



Role description:

Public Members for the Thames Valley & Surrey Secure Data Environment

We are looking for members of the public to sit on a number of committees that support and govern the Thames Valley and Surrey Secure Data Environment

Introduction

Information, or data, about patients is collected and used by the NHS to:

- provide individual care.
- plan health and care services.
- carry out research into new care and treatment.

To support planning and research the NHS is setting up a network of Secure Data Environments (SDEs). The SDEs will securely store patient data so that it can be used safely for planning and research. University or industry researchers, can apply to become approved users to access this data without it leaving the NHS. The data stored in an SDE has personal details removed, or replaced with a code, so that when the data is used, individuals cannot be identified (see appendix and our website for further information).

We need help from members of the public, carers and patients who live in the area covered by the Thames Valley and Surrey SDE, to make sure that our local SDE is set-up, and run, in a trusted and transparent way (figure 1).



Figure 1

What is happening locally?

Across the Thames Valley and Surrey (TVS covering the areas shown in this map) we are setting-up an SDE. The

SDE has a number of committees that support its safe and effective development and running. We are looking for public members for these committees.

Part of the NHS Research Secure Data Environment Network



The committees

The TVS SDE is governed, and supported by a number of committees which will include both staff and public members – please see figure 1.

We are looking to recruit a number of public members to support the work of the TVS SDE by sitting on these committees. The main committee we will be appointing to is the Services and data Access Review Committee. We encourage applications from individuals who are who are open to sitting on any of the committees, although please state on the application form if you have a specific interest in a particular committee. There is also an overarching **Programme Board** that these committees report to, we will be appointing public members to the Programme Board too.

Services and data Access Review Committee (SARC)

- sets policy relating to data held by the SDE and services provided
- · responsible for data access approvals
- members

Development Committee (DC)

- makes recommendations for strategic development of the platform and the service
- members include expertise in data science, intellectual property, practical and financial aspects of research delivery

Academic Research Advisory Committee (ARAC)

- discusses, reviews & guides direction of TVS SDE for collaborative academic research
- members include academic stakeholders & management

Commercial Research Advisory Committee (CRAC)

- discusses, reviews & guides direction of TVS SDE for collaborative commercial research
- members include commercial stakeholders & management

Healthcare Professional Advisory Committee (HPAC)

- discusses, reviews and guides direction of the TVS SDE around data quality, data use and use cases for Research and Development
- members include healthcare professionals and data managers



What is a public member, and why do we need them?

A public member is someone who does not work in the statutory health and care, or within research, and who sits on a committee to advocate for public, families, carers, patients and service users interests and views.

The TVS SDE are committed to including patients and the public in the design, delivery and governance structures and processes of our programme. In order to support this commitment, it is essential that our committees include diverse membership from the public, to ensure that the experience and views of the public, families, carers, patients and service users are understood and acted on.

The role

Whilst the different committees have specific focus, the role of a public member is the same, to:

- provide critical friend challenge.
- champion a diversity of patient and public views, and not just represent their own experience.
- support patient and public awareness of the TVS SDE Programme and its work.
- review and comment on documentation.
- comply with the Terms of Reference set out by the committee they are serving on.

Skills and experience

Public members come from a range of backgrounds, there is no standard set of skills or expertise. The following attributes, skills and experience are desirable:

- Experience of committee work this could be in a professional or voluntary capacity.
- The ability to provide constructive challenge e.g. exploring what has worked well, what could be even better and what can be learnt.
- The ability to interact with a wide range of people, understand what matters to them and represent their views rather than just putting forward a personal view.
- A commitment to openness, equality, diversity and inclusion.
- The ability to understand complex issues and ethical considerations
- An interest in health services and data.
- Self-motivation and organisation.
- Sound judgement and objectivity.
- Understanding the need for confidentiality.

Time commitment

- The appointment will be for 1 year in the first instance, with a review after 2 meetings

 the number of meetings per year will vary depending on the committee but will be between 4 and 12 a year.
- Meetings will be hybrid, with the option to attend in-person (usually in Oxford), or online, for some meetings in-person attendance will be encouraged
- Meetings will range from 1-1.5 hours, depending on the committee.
- Papers will be sent by email in advance of the meetings and can be prepared in alternative formats (e.g. large print) to help with accessibility. The public member will be expected to review the papers in advance of the meeting.
- Preparation time for each meeting is likely to be 1 hour.

Part of the NHS Research Secure Data Environment Network



Support for public members

- The public member will need to complete an induction. This will mainly be online and will provide background information about the TVS SDE and the committee to which you've been appointed. It will also involve meeting key members of the TVS SDE team and the committee.
- A review meeting will be held after attending two committee meetings. This meeting will be attended by:
 - the TVS SDE Coproduction Lead
 - o a member of the TVS SDE Management Team
 - o chair of the committee
- This meeting will provide opportunity to review how well the arrangement is working, highlight opportunities or learning, and determine whether the appointment will continue.
- Should the appointment be extended beyond one year, agreements will be made concerning on-going review meetings and support.
- Pre-meeting briefings will be provided where required.
- Public members will be reimbursed for their time spent preparing for, and attending, their committee meetings. This will be paid in line with <u>HIOTV payment policy</u>, at a rate of £20 per hour. Reasonable travel expenses will also be reimbursed.
- Other opportunities to be involved in further TVS SDE programme work will be shared with public members accordingly.

How to apply

If you are interested in applying, please complete the <u>separate application form</u> and email it to: Lisa-Anne Dallas at <u>community.involvement@healthinnovationoxford.org</u>

On the application form, there is the option to highlight a specific committee that you are interested in applying to become a public member for. It is not essential to select a specific committee.

Please also complete and return a diversity monitoring form.

Closing date for application: midday Friday 25th October 2024.

Online interview dates: Tuesday 5th November and Wednesday 6th November 2024.

If you have any questions about the role, please email Siân Rees on community.involvement@healthinnovationoxford.org

If you require this document, or either of the two supporting application documents, in different format, such as an accessible PDF, large print or hard copy, please let us now by emailing the above email address. We will consider each request and respond within 5 working days.

Part of the NHS Research Secure Data Environment Network



Appendix

What is NHS data?

The NHS has been collecting health and care data through its interactions with patients, since its formation in 1948. Your health and care information is held by organisations that provide care for you, like your hospital or GP. This data can be used to:

- **Provide your individual care** by providing accurate, up-to-date information about you to all staff who help look after you.
- Plan health and care services and carry out research by linking together small
 amounts of data from lots of patients, planners and researchers can look for patterns.
 This helps them identify ways to improve health and care services, understand more
 about disease, monitor safety, and develop new services and treatments.

Thames Valley and Surrey SDE

In the Thames Valley and Surrey (TVS), we are working with patients and the public, alongside health and care staff to develop a local SDE. Oxford University Hospitals NHS Foundation Trust (OUH) is the host organisation for the TVS SDE. Health Innovation Oxford and the Thames Valley (HIOTV) is supporting the SDE in a number of ways, including the delivery of its coproduction work.

Our SDE will benefit our communities by:

- supporting research for new and improved diagnostic tools, and treatments.
- helping the NHS plan better service.
- making sure that everyone can see how local patient data is being used and what impact it has.