

Consent and confidentiality—where are the limits? An introduction

P J Lachmann

Introduction to, and overview of, the contents of the Symposium on consent and confidentiality

The papers in this symposium are based on a meeting held by the Academy of Medical Sciences in London on 12 February 2002. The decision to hold this meeting, and to explore in detail these important and contentious issues, arose from a number of concerns that the Academy felt about what may reasonably be called “impediments to medical research”.

These include:

- The regulations arising from the implementation of the European data protection directive and their effect on the gathering and holding of data needed for disease surveillance as well as for research. Phil Boyd, in his paper, presents the views and the work of the Information Commission, the responsible UK body in this area.
- The “Source Informatics” case where the Department of Health requested a judicial review on the use, by this company, of anonymised prescribing data from general practitioner (GP) records for informing the pharmaceutical industry about patterns of drug use. Mr Justice Latham ruled that the use of even this anonymised data for commercial purposes could be a breach of patients’ rights to confidentiality. The Court of Appeal, however, emphatically reversed his decision and, no further appeal having been made to the House of Lords, the law of the land is now clear that there is no breach of confidentiality in the use of anonymised data. It did seem to us, however, that the General Medical Council’s guidance on the use of patient data could be seen as reversing the Court of Appeal on this point and could discourage doctors from participating willingly in public health surveillance; cancer registries being one case in point and infectious disease surveillance another. Leslie Turnberg, who is chairman of the Public Health Laboratory Service, writes on the difficulties that now beset the surveillance of infectious disease, and Jane O’Brien,

the head of the standards section, and Cyril Chantler, the chairman of the standards committee at the General Medical Council (GMC), in their paper discuss confidentiality in the context of a doctor’s duty of care and defend the point of view of the GMC.

- The Alder Hey case, which arose from the actions of one pathologist, with a research interest in cot death, who, without consent, collected extensive material from postmortem examinations on which, in the event, he never carried out any studies. When this became public knowledge, the public and media reaction was very hostile and was inflamed further both by the report of an inquiry into the events at Alder Hey—the Redfern Report¹—which was written in campaigning mode and used language rather more appropriate to tabloid journalism than to a judicial report, and by the intemperate response of the secretary of state to its publication. One outcome of Alder Hey was the creation of the National Health Service (NHS) Retained Organs Commission and Professor Margaret Brazier, who is its head, gives an account of its work in her paper
- The Kennedy report on the problems of paediatric heart surgery at the Bristol Royal Infirmary incorporates a large number of recommendations on medical training and practice. If these are implemented, they will have far reaching, but quite unpredictable, effects on British medicine. Many of these fall outside the scope of our meeting today. It does, however, extend the requirements for consent—for clinical examination involving touching the patient and to trivial procedures like venepuncture—to an extent that seems wholly ludicrous to some and merely good manners to others.²

While these were the immediate causes for holding this meeting, it did seem appropriate, having embarked on this topic, to bring together an eminent

group of experts to discuss the whole range of problems that relate to confidentiality and consent in the medical sciences. I am delighted that we have been successful in so doing. Onora O’Neill, a philosopher who specialises in the work of Kant, and Iain Torrance, a theologian who has specialised on bioethics, provide the basic background. Nick Partridge describes the lessons that have come from the AIDS epidemic. It is not that the problems raised by AIDS are essentially different from those that my generation of medical students discussed in relation to tuberculosis. It is the high political profile of HIV and AIDS and the scale of the catastrophe that have led to the problems being discussed on a much wider stage. Alistair Kent, from the Genetics Interest Group, considers consent and confidentiality from the perspective of another group of patients who have a major stake in these areas.

Three further important topics have been added. Vaccine safety, which is causing such hysteria in the country at this moment, is discussed by John Clements from the World Health Organisation (WHO), the body which is responsible for worldwide vaccination campaigns aimed at eradicating diseases from the planet; end of life decisions by John Harris, a bioethicist much admired for his well argued and robust views, and research on the mentally incompetent by Michel Cuenod from Lausanne, who is distinguished for his research on schizophrenia.

Attitudes to the questions to be considered reflect stark differences between two views of what should guide our behaviour. On the right (so to speak) are the libertarians—epitomised by Mrs Thatcher’s much quoted view that:

there’s no such thing as society. There are individual men and women, there are families. And no government can do anything except through people, and people must look after themselves first.³

Hard line libertarians believe that consent is not only necessary but also sufficient for almost all activities not actually forbidden by law. At the other pole are the utilitarians, who believe that actions should be guided by what produces the greatest good for the greatest number. Since we are not restricting discussion to the UK alone it is worth pointing out that utilitarianism is very much an “Anglo Saxon attitude” (as became very clear to me during the years I spent on the UNESCO bioethics

committee). This is not just because Jeremy Bentham was a Briton! Utilitarianism presupposes a basic confidence in the benevolence of one's government and, surprising though this may sometimes seem, the Americans, the British, the Australians, and Canadians and New Zealanders do believe that basically their governments are benevolent. Even I share this view! For entirely understandable reasons, however, the Germans and those from many other countries, are suspicious of utilitarian ethics because they can be, and have been, comprehensively abused by regimes now universally regarded as malevolent.

It is therefore necessary to find a middle way—and, guided by our contributors and those who contributed to the discussion, I believe that we have gone some way along that path.

It has become clear enough that neither philosophy, religion nor law recognises an absolute right to confidentiality either in principle or as applied to medical information in particular. The purpose of concern as Onara O'Neill has pointed out, is to prevent patients being coerced or deceived. It should not become a fetish to be pursued for other purposes and at any cost.

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Author's affiliation

Correspondence to: Peter Lachmann, Centre for Veterinary Science, Madingley Road Cambridge CB3 0ES, UK; pj11000@cam.ac.uk

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- 2 Learning from Bristol: the report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995. London: The Stationery Office, 2001. (Cmnd CM 5207).
- 3 **Thatcher M.** Society and responsibility. *Woman's Own* 1987 Oct 3: 8-10.