



**University College
London Hospitals**
NHS Foundation Trust

International Registry for Nanoknife™ prostate cancer treatments

This notice explains how your personal information is processed, used, and secured and details the ways in which you can exercise your individual rights with regards to your personal information contained within the Arc IRE Registry.

About the Registry

The Registry collects information about patients who have received Irreversible Electroporation (IRE) focal ablation in order to treat a diagnosis of prostate cancer, where those patients have consented to the inclusion of their data. Long term data is needed to show that it is effective in cancer control and understand the quality of life patients have following the procedure.

UCLH acts as Data Controller for the registry and partner hospitals will also invite their patients to take part.

Why does the Prostate IRE Registry collect data?

The registry collects and analyses data in order to:

- Understand the effectiveness of the Nanoknife™ treatment for men with prostate cancer
- Understand any impact Nanoknife™ treatment has on a patient's quality of life.
- Improve treatment - the data will allow better understanding of how different treatments affect patient outcomes and how treatments vary between hospitals.
- Evaluate policy - data enables comparisons of survival rates and outcomes with other countries and NHS Trusts
- Improve counselling of patients prior to the procedure

What data we collect

We will collect data from the medical records held by your hospital. This will include:

- Demographic information, like your name, date of birth and contact details
- Information about your condition
- Information regarding the medication you have taken, or are taking in relation to your condition
- Details about the Nanoknife™ procedure itself.
- Your local hospital number and NHS number so we can continue to add information about you progress after treatment.

How we use your data

The data used in the registry is collected by the doctors, nurses and hospital staff treating and managing patients before being uploaded. Once records have been uploaded, they can be reviewed only by authorised medical staff using an approved user account using a secure password.

We will securely store your email address so you can continue to update us on your health following the Nanoknife™ treatment. We'll intermittently send you a link to a questionnaire to



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allow for this. This is called ePROMs (electronic Patient Reported Outcome Measures) and is the gold standard for understanding how patients are progressing after treatment.

The data will be analysed by authorised staff in order to achieve the objectives listed above.

As a result of this analysis, UCLH may publish statistics, reports and outputs that contain only anonymous data which cannot be used to identify individuals. UCLH will never publish any data that could identify you.

Who we share with

We treat the data we hold with great care. All data which is held by UCLH is subject to robust rules relating to privacy, security and confidentiality and only the minimum amount of data necessary to achieve the relevant health and social care purpose will ever be processed. Wherever possible, de-personalised data or anonymous data is used to protect patient confidentiality.

In order to provide the registry, the system itself is provided by Dendrite Clinical Systems Ltd who act as a Data Processor on behalf of UCLH. UCLH has undertaken all relevant due diligence and have appropriate governance in place such as contracts.

Withdrawing consent

You can withdraw your consent at any time. Please contact your surgeon who will advise you or email the registry on ARCregistry@nhs.net

How long we keep your data for

We will keep your data for at least 20 years to allow us to determine the best treatments for patients, and to allow any regulatory monitoring that should occur.

Where we store data

The Arc IRE Registry and its processor only stores and processes data within the United Kingdom and Europe.

The legal basis to process your data

UCLH is the controller of the personal data held by the Registry under data protection law.

Under UK GDPR we can only collect and use personal data if we have a legal basis under Articles 6 and 9 of the UK GDPR.

Our legal basis for collecting and analysing personal data is Article 6(1) (a) (e), where processing is necessary for the performance of a task carried out in the public interest and with your explicit consent.



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As the data we collect is health data, which is a special category of data under UK GDPR, we also need an additional legal basis under Article 9 of UK GDPR. This is Article 9(2)(j), where processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes.

Your rights over your data

You have the right of access, rectification, erasure, restriction and objection to the processing of your data.

You also have the right to complain about the processing of your data. If you are dissatisfied, please contact the UCLH's Data Protection Officer in the first instance at uclh.igqueries@nhs.net. If you remain dissatisfied and you live or work in the UK, the relevant authority is the Information Commissioner's Office.

Our Data Protection Officer

Our Data Protection Officer is Matthew Hall, who can be contacted at uclh.igqueries@nhs.net.