

Minutes of the meeting

National Data Guardian's Panel Meeting



08.03.2022



Microsoft Teams Virtual Meeting

Panel members present:

Dr Nicola Byrne
Adrian Marchbank
Andrew Hughes
Dr Chris Bunch
Dr Edward Dove
Eileen Phillips
Dr Fiona Head
Dr Geoffrey Schrecker
Prof Ian Craddock

Prof James Wilson
Dr Joanne Bailey
John Carvel
Maisie McKenzie
Rakesh Marwaha
Rob Shaw
Sam Bergin Goncalves

Observers in attendance:

David Riley
Dr Arjun Dhillon

NDG Office staff in attendance:

Karen Swift
Ryan Avison
Dr Vicky Chico
Layla Heyes
Carl Beesley

Guests:

Michael Chapman
Ian Boyd
Dr Claire Bloomfield
Nicola Brassington
Richard Steele
Patrick Palmer

1. Welcome, apologies, and declarations of interest:

The National Data Guardian (NDG) Dr Nicola Byrne chaired the meeting. No apologies were received from panel members.

The NDG thanked exiting panel members Dr Geoffrey Schrecker and David Riley for their support, as this was their final meeting.

Sam Bergin Goncalves, the new lay panel member introduced herself and shared her background with panellists.

Dr Arjun Dhillon, as an NHS Digital employee, confirmed an interest in the items being brought for discussion by colleagues from NHS Digital.

No other declarations of interest pertaining to items on the agenda were recorded.

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

The minutes from the NDG's panel meeting held on 08 February 2022 were accepted as an accurate record of the meeting.

Head of the Office, Ryan Avison, provided an update on the one open action.

2020.05.20/5:2: The NDG office to work with NHS Digital to define the process for escalating disagreements between NHS Digital and IGARD about whether GP data collected for COVID-19 purposes is justified.

Dr Joanne Bailey stressed the importance of this issue being resolved as soon as possible given the length of time it has been open, i.e. since May 2020, which the NDG concurred with.

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

3. 1578: Secure Data Environments & Trusted Research Environment model, NHS Digital:

Nicola Brassington, Deputy Director for Data and Analytics and Dr Claire Bloomfield, Deputy Director and Senior Responsible Officer (SRO) for the Data for Research and Development (R&D) programme, NHS Transformation Directorate attended panel along with Michael Chapman, Director of Research and Clinical Trials and Ian Boyd, Programme Head, NHS Digital, to discuss their work to develop the policy, processes and infrastructure for the national and sub-national Secure Data Environments (SDEs)/Trusted Research Environments (TRE).

Panel members discussed the key themes from the presentation and made several observations and suggestions. Discussions explored what steps the programme could take to ensure that SDEs/TREs are established in a way that builds and maintains public trust.

A key discussion point was the importance of communications and demonstrating a commitment to transparency, and the bearing that this has on public trust.

Panel was pleased that:

- the programme was considering publishing communications/commentary about its development process as the project progresses, in the interest of transparency
- the One London deliberative engagement programme included a consideration of TREs, and delivered a potential route to co-create communications with the public
- the programme would be working with the data strategy team to use its communications campaign as a vehicle to engage on SDE/TRE policy principles.

It was suggested that the programme should consider:

- engaging with the risks (and safeguards/mitigations/sanctions) as well as the benefits in its communications.
- ensuring that the difference between an SDE and a TRE is clarified to lessen the confusion for the public and potential users.
- providing communications about SDEs/TREs that are appropriate not just from a lay-person's perspective, but also from the perspective of those who are more informed/interested.

Other key discussion points included the application of the national data opt-out; the assurance process for data applications and the importance of robust safeguards (including independent oversight and scrutiny, to this); the timescale for integration of social care data into the infrastructure; the importance of consistency across SDEs, and the scalability of the national SDE processes/approach to the smaller sub-national SDEs/TREs across the regions; work to identify/minimise exceptions (data sharing scenarios which don't lend themselves to data access inside of an SDE/TRE and may instead require disseminations).

The NDG thanked Nicola, Claire, Michael and Ian for attending and said that she and the panel would look forward to continued engagement and providing advice and guidance where it is helpful and within the NDG's remit.

2022.03.08/3:1: The office to collate panel members' feedback following the meeting and respond to the programme with the NDG's comments.

4. 1614: Acute Data Alignment Programme (ADAPt):

Richard Steele, Programme Head, Data Acquisitions & Covid Data Flows, NHS Digital and Patrick Palmer, the Private Healthcare Information Network (PHIN) attended panel to brief the NDG and her panel on the ADAPt programme including current pilot activity and future implementation.

Panel members considered the key points from the presentation and made several observations.

Panel expressed its support for the project's vision to link private healthcare data and NHS data to enable longitudinal care records and provide better visibility of care pathways where they cross between the NHS and private providers. They supported its objectives to align data and data standards (and how this is reported via systems across NHS and private healthcare) so as to improve the transparency, quality, and safety of care.

Panel was encouraged by the programme's commitment to engaging with stakeholders and patient representative groups.

Key areas of discussion included engagement and consultation and considerations around the national data opt-out, which touched on consent and opt outs arrangements in the context of what currently happens in private healthcare.

Panellists thanked Richard and Patrick for their update on the ADAPt programme.

2022.03.08/4:1: The office to collate panel members thoughts following the meeting and respond to the programme with the NDG's comments.

5. 655 Chair of the UK Caldicott Guardian's Council update:

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

Council Meeting 9 February 2022

They had two guest presentations:

Find Recruit and Follow-Up programme:

Dr Claire Bloomfield (NHS DigiTrials/NHS England) presented an overview of the Find, Recruit and Follow-Up programme which aims to exploit the potential of data and digital tools to speed up identification, recruitment and follow-up of patients who are potentially eligible for specific clinical research studies. The presentation discussed

benefits and achievements to date, the current data flows, and the future work of the programme.

Better Security Better Care:

Fiona Richardson and Helen Lancaster from the Institute of Public Care at Oxford Brookes University presented an overview of the Better Security, Better Care programme designed to improve data and cyber security in the adult social care provider sector. They were particularly interested in understanding how they can make the Caldicott Guardian role workable for very small social care organisations and how the Council could inform and support this work.

Integrated Care Systems:

Dr Dhillon has been speaking with Matt Neligan, Director of System Transformation at NHS England and NHS Improvement, to discuss the governance arrangements for Integrated Care Services (ICSs) and the role Caldicott Guardians might play in that space. Matt will be attending the next UKCGC meeting on 26 April 2022.

Virtual workshops:

The Council ran their first in a series of virtual workshops on Thursday 24 February, 'Caldicott Guardian function in care homes and smaller social care organisations'.

Caldicott Guardian eLearning:

The second in a series of three modules is going through some final review/amendments. The session focuses on what senior leadership teams/people need to know about the role. The final module will be aimed at Caldicott Guardians.

Panel members thanked Dr Dhillon for a very detailed update.

internal NHSE request. The NDG has been in active discussion with the DHSC on this point.

No other items were raised by members in advance of the meeting.

6. Any Other Business:

1535. Health and Care Bill:

Dr Vicky Chico, Senior Privacy Specialist in the Office of the National Data Guardian, provided an update on the provisions in the Health and Care Bill that allows for the merger of NHS Digital and NHS England. Peers had put forward an amendment at Report stage in the Lords of the Bill which aims to keep the provisions set out in the Health and Care Act 2012 for the Health and Social Care Information Centre. The Panel discussed how the merger needed to maintain, if not further strengthen, current independent oversight of data access, given the importance in the context of the merger of ensuring safeguards around data access and decision making are demonstrably trustworthy to the public, whether that access is sought via external or