

Information for Patients

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Background

A clinical data registry enables doctors to record information about the health status of their patients and the treatment that their patients receive over a period of time. Clinical data registries focus on patients who share a common reason for requiring health care and can provide an excellent way of improving the patient experience and treatment regimens and help to ensure high standards are maintained within healthcare settings. All data collected is subject to strict rules of confidentiality, so patients do not need to worry about any information falling into the wrong hands. Clinical data registries enable health care professionals to ask and answer important questions such as:

* What should we be doing?
* Are we doing it?
* How can we improve?

The data collected in a clinical data registry enables the data to be subject to audit. The information acquired from audits can then be used to assess various aspects of patient care. Information about the timeframes of treatment procedures can be assessed – for example the time duration between initial patient contact with a clinic and the time to treatment and treatment outcome. Information about the treatment process – the type of treatment different clinics/hospitals/doctors are using. Information about the outcome of successful treatment –the number of patients whose veins remain completely closed. A clinical data registry allows a multitude of questions to be asked, which allows a clinical data registry to function as a research database, providing a valuable resource for researchers to inform best practice, answering important questions such as:

* What treatment works best
* What can be done to improve the patient’s quality of life

What is The College of Phlebology Venous Registry?

The College of Phlebology Venous Registry focuses on patients that require health care assessment and treatment in the area of venous disease, either varicose veins of the legs and/or the pelvis. The College of Phlebology Venous Registry will collect information about the diagnosis, management and treatment of every patient newly diagnosed with venous reflux of the lower limbs or/and pelvis and their outcomes to treatment. A venous clinical data registry allows health care professionals to see what treatment options are available for treating venous reflux and, also how patients with different characteristics respond to the various treatment options. The information that is collected in the venous registry can then be used to inform both patients and health care professionals what may be the best course of treatment and importantly, to improve care for patients in the future. The College of Phlebology Venous Registry is a transparent system which has been set-up to improve knowledge and understanding of venous disease as well as ensuring that all patients receive the best possible healthcare. The College of Phlebology Venous Registry is a continuous process of looking at the care provided which enables the data collected to be audited which may enable previously unrecognised associations to be evaluated.

## Who manages The College of Phlebology Venous Registry?

The College of Phlebology Venous Registry is managed by The College of Phlebology – A group of vein experts dedicated to helping patients and the wider public understand more about veins and helping to ensure that patients understand what the very best treatment options available to them are. The College of Phlebology also helps fellow healthcare professionals and doctors working in the area of veins to understand more about veins, disseminating the newest research and information.

## What does The College of Phlebology Venous Registry measure?

The College of Phlebology Venous Registry will collect information form clinics and hospitals around the world that diagnose and treat patients with venous reflux of the legs or/and pelvis. This will enable us to assess the quality of care relating to:

* Service delivery and organisation
* Characteristics of newly-diagnosed venous reflux
* How the venous reflux was detected and the referral pathway
* Diagnosis and planning of initial treatment for varicose veins
* Treatments received
* Complications of treatment
* Success of treatment – complete closure of treated veins
* The causes of delay in the treatment pathway

## How is The College of Phlebology Venous Registry data processed?

The doctor/clinic/hospital trust providing your care will upload your information, using secure data transfer methods, to the College of Phlebology Venous Registry which is hosted by Dendrite Clinical Systems Ltd (**Dendrite**).

Dendrite will only process your data in accordance with a data processing agreement entered into with us and will store your data securely in accordance with applicable industry standards. Once a year Dendrite will combine the information from individual doctors/clinics/hospitals with data from other doctors/clinics/hospitals from across the world. They will process the data and organise it by location, clinic/hospital and consultant. They will then remove your name, date of birth, and any other information that could be used to identify you. The results of the College of Phlebology Venous Registry from regional level, hospital trust or clinic level and consultant level will be compared with each other.

## Who will benefit from The College of Phlebology Venous Registry data?

The College of Phlebology Venous Registry Stakeholders – which includes doctors, health care professionals, patients, carers, managers, the public and insurance providers will use The College of Phlebology Venous Registry reports to assess the quality of care provided.

The College of Phlebology Venous Registry annual reports will enable stakeholders to check progress and what improvements have been made. In the long term the new information collected by The College of Phlebology Venous Registry will help to define and refine existing quality standards. Of benefit to patients is that The College of Phlebology Venous Registry is a transparent system which will enable patients to have access to reports and make decisions about their treatment options as a result of information provided to them concerning the standard of treatment given at different locations and clinics/hospitals/consultants and the types of treatments offered.

The College of Phlebology Venous Registry data may be shared for research in a form that will not identify individual patients. The research will always be in line with the overall purpose of the audit aims, for example:

* Defining audit standards
* Publishing papers in medical journals to provide information about the best standards of care
* Providing information for public health

## Consultant Treatment Outcomes

Information about individual consultants and clinics/hospitals will be taken from The College of Phlebology Venous Registry and published each year. You will be able look at their results for a range of treatments to help you make decisions about your care. You will also be able to see how many times each consultant has performed a specific procedure. The data will show where the clinical outcomes for each consultant and hospitals/clinics sit against the national average. Where results differ significantly from the national average, there may well be good reason, and you can discuss this with your consultant.

## How reliable is The College of Phlebology Venous Registry data?

As The College of Phlebology Venous Registry is a large international registry some items are bound to be inaccurate or missing. Users of The College of Phlebology Venous Registry are health care professionals working towards the same common goal of trying to make sure that patients, the public and other healthcare professionals working in the area of veins really do understand the area of veins and venous disease better, as well as making sure that patients receive the very best standard of care for their varicose veins. Therefore, it is in the interest of The College of Phlebology Venous Registry users to enter data as accurately and completely as possible. Once your information has been added to The College of Phlebology Venous Registry only your clinicians will be able to access, check and change it. Dendrite will keep a record of all changes that are made.

## How we keep your information safe?

Data protection and privacy is an important part of The College of Phlebology Venous Registry - no individual patient names can be identified in the results.

Dendrite will make sure the data entered is subject to strict rules of confidentiality as laid down by Acts of Parliament, including the Data Protection Act 2018, UK GDPR and the Health and Social Care Act 2001.

How long will we keep your information?

By collecting a large amount of information, it is easier to identify the most effective treatments which can benefit patients. This can change varicose veins care so that in future patients will receive an improved treatment option and ensure a lower rate of recurrence and in the long term potentially prevent the onset of venous leg ulcers in susceptible patients.

We will retain The College of Phlebology Venous Registry data for a period of at least 10 years to enable us to collect, assess and report on the complications and outcomes of treatments.

## Can I opt out of The College of Phlebology Venous Registry?

A clinical data registry and national clinical audit is most effective and successful when as much information from as many patients as possible is collected. If you would like for your information not be used in The College of Phlebology Venous please inform the people who are treating you, either your health care providers or doctor. When the people who are treating you inform Dendrite about your decision, Dendrite will ensure that any information/data held about you within the registry will be deleted, which they will then confirm to the health care provider or doctor. This will not affect your treatment in any way.

## Contact details

If you have any questions about The College of Phlebology Venous Registry please contact [info@thecollegeofphlebology.co.uk](mailto:info@thecollegeofphlebology.co.uk)