Minutes of the meeting

National Data Guardian's Panel Meeting



NDG



National

for health and social care

Data Guardian

The Wesley Hotel & Conference Venue 81-103 Euston Street, London, NW1 2EZ

Panel members present:

Dame Fiona Caldicott – Chair John Carvel Professor Martin Severs Dr Joanne Bailey Dr Alan Hassey Professor James Wilson Rob Shaw Anne Stebbing Rakesh Marwaha **In attendance:** Dr Chris Bunch David Riley Mike Adams Jenny Westaway Rajoo Veeren

Guests:

Kathy Hall NHSx Peter Cook NHSE & NHSI Nick Dawson NHSE & NHSI James Cullen NHSE & NHSI Andrew Rawstron NHSE & NHSI Michael Lowe NHSE & NHSI Matthew Gould NHSx

1. Welcome, apologies and declarations of interest

Dr Joanne Bailey sent apologies that she could only attend the first two hours of the meeting. Apologies were also received from David Watts and Eileen Phillips.

Rob Shaw (independent consultant) and Mike Adams (Royal College of Nursing) attended panel for the first time and were welcomed by Dame Fiona.

2. Minutes from previous meeting, actions and decisions

The minutes from the panel meeting held on 14 November 2019 were accepted as an accurate record of the meeting.

It was agreed that there were three open actions; All other actions were agreed as having been completed prior to this meeting.

There was a discussion about the information that the 2019-20 Data Security and Protection (DSPT) returns would provide about compliance with the National Data Opt-out (NDOO). Panellists' understanding was that the 2019/20 DSPT returns would not give a clear picture of the extent to which organisations will be upholding the NDOO from the date when they had to be compliant, 31st March. This is because the information the DSPT captures comes from the previous financial year. The earliest complete information that the DSPT would be able to provide would be in the March 2021 returns for the year 2020/21. It was agreed that the office would check this understanding with NHS Digital and ask it to consider what more could be done to provide information about the upholding of the NDOO during the year.

2020.01.21/2.1: NDG Office to contact NHS Digital's Caldicott Guardian to see what could be done to provide an in-year view of National Data Opt-out (NDOO) opt-out compliance during 2020/21.

3. Sponsor's update

Kathy Hall NHSx joined the panel meeting to provide the regular sponsor update.

Kathy explained that information governance and data usage is a high priority for NHSx and she outlined the organisation's five missions. She outlined how the National Information Governance Board would bring together key stakeholders to ensure that existing guidance was reviewed, to develop new guidance where necessary and to ensure that all guidance was consistent, published and promoted in a coherent way.

She explained that NHSx was looking forward to hosting the roundtable that would be chaired by Dame Fiona and the Information Commissioner.

Panellists asked about patient access to health and care information in their records, clinical safety considerations with apps and devices, the importance of including social care, and more detail about the extent of plans to simplify the information governance framework.

4. Panel membership:

The Chair explained that she was to discuss how to manage panel terms with the CEO of NHSx in the coming days and would welcome hearing panellists' own views on their involvement in the panel.

2020.01.21/4.1 NDG office to provide reminders of panel terms to panellists. Members to let the office know their views on continuing on the panel.

5. UKCGC Domestic Violence template

Dr Chris Bunch presented a template which has been developed by UK Caldicott Guardian Council (UKCGC) members to help professionals consider requests to share information in cases of domestic violence.

Panellists advised further separation of the different types of cases that a professional might need to consider, as the tests to determine whether data should be shared would vary considerably depending on the type of case. There were some other suggestions for clearer language and formatting of the form.

Dr Bunch thanked colleagues for their advice, which he will relay to UKCGC members involved in the work.

Prof Severs suggested that it would be very useful if the UKCGC would consider developing a similar form for public interest tests.

6. Experian checks on NHS patient eligibility

Representatives of NHS England & Improvement (NHSE&I) and NHSx attended the panel to discuss its proposed pilot project for NHS trusts to use Experian to identify which patients might not be eligible for free treatment.

NHSE&I explained the purpose of the pilot, that the pilot is currently paused, and that they would welcome the NDG view on whether any changes are needed to it.

Panellists were interested in the take-up of the original pilot; what evidence there was of its effectiveness; the data security arrangements at Experian and in particular whether it shares any data, such incident logs, out of the EU; what considerations had been given to the common law duty of confidentiality and concepts such as proportionality and transparency.

It was agreed that NHSE&I would provide further information on some points before the NDG could give a view to the Information Commissioner's Office.

2020.01.21/6.1: NHSE&I to provide additional information to the NDG office.

7. Post-Experian panel only discussion

The Chair invited panellists to provide their thoughts on what further information we might seek from NHSE&I and what they thought the key issues might be.

2020.01.21/7.1: NDG Office to let ICO colleagues know that the panel has met with colleagues with NHSE&I to discuss the Experian pilot and to provide synopsis of future plans.

8. NHSx update

Matthew Gould, CEO of NHSx, joined the panel to discuss the work of NHSx.

Matthew apologised for not having been able to visit the panel meeting during the pre-election period. He thanked Dame Fiona for the leadership she has given in this area over many years and for the personal authority she has provided.

Matthew outlined that he wants to use policy and legislative levers to relieve the burden on staff, put services in hands of citizens and enable data to be safely accessed where it is needed in the system. He underlined that it was vital to work with the confidence of professionals and that there was no intention to compromise on patient confidentiality; the privacy of confidential patient data is sacrosanct.

Panellists raised topics such as liaison with the ICO, whether legislative change is being considered, how data can practically be put in citizens' hands, the role of the Caldicott Principles, how outdated guidance might be withdrawn.

2020.01.21/8.1: The NDG Office to send Matthew the Information Governance Review and the annual report that followed it.

9. Education and training survey

Dr Alan Hassey gave an overview of the initial findings from the NDG survey to identify what training and education initiatives might effectively tackle barriers to data sharing to support direct care.

Panellists discussed the headline findings around the definition of direct care and the support for patients to have access to their record. There was some disappointment that the survey indicated that long standing data sharing barriers persist.

10. Any other business

No items were raised by panel members during the meeting.