



SOUTH AFRICAN
**NON-COMMUNICABLE
DISEASES ALLIANCE**

**NATIONAL
NCDs STAKEHOLDERS
MEETING REPORT**

A CALL TO ACTION

Birchwood Hotel Conference Centre
11th - 12th February 2014



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SOUTH AFRICAN
NON-COMMUNICABLE
DISEASES ALLIANCE

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Supported by:



The NCD Alliance
Putting non-communicable diseases
on the global agenda



Made possible by a generous grant from:





1. EXECUTIVE SUMMARY

The newly formed SA Non-Communicable Disease Alliance (SA NCD Alliance) held its first key stakeholder meeting on 11 & 12th February 2014 in Johannesburg, South Africa.

Meeting goal:

- To galvanize awareness and unify support for non-communicable diseases (NCDs) prevention and management amongst key stakeholders with a “Call for NCDs Action”.

Meeting objectives:

- To support the NCDs strategic plan within the South African context
- To develop priorities for NCDs advocacy and action
- To develop a network of support for NCDs advocacy and action.

100 delegates from five vital sectors networked on important NCDs issues:

- Civil society/ NGO
- Government/ policy
- Healthcare providers
- Industry
- Research organisations/ universities.

Prof Krisela Steyn outlined the escalating burden of NCDs in South Africa to the present unacceptably high levels. With the exception of tobacco use, the preventable NCDs “lifestyle” risk factors, (unhealthy diets, lack of physical activity and the harmful use of alcohol) have all increased.

Prof Mel Freeman presented the Ministry of Health’s NCDs Strategic Plan 2013–2017. The plan outlines 10 ambitious NCDs targets that have broad support. Challenges relate to support, implementation and health system strengthening.

Katie Dain, NCD Alliance, outlined the global background to NCDs advocacy culminating in the WHO NCDs Global Action Plan 2013–2020 (GAP) with its nine NCDs targets. GAP is driving global action. In a separate presentation Katie Dain and Cristina Parsons–Perez explained the NCD Alliance’s advocacy including the civil society advocacy tool: the civil society national advocacy status report (CSSR).

Stakeholder groups performed a SWOT analysis on the challenges of NCDs to each sector. All groups clearly saw their own strengths and the NCDs Plan as an opportunity for transparent multisector collaboration. Universal weaknesses and threats are:

- Data inadequacies resulting in reduced evidence based practice
- Lack of collaboration
- Insufficient resources and funding
- Healthcare system weaknesses
- Competition and lack of transparency between stakeholders.

SA NCD Alliance founding partners (Cancer Association of South Africa, Diabetes South Africa, Heart and Stroke Foundation South Africa and the Patient Health Alliance of Non Governmental Organisations) each made a presentation to introduce the organisation.

Lessons must be learnt from local NCDs best practice with two illustrative presentations:

- HIV/AIDS early effective monitoring and management (Henry Mkwanazi)
- Civil society legislative advocacy against tobacco products (Dr Yussuf Saloojee)

Sector work groups deliberated on collective ways to support the NCDs Plan. The reports of each group are reflected in the resolution. The delegates resolved to support the following for NCDs action:

1. National NCDs Plan supported with government accountability
2. Collaborate to fight NCDs (within and across sectors) in the NCDs Multisectoral Working Group (nMWG)
3. SA NCD Alliance as the lead organisation in the fight against the NCDs epidemic
4. Strengthen national NCDs research agenda and capacity.
5. The consensually developed and final civil society status report as a tool for national NCDs advocacy.
6. Unrelenting action to strengthen NCDs systems to culminate in a stakeholder meeting in August 2014.



2. MEETING GOALS AND OBJECTIVES

Goal:

- To galvanize awareness and unify support for NCDs prevention and management amongst key stakeholders in a “Call for NCDs Action”.

Objectives:

- To support the NCDs strategic plan within the South African context
- To develop priorities for NCDs advocacy and action
- To develop a network of support for NCDs advocacy and action.

3. MEETING DESIGN FOR NCDs RESULTS

The mission of the meeting is to **galvanize** key stakeholders around NCDs prevention and control. It involves inspiring feelings and targeted activity in relation to NCDs

This presents a number of challenges:

- To accept and work with the new SA NCD Alliance, albeit with known and trusted partners (CANSAs, DSA, HSFSAs and PHANGO).
- Collaboration between people and organisations (previously known or not) for the greater good of all South Africans
- Putting aside unnecessary competition.

A combination of plenary and stakeholder group sessions were used to increase galvanization. Active participation is really important to share the message and get the feeling. Participation was encouraged in relation to the awareness campaigns of the Heart & Stroke Foundation, CANSAs and Diabetes SA. Delegates dressed in red, wore denim and donned wraps in wonderful variations. (See Figure 2: NCDs Stakeholder meeting delegates wear red to support the heart health of women and children and wraps to support CANSAs.)

This stakeholder meeting was more than just another get together, a talk show. It provided a unique opportunity to galvanize and build alliances. Thus, the meeting’s design is critical to the outcome of alliance building. This is lesson learned in the hard way, in the South African journey from its apartheid past.

3.1 Sector group work design

Group work used the opportunity to involving multiple sectors as a way of connecting participants and turning them into allies.

The following classification of stakeholder sectors is used throughout this document:

- NGOs and civil society (abbreviated as **NGOs**).
- Policy and government including national and provincial departments of agriculture, education, disabilities (abbreviated as **government**).
- Healthcare industry and relevant related industries, e.g. pharma, devices, food (abbreviated as **industry**).
- Healthcare providers including medical schemes (abbreviated as **healthcare providers**).
- Research institutions and universities (abbreviated as **research**).

It proved a resonant and robust way of grouping delegate by sectors (see Figure 1: Group allocation of delegates by sector by sector on registration.)

The registration form asked delegates to choose the sector to which they felt they belonged, with most responding as anticipated. A senior provincial official chose the healthcare provider group rather than the policy group. A professor of dietetics emphatically chose to be in the government group, “Policy is where my interest is.”

galvanize

verb: shock or excite (someone) into taking action.

“To galvanize awareness and unify support for NCDs prevention and management amongst key stakeholders.”

synonyms: *jolt, shock, startle, impel, stir, spur, prod, urge, motivate, stimulate, electrify, excite, rouse, arouse, awaken, invigorate, fire, fuel, animate, vitalize, energize, exhilarate, thrill, dynamize, inspire*

It is usually accepted that if you have the stakeholders on board from the beginning of a process you eliminate time-wasting later and everyone feels committed to the success of the project.

Prof Mel Freeman - National Department of Health

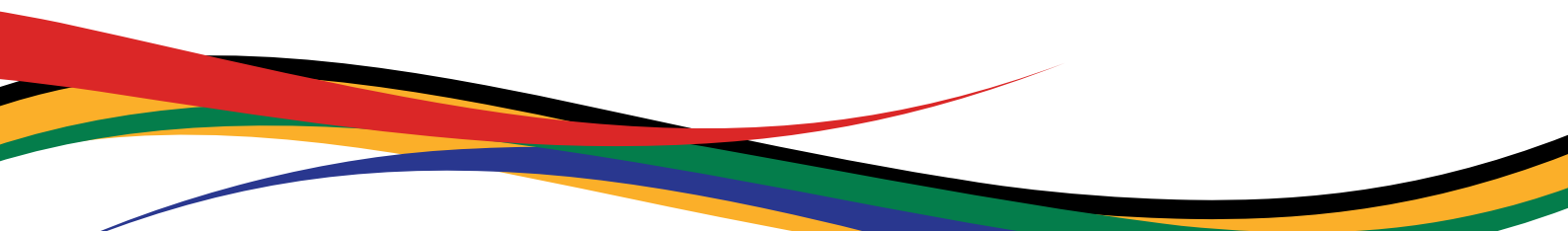
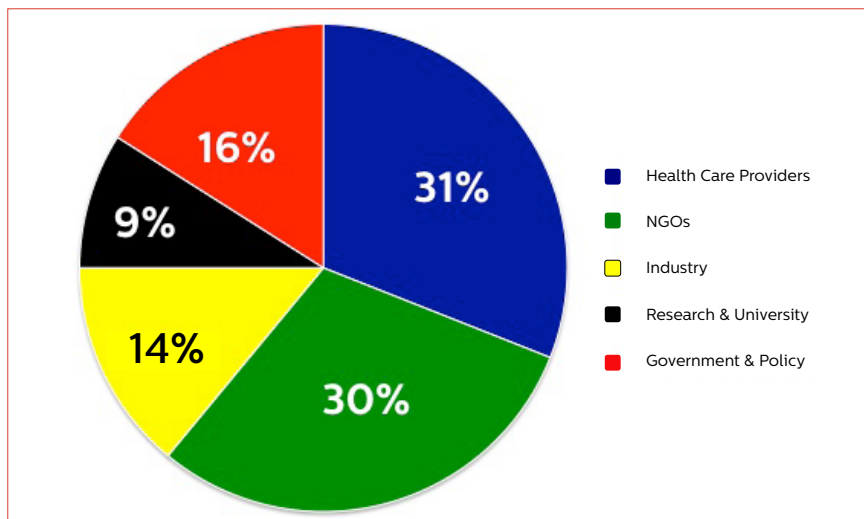




Figure 1

Group allocation of delegates by sector on registration



The five stakeholder groups are the basis for the ongoing stakeholder mapping exercise. As each new stakeholder is revealed mapping becomes more complex and layered (see [Figure 5: NCDs stakeholder network March 2014](#)).

3.2 Invitation challenges

South Africa prematurely went into annual summer shutdown due to the death of our beloved former President, Tata Madiba. He went to his final rest during persistent rain with the gates of heaven widely open to welcome him home.

South Africa summer holidays, from 16th December to the middle of January, are sacrosanct with the country in recess. So for administrative and social reasons, the first invitations were made by email on 13th January 2014 to existing SA NCD Alliance founding partner networks. With under a month to the meeting electronic distribution was preferred.

- Over 300 direct emailed invitations
- 2000 hits on the events section on the website
- 1000 e-newsletter recipients.

SA NCD Alliance contacts database are actively and comprehensively maintained to target ensure that communication is targeted.

Two groups (professional groups and the pharma industry) were under-represented. In some instances, it was due to prior commitments and the short notice of the meeting. It was resolved to ensure that stakeholder groups, organisations and individuals are informed of developments with an open invitation to participate.

Rain at an African funeral

Rain leading up to or on the day of the funeral is interpreted as a good sign that the heavens and the spiritual world are welcoming the dead.

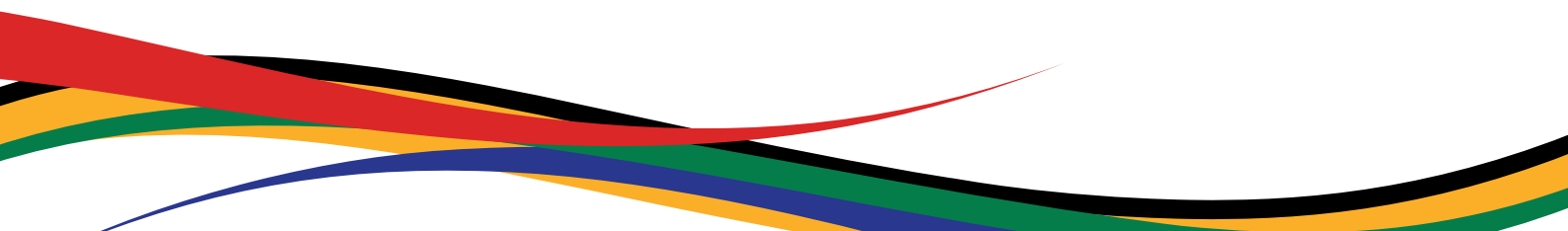




Figure 2:

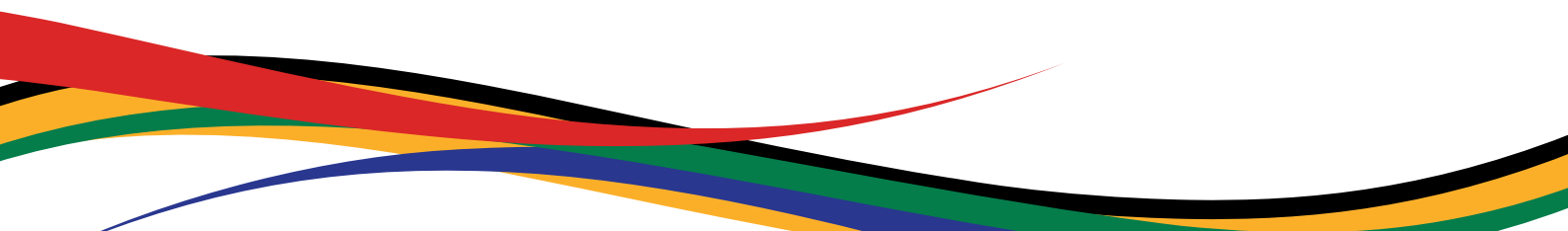
NCDs Stakeholder meeting delegates wear red to support the heart health of women and children and wraps to support CANSA.



3.3 Common NCDs agenda

During South Africa's transition to democracy, the nation learned to be inclusive rather than exclusive, when determining agendas that involve more than one group.

The stated purpose of the meeting was to broaden and open up the agenda around NCDs. The strategy was successful with the issues and priorities determined by the group. (See [Table 2: Outcomes of the NCDs stakeholder meeting](#))





4. NCDs IN SOUTH AFRICA PAST, PRESENT & FUTURE

Presentation by [Prof Krisela Steyn](#), University of Cape Town, Heart & Stroke Foundation of SA & SA Hypertension Society. To download a copy of the presentation [click here](#).

NCDs in South Africa

Prof Krisela Steyn

Past

"NCDs are not seen as requiring attention, it lacks the urgency in the face of all the other demands on the health services in South Africa" Steyn 2014

1990 – 2009

MRC leads ↑ research risk factors & burden of disease

1998 – SA Demographic & Health Survey & 2009 (NIDS)

Shows upward trend in risk factors & NCDs

2000 Burden of NCDs in SA

- 750/100 000 of population
- 40% of all deaths

Law changes past and ongoing

- Tobacco Control Act
- and food (labelling, production ↓ salt ↓ trans fats
- **Sin tax** Alcohol & tobacco

MODERN ERA

- 2011 NCDs summit convened by Health Department
- 2013 NCDs strategic plan 10 targets
- Management of NCDs
 - Interventions target whole of community
 - Early diagnosis & cost effective treatment

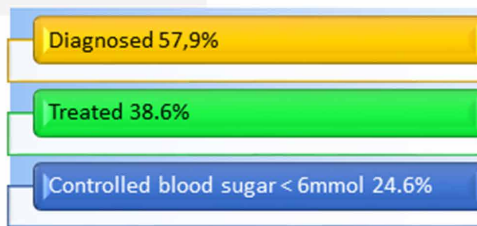
2013

Diabetes 'tsunami' hits South Africa

'The diabetes tsunami is here. And we in South Africa are in trouble.' This is the stark warning of an SA diabetes expert over the fast-growing diabetes numbers in South Africa.

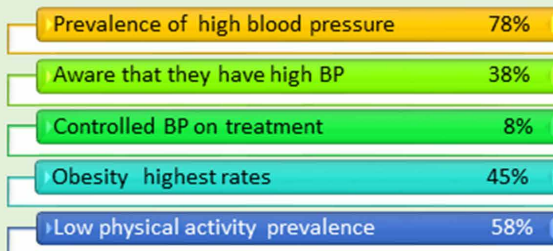


Levitt et al



2014 WHO SAGES STUDY

South Africa has world's highest rate of blood pressure, obesity & lowest physical activity in people aged 50+ years





5. INTRODUCING THE SA NCD ALLIANCE

Founding Members



THE HEART
AND STROKE
FOUNDATION
SOUTH AFRICA



Diabetes®
South Africa



PHANGO
PATIENT HEALTH ALLIANCE OF
NON GOVERNMENTAL ORGANISATIONS
UNITED FOR HEALTH

The founding members took the opportunity to showcase each organisation in brief presentations. These presentations are shown as info-graphics.

SA NCD Alliance facts:

- Established July 2013 with founding members CANSA, Heart and Stroke Foundation, Diabetes SA & PHANGO.
- Over 160 years of civil society NCDs support and advocacy experience.
- Affiliated to and supported by the [NCD Alliance](#), which unites a network of over 2,000 civil society organizations in more than 170 countries.
- Awarded a grant from [Medtronic Philanthropy](#) to Strengthen Health Systems, Support NCD Action Grant in September 2013 which funded this stakeholder meeting and other activities.
- One of only 7 national NCDs alliances in Africa
- Access to wide network of civil society organisations in South Africa through its founding members.
- [CANSA](#) has a national office supported by 31 CANSA Care Centres offering stoma support and organisational management; medical equipment hire
 - o 12 CANSA Care Homes in the main metropolitan areas for out-of-town cancer patients
 - o 1 hospitiium based in Polokwane
 - o CANSA-TLC lodging for parents and guardians of children undergoing cancer treatment
 - o Member [The Union for International Cancer Control](#)
- [Diabetes SA](#) – 1 national office and 8 branches and a volunteer network of 100 community based groups
 - o Member of the [International Diabetes Federation](#)
- [Heart & Stroke Foundation SA](#) – Leads the fight against preventable heart disease and stroke by: providing information and support to build healthy communities; advocating to minimise risk: supporting research for improved tools and methods of prevention
 - o Member of the World Heart Federation, World Stroke Organisation.
- [Patient Health Alliance of Non Governmental Organisations](#) – 30 health & patient related NGOs including all founding members.
 - o Member of [International Alliance of Patients' Organizations](#)

Figure 2:

SA NCD Alliance founding partner execs (Front) former CANSA CEO, Sue Janse van Rensburg, Vash Mungal-Singh, Heart & Stroke Foundation (Back) Leigh-Ann Bailie, Diabetes SA, Vicki Pinkney-Atkinson PHANGO





5.1 Cancer Association of South Africa (CANSA)

Presentation by [Sue van Rensburg](#). To download a copy of the presentation [click here](#).

CANCER REALITY CHECK

Every year 14 million people world-wide hear the words:
"You have cancer"

- 90% of cancers are caused by environmental & lifestyle factors such as smoking, diet & exercise
- More than 100 000 South Africans are diagnosed with cancer every year
- South African cancer survival rate is 6/10
- One in 4 South Africans is affected by cancer through diagnosis of family, friends or self

SA Men

1. Prostate
2. Origin unknown*
3. Lung
4. Colorectal
5. Oesophageal/Throat




SA Women

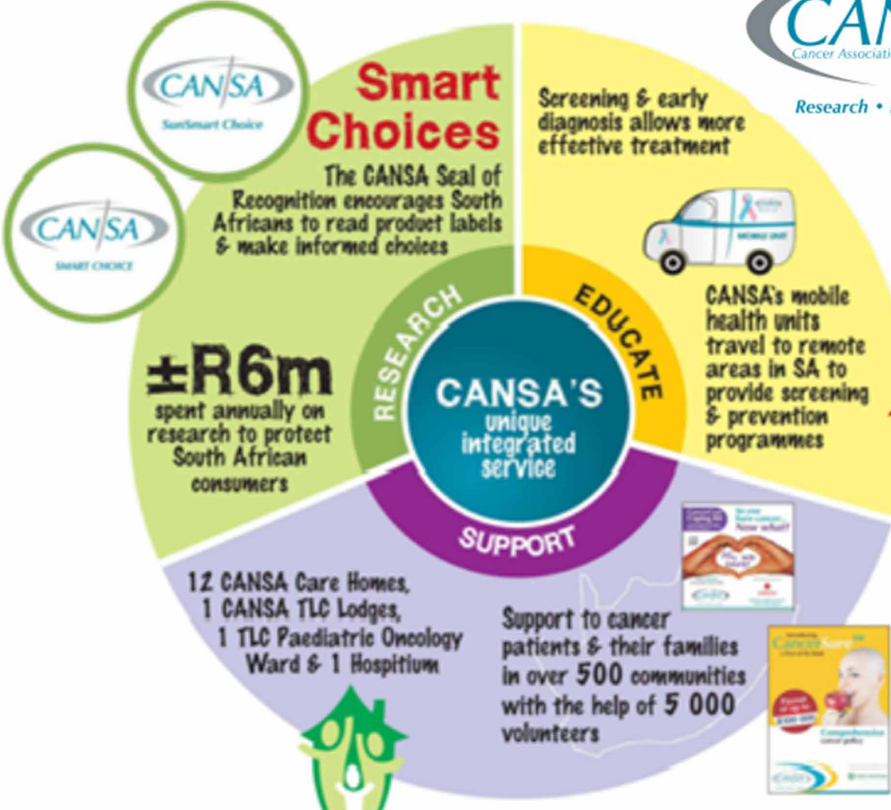
1. Breast
2. Cervical
3. Origin Unknown*
4. Colorectal
5. Kaposi Sarcoma

* Primary site unknown means that it is not possible to determine where the cancer originated in the body

CANCER > TB+AIDS+MALARIA
Globally cancer kills more people than TB, AIDS and Malaria combined




Research • Educate • Support



The diagram is a circular infographic with 'CANSA'S unique integrated service' at the center. It is divided into four quadrants:

- Smart Choices:** Screening & early diagnosis allows more effective treatment. Includes the CANSA Seal of Recognition and a mobile health unit.
- RESEARCH:** ±R6m spent annually on research to protect South African consumers.
- EDUCATE:** CANSA's mobile health units travel to remote areas in SA to provide screening & prevention programmes.
- SUPPORT:** Support to cancer patients & their families in over 500 communities with the help of 5 000 volunteers. Includes icons for care homes and hospitation.



Look for plastic bottles with this logo



5.2 Diabetes South Africa (DSA)

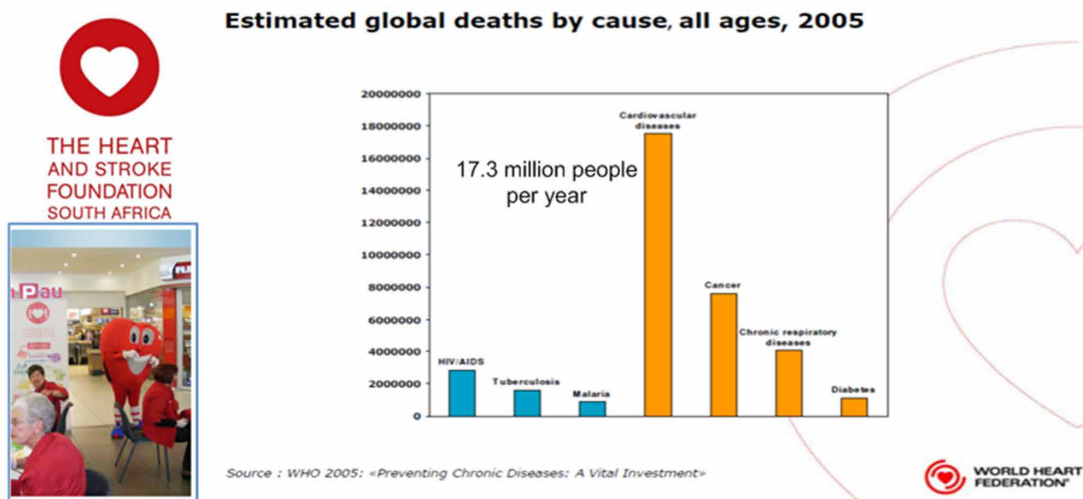
Presentation by **Leigh-Ann Bailie**. To download a copy of the presentation [click here](#).



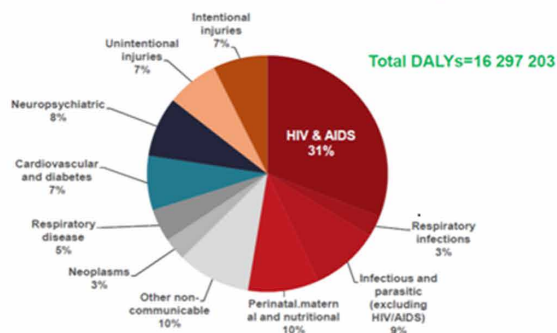


5.3 Heart and Stroke Foundation of South Africa (HSF)

Presentation by [Dr Vash Mungal-Singh](#). To download a copy of the presentation [click here](#).



National Burden of Disease Study 2000



Top ten causes of death in South Africa

Causes	Deaths (000)	(%)	Years of Life Lost (%)
HIV/AIDS	355	52	63
Cerebrovascular disease	30	5	2
Ischaemic heart disease	27	4	2
Lower respiratory infections	23	4	3
Violence	19	3	3
Tuberculosis	14	2	2
Diarrhoeal diseases	13	2	3
Road traffic accidents	13	2	2
Diabetes mellitus	12	2	1
COPD	9	1	1

Reduce your salt intake immediately!



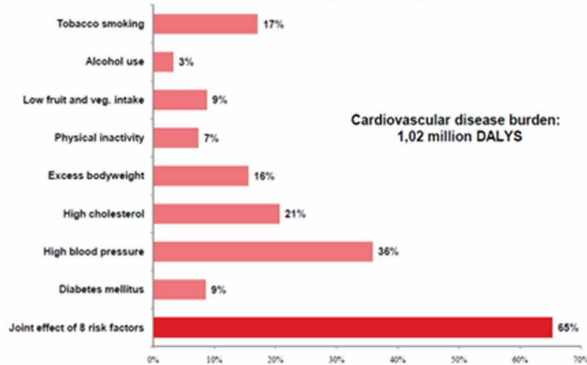
High salt intake is also associated with

- Hypertension
- Gastric cancer
- Osteoporosis
- Increased asthma severity
- Renal stones, progression of renal disease
- Obesity



Take the road to a healthy heart

Cardiovascular disease attributable to 8 risk factors South Africa 2000




Source: Joubert et al



5.4 Patient Health Alliance of Non-governmental Organisations (PHANGO)

Presentation by [Dr Vicki Pinkney-Atkinson](#). To download presentation [click here](#).




PHANGO

PATIENT HEALTH ALLIANCE OF NON GOVERNMENTAL ORGANISATIONS

United for health


**Speaking out for access
to quality health care
for all in South Africa**

**UNZIP YOUR
LIPS
speak **OUT**
about your
NCDs
experience**





PHANGO facts


- ✓ Advocated for better NCDs access & care at the Human Rights Commission in 2007
- ✓ SA NCDs Alliance founding member
- ✓ Implementing partner for NCD Alliance grant
- ✓ IAPO member





Just a few
of our 30
amazing
partners














































6. THE NCD ALLIANCE

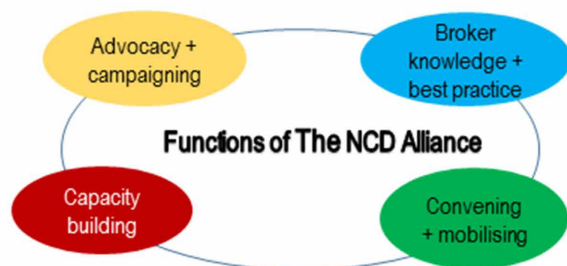
GLOBAL EPIDEMIC MEETS GLOBAL ACTION

Presentation by **Katie Dane**, Executive Director, NCD Alliance. To download a copy of the presentation [click here](#).

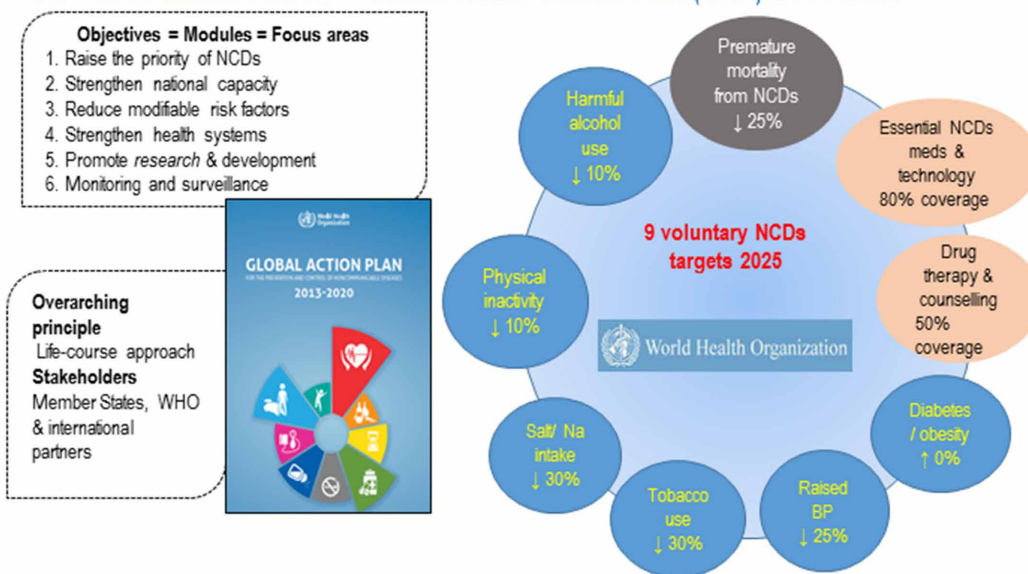
Global epidemic meets global action

Katie Dain

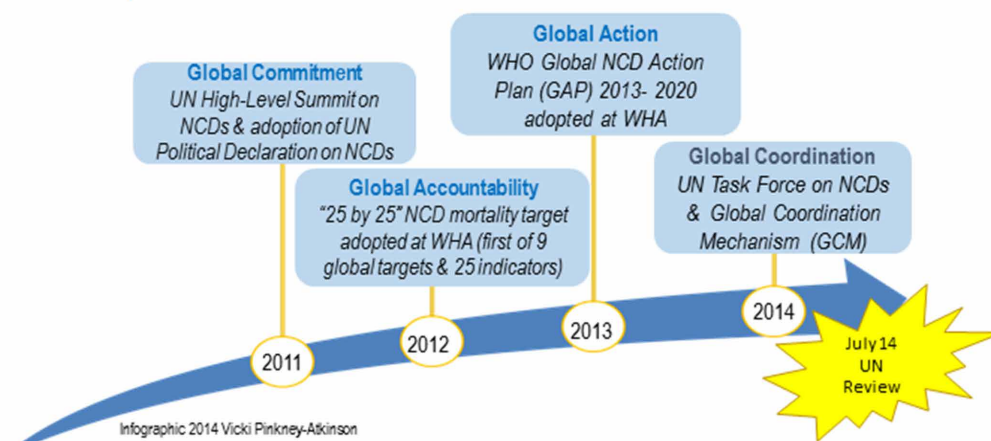
The NCD Alliance
Putting non-communicable diseases
on the global agenda



UN -WHO Global Action – Global NCDs Action Plan (GAP) 2013-2020



Global response to NCDs timeline





7. UNPACKING THE NCDs STRATEGIC PLAN TARGETS, STRENGTHS & CHALLENGES

Ministry of Health's Chief Director for NCDs, Professor Melvyn Freeman presented the new national [NCDs Strategic Plan 2013-2017 \(NCDs Plan\)](#). In a show of transparency he presented its strength and challenges which was highly appreciated by all delegates. Happily knowledge dissemination occurred when a copy of NCDs Plan was given to every delegate. To download a copy of the presentation [click here](#).

Table 1: South Africa's NCDs Plan- targets, strengths & challenges

10 NCDs TARGETS BY 2030	STRENGTHS	CHALLENGES
<ol style="list-style-type: none"> 1. <input checked="" type="checkbox"/> by 25% the relative premature NCDs-related mortality (< 60 years of age) 2. <input checked="" type="checkbox"/> by 20% tobacco use 3. <input checked="" type="checkbox"/> by 20% the relative per capita consumption of alcohol 4. <input checked="" type="checkbox"/> mean population salt intake to <5 g/day 5. <input checked="" type="checkbox"/> by 10% the percentage of people who are obese and/or overweight 6. <input checked="" type="checkbox"/> by 10% the prevalence of physical activity (150 minutes of moderate-intensity physical activity / week, or equivalent) 7. <input checked="" type="checkbox"/> prevalence of people with raised BP by 20% (through lifestyle & medication) 8. Every women with sexually transmitted diseases (STD) screened for cervical cancer every 5 years. If no STD, every women screened 3 time in life (and as per policy for women who are HIV/AIDS positive) 9. <input checked="" type="checkbox"/> 30% the % of people controlled for hypertension, diabetes and asthma in sentinel sites 10. <input checked="" type="checkbox"/> by 30% the number of people screened and treated for mental disorders. 	<ul style="list-style-type: none"> • Ministry of Health involved most stakeholders at 2011 NCDs National Summit • Full political leadership backing (Minister & Deputy Minister of Health, provincial Ministers of Health, unanimous adoption National Health Council) • Contextualised by: <ul style="list-style-type: none"> • National Development Plan (NDP) • 3 primary health care re-engineering elements • Universal healthcare access (National Health Insurance) & other policy • HIV / AIDS epidemic • UN Political Declaration & subsequent WHO recommendations. • NCDs are not only a health problem (see social determinants of health/ disease) • Features of the NCDs Plan are: <ul style="list-style-type: none"> • Broad definition of NCDs (includes more than cancer, cardiovascular disease, diabetes, chronic respiratory conditions) • Common risk factors • Specific objectives, ambitious targets (see column) and indicators • Based on "best buys or "bang for our buck" • Comprehensive approach (promote health, prevent; control through health systems strengthening & reform: monitoring and research of NCDs and risk factors) • Assumes growing co-morbidity between communicable disease and NCDs • Linked to the care and treatment model for roll-out of HIV/AIDS programme (Integrated Chronic Disease Management Model) • Community level programmes (education campaigns, school interventions, screening) • Individual lifestyle behaviour change critical • Ongoing regulatory mechanisms critical e.g. already implemented tobacco control, <input checked="" type="checkbox"/> salt, <input checked="" type="checkbox"/> alcohol related harm, <input checked="" type="checkbox"/> trans fat 	<ul style="list-style-type: none"> • Broad NCDs definition makes focus and prioritisation difficult • Targets are beyond those in the WHO Global Action Plan 2013-2020 with potential to embarrass and demotivation • Questionable data used as baseline • Data collections systems and monitoring • Scarcity of resources (human and financial) for full implementation • Full costing is difficult and incomplete with a trade-off for political backing <ul style="list-style-type: none"> o Some clinically oriented targets are lacking • Assumes a groundswell of advocacy which may not exist • Context of poverty and non-health promoting cultural norms



8. SWOT ANALYSIS OF NCDs CHALLENGES BY SECTOR

STRENGTHS	WEAKNESSES	OPPORTUNITIES	THREATS
NGOs			
1. Infrastructure and technical expertise <ul style="list-style-type: none"> National footprint Community mobilisation Volunteer network Structured campaigns 2. Existing partnerships with all stakeholder groups <ul style="list-style-type: none"> Government - strong political support Existing alliances: NGOs and other 3. Integrity, ethics & good governance	1. <input checked="" type="checkbox"/> inter-NGO collaboration due to competition for minimal resources 2. <input checked="" type="checkbox"/> resources and funding <ul style="list-style-type: none"> <input checked="" type="checkbox"/> sustainable resources Donors determine agenda & activities Human resources e.g., <input checked="" type="checkbox"/> volunteers 3. People Living with NCDs are not engaged or mobilised for advocacy & activations.	1. Establish working relationship with WHO Afro region and other organisations 2. Access to other resources & assets <ul style="list-style-type: none"> Academia and research Unions and nursing etc. 3. NGOs to hold government accountable for NCDs outcomes, policy & legislative framework.	1. Prevention is not prioritised & not all NCDs recognised 2. Socioeconomic factors <ul style="list-style-type: none"> Geographical Cultural differences and beliefs Poverty 3. Industry <ul style="list-style-type: none"> Health vs. business as a priority Challenge policies and legislation
Healthcare providers			
1. Strategies in place with policies and guidelines 2. Experience with current programmes (e.g. HIV/AIDS) 3. Interdisciplinary teams: <ul style="list-style-type: none"> Knowledge Skills Budget 	1. Data neither adequate nor adequately shared <ul style="list-style-type: none"> Resources: financial, human, material Information systems and logistics Physical infrastructure 2. Bureaucracy: <input checked="" type="checkbox"/> structural commitment to support NCDs. 3. NCDs target evaluation difficult (monitoring and outcome data)	1. <input checked="" type="checkbox"/> use of public-private partnerships (PPPs) 2. The use of new models to deliver care, data capturing, research etc. 3. <input checked="" type="checkbox"/> appropriate use of technology	1. Political interference 2. Stigmatisation and cultural diversity 3. <input checked="" type="checkbox"/> risk factors due to global economic and social dynamics 4. Traditional health providers
Industry			
1. Scale of reach locally or internationally such as: <ul style="list-style-type: none"> Media & education programmes Best practice or understanding Rolled out effectively in other countries 2. Partnerships existing and link to NCD space. <ul style="list-style-type: none"> Systems integration and data that exists. 3. Business approach to problems/ issues <ul style="list-style-type: none"> Health is the business driven by outcomes via implementation. Ethics & transparent agendas important. 	1. Much data exists but may not well used <ul style="list-style-type: none"> May not be what public sector needs. Competition & sharing don't go together. Companies drive different agendas & need to clarify these to enable collaboration. 2. Bureaucracy within the entire system. E.g., PPPs are often crippled before implementation by bureaucracy.	1. Tap into best practice: local and global. 2. Greater engagement be transparent as to desired objectives and outcomes. 3. Build capacity through existing educational programmes related to the products being sold.	1. Lack of transparent business agendas engenders <input checked="" type="checkbox"/> trust 2. Legislation is not enabling the vision of universal access. E.g. no regulations in equipment & device industry. 3. Resourcing (human, financial, etc.) excluded from SA NCDs Plan. E.g., WHO voluntary global target 80% availability of essential medicines & basic technologies.
Research			
1. Provides an evidence base for planning, policy making and interventions. E.g., burden of disease on society is evident if epidemiological/ surveillance data is available. 2. Collaboration and sharing information between research institutions and broader networks 3. Responsiveness of policymakers	1. Sub-utilization of research by policymakers due to <input checked="" type="checkbox"/> research translation with policymakers unable to implement recommendations. 2. <input checked="" type="checkbox"/> NCDs researchers: silos, <input checked="" type="checkbox"/> networking & bad research study designs. 3. <input checked="" type="checkbox"/> funding, monitoring and evaluation	1. Responsiveness of policymakers & possible access to global NCDs funds. 2. Collaborative nature of research, creation of data banks & champions 3. Locally specific information is yielded by research if needs have been identified	1. Biased research, vested interests of industry and competing priorities of researchers (publish or perish), 2. <input checked="" type="checkbox"/> funding 3. Brain drain: <input checked="" type="checkbox"/> researchers <input checked="" type="checkbox"/> succession planning & capacity building with failure to create attractive research careers.
Government			
1. Policy and enabling framework in place <ul style="list-style-type: none"> Comprehensive health approach not silos. 2. Intersectoral across government 3. Common objectives: targets, problem	1. Implementation process and timelines 2. <input checked="" type="checkbox"/> resources (people, money, equipment, standards, etc.) 3. Dissemination of the message including the NCDs Plan.	1. Share experiences, knowledge & information that S Africa can use. 2. Share meaning between sectors to prevent ideas & facts getting lost. 3. Develop common agendas using SA NCD Alliance network so that all important goals are emphasised and all sectors.	1. Some SA NCDs targets are more ambitious than WHO's GAP (page 5). 2. Disproportionate between NCDs vs. HIV/AIDS programmes E.g. budget allocation Mpumalanga HIV/AIDS R 880 million - NCDs, R 2 million 3. NGOs agendas may not be in the community interests but rather for profit.



9. NCDs NETWORK/COALITION FOR ACTION

In terms of NCDs advocacy, the formation of a network of stakeholders is an important milestone. Long before the last session it was apparent that all participants wanted to find a vehicle to work together to stop the epidemic of NCDs. It was just a question of who and how. The multisectoral groups will form the backbone of the NCDs Multistakeholder Working (nMWG) with the following delegates as volunteers:

- **NGOs** [Mike Boddy](#) (Chair, Arthritis Foundation SA), Karen Borochowitz (Dementia SA), Madeline Seguin (CANSAs), Adri Ludick (CHOC)
- **Industry** [Tanya Vogt](#)
- **Healthcare providers** [Lindsay van der Linden](#)
- **Research** Prof [Andre Kengne](#)
- **SA NCD Alliance** Leigh-Ann Bailie, Elize Joubert, Vash Mungal-Singh, [Vicki Pinkney-Atkinson](#)

(E-mail addresses are hyperlinked so that you can contact the relevant groups.)

It was generally accepted that a special case exists for the government officials who are in a complex and sensitive position of both provider and policy maker. Melvyn Freeman and Vimla Moodley, on behalf of the Department of Health, indicated readiness to participate in the NCDs network without being a member.

The nMWG will meet by May 2014.

Enable all providers (including nongovernmental organizations, for-profit and not-for-profit providers) to address noncommunicable diseases equitably while safeguarding consumer protection and also harnessing the potential of a range of other services such as traditional and complementary medicine, prevention, rehabilitation, palliative care and social services to deal with such diseases.

WHO - [Global NCDs Action Plan 2013-2025 p. 41](#)

Thanks go to the following participants for serving as scribes and sector group work facilitators: Pauvi Bhatt, Kathy Dennill, Col. Fezeka Mabona, Vicki Pinkney-Atkinson and Lindsay van der Linden.

Thanks go to the organising group: Leigh-Ann Bailie, Vash Mungal-Singh, David Pinkney-Atkinson, Vicki Pinkney-Atkinson, Sue Janse van Rensburg.

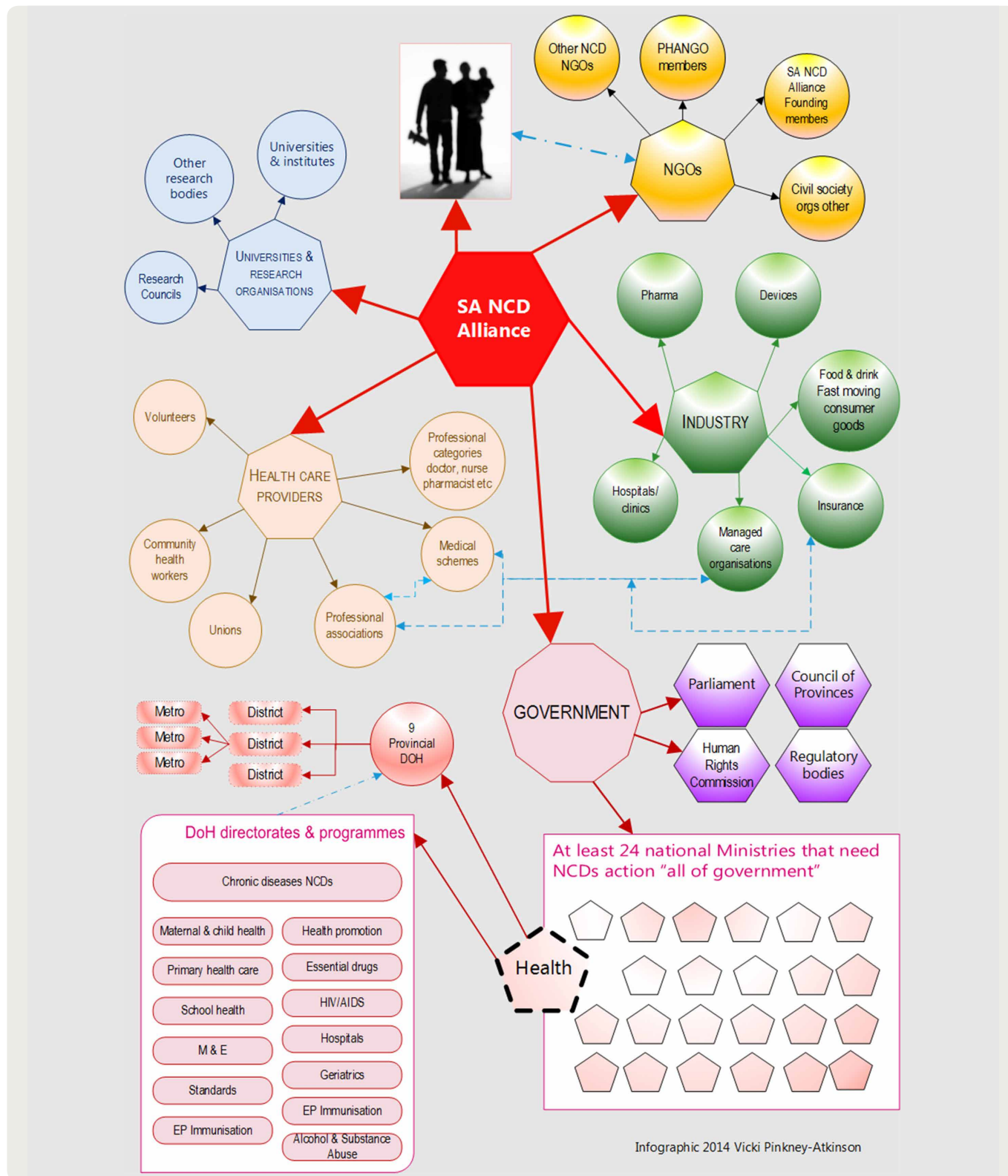
Figure 4

Elize Joubert, new Acting CEO of CANSAs was introduced at the stakeholder meeting.





Figure 5: NCDs stakeholder network March 2014

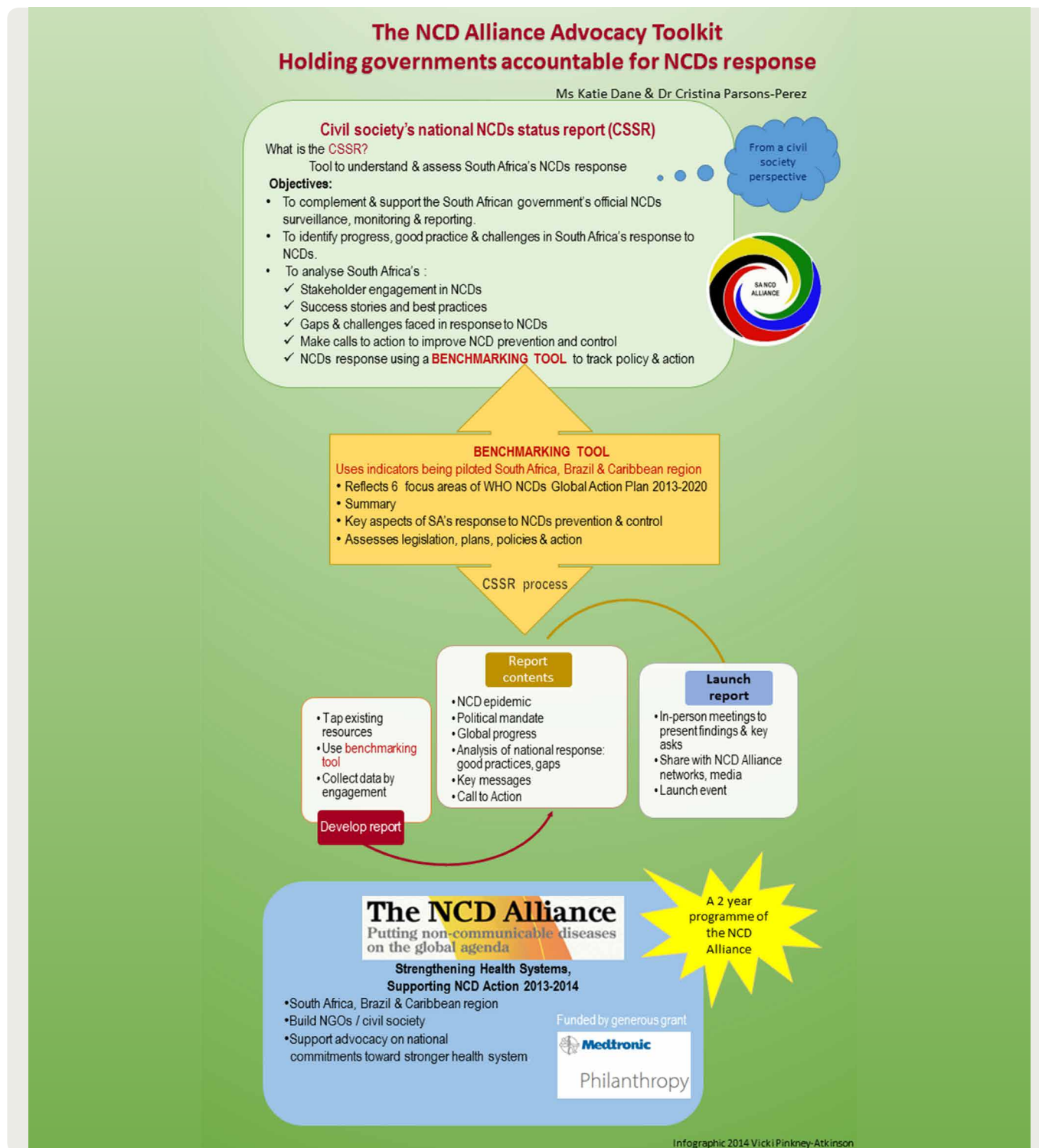




10. NCD ALLIANCE ADVOCACY TOOLKIT: NATIONAL STATUS REPORT & BENCHMARKING TOOL

Presentation by [Katie Dain](#) and [Dr Cristina Parsons Perez](#).

To download a copy of the presentation [click here](#).





11. LESSONS LEARNED

11.1 From HIV/AIDS management

Presentation by **Henry Mkwazazi**, Aid for AIDS .

To download a copy of the presentation [click here](#).

What lessons can NCDs learn from managing HIV/AIDS well?

Henry Mkwazazi

Managing the AIDS pandemic in the private sector

1998
1st HIV
disease
manager in
South
Africa

2014
210 000
patient
managed

2014
30 clients
(Corporate,
private,
PPPs)

Viral load
results
received &
%
suppressed
in last
12 months

81%
received

85%
suppressed

Work with doctors (health professionals) & funder (medical aid or government)	Ongoing patient treatment support for literacy & adherence	Clinical outcomes monitored and risk managed	Use of integrated systems
<ul style="list-style-type: none"> Ensure optimal therapy (Rx) using evidence-based standards Rationing of Rx not 1st step 	<ul style="list-style-type: none"> Telephone & written counselling SMS reminders (tests, visits, 	<ul style="list-style-type: none"> Monitor & evaluate clinical status Risk based triage to focus on those needing attention Aim to ↓ number of patients lost to follow up 	<ul style="list-style-type: none"> Interface with different stakeholder/ providers Medicines Pathology Counselling Funders

Disease Management Process Flow

```

    graph TD
      A[Collect, organise and interpret baseline data] --> B[Assess individual risk]
      B --> C[Triage for intervention]
      C --> D[Effect intervention]
      D --> E[Collect, organise and interpret follow-up data]
      E --> F[Reassess risk]
      F --> G[Assign new intervention level]
      G --> H[Effect new intervention]
      H --> I[Continue until commitment is achieved]
  
```


The way forward for NCDs

Lessons to learn from managing HIV/AIDS well

- ❖ Integrated approach looking at co-morbidities
- ❖ Resource mobilisation (financial & human resources used effectively and efficiently)
- ❖ Improve health system capacity
- ❖ NCDs likely to be more demanding than the AIDS response as it is more complex
- ❖ Collaboration & partnerships (public private partnerships, multisectoral, donor)
- ❖ Strong leadership - political & NGO advocacy
- ❖ Public and professional awareness initiatives needed

Infographic 2014 Vicki Pinkney-Atkinson



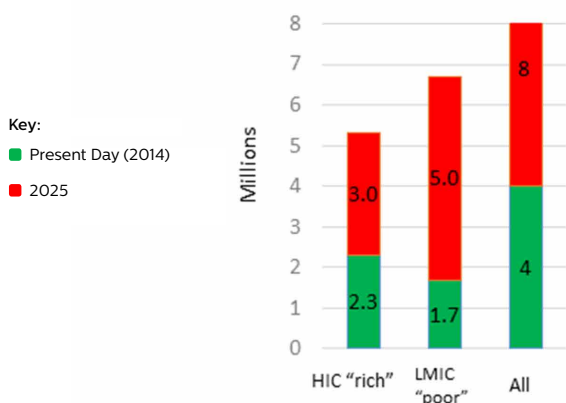
11.2 From anti-tobacco advocacy

Presentation “So you want to change the world?” by [Dr Yussuf Saloojee](#), National Council Against Smoking. To download a copy of the presentation [click here](#).

To be an advocate you need to know the facts

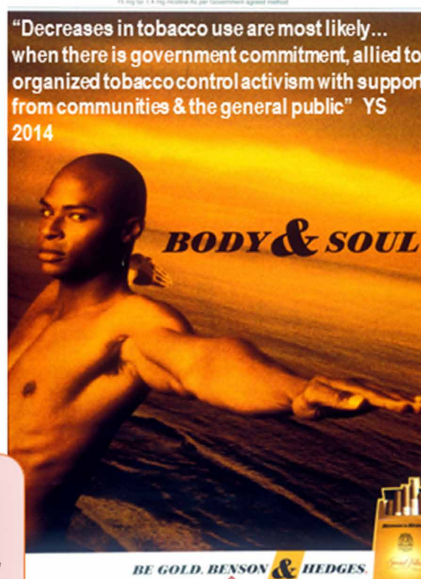
Dr Yussuf Saloojee

Smoking related deaths globally



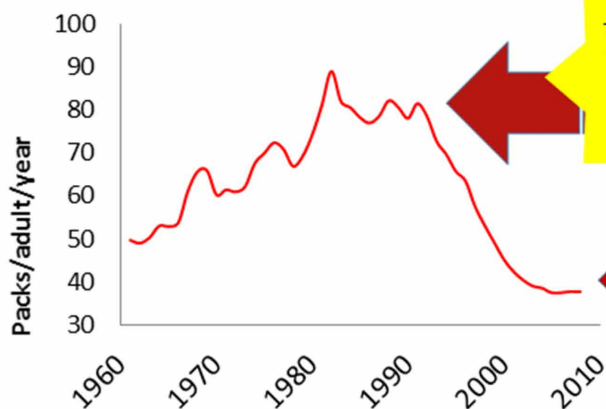
- South African tobacco related mortality**
- About 44,400 deaths a year (8%-9% of all deaths).
 - 3x more male deaths
 - Main causes: cardiovascular disease, COPD, Lung cancer, TB

WARNING:
DON'T SMOKE NEAR CHILDREN



How does advertising work?
Advertising = acceptability
Rather than selling a product.
It sells aspirations & lifestyles.

South Africa cigarette consumption 1960-2009



Success!
Tobacco Products Control Act 1993 passed
Alliance of NGOs Tobacco Action Group (TAG)

“Tobacco industry is more successful at getting people to smoke than public health is to get them to stop.” YS 2014



12. NCDs PRIORITIES FOR ACTION

The most important achievement of the final session was to get stakeholder inputs on the important issues that will influence the “next steps” to be taken by the SA NCD Alliance:

- Are you ready to participate as a sector group and an individual?
- How will your sector group work together?
- What will should the SA NCD Alliance do?

The final session was devoted to the report back of the sector groups on the task set for the groups in the text box (below)

- Presenters from each sector formed a panel to answer questions. However, presentations were accepted without any verbal objections.
- Dr Vash Mungal-Singh was responsible for enumerating and presenting the group feedback for this important session.
- Delegates unanimously agreed to the next steps or short-term action plan for NCDs action in [Table 2](#). The table does not imply any order of importance.
- Delegates accepted the challenge of presenting them to their organisations within their various stakeholder sector groups. They also committed to furthering the outcomes.

Group task: Sector action and commitment.

1. How will your sector respond to the challenges outlined in this meeting?
2. How will you collaborate as a sector to achieve and strengthen the NCD action plan?
3. How will your sector collaborate with the other sectors? Elaborate.
4. What can we expect from your sector’s group by the next stakeholder meeting in August 2014?
5. Briefly other important actions, issues or challenges that require attention and have not been dealt with during the meeting

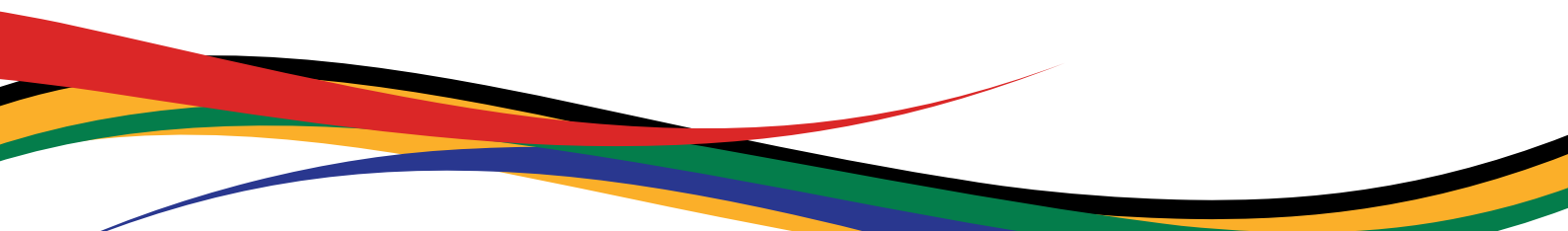




Table 2: Short-term NCDs action plan from stakeholder meeting

1. National NCDs Plan supported with government accountability
<p>1.1. The NCDs Plan appears acceptable to stakeholders but concerns for implementation, monitoring and health systems strengthening.</p> <p>1.2. Monitor government's progress on implementation of the NCDs Plan – Spearheaded by the SA NCD Alliance and responsibility of all delegates</p> <p>1.3. Raise awareness of the NCDs Plan with all stakeholder groups.</p> <p>1.4. Disseminate printed and electronic version widely.</p> <p>1.5. The government group recommended that the Department of Health convene an in-house workshop in April 2014.</p> <p>Objectives of workshops:</p> <ul style="list-style-type: none">• To review NCDs Plan;• To develop concrete actions• To commit to indicators and targets• To clarify working relationships between directorates and other government departments (e.g. Department of Basic Education, Agriculture, Disabilities, Women and Children).
2. Collaborate to fight NCDs (within and across sectors) in the NCDs Multisectoral Working Group (nMWG)
<p>2.1. Delegates unanimously agreed to share contact details with each other to mark the start of the coalition.</p> <p>2.2. Create the nMWG including all stakeholder groups and determine involvement categories: member, observers, volunteers, founders.</p> <p>2.3. Convene nMWG meeting by the end of April 2014.</p> <p>2.4. Develop a multisectoral collaborative NCDs Action Plan based on the NCDs Plan.</p> <p>2.5. Engage with groups below that were under- or not represented at the meeting:</p> <ul style="list-style-type: none">• NGOs• Professional societies / bodies• Funding bodies / entities• Food sector• Education sector (government and group)• Sports and recreation (government and groups)• Industry sectors• Provincial NCDs focus areas in Health Departments who did attend the meeting: Eastern Cape, Free State, KwaZulu-Natal, Limpopo, Northern Cape
3. SA NCD Alliance the lead organisation in the fight against the NCDs
<p>3.1. Delegates unanimously agreed there was a role for the SA NCD Alliance going forward.</p> <p>3.2. Agreed roles and functions:</p> <ul style="list-style-type: none">• Advocate for NCDs prevention, control, monitoring and research• Hold accountable sectors, members and government for quality NCDs prevention, control, monitoring and research• Develop and maintain:<ul style="list-style-type: none">o Manage knowledge NCDs (creation, collating, sharing and dissemination)o National NCDs database for organisations, services, products (campaigns or programmes), personnel.o Synchronise communication nationally with health calendar and share materials• Facilitate NCDs communication, coordination and resource mobilisation across sectors• Reporting and monitoring on NCDs and the NCDs Plan• Prioritise NCDs regular communications: website social and print media including media briefing as appropriate• Strategic plan including secretariat (administration), financial resources and sustainability etc. <p>3.3. Clarify terms of reference and categories of affiliation</p>
4. Strengthen national NCDs research agenda and capacity
<p>4.1. Clarify and prioritise NCDs research nationally.</p> <p>4.2. Disseminate available data.</p> <p>4.3. Economists to quantify cost of NCDs.</p> <p>4.4. Prioritise evidence-based best practice.</p>
5. Use the completed civil society status report (CSSR) as a national NCDs advocacy tool
<p>5.1. Participants agreed to give input and to critique of the first draft.</p> <p>5.2. Use the CSSR as an advocacy tool with all levels of government with media launch.</p>
6. Unrelenting action to strengthen NCDs systems culminating in a stakeholder meeting in August 2014
<p>With input from nMWG and based on CSSR.</p>



ANNEX A: KEY STAKEHOLDER MEETING FEBRUARY 2014 REGISTRATION & PARTICIPANT LIST

- Health care providers / professional societies / trade unions
- Industry including managed care organisations
- Policy and government organisations
- Universities and research organisations
- NGOs and civil society organisations

	Surname	Name	Title	Company/ Organisation
1	Allie	Razana	Ms	Diabetes Educators Society SA
2	Asomugha	Chika	Dr	Gauteng Dept of Health
3	Atkinson	Mary	Dr	Roche Diabetes Care
4	Bailie	Leigh-Ann	Ms	Diabetes SA / PHANGO/ SA NCD Alliance
5	Banda	Patricia	Ms	Gauteng Dept of Health
6	Basu	Debashis	Dr	Wits School of Public Health
7	Bayat	Zaheer	Dr	SEMDSA / WITS
8	Bhatt	Pauvi	Ms	Medtronic Philanthropy
9	Black	Peter	Mr	Centre for Diabetes and Endocrinology
10	Boboko	Ishmael	Mr	North West Dept of Health
11	Boddy	Michael	Mr	Arthritis Foundation of SA/ PHANGO
12	Borochoowitz	Karen	Ms	Dementia SA /PHANGO
13	Brown	Michael	Mr	Centre for Diabetes and Endocrinology
14	Carocari-Santana	Emma	Ms	Medtronic
15	Chambers	Cassey	Ms	SA Anxiety and Depression Group / PHANGO
16	Crickmore	Christelle	Ms	Heart and Stroke Foundation SA /PHANGO
17	Dain	Katie	Ms	The NCD Alliance
18	Dennill	Kathy	Ms	Kedibone Health System Consulting
19	Du Plessis	Janie	Mr	People Living with Cancer, PHANGO
20	Du Toit	Fanie	Mr	National Kidney Foundation of SA, PHANGO
21	Dube	Dudu	Ms	Gauteng Dept of Health
22	Faruk	Mahommed	Dr	Council for Medical Schemes
23	Freeman	Melvyn	Prof	Department of Health
24	Futshane	Zanoxolo	Ms	Ekurhuleni Metro Council
25	Gumedede	Sarah	Ms	Mpumalanga Dept of Health
26	Haldane	Cathy	Ms	Roche Diagnostics
27	Hall	Keegan	Mr	International Diabetes Federation Young Leaders in Diabetes
28	Hall	Nicolette	Ms	University of Pretoria
29	Hall	Thandi	Ms	Novo Nordisk
30	Herbst	Michael	Prof	CANSA /PHANGO
31	Hoffman	Karen	Prof	School of Public Health, Wits University
32	Janse van Rensburg	Sue	Ms	CANSA /PHANGO/ SA NCD Alliance
33	Joubert	Elize	Ms	CANSA / PHANGO
34	Joynt	Dale	Ms	Pfizer
35	Kengne	Andre	Prof	Medical Research Council
36	Keulder	Leon	Mr	Biokinetics Association of South Africa
37	Khan	Naazneen	Ms	Nestle
38	Kalideen	Savera	Ms	Soul City
39	Kuni	Ranga	Mr	Diabetes SA / PHANGO
40	Ludick	Adri	Ms	CHOC Childhood Cancer /PHANGO
41	Mabaso	Puseletso	Ms	Gauteng Dept of Health
42	Mabona	Fezeka	Col	Retired SA Medical Services / University
43	Maemetja	Selaelo	Dr	Council for Medical Schemes
44	Maredi	Meshack	Mr	Gauteng Dept of Health
45	Masemola	Madithapo	Ms	Democratic Nursing Organisation SA
46	Matlare	Elizabeth	Ms	SA Anxiety and Depression Group/ PHANGO
47	Masina	Thembani	Ms	Ekurhuleni Metro Council
48	Mashozhera	Nyasha	Ms	SA NCD Alliance
49	Mawela	Virginia	Ms	Gauteng Dept of Health
50	Mazibuko	Lungi	Ms	Gauteng Dept of Health





ANNEX A: KEY STAKEHOLDER MEETING FEBRUARY 2014 REGISTRATION & PARTICIPANT LIST (continued)

- Health care providers/ professional societies / trade unions
- Industry including managed care organisations
- Policy and government organisations
- Universities and research organisations
- NGOs and civil society organisations

	Surname	Name	Title	Company/ Organisation
51	Mbabazi	Christine	Dr	FHI360
52	Mdiya	Dominica	Ms	Ekurhuleni Metro Council
53	Mdolo	Kedibone	Ms	Democratic Nursing Organisation SA
54	Mkwananzi	Henry	Mr	Aid for AIDS
55	Moeng-Mahangal	Tshimi Lynn	Ms	National Department of Health
56	Mokgwasa	Bruce	Mr	Gauteng Dept of Health
57	Molebosi	Queen	Ms	Department of Health
58	Molefe	Meshack	Mr	North West Dept of Health
59	Molokoane	Tom	Mr	Novo Nordisk
60	Mungul-Singh	Vash	Dr	Heart & Stroke Foundation /PHANGO/ SA NCD Alliance
61	Moodley	Vimla	Ms	National Department of Health
62	Motaung	Abram	Mr	Gauteng Dept of Health
63	Mothopeng	Deborah	Ms	Gauteng Dept of Health
64	Mthombeni	Dudu	Ms	Gauteng Dept of Health
65	Ndhambi	Angeline	Ms	Ekurhuleni Metro Council
66	Ngcwabe	Themakazi	Ms	Ekurhuleni Metro Council
67	Nkombua	Lushiku	Dr	University of Pretoria
68	Nkonde	Sophie	Ms	Ekurhuleni Metro Council
69	Parsons Perez	Cristina	Dr	The NCD Alliance
70	Pillay	Ravi	Mr	Nestle
71	Pinkney-Atkinson	David	Mr	SA NCD Alliance / PHANGO
72	Pinkney-Atkinson	Victoria	Dr	PHANGO/ SA NCD Alliance
73	Pretorius	Agatha	Ms	Occupational Health South Africa
74	Ramafoko	Lebogang	Ms	Soul City
75	Rispel	Laetitia	Prof	Wits School of Public Health
76	Saloojee	Yussuf	Dr	National Council Against Smoking
77	Schonfeldt	Hettie	Prof	University of Pretoria
78	Seguin	Magdalene	Ms	CANSA/PHANGO
79	Sennelo	Nonceba		Gauteng Dept of Health
80	Serapane-Setlhare	Shirley	Ms	North West Dept of Health
81	Setlhare	Itumeleng	Mr	North West Dept of Health
82	Steyn	Krisela	Prof	SA Hypertension Society/ CDIA (university UCT)/ Heart and Stroke Foundation
83	Strauss	Gerda	Ms	CANSA /PHANGO
84	Theoa	Regina	Ms	Sedibeng District Health
85	Thsehla	Evelyn	Ms	Council for Medical Schemes
86	Tshetlo	Madile	Ms	Ekurhuleni Metro Council
87	van der Linden	Lindsay	Ms	Occupational Health South Africa
88	van Vuuren	Unita	Ms	Western Cape Dept of Health
89	Venter	Vlooi	Ms	CANSA / PHANGO
90	Verwey	Corinne	Ms	Roche Diabetes Care
91	Vogt	Tanya	Ms	SA Medical Device Industry Association
92	Wilson	Zane	Ms	SA Anxiety and Depression Group /PHANGO
93	de Klerk	Piet	Mr	Medtronic
94	da Fonseca	Jose	Mr	Life Scan/ Janssen Pharmaceutical
95	Bologna	Lucy	Ms	CANSA
96	Seftel	Effie	Dr	NCDs specialist
97	Adonis	Leegail	Dr	Wits School of Public Health
98	Paget	Sue	Ms	Rotary Family Health Days
99	Skinner-	Elizabeth	Dr	Abt Associates
100	Maringa	Suzan	Ms	Ekurhuleni Metro Council
101	Pretorius	Lauren	Ms	Campaigning for Cancer
102	Schurink	Eveline	Dr	UFF Agri Asset Management





ANNEX B: THE NCD ALLIANCE BENCHMARKING TOOL

SECTION	#	QUESTION/ INDICATOR	ANSWER*
1) Raise priority of NCDs through international cooperation & advocacy	1.1	Inclusion of NCDs in national development plans	Yes/No/partial
		If yes to 1.1, are NCDs included in sub-national development plans?	Yes/No/partial
		If no to 1.1, are NCDs included in sub-national development plans?	Yes/No/partial
	1.2	If no to 1.1, are NCDs included in the national health sector plan? (If a high income donor country uses this indicator) inclusion on NCDs in Official Development Assistance	Yes/No/partial
		(If a low/middle income country uses this indicator) Government Inclusion of NCDs in UN Development Assistance Frameworks (UNDAFs)	Yes/No/partial
		Operational national NCD alliance/coalition/network of NGOs that engages People Living with NCDs (PLWNCDs)	Yes/No/partial
1.4	Government-led, supported or endorsed national NCD conference/summit/meeting held in the last 2 years with active NGOs participation	Yes/No/partial	
1.5	Government-led or endorsed public media campaign on NCD awareness of NCD prevention partnering with NGOs and held in the last 2 years	Yes/No/partial	
2) Strengthening national capacity, multisectoral action, and partnerships for NCDs	2.1	Operational National NCD Plan (number of key elements outlined below): if score less than 4, refer to 2.2	Yes/No/partial
		2.1.1 National NCD Plan with a 'whole of government' approach, i.e. with areas for action beyond the health sector	Yes/No/partial
		2.1.2 Functional national multistakeholder NCD commission/mechanism (incl. NGOs, People Living With NCDs and private sector)	Yes/No/partial
		2.1.3 National budgetary allocation for NCDs (treatment, prevention, health promotion, surveillance, M & E, human resources)	Yes/No/partial
		2.1.4 NGOs and PLWNCDs engaged in national NCD plan development	Yes/No/partial
	2.2	Number of sub-national jurisdictions (province, district etc) with an operational NCD plan that meets the full criteria as outlined above	Yes/No/partial
	2.3	Number of operational NCD public-private partnerships (PPPs) supporting elements of National NCD Plans. If yes, list PPPs.	Yes/No/partial
	2.4	National Government partnerships with NGOs on NCD initiatives. If yes, describe the nature of the partnership and initiative focus.	Yes/No/partial
3) Reduce NCD risk factors and social determinants	3.1	Number of tobacco MPOWER policies/interventions in existence (of those listed below 3.1.1 - 3.1.6):	Yes/No/partial
		3.1.1 Existence of recent nationally representative information on youth and adult prevalence of tobacco use	Yes/No/partial
		3.1.2 National Legislation banning smoking in health-care and educational facilities and in all indoor public places including workplace, restaurants and bars	Yes/No/partial
		3.1.3 Existence of national guidelines for the treatment of tobacco dependence	Yes/No/partial
		3.1.4 Legislation mandating visible and clear health warnings covering at least half of principal pack areas	Yes/No/partial
		3.1.5 Legislation banning tobacco advertising, promotion & sponsorship OR legislation comprehensively banning all forms of direct tobacco marketing, covering all media form & advertising	Yes/No/partial
	3.2	3.1.6 Tobacco taxation policy of between 2/3 and 3/4 of retail price	Yes/No/partial
		National strategies on the major NCD risk factors (out of total listed below)	Yes/No/partial
		3.2.1 Tobacco	Yes/No/partial
		3.2.2 Harmful use of alcohol	Yes/No/partial
	3.3	3.2.3 Unhealthy diet	Yes/No/partial
		3.2.4 Physical activity	Yes/No/partial
	3.4	Increased taxes on alcohol in last 5 years	Yes/No/partial
	3.5	National policies & regulatory controls on marketing to children of foods high in fats, trans fatty acids, free sugars or salt	Yes/No/partial
3.6	National action on salt reduction	Yes/No/partial	
	3.5.1 National policies/regulatory controls on salt reduction	Yes/No/partial	
	3.5.2 Number of voluntary private sector commitments / pledges to salt reduction. Specify any the voluntary commitments	Yes/No/partial	
	3.6 Physical education in schools with resources and incentives	Yes/No/partial	
4) Strengthen & reorient health systems to address NCDs	4.1	Government initiatives strengthening the capacity of primary health centres for NCDs (out of the total list below 4.1.1 - 4.1.5)	Yes/No/partial
		4.1.1 Cancer - number of evidence-based guidelines for the cancers prioritized in the National Care Plan	Yes/No/partial
		4.1.2 Cardiovascular disease	Yes/No/partial
		4.1.3 Chronic respiratory diseases	Yes/No/partial
		4.1.4 Diabetes	Yes/No/partial
		4.1.5 Mental health	Yes/No/partial
	4.2	Government initiatives strengthening the capacity of primary healthcare for NCDs (see list below 4.2.1 - 4.2.4):	Yes/No/partial
		4.2.1 NCD health promotion and prevention (advocates to add own indicators)	Yes/No/partial
		4.2.2 Screening and early detection (advocates to add own indicators)	Yes/No/partial
		4.2.3 Treatment and referral (advocates to add own indicators)	Yes/No/partial
	4.3	4.2.4 Rehabilitation and palliative care (advocates to add own indicators)	Yes/No/partial
		Number of NCD medicines included in the country essential drug list (EDL) made available at low cost to patients with limited resources	Yes/No/partial
	4.4	National EDL list updated since last time WHO updated EDL? If yes, are NCD medicines included in the update?	Yes/No/partial
	4.5	NCD-related services and treatments are covered by health insurance systems. If only partially implemented, specify why.	Yes/No/partial
4.6	Operational NCD Surveillance system (number of elements below):	Yes/No/partial	
	4.6.1 Cause-specific mortality related to NCDs included in national health reporting system	Yes/No/partial	
	4.6.2 Population-based NCD mortality data and population-based mortality data included in national health reporting system	Yes/No/partial	
5) Promote national capacity for R & D on NCDs	5.1	National research agenda for NCDs	Yes/No/partial
	5.2	Government funding support for national research on NCDs	Yes/No/partial
	5.3	Number of published articles on NCDs in country in the last 5 years.	Yes/No/partial
6) M & E for NCDs progress	6.1	National NCD targets/indicator with monitoring mechanisms in place	Yes/No/partial