

NEWS RELEASE

UP and partners launch first national Type 1 diabetes burden study



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PRETORIA - The University of Pretoria (UP), in partnership with other South African universities, professional associations and the diabetes community, has launched the country's first nationwide study to measure the burden of Type 1 diabetes (T1D). The [South Africa Type 1 Diabetes Burden Study](#), supported by the [Life for a Child Program](#) of [Diabetes Australia](#), seeks to address a long-standing data gap by generating national estimates of how many people are living with T1D in South Africa, and where and how they are accessing care.

"The idea for this study arose from a glaring data gap: South Africa has no reliable information on the number of people living with Type 1 diabetes," said [Dr Patrick Ngassa Piotie](#), Senior Programme Manager at the University of Pretoria [Diabetes Research Centre](#) and Principal Investigator of the study. "Estimates used in national and global reports are extrapolated from studies conducted in other countries. This lack of local data severely hampers our ability to plan, allocate resources, and advocate for better care."

Background to the study

While Type 2 diabetes is widely recognised as a growing public health crisis in South Africa, Type 1 diabetes – an autoimmune condition that requires lifelong insulin therapy – is often overlooked. Like Type 2 diabetes, T1D can lead to serious complications such as kidney failure, blindness and cardiovascular disease. However, because most people with T1D are diagnosed in childhood or adolescence, the consequences of incorrect diagnosis or inadequate treatment can be even more severe – affecting growth, disrupting education, limiting employment opportunities and, in some cases, leading to premature death due to misdiagnosis or lack of access to care.

Currently, no national data exists on how many people are living with T1D in South Africa or how their condition is being managed. Existing estimates are extrapolated from other countries, limiting the ability of the national government, clinicians and advocacy organisations to plan, allocate resources or design effective interventions.

“For years, efforts to establish a national registry have been discussed in silos by researchers, clinicians and advocacy groups,” Dr Piotie said. “This is the first time we are coming together in a coordinated, national study that unites public and private sectors, academic institutions, professional societies, and people with lived experience. The idea is based on a simple but powerful premise: You can’t improve what you can’t measure.”

The project is led by UP’s Diabetes Research Centre in partnership with the University of Cape Town (UCT), University of the Free State (UFS), University of the Witwatersrand (Wits), Stellenbosch University (SU), and the University of KwaZulu-Natal (UKZN). It is supported by the [Society for Endocrinology, Metabolism and Diabetes of South Africa](#) (SEMDSA), the Paediatric and Adolescent Endocrinology and Diabetes Society of South Africa (PAEDS-SA), non-profits focused on empowering people with diabetes, the [Sweet Life Diabetes Community](#), and the [Diabetes Alliance South Africa](#).

Why participation and inclusion are important

The inclusion of people with lived experience has been central to the study from its inception.

“The fact that people with Type 1 diabetes have been included right from the start – that lived experience is a core part of this project – is so powerful. Finally, we can start building a map of Type 1 diabetes in South Africa, together,” said Bridget McNulty, co-founder of Sweet Life Diabetes Community and a person living with Type 1 diabetes.

From a provincial, national and institutional perspective, the study is a first. “This diabetes burden initiative will produce much-needed knowledge to allocate resources more effectively and raise public awareness around Type 1 diabetes in South Africa,” said Dr Lebohang Pitso, Head of Endocrinology at UFS and Universitas Academic Hospital.

“For us at the University of the Free State and the Free State society at large, it will be the first study of its kind, and the co-operation with other institutions will boost the positive effect it is projected to have on the lives of individuals with Type 1 diabetes,” Dr Pitso said.

By capturing data from both the public and private sectors, and incorporating the voices of those living with T1D, the study is designed to be inclusive, comprehensive and policy-relevant.

Why this study matters

The study directly supports [South Africa’s National Strategic Plan for the Prevention and Control of Non-Communicable Diseases \(2022–2027\)](#) and the World Health Organization’s call for improved diabetes surveillance. Once completed, the data will provide a foundation for establishing South Africa’s first national Type 1 diabetes

registry. The findings will also help guide the procurement of insulin and glucose monitoring tools, inform healthcare planning, and ensure stronger policy inclusion for T1D across all levels of the health system.

Above all, Dr Piotie pointed out, the study marks a turning point for the thousands of South Africans living with T1D. "This is about more than data. Once established, the registry will give us a national picture of T1D for the first time... Most importantly, it will give visibility to a community that has long felt invisible."

How to participate

Participation is open to anyone in South Africa living with T1D, including parents and guardians of children with T1D.

The online survey is written in clear, accessible language and takes approximately 20 minutes to complete, making it easy for individuals to participate from the comfort of their homes via the following link: <https://www.up.ac.za/diabetes-research-centre/article/3277672/welcome-to-the-south-africa-Type-1-diabetes-t1d-burden-study>

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ABOUT THE UNIVERSITY OF PRETORIA

The University of Pretoria (UP) is one of the largest contact and residential universities in South Africa, with its administration offices located on its Hatfield Campus in Pretoria. This 115-year-old institution is also one of the largest producers of research in South Africa.

Spread over seven campuses, it has nine faculties and a business school, the [Gordon Institute of Business Science](#) (GIBS). It is the only university in the country with a [Faculty of Veterinary Science](#), which is ranked the best in Africa. UP has 120 academic departments and 92 centres and institutes, accommodating more than 56 000 students and offering about 1 100 study programmes. It has the most academic staff with PhDs (70%), NRF-rated researchers (613).

The 2025 Times Higher Education subject rankings placed UP first in South Africa in the fields of [Accounting](#) and [Finance](#); [Architecture](#); [Electrical and Electronic Engineering](#); Law; Sport Science; and Veterinary Science. UP's Faculty of Law has been ranked as the top law school in Africa for a remarkable eighth consecutive year.

Quacquarelli Symonds (QS) ranked the University among the top five in Africa, as part of their [2024 World University Rankings \(WUR\)](#). UP was the only South African university featured in the [2023 World University Rankings for Innovation \(WURI\)](#), falling within in the 101-200 range of innovative universities.

For more information, please go to www.up.ac.za