

Panel members present:

Dame Fiona Caldicott - Chair
Dr Joanne Bailey
John Carvel
Mark Golledge
Dr Alan Hassey
Eileen Phillips
Professor Martin Severs
Anne Stebbing
Dr James Wilson

In attendance:

Dr Chris Bunch (dialled in for item 5)
Ross Thornton
David Riley
Jenny Westaway

Guests:

Lorraine Jackson
Dr Natalie Banner
Philippa Shelton

1. Welcome, apologies and declarations of interest

Apologies were noted from Chris Cox, Rakesh Marwaha and Dr Chris Bunch who was unable to attend in person but dialled in for item 5 on the agenda.

2. Minutes from previous meeting, actions and decisions

The minutes from the panel meeting held on 16 July 2018 were accepted as an accurate record of the meeting. There were three open actions. All other actions were agreed as having been completed prior to this meeting.

3. Sponsor's updates

Lorraine Jackson gave an update on progress of the Private Members' Bill to place the role of the National Data Guardian on a statutory footing. There is a briefing session scheduled for peers in the House of Lords (HoL) on 11 October 2018 and the second reading in the HoL has been confirmed for 26 October 2018.

Lorraine also provided detail to panel of the reporting statistics of the National Data Opt-out. Recent statistics have shown that there are currently circa 1,000 online interactions each month. As part of the iterative development of the National Data Opt-out system, the public can now use postcode and date of birth instead of NHS number as identification

when registering a preference for themselves. Lorraine also talked through the process for registering an opt-out on behalf of dependent family members, for instance children.

NDG Panel members enquired with Lorraine regarding progress of the NHS England Local Health and Care Record Exemplars IG Framework.

4. Following the launch of the National Data Opt-out

NDG Panel members discussed the importance of the balance between enabling ease of access, providing a good digital experience and ensuring the public are appropriately informed when making a decision. The Panel agreed that there is a clear need for continued engagement to build trust, both with the public and professionals to encourage an ongoing dialogue about the benefits of data sharing and what choices are available.

Panel members discussed the potential to increase awareness and support the continued conversation with the public through education and training programmes for professionals and frontline staff.

NDG Panel members also raised the importance of ensuring the ongoing conversation about data and choices is aligned with public engagement activities for other key areas, such as the NHS England LHCREs. This will help aid public understanding and reduce potential confusion as the opt-out is implemented across additional health and care organisations.

5. Pseudonymised data and GDPR

Following the introduction of GDPR into UK law, work has been undertaken by the Information Commissioner's Office, NHS Digital and NHS England to clarify how pseudonymised data should be treated under GDPR. Professor Martin Severs discussed the issues being explored and the associated implications of each.

NDG's Panel members discussed the Information Commissioner's Office (ICO) = anonymisation code, the anticipated new ICO guidance, the application of the National Data Opt-out and the common law duty of confidentiality.

The NDG suggested that the discussions should be raised with the DHSC Sponsor team for further consideration.

6. ONDG current year workplan, priority setting for next year

Jenny Westaway presented an update on the progress against the agreed NDG priorities for the current year and plans for the proposed meeting on 10 December 2018. The meeting will inform panel members of the progress and implications of the Bill, the preparations for statutory footing and discuss possible priorities for the coming year.

NDG Panel members discussed potential emerging areas of importance that the NDG may wish to explore or consider additional focus on including genomics, patient access to and control of records, education and training for the workforce on data issues, and the value of data to the public. Panel members also suggested it would be important to balance emerging priorities with continued focus on key areas such as public trust and engagement, and integration of health and social care.

7. Understanding Patient Data update

An update on the work of the Understanding Patient Data (UPD) project was presented by Dr Natalie Banner, Project Lead, and Philippa Shelton, Communications Manager. UPD advised NDG Panel members that UPD funding is currently in place until February next year and discussions on potential options for the future followed.

The NDG thanked UPD for their achievements over the last years and the significant contribution they have made in helping the public to understand how data is used in the health and care system.

8. Any other business

No additional items were raised for discussion under any other business.