

East of England Secure Data Environment Core Public Advisory Group



The East of England Secure Data Environment (SDE) is a digital platform that allows approved researchers to securely access de-personalised patient data for health research.

It has been built in partnership with NHS organisations across the East of England, with state-of-the-art cyber security measures, controlled access and robust oversight of data usage.

We've been working with a small group of people from across the East of England who meet with the SDE team about every 2 months to provide a public perspective on the project and to advise on its development.

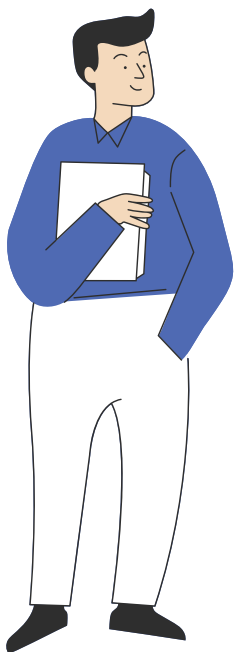
This group is called our 'Core Public Advisory Group' and we are welcoming applications for new members.

The East of England SDE is one of 11 others being funded by the NHS across England. The East of England includes the following regions, with a total population of about 7 million people:

- Norfolk and Waveney
- Cambridgeshire and Peterborough
- Suffolk and North East Essex
- Bedfordshire, Luton and Milton Keynes
- Hertfordshire and West Essex
- Mid and South Essex



Involving the public



The data in the East of England SDE ultimately comes from NHS patients across the region. It is very important to us that the SDE is created with members of the public to make sure that the project is **fair, ethical and acceptable**.

Our **Core Public Advisory Group (CPAG)** help us to understand and address people's hopes and concerns about this project. We meet online every 1-2 months, for about 2 hours and occasionally correspond via email.

We aim to maintain a group of 12 people on the CPAG, with a range of experiences, backgrounds and skills. We welcome applications at any time.

Who are we looking for?

We want to hear from people from all sorts of backgrounds and with all sorts of life experiences and opinions.

You need:

- ✓ To be aged **18 or over**
- ✓ Live in the **East of England** (see the map on the previous page)
- ✓ To be able to **attend online** meetings (meaning you have a stable internet connection and a laptop, tablet or phone that can run Zoom)
- ✓ To be **interested in making a difference** in how people's data is used in healthcare research
- ✓ To be able to listen to other people's views and contribute constructively to discussion





But you don't need:

- ✗ To know anything about data, research or Secure Data Environments. We will bring everyone up to speed.
- ✗ To have any **prior experience** as a "public representative" or to have done any "patient and public involvement" (but it's ok if you do!)
- ✗ To worry that you **won't have anything to say**.



So far the Core Group has done things like:

- **Share their** concerns about this project and work together to find ways of resolving them.
- Help us **plan community activities** and decide how we should act on people's feedback.
- Work with our technical and legal teams to ensure that **people's privacy is protected** and that their **data will be used ethically**, including ways to opt out.
- Help us develop information materials to **make sure the public is informed** about the project honestly and in language which is easy to understand.
- Work together with us **on long-term plans for continuing to involve the public** every step of the way.

What members of our Core Group say



"It's been gratifying to help ensure that our information will be used only in safe, ethical and acceptable ways."
- Phil



"It really feels rewarding to be part of the process, so to speak – to contribute thoughts and opinions within a lively and interesting group."
- Pat



Payment

CPAG group members are **offered** a payment of £25.00 per hour, **by cheque or voucher**, for their **active contributions**. This includes participation in online meetings and time required outside of meetings on things like reading draft leaflets or giving feedback on slides.

Group members can **choose not** to claim their honoraria or to ask for a lower amount if that better suits their financial circumstances. Reasonable, pre-agreed expenses will also be reimbursed.

Apply now!



If you would like to apply, please complete an application using the link below:

<https://forms.office.com/e/fTpNVtZAza>

What happens after I apply?

We are looking for a **range of people** for the group - spread across the East of England, age group, gender, experience etc.

We will review each application. If you match an opening on the group, we will ask you to join a brief meeting with us to discuss further.

If we already have similar people to you on our group, we will be in touch to let you know and ask if you would like to join our wider community to keep in touch, and the wait list should a further position open.

For any any questions about the SDE or the Core Group, please
contact: cuh.eoe.sde@nhs.net