National Data Guardian's Panel Meeting Monday 22nd May 2017

Trinity Room, The Holiday Inn London, Regents Park, Carburton Street, London, W1W 5EE.

Panel Members Present:

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

In Attendance:

Simon Gray
Jenny Westaway
David Riley
Lindsey Blake
Chris Bunch
Lorraine Jackson (Item 8, 9 and 10)
Will Smart (Item 8)
Dawn Monaghan (Item 5 and 6)

1. Welcome, apologies and declarations of interest

Apologies were noted from Terry Dafter. Alan Hassey stated that he would be chairing the meeting up until Dame Fiona arrived back from another meeting that she was required to attend.

2. Minutes from previous meeting and actions update

The minutes from the panel meeting dated 20 March 2017 were accepted with a minor amendment suggested to section 7 to make it clear that the NDG would be 'aligning timings of announcements with the ICO'.

The actions from the previous meeting were discussed and recorded as completed with one ongoing action being carried over to the next meeting in July.

It was agreed that the NDG Panel's Terms of Reference should be discussed further at the next steering group meeting to see if any amendments should be made ahead of the NDG role being placed on a statutory footing.

Action:22.05.17/2.1: The steering group to discuss the NDG Panel's Terms of Reference at their next meeting and to suggest any updates that can be made ahead of the NDG role being placed on a statutory footing.

3. Royal Free/DeepMind update

Lindsey Blake and Jenny Westaway provided an update based on recent discussions with the ICO regarding the progress of their investigation into the Royal Free.

Action: 22.05.17/3.1: The office to keep panel members updated on progress.

A discussion followed on the uses of health and care data in new technology. Professor Severs agreed to share some slides to aid a discussion at the next steering group meeting.

Action:22.05.17/ 3.2: The office to table Professor Severs' slides on machine learning and governance for discussion at the next steering group meeting.

4. Events update - Sheffield Seminar and Public Engagement Event

Jenny Westaway provided an update on the planned event to be jointly hosted with the University of Sheffield on 17 July 2017. The event entitled 'Sharing patient data: exploring consensus on reasonable expectations' aims to progress a consensus on how to improve understanding of when particular uses of data are lawful and the role that understanding and informing people's reasonable expectations play in this.

A discussion took place about when was the right time to engage with the public. Jenny explained that the Sheffield event would be a preparatory step towards engaging the public. The Sheffield event will seek to explore with clinicians, ethicists and legal experts the circumstances under which data may be legitimately shared, and the role that reasonable expectations plays in shaping these circumstances.

This would then be followed by a public engagement event aimed at testing some of the principles with the public.

5. GDPR implementation

Dawn Monaghan provided an update from her work as lead of the GDPR working group for health and social care. Dawn also talked the panel through its timelines for upcoming guidance to be produced by the group, the first of which is around 'what is new and what is not'.

Dawn outlined the role of the working group which was formed to facilitate the translation of ICO policy into the practical applications for health and care organisations. It is formed of many representative bodies, has a published work plan and an allocated task and finish groups for each topic. They are presently working through accountable sign off procedures and the IGA will be responsible for publishing the products.

A discussion followed about consent and the common law duty of confidentiality. It was agreed that it would be helpful to look further at the use and definitions of consent under common and data protection law.

6. Anonymised data

Dawn Monaghan provided a brief update on the discussions with the ICO regarding the definition of anonymised data. Given the importance of this issue Dawn will provide further updates as discussions progress.

7. A potential approach to an anonymisation standard.

Professor Severs outlined his presentation on a potential approach to an anonymisation standard and sought the views of the panel on taking this work forwards across health and care.

The panel agreed that this is important work and Professor Severs agreed to provide further updates on progress.

8. Cyber Incident update

Lorraine Jackson from the Department of Health and Will Smart, NHS Chief Information Officer, provided an update on the recent cyber incident and the mitigating actions that have been put in place since that attack.

Will stated that a number of reviews would be carried out as a result of this incident and that Dame Fiona would be sighted on early outcomes of these reviews.

Action:22.05.17/8.2: The office to work with the Department and Will Smart to keep the panel updated on progress on the reviews.

9. Sponsor's update.

Lorraine Jackson provided an update on the Government's response to the NDG's review which she hoped would be published shortly after the general election.

10. Implementation of the national opt-out.

Lorraine Jackson described some policy work which is being undertaken to support the implementation of recommendations in NDG's review.

The panel raised a number of questions and Lorraine agreed to follow up on and clarify these points at a meeting which would be set up to discuss these matters.

Action:22.05.17/10.1: Lorraine agreed to seek further information on some of the issues highlighted by members.

Action:22.05.17/10.2: The office to convene a future meeting between panel members and DH representatives to further discuss the issues raised and any potential solutions.

11. Any other business.

Alan Hassey said that he would like to share a short paper on some topical items and asked colleagues to consider if some 'education' on some of the items would be beneficial.

Action 22.05.17/11.1: Alan Hassey to share his paper with members and invite views on a potential panel educational session.