



# Independent Advisory Panel on Data Release (IAPDR)

## OFFICIAL

**Title of meeting** Independent Advisory Panel on Data Release  
**Date** 09 July 2020  
**Time** 13:00 – 15:00  
**Venue** Skype

### Attendees

Professor David Forman	IAPDR Chair
Jane West	National Institute for Health Research
John Marsh	Patient and Public Involvement Representative (IAPDR Deputy Chair)
Brian Deane	Association of the British Pharmaceutical Industry
Judith Bisatt	Patient and Public Involvement Representative
Ralph Sullivan	Royal College of General Practitioners
Ify Sargeant	Patient and Public Involvement Representative
Dharmishta Parmar	Faculty of Public Health
David Seymour	Health Data Research UK
xxx	Office for Data Release
xxx	Secretariat

### Apologies

Nicola Keat	NCRI
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### 1. Chair's welcome and attendance

20/001

The IAPDR Chair welcomed and thanked members for their enthusiasm to come together virtually at short notice. It was noted that given extraordinary circumstances surrounding COVID-19, the meeting scheduled to take place in March was postponed. It was noted that no papers, beyond the minutes, were circulated for this meeting.

The Chair noted apologies from:

- Nicola Keat (NCRI)

20/002 The Chair summarised changes to the representatives of the following professional communities:

- Faculty of Public Health (nomination of new member, Dharmishta Parmar to replace Mike Sandys)
- Office for the National Data Guardian (Anne Stebbing to step down)

20/003 Dharmishta Parmar was introduced to IAPDR. She explained that her background is in health research into cancer awareness, screening and early diagnosis and she holds a role as Senior Data Manager Centre for Cancer Prevention at the Wolfson Institute (QMUL). It was noted that alongside representing the Faculty's interests in how Public Health England supports access to data, Dharmishta has experience of submitting data requests to both the Screening Research Advisory Committees and to the Office for Data Release (ODR). IAPDR reflected that this duality of experience will provide further insight to members and aid recommendations to PHE.

20/004 The IAPDR Chair noted that Dr Ralph Sullivan has provided notice of his retirement from the Panel in late 2020 and contact will be made with the RCGP to ensure the nomination of another representative. The IAPDR Chair also reported that Dr Anne Stebbing had retired from her role at the Office for the National Data Guardian (NDG) and in doing so, relinquished her role on IAPDR. Discussions were ongoing to identify a representative of the NDG.

**Post meeting note: the Office of the NDG has now informed the Chair that it is unable to nominate a replacement for Anne Stebbing.**

20/005 IAPDR welcomed the use of virtual meetings, recognising that the members would have reduced travel requirements. It was agreed that the IAPDR Secretariat would explore transitioning future meetings to Microsoft Teams once this is available throughout PHE.

## **2. Minutes of the last meeting and matters arising**

20/006 IAPDR reviewed the minutes of the previous meeting and no corrections were identified. The minutes were approved subject to the following amendment:

- Page 1: Update to include apology from Dr Ralph Sullivan.

20/007 It was noted that publication would be organised with PHE Communications and the minutes would be made available on the IAPDR collections page on Gov.UK

20/008 The matters arising were discussed as follows, unless otherwise itemised on this agenda:

20/009 19/206- IAPDR Secretariat to liaise with the IAPDR Chair to agree approach to the handling of Official-Sensitive documentation by approved deputies.

The IAPDR Chair noted that the membership had stabilised and conversations regarding the use of proxies/deputies had not moved forward. It was noted that all IAPDR members are aware of their responsibilities when handling documents labelled with the government classification 'Official -sensitive.'

Post meeting note: Members are reminded that papers classified as 'Official-sensitive' will be shared with handling instructions.

20/010 19/230- IAPDR to table discussion about access to screening and screening-linked NCRAS data at the next Data Release Assurance Board meeting.

The IAPDR Chair noted that the Data Release Assurance Board had not met since the last meeting. It was accepted that this action would be rolled to subsequent meetings and the IAPDR Secretariat query with the Chair of the Data Release Assurance Board when future meetings would be held and how feedback between IAPDR and the Board could be further normalised and improved.

20/011 Action: IAPDR Secretariat to write to Chair of the Data Release Assurance Board regarding the arrangements for future meetings of the Board.

20/012 19/239 - ODR to invite the NDR development team to showcase the new data management system at the next IAPDR meeting.

Action postponed with the view to timetable at a subsequent meeting,

20/013 19/243 - IAPDR to contact University of Cambridge to remind them of the value of their feedback and should this be returned, the feedback to be circulated to IAPDR members.

Action complete with feedback circulate to members in December,

20/014 19/246 - IAPDR to will draft a response letter to Southampton City Council to explain the process better and share it with ODR before it is sent out

Action complete.

### **3. Impact of COVID on ODR functions and plans for the next few months**

- 20/015 IAPDR received a verbal update from the Office for Data Release regarding the impact of COVID-19 on the conduct of business as usual.
- 20/016 The Office for Data Release explained that a standalone process had been established to rapidly assess requests to access coronavirus data controlled by PHE through the National Incident Coordination Centre (NICC). This process was being led by the NICC Research and Science cell. It was noted that most requests are for time-limited access to confidential patient information under Regulation 3(4) of the Health Services (Control of Patient Information) Regulations 2002 and expertise from the Office for Data Release had been drawn into the cell to facilitate appropriate due diligence and privacy by control measures for these requests.
- 20/017 The Office for Data Release noted that it was primarily supporting access to pillar 1&2 a testing data and COVID-19 Hospitalisation in England Surveillance System (CHESS) data through this mechanism.
- 20/018 The Office for Data Release noted that through this approach, PHE has enabled a number of disclosures to NHS Digital and NHS England; as well as linkages with several research databases to support the ongoing study of the aetiology, natural history and epidemiology of COVID-19 in the general population and sub-populations identified as being clinically 'at risk'. These include:
- daily testing data sent to NHS Digital for processing in their data access environment
  - linkage of testing data to Qresearch
  - linkage of testing data to Clinical Practice Research Datalink
  - linkage of testing data to established cohorts, including UK Biobank and NIHR bio resources
  - linkage of testing data to the UK Renal Registry
  - identification of COVID positive patients to the NHS Blood Transplant Services for identification to participate in the convalescent plasma trial.
- 20/019 The Office for Data Release re-iterated PHE's commitment to enabling data to be processed by directors of public health across local authorities; to aid the management of local outbreaks, build local intelligence of the impact of COVID-19 on specific communities and enable other statutory public health functions to be delivered. There was ongoing work to support combined authorities.
- 20/020 The Office for Data Release provided a verbal update on the trends in non-COVID related data requests during the chronological year, with comparison made to the equivalent period in 2019.

- 20/021 The Office for Data Release noted that there was a clear downturn in the number of requests received in March 2020. However, since March, there has been a steady increase in the volume of new enquiries to access ODR Pre-application Support Service (PaSS) and the submission of valid applications.
- 20/022 The Office for Data Release reported that there was a decline in the number of data releases facilitated through the ODR, with 54 data releases supported between 31 January – 30 June 2020. It was proffered that this decline was probably due to a number of factors: the lessening of highly complex releases (i.e. quarterly reporting cycles of the national cancer audits); PHE analytical and scientific/epidemiological capacity within specific assets was limited due to significant redeployment of specialist colleagues to support the NICC and; overall effect of the Covid-19 pandemic and subsequent lockdown on academic teams and non-covid related work.
- 20/023 The Office for Data Release stated that it was beginning to observe that the lead time to applicants receiving their data was increasing; however more detailed analysis would be necessary to explore the extent of this variation compared to previously reported turnaround times.
- 20/024 The Office for Data Release further reflected a change in the proportion of applicants from industry. For the last two financial years, industry represented approximately 5% of all requests (enquiries and/or valid applications). This was now around 10%. It was noted that quality issues with these applications has created new challenges and as a result, the ODR has made significant updates to the ODR pre-application pack to provide more instructional materials for applicants about PHE's expectations. This includes detailed guidance on the content of privacy notices, data specifications and contractual requirements under the General Data Protection Regulation for instruction data processors. IAPDR welcome the development of these new resources. It was agreed copies would be circulated to members.
- 20/025 The ODR noted that such ODR Approval Guidelines will be published following the launch of v5.0 of the ODR data request form. This form build in conditional logic to aid applicant in their understanding of which section to complete, under specific circumstances.

#### **4. Role of NHSX gateway for research data requests and impact on ODR**

- 20/026 IAPDR raised questions about the relationship of the ODR with NHS X and the observed utility of NHS X providing a single front door to accessing any data about COVID-19. IAPDR noted that NHS X are

triaging these requests and redirecting them to PHE or other controllers.

- 20/027 IAPDR questioned if PHE was involved in the 'Open Safely' project. It was acknowledged that PHE spoke with the University of Oxford in their planning phase, however no formal requests to process data was pursued by the 'Open Safely' project team
- 20/028 IAPDR raised questions about the availability of metadata to support research into COVID-19. It was noted that the data sets continue to develop and there is not currently a set data standard. The importance of appropriate metadata was acknowledged in the context of supporting and accelerating research into the medium and long-term effects of COVID-19.
- 20/029 IAPDR questioned what lessons could be learnt from the current period, echoing calls from the research community regarding perceived barriers to accessing data had lessened during the pandemic. IAPDR noted that access to patient confidential data was aided by the notice under Regulation 3(4); however, it was also noted that the response from PHE would not be sustainable indefinitely without significant additional resourcing as colleagues across PHE are working significantly beyond their contracted hours.
- 20/030 IAPDR considered how other custodians have also behaved including the development of trusted research environment enabling virtual machine access to datasets. It was suggested the NHS Digital should be invited to explain how their trusted research environment operates.
- 20/031 Action: IAPDR Chair to extend an invitation to NHS Digital to describe how their trusted research environment operates

## **5. Information regarding data requirements/access for cancer projects relating to COVID**

- 20/032 IAPDR noted that the ODR had received a limited number of requests to process cancer registration data for research or other secondary uses linked to COVID-19. It was noted that the requests received were in regard to modelling exercises regarding excess cancer deaths and increases in interval cancers between screening rounds due to endoscopy and other screening services being limited in Q1.
- 20/033 The Office for Data Release explained the lags in the registration of new primary malignancies and how work is being conducted collaboratively with NHS Digital to enhance the rate at which a cancer registration can be finalised through a partnership project title Rapid 2020.

## **6. Office of NDG consultation (<https://www.gov.uk/government/news/national-data->**

**guardian-launches-public-consultation-about-the-caldicott-principles-and-caldicott-guardians)**

20/034 The IAPDR Chair introduce a consultation currently being undertaken by the Office of the National Data Guardian to add an eighth Caldicott Principle. IAPDR briefly explored the merits of submitting a response as the Panel and welcome members to engage with their own interest groups to respond too. It was agreed that a discussion regarding this consultation should be held at the subsequent IAPDR meeting.

20/035 Action: IAPDR to discuss their response to the NDG consultation at the August meeting.

**7. Future IAPDR meetings**

20/036 IAPDR reflected on the use of virtual meetings and agreed that the approach should be taken forward on a 4-6 weekly basis.

**8. Any other business**

ODR recruitment – Data Impact and Engagement Officer

20/037 The ODR noted that following two unsuccessful recruitment rounds, the post of Data Impact and Engagement Officer was to be re-advertised throughout July 2020. The ODR noted that should a candidate be appointable, they will support members with the logistics of IAPDR meetings and delivering its remit.

Update to ODR citations

20/038 The ODR provided a verbal update on the integration of the UseMyData citation into its contracts. This has been deployed since January and where prompted through amendment handling, this change has been incorporate into the responsibilities of data recipients through a letter of variation.

Data Release Register

20/039 The ODR provided a verbal update on progress with publication of the Data Release Register. Noting that the most recent update included all releases made in Quarter 1 (31 July 2019 – 31 January 2020). IAPDR noted that in light of pressures to support the COVID-19 response, the ODR has been delayed in preparing any subsequent registers. However, it is planned that an update will be made in August for all releases up to 31 July 2020. The IAPDR expressed that transparency of how and to whom data is released remains a priority in upholding public confidence in the use of PHE data.

- 20/040 IAPDR questioned if the update to the register would include releases of any asset pertaining to COVID-19. It was noted that requestors for this data have not provided ODR with the lay summary that would need to be in place to merge these records with the pre-existing format; so work would be needed to gather this.
- 20/041 IAPDR briefly discussed the format of the register and timeliness of publication, including the ability to dynamically search the register based on disease, event or population characteristics. The interaction with HDR-UK's programme was discussed in this context.
- D) Date of the next meeting
- 20/042 The IAPDR Secretariat confirmed that a Doodle poll would be circulated to arrange dates for virtual IAPDR meetings for the rest of the year.
- 20/043 The IAPDR Chair closed the meeting, thanking members for their involvement.

### **Actions**

<b>Reference</b>	<b>Action</b>	<b>Owner</b>
20/011	IAPDR Secretariat to write to Chair of the Data Release Assurance Board regarding the arrangements for future meetings of the Board.	IAPDR Secretariat
20/031	IAPDR Chair to extend an invitation to NHS Digital to describe how their trusted research environment operates	IAPDR Chair
20/035	IAPDR to discuss their response to the NDG consultation at the August meeting.	IAPDR Chair

**Approved by IAPDR on 29 September 2020**