

IS INFORMATION COLLECTED POST OPERATIVELY (AFTER THE OPERATION)?

Yes. If your details are on the register, follow-up assessments will be carried out by an INOR Audit Coordinator at six months after your surgery, and again at two and five years. If necessary, this nurse will refer you to the surgeon. At present, a surgeon will organise follow up assessment after surgery. At each assessment, you can ask any questions you might have about your surgery or joint replacement.

DO I HAVE TO CONSENT?

No. It is your decision whether your personal information is included on the register. We need your consent to record these details. You can change your consent at any time. To do this, contact the hospital where you had your surgery or write to NOCA. Contact details are provided on the back of this leaflet.

WHAT HAPPENS IF I DO NOT CONSENT?

If you do not give your consent, it will not affect your surgery, treatment or post-operative care. If you say NO to consent, your personal data will not be shared with NOCA but will be available to the hospital where you are receiving care and treatment. However, details about your surgery such as surgical technique, medications used, surgical approach, the date of your surgery, name of hospital and the implant will be recorded in a pseudonymised format on the register. You cannot be identified from this information.

HOW DOES NOCA KEEP MY INFORMATION CONFIDENTIAL?

It is our duty to keep your information confidential. We will do this by ensuring that:

- our staff know their responsibilities and are trained in handling information
- information is kept on secure computer systems
- we comply with all regulations relating to confidentiality and protection of data
- it is only seen by authorised staff
- your information is not changed in any way.

WHO CAN SEE MY RECORDS?

NOCA and the medical staff in the hospital where you had your surgery will have access to your information. NOCA will use your information to monitor implant and patient outcomes.

If you attend another hospital for another orthopaedic procedure, the medical staff at this hospital will be able to view your implant details and the name of the hospital where the first procedure was carried out through INOR. Every patient is given a unique number for the register. This number will be replaced by the Individual Health Identifier (IHI) when it is fully introduced across the health service in the coming years. Also, this unique identifier will assist in linking surgeries that may occur in different hospitals.

This provides the surgeon with basic information regarding previous surgeries. If the surgeon needs more information, they will have to contact you or the hospital where you had your earlier surgery.

You can contact the National Office of Clinical Audit at:

118 St Stephen's Green, Dublin 2, D02 X0N1.
Telephone: +353 1 4028577
Email: inor@noca.ie Website: www.noca.ie

NOCA National Office of
Clinical Audit

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INOR Irish National
Orthopaedic Register

**PATIENT
INFORMATION**
YOUR QUESTIONS ANSWERED

NOCA National Office of
Clinical Audit

WHAT IS THE IRISH NATIONAL ORTHOPAEDIC REGISTER (INOR)?

This Register is a patient safety project which aims to help orthopaedic surgeons and hospitals in Ireland to improve the quality of services and care provided to patients who are having or have had joint replacement surgery.

WHAT ARE THE BENEFITS OF THIS REGISTER?

The information we gather will help surgeons to decide which joint replacements are performing well and therefore improve patient safety and care. We, the National Office of Clinical Audit (NOCA), will produce national reports on factors that impact on the success of joint replacement surgery. You can find out more about INOR on our website www.noca.ie.

WHAT IS THE NATIONAL OFFICE OF CLINICAL AUDIT (NOCA)?

NOCA was set up in 2012 to support national clinical audits of healthcare in Ireland. National clinical audits regularly look at different areas of care to see how well services are working and where improvements can be made.

National clinical audits look at:

- how healthcare services are organised
- how care is provided
- the outcomes experienced by patients.

NOCA works with healthcare providers to help them understand and use this information so they can learn from it and improve patient care over time.

WHAT INFORMATION WILL BE COLLECTED?

INOR will collect and record your personal information and details about your surgery and implant. Personal information includes your name, address, date of birth, hospital number and sex. You may also be asked to complete a questionnaire about your wellbeing. This helps us measure and improve the quality of care for hip or knee or other joint replacement for patients.

WILL YOU TELL ME IF MY INFORMATION IS USED FOR THIS REGISTER?

Yes, we will tell you when we seek your permission (consent) to use your personal information. You will be asked to sign a consent form before your operation.

WHAT WILL HAPPEN TO MY INFORMATION?

INOR keeps your personal and orthopaedic information to monitor joint replacements and to improve the care delivered in Irish hospitals. You will get a unique number when you are registered on INOR. Your personal details and the unique number allow NOCA to link you to the implant(s) you received. This information is important if your surgeon or hospital needs to contact you.

INOR information will be published in national reports which will be available on our website. These reports will provide general information – no individual will be identified.

CAN MY INFORMATION BE USED FOR HEALTHCARE RESEARCH?

Health care research can also help to improve care. Subject to your consent, NOCA may allow health care researchers to access your data. Before this happens, the research must be approved by a research ethics committee.

Most research will use pseudonymised data. Pseudonymised means that information that could identify you, such as your name, address or date of birth, will NOT be given to a researcher and is replaced with a code. This means the data can be used for learning and improving care, but the people analysing the data cannot see who you are. You can decide whether you wish to participate in research or not. You have the right to say no and this will not affect your treatment in any way. You can also withdraw your consent at any time.

Research for INOR will usually include looking at factors that influence the outcome of surgery, whereby researchers investigate questions that are patient, surgery or implant related.

INOR Research will fall under the following categories:

- Implant assessment and outcomes
- Patient outcomes, safety, and risk management
- Health economics and cost effectiveness
- Surgeon education and training
- Patient information & shared decision-making
- Disease diagnosis and prognosis
- Disease causation, prevention and treatment
- Complications in the setting of joint replacement.

INOR AND OTHER HEALTH INFORMATION

Surgery and patient information in INOR may be used to link to other healthcare information, including data held by other HSE systems. This amalgamated data will always be anonymised for analysis before it is made available to surgeons, hospitals and other healthcare personnel without any of your personal details. Also, your pseudonymised data may be compared to similar information in other International Registers.

