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Editorials

Maximising research opportunities of new NHS information systems

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Nick Black, professor of health services research

[Author affiliations](#)

Nick.Black@lshtm.ac.uk

Don't ignore the potential of health services research

Amid all the controversy and debate around the introduction of a new national information technology programme for the English National Health Service (NHS), the needs of researchers for information have been largely ignored while—perhaps understandably—the immediate needs of clinicians, administrators, managers, and policymakers have been prioritised.

Reluctance to consider the needs of researchers may also reflect managers' fears of a loss of control of the data and the public's and politicians' concerns about breaches of confidentiality. Whatever the reason, researchers and research funders are increasingly concerned that the people responsible for designing the new system lack awareness of the potential research uses of routinely collected healthcare data. This is despite at least three recent documents showing the benefits of such data to the NHS and public health,¹²³ and examples of successful relationships between health systems and researchers, such as is seen in the United States⁴ and Canada.⁵

A further attempt to demonstrate the value of routine data for research has recently been made by the UK Clinical Research Collaboration (a partnership of all major funders of clinical research) through a joint initiative with Connecting for Health (the NHS agency responsible for instituting the new IT programme). The first product of a jointly convened advisory group appeared in June.⁶

Their report is based on simulations of four approaches to using routine NHS data for research—surveillance (to detect rare and long term adverse effects of healthcare interventions), support for clinical trials (to establish the effectiveness of interventions), longitudinal cohorts (to discover the causes of disease), and observational epidemiology (to determine the distribution and trends in the occurrence of disease in the population). Some common lessons from these simulations led to six recommendations for maximising the research potential of NHS data in the short term: mandatory use of patients' NHS numbers; greater recognition by IT managers of the importance of routine information for research; high level support for facilitating the linking of different databases (creating what they call a

federation); improvements in completeness and quality of data; removal of unnecessary data governance obstacles, while retaining necessary safeguards; and persuasion of clinicians regarding the benefits of research. Such proposals are likely to find widespread support, except from those adamantly opposed to any collective use of personal data.

While five of these six recommendations are neither novel nor contentious, the creation of a federation of existing databases is a welcome break with the past. Since the introduction of mainframe computers into the NHS several decades ago, government and NHS policy has been dominated by a command and control approach. Despite rapid evolution in hardware and software, this has remained an absolute and driving principle even for the current IT programme, although recent political signals have indicated that some central control might be relinquished.

To date, devolution and diversification of the collection and storage of data in the NHS has at best been ignored and at worst been actively discouraged. Despite this, groups of dedicated clinicians, sometimes allied with epidemiologists and statisticians, have established specialised databases⁷ that can complement the limited potential of routine administrative databases. Groups that have attracted adequate resources have often produced high quality databases that allow adequate adjustment of case mix for evaluative research to be carried out and for meaningful audit of outcomes.⁸

Unfortunately, despite the best endeavours of their creators, other databases have proved less successful. The recommendation to encourage a federation of databases should therefore be accompanied by greater support for the many specialised databases that exist and encouragement of others to emulate these successes. This could be aided by creating one or more clinical database support units along the lines of support units for clinical trials. In addition, the eHealth Research Board being established by the new committee that will coordinate publicly funded health research in the United Kingdom—the Office for Strategic Coordination of Health Research—will hopefully contribute to improving specialised databases.

Although the report⁶ makes a convincing case as to why research uses should be considered in the design and implementation of new IT systems in the NHS, the case could have been stronger. While the use of databases to support clinical research and public health research is well represented, the contribution of health services research is limited to its activities in evaluating clinical interventions (or health technology assessment). The potential contribution of the other principal activities of health services research—studying how services are organised and delivered and research to inform policy and evaluate policy—are ignored. This is particularly pertinent given that many of the questions in these areas can only be answered using databases.

Consider, for example, just three studies that illustrate the valuable contribution that health services research has made. One showed that discharging patients from adult intensive care units at night is dangerous,⁹ another showed that the quality of care for some conditions improved when payment for performance for general practitioners was introduced,¹⁰ and yet another established that the outcome of some surgical operations improves when a surgeon or hospital carries out the procedure more often.¹¹

If the contribution of such research is valued by clinicians, managers, and policymakers, it is essential that the needs of health services and healthcare policy research are taken into account alongside those of clinical and public health research. Research at the organisational and system levels has much to contribute and strengthens the case for the recommendations put forward in this recent report. The

three complementary areas of health research—clinical, health services, public health—all stand to gain from a wider recognition of the need for access to good quality routine data from the NHS.

Footnotes

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