



Patient Consent Form for the Indian Joint Registry

The purpose of the Indian Joint Registry (IJR) is to improve patient safety and the success of joint replacement surgery. By using the data provided to it, the IJR helps to monitor the performance of artificial joints and to determine the most effective types of surgery. The registry helps patients by:

- Helping surgeons to choose the implants that they use for knee and hip replacement surgery
- Improving patient safety by monitoring how well implants are performing and advising the authorities and surgeons when problems with implants are detected
- Providing information back to surgeons, hospitals, and the manufacturers of implants so that they can continue to improve patient care
- Assisting surgeons to quickly identify and review patients who may need further treatment following the identification of issues with an implant

What information does the IJR collect?

The data collected by the IJR will include the details of your operation and the implants used in your surgery. Your personal details will only be recorded if you give your consent.

Why does the IJR need your personal details?

Not only do your personal details (such as your name, date of birth, address) mean that the IJR can link you to the implants

used in your surgery, they can also be used to link your surgery to any other surgery you may have in the future on the same joint. By measuring the time between surgeries on the same joint for all patients, the IJR can see how well different implants and types of surgery are doing. Without your personal details, the IJR will not be able to see if there are problems and will not be able to achieve its goals of improving patient safety and the outcomes of joint replacement surgery.

The personal details collected by the IJR are:

- Name
- Date of birth
- Address and contact details
- Personal identification number (eg Aadhaar, PAN)

The IJR and Research

The IJR may sometimes need to use surgery and patient information for medical research which will help improve the understanding and treatment of joint problems in India. Most research uses data that has had patients' personal details removed, meaning that it is



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impossible to identify individuals. Sometimes, the researchers may require more information about you and your surgery but we will not provide your personal details to anyone without your permission. If you receive an invitation to take part in a research study, you do not have to take part. Saying 'no' will not affect the care that you receive.

The IJR and other healthcare information

In the future, your personal details may be used to link your surgery details to link to other health datasets. Following analysis, the information is provided to surgeons, hospitals, and implant manufacturers but without any data that would identify you. Linking to other health data will improve the monitoring of implants undertaken by the IJR.

Do I have to give my consent?

You do not have to give your consent. If you say 'no' the IJR will store only the information about your surgery, without your personal details. Without patient consent to store personal details, however, the IJR will find it more difficult to achieve its aims. If you change your mind about consenting to the IJR holding your personal details, please contact your surgeon who will let us know.

Securing your information

Your personal details are kept very secure and confidential at all times. Very strict rules and processes are in place to ensure that your information is kept safe.



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THIS FORM SHOULD BE KEPT AS PART OF THE PATIENT RECORD.

DO NOT SEND IT TO THE IJR CENTRE.

<p>Patient Details</p> <p>First Name _____</p> <p>Middle Name _____</p> <p>Last Name _____</p> <p>Date of Birth _____</p> <p>Address _____ _____</p> <p>Postcode _____</p>	<p>Mobile Phone _____ Or Home Phone _____</p> <p>Email address* _____</p> <p>Patient Identification Number Type** _____</p> <p>Identification Number _____</p> <p>Note: * You do not have to supply an email address ** Types include PAN and Aadhaar number or passport number for those who are not Indian citizens</p>
<p>To be completed by the hospital</p> <p>Hospital _____</p> <p>Height (cm) _____ Weight (kg) _____ Or BMI _____</p>	
<p>I CONSENT to my personal details being recorded in the IJR. I also understand that the IJR will not release my personal details unless required to do so by law or if it is the best interests of your care. If 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 in the IJR</p> <p>Signature _____ Date _____</p> <p>To be completed by the person in the hospital accepting patient consent</p> <p>Name _____ Signature _____</p> <p>Designation _____ Date _____</p>	