

## Independent Information Access Group (IIAG) Minutes

We take public involvement seriously. As well as the three London-wide public deliberations that were held since 2020, we have set up an Independent Information Access Group (IIAG) whose role it is to critique requests for information – a third of this group are citizen representatives.

On this page you can find the minutes from the IIAG which show what they have discussed. Click the hyperlinks to be directed to the exact meeting minutes.

- [May 2023](#)
- [September 2023](#)
- [March 2024](#)
- [May 2024](#)
- [July 2024](#)
- [November 2024](#)
- [January 2025](#)
- [May 2025](#)
- [July 2025](#)
- [September 2025](#)
- [January 2026](#)

## London Health Data Strategy

### Independent Information Access Group - Minutes

Monday 19<sup>th</sup> January 2026 @ 14:00 to 15:30

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 & Chair
Ian Colvin	GP, Islington GP Federation and NCL ICB Board Member of General Practice Provider Alliance	North Central London ICB	ICB Clinical Member
Caroline Law	Head of Information Governance and Data Protection Officer, Central London Community Healthcare NHS Trust	North West London ICB	ICB Clinical Member
Mark Agathangelou	Lived Experience Partner	North Central London ICB	ICB Citizen Member
Matt Laundry	Chief Clinical Information Officer	South West London ICB	ICB Clinical Member
Bill Jenks	Digital Manager and North East London Strategic Information Governance Network Chair	North East London ICB	ICB Expert Member
Sanjay Gautama	CCIO and Caldicott Guardian for Imperial, NWL ICB and OneLondon	OneLondon	
Nic Kirwan-Williams	Associate Director of Data and Information Governance at Londonwide LMC	Londonwide LMC	
Katherine Buxton	Consultant in Palliative Medicine & Clinical Lead for End of Life Care	Imperial College Healthcare Trust	
Katie Humphreys	Clinical Network Senior Manager	NHS England	
Samantha Edward		North London Hospice	

#### Item 1: Apologies Given or Assumed

Name	Role	Organisation	Programme Role
Lizzie Wallman	Deputy Chief Nurse	South East London ICB	ICB Clinical Member
To be Nominated / Recruited		North East London ICB	ICB Clinical Member
		North East London ICB	Expert Members
		South West London ICB	ICB Citizen Member
James Friend	Director of Digital Strategy	NHS England - London Region	Secretary

## Item 2: IIAG Terms of Reference Review

Bill Jenks and Sanjay Gautama set out the rationale for the IIAG ToR review which is only minor changes and not a revamp. The main context behind the review being the London Data Service and London Analytics platform nearing go live which will give the IIAG live data to make decisions on. There is also the merger of NCL and NWL ICBs on top of the ongoing consultations in the London ICBs which will see a drop staff and resources.

IIAG went through the membership to begin with and agreed this to be the

### Clinicians

- At least four NHS clinicians (one per ICB geography).
- One of these clinical representatives must be a GP.
- Clinical representation must include IT/IG understanding.

### Citizen Representatives

- Four citizen members (one per geography).
- Consider stronger linkage between DAC and IAG citizen reps.

### IG Representation

- Four IG representatives (one per geography).

### Research Representation

- Four Research/academic representatives (one per geography).

### LMC Representation

- Proposal to include Londonwide LMC representative (To be confirmed following discussion with LMC leadership)

### Quoracy

To be quorate there must be a minimum:

- One GP Representative
- One Health or Care professional from another partner sector
- One Patient Representative
- One Research Representative
- One IG Representative

### Role of the Group

- Remains a recommending body, not a decision-making committee.
- Recommendations flow to ICB DACs and data controllers.
- Data access forms for IIAG must be accepted directly by DACs to reduce duplication and administrative burden.
- IIAG must move to meeting monthly to meet the demand that will be coming

### Chairing Arrangements

- Proposal for Joint Chair model:
  - One clinician
  - One lay representative
- Chairs to be elected from within membership.

- Terms of Reference to clarify election process and term duration.
- Broad support for lay co-chair model to reinforce legitimacy and public confidence.

## Actions

Action	Owner
Raise DAC chair stakeholder engagement at IG Leads meeting	BJ
Discuss LMC representation and confirm nominee	NKW
Update ToR reflecting agreed membership simplification	BJ

### Item 3: Items for Noting

The minutes from November 2025 were captured as accurate

### Item 4: Palliative End of Life Care Data Access Request

This data access request is to help our clinical teams understand better the outcomes of patients at their end of life. Patients in London are typically above average in the numbers that die in a hospital environment (rather than in their homes or a hospice), and an outlier in terms of admissions to hospital in their last 90 days of life. There are potentially a number of different social and demographic reasons behind that, but the data needs to be explored to understand that.

Once the data is understood the idea would be to also link that into advance care planning for end of life and also mapping that to neighbourhood level work.

The group were supportive of the work. They do ask for more detail in the delivery element with a focus on the benefit realisation (potentially including cost savings) which will help support the adoption across by the ICBs. It would good to expand on how the programme will focus on what the patients wishes are in this area as well.

It is important that the team only use identifiable data for direct care and non identifiable for service evaluation. The team would benefit if they could produce a DPIA to capture all the data usage, but as they would be using the SDE to access the data they can use the DPIAs produced by the OneLondon team as the processing will take place in the SDE environment. Potentially they may need a DPIA if they are doing any work outside of the SDE.

IIAG agreed they do not need a further presentation on this request but just to see the resubmitted document for scoring.

Action	Owner
Data Access Request form to be updated with more detail as above and resubmitted	Palliative Care Team

## 5. SDE Driver Update

There was no detailed update but it was noted there is pressure for these projects to be approved.

### Dates of the next meeting:

23<sup>rd</sup> February 2026: 14:00 – 15.00

Agenda items would include:

- Review of the London Secure Data Environment Driver Projects if submitted.
- Update on IIAG Terms of Reference.

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

Monday 15<sup>th</sup> September 2025 @ 14:00 to 14:45

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 & Chair
Ian Colvin	GP, Islington GP Federation and NCL ICB Board Member of General Practice Provider Alliance	North Central London ICB	ICB Clinical Member
Caroline Law	Head of Information Governance and Data Protection Officer, Central London Community Healthcare NHS Trust	North West London ICB	ICB Clinical Member
Sarah Kinsella		North West London ICB	ICB Citizen Member
Mark Agathangelou	Lived Experience Partner	North Central London ICB	ICB Citizen Member
Matt Laundry	Chief Clinical Information Officer	South West London ICB	ICB Clinical Member
Bill Jenks	Digital Manager and North East London Strategic Information Governance Network Chair	North East London ICB	ICB Expert Member
James Friend	Director of Digital Strategy	NHS England - London Region	Secretary

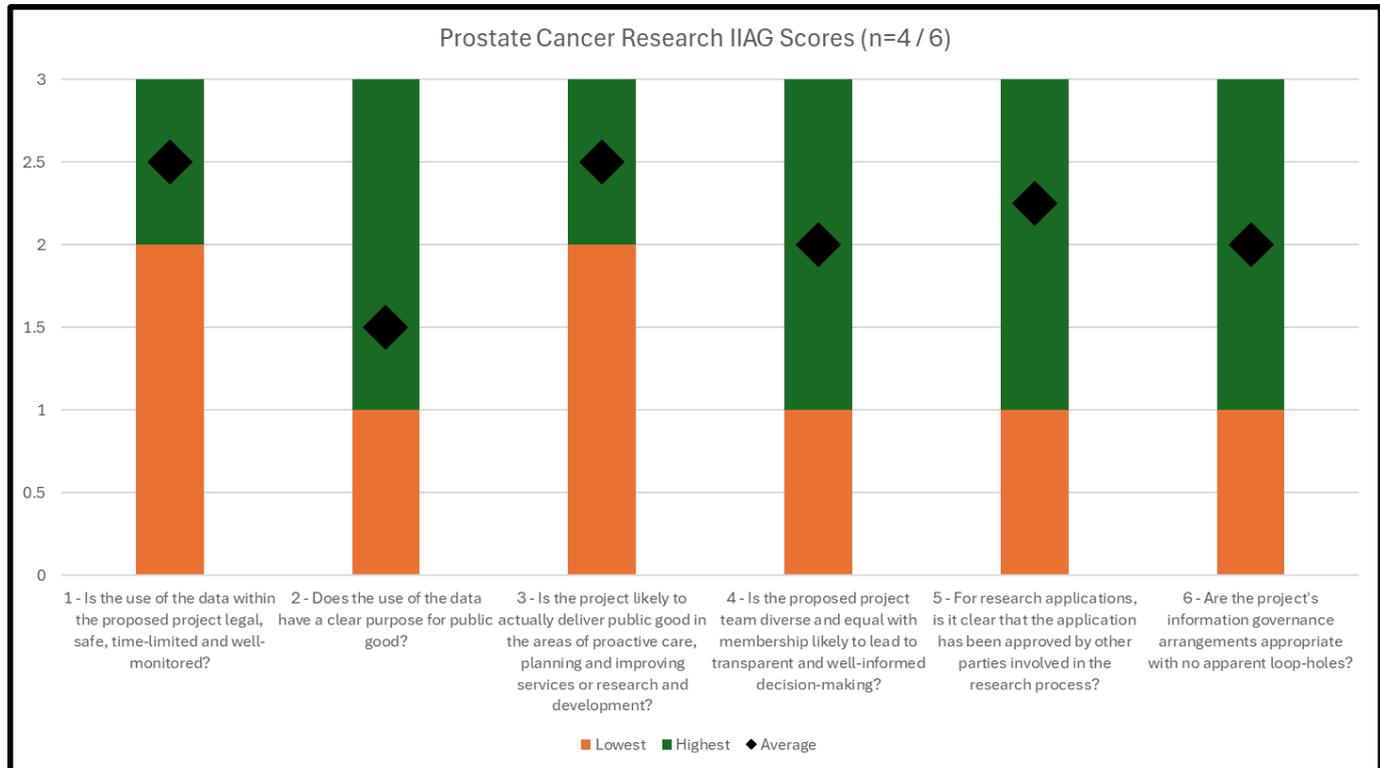
**Item 1: Apologies Given or Assumed**

Name	Role	Organisation	Programme Role
Lizzie Wallman	Deputy Chief Nurse	South East London ICB	ICB Clinical Member
To be Nominated / Recruited		North East London ICB	ICB Clinical Member
		North East London ICB	Expert Members
		South West London ICB	ICB Citizen Member



## Item 2: Prostate Cancer Research National Driver Project

James Friend summarised the scores received from the IIAG members prior to the meeting:



The positions on clarity of purpose (question 2) and team membership (question 4) were seen to be of concern and it was agreed that the project required further development before it could be recommended to ICB Data Controllers.

In particular:

- It was unclear from the application how the public in London would benefit in reality from the project's use of data. Further development is required to confirm the approach to Effector Functionality either pan-London or at Neighbourhood level and to clarify that the purposes is not solely for commercial gain and / or income generation. Data Controllers would want to see the aligned governance on data insight adoption.
- The timescale for data retention was seen to be excessive at 12 months. The approach of the project needs refinement to reduce the risk associated with an elongated duration, further justification to be given or a reduction to six months retention.
- The project delivery team lacked ongoing direct involvement of general practitioners and of patients, although the Public and Patient Engagement and involvement in the scoping of the project aims was noted.
- The linkage of data was confused and contradictory in the description of the planned approach to data handling. Further development is required to confirm the implementation plan. The timing in the approach of the processing of patient identifiable data was questioned in particular in the

method of gaining patient consent. Furthermore, the roles of Royal Marsden and of Imperial College Health Partners as data processors and controllers and whether effective agreements were in place needed clarification.

- It was unclear as to the extent of the Secure Data Environment's blanket Research Ethics approval and whether the scope of the project centring on commercial domain required additional Research Ethics Committee approval.

Members noted that it was a condition of the use of data from the Secure Data Environment that findings would be made available for publication at least through the OneLondon Health Data Strategy Annual Report.

### **Item 3: Items for Noting**

The minutes from the previous meeting on 21<sup>st</sup> July 2025 were approved.

It was noted that Bill Jenks had arranged for the Citizen Representative vacancy for North East London ICB to be circulated to the Citizen members of the ICB's System Panel. Bill noted that an ICB Clinician representative had been identified and would be in place for the next meeting.

### **Item 4: Any Other Business**

Members noted the potential changes in the statutory make-up of ICBs serving London and that their roles would continue until a formal change was enacted.

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

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

Agenda items would include:

- Review of the London Secure Data Environment Driver Projects if submitted.
- Implications of ICB developments, including reviewing the IIAG Terms of Reference for quoracy definition.

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

Monday 21<sup>st</sup> July 2025 @ 14:00 to 14:40

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
Caroline Law	Head of Information Governance and Data Protection Officer, Central London Community Healthcare NHS Trust	North West London ICB	ICB Clinical Member
Susan Ashbourne		South West London ICB	ICB Citizen Member
Mark Agathangelou	Lived Experience Partner	North Central London ICB	ICB Citizen Member
Matt Laundry	Chief Clinical Information Officer	South West London ICB	ICB Clinical Member
Lizzie Wallman	Deputy Chief Nurse	South East London ICB	ICB Clinical Member
Bill Jenks	Digital Manager and North East London Strategic Information Governance Network Chair	North East London ICB	ICB Expert Member
Sanjay Gautama	Chief Clinical Information Officer	North West London Integrated Care Board and OneLondon	For Item 2
Mark Kewley	Programme Director	London Secure Data Environment for Research & Development	For Item 2
Anneka Hon	Communications Manager	Health Innovation Network – South London	For Item 2
James Friend	Director of Digital Strategy	NHS England - London Region	Secretary

### Item 1: Apologies Given or Assumed

Name	Role	Organisation	Programme Role
To be Nominated / Recruited		North East London ICB	ICB Clinical Member
		North East London ICB	Expert Members
		North West London ICB	ICB Citizen Member

It was noted that recruitment to given roles had been impacted by the advent of the Model ICB template under the Government's reorganisation of the NHS. For example, North East London ICB have a consultation underway which completes at the end of July 2025 and there will be an opportunity for clarity on the way forward both on that and for wider ICB representation, given potential closer working between North Central London and North West London ICBs, at the next meeting. Healthwatch are similarly impacted.

## **Item 2: London Secure Data Environment Driver Projects**

Sanjay Gautama and Mark Kewley introduced the details of the process being followed to recruit three new driver projects as set out in the paper circulated before the meeting.

The call for projects builds from the Citizens Forums recommendation to demonstrate the purpose of the Secure Data Environment (“SDE”) between direct care and clinical academic research. The projects are postulated to help identify the next data sets to be developed beyond the SDE minimum viable product and were always planned to take place as part of the testing and scaling up the SDE - as a soft rollout.

It was confirmed that the call for driver projects has been placed via by Biomedical Research Organisations, advertising by the Health Innovation Networks across London and placement on the OneLondon website from the middle of June and that a webinar was hosted with MedICS being the forum that links the universities and the integrated care systems in London.

The timetable for the driver projects agreement was questioned by IAG members, noting that given they are not the data controllers this will have an impact, as well any outcomes from the IAG reviews that indicate further coaching development is required for the driver project application. It was noted that it may be beneficial to send all driver project applications through to the IAG rather than short listing beyond whether the application is a valid one rather than risk some or all of three shortlisted applications being rejected by the IAG.

The relationship between the Secure Data Environment Network which will become a Secure Data Environment for the nation working closely with the Government policy team and the £1,000,000 funding secured from Wellcome alongside £5,000,000 worth of central government funding was clarified, noting the driver projects must respect the compact or agreements reached with data controllers and the public.

A slightly revised Information Access Request Form will be used and this will be circulated for IAG agreement prior to the next meeting noting that the changes are minor and the original template came through North West London ICB, was clinically assured as part of the development of the IAG Terms of Reference and has been previously reviewed for continuous improvement by the IAG members.

It was suggested that driver projects might ideally have a positive focus on opportunities to demonstrate the use of the data to close health inequality gaps.

## **Item 3: Items for Noting**

The minutes from the previous meeting on 19<sup>th</sup> May 2025 were approved.

#### **Item 4: Any Other Business**

It was noted that there was at present no change to the role of ICB Data Controllers as no new legislation has been enacted but is currently being formally developed by the UK Parliament.

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

15<sup>th</sup> September 2025: 14:00 – 15:00

Agenda items would include:

- Review of the London Secure Data Environment Driver Projects
- Implications of ICB developments, including reviewing the IIAG Terms of Reference for quoracy definition.

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

Monday 19<sup>th</sup> May 2025 @ 14:00 to 14:40

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
Caroline Law	Head of Information Governance and Data Protection Officer, Central London Community Healthcare NHS Trust	North West London ICB	ICB Clinical Member
Susan Ashbourne		South West London ICB	ICB Citizen Member
Mark Agathangelou	Lived Experience Partner	North Central London ICB	ICB Citizen Member
Kerry Beadling-Barron	Director of Communications	Health Innovation Network South London	Public and Patient Engagement Lead
James Friend	Director of Digital Strategy	NHS England - London Region	Secretary

**Item 1: Apologies Given or Assumed**

Name	Role	Organisation	Programme Role
To be Nominated / Recruited		North East London ICB	ICB Clinical Member
		North East London ICB	Expert Members
		North West London ICB	ICB Citizen Member
Matt Laundy	Chief Clinical Information Officer	South West London ICB	ICB Clinical Member
Lizzie Wallman	Deputy Chief Nurse	South East London ICB	ICB Clinical Member

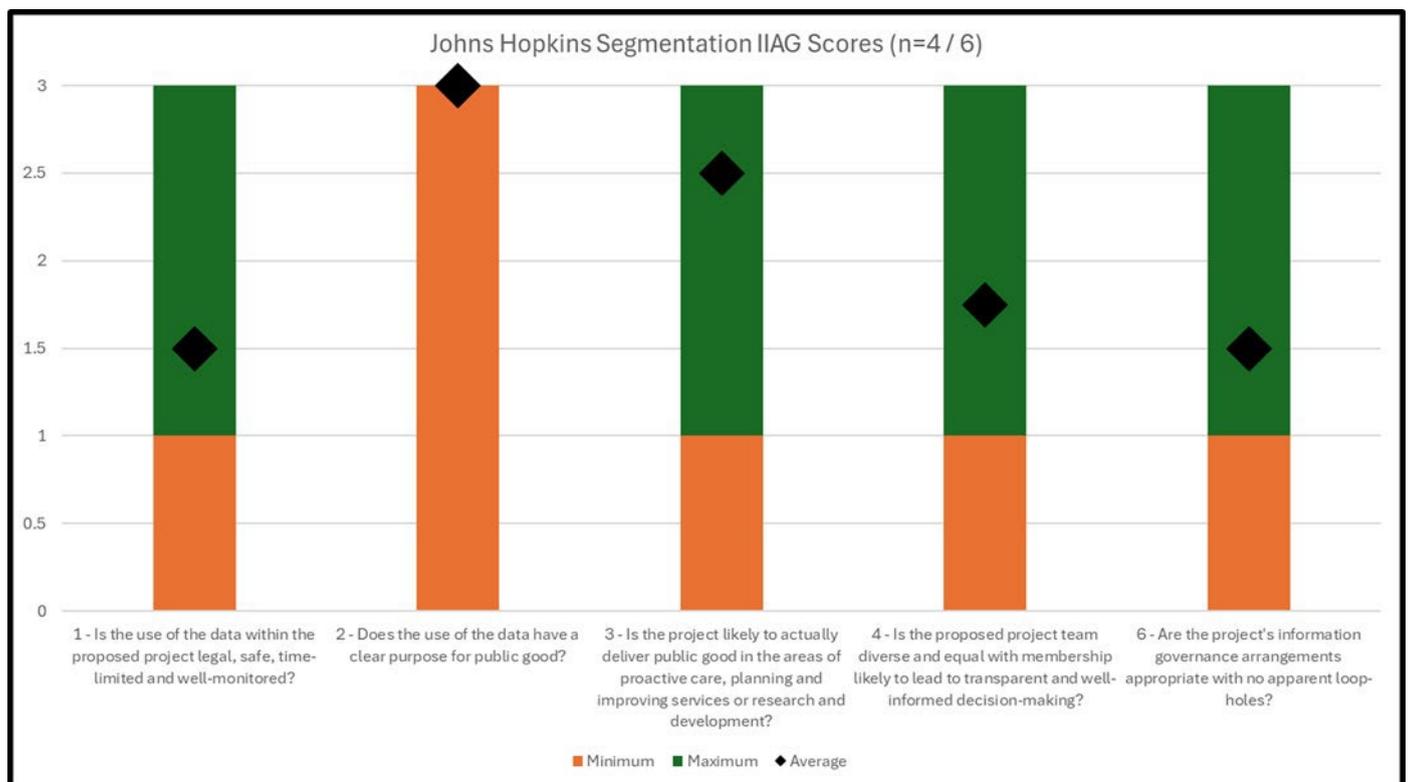
Bill Jenks, Digital Manager and North East London Strategic Information Governance Network Chair on behalf of North East London ICB was not present at this meeting and the ICB has not yet nominated a successor Citizen member. James Friend noted that he had written to the ICB to escalate this matter.

## Item 2: Use Case Review - NHS 111 Risk Stratification Use of Johns Hopkins Segmentation

The IIAG's Terms of Reference and operating process allows it to come to one of three conclusions:

- Recommendation to the Data Controllers that the proposed Pan London data use be considered by them
- Not to recommend the proposed Pan London data use to the Data Controllers
- To require and where appropriate support the project team to develop the use case for further consideration after specific feedback points have been addressed.

The outcome of the members review in the context of its Terms of Reference key lines of enquiry was as follows:



The IIAG noted that the proposal at this time is for an ongoing use of the data and is not time limited. It was also noted that confirmation was not stated as being in place that (a) the organisations accessing the data are Data Protection Security Toolkit compliant or that (b) team members had signed appropriate confidentially agreements.

It would therefore fall into the third category of requiring development before recommendation to ICB Data Controllers.

Given the nature of the application (i.e. not a vanilla Research & Development use case) and the development of the London Data Service to act as joint data controller going forward and which brings together general practice and secondary care data sets, the suggestion is that the project team progress these three feedback aspects directly with the London Data Service as they progress the work through to their Data Controller / Data Access Committee formally considering the use case, specifically:

- Agree a formal date for reviewing the clinical and operational benefit of the use of the data and whether to continue so to do. It was suggested by the IIAG that the date be set as being 12 months from the start of the operational use.
- Note that North East London ICB as the host of the London Data and Analytics Service are DPST compliant and if other organisations are involved who are only working towards DPST compliance then work with the Digital Transformation business partner team to clarify any concerns
- Given NHS staff have the confidentiality agreement within their terms of employment, note that if there are any non-NHS Staff accessing the data then confidentiality agreements must be entered into.

### **Item 3: Pipeline of Use Cases**

James Friend noted that a proposed use case to support the Eye Care Neighbourhood Pathway may be submitted for review at a future meeting.

The clinical pathway is demonstrated to work as a proof of concept and is to be developed through a scaled up approach using the nationally available digital infrastructure. Once that aspect of the Proof of Concept test with patient sets (GP practices) that are already commissioned to the Single Point of Access is developed the project team will move on to a Proof of Value stage by running it for a period of time alongside productivity and outcome metrics drawing data (baseline and comparator) from the London Data Service. IIAG use case review may be required to facilitate that, or it may be deemed appropriate to complete this phase when the use case is moving to a pan London footprint.

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

The minutes from the previous meeting on 17<sup>th</sup> March 2025 were approved.

### **Item 5: Any Other Business**

It was confirmed that North East London ICB are in the process of issuing funding Memorandum of Understanding documents to the four other ICBs, in the same process as for the prior year and the IIAG members or their employing organisations should continue to submit claims as previously.

Additionally, IIAG members noted the potential implications of the recently published Model ICB documents which indicated changes to responsibilities for digital and data governance, and concluded that the operational processes of the IIAG may need to be reviewed in due course as a consequence. It was additionally noted that effective Patient and Public Involvement and Engagement would be important both for the development of the revised ICB approaches locally and specifically for the Neighbourhood Providers / Integrated Neighbourhood Teams.

**Dates of the next meeting:**

21<sup>st</sup> July 2025: 14:00 – 15:00

**Agenda items would include:**

- Update from NEL ICB on the recruitment to their IIAG roles
- Update on the implications of the Model ICB on data controller roles

**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.

**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.

**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.

**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

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

Monday 18th November 2024 @ 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
Mark Agathangelou	Lived Experience Partner	North Central London ICB	ICB Citizen Member
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
Lizzie Wallman		South East London ICB	ICB Clinical Member
Deborah Millington	OneLondon Health Data Strategy Citizen Representative	North East 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.

## **Item 2: Informal Updates**

### **Chair Succession**

James Friend informed the group that following the request that any expressions of interest for the Chair role be sent to him by mid-August, Graham Head had kindly agreed to undertake this role for the remainder of 2024/25.

### **Recruitment Update**

James Friend updated the group that the clinical and expert representatives being recruited within NELICB had not been recruited as per the previously expected timescales. It was noted that NELICB also now need to recruit a successor Citizen Representative as Deborah Millington had retired from the role.

### **MoU Update**

MoUs for 2024/25 have now been sent to the ICBs by NELICB. James checked in with everyone to ensure they have been receiving the appropriate expenses remuneration. There are no current issues reported other than at NCLICB.

## **Item 3: London Region Transformation Strategy**

James Friend presented the Plan on a Page that had been previously circulated and noted the focus on Prevention, Digital Access, Long Term Condition Management, New Care Pathways, Mental Health and Children & Young People Services.

The approach was widely supported and welcomed. Ian noted that the slide summarised his professional for the previous decade and provided a good summary of the challenges and technology. It was anticipated that future Data at Scale for Improvement project applications are likely to fall into one or more of these six focus areas.

It was formally requested by the group that a foot note be added to clarify that part of the objective for the Digital Access focus was to free up capacity in physical access channels such that those without digital access (through choice or otherwise) were not excluded from service offerings, and indeed received accelerated access than today by “making the door wider for those that need it”.

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

The minutes from the previous meeting on 15th July 2024 were approved.

It was noted that SELICB Data Usage Committee have approved the CHILL study that was previously recommended by the IAG and that they would undertake to review the differences, if any, between the IAG paperwork templates and their local versions, during 2025.

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

20<sup>th</sup> January 2025: 14:00 – 15:00

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

Monday 15<sup>th</sup> July 2024 @ 15:00 to 16:30

Venue: TEAMS only

**Attendees:**

Name	Role	Organisation	IIAG Role
Victoria Mustafa	Digital Midwife	South West London ICB	ICB Clinical Member and Joint Chair
Ian Colvin	GP, Islington GP Federation and NCL ICB Board Member of General Practice Provider Alliance	North Central London ICB	ICB Clinical Member
Graham Head	South East London Healthwatch and Data Usage Committee	South East London ICB	ICB Citizen Member
Mark Agathangelou	Lived Experience Partner	North Central London ICB	ICB Citizen Member
Deborah Millington	OneLondon Health Data Strategy Citizen Representative	North East London ICB	ICB Citizen Member
Susan Ashbourne		South West London ICB	ICB Citizen Member
James Friend	Director of Digital Strategy	NHS England - London Region	Secretary
Fiona Nicholls	Chair of South East London Data Usage Committee	South East London ICB	ICB Clinical Member

**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
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.

Sonia Richardson was not present at this meeting. Victoria will check in with Sonia to check all is ok.

## **Item 2: Informal Updates**

### **Chair Succession**

James Friend informed the group that Victoria Mustafa has secured a substantive role within the London Regional Maternity Team and will therefore be stepping down as Chair of the IIAG. South West London ICB has been notified and is in the process of finding a replacement representative for SWL. James requested that any expressions of interest for the Chair role be sent to him by mid-August. Victoria will update those who were unable to attend today's meeting.

### **Recruitment Update**

James Friend updated the group that, based on an email exchange with Bill Jenks, the clinical and expert representatives are currently being recruited within NEL and are expected to be in place by the next meeting in September 2024.

### **MoU Update**

MoUs for 2024/25 are being sent out by NELICB instead of the NHS England London Regional Office as the programme funding resides with the ICB. James checked in with everyone to ensure they have received and are being paid correctly. There are no current issues reported other than at NCLICB.

## **Item 3: Review of Items for Noting**

The minutes from the previous meeting on 20th May 2024 were approved with a minor adjustment to Ian's title.

## **Item 4: AOB**

Fiona Nicholls announced her upcoming retirement and that this meeting would be her last. Her ICB has been informed and is in the process of finding her replacement for the IIAG. The group thanked Fiona for her contributions and wished her well in her future endeavours.

Ian Colvin requested an overview of the relationship between the IIAG and the Data Access Committees (or equivalents) at ICB level as he has been asked to join the NCLICB forum. Fiona clarified that the IIAG is an advisory group that reviews London-wide applications with a view to making recommendations to those local fora and that applications that relate to specific ICBs are dealt with directly by those local fora. All ICBs now have this IG governance structure in place or emerging.

James Friend thanked Victoria for her contributions as Chair of the IIAG and extended the group's best wishes for her future role.

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

9<sup>th</sup> September 2024: 15:00 – 16:30

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

Monday 20<sup>th</sup> May 2024 @ 15:00 to 16:30

Venue: TEAMS only

### Attendees:

Name	Role	Organisation	IIAG Role
Victoria Mustafa	Digital Midwife	South West London ICB	ICB Clinical Member and Joint Chair
Ian Colvin	GP, Islington GP Federation and NCL ICB Board Member of General Practice Provider Alliance	North Central London ICB	ICB Clinical Member
Graham Head	South East London Healthwatch and Data Usage Committee	South East 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
Mark Agathangelou	Lived Experience Partner	North Central London ICB	ICB Citizen Member
Deborah Millington	OneLondon Health Data Strategy Citizen Representative	North East London ICB	ICB Citizen Member
Susan Ashbourne		South West London ICB	ICB Citizen Member
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
Fiona Nicholls	Chair of South East London Data Usage Committee	South East London ICB	ICB Clinical Member
Sonia Richardson		North West London ICB	ICB Citizen 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.

### Item 2: Welcome to new citizen rep Sonia (NWL)

Unfortunately, Sonia Richardson was unable to attend for connectivity issues.

### **Item 3: Commissioning of the IIAG for 2024/25**

James Friend summarised that last week the OneLondon Health Data Board had provisionally agreed the overall programme budget for 2024/25 including the continuation of the IIAG and Citizen Engagement activities. This was subject to two points (a) the confirmation of the national programme funding for the year (which has subsequently been received) and (b) the confirmation of regional office funding of the capital charges. North East London Integrated Care Board (NELICB) works with University College Hospitals London NHS Foundation Trust for the financial management of the programme overall and it is expected that ICBs will receive Memorandums of Understanding for the IIAG roles from them in due course.

### **Item 4: Progress update on ICB and Expert Member Recruitment**

Deborah Millington was welcomed to the meeting as the NELICB Citizen Member. It was noted that Deborah is well versed in the workings of the IIAG having been part of the original group that reviewed the initial Terms of Reference.

### **Item 5: CHILL Study outcome – full confirmation for minute purposes**

The members confirmed their support for the CHILL project previously reviewed, with the additional information that had been seen following the last meeting.

The request has been taken to the North West London ICB Data Access Committee (DAC) following the recommendation from the IIAG and Caroline Law feedback informally that it had been agreed. The expectation is that the project will start with NWLICB data before the full data is available through the London Data Service.

NWLICB's DAC noted that these IIAG routed applications differ from those usually reviewed by them in not having an ICB level sponsor (not having one being one of the positive points derived from the Citizen Advisory Group sessions held in 2022). The feedback from the DAC reviews would be collated to inform the annual review of the IIAG processes and documentation later in the year.

At Graham's suggestion, Victoria Mustafa will provide the documentation to Fiona Nicholls for the South East London ICB Data Usage Committee to review in anticipation of their data being available.

### **Item 6: Review of Items for Noting**

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

### **Item 7: Items for Next Meeting**

The following items were agreed for the provisional agenda for the next meeting were agreed as:

- Review any applications (James Friend would circulate a log of those in progress).
- Items for Noting, including:
- Minutes from 20<sup>th</sup> May 2024

**Item 8: AOB**

Victoria Mustafa noted that there was no further update from the national team via Tom Wright who had previously presented to the IIAG.

James Friend was asked to circulate, in due course, any progress papers from the Data at Scale for Improvement Projects as they present to the OneLondon Health Data Board, to aid IIAG member learning and process review.

Ian Colvin noted that he had changed role at North Central London ICB, with his digital role ending and he is now NCL ICB GP Provider Alliance Clinical Member for Islington.

The next meeting will be held at 15:00 on Monday 15<sup>th</sup> July 2024.

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

Monday 18<sup>th</sup> March 2024 @ 15:00 to 16:30

Venue: TEAMS only

**Attendees:**

Name	Role	Organisation	IIAG Role
Victoria Mustafa	Digital Midwife	South West London ICB	ICB Clinical Member and Joint Chair
Fiona Nicholls	Chair of South East London Data Usage Committee	South East London ICB	ICB Clinical Member
Ian Colvin	GP, Islington GP Federation and Digital Clinical Lead for NCL ICB	North Central London ICB	ICB Clinical Member
Graham Head	South East London Healthwatch and Data Usage Committee	South East 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
Mark Agathangelou	Lived Experience Partner	North Central London ICB	ICB Citizen Member
Tom Wright	Data Access and Partnerships Directorate	NHS England	External member invited to speak.
Chris Griffiths	Professor of Primary Care	Queen Mary University of London (CHILL Study)	External member invited to speak.
Jenni Quint		CHILL Study member	External member
Jess Mitchell		CHILL Study member	External member

**Item 1: Apologies Given**

Name	Role	Organisation	Programme Role
To be Nominated / Recruited		North West London ICB	ICB Citizen Member
		North East London ICB	ICB Clinical Member
		North East London ICB	ICB Citizen Member
		North East London ICB	Expert Members
Susan Ashbourne		South West London ICB	ICB Citizen Member
James Friend	Director of Digital Strategy	NHS England - London Region	Programme Director

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.

## **Item 2: National Data Services for Commissioners**

Presentation by Tom Wright

Tom discussed the need to update the data services for Commissioners directions due to the shift from CCGs to ICS with the Health and Care Act of 2022.

The new direction aims to allow ICS's to collect local data and link it to national data for better health outcomes and strategic planning. Challenges include integrating data from non-commissioned services and smaller organisations, which the current direction does not allow. Tom provided examples of services like "Get You Better" and a dementia service that could not be linked under the current direction. The goal is to provide ICS's the flexibility to collect and link data for comprehensive analysis.

Questions were raised by attendees regarding the implications of the new direction, with Tom offering to provide further guidance and updates.

## **Item 3: New data at scale application – CHILL Study**

Presentation by Chris Griffiths (Chill Study):

Chris presented the Chill study, which aims to determine if London's ultra-low emission zone improves children's health.

The study compares cohorts of children in London and Luton, measuring lung capacity and growth, and now seeks to access health records. Consent was obtained from parents, and NHS REC approval was granted for an opt-out approach. Chris requested guidance on the process for accessing data across different ICS's and the associated costs. The group said they would confirm this with James.

The committee expressed strong support for the study and discussed the need to review the DPIA before endorsing the project. Victoria will action this and send around the DPIA.

## **Item 4: Progress update on ICB and Expert Member Recruitment**

In the absence of Bill Jenks and Victoria Mustafa there was no further update on this matter. Victoria will escalate this with Bill after the meeting.

## **Item 5: Review of Items for Noting**

The minutes from the previous meeting on January 15th were reviewed and agreed upon, with minor edits noted by Fiona.

## **Item 6: Items for Next Meeting**

The following items were agreed for the provisional agenda for the next meeting were agreed as:

- Tom Wright to reattend with any further updates on the National Data Service

- The committee agreed to review the Chill study documents within 2-3 weeks after receiving the DPIA.
- Victoria will follow up with James regarding the future of funding and member recruitment for the group.

Items for Noting, including:

- Minutes from 18<sup>th</sup> March 2024

#### **Item 7: AOB**

Concerns were raised about the low number of lay voices in the group, and the need for member recruitment was reiterated.

Caroline mentioned she would address the lay member aspect with northwest London.

The next meeting will be held at 15:00 on Monday 20<sup>th</sup> May 2024.

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

Monday 18<sup>th</sup> September 2023 @ 15:00 to 16:00

Venue: TEAMS only

### Attendees:

Name	Role	Organisation	IIAG Role
Victoria Mustafa	Digital Midwife	South West London ICB	ICB Clinical Member and Joint Chair
Graham Head	South East London Healthwatch and Data Usage Committee	South East 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
Mark Agathangelou	Lived Experience Partner	North Central London ICB	ICB Citizen Member
Susan Ashbourne		South West London ICB	ICB Citizen Member
James Friend	Director of Digital Strategy	NHS England - London Region	Programme Director
Kavitha Saravanakumar	Associate Director of Business Intelligence	North West London ICB	Presenter for item 2
Jonathan Watkins	Health Research Lead	Imperial College Health Partners	Presenter for item 2
Reuben Lewis	Operational Lead	DiscoverNOW Secure Data Environment	Presenter for item 2

### Item 1: Apologies Given

Name	Role	Organisation	Programme Role
Ian Colvin	GP, Islington GP Federation and Digital Clinical Lead for NCL ICB	North Central London ICB	ICB Clinical Member
Fiona Nicholls	Chair of South East London Data Usage Committee	South East London ICB	ICB Clinical Member
To be Nominated / Recruited		North West London ICB	ICB Citizen Member
		North East London ICB	ICB Clinical Member
		North East London ICB	ICB Citizen Member
		North East London ICB	Expert Members

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.

## **Item 2: How the Secure Data Environment works for NWL**

Kavitha Saravanakumar, Jonathan Watkin and Reuben Lewis gave a detailed review of the mechanisms used by the NWL Data Access Committee in reviewing applications to use the DiscoverNow Secure Data Environment. It was noted that the IIAG's documentation mirrored this (with thanks to NWL).

Graham head asked how the public are informed of applications to the Data Access Committee and it was explained that these, together with post project reports, are published on the DiscoverNow website for transparency. Caroline Law, who is a co-chair of the NWL Data Access Committee thanked the team there and noted that applications always centred on the direct impact for the public at large from the proposed use of the data.

Kavitha encouraged other ICBs to adopt a single data access committee model to cover all use case types as this avoids confusion and noted that ICBs should not underestimate the administrative work involved in reviewing and following up requests, starting from the initial triage process through to all the reasons that projects may not get completed.

## **Item 3: DSIP11 Agreement from all to send to ICB Data Controllers**

Based on the discussions and emailed responses received from the Lead Organisation, it was decided that this application should be sent to the ICB Data Controllers to ascertain whether it is a clinical priority and whether it meets their local Information Governance requirements. It was noted that Information Governance is more than a routine to be followed and that the tone of the application still had the opportunity to reflect the importance of this approach.

## **Item 4: Progress update with Level 2 London Health Data Service Development to support Data at Scale Improvement projects**

James Friend set out the progress being made, based on the presentation given to the Sub-National Secure Data Environment workshop during the summer and focused on the pace at which given data sets were expected to be linked to the data service. It was expected that these would enable each of the initially supported four project applications to be supported during the fourth quarter of 2023/24, subject to confirmation.

Kavitha added that whilst the technical dataset linkages were expected to be in place, the work to obtain the Information Governance commitments from the large number of data controllers, particularly voluminous in primary care, was not insignificant and had previously taken NWL around two years to complete.

It was noted that it is important to use consistent language in developmental documents so as to ensure that readers take the same meaning as each other. Kavitha set out that Section 251 / CAG approaches

differed across the sub-national SDEs and that London was seeking to build from and adopt the approach taken by NWL within DiscoverNOW.

#### **Item 5: Progress update on Expert Member Recruitment**

Bill Jenks was not present at today's meeting. Victoria Mustafa will email to ask for an update.

#### **Item 6: Data at Scale Improvement Project Funding update 2023/24**

James Friend updated the meeting that discussions were still ongoing with the NHS England – London Regional team as to when funding for the projects can be confirmed. The Regional executive are maintaining a positive approach and this is being taken through the bottom up budgeting exercise for the current year which has delayed confirmation of progress beyond the initial expectations.

Individual project applicants are being kept informed of the budget progress. Should the fifth project be approved by ICBs prior to funding being confirmed then a prioritisation exercise will be undertaken.

#### **Item 7: Review of Items for Noting**

- Minutes from 17<sup>th</sup> July 2023
  - These were noted.

#### **Item 8: Items for Next Meeting**

The following items were agreed for the provisional agenda for the next meeting were agreed as:

- Review of any subsequently received applications for Data at Scale for Improvement Projects
- Introduction to the potential concept of Trusted Partners to the London Sub-National Secure Data Environment
- Items for Noting, including:
  - Minutes from 18<sup>th</sup> September 2023

The next meeting will be held at 15:00 on Monday 20<sup>th</sup> November.

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

Monday 15<sup>th</sup> May 2023 @ 15:00 to 16:00

Venue: TEAMS only

### Attendees:

Name	Role	Organisation	IIAG Role
Victoria Mustafa	Digital Midwife	South West London ICB	ICB Clinical Member and Joint Chair
Graham Head	South East London Healthwatch and Data Usage Committee	South East London ICB	ICB Citizen Member
Fiona Nicholls	Chair of South East London Data Usage Committee	South East London ICB	ICB Clinical Member
Caroline Law	Head of Information Governance and Data Protection Officer, Central London Community Healthcare NHS Trust	North West London ICB	ICB Clinical Member
Mark Agathangelou	Lived Experience Partner	North Central London ICB	ICB Citizen Member
Ian Colvin	GP, Islington GP Federation and Digital Clinical Lead for NCL ICB	North Central London ICB	ICB Clinical Member
Bill Jenks	Digital Manager and North East London Strategic Information Governance Network Chair	North East London ICB	Attendee pre ICB Nominees Recruitment
James Friend	Director of Digital Strategy	NHS England - London Region	Programme Director

It was noted that four ICBs were represented in some fashion at the meeting.

Caroline Law started the meeting with the sad news of the passing of John Norton, North West London ICB's Citizen Member and Joint Chair of the IIAG. The group members recorded their gratitude for the contribution that John had made in his time with us.

### Item 1: Apologies Given

Name	Role	Organisation	Programme Role
Susan Ashbourne		South West London ICB	ICB Citizen Member
To be Nominated / Recruited		North East London ICB	ICB Citizen Member
To be Nominated / Recruited		North East London ICB	ICB Clinical Member

### Item 2: Sub-National Secure Data Environment - Citizen Advisory Group Public Deliberations

Amy Darlington set out the Citizen engagement work being undertaken within the London Sub-National Secure Data Environment work. Following the recommendations of the OneLondon Citizen Summit, the Citizen Advisory Group has been formed to be in place to be called upon at key times within the

programme. Over three days in June / July 2023, 100 Londoners will be introduced to complex subjects and will be asked to grapple with the trade-off decisions NHS leaders and Clinicians face for using data at scale for improvement, research and development. The deliberations will use the recommended best practice engagement methodology developed through previous work in London and will specifically look at additional criteria for selecting applications and how the pricing model could work for non-NHS organisations. An added benefit is that the continued membership of the Citizen Advisory Group means that people build their knowledge and can be called upon for other Patient and Public Involvement and Engagement.

It was noted that there are now multiple uses of the acronym “CAG” and it was important to be clear each time. Furthermore, the importance of the remuneration of the citizen members of the CAG was stressed to help facilitate a diverse membership. Amy undertook to return to the IAG after this round of deliberations to provide feedback and invited IAG members to shadow the deliberation events.

Finally, Fiona summarised the conversation at the recent London Information Governance workshop highlighting the importance of communication with the ICS Data Controllers as well as with citizens.

### **Item 3: Members Register of Interests**

James Friend invited members to submit any updates to the register of interests. Caroline Law has submitted a return.

### **Item 4: Progress update with ICB Data Controllers**

James Friend and Victoria Mustafa have held meetings with each of the ICB Data Controllers and / or their representative teams. Two questions have been set out for them to review – does the application accord with their IG requirements (or could it be made to accord with minor amendments) and is the application’s topic a priority for the ICB. It has been noted that the Data Controller teams have less awareness of the ICB priorities than had been assumed and so these questions have generally been taken in two stages by each ICB. The initial feedback appears to be that IG requirements are likely to be in line with expectations given the application process undertaken to date, but this remains to be formally confirmed by any ICB.

### **Item 5: Progress update on Expert Member Recruitment**

Bill Jenks noted that these roles were with the NEL ICB recruitment team. James Friend added that a potential lead for the independent Information Governance expert had emerged from the programme’s partner organisation the Greater London Authority and this was being taken forward.

### **Item 6: London Health Data Strategy – Annual Report to Citizens**

The Report was welcomed. It was noted that the technical nature of some aspects of the report could make public understanding more challenging and that a “Plain English” style review could add value. In particular phrases such as “Population Health” could be explained. James Friend agreed to feed this back to Kerry Beadling-Barron.

### **Item 7: Review of Items for Noting**

- Minutes from 27th March 2023
  - Data at Scale for Improvement Applications – it was noted that all applicants had now been notified of the IIAG outcomes.

### **Item 8: Items for Next Meeting**

The following items were agreed for the provisional agenda for the next meeting were agreed as:

- Feedback from the June and July Citizen Advisory Group Public Deliberation
- Feedback and learning from ICB Data Controllers on recommendations for Data at Scale for Improvement Projects
- Review of any subsequently received applications for Data at Scale for Improvement Projects
- Items for Noting, including:
  - Minutes from 15<sup>th</sup> May 2023

The next meeting will be held at 15:00 on Monday 17<sup>th</sup> July. Fiona Nicholls tentatively asked for her apologies to be noted in the event that she is unable to attend.