

Minutes of the meeting

National Data Guardian's Panel Meeting



19.01.21



Microsoft Teams Virtual Meeting

Panel members present:

Adrian Marchbank
Andrew Hughes
Eileen Phillips
Professor James Wilson
Dr Joanne Bailey
John Carvel
Maisie McKenzie

Professor Martin Severs
Rob Shaw

In attendance:

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

Guests:

Eva Simmonds
Peter Short
Susannah Strong
Dr Kevin Dunbar
Will Tate
Jonathan Hope
Dave Roberts

1. Welcome, apologies and declarations of interest:

Dr Joanne Bailey chaired the meeting.

No declarations of interest were noted.

Apologies were received from Dame Fiona Caldicott, David Watts, Dr Geoffrey Schrecker and Rakesh Marwaha.

2. Minutes from previous meeting, actions and decisions:

The minutes from the panel meeting held on 19 November 2020. were accepted as an accurate record of the meeting.

Jenny Westaway provided an update on the six open actions. The panel discussed closing actions 2020.07.14/5:1 & 2020.07.14/5:2 (as below). Panellists were disappointed that Alex Birtles from the NHS Test and Trace programme had failed to provide the office with an update and wanted the published minutes to reflect this.

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.

All other actions were agreed as having been completed prior to this meeting.

3. 965: GP data for planning and research update:

Members of the GP data for planning and research programme team attended the NDG's panel and provided an update on their work. This included Eva Simmonds (Programme Manager), Susannah Strong (Communications Lead), Dr Peter Short (Clinical Lead) and Andrew Thorne-Marsh (Project Manager).

The programme team is expecting that a legal direction from the Secretary of State directing NHS Digital to commence extractions. Panellists considered the programme teams plans and made some observations during the update. However, due to timing issues panellists did not get the opportunity to get to the programme team's key questions and to provide the team with input, steers or feedback during the session.

The programme team confirmed they would follow up with the NDG Office about issues on which they would welcome NDG input. In particular, they would like an NDG panellist to take part in an Expert Advisory Group to the programme.

2021.01.19/3.1: The GP for planning and research team to outline issues on which they would welcome NDG input and how they would propose this input is provided.

4. 1443: Cervical screening quality assurance – direct care?

Dr Kevin Dunbar, a Caldicott Guardian on the cervical cancer screening programme at Public Health England (PHE) attended panel. He asked the panel to consider whether quality assurance and clinical safety checks carried out by PHE should continue to be considered a secondary use of data that needs s.251 support to meet the duty of confidentiality. Or whether if this would be justifiable on the basis that this is part of direct

care or on the basis that the use accords with patients' reasonable expectations?

Panellists were keen to understand more about Dr Dunbar's position and asked a number of questions and a discussion followed.

Panellists thanked Dr Dunbar for his thoughtful presentation and asked him to consider some additional points. Dr Dunbar agreed to keep the panel informed of progress and to let the office know when he had progressed his thinking sufficiently for a further discussion.

After Dr Dunbar left the meeting, it was agreed that the office would provide him with a further note outlining the key points of feedback and explaining the NDG's remit in relation to what advice we can offer.

2021.01.19/4.1: The office to prepare a note to Dr Dunbar for review by some panel members. This should cover key points of feedback and the NDG remit.

5. 1446: Ethnicity data in GP records:

Will Tate from NHS England, and Dave Roberts and Jonathan Hope from NHS Digital, attended panel to seek advice on using ethnicity data held by NHS Digital to update ethnicity data in GP records.

The guests outlined that by undertaking this exercise, the reliability and coverage of ethnicity data in GP records could be improved. It was explained that the importance of improving ethnicity data in records has been highlighted during the pandemic as ethnicity has emerged as one of the factors that can influence clinical vulnerability to serious illness.

The panel was broadly supportive of the approach outlined during the presentation and the immediate plans to update patient records nationally using a combined HES (Hospital Episode Statistics)/GPES (GP Extraction Service) dataset. The Panel was also pleased to hear that the programme is engaging with the Royal College of General Practitioners (RCGP) and the British Medical Association (BMA) to discuss this matter.

The Panel also suggested that in the longer-term it will be important to engage the public and to enable the individual to state their own ethnicity. It would be helpful to explore the different mechanisms that could be used to empower the public to do this, such as using the NHS App and the potential to link to the Personal Demographics Service.

The panel asked Will, Dave and Jonathan to keep us informed of their discussions and progress on implementing their immediate plans.

2021.01.19/5.1: The office to follow up with the programme team and ask them to further engage with the NDG about both their short-term and longer-term plans in due course.

6. discussion time for any matters arising from items 3, 4 & 5:

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

Each workstream was debated in turn and several observations made.

7. Any Other Business:

The chair provided panellists with an update on the current NDG office arrangements.

No extra items were raised by members in advance of the meeting.