

British Society of Interventional Radiology Venous Registry

Patient Information Leaflet

Why have you received this leaflet?

The hospital involved in your care is participating in a national Registry that has been set up to improve the care of people with acute iliofemoral DVT (blood clot within the veins of the pelvis or upper leg) and chronic iliofemoral venous obstruction (blocked veins as a long-term complication of these blood clots). This document will group these conditions together and refer to them as 'DVT' (Deep Venous Thrombosis). The National Institute for Health and Care Excellence (NICE), the organisation that provides national guidance and advice to improve health and social care, recommends that doctors performing treatments for these conditions enter relevant information on this Registry. This leaflet tells you about this Registry.

What is the BSIR Venous Registry?

The BSIR Venous Registry is a clinical audit used to evaluate the safety and effectiveness of treatments for DVT. The more data we can collect, the better our understanding of these conditions and the better treatments we can offer to patients.

NHS hospitals in the UK are participating in the BSIR Venous Registry which is run by the British Society of Interventional Radiologists (BSIR).

What information is collected on me?

The BSIR Venous Registry collects information on the treatments you receive for these complicated DVTs. Only information related to these conditions and treatments is collected and includes information on the severity of your condition, and the types of investigations and treatment you receive. The BSIR Venous Registry does not require you to have any extra appointments or clinical tests. It does not affect the care you receive and it uses only information routinely collected by hospital staff. The Registry does not collect information on any care that does not relate to your DVT.

To help the BSIR Venous Registry provide an in-depth picture of care, the information provided by your specialist is linked to some other national health databases. This will mean keeping details such as your NHS number, date of birth and postcode to enable the databases to be linked. However, these personal details will not be shared with anyone outside the NHS.

What does the BSIR Venous Registry do with my information?

The data held on the Registry will be analysed by clinicians and statisticians who are part of the Registry Team, with the aim of improving the quality of care of people with these conditions. The reports will be available to the public, clinicians, hospital management and the National Institute for Health and Care Excellence.

The BSIR Venous Registry only publishes information describing the care received by groups of similar patients. It does not publish information on individuals and your personal details will not be made public.

Any reports that are published will be available on our website.

Occasionally, national registries are asked to support research to improve treatments. The information in the registry is only used for medical and scientific research after it has been made anonymous. Your personal details will not be passed onto researchers.

How will your information be kept safe?

The Registry has strict data security measures to keep the information held on you confidential. We follow rules about how the data are stored in a secure environment and that it is only made available to appropriate staff. The Registry conforms to the confidentiality rules established by the Data Protection Act 2018, the NHS Act 2006, and the Health and Social Care Act 2008. Your personal data will not be shared with anyone outside the NHS.

Patient Consent

We need your permission participate in the Registry and hold information that can identify you. You will be given a consent form to show whether or not you want the hospital to submit your personal details. Your care will not be affected by whether or not you consent.

If you change your mind and want to withdraw consent, please email council@bsir.org and put "Request to opt-out of Venous Registry" in the subject line.

Further information

If you would like more information about the BSIR Venous Registry you can email council@bsir.org or visit the BSIR website <https://www.bsir.org/registries/active-registries/bsir-venous-registry/>