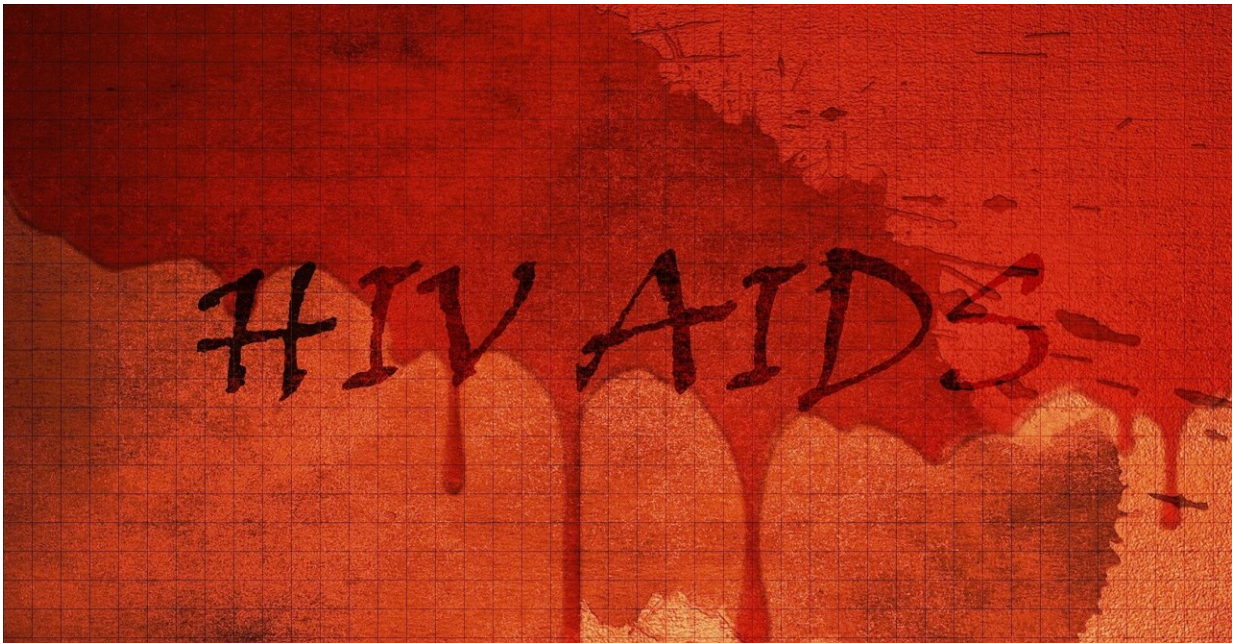


# Q & A: Unravelling the complexity of HIV/AIDS

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Dr. Josien de Klerk, Associate professor in Global Public Health at Leiden University College The Hague recently published some of her work on HIV/AIDS. In collaboration with a team of interdisciplinary researchers from the Amsterdam Institute for Global Health and Development she came to the conclusion that people who repeatedly participate in HIV testing campaigns in remote parts of Africa do so to monitor their health to achieve (temporary) reassurance, to alleviate

feelings of being at risk, and out of feelings of responsibility.

Reflecting on her research, she highlights the importance of interdisciplinary research, draws connections between the communication of health campaigns on HIV AIDS and COVID-19, and outlines her upcoming projects.

## **How did you arrive at this research topic and can you explain how this particular question has captured your interest and research focus?**

De Klerk: I have been working on HIV/AIDS in East-and briefly Southern Africa for more than 20 years but I have always approached it "sideways." I first worked directly on HIV/AIDS during my appointment for Doctors without Borders (MFS) in Kenya at the height of treatment activism, in 2000. We were all wearing t-shirts that said: "make HIV/AIDS medicines available to all." But our work was on HIV prevention, mostly for [young people](#). I consciously chose to not focus on the introduction of treatment for my Ph.D. study. Often attention goes to the technological intervention and we become blind for the other realities that are still out there. In this case we were at the brink of a major change but still many people were dying and [older people](#) were facing old age with severely affected informal care networks and bereavement. When treatment became available in 2004 I studied the transformation of HIV/AIDS into a different kind of chronic disease, one that came with constant need to self-care. For the past five years I have worked within a global health intervention as Social Science Coordinator for an interdisciplinary research project of the Amsterdam institute for Global Health and Development. The project studies the implementation of a community-based Test and Treat approach: basically it tries to find as many people living with HIV in remote places as possible and to have these people start treatment immediately,

regardless of their physical health.

My role in this project is an interesting one because I can follow how the intervention unfolds from the inside out and also keeps on changing. Both between the collaborating partners internationally and on the ground. Where the intervention started with literally driving a truck with a megaphone and white tents where people could test to very remote places, it changed to a more targeted approach focusing on places where likely more people living with HIV could be found. It also introduced index-testing, where the person testing positive was the starting point. We worked with health volunteers, often living with HIV themselves, who were tasked with tracking and testing contacts. That's tricky social navigation as you can imagine.

## **What is the significance of the research?**

De Klerk: The significance of ethnographic research for me lies in examining categories that are often taken for granted or unraveling the complexity of social realities in which these interventions are rolled out. In my Ph.D. research I showed how AIDS deaths were not a one off event from which old people recovered but that these events occurred multiple times. The social science component of the project I am involved in now shows how radical and rapid global policy shifts come to be meaningful and understood in local historical settings.

If the government's message has always been: "you start antiretroviral treatment when you are starting to become ill" and it then changes to: "you start lifelong treatment at the same moment you are tested positive," that is quite a shift that takes getting used to. You see the same thing with changing messages around COVID.

The article we just published shows that community-based testing campaigns are not just useful for finding people living with HIV, they

actually serve a preventative function for people who are negative but want to regularly check their health and might not have easy nearby access to a testing facility. The article we are working on currently examines the idea of "immediate linkage to care." The policy is that a person should start treatment within a week of a positive test. We showed, by interviewing people who were registered as "immediately linked," that many people had had a long trajectory. Some had tested positive two years earlier, seeking alternative treatment, needing time to come to terms with the diagnosis, needed to figure out what would happen to their relationship with a partner, or simply felt too healthy to start taking life-long treatment. So "immediate" linkage is indeed immediate for some but for many it isn't. This is significant because those people are still infectious and we argue that more social support is needed, counseling if you like. Yet most funding for social aspects of HIV has been cut dramatically in the past years. There is a tendency to fund the tech solution: pop pills in people.

## **What do you hope it will achieve?**

De Klerk: I really value the interdisciplinary collaboration in this project and I hope anthropology gains more of a place at the table of decision-making. That has been missing in the COVID response too. Maybe because we often make things uneasy and unruly. I also have this activist hidden away in me: health volunteers—expert clients—do so much care work that is intangible, difficult to measure. If you are paid by the number of people you link to care no-one sees the hard work of visiting continuously, gaining trust, spending your own funds: all that collapses in that one number. One of our alumni, Miriam Sijtsma wrote her capstone thesis on the work of these health volunteers in our project, she calls it relational care work. I hope that despite the move to defund and the appeal of technical solution there will be renewed attention for this labor of care and for the counseling and mental [health](#) needs of coming to terms with and living with a life long chronic condition.

## Where will your focus direct you next?

De Klerk: I am currently switching focus a bit. I am developing a collaboration with a South African NGO which focuses on supporting mothers of young infants. The NGO works with volunteer counselors, women, who visit these mothers regularly. They write the most amazing reflexive reports you have ever seen. If this collaboration works out, I will be working with the NGO and the home-visitors to together turn these reports into data and look at the work of care—both the intangible and tangible care work home visitors do in this intervention. The core of the intervention is "being with," sitting with mothers without doing. This is interesting because it is not measurable, so how do you trace this practice in written reports. How do home-visitors write about non-action? I find these fascinating methodological and theoretical questions. While there is continuity; I still study the politics of care in a community-based intervention. I do not focus directly on HIV/AIDS anymore in this project. I guess I am back to studying HIV/AIDS sideways.

Provided by Leiden University

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