

Minutes of the meeting

National Data Guardian's Panel Meeting



17.05.21



Microsoft Teams Virtual Meeting

Panel members present:

Adrian Marchbank
Andrew Hughes
David Watts
Eileen Phillips
Professor James Wilson
Dr Joanne Bailey
John Carvel
Professor Martin Severs

Rakesh Marwaha
Rob Shaw

In attendance:

David Riley
Jenny Westaway
Ross Thornton
Karen Swift
Dr Vicky Chico
Layla Heyes

Guests:

Dr Lisa Murphy

1. Welcome, apologies and declarations of interest:

Dr Nicola Byrne chaired the meeting. Apologies were received from Dr Chris Bunch, Dr Geoffrey Schrecker and Maisie McKenzie.

Dr Vicky Chico attended her first meeting following her appointment to the Office of the National Data Guardian.

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 25 March 2021 were accepted as an accurate record of the meeting.

Jenny Westaway provided an update on the four open actions.

The panel agreed to close 2021.01.19/3.1 (as below). The NDG provided feedback on a range of transparency and privacy notices in advance of the introduction of the GP Data Planning and Research Service and it was launched on 12 May 2021.

2021.01.19/3.1: The GP for planning and research team to outline issues on which they would welcome NDG input and how they would propose this input is provided.

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

3. 1412: The Centre for Improving Data collaboration: Value

Sharing Framework Patient, Public Involvement and Engagement (PPIE):

Dr Lisa Murphy, Programme Manager at the Centre for Improving Data Collaboration (CIDC), attended panel to provide an update on the establishment of the centre and to discuss its work to develop a Value Sharing Framework (VSF).

Panellists were keen to understand more about the VSF and what it currently says about public and patient involvement. Panellists asked several questions, made a number of observations and a discussion followed.

Panellists thought the theme of commercial value to be derived from the use of health and care data could be a controversial topic with nuance that is hard to communicate. One suggestion was that the word 'value' does have underlying connotations of financial value, framing around public benefits or public interests would be another option.

The phrase 'social contract' is used in the draft VSF. Panellists thought there might be potential for this to be interpreted as meaning the centre were advocating against people who use publicly funded services having any choices about the use of the resultant data about them, for instance not being able to opt out. Lisa had not been aware of this connotation and said she would take this into account.

Panellists also suggested that the Centre providing template contracts could be helpful as it would mean small organisations would not be disadvantaged due to a lack of commercial and legal expertise.

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

2021.05.17/3.1: The NDG office to follow up with the CIDC team on the next scheduled catch-up regarding the comments and suggestions in the Teams chat that were not able to be discussed during the meeting.

4. 1168: Public benefit guidance:

Dr Vicky Chico, Senior Privacy Specialist, Office of the National Data Guardian, presented an early draft of NDG guidance about evaluating public benefit for uses of data beyond individual care.

During May, the office are engaging with a range of stakeholders about this early draft, in preparation for a workshop in June. The workshop will bring together a cross-section of participants [from our public dialogue on this theme](#) with data users, data custodians and policymakers. Together they will further test the guidance and check that it meets their needs and expectations. That will be followed by further consultation, most likely to include a formal written consultation.

Panel members discussed the key themes from the guidance and made several observations. Members commented that when weighing up decisions there may be cases where there is a range of views regarding benefit. Panellists asked if there would be a process of adjudication in these difficult cases?

Members also thought that some examples might be helpful to help users understand what public benefit evaluations should look like. It was also suggested that the public benefit evaluation process should include reference to whether a proposed data use would be compatible with reasonable expectations.

Panel members discussed the potential downside of asking those doing evaluations to consider whether the benefit was clear or unclear at the outset of the process. This could lead to subjective conclusions (perhaps motivated by optimism bias) that the benefit is 'clear' and therefore the evaluation could be (inappropriately) light touch. It was suggested that the clear/unclear categorisation should be avoided, it was further suggested that to avoid over-optimistic positive evaluations, more focus was needed on the risk section. A risk or caution around using health data for non-health purposes should also be considered.

Vicky confirmed that discussions today will be reflected in the guidance.

Panel members thanked Vicky for her update and providing the timelines involved.

2021.05.17/4.1: The office to update the guidance and bring back a further iteration to panel for review.

5. Any Other Business:

The chair provided panellists with an update on the meetings she had attended. Nicola reiterated that she is working hard to build relationships in the sector and wants to ensure that she is involved in important workstreams at the get-go. Nicola will look at publishing a new blog shortly.

1458: Annual report – Layla Heyes, Communications Manager, Office of the National Data Guardian provided an update and said we will be on track to submit this for publication on 30 June 2021.

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