

INTERVIEW

Making equitable access to NCDs+ prevention and treatment a national priority: an Interview with Dr Vicki Pinkney Atkinson

Dr Victoria Pinkney-Atkinson, is the Director of the South African NCD Alliance. She holds a PhD in NCDs Healthcare Knowledge Management from the University of the Witwatersrand. She is a healthcare professional and activist with more than 50 years' experience in the field

Could you please introduce yourself?

My name is Victoria (Vicki) Pinkney-Atkinson. I am a health-care professional with over 50 years of diverse experience in many settings. However, having life-long lived experience is my most important qualification for being an NCDs+ activist. It is not a profession that anyone in their right mind would choose, let alone a child in the critical first 500 days of life. Indeed, without the chronic skin condition of psoriasis, I might well have done something suitably meaningful, but that didn't need quite so much passion and grit.

Within my first 500 days, the 'silly little skin disease' was diagnosed. It resulted in stigmatisation, disability, and many severe comorbid health conditions. In the 1950s and 60s, many of these complications had yet to be acknowledged or identified. The reality is that psoriasis is a common autoimmune condition going beyond skin deep, and its complications often go unacknowledged or misdiagnosed. In later life, responses to drug treatment and psoriasis complications led me to at least three near-death experiences.

Currently, I am the Director of the South African Non-Communicable Disease Alliance (SANCDAs), where my main focus is on NCDs+ activism framed by policy coherence.

What is SANCDAs's main advocacy objective?

Our main advocacy objective is that people in South Africa who use the public health services get equitable access to quality NCDs+ prevention and management throughout their life course without causing them financial hardship. If you recognise that is close to the definition of universal health coverage (UHC), well spotted!

Our advocacy has three main pillars that are parts of UHC: equity, quality and affordability (financial risk protection). The SANCDAs+ uses the government's communicable disease (CD) programme, specifically HIV, TB and sexually transmitted infections (STIs), as the benchmark for policy and programme criteria. The rollout of National Health Insurance (NHI) must make that transparent and evident.

- **Equity:** People living with NCDs+ (PLWNCDs+) want equitable access to NCDs+ prevention and management services. This implies access to medicines for common NCDs+ conditions, convenient pickup points, etc. Since 2014, the government's Central Chronic Medicines Dispensing and Distribution (CCMDD) programme has provided extensive support for HIV and TB medication access. We want something similar for insulin users and diabetic supplies at primary health care (PHC) level within NHI districts and services.

- **Quality:** PLWNCDs+ want quality NCDs+ services based on transparently developed and implemented guidelines implemented at the PHC level with the accompanying evaluation, as is done for HIV and TB.
- **Affordability:** PLWNCDs+ want the full agreed package of services available close to home without incurring transport and out-of-pocket expenses due to ongoing supply chain problems. Again, we use the CD programme as a benchmark.

The COVID-19 pandemic has exposed NCDs+ in the form of co-morbidities. How would you recommend they remain prioritised from a policy perspective?

Early in the pandemic, statistics from China showed that older persons were at the greatest risk of severe COVID-19 and death. This was markedly different from the Spanish flu of a century ago. Further analysis showed that while age is an independent risk factor, most seniors, and many younger people, have one or more NCD+.

NCDs+ are a significant part of the much-banded term 'co-morbidities' or 'co-morbid conditions'. It became clear that the early diagnosis and adequate treatment that formed an essential part of NCD+ management was also crucial here, especially so in the public sector. For example, if a person with diabetes keeps blood-sugar levels down below a set level for over three months, the risk of COVID-19 complications or death, was reduced. Control in this instance is measured by an HbA1C test, something sadly not available in many PHC settings.

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For people living with CDs, the parallel reality simply meant continuing the existing care and treatment for which there was significant access even in hard COVID-19 lockdown. In South Africa, we have the world's largest group of people living with HIV and in ARV treatment. So, from the start of the pandemic, the National Department of Health's (NDoH) communication team only acknowledged CD as the most critical co-morbidity. The bias toward CDs as the most critical co-morbidity is understandable given the NDoH's considerable investment of money and human lives.

NCDs+, including obesity, were ignored, thus reinforcing the long-standing neglect of NCDs+ in the public health services. Time and time again, the SANCDAs+ asked the NDoH to change its COVID-19 messaging about co-morbidities. To no avail: the state priority co-morbidities remained HIV and TB.

The reality is that only those who were poorly compliant or undiagnosed were at risk. Minister Mkhize included malaria as another critical CD co-morbidity on one memorable occasion. In mid-2021, government health messaging started including NCDs+ as significant co-morbidities.

The long-standing neglect of NCDs+ meant that most of the population that uses public health services go undiagnosed and untreated. When a person is diagnosed with an NCD+, the evidence shows that drug treatment is often not started or is poorly managed. So PLWNCDs+ are ripe breeding grounds for severe COVID-19 and death.

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How would you assess the impact of COVID-19 on those living with NCDs+ (PLWNCDs+)

It is a huge burden on the health system, but is hidden from sight because the statistics about NCDs+ are so poor. When we reflect on this pandemic, apart from the fact of corruption and the failure of the health services, the great scandal is the neglect of NCDs+ within the public health system.

It is simply the case that South Africa does not routinely collect national data on NCDs+ as it does for every aspect of health related to CDs. The epidemic's impact on NCDs+ is unknown, but we have more than an inkling about this from the hospital admission figures compiled by the National Institute of Communicable Diseases (NICD) in its DATCOV stats. Initially, only CD co-morbidities were recorded, but (thanks to the NICD's insistence) NCDs+ including obesity, were added to the list, albeit late in the day and not as part of the routine data collection. NCDs+ remained an optional extra!

Most people with COVID-19 die at home, possibly with an undiagnosed or uncontrolled NCD. The 'excess death rate' indicates we may be in for a rude awakening as we theoretically build back fairer post-NCDs+-19. The UN and WHO slogan for post-COVID-19 reconstruction as 'build back better'. In the case of NCDs+, this must be founded on UHC and include respect for human rights to start building back fairer.

The National Indicator Data Set (NIDS) collects vast amounts of CD information from the public health system and minimal NCDs+ data. That is the scandal. The NDoH doesn't care enough to know.

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How would you assess the varied impact on PLWNCDs+ from vulnerable and marginalised groups?

The COVID-19 pandemic has shown us that vulnerability comes in all shapes and sizes, and not just for the list of usual suspects. Until COVID-19, PLWNCDs+ were an unacknowledged vulnerable group.

Why? Government policy excluded PLWNCDs+ from equitable prevention, diagnosis and treatment despite being the fact of their being the leading cause of death in South Africa. NCDs+ are a priority neither in the National Development Plan nor for the government. Their cause has no champion amongst the political elites and parties.

What would you say is the main cause of the increasing burden of NCDs+ in the country?

- The epidemical transition of societies and economies. This is a global phenomenon.

NCDs+ are always present and seldom appropriately managed, particularly so among the poorest and most disadvantaged groups. These are euphemistically referred to as 'upstream' causes of health problems, or the social determinants of health. But they are much more than just the social. They include economic, commercial, and environmental causes. In South Africa that covers the broad swathe of people. The 2022 World Bank report regards South Africa as the 'most unequal country'. Most South Africans only have poor health care, and NCDs+, the largest group of health conditions, thrive in poverty.

- No political will to deal with NCDs+. The outdated government narrative dates back to the 2007 ANC Polokwane Conference when a focus on CDs was

vital and a new political elite swept into power. For example, the NDP, the NDoH and the President's labelling of NCDs+ as 'diseases of lifestyle' and seldom of poverty and inequity. As a lifestyle disease, the poor and neglected must take the rap of purposely getting an NCDs+. Blameworthiness is not a fault meted out to those who live with HIV or TB.

The National Development Plan (NDP) gets its mandate from the political domain, and the health chapter still champions CDs and millennium development conditions over NCDs+. NHI also appears in that chapter, but the abject failure of NHI to date mirrors the NDoH's continuing neglect.

Would you think that the approach of the government to focus on management rather than prevention of NCDs+ is the right way to go? What suggestions would you offer?

It is not about either prevention or management – that binary remains the fatal flaw of the NDP 2030. It's actually impossible to deal with the one without the other. South Africa has to do both simultaneously in a rational and non-siloed manner. The trouble is that there is no transparent, inclusive discussion on how to do this. It can't be done with HIV and TB at the centre of the narrative.

The failure to adapt the NDP leaves the many millions of PLWNCDs+ without equitable access to treatment: basics like screening, diagnosis and evidence-based treatment in the government health system.

The NDP and policy emanating from it, the Medium-Term Strategic Framework (MTSF) 2019–2024, make it clear that population prevention measures and 'healthy lifestyles' are the only real interest. The MTSF is unequivocal in stating that there is no direct funding for NCDs+. This is, of course, a disaster for those of us living with NCDs+.

What is your view on the NCDs+ National Strategic Plan (NSP) 2022–2027? Is this the document of your dreams?

The National Health Council approved the third NCDs+ NSP 2022–2027 recently and its launch [was] due at the end of May 2022. It certainly isn't a 'dream' policy; but it is a hard-won compromise that took all of the strength and limited resources of a determined group of NCDs+ activists.

The SANCDA+ forced the NDoH to address human rights issues, the exclusion of PLWNCDs+ and the issues of deliberate non-transparency. The gruelling eight-year advocacy battle involved influential stakeholder groups, including government departments and well-funded CD advocacy groups. Strong and well-connected forces supported the CDs status quo.

The third NCDs+ NSP is fundamentally different from its predecessor, which was, of course, neither funded nor implemented by the government. The NSP supports the concept of the Sustainable Development Goals (SDGs), but these goals are contraindicated by the existing siloed arrangements and would require truly integrated health care. That is the rub, and the point where the agreement ends.



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Over the years, you have worked extensively on NCDs+, focusing on addressing inequality in the health sector. Do you think there have been positive developments in this regard?

In the absence of political will, health inequity has grown because this suits the powerful. However, I think COVID-19 could be a great leveller if we take the lessons seriously and build back fairer. So far, COVID-19 has provided a window for policy change along with the alignment of Kingdon's three-streams theory. NCDs+ (hence the reason for the + throughout this interview) are a large, diverse group of conditions, including mental health, motor vehicle accidents and disability.

The SDGs drive us towards UHC, and this would require that our local variant of NHI consider the people's real needs. It is so much more than a financial risk management system. And no amount of political desperation will convince those who use public health services that the current model is in the people's best interests.

2022 is a year of party-political manoeuvring. No political party has found NCDs+ a sufficiently worthy cause to address in its manifesto, though there are many promises of change to the health system in the air in the run-up to December. However, until the NDP and the MTSF change fundamentally, there is little hope.

Change will only come if every politician, their families and civil servants are forced to use the government health services they created to support dysfunctionality. Ban them all from access to private health insurance, and perhaps political will might return. I took that step about five years ago. It simultaneously terrifies me and galvanises me to action. During COVID-19, it has been some small comfort to know that I am with the approximately 80% of the population who are in the same sinking ship.

SANCDAs+ recently resubmitted a complaint to the South African Human Rights Commission (SAHRC) addressing inequality regarding access to health care and medicine. What role can quasi-judicial bodies play in addressing some of these challenges in relation to NCDs+? What about the courts?

Our open SAHRC complaint is under way. In it, we list seven human rights that are currently being violated. We cite the government's (and the Presidency's) failure to support our request to uphold our rights. A 2007 SAHRC hearing noted most of this, but nothing has changed since then. The complaint was submitted in 2020 and later resubmitted to extend the complaint's address beyond the national and provincial departments of health.

We are thankful that the SAHRC has registered our case and that it is progressing there, even though this is a fraught process, and a very slow one. Not that we are not grateful to the SAHRC; but this goes along the lines of 'beggars can't be choosers'. Once again, we know what it is like to be stuck with an unsellable and unpopular health condition.

The SANCDAs+ human rights are a global first where we take all NCDs+, as a class of conditions, without fragmenting them into competing NCDs+ groups. NCDs+ advocacy organisations are the poorest of health civil society organisations

When discussing the prospect of litigation, there is inevitably the desire to pick a favourite NCD, depending on your worldview. Many factors colour this selection. These include the fact that many funding bodies want

to pick their target NCDs while others simply want to get the greatest media mileage from it. All this is very understandable.

One legal-cum-civil society organisation seriously said we should first raise R2 million (minimum), and then they would consider it. Even then, we might have to change our strategy and not ask for equity between NCDs+ and CDs. I kid you not.

NCDs+ are the greatest disease burden globally, but less than 2% of all donor funding goes toward NCDs+. Government funding for NCDs+ civil society activities is negligible. It stands at 1% compared to 99% for CDs. While CD funding is shrinking, it is still at levels beyond our wildest dreams. Yes, we know that much of this funding comes through donor funding and conditional grants. Facts are not equity food.

We secretly call the silent treatment we get from the government the 'Reverse Stalingrad Strategy'. We probably have had just one written response in eight years. It is as if their thinking is, 'If we don't respond and stay silent, you don't exist, and you will simply fade away. Stay schtum, and we will prevail.' So far, it has worked brilliantly and allowed state capture to flourish. We have extensive documentation of the neglect from government, politicians and officials.

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