

NatCen

Social Research that works for society

ELSA Wave 6

End of Life Interview

P1174

Interviewer Project Instructions



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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. At Waves 2, 3 and 4, we approached a close friend or relative of eligible ELSA respondents who had died and conducted an interview with them on behalf of the deceased ELSA respondent. This close friend or relative is called an End of Life informant or respondent.

The Health and Retirement Study (HRS) in the United States do 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 deceased respondent to those given in their End of Life interview to find out how their lives may have changed in the 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.

IMPORTANT: 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 allocated to another interviewer.

1.1.1 Fieldwork period

The fieldwork period will be 6 weeks from the beginning of fieldwork. It is possible an End of Life respondent is willing to do an interview but wants to complete it outside the fieldwork period. This is possible; please contact Brentwood if you find yourself in this situation.

1.2 Eligibility

We will only be conducting an End of Life interview for deceased respondents who were **Existing Sample Core Members** of ELSA and have had at least one productive ELSA interview previously. Wave 6 refreshment Core Members who have died are not eligible for an End of Life interview.

We will not be able to conduct interviews for everyone but we will interview as many as possible, a sample of at least 300 will be issued during Wave 6. Who and how many people we contact will depend on budget, timing, as well as issues of recall. We will prioritise sample from the most recently deceased and work backwards, prioritising people who died since Wave 5 and participated in Wave 4 or 5.

1.2.1 Source of the eligible cases

For those of you who have worked on the project already you will know we launched the Batch 1 sample for the End of Life interview in October 2012. This sample included existing Core Members who have been identified as having died, and had not yet had an End of Life interview. The Batch 2 sample will be the same as Batch 1 and will be launched in April 2013. Eligible cases have been identified from one of the following sources:

- Wave 6 main interview,
- Wave 5 main interview,
- Wave 4 main interview,
- Sample updates in the field or between waves,
- Mortality data from the NHS Central Register database.

There were no End of Life interviews at Wave 5. The information concerning how we found out about the death of the ELSA respondent will be provided on the sample coversheet.

1.3 Method of interview

All End of Life interviews are carried out face-to-face. 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.

There is no incentive for the End of Life interview.

1.4 Who acts as an Informant?

Any close relative, friend or carer of the deceased can complete the End of Life interview. We have attempted to identify a potential End of Life informant by prioritising possible interviewees in the following order:

(1) Potential informant identified by interviewer

Some of the sample members were identified as having died during the fieldwork for Wave 4, Wave 5 or Wave 6. In these cases, the interviewer would have attempted to identify someone who could be an informant for the End of Life interview. If someone was found, the contact details of this person are pre-printed on the front of the ERF. This person could be another member of the household, a proxy contact, a stable contact or another friend or relative.

(2) Another ELSA sample member in the household

For cases where an interviewer hasn't already identified an informant and there was another ELSA sample member in the household, this person will be identified as the potential End of Life respondent and the contact details of this person will be pre-printed on the front of the ERF.

(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. Again, the contact details of this person will be pre-printed on the front of the ERF.

(4) No potential respondent identified

If none of the previous three options are possible then we will NOT be issuing the deceased respondent to the End of Life sample. Due to the sensitive nature of the interviews you will not have to trace an End of Life contact for the interview.

1.4.1 End of Life Informant – Infrequent Scenarios

1. What if the named End of Life Informant refuses, but offers contact details of another person who could perform the interview?

This is the only situation where you can pursue an End of Life interview with a contact not named on the ERF.

For example, if the End of Life named informant is the wife of the deceased ELSA member and she is unable to do the interview but gives you the contact details of her son, then you can pursue an interview with this nominated contact if they are in your fieldwork area. If they are not in your fieldwork area then code 615 in the ERF and transmit back to Brentwood to re-allocate the interview.

2. What if the named End of Life Informant has died?

It's possible the named Informant on the ERF will have died. In this case do not pursue an End of Life Interview, code 310 and transmit back to Brentwood.

2 Documents

2.1 Advance Letters

You will be sent the Advance letter(s) to send to the End of Life informant. Please double check these letters have mail merged correctly and make sense in relation to the ERF. There is one type of advance letter; an example is included in your briefing pack (and is included below).



Mr Barry Briggs,
5 Grange Drive
Sheffield
S2 2BR

Dear Barry Briggs P1174/Serial: 130821631

Health and lifestyles of people aged 50 and over

We are sorry to have been notified that Mrs Gwen Briggs has passed away. You may be aware that Gwen took part in the English Longitudinal Study of Ageing (ELSA) before her death. ELSA explores the health, lifestyles and financial situation of people aged fifty and over.

You may also have taken part in this study, or your details were given to us by Gwen as a contact in the event of any change in her circumstances. In order to complete Gwen's contribution to ELSA we would like to conduct an interview with you about how her life may have changed in the two years preceding her death. The interview contains questions about Gwen's past health and finances.

Involvement with this study is entirely voluntary and any information you give is strictly confidential, and will be held anonymously. This brief interview will be in person.

Your interviewer will telephone or visit your household to invite you to take part and, if you agree, arrange a convenient time and place to do the interview. Alternatively, you may prefer someone else, such as another close friend or relative, to answer the questions on your behalf.

We hope that you will want to be involved in this short interview on behalf of Gwen. On the back of this letter there is more information about the study and how to contact us if you have further questions.

Yours Sincerely,



Professor Sir Michael Marmot
Principal Investigator



Pauline Burge
Project Coordinator

Your interviewer will be:

<i>Name:</i>	<i>Interviewer's ID number:</i>
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End of Life Briefing EXAMPLE

2.2 End of Life Interview Record Form (ERF)

There is one ERF. You should try to contact the named End of Life Informant at least six times, at different times of day, either over the phone or visiting their home. If after six attempts to contact the respondent, code 310 on the ERF and transmit back to Brentwood.

If the date of death is not given on the coversheet and is found out by you during the interview, please enter this at the top of page one of the ERF, before proceeding to question A1.

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. This is because the ERFs will not be looked at, but should be shredded. The Admin block follows a similar layout to the ERF.

The potential End of Life informant will be identified on the ERF. Their details will be printed on the left label 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 or stable contact). The deceased's name will be printed on the right ERF label.

2.2.1 ERF Contact Information

A: Contact Information

A: CONTACT INFORMATION			
A1	OUTCOME OF VISIT TO ADDRESS: Were you able to make contact with nominated/potential End of Life Interview respondent?		
		Yes C No D	Go to A3 Go to A2
A2	PLEASE RECORD REASON(S) WHY YOU ARE UNABLE TO MAKE CONTACT		Complete Section C
A3	Is this person willing and able to do an End of Life interview?	Yes E	Complete Section C
		No F	Go to A4
A4	Is this person unwilling for <u>ANYONE</u> to answer the End of Life interview?	Yes G	Go to Section C and code 431
		No H	Go to A5
A5	Has this person nominated another person who would be willing to complete the End of Life interview? (Please note: Any close relative/friend or carer of the deceased can complete the End of Life interview, as long as they know the deceased well enough)	Yes I	Go to Section B
		No J	Go to Section C and code 430

- A1 This question checks whether you were able to make contact with the potential End of Life respondent.
- A2 If you were not able to do so, record details in this question before proceeding to Section C.
- A3 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 an interview.
- A4 If this person is not willing or unable to do the interview, code whether they are unwilling for anyone to answer the End of Life interview. If this is the case give the outcome code of 431 in section C. If this is not the case, proceed to A5.
- A5 If the person is not willing to do the interview; will they nominate someone else who could do it on their behalf? If yes complete section B, if no code 430 at section C.

B: New Potential End of Life Respondent

In the instance where a new potential End of Life respondent is nominated, please complete Section B.

B: NEW POTENTIAL END OF LIFE RESPONDENT			
INTERVIEWER: You should not approach the Stable or Proxy contact of the deceased, nor any other family, friends or neighbours unless they have been explicitly nominated by the End of Life respondent listed on the ERF.			
B1	RECORD DETAILS OF THE POTENTIAL END OF LIFE INTERVIEW RESPONDENT		
	Name: _____		
	Address: _____ _____		
	Phone number: _____		
	Relationship to deceased: _____		
	Is s/he the stable address contact? : Yes.....1 No.....2		
	Is s/he the proxy contact? : Yes.....1 No.....2		
	Go to B2		
B2	Is this address in Britain?		
	In Britain	A	Go to B3
	Outside Britain	B	Go to Section C and code 780
B3	Is this address in your interviewing area? IF UNSURE CHECK WITH AREA MANAGER.		
	Yes	C	Visit address. Then go to B4
	No	D	Go to Section C and code 815
B4	Were you able to make contact with the person nominated to do an End of Life Interview at this address?		
	Yes	E	Go to B5
	No	F	Complete Section C
B5	Is this person willing and able to do an End of Life interview?		
	Yes	G	Complete Section C
	No	H	Complete Section C

- B1 If someone else was nominated, 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.
- B2 State whether this new address is in Britain. Go to Section C and code 780 if the address is not in Britain.
- B3 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, code of 615 in Section C. If the address is in your interviewing area, visit the address before proceeding to question B5.
- B4 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.
- B5 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, proceed to Section C.

C: Final Outcome Codes

Please give a final outcome code for the End of Life interview.

C: FINAL OUTCOME CODES			
Record Final Outcome Code for attempt to contact an End of Life respondent: SINGLE CODE ONLY			
PRODUCTIVE OUTCOMES			
C1			
	Complete full interview	110	END
	Complete partial interview	210	END
UNPRODUCTIVE OUTCOMES			
C3			
	Potential End of Life respondent refused and is unwilling for <u>ANYONE</u> to answer the End of Life Interview	431	Go to C5
	No contact with potential End of Life respondent	310	END
	Office refusal	410	END
	Potential EOL respondent refused and unable to find another EOL respondent	430	Go to C5
	Refusal during interview	440	Go to C5
	Broken Appointment – No re-contact	450	END
	Ill at home during survey period	510	END
	Away or in hospital all survey period	520	END
	Physically or mentally unable/incompetent	530	END
	Language difficulties	540	END
	Other unproductive	590	Go to C5
	Moved out of Britain or nominated an alternative contact outside of Britain	780	END
TEMPORARY OUTCOME			
C4			
	Given follow-up address in Britain, but not in interviewing area/temporary outcome	615	END
C5	PLEASE GIVE REASONS FOR USING OUTCOME CODES 430, 431, 440 AND 590		
			END
ANY ADDITIONAL INFORMATION:			

The final outcome code will need to be entered in the admin block in the End of Life CAPI program. C1 is for productive outcomes and C2 is for unproductive outcomes where the case was unproductive. If you have used outcome codes 430, 431, 440 or 590, you will be asked to give reasons for using them in question C5. 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 C5. 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.

2.3 Coversheet

A coversheet is integrated to the back of the ERF.

Coversheet – Further Information about the Deceased

Deceased Respondent Information

PNo	Title	Name	Surname	Sex
«EIPNo»	«W6title»	«EIName1»	«EIName2»	«EISex»

Info about deceased ELSA respondent

D.O.B	How NatCen found out about death	Date of death
«dob»	«Typecont»	(If known) «Deathdat»

Address	Postcode	Telephone
«W6add1» «W6Add2» «W6Add3» «w6add4» «W6add5»	«W6pcode»	«w6tel»

Address of deceased ELSA respondent

ELSA History for Deceased

W4 outcome	W5 outcome	Last Interviewer Name
«w4out»	«W5out»	«Interviewer»

Wave 4 & Wave 5 ELSA interview outcomes and name of last ELSA interviewer.

All ELSA Respondents in Deceased's Household (if any)

PNo	Title	Name	Surname	Age	Sample Type
«pno1»	«alltit1»	«allname1»	«allsum1»	«age1»	«SampType1»
«pno2»	«alltit2»	«allname2»	«allsum2»	«age2»	«SampType2»

Information about all members of ELSA in the Household and relationship to deceased ELSA member

Relationship to deceased
«allrest1»
«allrest2»

Further Contact Addresses for Deceased

Type	Name	Relationship to deceased	Address	Postcode	Telephone
Stable	«stnam»	«strel»	«stada» «stadb» «stadc» «stadd» «sade»	«stpcode»	«sttel»
Proxy nomination	«PNNam»	«PNRel»	«PNAdA» «PNAdB» «PNAdC» «PNAdD6»	«PNAdF»	«PNTel»

Stable and proxy contacts if the deceased ELSA member had them.
NB. this could be the same as the EoL respondent

The coversheet has details of the deceased respondent 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. 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 overleaf.

3 End of Life Interview CAPI Program

The End of Life interview has a separate project number (P1174).

If you are allocated an End of Life interview and you haven't already worked on the project then you will be sent this program and the cases you have been allocated. 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.

The End of Life interview will last around 30 minutes.

3.1 Content of End of Life interview

The interview is very similar to the Wave 4 End of Life interview program if you took part in this – only a few minor changes have been made. The questionnaire includes questions on the following topics:

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