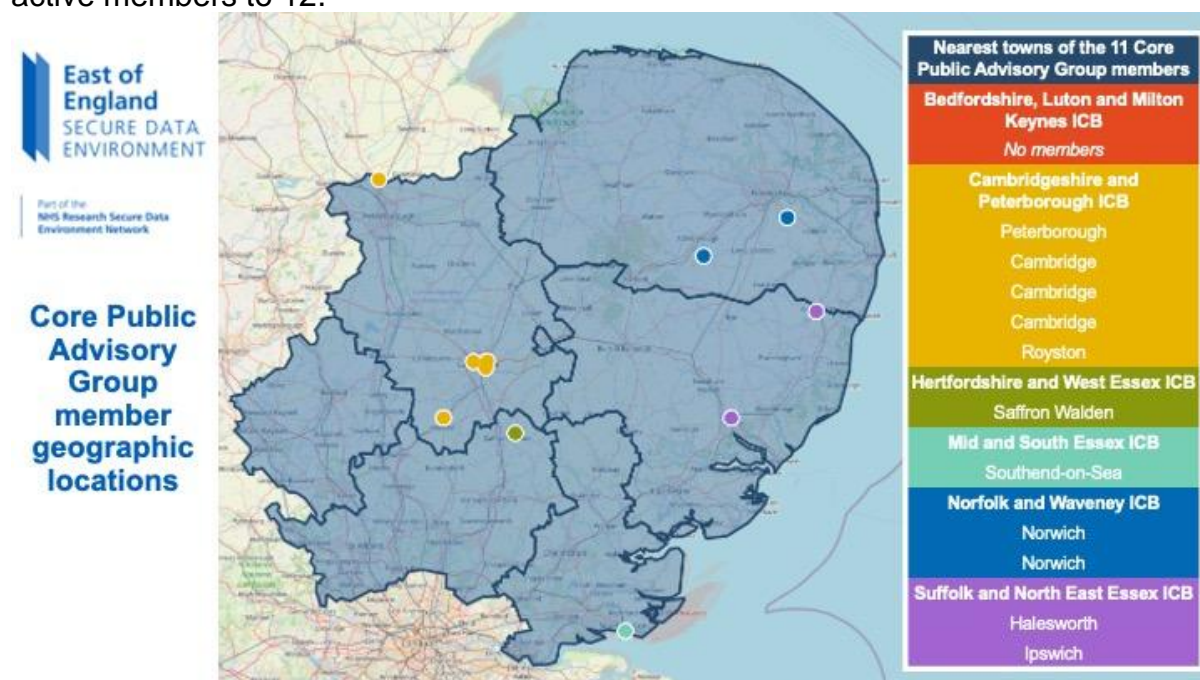# East of England SDE PPIE Summary: Jan – March 2025

Core Public Advisory Group (CPAG)

This quarter we have welcomed 5 new members of our CPAG group, bringing total active members to 12.
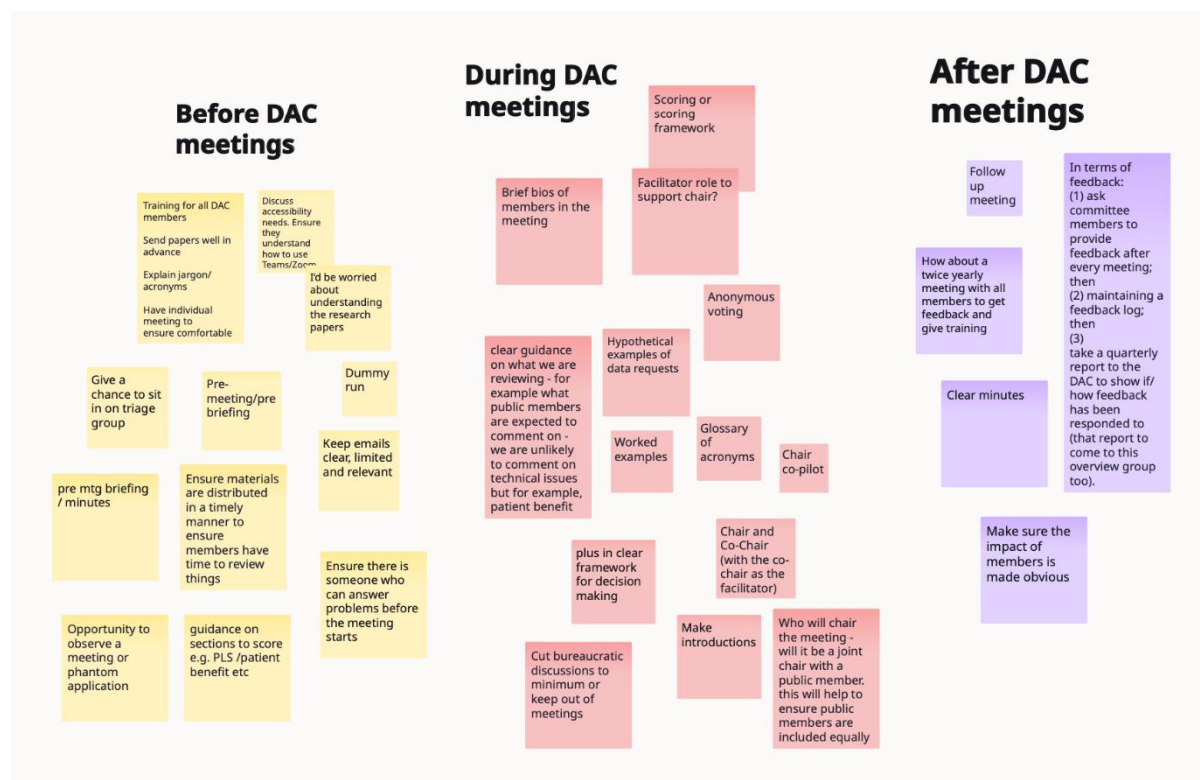

We have had two expressions of interest from the Bedford region (awaiting return from holiday to interview and induct into group), and will focus recruitment efforts for the next quarter on additional member(s) from Hertfordshire, Essex and the northern Norfolk coastal region.

In our February meeting, we welcomed new members (5 people) and the meeting focused on bringing the new members up to speed with the SDE and Data for R&D programmes; what our earlier PPIE activity has covered, the key learnings and how we have implemented them; and general Q&A.

In our March meeting (6 people), new and existing members of the CPAG joined to discuss how we can be support public members on the Data Access Committee to ensure that they have a meaningful impact on decision making. We used a white board, the chat, and verbal discussion to share ideas about how public and professional members can be supported before, during and after meetings, and what information would be important to include in training. Several members have expressed interest in joining a Task and Finish group to help develop training materials for DAC members.

Several CPAG members have agreed to support early DAC meetings as public members, while we recruit additional public members.

Before DAC meetings

- Training for all DAC members
- Send papers well in advance
- Explain jargon/acronyms
- Have individual meeting to ensure comfortable
- Discuss accessibility needs. Ensure they understand how to use Teams/Zoom
- I'd be worried about understanding the research papers
- Give a chance to sit in on triage group
- Pre-meeting/pre briefing
- Dummy run
- Keep emails clear, limited and relevant
- pre mtg briefing / minutes
- Ensure materials are distributed in a timely manner to ensure members have time to review things
- Ensure there is someone who can answer problems before the meeting starts
- Opportunity to observe a meeting or phantom application
- guidance on sections to score e.g. PLS /patient benefit etc

During DAC meetings

- Scoring or scoring framework
- Brief bios of members in the meeting
- Facilitator role to support chair?
- Anonymous voting
- clear guidance on what we are reviewing - for example what public members are expected to comment on - we are unlikely to comment on technical issues but for example, patient benefit
- Hypothetical examples of data requests
- Worked examples
- Glossary of acronyms
- Chair co-pilot
- plus in clear framework for decision making
- Chair and Co-Chair (with the co-chair as the facilitator)
- Make introductions
- Cut bureaucratic discussions to minimum or keep out of meetings
- Who will chair the meeting - will it be a joint chair with a public member. this will help to ensure public members are included equally

After DAC meetings

- Follow up meeting
- In terms of feedback: (1) ask committee members to provide feedback after every meeting; then (2) maintaining a feedback log; then (3) take a quarterly report to the DAC to show if/ how feedback has been responded to (that report to come to this overview group too).
- How about a twice yearly meeting with all members to get feedback and give training
- Clear minutes
- Make sure the impact of members is made obvious

Public Survey findings Jan – March

36 members of the public completed our digital survey between Jan and end March.

- 'Nothing' remains the most common response as to what concerns people have about their data being used for research (>30% of responses)
  - Next most common concern is around being able to be identified/data not being anonymous (25% of responses)

- The next most common themes are around data security/data breaches and inappropriate commercial use
  - Two respondents shared concerns about data being used to their disadvantage

No new themes emerged from the responses. Palantir is specifically mentioned in two responses as a risk and/or specific entity that people do not want to have access to their data.

Community Engagement Activity Jan – March

Our public engagement efforts aimed to raise awareness and foster dialogue around CPAG and DAC initiatives, focusing on community outreach, strategic partnerships, and digital visibility. We worked with community organisations across the East of England, distributing digital materials to local councils. Cambridgeshire County Council notably supported the initiative by sharing our content on social media.

Communities with whom we had established relationships—particularly Indian, Bangladeshi, and Romanian groups—remained actively engaged. Our materials were translated and featured in the socials of an Indian general entertainment channel, Magnavision TV and shared through WhatsApp groups with the support of community leaders, significantly extending our reach.

Irish and Italian communities have been responsive, actively sharing our materials during their regular meetings, which enhanced our outreach efforts. Most first survey respondents were engaged community members who felt their feedback was sufficient and didn't complete the second. There was still a positive interest in learning more about CPAG and DAC.

A significant success was our collaboration with West Herts College, where our materials were displayed on digital screens across campus. Future plans include promoting our content through their social media platforms to further extend our reach.