



Independent Advisory Panel on Data Release (IAPDR) OFFICIAL

Title of meeting	Independent Advisory Panel on Data Release
Date	16 November 2020
Time	15:00 – 17:00
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
Nicola Keat	NCRI
XXX	Office for Data Release
XXX	Secretariat
XXX	Secretariat

Apologies

1. Chair's welcome and attendance

20/087	The IAPDR Chair welcomed and thanked members for their attendance. No apologies were received.
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2. Minutes of the last meeting and matters arising

20/088	IAPDR reviewed the minutes of the previous meeting and no corrections were identified. 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
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- 20/089 The matters arising were discussed as follows, unless otherwise itemised on this agenda:
- 20/090 *20/049 - The IAPDR Secretariat welcomed IAPDR to contribute to the agenda of the next DRAB.*
- IAPDR Chair and Secretariat provided an update on the status of the reinstatement of the Data Release Assurance Board and noted that the next meeting was now scheduled to take place on 17 November 2020. The IAPDR Chair and Deputy Chair shared their intent to raise the concerns shared by the IAPDR about the future of the Panel, its function and line of accountability during the meeting. It was noted that feedback from this meeting would be tabled for discussion at the next IAPDR meeting.
- 20/091 The IAPDR Secretariat noted that an agenda was circulated to the membership that included itemised discussions about the effectiveness of DRAB within the current corporate governance structure, its governance and oversight of data sharing, opportunities to strengthen the function, lessons learned and in the context of the disbandment of PHE, how members could contribute to the design of future data sharing arrangements in NIHP or other host bodies.
- 20/092 Concerns were raised by IAPDR members about the frequency of DRAB's meetings. Further concerns were raised about what the data release management and monitoring processes controlled by PHE will look like once the Covid-19 regulations end and the COPI notice expires. It was noted that, NHS Digital will need to create a new authority to bring together and release data, as well as a control mechanism for it.
- 20/093 **Action: IAPDR Chair and Deputy Chair to circulate feedback from the DRAB meeting at the next IAPDR meeting.**
- 20/094 *20/031 IAPDR Chair to extend an invitation to NHS Digital to describe how their trusted research environment operates*
- The IAPDR Secretariat noted that this action was deferred at the last IAPDR meeting and instead, an invitation to present to IAPDR was extended to the PHE Transition Team. IAPDR expressed their continued interest in understanding the operational parameters and capabilities of the new NHS Digital TRE, in particular how this approach to data sharing could foster more efficient access to data.
- 20/095 The IAPDR Secretariat welcomed IAPDR members to share suggestions of speakers to invite from NHS Digital to speak on the role of the data access environment in NHS Digital. A number of suggestions were offered by members and it was agreed that Dr Sullivan would support the Secretariat in identifying suitable speakers to invite through his contacts at NHS Digital.
- 20/096 The IAPDR Secretariat further noted that is also an open action to invite the NDRS development team to showcase the new data management system and it was concluded invitations will be extended to this team for subsequent to attend an IAPDR meeting in the new year.

- 20/097 **Action: IAPDR Secretariat and Dr Sullivan to invite NHS Digital to present to IAPDR about how their new trusted research environment operates**
- 20/098 20/070 - ODR Secretariat to distribute a copy of the Terms of Reference to members.
The IAPDR Secretariat confirmed the action was complete.
- 20/099 20/072 - IAPDR Chair and Deputy Chair to consolidate feedback and circulate to members at the next IAPDR meeting.
Itemised as Item 3.
- 20/100 20/073 – IAPDR Chair to share the 12-month review report with PHE Senior Management and the Data Release Assurance Board
The IAPDR Chair noted that this action is yet to be undertaken. It was explained that the Chair is not planning to formally present the review to DRAB but will instead indicate to DRAB that the review is in progress and that it will be forwarded to the members of DRAB in preparation for publication once the review is signed off by the IAPDR panel.
- 20/101 20/078 – IAPDR Chair to write to the Chair of the Data Release Assurance Board and PHE Chief Executive to raise concerns about the delay in publication of the next Data Release Register.
The IAPDR Chair had completed this action and shared the contents of the letter with IAPDR members. The IAPDR Chair noted that no response to the letter has been received, however the Chair has received a holding reply that the letter is being considered by senior management within PHE.
- 20/102 20/085 – IAPDR Chair to write to the PHE Chief Executive to highlight concerns about how the redistribution of analytical resource towards COVID-19 is delaying access to data for other disease domains. It was noted this would include a request for additional capacity to enable the ODR to (1) expedite the disclosure of data to applicants who are in receipt of ODR Approval for non-COVID-19 requests and (2) support the ongoing publication of the Data Release Register/COVID Approvals Register.
The IAPDR Chair had completed this action and it was noted that these concerns were also covered in the letter sent to the Chair of the Data Release Assurance Board and PHE Chief Executive.
- 3. First year review of IAPDR**
- 20/103 The IAPDR Chair set the scene, reminding members that at the previous meeting an exploratory discussion was tabled to gather reflections about members perceptions of the value and impact of participation in IAPDR, and how the role and/or remit of IAPDR could be strengthened. In parallel to this discussion, IAPDR Members were asked to share any further thoughts in correspondence with the Chair. This feedback had been consolidated and a final draft paper circulated for agreement.

IAPDR favourably received the draft report and it was agreed that the emphasising the following would be strengthened understanding about the impact IAPDR has and could have:

- The role of IAPDR in the governance of PHE data.
- Opportunities to influence policy and functional design, including (1) how data access could be facilitated without data disclosure via trusted research environments and (2) resourcing and facilitation of novel data linkages.
- Improvements in outward facing communications, to ensure that IAPDR is responsive to stakeholder needs and can more clearly articulate the perceived barriers to data access.

20/104 The IAPDR Chair confirmed that the comments will be considered, and a final version of the review will be developed and circulated to the panel for sign off through correspondence.

20/105 **Action: IAPDR Chair to circulate final version of IAPDR review to members.**

4. Updates from the ODR

Overview of ODR activity

20/106 The Office for Data Release (ODR) presented an overview of business activity through the year to date; noting there were 242 new requests for ODR services covering amendments, applications and pre-applications support. The ODR supported 91 releases through business as usual activity. This measure does not include counts of COVID-specific requests. It was noted that the demand for access to the ODR'S Pre-application Support Service (PaSS) remains high and accounts for most of the outputs of ODR.

20/107 The ODR indicated that the temporal trends in new contacts with the ODR are similar to trends previously seen; it was observed that there was a drop in the volume of contacts to ODR comparatively to previous years. However, it was observed that there were substantially more releases in October (10 releases) compared to September (3 releases). It was reflected that this was aided by the return of analytical colleagues from secondments as part of the COVID-19 response.

20/108 The IAPDR reflected on the patterns of activity and proportion applicants from different organisation types.

20/109 The ODR noted that the proportion of the headline activity that relates to cancer accounts for 90-95% of activity historically and that this is expected be maintained across the remainder of the financial year. The Chair noted that there is still a relatively small amount of work that is not cancer related. The Secretariat commented that there were four non-cancer related requests received by the ODR in the last 4-5 months, excluding Covid-19 specific requests.

20/110 The ODR noted that the time of initial contact to data release interval is set at 93 days (unadjusted for non-business days or time with applicant), however the IAPDR acknowledged that the calculations are not accurate

because adjustments for time spent with the applicants in either the advice, design or contracting phases were not included. The Secretariat confirmed that the data would be cleaned to calculate an accurate interval from valid application to data release and these results presented at the next IAPDR meeting.

- 20/111 The ODR noted the onboarding of Rapid Registration Dataset as part of the NCRAS broader data offer. The IAPDR acknowledged that the ODR anticipates the release to increase the interest of researchers across the cancer community and therefore result in an increase in the number of application requests to the ODR. The IAPDR Secretariat noted that the ODR is ensuring that the correct documentation is in place in preparation to onboard data requests.

Covid-19 related activity of the ODR

- 20/112 The ODR explained that the bulk of the Covid-19 data sharing has been with the Directors of Public Health at local authorities to enable efficient and timely access to data for the purposes of the Covid response and local contact tracing and follow up. The ODR noted that data was shared to assist a number of large scale studies including clinical trials, the ALSPAC longitudinal study and the ONS household study. In addition, it was noted that QRResearch were receiving the most up to date data to develop a QCovid risk score.

- 20/113 ODR noted that the Covid rapid data sharing had been done in collaboration with the PHE Caldicott Function and a limited number of ODR staff to ensure the wider ODR team can focus on business as usual.

PHE Data Release Register

- 20/114 The ODR shared its plans to publish a revised version of the Data Release Register which will include all non-COVID releases until the end of September 2020 during the week commencing 30 November 2020. It was noted that within this revision, it was expected that a lay summary would be available for all releases supported through the ODR since 2017 (around 500 entries in the register). The Secretariat noted preparatory work with PHE Communication was ongoing to prepare for the publication of a Covid-19 Approvals Register. The publication of this Approvals Register will be subject to agreement by the Department for Health and Social Care.

Post meeting note: The Data Release Register was published w/c 30th November and is available [here](#).

At publication, five lay summaries were excluded by the ODR. Each is pending approval from the applicant following changes to the copy to improve readability and align to the editorial guidelines shared within the ODR's pre-application guidelines. These would be added to the Register as a batch.

- 20/115 IAPDR expressed their congratulations on the work on the lay summaries. The ODR noted that the work on the lay summaries reflects the need to review the information communicated to customers, due to the fact that many lay summaries require an update once they are presented to the ODR

because they do not fit the editorial style or contain technical language which does not fit with the required reading level of 13-14 years.

20/116 IAPDR Secretariat welcomed the appointment of the ODR Data Impact and Engagement Officer and explained that this role will explore opportunities to improve how the ODR appropriately communicates with external audiences, in terms of transparency and in regards to the Data Release Register, how the ODR enables applicants to share their intended uses of the data and anticipated benefits.

Availability and use of PHE data collections

20/117 IAPDR members raised concerns of a lack of understanding of the full breadth of data that is available beyond cancer and noted that there is an absence of a list that is available in the public domain. IAPDR expressed that researchers should be made aware of the breadth and richness of the data that is available to use and that this should remain a priority in communications, including an emphasis on the importance of the data to be used for purposes such as predicting trends for conditions other than cancer.

20/118 IAPDR Secretariat explained that there is an ongoing PHE project called PHISy to support additional metadata being recorded. The ODR are in agreement with the IAPDR that data products should be made available in the public domain to support the research community.

20/119 The ODR confirmed that this concern was highlighted to the transition board concerning the development of the new National Institute of Health Protection. It was expressed that the successor of PHE needs to have a strong handle on what data is being collected, what data is available to access, and how to access it. IAPDR agreed of the importance of communicating what data assets are available in the new organisation and noted that this was reflected in the limited number of assets being requested to the ODR.

5. Overview of PHE transition and opportunities to influence the data sharing strategies of new host organisations

20/120 The ODR noted that an invitation was extended by the IAPDR Secretariat to the PHE transition team to provide an overview, however, due to other commitments, their representatives were unable to attend this meeting. It was noted that an invitation will be extended to the PHE transition team to participate in the next meeting.

20/121 IAPDR raised concerns about what will happen to the panel moving forward. The ODR noted that the PHE transition team are looking at a number of work streams, including data resources and data assets. The ODR expressed that Peter Bradley will be responsible for the data work stream and will be able to provide an update on timelines regarding the transition during the next DRAB meeting and potentially provide a way for the IAPDR to engage in the process.

- 20/122 IAPDR questioned how the panel might contribute to the discussions around the transition in the next coming months and discussed the possibility of the adoption of the panel by the new institutes and what the function of the IAPDR will be, if any, beyond the end of PHE. IAPDR further questioned how they could practically support the ODR in the current interim stage that will add value and provide a lasting legacy of the IAPDR.
- 20/123 **Action: IAPDR Secretariat to extend invitation to a representative supporting the PHE transition to provide an overview of the transition.**
- 6. Any other business**
- Update of the review of the future of NDRS
- 20/124 The IAPDR Chair confirmed that the review of the future of NDRS has been submitted to PHE senior management and will be disseminated as a priority to staff within the NDRS and other stakeholders. It was confirmed that the Chair will circulate the review with the panel.
- 20/125 **Action: IAPDR Chair to circulate the review of the future of NDRS to the Panel.**
- 20/126 The IAPDR Chair noted that the key recommendation of the report will be that the disease registration function of PHE, including NCRAS and NCARDRS, and the registration data collection processes and associated analytical teams should move to NHS Digital. It was further iterated that certain teams in NDRS would be less appropriate to move to NHS Digital, such as the ODR, because NHS Digital has its own data release department (DARS). It was noted that it will be a requirement for any new organisations, including the new National Institute of Health Protection, to have a data release function. It was noted that the review includes a few recommendations for the future arrangements of the ODR.
- 20/127 IAPDR expressed that some members of the panel are associated with cancer data and other members are more associated with NHS data in general. The Chair questioned whether the panel would express an interest in contributing to the activities of NHS Digital or with NHS data more generally with assets that will be under control of the new National Institute of Health Protection instead.
- 20/128 The IAPDR Secretariat noted that NHS Digital are proposing to set up a non-disease specific dataset that will be available for research purposes based under the Health and Social Care Act. It was further iterated that, NHS Digital and other stakeholders have had ongoing discussions on whether the Digital Economy Act should be extended to include health data and as a result, there may be legislative changes early next year.
- 20/129 IAPDR expressed the view that there should be a social contract whereby sharing personal health data to understand health pathways is a condition as part of the management by the Health and Social Care system. IAPDR expressed concerns as a caveat that it is important to uphold patient autonomy and the protection of confidentiality. It was noted that there would be an impact on the quality of healthcare if data is too openly available, as

patients may feel compromised talking to healthcare professionals. The IAPDR Secretariat noted that this viewpoint has been echoed in the media.

20/130 IAPDR Chair noted that cancer is the most requested resource to the ODR from external stakeholders for the purposes of research, but it is also one of the most rich and complex datasets that are available as it has many different inputs and sub-datasets relating to radiotherapy, chemotherapy, among others. There is a specific community around cancer data and providing advice and expertise on this dense resource will be critical. It was expressed that the application of all learnings from cancer should be applied to other health data resources, which are currently managed by PHE and will go on to be managed by the successors of PHE.

Rapid Cancer Registrations Dataset

20/131 The ODR provided an overview of work by NCRAS to generate a Rapid Cancer Registration dataset as a proxy dataset for finalised cancer registrations for patients who diagnosed in 2018-2020. It was noted that access to this new cancer dataset would be facilitated by ODR. It was agreed that a copy of the data dictionary will be circulated to members for their information.

20/132 **Action: IAPDR Secretariat to circulate the Rapid Registrations data dictionary to the Panel.**

Date of the next meeting

20/133 The IAPDR Secretariat confirmed that the next meeting will be held virtually on 14 December 2020.

20/134 The IAPDR Chair closed the meeting, thanking members for their involvement.

Actions

Reference	Action	Owner
20/093	IAPDR Chair and Deputy Chair to circulate feedback from the DRAB meeting at the next IAPDR meeting	IAPDR Chair and Deputy Chair
20/097	IAPDR Secretariat and Dr Sullivan to invite NHS Digital to present to IAPDR about how their new trusted research environment operates	IAPDR Secretariat and Dr Sullivan
20/105	IAPDR Chair to circulate final version of IAPDR review to members	IAPDR Chair
20/123	IAPDR Secretariat to extend invitation to a representative supporting the PHE transition to provide an overview of the transition	IAPDR Secretariat
20/125	IAPDR Chair to circulate the review of the future of NDRS to the Panel	IAPDR Chair

20/132	IAPDR Secretariat to circulate the Rapid Registrations data dictionary to the Panel	IAPDR Secretariat
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