

National Joint Registry: Patient Consent Form



National Joint Registry

Working for patients, committed to excellence

What is the National Joint Registry?

The role of the National Joint Registry (NJR), which operates in England, Wales, Northern Ireland, Isle of Man and Guernsey, is to improve patient safety and monitor the results of joint replacement surgery. With your consent, the information held on the registry helps us to find out which are the best performing artificial joints, the most effective types of surgery and can also help surgeons to quickly decide whether patients need to return to hospital if implant problems are ever found.

How does the NJR help patients?

The NJR provides information and evidence to:

- empower patients by helping them find out more about the implants available to them.
- help surgeons choose the best artificial joints (implants) for patients.
- improve patient safety by monitoring how well implants, surgeons and hospitals perform and take action where it is needed.
- give hospitals, surgeons and implant manufacturers feedback about their performance to help them improve orthopaedic patient services.



What information is collected?



Details of your operation and your implants will be recorded on the registry by your hospital. Your personal details such as your name and address will only be recorded if you give your consent.

Why does the NJR need my personal details?

Your personal details allow the NJR to link you to the implant(s) you received during surgery. If, for instance, you need another operation in the future, we can measure the time between the operations. Adding together this information from all patient operations tells us how well different implants, hospitals and surgeons are doing.

Without using personal details to link operations, the NJR cannot find out about problems with implants, hospitals or surgeons.

Personal details needed by the NJR are:

✓ Name ✓ Date of birth ✓ Postcode ✓ NHS number ✓ Contact details

The NJR might also give you the opportunity to take part in patient feedback surveys in the future, to give your views on your experiences and how the surgery has made your life better so we can better understand patients' reported outcomes. You do not have to give us your contact details if you don't wish to take part in any surveys and if you don't participate this will not affect your care.



NJR data and other healthcare information

Operation and patient information in the registry is used to link to other healthcare information, including data held by NHS digital and the NHS Wales Informatics Service. Amalgamated data is analysed and made available to surgeons, hospitals and manufacturers - without any of your personal details - as part of our feedback services. Doing this improves our ability to monitor patient safety and patient outcomes. It also means that people and organisations involved in improving joint replacement surgery can better understand and develop improved, or more cost-effective medical treatments.



NJR and research

Operation and patient information in the NJR may be used for medical research. The purpose of this research is to improve our understanding and treatment of joint problems.

The majority of our research uses only anonymised information which means it is impossible to identify individuals. From time to time researchers may wish to gather further information. In these cases we would seek your approval prior to disclosing your contact details. You do not have to take part in any research study you are invited to take part in and saying no does not affect the care you receive.

Please be reassured that the storage, release and use of this data are subject to very strict controls.

You can find examples of how we use data for research at www.njrcentre.org.uk as part of our Research Library.



Do I have to give my consent?

No. If you do not consent, your operation details will be stored on the registry without any personal details, so you cannot be identified. If you change your mind about consenting to the NJR holding your personal details, please contact the NJR Service Desk – see 'Finding out more' below.

In order to ensure high quality of the information within the NJR and to avert unfair conclusions being made about performance related to hospitals, particular surgeons or types of joint replacement, we will periodically ask hospitals to send a list of related surgeries already registered in their own system and compare their data against the NJR's to look for any missing records. This list will include personal details of patients that haven't consented. Their personal data will not be stored in the registry but used only to report back to the hospital if any records are found to be missing.



Is my information safe?

Your personal details are kept confidential at all times. Very strict rules and secure procedures are in place to ensure that your information is kept safe. You can ask for a copy of your personal data held on the registry by emailing or writing to the NJR Service Desk.



Finding out more

NJR Website

www.njrcentre.org.uk

Email

enquiries@njrcentre.org.uk

NJR Service Desk

Tel: 0845 345 9991 – Mon-Fri 9am to 5pm (exc. public holidays)

NJR Service Desk

NEC Software Solutions, 1st Floor iMex Centre, 575-599 Maxted Road, Hemel Hempstead HP2 7DX



Giving your consent is voluntary and more information is available if you are unsure.
Whether you choose to consent or not, please sign this form.

Patient details

Surname

Forename

Date of birth

Postcode (home)

Mobile number (optional)

Email address (optional)

To be completed by the hospital

Hospital

NHS number (or equivalent) or local hospital ID:

Height cm Weight kg

or BMI

I CONSENT to my personal details being recorded within the registry. I understand that the NJR will not release my personalised data unless required by law or where there is a clear overriding public interest in disclosure. Where possible, I will be told if any disclosure is to take place.

I CONSENT to my contact details (entered above or from my hospital records) being recorded within the registry. The NJR will not release these details to any third party and will only contact me to ask about my care and treatment. YES ☐ NO ☐

Signature

Date

I DO NOT CONSENT to my personal details being recorded within the registry.

Signature

Date

To be completed by the hospital (person accepting patient consent).

Name

Signature

Position

Date

This form should be kept as part of the patient record. DO NOT send this form to the NJR Service Desk.

June 2022