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The Academy of Medical Sciences welcomes the value that the Government has placed on the use of information to improve health services and the need for greater openness and transparency for patients. Our 'Vision for medical science', published in 2010, stressed the need for political leadership that champions the importance of electronic health records in improving patients' health and healthcare. This is reinforced in our recently published review of the regulation and governance of medical research in the UK: 'A new pathway for the regulation and governance of health research'. We are concerned that the research community is not a specific target audience of the Information Strategy consultation. Research must be placed at the heart of UK healthcare. The NHS offers the UK a strategic advantage in performing medical research and the use of electronic health records is key to unleashing its research power. We would like to see greater emphasis placed on the use of information for research purposes in the Strategy.

'A new pathway for the regulation and governance of health research' reported that the regulation and governance of patient data is currently extremely complex, creating barriers to setting up studies and making patients aware of research opportunities. The legal framework around access to patient data is complicated involving UK legislation, case decisions, and an EU Directive. There are also a wide range of bodies involved in producing advice, each of which differs slightly in their focus, context and jurisdiction. This has resulted in conflicting interpretations of the regulation among stakeholders and a lack of clarity for patients and the public.

The report urges the Government to evaluate progress on taking forward the recommendations from the Data Sharing Review (2008), including the development of a system to allow approved researchers to work with healthcare providers to identify potential patients for research studies. Research would benefit from greater levels of secure information exchange; it is vital that the Information Strategy allows a more open flow of data and provides a strategic framework through which healthcare providers, universities and research funders can work in partnership. Interoperability is a vital component for success in using patient data effectively and the Academy welcomes the inclusion of this message in the Strategy. The Research Capability Programme provides a platform on which to develop the UK's capability in e-health. 'A new pathway for the regulation and governance of health research' urges the health departments to continue their work to establish safe havens through the Research Capability Programme and its equivalents in the devolved nations. It calls for the full system to be rolled out as soon as possible, incorporating lessons learnt from the pilot, to ensure the UK is maximising opportunities in this area. The report also recommends that the Ministry of Justice should undertake a thorough review of the UK Data Protection Act to identify aspects that require clarification in relation to health research.

Enhanced research access to data can provide a platform on which we can: improve the safety of medicines; better understand the causes of disease; identify research participants; and locate patients who would benefit most from targeted health interventions. Such outcomes would help to fulfill some of the objectives set out in the Health White Paper, including the aim to increase the volume of patients participating in clinical research. Further, greater research access to data can also help to strengthen the research base for public health and thus support the Government's commitment to improvements in this area.

[Response submitted online]