

Minutes of the meeting

National Data Guardian's Panel Meeting



21.03.2023



Microsoft Teams Virtual Meeting

Panel members present:

Dr Nicola Byrne
Mr Adrian Marchbank
Andrew Hughes
Dr Arjun Dhillon
Dr Chris Bunch
Dr Edward Dove
Eileen Phillips
Prof Ian Craddock

Jenny Westaway
Dr Joanne Bailey
John Carvel
Maisie McKenzie
Dame Moira Gibb
Sam Bergin Goncalves
Rob Shaw

NDG Office staff in attendance:

Dr Helen Bauckham
Karen Swift
Layla Heyes
Ryan Avison
Dr Vicky Chico

Guests:

Ben Moody
Margaret Charleroy
Ralph Evans
Paul Shepley
Gavin Freegard

1. Welcome, apologies, and declarations of interest

National Data Guardian (NDG), Dr Nicola Byrne, chaired the meeting.

Apologies were received from Dr Fiona Head, Prof James Wilson and Rakesh Marwaha.

Rakesh Marwaha and Dr Chris Bunch have stepped down from panel. This was Dr Bunch's final National Data Guardian's panel meeting. Dr Chris Bunch remains a member of the UK Caldicott Guardian Council. The NDG and panel members thanked Chris for his contribution to the work of the NDG and wished him well in the future.

There were no declarations of interest.

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

Panel accepted the minutes from its 21 February 2023 meeting as an accurate record.

Head of the Office, Ryan Avison, gave an update on one open action. All other actions were agreed as having been completed prior to this meeting.

3. Key updates

Ryan Avison, gave the following updates:

1589: NHS England statutory guidance

An updated draft of the [statutory guidance on NHS England's protection of patient data](#) has been shared with

the Office of the National Data Guardian (ONDG) for final comments in advance of publication. They have carefully considered the NDG's last points of feedback. The ONDG contacted the Department of Health and Social Care (DHSC) with a few questions and points of clarification on the most recent changes.

1565: UK data protection reforms

The Government has introduced the Data Protection and Digital Information Bill 2 into Parliament. The ONDG reviewed the previous Bill and will also review this one, to examine any changes.

786: National Data Opt-Out (NDOO) exemptions for national patient experience surveys

The NDG wrote to NHS England (NHSE) and DHSC on 6 February 2023 setting out her view on two matters:

- The proposal to permanently exempt the Children and Young People's Cancer Patient Experience Survey (CYPCPES) from the NDOO.
- A proposal for a wider policy position to exempt all future national experience surveys from the NDOO.

In response, NHSE sent a paper to the NDG containing further detail on the national patient experience surveys development process. The NDG intends to meet NHSE and the Health Research Authority's Confidentiality Advisory Group (CAG) to discuss in due course.

1405: NDG reasonable expectations project

The supplier tender process has now closed and the winning supplier identified. The contract is expected to be finalised imminently, after which the supplier can be announced. Project delivery is expected to start in April 2023.

585: ONDG hosting arrangements

The hosting of the NDG Office has moved into NHSE as NHS Digital was merged into NHSE. We are not expecting any changes to staffing in the immediate future.

629: Research Advisory Group

Dr Vicky Chico, Senior Privacy Specialist for the ONDG, attended the RAG meeting on 20 March 2023 as Prof. James Wilson's alternate. Vicky provided an update on the latest plans for NHSE Secure Data Environment (SDE) programme. RAG members had concerns that the current plans for regional SDEs will not be appropriately aligned to the national model which may jeopardise interoperability.

1538: GP Data Patient and Public Engagement and Communications Advisory Panel

Panellists discussed Eileen Phillips' feedback from the PPECAP away day on 2 March 2023. This included the application of type 1 objections (views for and against) and the governance and oversight arrangements for access to GP data. Panellists asked if the public would understand the difference between the Federated Data Platform (FDP) and a SDE. The NDG intends to meet the GPDPR SIRO for a programme update.

4. 1412: NHSE Centre for Improving Data Collaboration

Ben Moody, Head of Commercial Delivery, Margaret Charleroy, Head of Strategy, and Ralph Evans, Senior Commercial Delivery at the Centre for Improving Data Collaboration (CIDC), attended the NDG Panel to discuss their commercial principles for data access. The CIDC's aim is to foster more widespread data-driven innovation and better partnerships with researchers and innovators, harnessing more value for the NHS.

Ben, Margaret and Paul discussed how the public and policy mandate to ensure fair value for the NHS from NHS data and knowledge assets sits at the heart of the considerations behind CIDC's commercial approach.

Panel members discussed the key themes from the presentation and made a number of observations. Panellists were supportive of the CIDC's aims but had concerns about how this approach would be implemented and operationalised by the system. Panellists felt more clarity was needed on how the commercial principles will fit with integrated care systems and other NHS programmes (e.g., SDEs).

The NDG thanked Ben, Margaret and Ralph for the presentation and discussion.

5. 1706: Institute for Government research on pandemic data sharing

Paul Shepley, Data Scientist at the Institute for Government (IfG), and Gavin Freegard, Associate at the

IfG, attended panel to discuss their research on data sharing during the pandemic. The IfG is an independent think tank working to make the UK government more effective through research and analysis.

Paul and Gavin discussed how data sharing across and beyond the public sector was critical to the Government's pandemic response. This programme of research had a predominant health focus and considered the Clinically Extremely Vulnerable People Service, the NHS Covid-19 Data Store, General Practice Data for Planning and Research (GPDPR) and National-Devolved-Local data sharing. As part of this research, the IfG hosted a series of private roundtables with public servants, academics and private organisations to discuss six case studies. The findings have been collated into a final report.

Panel members had a lot of interest in the research study and discussions focussed on:

- Safeguards, governance and ethical considerations which need to be in place to build public confidence
- The report's contradictory view on legislation. While initially suggesting that legislation does not pose a barrier, it nevertheless then goes on to recommend amendments to the existing legislation
- Communication planning and how public engagement is critical for success

The NDG thanked Paul and Gavin for the presentation and discussion, noting the report's findings and recommendations were clear and helpful.

6. Any other business

A panel member suggested that the ONDG could improve its papers and pre-reading by being clearer, for each item, about why guests are attending and how their work/visit specifically relates to NDG's remit.