

## How we will use your data

**This information leaflet explains how the KCDHH Biobank uses information from patients. It is a supplement to the Patient Information Sheet you will be given by your healthcare professional.**

### **What is patient data?**

When you go to your GP or hospital, the doctors and others looking after you will record information about your health. This will include your health problems, and the tests and treatment you have had. They might want to know about family history, your lifestyle e.g., smoking, or what work you do. All this information that is recorded about you is called patient data or patient information.

When information about your health care joins together with information that can show who you are (like your name or NHS number) it is called identifiable patient information. It's important to all of us that this identifiable patient information is kept confidential to the patient and the people who need to know relevant bits of that information to look after the patient. There are special rules to keep confidential patient information safe and secure.

### **What sort of patient data do biobanks use?**

If you agree to take part in the biobank, your doctor and local research team will forward a copy of your signed consent form to the KCDHH Biobank staff to confirm that you are taking part. This will have some personal information on (your name, date of birth and hospital number), however this personal information will not be passed onto researchers.

The Biobank will collect a set of non-personalised information which are relevant to your clinical condition, this may be passed onto other researchers. This will include age at time of sample collection, gender, clinical diagnosis and test results relevant to your diagnosis. We may then collect follow-up data to see if your condition has changed, or if you have received treatment for your condition.

### **How does the KCDHH Biobank use patient data?**

All personal information that is collected about you will be kept strictly confidential and will only be accessible to the named KCDHH Biobank staff who need to know this information for administrative purposes. This personal information is linked to a unique Biobank patient identification number. Thereafter, samples and documentation related to you and your sample in KCDHH will only be identified by this identification number. This information is stored securely on a computer where data is encrypted and access is password controlled.

Any samples and accompanying data that are sent to researchers will be anonymised so that you cannot be recognised from them.

### **Where will my data go?**

Your samples and accompanying data may be shared with researchers working in hospitals, universities or companies developing new tests or treatments in the UK or in other countries. Research teams in other countries must stick to the rules that the UK uses.

All the computers storing patient data must meet special security arrangements.

**What are my choices about my patient data?**

You can withdraw from the Biobank at any time, without giving a reason. If you withdraw from the Biobank, the data and samples already collected from you will be used for future research unless you specifically withdraw consent for this.

Your rights to access, change or remove your information are limited as we need to manage your information in specific ways in order for the Biobank and all research projects to be reliable and accurate.

**How long will you keep identifiable information about me?**

King's College London will store the anonymised research data and any research documents with personal information, such as consent forms, securely at the King's College London for as long as it is required from the relevant regulatory bodies after the end of the biobank. The team at your local hospital site will keep identifiable information about you for as long as their organisational policies determine.

**Will my donated samples or clinical data be used by researchers after my death?**

Your donated samples and clinical data may be used by researchers after your death without the biobank seeking additional consent from your next of kin. We do not collect samples from individuals after death.

**Will the use of my data meet GDPR rules?**

GDPR stands for the General Data Protection Regulation. In the UK we follow the GDPR rules and have a law called the Data Protection Act. All research using patient data must follow UK laws and rules.

When companies do research to develop new tests or treatments, they need to be able to prove that they need to use patient data for the research, and that they need to do the research to develop new tests or treatments. In legal terms this means that they have a 'legitimate interest' in using patient data.

Universities and the NHS also need to be able to prove that they need to use patient data for the research. In legal terms this means that they use patient data as part of 'a task in the public interest'.

Researchers must show that their research takes account the views of patients and ordinary members of the public. They must also show how they protect the privacy of the people who take part. An NHS research ethics committee checks this before the research starts.

**Who can I contact if I have a complaint?**

If you wish to complain about any aspect of the way in which you have been approached or treated during the Biobanking process, or the way in which your information has been handled, in the first instance you should contact the Biobank Data Manager.

You may also contact the Director of Research Management and Director of Administration (Health Schools), King's College London, Strand, London, WC2R 2LS.