IS INFORMATION COLLECTED POST OPERATIVELY (AFTER THE OPERATION)?

Yes, If your details are on the register, this means that a schedule of post-operative assessments will be carried out at 6 months after your surgery and at two and five-year intervals by a specialist orthopaedic nurse. 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 to allow your personal information to be put on the register. We need your consent to record these details.

WHAT HAPPENS IF I DO NOT CONSENT?

If you do not give your consent, it will not affect your surgery or treatment or post-operative care. 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 an anonymised/unidentifiable 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 people;
- your information is not changed in any way.

WHO CAN SEE MY RECORDS?

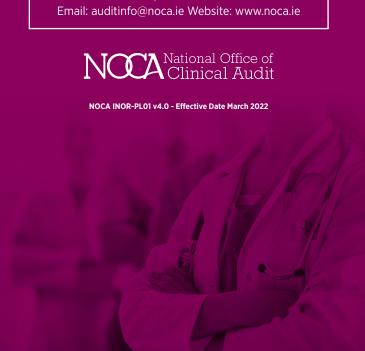
NOCA and the medical staff in the hospital where you had your surgery will have access to your information. NOCA will use your information to monitor implant and patient outcomes.

If you attend another hospital for another orthopaedic procedure, the medical staff at this hospital will be able to view (through INOR) your implant details and the name of the hospital where the first procedure was carried out. Every patient is provided with a unique identifier (specific to INOR only). This number will be re-placed by the Individual Health Identifier (IHI) when it is fully implemented 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:

2nd Floor, Ardilaun House, Block B, 111 St Stephen's Green, Dublin 2. Telephone: +353 1 4028577 Email: auditinfo@noca.ie Website: www.noca.ie





PATIENT INFORMATION

YOUR QUESTIONS ANSWERED





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 established in 2012 to create sustainable clinical audit programmes at national level. National clinical audit is an ongoing review of clinical practice - measuring structures, processes and outcomes to make improvements.

NOCA supports hospitals to learn from their audit cycles. NOCA is funded by the Health Service Executive Office of the Chief Clinical Officer and supported by the Royal College of Surgeons in Ireland.

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 gender. 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.

NATIONAL CLINICAL AUDIT IS AN ONGOING REVIEW OF CLINICAL PRACTICE - MEASURING STRUCTURES, PROCESSES AND OUTCOMES TO MAKE IMPROVEMENTS.

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.



INOR Irish National Orthopaedic Register

CAN MY INFORMATION BE USED FOR HEALTHCARE RESEARCH?

Health care research can also improve care. Subject to your consent, NOCA may grant health care researchers access to your data. This will only occur where approval has been granted by a research ethics committee.

Most research will use de-identified data. Your personal identifiable information – i.e. your name, address and date of birth will **NOT** be given to any researcher without your consent. 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 de-identified data may be compared to similar information in other International Registers.