Minutes of the meeting

National Data Guardian's Panel Meeting

📅 14.07.20   📍 Microsoft Teams Virtual Meeting

Panel members present:
Dame Fiona Caldicott – Chair
Adrian Marchbank
Eileen Phillips
Dr Geoffrey Schrecker
Professor James Wilson
Dr Joanne Bailey
John Carvel

Rakesh Marwaha
Rob Shaw

In attendance:
Dr Chris Bunch
David Riley
Jenny Westaway
Ross Thornton
Karen Swift
Rajoo Veeren

Guests:
Karen Dooley
Alex Birtles
Lorraine Jackson
Tracy Strathie
John Farenden

1. Welcome, apologies and declarations of interest:

No declarations of interest were noted.

Apologies were received from Dr Alan Hassey, Andrew Hughes, David Watts, Mike Adams and Professor Martin Severs.

Adrian Marchbank attended his first meeting following his appointment to panel.

2. Minutes from previous meeting, actions and decisions:

The minutes from the panel meeting held on 20 May 2020 were accepted as an accurate record of the meeting.

It was agreed that there were six open actions; Jenny Westaway provided an update on each action. All other actions were agreed as having been completed prior to this meeting.

3. 1387: COVID 19 App developments:

Professor James Wilson updated panellists on the Ethics Advisory Board (EAB) for the original COVID-19 App, which was due to have its last meeting that week. He believed the EAB had raised relevant questions and outlined sound principles for a trustworthy contact tracing app. However, it had faced a number of challenges in its work and it was important that these were addressed if the governance for the next version of the app is to be successful. Dame Fiona thanked James and Dr Alan Hassey for their commitment to the work of the EAB.

Dr Joanne Bailey and Jenny Westaway had attended a joint workshop about the proposed new approach to a COVID-19 app. It had been hosted by the Information Commissioners Office (ICO) and Department of Health and Social Care (DHSC). This discussed the proposed new app functionality, data processing arrangements, Data Protection Impact Assessment, and possible timeframes.

Dame Fiona, Jenny Westaway and Professor James Wilson also attended an introductory meeting with the CEO of the new COVID-19 app, Simon Thompson. Dame Fiona reiterated our willingness to contribute to the development of the COVID-19 app and asked how we could continue to help. Dame Fiona encouraged the app team to ensure sufficient attention is paid to the considerations which are particular to health and care data and to previous experiences to innovate in this area.

4. 592: NHSX data security programme update:

Karen Dooley, Deputy Director for Cyber Security, NHSx, attended to present an update on the NHSx data security programme. Karen explained the progress made, challenges, and set out the main cyber risks, their causes, and mitigations strategies.

Karen discussed the Data Security and Protection Toolkit (DSPT) and asked for feedback on how NHSx should manage the deadline for next year's submissions in 2021.

Panellists made several observations and a discussion followed. It was agreed that the training target in the DSPT is challenging but important. Panellists asked what was being done to address risks around medical devices and emphasised that this appears to be an important area to progress.

NHSx agreed to keep in contact about their work and where the NDG can help if appropriate.

2020.07.14/4.1: The office to ask Karen Dooley and the Data Security and Protection Toolkit (DSPT) team to engage with the members of the NDG Panel that are directly involved in social care, regarding the future DSPT submissions for social care.

5. 1350: NHS Test and Trace:

Alex Birtles, Advisor to Dido Harding from the NHS Test and Trace programme, and Lorraine Jackson and Tracy Strathie, representing DHSC, attended panel to provide a further update on the NHS Test and Trace programme.

Alex explained the current work of the programme, which included creating a business plan to ensure a resilient and stable organisation, thinking about the structure and the continuity of the organisation. Another key aim is to develop an effective insight and analytics function, with the correct data governance in place.

Alex also stated a new expert panel will be created to provide advice to the whole programme. The programme is working this up at the moment and would welcome advice from NDG panel members who had previously served on the EAB and would anticipate inviting NDG representation to the new panel. Alex also confirmed that the programme is actively looking at appointing a Caldicott Guardian.

Lorraine Jackson discussed progress that had been made on this complex and substantial undertaking. She emphasised that there was a strong understanding that public trust is vital to the programme's success and that engagement with the public needs to improve, so that citizens understand how data is being used.

Panellists welcomed the engagement with this programme and thanked Alex, Lorraine and Tracy for updating us. They committed to coming back to the NDG to update and to seek advice.

2020.07.14/5:1: The office to ask Alex Birtles to share the slide deck she presented at the panel meeting.

2020.07.14/5:2: The NDG office to work with Alex Birtles to facilitate advice about the new expert panel from NDG panel members who had previously served on the EAB.

2020.07.14/5.3: The office to Invite James Hatch, Chief Data Officer for the test and trace programme, to a future meeting.

2020.07.14/5.4: Lorraine Jackson to introduce Anna Kershaw to Dr Chris Bunch via email to advise on the recruitment of a Caldicott Guardian for the programme.

6. Panel discussion about items 3 and 5

The Chair invited panellists to provide their thoughts on agenda items 3 and 5 and how the NDG might support these items.

It was discussed that it was important that confidentiality custom and practice is well understood through the NHS Test and Trace programme and that the NDG could play an important role in supporting this.

It was agreed that the NDG would write a further letter to Baroness Dido Harding to offer more advice and reflections. This should be copied to our sponsor and other key personnel in the programme.

2020.07.14/6.1: The office to prepare a draft letter from the NDG to Baroness Dido Harding with further recommendations for ensuring the programme is demonstrably using health and care data in a trustworthy way.

7. 1255: Beyond the Control of Patient Information COVID-19 notices for Summary Care Record and GP connect:

John Farenden, Senior Programme Lead, Local Health and Care Records Programme, NHSX attended panel to provide an update on the changes made to Summary Care Record (SCR) and GP-Connect during the pandemic.

During the COVID-19 pandemic a change has been made to the SCR so that 'Additional Information' is now included by default for patients, unless they have previously indicated that they do not want this information to be shared. 87% of patients now have 'Additional Information' included in their SCR. NHS Digital provided a dashboard showing how the rollout of SCR with additional information is progressing in different regions.

John also discussed GP Connect, the service that allows authorised clinical staff to share and view GP practice clinical information and data between IT systems. To support the response to the COVID-19 pandemic, GP Connect has been enabled on EMIS and TPP GP clinical systems; discussions with Vision and Microtest to enable this functionality on their systems are ongoing.

These changes have been implemented while the Control of Patient Information (COPI) notices allowing confidential data to be shared for COVID-19 are in force. John wanted to explore the possibilities for retaining the changes made to SCR-AI and GP-Connect after the COPI notices expire.

John explained that consultation with key stakeholders and the public has indicated strong support for sharing data for direct care

Panellists welcomed the positive engagement with this programme. Many panellists reflected on evidence that patients support and expect good information sharing to support their own individual care. John agreed to keep in contact about this work and where the NDG can help.

2020.07.14/7.1: John Farenden to explore whether the public engagement he described identified reasons for people not wanting their information to be shared and provide this information to the Office of the NDG.

2020.07.14/7.2: The Office of the National Data Guardian to invite John to a future meeting to provide a further update as this work stream progresses.

8. Any other business:

No items were raised by members in the meeting.