Data Protection Privacy Notice

1. The purposes of the processing

The STandard versus Accelerated initiation of Renal Replacement Therapy in Acute Kidney Injury (STARRT-AKI) Trial is a randomised controlled trial funded by the National Institute for Health Research, the research funding arm of the NHS.

The trial aims to see whether there is any difference between early initiation of renal replacement therapy (RRT) and standard initiation of RRT in terms of survival and kidney function in critically ill patients with severe acute kidney injury (AKI) in the Intensive Care Unit. Effects on quality of life will also be examined.

A secondary aim is to understand the long-term effects of AKI. Currently we know little about how AKI affects patients' health in general, whether patients who had AKI need long-term dialysis treatment earlier than patients without AKI, whether patients need more help from social services and whether they need to see a doctor more often. The NHS routinely collects data on all patients admitted to an intensive care unit in the NHS to help hospitals to improve the quality of care. There are also a routine NHS databases which collect data when patients are admitted to hospital in each of the nations. In England, the database is called Hospital Episodes Statistics (HES). Patients who need long-term treatment with dialysis or a kidney transplant are routinely registered on the UK Renal Registry.

To improve our knowledge about the long-term effects of severe AKI, we plan to access the data that is recorded routinely on such NHS databases. Accessing these data directly will give us very important information. It will also cut down the burden on patients to provide the information or to have to do tell us about their health and avoids extra blood tests. These results will not be used for clinical decision making in the trial. The data will be stored on Kings College London's Data Safe Haven hosted at AIMES Data Centre.

2. The lawful basis for the processing

As a University we use personally-identifiable information to conduct research to improve health, care and services. As a publicly funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research.

The lawful basis for processing personal data for STARRT AKI is therefore Articles 6(1)(e) and 9(2)(j) of the General Data Protection Regulation (2018).

3. The categories of personal data obtained

Personal data will be collected from a number of sources. This will include identifiable data and information about your social and medical history.

- A researcher will ask participants and their family members questions and complete some forms
- The participant will be asked to complete some questionnaires
- Clinical data that is routinely collected about the participant will be collected from other health and social care databases including: Health Episodes Statistics, Civil Registration Data, Intensive Care National Audit & Research Centre (ICNARC), UK Renal Registry, Scottish Morbidity Records, National Records for Scotland (NRS), Scottish Intensive Care Society Audit Group (SICSAG), Department of Health Hospital Information Branch (DoH HIB) in Northern Ireland, and Northern Ireland Statistics and Research Agency (NISRA).

4. The recipients or categories of recipients of the personal data

Only the research team at Guy's & St Thomas' Hospital and King's College London will have access to participants' personal identifiable data and clinical data.

5. The retention periods for the personal data

Personal data will be stored for up to 15 years. Participants are consenting for their trial data to be linked to Hospital Episode Statistics, Civil Registration Data and other routine health and social care databases for long term follow up during and beyond the end of the trial (for up to a further 5 years). This requires the retention of identifiable data for linkage. As for the clinical data, we have therefore proposed that personal data is held for up to 15 years.

6. The rights available to individuals in respect of the processing

A participant's right to access their data

Participants have the right to see or have a copy of their personal information at King's College London without any charge. If a participant wants to access their information, they should make a written request to the research team at King's College London – see the section below on 'Contacting King's College London'. We will normally provide their information within one month of receiving all the information we need to respond to their request.

A participant's right to rectify their data

Participants have the right to have their information amended. If a participant wants to amend their information at King's College London, they should make a written request to the team at King's College London – see the section below on 'Contacting King's College London'.

We will normally be able to make these changes within one month of receiving all the information we need to respond to their request.

7. The right to withdraw consent

Participants can withdraw consent for the data collected about them from any source to be used. If a participant wants to withdraw consent for their data at King's College London to be used in the STARRT AKI trial they should contact their local STARRT AKI research nurse who will complete a 'change of permissions/ withdrawal' form and submit this to the team at King's College London. If the participant is unsure how to contact their local STARRT AKI research nurse they should contact the team at King's College London (see the section below 'Contacting King's College London').

8. The right to lodge a complaint with a supervisory authority

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer (see the section 'Contacting the King's College London Data Protection Officer') who will investigate the matter.

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office.

Information Commissioner' Office:

Wycliffe house
Water Lane
Wilmslow
Cheshire SK9 5AF

Tel: 01625 545745
www.informationcommissioner.gov.uk

9. The data controllers and how to contact them

King's College London is data controller for the STARRT AKI Study. Their contact information is as follows:

King's College London
Information Compliance
Department of Business Assurance
Room 5.35
James Clerk Maxwell Building
57 Waterloo Road
London SE1 8WA

Email: info-compliance@kcl.ac.uk
Tel: 0044 207 848 7816

10. Contacting the data protection officer for King's College London and Guy's & St Thomas' Hospital London

Data Protection Officer for King's College London

Mr Albert Chan
Assistant Director of Business Assurance
(Information Compliance)
King's College London

Contact:
info-compliance@kcl.ac.uk

Data Protection Officer for Guy's & St Thomas' Hospital London

Mr Nick Murphy-O'Kane
Data, Technology and Information
Directorate
Westminster Bridge Road
London

Contact:
dpo@gstt.nhs.uk

11. Changes to this notice

We may amend this privacy notice from time to time. If you are dissatisfied with any aspect of our privacy notice, please contact the data protection officer.