

Minutes of the meeting

National Data Guardian's Panel Meeting



13.07.21



Microsoft Teams Virtual Meeting

Panel members present:

Dr Nicola Byrne
Adrian Marchbank
Andrew Hughes
Eileen Phillips
Prof. James Wilson
Dr Joanne Bailey
John Carvel
Maisie McKenzie

Prof Martin Severs
Rakesh Marwaha
Rob Shaw

Observers in attendance:

Dr Chris Bunch
David Riley
Edward Dove

NDG Office staff in attendance:

Ross Thornton
Karen Swift
Dr Vicky Chico
Layla Heyes
Carl Beesley

Guests:

Dr Malcom Oswald (item 4)
Sabine Van der veer (item 4)
Jenny Firth (item 5)
Ruth Keeling (item 5)

1. Welcome, apologies and declarations of interest:

Dr Nicola Byrne chaired the meeting. Apologies were received from Dr Geoff Schrecker and David Watts.

Edward Dove, Director of Ethics and Integrity School of Law, University of Edinburgh introduced himself and explained he would be an observer at the meeting. He will be joining the National Data Guardian (NDG's) panel from September 2021.

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 17 May 2021 were accepted as an accurate record of the meeting.

Ross Thornton provided an update on the nine open actions. The panel considered how to expedite stakeholder responses to actions that remain open over a period of time and discussed the possibility of implementing an agreed escalation process, where appropriate to do so.

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

3. 786: National data opt-out (NDOO) panel only discussion:

Dr Vicky Chico, Senior Privacy Specialist, Office of the National Data Guardian, attended panel to discuss the NDOO. The proposed earliest date for commencement of the General Practice Data for

Planning and Research (GDPR) collection is 1st September 2021 and the deadline for health and care organisations to comply with NDOO policy is 30 September 2021. These two imminent events have recently led to an increased focus on the application and effect of the NDOO.

Members made several observations and considered the changes in the landscape that have led to increased interest in the NDOO across the sector, including the challenges of applying consistent anonymisation standards across different contexts and for a range of purposes, and questions around how to improve clarity of opt-out preferences when a two system model including NDOO and Type-1 Objections is still in operation.

Members reiterated the continued importance and relevance of recommendations included in the NDG's review of data security, consent and opt-outs and felt any proposals that could impact the NDOO should be given careful consideration. There was continued support for data that has been rendered anonymous to be exempt from the NDOO. However, members also noted concerns about the current lack of clarity in the language used to describe anonymisation, and the potential confusion this can cause the General Public.

Members thought clarifying policy in relation to both Type 1 and NDOO may be helpful, ensuring it is clear when the opt out should and should not apply. Panel members agreed that fundamentally the opt out is an effective means to maintain trust, enable choice, and provide control, that we must ensure continues to be upheld.

2021.07.13/3.1: The NDG office to prepare further information regarding the application and impact of the NDOO.

4. 1370: Citizens' jury on data use post COVID: update:

Malcolm Oswald, of Citizens Juries c.i.c, and Dr Sabine Van Der Veer, of Manchester University, attended panel to present the findings from their Citizens Jury on data use post COVID 19.

The juries were funded primarily by the National Institute for Health Research Applied Research Collaboration Greater Manchester (NIHR ARC-GM), with NHSX and the NDG provided additional funding.

Members discussed the key themes from the findings and made several observations. Members thought the importance of transparency came through clearly and that the views of citizens juries could be a helpful strategic tool for an organisation if they wanted to demonstrate public support for a decision.

Members also thought their findings had a great deal of synergy with the NDG's Public Benefit work which will be published later this year.

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

5. 1389: Draft data strategy for health and social care consultation:

Jennifer Firth (Deputy Director, Data Policy, NHSX) and Ruth Keeling (Head of Data Strategy, NHSX) attended panel to discuss the NDG's draft response to the data strategy for health and social care consultation.

Members discussed the key themes from the draft data strategy and made several observations and recommendations for the NDG to consider in her response to the consultation.

The Panel acknowledged the clear benefits the strategy aims to achieve, whilst also highlighting the importance of acknowledging and addressing public concerns to develop a balanced and honest view that helps to build and maintain public trust.

Members welcomed the positive engagement with NHSX and thanked Jenny and Ruth for continuing to listen to the NDG's feedback.

2021.07.13/5.1: The NDG office to circulate the NDG's draft consultation response to panel members for a final round of comments by 16 July 2021.

2021.07.13/5.2: The NDG office to incorporate panellists' feedback into the written NDG response to the consultation by the end of July 2021.

6. 1389: NDG panel only discussion to consider item 5 and inform the NDG's response:

The Chair invited panellists to provide their thoughts on agenda item 5 and how the NDG might support this item.

The workstream was debated and several observations made.

7. Any Other Business:

The chair provided panellists with an update on the meetings she had attended. Dr Byrne also talked about her forthcoming attendance at the one-off evidence session of the Health and Social Care Committee on General Practice Data for Planning and Research on 20 July 2021.

Members were asked to give feedback on the NDG priorities. They will be published shortly in the annual report. Members made a number of observations and a discussion followed. Members thought the priorities are broad enough to cover key areas of work and could be used to address any emerging issues and topics.

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

2021.07.13/7.1: The NDG office to update the priorities in the Annual Report and send to the NHSX sponsor team and Secretary of State for Health and Social Care.