

National Data Guardian's Panel Meeting
Tuesday 18th July 2017
Meeting Room 1, Richmond House,
79 Whitehall, London.

Panel Members Present:

Dame Fiona Caldicott - Chair
Alan Hassey
John Carvel
Mark Taylor
Anne Stebbing
James Wilson
Mark Golledge
Eileen Phillips
Chris Cox

In Attendance:

Simon Gray
Jenny Westaway
Lindsey Blake
Chris Bunch
Katie Farrington (Item 2 and 3)
Will Smart (Item 3)

1. Welcome, apologies and declarations of interest

Apologies were noted from Terry Dafter, Joanne Bailey, Richard Wild, David Riley and Martin Severs.

2. Sponsor's update

Katie Farrington (Department of Health sponsor team) provided an update on the recently published Government response to the NDG and CQC reviews. Katie reported that overall the response to this announcement has been positive.

Katie also informed the panel that the government is currently testing the presentation of the opt-out questions with 12,500 members of the public and that they plan to be able to share a private beta of the consent model at the end of September 2017 with a version that will be ready to start collecting preferences in March 2018. There is also an ongoing piece of work around engaging with the professions.

Katie updated the panel on a number of possible options for a vehicle for putting the NDG on a statutory footing and re-affirmed the government's commitment to do this at the earliest opportunity.

3. Update following Cyber-attack and progress of review.

Katie Farrington and Will Smart (NHS Chief Information Officer) attended to discuss some of the lessons that are emerging from the review of the cyber incident which took place in May 2017. Katie also confirmed that the new data security standards will become part of CQC inspections from September 2017. Katie and Will agreed to provide further updates to the panel as the review develops.

4. Minutes from previous meeting, actions and decisions

The minutes from the panel meeting held on 22 May 2017 were accepted with a small number of minor cosmetic amendments.

There were two open actions, both of which were addressed as part of the meeting agenda.

5. Amendments to NDG's Panel Terms of Reference.

Lindsey Blake referred panel members to the updated panel Terms of Reference document which has been amended and tightened in terms of scope so that it focusses on the remit of the panel, rather than the remit of the NDG and the office. Members were content with the amendments and agreed that the updated document should be shared with the DH sponsor team prior to its publication on the website.

Action:18.07.17/5.1: The office to share the updated Terms of Reference document with the DH sponsor team and then publish the final document on the NDG's website.

6. Office progress update and plan including events and communications.

Jenny Westaway introduced this paper to provide an update on the planned activities which will be undertaken to support the objectives of the National Data Guardian team during the remainder of 2017, of which communication and engagement activities are a key part. The panel were supportive of these priorities and objectives. The panel also suggested that a discussion should take place at the next steering group and panel meetings to determine any next steps or actions for the NDG team as a result of the publication of the Government's response.

Action:18.07.16/6.1: Jenny Westaway to share the NDG's work plan with the sponsor team for their information.

Action:18.07.16/6.2: The office to add an item for a future panel meeting to discuss the Royal Society's report on machine learning and the points made in Baroness O'Neill's paper for the Sheffield event.

Action:18.07.17/6.3: The office to table a discussion at the next steering group and panel meetings to determine any next steps or actions for the NDG team as a result of the publication of the Government's response.

7. Sheffield event update.

Those in attendance at the Sheffield event hosted by the National Data Guardian and Sheffield University provided an update on the discussions that took place around the use of implied consent and other alternative legal bases to support the sharing of identifiable data. The panel discussed the importance of this work, the need to maintain momentum and to ensure that the clinical and public views are properly understood. It was proposed that the next steps should be to explore these themes further with the UK Caldicott Guardian Council and clinicians before exploring them with the public in the planned citizens juries sessions.

Action:18.07.17/7.1: The office to arrange a further event to gather views from a range of clinicians on the use of reasonable expectations.

Action:18.07.17/7.2: The office to share papers and presentations from the Sheffield event with panel members who weren't in attendance on the day.

8. Application of the opt-out - discussion.

Simon Gray introduced the item on two matters relating to the implementation of the opt-out model on which the national opt-out team are seeking the advice of the panel.

The national opt-out team is planning a meeting on 2 August to discuss these matters further with representatives from the panel and CAG.

Action:18.07.17/8.1: The office to clarify with the DH sponsor team further details on how the engagement with 12,500 people will be undertaken.

9. Release of data during major public incidents.

The panel discussed the need to release patient data during such incidents as the Grenfell Tower fire and recent major terrorist incidents. It was agreed that Dame Fiona should formally write to Katie Farrington to encourage the government to review and update their guidance. The panel reviewed some of the helpful comments already made by Dr Alan Hassey and suggested some further points to be included in the letter.

Action: 18.07.17/9.1: Simon Gray to draft the letter for Dame Fiona to send to Katie Farrington.

10. Any other business.

Alan Hassey stated that he has been in touch with Professor Lionel Tarassenko who has agreed to deliver the first educational session for panel members in September 2017. The panel hoped that this would be the first in a series of such education sessions which will be held at the start of panel meetings.