



# 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.