

Information for patient consultees

We feel your relative/friend is unable to decide for himself/herself whether to participate in the National Joint Registry

To help decide if he/she should join the study, we'd like to ask your opinion whether or not they would want to be involved. We'd ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decisions they may have made about participating in research. These should take precedence.

If you decide your relative/friend would have no objection to taking part we will ask you to read and sign the consultee declaration on the last page of this information leaflet. We'll then give you a copy to keep.


If you decide that your friend/relative would not wish to take part it will not affect the standard of care they receive in any way.

If you are unsure about taking the role of consultee you may seek independent advice. We will understand if you do not want to take on this responsibility. The following information is the same as would have been provided to your relative/friend.

Monitoring what happens after joint replacement surgery

A leaflet about how the National Joint Registry helps patients

The NJR records and analyses joint replacement data for patient safety and to help provide better care



www.njrcentre.org.uk

 /nationaljointregistry
 @njrregistry



How does the NJR help patients?

The National Joint Registry for England, Wales, Northern Ireland and the Isle of Man (NJR) records details of joint replacement operations in order to monitor the results of joint replacement surgery and protect patient safety. We provide information and evidence to:

- Help surgeons to choose the best artificial joints (implants) for patients
- Empower patients by enabling them find out more about the implants available to them
- 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

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

side of your body the implant went into, as well as your name, date of birth, gender, postcode 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.

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

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 (NHS E) 'Expert Committee'. The NJRSC Chairman reports directly to the NHS E 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 overall operational and contract management of the NJR and for supporting the work of the NJRSC and its sub-committees.



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 box on right to see what datasets your NJR information may be linked with). It is also analysed and made available to surgeons, hospitals and manufacturers – without any of your personal details – as part of our feedback services.

Doing this improves the NJR's 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.

You can take a look at our *Joint Approach* newsletters or find out more about the NJR at www.njrcentre.org.uk

What information does the NJR provide for patients?

The NJR publishes a Public and Patient Guide to its main Annual Report every year. The main Annual Report contains analysis of the information that the registry collects for example, results on how well different types of implants are performing.

The Public and Patient Guide aims to make that data more readable and practical for patients, carers, family and friends. You can now choose to read a guide for each of the joint replacements recorded in the NJR on our website.

What datasets your information may be linked with

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

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.

The majority of our research uses only anonymised information which means it is impossible to identify individuals.

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 examples of how we use data for research at www.njrcentre.org.uk.

We take your privacy very seriously.
You can see our privacy policy at www.njrcentre.org.uk/njrcentre/AbouttheNJR/PrivacyPolicyGDPR/tabid/1517/Default.aspx

NJR PATIENT CONSULTEE DECLARATION FORM

Please initial box

I _____ [name of consultee] have been consulted about
_____ [name of patient]'s participation in the National
Joint Registry. I have had the opportunity to ask questions about the NJR and understand
what is involved.

In my opinion he/she would have no objection to taking part in the above study.

I understand that I can request he/she is withdrawn from the NJR at any time,
without giving any reason and without his/her care or legal rights being affected.

Name of Consultee	Date	Signature
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Relationship to participant:

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Hospital staff undertaking consultation:

Name	Date	Signature
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Patient Details (all mandatory)

Surname _____
Forename _____
Date of birth _____
Postcode (home) _____

To be completed by the hospital

Hospital _____
NHS or national patient number _____
Height m & Weight kg
or BMI _____

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