



## National Data Advisory Group Minutes

<b>Date</b>	03 May 2023	<b>Time</b>	10:30-12:00
<b>Venue</b>	MS Teams		
<b>Chair</b>	Louise Greenrod		
<b>Secretary</b>	[REDACTED]		

### Attendance

<b>Name</b>	<b>Title</b>
Louise Greenrod (chair)	Deputy Director, Data Policy and Digital Oversight, NHS Transformation Directorate
[REDACTED]	Head of Data Access and Linking Policy, NHS Transformation Directorate
[REDACTED]	Head of Data Strategy, NHS Transformation Directorate
[REDACTED]	Senior Policy Advisor, NHS Transformation Directorate
[REDACTED]	Head of Digital Oversight, NHS Transformation Directorate
[REDACTED]	Senior Policy Advisor, NHS Transformation Directorate
[REDACTED]	Senior Policy Advisor, NHS Transformation Directorate
[REDACTED]	Senior Policy Advisor, NHS Transformation Directorate
[REDACTED]	Senior Policy Advisor, NHS Transformation Directorate
[REDACTED]	Senior Policy Advisor, NHS Transformation Directorate
[REDACTED]	Senior Policy Advisor, NHS Transformation Directorate
[REDACTED]	Senior Policy Advisor, NHS Transformation Directorate
[REDACTED]	Senior Policy Advisor, NHS Transformation Directorate
[REDACTED]	Strategy Lead, NHS Transformation Directorate
Philippa Lynch	Senior Data Specialist, Local Government Association
Chris Carrigan	Expert Data Adviser, Use MY Data
Matt Hennessey	Regional system rep, Greater Manchester Health Social Care Partnership



Linn Philips	NHS patient and public voice partner
Ryan Avison	Head of the National Data Guardian's Office
Rachel Power	Chief Executive, Patient's Association
Dr Nicola Byrne	National Data Guardian
Louis Holmes	Policy Manager, Care England
Marc Farr	Regional system rep, East Kent Hospitals University NHS Foundation Trust
██████████	Communications Manager, NHS Transformation Directorate

## Apologies

Name	Title
Helen Stokes-Lampard	Chair of Academy of Medical Royal Colleges (AoMRC)
Nicola Perrin	Chief Executive, Association of Medical Research Charities

## Minutes

Actions			
#	Meeting Date	Action	Owner
6.01	03/05/23	██████████ to arrange discussion with Matt H on CAG approvals and local opt-outs.	██████████
6.02	03/05/23	██████████ to clarify access plans for PR campaign resources, especially the use of a logo.	██████████
6.03	03/05/23	Members to share any further thoughts or comments on our initial thinking around how to progress work on opt-outs to ██████████	Members



**Item 1) Welcome and introductions**

Louise Greenrod (LG) opened the meeting and welcomed attendees.

**Item 2) Actions and wider update**

Action log was shared prior to meeting.

There were no questions from the group.

**Item 3) Data Access and Linking Policy**

██████████ presented on Data Access Policy, updating members on work implementing the Data Strategy commitments to move to Secure Data Environments by default. ██████ outlined the work vision – to move from the current ‘Data Sharing’ model to a ‘Data Access’ model – recapped progress to date and updated on key next steps, including:

- Approach to oversight – good progress has been made.
  - Have engaged with the sector and come to the agreed approach, to expand existing UKSA platform accreditation process to include SDEs providing access to NHS data for research. This is a highly regarded and robust service and already accredits platforms that host health data for research purpose.
- Upcoming policy statement – sets out key policy decisions that have been made to date and aims to reassure the public and set clear expectations/create certainty for data controllers, data accessors and platform providers.
  - Ambition to take a proactive approach to update on development of policy thinking and/or decisions, through publishing this policy statement in draft to stimulate testing and feedback.

Discussion focussed on two main themes. Firstly – the importance of clarity, in terms of implementation direction and supporting policy/guidance (including which use-cases are/aren’t within scope of the guidance available to the system). And secondly – the need to ensure that the public and patient voice is considered, including the potential for work on the data pact to inform best approaches.

Additionally, members were supportive of the direction to utilise the existing UKSA framework for accreditation but raised questions around the language used in messaging (oversight vs accreditation).

Some specific questions and answers were taken in the meeting chat:

Q: As we are moving to data access as the default, rather than data release, how does this impact commercial companies who rely on data releases?



A: Yes, we are moving to data access by default, which will cover commercial users of the data too. This will be a shift for many and we definitely recognise this may face barriers/challenges. And these challenges need to be reflected in how we set any "cut-off" for data sharing.

Q: Will charities be able to get data access?

A: Yes, British Heart Foundation and other charities already use the existing National SDE - <https://digital.nhs.uk/services/secure-data-environment-service>

Q: Will the infrastructure allow a user to bring their own data to work on inside the SDE, alongside existing SDE data?

A: Yes, this is the goal – see NHSE national site for more details

<https://digital.nhs.uk/services/secure-data-environment-service#bring-your-own-data>

Q: Will exiting costs (for data release) be increased (for data access)?

A: There's a lot of work internally to developing models for costing access to data access to ensure a sustainable service can be provided.

#### Item 4) National Data Opt-Outs

██████████ presented, updating the group on our early thinking about how we can improve opt-outs short and long term, briefly:

- In the short term, making them simpler and clearer - digitising, improving information available and public engagement – and
- In the longer term, reviewing the process to address systemic problems, considering options such as separating planning and research, and making it easier to opt back in for Type 1s.

It was noted that engagement is key to this work - with NDAG, other stakeholders and the public - particularly when it comes to the longer-term future of opt-outs.

Discussion focussed on established existing complexities – including local opt-outs, whether there were trade offs or a separation between simplifying and clarifying and if this was a helpful way to look at the issue. Some members felt that simplification might not be the most useful framing for our approach and suggested a more open framing could be more suitable. Members discussed the importance of ensuring an authentic opt-out – one that is based on a properly informed decision and does what people expect it to do – and the need to ensure opt-outs remain fit for purpose and work with future technical and operational reality.

The need for an 'authentic' opt-out was linked to the issue of lack of public understanding of the opt-out, in particular the numerous exemptions which apply. Improving our understanding of public expectations will be a key objective of public engagement around the opt-out and will also tie in with wider comms and engagement



work ongoing and planned (including the planned ambient PR campaign, which looks to build confidence in how the NHS uses data).

**Action 6.01 – [REDACTED] to arrange discussion with Matt H on CAG approvals and local opt-outs.**

**Action 6.02 – [REDACTED] to clarify access plans for PR campaign resources, especially the use of a logo.**

**Action 6.03 – members to share any further thoughts or comments on our initial thinking around how to progress work on opt-outs to [REDACTED]**

#### Item 5) Commitment Delivery Update

[REDACTED] provided an update on the current implementation of Data Saves Lives strategy commitments – focussing on three keys areas: the overall picture and progress made, upcoming commitments, and most at-risk (red-rated) commitments.

As of the end of March this year, 50% of commitments had been completed. However, there have been some green commitments slipping into amber/red as coming into difficulty. Of the remaining, 13 commitments are on track (marked green) to be delivered by the dates published within the strategy, 25 commitments are subject to minor delays (marked amber) and 13 are facing significant delays and/or issues, including funding (marked red).

[REDACTED] gave an overview of the most common challenges reported for red-rated commitments: resourcing issues, budgetary issues, other clearance issues, and policy problems (e.g interrelation with other policy work).

There were no questions from the group. Members were asked to please let us know if would like discussion/focus on anything commitments or groups of commitments in particular at future meetings.

#### AOB and CLOSE

LG noted that, as we are coming up to a year of NDAG meetings, this summer (July) we would like to get reflections on the meeting, how it is working and any changes we might like to make going forward – with the intention to conduct a review and test ideas in August.



■■■ thanked ■■■■ for her work in setting up and supporting NDAG meetings, who is stepping away from managing these meetings as she takes on new work within the Data Policy Team. He also welcomed ■■■■ who has joined the team and will be supporting NDAG meetings going forward.

Next meeting will be held on 13 June 2023 at 10.00am, focused on adult social care.