

## “Hold on” (*Bambelela*)! Lyrical interpretations of participation in a HIV prevention clinical trial

### Abstract

During a five-day workshop, former clinical trial participants and local musicians wrote lyrics and recorded a song about an HIV prevention trial. Born of concerns about misconceptions regarding experimental drug trials, the aim was to engender engagement with medical researchers and open dialogue about the risks and benefits of trial participation. Composing lyrics that highlighted their credibility as communicators of medical scientific knowledge and their selfless sacrifice to stem the spread of HIV, women performed their social positioning and cultural authority in contrast to men as well as other women not part of the trial. While involvement in HIV prevention initiatives often attract stigma, scorn, and criticism, the song lyrics highlighted women’s newfound identities as heroes in searching for a solution to the spread of HIV, challenging these stereotypes. Methodologically, the paper describes a novel approach that uses artistic expression for public engagement with biomedical research.

Keywords: Lyrics, HIV prevention; clinical trials; public engagement; South Africa

## Introduction

1. *Iwari*<sup>1</sup>, igciniso, that we are dying
2. But since ngazi istatus sam
3. Ingiye ngacina isibindi, kwaphela, ukwesaba
4. Kwavuka ithemba
5. ngacoba le doubt ngangena ihighway
6. Kwabamnandi ngazazi ncono<sup>2</sup>

1. It is the truth that we are dying
2. But since I know my status
3. I became strong, my heart was not scared
4. I woke up and believed
5. I stopped doubting and entered the highway
6. It was nice to know myself well

These lyrics, written by Nombuyiso<sup>3</sup>, a young unemployed South African woman from Soweto, South Africa, offer a striking portrayal of her experience of volunteering as a research participant in a HIV prevention clinical trial. Nombuyiso's verse narrates a personal journey that starts with her feelings of hopelessness amid the catastrophic

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<sup>1</sup> '*Iwari*' is derivative of the Afrikaans word 'waar' meaning 'true' and common to *tsotsi taal* (gangster language) commonly spoken in South African townships and a feature of kwaito.

<sup>2</sup> Unless otherwise indicated, all lyrics were written in IsiZulu.

<sup>3</sup> All personal names are pseudonyms

AIDS epidemic (line 1), her courage to test for HIV (line 2 and 3), and culminates in a newfound social identity and awareness (line 4 to 6).

Nombuyiso wrote these lyrics having spent one year of her life in the trial, using an investigational drug, undergoing monthly clinical exams, HIV testing, safer sex and adherence counselling. By following the trial procedures, Nombuyiso contributed to the final trial results. Yet, as her lyrics convey, Nombuyiso's participation in the trial had profound social and personal consequences. While trial protocols are 'designed to minimize social contingencies and allow the objective, a-contextual measurement of reality' (Montgomery and Pool 2011, 1), Nombuyiso's words offer unique and privileged insights into the 'affective experience' (Lutz and White 1986) and 'moral experience' (Zigon and Throop 2014) of participating in the trial.

This is expressed by the lyrics that portray the contribution that the individual body makes to constituting the wellbeing of others. Medical trial managers may conceptualise trial participation solely in terms of benefits to individuals who make autonomous decisions to join trials. However, this perspective obscures the moral experience of trial participation, and the creation of new forms of sociality and relationships. For example, Wentzell (2017), suggests that Mexican men who participated in a human papilloma virus prevention trial conceptualised their involvement in terms of their contribution to the social body. Drawing on the idea of 'ethical intercorporeality', she argues that trial participants regard their emotional and biological selves as interconnected with others. In a similar fashion, the MDP301 trial participants' lyrics highlight their personal contribution toward improving the lives of others, through personal sacrifice, suffering, and forbearance.

This paper explores the narratives that women trial participants, like Nombuyiso, produced during a song lyric writing workshop about a HIV prevention clinical trial. Timed to coincide with the end of the clinical trial and the dissemination of its results to participants and publics, the song was recorded and broadcast on community radio and at events. Acknowledging the growing relevance of public engagement for medical research and critiques thereof (Fairhead, Leach, and Small 2006a), the lyrics were expected to generate discussion, raise awareness, and enhance understanding about medical research. As researchers, embedded within the trial, we had an opportunity to explore the significance of women's lyrical interpretations of their experience of participating in the trial. Our roles in the trial ranged from research management to undertaking ethnographic research within the clinic setting, the local communities, as well as the boardrooms where clinical decision making occurred.

Clinical trial research outcomes are seldom unequivocal, often ambiguous and potentially contentious (Epstein 1997). Communicating these complexities to publics and research participants presents challenges, particularly in contexts of limited scientific literacy. Trials that are closed prematurely, or report on null or negative effects may be sensationalised in the media, and accusations of exploitation and purposeful harm often abound (Geissler and Pool 2006; Saethre and Stadler 2013; Geissler 2005). The HIV AIDS epidemic provides particularly fertile ground, producing accounts that portray medicine as maleficent and virus spread as intentional (Niehaus and Jonsson 2005; Stadler 2003; Kaler 2009; Kroeger 2003).

Questions regarding the meaning of medical research for local actors have become highly relevant (Fairhead, Leach, and Small 2006a), as critiques of biomedical

research increasingly draw attention to the political and economic inequities inherent in research settings (Fairhead, Leach, and Small 2006b; Petryna 2007; Benatar 2002), and the variable ethical standards in different contexts (Petryna 2005; Harper 2007).

Addressing these concerns, researchers strive to improve informed consent procedures and particularly individual comprehension of the risks and benefits of research participation, by drawing on local knowledge to enhance its relevance (Boga et al. 2011).

Bridging the divide between ‘community’ and scientific interests is not simply a question of educating trial ‘naïve’ communities. Focussing solely on ‘gaps’ between local and scientific knowledge renders participants and publics passive subjects, lacking in agency. Instead, since the 1990s, growing emphasis has been placed on dialogical models of science communication that promote the importance of local knowledge and participation (Trench 2008). This reflects a shift from an emphasis on public ‘deficits’ in ‘scientific literacy’ towards more ‘open’ and egalitarian interactions and messaging (Schäfer 2009, 476). In communication studies, this is accompanied by a call for the ‘medialization’ of science: increasing its coverage; encouraging the participation of non-scientists in communicating science; and heightening the ‘controversiality’ of scientific issues in the media (Schäfer 2009, 477–78).

Drawing on these ideas about popular engagement with science and communicating scientific knowledge, the project we describe here offers the possibility for artistic expression as a means of producing dialogue between publics and trial participants and medical research scientists.

The decision to use song was inspired by the substantial response from popular musicians (See: Barz and Cohen 2011) and artists (See: Roberts 2001) to the AIDS epidemic. These engender multi layered meanings through metaphor and symbol,

articulating multi-vocal and divergent experiences (Treichler 1999) and ‘can allow for powerful, evocative and transformative modes of engagement with traumatic experience’ (Thomas 2014, 5).

Appropriating local images, popular song reveals the depth and complexities of understandings of the epidemic. The popular ‘Bongo Flava’ musical genre of Tanzania conveys the multifaceted entanglements between mobility, lust and the unchecked nature of epidemic spread, as well as promoting prevention and compassion for the ill (Bastien 2009). Luo pop music offers commentary on changes in social relations in western Kenya associated with the AIDS epidemic (Prince 2006). Musical expression has therapeutic applications that help people cope with, and counter, the alienation that AIDS illness produces, by redefining suffering and promoting healing (Whittaker 2016).

Several scholars note that popular music creates spaces in which the secrecy and rules of respect surrounding sexuality and AIDS can be breached. Describing how AIDS disclosure was possible for members of a Zulu choir, Black argues that within performance, ‘people are able to practice new emotions in a space that is safe because it is reflexive and set apart from everyday life. Performance thus makes it possible to communicate messages that are outside the boundaries of behaviour that is culturally appropriate in everyday talk’ (2015, 261). In Malawi, where AIDS is a ‘public secret’, song facilitates open public discourse and discussion about sexuality (Lwanda 2003); similarly in Kenya, taboo subjects are dealt with openly through popular song (Prince 2006). The performances of young female peer educators and the guitar songs of *Zwilombe* reveal that which is censored in normal everyday conversation in the Venda region of South Africa (McNeill 2011). During the *Muchongolo* dances performed in the South African lowveld region, men’s songs conjure visions of a virtual glorious

past, but also decry the devastation and misery caused by the AIDS epidemic, labelling women who cheat on their husbands as the bringers of disease (Niehaus and Stadler 2004).

Musical performance and song can serve as weapons of the weak, offering opportunities for open criticism. The songs performed by 'rural' women in KwaZulu-Natal, challenge male domination within marriage as the source of their vulnerability to AIDS (Phiri and Nadar 2009). Notably, women often take up public health messages and themes in their performances (Prince 2006). McNeill notes that young female peer educators' performances who sing songs of AIDS prevention, reveal their 'fluency in biomedicine as a means of asserting new individualised and entrepreneurial strategies of self-advancement' (2011, 156).

## **Background**

The lyric writing workshop was undertaken with participants, formerly of the Microbicide Development Program (MDP301). Microbicides are anti-HIV pharmaceutical agents that can be suspended in vaginal gel or film, or cervical rings. Initially envisioned as technologies that could empower women against HIV infection (Stein 1990), several microbicides have been tested in multi-country clinical trials.

The AIDS epidemic in southern Africa has assumed a peculiarly gendered shape, with marked differences in infection rates between same age males and females. As a result, gender inequities are identified as responsible for shaping the spread of HIV. Consequently, public health interventions seek to resolve what was regarded as the problem of (mainly black) women's lack of power within intimate relationships. Vulnerability to HIV infection attributed to the powerlessness of women, included the inability to negotiate for safer sex and insist on condom use (Pettifor et al. 2004) and the high prevalence of sexual violence (Jewkes and Abrahams 2002). Although condoms

are extremely reliable, these are impractical in many circumstances in which women find themselves. Realising the limitations of condoms, calls for methods of HIV prevention that are female controlled started to surface and captured the collective imagination of scientists, epidemiologists and AIDS activists.

Microbicides as technologies that circumvent men's roles in sexual choices, would disrupt cultural constructs of power relations, and subvert traditional gender norms. Implicitly, foreign technologies, designed to empower, would give women a needed weapon against male privilege and power. First championed by reproductive health researchers and driven by ideologies of social medicine and female empowerment, microbicides became the ideal female-controlled prevention method. Microbicides literally "put the power in women's hands" (Global Campaign for Microbicides 2007) and were lauded as "the gel of hope".

The MDP301 was a phase III randomised double-blind placebo-controlled trial conducted between 2005 and 2009 that aimed to assess the safety and efficacy of PRO-2000 (at concentrations of 2% and 0.5%) a microbicide in a vaginal gel. Undertaken in six sites in four African countries, the MDP301 enrolled 9,385 women. Recruitment took place in community clinics, at shopping centres and street corners. Potential volunteers were offered the opportunity to join the study and invited to the study clinics for screening.

To be eligible women had to be HIV negative, non-pregnant and not breastfeeding, and 18 years or older (apart from in Tanzania where the minimum age was 16). Once enrolled in the trial, participants were provided with gel, and tested for pregnancy and HIV, and STIs and offered treatment for STIs at quarterly clinic visits. Participation was voluntary, but transport and inconvenience costs were covered (in South Africa) by a ZAR150 (USD15) stipend. Women enrolled in the trial were



required to insert the gel into the vagina using an applicator up to one hour before sex (Nunn et al. 2009). In February 2008, the trial Data Safety and Monitoring Board (DSMB) recommended that the 2% PRO-2000 arm be discontinued due to futility, in other words, the initial results suggested that the gel was not efficacious and further trial time would not change that outcome. By December 2009, the results of the trial reported that although the gel was safe to use, it was also ineffective in preventing the acquisition of HIV (McCormack et al. 2010).

The MDP301 incorporated a significant social science component across the country sites which included serial interviews (up to three times) with trial participants, focus group discussions and participant observation. These researches were designed to explore sexual behaviours and adherence to the trial product (For a detailed discussion see Pool et al., 2010).

Community engagement activities were established at each site of the MDP301 trial, and community representatives met regularly with research staff to discuss trial progress and issues that posed barriers to the continuation of the trial. A prominent issue in most sites concerned rumours about blood draws. In Zambia, the MDP301 was labelled a Satanic organisation (Montgomery and Pool 2016), while elsewhere the trial was accused of profiting from blood sales and implicated in rumours of witchcraft (Stadler and Saethre 2010; Vallely et al. 2007). In Tanzania, community representatives were invited to the clinic to learn about the laboratory procedures of preparing blood to assuage the rumours (Vallely et al. 2009). Similar activities took place in Johannesburg; in addition a weekly health talk show featured the MDP301 trial, to encourage women to participate in the study (Medeossi, Stadler, and Delany-Moretlwe 2014).

The lyric writing workshop was exclusive to the Johannesburg site of the MDP301, representing the study clinics at Orange Farm and Soweto, located to the

south west of the city. Like engagement strategies elsewhere, the workshop sought to use participatory approaches to encourage open dialogue and conversation. Given that the trial had halted one arm of the trial, and anticipated finishing that year, the workshop focussed on local understandings of uncertainty as the scientific rationale for biomedical research. In contexts where biomedicine is framed as primarily therapeutic, misunderstandings abound regarding the distinctions between treatment and experiment (Sankar 2004). We therefore sought to explore this contradiction from trial participant's perspectives. Yet, participants' lyrics tended to dwell on their subjective experiences of the trial itself as transformative, reconfiguring their relationships with men and medical researchers. In this respect, the lyrics offered a social commentary on gender relations, and credited the trial with creating the space within which transformations could occur.

Our analysis of the lyrics suggests three interlinking themes: first, women's authoritative knowledge about the trial; second, the personal sacrifices that women made in participating in the trial; third and perhaps most significant, women's transformation and founding of new identities.

### **Research methods**

The workshop combined former trial participants who were all female, with all-male amateur musicians. The latter were selected for the workshop by submitting entries to a poetry writing competition in Orange Farm and Soweto, while former MDP301 trial participants were invited to attend the workshop via advertisements on community radio stations and leaflets distributed at the study clinics. Eight former trial participants participated in the workshop, while thirteen musicians provided musical content. The participants were predominantly young, unemployed women and men (Table 1). The gendered structure of the workshop reflects the dominance of young men in the

production of popular musical styles such as kwaito. Several trial staff attended the workshop, including researchers and community liaison officers.

<Insert Table 1 here>

Tasked with evaluating the workshop and the song, our research draws from two sources: participant observation during the workshop and the lyrics produced by participants; transcripts of focus group discussions that took place in July 2010. JS and HM co-facilitated and participated in the lyric writing workshop and JS and ES ran the focus group discussions.

Focus groups took place eight months after the workshop at an internet café in Orange Farm. The groups comprised participants from the song-writing workshop as well as additional former trial participants who had heard the song but had not attended the workshop. Six focus group discussions were held, three in Soweto and three in Orange Farm. Four of these were for former trial participants and two were with musicians who had participated in the workshop. The number of participants in each focus group discussion ranged from five to eight participants and 25 women trial participants and 13 musicians took part (Table 2). The focus groups were audio recorded, transcribed and translated into English. All research participants were requested to sign informed consent forms and the Wits University Human Research Committee (HREC) granted ethical clearance for the study.

<Insert Table 2 here>

Field notes, lyrics, and focus group discussions transcripts were loaded into an ethnographic software (Nvivo 10) database. Our analysis sought to link the key themes in the draft versions of the lyrics that were produced during the workshop and the final recorded version of the song, with focus group participant commentary.

### **‘There is a song in my story’: the lyric-writing workshop**

Seeking to include township participants’ perspectives as well as create a song that would have wide reaching appeal to Sowetans and Orange Farmers, we chose the popular music style called *kwaito*. Taking its name from the township *lingua franca* known as *tsotsi taal* or (gangster language), *kwaito* is derived from the Afrikaans *kwaai* used colloquially to denote something that is cool or hip (Coplan 2005). Born out of urban experiences of economic marginalization and ethnic blending, *kwaito* gives township residents a voice. The genre is emblematic of young black South Africans ‘insistence on enjoying their freedom and majority status with as much in-your-face sexuality as they can get’ (Coplan 2005, 20).

*Kwaito* is distinctly masculine and associated with the performance of violent masculinities (Steingo 2011), glorifies sexual violence and in some cases is literally the soundtrack of rape (Wood 2005). However, in the context of the workshop, *kwaito* was framed as a progressive style that would have broad appeal to young South Africans, who were also in the majority targeted by HIV prevention efforts. Eugene Mthethwa (a *kwaito* artist from Soweto since the early 1990s and of the band *Trompies*) was appointed as the musical director. Mthethwa a vocal advocate of using *kwaito* for AIDS education and awareness, notes that ‘*Kwaito* has been a dominant force in popular culture since 1995. If we use it constructively it could really empower’ (Mdladla 2001, 26).

Originating from Soweto, *kwaito* resembles house and hip-hop music but uses African sounds and samples. With percussive and melodic loops and deep bass lines, *kwaito* has a slower tempo range than other forms of house music. *Kwaito* lyrics are sung, shouted, and rapped. The lyrics are formed from everyday township life experiences (Coplan 2005) and the ‘meaning of songs does not solely reside in their

lyrical content' (Peterson 2003, 204); instead the songs communicate feelings and emotions through the musical style and arrangement.

With the theme of 'There is a song in my story', the weeklong workshop was intended to encourage participants to contribute oral and written accounts of their experiences of participation in the trial while the musicians listened and produced multiple drafts of the song. The workshop was held at a community hall in Orange Farm and following recording and production, was broadcast on the community radio stations in Orange Farm and Soweto, with whom the MDP301 trial had worked previously. The song was also played at meetings in December 2009 held to announce the final results of the MDP301 trial to former trial participants.

On the first day of the workshop, there was a noticeable division between the women trial participants and the male musicians. While the latter appropriated the space on the stage in the hall, performing their musical skills and rapping to recordings from their cell phones, the female workshop participants constituted the audience, largely passively and indifferently observing the musicians. Recognising this dynamic, the workshop coordinators encouraged the musicians and trial participants to form groups that combined both. As the trial participants spoke about their experiences, the musicians started to listen. By the end of the workshop, female participants were performing on stage and taking an active role in composing the melodic content. Two former trial participants sang in the studio recording of the song, adding female vocals to the track.

### **Knowledge, Hope, and Transformation**

Initially, the lyrics focussed almost exclusively on the trial procedures, echoing the exclusion and inclusion criteria of the trial and the rationale for the study itself. Having

participated in the trial for up to one year, women participants were familiar with the clinical procedures, and the scientific rationale of medical research. The first iterations of the song lyrics reflect this by repeating the main messages that were put forward by the trial through community outreach and informed consent education.

1. *Kodwa abanganalo iciwawane lekagawulayo*
2. *Uzocwaningisiswa kahle ukuthi ingasithiba na*
3. *Isifo socantsi. eish!*
4. *Kodwa abacelisayo*
5. *Hai kabe one side,*
6. *Hai kabe one side*

1. But those who are not infected
2. It is being researched to see if it can be prevented
3. Diseases of sex, eish!
4. Those who are breastfeeding
5. Without judgement, you are excluded
6. Without judgement, you are excluded

Echoing the trial exclusion and inclusion criteria, these lyrics point out the requirement to test HIV negative (line 1), and the exclusion of women who were breastfeeding (line 4). Importantly, the lyrics do not draw attention directly to HIV (line 1) but rather make an implicit reference to the disease. In everyday speech, the acronyms ‘HIV’ and ‘AIDS’ are often avoided, or may be replaced with phrases such as “House In Vereeniging” (a suburb toward the west of Johannesburg), “Z3” (a BMW

motor car). These omissions acknowledge the power of speech and the danger of HIV (Stadler 2003).

**The lyrics also communicate the importance of the scientific process of the trial.**

While the criteria result in the exclusion of some women (line 5 and 6: they stand to ‘one side’), the rules are applied ‘without judgement’ (line 5 and 6). In other words, exclusion is based on scientific rationale of the trial, to test an investigational drug; as stated in line 2: ‘it is being researched’. The prominence of lyrics about the trial procedures stems from an understanding of the song as primarily educational and a resource for promoting awareness. This interpretation was also shared by clinic staff who remarked that the song could have been useful during trial volunteer recruitment, and to encourage trial participants to be compliant with the clinical procedures.

Yet, the lyrics also served to position women as the source of technical biomedical knowledge about the trial. Not only was entry into the trial exclusive to HIV negative women, but their knowledge of the biomedical procedures of clinical trial research earned the respect of the male musicians in the workshop. This countered local narratives often found in rumour that portray women who join trials as reckless risk takers, jeopardising their health and their futures (Stadler and Saethre 2010). Challenging these stereotypes, the lyrics distinguish between enrolled women and other non-participants, as in the first line, ‘those who are not HIV infected’. Alluding to this, a focus group participant chooses the words ‘elite few’ to describe trial participants, noting that others are too afraid to test.

... it is not many people who are exposed to it [research] in the township. They feel that it is for the elite few, so this kind of a song can involve them too so that they can have interest that anyone can join. And then maybe it can also encourage them to know about their

HIV status because those who don't come to join the studies they are afraid to do that blood test. I mean the ticket for entering the study you have to test the blood. Maybe it will encourage them.

Combining the themes of bravery, hope and perseverance, the chorus urges listeners to be optimistic about an eventual solution to the AIDS crisis in South Africa.

1. Bambelela
2. Qinisela
3. Ungalahlithemba
4. Noma ku nzima

1. Hold on
2. Tight
3. Don't give up hope
4. Even when it is tough

For many, this was a call to hold onto the promise of pharmaceuticals. A former trial participant noted during a focus group discussion: 'To me this chorus *bambelela* is like they are saying there is still hope that there are medications that are being tested that might still prevent HIV'. This perspective was echoed by other trial participants: 'The lyrics of the song are saying "hold on" they will find that thing. "Hold on" means that we don't have to lose hope; we have to keep hoping that prevention will be found'. However, microbicides did not only promise to prevent HIV; through microbicides, women were able to assume control over their own bodies. A former participant related her sense of corporeal agency, fostered by using the gel:



I feel that maybe the song says that women should hold on to the hope that women also will have something that belongs to them. Without depending on men like if I am told that it is raining you should bring a rain coat [use a condom during sex]. If this gel works then I will just shoot [insert] my gel and keep quiet. It is my responsibility, it is my life, it is my body and I don't have to depend on someone for what it is mine.

These sentiments regarding the gel arise from its effects on women's bodies, sexual experience and relationships. Despite awareness that the gel was untested, women in the trial argued that it was effective in other ways. Experiencing discharge following gel insertion many noted that this indicated the expulsion of polluted substances from the womb, enhancing health and rendering them fertile (Saethre and Stadler 2010). The lubricating property of the gel eased penetration, and the act of insertion of the applicator into the vagina prior to sex, enhanced sexual interest (Montgomery et al. 2010; Gafos et al. 2010) stimulating men's interest in having sex (Mweemba 2014). Furthermore, having spoken to their partners about using the gel, women felt that this opened up possibilities for improved communication and intimacy (Stadler and Saethre 2011; Lees 2015). Importantly, this points toward women achieving autonomy in sexual decision-making and in reshaping vulnerabilities to HIV infection.

The third theme is of transformations in individual lives through the shared experiences of fear, and of sacrifice. The following lyrics that were presented in the workshop by one group, convey the importance of selfless sacrifice (Line 1) to be part of the trial, gaining courage (Line 2) and finally achieving 'control' (Line 4 and 5).

1. There's always hope nomangi sacrificer [when I sacrifice]
2. Full of FEAR but i-situation yangay i-courge [the situation gave me courage]
3. From bad to good azang' ngi luzi themba [I never lost hope]
4. Because I was in control
5. Azange ngi luzi [I never lost] hope because I was in control

Narratives recounting the journey from fear to control through sacrifice and faith continued to be voiced in a subsequent segment of the workshop, when women were asked to tell their individual stories through lyrics. Like many other participants, Nombuyiso recalled having to overcome her fear of HIV testing: 'I was asking myself many questions like 'what will happen if I find out that I'm positive? I wanted to go and join [the trial] but I was afraid. Then I waited for about two months having doubts'. Her discovery that she was HIV negative was a 'wake-up call ... because it gave me an opportunity to check myself and take responsibility for my own health'. Moreover, Nombuyiso notes that her 'sexual life improved so much and our relationship became so good'.

Another participant in the trial, Phetheni, also wrote about the transformative effects of trial participation. Referring to a Venda proverb observing that women possess the courage and strength necessary to accomplish difficult tasks such as holding hot objects and walking on thorns, Phetheni wrote (in Tshivenda):

1. Mufumakhadzi u a fara ludongo nga hufhisaho
2. Shangoni ho dala ruleme
3. Ndila ndi mupfa i a thavha

4. Ahuna tshithu tsho no fhatiwa nntha ha mazwifhi

1. The woman holds the hot clay pot
2. The world is full of hardships
3. The path is thorny and it punctures
4. Nothing can be built on lies

She compares this strength to her personal perseverance in completing the trial as a participant, and ultimately in ending the spread of HIV. This reflects the gendered nature of the HIV epidemic in South Africa where far greater numbers of women test for HIV and enter care than do men. Phetheni's lyrics continue this theme (in Tshivenda):

1. Ndo dzhena itshi mulingo fhedzi ha ndo fhedza
2. Ndo bvelela uri ndi do kona uri hu na bvelelaphanda
3. Ndo ima lurangala nga uri ndi do i vhona
4. Ro bebelwa u vha vhakundi

1. I enrolled in the examinations<sup>4</sup>but I have finished [them]
5. I chose to leave so that I could be able to make progress.
6. I stood up because I wanted to see it
7. We were born to be conquerors

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<sup>4</sup> Phetheni uses the word “*mulingo*” translated literally as “examination”, to represent “trial”.

Women are transformed from hopeless, ignorant, and fearful persons into courageous, hopeful, and brave subjects. Their fortitude allowed them to endure the trial – or pass the examinations as Phetheni put it – and have a greater capacity to bear the burden of suffering. Stressing women’s inherent strength, Phetheni portrayed participants as conquerors who had escaped the bonds of victimhood.

While the focus of transformation was largely on the female participants, the significance of this was not lost for the young male musicians. As we pointed out earlier, the composition of the workshop of male musicians and female trial participants initially reflected conventional gender dynamics. Yet, through the process of listening to women’s narratives of their experiences, the musicians composed a verse honouring the women’s bravery and altruism:

1. Thank our sisters for living sacrifice that you did
2. You give us hope in the moment of despair
3. Sacrificed and risked to be in that study
4. For all the homies [home boys]
5. Courage to be in control

And, reflecting on this during a focus group discussion, several of the musicians commented on the courage the women had in volunteering for the trial and ‘risking their lives’, by using an investigational drug and potentially risking HIV infection.

## **Discussion**

Public health discourses of ‘community’ engagement establish conceptual divisions between the interests of communities and scientists. This is articulated as a gap in

knowledge, for instance regarding informed consent and laboratory procedures. Moreover, while ““communities” demand certainty, ... science only offers probabilities and correlations...’ (Pollock 2009, 120). As noted earlier, expectations of medical research often mistake the experimental for the therapeutic, creating difficulties in communicating ideas about the randomisation of trial participants to placebos, and the outcomes of trials when these are unsuccessful. Finally, the ‘personal and emotional agendas’ of trial publics and participants that are regarded as being incommensurate with those of impersonal science (Pollock 2009, 120).

In the literature on clinical trials, bridging the divide between community and scientific understanding is resolved by transforming naïve publics into knowledgeable ones. Yet as our analysis of the lyrics suggest, for women in the MDP, trial participation attained highly personalised and nuanced meanings, beyond the narrow confines of the scientific subject in a clinical trial. In their lyrics and performances, women were not only knowledgeable of the science of clinical trials, but also possessed experiential knowledge from being actively involved in the trial. Furthermore, the trial was transformed from the enactment of procedures managed by research protocols to a means by which women gained the respect of men.

Of interest is that women’s subjective experiences of the trial, led to a reframing of identity. Women’s lyrical interpretations of their involvement in the trial reflect their newfound social position as ‘agential scientific citizens through their active contribution to the research’ (Montgomery and Pool 2016, 7). This was dramatized in the workshop context where they earned the respect of the male musicians through accounts of selfless sacrifice and risk taking in the trial.

Through their lyrics women powerfully asserted that it was their bravery to risk their bodies in acts of selfless sacrifice that could win the war against AIDS. They were

willing to undergo medical testing, face up to their fears of HIV testing, maintain their health, and use an untested microbicide. Through this process, they gained not only scientific knowledge about HIV and medical research, but also knowledge through experience. This resulted in recasting of their identities from victims of the AIDS epidemic to knowledgeable actors. Their lyrical representations and performances asserted their cultural competence as trustworthy interlocutors, emerging as brokers of knowledge between the trial and the public.

In contradistinction to bioethical requirements of risk and benefit, women's narratives embraced the dangers they perceived of using an experimental product and participating in a HIV prevention trial. Moreover, while benefitting from the resources the trial had to offer – cash reimbursements, superior health care, and HIV testing – women's lyrics suggested that the emotional benefits were of substantive importance. As observed in interviews and focus groups in the MDP site in Zambia, women felt 'enlightened' and 'liberated' (Montgomery and Pool 2016, 8).

## **Conclusion**

Arising from resistance to clinical trials in various settings (Mills et al. 2005), and local misunderstandings of the scientific rationale of medical research (Marsh et al. 2008), public engagement in medical research is now regarded as an essential component for recruitment, enrolment and retention of clinical trial participants. The production of Good Participatory Practice (GPP) and other 'best practices' and guidelines offer templates for engaging with 'community stakeholders' in trials (UNAIDS/AVAC 2007). Calls for a 'science of community engagement' suggests a far more rigorous and standardised approach to laying the foundation to avoid potential pitfalls in medical research in different settings: in other words, understanding the cultural, social and political context through qualitative and ethnographic research (Newman 2006).

Following the role of the medical humanities internationally, and its recent debut in South Africa (Reid 2014) the lyric writing workshop described here suggests that public engagement in biomedical research could be as much a ‘science’ as an ‘art’.

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