

# **SLSR Privacy / Fair Processing Notice**

(last updated June 2024)

## **For which purpose are personal data collected and used?**

The South London Stroke Register (called SLSR) is a register of everyone who has had a stroke since 1995 in a defined area of Lambeth or Southwark. The information we collect is used to understand more about stroke and how people are affected by having stroke. The study will help us improve treatments and care for people with stroke by identifying areas where improvements are needed, allowing planning of future services and reducing inequalities in access to care and outcomes after stroke, both short- and long-term.

## **Sources and management of participant data**

We are collecting information from stroke patients directly and their medical records for this research project. The SLSR currently has approval under Section 251 to screen hospital records for eligible patients (pre-consent) and include into the register anonymised data for patients who died before consent could be obtained. For all other eligible patients, the SLSR fieldworker team is seeking either informed consent or consultee advice. The data collected is used to do the research or to make sure that the research is being done properly (auditing).

Each participant is given a unique study ID so that after we have entered identifiable patient information on the patient database, personal and health data is separated, and no-one (apart from the study researchers) will be able to identify which health data belongs to which patient. The paper and electronic health data are stored without any identifying information (such as name or address) in a secure place that only we have access to.

The information we hold about participants on the patient database includes NHS number, name and contact details. We store these details securely at King's College London, so that our research team can contact participants to arrange follow-up interviews, and to post any study newsletters.

At regular intervals, we are asking NHS England to notify us of any hospital admissions and the death of any participant (using NHS number and date of birth).

Under a data sharing agreement with the national stroke audit "Sentinel Stroke National Audit Programme" (SSNAP) we are receiving additional information on acute stroke-related hospital care for SLSR participants who are also recorded in SSNAP. This linkage is carried out by sharing NHS numbers.

Participants who live in Lambeth can give additional (optional) consent for their primary care data held in Lambeth Data Net to be linked with SLSR data.

Participants can stop being part of the study at any time, without giving a reason, but we will keep information that we already have.

Once we have finished the study, we will keep some of the data so we can check the results. Identifiable data is kept for 5 years; other research data is kept for 20 years. We are involving

the relevant KCL services/contractors for secure storage and destruction of electronic/physical records as necessary.

This project is registered on the King's Data Protection Register (KDPR) to confirm compliance with the GDPR for Research Governance Purposes.

More information on data flows in the SLSR can be found in the other attachment on the project webpage.

### **What is the legal basis for processing the data and who is the data controller?**

The lawful basis for processing personal data is Article 6(1)e of UK GDPR and for processing special category data Article 9(2)j of UK GDPR, i.e. processing is necessary for the performance of a task carried out in the public interest. The research is carried out to promote the interests of stroke patients, service users and the public.

King's College London and Guy's and St Thomas' NHS Foundation Trust are joint sponsors and joint data controllers for the SLSR.

You can find out more about how we use your information:

- at [Patient information and health and care research - Health Research Authority \(hra.nhs.uk\)](https://hra.nhs.uk/patient-information-and-health-and-care-research)
- our leaflet available from: [Research and development - Data and research | Guy's and St Thomas' NHS Foundation Trust \(guysandstthomas.nhs.uk\)](https://guysandstthomas.nhs.uk/research-and-development-data-and-research) (For GSTT) and [King's College London Statement on Use of Personal Data in Research | King's College London \(kcl.ac.uk\)](https://kcl.ac.uk/king-college-london-statement-on-use-of-personal-data-in-research) (for KCL)
- by asking one of the research team
- by contacting the Data Protection Officer: (For Guy's and St Thomas' NHS Foundation Trust: Nick Murphy-O'Kane [DPO@gstt.nhs.uk](mailto:DPO@gstt.nhs.uk); For King's College London: Albert Chan [info-compliance@kcl.ac.uk](mailto:info-compliance@kcl.ac.uk))