Information for Health

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The use of computers to store, analyse and disseminate information is changing our lives, for better or worse (or realistically for better and worse!). New and important service industries are developing to take advantage of the commercial potential of this advance in technology. A huge challenge for governments is how to use, regulate and disseminate the avalanche of information about the lives of each and every one of their citizens.

Why is this topic relevant to the Wellcome Trust? Our mission as a major biomedical research charity, spending about £430 million each year, is to "foster and promote research with the aim of improving human and animal health". One important way of advancing this mission is to support research that uses information gathered from individuals and populations about interactions between health, the environment and genes. That is why we are funding the UK Biobank project in partnership with the MRC, the Department of Health and the Scottish Executive. Professor Rory Collins of Oxford University is leading this project, which will study over many years how the health of 500,000 people aged between 40 and 69 is associated with environmental and genetic factors.

No government or political party can afford to duck the issue of how to use information in a digital age, as good public policy demands the use of

objective evidence that can only be gathered by the systematic use of information. For obvious reasons I will advance my arguments around use of information in the field of health, but many of the principles apply equally to other fields such as transport, housing and education.

As a junior doctor, much of my time used to be taken up looking for lost X rays and blood test results, and repairing broken files of clinical records or creating new ones when the old had been lost. Much harm has been caused by the inefficiencies of record keeping using old methods, for example repeat X rays, drug prescription errors and misdiagnoses. We should therefore celebrate the initiative in the NHS's "Connecting for Health" which aims to integrate IT infrastructure and systems. One aspect of this will be the provision of an individual electronic care record for all England's 50+ million users, securely accessible to patients and their carers.

But, if we are to treat people better in the NHS, we need to be able to use these data for research. Indeed, a typical family may have as many as seven points of contact with national and local government agencies such as the NHS, Department of Work and Pensions, Inland Revenue, local councils and local schools. Increased linkage, access and the effective use of these data resources including their eventual linkage to personal care records would be invaluable to public policy development. For example, it is important that the NHS can understand and address health inequalities, and develop disease registers to improve delivery of care. Achieving this requires linking data on health, housing, employment and other measures of socio-economic status. These benefits will only materialise if these data can be shared and used for research.

The public and opinion formers can be wary of such initiatives. Understandably, there are concerns about the protection of personal information and privacy issues. A recent study, commissioned by the Council for Science and Technology highlighted many of these concerns, but also indicated that, as long as personal confidentiality is protected, the public wants data used in relation to health research[1]. Government does not always help its own case – for example current publicity from

the DWP in relation to benefit fraud states:

"We can compare information across Government Departments.[2] So if you're not completely honest, we will find out."

Use of such "Big Brother" style messages could seriously undermine public confidence and lead to resources of unique value being put out of reach of policy makers and academic researchers.

Responsible data sharing, access and data management are key to a vibrant research environment, allowing the exchange of ideas and research findings. There needs to be a regulatory and governance framework that minimises and manages the risks associated with such initiatives and one that inspires public confidence. Public engagement will be key to this, helping to ensure that Government achieves real benefits from data-sharing.

Technological change is not only affecting what research resources academics have access to for their studies but how the findings of their research are published. I argue that data must wherever possible be freely disseminated, subject to stringent safeguarding of data that could provide confidential information about individuals. Here the publication of the results of research is key. Not everyone shares this view – a publisher, responding to questions from the House of Commons Science and Technology Select Committee inquiry into open access publishing, stated:

"Speak to people in the medical profession, and they will say the last thing they want are people who may have illnesses reading this information, marching into surgeries and asking things. We need to be careful with this very, very high-level information."[3]

This statement implying that "knowledge is power" reinforces greatly my view that people who have illnesses should have access to every single element of this "very, very high-level information"! Indeed, the Wellcome Trust has had a long standing interest in ensuring free access to and rapid availability of research information to maximise the utilisation of research outputs and thereby their benefits to society. These principles were enshrined in

an agreement concerning the data emerging from the Human Genome Project. All information produced by the public-funded project was made immediately and freely available to everyone, via the Internet, with no restrictions on how it could be used. This immediate information release maximised the utility of the data to research scientists in both academia and industry.

With recent advances in Internet publishing, we are seeking to encourage initiatives that broaden the range of opportunities for the results of quality research to be widely disseminated and freely accessed by the reader anywhere in the world. It is now a condition of our funding that a copy of any original research paper published in a peer-reviewed journal must be deposited into subject-specific public access repositories, so that it is available to be read for free immediately or no later than six months after publication. We will provide the funds to enable this to happen.

Current and future technological advances are transforming the way we hold, access and use information. We must collectively engage the public and opinion formers to explore and communicate the benefits and risks associated with these advances and ensure a balanced regulatory and governance framework is established. A more streamlined, co-ordinated and coherent approach towards the personal data sets held across government departments could provide enormous benefits to individuals, society and to Government itself.

[1] Better use of personal information: opportunities and risks. Council for Science and Technology. November 2005.
[2] http://www.targetingbenefitfraud.gov.uk/on_to_you.html
[3] http:www.publications.parliament.uk/pa/cm200304/cmselect/cmsctech/399/4030102.htm