

Patient information sheet

What is the project?

This is a **national project**. All hospitals have to take part in this project.

Hospitals **collect information** about the **care** stroke patients receive.

This information will help find where **improvements** need to be made.

Participation shows that this organisation is committed to **improving stroke care**.

What information does SSNAP collect?

SSNAP collect data from **hospital** and **community** stroke care **teams**.

SSNAP collect data about the **care** stroke patients receive for the first **6 months** after their stroke.

From **April 2020**, SSNAP has been asking if the patient had **COVID-19**.

Does SSNAP collect my personal information?

SSNAP collect your:

- name
- date of birth
- Postcode
- NHS number (everyone has a unique number used by the NHS)

This lets SSNAP **link** stroke care data to other secure databases.

The SSNAP team will **never see** your personal information

How is my data kept safe?

There are **strict rules** for keeping information **safe**.

Hospital staff collect the information.

Only staff involved in **your stroke care** can see the information.

The hospital staff are **chosen by the hospital**.

The hospital staff **must be approved** by the hospital and by SSNAP.

Hospital staff send the information using a **secure website**.

Hospital staff must enter a **password** to see the information.

Hospital staff must **agree** to use the information properly.

Why do SSNAP collect my personal information?

NHS Digital (NHSD) and NHS Wales Informatics Service (NWIS) link your personal information to **two databases**:

1. NHS Digital (NHSD) database.

NHSD collects information about:

- **how many** people have **died**
- what **caused** their death

2. Hospital Episode Statistics (HES) database and Patient Episode Database for Wales (PEDW).

Hospitals give patients **codes**.

Hospitals send the codes to **HES** and **PEDW**.

SSNAP use these codes to:

- check **how many** people have had a **stroke**.
- show what is happening in **stroke care**.

This helps hospitals to **improve stroke care** for patients.

Why was I never asked about SSNAP in hospital?

It is **difficult** to ask someone for **consent** after a stroke.

Some patients find it **hard to communicate**.

Some patients **cannot speak**.

Some patients **won't** have relatives with them.

It is a **distressing** time for patients.

SSNAP **asked** stroke patients about this.

They thought SSNAP is **useful** because SSNAP can **improve** stroke services.

Because of this, SSNAP **do not** need **consent** from stroke patients for the first six months after their stroke.

What if I do not want to have my personal information included on SSNAP?

Please **tell** the person who gave you this leaflet.

Your personal information will then be **removed**.

National Data Opt Out

From the **31 July 2022**, patient data sent to SSNAP will be subject 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.

Contact the SSNAP team:

Telephone: 0116 464 9901

Website: www.strokeaudit.org

Email: ssnap@kcl.ac.uk

More info about how SSNAP process patient data: www.strokeaudit.org/SSNAP-Governance.aspx