



Independent Advisory Panel on Data Release (IAPDR) OFFICIAL

Title of meeting Independent Advisory Panel on Data Release
Date 15 March 2021
Time 15:00 – 17:00
Venue Microsoft Teams

Attendees

Professor David Forman	IAPDR Chair
John Marsh	Patient and Public Involvement Representative (IAPDR Deputy Chair)
Judith Bisatt	Patient and Public Involvement Representative
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
XXX	Public Health England (Item 5 only)
XXX	Public Health England (Item 5 only)
XXX	Public Health England (Item 5 only)
XXX	Public Health England (Item 5 only)

Apologies

Bryan Deane	Association of the British Pharmaceutical Industry
Russell Viner	National Institute for Health Research

1. Chair's welcome and attendance

21/001 The IAPDR Chair welcomed and thanked members for their attendance. Apologies were received from Bryan Deane and Russell Viner (newly appointed representative of NIHR).

2. Minutes of the last meeting and matters arising

21/002 IAPDR reviewed the minutes of the previous meeting and no corrections were identified. IAPDR asked for clarification on the post meeting note outlining that

user testing identified some minor issues with the import of live data in the new data management system. The ODR noted that the system mis-transposed dates which affected the order of amendments in the system. It was noted that the data was re-imported following some checks and the system is planned to go live imminently following data cleaning.

21/003 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.

21/004 The matters arising were discussed as follows, unless otherwise itemised on this agenda:

21/005 *20/145 – IAPDR Secretariat to circulate the Rapid Registrations data dictionary*

This action was completed. The ODR noted that following stakeholder feedback NCRAS plans to update the Rapid Registration Data Dictionary to include additional variables. Such revisions will be circulated to the Panel once they are published.

21/006 **Action: IAPDR Secretariat to circulate the revised Rapid Registrations data dictionary.**

21/007 *20/154 – IAPDR members to start defining what deliverables they would like to see reported based on the new data management system*

This action is ongoing. It was noted that input was received from John Marsh.

21/008 *20/167 – IAPDR Chair to table the review on the agenda of the next DRAB meeting and ensure the acting CEO receives a copy.*

The Chair confirmed that the CEO has received a copy, however there has been no information about upcoming DRAB meetings to table the review on the agenda.

21/009 **Action: IAPDR Secretariat to follow up on proposed dates for the next DRAB meeting with Chair.**

21/010 *20/170 – IAPDR Secretariat to publish the review on the website.*

This action was completed and the IAPDR Secretariat confirmed the report was announced on the ODR's relevant communications lists.

21/011 *20/173 – 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.*

This action was completed. The Chair noted that a new member, Professor Russell Viner, has been appointed as the new representative of the NIHR School for Public Health Research. It was noted that the IAPDR Secretariat is in contact with RCGP to nominate a new representative following Dr Sullivan's retirement from the Panel.

21/012 **Action: IAPDR Secretariat to follow up with RCGP to seek new nomination.**

21/013 20/174 – Jane West and Ralph Sullivan to share suggestions of possible replacements

This action was completed.

21/014 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

IAPDR Chair confirmed that the Panel previously had a representative from the Caldicott group who stepped down and due to a lack of resources, the group were unable to provide a nomination for a replacement. It was noted that IAPDR members should carry on thinking about possible organisations or individuals who could fill the in-depth independent legal, ethical and data governance function within the group, as part of the wider thinking on the future of the Panel as PHE transitions into NIHP and successor bodies.

21/015 **Action: IAPDR members to continue thinking about possible organisations or individuals who could fill the in-depth independent legal, ethical and data governance function within the group**

3. ODR – update on activity

21/016 The Office for Data Release (ODR) provided an overview of business activity through the year to date; noting that there were 356 new requests covering amendments, applications and pre-application support. The ODR supported an excess of 90 releases through business as usual activity.

21/017 It was noted that the ODR is working with the PHE communications team to secure a grid date to publish the COVID Approvals Data Release Register in April. The ODR indicated that for reporting purposes, the COVID Approvals Data Release Register will cover all requests the ODR has supported which underpin data releases, due to the various frequencies data is released depending on the need of customers, ranging from daily to monthly.

Post meeting note: The draft COVID Approvals Data Release Register is subject to Ministerial approval and the constraints on publishing during purdah.

21/018 The ODR indicated that activity during Q4 has focused on the digitisation of the approvals process to ensure the new data management system is fit for purpose with a view for the system to go live imminently. The ODR reflected that the new data management system includes data updated until the end of September 2020 and that the most up-to-date data will be transposed into the new system following data cleaning. It was noted that external communications tools have been updated, including the ODR data request form which has a 'drag and drop' functionality that was showcased at the last IAPDR meeting. The ODR reflected that this feature was received positively, and activity is now focused on ensuring the rest of the pre-application pack is visible online.

- 21/019 IAPDR were reminded to define the standard reporting they would like to see from the new data management system. It was noted that IAPDR would not be able to gain access to the system currently, however the ODR reflected that the ambition is to incorporate public facing modules to make the Data Release Register more dynamic and to include a portal for applicants to check their application status.
- 21/020 **Action: IAPDR members to define the deliverables they would like to see reported based on the new data management system**
- 21/021 The ODR noted that a significant extent of the ODR's current activity is focused on supporting transition planning, particularly the articulation of risks for PHE and receiving organisations. The ODR has supported the drafting of an options appraisal for senior colleagues looking at different options for the future of ODR based on critical assumptions of possible destinations of PHE assets and how the ODR can best leverage the capability of its workforce going forward.
- 21/022 The ODR reflected that within its current portfolio, there are 211 active requests, compared to 176 previously reported. It was noted that the increase in activity has been due to greater interest in new products which have gone live, including updates to CancerStats, revisions to the Rapid Registrations Cancer data dictionary and the emergence of wave 9 of the Cancer Patient Experience Survey.
- 21/023 The ODR noted that the proportion of headline activity that relates to cancer is 90%, which is the same as previously reported. The ODR reported that there has been a shift over the past month as the role of the ODR across the broader organisation has become clearer and as a result, there has been more requests to access cardiovascular disease, HIV, and biobank tissue sample data.
- 21/024 IAPDR raised concerns about the pressures on the ODR and its ability to provide timely access to data. IAPDR expressed that there is a lack of transparency regarding the data that has been released for both COVID and non-COVID purposes since September 2020. The ODR noted that the reported measures do not include counts of COVID-specific requests and the prioritisation of COVID activities is consistent across organisations other than PHE. It was noted that since the start of the COVID-19 pandemic and in addition to business as usual activities, the ODR has facilitated an excess of 330 contracts specifically for COVID purposes and that data access is dependent on the need of customers, ranging from daily to monthly. IAPDR reflected that the 211 active requests figure is a major underestimate of the amount of activity that ODR is currently engaged with.
- 21/025 IAPDR reflected that secondment requests for data analysts to provide additional support to the ODR was previously discussed and concerns were raised regarding the subsequent response times. The ODR reflected that both COVID and the transition of PHE has occupied the attention of the senior leadership, however it was noted that the request has since been approved by the NDRS leadership and business management teams and is pending final sign off from finance. The ODR indicated that the post could be filled

within the next month if the initial internal advertisement is successful, however it may take longer for external advertisements.

4. External engagement (Goldacre Review; H&SC Data Strategy; Data Alliance Partnership; Article 40 code of conduct)

- 21/026 IAPDR Chair noted that the Goldacre Review is considering many of the broader issues that IAPDR have discussed, including concerns about where data is held, the DARS process in NHS Digital and linkage of different datasets held by different organisations and data custodians. It was further noted that HDR UK, among many others, have contributed to the review process.
- 21/027 It was noted that the Data Alliance Partnership was convened by NHS X and considers how national bodies improve the access and sharing of data between NHS Trusts as well as outward to the research community. It was acknowledged that HDR UK is represented on the Data Alliance Partnership group and the UK Health Data Research Alliance group, including the Data Access Partnership Board and the Data Access and Sharing Task and Finish Group. IAPDR discussed whether it may be suitable to feed into these groups about the issues regarding the destination of PHE data.
- 21/028 IAPDR discussed the Article 40 code of conduct which has been set up for the sharing of health data for secondary uses and it was noted that it is in a relatively early stage of development. It was further discussed that the H&SC Data Strategy is due to be shared in draft form for wider consultation. It was noted that the Strategy references the Goldacre Review and includes a chapter on artificial intelligence.
- 21/029 The ODR noted that there are a number of workstreams around data access specifically for COVID and a number of Trusted Research Environments (TREs) that PHE are involved with to ensure there are easily accessible TREs for researchers to gain greater insight and knowledge of COVID without the involvement of PHE, such as the ONS TRE which includes links to COVID data, ONS household survey data and variant data. It was acknowledged that this will also relieve pressures on PHE.

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

- 21/030 The IAPDR Chair welcomed the Central transition team to present an overview of the transition and opportunities to influence the data sharing strategies of new host organisations. IAPDR discussed, in the context of PHE data assets, the risks, governance and timelines of transition and the impact IAPDR could have:
- It was noted that all data assets will be kept *in situ* whilst a phased transfer of data assets is planned. The aim is to ensure that access to data is retained from the 1 October 2021 when functions and people transfer. The Central transition team emphasised that conversations with receiver organisations will be important to the transfer of non-health protection assets, and the complexity of those assets and

systems will determine the speed at which PHE can disaggregate them.

- IAPDR expressed that focus seemed to be on existing data assets and internal users that already have access. IAPDR questioned whether consideration has been given to 1) external users of data and its recipients; 2) how new requests for data access will be handled during the transition period; and 3) the capacity of potential receivers to onboard and provide further access to the data.
- It was expressed that the Central transition team are aware of the issues IAPDR have raised and that these issues will be addressed throughout the transition process. It was acknowledged that sharing data externally is a key function that is being considered, particularly when identifying where functions would be best placed so that external stakeholders seeking or requiring access to data can continue to do so during the transition process.
- The transition team confirmed that transitional solutions will be sought for sharing data and managing the applications for data access in order to mitigate possible delays in timescales and to ensure that data access is not disrupted. It was discussed that future potential technological and longer-term solutions such as cloud-based systems where access is easily facilitated would be explored as part of the design activities.
- It was noted that the Public Health Reform Programme involves different levels of governance to enable a proportionate handling of risks arising from the data transition programme. It was further noted that there will be additional governance and workstreams set up to work alongside receiver organisations, such as NIHP and NHS Digital, to ensure the transition team feed in at the right point and make decisions about risk at the right level. It was noted that the transition team have had ample opportunities to influence the agenda of the data project board to raise the profile of data sharing. It was confirmed that decisions around where functions and people will move to will be made by Secretary of State.
- It was confirmed that there is a policy document due to be published at end of March which will set out broadly what is happening across the whole Public Health Reform programme and give a sense of direction in terms of where the functions are going, including the NDRS transfer of service and functions. It was noted that the report will not include details of particular data assets and their receiver organisations.
- The transition team noted that the Goldacre Review, NHS X Data Strategy and the Health and Social Care Bill are critical pieces of work that are being considered at both an institutional and broader system level to shape transition, identify future opportunities for data sharing and create a future vision for data in non-health protection areas.
- IAPDR Chair noted that the assumption is that there is a nascent function within NIHP for managing the release of data to external stakeholders. IAPDR discussed whether the advisory function of the Panel should be provided within both NIHP and other receiver organisations of PHE data assets going forwards. It was noted that the transition team will highlight the benefits of the IAPDR in future discussions regarding the design of NIHP, which going forward will require a function that releases data at scale.

21/031 The PHE transition team agreed to present an update to IAPDR at the next meeting following interest from the Panel.

Post meeting note: The policy paper 'Transforming the public health system: reforming the public health system for the challenges of our times' was published on 29 March 2021 and is available online [here](#).

Post meeting note: The UK Health Security Agency (UKHSA) has replaced the National Institute of Health Protection (NIHP) title.

6. Any other business

COVID Approvals Register

21/032 The ODR noted that the COVID Approvals Register is a record of the organisations PHE has shared data with during the pandemic rather than every time a release was made due to the various frequencies data is released depending on the need of customers.

21/033 It was noted that the COVID Approvals Register will be reviewed by the Incident Director prior to anticipated publication in mid-April and there will be an update to the register to follow which will include a summary of the modelling work that has involved COVID data.

Data Release Register

21/034 IAPDR Secretariat confirmed that the Data Release Register will be updated towards the end of April and will include all releases made up until the end of March 2021.

Post meeting note: It is anticipated the Register will be published on 10 May 2021 following the end of purdah.

Date of the next meeting

21/035 The IAPDR Secretariat reminded IAPDR to complete the doodle poll with their availability for the date of the next meeting.

21/036 The IAPDR Chair closed the meeting, thanking members for their involvement.

Actions

Reference	Action	Owner
21/006	IAPDR Secretariat to circulate the revised Rapid Registrations data dictionary	IAPDR Secretariat
21/009	IAPDR Secretariat to follow up on proposed dates for the next DRAB meeting with Chair	IAPDR Secretariat
21/012	IAPDR Secretariat to follow up with RCGP to seek new nomination	IAPDR Secretariat

21/015	IAPDR to continue thinking about possible organisations or individuals who could fill the in-depth independent legal, ethical and data governance function within the group	All
21/020	IAPDR members to define the deliverables they would like to see reported based on the new data management system	All