Patient information sheet

What is SSNAP?

The **S**entinel **S**troke **N**ational **A**udit **P**rogramme (**SSNAP**) is a national project.

It is run by **King's College London**.

When we say "we", we mean **SSNAP**.

We **measure**:

- stroke care in **hospitals**
- stroke care at **home**
- progress **6 months after stroke**

Hospital		Home		6 months

All hospitals must send **SSNAP** information on how they treat stroke patients.

We measure hospitals' **stroke care** against **national clinical guidelines**.

These **guidelines** tell services what care **stroke patients** should receive.

This helps to **improve the care** patients receive.

The information we collect

We collect data on the first **6 months** of care after stroke.

For full details, as the **person** who **gave** you this **leaflet**.

Collecting your personal information

To link your **stroke care** information to **other illnesses** we need to collect your:

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

NHS England (NHSE) and Digital Health and Care Wales (DHCW) connect your personal information with information from:

Civil Registration - Deaths (supplied by **NHSE**)

This collects information about

- people who have died
- what caused their death

Hospital Episode Statistics (HES) and **Patient Episode Database for Wales (PEDW)**

Everyone in hospital is given a **code** which is sent to **HES** and **PEDW**. This **code** tells us about different **illnesses** across the country. We use these codes to:

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

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

How personal information is kept safe

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

Hospital staff collect your **personal information**.

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

They must be **approved** by the hospital and us.

This information is sent to **SSNAP**.

Hospital staff use a **secure website**.

They must enter a **personal password**.

Only staff involved in your stroke care can see this information.

The permission we need to collect your information

The **NHS** has told us when to ask for patients' permission.

We **do not** need **permission** when:

- the patient is in hospital.

- the patient is receiving care at home.

This is because the NHS understands that this information is important**.**

Measuring stroke services helps to **improve stroke care.**

We can check that services are giving patients the **care** that they **need**.

If you **do not** want your personal information in SSNAP:

- Tell the person who gave you this leaflet

- Email **SSNAP** on ssnap@kcl.ac.uk

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

You can do this at **any time**.

The National Data Opt-Out

The National Data Opt-Out **does not** apply to data entered on **SSNAP**.

If you are on the National Data Opt-Out list, your data will still be **included** in **SSNAP**.

Other purposes

Researchers can **request** to use data collected by **SSNAP**.

There is a **strict** process to approve these requests.

A panel of **stroke doctors** must **agree** the research will help **understand** stroke care.

Mostly this **does not** include personal information.

The National Data Opt-Out **does** apply to data used for **research**.

If you **do not** want your information used in research:

- Tell the person who gave you this leaflet

- Email **SSNAP** on ssnap@kcl.ac.uk

None of your information will then be used in research.

You can do this at **any time**.

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:** https://www.strokeaudit.org/Patient-information/What-is-SSNAP.aspx

Consent form for information
to be collected by SSNAP

Have you **read** and **understood** the information sheet?

Have you had a chance to **ask questions**?

Yes ✓ ☐   **No** ✗ ☐

Do you **agree** to **SSNAP** collecting your patient identifiable information?

Yes ✓ ☐   **No** ✗ ☐

Do you **agree** to the use of your information in **research**?

Yes ✓ ☐   **No** ✗ ☐

Please sign here:

_____   _____   _____

Your name   Date   Signature

_____   _____   _____

Name of Assessor   Date   Signature