Another law change prevents proper healthcare delivery[1]

A year-old amendment to the Births and Deaths Registration Act, making the cause of death confidential to all but Statistics South Africa (Stats SA) officials, has effectively torpedoed mortality surveillance for public health planning in the Western Cape.

The Western Cape Department of Health (DoH) developed (from 2000 onwards) a sophisticated home-grown mortality data system, working with the City of Cape Town, the University of Cape Town and the South African Medical Research Council (SAMRC) to glean detailed public health information not available from national vital statistics. The province used this vital information not only for statistics but also to develop appropriately placed programmes to reduce diarrhoea deaths among children, and evaluate HIV, antiretroviral therapy (ART) and cervical cancer screening programmes. By January 2014, the City of Cape Town had developed an IT system that was capturing deaths by residential suburb within weeks of the date of death, automatically coding the underlying cause of death (CoD) in 70% of cases. The rapid availability of specific details of where people died and the CoD painted a much richer and clearer picture of the public health action required to address the problems faced by those specific communities. With limited resources and many competing needs, the data gleaned empowered health managers eager to make a difference. That all came to an abrupt end when the Department of Home Affairs (DHA), in an attempt to streamline its processing and maintain individual confidentiality, last February suddenly introduced a new death notification form with the CoD page sealed and only Stats SA legally empowered to open it.

Informed of the objections, Statistician-General Mr Pali Lehohla took a hard line, claiming that what the Western Cape had been doing was 'illegal' and citing the media's controversial accessing of the health records of the late Minister of Health Dr Manto Tshablala-Msimang as an example of the violation of the doctor-patient relationship. He said that this 'sacrosanct principle' held equally true for the dead. Questioning why it was necessary to wait for a death before interventions were put in place, Lehohla said that stats drawn from health records (i.e. living patient consultations) could help build disease profiles. Anonymity was a 'fundamental qualifier' to the aggregates Stats SA produced on any phenomena of public interest. 'Even with an application of the most sophisticated algorithm, such aggregates cannot be decomposed [*sic*] to reveal the specific individual to whom the phenomenon of public interest relates,' he added. Lehohla cited both the abuse by Nazi Germany of census records to kill Jews during World War II and an alleged raid by Israel on Palestinian census records in order to 'kill, maim and arrest' its enemies. He said that Stats SA worked in accordance with the Fundamental Principles of Official Statistics endorsed by the UN General Assembly in January last year, which stated that individual data should remain strictly confidential and be used 'exclusively for statistical purposes'.

Drs Pam Groenewald and Debbie Bradshaw of the SAMRC's Burden of Disease Research Unit.

According to Drs Debbie Bradshaw and Pam Groenewald, both highly respected researchers at the SAMRC's Burden of Disease Research Unit, without a duplicate CoD page to enable a 'feedback loop' to health authorities, death notification effectively becomes a one-way data flow, seemingly implying that the information is collected only for statistical purposes and displaying a low appreciation of the nation's need to take public health action based on such information. The latest CoD report from Stats SA showed that only 48.4% of deaths occurred in healthcare facilities, with 23.2% occurring in homes. 'It is precisely the deaths that occur without intervention which alert us to failings in our public health system, hence the tremendous value-add of CoD data which are universally sourced, irrespective of health service access,' they stressed. The Director-General of Home Affairs was within his legal rights to share CoD information with the province's health department – it was only when the Births and Deaths Registration Act was amended last year that this became 'illegal' through the death notification form. The law lacked a stipulation giving health departments access to such information, as was done in the UK. The pair remain convinced that it's possible to 'responsibly' recover this ability without compromising any of the principles highlighted by Lehohla.

Child pneumonia deaths at home – province now unable to respond

Groenewald said that following the significant reduction in diarrhoea deaths as a result of highly focused efforts informed by the diarrhoea death data, the City of Cape Town was currently on the brink of implementing a childhood pneumonia response after discovering that a significant number of young children were dying of the disease at home. 'These cases get certified in the forensic morgue, but unless the information from the death notification is available to the health department, they will be unable to respond.' Western Cape mortality surveillance had illustrated how morgue data and clinical data could be linked to death notification information to examine treatment failures and missed opportunities. She said that HIV and tuberculosis lent themselves to the monitoring of programme outcomes where loss to follow-up was identified as a problem. Being able to access CoD data and link them with ART registers enabled far more accurate assessment of treatment loss to follow-up, with the possibility of adjusting the programmes accordingly. Said Groenewald: 'In straight language, the legal amendment has torpedoed

an essential tool that enabled the provincial DoH to review their programmes.'

The system works like this: somebody dies, a doctor has to (correctly and accurately, it is hoped) certify the medical CoD, and helped by an undertaker the bereaved family files these forms with the local DHA office to register the death. A burial certificate to formally authorise the disposal of the mortal remains is issued after the DHA checks the integrity of the forms and registers the death on the population register. The form is then sent to the DHA's head office in Pretoria, where it is archived and sent on to Stats SA, who process the information for statistical purposes.

The system developed by the Western Cape DoH together with the City of Cape Town relied on obtaining the information from the regional offices of the DHA to create a surveillance system that was used to provide relevant local-level statistics as well as the opportunity for targeted public health action.

Other provinces: Why monitor causes of death when it's illegal?

Groenewald laments the closure of the only functional local mortality surveillance system in the country, as a growing body of evidence suggests that other provinces should be setting up similar systems. Lehohla hit back, saying this would undermine the country's statistics system and asking 'How much more will the state expose records of its citizens to unauthorised public display?'

Bradshaw said that DoH participation in mortality surveillance remained 'key'. 'It cannot merely be a statistical exercise. The National Health Act needs to enable Health to have access to identifiable CoD information so that it can be fully utilised to improve the health of the nation. Health handles confidential clinical information all the time and should be well placed to preserve confidentiality of cause-of-death details, but as this law stands only Stats SA may look at individual death records and are not allowed to share it with Health.'

Window of hope

Stats SA is currently leading an evaluation of the civil registration and vital statistics system, providing an opportunity for review of the current legislation. A specific data quality concern that Groenewald believes needs fixing is the collection of information about causes of injury deaths. Pathologists report the nature of the injury, but fail to note what *caused* it. 'So we don't know if it's an accident, homicide or suicide. When this information is coded, the international default is to allocate the unspecified injuries to accidents. Hence we see a lot of gunshot "accidents" in the national injury statistics,' she said. The solution to this would be an additional space in the death notification form, enabling the pathologist to actually record the cause of the injury (manner of death). Bradshaw said that the Stats SA evaluation was a great opportunity to ensure that the system of civil registration and vital statistics provided an effective platform for public health action as well as the compilation of national statistics. Both researchers are hoping for a meeting of minds – and that there will be a way to ensure that Health can access the vital data.

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S Afr Med J 2015;105(3):244-245.
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1. Bateman C. Zuma's legal advisors 'led him astray', turned health-care professionals into criminals. S Afr Med J 2015;105(3):196. [http://dx.doi.org/10.7196/SAMJ.9468]