



EUROPEAN VENOUS REGISTRY



A project from the European
Society for Vascular Surgery

INFORMATION LEAFLET FOR PATIENT



In collaboration with the
European Vascular
Research Collaborative

**Enhancing patient lives by improving
deep venous disease treatment**

WHAT IS EVeR?

Gathering information on outcomes of deep venous interventions has proven to be a challenge due to the **lack of robust data** on this topic.

The **European Venous Registry (EVeR)** was created in answer to a need for improved long-term data collection. It is an international registry of data on the **treatments and outcomes for people with deep venous disease**, designed to generate scientific evidence to improve clinical decision making.

Objectives of the initiative



Assess the quality and outcomes of venous treatments and interventions

Improve patient safety and care delivery by analysing treatment data and devices



Improve medical devices effectiveness



EVeR is a project developed by the European Society for Vascular Surgery (ESVS).



Improving vascular health for the public benefit is what drives the ESVS activities.

As a not-for-profit organisation consisting of more than 3000 vascular surgeons and specialists in Europe and beyond, the ESVS goals include **training, education** and the **promotion and development of science** in the field of vascular care. The ESVS is a European and scientifically independent platform including world-renowned venous specialists.

The management of people with venous disease is complex and benefits from **inter-disciplinary care**. The ESVS, along with a number of stakeholders, have designed and delivered the European Venous Registry. EVeR reflects the multidisciplinary approach to such care (vascular surgeons, interventional radiologists, haematologists, trainees, patients, regulators and medical device manufacturers).

EVeR was developed with the collaboration with the European Vascular Research Collaborative and European Research Hub



The European Vascular Research Collaborative (EVRC) is an experienced research collaborative composed of young vascular specialists.

The EVRC has been running successful research studies for a number of years. Their expertise will be valuable as a key partner within the EVeR project, to help set up and deliver the registry. The partnership also highlights the importance ESVS holds to support junior vascular specialists.





The European Research Hub was established in 2022 and seeks to increase participation in high-quality clinical research in vascular disease throughout Europe and internationally.

This initiative supports the advancement of vascular surgery training, vascular surgery courses, and vascular surgery procedures.



What You Should Know

What are you being asked to do?

- You are being asked to agree for data on your venous condition and any treatments to be recorded in a medical database (registry).

Whose data can be included?

- Patients suffering from deep venous disease of the lower limbs
- Patients who have had surgical or non-surgical treatment
- Patients who agree to be followed up over a period of 3-5 years



What data is collected in the registry?

Personal data

- Only your **hospital ID**, **year of birth**, and **gender** are used to securely identify your medical records for follow-up purposes.
- No names or personal contact details are stored.

Medical Data

- Information about your **diagnosis**, **treatment**, and **follow-up visits**
- Includes data related to any **procedures**, **rehabilitation**, or **outcomes**

WHY SHOULD YOU AGREE TO BE PART OF EVER?



Help future patients benefit from improved patient decision-making, treatment development and identification of trends in practice

Support healthcare providers, researchers and industry manufacturers to monitor and evaluate the quality of healthcare delivered



For more information



Or send an email to:
info@esvs.org



Who has access to your data?

All medical data has your name and address removed, so you cannot be identified. Only authorised people can access your data:

- Your hospital team
- ESVS who runs the registry
- Dendrite who stores the data securely
- Researchers and medical companies for research purpose and to improve treatments and devices

If data is shared outside the European Economic Area (EEA), strong data protection safeguards are used.



How is your data secured?

- Data is encrypted during transfer and securely stored.
- Compliance with data protection laws, including GDPR
- Personnel with data access are trained in confidentiality and data protection protocols
- Registry provider follows industry best practices for information security
- Facilities who have access to your de-identified data use strict physical and procedural measures to keep your data safe
- Annual data protection training is mandatory for staff to maintain patient confidentiality



What are your rights and how can you exercise them?

You are automatically covered under EU/UK Data Protection Laws. Under data protection laws you have the right to:

- Access your personal data
- Rectify your personal data
- Erase your personal data
- Restrict the processing of your personal data
- Port your personal data
- Object to the processing of your personal data
- Object to automated decision-making

If you wish to exercise any of these rights, contact:

EVeR.patientprivacy@mydatatrust.info



What if you change your mind?

- You may withdraw your consent at any time without affecting your current or future medical care
- To withdraw consent, contact your treating physician or ***EVeR.patientprivacy@mydatatrust.info***
- If you withdraw your consent, your information will no longer be collected, but data previously collected will remain in the study database to maintain scientific validity
- If we cannot provide the requested data or make the requested changes, we will provide reasons for the decision

GDPR



HOW CAN YOU PARTICIPATE?

Improve deep venous disease treatment with us!

If your hospital has already joined the registry

Allow your treating physician to register your data in EVeR registry by giving your consent

If your hospital has not yet joined

Share this QR code with your physician to visit the webpage on esvs.org or contact info@esvs.org

