

The National Data Guardian's Panel Meeting
Thursday 26th May 2016

Princess Elizabeth Room, Mary Sumner House, 24 Tufton Street,
Westminster, Greater London

Panel Members Present:

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

In Attendance:

Simon Gray
David Riley
Jenny Westaway
Karen Swift
Katie Farrington (Item 2)
Professor Stephen Powis (Item 6)
William Smart (Item 6)
Emma Kearney (Item 6)
Dr Cian Hughes (Item 6)
Dr Chris Laing (Item 6)
Mr Tosh Mondal (Item 6)
Mr Mustafa Suleyman (Item 6)
Masood Nazir (Item 7)
Hayden Thomas (Item 7)
Michael Chapman (Item 8)

1. Welcome, Apologies and Declarations of Interest

Apologies were noted from Mark Taylor, Lindsey Blake and Cameron Robson.

2. Update from the Department of Health Sponsor

Katie Farrington provided an update on the latest position regarding the publication of the NDG Review Report and the preparations being made by the Department to consult over its recommendations. Katie also provided information

about work being led by the Department to test prototype materials, which could be used to explain the opt-out with a number of user groups. Katie shared some of the early prototypes with the Panel and welcomed any comments members might have. She further updated the panel on plans to ensure that the implementation of the Review recommendations is appropriately supported.

4. Minutes from previous meeting, actions and decisions.

The draft minutes from the National Data Guardian's Panel meeting held on 24th March 2016 were confirmed as an accurate record of the meeting.

All actions raised at the meeting on 24th March were confirmed as having been completed and closed.

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

Dame Fiona referred panel members to an extensive list of meetings attended over the last couple of months. It was suggested that it would be useful to make information available to the public about the breadth of meetings and events undertaken by the NDG and other panel members.

Action 5.1: NDG Office to circulate this list of meetings to Panel members for information.

Action: 5.2: NDG Office to look at putting details of NDG meetings on the website.

6. Google DeepMind discussion

Following the recent media attention on the Royal Free's agreement with Google DeepMind to develop an app aimed at improving the identification and treatment of patients at risk of acute kidney injury, a number of representatives from the Royal Free and Google DeepMind attended the Panel meeting. A discussion took place around the clinical aims of the project, the data sharing and security arrangements, the information available to the public, and plans for next steps in developing the app and the underlying algorithm.

Action 6.1: NDG Office to draft a response on behalf of the Panel to the Royal Free to confirm the Panel's understanding of the discussion and the project and to raise any additional questions.

7. Record Sharing for Direct Patient Care

Masood Nazir and Hayden Thomas from NHS England attended to discuss the current legal and IG challenges for General Practice (data controllers) with local record sharing programmes arising from clinical information system providers (data processors). The panel agreed that it would be useful for clearer information, accessible to a GP audience, to be provided on the principles and legal framework for such sharing.

Action 7.1: The NDG will raise with the Department of Health sponsor the need for due priority to be given to this in its programme of work.

The panel thanked Masood and Hayden for the paper they presented, and made some helpful suggestions on how some aspects of it could be developed further.

8. Update on Informed Choice Review for Cancer Registration

As discussed at the March meeting of the National Data Guardian's Panel, Macmillan Cancer Support and Cancer Research UK are conducting a rapid review into how people living with cancer in England should be informed about the use of their data in cancer registration. Michael Chapman from Cancer Research attended to provide an update on the overall approach to the review, progress so far and future plans.

The discussion covered the progress the review has made in organising workshops with professionals and patients; the first was due to take place the following day. Panel members were keen to hear how the rapid review was to test the assumptions underlying its approach.

Eileen Phillips agreed to attend the rapid review event mentioned above to represent the NDG. Michael Chapman agreed to continue to update the Panel on the progress of their review.

9. Any Other Business

The Panel discussed an article referring to NHS England's plans to reduce the number of Clinical Reference Groups.