

## **Privacy Notice for ReIMAGINE Prostate Cancer Risk study**

University College London ("UCL", "we", "our", "us") respects your privacy and is committed to protecting your personal data.

Please read this Privacy Notice carefully – it describes why and how we collect and use personal data and provides information about your rights. It applies to personal data provided to us, both by yourself or by third parties.

We keep this Privacy Notice under regular review. It was last updated on 6<sup>th</sup> May 2020

### **1. About Us**

UCL, a company incorporated by Royal Charter (number RC 000631), is the entity that determines how and why your personal data is processed. This means that UCL is the 'controller' of your personal data for the purposes of data protection law.

#### ***General Information***

UCL aims to conduct research to the highest standards of research integrity. Our research is underpinned by policies and procedures that ensure we comply with regulations and legislation that govern the conduct of research; this includes data protection legislation such as the General Data Protection Regulation and the Data Protection Act 2018.

UCL uses personal data to conduct research to improve health, care and services. As a publicly-funded organisation incorporated under a Royal Charter, we ensure that it is in the public interest when we use personal data 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 personal 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 must demonstrate that our research serves the interests of society as a whole.

#### ***What is research?***

Research has a special status under data protection legislation. It is important therefore to specify what we mean by research. It is generally understood by universities that research makes an original contribution to knowledge. Research conducted by our staff and postgraduate research students is always intended to make an original contribution to knowledge. Such research is published in order to share that knowledge.

## **2. What is Personal Data (also referred to as a personal information)?**

'Personal data' means any information which relates to or identifies an individual. This includes information which may not explicitly identify you (e.g. where your name has been removed) but which does make it possible to identify you if it is combined with other information that is readily available. For example, this might be because the information available contains a postcode, your gender and date of birth; in these circumstances it might be possible to identify you by using other information available elsewhere. Therefore, in these circumstances, we would treat the details we hold as personal information and protect it accordingly.

We promise to respect the confidentiality of the personal information that you, as a participant in our research, provide to us; that we get from other organisations; and that we share with other collaborating organisations, such as other universities, consortium/project partners or our research funders. We will be clear with you when we collect your information how we intend to use it. We will not do anything with your personal information that you wouldn't reasonably expect. We will use your information only for the purpose of the research you are participating in and we will not usually use your information or contact you for any purpose other than research unless you have agreed to this. We commit to keeping your personal information secure.

## **3. Who is responsible for my personal information?**

UCL is the data controller for the ReIMAGINE Prostate Cancer Risk study (IRAS 251166), which means that UCL will decide how your personal information is created, collected, used, shared, stored and deleted (processed). We do so in line with the objectives of the research, ensuring we collect only what is appropriate and necessary and we have informed you of what we are collecting.

The other partners in the ReIMAGINE Consortium will **not** receive any of your personal data. They will only ever receive your information in a de-identified form. A list of consortium partners can be found on the project website: <https://www.reimagine-pca.org/consortium-partners>

## **4. What personal data do we use within this study and where do we get it from?**

### ***Personal data that we collect directly from you***

UCL will not collect any personal data directly from you.

### ***Personal data that we collect from other sources***

We receive your personal data, as listed below, from other sources, primarily from the local NHS Trust where you agreed to take part in the study ("Recruiting NHS Trust") and from your national NHS records (such as the Office for National Statistics, NHS Digital, Public Health England, and other applicable NHS information system, or national database).

#### ***Recruiting NHS Trust***

- Your participation consent form – name, signature
- Name, contact details, date of birth, NHS number, ethnicity, BMI, family history of prostate cancer
- Clinical information - this may include your medical history, medication history, haematology results, clinical staging, imaging results and pathology results
- Samples that you choose to donate to us (blood, urine, prostate tissue/cores, MRI scans)

- Imaging files and related meta data (MRI scan)
- Histology images and related meta data (prostate biopsy)
- Genomic data (derived data from the samples you provide)

*National NHS records (collected for a 3 year period from your prostate biopsy)*

- Clinical information – this may include your medical history, subsequent medical diagnoses and/or mortality data (where applicable).

To protect your privacy, all directly identifying data (example: name, medical record number, contact details) will be separated from the research data (such as measurement data) and replaced by a participant code. On all study-specific documents, other than the signed consent form, you will be referred to by a participant code, not by name.

### **Special category personal data**

Some of the personal data we collect about you is classed as being within 'special categories of personal data' under current data protection laws, for example information relating to your ethnicity or genetic data. Access to, and the sharing of, this information is controlled very carefully.

All our researchers are asked to de-identify (pseudonymise) (remove identifiers such as your name and replace this with a unique code or key) or delete personal information collected as part of their research at the earliest opportunity. All personal data is kept in line with our policies or any regulatory requirements.

## **5. Purposes for which we process your personal data and the legal basis for processing**

Data protection laws require us to meet certain conditions before we are allowed to use your personal data in the manner described in this notice, including having a "legal basis" for the processing. Where we process special category personal data, we are required to establish an additional legal basis for processing that data.

We take our responsibilities under data protection laws extremely seriously, including meeting these conditions. The main legal bases on which your personal data are processed for a particular purpose are also explained in the table below.

Purpose	Legal Basis
<p><b>To Carry out the Research Study</b></p>	<p><b>For all personal data</b></p> <p><b>Performance of a task in the public interest</b></p> <p>UCL will be processing personal data in its capacity as a public authority in connection with its core purposes of education, research and innovation. Please see our <a href="#">Statement of Tasks in the Public Interest</a> for further information.</p> <p><b>For special categories of personal data</b></p> <p><b>Research</b></p> <p>We will process your personal data on the basis that it is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes.</p>
<p><b>Share Information with your Doctor</b></p> <p>We may share information with your doctor if data becomes available through the course of research analysis that researchers feel may be important to you or your blood relative's health.</p>	<p><b>For all personal data and special categories of personal data</b></p> <p><b>Consent</b></p> <p>We will <i>only</i> share this information where you provide consent on the Participant Information Sheet.</p>
<p><b>Communication regarding further research studies</b></p> <p>Where you are interested, we may communicate with you regarding further related research studies.</p>	<p><b>For all personal data</b></p> <p><b>Consent</b></p> <p>We will contact you about further studies if you provide consent on the consent form.</p>
<p><b>Internal and statutory reporting, audit and other legal and regulatory obligations</b></p> <p>We may use your personal information to:</p> <ul style="list-style-type: none"> <li>• Comply with our legal and regulatory obligations in relation to carrying out this study;</li> <li>• Produce statistics and research for internal and statutory reporting purposes; and</li> <li>• Manage our accounts and records.</li> </ul> <p>This may include, where strictly necessary, the processing of special category personal data, e.g. information about your health or ethnicity.</p>	<p><b>For all personal data</b></p> <p><b>Compliance with a legal obligation</b></p> <p>Much of our processing of your personal data in this context will be in order to comply with our legal and regulatory obligations.</p> <p><b>Performance of a task in the public interest</b></p> <p>UCL will be processing personal data in its capacity as a public authority in connection with its core purposes of education, research and innovation. Please see our <a href="#">Statement of Tasks in the Public Interest</a> for further information.</p> <p><b>For special categories of personal data</b></p>

	<p><b>Research</b></p> <p>We will process your personal data on the basis that it is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes.</p>
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Please note that whilst you may have agreed to take part in this study, for the purposes of data protection law we do not generally rely upon the legal basis of consent to process your personal data for the research purposes of this study. We rely on the legal bases set out above. Where we do process your personal data based on your consent, such as for sharing information with your Doctor, we will inform you of this before we start the processing and you will have the right to withdraw your consent at any time. See "Your Rights" in section 12 below.

We do not use automated decision making (where an electronic system uses personal data to make a decision about you without human intervention) or profiling (where an electronic system uses personal data to try and predict something about you).

As explained above, we will pseudonymise your data as soon as we receive it. We will share your data in de-identified form with the ReIMAGINE Consortium partners for the purposes of furthering the research study. These partners are listed here <https://www.reimagine-pca.org/consortium-partners>, along with information on for what future secondary research & development purposes these partners might use the data.

## **6. Who will my personal information be shared with?**

Your personal data will be collected and processed primarily by UCL staff on receipt of your information from the Recruiting NHS Trust. Access to your personal data is limited to staff within the UCL project team who have a legitimate need to see it for the purpose of carrying out their job at UCL. Your personal information will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you.

Your personal data may be disclosed, where necessary, to other organisations as required by law e.g. for crime prevention, investigation or detection purposes or in order to protect your vital interests. In addition, where necessary, we may share your personal data, including special category personal data, with the following:

- Your Doctor (only where you have provided consent on the Participation Consent Form)
- Regulatory authorities (agencies and officials)
- Research Ethics Committee representatives involved in the study
- Sponsor's representatives involved in the clinical investigation

Information shared will be on a need to know basis, not excessive and with all appropriate safeguards in place to ensure the security of your information.

We also sometimes use products or services provided by external service providers who carry out a task on our behalf or used for sharing research data for collaboration, particularly in relation to our IT systems. These third parties are known as data processors and when we use them we have contractual terms, policies and procedures to ensure confidentiality is respected and the service provider is required to keep it safe and secure. This does not always mean that they access your information. We require all third parties to respect the security of your personal data and to treat it in accordance with the law. We do not allow our third party service providers to use your personal data

for their own purposes – we only permit them to process your personal data for specified purposes and in accordance with our instructions.

Personal data will be de-identified before being shared with other organisations, including the ReIMAGINE Consortium partners (except to the extent any act as a processor) as explained in the Participant Information Sheet. If you have any further questions about research collaborations, please contact the research team you are involved with.

No personal data will be published in any findings resulting from the research study. We will only publish anonymised information.

## **7. International transfers**

We do not systematically transfer your personal data outside the European Economic Area (EEA). There are also other circumstances in which we may transfer your personal data outside the EEA, e.g. where we use a third party cloud services provider based outside the EEA to store personal data.

Where we transfer your personal data across national boundaries to a third party, such as one of our service providers, we will protect your personal data by ensuring that those transfers are made in compliance with all relevant data protection laws. Generally, this means where we transfer your personal data to a third party that is located in a country which does not have adequate privacy protection, we will put in place a contract with the third party that includes the standard international data transfer contractual terms approved by the European Commission.

For further information on the measures in place, please contact us using the details set out under 'Who can I contact?' below.

## **8. Data retention**

We ask our researchers to de-identify information wherever possible (anonymisation or pseudonymisation). Information where you can be identified will, as such, be kept for a minimum amount of time and for as long as necessary to fulfil the purposes we collected it for, including for the purposes of satisfying any legal, regulatory, accounting, or reporting requirements.

For some research projects we cannot de-identify the information as it is necessary for achieving the outcome of the research. For such projects, we store your personal information as part of the research for the duration of the project and for a defined period after the project has ended. This is usually defined by external regulations but may be defined by our own policies and procedures.

UCL will keep information about you from this study for 25 years after the study has finished.

### **What safeguards do we have in place to protect your personal information?**

In order to protect your rights and freedoms when using your personal information for research and to ensure we meet the conditions set out in data protection law for processing special category information in a research context, we implement special safeguards, including the following:

- policies and procedures that tell our staff and students how to collect and use your information safely;
- training which ensures our staff and students understand the importance of data protection and how to protect your data;
- security standards and technical measures that ensure your information is stored safely and securely;

- all research projects involving personal data are scrutinised and approved by a research ethics committee;
- contracts with companies or individuals not associated with UCL have confidentiality clauses to set out each party's responsibilities for protecting your information;
- we carry out data protection impact assessments on high risk projects to ensure that your privacy, rights as an individual or freedoms are not affected; and
- if we use collaborators outside of Europe, we will ensure that they have adequate data protection laws or are part of privacy and security schemes such as the privacy shield in the U.S.

In addition to the above safeguards, data protection legislation also requires us to meet the following standards when we conduct research with your personal data:

- the research will not cause damage or distress to someone (e.g., physical harm, financial loss or psychological pain);
- the research is not carried out in order to do or decide something in relation to an individual person, unless the processing is for medical research approved by a research ethics committee;
- the Data Controller has technical and organisational safeguards in place (e.g. appropriate staff training and security measures); and
- if processing special category personal data, this must be subject to a further public interest test to make sure this particularly sensitive information is required to meet the research objectives.

## 9. **Your rights**

Under data protection legislation you have individual rights in relation to the personal information we hold about you. Subject to certain conditions, these include the right to:

- access your personal data
- correct any inaccurate data
- erase any personal data
- restrict or object to our processing of your personal data
- move your personal data ("portability")
- withdraw your consent where we are relying on it to use your personal data. Please note that a withdrawal of consent will not affect the lawfulness of processing based on consent before its withdrawal
- ask us not to use information about you in a way that allows computers to make decisions about you and ask us to stop

It is important to understand that the extent to which these rights apply to research will vary and that in some circumstances rights may be restricted. In certain circumstances, we may also need to restrict your rights in order to safeguard the public interest (e.g. the prevention or detection of crime) and our interests (e.g. the maintenance of legal privilege).

### ***How can I exercise my data protection rights?***

If you wish to exercise any of your rights, please consult UCL's data protection webpages or email [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk), telephone us on (0)20 7679 2000; or write to Data Protection Officer, UCL Gower Street, London WC1E 6BT.

### ***Who can I contact with questions?***

If you have any questions about how your personal information is used, please consult UCL's data protection webpages or email [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk). If you need further assistance, please contact UCL's Data Protection Officer, by email at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk); by telephone on +44 (0)20 7679 2000; or, by writing to: Data Protection Officer, University College London, Gower Street, London WC1E 6BT.

If we are unable to adequately address any concerns you may have about the way in which we use your data, you also have the right to lodge a formal complaint with the data protection authority in your country or our main data protection regulator, the Information Commissioner's Office. Full details may be accessed on the complaints section of the [Information Commissioner's Office website](#).