

Minutes of the meeting

National Data Guardian's Panel Meeting



12.07.2022



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
Dr Fiona Head
Prof Ian Craddock

Prof James Wilson
John Carvel
Maisie McKenzie
Rob Shaw
Sam Bergin Goncalves

NDG Office staff in attendance:

Ryan Avison
Carl Beesley
Layla Heyes
Dr Vicky Chico

Guests:

Matt Neligan
Ming Tang
Philip Walker
Narissa Leyland
Sasi Murakonda
Suzanne Weller

1. Welcome, apologies, and declarations of interest:

The National Data Guardian (NDG) Dr Nicola Byrne chaired the meeting. Apologies were received from Dr Joanne Bailey.

No declarations of interest were recorded.

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

The minutes from the NDG's panel meeting on 14 June 2022 were accepted as an accurate record.

Head of the Office, Ryan Avison, provided an update on the two open actions.

2020.05.20/5:2 - The NDG office to work with NHS Digital to define the process for escalating disagreements between NHS Digital and The Independent Group Advising on the Release of Data (IGARD) about whether GP data collected for COVID-19 purposes is justified.

This long-standing action around establishing an IGARD/NHS Digital escalation process was closed. The NDG felt that action should be owned by IGARD and NHS Digital, and she has been reassured that they are making progress. It was suggested that as part of the NDG's work to advise on the data governance structure post-merger, she may wish to invite the chair of IGARD to panel.

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

3. Key updates:

Head of the Office, Ryan Avison provided an update for panel on recent NDG activities:

1667: Secretary of State for Health and Social Care:

Following the departure of Sajid Javid MP, Steve Barclay MP has been named as the new Secretary of State for Health and Social Care.

1637: The Federated Data Platform Programme:

The NDG attended a call with Ming Tang, Chief Data Analytics Officer at NHS England, who provided an update on the federated data platform (FDP) programme and answered the NDG's questions.

1589: Merger redundancies and NDG hosting:

NHS England has announced that redundancies will be forthcoming, as the new, combined organisation will employ 30-40% fewer staff. As the NDG's team is hosted by NHS Digital, she will be seeking reassurances that her office will be not subject to change or disruption because of this. As an independent, it is important that the NDG has the power to determine the form and function of her supporting team, and that her business is not negatively impacted by third party decisions.

4. 655 - Chair of the UK Caldicott Guardian's Council (UKCGC) update:

Dr Arjun Dhillon provided an update for panel on recent UKCGC activities:

- Chaired the bi-monthly Council meeting where guests presented on trusted research environments and the federated data platform
- issued a letter to NHS England regarding the role of Caldicott Guardians on integrated care boards, offering UKCGC support
- considered how best to support Caldicott Guardians dealing with a change which now requires medical examiners to be granted

- access to patients' medical records for every death where a coroner is not involved
- delivered an online training/networking workshop aimed at new Caldicott Guardians.

Panel members thanked Dr Dhillon for his update.

5. 1601 - Implementing Integrated Care Systems (ICSs):

Matt Neligan (Director of System Transformation), Ming Tang (Chief Data Analytics Officer), Philip Walker (Data Director) and Narissa Leyland (Senior IG specialist) from NHS England and Improvement (NHSE&I) attended panel to provide an update on progress made so far on its journey towards implementing integrated care systems (ICS).

The presentation and subsequent discussion followed four specific strands: exploring the overarching ambitions of ICSs to join up health and care and encourage collaboration and decision making closer to local communities; population health management and the use of data by ICSs; the development of a federated data platform (FDP), and how FDP adoption and integration will work at a local level and cater for variance in system maturity/capability; and the mechanisms through which NHS England is providing a new support infrastructure for information governance (IG) staff, including networking opportunities.

Discussions focused on: Variation in digital maturity and information governance approaches across ICSs could make it difficult to speak with any certainty or consistency about what is happening with data nationally. Panel members highlighted the importance of getting the balance right between enabling a flexible, non-prescriptive approach (so that local variation can be accounted for and respected) and one which provides consistency of approach and national standards, (for matters such as IG and communicating with the public) where it is sensible, helpful and appropriate for these things to be sponsored/led/monitored nationally. The importance of local systems being supported by national guidance/frameworks was also stressed.

Panel felt that ICSs need to ensure that they get engagement with citizens about data right. It was suggested that if the great work being done on data and technology locally is to continue, communications, engagement and expectation setting with the public should be core priorities.

Dr Arjun Dhillon offered to work with the NHS England to ensure that all Integrated Care Board (ICB) Caldicott Guardians (a role all ICBs are required to have) feel supported in their work, and able to advocate for safe, ethical data use across their local system.

Dr Byrne thanked NHSE&I for their attendance and the discussion and said that she, the UKCGC and the panel would be happy to continue advising.

2022.07.12/5:1: The office to invite the programme to a further panel meeting in the new year to talk about how the journey towards the implementation of integrated care systems (ICS) is progressing.

6. 1103: Health Data Research UK (HDRUK) (DARE UK) Project advisory group on privacy risk assessment:

Sasi Murakonda (Research Scientist, Privitar) and Dr Suzanne Weller (Head of Privitar Labs) from the Privacy Risk Assessment Methodology research project (PRiAM) attended panel to present about the HDRUK DARE UK sprint exemplar project, which they are undertaking in collaboration with the universities of Southampton and Warwick.

The project's goal is to lay the foundations for a standard privacy risk assessment, enabling organisations to understand and manage privacy risk when sharing data and provisioning combined datasets to researchers. It was suggested by the project that its work could form the basis of the standardised governance wrapper required for data access in Trusted Research Environments (TREs). If all TREs use the same risk assessment methodology, then decisions remain consistent and there is a common, national language with which to determine/discuss risk. Panel members considered the presentation and offered advice to the PRiAM project team. This included:

- highlighting the value of transparency/case studies around other organisations' decision-making (when it comes to assessing who gets data access and why)
- referring them to the NDG's public benefits research report: Putting Good Into Practice, which panel felt might be of value to their work
- suggesting that they speak to the Health Research Authority's Confidentiality Advisory Group and the Independent Group Advising on the Release of Data (IGARD), both of which operate on a precedent set model
- instructing that they need to make specific reference to the common law duty of confidence in addition to data protection law
- advising that they factor in that when it comes to public trust in access to health and care data, people's concerns are not limited to risk to their privacy. People are also concerned about the way that the data might be used and by who. Empirical evidence shows that people are particularly concerned about uses of data that might exacerbate inequality, enable political gain or excessive profit.

Dr Byrne gave thanks to the project and requested that they share their final report later in 2022.

7. Any Other Business:

No further points were raised.