



Invitation to help improve aortic research

The European Society for Vascular Surgery is a charity. It works to improve care for people with blood vessel conditions. We are inviting people who are not healthcare professionals to help us review work about aortic stent grafts. Your experience can help us make this work clearer and more useful.

Taking part is your choice. You can say no or stop at any time. This will not affect your medical care. It will not affect your relationship with the Society or your healthcare team.

Please read this form before you decide. You can ask us about anything that is not clear.

1 Why we are inviting you

We have invited you because you have personal experience of an aortic or other blood vessel condition. We want to hear your own views. You do not need to speak for other people. You will not be asked to give medical advice or make scientific decisions.

Your role is to advise us. The Society and the project team will make the final decisions.

If you are interested in taking part, please contact info@esvs.org by **30th September 2026**.

2 About this work

Project type	Review of physician modified endografts (PMEG), which are aortic stent grafts adapted by a doctor
Project team	European Research Hub – part of the European Society for Vascular Surgery. You can find information on the internet, here: www.esvs.org
Contact via e-mail	info@esvs.org

What the project is about

The aorta is the main artery that carries blood from the heart. An aortic aneurysm is a swelling in this artery. An aortic stent graft is a fabric covered tube placed inside the aorta. It helps support the weak area and directs blood away from the swelling.

Some aneurysms are hard to treat with a ready made device. If no suitable device is available, or treatment is urgent, an experienced specialist may adapt a stent graft for one patient. The medical name for this is a physician modified endograft (PMEG).

The Society is reviewing how these grafts are used. It will look at published research, current care and the rules that apply. It will explain what is known about benefits and risks, what is still uncertain, and what research is needed. This can help patients, clinical teams and health services make informed choices.

Patients may notice issues that research papers do not fully cover. Your comments will help us consider how treatment choices are explained, what risks patients may accept, and which results matter to patients and families.

European Society for Vascular Surgery
275 boulevard Albert 1er, 33130 Bègles, France
www.esvs.org

Company limited by guarantee incorporated in England, Company No. 04524120, Charity Registration No. 1093753
Registered Office at: 7 Bournemouth Road, Chandler's Ford, Eastleigh, United Kingdom, SO53 3DA

What we will ask you to do

We will ask you to:

- read one draft report of about 10,000 words;
- send written comments using a form from the project team;
- tell us if the report reflects the experience of patients and families;
- point out benefits, risks, questions or results that need a clearer explanation; and
- tell us if any words or parts of the report are hard to understand.

You do not need medical or research training. The project team will support you.

Time needed

The work should take about 3 to 5 hours during one 10 day review period. We expect the review to start in October or November. Most contact will be by email. We may arrange one online meeting or phone call if we need to discuss your comments.

3 Keeping draft information private

You may receive drafts or other information that is not yet public. If you take part, you agree to:

- keep this information private;
- not share drafts or meeting discussions unless the Society gives you permission;
- use the information only for this project; and
- delete or return it when the Society asks, unless the law says you must keep it.

Drafts and other private project documents remain the property of the Society. We will also keep your personal information private and follow data protection law.

4 How we will use your comments

We will consider your comments with those from clinical staff, researchers, Society staff and other patients. We may not be able to use every suggestion.

If your comment has already been added to an approved or published document, we may not be able to remove it later.

5 How we will use your personal information

Who is responsible for your information

The European Society for Vascular Surgery decides how and why your personal information is used. In law, it is called the data controller. Its registered office is 7 Bournemouth Road, Chandler's Ford, Eastleigh, United Kingdom, SO53 3DA

Our data protection officer is MyData-TRUST, Boulevard Initialis 7, 7000 Mons, Belgium. Email: ESVS.dpo@mydata-trust.info.

European Society for Vascular Surgery France S.A.S.U., 275 boulevard Albert 1er, 33130 Bègles, France, is our data protection representative in the European Union.

Your agreement

We need your explicit consent before we use your personal information for this work. You can give your consent at the end of this form. You can take it back at any time.

Information we may collect

- your name, email address, phone number and country;
- your preferred language and any help you need to communicate;

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- a small amount of information about your condition or patient experience, when needed;
- notes about your role, availability, choices, comments and work;
- payment, bank and expense details, if you choose to receive money; and
- meeting records and, when used, photographs, recordings or written copies of speech.

Why we may use your information

- to manage your role in this project;
- to contact you about this work or other patient roles that suit your experience;
- to arrange meetings, share documents and give you support;
- to consider and record your comments;
- to make payments, repay agreed expenses or record a donation; and
- to meet legal, financial and record keeping duties.

Information about your health and experience

We do not need your full medical record for this role. If you reply to this invitation, we may understand that you have experience linked to the topic. We will use only the information we need to decide if the role suits you, manage your role and keep the records required by law.

Who may see your information

Only people who need the information for this work may see it. This may include authorised Society staff, committee members and project teams. If you receive money, authorised finance staff and payment, banking, accounting or audit providers may see the payment details they need.

Sending information to other countries

Some staff, project members or service providers may be in other countries. If your information is sent outside the United Kingdom or the European Economic Area, we will use a legal safeguard when the law requires one. This may be a finding that the country has safe data laws or an approved data protection contract. You can ask our data protection officer for a copy of the safeguard.

How long we will keep your information

- We will keep your patient role profile while you are in the programme and for 3 years after your last role or after you leave.
- We will keep payment and expense records for 7 years.
- We will delete meeting recordings within 6 months.
- We may keep some records for longer if the law, an audit, a financial check or a dispute requires this.
- We may keep written project records under the Society's record keeping policy.

6 Your choices and rights

Taking part is your choice. You may stop at any time and do not need to give a reason. We will stop contacting you about this work. We may not be able to remove comments that are already in an approved or published document.

You can ask us to:

- tell you what personal information we use and why;
- give you a free copy of your information;
- send your information to someone you choose;
- correct or complete your information;
- delete your information or limit how we use it; and

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- stop using information that you agreed we could use.

To use these rights, email our data protection officer at ESVS.dpo@mydata-trust.info.

How to make a complaint

You can complain to the data protection authority in your country. For European Union authorities, use this website: edpb.europa.eu/about-edpb/about-edpb/members_en

In the United Kingdom, contact the Information Commissioner's Office. Address: Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF. Phone: +44 (0)303 123 1113.

Website: ico.org.uk/global/privacy-notice/your-right-to-complain

For questions about this project or the patient programme, email info@esvs.org.

7 Payment and expenses

We value your time and experience. Before you start, we will confirm the work, the time needed, the rate of payment, how we will pay you, and who can answer payment questions.

For this pilot programme, we normally pay patient contributors €50 for each agreed hour.

Please tick one choice:

- ☐ I would like to receive the agreed payment.
- ☐ I would like to give the agreed payment to the Society's Foundation.
- ☐ I do not want a payment.

Bank details

Fill in this part only if you want to receive payment.

Name on the bank account

Bank name

International bank account number

Bank identification code if needed

We will pay in euros by bank transfer. A bank outside the euro payment area, or an account in another currency, may charge a fee. The Society cannot control these fees.

We will use your bank details only to pay you and will store them safely. If we agree before the work, we may also repay reasonable expenses under our travel and expense policy. You are responsible for any tax that you may need to pay.

8 Photos and recordings

We may record a meeting or make a written record. This may help us write notes, make the meeting easier to use, or support people who cannot attend. Only authorised people may use the record, and only for the reason we give you.

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If we want to use your photo, words, story or recording in public information, education or promotion, we will ask for your separate permission when needed.

9 Your agreement

Please tick each box that you agree with:

- ☐ I have read and understood this information.
- ☐ I know that taking part is my choice and that I can stop at any time.
- ☐ I understand that my role is to advise and that the project team makes final decisions.
- ☐ I agree to keep private any draft or unpublished information shared with me.
- ☐ I agree that the Society may use my personal information as explained in this form.
- ☐ I give my explicit consent for the Society to use the limited information about my health and experience described in section 5. It may use this information to decide if the role suits me and to manage my role.
- ☐ I understand the payment arrangements, if they apply to me.
- ☐ I would like to hear about other patient roles. **Optional**

10 Your details

Full name

Email address

Phone number including country code

Country

Languages you speak

Signature

Date

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