



Independent Advisory Panel on Data Release (IAPDR) OFFICIAL

Title of meeting Independent Advisory Panel on Data Release
Date September 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
Brian Deane	Association of the British Pharmaceutical Industry
Ralph Sullivan	Royal College of General Practitioners
David Seymour	Health Data Research UK
XXX	Office for Data Release, Public Health England
XXX	Secretariat
XXX	Secretariat
XXX	Head of Strategic Communications (Item 6 only)
Dr Natalie Banner	Understanding Patient Data (Item 8 only)

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
Nicola Keat	NCRI

1. Chair's welcome and attendance

- 19/154 The IAPDR Chair welcomed members of the IAPDR. Apologies were noted from:
- Anne Stebbing
 - Carole Longson
 - Caroline Cake
 - Mike Sandys
 - Nicola Keat
- 19/155 The Chair welcomed David Seymour, deputising on behalf of Caroline Cake and Brian Deane, deputising on behalf of Carole Longson.
- 19/156 The IAPDR Secretariat confirmed that biographies had been received from members and work was now ongoing with PHE Communications division to arrange publication.

2. Minutes of the last meeting and matters arising

- 19/157 IAPDR reviewed the minutes of the previous meeting and corrections were made as follows:
- Page 5: Text in 19/110 to be revised to remove bullet point 1 due to duplication with point 2.

Subject to the changes above, the minutes were approved. 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.

- 19/158 IAPDR discussed the matters arising as follows:

19/087 – IAPDR to work with PHE Communications to publish IAPDR member biographies

IAPDR Secretariat noted that the action was complete - all members have contributed biographies and these were now available on Gov.UK. Work was ongoing to update the publication to include photos of members.

19/095 – IAPDR Secretariat to circulate (1) dates for upcoming ODR webinars and (2) copies of the Moodle, when available

IAPDR Secretariat noted that invitations to attend future Introduction to ODR webinars were circulated to members following the last meeting. The internal Moodle training remains in development.

Post meeting note – the ODR Introduction webinars have been rebranded as ‘ODR Approval Explained: Applying for and Accessing PHE Data’. Future dates will be circulated to stakeholders, including IAPDR members in late October.

19/100 – IAPDR Secretariat to circulate actions within a month of the meeting

IAPDR Secretariat noted that due to personnel changes within the ODR, the Secretariat has experienced resource constraints and were unable to meet this commitment ahead of this meeting.

19/103 – IAPDR Chair and Deputy Chair to work with IAPDR Secretariat to select projects for audit discussions

The IAPDR Chair noted that a discussion around the framework IAPDR should applying to the routine audit of ODR’s activities would be discussed under Item 5.

The IAPDR Chair reiterated the concerns raised by the ODR regarding ensuring the selection process is not biased by the knowledge of ODR managers. It was noted that for this meeting, the selection process had been with the assistance of ODR, but the sampling frame was identified by the Chair and Deputy Chair. The Chair welcomed members to consider how this process should be taken forward, in a manner that supports the scrutiny of ODR’s processes and the autonomy of IAPDR.

19/106 – ODR to continue to engage with the Director of Communications to invite a representative to present at the next meeting

The Head of Strategic Communications would present the divisions ways of working in item 6.

19/112 – IAPDR Secretariat to revise [terms of reference] text and recirculate terms of reference at the next IAPDR meeting

The IAPDR Chair noted that, following discussions at the last meeting, members had discussed additional revisions to the terms of reference through correspondence. The IAPDR Chair noted that members would be asked to ratify the terms of reference under item 4. Following ratification, the terms of reference would be placed on the Data Release Assurance Board agenda for their information.

19/126 – IAPDR Secretariat to organisation a series of discussion points on the structure, format and distribution channels of a stakeholder survey, for discussion at the next meeting of IAPDR.

To be discussed under Item 7.

19/130 – ODR to send a reminder to applicant regarding contract expiration and re-submission of protocol

The IAPDR Chair reminded IAPDR of the discussions regarding an ongoing application, which was independently audited by the MRC Regulatory Centre. A progress update was provided by the ODR on the status of the application and agreed that the IAPDR Chair would make contact with the applicant to establish the appropriate course of action.

19/144 - IAPDR Secretariat to share the PHE Knowledge Strategy and Research Strategy with IAPDR members

The IAPDR Secretariat noted these strategy reports had been shared with members. Action marked as complete.

Members further asked for an update on point 19/142 – which referred to the development of performance dashboards. It was noted by the ODR that work was ongoing to deploy a new data management infrastructure and IAPDR members were encouraged to identify ODR metrics that could be measured through this system and built into public facing reports.

19/159 **Action: IAPDR Secretariat to circulate a link to the IAPDR website and document collections on Gov.uk.**

4. Ratification of the terms of reference

19/160 Following discussion at the previous meeting and opportunities for revisions via correspondence, the IAPDR Chair presented the final draft of the terms of reference for ratification. Members were asked to review each paragraph, one by one.

19/161 IAPDR considered if the title of the group would future proof, as given the move towards alternative pathways to accessing data (such as use of honorary contracts and virtual research environments) the use of 'data release' may not be as encompassing as necessary. IAPDR members considered if the group's name should be revised to 'Independent Advisory Panel on Data Access'. It was determined that the remit of IAPDR may extend in the future and at that time, members should consider if the title and remit remain consistent with the advisory function PHE is requesting.

19/162 IAPDR agreed to update the list in paragraph 3 to cite the NHS Constitution (which enshrines rights for patients, public and staff, as well as the NHS in England's commitments to its stakeholders).

19/163 To permit the remit of the IAPDR to organically reflect opportunities for maximises PHE data through controlled access, the IAPDR

discussed amending bullet point 7 (page 3). It was agreed that this bullet point would be revised to read 'access to'; reflecting that sharing (data disclosure) is a subset of data access processes. It was further noted that IAPDR should be used as a consistent acronym and the references to 'the Panel' should be changed accordingly.

19/164 **Action: IAPDR Secretariat to revise (1) paragraph 3 to reference the NHS Constitution, (2) to update bullet point 4 to read, 'with other relevant services' (3) bullet point 7 to reflect the changes outline in 19/163 and (4) all references to 'the Panel' to 'IAPDR' for consistency.**

19/165 IAPDR members agreed that subject to the above changes, the terms of reference would be formally ratified. It was noted the final version will be published on the IAPDR webpage on Gov.UK

19/166 IAPDR discussed quoracy arrangements, including the use of deputies. The IAPDR Chair requested that the IAPDR Secretariat maintain an attendance grid. This would be discussed at regular frequencies with the view to ensure that all invited stakeholders were adequately represented at meetings and where necessary, discussions prompted with members to ensure participation.

19/167 IAPDR agreed that the following text would be included to describe the use of deputies, "Members (representing professional communities) may nominate deputies to attend IAPDR meetings on their behalf, at the discretion of the Chair. Deputies will contribute to the quorum"

19/168 **Action: IADPR Secretariat to update the terms of text to insert text to read, "Members (representing professional communities) may nominate deputies to attend IAPDR meetings on their behalf, at the discretion of the Chair. Deputies will contribute to the quorum" under the sub-header 'Membership'.**

19/169 **Action: IAPDR Secretariat to produce and circulate to the Chair an attendance grid, documenting the scheduling of meetings and attendance by members.**

5. Audit of ODR data requests

19/170 The IAPDR Chair introduced the item and provided an overview of discussions held at previous meetings, regarding the routine audit of how ODR interacts with its customers and conducts its due diligence functions. It was noted that the conduct of such audits aligned to the core objective 'to provide the Data Release Assurance Board with independent advice and recommendations on the effectiveness and integrity of existing PHE policies and procedures to promote appropriate, timely data sharing for secondary purposes', including

whether there are opportunities to refine service delivery to better serve PHE stakeholders.

19/171 It was advised that IAPDR would have to consider the conduct of ODR in relation to three applications, selected with support from the IAPDR Secretariat.

19/172 Recognising that the framework for the conduct of such audits was yet to be fully defined, IAPDR was asked to:

- (a) Discuss the following proposals and consider opportunities for service improvement and/or stakeholder engagement*
- (b) Discuss and agree the method for prospective auditing of ODR's decisions and performance, including the selection process and audit framework*

19/173 Due to time-restricted, the ODR presented two of the three applications. The item was suspended due to lack of time (move to next meeting and the IAPDR agreed that the third application would be discussed at the December meeting.

19/174 IAPDR discussed the conduct of the audits and how it could provide the most value. It was agreed that IAPDR would review 1-2 applications per meeting. These would be selected at random by the Chair and Deputy Chair from the published data release register and a query developed by ODR to identify any requests that have been handled for greater than 60 working days. Selection would be independent of ODR to maintain autonomy of IAPDR in its auditing practices.

19/175 IAPDR considered how it would engage applicants in the auditing process; including the use of questionnaires or structured interviews. It was agreed that a short questionnaire would be developed and should members need further depth, applicants would be invited to participate in the meeting. IAPDR agreed the conduct of these interviews would be closed business, without ODR in attendance.

19/176 **Action: IAPDR to draft questionnaire for circulate to applicants engaged in the IAPDR spotlight audits prior to the next meeting.**

19/177 IAPDR further agreed that ODR should circulate to members details of the issue logs recorded for the selected applications.

6. Communication strategies to promote the use of PHE Data Collections

19/178 The PHE Head of Strategic Communications presented an oral update to members about PHE's communication priorities and ways of working; summarising how PHE currently promotes data and

highlighting opportunities for working with IAPDR to establish a communication strategy specific to the secondary use of PHE data.

19/179 IAPDR noted that PHE utilised a number of communication channels to disseminate information, guidance and evidence; including many public and professional information tools (including Public Health Outcomes Framework data and Practice profiles through Fingertips). A number of specific campaigns have also featured data, such as the use of norovirus surveillance in winter preparedness exercises.

19/180 The PHE Head of Strategic Communications noted that PHE conducts annualised mixed methods research into its stakeholders and their needs. This research is used to shape communication methods. It was further noted that at the PHE Annual Conference PHE's new five-year strategy would be announced. The Strategy features commitments to using data effectively – including the use of predictive prevention and an enhanced surveillance infrastructure.

19/181 IAPDR discussed the audiences ODR interacts with and their objective to better inform stakeholders about the availability of data; but equally, ensure that the public recognise and feel assured that PHE is a responsible and trust-worthy data custodian. IAPDR were asked to consider how PHE Communications could best support these objectives. It was specifically noted that PHE does not appear to be interacting with industry and that IAPDR was concerned by the low number of non-cancer data requests being receive by PHE. It was agreed that work was needed to address this imbalance.

19/182 David Seymour welcomed the engagement of PHE is the HDR-UK Health Data Alliance and welcomed participation from the PHE Communication division in future meetings to look for opportunities to raise the profile of PHE data across the academic community.

7. Stakeholder survey discussion

19/183 The ODR provided a summary regarding previous discussed about the conduct of a stakeholder survey, to establish the perception of PHE's data management and disclosure processes, and to establish parameters, such as communication preferences from stakeholders that do not currently interact with PHE.

19/184 IAPDR noted that PHE is currently investigating the delivery of a survey by an external contractor and the procurement processes for achieving this.

19/185 8. Understanding Patient Data Programme

19/186 The IAPDR Chair welcomed Dr Natalie Banner, lead for the Understanding Patient Data Programme.

- 19/187 Dr Banner provided an overview of the Understanding Patient Data (UPD) Programme, its history and forward view; explaining that since its inauguration in 2016, the programme has focussed primarily on supporting key stakeholders to communicate the ethics and governance of the use of health records, including how different people and/or organisation translate the concept of transparency into action. It was explained that UPD seeks to maximize the use and value of health, medical and genetic data while ensuring that people can have confidence that it's well protected and used in the public interest to benefit health. Funding for the programme was originally secured for a 2-year period, in the shadow of the challenges that arose from Care.Data. This has now been extended, with a further 5 years.
- 19/188 It was noted that UPD has developed a series of tools and resources to help support conversations about how patient health information is used. They have also commissioned research into public attitudes of agencies processing patient data for use beyond an individual's own care and treatment. This included an IPSOS Mori survey. Outputs from this research has included a 'spectrum of identifiability' – describing personally identifiable data, de-personalised data and anonymised data in a easy to understand graphic. It was noted this was likely to be re-designed to reflect the language used in GDPR and the processes involved to anonymise personally identifiable data either by design or though controls (or both). Recognising that context is an important aspect to whether data is personally identifiable or not.
- 19/189 IAPDR noted that UPD has also published a series of animations contextualising how data is processed from point of care by different organisations and for different medical purposes.
- 19/190 It was noted that UPD was building its internal resource and had established a steering Committee, which includes representation from PHE.
- 19/191 Dr Banner further explored how Understanding Patient Data was conducting citizen juries with the Office for Life Sciences to establish the parameters for fair partnership as part of the sector deal with industry. These juries will look at the policy framework in relation to how the NHS should interact with industry in the use of artificial intelligence.
- 19/192 **Action: IAPDR Secretariat to circulate the presentation to IAPDR members**
- Any other business**
- 19/193 IAPDR discussed the agenda of the next meeting; establishing that alongside standing items IAPDR would revisit the auditing of ODR

activities; in particular, further interrogation of the system, governance and organisational issues identified through the completion of data protection impact assessments by the ODR.

- 19/194 The ODR confirmed that the PHE Data Release Register was currently being updated to include releases to 31 July 2019. It was noted that lay summaries were now available for all releases since 1 April 2019. The IAPDR confirmed that they would include within the scope of the audit releases from this period and look at long standing requests to identify any barriers to access from a query raised by the IAPDR secretariat.
- 19/195 IAPDR discussed opportunities for learning and development; including extending invitations to the following organisations to share their work and provide further information about emerging policy areas (such as artificial intelligence):
- Genomics England
 - Office for Life Sciences
 - PHE Caldicott Guardian
 - Stakeholders involved in data access partnerships (such as Macmillan or the NHS England CADEAS programme); which are served without releasing data beyond PHE’s organisational boundary.
- 19/196 It was noted that the date of the next meeting was confirmed as 4th December. The meeting would be conducted in London and the subsequent meeting, at a venue outside of London.
- 19/197 The IAPDR Chair closed the meeting, thanking members for their involvement.

Actions

Reference	Action	Owner
19/159	IAPDR Secretariat to circulate a link to the IAPDR website and document collections on Gov.uk	IAPDR Secretariat
19/164	IAPDR Secretariat to revise (1) paragraph 3 to reference the NHS Constitution, (2) to update bullet point 4 to read, ‘with other relevant services’ (3) bullet point 7 to reflect the changes outline in 19/163 and (4) all references to ‘the Panel’ to ‘IAPDR’ for consistency.	IAPDR Secretariat
19/168	IADPR Secretariat to update the terms of text to insert text to read, “Members (representing professional communities) may nominate deputies to attend IAPDR	IAPDR Secretariat

	meetings on their behalf, at the discretion of the Chair. Deputies will contribute to the quorum” under the sub-header ‘Membership’.	
19/169	IAPDR Secretariat to produce and circulate to the Chair an attendance grid, documenting the scheduling of meetings and attendance by members.	IAPDR Secretariat
19/176	IAPDR to draft questionnaire for circulate to applicants engaged in the IAPDR spotlight audits prior to the next meeting.	IAPDR
19/192	IAPDR Secretariat to circulate the UPD presentation to IAPDR members	IAPDR Secretariat