

NJR Patient Consent Form

National Joint Registry –

What does it mean for you as a patient?

About the National Joint Registry (NJR)

Hip and knee joint replacements have become common and highly successful operations that bring many patients improved mobility and relief from pain. A number of people may at some time in the future need another operation on the same joint. This may occur for a variety of reasons, most commonly because the joint implant has worn out. There are many different types of hip and knee implants, many of which do not have data on their long-term effectiveness. To further improve the success of this surgery, the Department of Health and the Welsh Assembly Government have set up the National Joint Registry (also known as the NJR) to monitor the performance of joint implants.

The NJR is designed to record details of all hip and knee replacement operations in England and Wales. Both the NHS and the independent health care sector are included and to be successful the NJR needs to gather information on as many people having these operations as possible.

The benefits the NJR will bring to you;

The NJR data will be used to bring direct benefits to patients by:

- improving patient awareness of the outcomes of hip and knee joint replacement
- finding out how long the different joint replacements last
- helping to identify individual patients who have received an implant if there is a need for urgent clinical review

The NJR data will also be used to bring additional long-term benefits by:

- providing feedback to orthopaedic surgeons and teams to help maintain high clinical standards
- promoting open publication of performance of implants
- providing feedback on implant performance to regulatory authorities
- providing feedback to suppliers about the performance of their implants
- monitoring and comparing the performance of hospitals

Data collected via the NJR may be used for medical research, however this data will be anonymised so that it will not be possible to identify you. Research projects are subject to ethical review and will only be permitted if the outcomes are expected to provide significant benefits to the healthcare of patients.

How to find out more about the NJR

You can visit the NJR website at www.njrcentre.org.uk or contact the NJR Helpline

NJR Helpline Mon-Fri from 9am to 5pm (not including public holidays)

NJR Centre Peoplebuilding 2, Peoplebuilding Estate, Maylands Avenue, Hemel Hempstead HP2 4NW

Tel: 0845 345 9991 **Fax:** 0845 345 9992 **E-mail:** enquiries@njrcentre.org.uk

Patients should ensure that they return their signed consent form to their hospital and NOT the NJR Centre.

Personal information – what is required and why?

The information required for the NJR includes your personal details shown below and your operation details. It will link you to the implant(s) you receive as well as linking any future joint implant surgery you may have.

If the performance of any implant is identified as being a problem, having your personal details in the NJR will help us to make contact with you. We may also contact you in the future to ask you to complete a patient feedback questionnaire.

Data collection – its security and confidentiality

The NJR uses an electronic system for data collection. The data is securely coded for transfer to a central database. This avoids sending paper records through the post and ensures maximum data security.

Your personal information is confidential and cannot be used outside of the NJR. Procedures are in place to protect your information and keep it confidential, it will only be available to you and your surgeon. If you wish, you can obtain access to a copy of your own record in accordance with the Data Protection Act 1998.

Your participation is voluntary

This form asks for your consent for your personal information to be recorded by the NJR. Your participation in the NJR is entirely voluntary. If you agree and then change your mind, you may revoke this permission at any time by contacting the NJR Centre. If you do not agree, data about your operation will be entered but without any personal details attached. This will ensure that individual operation details are not traceable back to you. If you have any questions, concerns or need further information on the NJR or your rights under the Data Protection Act 1998, please contact the NJR Centre.

<p>Patient Details (all mandatory)</p> <p>Surname _____</p> <p>Forename _____</p> <p>Date of Birth _____</p> <p>Home Address Postcode _____</p>	<p><i>To be completed by Hospital</i></p> <p>Hospital _____</p> <p>NHS Number _____</p> <p>Height _____ & Weight _____</p> <p>or BMI _____</p>
<p>I CONSENT to my personal details being recorded within the NJR. 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. However, where possible, I will be told if any disclosure is to take place.</p> <p>Signature _____ Date _____</p>	
<p>I DO NOT CONSENT to my personal details being recorded within the NJR.</p> <p>Signature _____ Date _____</p>	
<p><i>To be completed by Hospital (person accepting patient consent)</i></p> <p>Name _____ Signature _____</p> <p>Position _____ Date _____</p>	

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