



Independent Advisory Panel on Data Release (IAPDR) OFFICIAL

Title of meeting Independent Advisory Panel on Data Release
Date 29 September 2020
Time 11:00 – 13:00
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

Apologies

1. Chair's welcome and attendance

20/044 The IAPDR Chair welcomed and thanked members for their attendance. No apologies were received.

2. Minutes of the last meeting and matters arising

20/045 IAPDR reviewed the minutes of the previous meeting and no corrections were identified. The minutes were agreed as an accurate reflection of the meeting.

20/046 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

20/047 The matters arising were discussed as follows, unless otherwise itemised on this agenda:

20/048 *20/011 IAPDR Secretariat to write to Chair of the Data Release Assurance Board regarding the arrangements for future meetings of the Board.*

The IAPDR Secretariat confirmed the Chair of the Data Release Assurance Board (DRAB) had been engaged about arrangements of future DRAB meetings. They had signalled the continuation of DRAB meetings; with provisional dates being held by the Secretariat for November 2020. It was noted the Secretariat has prompted the Chair to review DRAB's membership considering changes in personnel.

20/049 **Action: The IAPDR Secretariat welcomed IAPDR to contribute to the agenda of the next DRAB.**

20/050 Concerns were raised by IAPDR about the frequency of DRAB's meeting; with reference to the published minutes of the group dating to February 2019. It was noted that, as the primary route for IAPDR to be engaged by Public Health England, it was of utmost importance to the effectiveness of IAPDR that this group met or alternative corporate governance arrangements were presented to IAPDR.

Post meeting note: The last meeting of DRAB was held in May 2019. It is proposed the next meeting to be 17 November.

20/051 *20/031 IAPDR Chair to extend an invitation to NHS Digital to describe how their trusted research environment operates*

The IAPDR Chair noted this action is yet to be undertaken. It was explained the interplay with NHS Digital would be discussed under the next item. IAPDR agreed that the action would be carried over to the next meeting, with a request to extend the brief.

20/052 Dr Sullivan provided background to observations made by the Faculty of General Practitioners and from this the use of Trusted Research Environments by NHS Digital, and their ambition to support 80% of data sharing through this access mechanism. IAPDR noted that this would allow for further controlled access, with data 'releases' beyond NHS Digital limited to aggregated outputs compliant with appropriate anonymisation standards. IAPDR expressed their interest about learning more about such systems and how they could be deployed by Public Health England.

20/052 *20/035 IAPDR to discuss their response to the NDG consultation at the August meeting.*

IAPDR Chair noted that at the IAPDR July meeting it was agreed to dedicate a meeting to consolidate IAPDR's response to the National Data Guardian consultation on revisions to the seven existing Caldicott Principles, a proposed eighth principle, and the role of Caldicott Guardians.

20/053 Due to the postponement of the August meeting, discussions were held through correspondence and it was agreed IAPDR's position would be echoed within the submission by Health Data Research UK.

3. Consultation on the future positioning of National Disease Registration Service

20/054 IAPDR Chair noted that in July 2020, senior officials in NHS Digital asked Public Health England to consider the consolidation of all National Disease Registration Service functions (encompassing, cancer, rare and congenital anomaly registration, as well as the Office for Data Release and auxiliary business functions) into NHS Digital's Data Sciences division. This came in advance of the announcements from the Secretary of State about public health reforms. At the heart of this request is the belief that the disease registration would be more properly located in the NHS organisation for the maintenance and curation of information about NHS patients. In response to this request, Public Health England has commissioned a rapid review of the benefits/disbenefits of such a move. This review will be conducted by Professor David Forman.

20/055 The IAPDR Chair confirmed that the findings of the rapid review would be reported to PHE in late October; with recommendations imminently following.

20/056 The IAPDR Chair summarised the background to the review in further depth, confirming that the National Disease Registration Service consists of two constituent services, National Cancer Registration and Analysis Service; and National Rare Disease and Congenital Anomaly Registration Service. NHS Digital is the national information and technology partner for the health and care system; and compared to Public Health England (an arm's length body to the DHSC) operates within a different political landscape.

20/057 The IAPDR Chair noted that this review is against the background of much broader public health reforms and that currently, no formal announcements have been made by the Secretary of State, nor Department for Health and Social Care about the positioning of non-health protections functions that will complement the new National Institute for Health Protection. It was noted that a Stakeholder Advisory Group had been formed to pave the future of these functions and that suggestions on the table include integration with NHS England and the formation of a parallel institute, the National Institute for Health Improvement.

20/058 IAPDR members considered the uncertainty created for the functioning of the Office for Data Release, given that its function is already undertaken with NHS Digital's Data Access Request Service (DARS) and that regardless of disease registration, it serves to support access to a much broader range of public health data sets across PHE.

20/059 IAPDR members considered the status of the rapid review and provided the IAPDR with feedback on their immediate concerns. This included:

- the challenges the community has experienced in accessing data from NHS Digital and in particular, local authorities that have

experienced barriers to access data for health inequality assessments and joint strategic needs assessments.

- prohibitive costs
- slow turnaround times delivered by DARS
- lack of support to navigate through DARS processes and often unclear as to why decisions have been made on an application
- limited access to domain specific knowledge to frame applications cohesively
- limited understanding of the prevention agenda and projects negotiating on a one-by-one basis instead of adopting national solutions
- if application decisions made by ODR be upheld by NHS Digital or new applications will need to be submitted, leading to lags in the processing of cancer data requests
- development of new committees that take time to normalise processes and procedures
- separation of the cancer registration service and NHS Screening Programmes
- significant knowledge within ODR about the data, key stakeholders and their projects which could be lost.

20/060 The IAPDR Chair noted that these challenges had also been expressed by interviewees in the review who have experienced both services.

20/061 The Office for Data Release noted that NHS Digital is currently exploring approaches to updating their systems to allow for a single-front door to access DARS, automation of governance checks and improved communication with customers.

20/062 The IAPDR Chair further iterated that such feedback has been recognised and there is a high-level commitment from NHS Digital's CEO to improve the DARS services, both in terms of performance and user experience.

20/063 IAPDR members also reflected on the value of adopting closer ways of working, given NHS Digital's experience in curating and manipulating data. The Panel reflected:

- the addition of primary care data could be critical to understand patient pathways and clinical characterisation of at-risk groups.
- clinical and patient engagement must be at the heart of any new systems to make sure they are meaningful.
- duplication of effort, for example with the linkage of datasets, is wasteful and should be centralised within the NHS boundary.
- the NHS is perceived to be a trustworthy brand
- the pre-existing infrastructure to gather the views of academic researchers through the Research Advisory Group.
- NHS Digital could adopt learning systems that embrace a model of partnership working far closer to the parameters in which ODR operates.
- the scale of releases delivered by NHS Digital (>5000 reported on their release register) and that any triage systems must support more complex applications; and

- it is unclear what the future of IAPDR would be in light of emerging health protection functions.

20/064 IAPDR Members also considered the role of IGARD in handling of applications and the additional workload that would be placed on this group should NDRS move towards NHS Digital.

20/065 IAPDR Chair noted that timescales for public health reform had been reported publicly as to be implemented from Spring 2021 and that if staff were to transfer out of PHE, there would be statutory processes to follow under the protections offered to employees under the Transfer of Undertakings (Protection of Employment) regulations.

20/066 IAPDR reflected that any new organisations established as part of public health reforms will require comparable structures to the Office for Data Release to enable access to data and that the continued involvement of IAPDR members remains critical to an ongoing dialogue about appropriate data access.

20/067 IAPDR Members were thanked for their reflections and the Chair expressed his gratitude for the discussion.

20/068 IAPDR Members considered the opportunity to influence the forming of new data access mechanisms within the National Institute for Health Protection

4. First year review of IAPDR

20/069 The IAPDR Chair introduced the item as a 12-month review of the conduct of IAPDR. Members were asked to share their feedback and from the discussions, a paper collating these thoughts would be compiled and circulated by the Chair and Deputy Chair.

20/070 **Action: ODR Secretariat to distribute a copy of the Terms of Reference to members.**

20/071 The following views were noted:

- It was acknowledged that IAPDR momentum was lost as priorities needed to adapt rapidly to the emerging pandemic.
- There was broad recognition of the value of spotlight audits of specific applications. In particular, this offered insight into the challenges applicants may have or perceive they face. It was acknowledged also as reassuring that, from these audits, the ODR was operating as a learning system.
- Members expressed that the spotlight audits should continue; however, the format of these audits could be amended to include:
 - An invitation to the applicant to speak to their experience with submitting their application directly to IAPDR
 - Operating a 'you said, we did' feedback loop to demonstrate that IAPDR has recommended specific changes to ODR's actions/process and in turn, showing this impact not only to

the single applicant but more broadly through improved communications with stakeholders.

- Looking at stakeholder perspectives along different stages of the application process; in particular circumstances where the applicant does not proceed to submitting a formal application.
- Members expressed the view that there could be more opportunity for IAPDR to consider borderline cases and establishing precedent on such. Suggestion that this could be a prospective consideration, versus looking retrospective.
- There was acknowledgement that opportunities for system learning by interacting with IGARD, CAG and other similar assessment bodies to support system improvements and harmonisation are yet to be fully realised. It was felt this should be explored further.
- Concerns were raised about the loss of representation from the Office of the National Data Guardian and the lack of continuity of professional members at the Panel which may have lessened its effectiveness in the early days.
- It was further acknowledged that the membership may benefit from representation by individuals representing the legal and medico-ethics community and more direct contributions from applicants.
- Given the frequency of the Data Release Assurance Board meetings, members raised concerns about the diminishing feedback loop and the need for clear corporate governance to ensure that the Panel can effectively discharge its responsibility and consider questions raised by the Board directly. It was further noted that as the Panel was constructed on behalf of Duncan Selbie, the change in senior management within PHE could also be an opportunity to reinvigorate feedback mechanisms.
- Reflecting the terms of reference, it was felt that the Data Release Assurance Board had raised limited questions to IAPDR for its consideration.
- How could IAPDR support key messaging to ODR's prospective customers to ensure that it is clear that access is equitable and fair decisions based on a consistent framework is being applied.
- On a personal level, the members reflected the complexity of the landscape and challenge of acquainting oneself with use of acronyms. It was proposed that induction should be modular, so lessen the immediate information burden and to cement certain new knowledge.
- It was reflected that the governance arrangement of IAPDR could be improved by a rolling log of actions or milestones that accessible via SharePoint and that such approach could assist IAPDR in quantifying its impact.

- It was acknowledged that IAPDR offers stakeholders a useful conduit to raise concerns but as proactive communication about the role of IAPDR has been limited, few stakeholders have approached IAPDR directly. It was further reflected that there has been no proactive communication from IAPDR to demonstrate how and when IAPDR has successfully influenced PHE to change its strategy or practices. It was agreed a 'you said, we did' culture would encourage engagement and issues being raised with IAPDR, and further close the feedback loop with stakeholders.
- Members iterated their excitement to contribute to processes to ultimately improve use and access to data for the direct benefit of patients; however there is frustration that plans (such as a 360 user survey) have been stalled.

20/072 **Action: IAPDR Chair and Deputy Chair to consolidate feedback and circulate to members at the next IAPDR meeting.**

20/073 **Action: IAPDR Chair to share the 12-month review report with PHE Senior Management and the Data Release Assurance Board**

5. Updates from the ODR

Resource management and recruitment

20/074 The Office for Data Release noted that it is pursuing the secondment of analytical support to aid the timeliness of pre-application support and data preparation, noting observed delays in preparing cancer registration data. A business case has been submitted and additionally, the Chair of the Data Release Assurance Board has been advised of the pressures COVID is creating for business as usual activity. IAPDR was reminded that data releases to support the pandemic response are being prioritised.

20/075 The Office for Data Release has also successfully recruited to the new post of Data Impact and Engagement Officer. This post will support IAPDR members going forward in pursuing their remit. It is anticipated the candidate will commence their post in late October.

PHE Data Release Register

20/076 The Office for Data Release confirmed the pressures placed on the function to support COVID activities and resource constraints to draft and quality assure the next update to the register. The intent to publish a stand-alone COVID register of approvals was also signalled.

20/077 IAPDR members acknowledged the challenges faced by the Office for Data Release and significant resource pressures affecting delivery; however, expressed that the register must be kept as near to concurrent as possible to not undermine transparency and openness with the public. It was agreed that the IAPDR Chair would write to the Chair of the Data Release Assurance Board and PHE Chief Executive to highlight these issues.

20/078 **Action: 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.**

Overview of ODR activity

20/079 ODR presented an overview of business activity through the year to date. Noting there were over 200 new expressions of interest, applications or amendments to pre-existing approvals. This measure does not include counts of COVID-specific requests, which are being managed by exception through a partnership approach with the National Incident Coordination Centre. It was indicated that demand for access to the ODR's Pre-application Support Service (PaSS) remains high, with this accounting for approximately 70% of all new activity; however, the ODR had also observed that the conversion rate of pre-application enquiries to a valid application was on the rise. It was further confirmed that access to ODR service by different stakeholder types remains relatively static, with over 50% of request from the academic community.

20/080 The Office for Data Release also indicated the temporal trends in reduced contacts with the ODR; echoing the previously reported decline in activity in line with emergence of the pandemic and changes in work settings in academia.

20/081 It was noted that there has been a sharp decline since the start of the pandemic in the number of data releases made. It was noted this was in part because of a reduction in staggered releases but also the decline in analytical capacity.

20/082 It was noted that for the next meeting of IAPDR, the Office for Data Release would prepare a mid-year report, including burndown charts (a Kaplan–Meier survival plot) to highlight to IAPDR members the proportion of releases serviced within 60 working days from a valid application.

20/083 IAPDR asked that the report indicate breakdowns of metrics by asset and that artefacts in the data are clearly outlined.

20/084 IAPDR agreed that the IAPDR Chair would write to the PHE Chief Executive to highlight concerns about how the redistribution of resource to support the COVID-19 response was adversely impacting access to data for other disease domains. This would include requesting additional capacity to enable the ODR to deliver data to applicants who are in receipt of ODR Approval and the ongoing publication of the Data Release Register.

20/085 **Action: 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.**

Date of the next meeting

20/085 The IAPDR Secretariat confirmed that the next meeting will be held virtually on 16 November 2020.

20/086 The IAPDR Chair closed the meeting, thanking members for their involvement.

Actions

Reference	Action	Owner
20/049	The IAPDR Secretariat welcomed IAPDR to contribute to the agenda of the next DRAB.	All
20/070	ODR Secretariat to distribute a copy of the Terms of Reference to members.	ODR Secretariat
20/072	IAPDR Chair and Deputy Chair to consolidate feedback and circulate to members at the next IAPDR meeting.	IAPDR Chair and Deputy Chair
20/073	IAPDR Chair to share the 12-month review report with PHE Senior Management and the Data Release Assurance Board	IAPDR Chair
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.	IAPDR Chair
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.	IAPDR Chair