# Minutes of the meeting

#### **National Data Guardian's Panel Meeting**



NDG



National

for health and social care

Data Guardian

**Microsoft Teams Virtual Meeting** 

Panel members present: Dr Nicola Byrne Adrian Marchbank Dr Chris Bunch Dr Edward Dove Eileen Phillips Dr Fiona Head Dr Geoffrey Schrecker Prof Ian Craddock

Prof James Wilson **Observers in** Dr Joanne Bailev John Carvel Maisie McKenzie Rakesh Marwaha Rob Shaw

attendance: David Riley Dr Arjun Dhillon Sam Bergin Goncalves NDG Office staff in attendance: Karen Swift **Ross Thornton** Ryan Avison Dr Vicky Chico Layla Heyes Carl Beesley

**Guests:** Prof Steven Riley Tina Clapham

#### 1. Welcome, apologies, and declarations of interest:

The National Data Guardian (NDG) Dr Nicola Byrne chaired the meeting. Apologies were received from panel member Andrew Hughes.

Mr Adrian Marchbank attended the meeting between 12:00-13:00.

Sam Bergin Goncalves, prospective panel carer representative was an observer at the meeting.

The NDG informed panel members that Dr Geoffrey Schrecker and David Riley are due to leave panel and their last meeting will be 08 March 2022.

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 11 January 2022 were accepted as an accurate record of the meeting.

Ryan Avison provided an update on the two open actions.

John Carvel panel member asked if we could have a standing agenda item at future panel meetings for the office to inform panellists on what is happening across the system and on the horizon. He thought hearing notable updates through a regular standing item

would be more useful than via ad hoc updates in AoB. Professor James Wilson added his support to this proposal.

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

#### 3. 1489: Introduction to the UK **Health Security Agency (UKHSA):**

Professor Steven Riley, Director General Data & Analytics and Surveillance group and Tina Clapham, Deputy Director for Data Governance, Information Management and Privacy, UK Health Security Agency (UKHSA) attended panel to present on:

- Their vision for Data, Analytics and Surveillance
- The governance structures for the use of data
- Building and maintaining trust with the public

Panel members discussed the key themes from the presentation and made several observations. Panel were keen to ensure that the Common Law Duty of Confidentiality is sufficiently considered when sharing or using confidential patient information. They also advised that the UKHSA could helpfully provide more information for the public on its website about its use of data, including signposting to data protection impact assessments and data protection agreements.

Panellists discussed the License to Operate programme (LTOP) and suggested that the

UKHSA will need to engage with and involve the public to inform and strengthen its programmes and processes if a social licence is to be meaningfully achieved for their use of data. Panel noted that legal compliance for data use (into which the UKHSA is putting considerable thought and effort) is a necessary condition for securing trust, but it is not a sufficient basis alone to demonstrate trustworthiness.

The NDG thanked Steven and Tina for attending and said we would look forward to continuing to provide advice and guidance where it is helpful and within the NDG's remit to support the UKHSA.

**2022.02.08/3:1:** The office to collate panel members feedback following the meeting and respond to UKHSA with the NDG's comments.

## 4. 1168: Putting Good into Practice:

Dr Vicky Chico, Senior Privacy Specialist in the Office of the National Data Guardian, updated panel members on the Putting Good into Practice (PGiP) project. She said that despite positive feedback from many stakeholders, the office had also received important feedback from some that the process proposed in the guidance for evaluating public benefit may be difficult for some organisations to implement, thereby creating a potential burden for some parts of the system. Feedback that the guidance was too long and complex was also received from some lay people.

Dr Chico felt the office needed to take this feedback seriously, and presented a possible solution, which would shift the focus of the guidance to explaining the criteria for interpreting the concept of public benefit (as opposed to setting out the processes which should be in place to perform the evaluation). Panellists agreed that it was vital that this specific guidance should provide practical value by meeting an unmet need. And it could do so by pouring content and clarity into the concept of public benefit, which is often invoked as self-evident but in reality is vague and poorly understood - not least in terms of the importance of evaluating risk of potential harm and addressing people's legitimate concerns alongside potential benefits.

Panel suggested producing an annex to the guidance which outlines the principles that underpinned the dialogue participants expectations with regard to the process for evaluating public benefit.

Dr Chico will update the public benefit guidance to make the distinction between

guidance verses process and will consider how to take forward future engagement with the dialogue participants and project funders about the proposed changes.

#### 5. Any Other Business:

The chair provided panellists with an update on the following items:

#### 1523/1538: GP Data for Planning and Research (GPDPR), Check and Challenge group and the GP Data Editorial Advisory Panel:

The chair informed panel that she has discussed with the programme the need for greater public visibility of what it is doing to progress the commitments made in the letter to GPs from Jo Churchill MP. To this end, she had advised it to prioritise publishing information about the GPDPR oversight groups on its website.

#### 965: Retirement of General Practice Extraction Service (GPES) system and managing payments:

The chair discussed the feedback sent from the NDG to NHS Digital following their attendance at panel on 11.01.22, noting the importance of not conflating GPES (for the purpose of managing payments) with GPDPR (for planning and research), simply because the same people are delivering both programmes, as a lack of clear distinction between the two will potentially cause confusion for the public and professionals.

## 1581: Accelerating patient access to GP records:

The chair advised panel that she has had contact with the Royal College of General Practitioners (RCGP) about the programme and is aware of their concerns about the implementation timeframe and related safeguarding issues.

## 605: Sharing data for public good: Science and Technology Committee Inquiry:

The final version of our submission has been shared with the committee and panel members.

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