



National Joint Registry

www.njrcentre.org.uk

Working for patients, driving forward quality

The National Joint Registry (NJR) Enabling Improvements in Patient Outcomes

How **you** can contribute
to the work of the NJR



The National Joint Registry records and analyses joint replacement data to enhance patient safety and help to improve patient outcomes

 /nationaljointregistry

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How does the National Joint Registry help patients?

The National Joint Registry (NJR) records details of joint replacement operations in order to monitor the results, protect patient safety and improve outcomes.

Giving your consent to be included in the registry means that, should there ever be any problems, you can easily be identified by the NJR for follow-up through your hospital.

We provide information and evidence to:

- Empower patients by enabling them to find out more about the implants available to them.
- Help surgeons to choose the best artificial joints (implants) for patients.
- Improve patient safety by showing how well implants, surgeons and hospitals perform and to take action where it is needed.
- Give hospitals, surgeons and implant manufacturers feedback about their performance to help them improve patient care.
- Help surgeons quickly decide whether patients need to return to hospital if there are any reported problems with specific implants.

Giving your consent is voluntary but more **than 9 out of 10** patients agree to have their details added to the registry

What information is collected?

Your hospital will input specific details of your operation into the registry. These details include the type of implant you received, which surgical technique was used, which side of your body the implant went into, as well as your name, date of birth, gender, contact details and NHS number.

The NJR asks all patients to give their permission (consent) to have their personal details confidentially recorded with their operation details – this enables the NJR to be more effective in our role in protecting patient safety (and to get in touch if there is a need). To date around 3.5 million patient records have been included in the registry.

We ask you for your contact details so that we can send you questionnaires about your experiences. Providing these is optional and you can still take part in the NJR without participating in them.

The NJR asks patients about their treatment experiences as we want to use this feedback to help to improve the healthcare given to all patients.

Participation is voluntary and none of your personal information will be shared, but the hospital will need to take your contact details so that the NJR can use these to share the questionnaire with you after your treatment.

You should be asked by your hospital if you would like to give your consent and an **NJR patient consent form will be completed**

What happens if I don't consent?

If you choose not to consent for your personal details to be collected by the NJR, please tell the doctors or nurses looking after you. This will not affect your treatment in any way.

Because the NJR needs to understand how and where certain types of joint replacement are being used, we will still collect information about the type of surgery that you have had, but this record will not contain your personal details.

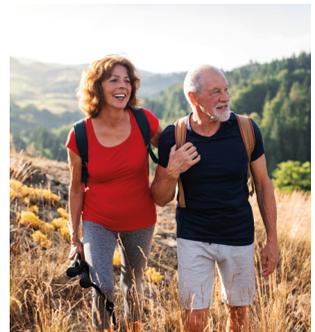
We need to ensure that the quality of the information that we collect is thorough, so that we don't make unfair conclusions about how surgeons, hospitals and types of joint replacement are performing. To do this, we periodically ask hospitals to send a list of all of the joint replacement surgery they have done, from their hospital computer system.

We can then compare this data to that on the registry to see if any information is missing. This list will include personal details for people that have not consented. This information is not stored in the registry and is only used to report back to hospitals about potential missing records.

A small number of patients having this type of surgery will be unable to consent because they have problems understanding or retaining information. In those cases, the hospital will ask someone else - normally a carer or relative, but sometimes a doctor can do this - to consider whether information can be shared with the NJR.

Sometimes, it isn't possible for the NJR to find out whether a patient has consented or not. This can be for a number of reasons, including if your operation was done as the result of an emergency. In this circumstance, in England and Wales we have permission under the law to record your personal details in the same way as we would if you consented.

The NJR has exemption from the National data opt-out programme in England and so to opt out of the NJR, you need to tell the hospital treating you that you do not wish to consent.



How the NJR is run

The NJR is hosted by the Healthcare Quality Improvement Partnership (HQIP) and overseen by a Steering Committee (NJRSC), which is designated as an NHS England and NHS improvement (NHSE) 'Expert Committee'. The NJRSC Chair reports to the National Medical Director of NHS England and Improvement.

NJR core services are managed under two contracts, these are held with: NEC Software Solutions: for collection and management of data and technology; and the University of Bristol: for provision of statistical support and analysis of data, to support NJR outcome monitoring, research activity and publications.

The NJR management team is responsible for the overall operational and contract management of the NJR and for supporting the work of the NJRSC and its sub-committees.

We aim to have patient representatives on all of our committees, ensuring patient considerations are embedded across our work and activities.

NJR data and other healthcare information

Operation and patient information that is held in the registry is used to link to other healthcare dataset information, including

We take your privacy very seriously. You can see our privacy policy at

www.njrcentre.org.uk/njrcentre/About-the-NJR/Privacy-Notice-GDPR

Datasets your information may be linked with:

Hospital Episode Statistics
Patient Episode Data for Wales
Patient Recorded Outcome Measures
Civil Registration Data

data held by NHS Digital and the NHS Wales Informatics Service (see green box above to see what datasets your NJR information may be linked with). Amalgamated data is analysed and made available to surgeons, hospitals and manufacturers (without any of your personal details).

Doing this improves the NJR's ability to monitor patient safety and patient outcomes. This means that people and organisations involved in improving joint replacement surgery can better understand and develop improved or more cost-effective medical treatments.

We also ask NHS Digital (on an annual basis) to supply us with a complete list of every patient who has had a joint replacement operation, along with other details from national datasets. This will include details of patients who have not given consent to be included in the registry.

We do not combine this information with that in the registry for patients who have refused consent and only use it to make sure the data is properly linked.

How can I use the Patient Decision Support Tool?

The Patient Decision Support Tool (PDST) is an online tool that generates a unique and tailored set of patient results for a variety of factors related to knee and hip surgery. Using the NJR's anonymised data, this tool was developed by the University of Sheffield and the University of Bristol, with funding support from Versus Arthritis. It has been a key initiative for the NJR to increase the public benefit of the data collected.

This easy-to-use tool can be accessed by patients at home or in consultation with their GP. It measures and estimates pain and function score both before and after surgery. It also shows how long an implant may last, thus assisting in a better understanding of the benefits

Using the NJR's Patient Decision Support Tool could help you see the impact joint surgery may have for you.

<http://www.njrcentre.org.uk/njrcentre/Patients/Patient-Decision-Support-Tool>

and risks of having a joint replacement. However it is not intended to provide a substitute for consultation with a medical professional.

We are thankful for the more than a million patients who have already undergone surgery and enabled their anonymised registry data to be used to generate the score outcomes for the tool.



See our website for further information for patients

<https://www.njrcentre.org.uk/patients/welcome-from-patient-representatives>

Medical research

Operation and patient information in the registry may be used for medical research and service evaluation to improve our understanding and treatment of joint problems.

Occasionally researchers may ask us if they can contact you to get involved. We will ask you first and all data is subject to very strict controls on storage, release and use. You can say no to participation and this won't affect your care.

You can find other examples of how we use data for research at www.njrcentre.org.uk.

To find out more about the NJR:



Visit our website at:
www.njrcentre.org.uk



Send an email to:
enquiries@njrcentre.org.uk



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Call the NJR Service Desk on:
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The NJR also provides information about surgeons and hospitals who carry out joint replacement surgery at
<https://surgeonprofile.njrcentre.org.uk>

More information

Your healthcare team (GP, consultant surgeon, anaesthetist, nurse, physiotherapist, occupational therapist) will be able to answer any questions you may have about your individual care.

There are lots of organisations that provide general information to inform and support patients undergoing joint replacement surgery.

Here is a link to the National Institute for Clinical Excellence guidelines for joint replacement:
<https://www.nice.org.uk/guidance/conditions-and-diseases/musculoskeletal-conditions/joint-replacement>

Here are some other helpful patient organisations' websites:

Versus Arthritis

www.versusarthritis.org

Arthritis and Musculoskeletal Alliance (ARMA)

www.arma.uk.net

BoneSmart

www.bonesmart.org

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