East of England SDE PPIE Summary: April - June 2025

Core Public Advisory Group (CPAG)

The CPAG met twice this quarter.

In April, we discussed the SDE’s involvement in a project called ‘VISTA’, which will test a tool called ‘SACRO’ that has been developed to support semi-automated checking of outputs from the SDE

SACRO = **S**emi-**A**utomated **C**hecking of **R**esearch **O**utputs

Output checking

It was a challenging discussion as the process of data analysis within the SDE is difficult for people to imagine, which in turn makes it hard to understand what either human or ‘semi-automated’ checkers would be looking for in the data. It was also tiring to navigate the use of acronyms related to this project – although they were considered necessary abbreviations, it added to the complexity of the discussion. CPAG members agreed that tools that support human checkers to do their jobs are useful, but they wouldn’t want to see human oversight entirely replaced. They also had questions about other checks that might take place beyond just checking for potentially identifiable data – for example, checking that the research matches what the researchers said they would do with the data.

Pricing model

CPAG members generally agreed/felt comfortable with the majority of the financial ‘principles’ set out in the national plan. They felt that the SDEs should operate like not for profit organisations that cover their costs but shouldn't be under pressure to make a profit, particularly if the costs limit people who would use it.

However, they felt less comfortable with the principle that ‘*The Value of Data will be determined based on the nature of the project in which it’s being used rather than the user organisation behind the project*’. CPAG members felt this gave insufficient weight to ability to pay, and might reduce the number of projects from NHS, universities or smaller enterprises, which may in turn reduce benefits to public health. There was discomfort with the sense that non-profit companies had to pay the same standard fees as for-profit companies, which the ‘value of data’ principle was not able to overcome. Similarly, although it was agreed that funds generated through the ‘value of data’ charge on commercial applications could be used to offset fees and charges from charity, NHS or academic studies, that this should not be in place of an alternative pricing structure that recognised a general ability to pay.

CPAG members also felt that there should be recognition (financial or otherwise) for developed data assets that could be reused by other researchers.

Finally, there was a sense of dismay and frustration about a perceived lack of public involvement – or even incorporation of existing findings from large-scale engagements – in the development of the national principles.

These findings will be used to create a ‘position statement’ that will be fed into the national team.

Commissioning data sets

CPAG members were not previously aware of commissioning data or what it contained, and there was some confusion about where these data fit in with other sources and what information they may contain.

CPAG members wanted to know who is currently able to access commissioning data sets and how the process would differ through the SDE. There was general agreement that, assuming the same criteria for de-personalisation and public benefit etc apply that this would be a useful additional source of data for access through the SDE. It was important to CPAG members that the SDE couldn’t be used as an ‘easier’ way to access these data in terms of reduced security or checking but equally that the SDE supported researchers through the process so that researchers were not tempted to access commissioning data separately when they wanted to use it through the SDE.

These findings will be used to update our public-facing materials and contribute to the development of an amendment to our current ethics approval to enable use of commissioning data within the SDE.

Public Survey findings Jan – March

15 members of the public completed our digital survey between April and end June.

- ‘Nothing’ remains the most common response as to what concerns people have about their data being used for research
- Next most common concern is around being able to be identified/data not being anonymous
- The next most common themes are around data security/data breaches and inappropriate commercial use

No new themes emerged from the responses.

Community Engagement Activity April - June

We shared campaign materials in Southend-on-Sea, King’s Lynn & West Norfolk, Bedford, Hertfordshire, and Norfolk and Norwich. Several city councils also featured our assets on their official platforms. We shared health data videos in native languages with Roma and Indian communities.

Looking ahead, we plan to expand engagement with young adults through colleges and universities across the East of England, and to spotlight community voices during South Asian Heritage Month. Particular emphasis will be placed on reaching communities in remote areas of the East of England, especially those who are less digitally connected.