National Data Guardian's Panel Meeting Tuesday 19 September 2017 Meeting Room 1, Richmond House, 79 Whitehall, London.

Panel Members Present:

Dame Fiona Caldicott - Chair Alan Hassey Mark Taylor Anne Stebbing James Wilson Mark Golledge Eileen Phillips Joanne Bailey Richard Wild

In Attendance:

Simon Gray Jenny Westaway Lindsey Blake David Riley Chris Bunch

Guests:

Professor Lionel Tarassenko (Items 1 and 2) Lorraine Jackson - Department of Health (Item 6) Rose Willis - Department of Health (Item 6)

Educational session "The possible uses of machine learning and Al algorithms to analyse health and care data"

Professor Lionel Tarassenko, Head of Engineering Science Department, University of Oxford delivered the panel's first educational session on the possible uses of machine learning and AI algorithms to analyse health and care data. Professor Tarassenko's thought provoking presentation covered the history of AI, machine learning in medicine, neural networks, deep learning and a number of concluding thoughts.

2. Questions to Professor Lionel Tarassenko

Panel members asked Professor Tarassenko a number of questions and a discussion followed.

Action:19.09.17/2.1: Alan Hassey to co-ordinate any further questions from panel members and send them to Professor Tarassenko.

3. Next steps on AI and further education sessions

Panel members agreed that this session had been very useful and that Dame Fiona would send a thank you letter to Professor Tarassenko.

Action:19.09.17/ 3.1: The office to send details of the panel member's bios from the website to Lionel Tarassenko for his information.

Action: 19.09.17/3.2: The office to circulate the slides and recording from Lionel's session to panel members.

Action 19.09.17/3.3: The office to draft a letter from Dame Fiona thanking Professor Tarassenko.

Action 19.09.17/3.4: The office to work with Panel members to schedule future educational items for Panel meetings.

4. Welcome, apologies and declarations of interest

Apologies were noted from Chris Cox, John Carvel and Martin Severs. No declarations of interest were noted.

Dame Fiona also informed panel members of the resignation of Terry Dafter due to a new role he has taken up which means he is unable to commit the necessary time to being a panel member. Dame Fiona also mentioned the recruitment of a new panel member, Mr Rakesh Marwaha, who will be joining the next panel meeting in November 2017.

5. Minutes from previous meeting, actions and decisions

The minutes from the panel meeting held on 18 July 2017 were accepted as an accurate record of the meeting. There were two open actions, both of which were addressed as part of the meeting agenda.

6. Sponsor's update, including the implementation of the opt-out and the cyber dry run

Lorraine Jackson attended to discuss implementation of the opt-out and a number of policy issues the Department is currently working through.

Rose Willis from the Data and Cyber security policy team attended to provide an overview of a planned cyber dry run exercise. The exercise will test the Department's and Arms Length Bodies (ALB) response plans for a cyber incident. A core part of this is rehearsing the different roles and responsibilities of the ALBs in responding to a national level cyber incident.

Action:19.09.17/6.1: The office to follow up with Rose Willis to find out how many boards have cyber champions and how many boards have undertaken accredited training.

7. Discussion on next steps following the recent publication of the NDG genomics report

Jenny Westaway referred members the panel of to the NDG genomics report which was published on 1 August 2017, alongside an authored article by Dr Mark Taylor. The report contains two suggested next steps:

- 1) Further work to explore appropriate consent for routine NHS clinical genetics and genomics services.
- 2) Use one or more privacy impact assessments (PIA) to examine suitable arrangements for the sharing of data within the NHS where genomic testing could be used as part of routine clinical care.

Panel members discussed these next steps and Jenny provided an update on work that NHS England (NHS E) and Genomics England (GEL) are doing in this area and the intention of the co-chairs of a NHSE/GEL joint working group on a consent model for the future NHS genomics service to engage with the NDG and her panel when its proposals are more developed.

Action:18.07.17/7.1: The office to find out when the first meeting of the genomics consent working group is to be held and to let Mark Taylor know.

8. NDG's 2017 Progress Report and discussion of NDG priorities

Eileen Phillips introduced the draft NDG's 2017 progress report which has previously been discussed at Steering Group.

This report which is intended to be accessible to the public as well as stakeholders, gives a summary of activities and impact since the creation of the NDG role in November 2014 and the priorities ahead of the NDG role being placed on a statutory footing. It was agreed that the next steps for the office is to share the next draft with stakeholders referenced in the report and also the sponsor team. It was agreed that the office should start preparations for publishing the report towards the end of the year. The panel were asked to provide comments back to the office.

Action:19.09.17/8.1: The office to liaise with Mark Golledge on the addition of some further examples of shared records.

Action:19.09.17/8.2: The office to share the next draft of the NDG progress report with stakeholders referenced in the report and the sponsor team.

Action:19.09.17/8.3: Panel members to provide comments on the draft progress report back to the office.

9. Reasonable expectations: write up on Sheffield event and update on further work

Jenny Westaway gave an overview of the event planned for October, which is being organised by the NDG office in conjunction with Sheffield University, to explore the concept of reasonable expectations with health and care professionals, as a follow-on from the event held in Sheffield on 17 July 2017.

A discussion took place about how to ensure the event meets its objectives, namely of exploring with health and care professionals whether they recognise challenges around the way that implied consent is used and whether the concept of 'reasonable expectations' might help. The panel raised a number of useful suggestions to take forwards, including ensuring that the various health and care professional groups are adequately represented.

10. NBO trace review response from NHS Digital

The panel discussed the recent letter received from NHS Digital. It was agreed that this matter will be discussed again following the publication of the NHS Digital report and further conversations have been held with key stakeholders. It was also agreed that Dame Fiona should write to the chair of the Commons Health Committee, which published correspondence on this issue earlier in the year.

Action 19.09.17/10.1: The office to draft a letter from Dame Fiona to Sarah Wollaston.

11. Any other business

No other business was raised at this meeting.