Cordotomy Registry Privacy Notice

This privacy notice intends to explain how patient’s personal information is processed, used and kept safe and it also details individuals’ rights with regards to their personal information contained within the Cordotomy Registry held by Dendrite Clinical Systems Limited (Data Processor).

 What is the Cordotomy Registry?

The Cordotomy Registry is the database used for collecting patient and surgical reported outcomes for pain outcomes after cordotomy. This information is extremely important as the ‘pool’ of data collected is hoped to inform future clinical practice and inform what is expected including success rate, side effects and complications from cordotomy. The Walton Centre NHS Foundation Trust is the Data Controller and the system itself is supported by Dendrite Clinical Systems Ltd who act as a Data Processor on behalf of the Cordotomy Registry and the Walton Centre.

What information does the Cordotomy Registry contain?

Clinical data is collected on cancer related pain and is submitted after cordotomy on pain scores, pain killers use, site, nature and location of cancer causing pain and impact (efficacy for pain relief, reduction in use of pain killers and side effects of cordotomy) of cordotomy procedure on cancer related pain.

 What happens to the data and who can see it?

The data used in the Cordotomy Registry is collected after cordotomy. This data is collected from those patients who have had the cordotomy procedure for severe cancer related pain. Every three to four years the data will be analysed to consider any relevant trends of significance and shared with other practitioners to inform future clinical practice and inform what is expected outcomes including success rate, side effects and complications from cordotomy.

Any information obtained for this purpose that can identify you will be treated as confidential and securely stored at The Walton Centre. The only identifiable data stored on the Registry that relates to patients of The Walton Centre, is date of birth and gender. The transferred data is protected from being accessed by unauthorized persons. Only hospital staff and medical audit workers can access the data. Dendrite will only access the data as instructed by The Walton Centre.

What is the legal basis to process personal data?

Personal data processed within the Cordotomy Registry relies on the following legal basis:

* Public task: the processing is necessary for you to perform a task in the public interest or for your official functions, and the task or function has a clear basis in law.

Special Category data is processed under the following condition:

* Health or social care (with a basis in law): (preventive or occupational medicine, for the assessment of the working capacity of the employee, medical diagnosis, the provision of health or social care or treatment or the management of health or social care systems and services).

Where is data stored and for how long?

The data will be held for a maximum of twenty years in line with research purposes - if consent is withdrawn any personal data would be immediately removed.

Security

 Information contained within the Cordotomy Registry is held on a server provided by Dendrite Clinical Systems Ltd. Dendrite uses a contracted sub processor called RedCentric. All data remains within the UK and is held by a secure tier three data centre.

Your rights

 Under Data Protection laws, you have rights which allow you to find out what information is held about you, on computer and in certain manual records. This is known as "right of subject access.

If you want to see or receive a copy of your records that are held in the Cordotomy Registry, please email wcft.dpo@nhs.net

Under the law, you may also have additional rights in relation to your information. For example:

 • You also have the right to request any decisions taken by automated decision making with regards to your information (where applicable);

• The right to rectification of your information is found to be inaccurate (in line with NHS Guidelines);

• The right to restrict processing (where applicable);

• The right to data portability (where applicable);

• You may have the right to erasure of your personal information held by us, in certain circumstances.

• You have the right to withdraw consent at any time, where consent has been given. If you wish to no longer take part and be removed from the Cordotomy Registry, please contact dpo@thewaltoncentre.nhs.uk

If a patient wishes to be removed from the registry, all data relating to this patient is removed from the registry.

Further information

If you would like to know more about how we use your information or if, for any reason you do not wish to have your information used in any of the ways described in this notice please speak to the consultant concerned with your care or contact the Walton Centre using the following details:

wcft.dpo@nhs.net

Further guidance about data protection can be obtained at www.ico.org.uk. You also have the right to lodge a complaint with the Information Commissioners Office.

The ICO’s address is:
Information Commissioner’s Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

Helpline number: 0303 123 1113
ICO website: [https://www.ico.org.uk](https://www.ico.org.uk/)