



Independent Advisory Panel on Data Release (IAPDR)

OFFICIAL

Title of meeting	Independent Advisory Panel on Data Release
Date	01 April 2019
Time	10:30 – 15.45
Venue	Wellington House, 133-135 Waterloo Road, London

Attendees

Duncan Selbie (welcome address only)	Chief Executive Officer, Public Health England (PHE)
Professor David Forman	Chair
Anne Stebbing	Officer for the National Data Guardian
Caroline Cake	Health Data Research UK
Ify Sargeant	Patient and Public Involvement Representative
Jane West	National Institute for Health Research
John Marsh	Patient and Public Involvement Representative (Deputy Chair)
Judith Bisatt	Patient and Public Involvement Representative
Nicola Keat	National Cancer Research Institute
Sophie Newbound	National Disease Registration Service, Public Health England (guest speaker)
XXX	Office for Data Release, Public Health England
XXX	Secretariat
XXX	Secretariat

Apologies

Carole Longson	Association of the British Pharmaceutical Industry (ABPI)
Mike Sandys	Faculty of Public Health (FPH)
Ralph Sullivan	Royal College of General Practitioners (RCGP)

1. Welcome address

- 19/001 The Independent Advisory Panel on Data Release (IAPDR) were welcomed by Duncan Selbie to their inaugural meeting.
- 19/002 Duncan Selbie expressed PHE's commitment to continuously improving the administration, performance management and accountability of its data release functions to maximise the use of data in PHE's custodianship, while upholding legal obligations to safeguard the individual's confidentiality. Duncan Selbie encouraged Members to feel empowered and enabled to challenge PHE's ways of working, so that PHE can maintain and build public confidence, support legitimate uses of data in a timely and critical manner, be held accountable for its actions and continue its trajectory as a world leader in accelerating the use of health data in public health practice and intelligence.
- 19/003 Duncan Selbie expressed his gratitude to all Members for their commitment to working with PHE and further thanked Professor David Forman for his efforts in launching the IAPDR.

2. Introductions, apologies and announcements

- 19/004 The Chair welcomed Members of the IAPDR to its first official meeting and noted the apologies.
- 19/005 The Chair invited Members to introduce themselves. It was noted that summary biographies would be published alongside the minutes of this meeting on the PHE website.
- 19/006 **Action: Members to provide a short biography (c.150 words) to the IAPDR Secretariat by 15 April 2019.**
- 19/007 The Chair noted that given this is the inaugural meeting of the IAPDR, there are no minutes to be confirmed or matters arising.
- 19/008 IAPDR agreed on the tone and conduct of the meeting. Members were reminded of the general working considerations; that all voices are equal and all comments should be respected and considered, the use of jargon terminology should be limited and acronyms are to be spelled out. IAPDR Members were reminded that all questions were welcomed.

3. Feedback from the IAPDR induction day and horizon scanning for future learning

- 19/009 The IAPDR Secretariat presented a paper summarising feedback received from Members regarding the induction day, held on 18 March.

- 19/010 A total of four responses were received and it was noted that some Members had not had the opportunity to contribute their feedback. It was agreed all materials would be recirculated.
- 19/011 **Action: The IAPDR Secretariat to re-circulate materials from the induction day including PowerPoint presentation from speakers during the day.**
- 19/012 IAPDR noted that the limited feedback was broadly positive and reflected their appreciation that the induction day balanced PHE's role as a data custodian with views from external stakeholders. It was further noted that the induction day should not be seen as the final training offer. Due to the breadth and complexity of the information they were asked to engage with, it was noted that content would likely need to be revisited along with issue-specific learning as the remit of IAPDR develops.
- 19/013 It was further noted that through the evaluation form, Members were asked to identify any further documentation or training they felt would be beneficial to their role, or to aid with understanding any of the content of the induction day. Members requested further training on:
- changes to the Information Commissioners' Code of Practice on Anonymisation
 - the content of data protection impact assessments by the Office for Data Release
 - Anonymisation techniques used in Privacy by Design approaches
 - Understanding Patient Data (UPD)
- 19/014 IAPDR discussed the relevancy of these training requests and agreed that for the next meeting of the IAPDR, a representative of the Wellcome Trust's Understanding Patient Data (UPD) initiative should be invited to deliver a presentation to Members about how they are engaging with data controllers to support better conversations about the uses of health data, including the risks and rewards of its use and how data is safeguarded.
- 19/015 **Action: The IAPDR Secretariat to invite a representative from the Understanding Patient Data (UPD) initiative to deliver an educational session at the next IAPDR meeting.**
- 19/016 IAPDR discussed the materials shared with Members as part of their induction pack, including suggested reading materials and glossary of terms. The Chair noted that Members will continue to receive updates when new reference materials and terms are added.

19/017 IAPDR discussed preferences for handling documentation (such as agenda and reading materials) as well as raising discussions amongst Members under a single electronic hub to limit reliance on email exchanges. It was agreed that a SharePoint site, or equivalent, should be established to enable the IAPDR Secretariat to manage and securely share information with Members.

19/018 **Action: The IAPDR Secretariat to appraise document management systems with the Chair and assess the feasibility of implementing a system for use by Members for accessing and managing business documentation.**

19/019 The Chair expressed gratitude to Members for sharing their feedback and encourages all Members to contact the IAPDR Secretariat should they have any additional thoughts about the induction day.

4. Governance of IAPDR and scope of remit

19/020 The IAPDR Secretariat presented a paper outlining the draft terms of reference for the IAPDR and asked Members to review, amend and ratify these terms of reference (TOR). Members were also asked to review the membership of the IAPDR in light of any changes to the terms of reference.

19/021 IAPDR discussed the interactions between existing governance structures within Public Health England, including the function of the Data Release Assurance Board, lines of accountability to the PHE Management Committee, as well as the roles of the Accountable Officer, Caldicott Guardian and Data Protection Officer. Questions were put forward to the IAPDR Secretariat by Members to seek clarification on if the remit of IAPDR extended to all uses of data by PHE and any similarities with NHS Digital's Independent Group Advising on the Release of Data (IGARD). It was relayed to Members that the role and remit of the IAPDR and TORs are for the Members to decide upon and DRAB were keen not to restrict the ability of the Panel to provide challenge to PHE. It was noted that the DRAB would be the parent function of IAPDR and that DRAB would seek independent advice from IAPDR, while also encouraging Members to make recommendations for meeting agenda items outside of any direct requests for advice.

19/022 Following discussion, IAPDR agreed the following changes to the terms of references:

- Background, paragraph 3; 'Oversight' to be amended to 'Assurance'
- Background, paragraph 4: text up reflect input of PHE's professional stakeholders.

- Objective 1: text to be amended to reflect the role of IAPDR in promoting appropriate data sharing.
- Objective 2: text to be amended to remove 'fair and due process' to read, '...cultures, policies and procedures..'
- Objective 5: text to be amended to reflect advice and recommendations about communication with professional audiences who currently or are likely to request data from PHE.
- New objective to be drafted to reflect the adequacy of systems in place to audit compliance with contractual controls placed on data recipients and associated governance incidents.
- Final paragraph of objectives to read, 'the Panel will not decide PHE policy.'

19/023 It was noted the terms of reference would further be updated to reflect discussions about ways of working (Item 5). IAPDR agreed to review the modified draft by correspondence, so that a copy can be shared with members of DRAB, ahead of their next meeting in May 2019

19/024 **Action: The IAPDR Secretariat to implement the agreed changes and circulate a copy of the revised TOR for agreement of Members by correspondence.**

19/025 IAPDR discussed the scope of the membership and whether the voice of ODR customers was sufficiently represented. Concerns were raised that representatives may be too detached from the customer and consideration should be given to openly recruiting customers to the membership.

19/026 The Chair felt that the current Members representing the research community (namely the National Cancer Research Institute, Health Data Research UK and National Institute for Health Research) would provide sufficient 'customer' representation, though if required, attendance of current research academics could be requested to join a single meeting on invitation.

19/027 It was agreed that the membership would remain as documented and be revisited should there be need to in the future.

19/028 The IAPDR Secretariat noted that to facilitate dialogue between external stakeholders and the IAPDR, impartial to the Office for Data Release, Members should consider establishing a specific email account.

5. Working arrangements for the conduct of the IAPDR

19/029 The Chair introduced a series of discussion points to support the IAPDR to effectively carry its duties.

6. Appointment of Deputy Chair

- 19/030 The Chair noted his consideration of appointment of a Deputy Chair to provide support and assistance in carrying out his duties, substituting as Chair when necessary and acting as a sounding board for the conduct of IAPDR business.
- 19/031 The Chair informed Members of his recommendation to appoint John Marsh (Advisory Panel Member Patient and Public Involvement) as the Deputy Chair and asked Members to ratify this decision.
- 19/032 IAPDR agreed the appointment of John Marsh and further recommended that the Deputy Chair should be an ex-officio member of the DRAB.
- 19/033 **Action: The IAPDR Secretariat to detail within the terms of reference the role and appointment of the Deputy Chair.**
- 19/034 **Action: The Chair to write to the Chair of the DRAB to request that the Deputy Chair is invited as an ex-officio member.**

7. Ground rules

- 19/035 The Panel agreed behaviours/ground rules for the conduct of meetings (as discussed in item 19/008).

8. Frequency and timings of meetings

- 19/036 IAPDR agreed to meet in person three to four times per year; with the option for more focussed teleconference calls on specific issues. It was further agreed that meetings could be held throughout England given PHE's presence in most major cities.
- 19/037 IAPDR agreed the scheduling of future meetings should be in consideration of timings of the DRAB, so that advice could be sought from Members and relayed back to the Board effectively. Members discussed IAPDR meetings in general being 4-6 weeks in advance of DRAB meetings.
- 19/038 **Action: IAPDR Secretariat to circulate options for meeting dates for the rest of 2019 taking into consideration the scheduling of DRAB meetings.**

9. Dissemination of the minutes

- 19/039 IAPDR agreed that minutes of the meeting will be drafted within 2-weeks post meeting and circulated to members within 1 month for their consideration. It was further agreed the minutes will be

captured as separate actions and tabled at the end of the paper. This will also be maintained within a separate action log.

19/040 IAPDR agreed that the minutes of their meetings would be published to support transparency and written in an accessible format.

10. Quoracy

19/041 IAPDR agreed the quoracy of meetings to be set as 6 (half the membership plus one, including either the Chair or the Deputy Chair).

11. Appointment of proxies

19/042 IAPDR agreed that, to support consistent decision making and to preserve business continuity, the use of proxies will be at the discretion of the Chair and should be limited to an exception basis.

12. Agenda setting

19/043 IAPDR agreed the following standing items for subsequent meetings:

- Welcome and introductions
- Minutes of the last meeting
- Matters arising
- ODR performance report

19/044 IAPDR discussed whether the Data Release Register should be considered at each meeting.

19/045 Members reflected on potential methods of transposing items on to future meeting agendas. It was noted:

The DRAB will be the conduit for PHE internally to propose items to be added to IAPDR meetings when an issue arises that required independent oversight and security. This will be disseminated via the Chair or Deputy Chair of IAPDR.

19/046 Members are encouraged to liaise with the Chair should they want to request specific discussion items placed on the agenda.

13. External groups wanting to raise particular issues or complaints

19/047 Members shared their concerns regarding external groups using IAPDR meetings in a manner that bypassed standard procedures for complaint handling. IAPDR agreed that requests from external

groups to place items on the agenda of IAPDR would be reviewed on a case by case basis by the Chair.

19/048 The IAPDR Secretariat asked Members to consider the process by which external groups could contact Members and request items to be raised on the agenda. IAPDR agreed an email address should be established to permit communication between external stakeholders and IAPDR. It was further agreed this email address would be communicated publicly on a webpage dedicated to the IAPDR.

19/049 **Action: The IAPDR Secretariat is to arrange for an email account to be set up – IAPDR@phe.gov.uk.**

19/050 IAPDR agreed that call for agenda items would be made a minimum of 4 weeks prior to the meeting and final papers would be distributed to Member a minimum of 10 working days prior to the meeting.

14. Handling of classified information

19/051 The IAPDR Secretariat informed Members that through the conduct of their business there may be a requirement for Members to handle information that has been classified as 'OFFICIAL-SENSITIVE', under the Government Security Classifications. This classification applies when the compromise, loss or misuse of this sensitive information may have a significant impact on an individual, an organisation, or on government business more generally. Members considered when information they are presented with would have this classification and raise concerns on acting openly and transparently.

19/052 IAPDR agreed that it would operate in accordance with the policy on Government Security Classifications and any documents given this classification would detail the appropriate handling instructions.

19/053 IAPDR agreed that occasions may arise when discussions about 'OFFICIAL-SENSITIVE' information should be part of closed business and agreed the terms of reference should reflect this approach.

19/054 **Action: IAPDR agreed that any business classified 'OFFICIAL-SENSITIVE' should be clearly identified on the agenda and all documentation given this Government classification must be provided with handling instructions that comply with Government Policy. IAPDR Secretariat to circulate to Members a documentation explaining handling of information that has been classified as 'OFFICIAL-SENSITIVE'.**

The Panel agreed that a non-disclosure agreement (NDA) would be signed by all Members to ensure documentation can be shared with the Panel.

19/055 **Action: IAPDR Secretariat to distribute NDA forms to Members for signature prior to the next meeting**

15. PHE Conflicts of interest

19/056 IAPDR Members are asked to register any conflicts of interest with the Chair and the Chair noted that where conflicts are identified, Members or representatives of Public Health England will be asked to withdraw from meeting. Declarations had already been received from some members. It was agreed that the declaration form would be recirculated. IAPDR discussed the publication of each member's conflicts of interest and it was agreed Government policy on managing conflicts of interest would be followed.

19/057 The Chair noted that emerging, conflicts of interest linked to specific agenda items should be declared at the beginning of each meeting.

19/058 **Action: The IAPDR Secretariat to circulate declared conflicts of interest form with the minutes of this meeting.**

19/059 IAPDR agreed the Chair will maintain a register of declarations of interest in line with the PHE Conflicts of Interest Policy and further agreed this register will not be published.

16. Advice and recommendations to the Data Release Assurance Board

19/060 The IAPDR agreed that advice and recommendations would be communicated to the DRAB through the minutes of the meeting.

17. Performance report – Office for Data Release

19/061 The Office for Data Release (ODR) presented a paper summarising the interactions customers have had with the ODR over the reporting period 1 April 2018 - 31 January 2019. This analysis included the volume of enquiries, applications and amendments, the customer profile of applicants, proportion of requests by source, and analysis of the unadjusted time from application submission to release. The ODR asked Members for input on the format of the information to support their oversight of the performance of the PHE data access functions.

- 19/062 IAPDR welcomed the summary report and acknowledged analysis of the complete financial period would be commenced in line with DRAB requirements.
- 19/064 **Action: It was agreed that the Panel would review data releases made between January – March 2019, to identify the usefulness and appropriateness of reviewing releases in future meetings.**
- 19/065 IADDR discussed the volume of requests per dataset and acknowledged that further work is necessary to promote the availability of non-disease registration or screening datasets, as fewer applications were submitted for data on communicable disease, lifestyle and behaviours. Questions were raised regarding the Communications Strategy in place to highlight the value and availability of PHE data. IAPDR agreed that it would be beneficial for their learning to invite the PHE communications division to share their Strategy.
- 19/066 **Action: IAPDR Secretariat to invite PHE Communication Division to highlight their strategy to the Panel.**
- 18. Improving the visibility of how PHE communicates about processing and sharing data**
- 19/067 The Head of Strategic Engagement and Development for the National Disease Registration Service (NDRS) presented a paper describing work by the NDRS to improve communication about the use of cancer data to people and their families who are affected by cancer
- 19/068 It was noted that in July 2016, the National Data Guardian's review of the use and management of health and social care data highlighted that peoples' awareness of cancer registration, particularly those recently diagnosed with cancer needed to be improved. This resulted in the Review of Informed Choice of Cancer Registration by Cancer Research UK and Macmillan Cancer Support, which made a number of recommendations about increasing awareness of cancer registration. One such action, in response to these recommendations, was the implementation of an acknowledgement policy in all publications involving the analysis of cancer data. This acknowledgement was further included within the contractual relationship agreed with prospective data recipients. Contract clauses are in place to mandate that all organisations using cancer registry data are required to cite and credit the registry in public communications.
- 19/069 It was explained that in November 2018, NDRS was contacted by a Patient Participation Group asking that NDRS revise this mandate to place to source of the data, the patient, at the heart of

the acknowledgment – reflecting that without the patient's experience of cancer, the data would not otherwise be available.

19/070 IAPDR were asked to review proposed changes to NDRS acknowledgement policy. The Panel broadly agreed with the revised citation and recommended that (1) NDRS reflect the language used by Understanding Patient Data and (2) PHE should consider the adoption of a corporate approach to acknowledging the source of the data. It was further suggested that PHE may develop a stamp or logo to signify PHE data being used. This would ensure acknowledgement of all PHE data usage in a consistent format and support awareness of PHE's role as a healthcare data custodian.

19/071 **Recommendation:** IAPDR to recommend to PHE that a corporate approach to communicating the source of data and the role of patients should be adopted through updates to PHE editorial standards or guidance so that every publication using data can be attributed to (1) the source of the data being the individual/patient and (2) PHE being the custodian of the data, to thus promote its use.

19. MRC Regulatory Support Centre (oral report)

19/072 The Office for Data Release provided an oral update on the conduct of an impartial audit of an academic institution following a long-standing complaint. The ODR apologised that this report was not made available to members because of considerations about the handling of 'OFFICIAL-SENSITIVE' business.

19/073 It was noted that the audit was conducted by the Medical Research Centre (MRC) on the instruction of PHE as a review of PHE's conduct to support continual service improvement. Throughout the review the organisation at the centre of this customer relationship has not been contacted by the MRC.

19/074 The IAPDR recognised the sensitivities of the handling of any audit of this nature and reflected that as the academic sponsor was not engaged the handling of this information was deemed 'OFFICIAL-SENSITIVE' and would not be the subject of these minutes.

19/075 **Action: IADPR agreed that, once the NDAs were in place, the report will be circulated by the IAPDR Secretariat to the Panel and placed on the agenda for full discussion at the next meeting.**

20. Educational session: The role of HDR-UK and the emerging UK Health Data Research Alliance

- 19/076 Dr Caroline Cake, (Chief Operating Officer), Health Data Research UK (HDR-UK) presented an overview of the emerging UK Health Data Research Alliance.
- 19/077 The Panel learned that this new Alliance of data custodians, including Public Health England and NHS Digital, has been established to unlock data-driven research and innovation. Through the Alliance, HDR-UK has the ambition to make the UK a global leader in data science, providing a portfolio of tools, processes, data, capabilities and information governance that will help organisations to maximise the rich health and administrative data within the NHS to accelerate progress in medicine and encourage better access to data.

21. Any of business (AOB)

- 19/078 The next meeting of the Panel is provisionally scheduled for 10 June 2019.
- 19/079 The Chair requested a Doodle Poll to be set up to schedule IAPDR meeting dates for the financial year 2019/2020.
- 19/080 **Action: The IAPDR Secretariat to circulate dates to Panel members via a Doodle Poll prior to the next meeting.**
- 19/081 No other business was raised.
- 19/082 The Chair thanked the Panel for a productive meeting.
- 19/083 The meeting was closed.

Actions summary table:

Item #	Action	Action owner
19/006	Members to provide a short biography to the IAPDR Secretariat by 15 April 2019.	Members
19/011	The IAPDR Secretariat to re-circulate materials from the induction day including PowerPoint presentation from speakers during the day.	IAPDR Secretariat
19/015	The IAPDR Secretariat to invite a representative from the Understanding Patient Data (UPD) initiative to deliver an educational session at the next IAPDR meeting	IAPDR Secretariat
19/018	The IAPDR Secretariat to appraise document management systems with the Chair and assess the feasibility of implementing a system for use by Members for accessing and managing business documentation.	IAPDR Secretariat
19/024	The IAPDR Secretariat to implement the agreed changes and circulate a copy of the revised TOR for agreement of Members by correspondence.	IAPDR Secretariat
19/034	The IAPDR Secretariat to detail within the terms of reference the role and appointment of the Deputy Chair.	IAPDR Secretariat
19/035	The Chair to write to the Chair of the DRAB to request that the Deputy Chair is invited as an ex-officio member.	Chair
19/039	IAPDR Secretariat to circulate options for meeting dates for the rest of 2019 taking into consideration the scheduling of DRAB meetings.	IAPDR Secretariat
19/050	The secretariat is to arrange for an email account to be set up – IAPDR@phe.gov.uk .	IAPDR Secretariat
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