

Minutes of the meeting

National Data Guardian's Panel Meeting



20.09.21



Microsoft Teams Virtual Meeting

Panel members present:

Dr Nicola Byrne
Adrian Marchbank
Andrew Hughes
Dr Edward Dove
Eileen Phillips
Prof Ian Craddock
Prof James Wilson
Dr Joanne Bailey

John Carvel
Maisie McKenzie
Rakesh Marwaha
Rob Shaw

Observers in attendance:

David Riley
Dr Fiona head

NDG Office staff in attendance:

Karen Swift
Ross Thornton
Ryan Avison
Dr Vicky Chico

Guests:

Lorna Fraser
Dr Hilary Cass
Daniel Gosling
Karl Atkin

1. Welcome, apologies and declarations of interest:

The National Data Guardian (NDG) Dr Nicola Byrne chaired the meeting. Apologies were received from Dr Chris Bunch, Dr Geoffrey Schrecker, Prof Martin Severs and David Watts.

Dr Edward Dove and Prof Ian Craddock attended their first meeting following their appointment to the National Data Guardian's panel.

Ryan Avison also attended his first meeting following his appointment as the new Head of the Office of the National Data Guardian.

Dr Fiona Head, Medical Director NHS Cambridgeshire and Peterborough Clinical Commissioning Group introduced herself and explained she would be an observer at the meeting.

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 10 August 2021 were accepted as an accurate record of the meeting.

Ross Thornton provided an update on the six open actions.

2020.05.20/5:2 The NDG office to work with NHS Digital to define the process for escalating disagreements between NHS Digital and IGARD about whether GP data collected for COVID-19 purposes is justified.

Panel members enquired if it was known what was delaying the draft process. The NDG agreed to raise this with Jackie Gray, NHS Digital's, Director of Privacy Transparency and Ethics for an update.

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

3. 786: Update on National Data Opt Out (NDOO):

Dr Vicky Chico, Senior Privacy Specialist in the Office of the National Data Guardian, attended Panel to present a short update about NDOO. Vicky confirmed that she is engaging with Health Data Research UK (HDRUK) to see how an increase in NDOO might affect research.

Panel members discussed exemptions to NDOO across the sector and how this can be confusing for the general public. The office has engaged with the NHSX Data Policy team to clarify the potential exemptions policy process and improve understanding of how and where the Opt-out may apply.

The office confirmed that they are also continuing to have a dialogue with the General Practice Data for Planning and Research (GPDPR) team to discuss the

current development of the solutions regarding opt out choices that were committed to in Jo Churchill, outgoing Parliamentary Under Secretary of State at the Department of Health and Social Care's letter to GPs.

Vicky reiterated the continued importance and relevance of recommendations included in the NDG's review of data security, consent and opt-outs regarding use of anonymised data and that the NDG is still supportive of this position.

4. 1560: Panel discussions regarding the Independent Review into Gender Identity Services for Children and Young People:

The panel heard from The Cass Review, the aim of which is to ensure that children and young people who are questioning their gender identity or experiencing gender dysphoria, and who need support from the NHS, receive a high standard of care.

Panel members discussed the proposed research project and were supportive of the aims noting however that there are important and complex dependencies around confidentiality, consent, relevant legislation, and public engagement that need to be considered and clearly demonstrated to the appropriate regulatory bodies that would approve this research.

2021.09.20/4.1: The NDG office to provide a written response to the independent review team considering the project, the NDG's point of view and some of the discussion points from the meeting.

5. Any Other Business:

The chair provided panellists with an update on the following items:

1558: Police Crime and Sentencing Courts Bill (PCSC):

The chair shared with panel her concerns regarding the Police Crime and Sentencing Courts Bill (PCSC) and particularly the Provisions in Part 2, Chapter 1 of the Bill that allow for the 'setting aside' of the duty of confidentiality relating to health and social care data collected when providing care. The NDG is recommending the Bill is amended to remove provisions in Part 2 Chapter 1 that provide disclosures of information would not breach health professionals' obligations of confidence.

Dr Byrne is engaging with her sponsor team and other stakeholders regarding her concerns and will seek an acknowledgement to her letter which was sent to the Home Office on the 09 September.

1565: Data: A new Direction - Public consultation on reforms to the UK's data protection regime:

The office will develop a first set of considerations for the response. Once we have developed the response we may then share with the Panel for further comment, prior to sign off from the NDG before submission.

Rob Shaw, panel member raised an item about the pressure from service users to review smartcard use and mentioned that there is a proposal that may be developed looking at moving away from smartcards and looking at other opportunities.

Ross Thornton from the office confirmed that we are currently engaged on two existing work streams related to this item:

- Sean Kirwan at NHSE is leading a review/refresh of the Care Record Guarantee.
- NHSX ran a Role Based Access Controls (RBAC) policy development consultation in late 2019 that we are still awaiting feedback from.

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