

ensure that linking different datasets does not lead to an increased risk of identifying patients. Note that CPRD never has access to any of the personal identifiers, and only receives the linked data with the pseudonymised CPRD patient identifier.

Can I choose not to participate in CPRD?

Yes. CPRD will not receive information on patients who have registered their dissent from their data being collected with their GP. If you have already opted out, you do not need to do anything else.

We would, however, very much like to encourage all patients to participate in the scheme. CPRD 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 CPRD data is available at www.cprd.com.

Examples of CPRD research

CPRD data has been used to define the important clinical features of bladder cancer in primary care, leading to new approaches to early diagnosis [1].

In cardiovascular disease research, CPRD has aided the discovery of an association between systolic and diastolic blood and all-cause mortality in people with newly diagnosed Type Two Diabetes, which highlighted the risks associated with blood pressure management in diabetic patients [2].

In the field of Alzheimer's disease, CPRD was used to test the hypothesis that angiotensin- renin blocking drugs might have a protective effect on the risk of dementia. Data from CPRD were used to replicate previous studies and a possible therapeutic effect was identified [3].

[1] Shephard EA, Stapley S, Neal R, Rose P, Walter FM, Hamilton WT
Clinical features of bladder cancer in primary care Brt J Gen Pract 2012X654560

[2] Eszter Panna Vamos, Matthew Harris, Christopher Millett, Utz J Pape, Kamlesh Khunti, Vasa Curcin, Mariam Molokhia, Azeem Majeed
Association of systolic and diastolic blood pressure and all cause mortality in people with newly diagnosed type 2 diabetes: retrospective cohort study
British Medical Journal 2012 345

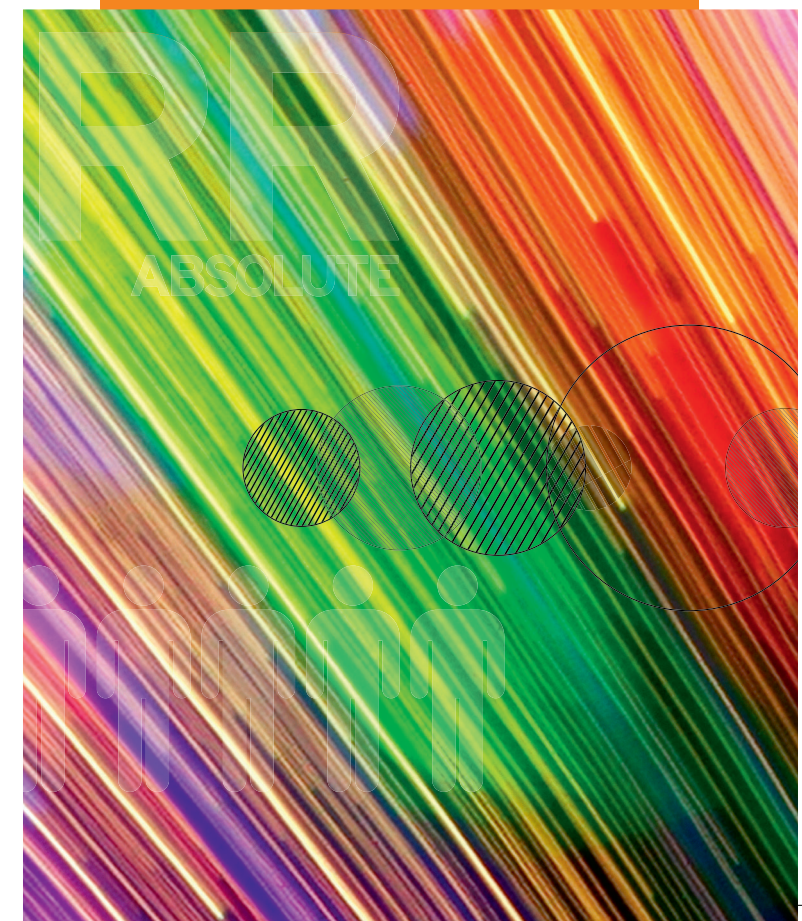
[3] Davies NM, J Kehoe PG, Ben-Shlomo Y, Martin RM
Associations of anti-hypertensive treatments with Alzheimer's disease, vascular dementia and other dementias
J Alzheimer's Dis 1 (2011) 1-10. DOI 10.3233/JAD – 2011-110347



Quality • NHS Clinical • Linkage • Real world • Randomised • PROs • Population 52M+

The Clinical Practice Research Datalink (CPRD)

Patient Information Leaflet



What is CPRD?

CPRD is a not-for-profit government organisation that makes anonymised primary care data available for approved medical research projects. CPRD services enable many types of observational and interventional research that are beneficial to improving and safeguarding public health. CPRD has over 20 years of experience working with this data with a proven track record in patient confidentiality. CPRD utilises the comprehensive 'journey of care' patient records that are unique to the NHS for the benefit of patients.

What is CPRD used for?

CPRD data is used for approved medical and public health research including:

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

Why is CPRD important?

Public health research often requires information about large numbers of patients collected over many years so that rare diseases or those which take several years to develop can be studied. The NHS is a unique resource for this unbiased information.

CPRD is the largest database of its kind in the world, which has captured high quality information for over 20 years. As such, it is a major asset in the improvement of public health, both in the UK and overseas. Over 1,000 published studies in reputable

medical and statistical journals testify to this, in areas such as heart disease, cancer, mental health, diabetes, asthma and women's health.

What data are collected?

CPRD collects all coded data such as diagnoses, treatments, referrals, results, demographics, vaccinations, pregnancies, outcomes of birth, and lifestyle factors. This includes the data of patients who are deceased or have transferred out of the practice. All data is collected electronically from GP practices who have agreed to contribute data. CPRD does not receive NHS numbers, names, addresses or post codes. Researchers will never know the identity of patients, GPs or practices that contribute.

Who uses CPRD?

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

Is CPRD safe and secure?

CPRD has been operating for over 20 years (as CPRD and its predecessor GPRD), and has an effective and approved information governance approach to security and confidentiality. The governance arrangements for the storing and use of the data are known and approved by an Ethics Committee, the Confidentiality Advisory Group (CAG), and the British Medical Association (BMA) and Royal College of General Practitioners (RCGP) Joint IT committee.

Access to CPRD is granted only to appropriate 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.

How is CPRD financed?

CPRD is funded by the NHS National Institute for Health Research (NIHR) and the Medicines and Healthcare Products Regulatory Agency (MHRA). CPRD is housed within the MHRA trading fund and operates within a global market for research services and charges users of its services to ensure costs are recovered.

Why does your practice contribute data to CPRD?

First and foremost, your practice contributes to CPRD because of the enormous contribution it makes to public health research.

Additionally, your practice receives important feedback on the quality and completeness of data it contributes. This supports accurate recording of important medical and administrative information including registration details, medical conditions, prescribing, births and deaths.

Finally, the practice receives opportunities to invite patients to participate in clinical trials and interventional studies. The practice receives financial compensation for any additional work involved.

What is data linkage?

Primary Care Data (i.e. GP data) can be linked to secondary sources such as Hospital Episode Statistics (HES) and the Cancer Registry data. This helps to improve the extent and validity of research as much of this information is not included in your GP record.

The linkage to these secondary sources is undertaken in a highly secure manner by a trusted third party that uses personal identifiers such as NHS Number to provide a link to the other datasets. We have in place robust legal controls to