

The National Data Guardian's Panel Meeting

Wednesday 6th July 2016

Meeting Room 2, Richmond House, London

Panel Members Present:

Dame Fiona Caldicott - Chair

John Carvel

Eileen Phillips

Anne Stebbing

Alan Hassey

Mark Golledge

Martin Severs

Mark Taylor

In Attendance:

Simon Gray

Jenny Westaway

Lindsey Blake

Cameron Robson (Item 2)

Kemi Adenubi (Item 7)

1. Welcome, Apologies and Declarations of Interest

Apologies were noted from Ian Atkinson, James Wilson, Joanne Bailey, Chris Cox, Richard Wild, David Riley and Terry Dafter.

Alan Hassey declared that he has worked in an advisory capacity to the HSCIC on the Data Services Platform programme, in relation to item 7 on the agenda.

2. Sponsor's update, NDG Review update and consultation.

Following the publication of the NDG's Review which has been published this morning, Cameron confirmed that the DH Consultation on the Review is now live and will run until 7th September 2016. He went on to state that there is much work that can be done before the closing date including testing of the consent model's language with clinicians and patients. He confirmed that six events have been run in the last few weeks with rich feedback received. Dame Fiona acknowledged that there needs to be a lot of collaboration regarding implementation, not just with the Department and the HSCIC but that the Panel will also have a part to play in this work.

Cameron updated the panel on his new role within the DH internal audit department and confirmed that this would be his last Panel meeting attendance. Dame Fiona and the Panel members thanked Cameron for his support and contributions over the last year and wished him well in his future role.

Action 2.1: Cameron Robson agreed that his team would provide feedback on any emerging themes from the NDG Review consultation as and when necessary. It was agreed that an ad-hoc meeting may need to be arranged as the consultation closes before the next Panel meeting in September. The Office will keep the Panel updated on developments.

3. Minutes from previous meeting and actions update

The draft minutes from the National Data Guardian's Panel meeting held on 26th May 2016 were confirmed as an accurate record of the meeting.

The actions from the previous meeting were discussed with one action being carried forward to the next meeting.

4. Data Science Ethics Framework discussion

The Panel discussed a note from James Wilson regarding his attendance at the launch of the Cabinet Office Data Science Ethics Framework on 19 May.

Dame Fiona's agreed to keep the panel members updated on developments of the framework through her attendance at the Cabinet Office Data Steering Group meetings.

The panel also agreed that it would be helpful to have a discussion at their next meeting regarding any ethical issues associated with the use of health and care data in the development of new technology.

5. Royal Free and Google DeepMind update discussion

The Panel reviewed the recent letter from the Royal Free and the information contained within it. It was agreed that a further review of this matter would take place at the next Panel meeting.

Action 5.1: Simon Gray to continue liaising with the ICO and to report back to the Panel.

6. Cancer Registries update discussion

Alan Hassey and Eileen Philips provided an update from the various Cancer Research UK and Macmillan meetings and events they have attended over the last few weeks.

Action 6.1: Simon Gray to check with Michael Chapman (Cancer Research UK) whether they would be willing to share their headline findings with the Panel prior to their Cancer Registry Review meeting on the 21st July.

7. Data Services Platform (DSP) programme overview

Kemi Adenubi, HSCIC Programme Director for the Data Services Platform, attended the Panel to provide an overview of the programme which, through its implementation, will support HSCIC in fulfilling its role as a Safe Haven for personal confidential data.

Kemi provided details about each of the three themes which will underpin the proposed approach to implementing the DSP, these are:

- Support and Improve Current Data Use
- Build Trust with the Public and Clinical Professionals
- Embed DSP as a Key Element of a New Data Sharing Culture

Kemi answered questions raised and agreed to keep the Panel updated on future developments. Dame Fiona thanked Kemi for her attendance and overview of this work.

8. Any Other Business

No other business was raised at this meeting.