

Health and Social Care Bill

Clause 67 Impact Report

PRESS LAUNCH

Tue 13th Mar

An expert meeting and press conference to launch the Clause 67 Impact Report, will be held in The Moses Room, House of Lords, from 11.30 (sharp) – 12.30, Tuesday March 13 2001. House of Lords

1 Background

Clause 67 of the Health and Social Care Bill, currently before the House of Lords, will give the Secretary of State the power to collect all medical records in the UK and to regulate their use for any purpose. The Department of Health claims these powers are necessary for cancer registries. This is an attempt to sideline an ethical ruling by the General Medical Council that research data should only be collected with patient consent.

Yet the powers are very general in nature and can be exercised in an almost limitless range of applications.

- Doctors' leaders have strongly criticised the clause, stating that any decision to override the citizen's right to privacy should be exceptional and must only be made - other than in an extreme medical emergency - after rigorous parliamentary scrutiny.
- Ethicists are alarmed that patients will no longer have control over the use of their personal health information. For example, data about a woman's irregular periods could be used in contraceptive research, even if she had a deeply-held religious objection to this.
- Researchers are concerned that the erosion of patient trust will make it much harder to recruit volunteers for trials, and that if Britain has lower ethical standards than other developed countries, it will make it much harder to collaborate with researchers abroad.

The Impact Report is an academic examination of the potential impact of Clause 67 of the Bill, and was commissioned by the Nuffield Trust with a view to facilitating this scrutiny. It has been edited by Simon Davies, Visiting Fellow in Informatics at the London School of Economics.

2 Quotes

‘The new powers will in effect nationalise Britain’s medical records,’ said report editor Simon Davies. ‘Information that used to be held by GPs and hospitals will now become the property of the Secretary of State. Individuals will lose their veto over the purposes for which their personal health information will be used.’

‘These powers will also allow data matching between the NHS, police, Social Services, the Home Office and the Benefits Agency’, says Davies. ‘This is an extraordinary attempt to extend the powers of the state by sneaking through wide-ranging legislation in the last days of a parliament.’

Ross Anderson, chair of the Foundation for Information Policy Research, said that the clause was ‘at odds with the welcome declaration of the Secretary of State, in the wake of the Alder Hey scandal, that the days of the old paternalistic NHS are over and that patient consent must be paramount in future.’

The meeting will be chaired by Baroness Gould of Potter Newton, and is supported by

- The Patients Association
- ACHEW (Association of Community Health Councils of England and Wales)
- POPAN (Prevention of Professional Abuse Network)
- BMA Foundation for AIDS (an independant charity)
- FIPR (The Foundation for Information Policy Research)

All members of the House of Lords were invited by a personal letter last Thursday. The audience will include, in addition to members of the House of Lords, MPs, and representatives of patient and health professional organisations.

3 Notes for editors

For background to the bill, see the FIPR web site: <http://www.fipr.org/>

For more about the campaign against Clause 67, see the website of the Campaign for Medical Privacy: <http://www.gorjuss.com/medicalprivacy/>

For more on the Nuffield Trust, see <http://nuffieldtrust.org.uk>

4 Contact

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