Public Health England

Protecting and improving the nation's health

Public Health England Data Release Register

Guidance Notes v3.0

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-class 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 are a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

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Executive summary

Public Health England 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 disclosing data and an individual's right to confidentiality.

To address the challenges of providing access to data, Public Health England established the Office for Data Release to provide a systematic approach to reviewing requests to release personal confidential data.

The Office for Data Release operates within the legal frameworks of the Common Law Duty of Confidentiality, the Data Protection Act 1998 and the Caldicott Principles.

All applicants to the Office for Data Release must demonstrate why they need access to data held by PHE, how they will use it and how they will protect it from unauthorised use, disclosure or loss.

Data Release Register

Public Health England is committed to informing the public about how we process applications for personal confidential data. The publication of a timely Data Release Register demonstrates our commitment to openness, transparency, and accountability about who we are disclosing personal confidential data to and for what reason.

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.

Subsequent updates to the Data Release Register are published on a quarterly, fiscal - year basis.

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.

Contact the Office for Data Release

If you wish to provide feedback regarding the contents or format of the register, please contact the Office for Data Release.

Data Release Register tab descriptions

The Data Release Register is provided as a Microsoft Excel workbook containing separate spreadsheets (or tabs) that provide an overview of the contents of the register alongside instances where data has been disclosed.

- tab 1 - overview of the Data Release Register and the Office for Data Release
- tab 2 - data releases for the named fiscal year
- tab 3 - details of any amendments made to the register for the named fiscal year

The Data Release Register will be updated every fiscal quarter. Fiscal years will be addressed in separate documents.

Column descriptions in tab 2

The Data Release Register contains 9 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.

Row ID: denotes the number in the register. This column denotes the position of a particular application or enquiry at the time of entry within the whole database.

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

- applications received during the 2014/15 fiscal year are denoted as ODR_2014_nnn
- applications received during the 2015/16 fiscal year are denoted as ODR1516_nnn.
- applications received during the 2016/17 fiscal year are denoted as ODR1617_nnn
- applications received during the 2017/18 fiscal year are denoted as ODR1718_nnn

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

Organisation type: category of the organisation that has applied for data from the Office for Data Release.

Purpose: this column describes what the data will be used for (such as the research question, aims and objectives).

Data source: name(s) of one or more collections or groups of data that has been disclosed to the data recipient.

Data type provided to the applicant: denotes the extent to which information could be used to identify an individual. The ODR records all releases into three categories:

Category	Definition	Example
Personally identifiable	The data includes direct identifiers (eg name, address, NHS number, date of birth, date of death) 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 release 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 (eg ethnicity, sex, month and year of birth, admission dates, geographies or other personal characteristics). The data must meet the	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

	standards set out in the ICO Anonymisation: managing data protection risk code of practice.	
Anonymised	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. 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. Where controls, such as an end-user license or contract are put in place, the release will be recorded on the register.	The number of people who have been prescribed a certain medicine over ten years in five cities.

Legal basis for the release of personally identifiable information: Where the data released is personally identifiable, this column identifies the legal basis that allows the data recipient, or a data processor acting on their behalf, to lawfully process personally identifiable data (eg informed patient consent or a statutory basis such as section 251of the NHS Act 2006). Where a legal basis is not needed, 'no legal gateway required', will be stipulated.

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

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 patient 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.

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.