

Quarter 3 2025 OneLondon Health Data PPIE Impact Report

Q3 began with the in-person National SDE Patient and Public Member Event in central London, which was hosted by the NHS Research SDE Network. Public representatives from SDEs across the country were invited to celebrate their achievements as well as share learning and experiences. Four members of our Citizens' Advisory Group (CAG) attended, contributing to discussions on the future of the programme as we move towards a Health Data Research Service. A follow up online webinar was then held on 15 December to accommodate public members who could not attend the initial event, with similar discussions taking place. A final report is being prepared by the NHS Research SDE Network team and is scheduled to be published in Q4.

In November, we officially launched the London SDE to industry. We welcomed approximately 100 senior stakeholders from within the NHS, industry and public members to an all-day event at the London Institute of Healthcare Engineering. Three members of our CAG spoke at a panel on 'Building Public Trust', sharing their journey so far in public engagement work with the London SDE. Details of the day were shared with our wider CAG group via our bi-monthly newsletter update.

We also launched our four London Driver Projects at the London SDE launch event with the approval of our Independent Information Advisory Group (which includes lay members). These projects have been co-funded (each up to £250,000) 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
- **OncoLlama** - an NHS-developed AI tool that reads clinical documents and automatically extracts detailed cancer information with over 98.5% accuracy across 20 types of cancer in adults. This project is a collaboration between national SDEs (East of England SDE, Kent, Medway and Sussex SDE, Yorkshire and Humber SDE), NHS partners and external partners (Amazon Web Service, Meta, Flatiron and more). The project seeks to validate OncoLlama-generated data, conducting a joint analysis of cancer inequalities

across the partners' areas to understand differences in diagnosis, access to treatment including trials, and outcomes.

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.

In December, we held the final quarterly NIHR workshop of 2025. We also began preparations for an online PPIE session for OncoLlama in January 2026. The workshop aims to understand public perspectives on the use of synthetic data in health and care research, ideal communication pathways for findings on health inequalities in cancer and NHS partnerships with the technology industry.

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At the start of Q2, we published the full report of our June 2025 co-design workshop on opt-out processes and effective messaging with our Citizens' Advisory Group (CAG), where 20 members from a diverse range of backgrounds were selected to participate. Topics they covered on the day included the options people have for opting out of sharing their health data nationally and locally, what information they felt people would need to make an informed decision about opting out, and the best way to communicate it, including preferences for tone and language. The report reflects their outputs, which have been shared back with the CAG via our July CAG newsletter.

Our Independent Information Advisory Group (which includes lay members) also met in July to discuss our local driver project call, which will co-fund up to three initiatives (each up to £250,000) that aim to demonstrate the potential of the London SDE, support its development, and deliver tangible health improvements for Londoners. This was met with approval.

In August, we helped in organising the London SDE launch event scheduled for November alongside external partners. We also worked with the national team 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 a collaboration between national SDEs (East of England SDE, Kent, Medway and Sussex SDE, Yorkshire and Humber SDE), NHS partners and external partners (Amazon Web Service, Meta, FlatIron and more). It is an NHS developed Large Language Model built on open-source technology that can process millions of documents within the safety of NHS firewalls, to extract detailed cancer profiles for patients. The project seeks to validate OncoLlama-generated data, conducting a joint analysis of cancer inequalities across the partners' areas to understand differences in diagnosis, access to treatment including trials, and outcomes.

Preparations were made for the fourth NIHR colleague workshop, which was initially scheduled for 12 September, but this was unfortunately cancelled due to unforeseen circumstances. We worked on the OneLondon Health Data Strategy 2025 Refresh report while starting to create patient-facing marketing materials for the London SDE, which has been informed by the June 2025 co-design workshop report.

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In Q1, significant progress was made across various areas of our public and patient involvement and engagement (PPIE) work.

In April, the final report on the patient engagement survey and February focus groups with our Citizens' Advisory Group (CAG) - which consists of 102 Londoners from a diverse range of backgrounds – on the use of data was completed.

May's activities included the distribution of the bi-monthly engagement update to CAG members. The results of the March engagement survey were shared as part of this update, alongside the full analysis report from the two February online focus groups, which examined the use of Section 251 consent within Secure Data Environments (SDEs). Preparations were also made for two events in the following month – the third NIHR colleague workshop, scheduled for 6 June, and a CAG workshop on opt-out processes set for 27 June.

In June, a face-to-face co-design workshop was held focusing specifically on opt-out processes and effective messaging. This workshop was opened to all members of CAG to express an interest and a diverse group of 20 were chosen to participate. Topics they covered on the day included the options people have for opting out of sharing their health data nationally and locally, what information they felt people would need to make an informed decision about opting out, and the best way to communicate it, including preferences for tone and language. A full report is due in July with the outputs will be used to inform the opt out materials being developed.

In June the third in-person NIHR colleague workshop was also held with 20 participants from institutes from across London, where updates were shared by working groups covering policy alignment, tool development, and infrastructure design. We then promoted the launch of our local driver project call, which will co-fund up to three initiatives (each up to £250,000) that aim to demonstrate the potential of the London SDE, support its development, and deliver tangible health improvements for Londoners. The shortlisted projects will then go to the Independent Information Advisory Group (which includes lay members) in September 2025 for recommendation.