



**DIABETES
ALLIANCE**

Diabetes Charter

Prepared by the [Diabetes Alliance](#)

November 2021

Background

This Diabetes Charter was prepared by the Diabetes Alliance, following a consultative and collaborative process with volunteer workstreams – each of which included numerous people living with diabetes (PLWD). While this Diabetes Charter recognises the cluster of conditions such as obesity, diabetes, cardiovascular diseases and other comorbidities, the Diabetes Alliance focuses on the challenges and proposed solutions for diabetes in South Africa, as that is our collective area of expertise.

We believe a South African Diabetes Charter is necessary to unite the disparate voices working with diabetes in South Africa, to start a discussion about the best ways to solve the most obvious challenges, and to point towards the development of an effective diabetes response. The World Health Organization (WHO) launched the Global Diabetes Compact¹ in 2021 with the vision of “reducing the risk of diabetes, and ensuring that all people who are diagnosed with diabetes have access to equitable, comprehensive, affordable and quality treatment and care”.

The World Health Assembly (WHA) Resolution WHA74.4² urges Member States to “raise the priority given to the prevention, diagnosis and control of diabetes as well as prevention and management of risk factors such as obesity”. It is within this context that the Diabetes Charter was developed.

Diabetes in South Africa

Diabetes accounted for 25,255 (5.5%) of deaths in South Africa in 2017 and it was the leading cause of death among women.³ We know that South Africa also faces an extremely high obesity rate, with 68% of women and 31% of men being overweight or obese.⁴ These alarming rates of obesity contribute to the high prevalence of diabetes. Diabetes clusters with other chronic inflammatory diseases⁵ and conditions as part of the metabolic syndrome.⁶

The direct medical cost of Type 2 diabetes, which accounts for 90% of diabetes cases in South Africa and worldwide, is also significant. In 2018, public sector costs of people diagnosed with Type 2 diabetes were approximately ZAR 2.7 bn and ZAR 21.8 bn – if both diagnosed and undiagnosed people with diabetes are considered. In real terms, the estimated 2030 cost of all Type 2 diabetes cases is ZAR 35.1 bn. 51% of these costs can be attributed to the management of Type 2 diabetes, and 49% to complications.⁷ Addressing diabetes in South Africa should be approached as a matter of the utmost urgency.

Alignment with the South African National Strategic Plan

The South African National Department of Health (NDOH) National Strategic Plan (NSP) for

Non-Communicable Diseases⁸ (NCDs) will direct the actions undertaken between 2021 and 2026 across sectors to redress and reverse the growing threat posed by NCDs. While we recognise that this plan is currently in draft format and that it could still change or not be approved, we have aligned each of the themes in this charter with one of the NSP's goals – ensuring coherence and cooperation in the pursuit of our mutual objectives.

The NSP's overarching objective is to prepare South Africa to achieve the Sustainable Development Goal pertaining to NCDs: to reduce premature mortality from NCDs by one third, through prevention and treatment; and promote mental health and well-being by 2030 (Goal 3.4). These goals and their implementation are informed by the WHO NCD Discussion paper⁹, with recommendations to strengthen and monitor diabetes responses. We believe our diabetes objectives should approximate those of HIV targets – 90/90/90. Although we are well short of these targets – or indeed any current diabetes targets¹⁰ – this should be our goal.

The proposed innovations in this Diabetes Charter are aligned with the NCD strategy – which is to implement evidence-based NCD prevention interventions focusing on health promotion that is people-centred, culturally sensitive and cost-effective. The NDOH also recognises the power of technological innovations, including m-health for the prevention and improvement of disease management and control. We believe that many of the proposed solutions in the Charter could be included in a revised NSP in future.

The Diabetes Charter process

The Diabetes Charter is divided into 5 themes, which are all aligned with the WHO Global Diabetes Compact:¹

1. Awareness and prevention
2. Education
3. Management and access to care
4. Surveillance
5. Research and innovation

Each of these themes was explored by a volunteer workstream made up of members of the Diabetes Alliance, as well as other individuals and organisations who accepted the invitation. The workstreams all included PLWD, as we support the WHO's call: "Nothing for Us, Without Us". After the initial submission from the workstreams, the Charter was reviewed by a panel of South African diabetes experts, including academics, endocrinologists, doctors working in primary healthcare (PHC) clinics, civil society organisations and professional organisations aligned with diabetes. It was then submitted to the Diabetes Alliance for adoption, and will be publicly presented during the inaugural South African Diabetes Summit on 10 November 2021.

Throughout this charter, we've referred to 'people living with diabetes' (PLWD) rather than 'diabetics', and 'people with diabetes' rather than 'patients'. While these might seem like minor

details, it has been shown that the words used about diabetes affect the physical and emotional health of people living with diabetes. “They also affect how individuals and society view people living with, or at risk of, diabetes.”¹¹ To reduce the stigmatising effect of diabetes language – in the media¹² and in healthcare – we should make a cohesive effort to change the language used around diabetes.

One of this Diabetes Charter’s main aims is to fuel discussions about the best ways to solve the most obvious challenges related to diabetes in South Africa, and to point towards the development of an effective diabetes response. We welcome all input towards achieving this goal.

References:

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6. [Inflammatory mechanisms linking obesity and metabolic disease](#)
7. [The direct medical cost of type 2 diabetes mellitus in South Africa: a cost of illness study](#)
8. [South African National Strategic Plan for NCDs](#)
9. [Draft recommendations to strengthen and monitor diabetes responses within national noncommunicable disease programmes, including potential targets \(WHO, 2021\)](#)
10. [Diabetes targets would cost more but the impact would be worth it: here’s how](#)
11. [Our language matters: Improving communication with and about people with diabetes. A position statement by Diabetes Australia](#)
12. [‘I call it the blame and shame disease’: a qualitative study about perceptions of social stigma surrounding type 2 diabetes](#)

1. Awareness and prevention

This theme is in alignment with Goal #1 of the National Strategic Plan for NCDs:

Increase Life Expectancy, Improve Health and disease

Improve health outcomes by responding to the quadruple burden of disease of South Africa

Challenges

50% of PLWD undiagnosed

1 in 2 people with diabetes in South Africa are undiagnosed, which means that half of South Africans who have diabetes don't even know they do. This reduces their chances of managing the condition properly and as a result, they risk serious complications if not treated timeously. Undiagnosed Type 2 diabetes places a heavy burden on the healthcare system – COVID-19 brought this into the spotlight when those presenting with COVID-19 and diabetes were twice as likely to be hospitalised, and three times more likely to be admitted to ICU.¹ Many of those with diabetes were undiagnosed until they were hospitalised.

Stats SA reported that diabetes is the number one killer of women in South Africa, and the second leading cause of death in men.² This is despite the fact that Type 2 diabetes is a manageable condition when it's diagnosed early enough.

High prevalence of prediabetes

65% of South Africans are currently in the prediabetes range.³ If nothing is done, 2 in 3 people will develop Type 2 diabetes. The SA Demographic and Health Survey reports that “a large proportion of adults are either not aware of their condition or not aware that they are at risk for diabetes”. There is also a strong genetic predisposition element to Type 2 diabetes that is not adequately addressed.¹⁴

Gestational Diabetes not used as a learning opportunity

Gestational Diabetes Mellitus (GDM) affects about 10% of pregnant women in South Africa. This has been shown to progress to Type 2 diabetes in roughly 50% of cases by 5 years, with half of these cases unaware of their Type 2 diagnosis. GDM is not only associated with an increased risk for Type 2 diabetes, but also with an increased risk for cardiovascular disease. Furthermore, the foetus is exposed to hyperglycaemia during pregnancy, with long-term consequences.⁴

Lack of awareness of symptoms and risks (Type 1 and Type 2 diabetes)

There is low awareness among ordinary South Africans of the symptoms of diabetes, and the diagnostic criteria aren't always understood by healthcare professionals (HCPs). Although the Society for Endocrinology, Metabolism and Diabetes of South Africa (SEMDSA) Guidelines⁵ include prediabetes criteria, there is limited awareness of prediabetes among HCPs (especially in primary care). Too often, HCPs only act once hyperglycaemia is severe enough to be classified as diabetes.

Additionally, the link between obesity and diabetes⁶ is not clearly identified. People may be aware that they are carrying too much weight, but they are not aware that their lifestyle is driving their weight – or that their current lifestyle will eventually lead to diabetes, as well as the potential for the devastating consequences of untreated diabetes. The symptoms of Type 2 diabetes often take several years to develop.

Food insecurity

Food insecurity is a major problem in South Africa. The country is food secure at national level, but still food insecure at household level,⁷ as not all households have access to adequate food supplies. Much of the population don't have the finances to afford the food they should be eating because "healthy" food is generally more expensive.

Unhealthy food exposure

In addition, poor food messaging, unhealthy food marketing and food pricing are challenges, compounded by what are known as "obesogenic environments". These environments include exposure to affordable unhealthy food, limited recreational space for physical activity or unsafe environments due to crime, and stressful lifestyles.⁸ Individuals consume cheap, high-calorie, nutrient-poor, overly processed foods promoted by big food companies.⁹ We know that an unhealthy diet and physical inactivity are risk factors contributing towards overweight, obesity and Type 2 diabetes.

Stigma surrounding Type 2 diabetes

While health-related stigma has been the subject of South African research in other conditions (particularly HIV/AIDS),¹⁰ it has not been studied locally in diabetes. Internationally, studies have shown that stigma surrounding Type 2 diabetes is of significant concern, with 84% of participants¹¹ indicating that "they believed Type 2 diabetes was stigmatised, or reported evidence of stigmatisation".

Proposed solutions

Screen to reach at-risk South Africans

It is crucial to screen all at-risk persons throughout primary healthcare in a broader community-oriented primary care context – not just those who present in PHC clinics. This is aligned with SEMDSA's recommendations, which outline the need for screening if an individual is overweight/obese (BMI > 25kg/m² or > 23kg/m² in Asians) with one or more additional risk factors:⁵

- Physical inactivity
- Hypertension [blood pressure (BP) ≥ 140/90 mmHg] or treatment for hypertension
- First-degree relative with diabetes
- Dyslipidemia (high cholesterol)
- Polycystic ovarian syndrome
- High-risk race/ethnicity (Asian Indian, Coloured)
- History of cardiovascular disease
- Gestational Diabetes or a baby over 4kg⁴
- Previous impaired fasting glucose (IFG) or impaired glucose tolerance (IGT)
- Other conditions associated with insulin resistance (severe obesity, *acanthosis nigricans*)

Ethically, an increase in screening must be paired with an improved ability to service those who need care. There is a significant gap between screening and linkage to care that requires attention.

A successful Prediabetes Awareness Campaign in the US¹² could be adapted to the South African context, provided specific programmes are developed that will be accessible to all South African communities.¹³ It needs to link to a clear programme of behaviour change with information about Type 2 diabetes, access to HCPs, training for HCPs, as well as guidance for a lifestyle change programme that's tailored to the South African context. This could be delivered by community healthcare workers (CHWs) or health-promotion officers who have undergone training.

Heighten awareness of risk factors

When looking at the risk of developing Type 2 diabetes, it's important to take South Africa's diverse population¹⁴ into account, and to tailor awareness and education accordingly. While SEMDSA¹⁵ and The Knowledge Translation Unit's (KPU) Practical Approach to Care Kit (PACK)¹⁶ provide clear guidelines, these aren't always clearly understood or implemented by HCPs.

It is pivotal to clearly identify Gestational Diabetes as a risk factor for developing Type 2 diabetes. It's also vital to highlight obesity as a risk factor. It's a barrier that a large proportion of South

Africa's population regards obesity as a norm and in some populations, a desired trait. In addition, a variation in fat distribution contributes to ethnic differences in the prevalence of obesity-related diseases.¹⁷ Practically, it is cumbersome to measure Body Mass Index (BMI), especially when there are resource constraints (scales don't have batteries, are often broken and are never calibrated). A more pragmatic approach is waist circumference, which gives better insight into visceral adipose distribution than weight alone.¹⁸

While the HCPs play an important role, the messaging should not be left to HCPs alone. We suggest a life-course approach to avoiding obesity - a WOSA (whole of society approach) to provide a nurturing environment in which people can confront their weight. This could avoid HCPs using BMI guidelines as a form of body-shaming. Behaviour change education should also be mindful of avoiding fat-phobic sentiments and stigma, and ensure that HCPs aren't biased in their treatment of overweight and obese people.

Increase NCD awareness drive

Multisectoral action in the prevention of diabetes is necessary to create change. It's pivotal to create environments and communities that promote a healthier lifestyle, with different governmental and non-governmental organisations contributing to this impact. Ideally, there should be support structures for PLWD across the board: within the health system and communities; and from employers, family and friends.

To create real change in NCD awareness, we need to work collaboratively with all stakeholders – including the Department of Agriculture, the formal trade sector, the food and beverage sectors, the Healthy Living Alliance (HEALA), and the NCD Alliance. A good example is the HIV awareness drive in the early 2000s, which was a national, multisectoral effort. It encompassed mass and outdoor media, print materials in facilities, focused attention by healthcare workers, new technologies to track and trace people with HIV/AIDS, and a dedicated commitment by public and private healthcare providers – backed by national policies and guidelines. This was in large part due to the resources devoted to HIV awareness.

Perhaps some of the resources from an increased Health Promotion Levy could be used for a coherent, multisectoral plan aimed at diabetes prevention and early diagnosis. The cluster of NCDs that include diabetes should be treated in the same way as HIV – and needs to be prioritised as a public healthcare crisis.

Address diabetes in media and schools

The stigma related to Type 2 diabetes should also be addressed – particularly in the media. People with diabetes need to feel comfortable speaking about their condition, without the fear of being blamed and shamed.

Schools could teach a structured, cohesive and high-quality diabetes education programme as part of the curriculum.¹⁹ While some information currently forms part of the subject known as Life Orientation, it should be updated and made accessible to learners, who can then educate their parents in turn.

Create a diabetes portal

Access to accurate information lies at the heart of diabetes awareness and prevention. A diabetes portal similar to the COVID-19 portal²⁰ could reach all stakeholders and provide scientific information, useful resources and the latest updates – while dispelling myths and misinformation. This central portal could also include information about healthy food choices and simple behaviour changes that could lead to better health for all South Africans. It could house and drive all communication and awareness, and provide a central access point for employers to empower their employees. The portal's control and management would need to be carefully managed and defined so that it is easily accessible to PLWD and HCPs, regularly updated, and meticulously monitored and evaluated.

We recognise that many PLWD have other comorbidities, and would welcome discussions on a joint portal that includes all the necessary diabetes resources, as well as information on related conditions.

Increase the Health Promotion Levy

The optimal utilisation of the existing Health Promotion Levy (the so-called sugar tax), as well as an increase thereof, could help to shift the needle and change behaviour via economic rather than educational measures, as evidence points to its impact working at scale. The levy has proved to reduce harmful behaviours²¹ and the merits of doubling it have already been outlined in detail.²² The poorest socioeconomic classes are especially influenced by economic nudging, and they are the ones with the highest risk of being undiagnosed with Type 2 diabetes.

To ensure the greatest impact, this initiative would require mobilisation and advocacy, working alongside other non-profits.

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2. Education

This theme is in alignment with Goal #1 of the National Strategic Plan for NCDs:

Increase Life Expectancy, Improve Health and disease

Improve health outcomes by responding to the quadruple burden of disease of South Africa

Challenges

Lack of access to cohesive quality diabetes education

Diabetes education is a major problem in the public as well as the private sector. There's currently no standardised programme for either PLWD or HCPs, and although many kinds of educational materials exist, there is no cohesion. Added to that, a lot of the current material is in English, which isn't the first language of many of those receiving the education.

Inadequate health literacy¹ is another huge concern, as the available educational materials aren't always easily understood by PLWD. Diabetes education is only provided once-off – at diagnosis – and never updated, and misinformation is a challenge for both PLWD and HCPs.

It's important to recognise that care for PLWD does not solely depend on the doctor. It requires a team approach that needs to include:

1. Diabetes Nurse Educators (DNEs) in each district who are responsible for training nurses, CHWs and peer supporters.
2. Nurses/CHWs/health promotion officers/peer supporters to educate people with diabetes. The focus would be on educating and enabling people with diabetes to self-manage their condition.
3. Dietitians clearly explain how to adjust daily meals to be healthier.
4. Doctors, whose role needs to be to assess the presence of complications and comorbidities, and to initiate or adjust medication.
5. A diabetes education programme that takes place over multiple visits, at the appropriate level of health literacy, using a guiding and non-didactic style.

There isn't a standard set of diabetes educational materials in all languages – essentially, some simple resources to share with people with diabetes – that are available at public clinics/hospitals.

Limited Diabetes Nurse Educator positions

There are currently only a few Diabetes Nurse Educator positions available in the public sector, where the majority of PLWD receive their care. The role of diabetes educator is not recognised with SAQA (the South African Qualifications Authority), and diabetes education is treated as an adjunct. Yet for many PLWD, education and support are primary requirements. While a combined NCD educator approach might work for people living with Type 2 diabetes and other comorbidities, people living with Type 1 diabetes (and their families) need extensive counselling to manage the condition, not only at diagnosis. Currently, that burden falls on dietitians in the public sector, who already have an excessive workload due to their limited numbers.

No ongoing daily support

Diabetes is a self-managed condition, requiring the full participation and involvement of PLWD and their families. Yet PLWD don't have adequate information to manage their condition. Self-management support involves educating people with diabetes about their condition to empower them to maintain greater control, enabling them through the provision of devices and strips so that they can be involved in monitoring, and giving them the tools they need to take action.³

Peer support groups are rarely available and family members aren't educated or don't understand the diagnosis or treatment.² Furthermore, not all PLWD have access to resources such as the internet or social media channels. Diabetes education is also not updated across the life span⁴ – so there is no individualised approach.

HCPs are often not specifically trained in diabetes management and therefore, they don't have the tools or in-depth knowledge to educate PLWD effectively. Beyond the diagnosis of diabetes and diabetes ketoacidosis (DKA) management, almost nothing about diabetes education is included in the MBBCh curriculum. Many HCPs have never seen an insulin pen and wouldn't know how to educate people with diabetes about the correct injection technique. Scare tactics are used as HCPs understand the implications of poor control, but they have no effective tools to teach PLWD how to successfully manage their condition on a daily basis.

Service provision

Many HCPs in the public health sector are working in severely under-resourced and under-staffed health facilities and therefore, diabetes education is not a priority for them. CHWs, health promotion officers, some doctors and CNPs do offer some education for people with diabetes, but it is limited to their level of knowledge as HCPs.

Additionally, although NCDs are a priority on paper and in policies, advocacy for diabetes awareness and education needs to be robust.

Proposed solutions

Access to quality diabetes education within cohesive service delivery platforms

A standardised education programme for PLWD and HCPs is needed – with a structured educational framework so that everyone understands the basics. It should be tiered, starting with prevention information, then the basics at diagnosis, and further detail given each year. Educational material should also be available in home languages⁵ at the appropriate health literacy level.

Diabetes Nurse Educator positions

Should the role of DNE be formalised, regulated and recognised, it will prompt its incorporation into guidelines – including its reimbursement. This could be in a context of task-sharing. There is a critical need for the South African Nursing Council to recognise the specialty of diabetes education, along with DNE posts within each district. These DNEs would be responsible for upskilling CHWs, peers and nurses so that these groups could provide diabetes education. In addition, the educators could provide support for the initiation of insulin and the promotion of self-care.

This is not a suggestion to introduce verticalised care, but rather to support a comprehensive, integrated approach to health services. The DNE could be a district-level expert who enables generalists to provide the best possible care. They would be responsible for upskilling CHWs, nurses and doctors in an educational, training and capacity-building role.

Ongoing daily support

It's important to link the support that's currently available, particularly from CHWs and Ward-based Primary Health Care Outreach Teams (WBPHCOT).⁶ WBPHCOT members are provided with cell phones and trained to collect and send patient information with these. If used properly, this method could improve the turnaround time for required patient interventions, as well as for data quality.

Diabetes education shouldn't rely on pamphlets: mobile penetration in South Africa is significant,⁷ with only 5% of adults not owning or sharing a phone. WhatsApp-based diabetes education could be one part of this solution, as it relies solely on the PLWD having a phone, with WhatsApp installed. This should ideally be zero-rated, to avoid data costs, and would need to be supported nationally to ensure penetration. There are currently also successful peer support projects in some South African provinces, which could be expanded to all provinces.

The creation of diabetes education material in most of SA's official languages⁸ is essential. Diabetes distress (an emotional state arising from living with diabetes and the burden of self-management⁹, which causes PLWD to experience feelings such as stress, guilt or denial) and mental health also need to be addressed.¹⁰ An actuarial approach to diabetes education would help us to reframe the problem: spend more now to save more in future.

Service provision

An important first step is to educate people with diabetes about the services they are entitled to, as they should feel empowered to insist on these services without fear.

Diabetes education requires a multidisciplinary approach. There are various service-provision solutions to consider, including structured diabetes education programmes run at primary healthcare level¹¹ – by trained lay counsellors or CHWs¹² – and increased access to diabetes management courses for HCPs who care for PLWD.¹³ These would have to be monitored and evaluated to ensure that they remain current and relevant.

A longer-term solution could be a Diabetes Centre in one primary clinic per district. These could become teaching opportunities for HCPs in primary care, recognising that you don't always need to refer up. In turn, this could lead to fewer admissions.

An essential first step is to ensure that the role of DNE becomes a specialist track for HCPs and clinical associates who are well-positioned to provide appropriate diabetes education.

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3. Management and access to care

This theme is in alignment with Goal #2 of the National Strategic Plan for NCDs:

Quality Improvement in the provision of care

Improving availability to medical products, and equipment

It also supports Pillar 2:

To ensure improved access to essential medicines, vaccines and medical products through better management of supply chain equipment and machinery

Challenges

Poor levels of care

Health system interventions are currently developed without prioritising outcomes for people receiving care.¹ There is, overall, suboptimal annual monitoring for complications and comorbidities. Foot care and eye screening are the least-monitored complications, yet eye problems and peripheral neuropathy are the most common self-reported and medically recorded complications.² Foot care and eye screening are two of the WHO “Best Buys”³ as the most cost-effective strategies to support PLWD. There is a dire need for podiatrists in the public healthcare sector. For example, there are currently two podiatry posts at the KwaZulu-Natal (KZN) Department of Health – and that’s for a registered population of close to 1.3 million PLWD in the province.⁴

Because records are largely paper-based, they can be lost. There is often no continuity with HCPs, so PLWD are not receiving cohesive care. Clinical inertia is also a problem, as people with diabetes come back to the clinic each month for medication, but nothing changes. The basket of medications, insulin and diabetes supplies required for optimal care also need to be coordinated. For example, lancets aren’t always available for testing blood glucose; and the same goes for syringes or pen needles for people using insulin. To empower PLWD, we need more than routine care.

Lack of monitoring

In the public sector, only people with diabetes on insulin are provided with glucometers and test strips, and most people with Type 2 diabetes are on oral medication. In practice, this means that the majority of people in the public sector with diabetes have no experience of glycaemic monitoring or control. They just receive a single glucose test when they come for their clinic

appointment (this may be fasting or random). Based on this single measurement or an old HbA1c result from their previous visit, their medication is then adjusted.

Similarly, HbA1c tests aren't always available. The lack of availability of HbA1c for decision-making at the time of the appointment is a major deterrent to optimal care and achieving glycaemic targets.⁵

The DISCOVER study⁶ suggests that South Africans are neither being sufficiently monitored, nor having their medication adjusted appropriately or timeously. Referrals are also not used appropriately, despite a high level of comorbidities. Each PLWD is unique, with different risk factors, trajectories, complications and outcomes that can be modified by improving access to care, education and medications – and by changing behaviours and social habits.⁷

Standards of key processes

It's been found that HCPs' compliance to the standards of key processes of diabetes care and glycaemic control is poor.⁸ The finding of poor glycaemic control in this study aligns with previous South African studies that have reported poor glycaemic control in 2.6% to 33.0% of people with Type 2 diabetes in treatment. This pervasive poor glycaemic control signifies that the risk of microvascular complications is substantial, while cardiovascular risk factors such as hypertension and hyperlipidaemia are highly prevalent, but also suboptimally managed. Research also shows an increase in diabetes-related lower-limb-amputations.⁹

Proposed solutions

Necessary changes within the current delivery of diabetes care

Key process and outcome indicators should be advocated and audited regularly, with feedback to clinics regarding their performance. It has to be a structured process with a continuous feedback loop and built-in education for facilities.

For example, tests could include HbA1c, serum creatinine, urine albumin creatinine ratio (UACR), as well as a foot exam, eye photos and blood pressure. Targets could be that 80% of people with diabetes should have an HbA1c done, and 70% of these should be below 7%. The HbA1c should be done at the time of the clinic visit to obviate the current practice of basing clinical decisions on results from months earlier.⁵

Retinal cameras should be available for eye screenings. For example, there should be a camera at a community health centre (CHC), so surrounding clinics could refer to this centre, which could then refer to a tertiary care ophthalmology unit, when necessary.

In addition, primary care HCPs need to be trained about these goals and how to achieve them in a systematic, structured and certified way.

Medication options should be standardised according to local (SEMDSA) as well as international guidelines, allowing context and costs to play their part. There should be Standard Treatment Guidelines (STGs) at all levels.

To counteract clinical inertia, more intensive alternative intervention triggered by a higher HbA1c¹⁰ is needed. Point of Care (POC) testing for HbA1c that offers immediate results would be very beneficial in this context.⁵

Provision of integrated care

Integrated care should be provided to overcome clinical inertia and non-adherence. When developing this approach, it's important to align it with the WHO's global strategy on integrated people-centred health services.¹¹

A basket of interventions could be offered:

- Ensuring that people with diabetes have an annual review to assess complications/comorbidities as per SEMDSA guidelines.
- An introduction of targets for each person with diabetes and each facility, and the use of a structured feedback loop to enhance diabetes care and outcomes.
- A structured education programme to enhance self management.¹²
- Ensuring uninterrupted access to medication and monitoring.

Diabetes management has become increasingly complex, with many technological advancements – including the use of multiple oral medications and injectables, continuous glucose monitoring (CGM), insulin delivery systems, and metabolic surgery. There are also emerging technologies such as the use of biogenetic markers in precision medicine. To ensure that PLWD receive the benefits of these advancements, the curriculum of undergraduate programmes needs to expand with ongoing postgraduate and professional training in diabetes and other NCDs.¹³

While podiatry services are extremely limited, it is possible for other HCPs to evaluate the feet of a PLWD, and identify a foot at risk within 60 seconds.¹⁴ The person with diabetes can then be referred to podiatry services long before complications arise.

Specialised diabetes centres based in hospitals and affiliated with academic institutions are in a good position to set up accreditation programmes in the management and education of diabetes. Mental health services should also be provided. Mental health (including diabetes distress)¹⁵ is a common comorbidity of diabetes, and contributes to inertia experienced by people with diabetes. These centres work closely with primary care physicians to provide collaborative care.

Management of Type 2 diabetes

Guidelines need to outline a distinct time limit within which glycaemic targets should be met once a person with diabetes has been initiated on oral medication or insulin. This will prevent treatment inertia. If they haven't achieved targets, they should be referred up to district or regional level.

The PLWD should have access to a glucometer and test strips, which should be used in such a way as to maximise data on trends and timing of hyperglycaemia. This data will allow the HCP to titrate or change insulin by someone who is experienced in interpreting self-monitoring of blood glucose (SMBG), since HbA1c is not enough to adequately titrate insulin.¹⁶

The supply of glucometers and test strips should become a priority. In conjunction with this, it's vital to train HCPs at district hospitals to understand and interpret SMBG with the titration of insulin.

Individualised approach to diabetes therapy

In contrast to algorithmic sequential treatment (as in South Africa), more recent guidelines recommend an individualised approach to diabetes therapy, with particular attention to comorbidities.¹⁷ A unique identifier would allow every person's data to be easily pulled up at each appointment. This would motivate PLWDs, as they would be offered cohesive care, as well as HCPs, as they would see the progress made by people with diabetes. It's an empowering solution for both.

The integrated chronic disease management (ICDM) model is presented as an innovative vehicle to improve the management of chronic conditions including diabetes.¹⁸ The ICDM uses a public health approach to empower the individual to take responsibility for their own health, while simultaneously intervening at a community and health service level. Standardised clinical care based on national treatment protocols is supported by the introduction of a standardised chronic record for each person.

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4. Surveillance

This theme is in alignment with Goal #4 of the National Strategic Plan for NCDs:

Build Health Infrastructure for effective service delivery

Robust and effective health information systems to automate business processes and improve evidence-based decision-making

It also supports Pillar 9:

Develop an Information System that will guide the health-system policies, strategies and investments

As described by the WHO, public health surveillance is the continuous, systematic collection, analysis and interpretation of health-related data.¹ Thacker et al. define surveillance as “the ongoing systematic collection, analysis and interpretation of health data essential to the planning, implementation, and evaluation of public health practice, and the timely dissemination of these data for action”.²

Surveillance is essential to determine the public health impact of disease by:

- Monitoring the burden of disease and disease trends; mortality and morbidity
- Enabling monitoring and evaluation of the impact of an intervention, tracking progress towards specific goals; and
- Monitoring and clarifying the epidemiology of health problems, guiding priority-setting, and planning and evaluating public health policy and strategies.

Surveillance methods include national health surveys, registries and electronic health records. Registries are a necessary first step towards improving the quality of care. However, they must still lead to other quality improvement strategies, such as providing feedback on results or the management of high-risk cases. Registries need to be informed by national diabetes management policies and protocols, which should inform the national standard data set of measures for surveillance and outcome measurement.

The WHO discussion paper³ on the draft recommendations to strengthen and monitor diabetes responses within national NCDs programmes, including potential targets, offers the following recommendations for Member States:

1. Develop and strengthen surveillance and monitoring systems for diabetes and other NCD risk factors, guided by the WHO NCD surveillance framework.
2. Develop and strengthen monitoring systems to evaluate the treatment gap and clinical outcomes (morbidity and mortality) and health system performance (capacity and interventions) through the systematic collection of standardised routine facility-based diabetes care indicators.

South Africa's updated *Management of type 2 diabetes at primary care level* document⁴ indicates that an essential part of the process in diabetes care is “a register of all patients”, as well as “a process of regular audit that needs to be instituted, to review the implementation of interventions, to improve the standard of care”.

Challenges

There is limited regular surveillance for diabetes in South Africa. However, several surveys have been periodically conducted, which collected data on NCDs and their risk factors. These include the South African Demographic and Health Survey (SADHS), the South African National Health and Nutrition Examination Survey (SANHANES), the National Income Dynamic Survey (NIDS), the Study on Ageing and Adult Health (SAGE), and the Youth Risk Behaviour Survey. Unfortunately, these studies are not regular and not standardised, with non-representative samples. Therefore, data is usually not comparable.

Surveys tend to be once-off and don't use standardised and comparable methodology. They also don't provide for a differential between Type 1 and Type 2 diabetes, or other types of diabetes, as per the WHO report on the classification of diabetes.⁵ Type 1 diabetes is not likely to account for more than 10% of cases at most.

According to the International Diabetes Federation (IDF), there are an estimated 1,600 children and adolescents with Type 1 diabetes in South Africa (0-19 years). However, data from the Council for Medical Schemes Annexures to the 2019/2020 Annual Report⁶ indicates that 4,276 children and adolescents (0-19 years) with Type 1 diabetes were treated within the privately insured population of South Africa.

It's projected that approximately 16.4% of South Africans⁷ have private medical insurance, so the total number of children and adolescents with Type 1 diabetes is likely to be considerably higher than 4,276, but there is no accurate data for the public sector where the majority of people with Type 1 diabetes are likely to receive their care.

The District Health Information System (DHIS) does not capture outcomes data or clinical indicators for people living with diabetes (PLWD). The Provincial Health Data Centre (PHDC) in the Western Cape can use two proxy data sources to estimate the Type 1 population: age and people on insulin only. The figure in most PHC facilities is about 9% of the total number of people diagnosed with diabetes.

There is currently no registry for diabetes in South Africa, even though it is an ideal condition for a registry-based system, since it is clearly a data-driven condition. There are however registries for cancer, HIV and TB.

Proposed solutions

1. Prioritise the establishment of a national diabetes surveillance programme within the existing national surveillance systems.
2. Such a surveillance programme should be informed by national diabetes policy and guidelines based on evidence-based medicine, and the analysis of health economic outcomes.
3. Create a diabetes registry with standardised data to be collected annually to assess levels of control/complications. This would also enable the assessment of complications, and look at the impact of interventions on complication reduction.
4. Conduct a 5-yearly Demographic and Health Survey (DHS) to assess the prevalence of diabetes.
5. Establish and publish a standardised data set of measurements for Type 1 and Type 2 diabetes, to be adopted for diabetes surveillance in South Africa. This would need to be defined and developed by a representative group.
6. Ensure that the surveillance programme is independent and free from commercial involvement and political interference. Funding could be distributed to coordinate the establishment of a registry through all South African academic centres.
7. Provide dedicated resources and investment for the diabetes surveillance programme's development and ongoing implementation. Once standardised data-set elements have been created, diabetes targets need to be set.⁹
8. Encourage and support stakeholder engagement across all levels of the healthcare system to ensure adoption and implementation.
9. Include surveillance in the education and training of healthcare workers at all levels.
10. Consider leveraging existing surveillance systems and enhancing them to include diabetes surveillance. This should be considered only once the standard data set for diabetes has been established.
11. Support the mandate of the National Public Health Institute of South Africa (NAPHISA), as described in Gazette B 16B-2017,¹⁰ "to coordinate, and where appropriate to conduct disease and injury surveillance; to provide for specialised public health services, public health interventions, training and research directed towards the major health challenges affecting the population of the Republic; and to provide for matters connected therewith".

In conclusion, as recommended by the WHO Discussion paper³ and the WHO Diabetes Compact⁸, countries should prioritise establishing diabetes-specific targets. This will require reliable, consistent and regular data to effectively implement and monitor progress towards these targets.

The optimal management of diabetes requires a coordinated approach from a range of HCPs, including access to medicines and technologies and a system that supports PLWD

empowerment. This has relevance beyond diabetes, and diabetes could serve as a tracer condition for the strength of the national responses to NCDs.

Establishing a national diabetes surveillance programme based on standardised data set measures for diabetes, will lay the foundation for the coordinated approach that is needed to halt the rise and harmful health impact of diabetes in South Africa.

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5. Research and innovation

This theme is in alignment with Goal #4 of the National Strategic Plan for NCDs:

Build Health Infrastructure for effective service delivery

Robust and effective health information systems to automate business processes and improve evidence-based decision-making

It also supports Pillar 9:

Develop an Information System that will guide the health-system policies, strategies and investments

Challenges

Diabetes research is not a national priority

There is currently no national agenda for diabetes research, and no funds earmarked for diabetes research and innovation. As a result, there is a paucity of diabetes research being undertaken. Researchers who are testing various interventions need to be supported, and there should be a major focus on the implementation and scale-up of what has been proven to work. Prioritising and investing in implementation research could assist the various projects that are currently succeeding to be realised at scale.

Self-management is suboptimal

People with diabetes in South Africa are not receiving optimal care.¹ Numerous studies report that glycaemic control is suboptimal, with PLWD failing to achieve the recommended disease management targets. PLWD are not empowered: they lack knowledge and self-efficacy to demand the care they deserve and change their life experience. It's necessary to acknowledge the deeply embedded socio-cultural norms that are obesogenic and diabetogenic, as well as the economics of food distribution.

Approach to healthcare is outdated

The current approach to healthcare is fragmented and siloed, and not yet individualised or person-centred – despite attempts to work towards this goal. What's more, healthcare decisions can be difficult to understand. Many innovative companies are offering solutions – including diabetes tech like CGM and flash glucose monitors – but they are niche innovations and either lack scale or are unaffordable at present.

Access to specialists is limited

Despite the large number of lower-limb amputations in South Africa,² there is an absence of foot health practitioners in public care. There is also a significant incidence of both diagnosed and undiagnosed diabetic retinopathy (DR) in PLWD.³ Contributing factors include a lack of suitably trained diabetic retinopathy screeners, an extremely high individual-to-ophthalmologist ratio, and a lack of resources and equipment. The presence of DR is a significant marker for the presence of diabetic neuropathy and nephropathy, and screening is a simple, non-invasive process.

Proposed solutions

Create a national agenda for diabetes research

There should be a national agenda for research supported by the NDOH. In this context, it would be possible to support current researchers who are testing various interventions, and commit funds to diabetes research and innovation. More funding and investments for diabetes research in South Africa is necessary. Additionally, bursaries and scholarships at postgraduate level would help to develop young researchers and prepare them for a career in diabetes research.

Career paths in diabetes research also need to be advertised. Many undergraduate medical scientist students are not aware of such opportunities, and may be very interested. Advertising diabetes research facility programmes can help to attract young, motivated individuals who may have access to National Research Foundation funding. It's also important to create active collaborations between academic centres so that data and resources can be harnessed from all of South Africa's provinces.

Empower PLWD for self-management

Achieving equity in health service delivery is fundamental to achieving the target sets under the national NCD plan. This would include ensuring access to services for vulnerable populations – for example, rural and disadvantaged communities and those requiring interprovincial services, as well as addressing stigma associated with diseases. WhatsApp-based diabetes education can reach those in rural and remote locations, who do not currently have access to diabetes educators or accessible diabetes education. In addition, the entire primary care workforce needs to be upskilled in the management of diabetes, particularly empowering PLWD and giving them support for self-management.⁴

It's essential to develop an integrated team approach to diabetes monitoring, in which every team member has distinct roles and responsibilities, with the aim to promote self-management, the achievement of targets, as well as screening for and managing complications.

Adopt a peer support model

Taking the public health facility challenges in SA into consideration, a peer support model could be effective.^{5,6} It's not sufficient to provide information to enable behavioural change without offering motivation and a supportive environment. This could be in the form of facility- or community-based groups, and focused on newly diagnosed or uncontrolled PLWD⁷. It's also important to harness the power of the community-orientated primary care approach.⁸ CHWs can be integral in health promotion, disease prevention, medication delivery, clinical and adherence support.

Use telehealth effectively

Telehealth offers the potential for PLWD to engage with specialists in the right context. Its value was demonstrated while being successfully used during COVID-19 in the Western Cape. Telehealth and m-health technologies to enable and enhance disease risk management strategies must not be underestimated. Regular contact with a Diabetes Educator or clinician to follow up on PLWD is an invaluable tool. The VULA Mobile App and technology link field healthcare workers (HCWs) with specialists and generalists in tertiary institutions for guidance and referral. The use of fundus cameras and telemedicine to detect retinopathy is supported by local evidence – and it is cost-effective.^{9,10}

It is necessary to strike a balance to ensure that language and cultural barriers, which may not be possible to address in a telehealth environment, do not result in PLWD failing to properly adhere to care prescribed by either generalists or specialists.¹¹

To use telehealth effectively, funding is necessary. Recognising telehealth as a legitimate healthcare service and appropriate funding will drive effective usage.

Modernise approach to healthcare

Innovative interventions can improve all areas of the diabetes response, and person-centred care using a team approach to enhance self-management is at the core. A digital-first approach, with a triage model to find out who actually needs to see an HCP – before they stand in a queue at a clinic all day, could be effective. This should be researched and tested with the goal to develop a truly person-centred system, with attention paid to the user experience. In addition, success should be measured by outcomes, not by volume: a value-based care approach.¹²

To strengthen health systems, there is a need to improve integration and address human and financial deficiencies.¹³ As part of a package of care, digital health for diabetes offers great opportunities. Funding and support should be available to develop those digital health solutions specific to the South African context, and an electronic medical record that integrates information for each PLWD is an essential component of this. It will improve coordination, continuity and the triage of risk groups, and also prompt appropriate action.

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Comments on the Diabetes Charter

Readers who wish to comment on the Diabetes Charter are invited to do so by emailing info@diabetesalliance.org.za

This Diabetes Charter will be revised in November 2023.