



CITIZEN SCIENCE

– engaging study participants as partners in research

Allanise Cloete has carved her research path around the belief that people are experts in their own lives. Over the course of a 16-year career at the HSRC, Cloete has documented the experiences and healthcare needs of transgender people, people living with HIV, sex workers, people who use drugs and other marginalised individuals in South Africa. By involving participants in the research process – from interviews to write-ups – Cloete ensures that her research has real-world implications. In the process, she is challenging the power dynamics at the heart of academic research. She spoke to *Andrea Teagle*.

In December 2020, Dr Allanise Cloete and her colleagues responded to a call for proposals to look at how stigma works in South African contexts, and specifically how people (including adolescents) living with HIV experience stigma. The study is part of the International AIDS Society’s ‘Getting to the Heart of Stigma’ project that aims to consolidate the evidence-base of HIV-related stigma and stigma-reduction efforts.

Originally, the proposal was that the study would follow the typical process: researchers would interview participants, analyse the data and disseminate the findings. But something was irking Cloete, an anthropologist who has worked with people living with HIV, trans and gender-diverse people, and other marginalised groups throughout her career at the HSRC.

“We were always left with the feeling, after the research is done,

of ... what next? What does it do? What difference does it make in people’s lives? So often, there’s an understanding – even though it’s sometimes unsaid – that although the participants are happy to share their stories, they also require real-life solutions.”

Cloete and her colleagues felt that it was important that the adolescents living with HIV who participated in the study were at least referred for counselling after the study.



Dr Allanise Cloete
Photo: Antonio Erasmus

They decided to rework the proposal. The team approached the [Positive Women's Network](#) who agreed to help them identify sector representatives who have counselling experience to conduct the interviews. This way, adolescents could be central to the research process and could help to link participants to healthcare services.

A different kind of research

At the centre of Cloete's research approach is the belief that people are the experts in their own lives. "So often still, we do research *on* communities and not *with* them," she says.

Having grown up an outsider in a township on the Cape Flats, Cloete has first-hand experience of violence and ostracisation. "My father is from the Northern Cape, and my mother from a small town in the Swartland, so we had this very different Afrikaans vernacular," she recalls. Her different way of speaking and her pale skin made her a target for bullying. "I was teased, my hair was pulled, I was called all kinds of names."

Thinking back on it now, Cloete believes this experience drew her to working with marginalised groups. "I think that kind of vulnerability and social rejection that I felt created a sense of empathy for others who had also experienced social rejection.

"Of course, my social rejection and victimisation is not the same as the structural oppression that groups I do research with suffer every day, like transgender women or gender non-conforming men, or people living with HIV," she adds. This is why she makes sure that the voices of people she works with remain central to the research process.

"I want to have the community lead the projects, do the interviews and participate in the write-ups and in the policy briefs. So that's something that has changed significantly for me."

Cloete and her colleagues are currently compiling a policy brief advocating equity of healthcare service delivery for people living with HIV who use drugs in South Africa.

True to her research philosophy, she is working with AIDS activists to ensure that the policy recommendations to reduce stigma in South Africa are led by the sector.

The policy brief write-up is the final stage of a study, which used a [standardised, international tool](#) to document experiences of HIV-related stigma in South Africa. Led by Cloete, the HSRC research team gathered information from a total of 3 716 people living with HIV from three provinces of South Africa with the greatest external and internal HIV-related stigma.

Stories of resilience

Cloete works closely with Gender Dynamix (GDX), a trans and gender-diverse rights advocacy group. In one study, the team is examining the experiences of trans and gender-diverse students at South African universities, based on online survey data and focus groups.

Although the question of whether transgender individuals should be allowed to use bathrooms that correspond with their expressed gender is often at the centre of debates around trans rights, Cloete says there are many other issues that do not receive enough focus. For example, she and the study team are interested in whether universities provide trans-inclusive healthcare services.

"If I'm trans and gender diverse, do I feel comfortable going to the healthcare facilities at university? Are they friendly to me? Do I feel safe on campus?"

In another HSRC and GDX collaboration Cloete is leading a regional study to generate knowledge

on how structural, systemic and interpersonal violence against trans and gender-diverse persons is maintained and reinforced through policy design and political, social and professional practices and discourses.

The team will recruit participants by working with transgender advocacy organisations within the seven Southern African countries. Trans and gender-diverse persons in Southern Africa face many legal challenges, Cloete says.

"South Africa is still the only African nation to allow same-sex marriage. This means that same-sex marriages in Botswana, Eswatini, Zambia, Zimbabwe, Malawi and Namibia are still not legally recognised. Here we are reminded of the inequalities faced by trans and gender-diverse persons in Africa."

The study will also look at stories of social acceptance or instances of resilience in these communities. "Stories of resilience and positivity work against stigma, discrimination and victimisation."

Cloete hopes that studies like these might eventually help to improve the lives of trans and gender-diverse people in these countries. "If we can use the data in some way to impact on policies that are still oppressive, then you know that has to do something and has to mean something."

Contact: Dr Allanise Cloete, a senior research specialist in the Identity and Belonging unit at the HSRC's Human and Social Capabilities division
acloete@hsrc.ac.za

Author: Andrea Teagle, a science writer in the HSRC's Impact Centre
ateagle@hsrc.ac.za