



Independent Advisory Panel on Data Release (IAPDR) OFFICIAL

Title of meeting Independent Advisory Panel on Data Release
Date 04 December 2019
Time 10:30 – 15.15
Venue Wellington House, 133-135 Waterloo Road, London

Attendees

Professor David Forman	IAPDR Chair (until item 7)
Jane West	National Institute for Health Research
John Marsh	Patient and Public Involvement Representative (IAPDR Deputy Chair)
Judith Bisatt	Patient and Public Involvement Representative
David Seymour	Health Data Research UK
XXX	Secretariat
XXX	Secretariat

Apologies

Anne Stebbing	Office for the National Data Guardian
Carole Longson	Association of the British Pharmaceutical Industry
Brian Deane	Association of the British Pharmaceutical Industry
XXX	Office for Data Release
Ralph Sullivan	Royal College of General Practitioners
Caroline Cake	Health Data Research UK
Mike Sandys	Faculty of Public Health
Nicola Keat	NCRI
Ify Sargeant	Patient and Public Involvement Representative

1. Chair's welcome and attendance

19/198 The IAPDR Chair welcomed members of the IAPDR. Apologies were noted from:

- Anne Stebbing
- Carole Longson
- Caroline Cake
- Mike Sandys
- Nicola Keat
- Ify Sargeant
- Ralph Sullivan
- Office for Data Release

19/199 The Chair summarised changes to the representatives of the following professional communities:

- ABPI (Carole Longson to be replaced by Brian Deane)
- HDR_UK (Caroline Cake to be replaced by David Seymour)
- Faculty of Public Health (Mike Sandys to step down)

2. Minutes of the last meeting and matters arising

19/200 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.

19/201 IAPDR noted that the ODR webinar series had been rebranded and ODR had observed a considerable increase in uptake.

19/202 The matters arising were discussed as follows, unless otherwise itemised on this agenda:

19/203 *19/159 - IAPDR Secretariat to circulate a link to the IAPDR website and document collections on Gov.uk.*

IAPDR Secretariat had completed this. Action closed.

19/204 *19/164- IAPDR Secretariat to revise terms of reference (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 outlined in 19/163 and (4) all references to 'the Panel' to 'IAPDR' for consistency.*

IAPDR Secretariat had completed this and the terms of reference had been approved by Chair's action and published on the IAPDR pages of Gov.UK. Action closed.

19/204 19/168 - IAPDR Secretariat to update the terms of reference 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'.

IAPDR Secretariat noted that this change had been made and raised reservations about the handling on deputies in lieu of access to Official-Sensitive' documents, with specific handling instructions.

19/205 The IAPDR Chair noted that concerns raised about the handling of Official Sensitive documents by deputies should be considered outside of the meeting to ensure appropriate controls are in place, while also optimising the expertise of external communities.

19/206 Action: IAPDR Secretariat to liaise with the IAPDR Chair to agree approach to the handling of Official-Sensitive documentation by approved deputies.

19/207 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 have made the attendance grid available to the IAPDR Chair and Deputy Chair. A copy has also been added to the IAPDR Sharepoint.

19/208 19/176 - IAPDR Chair and Deputy Chair to draft questionnaire for circulation to applicants engaged in the IAPDR spotlight audits prior to the next meeting.

The questionnaire has been drafted and sent out to principal investigators (PIs) of the two applications selected for the spotlight audits (item 5). The questionnaire is currently a Microsoft Word document and needs to be redeveloped as a web tool.

19/209 19/184 - ODR to report back to IAPDR on progress made with the development and deployment of a stakeholder survey at the next IAPDR meeting.

Itemised as Item 6.

19/210 19/192 - IAPDR Secretariat to circulate the UPD presentation to IAPDR members

IAPDR Secretariat had completed this. Action closed.

3. Accessing Screening histories from the National Bowel, Breast and Cervical Screening Programmes for secondary purposes; and

potential for linkage to the National Cancer Registration and Analysis Service (NCRAS)

- 19/211 The IAPDR Chair introduced the item, noting that feedback had been received from PHE stakeholders regarding difficulties reported in obtaining access to linked screening-cancer registration data for research purposes. These concerns had further been mirrored in a recent independent review of national cancer screening programmes in England by Professor Mike Richards. The IAPDR Chair noted that it was felt members would benefit from understanding the interactions between the Programmes and NCRAS, so recommendations could be made to the Data Release Assurance Board in support of improved data access.
- 19/212 IADPR received presentations from the PHE Screening Programmes and National Cancer Registration and Analysis Service.
- 19/213 PHE Screening Programmes provided an overview of the delivery of the three cancer screening programmes and interactions between PHE, NHS England and deliver of the programmes by NHS providers. IAPDR noted ongoing work with NHS X and NHS Digital (a supplier of ICT systems to PHE) to improve data capture, system architecture and future proof the integrity of screening's digital delivery of the Programmes. It was noted that transitioning the cervical screening to a new system was the primary focus of work with NHS X and NHS Digital at this time. However, in recent years, substantial development was necessary within the bowel programme to support the population roll out of faecal immunochemical testing (FIT), as a replacement for the guaiac FOBt.
- 19/204 It was noted that each of the cancer screening programmes operates within its own distinct digital environment; with some programmes having legacy arrangements (lots of systems which speak to one another) and others being integrated as a single, national system.
- 19/215 The interactions between the different systems involved in the screening pathway were discussed for each of the cancer programmes, including ongoing work to streamline the cervical programme from 83 instances of a system to a single national approach, and work since 2016 to create Breast Screening Select, which now curates a single record per woman for most of the breast screening pathway. It was further explained that these systems are provided by NHS Digital, acting under instruction of Public Health England - therefore when changes are made, these have to be commissioned in partnership with NHS Digital and this process can take considerable time to negotiate.
- 19/216 It was noted that one of the issues being discussed within the programme that is influencing changes to systems include the impact of telemedicine (such as GP at hand) and assignment of registered patients, using digital GP services, to the correct geography, as well as the roll out of HPV test, high risk surveillance (such as identified through

the Breast Screening after Radiotherapy (BARD) project), changes to the 2013/14 operating model and British Society of Gastroenterology guidelines on appropriate screening intervals for colorectal cancer.

- 19/217 Arrangements for sharing data with NCRAS were discussed and examples, such as routes to diagnosis analyses, provided as the output of this exchange.
- 19/218 Opportunities, including the development of a simulacrum, to support data access were also discussed.
- 19/219 IAPDR received a second presentation from the Head of Cancer Analysis with the National Cancer Registration and Analysis Service.
- 19/220 An overview was presented about the role of the National Cancer Registration and Analysis Service (NCRAS) in curating data to enable the complete case ascertainment of invasive and certain non-invasive tumours for the resident population in England. The history of NCRAS and organisations that were merged as part of the registry modernisation in 2013 was further explored as background, with a timeline of how different bodies have emerged or combined since registration in England commenced at a population level.
- 19/221 It was explained that, since 2015, cancer registration and analysis (previously provided by the National Cancer Intelligence Network) were controlled through a single management system.
- 19/222 IAPDR was provided with an overview of the mandatory data standards the are imposed as part of the NHS contracts and the flows of additional data sources (such as hospital episode statistics). Together this information supports the registration of over 400,000 cases per year and supports outputs, such as national statistics, audits and other insight for the NHS and public.
- 19/223 Examples were provided about how these outputs include PHE Screening Data – such as the routes to diagnosis analysis, which categorises how a tumour is diagnosed into one of eight distinct pathways. This has been considered a flagship project and is often cited by Government. It was explained that in a typical year, there were over 200 outputs (including peer review publications). It was noted that NCRAS is also a delivery partner in a range of screening research programmes, including the lung cancer screening trial in London, COloRECTal Repository (CORECT-R), the Age Extension Trial (Age X trial) and the ongoing evaluation of the efficacy of the HPV vaccination in reducing HPV-related cancers.
- 19/224 Questions were raised to the speakers about the ways both teams interact with one another and IAPDR re-iterated feedback received from stakeholders regarding data access.

- 19/225 The speakers confirmed that summary data on screen-detected cancers is available via NCRAS, however more rich data about each screening episode is not currently. It was broadly agreed there would be merits in NCRAS receiving this data, however for a number of research programmes, academic researchers are interested in all screened participants, not just those identified to have a registerable tumour.
- 19/226 IAPDR considered the role of the PHE Screening Research Advisory Committees (RACs) and how these RACs interact with the Office for Data Release. The objectives of the RACs were broadly summarised by as follows:
- support and advise the programmes in relation to research, evaluation and audit, and ensure any secondary purpose does not adversely affect the uptake, acceptability and delivery of the programmes
 - review the scientific merit and feasibility of research, evaluation and audit applications, and requests for data, and their impact on the programmes
 - determine which research, evaluation and audit applications will have access to individuals invited as part of the programmes
 - seek appropriate professional advice on applications where required, for example from PHE's head of research and development
- 19/227 It was noted that the terms of reference of the RACs had been rationalised within the last 18 months, however the committees remain operationally different. Each RAC has a multi-disciplinary membership, of which many of the applicants for screening data are members.
- Post meeting note: the RAC terms of reference are available here: <https://www.gov.uk/government/publications/nhs-population-screening-research-and-data-requests-terms-of-reference/research-advisory-committees-terms-of-reference>*
- 19/228 IAPDR agreed that access to screening or screening-linked NCRAS data offers considerable opportunities to enhance the early diagnosis of cancer and health service research. IAPDR considered how improvements could be made to internal approval systems and whether the role of the RACs was restrictive, not conducive to supporting high quality research, audit or evaluation. It was agreed that the RACs serve an important function in this landscape; however, IAPDR agreed that the perceived lack of integration between different PHE functions and the addition of this process, may be prohibitive to research being delivered at pace. IAPDR further expressed that the difference in reported time from application to data access for screening data is concerning; and signalled that approaches, such as development of standalone research databases should be considered to support observational research and lessen the risk to operational systems.

19/229 IAPDR agreed to reflect on the conversations had and to raise their concerns to the Data Release Assurance Board.

19/230 Action: IAPDR to table discussion about access to screening and screening-linked NCRAS data at the next Data Release Assurance Board meeting.

4. ODR mid-year review (Enclosure 002)

19/231 The Office for Data Release presented a paper summarising activity during the first 6 months of the financial year. IAPDR was asked to

- a) note the year to date business trends for the Office for Data Release.
- b) comment on the metrics the IAPDR would like to be built into the ODR Application Management System for future reporting.

19/232 The ODR noted that during this period, it has received 36 valid applications, 44 amendment requests and a further 112 enquiries. Further analyses, including the proportion of customers from different organisation types and proportion of research requests were also discussed.

19/233 The ODR noted that during this period 84 releases had been made and reflected that this was a slight decline on the equivalent period in the previous year, though anecdotally reflecting a change in the proportion of staggered releases (where large data requests are split into constituent tables, released over multiple days).

19/234 IAPDR discussed the availability of metadata on non-cancer related datasets and considered if this influenced the type of requests made to ODR. It was noted that while the number of applications for data have remained predominately for cancer registration data; the case mix of enquiries has broadened and ODR is more often handling requests to access data from surveillance systems about hospital acquired infections, notifiable pathogens and flooding data.

19/235 IAPDR discussed the time from application to data access and requested that future analysis was descriptive of why an application has breached 60 working days. It was further agreed that the proportion of applications resolved in less than 40 working days was positive.

19/236 The ODR provided an overview of work with the NDRS development team to develop a new application management portal. It was noted that the beta site was now in test phase and work was underway to migrate existing data into this new environment to support a seamless transition from the legacy system. IAPDR noted that the focus of the current sprint is to develop a minimum viable product to transition from the legacy system; however, the longer-term ambition is to have a customer facing portal, which digitises the end-to-end process of ODR requests and of

requests to the Screening (or other specific) research advisory committees.

- 19/237 IAPDR welcomed the report and expressed that for the end of year review more comparative analysis would be welcome to consider temporal trends, as well as information about any backlog and requests that are rejected.
- 19/238 IAPDR welcomed the development of the new operating system and reflected that any customer facing portal should embed opportunities to curate timely feedback, to continually measure satisfaction with ODR and broader PHE services.
- 19/239 Action: ODR to invite the NDR development team to showcase the new data management system at the next IAPDR meeting.

Post meeting note: NDR development team welcome this invitation; however is not available on March 12th.

5. Spotlight audits of data access and customer perception (Enclosure 003a and 004a)

- 19/240 The IAPDR Chair introduced the item and explained that the IAPDR had agreed to conduct spotlight audits of 2 or 3 studies where data have been requested from PHE, with the aim to find out users' experiences in obtaining the data, the advice/support received from ODR, frustrations in the process and suggestions for improvement. It was noted that the IAPDR Chair and Deputy Chair had randomly selected two applications – one that was resolved and in receipt of PHE data and one where access to data was under consideration and/or pending release. The IAPDR Chair noted that two applications had been selected and the investigators leading these projects had been contacted.
- 19/241 **Spotlight 1: University of Cambridge**
- The Office for Data Release provided an overview of an ongoing application from the University of Cambridge; summarising the timeline for key milestones and pinch points experienced by both ODR and the application. It was noted that IG requirement had been met and the applicant had experienced funding issues to support their research programme.
- 19/242 IAPDR Chair noted that the University of Cambridge did not respond to the audit questionnaire by the deadline. IAPDR agreed that the applicant would be contacted again by the IAPDR Chair, reflecting the usefulness of their feedback in understanding how PHE could transform its services.

19/243 Action: IAPDR to contact University of Cambridge to remind them of the value of their feedback and should this be returned, the feedback to be circulated to IAPDR members.

Post meeting note: Following a reminder shared by the IAPDR Chair, the University of Cambridge shared their feedback. Their response has been circulated to members.

19/244 **Spotlight 2: Southampton City Council**

The Office for Data Release summarised an application received from Southampton City Council for the conduct of a health equity audit. It was noted that this application was now resolved and the council are in receipt of the required data – controlled under contract.

19/245 The IAPDR Chair noted that feedback was provided by the applicant and the applicant had request this feedback was not shared directly with the Office for Data Release. The feedback was discussed as closed business.

19/246 Action: IAPDR to will draft a response letter to Southampton City Council to explain the process better and share it with ODR before it is sent out

6. Update on extending the reach of NDRS communications and the use of a standard citation

19/247 IAPDR received a verbal update from Head of Strategic Engagement and Development, about ongoing work to improve the transparency of the uses of cancer registration data. It was noted that IAPDR had previously provided their feedback on the proposed revision to the NDRS citation policy to ensure all NDRS publications clearly cite the provenance of the data. It was noted that ODR contracts also include an iteration of this citation too, which is embedded as a standard clause within the contractual frameworks used for personal identifiable or de-personalised data.

19/248 IAPDR noted that the citation statement had been refined in collaboration with Use My Data patient and public advocates, and the Plain English Campaign approached to qualify that revisions are accessible to their crystal mark. It was explained that the latter standard was not met and consideration was made to degrading the citation to appease the Plain English standard, at risk of loss of meaning.

19/249 IAPDR noted that the revised statement would be rolled out in ODR contracts and welcomed the approach taken. Questions were raised about the uptake of the current citation and it was confirmed that this wasn't measured routinely by the Office for Data Release.

7. Update on the ODR Stakeholder Survey

- 19/250 IAPDR received a presentation from the Head of Strategic Engagement and Development on an NDRS-led discovery exercise. It was noted that a commercial company, called Unboxed Consulting, which specialises in service design and digital product development had been commissioned by NDRS to aid the understanding of stakeholder needs, including perceived barriers to accessing data. It was expressed by the ODR that there is an overlap between by the proposal ODR survey.
- 19/251 IAPDR noted that the analysis commissioned deployed a number of methodologies to understand stakeholder needs, including:
- Stakeholder mapping
 - Project goals
 - User personas
 - Journey mapping
 - Risks and assumptions
- 19/252 It was noted that Unboxed has identified 12 personas, 3 user journeys created, and for future activities 5 user groups prioritised for further in-depth discovery. Stakeholders from these groups have been interviewed and the qualitative analysis of their feedback will be consolidated into a report. The final combined report should be completed by January 2020
- 19/253 IAPDR welcomed the update from NDRS and the congruence between this discovery exercise and the proposal for a survey of ODR customers. IAPDR agreed that a copy of the report should be made available to members, to highlight any barriers related to data access that they could influence.
- 19/254 IAPDR agreed an update should be provided by ODR at the next IAPDR meeting, about progress on commissioning an independent survey.

8. Any other business

A) Data Release Register

- 19/255 The ODR provided a verbal update on progress with publication of the Data Release Register. Noting that the most recent update included all releases made in Quarter 1 (01 April – 31 July 2019). For these releases, 100% of the releases included a lay summary. ODR further noted that there remain some gaps in the Register for releases made in previous financial years. ODR continues to work with stakeholders to agree appropriate summaries, which will then backfill any gaps.
- 19/256 IAPDR briefly discussed the format of the register and timeliness of publication, including the ability to dynamically search the register based on disease, event or population characteristics. The interaction with HDR-UK's programme was discussed in this context.

- 19/257 IAPDR noted that work was ongoing to prepare the next register and that any publication of the Register would need to be outside of the election period purdah.
- B) Value of spotlight audits
- 19/258 IAPDR discussed the value of the spotlight audits and members felt that this approach offered important insight into how PHE supports access to data and perceived barriers to stakeholders. IAPDR discussed the merits of selecting specific customer groups – specially that the focus of the March meeting should be on commercial and NHS Trusts.
- C) Horizon scanning for next meeting
- 19/259 IAPDR were provided with an overview of work to develop the Health Data Research Innovation Gateway and its planned soft launch. It was agreed that a more focused update on how HDR-UK is developing this product would be welcomed at the next week.
- 19/260 IAPDR requested an update from the ODR on the commissioning of a Survey on data access.
- D) Date of the next meeting
- 19/261 The IAPDR Secretariat confirmed that the next IAPDR meeting is scheduled for 12 March 2020. This meeting will be organised outside of London, at the request of members.
- Post meeting note: the next meeting will be held in Birmingham.*
- 19/262 The IAPDR Deputy Chair closed the meeting, thanking members for their involvement.

Actions

Reference	Action	Owner
19/206	IAPDR Secretariat to liaise with the IAPDR Chair to agree approach to the handling of Official-Sensitive documentation by approved deputies.	IAPDR Secretariat/IAODR Chair
19/230	IAPDR to table discussion about access to screening and screening-linked NCRAS data at the next Data Release Assurance Board meeting.	IAPDR Chair
19/239	ODR to invite the NDR development team to showcase the new data	ODR

	management system at the next IAPDR meeting.	
19/243	IAPDR to contact University of Cambridge to remind them of the value of their feedback and should this be returned, the feedback to be circulated to IAPDR members.	IAPDR Chair
19/246	IAPDR to will draft a response letter to Southampton City Council to explain the process better and share it with ODR before it is sent out	IAPDR Chair