

# CARD M6

## Cancer and Death Records

We have asked about your health. To make this information complete we would like to be informed **about cancer and death records** held and managed by **NHS Digital**, the national controller of health data.

These records will help us by adding more information to the responses you have provided. The data accessed would be the **type of cancer and/or cause of death**. If a person who took part in ELSA gets cancer or dies, the information about the type of cancer and/or cause of death will be linked with their answers to the survey.

We need your permission for any information to be released. Permission from ELSA participants to use these records will help to improve research into what happens to people in later life, as well as improve our understanding about who is affected by cancer, inequality in cancer care, and how having cancer affects other aspects of your life. You do not have to give your permission for us to collect this data if you don't want to.

If you do give your permission, the ELSA Research Team will pass your name, address, sex, date of birth, and NHS Number to NHS Digital. Then NHS Digital will provide the ELSA Research Team with information about your cancer and death records.

This information will be used for statistics and research purposes only. The data will be used by the ELSA Research Team consisting of researchers at University College London (UCL), Institute for Fiscal Studies (IFS), University of Manchester, University of East Anglia, and NatCen under restricted access arrangements which make sure that the information is used responsibly and safely.

**Only the ELSA Research Team** will have access to information that can be used to identify you – like name and address. Access to the data for other qualified researchers can only be granted by the ELSA Research Team through a separate written application process that has been approved by NHS Digital. The information will be completely confidential and will be used for research purposes only by academic or policy researchers under restricted access arrangements.

As we would like to look at long term trends in people's health, we have not set a limit on how long we would like to keep your information. ELSA has been running since 2002 and is very valuable for looking at how people's health changes over time.

**Please ask the interviewer about anything that concerns you** or you can call the ELSA team on the freephone number on the leaflet and letter we sent you. **You can cancel this permission at any time** in the future by contacting NatCen.