



Independent Advisory Panel on Data Release (IAPDR) OFFICIAL

Title of meeting Independent Advisory Panel on Data Release
Date 14 December 2020
Time 15:00 – 17:00
Venue Microsoft Teams

Attendees

Professor David Forman	IAPDR Chair
John Marsh	Patient and Public Involvement Representative (IAPDR Deputy Chair)
Bryan 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
Garry Coleman	NHS Digital Associate Director (Item 2 only)
XXX	NDRS Head of Technology (Item 4 only)

Apologies

Jane West	National Institute for Health Research
-----------	--

1. Chair's welcome and attendance

20/135 The IAPDR Chair welcomed and thanked members for their attendance. Apologies were received from Jane West.

2. Overview of the role of NHS Digital's Trusted Research Environments (invited speaker)

20/136 The IAPDR Chair welcomed Garry Coleman, the Associate Director for NHS Digital. Garry Coleman presented an oral update to members about the role of NHS Digital's Trusted Research Environments (TREs); summarising how

TREs can provide more timely access to data and create a safer environment to hold data in.

3. Minutes of the last meeting and matters arising

- 20/137 IAPDR reviewed the minutes of the previous meeting and three 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
- 20/138 The matters arising were discussed as follows, unless otherwise itemised on this agenda:
- 20/139 *20/093 – IAPDR Chair and Deputy Chair to circulate feedback from the DRAB meeting at the next IAPDR meeting.*
- The Chair and Deputy Chair attended the meeting and feedback is discussed under item 7.
- 20/140 *20/097 – IAPDR Secretariat and Dr Sullivan to invite NHS Digital to present to IAPDR about how their new trusted research environment operates*
- Itemised as item 2.*
- 20/141 *20/105 – IAPDR Chair to circulate final version of IAPDR review to members*
- Itemised as item 7.*
- 20/142 *20/123 – IAPDR Secretariat to extend invitation to a representative supporting the PHE transition to provide an overview of the transition.*
- The IAPDR Chair noted that an invitation was issued, however due to the vast amount of work placed on the transition team, no one was available to speak. It was acknowledged that the ODR Secretariat will provide a brief summary about where matters lie with the transition of PHE under item 5.
- The IAPDR Secretariat noted that the ODR, alongside other colleagues that work across the data science division, are starting to articulate the emerging risks associated with the transition. It was further noted that there will be a broader consultation exercise starting in 2021, but timelines have not been determined yet by colleagues in the transition team. It was acknowledged that the ODR are indicating to colleagues in the transition engagement team that there is a willingness across IAPDR members to frame what data sharing would look like and what the data environment would need to be to foster that in the successor organisation(s) of PHE. The ODR will share updates of timelines and how the IAPDR can contribute.
- 20/143 *20/125 – IAPDR Chair to circulate the review of the future of NDRS to the Panel*
- This action was completed.

20/144 *20/132 – IAPDR Secretariat to circulate the Rapid Registrations data dictionary to the Panel*

It was noted that this action is ongoing and that the IAPDR Secretariat will circulate the Rapid Registrations data dictionary after the meeting.

Post meeting note: Copy of the RCRD data dictionary and v4.3 of the NCRAS dictionary circulated with these minutes for reference.

20/145 **Action: IAPDR Secretariat to circulate the Rapid Registrations data dictionary**

4. Overview of the new NDRS data management system (invited speaker)

20/146 The IAPDR Chair welcomed Neelam Alhaddad, Head of Technology at NDRS. Neelam Alhaddad showcased the data management system which was developed to digitise the ODR's existing workflows. The ODR required from the new system 1) stability; 2) the ability to look at timelines at a more granular level to identify the specific bottlenecks across the customer journey which could be resolved from actions from the ODR; and 3) integration of the Data Privacy Impact Assessments (DPIAs) to support audit trails and for effective record keeping for amendments and returning customers.

20/147 The functionality of creating expression of interests and the process of logging requests for data were showcased. It was noted that the multi-user system is time efficient and that the system allows for the ODR to measure the number of applications that have been processed by the team. The system has the due diligence embedded that the ODR goes through when processing an application, including moderation and senior approval controls for application contracts and for data releases. Furthermore, the system could support greater visibility to researchers on the progress of their application because of the notifications function within the system which notifies applicants when their application status changes.

20/148 The ODR noted that the system is currently the ODR's minimum viable product to replace the current system to provide an overview of what the current portfolio of the ODR is and to assist with the auditing process. The ODR acknowledged that there are opportunities to engage with other partners to have an interoperable system with a public facing domain and the potential for this system to be extended to any data asset which is built into the ODR's offer.

20/149 The ODR noted that there are further opportunities relating to the role-based functionality set up within the system that could be valuable in the future, such as opportunity for a team application rather than an application being associated with a particular individual.

20/150 IAPDR asked whether they could expect a standard monthly report indicating how many applications are at each stage of the application process and how many customers have progressed through each stage, in order to identify any possible bottlenecks in the customer journey. IAPDR

were asked to start defining what deliverables they would like to see reported based on the system, so that the ODR can make these available to IAPDR.

20/151 It was noted that ODR data was migrated into the new system up until October 2020 and that, pending sign off from the team, the data will be brought up to date and the system will be used in the New Year.

Post meeting note: User testing has identified some minor issues with the import of live data. These are under investigation.

20/152 The ODR explained that the system offers a drag and drop feature which will save time for the ODR when processing applications. The ODR has developed a new data request form and associated guidance, which is currently in the quality assurance process with an aim to be launched in the first week of January as part of the ODR's pre-application pack. The form embeds conditional logic and will assist applicants in their thinking about which sections to complete based on their project type.

Post meeting note: The data request form and associated guidance was soft launched to customers on 11th January 2021.

The data request form and associated guidance, pending approval from the Communications team, is available on Gov.uk [here](#).

20/153 IAPDR acknowledged the demands placed on ODR and appreciated the significant benefits that this new system will deliver.

20/154 **Action: IAPDR to start defining what deliverables they would like to see reported based on the new data management system.**

5. Update of review of the future of NDRS

20/155 The IAPDR Chair noted that transition discussions are in progress within PHE. It was noted that the recommendation from Professor David Forman's review for NDRS to move to NHS Digital is highly likely to be accepted, however there will be discussions around the future of the ODR due to the requirement of ongoing ODR services within successor organisations to PHE, including NIHP. The IAPDR Secretariat noted that it is expected that NIHP will be a legal entity from 01 April; however, the complete transfer of functions and staff is currently projected to span into late 2021.

20/156 IAPDR raised concerns about the introduction of the new data management system and questioned whether moving systems is worth it in the short-term with the consideration that NDRS are moving into a different organisation. IAPDR Secretariat expressed the view that the new data management system is necessary because the current system is not fit for purpose to enable business as usual. Despite operating in a period of uncertainty, the new data management system will enable the ODR to keep a real-time log of data requests, which is not possible within the current system. It was noted, however, that there is a likelihood there will be other systems that the

ODR will need to integrate with in the future depending on the circumstances that will arise from the transition.

20/157 IAPDR noted that the new data management system has been developed by the IT team within NDRS, and that this team will probably be moving to NHS Digital. IAPDR expressed therefore the view that risk mitigation is required, and appropriate service support arrangements need to be put in place. The IAPDR Secretariat noted that these considerations are being discussed currently, specifically around how to maintain fit for purpose services and the residual impacts of teams being split between different organisations.

6. ODR November Report

20/158 The ODR presented the November report, providing a summary of how the ODR is currently performing, the impact of Covid-19 on business as usual activity, and the challenges and achievements across the first three quarters of the financial year.

20/159 The ODR indicated that there were 266 new requests for the ODR's Pre-application Support Service (PaSS) and 64 new applications. It was noted that long lead times between an initial inquiry and an application received are common due to funding, REC and other information governance requirements.

20/160 The ODR noted that there were 87 releases between April and end of November, which is less than anticipated however this was a reflection of the bottlenecks previously discussed, such as a decline in the availability of analytical resource.

20/161 The ODR noted that there was a high number of amendments received this year, which were prompted by changes in working habits and a move towards cloud processing to access data.

20/162 The ODR reflected that the average time taken from a valid application being received by ODR to data being disclosed to that requester was extended to 87 working days unadjusted. The ODR noted that this was previously reported as 54 working days. The ODR explained that this was due to the limitations within the current data management system. It was further explained that lead times were extended because 1) the provisioning of data following approval has taken longer because of the re-deployment of colleagues internally; 2) the changes to homeworking created challenges locally and caused delays to the time taken for contracts to be executed; and 3) the change to cloud processing environments requiring the engagement of third parties within the scope of contractual controls prolonged the process.

20/164 IAPDR questioned if there is a recovery plan in place to bring timescales back down to levels previously reported. The ODR reflected that there is already some recovery and that data access is speeding up due to the return of the analytical community who were deployed over the initial 6 months of the pandemic, which is having a significant impact on timelines. It was further noted that there are discussions with senior leadership on

whether additional resource needs to be allocated to ODR in order to ensure there is sufficient time allocated to planning around the transition. The ODR are looking to increase the number of posts to cover the information governance functions.

20/164 The ODR noted that within the current portfolio, there are 176 active projects which are at different points in the pipeline. As previously reported, the pipeline is dominated by PaSS which reflects over 50% of total activity. It was noted that there are 36 requests which are at the point of contracting or data being disseminated.

20/165 The ODR noted that proactive communication about the transition and timelines will be shared with stakeholders to keep them informed once there is a better understanding.

7. Any other business

Data Release Assurance Board

20/166 The IAPDR Chair and Deputy Chair commented that the Data Release Assurance Board (DRAB) expressed thanks to the IAPDR and appreciated the Panel's efforts. It was noted that, given DRAB have not met for 18 months, there was no oversight of the expectations for the future in regards to the transition. However there was a commitment to continue DRAB meetings and it was noted that the IAPDR Chair will formally table the IAPDR review on the agenda of the next DRAB meeting for a solid starting point for a discussion, as well as discussions of the future of NDRS and the ODR.

20/167 **Action: IAPDR Chair to table the review on the agenda of the next DRAB meeting and ensure the acting CEO receives a copy.**

IAPDR Review

20/168 The Chair confirmed that all IAPDR members received finalised copies of the review and were given opportunities to review the document. The IAPDR identified one correction in Annex 2 of the review.

20/169 IAPDR signed off the review and the IAPDR Secretariat will publish the review on the website.

20/170 **Action: IAPDR Secretariat to publish the review on the website.**

Post meeting note: The IAPDR review is available on the IAPDR website document library [here](#).

IAPDR Membership Terms

20/171 The Chair noted the retirement from IAPDR of the representatives from the Royal College of General Practitioners and the National Institute of Health Research, Ralph Sullivan and Jane West, respectively, at the end of 2020. The Chair commented that there is a clear requirement to identify replacements once the future of the Panel has been established following

the transition of PHE. The Chair confirmed that PHE has indicated that there is an ongoing requirement for IAPDR in 2021 at a minimum and possibly into the successor organisations of PHE, including NIHP. PHE were supportive of seeking further nominations to refill the posts and to maintain the committee at its full strength. With this in mind and together with IAPDR Secretariat, the IAPDR Chair will be asking the two bodies concerned to provide nominations for replacement members.

- 20/172 IAPDR members expressed, given the withdrawal of the representative on the Panel from the Office of the National Data Guardian and the lack of a replacement, that the Panel is lacking in-depth independent legal, ethical and data governance expertise and that this would need to be addressed urgently. The IAPDR noted that thinking about who and where to make the approach to fill this particular area of expertise needs to be actioned.
- 20/173 **Action: IAPDR Secretariat and Chair to ask the Royal College of General Practitioners and the National Institute of Health Research to provide nominations for replacement members.**
- 20/174 **Action: Jane West and Ralph Sullivan to share suggestions of possible replacements.**
- 20/175 **Action: IAPDR members to think about who and where to make the approach to fill the in-depth independent legal, ethical and data governance gap of expertise.**
- Date of the next meeting
- 20/176 The IAPDR Secretariat reminded IAPDR to complete the doodle poll with their availability for the date of the next meeting.
- 20/177 The IAPDR Chair closed the meeting, thanking members for their involvement.

Actions

Reference	Action	Owner
20/145	IAPDR Secretariat to circulate the Rapid Registrations data dictionary	IAPDR Secretariat
20/154	IAPDR members to start defining what deliverables they would like to see reported based on the new data management system.	All
20/167	IAPDR Chair to table the review on the agenda of the next DRAB meeting and ensure the acting CEO receives a copy.	IAPDR Chair
20/170	IAPDR Secretariat to publish the review on the website.	IAPDR Secretariat
20/173	IAPDR Secretariat and Chair to ask the Royal College of General Practitioners and the National Institute of Health Research to	IAPDR Secretariat and Chair

	provide nominations for replacement members.	
20/174	Jane West and Ralph Sullivan to share suggestions of possible replacements.	Jane West and Ralph Sullivan
20/175	IAPDR members to think about who and where to make the approach to fill the in-depth independent legal, ethical and data governance gap of expertise.	All