

# Minutes of the meeting

## National Data Guardian's Panel Meeting



17.01.2023



Microsoft Teams Virtual Meeting

### Panel members present:

Dr Nicola Byrne  
Mr Adrian Marchbank  
Dr Chris Bunch  
Dr Edward Dove  
Eileen Phillips  
Dr Fiona Head  
Prof Ian Craddock  
Prof James Wilson

Jenny Westaway  
Dr Joanne Bailey  
John Carvel  
Maisie McKenzie  
Dame Moira Gibb  
Rakesh Marwaha  
Rob Shaw  
Sam Bergin Goncalves  
Dr Arjun Dhillon

### NDG Office staff in attendance:

Carl Beesley  
Dr Helen Bauckham  
Layla Heyes  
Ryan Avison  
Dr Vicky Chico

### Guests:

Robert Jordan  
Adam Wimpenny  
Dr Robert Jeeves

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

National Data Guardian (NDG), Dr Nicola Byrne, chaired the meeting, confirming that it would be a shorter session as two programmes due to attend had sent their apologies.

Apologies were received from Andrew Hughes.

Dr Byrne welcomed two new panel members, Dame Moira Gibb OBE and Jenny Westaway, who introduced themselves and gave a brief background of their experience.

Dr Arjun Dhillon declared a conflict of interest with item 4, as Summary Care Record Additional Information (SCRAI) is an NHS Digital (now NHS England) programme, and as NHS Digital's Caldicott Guardian, he advises them in that capacity. The chair agreed that Dr Dhillon could provide factual clarifications on the item if required.

There were no other declarations of interest.

## 2. Minutes from the previous meeting, actions, and decisions

Panel accepted the minutes from its 13 December 2022 meeting as an accurate record.

Head of the Office of the National Data Guardian (ONDG), Ryan Avison, gave an update on the actions, confirming they were all complete.

## 3. Key updates

Head of the ONDG Ryan Avison gave the following updates:

### 1168: NDG public benefits guidance:

The NDG's public benefits guidance was launched on 14 December 2022. Further communications activity is underway to operationalise the guidance by ensuring it reaches key users and is embedded within/signposted to from external guidance, frameworks and websites.

### 1405: NDG reasonable expectations project:

The Department of Health and Social Care (DHSC) has confirmed funding for the project, and the Office is now working through the commercial aspects; we will shortly go out to tender for a supplier to support this research. If the procurement timetable goes to plan, we will start the project in March 2023.

**2023.01.17/3.1:** The Office to share the research proposal with the panel members for information.

### 1637: NHS federated data platform procurement:

NHS England launched the NHS federated data platform (FDP) procurement on 10 January, with a deadline of 9 February for the return of initial bids. The contract is valued at £360 million for five years, with the option to extend this for another two years (worth an additional £120 million). The contract is due to be awarded in September 2023.

The NDG confirmed that advising the programme on the procurement process falls outside her remit. However, she has continued to speak in more general terms, repeating key points about the importance of transparency and

safeguarding against any threats to people's confidence in how the system handles their data.

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## 4. 1255: Summary Care Record Additional Information update:

Robert Jordan, Adam Wimpenny and Dr Robert Jeeves from NHS Digital's [Summary Care Records](#) (SCR) live service team gave a presentation in which they explained that:

- In support of pandemic management, additional information (AI) was uploaded to people's summary care records without requiring their explicit consent, unless the individual had previously told the NHS that they did not want this information to be shared.
- 57.5 million patient records now contain AI, compared to 3 million pre-pandemic, and evidence of the benefits this is delivering is strong.
- However, the current policy position on AI was set in 2010, which was that it should only be uploaded with the individual's explicit consent.
- The pandemic established a new 'status quo,' and clinicians now routinely rely on accessing SCRAI to support people's care. Usage of SCR is up 70%, and when surveyed, 100% of clinicians advised that it shouldn't be withdrawn.
- Rolling back the change by removing AI from the records of those who had not explicitly consented would arguably represent a step backwards, creating a barrier to sharing crucial clinical information that would negatively impact on the safety of patient care.
- Research (including a [citizens' jury](#)) indicates that the public now expects/supports this information being shared to help their care.
- The SCR team understands the importance of being transparent about what's being shared in what situations and the benefits and safeguards.
- The SCR team will continue to offer individuals a choice with regards to having a SCR with Additional Information, a core only SCR (medications and allergies) or opting out of SCR.
- Taking all of the above facts together, the SCR team thinks it would be sensible and appropriate to rely on the concept of implied consent for direct care for the Summary Care Record with Additional Information.

The SCR team asked whether the NDG might support the position of relying on implied consent for direct care. It was also discussed whether and what engagement activities might be appropriate to communicate about this with the public/profession.

There was significant support from panel for how SCRAI is demonstrably helping medical care. It was pointed out that the NDG position has always encouraged better sharing of information for direct care. However, because of its historic pledges around explicit consent and seeking permission to view, the SCR team is in an unusual

position compared to other direct care initiatives: it is impeded by history in an unhelpful way.

There was agreement that it is likely to be within patients' reasonable expectations that the information in Summary Care Records with Additional Information will continue to be available to clinicians. Considering the qualitative and quantitative evidence provided in case studies, the citizens' jury report, and in the clinical risk assessment of removing additional information, it was felt that there was a strong case for continuing with SCRAI on the basis of implied consent for direct care. However, the NDG wanted to explore the topic in greater detail than time permitted.

**2023.01.7/4.1:** The office to arrange a meeting with the SCR team and the NDG office.

**2023.01.17/4.2:** The NDG is to set down her formal position in a letter to the SCR team.

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## 5. Any other business

### 1589: Advising on the NHS Digital NHS England merger:

DHSC has responded to some of the concerns the NDG raised about the merger's Statutory Instrument. In response, DHSC will change the [statutory guidance](#) that accompanies the Statutory Instrument. In addition, it has asked for further advice on a Secretary of State Direction. The ONDG has also commented on the Data Advisory Group terms of reference.

**2023.01.17/5.1:** Ryan Avison to provide a more detailed update to share with panel members.