

Public Involvement Update 2025/26

Patient and Public Involvement and
Engagement (PPIE) in the **London Secure Data
Environment (SDE)**



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Introduction

Our ambition is for London to be the healthiest global city, and the best in which to receive health and care services. Joining up Londoners' health and care information across the Capital through the London Secure Data Environment (SDE) will be key to this.

The London SDE will be a world leading resource for health and care improvement providing secure access to linked primary and secondary care data, mental health and community datasets, and population health indicators, supporting direct patient care and healthcare planning as well as research.

Public involvement is, and always will be, central to the London SDE. By working closely with Londoners, we ensure that the way health and care data is used within the London SDE delivers genuine public benefit, supports better decision-making, and reflects the values of our city's diverse communities.

Over the past year, we have continued to build on this commitment with the OneLondon Citizens' Advisory Group (consisting of 100 Londoners reflective of the Capital's diverse population) and PPIE groups across the country. We have engaged with hundreds of people through surveys, workshops, speaking panels, and targeted involvement initiatives that help shape our work at every stage.



Listening to Public Priorities

69 Londoners took part in **surveys and focus groups** exploring how health data should be used, what safeguards matter most, and how to communicate clearly about people's choices. Discussions focused on people's expectations around data use, trust, transparency, and the general use of Section 251 consent within SDEs. [View the report on the full findings here.](#)

A dedicated **co-design workshop** in June 2025 brought **20 Citizens' Advisory Group members** together to shape more accessible and trustworthy messaging about opt-out options and data use. Participants shared their preferences on tone, clarity, and the types of information people need to make informed choices. [View the report on the full findings here.](#)



"It makes sense that researchers should be able to see all the relevant data they need in one place. It feels more secure - and more modern - to have the data stored and accessed in an SDE than sending copies around. It also seems good that there's more accountability and transparency..."

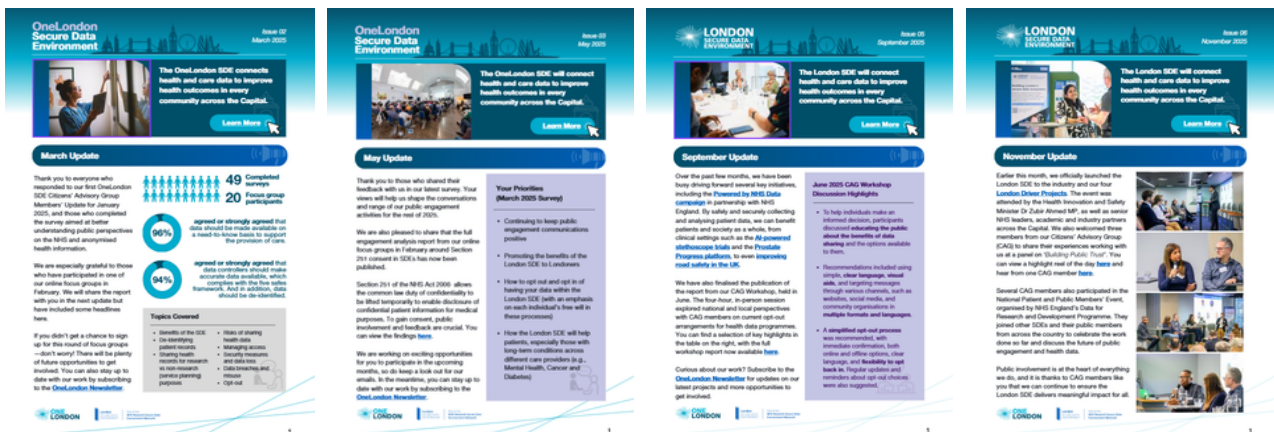
OneLondon Citizens'
Advisory Group Member



Strengthening Transparency

The [London SDE Data Use Register](#) went live on the OneLondon website, allowing the public to see which projects have been approved to access datasets within the London SDE since December 2025. Information about projects completed before this date can be viewed [here](#).

A total of **eight bi-monthly newsletter updates** were shared with our Citizens' Advisory Group. These provide programme and project-specific updates, including upcoming PPIE opportunities across the Capital and published reports from workshops and focus groups.



Our pan-London **Independent Information Access Group (IIAG)** met four times over the year. The IIAG consists of clinical and public representatives from each of London's Integrated Care Systems (ICS) and Data Access Committees which each represent an area of London. The IIAG issues recommendations to the Data Access Committee (DAC) within the relevant ICS, which then decides if a project application is approved or not. Each ICS-level DAC represents a different area of London and includes representatives of health and care organisations and patient representatives. [Minutes from this year's meetings can be found here](#).

National and Regional Collaboration



Four of our Citizens' Advisory Group members joined other public representatives from SDEs across the UK at the **National SDE Network's Patient and Public Member Event** in November (including a follow up online session in December). The event showcased the SDEs' public engagement achievements to date, with participants also discussing how PPIE work will continue as we transition to the Health Data Research Service.



"Imagine a world where everybody speaks the same language. That's what we're trying to achieve, that everybody speaks from the same system."

OneLondon Citizens' Advisory Group Member



We worked with the **NHS Research Secure Data Environment Network** on communications for the [national driver projects](#), which will grant a total of £1.5 million as investment funding for the successful projects chosen across the country.

London SDE's driver project, [OncoLlama](#), is an artificial intelligence (AI) tool that explores how unstructured clinical notes could be used more effectively for research and service planning, with the aim of improving understanding of cancer pathways, outcomes and inequalities. The project is a collaboration between national SDEs (East of England SDE, Kent, Medway and Sussex SDE, Yorkshire and Humber SDE), NHS and external partners.

In January 2026, we held a dedicated **OncoLlama public webinar** with **24 PPIE representatives from across all partner regions**. Participants discussed the use of unstructured clinical notes, their views of the project, and how the work should be communicated to build public trust. [The full findings report was published in March and can be viewed here.](#)



"There is a huge, untapped value in that data [unstructured clinical notes]. It tells the story of the patient's journey in a way numbers just don't."

PPIE Representative
OncoLlama Public Webinar



"A lot of information is currently lost to research. This [using unstructured clinical notes] opens up a whole new richness of data."

PPIE Representative
OncoLlama Public Webinar



In November 2025, we held a **partner event during London Life Sciences Week** for **over 100 colleagues** from across the London NHS, academia and industry. **Three of our Citizens' Advisory Group members spoke on the panel 'Building Public Trust'**, sharing their experiences and insights. Attendees were able to hear about all the progress we have made together with partners in terms of using data at scale to deliver health improvements for London and beyond. [You can watch our event highlights video here.](#)



"OneLondon is an exemplar to the rest of the country as to how we can harmonise the flows of data for the benefit of patient care research, but also how we can turbocharge our life sciences economy."

Dr Zubir Ahmed MP
Minister for Health
Innovation and Safety

Health Data for London was launched - a major new partnership of London's NHS trusts, Integrated Care Systems and academic institutions to coordinate the Capital's health data and strengthen how London works with research and industry.

Three in-person NIHR (National Institute for Health and Care Research) workshops were held, where colleagues from across the NHS, academia and industry came together to share progress from their individual workstreams, align approaches, and develop new tools.

London Driver Projects

At our November 2025 partner event, we launched the [London Driver Projects](#). These projects have been co-funded and selected to demonstrate the potential of the London SDE, support its development, and deliver tangible health improvements for Londoners.

- [Project CARDINAL](#) – transforming the prevention, detection, and treatment of cardiovascular disease (CVD), through three scalable programmes (VISOR, TRICORDER-PLUS, STAR-PULSE)
- [MINDS-LC](#) – building a smarter, more inclusive mental health system by linking data from schools-based mental health, social care, and other health services through the London SDE
- [RADIX](#) – the Real-time Antimicrobial Digital Intervention Exchange will use data in the London SDE to deliver insights that improve clinical decision-making regarding antibiotic prescribing and patient outcomes from growing antimicrobial resistance

To promote the London Driver Projects to the wider public, dedicated videos and marketing materials for each project are currently under production in collaboration with project leads and their PPIE members. [You can view the completed videos on our website.](#)



Looking Forward

Many exciting activities have already planned for the upcoming year, including:

- Refining the Data Use Register in line with public feedback
- Delivering public communications for the London SDE
- Continuing to involve Londoners in shaping our work through a range of engagement initiatives
- Continuing our regular bi-monthly CAG updates
- Working closely with the NHS Research SDE Network as we transition into the Health Data Research Service

We look forward to continuing our work with the public in 2026/27, ensuring that Londoners remain at the heart of decisions about how their data is used for public good.



“Having been part of the conversations since early on, it is gratifying to see the progress being made with the London SDE. It’s been a very exciting journey helping to make decisions on how data can be used for the best purposes in relation to care or research. Ultimately patient outcomes should improve as a result of this.”

OneLondon Citizens’
Advisory Group Member



Get Involved

We would like to thank everyone who has offered their time to come to our events, speak to us and give us their views. You are helping us join up information in a safe and secure way to transform London's health and care services.

To find out more about the London SDE or get involved with our public engagement work, visit our website or contact us at:



<https://onelondon.online/involving-londoners/>



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