcome code of 431 in section E. If this is not the case, proceed to Section C.

B Mover Tracing Section

- B1 Tick in the boxes provided any steps you make to trace the potential End of Life respondent.
- B2 Record here if you have taken any other steps that are not given in B1.
- B3 Code whether you were able to successfully trace the potential End of Life respondent. Proceed to Section C if you were not able to do so.
- B4 Record the address and the telephone number of the potential End of Life respondent covered by the tracing attempt. Please also write in any notes on the address location, if any.
- B5 State whether this new address is in Britain. If it is not, proceed to Section C.
- B6 If this new address is in Britain, assess whether it is in your interviewing area. Please check with your area manager if you are uncertain. If it is not in your interviewing area, complete Section D before giving an outcome code of 615 in Section E. If the address is in your interviewing area, visit the address before proceeding to question B7.
- B7 This question checks whether you were able to make contact with the nominated End of Life respondent at the new address. If you were not able to do so, proceed to Section C.
- B8 If you were able to make contact with the nominated End of Life respondent, code whether this person is willing to do the End of Life interview. If they are, complete Section D before proceeding to Section E.
- B9 If this person is not willing and able to do the interview, code whether they are unwilling for anyone to answer the End of Life interview. If this is the case,

complete Section D before giving an outcome code of 431 in section E. If this is not the case, proceed to Section C.

C *New Potential End of Life Respondent (1)*

In the instance where you need to find a new potential End of Life respondent, please do so by trying to approach 1) proxy nomination 2) stable address contact 3) other household members 4) other family members 5) neighbours (not necessarily in this order).

- C1 This question checks whether you have found anyone else to be the End of Life respondent. If you were not able to do so, complete Section D before proceeding to Section E.
- C2 If you were able to find someone else, record the name, address, telephone number of the potential End of Life interview respondent. Also record their relationship to the deceased, and state whether they are the stable address or the proxy contact.
- C3 State whether this new address is in Britain. If it is not, proceed to question CC1.
- C4 If this new address is in Britain, assess whether it is in your interviewing area. Please check with your area manager if you are uncertain. If it is not in your interviewing area, complete Section D before giving an outcome code of 615 in Section E. If the address is in your interviewing area, visit the address before proceeding to question C5.
- C5 This question checks whether you were able to make contact with the nominated End of Life respondent at the new address. If you were not able to do so, proceed to question CC1.
- C6 If you were able to make contact with the nominated End of Life respondent, code whether this person is willing to do the End of Life interview. If they are, complete Section D before proceeding to Section E.
- C7 If this person is not willing and able to do the interview, code whether they are unwilling for anyone to answer the End of Life interview. If this is the case, complete Section D before giving an outcome code of 431 in section E. If this is not the case, proceed to question CC1.

CC *New Potential End of Life Respondent (2)*

This Section is very similar to Section C. It is to record your second attempt to find another potential End of Life respondent. All questions follow the same routing as those in Section C, except that if you were not able to find another potential respondent (question CC1), the address you found is outside Britain (question CC3), you were not able to make contact with the person, or they are not willing to do the End of Life interview (question CC5-CC7), then you complete Section D before proceeding to Section E.

D Summary of Attempts to Find End of Life Respondent

In this section, please tick to indicate who you contacted in your attempt(s) to find an End of Life respondent. Record in D6 any other person(s) you have contacted if they are not already given in D1-D5. Proceed to Section E after completing this section.

E Final Outcome Codes

Please give a final outcome code for the End of Life interview. This will need to be entered in the admin block in the End of Life CAPI program. E1 is for productive outcomes and E2 is for the unproductive outcome where you were not able to find anyone who could be a potential End of Life respondent. E3 is for unproductive outcomes where you found a potential respondent but the case was unproductive. If you have used outcome codes 310, 331, 430, 431, 440 or 590, you will be asked to give reasons for using them in question E5. Please give as much information as you can because we will need to decide whether to re-issue these cases in the future. If you would like to give any additional information that may be useful for the survey, please write it in the box below question E5. If you found a follow-up address that is out of your interviewing area, please give a final outcome code of 615. This case will then be re-allocated to an interviewer who is in the area.

Coversheet

A coversheet will be attached to the back of ERF, with the front page facing inwards to the ERF for confidentiality reasons. It will have details of the deceased including their last known address, date of death (if known) and how we found out about their death. It will also have the deceased's ELSA history such as their outcomes at previous waves and the names of their previous ELSA interviewers (even if an interview was not actually carried out). It will also provide details of all other ELSA respondents, if any, in the household. The contact details of stable and proxy nomination will be provided if available. Any notes given by previous interviewers will be provided in the notes section.

1.8 End of Life interview program

The End of Life interview has a separate project number (P2896).

If you are allocated one of the cases issued in November 2008 (i.e. those cases whose death we already know about) then you will be sent this program and the cases you have been allocated.

If you record an eligible respondent as having an outcome of being dead in the main ELSA Wave 4 admin block and you transmit this back to the office, you will automatically be sent the End of Life interview slot for this person. This should be sent to you within a few days.

If you require the End of Life interview program and it is not already loaded on your computer, please contact Brentwood and allow at least 2 days for it to become live.

Content of End of Life interview

The interview is very similar to the Wave 2 and 3 End of Life interview programs – only a few minor changes have been made. The questionnaire includes questions on the following topics:

- Health of deceased in year preceding death (physical and mental)
- Care and support needed in 3 months preceding death
- Memory/mood in last year preceding death
- Problem behaviour
- Financial questions – private health care, funeral expenses, inheritance – houses, businesses, other assets.