



## National Data Advisory Group Minutes

<b>Date</b>	22 March 2023	<b>Time</b>	14:30-16:00
<b>Venue</b>	MS Teams		
<b>Chair</b>	[REDACTED]		
<b>Secretary</b>	[REDACTED]		

### Attendance

<b>Name</b>	<b>Title</b>
[REDACTED] (chair)	Head of Data Access and Linking Policy, NHS Transformation Directorate [Deputising for Louise Greenrod]
[REDACTED]	Head of Digital Oversight, NHS Transformation Directorate
[REDACTED]	Senior Policy Advisor, NHS Transformation Directorate
[REDACTED]	Senior Policy Advisor, NHS Transformation Directorate
[REDACTED]	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
Nicola Perrin	Chief Executive, Association of Medical Research Charities
Matt Hennessey	Regional system rep, Greater Manchester Health Social Care Partnership
Linn Philips	NHS patient and public voice partner
Helen Stokes-Lampard	Chair of Academy of Medical Royal Colleges (AoMRC)
Maya Anaokar	Patient's Association
Ryan Avison	Head of the National Data Guardian's Office



## Apologies

Name	Title
Louise Greenrod	Deputy Director - Data Policy and Digital Oversight
Mavis Machirori	Senior Researcher, Ada Lovelace Institute
Marc Farr	Regional system rep, East Kent Hospitals University NHS Foundation Trust
Rachel Power	Chief Executive, Patient's Association
Dr Nicola Byrne	National Data Guardian
Louis Holmes	Policy Manager, Care England

## Minutes

Actions			
#	Meeting Date	Action	Owner
5.01	22/03/23	Data Strategy Team to ensure expected completion dates are included for actions at future meetings	Data Strategy Team
5.02	22/03/23	██████ to feedback name change suggestion for data advisory group referenced in the statutory guidance to NHSE team	██████████
5.03	22/03/23	██████ to establish working group of volunteers to progress development of a measure to monitor public trust, as per data strategy commitment.	██████████ ██████████
5.04	22/03/23	██████ to include list of Red RAG rated commitments in next implementation update.	██████████



**Item 1) Welcome and introductions**

██████████ opened the meeting and welcomed attendees.

**Item 2) Actions and wider update**

Action log was shared prior to meeting.

Action 1.05, 4.02, 4.03 and 4.04 were closed.

The group asked that where actions have been delayed, can an expected completion date be included so the group are aware of when things will be brought back to the meeting.

**Action 5.01** – Data Strategy Team to ensure expected completion dates are included for actions at future meetings.

**Action 3.06 and 4.01** - The group wanted to understand whether actions relating to opt out should wait for decisions to be taken elsewhere before being presented to the group, or whether the group could provide advice before the decision is made.

██████████ responded that there had not yet been a decision made on opt-out but welcomed advice the groups advice.

**Wider update on transfer of NHSD functions**

██████████ updated the group on the transfer of functions from NHSD to NHSE:

- Draft of statutory guidance was made public in January for comment. The team is reviewing feedback and addressing issues in the draft.
- Aiming to publish the amended version as soon as possible, just awaiting approval by ministers.
- Once published the guidance will be kept under review, at a minimum every 12 months. NHSE will be assessed each year at meeting its data requirements – reporting to parliament.
- ██████████ clarified that whilst this is referred to as guidance, it is not optional for NHSE to follow and any divergence requires robust justification, which can be challenged in court. DHSC has direct powers of direction and intervention over NHSE to ensure compliance with the guidance but this is not anticipated being required.

The group raised that there is a data advisory group referenced within the guidance and wanted to clarify that this does not mean the NDAG as this may cause confusion.

██████████ mentioned that the NHSE team were considering the name of the group so he will pass along this feedback.

**Action 5.02** – ██████████ to feedback name change suggestion for data advisory group referenced in the statutory guidance to NHSE team



### Item 3) Evaluation of the Data Strategy

██████████ provided an overview of the proposed approach to evaluating the impact of the Data Saves Lives strategy.

This approach covers two areas:

1. An end of strategy report
2. A one-year on update/assessment

#### End of strategy evaluation

The proposed approach proposes two overarching impacts of the strategy:

1. Public support for data related improvements to health and care services
  - a. Public confidence in the health and care systems use of health data
2. Effective uses of data to improve service delivery
  - a. Workforce. Researchers, and innovators empowered in skilled and confident use of health data
  - b. Data can be accessed when, where and how it is needed

The group were asked whether these proposed impacts reflected the intent of the data strategy.

The group discussed the proposal and were encouraged by the teams' efforts to progress an evaluation, reflecting that this is not always the case for all strategies.

The group offered suggestions to make the evaluation more robust. This included ensuring that the experiences of patients and the workforce were included to demonstrate impact. The group discussed making the benefits of impacts clearer to show the commitments are being delivered with a purpose. There was discussion about the scope of the evaluation to go beyond improvements to service delivery alone and instead to reflect the full breadth of the data strategy which includes development of new services.

#### One-year on update/assessment

AI outlined potential plans for a one-year on update of the data strategy. The group were asked what communications would be beneficial to the wider system.

The group were supportive of a one-year on update. Emphasising the opportunity to communicate progress with numerous audiences including the public, the workforce and wider system.

The group did however highlight the scale of the strategy adds lots of complexity for audiences to digest so it may be more beneficial to focus on delivery/implementation plans on specific programmes/policies such as the national data opt out. This could be a similar approach to the Clinical Research Vision which has two- and three-year implementation plans.

██████████ welcomed the groups input on which commitments should be focused on as it will need to be limited.

### Item 4) Monitoring Public Trust



■■■■ recapped the data strategy commitment to develop a suitable, transparent, measure for monitoring public trust, in collaboration with the NDAG.

The Data Strategy Team are currently producing an internal public perception tracker, which was presented to the group at the last NDAG meeting but this is not accessible to the public or suitable for demonstrating change over time.

As the commitment is to collaborate with the NDAG, DL proposed a voluntary working group of NDAG members to develop potential measures.

The group expressed a willingness to participate in a working group but offered alternative approaches as well. The group discussed whether the proposed measures could be developed by the Data Strategy team and then presented to the various groups that already exist in this space, rather than creating a new group.

■■■■ noted that it may be a case of sequencing when groups are held or consulted to gather input.

Focusing on the proposed measures, ■■■■ asked the group what metrics should be included in a measure of public trust. And if the group felt it was appropriate for DHSC/NHSE to undertake that analysis.

Discussion highlighted no real preference for the analysis to be undertaken by an external organisation or DHSC/NHSE, but available resourcing to support this would need to be understood before taking a decision. The importance of understanding the relevant feedback mechanisms that will be put in place to respond to the measures was also raised.

The group offered multiple examples of existing public attitudes measuring such as work undertaken by University of Manchester, Shared Care Records, and the GDPR programme.

The discussion concluded with volunteers for a working group to discuss delivery of this commitment, should that approach be taken.

**Action 5.03** – ■■■■ to establish working group of volunteers to progress development of a measure to monitor public trust, as per data strategy commitment.

#### Item 5) Commitment Delivery Update

■■■■ provided an update on the current implementation of Data Saves Lives strategy commitments.

The implementation report, shared ahead of the meeting, showed a further four commitments have been completed since the last NDAG meeting, taking the total completed to 44.

A further 20 commitments are on track (marked green) to be delivered by the dates published within the strategy. 27 commitments are subject to minor delays (marked



amber) and 11 are facing significant delays and/or issues, including funding (marked red).

The group queried the current RAG rating of the national opt out policy commitment as the group has not been informed of much progress. This led to discussion regarding the future presentation of red rated commitments so the group can advise on prioritisation.

■ explained that ratings are assigned in relation to the published dates in the data strategy so may appear green if the date is in the future but recognises that progress may not match expectation. SR said he will ensure red rated commitments are more visible in the next report.

**Action 5.04** - ■ to include list of Red RAG rated commitments in next implementation update.

#### AOB and CLOSE

■ asked for the group's thoughts on hybrid meeting approach to NDAG.

The group highlighted that technology issues made it more difficult to engage with the rest of the group if joining online, but that there were benefits to collaboration.

■ summarised views of the group: we should continue to hold the meetings virtual by default, with option to plan in-person meetings for specific purposes.

Next meeting will be held on 3 May 2023 at 10.30am.