



## Patient Information

### What is the National Neuromodulation Registry?

Nowadays, it has become very important to collect information about the surgery and treatment we do for patients. This allows Doctors and the National Health Service to monitor why we do certain procedures and the benefits they bring for patients. The registry will record all patients in the United Kingdom who receive a device implanted to treat pain, spasticity (stiffness) or other nerve disorders. This allows the specialists to track the usefulness and safety of these devices and what improvement there has been from the treatment. This is already happening in other areas such as Joint Replacement, Spinal and Cardiac surgery.

### How does the NNR help patients?

The NNR provides information and evidence to:

- Improve patient safety by checking how good implants, surgeons and hospitals perform and take action where it is needed
- Provide hospitals, surgeons and implant manufacturers feedback about their performance to help them improve patient care
- Help surgeons decide whether patients need to return to hospital if critical implant problems are found

### What data is collected?

Your personal details allow the NNR to link you to the surgery you have had and any device that has been implanted. This allows us to link together all the questionnaires you complete about your condition, how it affects you, and how you have responded to treatment.

The NNR will collect details of your name, gender, date of birth, address, email, hospital number and NHS number.

Your details are treated as confidential at all times and kept on a secure database. This data is stored outside the NHS by an Organisation (Northgate Public Services) who also run the National Joint Registry and are fully compliant with data security regulations. The data is owned and controlled by the Neuromodulation Society of the United Kingdom and Ireland (NSUKI). Personal details apart from gender and age are removed before any data is analysed. Your personal data and email address will not be made available to anyone outside NSUKI or its secure IT provider (Northgate PS). Anonymised data may be released to approved organisations for research and specified purposes but a signed agreement restricts what they can do with the data so that patient confidentiality is maintained and data release will only be permitted by NSUKI through its own Governance Committee.

Your personal data needs to be collected for the Registry as this allows us to link details of your diagnosis and surgery with any problems or complications after surgery. You will be asked to

complete questionnaires before and after surgery so we can work out how successful the surgery has been. We have to be able to connect you to the questionnaires through your personal details. Assessing outcomes over a long period of time using the Registry will help us monitor how effective treatments are and help us adjust and change treatments to reduce risks and improve treatments for all our patients.

### **Do I have to give consent?**

No. If you do not consent, your operation details will be stored on the NNR without any personal details, so you cannot be identified. Your clinical care will not be affected by your decision on taking part in the registry. If you change your mind about consenting to the NNR holding your personal details, please contact the NNR Centre – see ‘Finding out more’ below.

### **Research**

Giving your consent also allows the Registry to study the details of your diagnosis, surgical procedures, complications, outcome after surgery and your questionnaires. These are known as “audits” or “service evaluations”. This information may be used for research to improve our understanding of the conditions that respond to neuromodulation treatments and which conditions respond best to particular therapies. Research uses only anonymised information that makes it impossible to identify individuals. Occasionally, you may be contacted by researchers asking for more information about your condition but we would always ask you first for your approval before disclosing your contact details to them. You will never have to take part in any research study unless you are willing to take part, and saying no does not affect the care you receive.

### **Children**

Parents are asked to consent to data collection from their child if he or she is under the age that they can legally give their own consent. It is important to us that data is collected on everyone undergoing neuromodulation therapies to make the data as useful as possible.

### **Finding out more**