

The General Practice
Research Database (GPRD)

**Further Information for Patients** 

### The General Practice Research Database (GPRD)

### What is the GPRD?

The GPRD is a computerised database of anonymised data from patient records. Data have been collected continuously since 1987. Currently, information on approximately 4.8 million patients in the UK, equivalent to about 7% of the population, are collected from nearly 600 general practices nationwide.

### Who runs the GPRD?

The database is run, on a non-profit making basis, by the UK Medicines and Healthcare products Regulatory Agency (MHRA) in London. The MHRA is an Executive Agency of the Department of Health. It fulfils a critical public health role in the UK by ensuring that all medicines and medical products meet appropriate standards of safety, quality and efficacy. The MHRA has a long history of handling patient data responsibly, in the course of monitoring safety of UK medicines. Guidance from the General Medical Council strongly encourages doctors to 'co-operate by providing relevant information wherever possible' to bodies such as the MHRA.

#### What is the GPRD used for?

Information from the GPRD is used for a variety of medical and public health research purposes including:

- investigating side effects of medicines
- investigating causes of disease and medical disorders and associated risk factors
- looking into the outcomes of treatments
- · examination of areas of unmet medical need
- identifying ways of improving screening or diagnosis
- the evaluation of which services or treatments work best.

### Who uses the GPRD?

A wide range of UK and international organisations use or commission research from the GPRD. These include universities, government departments and the NHS, the pharmaceutical industry and charities. The MHRA is also a user of the database, primarily for better understanding of drug safety issues.

### Can anyone use the GPRD for research?

No. Access to GPRD is overseen by the MHRA, and is granted only to bona fide organisations with capabilities in public health research. An expert Independent Scientific Advisory Committee oversees research protocols to ensure they are scientifically valid and adhere to internationally recognised guidelines.

### Why is the GPRD important?

Public health research often requires information about large numbers of patients to be collected over many years so that rare diseases or those which take several years to develop can be studied.

The GPRD is the largest and best quality database of its kind in the world. As such, it is a major asset in the improvement of public health, both in the UK and overseas. Over 700 published studies in top quality medical and statistical journals testify to this, in areas such as heart disease, cancer, mental health, diabetes, asthma and women's health.

# Why does your practice contribute data to the GPRD?

First and foremost, your practice contributes to GPRD because of the enormous contribution the database makes to public health research. Additionally, your practice receives important feedback on the quality and completeness of data it contributes - supporting accurate recording of important medical and administrative information including registration details, medical conditions, prescribing, births and deaths. Finally, the practice receives a payment of 10 pence per patient per year, which helps to offset the administrative costs incurred as a result of participation in the scheme.

### How are the data collected?

Practice staff enable the extraction of data from the practice's computer system on a regular basis. Information is extracted about vaccinations, medicines prescribed, illnesses, investigation and test results, referrals to hospital, pregnancies and outcomes of birth, measurements such as height, weight and blood pressure as well as lifestyle factors such as smoking habits. This anonymised data is then transferred to the MHRA by secure means.

## Confidentiality and anonymity

Your clinical data only ever leave the practice in an anonymised format. However, this information may be linked with hospital or disease registry data using person identifiers. This is done in a highly secure manner by a trusted third party and, importantly, no researcher ever sees other than anonymised data.

A free text field which can occasionally contain names or hospital details is also collected. The doctors who have access to this information at the MHRA have a legal obligation to keep any such identifying information confidential. Researchers using the GPRD never have access to any information that could identify patients, their doctors or general practices.

## Can I choose not to participate in the GPRD?

Yes. If you do not want data about you to be held in the GPRD please discuss this with your GP or a member of practice staff who will mark you as 'opted out' of the scheme. We would, however, very much like to encourage all patients to participate in the scheme. The GPRD exists for the public benefit, and the research studies which are based on it are used internationally to improve public health. If significant numbers of patients opt out, the results of these research studies may be distorted and the benefit of improved public health reduced.

### How can I find out more?

Further information, including a bibliography of research papers based on the GPRD is available at www.gprd.com

# Examples of the research that GPRD is used for

The following are some of the medical papers that have resulted from research using the GPRD:

1 What is the harm-benefit ratio of Cox-2 inhibitors? van Staa TP, Smeeth L, Persson I, Parkinson J, Leufkens HG.

Int. J Epidemiol. 2008 Apr;37(2):405-13. Epub 2008 Feb 8.

This aim of the study was to determine the balance of potential harm and benefit related to Cox-2 inhibitors' exposure. The results showed that the benefit of Cox-2 inhibitors in reducing the frequency of upper GI events may be offset by their cardiovascular harm, particularly in patients with risk factors for cardiovascular disease.

2 Dopamine agonists and the risk of cardiac-valve regurgitation.

Schade R, Andersohn F, Suissa S, Haverkamp W, Garbe E.

N Engl J Med. 2007 Jan 4;356(1):29-38.

This study showed the use of the dopamine agonists pergolide and cabergoline was associated with an increased risk of newly diagnosed cardiac-valve regurgitation.

3 Risk of myocardial infarction and stroke after acute infection or vaccination.

Smeeth L, Thomas SL, Hall AJ, Hubbard R, Farrington P, Vallance P.

N Engl J Med. 2004 Dec 16;351(25):2611-8.

This study showed that acute infections are associated with a transient increase in the risk of vascular events.

4 MMR vaccination and pervasive developmental disorders: a case-control study.

Smeeth L, Cook C, Fombonne E, Heavey L, Rodrigues LC, Smith PG, Hall AJ.

Lancet. 2004 Sept 11-17;364(9438):963-9

The study showed that MMR vaccination is not associated with an increased risk of pervasive developmental disorders.



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