

**National Data Guardian's Panel Meeting**  
**Tuesday 29<sup>th</sup> November 2016**  
**Regus London Victoria, Greycoat Place, 10 Greycoat Place,**  
**London, SW1P 1SB**

**Panel Members Present:**

Dame Fiona Caldicott - Chair  
John Carvel  
Alan Hassey  
Mark Golledge  
Martin Severs  
Mark Taylor  
Richard Wild  
Terry Dafter

**In Attendance:**

Simon Gray  
Jenny Westaway  
Karen Swift  
David Riley  
Tim Yates  
Lorraine Jackson (item 3)  
Professor Jonathan Montgomery (item 4)  
Alison Whiting (item 4)  
Janet Messer (item 12)

**1. Welcome, apologies and declarations of interest**

Apologies were noted from Anne Stebbing, Joanne Bailey, Ian Atkinson, Chris Cox, James Wilson and Lindsey Blake.

Mark Taylor stated he has assisted with the HRA project that Janet Messer will present under agenda item 12.

**2. Minutes from previous meeting and actions update**

The minutes from the panel meeting dated 19<sup>th</sup> September 2016 were accepted with two minor amendments to be made:

- a) Insert the title of item 9 from the last meeting for Alan Hassey's declaration of interest.
- b) Under Lorraine Jackson's contribution: amend 'putting Dame Fiona Caldicott's Role on a statutory footing to 'putting the National Data Guardian's role on a statutory footing'.

The actions from the previous meeting were discussed with the action regarding the Data Services for Commissioning PIA being carried forward to the next meeting

**3. Sponsor's update**

Lorraine Jackson updated the panel on the government's response to the NDG review, and talked through the key issues that the team are working to address as part of finalising the response. The response will be published as soon as the appropriate reviews and approvals have been given.

Lorraine also provided an update on the progress of the bill to put the NDG role on to a statutory footing. The Bill is due to be published on the 9<sup>th</sup> December with a second reading in parliament on the 16<sup>th</sup> December 2016.

#### **4. Guest speakers - Professor Jonathan Montgomery and Alison Whiting - GMC's Guidance on Confidentiality**

Professor Jonathan Montgomery and Alison Whiting attended the meeting to provide an update on the development of the revised guidance. Jonathan and Alison talked the panel through the engagement that the team had undertaken with both the public and professionals - including Caldicott Guardians. They also provided an update on the key amendments which are being made to the guidance.

Panel members felt that this was a clear and helpful guidance document and made a number of suggestions as to how to how further clarity could be brought to some areas. Jonathan stated that the plan is to publish the document in January 2017 with implementation in April 2017.

#### **5. Chair's update from key meetings and relevant meetings attended by Panel members**

Dame Fiona thanked the Office team for providing a helpful summary of the many meetings and events that both she and Panel members have attended, and thanked her colleagues for their ongoing support.

Alan Hassey provided an update on the Citizen Juries for the Connected Cities initiative that he has attended, and agreed to send the outputs to the panel when they become available. Dame Fiona also mentioned that she had participated in the Alumni Christmas University Challenge special.

**Action 29.11.16/ 5:1:** Alan Hassey to distribute the summary documents from the Citizens Juries events to panel when they become available.

#### **6. Re-visiting 'direct-care' and 'implied consent' and agreement of next steps**

Alan Hassey thanked the members for their helpful feedback and comments on his paper and provided a summary of the key updates that he has made. He also said that colleagues from both the RCGP and the IGA have been very helpful in providing comments. Alan confirmed that the paper does align with the GMC's revised Guidance on Confidentiality.

There was some discussion regarding the rationale for the use of the term "Confidential Personal Information", which Alan committed to discussing with colleagues outside of the meeting.

The panel suggested that Alan's paper is presented as a thought piece and shared with some wider stakeholders including the GMC, HRA and Wellcome Trust.

**Action 29.11.16/6.1:** Alan to work with the Office team to progress his paper as a thought piece and to liaise with key stakeholders where appropriate.

**Action 29.11.16/6.2:** Alan to clarify the rationale for the use of the term "Confidential Personal Information" in his direct care paper.

## **7. Ethics of data usage in machine learning and artificial intelligence**

Simon Gray provided the panel with an update on the discussion that he has had with the Royal Society regarding their machine learning project. It was agreed that the panel would discuss this item further once the Royal Society have published their reports in February 2017.

## **8. SPIRE briefing**

Following Dame Fiona's meeting with Dr Libby Morris at EHI Live, Jenny Westaway and Alan have engaged with Dr Morris to better understand the key aspects of the SPIRE project. Alan provided an overview of the project and the approach being taken to anonymisation and opt out. Members suggested that Dr Morris be invited to the next Steering Group meeting to discuss some of these issues in further detail.

**Action 29.11.16/8.1:** The office to invite Dr Libby Morris to Steering Group on the 13<sup>th</sup> December 2016.

## **9. Update on Genomics evidence session**

Mark Taylor provided an update on the evidence session which was held with the PHG Foundation and Association for Clinical Genetic Science (ACGS) on the 18<sup>th</sup> October 2016. The panel were in agreement that the issues described are complex, and agreed with the three approaches suggested to take these issues forward:

1. Exploration of implicit consent and the boundaries of direct care
2. Exploration of explicit consent as an option
3. Use one or more privacy impact assessments (PIA) to examine current and possible further steps for sharing data

The panel suggested that a letter be sent to the Academy of Medical Royal Colleges to highlight the work that has been undertaken and the challenges which have been identified, and suggest that it would be helpful for the academy to look at this given that these issues are pertinent to a wide range of medical disciplines.

Mark Taylor also suggested that he discuss the issues and suggested actions with the chair of the British Society of Genomic Medicines, given the work by their Joint Committee on Genomics in Medicine to update the consent and confidentiality guidelines from 2011.

**Action 29.11.16/9.1:** The office to draft a letter for Dame Fiona to send a letter to the AoMRC to highlight the work that has been undertaken and the challenges which have been identified.

**Action 29.11.16/9.2:** Mark Taylor to speak to the chair of the British Society of Genomic Medicines.

#### **10. NDG Advice on Data Extractions**

It was agreed that panel members should send comments on the paper to Simon Gray, and that it be reviewed in detail at Steering Group meeting on the 13<sup>th</sup> December 2016.

#### **11. Royal Free/Google DeepMind update**

Tim Yates left the meeting for this discussion.

The Panel reviewed information received from the Royal Free, and discussed any issues that might have arisen from the trust's sharing of patient data with Google DeepMind. It was agreed that Dame Fiona would reply to the Royal Free's letter of 21<sup>st</sup> November and that Martin Severs would produce a paper on use of health and care data in the deployment of applications and systems.

**Action 29.11.16/11.1:** The office to draft a letter of response for Dame Fiona to send to the Royal Free.

**Action 29.11.16/11.2:** Martin Severs to report back on the work he is undertaking with colleagues in ALBs on the issue of the 'use of health and care data in the deployment of applications and systems'.

#### **12. Guest speaker - Janet Messer - HRA Approval and information governance compliance**

Janet Messer presented to panel the process for 'HRA approval and information governance compliance'. Janet went through the key points with panel members asking a number of questions and clarifying their understanding. It was agreed that it would be beneficial for the office to engage with the HRA to ensure alignment on the key issues of interest.

**Action 29.11.16/12.1:** The office to engage with the HRA to ensure alignment on the key issues of interest.

#### **13. Any other business.**

No other business was raised at this meeting.