

Minutes of the meeting

National Data Guardian's Panel Meeting



10.08.21



Microsoft Teams Virtual Meeting

Panel members present:

Dr Nicola Byrne
Adrian Marchbank
Eileen Phillips
Dr Geoff Schrecker
John Carvel
Maisie McKenzie
Prof Martin Severs
Rakesh Marwaha

Rob Shaw

Observers in attendance:

Dr Chris Bunch
David Riley

NDG Office staff in attendance:

Ross Thornton
Karen Swift
Dr Vicky Chico
Layla Heyes
Carl Beesley

Guests:

Reema Patel (item 3)
Tina Woods (item 4)
Gavin Starks (item 4)
John Hodson (item 6)
Graham Hetherington (item 6)

1. Welcome, apologies and declarations of interest:

Dr Nicola Byrne chaired the meeting. Apologies were received from Andrew Hughes, David Watts, Dr Joanne Bailey and Prof James Wilson.

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

2. Minutes from previous meeting, actions and decisions:

The minutes from the panel meeting held on 13 July 2021 were accepted as an accurate record of the meeting.

Ross Thornton provided an update on the seven open actions.

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

3. 1431: Data driven tech and health inequalities:

Reema Patel, Head of Public Engagement at the Ada Lovelace Institute returned to Panel to present a short update about their project, on tackling health and social inequalities in data-driven systems. The project focuses on the risk that data-driven approaches may exacerbate health inequalities and the potential to address these inequalities when data driven approaches are designed well.

Panel members discussed the key points from the presentation and made several observations. Overall, there was a lot of interest and support for the research study.

Panel members suggested it may be helpful to engage with the voluntary and community sector to inform this research and develop case studies. The voluntary and community sector would have close links with specific communities who both do and do not have access to digital technologies.

The NDG and members of her panel thanked Reema for attending the meeting and asked her to keep us informed of progress on this project.

4. 1421: All Party-Parliamentary Group (APPG) for Longevity - Open Life Data Framework working group:

Tina Woods the CEO and co-founder of Longevity International UK, and Gavin Starks, CEO of Icebreaker One, attended Panel to discuss the work of the APPG for Longevity Open Life Data Framework. The Open Life Data framework was a recommendation of The Health of the Nation Strategy published in February 2020 by the All-Party Parliamentary Group for Longevity to deliver the government goal of 5 extra years of healthy life expectancy while reducing health inequalities.

Discussions explored what steps the APPG group could take to ensure the project is conducted in a way that builds and maintains public trust. Panel members highlighted the importance and relevance of ensuring the APPG group is clear on the guiding principles underpinning the framework and communicating these effectively to the general public by using plain English and language that is clear and accessible.

Panel members also suggested consideration be given to the fundamental importance of doctor-patient confidentiality, right to privacy, importance of informed consent and the need for

transparency. This will help to reassure the general public that their data is being managed properly with the appropriate safeguards in place.

Tina confirmed that she would follow up with the NDG Office regarding the areas where they would welcome NDG input. In particular, they enquired if it would be possible for an NDG panellist to support the development and review of the Open Life, 'Can data help us live healthier lives for longer?' report that is expected to be published in October 2021.

2021.08.10/4.1: The NDG office to consider the request for further engagement with the APPG for Longevity - Open Life Data Framework working group to explore how best we can advise on the development of the principles for this project.

5. 1168: Public benefit guidance:

Dr Vicky Chico, Senior Privacy Specialist in the Office of the National Data Guardian, attended panel to discuss the public benefit guidance. Vicky provided a brief update for panel on the reviews that have already taken place and the next steps required as we progress to consulting with key stakeholders and the public dialogue participants to gain feedback.

Members discussed the current version of the guidance and agreed that following the rounds of feedback this was now ready to be shared more widely once the Office has undertaken the necessary preparations to support the consultation.

6. 721: Data Security Protection Toolkit (DSPT) update:

John Hodson, Senior Information Assurance, and Graham Hetherington, Service Lead, from NHS Digital attended panel to discuss the findings from the 2020/21 submissions to the DSPT.

The Data Security and Protection Toolkit (DSPT) was developed in response to the 2016 NDG review of Data Security, Consent, and Opt-Outs and the subsequent Government acceptance of its recommendations.

Panel members made several observations and a discussion followed. Members were not surprised to see that the 95% staff training target remains one of the most challenging requirements. But they understood the rationale for keeping this target high as it may help to encourage a higher attainment level.

The NDG and members of her Panel were very interested to see these findings and thanked John and Graham for attending the meeting and engaging in discussions.

2021.08.10/6.1: John Hodson to provide the office with information on National Data Opt Out (NDOO) compliant organisations extracted from this year's DSPT submissions.

7. Any Other Business:

No additional items were raised by members in the meeting.