

**London Health Data Strategy  
Independent Information Access Group - Minutes**

Monday 20<sup>th</sup> January 2025 @ 14:00 to 15:00

Venue: TEAMS only

**Attendees:**

Name	Role	Organisation	IIAG Role
Graham Head	South East London Healthwatch and Data Usage Committee	South East London ICB	ICB Citizen Member & Interim Chair
Ian Colvin	GP, Islington GP Federation and NCL ICB Board Member of General Practice Provider Alliance	North Central London ICB	ICB Clinical Member
Susan Ashbourne		South West London ICB	ICB Citizen Member
Lizzie Wallman	Deputy Chief Nurse	South East London ICB	ICB Clinical Member
Mark Agathangelou	Lived Experience Partner	North Central London ICB	ICB Citizen Member
Kerry Beadling-Barron	Director of Communications and Corporate Affairs	Health Innovation Network South London	For Item 2
James Ray	Regional Clinical Director UEC London (IUC/Digital)	NHS England - London Region	For Item 3
James Friend	Director of Digital Strategy	NHS England - London Region	Secretary

**Item 1: Apologies Given**

Name	Role	Organisation	Programme Role
To be Nominated / Recruited		North East London ICB	ICB Clinical Member
		North East London ICB	Expert Members
Sonia Richardson		North West London ICB	ICB Citizen Member
Caroline Law	Head of Information Governance and Data Protection Officer, Central London Community Healthcare NHS Trust	North West London ICB	ICB Clinical Member

Bill Jenks, Digital Manager and North East London Strategic Information Governance Network Chair on behalf of North East London ICB was not present at this meeting and the ICB has not yet nominated a successor Citizen member.

South West London ICB have not yet nominated a successor Clinical member and this action is with Matt Laundry their Chief Clinical Information Officer.

It was noted that the contact details for Sonia Richardson were being reconfirmed.



## Item 2: Discussion on the use of confidential patient information

Kerry Beadling-Barron, in her role as Communications lead for the OneLondon Health Data Strategy, provided a brief overview on the five public deliberations held to date and introduced the “What do Londoners think?” infographic snapshot of public expectations concerning access to health and care data.

**What do Londoners think? A snapshot of public expectations concerning access to health and care data.**

**Public expectations for access to identifiable health and care data for direct care purposes: to support care at the time patients need it**

- Data should be available on a need-to-know basis to those caring for a patient to enable the provision of safe and efficient care.
- There should be background checks for staff being given direct access, mandatory training and additional safeguards in place such as confidentiality agreements, passwords to enter databases and audit trails in place.
- There should be serious consequences for anyone who misuses data and sanctions in place to deter this from happening.

**Public expectations for access to deidentified health and care data for secondary purposes: to support planning and prevention to improve research**

- Data controllers should make accurate data available within a secure data environment (SDE) that complies with the live safety framework, and it should be de-identified when used for planning and research.
- Data to be accessed for an agreed purpose, for an agreed timescale and only access to relevant data should be given.
- Patients should have the option to opt-out of their data being used for secondary purposes and opt back in if they change their mind.

**Access rules**  
Independent data access committees made up of NHS clinicians, researchers, lay members of the public, patients, data protection and legal experts should use the following rules in deciding who has access to health and care data for secondary purposes.

- The request should demonstrate a clear public benefit.
- There must be a clear rationale as to why London's population data is necessary or beneficial to the project.
- Existing health inequalities should not be exacerbated through the work, and no groups should be negatively impacted or harmed.
- No access should be given to organisations who are not already part of the London secure data environment who cannot cover their costs.
- The police should not be given direct access to health data in the London secure data environment.

**PRICE LIST**  
The London SDE should operate tiered pricing for access to data, based on profit making and turnover. Benefits arising from data use should be shared across the NHS, starting with London.

- Profit-making companies should pay the most (£££)
- Charities, local authorities and universities should pay somewhere in the middle (££)
- Organisations part of the London SDE should pay the least for access to data (£)
- UK companies should pay less
- Non-UK companies should pay more

**Discounts for...**

- Projects that can save the NHS money
- Projects that can benefit the NHS
- Projects that are aligned with the NHS priorities in London
- Projects that have the potential to deliver exceptional patient benefits

**Additional charges**

- Projects that require more support from the NHS secure data environment operators
- Projects that require access to data for a longer period of time
- Projects that require access to large amounts of data and/or more sensitive data.

**RED LINES**

- Data must never be shared with or sold to insurance companies or for marketing purposes.
- Data should not be used for reasons which are not in the public's interest and there should be severe punishments for misuse.

**To reassure people and engender trust, the public should be informed and educated about...**

- how the NHS uses health and care data, and the benefits of this
- who is accessing health and care data, for what purposes
- their rights concerning the national data opt out for research and planning

**References:**  
Public-deliberation-in-the-use-of-health-and-care-data.pdf (onelondon.online) Citizens Advisory Group | Discover Now (discover-now.co.uk) London Health Data Strategy Deliberation (onelondon.online) Ipsos report (onelondon.online) OneLondon-Citizens-Advisory-Group-Report-1-page-summary.pdf

This infographic was formed from five public deliberations that have taken place in London since 2020 and involved 301 participants reflective of our diverse population.

IMPERIAL COLLEGE HEALTH PARTNERS

Ipsos

In March 2024, the third public deliberation focused on the use of Opt Out supported by specific focus groups as outreach; a survey was sent to the 102 Citizen Forum members for direct care and research development and this has aligned to a specific ask from national colleagues as part of the Section 251 application.

The programme proposed to re-use that engagement structure of a survey (unpaid to respondents) followed by specific focus groups (expenses paid) to delve further into issues arising from the survey responses. IAG members were asked whether this approach seemed appropriate and if so, on the basis of their experience as an IAG member and beyond, which themes might be subject to deliberative engagement.

IAG members supported the methodology and suggested themes around Learning Disabilities & Autism, deprivation and socio-economic factors, the use of Artificial Intelligence to process data & what safeguards

should apply and the linkage to non health data. It would also be important to consider how to access the views of younger people, the digitally excluded and those who require different languages.

Kerry added that the focus groups would be held from 5:30pm on-line with a facilitator working with 8-10 citizens in order to make the discussion regular and insightful – although with a narrowed focus for each. It was noted that the process could evolve based on experience.

Susan Ashbourne confirmed that she would be happy to be involved given her understanding of the issues to date. Kerry added that a regular newsletter will be produced for the Citizen Forum members and that IAG members would be added to the circulation.

### **Item 3: Data at Scale for Improvement Project Application - NHS 111 Risk Stratification Use of Segmentation Proposal**

It was noted that the Data Access Request Form had not yet been received from the project and so this agenda item was converted into an introduction to the proposal rather than a form a review against the six questions from the IAG's Terms of Reference.

James Ray introduced the proposal to use the data within the Secure Data Environment (Primary Care, Secondary Care and eventually Social Care) to segment patients according to the John Hopkins risk stratification tool into Red Amber and Green cohorts such that when a patient contacts NHS111 the response they receive can be personalised with only green, lowest needs, patients being recommended to contact an alternate service for same day needs.

Ahead of receiving the full details, IAG members identified a number of potential questions for the project team to consider including:

- Having sufficient representation of GPs in the project team, to ensure that the data interpretation was appropriate, and for oversight. James Ray noted that, amongst others, Agatha Nortley-Meshe, Regional Medical Director for Primary Care, is involved in championing the proposal.
- How to truly measure the benefit (attributable cause and effect)
- How to ensure that other needs, such as safeguarding, that GP surgery team might take into account in current processes, were effectively included. James Ray noted that other health systems such as Frimley had been working on solutions to address this and that the same learning would be applied and then continuously improved.
- Where the segmentation data would be held within the record
- The need to treat patient equitably whether they call NHS 111 or access NHS healthcare through other routes

IAG members positively recognised the challenges with the low risk threshold for channelling patients to face to face general practice that current online consultation tools deploy and therefore the opportunity for this intended improvement using data at scale. James Ray summarised the opportunity to take out

demand from Primary Care to allow General Practice to focus on those patients that needed continuity of primary care.

#### **Item 4: Items for Noting**

The minutes from the previous meeting on 18<sup>th</sup> November 2024 were approved.

#### **Dates of the next meeting:**

17<sup>th</sup> March 2025: 14:00 – 15:00

Agenda items would include:

- Review of the scores reached by IIAG members for the NHS 111 Risk Stratification proposal
- Update from NEL ICB on the recruitment to their IIAG roles