

## 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 IAG 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.