



Patient information

The Indian Joint Registry (IJR) has been established by the Indian Society of Hip and Knee Surgery (ISHKS) to collect information about hip and knee joint surgery in India. The purpose of collecting the data is to monitor the performance of the artificial joints, or implants, used in joint replacement surgery and to ensure that all patients receive the best possible result from their operation.

With many thousands of such operations taking place in India each year, recording the details and tracking patient outcomes is essential for the monitoring of the performance of implants and furthering important orthopaedic research in India. Only in this way can patient safety and patient outcomes be improved.

Benefits for all patients

By recording the information, the IJR will be able to:

- Provide reassurance to patients about the safety and the quality of care that they receive.
- Monitor the performance of implants so that potential problems can be identified early and, if necessary, assist in the recall of patients to the hospital for review.
- To provide information to surgeons, hospitals, and manufacturers of implants so that they can ensure that the highest standard of care is given to patients.
- To provide information to patients so that they can make informed decisions about the types of treatment available and where to get it.

So that the IJR can improve your care and the outcomes for all joint replacement patients, we would like you to agree to the IJR collecting data about you and your surgery. Unless you consent to the IJR collecting this information, we will not be able to meet our goals. The

personal information that we will collect about you is:

- Full name
- Gender
- Date of birth
- Address
- Identification number (e.g. PAN, Aadhaar, or passport number)

Why do we need to collect your personal details?

Firstly, if the IJR becomes concerned about a particular implant, we will be able to notify the hospital that carried out your operation, and they will be able to contact you and ask you to return to the hospital if a review is necessary.





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Secondly, in order to be able to determine how well implants are performing and to enable further analysis and research, the IJR has to be able to link all operations on the same joint for the same patient. It is only by linking your first (primary) operation to any subsequent (revision) operations that you may have on the same joint, that we can determine the outcomes for all patients. The linkage of the operations is done by matching the personal information that you provide us with: this is why your consent is so important.

We may also, from time to time, send you questionnaires asking about your recovery after your operation, and to see how you are getting on with your new joint. You do not have to complete any questionnaire that we send you but your answers will benefit future patients and help us to monitor the safety and effectiveness of all joint replacement surgery in India.

Confidentiality

Your personal information will be handled securely and be afforded strong protection: it will only be shared with the surgeons directly involved in your care. The IJR will not release your information to anyone without your permission unless it is required to do so by law. However, this is very unlikely.

Any data or information that is published or made available to the manufacturer of your implants, the surgical profession, or to the public will have had your all personal information removed. The IJR will ensure that you cannot be identified as an individual.

Consent

By signing the consent form, you are agreeing to:

- The IJR holding your personal details for the purposes of monitoring the performance of implants, ensuring patient safety, improving the outcomes of joint replacement surgery, and enabling orthopaedic research in India.
- Allowing your personal details to be used for the purpose of contacting you to ask you to complete questionnaires about how you are getting on after your surgery. We may also invite you to take part in research projects.
- Your data is being securely stored and processed by NEC Software Solutions Limited.

Your participation is voluntary

If you do not want your personal details to be collected, all you have to do is select 'No' on the consent form. If you do consent and wish to change your mind later, all you need to do is notify us, and we will remove your personal data from our records. We will, however, retain the details of the operation and the implants used.

Queries

If you have any further queries about the IJR, please either discuss them with your surgeon or call the IJR Helpline on +91 22 50323085.

