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PERSONAL DATA RESEARCH MEANS BETTER HEALTHCARE

There is an urgent need to reform regulations governing personal medical data to improve public healthcare – according to a report published today by the Academy of Medical Sciences.

The report claims that research has been inhibited by confusing regulatory guidance, stifling bureaucracy and unnecessary constraints on researchers' access to health data.

The large numbers treated by the NHS and the use of electronic records should allow the UK to lead the field in analysing health data to allow better understanding and tackling of disease. Instead it has been hidebound by bureaucracy according to the authors of the report: *Personal data for public good: using health information in medical research.*

Professor Robert Souhami, who chaired the report's working group, urged decision makers in Government and the NHS to work with researchers and the public.

"It is essential to build trust, maintain the integrity of this form of research and ensure that important medical advances are not impeded," he said.

"When access to data is restricted there is a danger of bias which reduces reliability of research results. We hope the Academy's report will provide the necessary stimulus for action."

Identifying the causes of disease, investigating treatment outcomes and improving health care services all depend on researchers having access to large, representative samples of accurate population data.

The report says that a lack of evidence on public attitudes and complex legislation have led regulatory authorities to act conservatively in allowing researchers access to data.

Prof Souhami said: "The UK has an outstanding track record in the use of health data for epidemiology and public health research. Think of the late Sir Richard Doll who used medical records data to identify the link between smoking and lung cancer.

"It is essential that data about the health of individuals are only used under conditions of confidentiality that enjoy public support. Researchers must be seen to conform to the highest standards.

"Our report highlights the need for good research practices and recommends greater engagement with the public about how their health records are used for medical research.

"For the majority of medical research projects the risk of disclosure of sensitive information is extremely low. On the other hand, the risks to public health of impeding such research are potentially very large. The emphasis placed on individual privacy by the regulatory authorities often fails to take proper account of the balance of risks involved."

Notes for Editors

1. For further information please call Helen Munn on 020 7969 5234.
2. The independent Academy of Medical Sciences promotes advances in medical science and campaigns to ensure these are translated as quickly as possible into benefits for patients. The Academy's eight hundred Fellows are the United Kingdom's leading medical scientists from hospitals, academia, industry and the public.
3. The report, partly funded by Cancer Research UK, was prepared by an Academy of Medical Sciences Working Group of Professor Robert Souhami CBE FMedSci (Chair), Dr Sandy Chalmers, Professor Rory Collins FMedSci, Professor Karen Luker FMedSci, Professor John Newton, Professor Alan Silman FMedSci, Professor Graham Watt FMedSci, Professor Simon Wessely FMedSci and Dr Ron Zimmern.
4. The Academy Officers are Sir Keith Peters FRS PMedSci *President*, Sir John Skehel FRS FMedSci *Vice-President*, Sir Michael Rutter FRS FBA FMedSci *Vice-President*, Professor Ian Lauder FMedSci *Treasurer* and Professor Patrick Vallance FMedSci *Registrar*. The Executive Director is Mrs Mary Manning.
5. Further details and copies of the report may be obtained from:
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