

# The CPRD and the RCGP:

building on research success by enhancing benefits for patients and practices

Anonymised primary care electronic health records (EHR) have been available for research in the UK for at least two decades. The time has come for a rethink in how we coordinate the sharing of data for research, in a way that provides clear benefits for patients and practices as well as researchers. Up until now, sharing data for research provides long-term benefits for the public, patients, and practitioners as a result of the implementation of these research findings. While these benefits are clearly in the public interest, our current approach provides few immediate benefits.

### THE CLINICAL PRACTICE RESEARCH DATALINK (CPRD)

The Clinical Practice Research Datalink (CPRD) is one of the largest databases of longitudinal medical records from primary care in the world. It was established in 1987 and named the General Practice Research Database (GPRD) until April 2012. This was initially part of Value Added Medical Products (VAMP), a commercial company located in London, which was the first in the late 1980s that designed and marketed a general practice office computer system allowing for comprehensive recording of medical information for individual patients.<sup>1</sup> Electronic health databases, especially primary care data, have been used widely in health research in recent decades.<sup>2</sup> The longest standing such database is the Royal College of General Practitioners (RCGP) Research and Surveillance Centre (RSC), established in 1957. Others include QResearch, ResearchOne, and The Health Improvement Network (THIN). Such databases consist of data derived from routinely collected health records generated by daily clinical practice. Their collective impact has been enormous.

CPRD is continuously collecting anonymised clinical records from millions of individuals, currently representing almost 10% of the UK population, with demonstrated reliable research standard data.<sup>3</sup> It comprises the computerised medical records maintained by GPs in the UK. GPs play a key role in the NHS, as they are responsible for primary health care and specialist referrals; thus data recorded in the CPRD include demographic information, prescription details, clinical events, preventative care provided, specialist referrals, hospital admissions, and their

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major outcomes. All general practice encounters are recorded electronically and practitioners are encouraged to make these records available for research. This clinical picture is further complemented through secure anonymised linkage to secondary care datasets, such as hospital events or specialist registries.

### RESEARCH IMPACT USING ROUTINE DATA

Data from CPRD have been used to produce close to 2000 research reports, published in peer-reviewed journals, many of which have had a direct impact on public health, in all major therapeutic areas.

A recent study in cardiovascular disease indicative of the value of CPRD research has confirmed the importance of prescribing anti-platelet medication after myocardial infarction (MI). This study of 7543 linked patients found that discontinuing clopidogrel within 12 months after a non-fatal MI was significantly associated with increased rates of death or MI, whereas receiving a prescription for clopidogrel in primary care within 3 months of hospital discharge was associated with lower rates.<sup>4</sup> An association between systolic and diastolic blood pressure and all-cause mortality was discovered in another retrospective cohort study of 126 092 patients newly diagnosed with type 2 diabetes; this highlighted the risks associated with blood pressure management in patients with diabetes and suggested that ‘the lower the better’ approach may not apply to blood pressure control beyond a critical level of 130/80 mmHg in high risk patients.<sup>5</sup>

CPRD research into aspects of cancer has had significant impact on approaches to diagnosis, particularly in primary care. In a large study of alarm symptoms in the early diagnosis of cancer in primary care, the risks associated with the presentation of symptoms such as rectal bleeding, haemoptysis, dysphagia and haematuria have been quantified; these results have

suggested a need for improved diagnostic methods and early evaluation of symptoms especially for patients at earlier stage or for those whose bladder cancer presents without visible haematuria.<sup>6</sup> Building on such studies, the recently published influential draft consultation document by the National Institute for Health and Care Excellence (NICE),<sup>7</sup> derived its evidence for management, investigation, and referral for most of the cancers discussed largely from GPRD and CPRD studies and, for some, entirely from database research. These draft guidelines give clearer and updated information on the recognition of early signs and symptoms of over 200 different types of cancer and the criteria that warrant further investigations or referral to specialists. The threshold for whether a sign or symptom could indicate cancer has been lowered compared to the previous guidance. Particularly targeted at GPs, the document cites, for example, a CPRD study on the risk of oesophago-gastric cancer in which the important warning symptoms, previously studied only in hospitalised patients, were clarified for doctors working in primary care.

In the field of digestive diseases, the CPRD has generated a number of important studies impacting clinical care, including detailed descriptions of the associations between irritable bowel syndrome (IBS) and venous thromboembolism, and a series of studies on the complications of IBS (and the epidemiology of gastrointestinal bleeding in particular), which led to a modification of the NICE guidance on gastrointestinal bleeding, as well as a revisiting of the risk estimates of these conditions in clinical practice.<sup>8</sup>

Further, a large study in 123 practices on IBS demonstrated the extensive physical (a range of problems including asthma and symptoms of urinary tract infection) and psychological (namely anxiety and depression) comorbidities associated with IBS.<sup>9</sup> These studies have implications for

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the management of patients with long-term physical and psychological comorbidities in general practice.

CPRD data has also been widely used for drug safety and pharmacoepidemiology and has impacted on GP prescribing; for example, in the primary prevention of osteoporotic fragility fractures in postmenopausal women or long-term contraception.

Where CPRD has made its data widely available, the RCGP RSC has occupied a niche position, primarily reporting on influenza epidemics and vaccine effectiveness.<sup>10</sup> This has been a long-term and highly successful collaboration with Public Health England and its predecessor bodies.

#### UNMET RESEARCH NEEDS

Demonstrating those impacts of CPRD in particular, and healthcare data research in general, while consistently maintaining the highest standards of patient confidentiality, has been a major factor in the increasing popularity of medical informatics research in the UK. Moreover, CPRD could improve its capacity to study rare disease and rare drug effects, diseases in subgroups of the population, and infectious disease epidemiology.

The RCGP RSC is an untapped research resource outside its key areas of activity. Further, the RCGP has also developed a network of Research Ready practices who have expressed an interest in research, which may include readiness to share data for research or surveillance.<sup>11</sup> Many of these Research Ready practices are not members of either RCGP RSC or CPRD.

Thus, the momentum is right to revisit how we align the sharing of data for research in ways that clearly benefit practices and patients both short and long term, especially in the context of the ‘commitment of the NHS to the promotion and conduct of research’ as confirmed in the NHS Constitution. An emerging collaboration between the RCGP RSC and CPRD suggests how this can be done. Alongside the observational and clinical research carried out through CPRD data, surveillance, and other research carried out by the RSC, it will also pilot methods and

develop an evidence-base of how feedback and quality improvement may lead patients, their carers, and practices to realise short-term benefits from participation in research. The RCGP Research Ready practices from across the UK can be the place to start recruitment.

Sustainability of such databases relies on a wide range of factors, the most important of which are that the activities undertaken are in the public interest and that patients’ and practitioners’ privacy are appropriately protected. This needs to include a dissent option for those patients choosing not to participate and is something CPRD has always provided. We are looking to take the lead in enhancing the public interest case for using routine health data for research by building an evidence-base for how best to provide more immediate benefits for patients and practices participating in research.

It is hoped that through providing benefits to practices, making data available for surveillance, research, and quality improvement, more practices will agree to share these data. As the evidence is collected on the value, and public health and clinical impact of this research, we hope that many more practices and their patients may wish to participate in research activities.

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