

Minutes of the meeting

National Data Guardian's Panel Meeting



10.05.2022



Microsoft Teams Virtual Meeting

Panel members present:

Dr Nicola Byrne
Dr Arjun Dhillon
Dr Chris Bunch
Eileen Phillips
Dr Fiona Head
Prof Ian Craddock
Prof James Wilson
Dr Joanne Bailey
John Carvel

Maisie McKenzie
Rakesh Marwaha
Rob Shaw
Sam Bergin Goncalves

NDG Office staff in

attendance:
Karen Swift
Ryan Avison
Carl Beesley
Layla Heyes

Guests:

Sophie Newbound
Megan Inett
Michael Chapman
Michael Eden

1. Welcome, apologies, and declarations of interest:

The National Data Guardian (NDG) Dr Nicola Byrne chaired the meeting. Apologies were received from Mr Adrian Marchbank, Andrew Hughes and Dr Edward Dove.

No declarations of interest pertaining to items on the agenda were recorded.

2. Minutes from previous meeting, actions, and decisions:

The minutes from the NDG's panel meeting held on 12 April 2022 were accepted as an accurate record of the meeting.

Head of the Office, Ryan Avison, provided an update on the one open action.

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

3. Key updates:

Head of the Office, Ryan Avison, provided an update for panel on recent NDG activities:

The Queen's speech:

His Royal Highness the Prince of Wales announced that a Data Reform Bill will be introduced to reform the UK's data protection regime. Panel members thought it would be important for the NDG to review and respond to the content of that bill, including its impact on the EU GDPR data adequacy decision.

1637: NHS England Federated Data Platform Programme gateway review:

The NDG was invited to participate in the programme's Gateway 2 Review and took part in an interview with the review team.

4. 655 Chair of the UK Caldicott Guardian's Council update:

Dr Arjun Dhillon provided an update for panel on recent UK Caldicott Guardian Council (UKCGC) activities:

Council Meeting 26 April 2022:

They had two guest presentations:

Integrated Care Systems (ICS):

Matt Neligan (Director of System Transformation) and Dawn Monaghan (Director of IG Policy, Ethics and Head of Profession) from NHS England & Improvement and Helen Duckworth from the Cheshire & Merseyside Integrated Care System presented to the UKCGC about the journey toward integrated care systems. They discussed the ICS Implementation programme, the uses of data in ICSs, and the opportunities and challenges of information sharing.

National Medical Examiner new system:

Dr Alan Fletcher (National Medical Examiner) attended a UKCGC council meeting to talk about the national medical examiner system. The system is being rolled-out across England and Wales to provide greater scrutiny of non-coronial deaths across all health settings.

Dr Arjun Dhillon key meetings:

Dr Dhillon updated panel on the key meetings he has attended including:

Roy McClelland, OBE, the chair of Northern Ireland's Privacy Advisory Committee.

Simon Gregory from Health Education England (HEE) - they discussed how freedom to speak up guardians could potentially work with Caldicott Guardians.

Professor Stephen Powis the National Medical Director of NHS England.

Panel members thanked Dr Dhillon for a very detailed update.

5. 1561/882: National Disease Registration Service (NDRS) & National Cancer Registration and Analysis Service (NCRAS) updates:

Michael Chapman, Director of Research and Clinical Trials, Sophie Newbound, Head of Partnership and Awareness, Megan Inett, Engagement and Awareness Manager at NHS Digital and Michael Eden, Caldicott Guardian for NDRS and a clinical pathologist at Addenbrooke's hospital, attended panel to present an annual summary on NDRS / NCRAS, the transition of NDRS to NHS Digital and how the national data opt-out is applied.

Panel members considered the key themes from the presentation and made several observations. Discussions also focused on: opt-out enquiries and how these are currently handled; whether there were plans to assess the impact of the programme's communications and engagement strategy/materials; the go-live of the new NDRS website; and piloting new approaches to the distribution of patient information materials.

Dr Byrne thanked the programme for their attendance and the discussion and said the NDG Office team would liaise with them about a future visit.

2022.05.10/5.1: The office to respond to the programme and suggest they return to a roundtable meeting in the autumn to talk about how the development of their website and other materials is progressing.

6. 1270: Information sharing for individual care:

NDG lay panel member Sam Bergin Goncalves gave a lived experience presentation about information sharing for direct care: *Know me, not my disability: putting people at the heart of care*. Sam talked about her personal experience of supporting her son Shane, a young adult with complex health and care needs, and the information sharing mechanisms she uses to ensure that those caring for him understand not only his specific medical needs but also his personal preferences and the things that are important to him an individual.

Panellists thanked Sam for the very interesting and moving presentation and made several observations. They commented that Shane's story was thought-provoking, and a reminder of the power of information sharing at an individual level.

Dr Nicola Byrne suggested the team and some panel members with related expertise consider whether there was anything the NDG could do to assist Sam and the Professional Records Standards Body (PRSB) as they look to develop and promote their '[About Me](#)' standard, which Sam is supporting the PRSB with, alongside considering the broader complex question of how information held in apps or wiki platforms such as Shane uses can be accessible to health and care staff when they need it.

2022.05.10/6.1: Dr Byrne to follow up at a round table about the issues raised around the awareness / promotion and integration challenges for platforms such as Sam uses to document her son's important information.

7. Any Other Business:

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