

Minutes of the meeting

National Data Guardian's Panel Meeting



11.10.2022



Microsoft Teams Virtual Meeting

Panel members present:

Dr Nicola Byrne

Mr Adrian Marchbank

Dr Arjun Dhillon

Dr Chris Bunch

Dr Edward Dove

Dr Fiona Head

Eileen Phillips

Prof James Wilson

Dr Joanne Bailey

John Carvel

Maisie McKenzie

Rakesh Marwaha

Sam Bergin Goncalves

NDG Office staff in

attendance:

Ryan Avison

Carl Beesley

Layla Heyes

Dr Vicky Chico

Karen Swift

Dr Helen Bauckham

Guests:

Kathy Hall

Louise Greenrod

Tony Calland

Paul Mills

Lorna Fraser

Diana Robbins

Gareth James

1. Welcome, apologies, and declarations of interest

National Data Guardian (NDG), Dr Nicola Byrne, chaired the meeting. Apologies were received from Andrew Hughes, Professor Ian Craddock, and Rob Shaw.

Following her recent appointment to the Office of the National Data Guardian as a project manager, Dr Helen Bauckham introduced herself and received a welcome.

There were no declarations of interest.

2. Minutes from the previous meeting, actions, and decisions

Panel accepted the minutes from its 13 September 2022 meeting as an accurate record.

Head of the Office of the National Data Guardian (ONDG), Ryan Avison, gave an update on the actions, confirming they were all complete.

3. Key updates

Ryan Avison updated on recent activities:

1668: Cyber-attack clinical impact

The NDG has met with Professor Jonathan Benger CBE, interim Chief Clinical Information Officer (CCIO) for NHS England and Dr Henrietta Hughes, Patient Safety Commissioner for England to discuss the clinical impact of the cyber-attack on software supplier Advanced.

1168: Public benefit guidance

The ONDG is incorporating the final round of stakeholder feedback into its public benefit guidance. Dr Vicky Chico, who is leading the project, will present the final draft to panel on 8 November 2022 for approval.

1565: UK Data Protection Reforms Bill

The Rt Hon. Michelle Donelan has announced, "[The UK] will be replacing GDPR with our own business and consumer-friendly, British data protection system. We don't have any clear answers yet – but the work is taking place in government to provide answers as soon as possible." The NDG will monitor the matter closely.

4. Introduction to the new sponsor team: Kathy Hall and Louise Greenrod

Panel was joined by the NDG's new sponsors: Kathy Hall (Director for Digital Transformation and Head of the Joint DHSC/NHSE Digital Policy Unit) and Louise Greenrod (Deputy Director, Data Policy and Digital Oversight).

Both introduced themselves and described their key priorities. Discussions focussed on delivering the government's data strategy, emphasising the challenge of building public trust during a time of profound change for the system.

They also discussed the nature of their working relationship with the NDG. Kathy stated that they are eager to establish a trusted and open relationship. They would like the opportunity to test ideas with the NDG and discuss challenges openly. Dr Byrne agreed, saying that her panel and the UK Caldicott Guardian Council would

welcome working with them, and they can visit the panel whenever needed.

5. 1557: Update from Confidentiality Advisory Group (CAG)

Representatives from the Health Research Authority's Confidentiality Advisory Group (CAG) visited panel to discuss the process for postponements and exemptions to the national data opt-out (NDOO). In attendance were Dr Tony Calland (chair), Dr Paul Mills (service manager), Professor Lorna Fraser (expert CAG member) and Diana Robbins (lay member).

The NDG and CAG both have an interest in the NDOO and how it operates. This includes an interest in those requesting postponements or exemptions from applying it. For example, healthcare quality audit programmes, whose work relies on having complete information about care and treatment received, and for whom using data to which the NDOO has been applied could have negative clinical safety consequences.

A key discussion point was transparency around decision-making and the importance of ensuring that appropriate steps are taken to inform the public about exemptions and postponements. This includes explaining, in a format and language that is easy to understand, where opt-outs are not being applied and the reasons why.

The NDG thanked Tony, Paul, Lorna and Diana for attending and said she and the panel would look forward to continued engagement with CAG.

2022.10.11/5.1: The NDG and CAG teams agreed to provide joint feedback to the NHS Transformation Directorate Data Policy team regarding what might be done to improve communications around the national data opt-out policy postponement and exemption process.

6. 1589: NHS England data safe haven update

Gareth James, Head of Digital Oversight, Department of Health and Social Care, attended panel to update the NDG on plans for the transfer of NHS Digital's data safe haven into NHS England (following Laura Wade Gery's recommendation in her review, 'Putting data, digital and tech at the heart of transforming the NHS.')

Regulations will enable the transfer of functions and will be subject to pre-legislative scrutiny and the affirmative process in Parliament.

The regulations will enable a like-for-like transfer of data functions from NHS Digital to NHS England. NHS England will also develop accompanying statutory guidance. It will cover topics such as when, how and from whom NHS England should seek external independent advice, oversight and scrutiny (for example, to consider data

access requests). The NDG will get the chance to feed into this guidance.

Panel noted that the Independent Group Advising on the Release of Data (IGARD) had been an important safeguard that has provided external scrutiny and encouraged public trust. Gareth confirmed there would be a function similar in spirit to IGARD to advise NHS England. The need for NHSE to have an independent oversight committee would also be provided for in the statutory guidance.

Gareth reassured the panel that transparency about how NHS England manages and runs its data functions would be important. NHS Digital publishes a register of data uses, and this will continue. There will also be transparency around the data access application process.

Gareth noted concerns from NDG and others about problems that could arise when NHS England becomes its own data customer, and the effect of that on trust, oversight and accountability. He said there would be a clear separation between the people who use data and those in charge of policing the system. They will report to different parts of the organisation, and there will be board-level scrutiny and a data-specific committee to oversee these arrangements.

The panel suggested that transformation is an opportunity to strengthen current NHSD good practice and recommended that patients and the public be involved in the design and delivery of its data governance processes.

Gareth suggested that NHS England could build into the statutory guidance a requirement for the NDG to review its guidance and processes. The NDG said that she would welcome this, meanwhile noting it will be just as important to look at the balance of power within the future operational reality, as what is documented on paper. Dr Byrne thanked Gareth and requested that she be sent the regulations, guidance, and associated process information when available.

7. Any other business

1581: Accelerating patient access to GP records
Panel member Dr Joanne Bailey represents the NDG at *Accelerating patient access to GP records SRO steering group* meetings. She updated the panel on how the project is progressing as it moves towards its 1 November 2022 go-live date.