



# Independent Advisory Panel on Data Release (IAPDR)

## OFFICIAL

**Title of meeting** Independent Advisory Panel on Data Release  
**Date** 10 June 2019  
**Time** 10:30 – 15.15  
**Venue** Wellington House, 133-135 Waterloo Road, London

### Attendees

Professor David Forman	IAPDR Chair
Ify Sargeant	Patient and Public Involvement Representative
Jane West	National Institute for Health Research
John Marsh	Patient and Public Involvement Representative (IAPDR Deputy Chair)
Judith Bisatt	Patient and Public Involvement Representative
Nicola Keat	National Cancer Research Institute
Ralph Sullivan	Royal College of General Practitioners
XXX	Office for Data Release, Public Health England
XXX	Secretariat
XXX	Secretariat

### Apologies

Anne Stebbing	Office for the National Data Guardian
Carole Longson	Association of the British Pharmaceutical Industry
Caroline Cake	Health Data Research UK
Mike Sandys	Faculty of Public Health

## 1. Introductions, apologies and announcements

19/084 The IAPDR Chair welcomed members of the IAPDR. Apologies were noted from:

- Anne Stebbing – Office for the National Data Guardian
- Carole Longson – Association of the British Pharmaceutical Industry
- Caroline Cake – Health Data Research UK
- Mike Sandys – Faculty of Public Health

19/085 The IAPDR Chair invited IAPDR to introduce themselves and were reminded of the intent to publish biographies on dedicated IAPDR pages on GOV.UK.

19/086 The IAPDR Secretariat confirmed that biographies had been received from members and work was now ongoing with PHE Communications division to arrange publication. The IAPDR were asked to contribute photographs, so these could be integrated into a subsequent publication.

*Post meeting note: Individual and a group photos will be arranged at the September meeting of IAPDR.*

19/087 **Action:** IAPDR Secretariat to work with PHE Communications to publish IAPDR member's biographies on Gov.UK.

## 2. Minutes of the last meeting, matters arising and IAPDR action log

19/088 IAPDR reviewed the minutes of the previous meeting and the following corrections were agreed:

19/089 *19/064 – IAPDR to review data releases made between April – June 2019*

Page 10: Action *19/064* to be revised to read from “data release made between April – June 2019” to read as “January 2019 to March 2019”.

19/090 *19/079 – Doodle Poll to be set up to schedule IAPDR meeting dates for the financial year*

IAPDR agreed that associated text should be corrected from “..the financial year 2019/2019.” to read as “..the financial year 2019/2020”.

19/091 IAPDR discussed the matters arising as follows:

19/092 *19/013 – IAPDR members to identify further documentation or training*

The IAPDR Chair encouraged members to continue to provide feedback on their training requirement to the IAPDR Secretariat or Chair directly. Noting that the training day should be recognised as introductory and not the total training offer.

19/093 ODR invited IAPDR to participate in their webinar series, which aims to communicate to prospective applicants how to successfully complete an ODR application, what support is available through pre-application and the tools (such as data dictionaries) available. These webinars are held quarterly. Details of the webinars would be circulated to IAPDR after the meeting.

19/094 ODR further noted the development of a new training offer for PHE staff, using Moodle. Questions were raised over the availability of this training for IAPDR members. It was agreed this would be explored as Moodle is hosted on an internal server and it is unclear if it will be possible for non-PHE users to access it. It agreed that IAPDR would receive the materials as a Powerpoint or PDF, if feasible.

19/095 **Action:** IAPDR Secretariat to circulate (1) dates for upcoming ODR introductory webinars for 2019 and (2) PowerPoint copies of E-learning Moodle to IAPDR, if feasible.

19/096 *19/015 – Representative from the Understanding Patient Data (UPD) Initiative to deliver an education session*

The IAPDR Secretariat noted that an invitation was extended to UPD representatives by the IAPDR Secretariat, however, due to other commitments, their representatives were unable to attend this meeting. On confirmation of the date of the next meeting, an invitation will be extended to UPD to participate in the next meeting.

19/097 *19/018 – Appraisal of document management systems for use by Members*

The IAPDR Secretariat noted that work was ongoing to appraise document management systems, with PHE ICT (including the development of a SharePoint site). A progress update will be provided to the IAPDR at the next meeting.

19/098 *19/024 – Implement agreed changes and circulate a copy of the revised Terms of Reference (ToR) for agreement by Members*

Itemised as item 3 on this agenda.

19/099 *19/039 – Circulation of IAPDR meeting minutes*

IAPDR agreed that the minutes of the meeting should be made available as soon as possible to members, however reflected that a

set schedule may not be feasible given other demands on the Secretariat. It was agreed that actions of the meeting would be circulated within 1 month of the meeting and the full minutes on agreement with the IAPDR Chair.

19/100 **Action:** IAPDR Secretariat to circulate actions within 1-month.

19/101 *19/064 – IAPDR to review data releases made between April – June 2019*

The IAPDR Chair scheduled a review of the latest 3 months of data releases made through the Office for Data Release for the next IAPDR meeting. IAPDR will be asked to consider the appropriateness of this review being a standing item at the subsequent IAPDR meetings.

19/102 IAPDR discussed the value of spotlight audits of applications resolved by ODR and considered the merits of reviewing 2 – 3 data releases per meeting to gain a greater understanding of the breadth of applications received by ODR, the challenges in ODR approval (system, behaviours etc.) and to identify opportunities for system improvement. IAPDR agreed the Chair and Deputy Chair will work with the IAPDR Secretariat to select a list of projects for discussion.

19/103 **Action:** IAPDR Chair and IAPDR Deputy Chair to work with the IAPDR Secretariat to select a list of ODR projects for discussion at the next meeting.

19/104 *19/066 – PHE Communication Division to highlight strategy to the IAPDR*

The IAPDR Secretariat advised that an invitation was extended to the PHE Communications Division to attend this meeting to highlight their communications strategy and support IAPDR to gain greater insight about how PHE's corporate functions can be more closely aligned with the operational parameters of the ODR. In particular, IAPDR were interested in understanding what resources are available, as well as strategic and/or tactical approaches currently being deployed to advertised to PHE's external users and stakeholders the availability of data for secondary purposes.

19/105 The IAPDR Secretariat noted the difficulties with securing a speaker and that discussions continue with the Director of Communications. This item would be postponed, with a view to a presentation at the next IAPDR meeting. IAPDR actioned that the Chair is informed of progress.

19/106 **Action:** ODR to continue to engage with the Director of Communications to invite a representative to present at the next meeting.

19/107 19/079 – Doodle Poll to be set up to schedule IAPDR meeting dates for the financial year

The IAPDR Secretariat noted a Doodle Poll had be circulated. IAPDR agreed that responses should be provided by 14<sup>th</sup> June 2019.

19/108 IAPDR were reminded that in line with the agreed publication schedule and internal approval procedure, the approved minutes alongside the agreed web text for the IAPDR page would be made publicly available on GOV.UK within 2-weeks of the meeting.

### **3. Ratification of the IAPDR Terms of Reference**

19/109 The IAPDR Chair presented the revised terms of reference for the IAPDR and asked IAPDR to ratify the terms.

19/110 IAPDR discussed the revisions and agreed the following additional changes to the terms of reference;

- New amendment to paragraph 3, text to be amended to read as follows, ‘..it is critical to ensure that there are adequate safeguards in place to maintain the balance between the potential benefits of releasing data and potential risk of unduly comprising of an individual’s rights to confidentiality’.
- Under membership, paragraph 1; text to be amended to reflect extension of tenure, ‘Membership is for 12 months and up to a maximum of five-year term’.
- Addition of review schedule to ensure terms remain fit for purposes throughout IAPDR’s tenure.

19/111 IAPDR discussed the management of recruitment cycles to ensure seamless continuation of the group and knowledge translation between members. It was also noted that inclusion of a review date to the terms of reference would be deemed useful, for members to keep abreast of iterative changes to the objectives of the IAPDR.

19/112 **Action:** IAPDR Secretariat to revise text and re-circulate ratified terms of reference at the next IAPDR meeting (September 2019) and then at the Data Release Assurance Board meeting (October 2019).

### **4. Update from the PHE Data Release Assurance Board**

19/113 The IAPDR Chair provided a verbal update on the agenda and outcomes of the Data Release Assurance Board (DRAB), which took place on 8 May 2019.

- 19/114 It was noted that the DRAB welcomed the formation of the IAPDR and extended their gratitude to Professor Forman for his efforts through recruitment and the convening of IAPDR. It was noted that DRAB were pleased to endorse the proposed terms of reference of IAPDR.
- 19/115 The IAPDR Chair noted that DRAB conducted a review of its terms of reference, membership of the Board and the effectiveness of the Board in discharging its responsibilities, delivering its objectives and complying with its terms of reference over the previous 12-month period. No substantial changes were made to its remit. Changes to the membership of DRAB were further discussed, reflecting changes in personnel within the Caldicott Guardian function.
- 19/116 The IAPDR Chair noted that DRAB further received a report from the ODR summarising activity throughout the 2018 – 2019 financial year. It was noted this was itemised for review by IAPDR also.
- 19/117 The IAPDR Chair noted that two recommendations from IAPDR were considered by DRAB:
- 1) Recommendation to update DRAB membership to include IAPDR deputy chair
  - 2) Recommendation to update the PHE editorial guidance to improve public dialogue about the source of PHE data
- 19/118 The DRAB was satisfied it could accommodate IAPDR's recommendation to extend its membership to include the IAPDR Deputy Chair.
- 19/119 The DRAB discussed the merits of applying a PHE-wide standard citation. The Board were supportive of IAPDR's recommendation on the use of a citation clause and agreed that, this approach should be applied across all PHE datasets, and not just those within National Disease Registration. The ODR were actioned to follow this up with the Head of Publications.
- 19/120 The IAPDR Chair advised that DRAB has requested advice and/or comment on the following:
- 1) Advice on how PHE could monitor stakeholder satisfaction in its data access function through the deployment of stakeholder satisfaction surveys (itemised as Item 5)
  - 1) Advice on action to be taken in response to the Independent review of data access (Itemised as Item 7)

## **5. Requests for advice and/or recommendations**

- 19/121 The DRAB asked the IAPDR to (1) consider the value for the distribution of a stakeholder satisfaction survey, (2) for advice on the

structure, format and distribution channels these surveys could be deployed to.

19/122 IAPDR were supportive of the use of survey instruments for understanding the attitudes of PHE stakeholders to ODR services, unmet and/or perceived need for access to specific resources and opportunities for innovation. IAPDR considered qualitative data on customer experience to be of value to the delivery and function of the ODR going forward. The ODR noted that a full 360-degree stakeholder review hadn't been conducted historically.

19/123 IAPDR considered the technical methodologies that could be deployed and what key metrics should be captured.

19/124 IAPDR recommended that the ownership of any stakeholder survey results and corresponding action planning is undertaken by the IAPDR.

19/125 The IAPDR Chair noted that the undertaking the stakeholder surveys should not impact on the ability of ODR to carry out its day-to-day functions (especially for the Data Access and Confidentiality Managers).

19/126 **Action:** IAPDR Secretariat to organise a series of discussion points on the structure, format and distribution channels for the Stakeholder Survey to be discussed at the next meeting.

## **6. Communication strategies to promote the use of PHE Data Collections (invited speaker)**

19/127 As itemised in item 6 of this agenda. Item has been postponed to the next IAPDR meeting.

## **7. Independent Review of data access**

19/128 IAPDR were asked to (1) review and comment on the report's recommendations, (2) identify opportunities for learning, changes to ODR systems and communications with prospective/current applicants for recommendation to the Data Release Assurance Board.

19/129 IAPDR reviewed the report and discussed the recommendations presented. IAPDR agreed that PHE could not release data to the applicant and were supportive of the report's findings.

19/130 **Action:** ODR to send a reminder email to the applicant regarding contract expiration and resubmission of protocol.

19/131 IAPDR noted suggestions for the ODR, as follows:

- 1) Validation checklist: Introduction of a validation checklist i.e. a list of criteria that must be met before an application is admitted into an approval process. This will allow some flexibility in assisting researchers, but have set a clear bar that must be reached.
- 2) Involvement with research sponsors: ODR should be more involved in with the researcher's sponsor. It was noted that the more that a sponsor is involved in applications and associated discussions, the more likely any issues can be resolved.
- 3) Optimisation of current systems: forging stronger links with other approvers / data providers who may be able to provide relevant information or paperwork rather than repeatedly approaching researchers.

### 3. ODR End of Year Report

- 19/132 The ODR presented a paper summarising the level of business activity of ODR for the 2018-2019 financial year (01 April 2018 – 31 March 2019).
- 19/133 IAPDR were asked to note the annual business trends of ODR for 2018-2019. Questions were raised to the ODR about the analysis presented, including:
- Frequency of applications rejected by ODR
  - Decline in requests from the NHS
  - Proportion of requests to access non-cancer data collections
  - Comparative analysis to previous financial years
  - Variance on the anticipated income generated through full economic cost recovery
  - Frequency of applications where full economic cost recovery was applicable and reasons why charging was waived.
  - Primary causes to delays in ODR approval and data access
- 19/134 The ODR confirmed that following submission of a complete application that zero applications have been formally rejected during the financial year; however, applicants have increasingly been subject to non-standard conditions of approval, including revisions to their lay summary to ensure language is in plain English and suitable for a non-expert reader. The ODR noted that it is standard practice of the ODR to confer to applicants that applications will only be accepted for specific purposes and to this regard, deter applications being submitted that would not meet these criteria.
- 19/135 IAPDR noted that 87% of data releases are for cancer or cancer screening data. IAPDR asked that further works must be done to address this imbalance, given the breadth of non-cancer data collections within PHE and their intrinsic value to the NHS, research and innovation. IAPDR called for further discussion about proactive



communications that promote the use of these non-cancer data collections.

- 19/136 IAPDR noted that reporting would benefit from further comparative analysis, akin to the temporal trends in the frequency of applications reported in Figure 2.
- 19/137 IAPDR discussed the charging regime set out in the ODR Products and Services Cost Recovery Policy, how this is applied and the need for costs to access data to be more transparent to stakeholders. It was reaffirmed that PHE charges applied to the direct costs to (1) executed a data sharing contract or licence and (2) the preparation and quality assurance of the data extract. At no point are additional charges for the collation of data applied. The IAPDR were informed of the charging regimes of NHS Digital and CPRD for comparison.
- 19/138 The ODR noted that 59% of ODR requests to access PHE data were cost recoverable in the reporting period. Full economic cost recovery is waived for direct care requests, PHE commissioned activity and for access to data by local authorities for the conduct of their statutory public health functions under the Health and Social Care Act 2012.
- 19/139 IAPDR expressed their support in that the median elapsed time from complete application to data access was 54 working days. Discussion was had about the primary reasons, internal to PHE, that lengthen the lead time to data access, and those which are outside of PHE's control; including resourcing of the data access infrastructure within PHE and applicant understanding of requirements to demonstrate GDPR compliance.
- 19/140 ODR noted that whilst overall median elapsed time was less than 60 working days, work is still needed to identify opportunities to lessen this turnaround time. ODR will be conducting case reviews to reflect on what goes well and where improvements can be made to ODR processes.
- 19/141 IAPDR questioned if it would be beneficial to make attendance at an ODR external webinars mandatory prior to completing the ODR request form. The merits of this approach were considered.
- 19/142 The ODR noted that the DRAB has requested a public-facing dashboard is generated to share these types of metrics on a monthly or quarterly basis. Work is ongoing to build standard reports into the new ODR database to enable this going forward.
- 19/143 IAPDR noted references within the report to the PHE Knowledge Strategy and requested this is shared for IAPDR learning. The IAPDR Secretariat summarised the content of this Strategy and agreed to circulate it alongside the Research, Translation and Innovation Strategy for information.

19/144 **Action:** IAPDR Secretariat to share the PHE Knowledge Strategy and Research Innovations with IAPDR members.

19/145 IAPDR noted that a decline in the volume of applications received from the clinical community for local service planning or improvement to observe their own service delivery functions and processes. It was explained that there is no clear evidence as to why this decline is occurring but anecdotally, this may be due to lack of awareness of PHE data or due to sufficient availability of data within their own database systems. PHE has also made significant investment in upgrading its open data tool, Fingertips, as a single point of information for the NHS.

#### **4. Any of business (AOB)**

##### *Cost recovery*

19/146 ODR noted Parliamentary interest in how charges are applied to data access requests by different health data controllers, including PHE; how these charges are calculated, including the mean costs per request. It was noted that PHE has contributed to the preparation of evidence for the Secretary of State; however, no outcome of his consideration has been conferred back to PHE by the Department or through ministerial directive.

##### *Set up and function of IAPDR email account*

19/147 The IAPDR Secretariat confirmed that an IAPDR specific email address has been set up to support direct communication between PHE stakeholders and IAPDR. This email address will be promoted via GOV.UK. The meeting minutes, member biographies, terms of reference, future meeting dates and other documentation (e.g. consultations) that IAPDR see fit to promote will also be published on GOV.UK.

19/148 The IAPDR Secretariat noted that this new account would not be accessed directly by the Office for Data Release (ODR), to give PHE stakeholders the confidence that issues they want to address about the ODR are handled independently and without any perceived or actual conflicts of interest. Responses to any correspondence sent to this mailbox would be handled by the IAPDR Chair and IAPDR Deputy Chair directly. Standard operating procedure for the management of the inbox are in draft and will be shared with the IAPDR Chair in due course.

##### *Med Confidential website*

19/149 IAPDR were informed by the ODR, that the PHE Data Release Register will be reformatted on the Med Confidential website and published. Further details will be made available, once known.

*Date of the next Independent Advisory Panel on Data Release meeting*

19/150 The next meeting of IAPDR will be confirmed following all members sharing their availability. It was noted the Doodle Poll will close on 14 June 2019.

19/151 Future meeting dates (for September 2019, December 2019 and March 2020) to be circulated shortly after this deadline date.

19/152 No further updates were received.

19/153 The meeting was closed.

## Actions summary table

Item #	Action	Action owner
19/087	IAPDR Secretariat to work with PHE Communications to publish IAPDR member's biographies on Gov.UK.	IAPDR Secretariat
19/095	IAPDR Secretariat to circulate (1) dates for upcoming ODR introductory webinars for 2019 and (2) PowerPoint copies of E-learning Moodle to IAPDR, if feasible.	IAPDR Secretariat
19/100	IAPDR Secretariat to circulate actions within 1-month.	IAPDR Secretariat
19/103	IAPDR Chair and IAPDR Deputy Chair to work with the IAPDR Secretariat to select a list of ODR projects for discussion at the next meeting.	IAPDR Chair, IAPDR Deputy Chair, IAPDR Secretariat
19/106	ODR to continue to engage with the Director of Communications to invite a representative to present at the next meeting.	Office for Data Release
19/112	IAPDR Secretariat to revise text and re-circulate ratified terms of reference at the next IAPDR meeting (September 2019) and then at the Data Release Assurance Board meeting (October 2019).	IAPDR Secretariat
19/126	IAPDR Secretariat to organise a series of discussion points on the structure, format and distribution channels for the Stakeholder Survey to be discussed at the next meeting.	IAPDR Secretariat
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