

Minutes of the meeting

National Data Guardian's Panel Meeting



28.09.20



Microsoft Teams Virtual Meeting

Panel members present:

Dame Fiona Caldicott – Chair
Adrian Marchbank
David Watts
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
Jenny Westaway
Ross Thornton
Karen Swift
Rajoo Veeren

Guests:

Dr Malcolm Oswald
Sabine Van der Veer
Lorraine Jackson
Paul De-Laat
Puja Myles,
Richard Branson
Allan Tucker
Professor Jeremy Wyatt
Sara Payne

1. Welcome, apologies and declarations of interest:

No declarations of interest were noted.

Apologies were received from Andrew Hughes and Mike Adams.

Maisie McKenzie attended her first meeting following her appointment to panel.

2. Minutes from previous meeting, actions and decisions:

The minutes from the panel meeting held on 14 July 2020 were accepted as an accurate record of the meeting.

It was agreed that there were seven open actions; Jenny Westaway provided an update on each action. Panellists agreed that we should continue to follow the outstanding actions until we have a resolution.

2020.01.21/2.1: It was agreed that the item on the National Data Opt-out should be reopened until we get a suitable answer.

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

3. 1370: Malcom Oswald proposal for citizen jury:

Malcolm Oswald, of Citizens Juries c.i.c, and Dr Sabine Van Der Veer, of Manchester University, attended panel to present their proposal for a citizens juries.

Citizens' juries provide informed public views and

Inform and add legitimacy to public policy decisions. The general topic of the proposed project, which would be run with at least two juries, will be health and social care data sharing in a pandemic.

Panellists asked several questions about potential questions to be put to the juries, the commissioners of this project, the timelines involved and the extent to which the juries can be representative of the wider population. Panellists were keen to know how the juries would be facilitated to minimise bias. A suggestion was to have three uses to put to the jury – direct care, one for research and one for another secondary use.

4. 1370: Citizen jury panel discussion:

The Chair invited panellists to provide their thoughts on the citizen jury proposal and whether they would support the NDG contributing to this jury.

Panellists agreed the project was considering important questions and that on balance the NDG should contribute funding and sit on the commissioning group, which will set the direction and questions to be put to the juries.

2020.09.28/4.1: The office to confirm participation in the citizen juries project and to nominate a representative from the NDG to join the commissioning group.

2020.09.28/4.2: The office to provide panellists with some supporting information and links with regards to citizens juries.

5. 1350: NHS Test and Trace:

Paul De-Laet, the Chief Data Officer for NHS the Test and Trace programme, Monica Siddique, privacy advisor to the programme, and Lorraine Jackson from the Department of Health and Social Care (DHSC), attended the NDG panel to discuss the use of data by Test and Trace.

Paul explained the current work of the programme and mentioned that the organisation is quite young and is working hard to achieve the increase in testing targets ahead of winter

Panellists made a number of observations and a discussion followed. Panellists were keen to understand more about how the programme was ensuring that it had appropriate understanding of the particularities relevant to the use of health and care data, so that there was a firm knowledge about the expectations of patients and citizens regarding this confidential information. It was agreed by all in the meeting that this was important. Lorraine confirmed the DHSC is moving forward with the appointment of a Caldicott Guardian and it was agreed that the role can help ensure this understanding is present. It was suggested that the programme should also consider this and other options so that there is a clinical perspective when decisions are taken about how data is used.

They were also interested to know if plans had progressed to ensure that there is independent oversight and scrutiny of the programme's use of data, which could help to ensure trustworthy use of data and external assurance that the right steps are being taken. Colleagues from the test and trace programme said that there was a question over whether the programme was yet mature enough to build this in.

Panellists thanked Paul, Monica and Lorraine for attending the panel and engaging in discussions.

2020.09.28/5:1: The office to raise the outstanding questions/comments added from panellists in the Microsoft teams chat function with the Test and Trace programme.

6. 1348: MHRA Synthetic Data Project:

Dr Puja Myles - Head, Observational Research, Clinical Practice Research Datalink (CPRD), Medicines and Healthcare products Regulatory Agency (MHRA); Richard Branson – Project Lead, MHRA; Emeritus Professor Jeremy Wyatt - Director of Digital Healthcare, Wessex Institute of Health Research, University of Southampton; Dr Allan Tucker - Head of Intelligent Data Analysis Group, Brunel University London; and Sara Payne – public representative, MHRA synthetic data project steering group attended panel to present the MHRA's synthetic data project.

The panel heard about the work to develop a methodology for generating and evaluating synthetic datasets - realistic (but not real) patient records and which can be used for purposes beyond direct care. The project also aims to demonstrate that synthetic datasets could be used to train and validate machine learning algorithms.

The NDG and members of her Panel were very interested to hear about this work and impressed with the clear consideration given to privacy issues. A number of technical and ethical considerations were discussed, including the extent of risk that synthetic data might reveal the real world patients, the steps the team thought were needed to manage this risk and whether synthetic data should be used 'freely' for any purpose as if it were entirely anonymised real world data. Puja and her colleagues are working on the basis that synthetic data should not be used for purposes which would not have been acceptable for the real world data on which it was based.

Puja agreed to keep in contact about this work and where the NDG can help

7. Panel discussion about items 5 and 6

The Chair invited panellists to provide their thoughts on the last two agenda items and how the NDG might support these items.

Item 5 – 1350: NHS Test and Trace:
Panellists discussed what more the NDG could do to support good accountability and governance of health and care data by this important programme.

Item 6 – 1348: MHRA Synthetic Data Project:
Panellists discussed a couple of queries regarding whether Bayesian network differed where the underlying data was collected in different clinical systems and whether the project had considered that changes in clinician's coding behaviour could change the Bayesian networks over time.

It was also discussed that the synthetic data project team had mentioned the development of a regulatory framework to ensure synthetic data is used appropriately. This will be an area where the NDG may be able to help.

2020.09.28/7:1: The NDG office to consider further steps to support good governance of health and care data by the test and trace programme.

2020.09.28/7:2: The office to follow up with the synthetic data project team and find out if the Bayesian networks differ depending on the supplier system.

2020.09.28/7:3: The office to follow up with the synthetic data project team and establish if consideration has been given to how different clinical systems create different use of the system and unique behaviours.

2020.09.28/7:4: The office to follow up with the synthetic data project team and find out who is leading on development of a regulatory framework for this sort of data and ask them to put us in touch with the relevant contacts.

8. Any other business:

No items were raised by members in the meeting.