



National Joint Registry

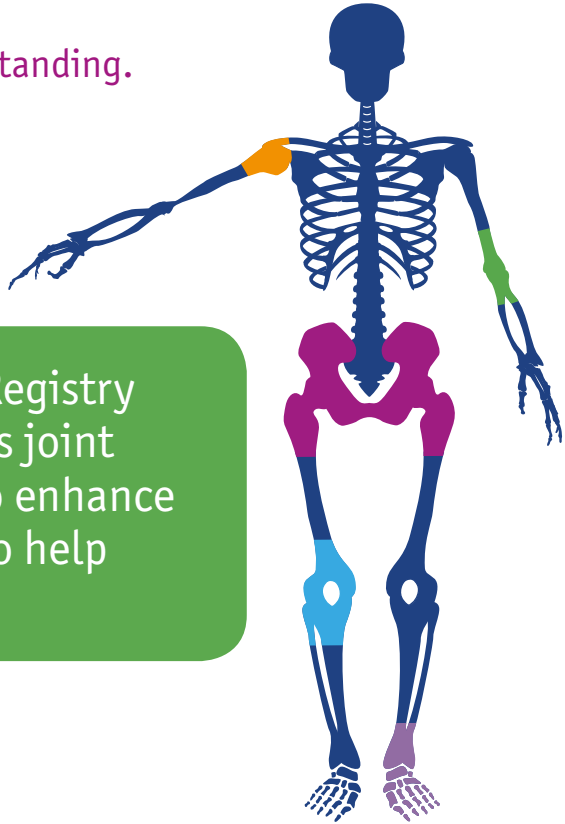
www.njrcentre.org.uk

Working for patients, driving forward quality

The National Joint Registry: Enabling Improvements in Patient Outcomes

How **you** can contribute
to the Registry's understanding.

The National Joint Registry records and analyses joint replacement data to enhance patient safety and to help provide better care.



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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.

What information is collected?

Your hospital will input specific details of your operation into the NJR. 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 its role in protecting patient safety (and to get in touch if there is a need). To date around 3 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 is asking patients about their experiences during their treatment as we want to use this feedback 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.

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

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 as part of the NJR 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 to the NJR 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 NJR 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. If that's the case then 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.

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 (NHSE) 'Expert Committee'. The NJRSC Chairman reports directly to the NHSE Medical Director.

NJR core services are managed under two contracts held with: Northgate Public Services: 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, based at HQIP, 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 in the NJR is used to link to other healthcare information, including 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).

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

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

What datasets your information may be linked with

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

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 NJR.

We do not combine information with the NJR for patients who have refused consent and only use it to make sure the data is properly linked. If you don't want us to use your personal information at all, then you can register an opt out under the national data opt out programme at

<https://www.nhs.uk/your-nhs-data-matters/manage-your-choice/>

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 the better understanding of the benefits and risks of having a joint replacement.

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>

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.



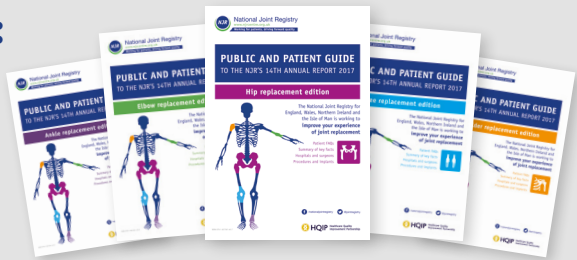
Medical research

Operation and patient information in the NJR 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.

Further resources: the NJR's Public and Patient Guides to joint replacement



Available at: <http://www.njrcentre.org.uk/njrcentre/Reports-Publications-and-Minutes/Public-and-Patient-Guide>

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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Write to:
**NJR Centre - Peoplebuilding 2
Peoplebuilding Estate
Maylands Avenue
Hemel Hempstead HP2 4NW**



[@jointregistry](https://twitter.com/jointregistry)



Call the NJR helpline on:
0845 345 9991

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 questions about your individual care.

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

Here are some other helpful organisations' websites:

Versus Arthritis

www.versusarthritis.org

Arthritis and Musculoskeletal Alliance (ARMA)

www.arma.uk.net

BoneSmart

www.bonesmart.org

