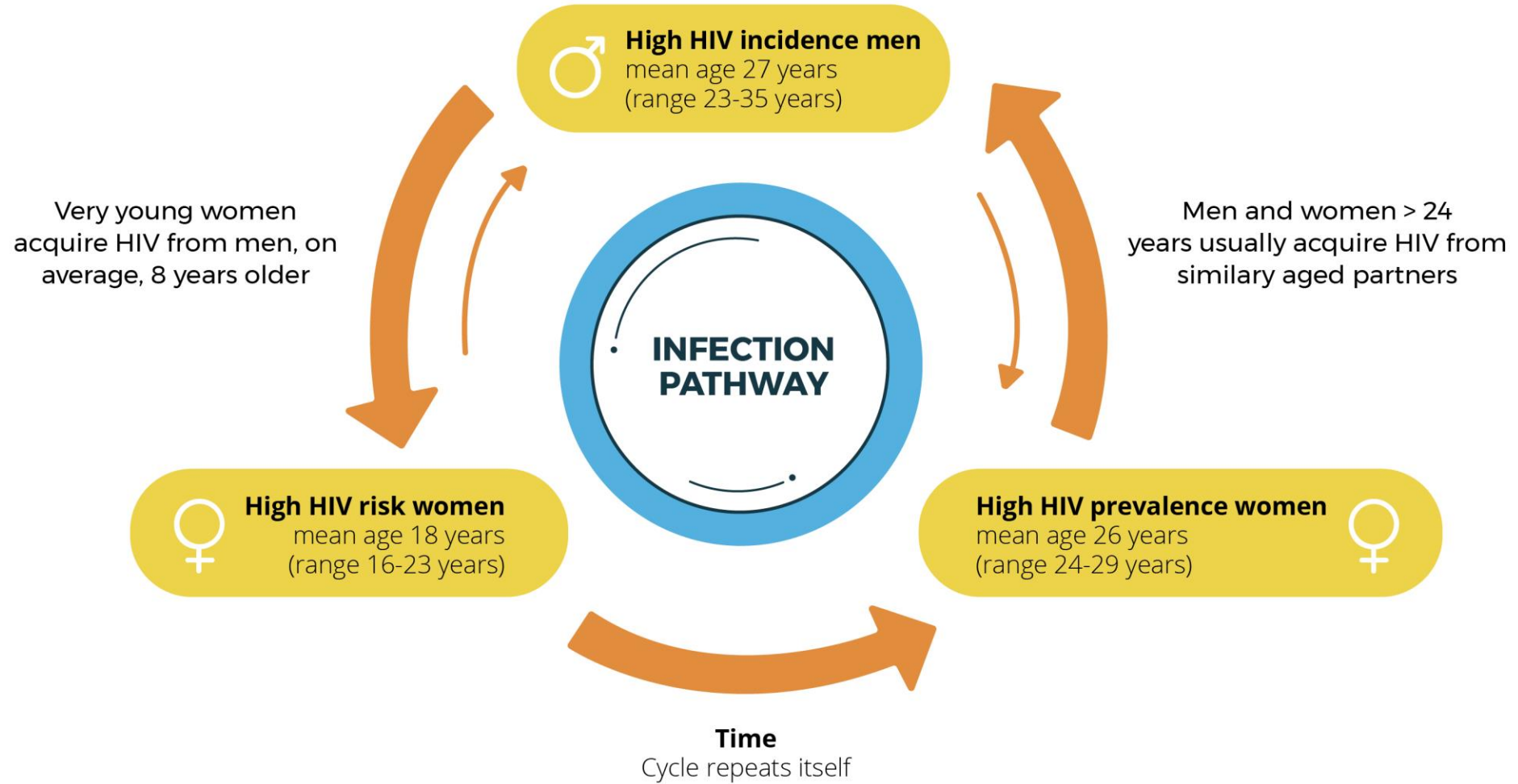


Breaking the Cycle of Transmission:

Increasing uptake of HIV testing, prevention and linkage to treatment among young men in South Africa.

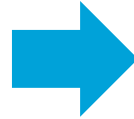


The challenge



Approach and objectives

User-centred research—talking directly to young men to gain a better understanding of individual, social and structural barriers and enablers



Human-centred design and piloting—developing and testing some new approaches based on what we have learned, and co-designing tools and resources with and for stakeholders



1. How can we **better understand young men's decisions and behaviours** with regard to HIV testing, prevention and treatment?
2. How can we **identify different segments** of young men to enable better tailoring/targeting?
3. How can we **reach each segment more effectively** with HIV prevention, testing and treatment?

Project cycle

 We are here



Ethnography: Participant led observational method

QUALITATIVE RESEARCH



Patient Pathways + Provider Archotyping: Framing journeys through care systems



Segmentation: Quantifying journeys and clustering different group pathways

QUANTITATIVE RESEARCH



Designing and piloting new interventions and monitoring to see whether we are moving the needle

PILOTING

Study Design

Geographic focus

- 5 districts of KwaZulu-Natal (eThekweni, King Cetshwayo, Ugu, uMgungundlovu, Zululand)
- 3 districts of Mpumalanga (Ehlanzeni, Gert Sibande, Nkangala)

Demographic focus

- Men 25-34, sexually active, uncircumcised, black African, matric or less, mix of HIV+ (linked and not linked) and HIV-



Study Design

Sample size

- Ethnography: Eight-hour filmed shadowing of 18 men, 4 healthcare providers
- Qualitative: Two-hour in-depth interviews with 58 men, 64 healthcare providers
- Quantitative: Ninety-minute survey with 2000 men (*to be conducted in Q4 of 2018*)



Moderators

- Recruited from the sample area
- Native speakers of local languages
- Reflecting the demographics of the target group
- Trained/experienced in ethnography and in-depth interviewing

Sample Design

Province	District	MEN					HEALTHCARE PROVIDERS				
		Urban	Rural	25-29	30-34	Total	Urban	Rural	Comm	Clinic	Total
KwaZulu-Natal	eThekweni	11	0	5	6	11	13	0	6	7	13
	Ugu	0	8	4	4	8	0	10	5	5	10
	Zululand	0	9	5	4	9	0	10	5	5	10
	Umgungundlovu	10	0	5	5	10	10	0	5	5	10
	Province total	21	17	19	19	38	23	20	21	22	43
Mpumalanga	Ehlanzeni	9	0	5	4	9	7	0	3	4	7
	Gert Sibande	0	6	3	3	6	0	7	4	3	7
	Nkangala	0	5	3	2	5	0	7	4	3	7
	Province total	9	11	11	9	20	7	14	11	10	21
	Grand total	30	28	30	28	58	30	34	32	32	64



Men	Frequent tester	Infrequent tester	Never tested	HIV+ linked	HIV+not linked
25-29	5	7	9	2	7
30-34	4	5	11	7	1

A photograph of a man with short, dark hair, wearing a brown jacket over a green shirt. He is sitting outdoors in front of a red brick wall. The background is slightly blurred, showing a dirt ground. A large yellow circle is overlaid on the left side of the image, containing text.

Findings from the ethnographic and qualitative research

We misread men as indifferent, but behind the mask they are often deeply afraid.

Fear of...

- The rawness of emotions
- Consequences of actions
- Guilt and shame
- Sickness and death
- Becoming their parents (living a painful experience of HIV/AIDS)
- Disclosure
- Disappointing their family
- Dependence on others
- Being judged in the community
- Being negatively stereotyped
- Letting relatives (living or dead) down
- Contributing to the scourge of HIV in South Africa

Loss of...

- Relationship harmony
- Control
- Identity as a man (within his family and community)
- Lifestyle
- Sex
- Dopamine hits (which come with risk-taking)
- Certainty and security

How might we reframe our messages and services in a way that alleviates fear rather than reinforcing it?

When I first heard of HIV it was the scariest disease that anyone can think of, it was even scarier than cancer.

- Man, 25, frequent tester

I was terrified. I was not ashamed or embarrassed, I was just terrified.

- Man, 28, infrequent tester

"I don't trust myself. I'm so scared. I think I will test positive. It will just kill me.

- Man, 30, never tested

[Testing] was tough, really tough. I actually felt like I was in a dark forest. I was numb with fear, I can't lie to you. Until the sister said that I am negative, that is when I was free.

- Man, 28, frequent tester

Many men live in an environment of stress, violence, trauma and uncertainty

Daily life full of stress and uncertainty

- Poverty and unemployment
- Financial instability
- Violence
- Thwarted ambitions

Absence of joy or hope

- Unresolved grief and trauma
- Signs of depression
- Feelings of fatalism and learned helplessness

Dissonance between aspirations and reality

- Aspires to be a provider and protector, but often without the means to play these roles
- Aspires to be virile, but virility is linked to fear of HIV
- Aspires to father children, but does not always raise or support them
- Aspires to be respected, but often feels shame about his station in life



We might not reach these men if HIV testing, prevention and treatment feel like yet another burden, rather than a relief.

I lost people who died from AIDS. I've only just realised now that my mother died from an illness and I believe it was not just TB, it was AIDS. My uncle also died with exactly the same illness as my mum. I think he also died of AIDS...I think the family were trying to hide it from us.

- Man, 28, never tested

My father died of HIV. It really devastated me. I was very close to him.

- Man, 27, HIV+, not linked

All of my immediate family are all dead. My mom, my dad, and my brother all died. I am the only one still living.

- Man, 32, infrequent tester

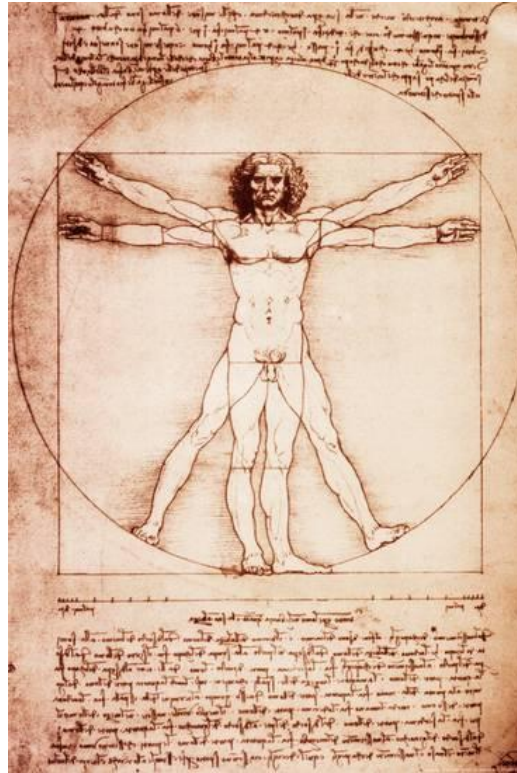
He is an orphan because both parents died. When I tried to talk to him, he said to me 'like father, like son'.

- Nurse

Masculine norms and expectations are deeply rooted and impede health-seeking

Men are expected to be:

- Strong (physically and mentally)
- Naturally healthy
- Self-sufficient
- Fearless
- Able to “power through” whatever illnesses or injuries they may experience



These expectations impede health seeking behaviour, particularly around HIV:

- Seeking help and depending on medication seen as weakness
- Carrying pills viewed as feminine
- Clinics seen as feminine spaces
- HIV diagnosis perceived as making a man less manly
- Few spaces for men to speak openly about their fears

Men don't take men who take medication or tablets every day seriously. There is a mindset that men are naturally strong.
- Man, 26, infrequent tester

You will lose respect if you continuously ask for help.
- Man, 25, never tested

I do not take medication at all right now, I fear medication. When I have a cold I struggle to finish my medication. I need reminders until I get used to it. I am battling by myself - if I give in to the pills will I be able to take them daily?
- Man, 27, HIV+ unlinked

Loss of a sense of control and personal autonomy feel threatening

We think we are 'reaching' men, but many experience it as being 'hunted'

Disclosure is difficult, but involuntary disclosure feels particularly threatening. Men fear their privacy and confidentiality will not be protected, and they will not be able to control who knows their status.

Men who did not actively choose to test may be less likely to start treatment. They feel ambushed by provider-initiated testing and appear more likely to go into denial rather than accepting their diagnosis.

They are so difficult, especially the ones that are referred...They come here and they tell you "I am not here for an HIV test." Sometimes we must beg them to get tested. Some are positive then they default because they say they were not at the clinic for that.

- Nurse

I don't like the fact that when I go in for a headache the nurse will ask me when I last tested for HIV and now I will be compelled to test even though that's not what I came in for. - Man, 30, infrequent tester

Many are engaged in high-risk behaviours that they misunderstand or rationalize

Many men gauge HIV risk not only according to appearance but also according to degree of familiarity. Condoms may be used on the first or second encounter but are rarely used thereafter.

A negative test result can reinforce high-risk behaviours. Anxiety quickly dissipates, the 'cliff edge' of HIV recedes, and a man may conclude that his behaviour was not so risky after all.

Those who have never tested often assume their status or use their partner as a proxy. Both options absolve them from needing to face a test.

Their attitudes towards sex are complicated. It is one of few available sources of escape and enjoyment, as well as connection and intimacy. It affirms their masculinity. Yet it is also triggers fears of contracting HIV.

If I have sex with someone then I think I won't get sick if she is beautiful. I can tell the difference between a sickly person and one who is not sick. I just look at the person's eyes and I tell my friend 'You are going to die there, don't go there.'


- - Man, 27, never tested

PrEP seems very appealing, though there are also barriers.

PrEP is intuitively appealing to these men. They are fearful of HIV but unlikely to use condoms consistently or to reduce their number of partners. They see PrEP as allowing them sexual freedom while keeping them away from the 'cliff edge' of HIV

But there are also potential barriers once they begin to consider the implications:

- Disclosure to partner (voluntary or involuntary) and implication of infidelity
- Being perceived as HIV-positive
- Costs in time and money
- Potential side effects
- Having to test for HIV before starting PrEP

A man with short, dark hair and a serious expression is sitting in front of a red brick wall. He is wearing a brown jacket over a green shirt. The background shows a rural setting with a thatched-roof building and a person in the distance. A semi-transparent grey bar is overlaid on the bottom half of the image, containing white text.

What prevents these high risk men from testing for HIV and linking to treatment if positive?

Testing brings many anticipated costs and offers few compelling benefits

Testing positive can feel like life is literally over. Despite knowing that treatment is available, many still associate HIV with sickness and death due to unresolved grief and trauma.

Fear of disclosure to their main partner can be paralyzing. They fear it will result in relationship conflict or loss.

Testing positive can feel like life as they know it is over. They fear it will mean giving up everything in life that gives them pleasure (sex, alcohol, junk food).

They also fear that disclosure to peers, family and community will result in disappointment, judgment, loss of status and a diminished image of virility.

I would be worried if they tell me that I am indeed positive, then it will be game over. I will no longer be [Thabo].*

- Man, 30, never tested

**name changed*

Testing also means the cost, inconvenience and unpleasantness of engaging with clinics

Clinics are not particularly welcoming for either gender.

Long queues generate anxiety and frustration in patients and leave providers feeling rushed.

Many healthcare providers think of men as 'the problem', and that attitude often reflects in their demeanor and communication.

The clinic can be an unfamiliar space

That many men feel incompetent in navigating.

Counselling is often scripted and didactic, and does not surface or address individual issues and challenges.

Healthcare providers often show empathy only up to the point that a patient is compliant.
'Problem patients' are often treated poorly.

Many healthcare providers also feel disempowered, frustrated and demoralized.

My male patients are ignorant. We can't teach our male patients anything... I've noticed that men don't take anything you tell them, they will implement very little or none of what you advise them to. I'm not sure why it's like that.

- Nurse

Testing seems to offer few compelling benefits.

Some men are unaware that early treatment can mean a longer and healthier life. Some know but find it too vague and distant to be compelling.

Treatment as prevention, and the principle that undetectable equals untransmittable, are virtually unknown among these men.

I went home and I was overthinking it, but then I thought I'm okay, I'm healthy and everything is normal, so I just kept it all to myself.

- Man, 27, HIV+, not linked

Facing a cost/benefit analysis that does not seem to compute in their favor,
many men rationalize not testing or starting treatment.

Assume their status based on their risk perception.

Use their partner's status as a proxy for their own.

Wait until they are symptomatic to test or start treatment.

Lindo goes to the clinics for check-ups. She's the one who tells me whether we are OK or not.

- Man, 28, never tested

Among those who test positive, there is a journey to either acceptance or denial.

Men who proactively sought an HIV test, have a strong social support network, have set tangible life goals, and focus on developing coping strategies appear to be more accepting of their diagnosis and likely to start treatment.

Men who are reached via provider-initiated testing, lack a trusted confidante, see little hope of achieving their goals, and focus on blaming the person who infected them appear to be more likely to go into denial and avoid starting treatment.

A man with short, dark hair and a serious expression is sitting in front of a red brick wall. He is wearing a brown jacket over a green shirt. The background shows a rural setting with a thatched-roof building and a person in the distance. A semi-transparent dark grey bar is overlaid at the bottom of the image, containing white text.

Where do we go to from here?

What is needed? Some overarching recommendations

- Services that are more convenient, responsive and empowering for all patients. Many of the identified barriers, particularly those related to quality and access, are cross-cutting and affect both men and women.
- Training and support for healthcare providers that empowers them to provide quality care that reflects an empathetic, patient-centred, problem-solving mindset.
- Services and messages that take men's specific barriers and motivators into account, help them to process fear and loss, and make HIV testing and linkage more acceptable within their identity as men.

Next steps

- Quantitative survey and segmentation
- Design and piloting
- Demand-driven technical assistance

Recap of insights - A journey characterized by fear and loss

1. Whilst men may display indifference to HIV, they are actually paralysed by fear
2. They live in an extremely challenging environment of stress, violence, trauma and uncertainty
3. Many struggle with dissonance between their aspirations and their reality, and the gap is often rooted in masculine expectations
4. Masculine norms impede health-seeking. These men perceive healthcare and the health system as intrinsically feminine
5. They want to be in control of their own decisions around testing, treatment, and disclosure. Instead, they often feel hunted, ambushed and coerced
6. They are engaged in high-risk behaviours that they rationalize or misunderstand, and hold onto inaccurate but assuring indicators of risk
7. They see the appeal of PrEP but have not always thought through the barriers and drawbacks
8. Testing positive can feel like life is over. Men associate HIV either with sickness and death or with loss of identity, status and pleasure
9. The benefits of early testing and linkage to treatment are virtually unknown, or too vague and distant to be compelling
10. Fear of disclosure can be paralyzing. Men fear it will result in relationship conflict or loss, as well as loss of status in their community
11. The clinic environment is not welcoming or familiar. Healthcare providers show limited empathy, and counselling is scripted and didactic
12. Men who proactively sought an HIV test, have a support network, and have set life goals find it easier to accept their status and start treatment

Acknowledgements

We gratefully acknowledge the guidance and support that we have received from more stakeholders than we have space to mention. Particular thanks to:

- National Department of Health
- Provincial Department of Health in KZN and MPU
- Premier's Office/Provincial AIDS Council in KZN and MPU
- District teams in Ehlanzeni, eThekweni, Gert Sibande, King Cetshwayo, Nkangala, Ugu, uMgungundlovu and Zululand
- South African National AIDS Council (SANAC)
- Foundation for Professional Development (men's research co-sponsor)
- including Anova, BroadReach, CCI, CHAI, FHI 360, Health Systems Trust, MatCH, NACOSA, Right to Care, SFH and Sonke.
- Research organisations including AHRI, FHI 360, CAPRISA, Epicentre, Genesis Analytics, HSRC, MRC, and Pop Council.
- Funding institutions including the Bill & Melinda Gates Foundation, CDC, Global Fund, UNITAID and USAID.