

DINNER/DISCUSSION SUMMARY

Can better use be made of public data for example in health research?

Held at The Royal Society on 8th June, 2011

The Foundation is grateful for the support for this meeting from
getstats at the Royal Statistical Society, Lloyd's Register and Research Councils UK

Chair: **The Earl of Selborne GBE FRS**
Chairman, The Foundation for Science and Technology

Speakers: **Professor Paul Boyle FRSE**
Chief Executive, Economic and Social Research Council
Baroness O'Neill of Bengarve CBE FBA HonFRS FMedsci
House of Lords
Stephen Penneck
Director General, Office for National Statistics (ONS)

PROFESSOR PAUL BOYLE said that the data routinely collected by different Government departments and Government agencies to serve the needs of public administration constituted a resource of immense potential value not only for health research but also for research across a wide range of social and economic subject areas. For this potential to be realised acceptable ways needed to be found to improve the links between the different datasets and to improve accessibility. But there was an inherent tension between the desire to protect personal privacy and the desire to harness this resource of public data for the benefit of the public. He believed that present legislation struck the wrong balance between these conflicting desires. Too high a price was being paid by people collectively in order to protect the privacy of people individually. He gave an example (a study in Finland to see whether the prevalence of a particular form of motor neuron disease was the result of genetic or environmental factors) of the benefits which could flow from making better use of routinely collected administrative data. He described the Scottish Longitudinal Study (SLS) which had made it possible to bring together census data, population data, health data, education data and personal vital statistics and to enable that combined data resource to be accessible to researchers with viable measures to avoid compromising the personal privacy of the individuals covered by those data. If the impediments to better access and better linkage were to be removed, scientists needed to demonstrate to politicians and the general public both the benefits of wider and better use of public data and the adequacy of the arrangements in place to avoid misuse and protect personal privacy. He proposed a national task force, drawn from Government and academia, to devise a UK wide national data centre, drawing on the experience gained in the SLS.

BARONESS O'NEILL OF BENGARVE argued that current UK Data Protection legislation created substantial difficulties for medical and social research and at the same time failed to provide adequate protection of personal privacy. She underlined the particular difficulties created by the requirement for specific re-consenting to enable impersonal secondary use of legitimately acquired and lawfully held data. She believed that basing data protection law on specific types of information or content rather than on specific acts by which information or content was communicated had been misconceived; it was not possible to provide a workable or coherent distinction between personal and non-personal information and the definition of "processing" of information was so wide that it effectively sought to regulate every conceivable type of action. She pointed to the illogicality of

people wanting data about their own medical treatment to be kept strictly private while at the same time expecting medical practitioners to base that treatment on the maximum use of data derived from the treatment of other patients. Consultation was in train about redrafting the 1995 EU Data Protection Directive. It was important for the UK to take this opportunity (and the opportunity provided by any subsequent legislative changes in the UK) to make radical reforms which would focus on regulating the acts by which content is communicated and not on "processing" ill-defined types of informational content. It was also important for the UK to be closely involved with the EU process to ensure that any reforms were not inimical to this country's interests. Those devising ways of improving accessibility needed to be alert to the risks of misuse and the difficulties of tracing the sources of misuse.

MR STEPHEN PENNECK described the roles of the Office of National Statistics (ONS) as collector and protector of data and underlined the importance for the ONS of public confidence in its trustworthiness in respect of both roles. ONS firmly believed that private data had to be kept private and that public data had to be made more public – widely available to researchers, commerce and industry as well as the general public. He outlined actions which ONS had taken, and was continuing to take, in order to make best use of the data revolution of the development of web technology to increase accessibility to publicly collected data. He also outlined some of the measures taken by ONS to protect the confidentiality of personal data; he was aware that public confidence was hard to win and easy to lose. The emergence of "social media channels" and the wider use of mobile telephones presented new opportunities for ONS to disseminate public data as well as raising new challenges for the avoidance of misuse and the protection of privacy. He pointed out that the coalition Government had clearly signalled its desire for greater transparency and wider access to public data. This unique opportunity for improving the present situation should be exploited to the full. There needed to be more collaboration between public and private sectors and between Government departments.

In the two discussion periods there was widespread support for the need to make better use of publicly collected data and to harness that data resource effectively to the advancement of science and eventual economic and social benefit. Many argued that the UK had comparative advantage in the quality and extent of such data and felt that legislative impediments and public attitudes undesirably impeded the full exploitation of that advantage and threatened to diminish the attractions to multinational enterprises of the UK as a key centre for carrying

out research. Scientists needed to make a well-argued case, supported by clear examples of the potential benefits, to politicians and the public at large to ensure that legitimate concerns about the protection of personal privacy did not exert an unacceptably large influence.

Some speakers referred to improved ways of increasing access to public data by researchers while safeguarding privacy concerns (e.g. "safe havens"). At the same time some speakers warned about the increasing skills of those who wanted to breach the defences erected by holders of datasets for the protection of the identity of those about whom information was contained in those datasets. The more data were publicly available the greater the scope for making linkages which would reveal identity. The ways in which totalitarian regimes had been able to misuse personal data for undesirable political ends should not be forgotten. So there needed to be constant vigilance to ensure that safeguarding measures continued to remain ahead of the efforts of those who might seek to undermine those measures. And legislation needed to be sufficiently flexible to allow for such developments.

A problem for those dealing with EU legislation about data protection was the existence of different cultural attitudes towards privacy in other countries. Some information which in the UK would be regarded as requiring privacy protection was in other countries accepted as being in the public domain. There were also generational differences about the boundary between public and private information.

It was suggested that the useful and successful experience of the SLS might not be readily transferable to the UK as a whole. The bigger the scale, the greater the problems, especially when it came to breaking down the barriers which seemed to impede the readiness of Government departments to share data with each other. Some of those impediments might result from undesirable competitive concerns but some might result from genuine and reasonable commitments made when the data had been collected.

One or two speakers reminded the meeting that much data of value more widely was routinely collected in the private sector in many cases without the public being aware of the fact and of the potential privacy protection implications. There was a good case for seeking to ensure greater co-operation between public and private sectors when seeking to strike the right balance between protection and accessibility. Some data collection might be better undertaken by the private sector than by the public sector but it would be important to ensure that any shift of responsibility did not result in impaired access to the data.

The pharma sector was particularly frustrated by the lack of progress in improving access to public data for health research. Access to research data could only be for the good of patients – the sector would look to other countries if the UK could not soon get its act together.

The general consensus of the discussion was that the issues raised by the various speakers from the platform and from the floor were of major topical importance. There were many barriers preventing the full beneficial exploitation of the national public data resource. Current legislation needed to be brought up to date so that it properly related to the rapid and continuing changes being made in data collection, handling and transmission and so that it better served the desirable objectives of ensuring the reasonable protection of privacy and of allowing the national data resource to be

harnessed to the greater economic and social benefit of the whole community. There was much work to be done to ensure that the outcome of the current EU Directive review was beneficial to the UK's interests. And there was much work to be done to enable politicians and the public to appreciate the major benefits which improved access to and improved sharing of data could bring.

Sir John Caines KCB

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www.acmedsci.ac.uk

Department of Health Chief Medical Officer
www.dh.gov.uk/en/Aboutus/MinistersandDepartmentLeaders/ChiefMedicalOfficer/index.htm

Economic and Social Research Council
www.esrc.ac.uk

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www.foundation.org.uk

Global Medical Excellence Cluster (GMEC)
www.gmecuk.com

Information Commissioner's Office
www.ico.gov.uk

Lloyd's Register
www.lr.org

NHS
www.nhs.uk

Office for National Statistics (ONS)
www.statistics.gov.uk

Research Councils UK
www.rcuk.ac.uk

Royal College of Physicians
www.rcplondon.ac.uk

The Royal Society of Medicine
www.rsm.ac.uk

The Royal Society
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Royal Statistical Society (getstats campaign)
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