Sentinel Stroke National Audit Programme

Information sheet for patients being assessed at six month following stroke

Why are you collecting my information?

SSNAP is a national project by King's College London (KCL) and funded by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh Government. It collects information on the care that you are given starting from the time you arrive in hospital until you have this follow up, around six months after your stroke. Collecting information about your health six months after your stroke is really important as it helps us to understand how well people recover from stroke.

What confidential (patient identifiable) information about me is collected?

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

This is the first time I have heard about SSNAP. Why didn't the hospital staff who treated me ask for permission to use my information?

It is very 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. The SSNAP team consulted stroke survivors about this who said that they thought the positives (the potential to improve stroke services) outweighed the negatives.

Because of this, the SSNAP team have an exemption from obtaining explicit consent from each patient to collect confidential information up to six months after a patient has had a stroke. This exemption is granted by the NHS Health Research Authority (HRA) Confidential Advisory Group (CAG) and you can find out more about it by going to this website: https://www.hra.nhs.uk/hra-confidentiality-advisory-group/cag-advice-and-approval-decisions/

All organisations that participation in SSNAP are encouraged to talk to patients about SSNAP where this is possible and are asked to display information about SSNAP on the ward.

Why are you asking for my consent now?

We are asking for your consent to use your confidential information because we understand that many people wish to be informed about how their information is being used and for what purpose.

How is my information collected and how is it handled?

The hospitals and other organisations involved in your care collect your personal details and information on the care that they provided to you. This information is entered onto a secure website which can only be accessed by registered staff at relevant healthcare organisations. Staff must have a password and they must agree to Terms and Conditions that protect your information.

The SSNAP team at King's College London (KCL) then process the data entered to create reports which show how well each hospital or stroke team is performing. This analysis is anonymised.

The information is held on a website run by a company called Net Solving Ltd. Net Solving have put many measures in place to make sure your information is secure.

The Healthcare Quality Improvement Partnership (HQIP) is the organisation that funds SSNAP. They are called a data controller. HQIP are joint data controllers with NHSE for England data and Digital Health and Care Wales for Wales data. This means that they can decide what the data collected is used for – in this case reporting on how good stroke care is across England, Wales and Northern Ireland.

The SSNAP team will destroy your confidential information five years after the SSNAP project finishes.

If my confidential information is anonymised why is it necessary to collect it?

SSNAP needs to match information about stroke services and stroke care with other information:

- **Hospital Episode Statistics (HES) and Patient Episode Database for Wales (PEDW)**
  Everyone who goes to hospital receives a code based on the type of illness that they are treated for. By linking to HES and PEDW the SSNAP team can see that we are collecting information on nearly all stroke patients in the country This is very important because we want to report results which are representative of the care that all patients receive in hospital.
- **Mortality data**
  NHS Digital supplies data on people who die and what caused their death in the Civil Registration – Deaths database. It is important for SSNAP to be able to know whether or not people died after having a stroke, because if we can show that patients are less likely to die or have another stroke when they get good care it will encourage organisations to improve stroke services. Linking with this data also helps to make sure that families of stroke patients who died don't get inappropriately contacted, for example, for a six month follow up assessment.

SSNAP gets HES and mortality data from NHS Digital and PEDW data from the NHS Wales Information Service (NWIS) and so needs to use your confidential information to share with NHS Digital and NWIS to match the data.

Sometimes the SSNAP team receives requests from another organisation to use data already collected by SSNAP, for example from researchers who are interested in a particular aspect of stroke care. There is a very strict process which covers these types of requests, including that a panel of stroke doctors must agree that the proposal has research value and will help to further the understanding of stroke care.

What if the information gets lost or stolen?

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

What if I do not want my confidential information included in SSNAP?

Please tell the person who gave you this leaflet. If you do not want to have your confidential information included in SSNAP, your confidential information will be deleted from SSNAP. Opting out will not affect your medical care and you are free to withdraw your consent at any time.

Where can I find out more information about SSNAP?

SSNAP produce a wide range of reports on stroke care and these reports are updated four times a year. We also have Easy Access Versions of our reports, which we designed with stroke survivors and stroke charities; you can access these by going to the SSNAP website: www.strokeaudit.org/results.

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

Contact the SSNAP team

Tel: 0116 464 9901

Email: ssnap@kcl.ac.uk

Website: www.strokeaudit.org

Consent form for participation in Sentinel Stroke National Audit Programme (SSNAP)

Please tick box

1. I confirm that I have read and understood the SSNAP information sheet for patients being assessed at six months following stroke and have had the opportunity to ask questions ☐

2. I give my consent for my personal information to be shared with NHS Digital and NHS Wales Information Service, to link SSNAP data to: ☐
   a. Hospital Episode Statistics (HES) data or Patient Episode Database for Wales (PEDW) data
   b. Mortality data supplied by NHS Digital

_____   _____   _____

Name of Participant   Date   Signature

_____   _____   _____

Name of Assessor   Date   Signature