





# **National Vascular Registry**

# **Patient Information Leaflet**

# Why have you received this leaflet?

The hospital at which you will have vascular surgery is participating in a <u>national clinical audit</u> that is set up to improve the care of patients with vascular disease.

# What is the National Vascular Registry?

The National Vascular Registry (NVR) is a clinical audit that hospitals use to monitor their practice. Hospitals enter data into the NVR IT system and the NVR team analyses this to provide information on their standard of clinical care and patient outcomes. This allows hospitals to know where they are doing well, as well as seeing areas that they can improve.

All NHS hospitals in England, Wales, Scotland and Northern Ireland carrying out vascular surgery participate in the NVR. The NVR is part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP) and is commissioned by the Healthcare Quality Improvement Partnership (HQIP). The NVR is run by the Clinical Effectiveness Unit of the Royal College of Surgeons of England in collaboration with the Vascular Society of Great Britain and Ireland (the professional society for vascular surgeons in the UK and Ireland).

# What information is collected on me?

The NVR collects information about the vascular surgery you have whilst in hospital. Only information related to your surgery is collected, such as the severity of your condition, the types of investigations and treatment you receive. The NVR does not require you to have any extra appointments or medical tests. It does not affect the care you receive and it uses only information already collected by hospital staff.

The NVR also collects information on the type of implantable devices (such as a graft or stent) used for AAA repairs (one of the vascular procedures collected by the NVR). This is in order to collect information on individual devices to monitor their performance and safety over time. For more information, please see our <u>datasets</u> and full <u>data dictionary</u> on our website.

### **Patient Consent**

If you are having an elective (non-emergency) vascular procedure, we need your permission to hold information that can identify you (name, NHS/CHI number, date of birth and postcode). You will be given a consent form to show whether or not you want the hospital to submit your personal details to NVR. Your care will not be affected by whether or not you consent.

If you give consent and then change your mind, please send an email to <u>nvr@rcseng.ac.uk</u> and put "Request to opt-out" in the subject line. On receipt of your email, we will remove your personal details from the NVR IT system.

Alternatively, you can notify a member of your local care team that you wish to opt out. They will then ensure that your personal details are removed from the Registry.

Because patients having emergency surgery are often very sick, it is sometimes impossible to ask them for consent. The NVR has approval from the Secretary of State for Health to store and use information from emergency patients without their consent, under a legal basis called Section 251 of the NHS Act 2006 (reference number: CAG 5-07(f)/2013). For more information on this, please see the following website: <u>http://www.hra.nhs.uk/about-the-hra/our-committees/section-251/what-is-section-251/</u>.







It is important that the NVR has information from all patients, not just those that are well enough to give consent, to give an accurate picture of the vascular care delivered in the NHS.

In 2022, NHS Digital introduced the <u>National Data Opt-Out</u> to allow individual patients to choose if they do not want their confidential patient information used for purposes outside of their individual care (e.g. national clinical audits, research and planning). The national opt-out only applies to patients whose data is collected without consent, under Section 251 (see above) and not to those who have provided consent for their data to be collected for a specific purpose (such as the NVR).

The request to defer application of the National Data Opt-Out was reviewed by the Confidentiality Advisory Group (CAG). CAG recommended that our request should be supported and the Secretary of State for Health and Social Care approved this. This means that confidential patient information collected under Section 251 can still be entered into the NVR and used for the purposes stated in the 'How will your information be used?' section of this leaflet.

#### How will your information be kept safe?

The NVR 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 UK GDPR, the UK DPA 2018, the NHS Act 2006, and the Health and Social Care Act 2012. Your personal data is needed to carry out a task in the public interest to ensure high standards of quality and safety of healthcare and will not be shared with anyone outside the NHS.

#### How will your information be used?

The NVR 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.

The information collected by the National Vascular Registry is used:

- To produce information on the quality of care received by patients having vascular surgery in NHS hospitals. The NVR produces reports each year that describes whether care is meeting national standards. The reports are available to the public, vascular surgeons, hospital management, and the wider NHS.
- To share areas of good practice with all NHS organisations.
- To provide patients with information about vascular services at different hospitals, such as the number of operations done each year, and the rates of survival after surgery.
- To help commissioners and policy makers with decisions about how vascular surgery should be organised within the NHS.

#### **Data Sharing**

The NVR may share data with researchers, other audits or other healthcare providers in order to help improve patient care. We will NOT share personal identifiers (such as NHS number, name, postcode or date of birth) with anyone else unless the appropriate legal, ethical and security arrangements are in place to keep your personal details safe and secure. Very occasionally, personal data may be processed by an authorised third party such as NHS England, again, only with the necessary regulatory permissions. They have very high levels of security and will keep these data very safe.

We have a rigorous process of assessing the merit of requests for data and information and these are controlled by the commissioners of the NVR (HQIP) and all requests go through their Data







Access Request Group. More details about the HQIP data request process can be found at: <u>https://www.hqip.org.uk/national-programmes/accessing-ncapop-data/</u>

#### **Further information**

If you would like more information about the National Vascular Registry, please ask your vascular team. Please scan the QR code below or follow the link to see the NVR's full privacy notice which contains more detail on what data is collected on the NVR and how it is used.

You can also email nvr@rcseng.ac.uk, or visit the NVR website at: www.vsqip.org.uk



https://www.vsqip.org.uk/resources/information-governance/nvr-privacy-notice/