

National Data Guardian's Panel Meeting
Monday 19 March 2018

Broadway House Conference Centre, Tothill Street, London, SW1H 9NQ

Panel Members Present:

Dame Fiona Caldicott - Chair
Dr Alan Hassey
Dr James Wilson
Dr Joanne Bailey
John Carvel
Professor Martin Severs
Chris Cox
Mark Golledge

In Attendance:

Jenny Westaway
Ross Thornton
Dr Chris Bunch
David Riley
Neil Lawrence, NHS Digital Clinical Fellow

Guests:

Lorraine Jackson
Tim Magor
Susannah Strong
Rachel Merrett
Jem Rashbass
Robert Kyffin
Max Pragnell

1. Welcome, apologies and declarations of interest

Apologies were noted from Eileen Phillips and Rakesh Marwaha.

2. Minutes from previous meeting, actions and decisions

The minutes from the panel meeting held on 15 January 2018 were accepted as an accurate record of the meeting. There were three open actions. All other actions were completed prior to this meeting.

3. Sponsor's updates

Lorraine Jackson from the Department of Health and Social Care (DHSC) provided an update on the status of the Health and Social Care (National Data Guardian) Bill 2017-19 and preparations being made to enable the bill to progress to committee stage. Dame Fiona is due to meet with MP Peter Bone to discuss the bill after the 19 March 2018 NDG's panel meeting.

The expected 21 March 2018 launch of the Local Health and Care Record Exemplars (LHCRES) prospectus was discussed. Panel members raised questions about the Information Governance (IG) arrangements and the due diligence undertaken for exemplars.

Panel members were also advised that the judicial review of the Memorandum of Understanding between NHS Digital, DHSC and the Home Office is expected to take place in the summer.

4. National Data Opt-out implementation: policy update

Panel members were advised of the latest discussions at the last ministerial board regarding the data definition for the implementation of the National Data Opt-out. Panel members discussed the importance of a clear message being given to the public about where the opt-out would and would not apply.

5. National Data Opt-out Public Communications

Lorraine Jackson from DHSC advised panel members there had been progress with the National Data Opt-out communications including the wording of the draft National Data Opt-out materials and progressing the wider story of data sharing in health and care.

National Data Opt-out Programme representatives Rachel Merrett, Tim Magor and Susannah Strong then presented to Panel members the National Data Opt-out Programme communications approach, setting out the context, the strategy, the plan and stakeholder engagement activities.

Panel members discussed the approach and agreed to provide further feedback direct to the National Data Opt-out Programme.

6. Cancer Registries

Colleagues from Public Health England (PHE) discussed issues related to the cancer registries and the work they have undertaken to increase awareness of the choices available to cancer patients. PHE colleagues discussed their engagement approach including the distribution of communication materials (such as leaflets and posters) and working with clinical teams to improve public awareness regarding the cancer registries.

7. Reasonable Expectations

Jenny Westaway from the Office of the NDG provided an overview of the recent Manchester Citizens' Jury on Reasonable Expectations. Panel members discussed the potential synergies with the current code of confidentiality review and how best to progress the reasonable expectations work.

8. Any other business

There was some discussion of the recent evidence session held by the Health and Social Care Select Committee on the subject of the Memorandum of Understanding between NHS Digital, DHSC and the Home Office.