



## Public Health England: what we do, how we use personal information, and your options

**This leaflet explains what Public Health England (PHE) is and does and why we need information about people's health. It also explains who we sometimes share information with, how we protect the information we use, and what your options are with regard to any information we may hold about you.**

### What PHE is and does

PHE exists to protect and improve the nation's health and wellbeing, and to 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 operationally autonomous executive agency of the Department of Health. We are not part of the NHS but work very closely alongside it. Our main responsibilities are to:

- protect the public from infectious diseases, like influenza and tuberculosis, and other hazards to health
- monitor patterns of disease like cancer, heart disease and poor mental health, and work with the NHS and others to improve their diagnosis and treatment
- work with local authorities and other bodies to reduce social, economic, behavioural and environmental risks to health and wellbeing like smoking, low levels of physical activity, obesity, poor housing and unemployment

### What information PHE uses and why

To do our job, we need information about people's health and wellbeing. This information comes from many places. Some is collected directly by us. For example, our laboratories produce test results for infectious diseases such as meningitis and tuberculosis and send this information to doctors to help treat patients and manage outbreaks of disease. We also

use laboratory test results to monitor disease trends and guide the way treatment and prevention services are provided.

We are also responsible for:

- registering cases of cancer to improve our understanding of its causes and how to treat it
- inviting eligible people to be screened for a range of cancers and other health problems (such as hearing tests on newborn babies and conditions such as abdominal aortic aneurysm) to help diagnose these diseases early
- registering birth defects in babies and other rare diseases to improve our understanding of what causes these conditions
- monitoring the use of drug treatment services to improve our understanding of patterns of drug use and the most effective treatments

Some of the data we use to do this comes from the NHS. For example, information on admissions to hospitals helps us understand patterns of heart disease among different groups of people, and to monitor the safety of new vaccines. Information from GP practices allows us to monitor the uptake of important immunisations, such as measles among children and the flu vaccine among older people.

We also use information from surveys to understand more about people's behaviour in relation to health issues such as smoking, alcohol and exercise.

In collecting this information, we have one aim — to protect and improve the health of everyone in England.

## The kinds of information PHE uses

Some of the information we use is in aggregate form, in other words, it is made up of statistics that relate to groups of people. For example, we use aggregate data to produce the many statistics we publish on health outcomes, for example the Public Health Outcomes Framework. These statistics help the NHS and local authorities identify the public health priorities for the communities they serve.

Much of the data we use relates to individuals. Sometimes this information is needed to ensure patients get the right healthcare. For example, the laboratory test results we provide to doctors help them diagnose and treat individual patients. In the case of some infectious diseases such as tuberculosis, doctors can also trace people who have been in contact with an infected patient to check whether they have been infected. We also use personal information to invite eligible people to be screened at hospital for different types of cancer.

Sometimes we need the personal details about individual patients to link different sources of information together. For example, we link records from cancer registration (which include name, address, sex, date of birth and type of cancer) with information from hospitals about the treatment offered to these patients and what the outcome was. With a better understanding of the effectiveness of different treatments, cancer services across the country can continue to improve.

When we do need to use personal information, we try to remove as much of the detail as possible that could identify an individual. For example, we replace date of birth with age in years and addresses with codes that cover larger geographical areas. When this can't be done, we always explain the reason why in the information we provide about that service.

## How PHE protects the information it uses

We take our legal and professional obligations to protect the confidentiality of patient information very seriously.

Where possible, we obtain the consent of patients to hold personal information about them. For example, we ask people who use drug treatment services if they will allow us to use their data to analyse which treatments are most effective.

When it is not possible to obtain consent, we only use personal information if we have legal permission to do so. For example, we have a number of duties under the law to collect information on infectious diseases, such as tuberculosis, that present a risk not just to the health of individual patients but to the public more widely if left untreated.

Some of the public health services we provide are under the authority of the Secretary of State for Health. For example, we use personal information held by GPs to ensure that people are invited to be screened for breast, bowel and cervical cancer at the right time.

As well as limiting the amount of personal information we hold, we make sure that our staff can only see information that is essential to their job. Some of the personal information we use is held on paper and some is held on computers. In both cases, we have processes to securely protect these records and to permanently delete any information that we no longer need to hold.

## Who PHE shares information with

Much of the information we produce is in the form of anonymous statistics published mostly through the PHE website.

We never publish information that could be used to directly identify an individual.

We only share information about individuals when the direct consent of patients has been obtained or when there is a clear basis in the law for that information to be shared. This includes the information we share with:

- doctors, to help them provide care directly to patients
- NHS hospitals, to help them provide a range of services such as ensuring that the right people are invited at the right time for the right cancer screening test
- environmental health officers, to help when they investigate food poisoning cases
- researchers, to help improve our understanding of patterns of disease and the most effective treatments (but only if they have the approval of an ethics committee and the Health Research Authority's Confidentiality Advisory Group)

## How to find out if PHE holds any information about you

If you would like to find out if we hold any personal information about you, then you can write to us at the following address: Head of Public Accountability, Public Health England, Wellington House, 133–155 Waterloo Road, London SE1 8UG or by email at [FOI@phe.gov.uk](mailto:FOI@phe.gov.uk)

To help us provide the information you want, you will need to tell us about which part of PHE you have been dealing with and why you believe we may hold information about you.

Alternatively, some of the services we provide can be contacted directly if you believe they hold information about you.

# Your personal information and your rights

The law provides you with the right to object to us holding personal information about you. We hope that in explaining the important reasons why we sometimes need to use personal information, and the careful steps we take to protect confidentiality, you will not wish to have your personal information removed from our records.

The law does not – in the wider public interest – allow patients with infectious diseases to object to their personal information being used by us. This is so we can prevent the spread of certain conditions like tuberculosis, Legionnaires' disease and severe acute respiratory syndrome (SARS).

That exception aside, you can, depending on the service concerned, ask for one of the following to happen:

- any confidential information about you to be deleted but information that doesn't directly identify you to be retained by us
- all confidential about your health and treatment to be deleted but some personal information to be retained so that we know not to use any information we might receive about you in future
- all the information held by us about you to be removed

To ask for some or all of your information to be removed from our records, you can write to us at the following address: Head of Public Accountability, Public Health England, Wellington House, 133–155 Waterloo Road, London SE1 8UG or by email at [FOI@phe.gov.uk](mailto:FOI@phe.gov.uk)

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