

**ST JAMES'S
HOSPITAL**



Ankylosing Spondylitis Registry Ireland (ASRI) Privacy Notice

Introduction

ASRI was established in 2013 as a national registry for patients with Ankylosing Spondylitis, a form of inflammatory arthritis that predominantly affects the spine, resulting in pain and stiffness, and ultimately resulting in progressive restriction in range of motion of the entire spine potentially. To date 12 individual hospitals, including St. James's Hospital, has contributed patients to ASRI. The registry is set up so that each centre has a local lead Consultant Rheumatologist. The local lead approaches their patients and asks them to participate in the ASRI. Data is collected locally at each site and stored on a secure web-based software system.

Our aim is to be clear and transparent about the personal data which is collected as part of this process and how this data is used by the hospital.

In the following paragraphs we set out information in relation to:

- The Data Controller.
- The Data Protection Officer (DPO).
- What Personal Data we collect.
- What we use your Personal Data for.
- How long will we hold onto your Personal Data.
- Who will have access to your Personal Data.
- International data transfers.
- Your rights.
- How we keep your Personal Data secure.
- Legal basis for processing Personal Data.
- Research Collaborations/Publications
- Complaints.

The Data Controller

St. James's Hospital is one of the 12 participating sites that jointly control the registry. Dr Barry O Shea is the Consultant responsible for ASRI patients in St James's Hospital and is currently the Principal Investigator of ASRI. Dr O Shea is a member of the ASRI Steering Committee which governs how the registry is run.

The hospital, and the other participating sites, operate within the provisions of the General Data Protection Regulation and Data Protection Acts.

The Data Protection Officer (DPO)

The hospital Data Protection Officer (DPO) can be contacted directly at dataprotection@stjames.ie or Tel: 01 410 3021.

What personal data is collected?

Personal data means any information about you which allows the hospital to identify you. The data collected from patients for inclusion on the registry consists of demographic (e.g. date of birth, sex, age etc.), medical history, clinical measures to assess disease level, biometric measures (height, weight, waist and hip circumference) medication history, x-ray and blood test results, family history relating to AS, questionnaires required to measure response to treatment and current disease activity.

Participants are also asked to give a once off blood sample for genetic studies. All the data and samples will be coded and rendered pseudonymous (you can be identified by a number only retained by your clinic) once collected. The staff involved in collecting samples and the data will be responsible for safeguarding anonymity.

Your research blood samples will be processed and stored at the Trinity Translational Medicine Institute, Department of Clinical Medicine & Trinity Centre for Health Sciences, St James's Hospital, on behalf of the participating sites.

What we use your personal data for?

The main aim of the study is to establish a registry of patients with Ankylosing Spondylitis (AS). This will include adult patients who have been diagnosed with AS and have been reviewed in a hospital setting within the past 3 years.

This database of patients will facilitate clinical and research studies to allow us to better understand the disease and measure its impact on those who suffer from this disease. Data and samples from the registry will be used for research project with academic and commercial partners. More information on this is outlined in the Patient Information Leaflet provided when participants sign up to take part.

How long will we hold onto your personal data?

The ASRI Registry will only retain your personal data for as long as it is necessary to fulfill the purposes it is being processed for. All pseudoanonymised data will be kept as long as the registry is active, so for an extended period. This is nature of how registries operate.

Who will have access to your personal data?

Your personal data will be stored on our web-based system and will only be made available to and shared with others on a strict "need to know" basis and in compliance with the data protection legislation. Only staff at your participating site, e.g. St. James's Hospital, will be able to view your identifiable information.

Any other sites or research collaborators will not be able to view or access your identifiable information. As outlined above a pseudonym will be applied to your data to maintain anonymity.

Will my personal data be transferred outside of the European Economic Area (EEA)?

If there is an international research partner pseudonymised personal data may leave the EU i.e., date of birth /and or gender may accompany a blood sample when necessary for a genetic study. If data or samples are to be transferred outside the EU as part of a research collaboration a legally binding agreement will be put in place to protect your data and/or sample.

What are your Rights

Every patient has the right to access their personal data. This includes the right to ask if the ASRI processes personal data about you. To obtain a copy of this personal data and to obtain additional information such as the personal data the ASRI processes about you and for what purpose, with whom, how it's collected, and how long data is kept for.

You have the right to correct incomplete or erroneous information and to request the removal of personal data from ASRI. If you wish to withdraw consent to use your data, you can do this by notifying your treating consultant. The ASRI will ensure your data is removed and that it is not included in future studies. It is not possible to remove the data from studies already completed and published.

The right to lodge a complaint with a supervisory authority, the Data Protection Commission. Contact details can be found [here](#).

If you have any issues/queries you can contact the local consultant or ASRI Coordinator to try and resolve any issues.

Contact Details:

Dr Barry O Shea, Consultant, Rheumatologist, St. James's Hospital.

Email: foshea@stjames.ie or doransec@stjames.ie / Telephone: 01 416 2551

Or

Mythri Shaji, Irish Society for Rheumatology (ISR) Registries Coordinator

Email: mythri@isr.ie

How do we keep your personal data secure?

The hospital has legal obligations under the EU General Data Protection Regulations (GDPR) and the Data Protections Acts 1988 – 2018 to ensure all personal data which it collects, and processes is kept confidential and secure.

To comply with these legal obligations the hospital has implemented a number of technical and organisational measures to protect the data collected against unauthorised or unlawful processing, accidental loss, destruction, or damage, which include:

- Storage of your data in a secure web-based database.
- Database access is managed at each site based on staff member's role.
- Pseudonymisation of your data for anyone accessing the data outside St. James's Hospital.
- Sharing of data with any third parties, including those outside the EU, is done so based on binding agreements that ensure the equivalent level of data protection as in the EU.

What is the legal basis for processing?

In the first instance the hospital will rely on the following legal bases under the General Data Protection Regulation (GDPR) to process data in the registry.

- processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller.

For special category data (health/genetic data) an additional legal basis is required.

- processing is necessary for archiving purposes in the public interest, scientific or historical research purposes.

We will also seek your consent providing comprehensive information in the ASRI Patient Information Leaflet.

Changes to this Privacy Notice

This Privacy Notice may change from time to time and any changes to the Notice will be communicated by way of a notice on our website.

Research Projects/Collaborations/Publications

Since its commencement ASRI has contributed data and samples to research projects, details of which can be found on our notice board in clinic or online at:

- [Genomewide association study of acute anterior uveitis identifies new susceptibility loci](#)
- [Multimorbidity in Axial Spondyloarthritis and Its Association with Disease Outcomes: Results from the Ankylosing Spondylitis Registry of Ireland Cohort.](#)
- [Advances in treatment of axial spondyloarthritis are associated with improved patient outcomes: data from the Ankylosing Spondylitis Registry of Ireland \(ASRI\).](#)
- [The negative impact of undiagnosed depression in axial spondyloarthritis.](#)
- [Central Obesity in Axial Spondyloarthritis: The Missing Link to Understanding Worse Outcomes in Women?](#)
- [The toll of unemployment in axial spondyloarthritis: high prevalence and negative impact on outcomes captured in a national registry.](#)
- [The Same But Different? An Analysis of Late-Onset Axial Spondyloarthritis.](#)
- [The negative impact of depression in women with Axial Spondyloarthritis.](#)

- [What to expect when women with axial spondyloarthritis are expecting: Prevalence of complications of pregnancies in women with axial spondyloarthritis.](#)
- [The genetic backbone of ankylosing spondylitis: how knowledge of genetic susceptibility informs our understanding and management of disease.](#)

Making a complaint

In the event that you wish to make a complaint about how your personal data is being processed by the hospital, or how your complaint has been handled, you have the right to lodge a complaint directly with the [Data Protection Commission](#).

Telephone: 01 7650100 / 1800437 737

Postal Address: 21 Fitzwilliam Square South Dublin 2 D02 RD28 Ireland