

Confidentiality a cause for lack of cancer statistics

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An unresolved debate about patient confidentiality has left cancer researchers without information on new cancer cases for the past decade - although this is crucial for health planning.

The National Cancer Registry (NCR) hasn't produced a report since 2005, and that was based on data that's now 10 years old.

Now draft regulations are under discussion to make cancer a legally reportable disease to get the registry going again. Cancer researchers, the NCR and health officials are due to meet next week to discuss the regulations and how to get the registry a comprehensive flow of data again.

The department of health's cluster manager for non-communicable diseases, Christelle Kotzenberg, said a decision to set up a task team to develop a regulation on cancer registration was made on October 3 and the first meeting to discuss the draft regulations would be today.

Kotzenberg couldn't say why it

had taken so long to address the problem, except that this was "mainly I think because there was no concerted effort".

One researcher said there was now a "conducive environment" to get the process under way after years of it not being a priority.

The draft regulations on cancer registration propose making it compulsory to register all cases of cancer. This means hospitals must keep cancer databases.

Failure to register cases could mean a fine of up to R20 000.

The regulations propose getting the NCR running again, and after a year, the setting up a population-based registry, which is more comprehensive, uses more sources to identify cases, and costs a lot more.

The regulations require "limited and well-defined access" to the registries to protect patients. There are no details on exactly what information should be collected.

The problem arose about seven years ago when the private pathology laboratories stopped sending details of cancer cases to the registry.

The NCR relies entirely on cases confirmed by pathology labs for its information.

But when debates around patient confidentiality arose at the end of the 1990s, the private labs worried they were breaking the law by sending cases with patient details to the NCR.

"Currently pathologists do not feel secure they were not violating patient rights in sending the data to the registry," said Dr Tjaart Erasmus, the president of the National Pathology Group (NPG).

The NPG is part of the South African Medical Association and represents private and state pathology labs.

The labs don't deal with patients directly so could not get informed consent from patients allowing their information to be passed on to a third party, the NCR. What the labs wanted was a legal "blanket ruling" allowing them to pass on the data.

It's the department of health's responsibility to make such legal provision, but for years the matter was debated and nothing happened.

"We really tried," said Erasmus. Although many of the private labs stopped sending data to the NCR years ago, they still have it.

"The laboratories felt they were morally obliged to continue keeping the data," said Erasmus.

The problem means the NCR has lost about a third of its data, said NCR acting manager Patricia Kellett.

She understands the labs' ethical dilemma. "All they want is the okay from somebody in government to release the data."

Kellett said the data from the labs was very good and provided a reliable source of statistics.

The confidentiality issue arises because the registry needs case information which identifies the patient. This is because a single patient may have numerous tests, may have more than one site of cancer, and may have a cancer which recurs after being dormant for years. As the NCR counts new cases, it needs some way to identify linked cases to prevent double-counting.

"Once is once. They might present again but we're not going to

count them as a newly diagnosed cancer," said Kellett.

The NCR data is crucial for health planning. "It's hugely important," said Kellett, explaining it was needed to assess trends, geographical incidence of disease, life-time risks, age-related incidence and whether screening for cancers worked.

"If you don't have stats, how do you know if anything's working?"

The NCR has also been hampered by lack of key staff. The small unit's director left years ago and the acting director has also gone.

"It's a tragedy that we've missed so many years with not having this information," he said. Kotzenberg said although the last published NCR data was old, it was not useless.

"Luckily the trend of non-communicable diseases does not change dramatically over a short period of time, as you can find with communicable diseases," she said.

"The national department does not render services thus we use the information for strategic planning and projections. Provinces will use the information for short-term plan-



Basal cell cancer (a type of skin cancer) is the most common cancer for both men and women.

ning." During 1998/9, the last years for which data was analysed by the NCR, about 60 000 new cases a year were reported.

Preliminary unpublished infor-

mation from 2000 and 2001 NCR data is that, despite the drop in case reporting, the total number of newly diagnosed cancer cases remained constant.

