



Letters

Patients' denial of disease may pose difficulty for achieving informed consent

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EDITOR—The 1998 Data Protection Act and the General Medical Council's guidance on confidentiality have resulted in uncertainty about whether patient consent is necessary to fulfil statutory requirements for fair and lawful processing of personal data such as the identifiable health information collected by cancer registries. **1 2** A regulation is expected under the Health and Social Care Act 2001 for England and Wales, while a consultation process is ongoing in Scotland and Northern Ireland, where health is a devolved matter.

If we wish to retain population based surveillance of cancer, the options include anonymisation of data, informed consent, statutory regulation under the 2001 act, or primary legislation to make cancer statutorily registrable, as for many infectious diseases. Anonymisation or pseudo-anonymisation would render the data invalid, since identifiable data are required to ensure quality control, investigate cancer clusters, and perform survival analysis by linking cancer and death records. The cost and difficulty of administering informed consent and the unquantifiable bias in cancer information due to the incompleteness of obtaining consent have been highlighted.**3**

Denial of the disease among a subgroup of patients would compound the threat to the utility of health surveillance data from a requirement for patient consent. Denial is a recognised way of coping with bad news such as a cancer diagnosis and doctors may “collude” in denial to help the patient cope.**4** Denial would prevent doctors from asking permission to record the diagnosis in a cancer registry.

An audit by retrospective case note review of all patients diagnosed with cancer of the lung, breast, colon, rectum, or ovary in Northern Ireland in 1996 (n=2222) shows that non-discussion of diagnosis was part of active patient management in 14% of lung cancer patients, 9% of colorectal, 4% of breast cancer patients, and 7% of women with ovarian cancer (table). These patients tended to be older than average.

The actual figures for non-discussion could be higher, since in 28-55% of notes there was no record of such discussion. A questionnaire survey of 500 cancer patients diagnosed more recently (1998-9) in

one part of Northern Ireland showed that even six months after diagnosis, 4% of patients still denied that they had cancer (M J Thompson, personal communication).

	Lung (n=670)	Colorectal (n=737)	Breast (n=678)	Ovary (n=137)
Diagnosis:				
Discussed	58	52	41	52
Not discussed	14	9	4	7
Not recorded	28	39	55	41
Average age of patient (years):				
Cancer discussed	67	66	58	59
Cancer not discussed	72	74	69	72

Discussion of diagnosis of cancer with patient by type of cancer. Values are percentages unless stated otherwise

Requiring informed consent for cancer registration and patient denial of the diagnosis would cause further loss of data of some 4-14%, depending on the cancer.

Footnotes

- Competing interests The Northern Ireland Cancer Registry acknowledges funding from the Department of Health, Social Services and Public Safety, Northern Ireland.

References

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4. Dunkel-Schetter C, Feinstein LG, Taylor SE, Falke RL. Patterns of coping with cancer. *Health Psychol* 1992; **11**:79–87.