

National Data Guardian's Panel Meeting
Tuesday 22 May 2018
Friends' House, Euston Road, London, NW1

Panel members present:

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

In attendance:

Dr Chris Bunch
Layla Heyes
David Riley
Jenny Westaway

Guests:

Lorraine Jackson, Department of Health and Social Care (DHSC)
Iain O'Neill, DHSC
Dan Taylor, NHS Digital
Tim Atkins, Care Quality Commission
Sharon Blackburn, National Care Forum
Carey Bloomer, Nursing Director at Marches Care and member of the UK Caldicott Guardian Council
Professor Mark Caulfield, Genomics England
Christine Patch, Genomics England
Hayden Thomas, NHS England

1. Welcome, apologies and declarations of interest

Apologies were noted from John Carvel, Rakesh Marwaha and Rich Wild.

2. Minutes from previous meeting, actions and decisions

The minutes from the panel meeting held on 19 March 2018 were accepted as an accurate record of the meeting. There were four open actions. All other actions were agreed as having been completed prior to this meeting.

3. Sponsor's updates

Iain O'Neill gave an update on action that DHSC and arms-length bodies are taking to ensure that the health and care system is taking heed of and responding in an appropriately timely manner to advice and alerts about cyber security threats. Iain also outlined work which is being led by a group to be convened by NHS England Chief Clinical Information Officer. It will look at the regulatory framework for emerging technology being developed for health and care purposes.

Lorraine Jackson gave an update on progress on the Private Members' Bill, which is being taken forward to put the NDG role onto a statutory footing. The money resolution had been passed the previous day and preparations were already being made for the committee stage. Lorraine also updated panel members on work to produce a revised version of the Memorandum of Understanding between NHS Digital, the Home Office and

the Department of Health and Social Care. Lorraine also provided detail to panel of the approach to be taken to launch of the National Data Opt-out on May 25, including a phased communications approach to October 2018 in order that feedback can be captured and improvements made where necessary.

4. CQC and NHS Digital Cyber Security, KLOEs and inspections

Tim Atkins and Dan Taylor provided an overview of work to incorporate assurance against the NDG Data Security Standards into CQC inspections. This included the development of new Key Lines of Enquiry (KLOEs) into the CQC's well-led inspections. They described a pilot project between NHS Digital and CQC whereby NHS Digital has provided additional intelligence and technical knowledge to support the CQC inspections. The redesigned Data Security and Protection Toolkit is a key part of this new approach. This pilot will be reviewed to assess the most effective approach in the future. Panel members welcomed the description of the inspection approach, with the emphasis on engaging leaders, achieving realistic assessment of maturity on data security, using the toolkit and identifying where improvements can be made and learning shared.

5. Social care and the NDG standards

Mark Golledge, Sharon Blackburn and Carey Bloomer provided an informative presentation on the social care sector with particular relation to the opportunities and challenges of the sector implementing the NDG Data Security Standards. Mark explained that he was speaking in his LGA role, rather than as a panel member for this item.

The presentation gave an overview on the large number and variety of different organisations involved in delivering social care, highlighting the variability in levels of knowledge about information governance and data security and capacity to meet the NDG standards. It was agreed that new Data Security and Protection Toolkit will be more relevant to the social care sector, compared to the Information Governance Toolkit. There was also discussion of how the NDG and her panel might be able to support this work. The need for better education and training around confidentiality and data protection among the diverse social care workforce was a key topic of discussion.

6. NHS Genomics Medicine Service

Professor Mark Caulfield, Christine Patch and Hayden Thomas attended panel following a discussion at January's panel to provide an update on the project to develop an NHS Genomic Medicine Service (NHS GMS). Panellists welcomed the clear way that the guests outlined how advice provided in January by the NDG and her panel had impacted on the NHS GMS project, specifically in the areas of references to clinical uses of data, the presentation of patient choices and the clarity around GDPR and Common Law legal bases for processing. There was discussion about how the service would approach situations where a patient had limited or no choice about the way data would be used/ uploaded to the central database and the need to be transparent about this. The panel also welcomed further clarification of how patients could withdraw previously provided consent.

8. Any other business

There was discussion of the use of analytics on websites in the context of GDPR.