The UK could significantly enhance its health research capability by making effective use of data from electronic patient records for secondary research. This would have major benefits for many types of research; for example through enhancing the understanding of the natural history and epidemiology of diseases, and optimising healthcare delivery. In recent years, we have already seen many examples of research from electronic patient records that could have had a major impact on healthcare delivery and health policy. These studies include the development of algorithms for measuring cardiovascular risk, studies evaluating the impact of pay for performance schemes on health inequalities and the development of case-mix measurement tools for examining medical practice variations.

However, significant concerns remain around the ethical and legal issues of using information from patients’ medical records without their consent. There is also uncertainty amongst general practitioners (GPs) and the other custodians of medical records around what processes should be used when information from patient records is made available for research. This lack of consistency and confidence around how these records should be accessed led to the Wellcome Trust hosting a meeting in May 2008 to address these issues. The report that was published after the meeting was based on three overarching principles: safeguarding patient confidentiality and privacy, the role of the GP and healthcare professional as patient advocate, and the need to improve public awareness and understanding.

The report provides advice on best practice for ways in which patient records may be used in research, targeted at GPs and other primary care professionals.

The Wellcome Trust report highlights the importance of protecting patient confidentiality and safeguarding privacy, which requires clearly defined processes and controls on the use of patient data. In the past, it has often been common practice for members of a research team to run searches on GP electronic patient record systems to identify patients who may be eligible for a study. However, this practice would appear to be a breach of the guidance stating that people not directly involved in a patient’s clinical care should not have access to identifiable data about them. Although the idea of an ‘approved researcher’ who is also bound by the same duty of confidentiality as the clinical team and with the same penalties has been suggested, this would also not seem compatible with best practice on confidentiality. Hence, systems that use members of the clinical team or technology-based solutions may be the best way to take these recommendations forwards.

In some parts of England, Comprehensive Local Research Networks, working in collaboration with the Primary Care Research Network, have established schemes whereby practices can be reimbursed for carrying out such searches; and for then either giving research staff anonymised data or writing to patients on their behalf to seek consent to be approached about a study. Thanks to the financial support from the National Institute for Health Research (NIHR), where these schemes are in place, practices no longer need to bear the financial burden of helping research teams to carry out searches on their electronic patient record system. When combined with training on best practice for accessing records for secondary uses and the importance of accurate clinical coding, these schemes could have benefits for the primary healthcare team as well as the research team.

A second method of giving researchers access to anonymised data for research has been through the use of ‘data warehouses’ or similar systems for holding data in a central repository. The best known examples of this approach are the large primary care databases, such as the General Practice Research Database and QRESEARCH, and the Weekly Returns Service.
databases are extensively used for research and have made major contributions to research in such areas as drug safety and disease epidemiology. We are now seeing locally developed systems for data warehousing being implemented in many primary care trusts. Although initially developed for health service delivery and monitoring, these systems also have great potential for research use, particularly where anonymised data is needed; for example, for assessing the feasibility of a study. Some primary care trusts are also using such systems to develop integrated records to improve service delivery; for example, by linking data from primary care and secondary care for people with diabetes. These linked data sets can bring additional benefits to researchers by adding information from external patient record systems, such as from diagnostic laboratories. Because data extraction is generally automated, clearly defined data sets that do not breach any ethical guidelines can be extracted, with minimal workload or disruption for general practices. In the longer term, we await the rollout of the Research Capability Programme in England and similar schemes in the devolved nations. These programmes will be responsible for data linkage of different NHS patient record systems and for ensuring that only anonymised data is released to researchers, unless consent is obtained to use identifiable patient data.

In the process of using data for secondary purposes, GPs and healthcare professionals must act as an advocate for the patient and retain ultimate responsibility for ensuring confidentiality and appropriate access to data. GPs need to be aware that any research must comply with research governance standards; that is, it should have obtained ethical approval and have been approved by the Research Governance Lead in the local primary care trust, and have an approved sponsor (generally the academic institution which is hosting the study). A key aim for primary healthcare teams is to improve performance in UK primary care.

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