

Cancer registries fear imminent collapse

Phyllida Brown *Exeter*

Britain's system for monitoring cancer trends could collapse if new guidance from the General Medical Council is implemented, warn researchers.

The guidance, intended to protect patients' confidentiality, says doctors should not transfer individuals' details to cancer registries without their consent. But the GMC's critics say that the guidance is unworkable and that most clinicians will stop registering data.

The guidance, dated June 2000 but issued in September, came just before the government pledged in its National Cancer Plan to improve Britain's cancer survival rates to equal the best in Europe.

But Dr Monica Roche, chair of the UK Association of Cancer Registries, said it would be impossible to monitor survival

trends if population-wide data stopped flowing in. "The only reason we knew there was an issue [with survival rates] in the first place was because of the national registration scheme," she said.

Eleven government funded cancer registries in the United Kingdom have maintained records on cancer incidence and mortality since the early 1960s. The data are collated by the Office for National Statistics. The data help to identify causes of cancer and reveal trends, and they can also be used to monitor the effectiveness of treatment.

At present, personal data are transferred automatically from oncology and pathology records to the registries, says Dr Roche. The GMC says, however, that "the automatic transfer of personal information to a registry...

before informing the patient... is unacceptable save in the most exceptional circumstances."

Researchers argue that cancer data, unlike data for some other conditions such as HIV infection, cannot be "anonymised" but must be linked to individuals. This is to enable statisticians to follow up how long individuals survive, to avoid counting cases twice, and to crosslink the data with occupational information.

The registries accept that there is a real risk that personal data could be abused—for example, by insurers or employers. But Dr Roche says there are tough protection procedures and insists that there has never been a serious breach of confidence.

"This is a matter of principle," said a GMC spokesman. "Patients are no longer pre-

pared to accept that doctors make decisions without consulting them." The council dismisses fears that the system will collapse, arguing that the vast majority of patients will consent to the use of their personal data.

But critics say that even a very small percentage of refusals would bias the data, making them worthless. "The system will collapse unless this is dealt with immediately," says Dr Roche.

The GMC says doctors should seek patients' consent for registering their data at the first consultation or at another suitable occasion. (See p 850.) □

A statement from the UK Association of Cancer Registries can be accessed in News Extra at bmj.com.

Full story in News Extra at bmj.com

UK death rates from breast cancer fall by a third

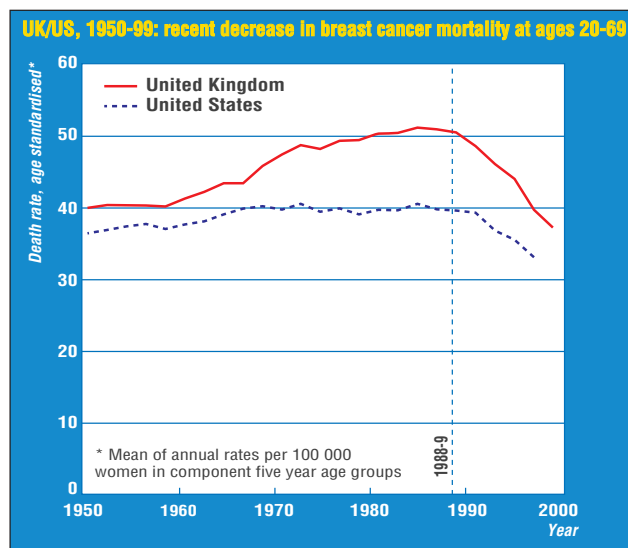
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The United Kingdom saw an unprecedented fall in the death rate from breast cancer during the 1990s, a new analysis finds. Researchers believe the improvement is due mainly to better treatment, especially the widespread use of the drug tamoxifen.

"This is the first time that improvements in the treatment of any type of cancer have ever produced such a rapid fall in national death rates," said Sir Richard Peto, professor of medical statistics at the University of Oxford. Peto last week presented the results of an overview of 300 treatment trials, involving some 200 000 women worldwide, to the second European breast cancer conference in Brussels.

Until the late 1980s, death rates from breast cancer climbed steadily in many Western European countries, although not in the United States. The reasons for the increase in Europe were unclear, said Peto, although later childbearing, earlier menarche, and other hormonal influences were probably important. But since 1990, the death rate from breast cancer has fallen in the UK by about 30% overall. The United States has also seen a decline, and other European countries are beginning to follow suit.

The use of adjuvant treatments after surgery—tamoxifen, chemotherapy, and well-targeted radiotherapy—can account for



much of the improvement in Britain, says Peto, together with earlier diagnosis of the disease through screening. Tamoxifen may particularly help to explain Britain's lead because British doctors adopted its widespread

use in around 1985, earlier than in the United States or other European countries.

As treatment is still improving in Britain and elsewhere, death rates are expected to continue to fall, Peto said. □