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English Longitudinal Study of Ageing (ELSA)

Wave 2 to Wave 6

User Guide to the End of Life
interview datasets

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1 Overview of the Survey.

This User Guide provides information about the End of Life interviews carried out during the first six waves of ELSA. There are 4 datasets available to download from the UK Data Service [here](#).

1.1 Background and Aims

The English Longitudinal Study of Ageing (ELSA) began in 2002. It is a large scale longitudinal panel study of people aged 50 and over and their partners, living in private households in England. The sample was drawn from households that had previously responded to the Health Survey for England (HSE) between 1998 and 2011. The sample has been refreshed at several waves (waves 3, 4 and 6) so not all respondents have participated since 2002.

The same group of respondents have been interviewed at two-yearly interviews, known as 'waves' to measure changes in their health, economic and social circumstances. ELSA can complete the picture of what it means to grow older in the 21st century, and help us understand what accounts for the variety of patterns that are seen.

At wave 2, an End of Life interview was introduced to the study. The aim of the End of Life interview is to complete the information collected at previous waves of ELSA by interviewing a close friend or relative of the deceased ELSA sample member after their death. This provides information about how deceased ELSA sample members' lives may have changed in the years preceding their death. The focus of the interview is on their health, social circumstances, and financial situation during this time, and what happened to their assets after they died. End of Life interviews have been carried out at wave 2, 3, 4 and 6. No End of Life interviews were carried out at wave 5.

Many of the measures adopted in ELSA are comparable with measures used in the US Health Retirement Study (HRS) and the Survey of Health, Ageing and Retirement in Europe (SHARE).

ELSA is the result of collaboration between University College London (UCL), the Institute for Fiscal Studies (IFS), and NatCen Social Research. Other academic collaborators based at the Universities of Cambridge, Exeter and East Anglia provided expert advice on specific modules. Funding for the first six waves of ELSA has been provided by the US National Institute on Aging, and a consortium of British Government departments¹.

1.2 Ethical Clearance

Ethical approval for all the ELSA waves was granted from NHS Research Ethics Committees under the National Research and Ethics Service (NRES). For further information see here: <http://www.nres.nhs.uk/>

¹ More detailed information about funding can be found in the User Guide to the core datasets which is available to download from the UK Data Service.

1.3 Contact Details

Any queries related to this study should be sent to: elsadata@natcen.ac.uk

2 Sample design.

2.1 End of Life interview sample

The ELSA sample has been designed to represent people aged 50 and over, who were living in private households in England in the first wave of ELSA (2002/2003). Three years of the Health Survey for England (HSE) were selected as the sampling frame: 1998, 1999 and 2001. These years were chosen because they were recent and could provide a sufficiently large sample size. ELSA used the core samples for these years, all of which were nationally representative.

As the sample has aged, it has been refreshed at various waves to ensure that at each wave, it is representative of the population. The refreshment samples have been selected from later years of the HSE. For more detailed information about sampling at each wave of ELSA, please see the User Guide to the core datasets.

Core sample members² who had died between two waves of ELSA and had contact details for an appropriate End of Life interview informant were eligible for an End of Life interview.

Sample members were identified as having died from one of the following sources:

- Sample updates in the field or between waves,
- Mortality data from the NHS Central Register database.

2.2 End of Life interview informants

Any close relative, friend or carer of the deceased can complete the End of Life interview. Interviewers were provided with the contact details of a potential informant from previous waves of data. End of Life informants were prioritised in the following order:

(1) Potential informant identified by interviewer

Some of the sample members were identified as having died during main ELSA fieldwork. In these cases, the interviewer would have attempted to identify someone who could be an informant for the End of Life interview. This person could be another member of the household or another friend or relative.

(2) Another ELSA sample member in the household

For cases where an interviewer had not already identified an informant and there was another ELSA sample member in the household, this person was identified as the potential End of Life informant.

(3) Proxy nomination/stable contact

² There are a number of different individual level sample types within the main ELSA sample. Individual sample type is based on age, participation at each wave and which cohort of HSE respondent was sampled from. More detailed information on individual level sample types can be found in the User Guide to the core datasets [here](#).

If the deceased gave details for a proxy nomination or stable address contact during interviews at a previous wave then this person would be contacted as the potential End of Life respondent.

(4) No potential respondent identified

If none of the previous three options applied, the case was ineligible for interview. Due to the sensitive nature of the interviews, interviewers were not asked to trace an End of Life contact for cases where no appropriate contact was identified.

3 Interview content

The interview takes approximately 30 minutes to administer face to face. 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.

The full documentation of the End of Life interview questionnaire is available to download from the UK Data Service. The questionnaire has changed slightly between waves and individual questionnaire documentation is needed for each Wave.

4 Fieldwork and response rate

4.1 Fieldwork – Overview

Interviews were provided with instructions prior to starting each wave of fieldwork. Fieldwork was ordered so that the deceased sample members who died most recently were the first to be issued. It should be noted that for this element of the survey there are multiple and complex definitions of eligibility. The widest definition is that a core sample member has died and not yet had an End of Life interview about them. However we do not have full information about all sample members; some may have died and we are unaware so we can only issue cases known to have died. In practice some cases may not be issued if the death was too recent. In addition once the death occurred more than two waves ago it is not practical or ethical to issue the case to End of Life fieldwork at a later wave even if an interview has not been obtained before. Cases are only issued to End of Life fieldwork once. If they are unproductive are not issued again subsequently.

There are also practical issues surrounding being able to identify a suitable End of Life interview respondent. Without such a respondent the case cannot be issued to fieldwork. Below we have set out the key information for each wave. However as rules surrounding how long after the death should be allowed before conducting an End of Life interview have

changed and as there have been two waves with no End of Life interview, response rates cannot be compared between waves.

4.2 Response at wave 2

Wave 2 fieldwork ran from June 2004 - July 2005.

408 core members were recorded as died at Wave 2. Only those who had died at least 6 months before were eligible for an interview. Of the 408 cases known to have died, 184 were eligible, 69 were not eligible and in 155 cases it was unknown whether they were eligible (based on the 6 month rule). Of the 408 cases known to have died, 204 cases were issued to fieldwork. The ELSA wave 2 End of Life fieldwork produced 135 productive interviews (66% of issued cases).

4.3 Response at wave 3

Fieldwork for wave 3 of ELSA began in May 2006 and spanned 15 months, finishing in August 2007.

The sample for the interview included 762 cases. For 68 of these cases, fieldwork was not attempted. The remaining sample of 694 cases included those already known to have died at the start of Wave 3 mainstage fieldwork who had not yet been interviewed at Wave 2 End of Life (569). The ELSA wave 3 End of Life interview fieldwork produced 375 productive interviews (54% of the 694 cases where fieldwork was attempted).

4.4 Response at wave 4

Fieldwork for wave 4 of ELSA began in May 2008 and spanned 14 months, finishing at the end of July 2009.

At the start of Wave 4 mainstage fieldwork 1,450 cases were identified as being ELSA core members who were known to have died. 908 of these had already been issued to an End of Life interview at Wave 2 or 3 and so were not eligible for Wave 4 End of Life. 337 of the remaining cases were judged not to be eligible for the initial Wave 4 End of Life fieldwork either because the information had come from a telephone interview (41), they had died before the start of Wave 3 fieldwork (103) or they had been identified from a linked mortality file update between waves 3 and 4 (193). After excluding these groups 205 cases were issued to fieldwork initially. Later, a further 214 cases were issued to fieldwork during the course of Wave 4 mainstage fieldwork. These 214 cases included at least some of the 193 cases identified from the mortality update between the waves. The ELSA wave 4 End of Life fieldwork produced 244 productive interviews (58% of the 419 cases issued to fieldwork). In the final archived version there are only 242 cases after cleaning.

4.5 Response at wave 6

Fieldwork for wave 6 of ELSA began in May 2012 and spanned 13 months, finishing in June 2013.

4,709 of ELSA respondents were known to have died before Wave 6 fieldwork started. 1,341 of these were core members who had died but had never been selected for an End of Life

interview previously (making them potentially eligible for an End of Life interview). Of these, 416 had died since the end of Wave 4 and had taken part in interviews at Wave 4 mainstage. We restricted the eligibility for Wave 6 End of Life to this group to focus resources on those cases with the most useful data and where it was most likely we would obtain an End of Life interview. In addition to the people known to have died prior to Wave 6 and eligible for interview (416), an additional number of respondents were found to have died when we made contact at Wave 6 (146) making a total potential sample of 562. We issued 326 of those 562 cases who had died since Wave 4 and had been productive at Wave 4 or Wave 5. 236 cases were not issued for the following reasons:

1. Unable to locate an End of Life respondent (for example inadequate or incorrect proxy, stable or End of Life respondent details),
2. End of Life respondent located at main interview stage and refused to take part, and refused to allow a different End of Life respondent to take part,
3. Spouse of deceased ELSA member also deceased with no other End of Life respondent to contact.

During Wave 6 End of Life fieldwork, interviews were obtained with 240 of the 326 issued cases (74%).

5 Dataset information.

This User Guide refers to the End of Life datasets that have been archived for ELSA Waves 2, 3, 4 and 6. These datasets list cases at an individual level.

Data for ELSA respondents collected during HSE (referred to as “wave 0” data) and ELSA waves 1-6 main interview data can be used for longitudinal analysis. All of these data are available from the UK Data Service.

5.1 Serial Numbering

All the ELSA data files deposited in the archive contain a unique individual analytical serial number (**IDAUNIQ**) to enable users to link the different files. Each respondent will have a unique value for **IDAUNIQ**, which will remain constant across all data records at all waves. In the End of Life dataset the **IDAUNIQ** is the individual serial number of the deceased ELSA respondent (not the serial of the person actually responding to the questionnaire).

5.2 Dropped Variables

All variables in the questionnaire documentation with an @ symbol next to their name have been deleted from the archived dataset.

The following types of variables have been deleted in order to reduce the potential to identify individuals and for other reasons (specified below):

1. Those containing text

-
2. Those which contained a personal identifier (e.g. name/address)
 3. Those considered to be disclosive, such as:
 - Full interview date
 - Full date of birth
 - Specific financial variables
 4. Timing variables, which give the time at specific points in the interview (used for administration purposes)
 5. Variables that only contain missing values – excluded because they are not useful. Such variables have only been kept if they are integral to the structure of the data. (please note that this applies to some financial variables in these data sets)

The only geographical variable available in the archived datasets is Government Office Region (GOR). This is available on the main interview datasets. Other geographical variables can be requested via the NatCen Data Release Panel. Please contact elsadata@natcen.ac.uk for more details.

5.3 Missing Values

For most questions there are the following missing values:

- 1 Not applicable
- 8 Don't know
- 9 Refusal

For some questions, a response of 'don't know' or 'refusal' was not permitted. This is indicated in the questionnaire.

For various reasons, some respondents did not complete the entire interview. Where possible, for these 'partial' interviews, the questions that were not asked were coded as '-1' (not applicable).

5.4 Financial data

The End of Life data sets contain detailed financial information about the deceased person's estate. Where these are disclosive and there are sufficient cases for analysis a derived variable which groups the data has been created (DVEIxxxx). In other cases the data have not been archived because there are insufficient cases for useful analysis so grouped derived variables have not been created. Please contact elsadata@natcen.ac.uk for more information.

5.5 Weights

There are no weights on the end of life data sets.

5.6 Changes to questions between waves

The End of Life questionnaire has remained quite consistent over time. However there have been a small number changes between waves which are highlighted here.

Variable	Notes
EIRKNO, NUMMTH, NUMYR	At wave 2 EIRKNO was used for the interviewer to record whether the respondent gave their answer in months, years or ages. This then led to routing to questions which collected the information in the right format. From Wave 3 onwards EIRKNO was used to record whether the answer was less than a year, one to two years or more than two years. This then routed to a question about months known or years known accordingly. EIRKNO, NUMMTH AND NUMYR from wave 2 are called EIRKNOW2, NUMMTH W2 AND NUMYR W2 to distinguish them. Three additional questions AGEMET, YRMET, MTHMET were only included in wave 2
EiLive	At wave 4 and wave 6 there is a new category 9 (guest house or B and B which did not appear in waves 2 and 3.
EIHOMESTY	The category 3 'both relative and non-relative' was added at wave 4
EIADLA2(W2) EIADLB2(W2) EIADLC2(W2) EIADLD2(W2) EIADLE2(W2) EIADLF2(W2) EIADLG2(W2) EIADLH2(W2) EIADLI2(W2) EIADLJ2(W2)	At Wave 2 questions about how long help had been received for asked for an answer format (months and years or since age) followed by asked months and years or age. This was changed at wave 3 and all subsequent waves to ask rough time scale followed up by questions about weeks, months or years. The wave 2 only versions of the initial question have W2 at the end. In W2 the subsequent questions end 2a,2b,2c, at waves 3 onwards they end 2W, 2M, 2Y. This change was made because very few respondents chose the age way of answering the question.
EIWHLP	The answer categories on this question changed between waves 3 and 4. The wave 2 and 3 version is called EIWHLPS and the version for W4 and W6 is called EIWHLP. Each has a series of numbered variables (mentioned/ not mentioned). Note that EiWHLP1 does not refer to the same helper as EIWHLPS. In order to use W2/3 and W46/ data together the variables would need to be recoded or a combined one derived

EIWHLPF	This question about formal providers was added at Wave 6 (not found at waves 2,3,4,). However owing to an error in the CAPI specification it overlaps with categories of EIWHLP.
EILONG	At W3, W4 and 6 – no category for one or two hours so answer categories for wave 2 variable does not correspond with waves 3,4,6 so the wave 2 version is called EILONGW2
EICOGP, EICOGS	These questions asked about format of answer at wave 2 but this changed to asking rough time period at waves 3,4 and 6. The follow up questions about time are different in wave 2 from the other waves and so all these questions have W2 in variable name or a variable name which is different from W3, 4, 6. See questionnaire documentation.
EIMHFF	This questions asked about format of answer at wave 2 but this changed to asking rough time period at waves 3,4 and 6. The follow up questions about time are different in wave 2 from the other waves and so all these questions have W2 in variable name or a variable name which is different from W3, 4, 6. See questionnaire documentation.
EIDIAA	At wave 2 the category 9 high cholesterol was not included.
EiBP	This question about when told about high blood pressure only appears in wave 2.
EIAGM2 EINMST	In Wave 4 and Wave 6 there was a new question about number of strokes (EINMST) instead of the question from Waves 3 and 2 about whether they had a stroke (EIAGM2)
EIYR2, EINMMI	In Wave 4 and Wave 6 there was a new question about number of heart attacks (EINMMI) instead of the question from Waves 3 and 2 about whether they had a heart attack (EIYR2)
EIDIAB, EILEUK, EIAGK	A new category 10 was added at Wave 4 and does not appear in Wave 2 or 3 (Malignant blood disorder, e.g. leukaemia. Two follow-up questions (EILEUK, EIAGK) about this condition were also added from Wave 4 but do not appear in waves 2 and 3.
EiHMed	Does not appear in wave 2, only in waves 3,4,6.
EiCanM	Does not appear in wave 2, only in waves 3,4,6.
EIMEDE	This question about whether the joint was removed or replaced was removed at wave 4 so is only found in the wave 2 and 3

	data.
EIMEDEA	This question was only asked in wave 2, not waves 3,4,5.
EIHDT, EIHT etc (health care decisions module)	The questions about health care decisions were only asked at wave 6 and were not included in waves 2,3,4.
EIPTYPE	At Wave 4 a new Spontaneous category was added for 'Self-invested personal pension'. At wave 6 this category started to be shown on the showcard and another new category was added: 'National Employment Savings Trust'
EIHOWN22, EIOTHN22, EIOINN22, EIHWN22, EIHOWH22	Note that in some waves of the data the category 22 for some variables is labelled 'other friends' when it should be 'other relative'. The wording in the questionnaire documentation is correct.

In the wave 2 version of the data the final questions on assets and inheritances are not included in the archived dataset. Questions from WillPro onwards are not included. The numbers for each question are small. Should you require these data please contact elsadata@natcen.ac.uk