

National Joint Registry 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

 @jointregistry

www.njrcentre.org.uk

We would like to invite you to have your data included in the National Joint Registry (NJR). You have been invited because you have had, or will shortly be having, a joint replacement operation. This leaflet provides some more information about what the registry does.

How does the National Joint Registry help patients?

The 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 with your implant brand, 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 NJR

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, sex, 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 us to be more effective in our role in protecting patient safety (and to get in touch if there is a need). To date, over four million procedure 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 registry 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 joint surgery will be unable to consent to being on the registry because they also 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 had 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 to being on the registry.

You can withdraw from the NJR at any time by contacting the hospital who carried out your surgery, or by contacting the NJR directly.



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) 'Advisory Committee'. The NJRSC Chair reports to the National Medical Director of NHS England.

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 data held by NHS England and Digital Health and Care Wales

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

(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 linking activity 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 medical treatments that present best value.

We also ask NHS England (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.

The 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 de-identified information which means it is not possible 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 will not affect the care you receive.

Please be assured 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.

How will we use information about you for research?

We will need to use information submitted by your surgeon for research projects as part of our research database.

This information will include your name, date of birth, sex, contact details and NHS number. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once a researcher has finished a study, we will keep some of the data so we can check the results. We will write our reports in a way that no one can work out that you took part in the study.

What are your choices about how your information is used?

You can withdraw from having your details on the NJR registry at any time, without giving a reason, but researchers will keep information about you that we have already shared with them prior to you withdrawing from the registry.



For further information and for details on how you can join our Patient Network and contribute to the work of the NJR, visit <https://www.njrcentre.org.uk/patients/njr-patient-network>

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

To find out more about the NJR:



www.njrcentre.org.uk
reports.njrcentre.org.uk



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The National Joint Registry



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C/o NEC Software Solutions UK
1st Floor iMex Centre
575-599 Maxted Road
Hemel Hempstead
Herts HP2 7DX

Suggestions, complaints and concerns
njr@njr.org.uk

Data Protection Officer
data.protection@hqip.org.uk

The NJR also provides information about surgeons and hospitals who carry out joint replacement surgery:

<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 many 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>

For more information about research in the NHS, see www.hra.nhs.uk/information-about-patients/

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With thanks to the NJR Patient Network for their valuable thoughts and comments in the development of this patient information leaflet.

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



Working for patients, committed to excellence