



Public Health
England

Protecting and improving the nation's health

Public Health England Data Release Register Guidance Notes 2017/18 v1.0

Accompanying guidance for PHE Data
Release Register 2017/18 only

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-leading science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health and Social Care, and a distinct delivery organisation with operational autonomy. We provide government, local government, the NHS, Parliament, industry and the public with evidence-based professional, scientific and delivery expertise and support.

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Executive summary

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 that affect health outcomes. These data are used to enhance health care experiences for individuals, expand knowledge about disease and appropriate treatments, strengthen understanding about the effectiveness and efficiency of our health care system and support the improvement of public health outcomes.

It is critical to ensure there are adequate safeguards to maintain the balance between the benefit of sharing data and an individual's right to confidentiality.

The Office for Data Release (ODR) is responsible for providing a common governance framework for responding to requests to access personally identifiable or de-personalised data controlled by PHE for secondary purposes, such as:

- service improvement
- surveillance
- ethically approved research

All requests to access personally identifiable or de-personalised data are reviewed by the ODR and are subject to strict confidentiality provisions in line with the requirements of:

- the common law duty of confidentiality
- data protection legislation (including the General Data Protection Regulation)
- 7 [Caldicott principles](#)
- the Information Commissioner's statutory [data sharing code of practice](#), and;
- where applicable, the [National Data Opt-out Programme](#)

Purpose of this document

This document explains what information the Data Release Register contains and clarifies any subject-specific terminology which will be helpful in interpreting the register. You can learn more about the register content, presentation and background by reading the guide to column headings, terms and abbreviations within this document.

Data Release Register

PHE is committed to informing the public about who we are disclosing data to and for what reasons. The Data Release Register is a record of all the personally identifiable or de-personalised data we have shared through the ODR with other organisations and demonstrates our commitment to openness, transparency, and accountability.

We publish details of each organisation we have released data to, alongside the type of data released, the legal basis for release and the purpose for which the data was provided.

Open data releases facilitated by the ODR are not recorded on the Data Release Register. Where it is possible to release data openly under an [Open Government Licence](#), these resources will be published and searchable through [data.gov.uk](#).

How the Data Release Register continues to evolve

PHE wants to help people understand about the use of their data. Since the launch of the Data Release Register in 2015, we have worked with patient and public representatives; listening to their unique perspectives and together, identifying ways that the Register can be enriched to improve how everyone understands how PHE data is shared.

In response to feedback and collaborating with these representatives, PHE has adapted the Data Release Register to:

- implement language used by the [Understanding Patient Data Initiative](#) to describe the identifiability of the data shared
- mandate that all releases reported on the Register are accompanied by a lay summary. A lay summary is a brief summary of the project that explains the complex technical and scientific approaches being taken in a way that a general audience can understand
- indicate whether patient opt-outs, as part of the National Opt Out Programme, have been applied to a specific release

Updates to the Data Release Register

Updates to the Data Release Register are published on a quarterly, financial-year basis.

Data Release Register tab descriptions

The Data Release Register 2017/18 is provided in a Microsoft Excel workbook. The workbook contains separate spreadsheets (or tabs) that provide an overview of the contents of the register alongside instances where data has been shared.

- tab 1: coversheet containing an overview of what the Data Release Register is and the function of the Office for Data Release (ODR)
- tab 2: summary guidance notes explaining the information being reported on the register, including key terms and abbreviations
- tab 3: data releases made for the financial year (April to March)
- tab 4: details of any amendments made to the register following publication

The Data Release Register is updated every financial quarter with details of the data releases supported by the ODR in the previous quarter. Where amendments to the register are required, they are also documented.

Column descriptions in tab 3

The Register contains 14 columns. From left to right, the definitions of the column headers are shown below. Please note that further detail is included in the 'Key terms and abbreviations' section of this document.

ODR reference: a unique reference number assigned by the Office for Data Release on receipt of an application.

Applicant's organisation: the name of the organisation receiving data as recorded on the Office for Data Release request form.

Applicant's organisation type: the type of the organisation that has applied for data from the Office for Data Release (e.g. NHS, Academic, Charity).

Technical summary: overview of the project PHE data has been shared to following ODR approval.

Lay summary overview: describes in plain English the rationale for conducting the project (i.e. why a particular question is being addressed) and why PHE data is needed for the project.

Why is this project being conducted: describes in plain English the reason for the data being disclosed to the data recipient.

How the data will be used: describes in plain English how the data recipient will use the data (including how they will analyse the data or link it to other datasets).

Anticipated public health benefit(s) and/or impact of conducting the project: describes in plain English the anticipated outcomes of the project.

Funders and collaborators: name(s) of any funders or sponsors for the project, and of any collaborators that have supported the work.

Data source: the specific PHE data collection(s) shared with the Applicant.

Type of data: this column categorises the extent to which information could be used to identify an individual. This level of identifiability is defined in accordance with best practice published by the Wellcome Trust's Understanding Patient Data Initiative. Further details can be found here: <http://understandingpatientdata.org.uk/what-does-anonymised-mean>

Category	Definition	Example
Personally identifiable	The data includes direct identifiers (e.g. name, address, NHS number, date of birth) or is coded (pseudonymised), but would be directly identifiable in the hands of the data recipient (such as by hospital number or a cohort-specific identifier). The legal basis for the Data Recipient to process personally identifying information is captured under 'Legal basis for the processing of personally identifiable information'	A patient's medication history, including their NHS number (but no contact details).
De-personalised (ICO Anonymisation Code of Practice compliant)	The data is stripped of direct identifiers but contains fields which could be used to indirectly identify an individual through combinations of information, either by the people handling the data or by those who see published results (e.g. ethnicity, sex, month and year of birth, admission dates, geographies or other personal characteristics). The data must meet the standards set out in the ICO Anonymisation:	A report that someone has suffered side-effects from a common medicine, including the patient's age and gender but with name, NHS number and date of birth removed

	managing data protection risk code of practice.	
Anonymous	<p>The data is stripped of direct identifiers and techniques such as suppression, offsetting and aggregation are applied to render the data anonymous in line with the ISB Anonymisation Standard for Publishing Health and Social Care Data.</p> <p>Where possible, data will be released under an Open Government Licence (OGL) with no further control. These releases will not be recorded on the register.</p> <p>Where the data release meets the ISB standard but controls, such as an end-user license or contracts are put in place at the request of the PHE Caldicott function, the release will be recorded on the register as de-personalised.</p>	The number of people who have been prescribed a certain medicine over ten years in five cities.

Legal basis for processing personally identifiable data: where the data released by PHE is personally identifiable, this column describes the legal basis that allows the data recipient, or a data processor acting on their behalf, to lawfully process personally identifiable data (e.g. informed consent). Where a legal basis is not required because no personally identifiable data is being shared, this column will state, 'no legal gateway required'.

National Data Opt-Out Programme applied: details on whether the preference for people to opt out of their confidential patient information being used for secondary use has been applied to the data prior to release.

Date of release: the date on which the data was released.

Description for tab 3

This tab will detail any corrections made to the Data Release Register following publication.

Terms and abbreviations

Legal basis for the release of personally identifiable information:

1. Informed consent

Any freely given, specific and informed indication of a data subject's wishes which signifies their agreement to their own personal data being processed.¹

2. Direct care

Direct care is defined as a clinical, social or public health activity concerned with the prevention, investigation and treatment of illness and the alleviation of suffering of individuals. It includes supporting individuals' ability to function and to improve their participation in life and society as well as the assurance of safe and high quality care and treatment through local audit, the management of untoward or adverse incidents, and measuring person satisfaction including outcomes undertaken by one or more registered and regulated health or social care professionals and their team with whom the individual has a legitimate relationship for their care.²

3. Regulation 2 of the Health Service (Control of Patient Information) Regulations 2002

Regulation 2 enables the common law duty of confidentiality to be overridden to enable disclosure of confidential patient information relating to patients referred for the diagnosis or treatment of cancer to be processed for the following purposes:

- the surveillance and analysis of health and disease
- the monitoring and audit of health and health related care provision and outcomes where such provision has been made
- the planning and administration of the provision made for health and health related care
- medical research approved by research ethics committees
- the provision of information about individuals who have suffered from a particular disease or condition where:
 - that information supports an analysis of the risk of developing that disease or condition
 - required for the counselling and support of a person who is concerned about the risk of developing that disease or condition

¹ Caldicott, Fiona. March 2013, 'Direct care of individuals', The Information Governance Review, p35-37,

² Caldicott, Fiona. March 2013, 'Direct care of individuals', The Information Governance Review, p35-37.

4. Regulation 3 of the Health Service (Control of Patient Information) Regulations 2002

Regulation 3 enables the common law duty of confidentiality to be overridden to enable disclosure of confidential patient information to be processed for communicable disease and other risks to public health purposes including:

- diagnosing communicable diseases and other risks to public health
- recognising trends in such diseases and risks
- controlling and preventing the spread of such diseases and risks

5. Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002

Regulation 5 enables the common law duty of confidentiality to be overridden to enable disclosure of confidential patient information for medical purposes, where it was not possible to use anonymised information and where seeking consent was not practical, having regard to the cost and technology available.

6. Data sharing contract

The data sharing contract stipulates how long the data recipient can hold the data and for what agreed purpose. The contract will also set out the obligations the data recipient must adhere to in relation to storing, sharing, using and eventually destroying data once their purpose is fulfilled.

Any data recipient found to misuse the data provided by PHE under contract would be in breach of this agreement and could also be acting unlawfully.