

REVIEW OF THE PUBLIC HEALTH ENGLAND INDEPENDENT ADVISORY PANEL ON DATA RELEASE

April 2019 – November 2020

The Independent Advisory Panel on Data Release (IAPDR) was established by Public Health England (PHE) early in 2019 to provide independent advice on the opportunities and challenges of data sharing. In particular, the Panel makes recommendations on how PHE can facilitate timely and secure access to data, conditions for use (including information governance, relevant acknowledgements and cost recovery) and how systems can be improved to best meet the needs of those who require data access for clinical audit, service evaluation and research. The Panel also retrospectively audits specific data releases. It does not routinely review or provide specific advice regarding new applications. Terms of Reference are provided in Annex 1.

The IAPDR is a multi-disciplinary group which draws together the expertise of individuals representing public and patient voices, as well as professional bodies and the research community. The membership (2019 to 2020) comprises:

- chair
- three patient and public voice representatives (one as Deputy Chair)
- a representative of the UK Faculty for Public Health
- a representative of the Royal College of General Practitioners
- a representative of the National Cancer Research Institute
- a representative from the Association of British Pharmaceutical Industries
- two representatives of the academic community, nominated by Health Data Research UK and the National Institute for Health Research
- representative of the Office of the National Data Guardian (withdrawn)

The chair and the three patient/public representatives were appointed following an open advertisement and interview process. The professional and research representatives were nominated by their respective organisations. The membership for the review period is provided in Annex 2. The Secretariat for the Panel is provided by the PHE Office for Data Release (ODR).

Following an induction day on 18th March 2019, IAPDR held its inaugural meeting on 1st April 2019. Since then IAPDR has met on a further five occasions (10th June 2019, 9th September 2019, 4th December 2019, 9th July 2020, 29th September 2020, 16th November 2020). As a result of the COVID-19 pandemic, all meetings in 2020 were held virtually. Minutes of each meeting, after approval, and other information about IAPDR are published on its website: <https://www.gov.uk/government/publications/accessing-public-health-england-data/independent-advisory-panel-on-data-release>.

A summary of the substantive items considered by IAPDR over this time period is provided in Annex 3.

At its meeting on 29th September 2020, the Panel reviewed its performance and contributions made in the period since its inception in April 2019.

Key points from review:

- **Ongoing requirement for independent advice**

The Panel is aware of the significant changes to PHE that will be made during 2021, including the formation of the National Institute for Health Protection, a new organisation that will take responsibility for health improvement and the likely transfer of the disease registration service within PHE to NHS Digital. The requirement for independent advice will need to be considered for future data release/access processes under new organisational structures and the Panel recommend that, however the future organisations would be constituted, there should be an independent mechanism to review data access processes. Obtaining data access via Trusted Research Environments and increased novel data linkages with datasets under control of others are two specific areas where an independent panel would be able to add value to PHE (and its successors) thinking on data release. There was acknowledgement that opportunities for system learning by interacting with similar assessment bodies from other organisations (such as the Independent Group Advising on the Release of Data (IGARD) in NHS Digital and the Confidentiality Advisory Group (CAG) in the Health Research Authority) to support system improvements and harmonisation could be progressed.

- **IAPDR was beginning to fulfil its brief but initiatives halted by COVID-19 pandemic**

After a slow start, the Panel became familiar with and developed a shared level of understanding concerning the complex issues around data release and how ODR functioned to provide a data access service. An initial lack of continuity in some of the professional members of the Panel may have lessened effectiveness in early meetings. This development process was halted and momentum lost when the planned sequence of meetings was interrupted by the COVID-19 pandemic.

- **Value of spotlight audits**

It was considered that the process of retrospective review (or spotlight audit) by the Panel of selected applications, with written feedback provided by applicants, was a highly successful initiative that should be maintained. The audits provided insight into challenges applicants may have experienced (or perceived) when accessing data. Moving forward, the Panel recommended that applicants should be invited to participate directly in discussions with the Panel and a 'you said, we did' feedback loop implemented to demonstrate how IAPDR has recommended specific changes to ODR's actions/process. In turn, impact would be demonstrated to specific applicants and, more broadly, through improved communications with stakeholders. Consideration by the Panel of initial enquiries that did not turn into formal applications and rejected applications should also be considered as part of the audit process. This would allow the Panel to consider the appropriateness of application rejections and whether the information available to applicants and the review

process might be improved to help more applications be successful. Avoiding wasted time (researcher and ODR) on inappropriate enquiries or applications was a key consideration.

It had been intended that audits of individual cases would be supplemented by a full 'User Survey' using an online questionnaire to gain wider feedback on the application process. Planning for this survey had commenced but was put on hold due to the pandemic

- **Extension of the brief might be beneficial.**

Panel Members recommended that some consideration should be given to extension of the brief of the Panel to include review of marginal cases prior to decision. It was recognised that this would be a significant change to ODR processes and would necessitate more frequent meetings. Prior to recommending any such decision to expand its brief, the Panel would wish to be informed of the experience of IGARD and CAG which have such a function in their terms of reference.

- **Changes to membership would be appropriate.**

Given the withdrawal of the representative on the Panel from the Office of the National Data Guardian and the lack of a replacement, it was considered that the Panel would be lacking in-depth independent legal, ethical and data governance expertise and this would need to be addressed urgently. The representatives from the Royal College of General Practitioners and the National Institute of Health Research have informed that they will be withdrawing from the Panel at the end of 2020. There will be a clear requirement to identify replacements once the future of the Panel has been established after the current PHE reorganisation.

Members also considered that the Panel would benefit from 'coal-face' experience from the research community who had experience of the customer side of applications to ODR and issues they might have in aligning ODR processes to the processes they have to follow in their own organisations.

- **Stakeholder engagement limited.**

It was acknowledged that IAPDR offers stakeholders a useful independent conduit to raise concerns about access to (or security of) PHE data resources. Proactive communication about the role of IAPDR has, however, been extremely limited and very few stakeholders have approached IAPDR directly. It was further reflected that there has been no communication from IAPDR to demonstrate how and when IAPDR has successfully influenced PHE to change its strategy or practices. The audit process and the stakeholder survey would encourage engagement and issues being raised with IAPDR improving the feedback process with stakeholders. The stalling of these initiatives as a result of the covid-19 pandemic has been, therefore, particularly frustrating. Nevertheless, Panel members continue to express enthusiasm about contributing to processes which will ultimately improve use and access to data for the direct benefit of patients. IAPDR is keen to support key messaging to ODR's prospective customers to ensure that it is clear that access is equitable and fair decisions based on application of a consistent framework.

- **A major concern was expressed about the ability of the Panel to influence the data release policy of PHE.**

Whilst the Panel was able to make recommendations on the day-to-day processes of ODR, there was a strong feeling that the Panel did not have the mechanisms to influence policy at a higher level within PHE and thus the value added by the Panel has to be questioned.

Nominally, the Panel reports to the PHE Data Release Assurance Board (DRAB) of which both the Panel Chair and Deputy Chair are members. However, DRAB has not met since May 2019 and so there is no effective upwards reporting mechanism for any policy concerns or recommendations that the Panel might wish to make. Equally there was no effective mechanism for PHE to channel questions for consideration by IAPDR.

This is a very significant constraint on the effectiveness on the Panel which should be rectified. This is likely to become more rather than less significant during the changes that PHE and its data stewardship and release responsibilities are about to experience. The Panel can give an independent view of the consequences and risks during the change process but that cannot be effective if the Panel does not have a clear and working reporting line to senior management.

Given this constraint on ability to influence policy, the Panel raised the question as to whether it had been a net burden on the workload of the ODR Team or had been helpful to the Team's operations.

Conclusions

IAPDR concluded that, prior to the COVID-19 pandemic, it had started to add value, but its effectiveness was necessarily limited by the lack of a suitable upwards reporting mechanism.

IAPDR considered that there would be an ongoing need for independent review and advice and the Panel could and would be pleased to provide that independent support but this support will be effective if and only if there is a satisfactory reporting process for the Panel.

The Panel thanked the ODR Team for the excellent support they had been given to support its activities.

Recommendations:

1. There should continue to be independent mechanisms to review data access processes however the organisations that succeed PHE are constituted.
2. Opportunities for systems learning by working cross-organisationally with bodies such as IGARD within NHSD and CAG within HRA should be encouraged.

3. Spotlight audits of specific data releases with feedback from the applicants, as initiated by IAPDR, supplemented with a full user survey should be prioritised within the data access review process.
4. Some consideration should be given to extension of the brief of IAPDR to include review of marginal cases prior to decision.
5. If IAPDR is to continue the membership should include representation from an organisation with relevant information governance expertise and from external data users. Professional bodies should be asked to renominate representatives where existing members have stepped down.
6. Proactive communication about the role of IAPDR should be facilitated within the stakeholder community.
7. The line of reporting from IAPDR to DRAB (or a similar group) should be strengthened.



Independent Advisory Panel on Data Release (IADPR): terms of reference

Purpose

These terms of reference describe the objectives and functions of the Independent Advisory Panel on Data Release (IAPDR), an independent advisory group appointed on behalf of the Accountable Officer.

Background, context and aims of the Panel

Public Health England (PHE) collects, collates and uses data on individuals, their health and wellbeing, and their interactions with the NHS, as well as data on the wider social, economic and environmental determinants of health outcomes. These data are used to enhance health care experiences for individuals, expand knowledge about disease and appropriate treatments and strengthen understanding about the effectiveness and efficiency of our healthcare system.

When sharing NHS and other data about people, their health and treatment they receive, it is critical to ensure that there are adequate safeguards in place to maintain the balance between the potential benefits of releasing data and potential risks of unduly compromising an individual's right to confidentiality.

To address these challenges, PHE established the Office for Data Release (ODR).

The ODR provides a systematic approach to reviewing requests to share PHE data with PHE stakeholders (such as universities and the NHS) where the data could identify an individual, either directly or indirectly. The ODR ensures that all data sharing complies with PHE's obligations under the:

- [Data Protection Act 2018](#)
- [General Data Protection Regulation](#)
- [Caldicott Principles](#)
- [NHS Constitution](#)
- [National Opt Out Programme](#)
- requirements of the [Information Commissioner's Office](#)

In addition, the ODR is responsible for ensuring that for all releases of data via ODR, information about who the data has been shared with and for what purpose, is made publicly available on the PHE Data Release Register.

Assurance of the policies, procedures and systems PHE has in place to support lawful and legitimate data sharing is provided by the PHE Data Release Assurance Board. The Board is accountable to the PHE Accountable Officer (the Chief Executive), who has overall responsibility for ensuring that any risks surrounding the use of PHE data are appropriately managed and mitigated.

PHE is committed to transparency, accountability, and consistency in the manner it shares data and believes that public/patient and professional voices should be at the centre of shaping how PHE supports and promotes appropriate data access, where it is lawful and legitimate to do so.

As such, the Data Release Assurance Board has formed an Independent Advisory Panel on Data Release (IAPDR) to the Board; drawing together individuals representing the public and patient voice and PHE's professional stakeholders to provide impartial advice, and challenge on the strategic and operational approaches PHE deploys to support appropriate data access for secondary purposes, such as research.

Objectives of the IAPDR

Under these terms of reference, the IAPDR will provide the PHE Data Release Assurance Board with authoritative and independent advice, and make recommendations, on:

- the effectiveness and integrity of existing PHE policies and procedures to support and promote appropriate, timely data sharing for secondary purposes
- the effectiveness and integrity of existing PHE policies and procedures to audit data recipients' compliance with conditions of access and handling of associated governance incidents
- the extent to which PHE organisational culture, policies and procedures with regards to data sharing are customer-centric and focused on improving operational delivery for service users
- the interactions, alignments and responsibilities of the Office for Data Release with other relevant services, including third party agencies (such as NHS Digital)
- the adequacy of current independent oversight, advocacy and complaints mechanisms for complaints or appeals made to the Office for Data Release
- delivering transparent and effective public and/or professional facing communication related to PHE data sharing for secondary purposes; and
- any other issues that IAPDR believe are necessary to be considered by the Data Release Assurance Board, in support of legitimate and lawful access to PHE data for secondary purposes

IAPDR will not decide PHE policy but will give advice and recommendations to the Data Release Assurance Board.

Accountability

IAPDR is accountable, via the Chair, to the PHE Chief Executive for the quality and timeliness of its advice and reports.

Membership

IAPDR shall consist of a chair and deputy and up to eight other members. The final panel size shall be dependent upon the size of the community and the need to ensure that the panel membership fully reflects the breadth of the community. Membership tenure will be for a minimum of 12 months to a maximum of five years.

Members will be appointed following an open recruitment (public and patient voice) and nomination process (professional).

A Deputy Chair will be appointed by Members.

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.

Conduct of business

IAPDR will agree an approach with the Chief Executive for carrying out its role. This will specify the content and frequency of its meeting and reporting. It is envisaged that the IAPDR will initially meet 3-4 times per year.

The quorum for the IAPDR will be half the membership plus one; including either the Chair or their appointed deputy, and a minimum of one patient and public voice representative.

Review

These terms of reference will be reviewed annually by the IAPDR. The IAPDR will also evaluate its performance at least annually and report to the PHE Chief Executive.

ANNEX 2

List of IAPDR Members

| Member | Organisation | Membership status |
|-------------------|--|--------------------------|
| David Forman | Chair | April 19 - Ongoing |
| Judith Bisatt | Patient/Public Representative | April 19 - Ongoing |
| John Marsh | Patient/Public Representative | April 19 - Ongoing |
| Ify Sargeant | Patient/Public Representative | April 19 - Ongoing |
| Dharmishta Parmar | Faculty of Public Health | July 20 - Ongoing |
| Mike Sandys | Faculty of Public Health | April 19 - July 20 |
| Ralph Sullivan | Royal College of General Practitioners | April 19 - Nov 20 |
| Nicola Keat | National Cancer Research Institute | April 19 - Ongoing |
| Carole Longson | Association of the British Pharmaceutical Industry | April 19 - June 19 |
| Bryan Deane | Association of the British Pharmaceutical Industry | June 19 - Ongoing |
| Caroline Cake | Health Data Research UK | April 19 - June 19 |
| David Seymour | Health Data Research UK | June 19 - Ongoing |
| Jane West | National Institute of Health Research | April 19 - Nov 20 |
| Anne Stebbing | Office of the National Data Guardian | April 19 - Dec 19 |

ANNEX 3

Topics discussed in IAPDR meetings (April 2019 – November 2020)

IAPDR Terms of reference, governance and working arrangements

IAPDR Spotlight Audit procedures

Improving visibility of how PHE communicates about processing and sharing data

Review of data access procedures

Mid- and end of year reviews from Office for Data Release (ODR)

ODR Data Release Register content and updates

Developing an ODR stakeholder survey

Promoting the use of PHE data collections

Developing a standard data citation for academic papers using PHE data collections

Impact of covid-19 pandemic on ODR functions

Use of NHS-X gateway for research data requests and impact on ODR

Office of the National Data Guardian consultation exercise

Future positioning of the National Disease Registration Service

Overview of PHE transition and opportunities to influence the data sharing strategies of new host organisations

Spotlight audits conducted on data access requests from:

Royal College of Physicians

Genomics England

University of Cambridge

Southampton City Council

Presentations:

The role of HDR UK and the emerging Health Data Research Alliance (Caroline Cake)

The programme of Understanding Patient Data (Natalie Banner)

Accessing cancer screening histories and linkage to NCRAS (Lucy Elliss-Brookes & Suzanne Wright)

Work to improve the transparency of the uses of cancer registration data (Sophie Newbound)