

National Data Guardian's Panel Meeting
Monday 19th September 2016
Meeting Room 1, Richmond House, London

Panel Members Present:

Dame Fiona Caldicott - Chair
John Carvel
Anne Stebbing
Alan Hassey
Mark Golledge
Martin Severs
Mark Taylor
Joanne Bailey
James Wilson
Ian Atkinson
Chris Cox
Richard Wild

In Attendance:

Simon Gray
Jenny Westaway
Lindsey Blake
David Riley

1. Welcome, Apologies and Declarations of Interest

Apologies were noted from Terry Dafter. Alan Hassey stated he has provided IG advice in NHS Digital on the work programme relating to agenda item 9 - Protecting patient privacy and delivering data for commissioning.

2. Minutes from previous meeting and actions update

The draft minutes from the National Data Guardian's Panel meeting held on 6th July 2016 were confirmed as an accurate record of the meeting.

Updates from actions from the previous meeting were discussed and closed, as appropriate. Jenny Westaway stated that the office is now using Twitter and the blog function on gov.uk to highlight meetings that Dame Fiona and the Panel are attending.

3. Chair's update from key meetings and relevant meetings attended by Panel members

Dame Fiona gave an update on the recent EXPO event she attended on 8th September. Mark Taylor gave an update on an event he attended held by The Royal Society and The British Academy: connecting debates on the governance of data and its uses. Simon Gray gave an update on an event he attended in Sheffield last week on Big Data.

Action 3.1: Simon Gray to distribute the slides from the members of the public who presented at this event to Panel members for information.

It was agreed that the office would provide a list of relevant meetings attended by the NDG and Panel members with the papers so that they would have the opportunity to review it prior to the meeting.

Action 3.2: The office to provide members with the list of meetings attended by the NDG and Panel members for their information with the Panel papers.

Action 3.3: Simon to speak to Katie Farrington about the future Terms of Reference for the ISRB and how the NDG would be represented on it.

4. Wellcome Trust Independent Taskforce update.

Nicola Perrin attended the meeting to provide an update on the work of the Wellcome trust in taking forward an independent taskforce on patient data. Nicola stated that this work was born out of the call for a much fuller conversation with the public in Dame Fiona's review and due to the current low awareness amongst the public regarding how their health data is used. This work is intended to complement rather than duplicate the work of NHS Digital and NHS England and Nicola stated that there is no single figurehead to represent this work but rather a broad ownership with a number of champions across sectors.

Nicola gave an overview of the initial three priorities of the taskforce which are:

- Resources and tools for conversations - vocabulary, analysis of public benefit, bank of case studies.
- Stakeholder engagement - with a broad range of professions and the public.
- A forward look - emerging digital technology (apps, wearables) and data linkage.

Nicola went on to discuss the team's initial thoughts on vocabulary and the importance of getting this work right. They are currently doing some work on the vocabulary to be used in the engagement with the public and aim to have this finished by November. They confirmed that they are linking in with the work done by the IGA on a new glossary and are in discussions with the Department of Health regarding the ongoing public engagement events.

5. Sponsor's update and Consultation update.

Katie Farrington attended from the Department of Health along with Lorraine Jackson, the new Deputy Director for Data Sharing & Cyber security, who was attending a meeting of the Panel for the first time.

Lorraine talked about the responses received from the Department of Health's consultation to Dame Fiona's review which was published in July. There were over 650 responses which are currently being analysed and Lorraine shared some early

emerging themes from those responses. She highlighted that there is a lot of support for further conversations with the public.

Lorraine also gave an update on progress and likely timelines for the proposed bill to put the National Data Guardian's role on a statutory footing.

6. Review of Informed Choice for Cancer Registration update

The Panel discussed the recent response to the NDG's Review from Macmillan and Cancer Research regarding the opt-out for data held on the Cancer registries. The Panel were in general agreement that the work has been helpful in highlighting the benefits of these registries, whilst acknowledging the importance of informing patients of the uses of their data according to the principle of 'no surprises'.

7. Royal Free and Google DeepMind discussion

The Panel reviewed information received from the Royal Free, and discussed any issues that might have arisen from the trust's sharing of patient data with Google DeepMind. It was agreed that Dame Fiona would write to both the ICO and MHRA to highlight these issues, prior to engaging further with the Royal Free.

Action 7.1: The office to draft a letter to the ICO and MHRA and share with the Panel for review.

Action 7.2: The office to circulate the NDG's MOU with the ICO to Panel for information.

8. Re-visiting 'direct care' and 'implied consent'

The Panel discussed Alan Hassey's draft paper on the definition of implied consent for direct care. A number of points were raised in the meeting and Alan agreed to work up a further version for the next Steering Group meeting.

Mark Golledge highlighted that the IGA have produced a paper on the 'Limits of Implied Consent' which Alan may wish to consider.

Action 8.1: The office to send out Alan's paper to Panel members for comment prior to the next Steering Group meeting.

9. Protecting patient privacy and delivering data for commissioning

Following her presentation at the NDG's Steering Group meeting on 6th September, Ming Tang dialled into the meeting to provide an overview of the work that she is undertaking on a standard set of identifiers, which she is currently taking through the SCCI (Standardisation Committee for Care Information) process.

Ming's presentation covered how the following measures will address patient privacy considerations and allow commissioners to fulfil their statutory duties:

- The use of patient-level data, anonymised in line with the ICO Anonymisation Code of Practice, and;

- The collection of a standardised set of identifiers for all commissioning datasets flowing to NHS Digital.

The Panel members asked a number of questions regarding the application of a common pseudonym, the context in which the data would be held, and the basis on which it would be shared. Ming confirmed that the data would only be shared with organisations in order to enable them to meet their statutory commissioning duties.

Action 9.1: The office to request a copy of the PIA from Ming Tang.

10. Any other business.

No other business was raised at this meeting.