North East and North Cumbria Secure Data Environment (SDE) Patient Public Involvement and Engagement

In 2023 NHS England created a network of 'Secure Data Environments' (SDE). It looks at how research can use patients' health and care records. This is to help create new treatments and services. SDEs supports the work the Government talked about in their strategy: [Data Saves Lives: Reshaping health and social care with data](#)

SDEs can link together as part of a national network. There are 11 SDEs set up across England. There is one in the North East and North Cumbria. Health Innovation North East and North Cumbria (HINENC) host the SDE for our region. They do this on behalf of the NENC ICB.

Involving the public

A key part of a SDE is patient and public involvement. Members of the public help to shape the programme. This helps to build public trust. This was an important learning from failed past IT and data projects. We developed a patient, public involvement, and engagement strategy for the SDE. This sets out the ways people can get involved. We wanted to talk to local people about what is important to them. We also wanted members of the public to be part of decision-making groups.

Public members group

In September 2023, we set up a Public Members Group. There are 14 members of the public in this group. They receive payment for the work they support. The work the group has supported has influenced the SDE programme. The group meets every month for a two-and-a-half-hour workshop. They also do other tasks online. The group see how important it is to use data correctly. They make sure the programme considers what is best for members of the public. The group has a lot of different people in it. People:
- are from different parts of our region
- are different ages
- are from different ethnic backgrounds
- are a mix of men and women
- have different levels of experience
- have different health conditions.

For more information: [Secure Data Environment | North East and North Cumbria NHS](#)

Including listening in decision making groups. SDE. Dec 2024

Since being established the public members have:
- given 512 hours of their time
- taken part in 15 task and finish groups
- taken part in 13 workshops
- taken part in four focus groups
- reviewed eight key documents
- attended eight strategy boards
- co-produced plans, including:
  o the involvement strategy
  o public survey questions
- wrote research and non-research terms in plain language
- developed evaluation criteria for assessing research applications for the SDE
- developed public messages for complex data topics
- designed information for the public. Such as branding, leaflets, and website content.

Public involvement in approving research applications

The people who want to study health data will send an application. This will be to use data in the North East and North Cumbria SDE. The Data Access Committee (DAC) will review these applications. They will decide whether to approve or decline them.

The Patient Evaluation Group (PEG) also has a say on applications. The PEG includes members of the public. They help make sure the DAC considers what members of the public think. The PEG reviews the recommendations made by the DAC on each application. They agree or reject the recommendations. They do this based on PPIE evaluation criteria. The PEG or DAC cannot make final decisions on applications.

For more information: Secure Data Environment | North East and North Cumbria NHS