National Data Guardian

National Data Guardian's Panel Meeting
Monday 15 January 2018
Conference Room 2/3 - 39 Victoria St, Westminster, London, SW1H 0EU

Panel Members Present:

Dame Fiona Caldicott – Chair
Dr Alan Hassey
Dr James Wilson
Dr Joanne Bailey
Rakesh Marwaha
John Carvel
Professor Martin Severs
Richard Wild
Chris Cox
Mark Golledge

In Attendance:

Jenny Westaway
Ross Thornton
Dr Chris Bunch
David Riley

Guests:

Idris Jahn (Internet of things educational session)
Lorraine Jackson (item 4)
Professor Mark Caulfield (item 7)
Professor Sue Hill (item 7)
Professor Michael Parker (item 7)
Rachel Dunscombe (item 5 via WebEx)

1. Educational session - Internet of Things

Idris Jahn, Principal Internet of Things (IoT) Consultant at Digital Catapult provided a presentation about IoT. The presentation included practical examples relevant to health and care and potential considerations regarding data ethics, data security and the impact on public trust. This was followed by a Q&A session with members of the panel.

2. Welcome, apologies and declarations of interest

Apologies were noted from Anne Stebbing and Eileen Phillips, declarations of interest were noted from Professor Martin Severs for the NHS Digital, Department of Health and Social Care (DHSC), Home Office MoU discussions (item 8).

3. Minutes from previous meeting, actions and decisions

The minutes from the panel meeting held on 21 November 2017 were accepted as an accurate record of the meeting. There were six open actions. All other actions were completed prior to this meeting.

4   Sponsor's updates

Lorraine Jackson from the DHSC advised that due to the recent cabinet changes the DHSC e-mail addresses will be changing to reflect the new social care responsibilities.

Panel members discussed the data definitions to be used for implementation of the National Data Opt-out is expected to apply to

Panel members discussed the importance of the clarity of the Opt-out communications to help members of the public understand their choices. Lorraine Jackson described ongoing work to ensure the National Data Opt-out is presented clearly to the public.

5   NHS Digital Academy development – via WebEx/Skype

Rachel Dunscombe provided an overview of the NHS Digital Academy, advising that the first 100 candidates for the NHS Digital Academy commence a residential course during April 2018. Panel members enquired about the syllabus for prospective candidates, how this aligns with other national learning initiatives and if it included topics relevant to National Data Guardian work. Rachel offered to share the syllabus with panel members.

6   Summary Care Record

Professor Martin Severs discussed the Summary Care Record (SCR) and the views of panel on NHS Digital considering extending the current scope of information included in and the access provided to the SCR. The Panel discussed the potential issues that Professor Severs may wish to consider and were supportive of Professor Severs progressing this work.

7   The proposed consent model for future NHS genomics

Professors Mark Caulfield (Chief Scientist, Genomics England), Michael Parker (Chair of the Genomics England Ethics Advisory Committee), Sue Hill (NHS Chief Scientific Officer, NHS England) and Hayden Thomas (NHS England Data and Privacy Sharing Unit) presented and discussed the ongoing work to establish a National Genomic Medicine Service and sought advice from the National Data Guardian's Panel. The discussion covered considerations of the Common Law Duty of Confidentiality, the National Data Opt-out and direct care. Genomics England thanked the panel for their views and advised they would consider how best to progress the project and will keep the panel informed.

8   Any other business

The National Data Guardian raised the topic of the imminent Health Select Committee (16 January 2018) to discuss the Memorandum of Understanding (MoU) between NHS Digital, DoH and the Home Office. Dr Joanne Bailey discussed her preparations and panel members reflected on discussed likely areas of focus for the Health Select Committee.