

Minutes of the meeting

National Data Guardian's Panel Meeting



19.11.20



Microsoft Teams Virtual Meeting

Panel members present:

Dame Fiona Caldicott – Chair
Adrian Marchbank
Andrew Hughes
Eileen Phillips
Dr Geoffrey Schrecker
Professor James Wilson
Dr Joanne Bailey
John Carvel

Maisie McKenzie
Professor Martin Severs
Rakesh Marwaha
Rob Shaw

In attendance:

Dr Chris Bunch
David Riley
Ross Thornton
Karen Swift
Rajoo Veeren

Guests:

Jo Roach
Saskia Sanderson
Dr Andrew Roddam
David Seymour
Caroline Cake
Sinduja Manohar
Ming Tang
Tom Bullimore

1. Welcome, apologies and declarations of interest:

No declarations of interest were noted.

Apologies were received from David Watts.

Rakesh Marwaha and Dr Joanne Bailey had informed the NDG in advance of the meeting that due to other commitments they would unfortunately be unable to attend the later part of the meeting.

2. Minutes from previous meeting, actions and decisions:

The minutes from the panel meeting held on 28 September 2020. were accepted as an accurate record of the meeting. One minor typo was highlighted under item 6 to be corrected before publication.

Ross Thornton provided an update on the five open actions. The panel discussed how best to progress action 2020.01.21/2.1 (as below) following responses from NHS Digital and NHSx. The NDG agreed with panel members that it may be helpful to raise this for discussion with her sponsor team.

2020.01.21/2.1: NDG Office to contact NHS Digital's Caldicott Guardian to see what could be done to provide an in-year view of National Data Opt-out (NDOO) opt-out compliance during 2020/21.

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

3. 1397: ADD (Accelerating Detection of Disease) population cohort study:

Dr Andrew Roddam (CEO Early Disease Detection Research Project UK), Jo Roach (Executive Director of Platform and Products), and Saskia Sanderson (Chief Behavioural Scientist) attended panel to outline plans for the Accelerating Detection of Disease (ADD) programme. ADD aims to recruit 5 million participants from the UK population to a cohort study.

Panellists considered the ADD plans and asked several questions about the recruitment specification, size and scope of the study. There was particular interest in plans the project team have to engage with hard-to-reach communities.

Discussions explored what steps the ADD team could take to ensure the programme is conducted in a way that builds and maintains public trust. Panel members also commented that applying a good accountability and governance structure will be important to demonstrate transparency.

Dr Andrew Roddam agreed to keep the NDG Informed about this work. The NDG asked ADD colleagues to let her know if we can help further.

4. 1103 / 1399: HDR-UK: National Covid-19 data and connectivity study:

Caroline Cake (Chief Executive Officer), David Seymour (Alliance Executive Director) and Sinduja Manohar (Public Engagement and Involvement Manager) attended Panel to update the NDG on their involvement in work that is being developed by the UK Government and led by the

government's Chief Scientific Adviser Patrick Vallance, to support and accelerate the UK's research response to COVID-19. HDR-UK and the Office for National Statistics (ONS) are leading the national COVID-19 data & connectivity study.

Panellists were keen to understand more about the health data research infrastructure and how storing more linked data in Trusted Research Environments would work in practice. They also wanted to know about the COVID-19 exit strategy from current measures such as the COPI notices. Caroline confirmed the funding period for this study expires on 31 March 2021.

Members suggested that ongoing engagement and communication with public and patient groups to support the development of their study would be key, particularly as we move towards the recovery/vaccination phase of the pandemic. Panellists also advised that it might be helpful for HDR UK to speak with Understanding Patient Data (UPD) to discuss their recent project "What we learned from not talking about data".

Several panellists discussed the visibility of HDR-UK as an organisation – that considering the established organisations in this sector they are still relatively new. Therefore, there is a need to raise awareness of the organisation's purpose, governance and how its services can best support the system.

Caroline agreed to keep the NDG and her panel informed of progress and to let the NDG know where they can help.

5. 1323: Data store

Ming Tang (National Director for Data and Analytics) and Tom Bullimore (Senior Project Assistant) from NHS England and NHS Improvement (NHSE/I) attended panel to talk about the NHS COVID-19 Data Store. NHSE/I established the data store in April to bring together, analyse and disseminate a range of data for the purpose of responding to the pandemic.

Panellists were keen to understand more about the current operation of the data store, its future plans, the scrutiny and approval process and the data release register. Discussions focused on the challenge of communications around the data store and the NDG offered to support NHSE/I by reviewing communications materials.

Ming informed members that there is an intent to continue the data store post-COVID and confirmed that NHSE/I is currently investigating options to ensure that there is a clear legal basis for this. The programme is also awaiting further guidance from the European Data Protection Board (EDPB) and Information Commissioners office (ICO), following the Schrems II judgement.

The NDG and members of her Panel were very interested to hear about this work and thanked Ming and Tom for attending the meeting and engaging in discussions.

2020.11.19/5:1: *Ming Tang to share her draft organisational partner communications paper with the NDG for review and feedback.*

6. Panel update on various items:

1330: Scope of the Caldicott Principles:

The chair outlined the conversations which have taken place with the Department of Health and Social Care (DHSC) about the NDG's recent consultation about the Caldicott Principles and Caldicott Guardians. These discussions had particularly focussed on ensuring the wording of the introduction to the principles was clear.

Panel members discussed this item and the Chair invited panellists to provide their thoughts. There was support for the draft wording that has been prepared for publication based on the feedback received during the consultation.

2020.11.19/6:1: *The office to consider writing a note to the sponsor to confirm the NDG has listened to a range of views and is content that the introduction to the principles is clear.*

7. Any Other Business:

1248: NHS Business Services Authority (BSA):

Panel member Rob Shaw raised the recent Information Rights tribunal decision involving the BSA. The office updated Panel members on the outcome of the NHS BSA appeal against an ICO decision that the BSA should disclose data in response to a Freedom of Information request. The BSA is concerned the small numbers and dispenser / prescriber information could lead to re-identification of patients.

The NHS BSA would appreciate the NDG's views on the matter. Members agreed that this could be a significant case with consequences for future statistical disclosures and that it is important for the NDG to review the case and to respond appropriately.

2020.11.19/7:1: *The office to ask panellists for any immediate comments or feedback so that we can provide some informal considerations to the NHS BSA.*

1370 – Citizens jury update:

John Carvel has joined the commissioning group for the citizen juries project and provided a broad outline of the plans for the juries for panel members.

The juries will focus on three uses of data:

- Direct care
- Planning (for running of health service and data store)
- Research

The group is still developing the questions and John will seek comments about the research topic in due course.