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Data Sharing

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SCRIPT OPINION – 1:2008

DATA SHARING
RESPONSE TO MINISTRY OF JUSTICE CONSULTATION

(note: This opinion was submitted before the Centre rebrand)

14 February 2008

Dear Sirs,

Data Sharing Review: Response from the AHRC Research Centre for Studies in Intellectual Property and Technology Law, University of Edinburgh

I am the Director of a law and technology research centre based in the School of Law at the University of Edinburgh and sponsored by the Arts and Humanities Research Council. Our work centres on themes of privacy & openness and regulation & trust and I write on behalf of our centre in response to the call for views on data sharing.

We welcome this review at a time when there appears to be more confusion and caution than ever before about the nature and scope of privacy protection in the United Kingdom. Despite a morass of laws and a plethora of guidance, a culture of caution has grown up around data sharing in certain contexts, most particularly in the realm of medical research. This is exacerbated by what one of us has called "the fetishisation of consent" in various quarters (see below, Laurie, *Promoting Public Interest and Patient Rights*, Inaugural lecture, 1 May 2007). This is an attitude prevalent among many regulators, including ethics committees, whereby the obtaining of consent has come to be seen as both necessary and sufficient to legitimate data handling and sharing when it is neither; nor, is it achievable or even desirable in some cases. This is not to belie the importance of informing individuals about data processing or the value of consent in appropriate circumstances, but it does suggest that more should be done to stress the important public interests which can be served by legitimate data sharing, especially in the context of robust scientific and medical research. Moreover, more could be made of the flexibilities within law which allow data sharing for legitimate purposes without the need for explicit informed consent. In this last respect we endorse the recommendations in the recent report from the Academy of Medical Sciences on *Personal Data for Public Good: Using Health Information in Medical Research* (2006).

The fundamental value at stake is privacy, but privacy is neither an absolute right nor an unqualified privilege. This is perfectly well reflected in data protection law and the Human Rights Act 1998, which embodies the European Convention on Human Rights Article 8 right to respect for family and private life, while allowing necessary and proportionate departures, inter alia, for the protection of health, morals or the rights and freedoms of others. This is now well recognised by our courts, including the House of Lords, see *Campbell v MGN Limited* [2004] UKHL 22.

Bodies such as the Patient Information Advisory Group serve a very valuable purpose in authorising data usage when consent is not possible or desirable, but it is important to

note that this body was established on a temporary basis and within the ethos of the informed consent paradigm. Scotland has no equivalent body established by statute, but has the Privacy Advisory Committee (PAC) to the General Register Office for Scotland and the Information and Statistics Division of NHS Scotland (Laurie is the current Chair of PAC). PAC has published guidance on its approach to decision-making for the public and research community alike. These bodies provide a vital safeguarding function to respect and protect patient privacy while authorising sound research which can be justified as necessary and with proportionate minimal risk to privacy. The ad hoc nature of this work should not continue and proper recognition should be given to these mechanisms which, we believe, strike a good balance between protecting privacy and allowing research in the public interest.

The Confidentiality and Security Advisory Group for Scotland reported in 2002 and recommended that there was no need for legislation. We would suggest that this recommendation should be revisited and that legislation is required for the United Kingdom which embodies the twin principles of adequate privacy protection and promotion of good medical research.

Yours faithfully,

Graeme Laurie
Director and Professor of Medical Jurisprudence

References

Graeme Laurie, *Promoting Public Interest and Patient Rights*, Inaugural lecture at the University of Edinburgh, 1 May 2007, audio stream available here:

<https://www.escript.law.ed.ac.uk/support/audio/index.htm>

Privacy Advisory Committee for Scotland, more information here:

<http://www.isdscotland.org/isd/2466.html>

Academy of Medical Sciences on *Personal Data for Public Good: Using Health Information in Medical Research* (2006), report available here:

<http://www.acmedsci.ac.uk/p99puid62.html>

Confidentiality and Security Advisory Group for Scotland, report available here:

<http://www.confidentiality.scot.nhs.uk/externalresources/csags.htm>

AHRC Research Centre:

<http://www.law.ed.ac.uk/ahrc>