

Sentinel Stroke National Audit Programme (SSNAP)

Why is this hospital/team collecting my information?

This is a national project. All health care settings (hospitals and organisations that provide services for stroke patients directly from 0-6 months) will take part. Participation shows that this organisation is committed to improving stroke care.

What information is collected?

Information collected can be used to decide where improvements need to be made. The hospital collects information on the care that you are given over a 6 month period, starting from the time you arrive in hospital. For full details of what is collected, please ask the person who gave you this leaflet or contact the SSNAP team.

From April 2020, SSNAP is now collecting information on confirmed or suspected COVID diagnosis.

What confidential information is collected?

Your name, date of birth, postcode, and NHS number (everyone in the country has a unique number that is used by the NHS).

Why is it necessary to collect confidential information?

This is so that the information about the care each patient receives can be matched up with other information. For example, the SSNAP information can be linked with other sources to find out which patients later died. This means that we can see if patients who get better care are less likely to die.

Why is this helpful?

If we can show that patients are less likely to die or have another stroke when they get good stroke care, it will encourage all healthcare settings to improve their stroke services. It will also encourage the funders to support the most important stroke services.

Where does my confidential information go?

There are very strict rules about what happens to your confidential information. The hospital provides information about the care you receive with your confidential information to SSNAP via a highly secure website. Only relevant organisations have access to this website, and only registered staff are able to enter it. They must have a password and they must agree to terms and conditions that protect your information.

Outside of the health care setting, your confidential information is only used to link to other sources of data and this is achieved without the project team seeing your identifiable information - data sources that we link with include Hospital Episode Statistics (HES), PEDW (Patient Episode Database for Wales) and NHS Digital (NHSD). Previously, data was also linked to the Office of National Statistics (ONS).

What if the information gets lost or stolen?

The methods for keeping your information safe are very advanced. Your information is stored safely in accordance with NHS recommendations and standards.

Why haven't the hospital staff asked for my permission to use my information?

It is difficult to ask all patients for their consent just after they have had a stroke. Some patients find it hard to communicate after they have had a stroke, some cannot speak and some won't have relatives with them. It is also a very distressing time for patients, and asking them about this project at this time would not be the most important priority. We have asked stroke survivors about this and they thought that the positives (the potential to improve stroke services) outweighed the negatives.

National Data Opt Out

From 30 September 2021, patient data sent to SSNAP will be subject to the National Data Opt Out. All healthcare providers in England must comply with the National Data Opt Out. If you are on the National Data Opt Out list, your data will not be submitted to SSNAP.

What if I do not want to have my confidential information included?

Please tell the person who gave you this leaflet or you can contact the SSNAP team by email ssnap@kcl.ac.uk or by telephone 0116 464 9901.

Further details about how we process your data:

A full fair processing statement outlining the legal basis for processing your data is available at <https://www.strokeaudit.org/SSNAP-Governance.aspx>