

## Registries will have to apply for right to collect patients' data without consent

Zosia Kmietowicz *London*

An amendment to the Health and Social Care Bill passed by parliament last week should clear the way for health registries in the United Kingdom to continue collecting data on public health without patients' consent, the General Medical Council has said.

Guidance produced by the council on patient confidentiality and informed consent caused a furore throughout the medical and research communities when it was issued last year (*BMJ* 2000;321:849).

It said that it was illegal for doctors and hospitals to supply personal information on their patients to research projects or registries without first obtaining the permission of their patients. Doctors claimed, however, that the guidance was unworkable

because to ask patients for their consent immediately after telling them they had a serious disease, such as cancer, would be inappropriate in many cases.

An estimated 15 trusts immediately banned doctors from passing on patients' personal details to cancer registries for fear they would be breaking human rights and data protection laws. The viability of the UK national cancer registration system—considered one of the best in the world—was put in jeopardy. The bans were temporarily lifted, however, when the GMC announced that it would delay introduction of its guidance until October this year.

Speaking at a meeting last week to raise awareness of the threat to future research, Professor Richard Peto, a director of the clinical trial service and epidemio-



Richard Peto: "[Patients'] rights also involve responsibilities"

logical studies unit in Oxford, said: "Every UK citizen has the right to medical care, but those rights also involve responsibilities. Better treatments that save more lives come from research into previous patients' experience."

The GMC thinks that a permanent solution to the problem will be made possible, however, by a new body that is being set

up under the Health and Social Care Bill, called the Patient Information Advisory Group. Individual registries who want to be exempt from the council's guidance on informed consent can appeal to this group, which will decide whether to recommend to the secretary of state that they be exempt. The secretary of state will then pass a "simple regulation" to grant exemption (see article below).

David Forman, deputy chairman of the UK Association of Cancer Registries, said that researchers were not against informed consent but were concerned that if some patients refused to let their details go to the cancer registries then the epidemiological picture of the disease would be distorted.

However, there was still a danger that the registries would collapse if the new law did not come into force before October, when the GMC's guidance would be imposed, said Professor Michel Coleman, head of the cancer and public health unit at the London School of Hygiene and Tropical Medicine. □

## Community health councils temporarily reprieved

Anne Gulland *London*

The government managed to rush the Health and Social Care Bill through its last stages in parliament last week when it agreed a temporary reprieve for community health councils and a statutory body to safeguard patient confidentiality.

Ministers bowed to pressure from the House of Lords not to scrap community health councils immediately but have pledged to revisit the issue after the election. The government's proposals to introduce independent advocacy services remain, however (*BMJ* 2000;321:315-6, 317). The bill received royal assent last Friday, just before parliament rose in preparation for the general election on 7 June.

Health minister John Denham told the House of Commons that he had sacrificed some

clauses of the bill because he was "not prepared to put at risk free nursing care for the elderly," one of the most substantial changes being made by the bill. His claim was dismissed by the Conservatives' health spokesman, Liam Fox, as "drivel."

Patients groups and MPs had rounded on the government when it announced that community health councils were to face the axe. The health select committee was particularly angry at the government's proposals, which meant that patient advocacy services would be operated within individual trusts.

Donna Covey, director of the Association for Community Health Councils in England and Wales, gave the announcement a cautious welcome. "The proposed abolition of community health councils has caused concern across the health community. However, the government's announcement provides an opportunity for reflection on this controversial issue."

The government also came under fire for plans that will give the health secretary, Alan Milburn, the discretion to allow patients' information to be disclosed to third parties, such as

disease registries, without patient consent.

Ministers are to press ahead with this clause but, after discussions with the BMA, have agreed to set up a statutory Patient Information Advisory Group (see article above).

Its members will include representatives from the BMA, the General Medical Council, the Medical Research Council, the Public Health Laboratory Service, and a national group representing patients. The BMA failed in a bid to lobby ministers to write into the wording of the bill that any breaches of patient confidentiality would be rare and exceptional.

Dr Vivienne Nathanson, head of ethics and policy at the BMA, said the new body would "alleviate everyone's concern about the way in which decisions will be made." She added: "The government accepts that in the main there must be patient consent—we're going into a general election and whichever party wins there will be a new government. We have been given assurances that any breaches would be rare and exceptional, but we wanted this written on the face of the bill."

Dr Nathanson dismissed claims that the clause could lead to insurance companies and employers getting hold of confidential information. The pharmaceutical industry also succeeded in persuading the government to remove two clauses that would have given the health secretary the power to make regulations restricting the processing of anonymous patient information for commercial purposes. □

## Correction

*Audit shows weaknesses in cervical cancer screening*

The first sentence of this news story by Annabel Ferriman (12 May, p 1141) should have read: "An audit of cervical cancer screening in Leicestershire has shown that 1 in 3 women who developed invasive cancer and who had had a cervical smear was given a misleading result." The sentence incorrectly said: "An audit of cervical cancer screening in Leicestershire has shown that 1 in 3 women who go for screening may be given an incorrect result." We apologise for the error.