

## Cancer data collection: blunt instruments get some honing



Lauren Pretorius, Head of Strategy and Operations in 'Campaigning for Cancer'.

Picture: Chris Bateman

**South Africa's pathology laboratory-based cancer registry is seven years out of date and conclusions based on its data are a decade old, making an appropriate and properly tailored strategic national response to this highly prevalent disease extremely difficult.**

This emerged at a 'Voice of Cancer' survivor forum attended by all but one

of the major cancer NGOs, government officials and survivors at the Civic Centre in Cape Town last month. According to the National Cancer Registry (NCR), run by the National Health Laboratory Service (NHLS), South African men have a lifetime risk of 1 in 6 of developing cancer and women a 1 in 8 lifetime risk. The time, money and resources needed for hospital

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The good news is that senior staff from all nine provinces, most of the 16 academic oncology units and the national department of health have begun a series of meetings to fast-track and streamline data collection and translation of the NCR. This follows a long-awaited move by government last year to render cancer a notifiable disease in order to overcome patient confidentiality clauses in the National Health Act which choked data collection. The new regulations will galvanise the NCR into an active registry, forcing the reporting of all clinical and laboratory-diagnosed cancers in both the public and private sectors, swelling the data base and thus the accuracy on which to base future policy and management plans.

### **Government believes cancer is 'a white man's disease' – claim**

Lauren Pretorius, Head of Strategy and Operations in 'Campaigning for Cancer', said a problem with a path-lab-based registry was that often cancers in patients living in rural areas were so far advanced that they were not registered. She pleaded with government to fund the registry adequately, monitor reporting and impose heavy penalties on path labs that failed to comply. Pretorius said a national cancer control plan had been in draft form for ten years. She hoped the new legislation would stimulate its finalisation. Activist and cancer survivor, Lynda Marthinus, said the South African health ministry had committed to its international peers that it would fast-track the NCR, and 'we as cancer patients are happier now'. 'But

we must get in front of government and use the media to ask how [do we progress]. Until government sees that its own people are suffering from this illness, we'll never get movement. We must get beyond policy to action,' she added. Marthinus earlier cited one of the major barriers to action as the government's perception that 'cancer is a white man's disease'.

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'Let's use the government's own people (cancer survivors) and partner with them! The majority of known cancer patients are black and suffering from AIDS. We need a bold step like presenting to the health portfolio committee the age, gender and racial composition once we've unpacked these data from the registry.' She said that in terms of the new regulations the health minister was obliged to update parliament twice a year on the register, 'so from next year we must be there as survivors to hear what he says and ask questions.'

### **Global ignorance of African cancer burden**

Ann McMikel, Director of Planning and Operations at the American Cancer Society, said that prior to survivor forums being held in Africa, a volunteer on her national board who had been working for 15 years on the continent had 'no clue' of the weight of the cancer burden here and neither had one of her major funders. 'That's why it's critical that we bring to the world's attention the cancer burden in South Africa – it's not known by many of the well-meaning, bright leaders on the global stage,' she stressed. In September this year the United Nations would convene

a meeting of heads of state, world leaders and civil society to see what was possible in addressing cancer (responsible for more than 60% of deaths world-wide) and other chronic diseases. McMikel said cancer was excluded from the Millennium Development Goals and 'this [meeting] gives us a huge opportunity to change that by informing them of the issues – the data are beginning to tell the story'.

South Africa's NCR has a staff complement of 25 and a report-writing team drawn from the major public health and oncology departments at medical schools across the country. Peer review is supported by links to the MRC, the International Association of Cancer Registries in Lyon, France, and the Cancer Council in New South Wales, Australia.

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### **Kick-starting a slumbering data giant**

It received over 95 000 cancer notifications during 2009 through passive reporting from pathology laboratories, taking over 15 months to remove duplicates, code, enter and analyse and report back on an annual basis. A task group is currently probing the possibility of automating data coding and entry to speed up analysis and reporting times. An NCR spokesperson said a case-control study of 17 000 patients diagnosed with cancer at Charlotte Maxeke Academic Hospital in Johannesburg (120 new patients every month and begun in 1995), had highlighted the changing profile of cancer due to the HIV epidemic. These data had contributed to the 'correct positioning' of screening, diagnostic and treatment



*Danuta Kielkowski, Deputy Director, National Health Laboratory Service, who helps oversee the cancer registry via a computer system linked to 630 laboratories country-wide.*

*Picture: Chris Bateman*

programmes in the public sector. Similar studies would shortly be extended to the major oncology departments in Durban and Cape Town. A prospective study would also be developed to review cancer treatment outcomes.

- Sue Janse van Rensburg, CEO of the veteran Cancer Association of South Africa (CANSAs), said her 80-year-old organisation was not invited to the forum. CANSAs participated in the initial 'survivorship' meeting last year but had not heard from the forum organisers since. 'At the beginning of this whole thing they wanted our data base. You can call that politics or whatever you want but that's our intellectual property.' She said CANSAs was willing to work with 'anybody in the field' and described their alleged exclusion as 'pretty sad'.

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### **National Call to Action**

The Voice of Cancer Survivor Forum called for the urgent setting up of:

1. A National Cancer Advisory Council by the Minister of Health
2. A national cancer control plan that is succinct, implementable, and with quality access
3. A cancer registry that is well funded, resourced, accurate and maintained – with accessible data and incidences
4. National, government-prioritised budgeting and funding for cancer control services
5. The scrapping of any (unconstitutional) regulation that defines cancer as treatable or untreatable.