

SOUTH AFRICAN HUMAN RIGHTS COMMISSION

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2198



SOUTH AFRICAN HUMAN RIGHTS COMMISSION COMPLAINT FORM

For office use only

Province:		City/Town:		Reference No	GP/2122/0026/BJ/K
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PART A: YOUR DETAILS

Name and surname: Victoria Jane Pinkney-Atkinson Nickname: Vicki

ID number: 521103 0004 087

Race: white

Gender: female

Address and contact numbers

Street address of the South African NCDs Alliance (SANCD A) is that of our fiscal partner c/o

The Cancer Association of South Africa (CANSA), 26 Concorde Rd West, Bedfordview, 2007

The address where we can send letters to c/o CANSA PO Box 2121, Bedfordview, 2008

The telephone number at work, home, cell: 083 38 38 159

Whose telephone number is it?: VJ Pinkney-Atkinson

E-mail address: vjpa@live.com vicki@sancda.org.za

PART B: DETAILS OF PERSON ON WHOSE BEHALF YOU COMPLETE FORM (PERSON OR ORGANISATION)

South African Noncommunicable Diseases Alliance. (SANCD A)

Registration number:

The SANCD A's fiscal partner is CANSA and uses its registration number **000-524 NPO**

What does it do (e g., civil, business, retailer, factory, NGO, etc.)?

Civil society organisation, NGO.

Who should we talk to there? SANCDAs: Vicki Pinkney-Atkinson, Director

CANSA Elize Joubert, CEO

The address where we can send letters to c/o CANSA PO Box 2121, Bedfordview, 2008

PART C: THE COMPLAINT

12. Date

On what date did it happen?

The violation of the health and human rights of people living with non-communicable diseases (PLWNCDs+) is ongoing ([see list section 15 below](#)). It has its origins in the under-resourcing and neglect of non-communicable diseases (NCDs) by the national and provincial departments of health. PLWNCDs+ are a vulnerable group that requires prioritisation because they have long-term health conditions making them more susceptible to severe COVID-19 infection and/or death. Furthermore, the COVID-19 pandemic has exposed this long-neglected and vulnerable patient-caregiver community. Annexure A outlines the history of the violation from 2006 when the [first national NCDs policy](#) was published.¹

To properly describe the complainant community in this matter, we recommend the use of the acronym NCDs+ for the broad class of non-communicable diseases. Similarly, using PLWNCDs+ to describe people living with non-communicable conditions. This technical debate starts with [the National Health Act](#) and has major ramifications for PLWNCDs+. Suffice it to say that South Africa uses a definition that is at odds with global norms.

PLWNCDs+ are a fast-growing community prevailing with potentially life-threatening conditions, including but not limited to cancers, diabetes, heart and circulatory, chronic respiratory diseases, and mental health conditions. According to the 2018 World Health Organization (WHO) report ([NCDs Time to Deliver pp. 6-8](#)), NCDs+ as a group of health conditions that pose the most significant threat for premature mortality and disease burden, especially in low- and middle-income countries. Likewise, the most recent [South Africa mortality report for 2018](#) shows that NCDs are the leading cause of death (57.7%), increasing every year since 2011 when they overtook communicable diseases as the leading cause of mortality and morbidity. If external causes (e.g., motor vehicle accidents and suicide) are added to the NCDs+ group, as happens globally, then this rate is over 60% mortality in South Africa.

¹ Annexure A is a timeline showing policy and SANCDAs interventions since 2006, the date of first NCDs national policy. There are hyperlinks to the relevant documents. The timeline, in spreadsheet format, is updated frequently please enquire for the latest version. info@sancda.org.za

Therefore, PLWNCDs+ urgently require a full continuum of care from screening, prevention, diagnosis, treatment, including [access to medications](#), and ongoing chronic care. These are the essential elements of an effective public health response considering that the NCDs+ burden is escalating rapidly and remains insufficiently addressed and poorly resourced (in terms of prevention **and** treatment). PLWNCDs+ require that their health conditions get robust national policy interventions, including technical and financial resources similar to those committed to controlling and treating communicable diseases like HIV/AIDS, tuberculosis (TB) and sexually transmitted infections (STIs). See [Health Budget 2021-22](#). with particular reference to Programme 3 Communicable and NCDs+ (pp. 9-12)

Historically, the South African Human Rights Commission (SAHRC) Public Inquiry: Access to Health Care Services (2007) addressed many of the aforementioned challenges. Some of the current SANCDA members presented the case for the equitable, just and fair allocation of health resources to address the national burden of NCDs+, at the Inquiry. However, for PLWNCDs+, the [Inquiry's report](#) conclusions and specific recommendations neither advanced the progressive realisation of the right of PLWNCDs+ to access essential and potentially life-saving treatments nor did it provide for essential services for PLWNCDs+ like was done for people living with communicable diseases (HIV, TB, and STIs). Fifteen years later, PLWNCDs+ still experience a lack of national prioritisation and adequate resource allocation. A proper national and provincial NCDs+ response will require policy coherence to achieve integrated, evidence-based and people-centred health services from the community level to national and provincial public health policy-making levels. ([See 2016 WHO report on integrated person-centred services.](#))

"During the public hearings, the DoH indicated its explicit commitment to the progressive realisation of the right of access to health care services.

However, it is the implementation of policies which has proved to be a major stumbling block." Inquiry Report 2007 p10

The South African Non-Communicable Diseases Alliance (SANCDA) which is the lead complainant in this matter, is a robust national network of approximately 100 civil society organisations and individuals seeking equitable, fair, non-discriminatory and urgent national and provincial responses to NCDs+ prevention and treatment.(See Annexure B for a current list of network.) Our allies collectively have decades of experience in health equity advocacy, community outreach, public education on various NCDs+ diseases and biomedical research. We have a countrywide footprint in all provinces, so our health and human rights activism has a national impact. Our network is active in various NCDs+ and health spaces from communities to regional and global fora.

We hereby request the SAHRC to assist our organisation in engaging with the National Department of Health (NDoH) and the nine provincial departments of health (PDsoH) on the realisation of the health and human rights of PLWNCDs+.

For over a decade, PLWNCDs+ and related civil society organisations, including the SANCTA, have implored the South African government to honour its health and health-related human rights owed to them under domestic ([section 27 & 28 South African Constitution](#)), [regional \(Art.16 Banjul Charter\)](#) and [international laws \(Art.12 of ICESCR\)](#).

13 Is it still happening?

Yes. The under-resourcing and neglect of NCDs+ have continued unabated since 2007.

Annexure A (as noted in Section 12) is a comprehensive timeline of activities and events, meetings, reports and letters, policy documents which in part documents communications with various government departments and officials in the SANCTA's unsuccessful attempts to stake the health and human rights of PLWNCDs+.

14 Where did it happen?

All over South Africa, in every province to a greater or lesser degree.

15. If you know, which right(s) in the Bill of Rights were violated or are being violated?

- **Equality - Section 9** - All persons are entitled to the right to health services without discrimination based on the type or cause of their health conditions.
- **Dignity -Section 10** - Some PLWNCDs+ are stigmatised or disapproved of due to their health condition. For example, people with epilepsy, mental health conditions, albinism and cancer.
- **Life - Section 11** - Failure to access essential medicines and treatments is life-threatening for PLWNCDs+. During COVID-19, access to medication due to the lack of alternatives as available for the HIV public sector community ([CCMDD](#)). This crisis existed before COVID-19. The failure to link screening for NCDs+ with accessible diagnosis and treatment is a hallmark of NCDs+ national policy.
- **Environment - Section 24 (a)** - A clean environment with clean air and water is essential for optimum community health. Air pollution is the greatest environmental risk factor for [heart and lung NCDs](#).
- **Health care, food, water and social security - Section 27** – Poor access to essential treatments and social services lead to poor disease outcomes for PLWNCDs+.

- **Children - Section 28** – Children living with NCDs are often neglected in national NCDs+ discourses. For example, [access to pain medication for children](#) living with cancer and other NCDs+ is a long-neglected issue.
- **Access to information - Section 32** We want information on how NCDs+ are funded and resources within the Republic and access to the regular, public and evidence-based health information on NCDs+ prevention and control. For example, the amount of money spent on NCDs+ at a provincial and district level is undisclosed despite frequent requests. How has the NDoH spent the Health Promotion Levy since its inception?
- **Just administrative action - Section 33** – PLWNCDs+ have a right to ask the government to transparently account for their inadequate response to NCDs+ prevention and control. Example; failure to include PLWNCDs+ timeously in policy development, failure to respond to requests for meetings, correspondence.

16. If you know, the full name(s) and surname(s) of person(s), association, organisation or organ of state who violated these rights, please tell us

We hold the executive and legislative tiers of government responsible for the failure to ensure that the health and human rights of PLWNCDs+ are prioritised, progressively and adequately met. ([See item 15](#)).

- The Presidency including the National Planning Commission, and Department of Planning, Monitoring and Evaluation;
- The executive authority at national and provincial levels with its accompanying structures of elected officials leading and civil servants. (See Table 1)
- The legislature includes the National Assembly, Portfolio Committee on Health, and the National Council of Provinces.
- National and Provincial Departments of Health.

The complaint is directed at the national level to the executive (Cabinet), the responsible senior government officials of the NDoH and PDsoH in line with their duty to deliver NCDs+ related health services, and the implementation of policies targeting the prevention and control of NCDs+ in South Africa.

Table 1: National examples of politicians and officials who violated human rights of PLWNCDs+

Health		
<p>Minister of Health</p> <ul style="list-style-type: none"> • 2009-2019 Dr Aaron Motsoaledi • 2019-2021 Dr Zweli Mkhize • 2021 Dr Joe Phaahla <p>Deputy Minister</p> <ul style="list-style-type: none"> • 2014-2021 Dr Joe Phaahla 	<p>Director-General</p> <ul style="list-style-type: none"> • 2010-2019 Ms Precious Matsoso • 2019 Dr Sandile Buthelezi <p>Deputy Director-General</p> <ul style="list-style-type: none"> • 2010- Dr Anban Pillay • 2010-2020 Dr Yogan Pillay 	<p>Chief Director:</p> <ul style="list-style-type: none"> • 2012-2018 NCDs Prof Melvyn Freeman • 2012-2021 Health Prevention & Nutrition Ms L Moeng Mhlangu

Presidency		
President Cyril Ramaphosa	Special Advisor Prof Olive Shisana • President's Health Summit • Health compact	National Planning Commission

17. Where can we contact them?

As per websites for government departments, [click here for the directory](#).

18. If you do not know his/her/its/their names, please tell us anything you do know about him/her/it/them N/A See table 1 above.

19. Did anybody see or hear what happened (only people who actually saw or heard what happened, not people who heard about it from someone else)

The SANCDA and allies have documented many of these matters through various reports. See Annexure A. The SANCDA's 2019 [letter to the Minister of Health](#) and its [accompanying report](#)² remain unaddressed, unresolved and have significantly worsened during the COVID-19 pandemic.

20. In your own words, tell us exactly what happened (include all information but be as brief as possible)

The government (politicians and senior civil servants as listed in section 16 above and Table 1) have neglected to prioritise and to effectively implement policies that address the burden of NCDs+ and the social determinants of health that aggravate them. The long-term systemic policy neglect resulted in a failure to address the health and human rights of PLWNCDS+ using four categories.

Category 1: Failure to make NCDs+ a priority according to the burden of disease & needs of the population before, during, & after the COVID-19 pandemic

The failure to substantively meet the health needs of the PLWNCDS+ according to disease epidemiology and failure to manage NCDs+ related risk factors within the population

- i. The [National Development Plan](#) (2012) and its subsequent amended versions have never prioritised NCDs+. Communicable diseases remain our nation's only condition-specific priority.
- ii. The failure to prioritise NCDs+ is prevalent at all policies levels - from the NDP to the provincial and national levels through to successive **Medium-Term Strategic Frameworks** (MTSF). The aim of the MTSF is "to ensure policy coherence, alignment and coordination across government plans as well as alignment with budgeting processes."

² Report [Moving forwards taking NCDs into the SDG era with political will, policy coherence & stewardship](#) 2019 VJ Pinkney-Atkinson

- iii. The first [MTSF in 2014](#) stated the goal of significantly reducing the burden of communicable diseases with the expansion of existing programmes for HIV, TB, sexual and reproductive health (the Millenium Development Goal [MDG] conditions). By contrast, national responses to address the fast-growing burden of NCDs+ only focus on population behaviour modifications to curb these "lifestyle diseases". (Page 18) This response stigmatises PLWNCDS as responsible for getting sick due to their poor lifestyle choices instead of adequately meeting the government's obligation to adequately provide for this vulnerable community's health rights - prevention, treatment and psycho-social needs.
- iv. In part, [Priority 3](#) of the [MTSF of 2019](#) focuses on health and NCDs+ prevention and control strategies are limited to wellness and healthy lifestyle campaigns. Furthermore, the section expressly notes that:

There is no budget for addressing non-communicable diseases. Interventions are implemented cross budget programmes. (Page 107)

The only NCDs+ indicators and targets related to screening for high blood pressure and diabetes downplay the burgeoning burden of NCDs+ (2/8 specific targets). The most recent [South Africa mortality report for 2018](#) shows that NCDs+ are the leading cause of death in SA (57.7%), increasing every year since 2011 when they overtook the national burden of communicable diseases.

Category 2: Failure of NCDs+ data collection, surveillance, monitoring

- i. The current NCDs+ related policies are outdated (e.g., the NCDs+ National Strategic Plan (NSP) 2013-2017). The current situation of a siloed approach to NCDs+ continues with poor access to prevention and treatment.
- ii. The [National Indicator Data Set](#) (2016) contains very few indicators for NCDs+. The majority relate to HIV and the MDG conditions, including health system strengthening. So this means there is little South African evidence for SDG conditions, and the neglect of health conditions impacting most people continues.

Category 3: Failure to implement and evaluate NCDs+ policy at all levels

The NDoH and PDsoH do not follow [national norms for policy development](#), implementation, and [evaluation](#) (2020) as laid out in the government's guidelines. The same is true of the 2019 [contested concept note on NCDs+](#), and the [draft 5 NCDs+ NSP 2022-2027](#). At the time of writing this report, current NCDs+ NSP has remained under development since 2018.

Category 4: Failure to provide resources and related health services to prevent and control NCDs+.

The failure to provide for the health and human rights of PLWNCDS+ extends to disease prevention and access to treatment, rehabilitation and palliative care at all ages and all

provinces. The NCDs+ policy failure and lack of resource prioritisation disproportionately affect the poor, women and vulnerable communities. The many risk factors for NCDs+ lead to a vicious cycle of poverty when neglected in childhood, influencing long-term health prospects. Examples are childhood obesity, lack of physical activity, and many linked NCDs leading to the prevalence of overweight and mental conditions (stress anxiety and depression) NCDs+ occur due to a combination of genetic, physiological, socio-environmental and behavioural factors. [A recent resource](#) states that over half of the SA population live in poverty, with childhood poverty affecting 66% of children. This implies negative childhood development and health deterioration in adulthood or with ageing.

21. Have you reported the matter to anyone else? YES

If yes, who (e.g. Police, lawyer, Public Protector)?

To the incumbent Minister of Health and Director-General of Health. Numerous letters and requests for national and provincial NCDs+ status report since 2018. The SANCDA did not receive any response or acknowledgement of receipt of its correspondence.

(See Annexure A)

22. Were any steps taken by the person/association/organisation/organ of state to resolve the matter?

Yes _____ No _____

If yes, please tell us what _____

23. What outcome do you propose or expect from this complaint (tell us what you would like to achieve with this complaint and the relief sought)

The main objective of this complaint is to hold the South African government accountable for the realisation of the health and human rights entitlements of all PLWNCDs+ within the Republic. We request an Inquiry into the contents of this complaint that builds on previous NCDs+ related SAHRC investigations and reports.

Government must be compelled to ensure regular, affordable and equitable access to NCDs+ diagnosis, medicines, treatment and palliative care for all who need it within the UHC/NHI framework and programme as part of a package of essential health services.

Government must be compelled to communicate timeously and transparently with civil society organisations and provide the necessary data about the status of NCDs+ and risk factors. E.g. expenditure on NCDs+ at a primary health care level by diagnosis, medications and treatment.

Government must be compelled to expressly prioritise NCDs+ in its national COVID -19/ Disaster Management Act 2005 responses. Furthermore, the SANCDA asks that national COVID-19 structures routinely publish information on the extent to which PLWNCDs+ are affected. It must share these data with health care professionals and NCDs+ non-profit organisations. This sharing of information will assist government departments and civil society in promoting safe access to services, medicines and supplies.

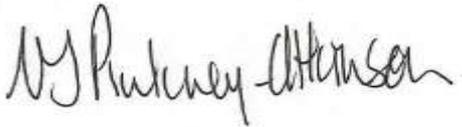
24. Do you need an interpreter when attending any proceedings, investigations or hearing at our offices?

Yes _____ No _____

If yes, the language you speak _____

25. Can we use your name in news reports or letters we write regarding this matter/complaint

Yes _____ No _____



Signature/mark of complainant

18 DECEMBER 2020 Original submission

26 JANUARY 2022 Revised submission

Date

SOUTH AFRICAN NCDsALLIANCE
