Research Secure Data Environment NETWORK

NHS

NHS Research Secure Data Environment Network

Review of Patient and Public Involvement and Engagement in 2025/26

June 2026

Research Secure Data Environment NETWORK

NHS

Contents

1. Summary

This review provides an overview of Patient and Public Involvement and Engagement (PPIE) activity across the NHS Research Secure Data Environment (SDE) Network during 2025/26. It also highlights some key insights gathered and shows the impact that PPIE has had, along with identifying priority areas for further work.

PPIE plays a central role for SDEs, ensuring that the use of health and care data for research is transparent, ethical, and aligned with public expectations. Its core role is to bring the voices of patients, carers, and the wider public, particularly those with lived experience, into decision-making about how data is accessed, used, and governed.

In practice, PPIE in SDEs helps to:

- **Build trust and transparency** by making sure the public understands how their data is used and by influencing products such as data use registers and public-facing materials.
- **Inform decision-making** by involving contributors in the review of data access applications, ensuring that proposed uses of data reflect public values and benefit patients.
- **Strengthen governance** through embedding public members in boards, advisory groups, and oversight committees, where they can challenge, scrutinise, and shape policies and processes.
- **Promote inclusivity and equity** by actively engaging under-represented and seldom heard communities, ensuring diverse perspectives are reflected in how data is used for research.
- **Improve systems and processes** by feeding back insights from engagement activity, which can lead to changes in policies, communication, safeguards, and user experience.
- **Enable co-production** by working collaboratively with the public to design engagement approaches, develop resources (e.g. plain English materials), and shape SDE priorities.

Overall, PPIE ensures that SDEs operate not just as secure technical platforms, but as socially legitimate and publicly accountable systems that use data in ways that are trusted and beneficial.

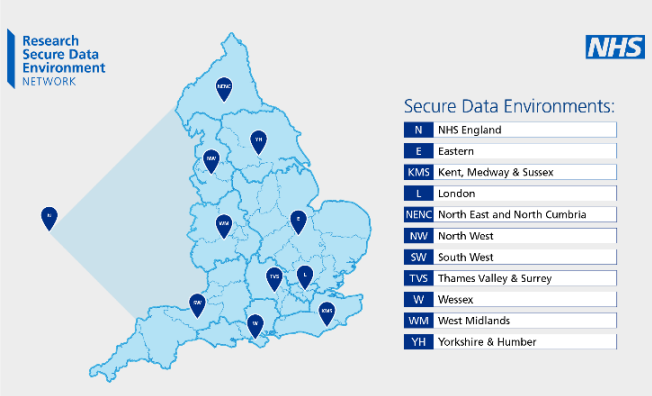
2. Key insights

The evidence reviewed for this report identifies a number of key insights about SDE PPIE activity and achievements in 2025/26:

- **Public contributors are embedded in governance structures** (e.g. Data Access Committees, advisory groups, boards)
- **Public involvement influences decision-making on data access, governance and policy**
- **Focus on transparency** (e.g. Data Use Registers, public-facing materials, opt-out information)
- **Engagement activity used mixed methods** (workshops, focus groups, surveys, events)
- **Inclusion of diverse and seldom heard communities**
- **Evidence of co-production approaches with public contributors**
- **Public input leading to changes in processes, policies, communications, and governance.**

3. Background and methodology

The SDE Network was funded through NHS England's Data for Research and Development Programme (Data for R&D Programme) from its creation in November 2022 through to 31 March 2026 when the Programme transitioned into the SDE Network Core Hub. The core hub has taken on funding and other key support functions previously provided through the Data for R&D Programme.



The SDE Network was established to support delivery of the Data for R&D Programme's mission to advance the secure, transparent and ethical use of NHS data to support transformative research, improve patient outcomes, and transition from a data-sharing to data-access model.

The patient and public voice has shaped the form, function and plans of the Programme and SDE Network and will continue to do so in the future. Recognising that "the opportunity to leverage health data can only be achieved if it is done in a way which is secure and trusted by members of the public" (Data for R&D Programme Business Case, 2022), the Programme was also the principal funder of a national-scale public engagement initiative, allocating £1.5 million to explore public perspectives on NHS data usage, particularly for secondary purposes such as research.

In April 2026, all SDEs were asked to provide information about their PPIE activity during 2025/26, including the scope of the work, the groups or communities engaged with, and the impact. SDEs also provided information about the ways in which PPIE is part of the SDE structure and processes. The information provided by SDEs was supplemented with desk research and review of PPIE activity published on SDE websites. As such this report relies on self-reported and publicly available information and is not a formal audit of SDE PPIE capability or impact.

The table below summarises sources of information for each SDE:

SDE name	Web review	Summary report
Eastern	Y	N
Kent, Medway and Sussex	Y	Y
London	Y	Y
NHS England	Y	Y
North East and North Cumbria	Y	Y
North West	Y	N
South West	Y	Y
Thames Valley and Surrey	Y	Y
Wessex	Y	Y
West Midlands	Y	N
Yorkshire and Humber	Y	Y

4. SDE PPIE activity and impact

502,139

people engaged across the SDE Network in 2025/26

The total engagement reach was achieved through a range of regional patient and public engagement activities. PPIE activity was locally determined and focused by SDEs according to their populations and priority areas.

The section below summarises the PPIE activities conducted by each SDE this year.

4.1. Eastern England SDE

Structural

Patients and the public are embedded in Eastern England SDE governance through the Core Public Advisory Group (CPAG), public membership of the Data Access Committee, and representation in wider governance structures, including the Delivery Board. Public contributors provide scrutiny, challenge and advice on data access, public benefit, transparency, safeguards, and the wider development of the SDE.

During 2025/26, CPAG contributed to strategic and operational decision-making across a range of areas including data access processes, commissioning datasets, pricing models, statistical disclosure control, AI governance, data federation, data pooling and the merger of the East of England and East Midlands SDEs. Public contributors also helped identify public considerations relevant to CAG and REC submissions, supporting public assurance around the development of the Eastern England SDE.

Engagement activity

During 2025/26, Eastern England SDE delivered 10 CPAG meetings, public webinars and wider engagement activities across the region.

A frontline health engagement survey gathered feedback from 180 respondents across the region, and public webinars held between September and November were attended by 36 participants.

A major focus was the Genomics Public Deliberation programme, which explored public views on the use of genomic health data within the SDE. This engaged 85 participants through nine focus groups and a public panel, delivered with Healthwatch partners across Essex, Hertfordshire, Leicester and Norwich. The programme placed particular emphasis on engaging communities that are traditionally underrepresented in genomic research, including minority ethnic and minority faith communities. One focus group in Leicester was designed specifically for Muslim women, creating a culturally appropriate setting for participants to share their views.

The SDE also worked to improve accessibility of public-facing information. In partnership with Understanding Patient Data, SDE information videos were translated into British Sign Language, Urdu, Punjabi, Romanian and Polish and shared through the website and social media. The team is also investing in Easy Read training to support more accessible communications for people with learning disabilities, neurodivergent people and others who may benefit from clearer formats.

Impact

Public involvement has strengthened governance, transparency and accountability within the Eastern England SDE. CPAG members have influenced data access processes, public benefit considerations, statistical disclosure control, AI governance, federation and multi-SDE research arrangements. Their input has helped ensure that decisions are informed not only by technical and regulatory requirements, but also by public expectations around privacy, security, fairness and responsible data use.

Public contributors have also shaped AI-related work through the VISTA project, including feedback on the AI Risk Assessment Toolkit and discussion of safeguards to reduce the risk of inadvertent disclosure through AI models.

Engagement insights have informed public-facing information, communication approaches, ethics-related materials, and the way health data use is explained to public audiences.

The genomics deliberation work broadened participation and strengthened representation, particularly in the East Midlands. One participant from the deliberations subsequently joined

CPAG, creating a clear pathway from public engagement into ongoing governance and advisory roles. Overall, the Eastern England SDE has used PPIE to strengthen public assurance, improve accessibility, inform policy and governance development, and keep public perspectives central to the responsible use of health data.

Sourced from the Eastern SDE website and additional programme evidence, see Appendix A for further information.

4.2. Kent, Medway and Sussex SDE

Structural

Public contributors are embedded in governance, with a formal Advisory Group feeding into the Programme Board, representation across local involvement groups, and roles on the Data Access Committee (DAC). Public members make up 30% of the DAC and contribute directly to decision-making.

Engagement activity

The Kent, Medway and Sussex (KMS) SDE engaged widely, with around 40 regular public contributors, 15 members on the DAC, and a further 400 people reached through targeted engagement and surveys. Participants reflected diverse communities, including those with lived experience of health conditions, global majority groups, people with lower digital confidence, and Voluntary, Community, and Social Enterprise (VCSE) partners. For example, targeted engagement activities reached over 100 participants from Women of Faith communities and over 100 from Gypsy, Roma, and Traveller communities, alongside involvement from organisations such as MIND, Healthwatch and Age UK.

Engagement covered a broad range of topics including governance, data access, ethics, transparency, opt-out, data quality, financial value, and social licence. Activity included 40 engagement sessions using co-production and deliberative approaches across advisory groups, panels, surveys, and targeted community work. This included surveys and deliberative engagement, with 37 contributors shaping validation (now known as registration) policy and additional survey responses gathered across regional involvement groups.

Impact

This involvement has led to several changes, including updates to the commercial model and Data Use Register, the co-design of ethical guardrails and governance structures, improvements to transparency and communications (including opt-out and financial information), and the development of social licence principles. For example, public contributors co-designed ethical guardrails now used to inform DAC decisions, influenced the local commercial model, and shaped how SDE surplus funding should be used to support direct patient care. This includes social licence principles co-designed with people and communities and adopted across the system to guide how data is used and build public trust.

Public input has also strengthened transparency and communication. This includes shaping the content and accessibility of the Data Use Register, and informing opt-out

communications and materials for the public, including clear public information on people's rights and choices about how their data is used and how to opt-out. It has also supported improvements to data governance and data quality, including better documentation, monitoring, and clarity around how data is used within the SDE. This is reflected in ongoing monitoring and reporting to show how public input is influencing decisions.

Public input has also contributed to national work, including informing submissions to the Confidentiality Advisory Group and input into wider SDE events, networks and discussions.

Insights from public contributors have been used in practice, for example shaping validation policy (including how some organisations are assessed and escalated), influencing how public benefit and risk are considered in data access decisions, and ensuring local voices remain part of developing collaborative arrangements across the Southern SDE Partnership (comprising Kent, Medway and Sussex SDE, South West SDE and Wessex SDE).

Sourced from the KMS SDE website, see Appendix B for further information.

4.3. London SDE

Structural

Patients and the public are embedded across London SDE governance through the Citizens' Advisory Group, representation on the Independent Information Access Group (IIAG), and involvement in ICS-level Data Access Committees. They play an active advisory role, informing data access decisions, safeguards, and wider national SDE discussions.

Activity

The London SDE engaged a broad range of participants, including 69 Londoners through surveys and focus groups, 20 Citizens' Advisory Group members in co-design workshops, and 24 PPIE representatives via a public webinar, alongside ongoing involvement from a wider Citizens' Advisory Group of around 100 members. Participants reflected London's diverse population, including members of the OneLondon Citizens' Advisory Group representing all ICSs, national PPIE representatives from other UK SDEs, and individuals with lived experience or interest in areas such as cancer, mental health, cardiovascular disease, antimicrobial resistance, and health data use.

Key engagement topics focused on the use of health and care data within an SDE, particularly around public trust, transparency, accountability, safeguards, and governance. Additional areas included Section 251 and opt-out choices, as well as the use of unstructured clinical data in cancer care (OncoLlama), reflecting wider engagement activity used to inform decisions on data use and Section 251 applications.

Reports on the full findings from these areas of work have been published and can be found here:

- Public expectations and Section 251 consent report
- Co-designing messaging around opt-out choices report
- OncoLlama public webinar report

Additional engagement activities included NHS England SDE patient and public events (both in-person and online), participation in a panel session at an industry launch during London Life Sciences Week, and four meetings of the Independent Information Access Group (IIAG). Members of the public have also been actively involved in the London Driver Projects, advising on project decisions through lived experience.

Impact

Engagement has led to the launch of the London SDE Data Use Register to improve transparency, clearer communications on data use and opt-out choices, and refinements to the OncoLlama project in response to findings from the public webinar. Ongoing public input continues to strengthen governance and accountability processes.

See Appendix C for further information.

4.4. NHS England SDE

Structural

Lay members were embedded within the Advisory Group on Data (AGD), contributing lived experience as patients, carers, service users and research participants to the review of data applications. Insights from this work have driven meaningful improvements, including updates to the Data Use Register, the co-development of a plain English glossary in partnership with learning disability and autism forums, and enhanced feedback processes to support the data application journey.

Activity

Over 25 public contributors were actively engaged, with a strong emphasis on involving people with lived experience of learning disability and autism, as well as individuals from global majority communities. Activity focused on the Data Use Register and on strengthening public and patient involvement in reviewing data applications, ensuring that patient perspectives directly inform national-level data decision-making. During 2025/26, seven online engagement events were delivered, including focus groups and co-production workshops designed to support accessible and inclusive participation.

Impact

These activities support the NHS England SDE approach, which enables approved researchers to securely access de-identified NHS data within a controlled environment, ensuring strong governance, privacy and public confidence in how data is used. They also align with the wider SDE Network and Health Data Research Gateway model, which improves transparency and access to health data at scale, including through mechanisms such as Data Use Registers that show how datasets are used and for what purpose.

Evidence provided in Appendix D.

4.5. North East and North Cumbria SDE

Structural

Public involvement is strongly embedded within North East and North Cumbria (NENC) SDE's governance structures and public contributors have had a tangible impact on the SDE's development. 10 public contributors are actively involved across programme governance, with representation on key decision-making bodies. A dedicated public group plays a formal role in assessing whether projects meet defined public interest criteria and is represented on the Data Access Committee (DAC), which oversees controlled project approval processes. This ensures that only projects meeting strict governance and public benefit standards are approved.

Transparency is further supported through mechanisms such as the Data Use Register, which publishes information about approved projects and how data is used, reinforcing public trust and accountability.

Activity

NENC SDE has undertaken extensive public engagement, reaching approximately 160 individuals, including people aged over 60, those with vision loss, and individuals under 25. Engagement activities were delivered through a mix of face-to-face and online formats, including discussions, presentations, and focus groups. These efforts gathered feedback on both general SDE development and multi-SDE working.

Impact

Public and patient input has:

- Improved the quality and accessibility of plain English summaries
- Strengthened assurance around demonstrating public benefit
- Raised concerns regarding multi-SDE projects, particularly in relation to security and governance
- Influenced governance arrangements for non-research use cases
- Helped define the public interest criteria used to assess data access applications

These activities align with the broader role of the NENC SDE as part of the NHS Research SDE Network, which provides secure, controlled access to health and care data to support research and innovation while improving patient outcomes.

Overall, the NENC SDE demonstrates a mature approach to embedding public voice in governance, ensuring that data use is not only secure and efficient, but also aligned with public expectations and benefit.

Evidence seen in Appendix E.

4.6. North West SDE

Structural

The North West SDE has a clear commitment to PPIE. Our approach has been to ensure the local voice is heard through delegating PPIE activity to the local Integrated Care Board (ICB) areas. Through this the SDE has developed a framework that links the regional Public Advisory and Accountability Group to the three local patient groups:

- Cheshire and Merseyside Data Into Action Patient and Public Advisory Group
- Greater Manchester SDE Citizens Advisory Panel
- Lancashire and South Cumbria Public Advisory and Accountability Group.

The SDE has developed a structured engagement framework that goes beyond one-off consultation, incorporating continuous community engagement, analysis of feedback, involvement of staff and leaders, and transparent reporting back on progress. This reflects a commitment to meaningful, cyclical PPIE where public input actively shapes priorities and delivery. Alongside this, the SDE offers opportunities for involvement such as public participation in research and advisory groups and have supported initiatives like the User Advisory Group to co-design aspects of the SDE service.

It is intended that each of the three ICB areas has a Data Access Committee (DAC). PPIE representation is included as core membership for the DACs.

In terms of current work, the North West SDE is focused on enabling safe, de-identified health data to support research that improves care and outcomes across areas such as mental health, asthma, and cancer. Public involvement underpins this work by helping to define acceptable uses of data and ensuring research addresses issues of importance to patients and communities.

Activity

The three ICB PPIE teams regularly undertake engagement activity ranging from large scale SDE specific events to subject specific workshops. Representatives from the patient groups have also contributed to engagement at a national level.

The delegation of PPIE activity to the local teams has meant that the SDE can be discussed in context within the wider digital and data strategies for the different ICB areas. This has allowed patients and public to understand where the SDE aligns the wider vision and further engage on the wider public benefit.

Impact

The patient and public input has impacted both at a local ICB level and a regional level. Regionally it has:

- Improved the quality and accessibility of the website. Including better navigation of the frequently asked questions
- Provided input and feedback on specific workstreams such as In Silico Trials

- Provided input and feedback to wider programmes of work that link in with the North West such as an interactive web tool workshop, PANORAMA and the Northern SDE Partnership
- Provided representation at a national level to help inform the wider programme and the national engagement activity.

Continued work through 2026/27 will ensure the patient and public benefit and voice is at the centre of the North West SDE delivery plan

Evidence provided in Appendix F.

4.7. South West SDE

Structural

Public involvement is embedded through an expanded network of Digital Critical Friends (DCFs), now 14 strong, with representation across workstreams, leadership, and the Data Access Committee to ensure independence and a consistent public voice.

DCFs are actively involved at all stages of programme development and governance, helping to shape data access decisions, partnerships, and strategic direction. They have directly influenced funding decisions, governance discussions, communications, national policy input, and outreach to underserved communities, ensuring the programme remains grounded in public perspectives as it grows. This reflects South West SDE's commitment to embedding public voice in decision-making structures and maintaining transparency and accountability.

Activity

The South West SDE engaged 156 people across the region through a series of 13 in-depth workshops, ensuring diverse representation including underserved and global majority communities. Engagement focused on key aspects of setting up and running an SDE, such as data security, governance, data access, opt-out, and public benefit.

Impact

Engagement has reinforced key principles for public trust, including confidentiality, security, transparency, clear opt-out, and demonstrable public benefit. These principles are aligned with the SDE's overarching mission to provide secure, trusted access to health and care data while ensuring strong governance and public confidence in how data is used.

Evidence in Appendix G.

4.8. Thames Valley and Surrey SDE

Structural

Patients and public contributors are integrated throughout the Thames Valley and Surrey (TVS) SDE governance structure, with representation on all key committees and advisory groups, including Services and Data Access Review Committee (SARC), Programme Board, Commercial Research Advisory Committee (CRAC), and Academic Research Advisory Committee (ARAC) – see governance details. They play an active role in decision-making, holding voting positions on SARC, and directly contributing to data access decisions and policy development. Their involvement ensures transparency, fairness, and constructive challenge, with significant time committed to supporting robust governance across the programme.

Activity

Over 180 individuals were engaged over the year, representing unique instances of participation rather than a single headcount, as some people were involved in multiple activities. Engagement covered a wide range of involvement, including governance roles, co-production work, outreach with seldom-heard communities, and attendance at events, workshops, and courses, with publicly available reports and outputs available here.

Key groups engaged included patients and the public across the Thames Valley and Surrey region, recruited public members with lived experience; Gypsy, Roma and Traveller communities, people experiencing homelessness, trans communities (young people and adults), health and care staff working alongside public contributors, and data users and students. See engagement outputs here.

Insights from this engagement are helping shape approaches to trust, transparency, language, and improving public understanding of complex data use, with findings shared through engagement activity and events including this session.

Key engagement topics included the trusted use of health and care data for research and planning, the use of sensitive, genetic and genomic data, and the linking of datasets across health, local authority, and national systems. Work also focused on data access, transparency, and clear communication, alongside building trust, safety, and public confidence in SDEs, including governance, access review, and delegated decision-making.

Engagement activities included a mix of ongoing and one-off approaches, such as regular co-production workshops (covering sensitive data, genomics, and data linkage), engagement with seldom heard communities through fieldwork, interviews and focus groups, and public-facing events and showcases, including the programme event in December 2025. Activity also included online engagement (videos, animations, national events), training and capacity building (e.g. Health Data Guides course), participation of public contributors in national SDE events and a survey of SARC members.

These efforts were supported by an active communications programme, including published reports and animations, website updates, national recognition (HSJ Awards), public events,

national network contributions, media coverage including the Radio 4 feature, and regular newsletters and stakeholder updates.

Impact

Patient and public involvement has driven meaningful changes across governance, data access, transparency, co-design, and workforce. Governance has been strengthened with a 50/50 split between public and professional voting members on SARC and ongoing work to expand diverse representation. Engagement has also shaped data access policies and review processes, improving how decisions are made.

Work on awareness and transparency includes co-design of the Health Data Guides course and targeted pilots with seldom-heard communities. Co-design insights, particularly around genomics, have informed policy development and future engagement plans. Workforce considerations, such as exploring DBS checks to build trust, have also emerged.

More broadly, this work has contributed to cross-regional collaboration through the emerging Deep Data Service, aligning approaches to governance, communication, and public involvement to strengthen trust, consistency, and transparency as data use expands, supported through national SDE Network activity.

Evidence can also be seen in Appendix H.

4.9. Wessex SDE

Structural

Wessex SDE embedded public contributors across governance and delivery, with 16 active Digital Critical Friends (DCFs) involved in seven standing governance, scrutiny and engagement groups. DCFs contributed at the SDE's core decision points: strategy, data access, regulatory change, research scrutiny, public explanation, and national learning. This gave public contributors a line of sight from Board assurance and DAC decisions to HRA materials, research outputs, communications and monthly Town Hall review, creating continuous public oversight from strategy to operational delivery.

This governance model was supported by structured engagement with voluntary and community sector partners, focused on marginalised and historically under-represented communities. Target groups were identified using Core20PLUS5, local Joint Strategic Needs Assessment (JSNAs) priorities and equalities considerations, helping engagement reach beyond already confident or research-active voices.

A further structural element was Wessex SDE's communications and transparency model. This uses tiered information provision: broad public awareness through campaigns such as *Improving Tomorrow's Health*; simple patient notification materials and explainers on the SDE, data use and choices; and detailed transparency through the Data Use Register, Data Capabilities Register, governance materials and published policies, in line with the Transparency Policy.

Activity

Wessex's 2025–26 PPIE programme combined depth and reach: more than 30 scrutiny meetings, 14 committee meetings, 10 focus groups, monthly Town Halls, national and regional events, a public survey, 55 media stories, 172 stakeholder social posts and more than 500,000 people reached through *Improving Tomorrow's Health*. More than 50 people were actively involved in structured engagement and governance roles.

Activity followed a clear model: reach the wider public, return to communities involved during programme development, and bring public insight into live governance.

The *Improving Tomorrow's Health* campaign, which completed and reported in 2025–26, raised awareness of SDEs, explained how NHS data supports research, and tested whether social licence conditions co-designed through earlier deliberation held with a wider public audience. The campaign began in the previous year, but its media footprint fell principally in 2025–26, supported by stakeholder social activity and polling of more than 2,000 people.

Wessex also published its seldom heard groups report, drawing together insights from more than 600 people across 37 sessions during programme development. This reported on how the SDE closed the loop with eight Hampshire and Isle of Wight groups involving 104 participants, while during the year the team commissioned and began follow-up engagement in Dorset with support from Bournemouth University's PIER Partnership. This wave of activity used the Connect-D dementia driver programme as a live case study. This will report fully in 2026–27.

Public insight was also brought into operational scrutiny through a targeted DCF review of the SDE policy suite. DCFs reviewed 36 policy documents, prioritised them by public interest, risk and complexity, and took eight high-priority areas into deeper scrutiny. Outputs were reported to the SDE Board, with delivery delegated to SDE Operations.

Impact

Public involvement strengthened how Wessex SDE is governed, explained and held to account. By year-end, the SDE had captured 93 public recommendations and addressed 90% fully or partly, using this as a live tracker for action, progress and unresolved issues.

This supported delivery of the Transparency Policy. Public input shaped the website refresh, patient notification materials, public explainers, privacy and equality materials, published governance information, the Data Use Register and the launch of a new Data Capabilities Register. The policy review also strengthened

internal governance by testing whether key policies were understandable, credible and workable in practice.

Overall, PPIE helped Wessex SDE move from public engagement during service design to public involvement in live service delivery, giving the Board, DAC and operational team clearer evidence of public expectations and how these were being addressed.

Evidence seen in Appendix I.

4.10. West Midlands SDE

Structural

Patients and public contributors are involved through the Patient and Public Advisory Group (PPAG) and are embedded within West Midlands SDE governance structures. This ensures that public perspectives inform programme development, decision-making and oversight.

Public contributors also support data access processes, including involvement in committees that review applications to ensure data is used appropriately, safely and in the public interest. Researchers are expected to demonstrate evidence of PPIE within their projects, reinforcing the importance of public benefit and transparency.

Activity

Given the comparatively younger population profile of the West Midlands, the SDE has delivered a communications and engagement programme with a particular focus on children and young people. Activity was designed to support meaningful participation, enabling young people to share their views, feel heard and contribute to discussions about the use of health data for research.

More than 150 children and young people aged 12–26 were engaged through 12 regional sessions, covering all areas of the West Midlands, and were delivered online and in-+person, alongside a final young people's event in Birmingham for those aged 18–25. Sessions focused on transparency, accessibility and improving understanding of how health data is used within SDEs. The final event also included a creative element, with participants developing a storyboard to support a future animation for wider engagement.

This activity is supported by ongoing work to broaden participation and strengthen diverse representation, including emerging opportunities for children and young people to help shape future research priorities and engagement approaches.

Impact

Public contributors have played an active role in reviewing and shaping SDE activity, including communications, public-facing materials, commercial approaches and wider programme development. Their involvement has helped ensure that engagement resources, such as leaflets, presentations and workshop materials, are accessible, relevant and aligned with public expectations. The contributions of children and young people during the engagement sessions will be used to inform the future engagement strategy for 2026/27.

Evidence seen in Appendix J.

4.11. Yorkshire and Humber SDE

Structural

Patients and the public contribute through the Patient and Public Advisory Group and involvement in the Data Access Committee, influencing leadership discussions and reviewing research applications.

Activity

Over 900 people were engaged with by Yorkshire and Humber SDE, including young people, focusing on topics such as SDE federation, building community trust, GP understanding of research and data, and public attitudes to data sharing. Engagement included 20 activities, such as citizens' juries, workshops, surveys, advisory group discussions, interviews, and podcasts.

Impact

Patient and public input has shaped website development, communication resources, a glossary of terms, and a community engagement toolkit, as well as highlighting data quality issues. These insights are informing future strategy and approach for 2026/27.

Evidence was provided which can be seen in Appendix K.

5. Key successes

Embedding PPIE in governance and decision-making

Across the SDE Network, patient and public involvement is embedded within governance structures. Public contributors are actively involved in Data Access Committees, advisory groups, and programme boards, where they contribute to reviewing data access applications, shaping policy, and providing constructive challenge.

In several regions, this involvement extends to formal decision-making roles, including voting positions and defined responsibilities in assessing public benefit.

Strengthening trust, transparency, and public confidence

A key SDE Network-wide success is the focus on trust and transparency, supported by public input. Engagement activities across SDEs have informed the development and improvement of tools such as Data Use Registers, clearer communication around opt-out choices, and more accessible public-facing materials.

These changes have helped improve public understanding of how health and care data is used and the safeguards in place, strengthening accountability and confidence in SDEs.

Inclusive engagement with diverse and seldom heard communities

SDEs have engaged a broad and diverse range of participants, including under-represented and seldom heard communities. Targeted engagement has included work with Gypsy, Roma and Traveller communities, global majority groups, people with learning disabilities and autism, young people, and individuals with lived experience of health conditions.

These approaches have ensured that a wide range of perspectives are reflected in decision-making about data use.

Demonstrable impact of PPIE on governance and practice

PPIE has led to changes across multiple SDEs, demonstrating the impact of engagement. Public input has influenced the development of ethical guardrails, governance frameworks, registration (previously known as validation) policies, and approaches to assessing public benefit.

It has also contributed to improvements in processes such as data access applications and the quality of plain English summaries.

Growth of co-production and collaborative approaches

Co-production is evident across the SDE Network, with patients and the public working in partnership with SDE teams to design and deliver key elements of the work.

This includes the co-design of governance models, engagement approaches, and public-facing resources such as glossaries and guidance materials. These collaborative approaches help ensure outputs are accessible, relevant, and aligned with public expectations.

Expansion and diversification of engagement activity

Engagement activity has been delivered at scale across England, using a range of approaches including workshops, citizens' juries, focus groups, surveys, national events, and digital content.

This has enabled SDEs to reach a wide range of audiences and gather insights on topics such as data sharing, governance, and the use of health data for public benefit.

6. Key Challenges, Learnings and Considerations

Terminology and Inclusive Language

Views differed across the SDE Network regarding the use of the term *"Seldom Heard Groups"*. Some SDEs felt the term remains a useful and widely recognised description for communities that may face barriers to participation. Others preferred terms such as underrepresented groups, underserved communities, or people and communities experiencing health inequalities and/or who are marginalised. Feedback highlighted the importance of language that reflects the responsibility of organisations and systems to create opportunities for engagement and inclusion, rather than implying that communities themselves are difficult to reach. This is an area where further discussion across the Network may be beneficial.

Public Contributor Payments

Most SDEs reported few issues relating to public contributor payments during 2025/26. Established payment policies and procedures have helped support timely reimbursement and reduce barriers to participation. However, some challenges were identified. NHS England SDE noted that limited funding for honorarium payments restricted opportunities to engage beyond existing public groups. Eastern SDE reported a successful move from voucher payments to bank transfers, although payment processing times can be longer due to organisational payment schedules. Sharing existing payment policies and processes across the Network may help support consistency and identify opportunities for improvement.

Adapting Engagement Approaches

Feedback highlighted the importance of taking flexible approaches to engagement and involvement. Several SDEs adapted activities to suit the needs of particular communities or to overcome recruitment challenges. Examples included delivering engagement in familiar community settings, changing focus groups to one-to-one interviews where recruitment was lower than expected, and working with partner organisations to ensure sufficient participation in deliberative activities. These experiences underline the value of tailoring engagement methods to different audiences and working collaboratively with trusted community partners.

Demographic Information and Monitoring

The collection of demographic information varied across the Network. Some SDEs were able to provide detailed participation data and demographic insights, while others identified opportunities to strengthen data collection and reporting. Eastern SDE reported engaging 462 individuals through a range of activities, including public deliberations, advisory groups,

surveys and targeted community engagement. NHS England SDE has identified demographic monitoring as an area for development and plans to strengthen data collection during the coming year. More consistent approaches to demographic monitoring would support a better understanding of the reach and inclusivity of engagement activities across the Network.

7. Next Steps and Future Priorities

This review highlights the range of PPIE activity taking place across the SDE Network during 2025/26. Public contributors continue to play an important role in governance, advisory groups and decision-making processes, helping to shape data access decisions, policies, communications and public engagement activities. The review also demonstrates a continuing commitment to transparency, co-production and inclusive engagement.

During 2026/27, SDEs will:

- Include patient, public and subject matter expert representation within governance structures.
- Maintain regional PPIE programmes aligned with national priorities.
- Participate in SDE Network-wide PPIE and communications working groups.
- Support national engagement and deliberation activities where appropriate.
- Strengthen demographic monitoring and reporting.
- Demonstrate how user research and public involvement contribute to service improvements.
- Continue to develop approaches that support participation from underrepresented communities and people experiencing health inequalities.

The SDE Network Communications and PPIE Working Group will continue to support shared learning and collaboration across the Network, with a focus on the following areas:

Public Involvement in Decision-Making and Accountability

Many SDEs have embedded public contributors within governance and decision-making structures, including data access committees, advisory groups and programme boards. Public contributors help review research applications, shape governance arrangements and contribute to discussions about data use and public benefit. Examples from Thames Valley and Surrey SDE and Kent, Medway and Sussex SDE demonstrate how public involvement can be integrated into decision-making at all levels.

Transparency and Public Communication

PPIE activity has contributed to improvements in transparency across the Network. This includes the development and refinement of Data Use Registers, public-facing resources, and communications explaining how health and care data is used, shared and safeguarded. These activities help improve public understanding and support accountability.

Inclusive Engagement

The report highlights engagement with a wide range of communities, including Gypsy, Roma and Traveller communities, global majority groups, people with learning disabilities and autism, young people, and people with lived experience of health conditions. These activities reflect a commitment to ensuring a diverse range of views and experiences inform SDE work.

Measuring Impact

There are clear examples throughout the report of public involvement influencing policy, practice and governance. Public contributors have informed the development of ethical frameworks, validation policies, governance processes, plain English summaries and public-facing materials. Building a more consistent approach to recording and reporting impact across the Network will help demonstrate the value of this work.

Co-production and Capacity Building

Many SDEs are increasingly working in partnership with public contributors to design governance arrangements, engagement approaches, training materials, and communications resources. These approaches help ensure that outputs are relevant, accessible, and informed by public perspectives from the outset.

National Collaboration and Shared Learning

The report shows ongoing collaboration across the SDE Network through national working groups, events, engagement activities and shared projects. Continuing to share experiences, resources and learning will help strengthen PPIE practice and support greater consistency across the Network.

8. Conclusion

This review demonstrates that PPIE is now a well-established and integral component of the SDE Network. Across the Network, public contributors are actively involved in governance structures, advisory groups, engagement activities and decision-making processes, helping to shape how health and care data is accessed, used and governed. Their contributions have informed policies, data access processes, communication materials and public-facing

resources, helping to ensure that SDE activities remain grounded in public expectations and deliver clear public benefit.

The findings highlight the significant progress made by SDEs in embedding meaningful involvement and engagement activities within their programmes. There is strong evidence of organisations working collaboratively with patients, public contributors and communities to improve transparency, strengthen accountability, and build public trust in the use of health and care data. The increasing use of co-production approaches, targeted engagement activities and public representation within governance arrangements demonstrate a growing maturity of PPIE practice across the Network.

The review also identifies several areas for continued development. Approaches to collecting demographic information and evidencing impact vary across SDEs, making it difficult to consistently demonstrate reach, inclusivity and outcomes at a network level. The review also highlighted differing views on terminology relating to communities experiencing barriers to participation, underlining the importance of adopting language that is inclusive, respectful and meaningful. In addition, while most SDEs reported effective arrangements for renumerating public contributors, some identified funding constraints that may limit opportunities to engage a broader range of people and communities.

Looking ahead to 2026/27, SDEs will continue to strengthen patient and public involvement through representation within governance structures, participation in Network-wide PPIE activities, support for national engagement initiatives and the delivery of regional programmes aligned to national priorities. There will be a greater focus on improving demographic monitoring, demonstrating the impact of involvement activities, and evidencing how public insight influences service design, governance and decision-making. The Network will also continue to build on existing work to engage underrepresented communities and people experiencing health inequalities, ensuring that a wider range of perspectives are reflected in the development and use of health data services.

The SDE Network Communications and PPIE Working Group will play an important role in supporting this work through the sharing of learning, resources and best practice. Areas of focus will include strengthening public involvement in decision-making, improving transparency and communication, expanding opportunities for co-production, developing more consistent approaches to impact measurement and fostering greater collaboration across regions.

Overall, this review provides a strong foundation for future development and demonstrates the value of a coordinated, network-wide approach to PPIE. By continuing to learn from one another, address emerging challenges and build on existing good practice, the SDE Network is well placed to further strengthen public confidence, enhance accountability and ensure

that the use of health and care data continues to reflect the needs, priorities and expectations of the people and communities it serves.

Appendices

Appendix A – Eastern SDE

- Home - Eastern England SDE
- Eastern England Secure Data Environment - NHS England Digital
- East-of-England-PPIE-summary-April-June-25.pdf
- Insights from public survey - Eastern SDE.pptx
- Genomics demographics - Eastern SDE.xlsx

Appendix B - Kent, Medway and Sussex SDE

- KMS Social licence case study V2
- KMS SDE - Public and Patient Advisory Group - 08.04.25.pptx Slide 17 – 19.
- PPAG Value of Data Planned Response.pdf
- SDE Programme Response to the PPAG Recommendations on the DAC_READ ONLY.docx
- FINAL Proposal for Public Members on the Kent, Medway and Sussex Data Access Committee.docx
- KMS SDE Data Access Committee Ethical Guardrails FINAL DRAFT VERSION.pdf
- Kent and Medway Social Licence | NHS Kent and Medway
- Social Licence for Data Use in Sussex Healthcare
- KMS SDE - Public and Patient Advisory Group - 16.12.25 pptx (3).pptx, slide 17 – 24.
- KMS SDE - Public and Patient Advisory Group - 22 April 2026.pptx, slide 21-24
- Our legal duty, your rights and choices | ICB
- Secure data environment for research | NHS Kent and Medway
- KMS SDE - Public and Patient Advisory Group - 26 March 2026.pptx, slide 5 –10d
- [sussex.ics.nhs.uk]

Appendix C - London SDE

- London Secure Data Environment - NHS England Digital
- [hdruk.ac.uk]
- London Secure Data Environment - OneLondon
- Involving Londoners - OneLondon
- https://onelondon.online/wp-content/uploads/2026/04/2025-PPIE-Impact-Report.pdf
- https://onelondon.online/wp-content/uploads/2026/05/OLHDS-Involvement-Update-2526.pdf
- London Secure Data Environment Driver Projects - OneLondon
- Projects Archive - OneLondon

Appendix D – NHS England SDE

- [nature.com]
- [scie.org.uk]
- [pmc.ncbi.nlm.nih.gov]

Appendix E - North East and North Cumbria SDE

- [digital.nhs.uk]
- Secure Data Environment | North East and North Cumbria NHS

Appendix F - North West SDE

- [northwestsde.nhs.uk]
- [northwestsde.nhs.uk]

Appendix G - South West SDE

- [southwestsde.nhs.uk]
- [healthinno...thwest.com]

Appendix H: Thames Valley and Surrey SDE

Throughout 2025/26, PPIE insights were amplified through an active communications programme:

- Publicly available reports and animations from seldom heard engagement https://thamesvalleyandsurreyhealthandcaredata.nhs.uk/get-involved/
- Website updates introducing committees, public members and governance https://thamesvalleyandsurreyhealthandcaredata.nhs.uk/using-patient-data/the-tvs-sde-programme-team/
- HSJ Partnership Awards recognition and accompanying public-facing films March 2026 https://thamesvalleyandsurreyhealthandcaredata.nhs.uk/thames-valley-and-surrey-health-data-research-programme-shortlisted-for-national-hsj-award/ https://www.youtube.com/watch?v=PksiI0VEs2s
- SDE Network Lunch and Learn – Attitudes to Healthcare Data for Planning and Research Feb 2026 https://thamesvalleyandsurreyhealthandcaredata.nhs.uk/sde-network-lunch-learn-attitudes-to-healthcare-data-for-planning-and-research/
- Programme event bringing together public members, committees and partners Dec 2025 https://thamesvalleyandsurreyhealthandcaredata.nhs.uk/tvs-sde-event/

- National SDE Network PPIE events and videos featuring TVS public members Dec 2025 https://thamesvalleyandsurreyhealthandcaredata.nhs.uk/national-ppie-event/
- https://www.youtube.com/watch?v=WXlECyySkxY
- Radio 4 Broadcasting House feature including patient, researcher and SDE voices May 2025 https://thamesvalleyandsurreyhealthandcaredata.nhs.uk/tvs-sde-featured-on-radio-4-broadcasting-house/
- Health Research Showcase in Oxford May 2025 https://thamesvalleyandsurreyhealthandcaredata.nhs.uk/sde-joining-the-health-research-showcase-in-oxford-29th-may-2025/
- Bi-monthly newsletters and stakeholder updates

Appendix I - Wessex SDE

- WSDE – Wessex Secure Data Environment

Appendix J - West Midlands SDE

- westmidlandssde.nhs.uk/resources/reports/
- westmidlandssde.nhs.uk/resources/
- westmidlandssde.nhs.uk/get-involved/

Appendix K - Yorkshire & Humber SDE

- Home - Yorkshire & Humber SDE