Articles

QRESEARCH: a new general practice database for research

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This article describes a major new general practice database for medical research in the United Kingdom (UK) known as QRESEARCH. When fully established, QRESEARCH will be a consolidated database housing the fully anonymised health records of more than four million patients who have been registered at any time with about 500 general practices spread throughout the UK. The quality of these data is assessed in terms of completeness and accuracy, and accredited. QRESEARCH is a not-for-profit venture by the University of Nottingham and Egton Medical Information Systems Ltd (EMIS), the largest supplier of computer systems for primary care in the UK.

The database has two main aims. The first is to provide very good access to high-quality validated data for use in ethical research. Research is defined as any project that tests a hypothesis or asks a research question, the results of which are intended for publication. All such projects are reviewed by Trent Multi-Centre Ethics Committee and the independent QRESEARCH Scientific Board. Once approved, researchers are provided with anonymised patient-level data in order to answer their research question.

The second aim of QRESEARCH is to make morbidity statistics available to the health community at large. QRESEARCH undertakes to provide an analysis service: potential clients specify what information is needed, and QRESEARCH then produces tailored analyses and reports with tabular data in discussion with those who have commissioned it. This service is available to the health service, including strategic health authorities, primary care trusts, public health observatories and other government bodies. Early projects for QRESEARCH have been successfully undertaken for the National Stroke Audit and the Medicines Partnership and these reports are available on request.

QRESEARCH is also able to undertake sample-size calculations on behalf of researchers to support applications for research grants (particularly randomised controlled trials). QRESEARCH does not provide a post-marketing surveillance service to the pharmaceutical industry as there is adequate provision for this service elsewhere. The analysis service is chargeable and the costs are carefully controlled to ensure good value for money as well as allowing the scheme to be self-funding and provide low-cost access for researchers.

Practices contribute data to QRESEARCH in return for comparative feedback on the quality of their data. This feedback is still being established, but it is anticipated that it will cover a range of conditions of interest to the practices as well as the general medical services contract indicators. Practices are asked to display a notice in their surgery waiting-rooms to inform patients about their participation in QRESEARCH, and patients who do not wish their anonymised data to be included are able to opt out of the uploads.

We have enlisted the support of the medical profession, and the views of many stakeholders are well represented on the QRESEARCH Advisory Board, where representatives of the British Medical Association, Central Office for Research Ethics Committees, Patient Information Advisory Group, the General Practitioner Committee and the EMIS National User Group join representatives from EMIS and the University of Nottingham to discuss policy and its implementation and monitoring. All uses of the database require approval from the Advisory Board.

Two key developments have facilitated the creation of this dataset. First, technological barriers have reduced in recent years. This includes availability of relatively cheap file servers capable of handling such volumes of data; protocols for transferring data electronically, including daily uploads; and the availability of encryption and pseudo-anonymisation techniques. The medical records held by general practitioners (GPs) include details of all diagnoses and prescribed drugs, in many cases extending from birth. In an increasing number of general practices, these records are held almost entirely in structured electronic format and therefore offer unique opportunities to plan and monitor health services, measure the quality of care provided by the National Health Service and undertake population-based research.

The second recent change has been in general practice clinical databases. Virtually every practice now has a clinical computer system. While many use it for basic administrative tasks such as prescribing, call and recall, and disease registers, we estimate that a third are now using their clinical computer for all their medical records. This means that the range of data has increased in these practices, but so also has the accuracy and completeness of data. The data within clinical databases in general practice derive their value from high levels of patient registration with GPs and good recording of illnesses or episodes of care. Entries in these databases are made by all

doctors, practice nurses (but not commonly community nurses) and administrative staff, all of whom have a strong interest in the accuracy and completeness of the electronic record.

QRESEARCH is a major new development which will complement older general practice aggregated databases. It is the first to include significant numbers of EMIS practices.

For more information visit www.qresearch.org

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