

Minutes of the meeting

National Data Guardian's Panel Meeting



21.02.2023



Microsoft Teams Virtual Meeting

Panel members present:

Dr Nicola Byrne
Mr Adrian Marchbank
Dr Chris Bunch
Dr Edward Dove
Eileen Phillips
Jenny Westaway

John Carvel
Dame Moira Gibb
Sam Bergin Goncalves
Dr Arjun Dhillon

NDG Office staff in attendance:

Carl Beesley
Dr Helen Bauckham
Karen Swift
Layla Heyes
Dr Vicky Chico

Guests:

Louise Whitworth
Michelle McDermott
Rebecca Pierce
Andy McCarthy
Dr Bill Kirkup
John Cairncross

1. Welcome, apologies, and declarations of interest

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

Apologies were received from Andrew Hughes, Dr Fiona Head, Prof Ian Craddock, Prof James Wilson, Dr Joanne Bailey, Maisie McKenzie, Rakesh Marwaha and Rob Shaw.

Dr Arjun Dhillon declared a conflict of interest with item 5, *GP Connect National Data Sharing Agreement*. GP Connect is an NHS Digital (now NHS England) programme, and as NHS Digital's Caldicott Guardian, he advises them in that capacity. The chair agreed that Dr Dhillon could provide factual clarifications if required.

There were no other declarations of interest.

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

Panel accepted the minutes from its 17 January 2023 meeting as an accurate record. One minor amendment was highlighted under item 4 to be corrected before publication.

Senior Privacy Specialist, Office of the National Data Guardian (ONDG), Dr Vicky Chico, gave an update on one open action.

All other actions were agreed as having been completed prior to this meeting.

3. Key updates

ONDG Privacy Specialist, Carl Beesley, gave the following updates:

1405: NDG reasonable expectations project:

The ONDG has gone out to tender for a supplier to support the research for the reasonable expectations project and is now at the stage of evaluating the bids. Suppliers had asked for a week extension on writing bids, so the start date has been pushed back a little. However, the ONDG still plans to begin the project in late March 2023. Once a supplier is in place and a contract awarded the NDG will issue a blog to announce the project.

786: Implementation/Application of the National Data Opt-out:

In November 2022, the ONDG met with the National Data Opt-out (NDOO) team to discuss the information and transparency materials on the NDOO pages. Our initial feedback focused on:

- The need for clearer language
- The need for good explanations of the reasons why each exemption was granted
- Making further and more detailed information easy to find and accessible for those interested in understanding more about their choices and the limitations of their choices

The ONDG team has been sent updated documents to review and we will be feeding back on those by mid-March 2023.

1589: Merger/safe haven:

NHSE has published '[Protecting and safely using data in the new NHS England](#)' online and the ONDG has given

feedback on that. The feedback focuses on changes we feel would be helpful to improve its readability for a general public audience, and ensuring it explains how it relates to the wider data landscape and commitments made in the data strategy last year. We submitted this feedback after its publication and have not yet had a response.

The Health Service Journal (HSJ) published an article on 8 February 2023 based on an interview the NDG gave regarding the IG arrangements of the merger, and the importance of ensuring the data safeguards in place at NHSE are as robust as those established by NHSD.

The ONDG received a couple of questions from panel regarding the interim arrangements for reviewing NHSE's data access applications now that the Independent Group Advising on the Release of Data (IGARD) has been disbanded. It was confirmed that until the new advisory group is up and running, there is an interim group meeting weekly to support continued data disseminations. The group is made up of independent advisers and some NHSE staff.

Panel asked ONDG whether the data uses register is to be maintained. It was confirmed that it will be, alongside a new "Internal data flow record" that will provide transparency of data flows within NHSE.

1724: Joint video on data sharing with ICO, CMO and NDG:

This week, the NDG is filming a short video with the Information Commissioner, John Edwards, and the Chief Medical Officer, Professor Chris Whitty. Its purpose is to encourage better data sharing for direct care and to alleviate front line staff worries about breaching confidentiality and GDPR where data is shared for an individual's care. The key message is that information governance should not be a barrier to sharing information to support an individual's care and treatment.

2023.02.21/3.1: ONDG to find out where the video will be located and how it will be promoted and inform panel.

149/585: Changes to panel frequency and pay:

The ONDG has developed a pay policy for NDG panel members to formally document and communicate remuneration arrangements.

The NDG is reducing panel meetings to once every two months. In between panel sessions, the NDG will hold smaller but more focused meetings to progress specific work items. One or more panel members may be invited, depending on the expertise required.

In March 2023, the NDG will be carrying out a panel membership review with all panel members (except those who recently joined). The NDG will write to panellists individually to arrange this discussion.

2023.02.21/3.2: The ONDG to consider the timing of the next face to face meeting in London and how we communicate updates on key matters in a timely way to panel members when we aren't meeting as often.

4. UKCGC update:

Dr Arjun Dhillon provided an update for panel on recent UK Caldicott Guardian Council (UKCGC) activities:

- Dr George Fernie has been successfully appointed as the new UKCGC vice-chair and will be replacing Dr Chris Bunch (likely in March 2023).
- The HC-UK annual national Caldicott Guardian will be sponsored by UKCGC this year. UKCGC will be providing support for the development of the conference programme.
- The last UKCGC meeting took place on 18 Jan 2023. The Federated Data Platform (FDP) programme presented an update. There was also an update on progress with developing guidance on information sharing with the police.
- The UKCGC has set up a working group to consider training courses and professional standards for Caldicott Guardians.
- The UKCGC is currently looking into continuing professional development (CPD) accreditation for its training workshops and is asking UKCGC members to volunteer to run workshops.

2023.02.21/4.1: The UKCGC secretariat to ensure panel members are sent the UKCGC newsletter.

5. 1551: GP connect National Data Sharing Agreement:

Louise Whitworth-Woodhead, Associate Director Operational Information Governance Delivery, Michelle McDermott, Programme Head, Rebecca Pierce, Project Manager and Andy McCarthy, Senior Project Manager, from NHS England attended the NDG's Panel. They were seeking feedback on, and support for, the proposed GP Connect National Data Sharing Agreement (NDSA).

They gave a presentation in which they explained that:

- NHS England is working with national stakeholders to ensure that data sharing for direct care via GP Connect continues on a national basis following the expiration of the control of patient information (COPI) notices in 2022. This includes developing a national data sharing agreement (NDSA).
- Local data sharing agreements were in place for GP Connect users before the COVID-19 pandemic. These were not legally needed but were identified by the Information Commissioner's Office as good practice.
- A NDSA is being prepared to follow the precedent and to support users of this service.

Panel members discussed the similarities between the Summary Care Record with Additional Information (SCRAI) and GP Connect services, recognising that they are linked but are being developed separately for the time being. Panellists also discussed the main controls that are in place for use of GP Connect products, and were reassured that the use of GP Connect for purposes beyond individual care is prohibited.

The group discussed the plan for communicating messages around this change. The NDG expressed her view that in general, data communications with the public should be coordinated centrally and delivered as part of a

single narrative about data rather than at a project, programme or initiative level. Panellists thought the messaging should be simple and in one place, with signposting to additional information if users want it.

The NDG and her panel support the ambitions of the GP Connect programme and what they are trying to achieve by developing a national data-sharing agreement. The NDG will write to the team to provide feedback on communications relating to GP Connect and its alignment with other national initiatives.

2023.02.21/5.1: ONDG to write to the GP Connect team regarding communications relating to GP connect and alignment with other national initiatives.

6. 1707: Maternity and neonatal services in East Kent: 'Reading the signals' report:

Dr Bill Kirkup and John Cairncross attended panel to present a summary of the findings of their review and its report: [Maternity and neonatal services in East Kent: 'Reading the signals'](#).

The report, published in October 2022, covered the clinical safety failings of maternity services in two hospitals, the Queen Elizabeth The Queen Mother Hospital (QEQM) at Margate and the William Harvey Hospital (WHH) in Ashford, between 2009 and 2020.

In his presentation, Dr Kirkup outlined the situation and underlying problems that led to the review and set out the review's four proposed action areas. Of most interest to the NDG was *Key Action Area 1: Monitoring safety performance – finding signals among noise* due to the part that data could play in alerting organisations to safety concerns sooner.

Dr Kirkup explained he is hoping to set up a project to develop and implement a maternity signalling system, which will include outcome measures. Other specialties (e.g. cardiac) have shown that this can be done; the same techniques could be applicable (with modification) to maternity services.

Dr Kirkup said he is still waiting for a formal response from ministers for his report, but that NHS England is keen to take this forward.

Panel members considered the key themes from the presentation and made several observations. Panellists agreed that the review's findings illustrated very clearly that better routine visualisation and use of data to identify unacceptable variation in care is needed. The NDG stated that as one of her strategic priorities is to encourage the safe, appropriate, and ethical use of data, she is strongly supportive of the review's recommendation regarding data use. She will also be seeking to understand more about current work nationally regarding the better use of data to drive better care and outcomes more broadly across health and care with NHSE, and whether she might be able to play any

active role in supporting, including amplifying the importance of, this work.

7. Any other business

No further points were raised.