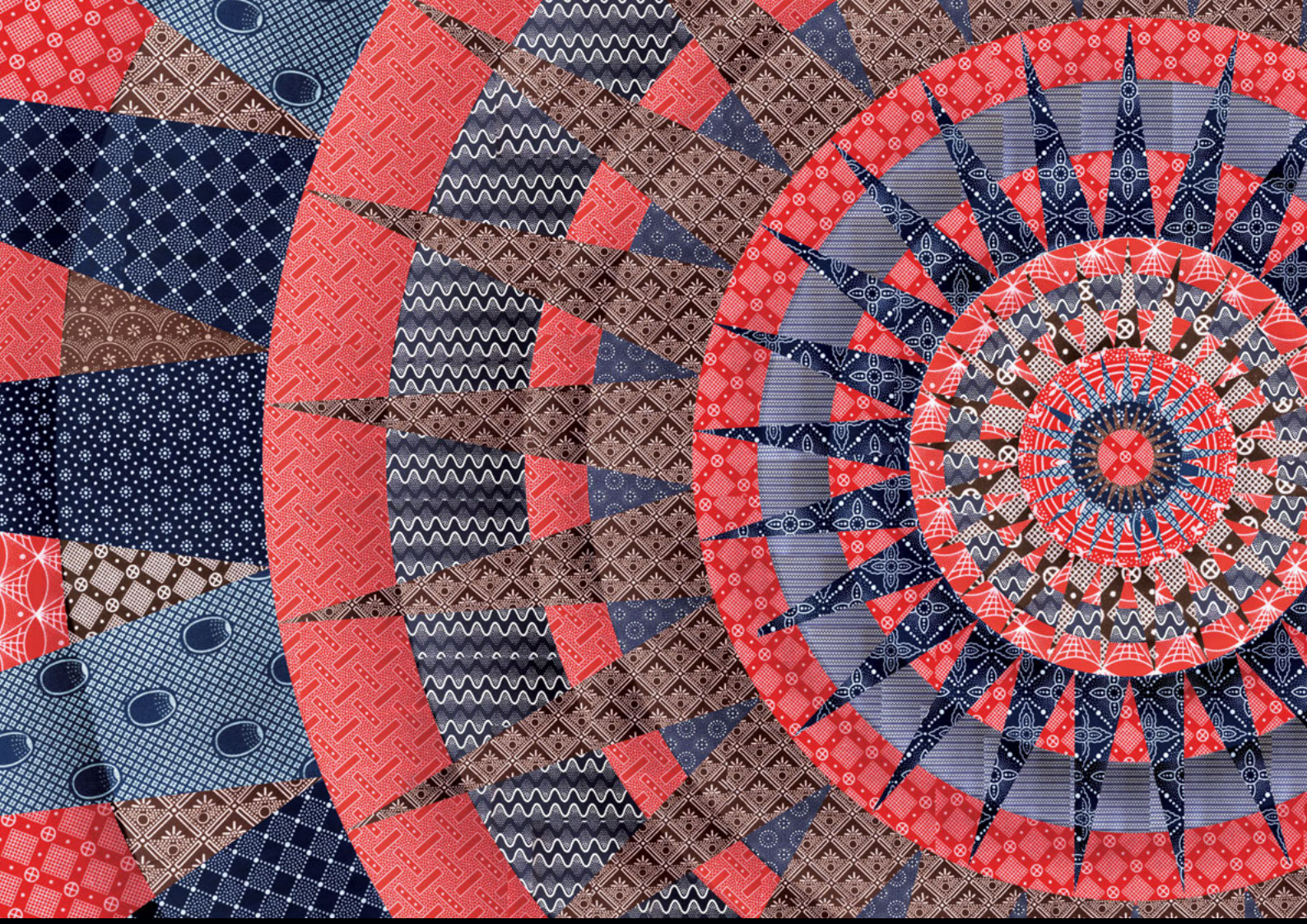
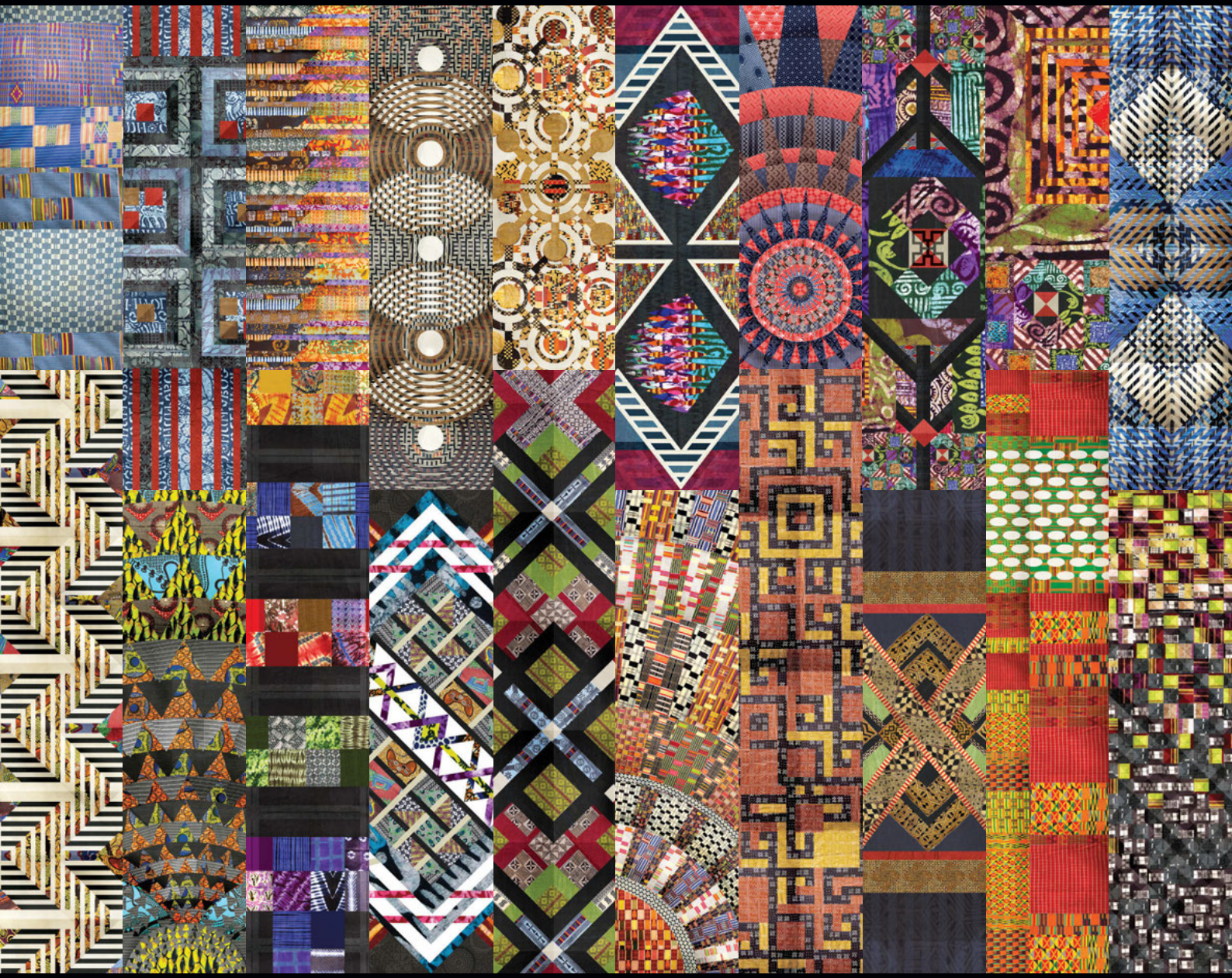


Off Label

AIDS Review 2012

Jonathan Stadler and Eirik Saethre | Series Editor: Mary Crewe



Off Label

AIDS Review 2012

About the authors:

Jonathan Stadler is a technical head at the Wits Reproductive Health and HIV Institute. His research focuses on the ethnography of HIV/AIDS, clinical HIV prevention trials (specifically microbicides), and community engagement with medical research in rural and urban South Africa.

Eirik Saethre is an assistant professor of anthropology at the University of Hawaii at Mānoa. His research examines responses to disease, medical intervention and pharmaceuticals in urban South Africa and remote Aboriginal Australia.

Jonathan Stadler can be contacted at jstadler@wrhi.ac.za
Eirik Saethre can be contacted at saethre@hawaii.edu

The views expressed in this *Review* are solely those of the authors and the Centre for the Study of AIDS.

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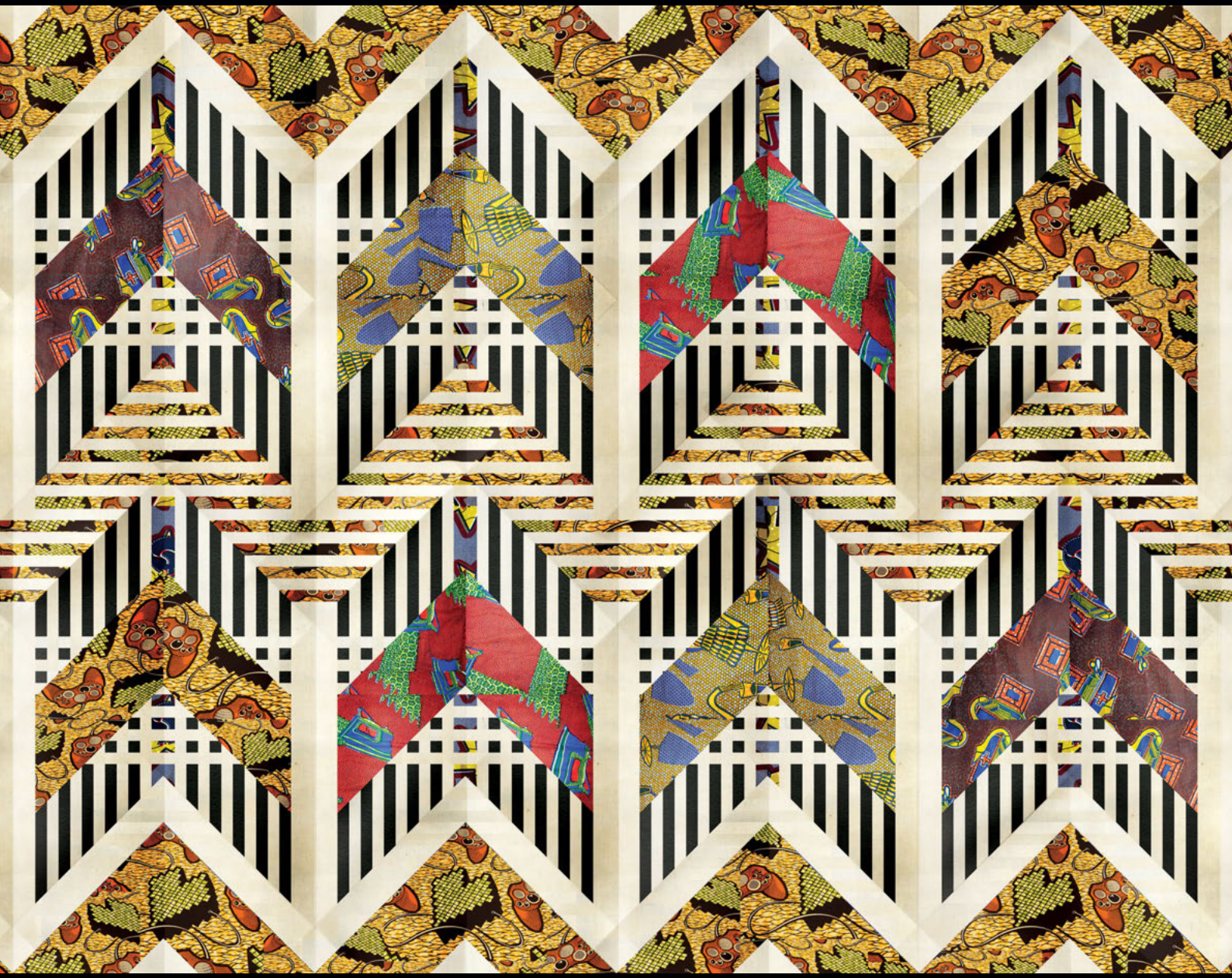


Foreword

In this *Review – Off label* – the experience of participants in a microcode trial is analysed, operating from the idea that "as condoms and gels are employed (or not employed) in people's everyday lives, these technologies acquire their own unique signification. In some cases, these meanings could be quite different to those intended by health care professionals" (p20). These meanings and explanations are 'off label' in that while the health care professionals believe that the ways in which a trial will unfold and be experienced is based on how well the professionals understand the trial and the participants, it is the participants who take the intervention, interpret it, transform it, accept or reject it. Participants use trials to re-define themselves as knowledgeable participants, and to assert their individuality and choice.

"Clinical research attempts to address a relatively straightforward and extremely important challenge: how do we determine whether a new medical intervention represents an advance over current methods, whether new interventions would avoid harms currently incurred, whether it would save lives currently lost? And critically – we need to think about when it is acceptable to expose some people to risks of harm for the potential benefit of others".[1]

The harms that may be incurred by a medical intervention are not merely physical harms and hurts or harm to health. Harm may also come from the ways in which participants in clinical trials are recruited and treated, how their expectations are created or dashed, and how they understand trials and placebos. How are these hopes and expectations mediated by their partners and families and what are the stories they tell about what the medications will do, the effects they will have and their role in medical advances? There are many stories that people tell and weave – some true and some more imaginative – but in one way or another they are all a reflection of the reality of being part of a clinical trial.

As *Off label* highlights, in microbicide trials important questions arise about who represents and speaks for women and the community. What is understood by community involvement in selecting trial participants, and to what extent should community structures be involved?[2] Once the participants are selected, how valid is the process of informed consent and how is this mediated throughout the trial? How people understand the trial at the start may of course be very different from how they understand and experience it during the trial itself. Health professionals and researchers may have one view, the participants another, and so providing information, ensuring consent and feeding back experiences are very important. Health care professionals may find that their assumptions

and attitudes are challenged by the ways in which the participants translate their experiences into meanings and they need to be able to understand this issue.

Similarly, there are critical issues regarding confidentiality and ensuring confidentiality about who is or is not participating. Participants need to be HIV negative and so the process of screening out certain women is crucial in terms of privacy and protection. These concerns are also critical when addressing the partners of women wishing to join or joining the trials. How are men included in the process while at the same time ensuring and protecting women's agency, autonomy and safety? It is important for men to be involved as equals and not as definers or in a coercive way and to ensure that they do not undermine the study. Their involvement is essential to understand how acceptable microbicides will be to men after the study. Their involvement is also important in understanding the benefits and care in and beyond the trial and the ways in which incentives operate.

In 2010, the CSA produced a calendar, *Fabrications*. In that we wrote: "the notion of fabrications was inspired by the many stories of the AIDS quilts …. [and] a fabrication is in this sense both a physical construction of fabrics, but also a psychological and social construction, the story of a life". *Off label* is the story of the lives of people in one microbicide trial – their fabrications – and the illustrations are inspired by African fabrics.[3]

Many of the stories that people tell about HIV and AIDS and their experiences are a fabrication – a blend of truth, memory, fantasy and drama. As this *Review* shows, it is the fantasy and the fiction that are just as fascinating as the 'truth'. In the same way, we wrote in 2010, that people mythologized the dead, we as societies and as trial participants, deal with HIV and AIDS by creating our own myths and fabrications – craft our own interpretations of events – to make sense of AIDS and the many different roles that we play in the epidemic.

Off label discusses the experiences of a group of women, their partners and their community in making sense of a recent microbicide trial. Clinical trials seldom have social scientists working as part of the team. There is rarely a sense of a contemporary ethnography that works with – and alongside – the medical findings. Often the results of the trials are reported as medical – rather than as socio-medical – and a vast possible wealth of information and understanding is then lost. The social is critical to how we understand the value of a clinical trial intervention (or indeed of a randomised control trial) but the social is seldom given space for the necessary reflection of how people understand, create and make sense of a new technology. This understanding is essential for the success or failure of the intervention when it is deemed suitable for general roll out. What the 'off-label' responses in the trial tell us is what the off-label responses in the wider public domain might be.

As *Off label* shows with this ethnography, the trial is put into the wider domain of how post-colonial identities are forged and created – how colonial images of Africa have affected the ethos behind many trials and how sexuality, feminities and masculinities, gender and power all have a powerful interplay with the actual technological intervention.

Off label gives the other side to the microbicide trial – the personal, political, social and emotional experiences of the participants, as much as the medical findings. It tells the story of how women are changed, defined and shaped in new and fascinating ways by participating one of the microbicide clinical trials and taking it off label.

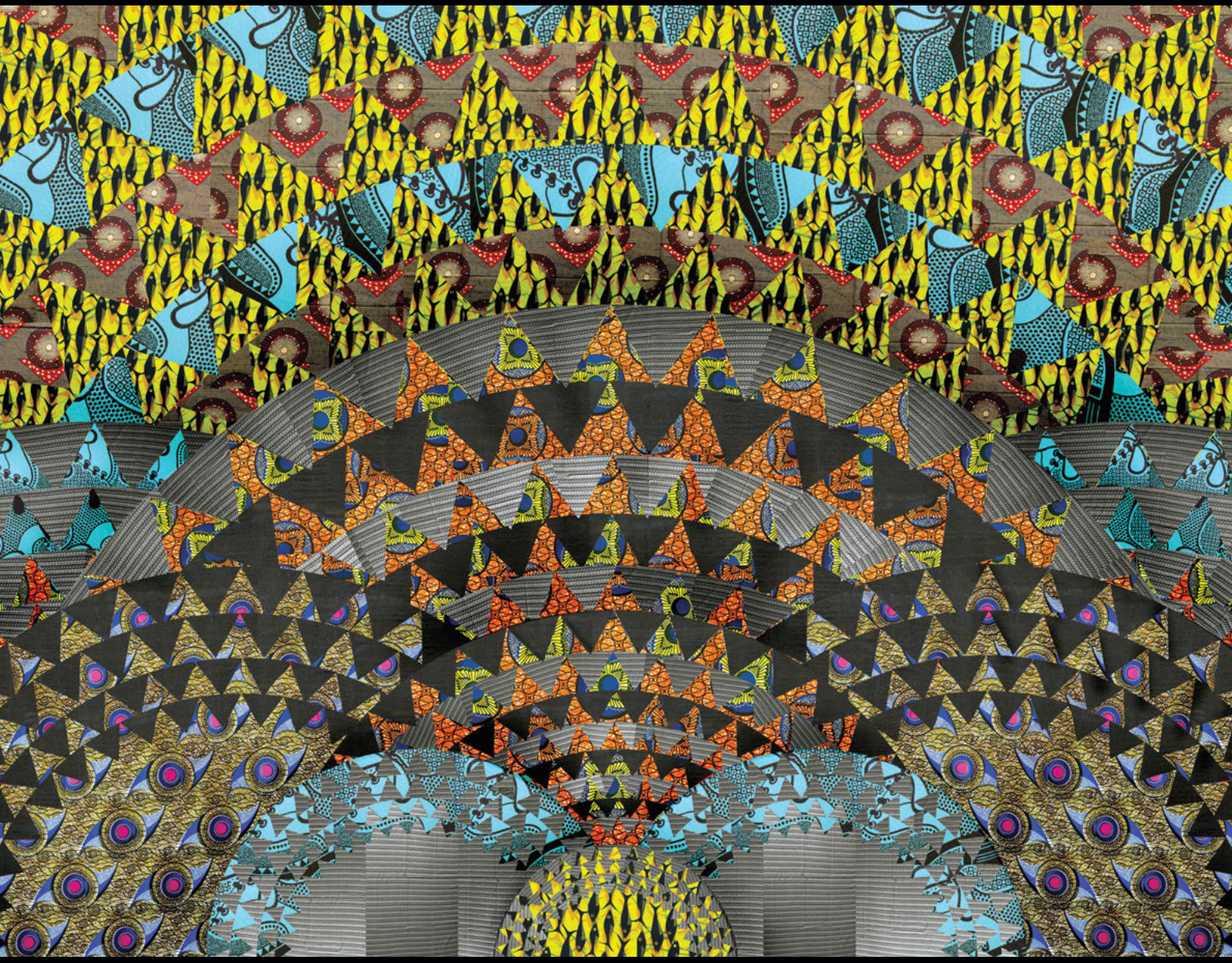
Mary Crewe
Director, Centre for the Study of AIDS

Notes

1 The Ethics of Clinical Research (revised 20 September 2012) accessed at http://plaot.stanford.edu/entries/clinical-research/
2 See Global Campaign for Microbicides accessed at www.global-campaign.org
3 Centre for the Study of AIDS 2010 Calendar *Fabrications.*

AIDS REVIEWS

2000 – *To the edge* by Hein Marais
2001 – *Who cares?* by Tim Trengove Jones
2002 – *Whose right?* by Chantal Kissoon, Mary Caesar and Tashia Jithoo
2003 – *(Over) extended* by Vanessa Barolsky
2004 – *(Un) Real* by Kgamadi Kometsi
2005 – *What's cooking?* by Jimmy Pieterse and Barry van Wyk
2005 – *Buckling* by Hein Marais (an extraordinary *Review)*
2006 – *Bodies count* by Jonathan D. Jansen
2007 – *Stigma(ta): Re-exploring HIV-related stigma* by Patrick M. Eba
2008 – *Balancing acts* by Carmel Rickard
2009 – *Magic* by Fraser G. McNeil and Isak Niehaus
2011 – *(B)order(s)* by Vasu Reddy
2012 – *Third degree* by Cal Volks, Pierre Brouard, Mary Crewe, Relebohile Moletsane and Sylvia Tamale (an extraordinary *Review)*
2012 – *Off label* by Jonathan Stadler and Eirik Saethre



CHAPTER 1
FOREIGN TECHNOLOGIES/ LOCAL BODIES

AIDS Review, Off label is about HIV prevention in the context of randomised clinical trials that test innovative biotechnologies. As the HIV/AIDS pandemic continues, medical science searches for new drugs and means to treat and prevent HIV infection. While initially developed in laboratories, it is through the clinical trial that the efficacy of pharmaceuticals is determined. Clinical trials flourished after the Second World War as a way of strengthening the science of drug testing by attempting to eliminate social responses to treatment (Lowy 2000, 50). Clinical trials have become the 'gold standard' in demonstrating efficacy. Today, many trials are conducted in the developing world, although they are funded by pharmaceutical companies and research organisations from industrialised nations. There is a growing concern over the power of pharmaceutical companies to dictate the ethical parameters of these trials, as well as the inadequacy of many of the current protocols governing informed consent (Craddock 2004; Leger 2008; Petryna 2006). Clinical trials in sub-Saharan Africa, in particular, have been critiqued in light of vast differences in understandings, resources, and rights (Craddock 2007). However, to date, little attention has been paid to the experiences and perceptions of clinical trial participants or the social contexts in which they are situated (Saethre & Stadler 2010).

In the *Review* we draw extensively on our experience as anthropologists and as members of a team of social scientists embedded in a clinical trial. Jonathan Stadler is based at the Wits Reproductive Health and HIV Institute (WRHI) and has worked on several HIV biomedical prevention trials. Eirik Saethre is a frequent visitor to the Institute and worked with the research team on the Microbicide Development Program 301 trial (MDP 301). Our intimate involvement within clinical trial settings means that, in addition to formal data collection activities, we are able to observe and participate in the day-to-day running of clinical trials. During the MDP 301 trial we observed interactions in the clinic waiting areas, attended clinic and community meetings, and chatted to staff, participants and community residents. Our status as insiders is fairly unique and not often afforded to social scientists, who usually view

clinical trials from the outside. We have a privileged view of the inner workings or the 'backstage' (Goffman 1959). This has enabled a holistic view of the trial from multiple perspectives. It is this perspective that has led us to appreciate the agency of trial participants who actively engage with biotechnologies and drugs, reshaping these in terms of local beliefs and experience.

Biomedical trials are strictly controlled in accordance with protocols and procedures that are applied in a uniform manner, overseen by regulatory authorities and audited by national and international monitoring authorities. The messages disseminated to participants during the trials are regulated by ethics review boards and committees. These structures also ensure that clinical trials are run according to 'Good Clinical Practice' guidelines[1] that describe the procedures for managing research subjects' participation, information flow and safety. The interactions with the communities in which trials are conducted are similarly guided by Good Participatory Practice guidelines, recently formulated by the World Health Organisation (UNAIDS/AVAC 2011).

The success of a clinical trial depends largely on its ability to recruit and retain participants, and to control their behaviour.

The success of a clinical trial depends largely on its ability to recruit and retain participants (Gappoo *et al*. 2009), and to control their behaviour. For example, in microbicide trials, women's use of vaginal cleansing products, anal sex, and pregnancy can 'dilute' the ability of the trial to test a microbicide (Mâsse *et al.* 2009). Incorrect or inconsistent use of the trial product similarly undermines demonstration of efficacy (Mâsse *et al.* 2009). Anticipating sub-optimal adherence and incorrect use of trial products, a great deal of emphasis is placed on educating trial participants. Prior to enrolling in a trial, volunteers are screened and tested on their comprehension of informed consent documentation. These lengthy forms describe in detail each component of the trial process and at subsequent clinic visits, trial participants are counselled on adherence to the product. Because trials deal with untested technologies that are uncertain, this create spaces in which new meanings are created and biomedical assumptions are challenged. Outside of the clinic setting, trial subjects rediscover and reinvent the study products. It is this creative engagement with medicine that lies at the heart of our investigation.

In the *Review* we draw on data collected from the MDP 301, a randomised, double-blind, controlled trial that was designed to assess the efficacy and safety of PRO-2000, a microbicide suspended in a vaginal gel to prevent HIV infection in women.[2] Although this was a microbicide trial, participants were encouraged to use condoms; the efficacy of the gel had not been established, and roughly half the women would be assigned to a placebo gel. This

design afforded the opportunity to compare responses to condoms, a familiar technology for HIV prevention, with the microbicide gel, an unfamiliar method with unknown effect.

Drawing on a vast database of interviews, observations and focus groups, we describe how women enrolled in the trial, their male partners, and the broader community responded to the trial and the microbicide gel, and how this reflects broader social discourses about gender, sexuality, illness, culture, social reproduction, medicine, morality and cash. We argue that condoms and microbicides are not simply medical technologies; they have been imbued with meaning in the North and in South Africa. Describing and analysing popular narratives of condoms and microbicides, we assert that condoms and microbicides are nexuses through which social, economic, political, and gendered struggles are given voice. These struggles are not confined to South Africa but are played out in newspaper headlines and HIV campaigns around the world.

Condoms and microbicides are not simply medical technologies; they have been imbued with meaning in the North and in South Africa.

In this chapter we set the scene for the remainder of the *Review*, with a brief overview of the social history of condoms and microbicides. In particular, we link the search for novel technologies to global discourses about the vulnerability of women to HIV infection and their empowerment through technology. We then describe the MDP 301 trial and end with an outline of the *Review*.

THE CONDOM

In 1987, almost one hundred years after the invention of the rubber condom, the US Surgeon General recommended the use of condoms to prevent HIV, particularly for people who were unaware of each other's sexual histories (Youssef 1993). These recommendations were based on solid evidence: condoms are highly efficacious as a barrier at the level of a virus and consistent use of condoms results in an 80% reduction in HIV incidence (Wilkinson 2002).

In line with the goals set by the Global Programme, in 1995, South Africa's first National AIDS Plan called for condom use as the best available method to fight the epidemic (Bermudes Ribiero Da Cruz 2004, 136). As the epidemic grew, the number of condoms distributed to sub-Saharan Africa increased from 18 million in 1990, to 236 million in 1998 (Iliffe 2006, 70); currently, approximately 450 million condoms are distributed every year. Recent HIV sero-prevalence and behaviour surveys observe increases in reported condom use, particularly amongst younger South Africans, a population that has also

experienced modest reductions in HIV infection (Shisana *et al.* 2009).

Although the condom is heralded as the flagship of HIV prevention, there is widespread recognition that condoms have limited effectiveness at the population level in terms of the spread of HIV. Despite its efficacy – or ability to act as a barrier to viruses – the condom's effectiveness also depends on being used correctly. Even widespread condom use is not effective in stemming the spread of HIV. This is mainly because condoms are often applied inconsistently and usually selectively (Hearst & Chen 2004). For example, condoms may be used in relationships that are regarded as risky and temporary, but not in long-term relationships (see MacPhail & Campbell 2001).

Men shrug off the call to use condoms to prevent HIV infection and women are often unable to convince them otherwise.

Underlying this problem is the difficulty that women experience in convincing their male partners to use condoms and, therefore, to avoid HIV infection. Men shrug off the call to use condoms to prevent HIV infection and women are often unable to convince them otherwise. This is especially poignant given that women, particularly younger women, are most vulnerable to HIV and other types of sexually transmitted infections (STIs) (Chersich & Rees 2008).

Researchers focus on the inequalities in gender relations and argue that patriarchal dominance in South African society explains unevenness in condom use. Enforcing condom use is dependent on power dynamics within relationships that undermine women's choices and agency (Thege 2009) and that place women at risk of HIV infection. This dovetails neatly with research findings that report coercion in sexual relationships in South Africa in relation to HIV susceptibility (Dunkle *et al.* 2004; Jewkes *et al.* 2003; Wood *et al.* 1998).

Yet, it is important to recognise women's agency in sexual negotiations and the possibility of resistance to male dominance. For example, sex workers in Hillbrow charge higher rates for condomless sex with their clients (Wojcicki & Malala 2001). Condom use may also be mediated by concerns other than acquiescence to male dominance or resistance. Decisions about condom use often depend on perceived categories of sexual partner. Sex workers choose not to use condoms with romantic partners and regular clients (Varga 1997; Wojcicki & Malala 2001).

The association between condoms and risky relationships that was reinforced in messaging early in the AIDS epidemic means that condoms are regarded as inimical in relationships based on the idea of trust (see Sobo 1995),[3] and where reproduction is desired. Therefore, condoms are often regarded as irrelevant in longer-term relationships,

and within marriage in particular (e.g. Chimbiri 2007). In contexts where marriage has all but disappeared, such as rural KwaZulu-Natal, condoms are used selectively. Mark Hunter (2010) describes Fikile, a young unmarried woman who has left her rural homestead to work in an urban area. Her two male lovers supplement her meagre wage as a domestic worker. With one partner, a secret lover, she uses condoms. Her principal boyfriend provides her with regular support and they do not use condoms, since her boyfriend from her natal home is regarded as her indoda *yami ngempela ngempela* (my man, for real, for real).

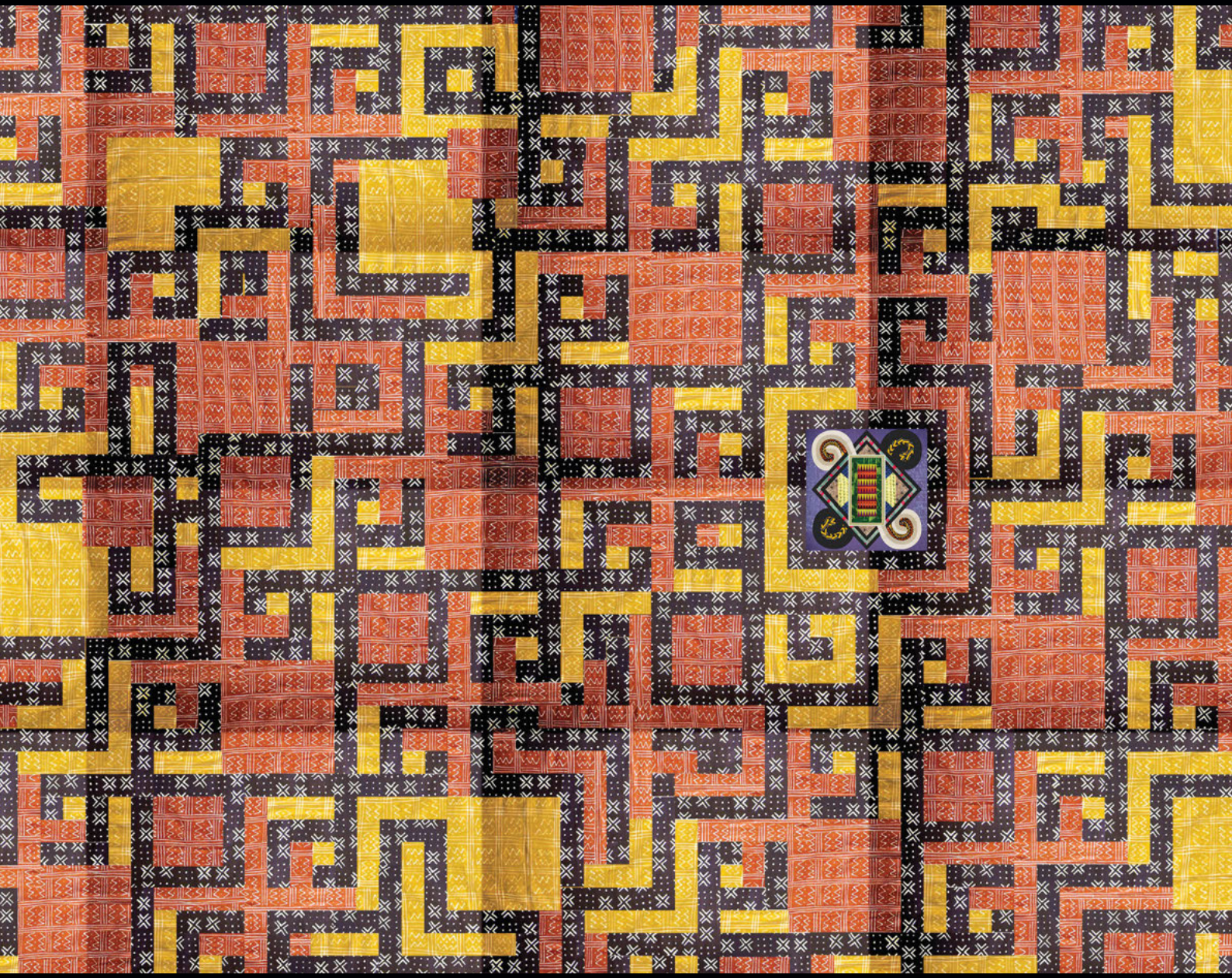
Although condoms are designed as barriers and receptacles to contain semen, the condom is seldom interpreted instrumentally. Instead condoms can be interpreted as 'signs'. Or, as Middelthon (2001) suggests, the condom is a 'sign-vehicle' that conveys multiple, often contradictory meanings. These meanings shape use and non-use in complex ways; personal risk of HIV infection and transmission is only one possible meaning.

MICROBICIDES AND EMPOWERMENT

Microbicides are positioned to realign gendered inequalities and women's vulnerability to HIV infection. These are 'medical technologies intended to empower women' (Bell 2000). They support female autonomy in sexual decision-making and, therefore, in HIV prevention. Unlike condoms, which need male co-operation in order to be used, microbicides 'put the power to prevent in women's hands' (Global Campaign for Microbicides 2009). This is because they can be used clandestinely, or without the explicit acquiescence of a male partner. In the early 1990s, Zena Stein, the grand doyen of microbicides, wrote '[…] the empowerment of women is crucial for the prevention of HIV transmission to women. It follows that prophylaxis must include procedures that rely on the woman and are under her control. A wider range of chemical and physical barriers that block transmission through the vaginal route must be developed and tested' (Stein 1990, 460).

Microbicides are positioned to realign gendered inequalities and women's vulnerability to HIV infection.

These sentiments echo recommendations made by the International Conference on Population and Development[4] held in Cairo in 1994. Global leaders expressed their commitment to championing the development of technologies to bolster women's right to protection from HIV. In the post-Cairo conference era, advocates and researchers formed alliances to search for technologies to empower women against HIV infection (Bell 2000). This framing of microbicides as 'empowering' technologies 'in the war against HIV' has been a highly influential and compelling



driver behind research, development and advocacy (Bell 2000, 2003; Kutikuppala *et al.* 2004; Mantell *et al.* 2006; Mantell *et al.* 2005). Clinical trial researchers explicitly state their aim to be 'female empowerment' and refer to microbicides as 'female-controlled mechanisms'. McCormack, who heads up the Microbicide Development Program, writes: 'Women in Africa are disproportionately affected by HIV-1 and many are unable or unwilling to negotiate condom use, want to conceive, or both. Vaginal microbicides are a potential method for prevention of HIV-1 transmission that is controlled by the woman' (McCormack *et al.* 2010, 2).

The microbicide field has been beset with failed products and uncertain outcomes. However, the industry is propelled by massive investments in the 'political economy of hope'

The microbicide field has been beset with failed products and uncertain outcomes. However, the industry is propelled by massive investments in the 'political economy of hope' (Good 2001). This continued investment is sustained through the hope generated, 'not necessarily from material products with therapeutic efficacy but through the production of ideas, with potential although not yet proven therapeutic efficacy' (Good 2001, 397).

Clinical trials follow a prescribed path, from testing an agent *in vitro* in the laboratory, to animal studies (usually involving Macaque monkeys), and only then human safety trials. Once safety is established, the new drug is tested on larger populations of trial participants in Phase Two and Phase Three trials. These trials assess efficacy and safety, the two components critical for drug registration.

The first microbicide tested in a Phase Three trial was Nonoxynol-9, a spermicide that demonstrated *in vitro* effectiveness against HIV. However, during human trials HIV infections increased among women who used the product more than three times per day, possibly because it caused irritation to the vaginal mucosa, creating entry points for HIV (van Damme, Chandeying, *et al.* 2000). These results were hugely damaging for the field of microbicide research (Ramjee *et al.* 2007).

Similar outcomes were reported in 2007, when a trial testing a microbicide called Cellulose Sulphate was halted due to higher rates of HIV infection amongst those using the product, compared to those randomised to the placebo, despite previous safety studies showing that the gel was safe (Ramjee *et al.* 2007). Reacting to this news, the South African Department of Health suspended temporarily all microbicide research to investigate the ethical conduct of these trials.

In 2008, the Microbicide Development Program (MDP 301) halted testing of a higher dose (2%) of the microbicide

PRO 2000 following a review by the Data Safety Monitoring Board (DSMB).[5] The review showed that it was unlikely that continuing this arm of the trial would demonstrate efficacy of the 2% dosage of PRO 2000 (Alcorn 2008). The trial was allowed to continue testing the lower 0.5% dose of PRO 2000. Despite a smaller study (HPTN 035) showing that PRO 2000 gel (0.5% dose) was 30% effective in preventing HIV infection, these results were challenged by the outcomes of the MDP 301 trial that showed that the same product – PRO 2000 (0.5% dose) – was ineffective in preventing HIV infection. Although it was shown to be safe to use, equal numbers of women in the product and placebo arm were infected with HIV (Chisembele *et al.* 2010).

In the wake of these disappointments, renewed hope for finding an effective microbicide was signalled in 2010 when the Centre for AIDS Prevention in South Africa (CAPRISA) released the results of the CAPRISA 004 trial of an antiretroviral containing gel (Tenofovir) that reduced HIV acquisition by an estimated 39% overall, and by 54% in women with high gel adherence (Karim *et al.* 2010). Taken before and after sex, this seemed to be an effective mechanism for prevention. Yet, following broad consultations, the US Food and Drug Administration (FDA) and the South African Medicines Control Council (MCC) argued that a larger study needed to be conducted to confirm these results.

In 2011, the South African-led 'Follow-on African Consortium for Tenofovir Studies' (FACTS) launched FACTS001, which aimed to confirm the results of CAPRISA 004 (http//www.facts-consortium.co.za). This trial is currently on-going. In the meantime, the Microbicides Trials Network 003 trial (VOICE), that tested the efficacy of Tenofovir gel applied once daily, halted the trial due to 'futility' because if the trial had continued it was unlikely that a positive result would have been found.[6] This shopping list of trials and their failures and successes underscores the massive uncertainties that surround HIV prevention trials.

Departing from its usual business model, Indevus manufactured PRO 2000 not for profit, but to be affordable for women living in the developing world.

We now turn to explore in more detail the MDP 301 trial.

THE MDP 301 TRIAL

The chemical compound PRO 2000 was invented in the 1990s by the company Procept Inc., and acquired by Indevus in 2000.[7] Departing from its usual business model, Indevus manufactured PRO 2000 not for profit, but to be affordable for women living in the developing world. This is the basis of the agreement with the British Medical Research Council, which funded the MDP 301 trial through a grant from the UK Department for International Development (DfID).

The Microbicides Development Program is an international collaboration set up to conduct research on the efficacy of vaginal microbicides to prevent HIV transmission (www.mdp.mrc.ac.uk). The MDP 301 trial, conducted at multiple sites, was a randomised, double-blind placebo controlled trial. It aimed to determine the safety and efficacy of PRO-2000 gel in preventing HIV infection. The trial was conducted at six African sites, including three in South Africa (Johannesburg, Durban and Hlabisa), and in Uganda, Zambia and Tanzania. The enrolment of 9 385 women was completed in August 2008 and follow-up finished in August 2009. Participants were recruited from four main populations: women with access to primary health care facilities (South Africa and Zambia); or who were entitled to primary care, either through their employment or their partner's employment (Zambia); women working in bars, hotels, guesthouses, and other food or recreational facilities (Tanzania); and women in HIV serodiscordant relationships (Uganda). To participate, women had to be 16 years or older in Tanzania and Uganda, or 18 years or older in the other countries, sexually active, HIV negative and not pregnant (Nunn *et al.* 2009).

The MDP 301 trial, conducted at multiple sites, was a randomised, double-blind placebo controlled trial. It aimed to determine the safety and efficacy of PRO-2000 gel in preventing HIV infection.

All trial participants had four-weekly clinic visits during which they received gel and condom supplies, returned used and remaining unused gel applicators, and were interviewed using a CRF. The visits at 4, 24, 40 and 52 weeks respectively were longer as they included a clinical interview and examination, and the CRF interview was more detailed, containing questions about gel use, vaginal washing and other practices, and detailed questions on each sex act during the last week (or during the past four weeks if the participant had not had sex in the last week). The results of the MDP 301 trial were announced in late 2009, showing no evidence that PRO-2000 provided protection against HIV infection (McCormack *et al.* 2010).

At each of the six African centres a subset of women was randomly assigned to the social science component of the study. By the end of recruitment we had recruited a total of 725 women (7.7% of the trial population). In-depth interviews were held at clinic visits, at 4, 24 and 52 weeks. The main purpose of these interviews was to compare data on the use of the gel and on use of condoms collected through other means (a diary, a questionnaire) with information provided in the in-depth interview. The interview also included questions about individual experiences of gel and condom use, partnership dynamics and experiences of the trial. A few men, trial participant partners, were also interviewed using a similar set of questions. The interview schedule was open ended to provide the opportunity for participants and researchers to explore

specific areas of interest. Focus group discussions were held with enrolled women, their male partners and community members.

The data presented in the *Review* is based on 401 interviews with 179 female trial participants, 28 interviews with 18 male partners and 42 focus groups.[8] Apart from these formal research activities, the researchers were encouraged to take extensive field notes of conversations in the clinic waiting rooms and while walking around the neighbourhood surrounding the clinic. This was most productive in Orange Farm, where the clinic waiting room was small and usually congested, with up to 15 participants waiting to be seen. Some sat watching Nigerian horror movies and South African soap operas playing on the television set, while others engaged in colourful conversations about sex, the gel, boyfriends and husbands, money and everyday life.

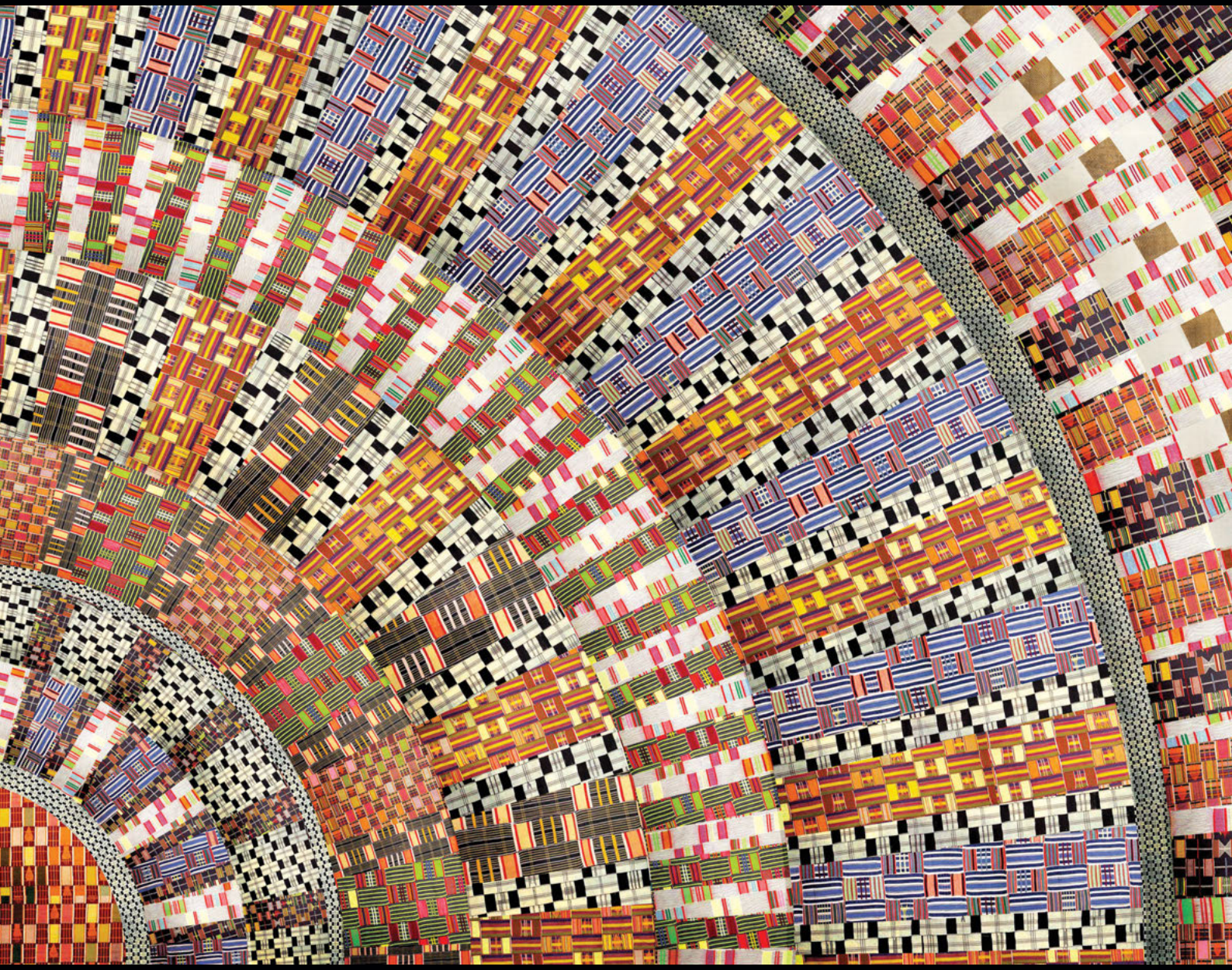
The data presented in the* Review *is based on 401 interviews with 179 female trial participants, 28 interviews with 18 male partners and 42 focus groups.

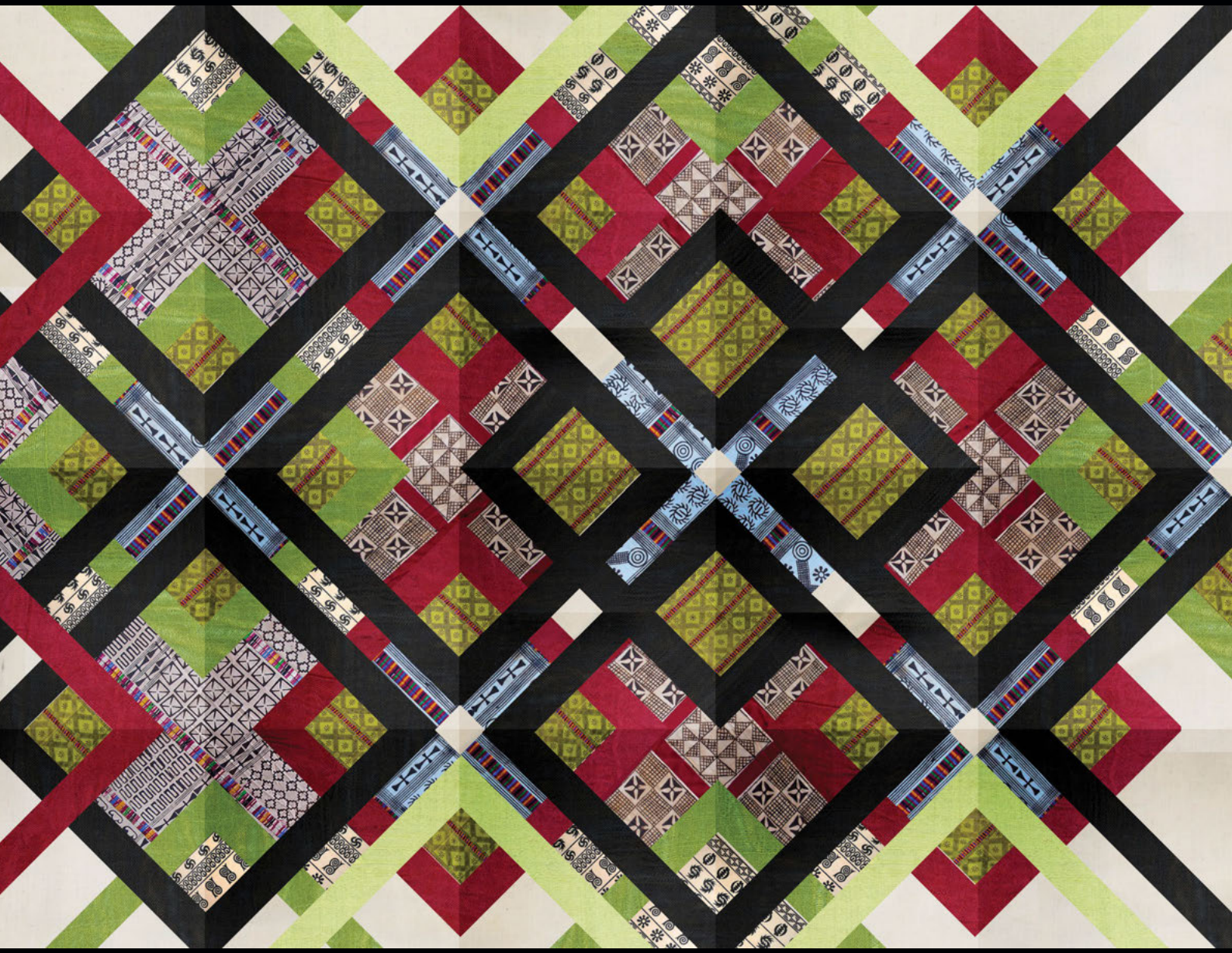
OUTLINE OF THE *REVIEW*

Chapter 2 begins with a detailed exploration of women's experiences of condoms and gels in the setting of the MDP 301. Despite the proven efficacy of condoms in preventing HIV infection, and the unproven nature of PRO 2000 gel, women participants attributed both preventive and therapeutic effects to the gel. However, their beliefs about the gel were not based on received knowledge from the clinical trial, but rather on their experiences of the side-effects of using the gel and condoms. These narratives are explained with reference to local constructs of the importance of the flow of fluids within women's bodies in maintaining health and the gel's contribution to maintaining this flow.

Chapter 3 shifts attention from the individual, embodied experiences of trial women to public narratives that tell imaginative tales of condoms and gels infected with HIV and the clinical trial as profiting from women's blood. These accounts were by no means unanimous. Tales of lethal technologies were not uncontested and did not exist in isolation. Instead, they were part of a larger series of complementary and contradictory narratives that explicitly addressed themes of gender, cash, social reproduction, morality and medicine.

Chapter 4 sums up the main arguments presented in the *Review*. A key theme of the *Review* has been to recognise the power of individuals in South Africa to evaluate on their own terms and thereby reinvent biomedical technologies and interventions such as the randomised clinical trial. As condoms and gels are employed (or not employed) in people's everyday lives, these technologies acquire their own unique signification. In some cases, these meanings could be quite different to those intended by healthcare professionals.





CHAPTER 2

MANAGING FLOW: CONDOMS VERSUS GELS

INTRODUCTION

Medical technologies do not only offer the promise of a return to health. They are objects that have social lives (Appadurai 1986), social uses and consequences, and they acquire new meanings as they are used, exchanged, transported and administered (van der Geest & Whyte 1996; Whyte *et al.* 2002) and have a symbolic or cultural logic (van der Geest & Whyte 1996). The meanings that they acquire are not predictable. The perception of the primary and intended effect of a pharmaceutical, as defined by its developers and distributors, is not necessarily shared by the end user. Side-effects or secondary effects may be more meaningful than the intended effect (Etkin 1992). Side-effects may from a user perspective be the primary motivation for non-use (Pound *et al.* 2009), or can also be an indicator of the potency of pharmaceuticals (van der Geest & Whyte 1996).

The new and often surprising meanings that experimental medical technologies may acquire form the main focus of this chapter. We suggest that trial participants in the MDP 301 reinvented condoms and microbicides in creative ways that were unanticipated by the trial managers and researchers. The condom is a tested technology that has proven efficacy in preventing HIV infection. However, women and men pointed to the unhealthy effects of the condom on their relationships as well as in their bodies. The microbicide gel was untested and unproven in preventing HIV infection. Yet, women enrolled in the trial and their partners pointed to its benefits for their relationships and in maintaining good health. The emergent narrative pitted the 'unhealthy condom' against the 'healthy gel'. This narrative has its origins in constructs of vaginal health.

In southern Africa, vaginal health is often considered dependant on the movement of substances (Bagnol & Mariano 2008). Trial participants raised concerns about maintaining a consistent flow of fluids within their bodies, as well as between themselves and their partners. Their narratives asserted that the gel was effective in maintaining this flow. However, where the gel appeared to facilitate the

flow of substances and promoted vaginal and general health and healthier relationships, the condom caused blockage, poor health and disharmonious relationships.

In the sections below, an examination of these statements and the justifications that women give for their beliefs will be reviewed, first with regard to the condom and then with regard to the gel. Then beliefs regarding the role of cleanliness and the flow of bodily fluids in maintaining health will be explored. Our conclusions raise questions about clinical trial ethics and informed consent in the light of our findings.

OBSTRUCTING FLOW: CONDOMS

Trial participants received regular supplies of condoms ('Choice', a latex lubricated condom[9]) from the MDP 301 clinic. During safer sex counselling sessions participants were encouraged to use condoms with each sex act as the gel had not been proven to be effective, and because they may have been randomised to receive a placebo gel. In our interviews, women demonstrated understanding of this message. However, they also questioned how the trial would be able to assess the efficacy of the gel if they were using condoms consistently. Condom use was also inconsistent, a factor that the design of the trial relied upon. Sex acts that involved gel use only are key to the trial's ability to measure efficacy.[10]

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Women trial participants asserted that condoms are the only method that could guarantee protection against HIV acquisition as these create a physical barrier against semen entering the womb. A 22-year-old woman said "I have been using condoms all the time since I started to have sex. I always played safe because I do not want to get sick." Another, aged 21 years, agreed: "… they protect against HIV and other STIs. I have a guarantee when I use them that I am safe." Yet, in the same breath participants pointed out that condoms had not been particularly effective in stemming the AIDS epidemic.[11] A 28-year-old female trial participant summed up the situation neatly: "Here in Orange Farm we have access to condoms but still we have many people who are HIV positive."

Reported use of condoms was relatively high amongst women in MDP 301. More than two thirds of the women enrolled in the trial reported having used condoms: 68% reported to a nurse that they had used a condom in the last four weeks, while 30% had not. However, this is a weak proxy for assessing patterns of condom use. Our conversations with trial women revealed that condom use fluctuated dramatically depending on partnership

dynamics, the context of sex, the number of sex 'rounds' (acts), and the meanings associated with condom use or what condom use signified.

Condoms were used occasionally when men 'felt like it'. A 21-year-old woman said about her partner: "He likes them [condoms] but sometimes he tends to get upset and says to me that we must not use a condom. He said that he wanted to experience what sex is like without a condom." Men objected to condoms because of inhibited sexual pleasure. A 26-year-old unmarried woman said her boyfriend often put on a condom but removed it after struggling to achieve orgasm: "We used it but he would just take it off during the process, saying it makes him not to ejaculate." On some occasions condom use simply depended on mood; "if the man is happy then he may use a condom to please you". Yet, he might abandon the condom in subsequent sex acts.

Although women and men recognised the efficacy of the condom they also expressed reservations regarding its reliability.

It would be a mistake to assume that these accounts reflect men's concerns alone. A 23-year-old woman said she missed sex without condoms, because "it takes all the pleasure away." Each month she and her partner had sex once or twice without condoms so that "I can enjoy that physical contact with my partner." Another female trial participant (29 years old) reflected: "I was not using a condom on a daily basis […]. I only used it when I felt that there were some changes in my body, especially when I suspected that I was pregnant I asked my partner that we use a condom. Sometimes I used a condom when I was not feeling well, especially after I consulted a doctor and prescribed some medication for me and told me not to have sex or to use a condom during sex. So, mainly we use it mainly under certain conditions." For others, it seemed to be a question of identity. A woman commented on her dislike of condoms: "You know I have problem with condoms, as I said before, that maybe I am too African, I do not know."

Although women and men recognised the efficacy of the condom they also expressed reservations regarding its reliability. Following media reporting about faulty condoms, distrust of the condom grew (SAPA 22/10/2007). According to a female focus group participant, condoms ruptured during sex because "men do have not the same size [penis]." Others agreed, claiming that men's pubic hairs made holes in condoms: "you can put on a condom the right way, but when you are very busy, bah! [the condom bursts]." Condoms also slipped off during sex and became stuck inside the womb, participants claimed. A 23-year-old focus group participant exclaimed: "You will be surprised when you pass urine to see a condom coming out". Condoms could burst, leaving small pieces of latex inside the womb, thereby creating

an obstruction in the fallopian tubes and resulting in the build-up of fluids inside the womb.

Women associated condoms with unfavourable side-effects. They reported genital rashes, vaginal dryness and pain during sex. A 21-year-old trial participant reported to the MDP 301 staff that when she used a condom she had rashes, swellings and pain. Other women said that condom lubricants ('oils') accumulated in the womb and caused infections (Thornton 2003; Wojcicki & Malala 2001). Others voiced suspicions that condoms themselves were contaminated with diseases. This was occasionally expressed in terms of a popular South African conspiracy theory that condoms contained diseases to target black people (Niehaus & Jonsson 2005; Stadler 2003). A 24-year-old woman said: 'Most people think things like condoms that are made by white people are the things that give black people diseases'. Others alluded to the contamination of condoms with HIV and alleged that they contained microscopic organisms or virus-like 'worms' (see Chapter 3).

Decisions regarding whether or not to use condoms are also dependent on the length and type of partnership.

Decisions regarding whether or not to use condoms are also dependent on the length and type of partnership. A young man explained: "for the first three months I will use condoms and then leave it later on." This is because of the idea that long-term partners are trusted to be faithful. Condoms are more appropriate with one-night stands (Zulu: *amashaya*). A 31-year-old married man said: "If it's my wife we won't use it [a condom], because you trust her, she's the lady of the house. But these other ones outside [one-night stands], you can also throw on a plastic bag [a condom] for extra protection, because if it's somebody from outside, you can never know with them [whether or not they are infected]."

In this regard, using a condom not only signifies the intention to prevent HIV; it is emblematic of a lack of trust (Sobo 1995). A young man remarked: "I use a condom when having sex with someone I do not trust." A 38-year-old trial participant tried to insist on condom use with her husband because "I do not trust my partner, because where he goes I am not with him." As a female participant in a focus group related: "I asked that we use a condom because I did not trust him." However, after the first 'round' of sex, "I did not ask him to use one and he did not say anything either. We just had sex without a condom." A 28-year-old woman spoke at length about the uncertainty she faced with her husband and how this influenced her attempts to use condoms:

> I use condoms especially if he does not spend a night at home because I would not know what he was up to. Sometimes he can go away for the whole month without any of us knowing where

> he is; when you ask him he will tell you he went away because of his job. He is working as an engineer, so on days when he went away for many days I tell him that we will use a condom, I show him [I tell him] "I am using a condom and you should use yours … because I don't know what you were up to when you were not around, maybe you slept with someone who has AIDS and you may pass it on to me so use a condom". He feels bad but I don't care, because I am protecting myself. I told him, "It is not like you are travelling from one country to another in your line of work, so I don't understand why you don't spend some nights at home". He came with different excuses, like "I knocked off late at 22 hours and there was no transport, I spent the night at work". But all this time he knew he was going to Meyerton. I don't even know the place.

Her suspicions were confirmed when a neighbour told her that her husband had been seen in another town, buying bread. Yet, that night he did not return with the bread. "I don't trust him anymore because he is unfaithful, so every time we have sex we use a condom."

Highlighting the implicit meaning of the condom as the antithesis of trust and love, a young married woman forced her husband to use a condom to "punish him […] if he has not slept at home." In a group discussion, women in Orange Farm said that they could not force their partners to use condoms owing to the fear of losing support. An older woman remarked: "They [men] can always leave them for the next woman who does not mind whether a condom is used or not, and they [women] don't want that to happen because they don't want their children to lose their fathers because of condoms. If you let him go what will you say to your children, they will blame you if they don't have things their father used to do for them and you cannot tell them their father has left because you did not want to have sex with him without a condom."

The mixing of sexual fluids enhanced feelings of intimacy between men and women. Condoms disrupted this mixing.

The mixing of sexual fluids enhanced feelings of intimacy between men and women. Condoms disrupted this mixing. A 30-year-old married man was enraged when his wife suggested they use condoms. He said that married couples ought to have sex without condoms, because this "binds us together when we mix our fluids. We become one unit through this act. When we use condoms the bond is broken." Condom use, he asserted, "… is causing trouble in people's marriages." Condoms also threatened the reproduction of the family: a younger man said he did not use a condom because he did not want his semen to "end up in the dustbin". Another agreed that using condoms meant that his future progeny "would be killed". In a focus group discussion, several men admitted to making holes in condoms, in their words to make "sex taste sweeter".

Condoms were regarded as efficacious in preventing HIV, but were regarded as unreliable, rumoured to be contaminated with diseases and antithetical to harmonious spousal and romantic relations. Challenging conventional assumptions about male resistance to condom use as patriarchal dominance (Thege 2009), men and women shared similar concerns about condoms restricting flow. In contradiction of public health messaging that stresses the risk of HIV infection for the individual, MDP 301 participants' comments on condoms highlighted the implications of condom use for social relations and the social body.

The AIDS epidemic, constructed as a globalising public health discourse, is often challenged through local discourses (see Heald 2002). The beliefs about condoms expressed by MDP 301 participants and their partners transform condoms from an effective technology in reducing risk of HIV acquisition to one that is potentially dangerous. Their narratives revealed the social significance and meanings of condoms that go beyond biomedical concerns of individual sexual hygiene. Acknowledging the role of condoms in preventing infection, our informants saw these as symbols of mistrust, as antithetical to the intimacy of sexual relations, depending on the context of use. In some cases the condom was used as a vehicle to convey distrust, and in other contexts, humiliation and discipline. Underlying these references is the idea of the condom as blocking the flow of sexual substances. This works as a metaphor for the threat that condoms pose for the reproduction of social relations, both horizontally and vertically. The healthy flow of substances between bodies allows these to mix, allowing distinct lines of descent to merge into one. Disrupting this flow alienates bodies and fluids from one another, causing dissent. Condoms also alienate the living from the dead, obstructing the flow of blood that courses through the line of descent (Thornton 2003).

Their narratives revealed the social significance and meanings of condoms that go beyond biomedical concerns of individual sexual hygiene.

FACILITATING FLOW: HEALTHY GELS

In contrast to their opinions regarding condoms, trial participants were highly enthusiastic about the gel; many said it was "number one!" Adherence to gel use was relatively high throughout the trial. Of all unprotected sex acts (without a condom), 74.7% involved gel use (Crook *et al.* 2009). The gel was regarded as highly 'acceptable' by MDP participants. Only 11 out of the 401 in-depth interviews described the gel as 'unacceptable'. In six of these interviews, women said that their male partner disliked the gel, while the remaining five reported unwanted symptoms, reduced sexual enjoyment and inconvenience. Of those who found the gel acceptable, almost half (190 out of 401, or 47%)

reported that the gel increased sexual enjoyment, while only a few (27) thought the gel might protect them against disease. Other reasons for finding the gel acceptable included ease of use, cleansing, removal of bad odours, vaginal dryness, a lack of side-effects and normalised menstrual flow.

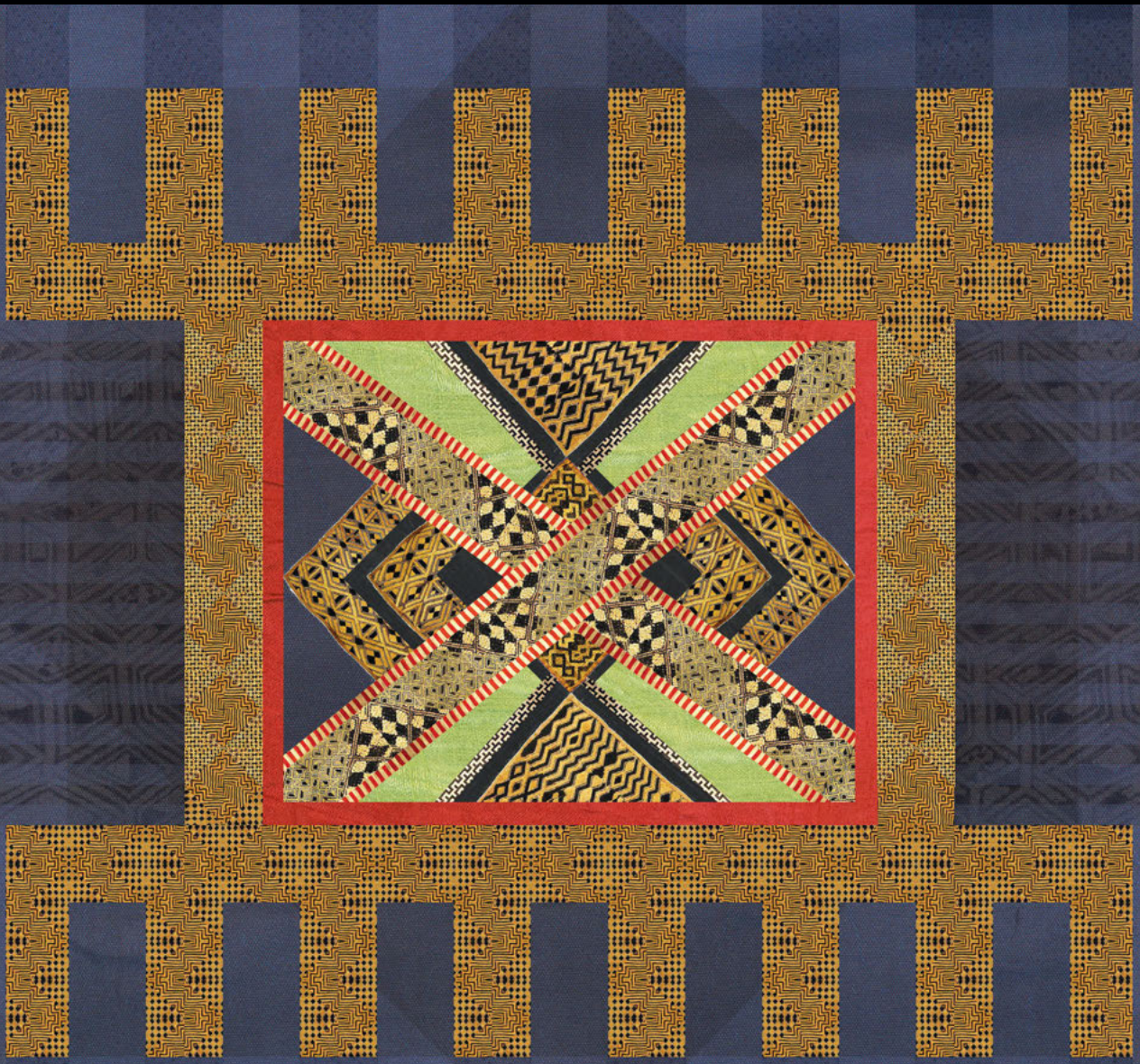
'Acceptability' is usually defined narrowly from a disease prevention framework that includes product characteristics, willingness to use the product and the reduction of risk (Montgomery *et al.* 2010) while the intention to use a particular drug relies on an individual's perception of personal risk (Weeks *et al.* 2004). Our research identified a different set of concerns that influenced acceptability and use of the trial gel. Most often these related to 'side-effects' of gel use.

Women believed that the gel cleansed the vagina and helped to maintain reproductive health.

In interviews, women reported experiencing several physical sensations while using the gel: coldness, wetness, tingling, itching and burning. Yet, the most obvious and immediate effect of gel use was vaginal discharge, particularly after engaging in sexual intercourse. These perceived side-effects were often discussed by participants with other women in the trial, with friends, and with sexual partners.

Women believed that the gel cleansed the vagina and helped to maintain reproductive health. They spoke of their vaginas as reservoirs within which 'dirt' collected. Through the use of PRO 2000, dirt was portrayed as being 'drawn out', 'dragged', and 'flushed' from the vagina, which was subsequently described as 'clean' or 'cleansed'. As evidence of this process, women usually identified vaginal discharge: "I can see dirty things that have come out, so that means it cleans everything that is in my womb." Another participant noted, "I was happy when it came out, especially when I saw that it was dirty, it meant that the gel was cleaning me." Some women commented that when they first began to use the gel, their discharge was opaque and pungent. This was believed to be a sign of disease: 'If you have an infection the gel will clean it out, and it will show on the discharge that there is something wrong with your womb.' Women reported that over time, discharge tended to become clear and odourless – a sign of vaginal cleanliness.

Semen, condom lubricants and other substances were believed to accumulate in the womb. These caused infections, the symptoms being chronic, thick and foul-smelling discharge. Trial women often reported histories of chronic vaginal discharge. A 21 year old recalled: "People told me to wash with different things but it didn't help. I even consulted different clinics and they gave me some tubes [ointment] to use but it didn't help either." Another (28 years old) resorted to wearing sanitary pads: 'The amount of discharge that was coming out was too much. I was



changing underwear every time'. The efficacy of the gel from the participants' perspective was visible from changes in the consistency, colour and odour of vaginal fluids and discharge. They noted the following changes to their discharge: "I saw my discharge when it comes out, it is white and clear." And, "I saw some changes, I had this thick discharge coming out but after that I was fine." Many women claimed that the gel was more effective in treating discharge than clinical drugs. The gel was also effective in cleansing the lubricants found in condoms: "Condoms have oil [lubricant] and I believe that the gel reduces the amount of condom oil in my body."

Good vaginal hygiene resulted in an overall feeling of wellness. Women who used the gel often claimed it had purifying and rejuvenating properties that enhanced their general sense of well-being and healthiness: "As a result of continuous use, my pores are now open. My body is no longer stiff and I don't get tired any more. I am not unsure about my health anymore. Since I started using the gel, I am always energetic like somebody who is using drugs. It has even opened the veins to my kidneys." Others remarked on how the gel made them feel complete or whole: "I feel like I am a person" (Zulu: *ngizizwa ngingumuntu*).

Male partners of trial women tended to concur with the idea that the gel had a revitalising effect. A 33-year-old man married to a trial participant commented on the physical and emotional transformations that his wife had undergone since using the gel: "I realised that since she started to use the gel her vagina is dry after she has washed. She is no longer as wet as she used to be. She used to have discharge that smelt bad. She used to go to the clinic for that but it never went away until she started to use the gel. She also started gaining weight and her face is brighter."

Those stating that they were using an active gel often added that PRO 2000 was also viewed as both preventative and therapeutic.

Women participating in MDP 301 were randomised to receive an active or a placebo gel. Even though their randomisation was not known to the participants or study staff, participants claimed to know which gel they had been assigned to. Some believed that the study staff changed them from placebo to active gel during the trial. Those stating that they were using an active gel often added that PRO 2000 was also viewed as both preventative and therapeutic: "I thought that it was searching for diseases inside me whilst protecting me at the same time by removing all the dirt, even if I had come in contact with someone who is infected with HIV." Consequently, the active gel was seen to protect women against contracting many STIs: "Let's say my partner had 'dirt sickness' [STI] and I did not know about that but

since I use the gel I would not need to go to the clinic or have a problem with STIs." Women who recovered from vaginal infections after joining the trial often attributed their improved health to PRO 2000, despite being prescribed antibiotics: "I had a womb problem but now I do not have that problem, that is why I say the gel cleans me." Through the process of cleansing the womb and removing impurities, the active gel was also believed to eliminate HIV before transmission can occur: "The gel is preventing us from many diseases including HIV because it flushes out everything that is dirty." However, none of the women interviewed stated that the PRO 2000 could cure HIV if it had been previously contracted.

These narratives evoke a link between the accumulation of dirt and the onset of HIV infection. Sobo, in her Jamaican ethnography, notes that the physical signs of AIDS such as body sores are regarded as the physical manifestation of the decaying body, caused by accumulated dirt (Sobo 1993b). Niehaus writes that in the South African Lowveld, those who are ill with AIDS are believed to be the living dead, decomposing while they are still alive (Niehaus 2007). Stadler reports the belief that AIDS represents maggots that consume the body internally (Stadler 2012).

These narratives evoke a link between the accumulation of dirt and the onset of HIV infection.

The success of the gel lies in its effect in flushing out accumulated dirt. Because of its cleansing abilities, trial participants, their partners and other community members credited PRO 2000 with alleviating a number of other complaints, including vaginal itching, vaginal sores, rashes, menstrual pains, abdominal pains and lethargy. As a result of cleansing, women stated that fertility would improve: "She can fall pregnant because it cleanses her body and the man becomes more virile because the vagina becomes small and becomes dry." These statements were occasionally corroborated by women who, after months or years of attempting to become pregnant, said they had been successful only after joining the trial. A 35-year-old woman, who had repeatedly failed to conceive, said that she fell pregnant while using the gel because it had cleansed her: "The gel is good for women because it has cleaned me and I fell pregnant." Others cited similar successes with falling pregnant: "It shows that the gel is working because I fell pregnant."

Others contended that the gel was an antidote to the long-term effects of hormonal contraception by "cleans[ing] the injectable [hormonal] contraceptives out of the system." Ironically, clinic staff urged participants to use contraception to prevent pregnancy, as those who fell pregnant were suspended from the trial. Over the period of the trial, 613 pregnancies were reported across all MDP 301 trial sites, with a pregnancy rate of 11.1%; 246 pregnancies (10%) were recorded for the Johannesburg site.

Accounts of PRO 2000's therapeutic abilities motivated some women to enrol: "My mother felt that the gel would help relieve the thrush and told me to [join the trial]. After using the gel for about two months, I no longer had a problem with vaginal thrush. I think the gel stopped it." These effects led to using the gel in non-prescribed contexts, outside of sexual intercourse. "I would sometimes insert the gel without having sex for it to clean my system." Another participant used the gel to treat the pains in her womb: "I insert the gel and when it comes out, it comes with dirty discharge and the pain gone." Participant experiences led them to re-evaluate user guidelines: "They said I must insert the gel before sex, but I thought it is better if I insert it even if I do not have sex because there are dirty things that come out. I use it twice a week so that it can clean me."

Women who believed they were using an active gel and that it protected or cleansed their vaginas were also well aware that PRO 2000 had not yet been successfully proven to do either of these things.

While sitting in the clinic waiting for their monthly visit, women discussed when and how often they used the gel. A participant advised a friend who was complaining of abdominal pain: "I told her to insert the gel even though she was not having sex, and the following day when we spoke she said the pain has stopped and she was able to walk. She said it has removed dirt from her womb." A number of women reported being encouraged by these conversations to use the gel on a regular basis regardless of sexual activity. When asked about her gel use in an interview, a participant responded, "Even now as I am talking to you I have it inside me." Women enrolled in the trial used the gel in creative ways, as the following excerpt from our field-notes illustrates:

> She told us that her friend gave her five gels so that she uses them to experience how they are. She used one without sex before bedtime and she gave some gels to her two daughters because they also wanted to try them. One daughter [the youngest one] used one gel and the other [older daughter] used three. All tried the gel on the same night without sex. She told us that she felt some sensations in her lower abdomen throughout the night after using the gel; she said she thought that the gel was cleaning the womb. She was afraid that she might fall pregnant and she does not need children anymore.

Women who believed they were using an active gel and that it protected or cleansed their vaginas were also well aware that PRO 2000 had not yet been successfully proven to do either of these things. Through trial interviews and procedures such as the comprehension checklist, women generally possessed a good knowledge of trial protocols and information. Nevertheless, some women continued to assert their own belief in the efficacy of PRO 2000: "They said that they are still testing the gel to see if it can protect against HIV infection but I believe that it can protect me."

These assertions were once again based on physical experiences. The presence of side-effects and the subsequent belief that the participant had an active gel was often invoked: "I think I am using 2%.[12] I think it is the one that can prevent HIV. But they are not yet sure that it can prevent it and that is why they said that I have to use condoms when I use the gel." The cleansing properties of PRO 2000 as well as vaginal discharge were also factors mentioned: "I think it works because it is able to clean the woman's womb, so the chemical inside the gel is able to kill the virus." Trial participants asserted that their beliefs regarding the active gel would be eventually confirmed by medical professionals.

Many writings on microbicides point to a concern that the lubricating properties of the gel will be unacceptable in cultural settings where dry sex is preferred.

DRY AND WET

Many writings on microbicides point to a concern that the lubricating properties of the gel will be unacceptable in cultural settings where dry sex is preferred. They assert that African men have a preference for dry sex, which can cause the vagina to tear and thereby become more susceptible to HIV infection (Brown *et al.* 1993; Runganga & Kasule 1995; van de Wijgert *et al.* 1999). While women in the trial talked about the desirability of dry vaginas, they did not support this as a sexual practice per se. Nor, according to their reports, did their male partners eroticise 'dry vaginas'. Instead, the idea of dryness defined health and cleanliness and a woman's moral constitution (Beksinska *et al.* 1999; Leclerc-Madlala 2001).

Women in the MDP 301 trial believed the gel cleansed the vagina and made it 'dry'. The vagina and the womb are regarded as the main sites of infectious agents and therefore the focus of efforts to cleanse. Yet, the meaning here did not suggest a physical dryness, but, rather, being free of germs. Women used the English word 'dry' or the Zulu equivalent *wu omisa*. Vaginal cleansing practices aim to expel dirty fluids from the vagina. Participants recalled that their female elders instructed them to clean the outside as well as the inside of their vaginas by using their fingers, to remove 'dirty stuff'. Others washed thoroughly with caustic and anti-bacterial soap and cold water. They also used blotting paper and herbal concoctions to soak up and remove excess fluid from the vagina. Similarly, the gel cleansed and dried the vagina by removing accumulated fluid: "I like the gel because it keeps me dry and cleanses me. I feel dry. Before I started to use the gel I used to feel like the sperms were coming out all day and my pants would be wet as a result. But when I started using the gel, it comes out with all the dirt and I remain nice and dry. The proof is I can put on panties and they stay dry." The gel, like other substances that

some women use, 'dried' the vagina by removing dirt and excess fluids. This created a healthy environment free of disease.

The desirability of a dry vagina reflects ideas about the body, inner health and emotional well-being, adequately captured by women's statements about becoming a 'complete person' described in the previous section. Vaginal cleanliness was reportedly appreciated by male sexual partners who noted an improvement in sexual sensation. A 42-year-old married woman said: "He [her sexual partner] said he feels me, you know, a woman can be a little wet down there, so he said that since I have used the gel I am dry and I feel so nice." They described this feeling as 'just dry, but not too dry'.

The desirability of a dry vagina reflects ideas about the body, inner health and emotional well-being, adequately captured by women's statements about becoming a 'complete person'.

Almost all participants we interviewed commented on how the gel made sex less painful and more pleasurable because of its lubricating effect. Some women used lubricants and creams (baby oil, Vaseline, KY Gel) or saliva to moisten the vagina and ease penetration. The trial gels served a similar function. For example, a 24-year-old unmarried woman noted the difference before and after using the gel: "The difference is that before I used to be dry and that caused pain sometimes. The gel keeps me moist and I do not experience any pain."

While the added lubrication eased the pain associated with penile penetration, it also increased sexual libido. The gel "makes me hot. I feel like a young girl." Women referred to a sensation of vaginal tightening that was also attributed to the gel. Some joked about their increased desire for sex: "Who knows, maybe I will be introduced to the fourth round [sex act]." Other gel users confirmed these feelings: "I have really been enjoying sex." And: "I enjoy sex so much that I do not think I am going to finish making love." The gel also stimulated men's desire. One woman reported an increase in intimacy with her partner: "When you are with your partner he feels like to have sex with you all the time." Another commented that she and her husband were spending more time together and having more sex. Some women speculated that increased desire was due to the chemical properties of the gel: "I think there is something that they have put into the gel that they are not telling us about."

The gel could be used secretively by women who wished to; they could insert the gel in the toilet or in the room when the lights were out. However, many women in the trial often told their partners that they were using it. The act of inserting the gel was erotic for women and their partners. For example, a married woman said that her husband inserted the gel for her as part of foreplay:

"Sometimes he inserts it for me. I have showed him how to insert it. We start with foreplay and then when we are about to have sex he takes it and inserts it." Increased sexual pleasure also had a favourable impact on the quality of relationships. Gel use transformed sexual relations as well as the quality of the relationship overall.

BLOCKAGE AND FLOW

The material presented above has shown how women in the trial positioned the gel in opposition to condoms. Where condoms inhibited sexual intimacy and were associated with a lack of trust, the gel intensified sexual experience, and enhanced the sense of intimacy and togetherness. And whereas condoms could rupture and result in 'blocked tubes', the gel was an effective antidote, creating flow and thereby cleansing the womb of impure substances, stimulating fertility.

Where condoms inhibited sexual intimacy and were associated with a lack of trust, the gel intensified sexual experience, and enhanced the sense of intimacy and togetherness.

The interpretation of the gel as a cleanser is based on its side-effects, primarily the vaginal discharge that women reported. Signifying internal processes, even when separated from the physical self, fluids mark the ways in which bodies interact with the world and others (Grosz 1994; Kristeva 1982). For many women in the trial, vaginal discharge indicated health or illness, cleanliness or pollution. These ideas are tied to larger notions of dirt and the role of bodies within society. Douglas (1966) notes that pollution signifies that which is out of place and acts as a fundamental explanatory framework from which the social world can be understood. Consequently, to understand the ways in which women make meaning through their experiences of the gel, it is important to first examine concepts of dirt and pollution, as well as the way in which they are embodied in bodily processes.

Ashforth (2005, 156) notes that in South Africa, "dirt is ubiquitous". In southern Africa, tradition (Green 1999; Hammond-Tooke 1989; Ngubane 1977), Christian missionary teaching (Comaroff 1985; Comaroff & Comaroff 1997; Moffat 1842), biomedical notions (Department of Health 1997; Manganyi 1974), and marketing (Burke 1996) have all influenced beliefs regarding the ability of pollutants to cause harm. Disease is often thought to result from dirt that is not properly cleaned from various parts of the body. The vagina, in particular, is considered to be a conduit for dirt into the body. Menstruation acts as an important natural process through which dirt is removed (Jewkes & Wood 1999; Leclerc-Madlala 2002), resulting in a belief that menstrual blood is potentially polluting (De Heusch 1980; Hammond-Tooke 1981; Ngubane 1976; Niehaus

2002; Pauw 1990). Trial participants in MDP 301 regularly stated that they did not wish to have sexual intercourse when menstruating for fear that the dirt being expelled would cause their partner to become ill. Many women also reported cleaning their vaginas on a regular basis through douching or inserting substances to flush contaminants from their bodies. Just as a woman's vagina needs to remain free of dirt for wellness, so too do other regions of the body, such as the digestive tract. To ensure abdominal health, adults regularly administer enemas to themselves and their children (Lusu *et al.* 2001; Moore & Moore 1998). One survey conducted in KwaZulu-Natal reported that 89% of the 107 infants surveyed received enemas, often more than once a week within the first three months of life. The most common reasons given were constipation or the need to be 'cleaned out' (Bland *et al.* 2004).

Flow, the transfer of liquids through bodies, is an important theme in narratives of health and cleansing throughout southern Africa.

Flow, the transfer of liquids through bodies, is an important theme in narratives of health and cleansing throughout southern Africa (Thornton 2008). Defecation and menstruation are vital processes that ensure dirt is removed from the body. Individuals regularly monitor the states of their bodies and take steps to encourage flow if it is not occurring naturally. Constipation is counteracted by an enema, which visibly flushes contaminants from the body. Similarly, trial participants reported douching when they felt that dirt had built up in their vaginas. Responses to PRO 2000 can be grounded in terms of women's experiences of the gel, coupled with beliefs regarding dirt and the importance of flow for its removal. Like the experience of douching and enemas, the primary side-effect of the gel, increased vaginal discharge, results in liquids flowing out of the body. In their statements, many women cite discharge as 'proof' that what they believed to be the active gel removed impurities. As with douching and enemas, individuals see and feel substances identified as dirt-laden expelled from their bodies.

Narratives about the gel versus the condom correlate with fundamental concerns about maintaining and controlling a flow of sexual fluids. Interviews with women enrolled in the trial highlighted the importance of releasing fluids for health and emotional well-being. The condom stood in direct opposition to fluid flow, created blockage and, therefore, caused ill health. Anxieties about condoms causing blockage are relatively widespread (Allen & Heald 2004; Gupta & Weiss 1993; Sobo 1993a; Taylor 1990), as is the contamination of condoms with HIV (McNeill 2009; Stadler 2003; Thornton 2008) and the side-effects of condom 'oils' (Wojcicki & Malala 2001). These anti-condom sentiments may have something to do with the value of semen, not only for fertility, but also in terms of individual development.

For example, amongst the Maasai, semen is regarded as beneficial for women and the social and physiological development of young girls (Coast 2007). It also relates to the desire to allow the free flow of fluids – seminal and vaginal secretions – between partners. The transfer of fluids is conceptualised as the exchange of gifts, essential to the constitution of personhood (Thornton 2008). Failure to allow the flow of substances results in blockage and the erosion of person (Taylor 1990).

Concerns that our research participants expressed regarding burst condoms, stuck condoms, condom oils and contamination with deadly viruses may be seen as metaphors for the dangers of disrupting the flow of substances. Condoms were regarded as incongruous in long-term relationships (longer than three months), when the intermingling and exchange of fluids is most desirable. This also helps us to understand why men 'sabotaged' condoms by piercing them to allow semen to escape and why they said this 'tasted good'. Sex and the intermingling of fluids are necessary to maintain good health (Niehaus 2002).

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In terms of this local model of health and illness, the failure to release blood through sexual intercourse has negative health outcomes. Amongst adolescents in the South African Lowveld, facial acne, irritability and dark patches of skin are believed to be a result of insufficient sexual contact (Collins & Stadler 2000). In another study (Wood & Jewkes 2006), adolescent girls reported symptoms of 'abdominal discomfort, bodily swelling, headaches (the blood was 'blocked in the head'), tiredness, sores on the body, infections, weight gain and skin changes' and temporary infertility due to hormonal contraception that caused sporadic spotting and low volumes of menstrual fluid (Wood & Jewkes 2006, 12).

Although healthy and enjoyable sex encompasses the sharing of fluids, excessive mixing with many partners can also result in illness (Niehaus 2002). Men are in danger of absorbing not only women's 'blood', but also that of her other sexual partners. Menstruation is a particularly inauspicious time to have sex. Menstrual fluid cleanses the body of 'dirty blood' and is therefore highly polluting (Hammond-Tooke 1981; Ingstadt 1990).

In microbicide safety and tolerability studies, vaginal discharge is in some cases categorised as a side-effect or an 'adverse event' (Mayer *et al.* 2003), attributed to expulsion of the gel, and 'normal cervical discharge' (van Damme, Wright, *et al.* 2000). Amongst women in our study, vaginal discharge was extremely significant and demonstrated the efficacy of the gel. Rather than a side-effect, the expulsion

of fluid from the vagina became for them, the primary effect of the gel. As Etkin (1992, 102) observes, biomedical therapeutics have a dynamic quality – sometimes, the side-effects of medicines are invested with greater significance than the intended primary effects: "That which may be defined as a side-effect in terms of biomedical construction maybe embraced as a pre-requisite part of the process that demonstrates healing." The gel performed an important part in the process of unblocking the flow and ridding the body of polluted substances, enhancing fertility and readiness for pregnancy. Improvements to women's reproductive health were attributed to gel use and, to a lesser degree, to the regular clinic check-ups and STI treatment female participants received from the trial clinic. Women did not doubt the efficacy of clinical treatment for STIs, but regarded the cleansing properties of the gel as essential for the completion of the healing process.

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Previous research in southern Africa has documented the ways in which substances drawn from a variety of sources are utilised for removing dirt from bodies. Burke (1996) notes that building upon earlier missionary ideas of bodily discipline and cleanliness, soaps such as Sunlight soap have been used throughout southern African for decades. Through post-war marketing messages and experimentation, new products were employed in a variety of ways, such as using petroleum jelly or body lotions to reinvent the southern African practice of 'smearing' (Burke 1996, 171). In South Africa, substances that are commonly used for enemas include salt water, topical antiseptics such as Dettol, Sunlight soap and herbal mixes, although more caustic agents such as bleach, vinegar, potassium dichromate, copper sulphate and potassium permanganate are also used (Ashforth 2005; Dunn *et al.* 1991; Segal & Tim 1979). HIV/AIDS research has documented that women will most often douche with commercial products such as bar or laundry soap, antiseptics, vinegar, salt water and industrial detergents, and, to a lesser extent, local preparations from plant or animal materials (Morar & Abdool Karim 1998; Myer *et al.* 2006; Scorgie *et al.* 2009). Confirming these findings, women participating in the trial also described employing many of these products as vaginal cleansing agents. In addition, women stated that PRO 2000 could also be used and, for some, it was considered to be more effective than other substances. New technologies are regularly incorporated into existing habits, despite the messages of trial staff.

Individuals are comfortable with innovating new solutions to fit changing circumstances. Assertions that PRO 2000 cures infections, prevents the transmission of HIV

and facilitates pregnancy are grounded in beliefs regarding cleanliness, the absence of dirt, and health. Like pollution, STIs and HIV create bodily and social disorder (Henderson 2004). Trial participants frequently conflated dirt, disease and STIs: "Bacterium is dirt. And in my knowledge it means that it is the same as a STD."

Several women attributed STIs to dirty blood or semen in the vagina, which, it was believed, could be flushed out through gel usage. Despite being prescribed a regimen of antibiotics, women continued to credit PRO 2000, owing to a visible demonstration of vaginal cleansing through the presence of discharge. While PRO 2000 was not believed to cure HIV, the active gel was thought to act as protection against infection. These beliefs were frequently linked to ideas regarding dirt. After stating that PRO 2000 could prevent HIV transmission, one woman commented, "When it comes out it removes the dirt. That is why I say it must remove the virus as well." An absence of dirt is not only necessary for health, but also for conception. Through the natural cleaning process of menstruation, the vagina is made ready for pregnancy. Consequently, the single act of flushing pollution from the vagina is thought to precipitate a number of health outcomes for women using PRO 2000.

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As new technologies to prevent the spread of HIV are created and subsequently evaluated through large clinical trials, it is not only medical professionals who are determining the efficacy of these pharmaceuticals, but so too are the individuals enrolled in the trial. Any pharmaceutical or medical product will most likely only be used if people consider it to be effective and appropriate. Comparing the perceptions of South African women to those of Americans who participated in a phase I trial of PRO 2000 reveals that South Africans found 'leakage' to be more acceptable (Morrow *et al.* 2003). Like the use of Ponds body lotion for 'smearing' or Dettol for enemas, PRO 2000 is a product that has been incorporated into existing ideas regarding the body and cleanliness. Despite information provided by the trial staff, women have their own 'gold standard', which is based upon their experiences using the gel. As research has shown, AIDS medicines and prevention technologies are not only evaluated pharmacologically but also socially (Whyte *et al.* 2006). Etkin (1992) notes that side-effects which a health professional might dismiss as a proximal cause could be interpreted experientially by those using the drug as a primary cause, and therefore proof of efficacy. For some trial participants, vaginal discharge was not simply a side-effect, but was evidence of the cleansing properties of PRO 2000. Although developed and tested internationally,

participant responses to PRO 2000 drew from local ideas regarding pollution, flow and vaginal discharge.

Trial women's narratives highlighted the significance of the gel in promoting the flow of fluids within their bodies and between bodies, while condoms were seen to block this flow. The idea of flow not only defines physical health, but emotional and social well-being. Flow enhances intimate relationships and sexual pleasure, as well as reproductive and general health.

CONCLUSIONS

Trial participants in MDP 301 assured trial staff and social science researchers that they were aware that the efficacy of the gel was unproven, that they needed to use condoms, and that they would have to stop using the gel if they fell pregnant. Yet, at the same time, the unproven nature of the gel, the need to use condoms, and the warnings about pregnancy seemed to have little bearing on women's use and their experiences of condom and gel use. Their narratives of gel and condom use suggested alternative interpretations that subverted clinical certainties about condoms and the unproven status of the gel. Indeed, MDP 301 participants stated that they knew what trial researchers did not – that the gel worked.

Employing shared information, experiences and local conceptions of vaginal health, women independently evaluated the gel containing PRO 2000. This is to be expected. Around the world, individuals informally test the pharmaceuticals that they are prescribed, often reaching conclusions that differ from those of medical professionals. However, unlike these cases, PRO 2000 has yet to be proven clinically effective. As a result, women's knowledge of PRO 2000 was not directly contested by medical researchers. Possessing limited data regarding *in vivo* use, medical professionals and trial staff relied on the experiences of participants to gather information about the gel. The opportunity to make meaning within the clinical trial encouraged women to actively produce knowledge regarding PRO 2000.

Around the world, individuals informally test the pharmaceuticals that they are prescribed, often reaching conclusions that differ from those of medical professionals.

From a bioethical perspective this appears to suggest that women in the MDP 301 trial had confused 'treatment' and 'research', or shared a common therapeutic misconception regarding the efficacy of the gel. This is attributed to inadequate appreciation of the risks of participation in experimental procedures and trials (Lidz *et al.* 2004), and 'wishful thinking' amongst patients desperate for a cure (Sankar 2004). In prevention trials, therapeutic misconceptions could result in trial participants taking greater risks if they are under the impression that the product

is actually effective in preventing infection. It is thought that in clinical trials, individuals adjust behaviour in response to perceived changes in their vulnerability to disease (Kalichman *et al.* 2007). People who imagine or perceive that they are protected may take greater risks in their sexual relationships (McCormack *et al.* 2001).

Risk compensation is believed to be a significant flaw in HIV vaccine trials, circumcision, pre-exposure prophylaxis and treatment trials. (For examples see Cassel *et al.* 2006, and Eaton & Kalichman 2007.) It can have serious implications for policy and result in delays in rolling out interventions. For example, despite recent studies that demonstrate the efficacy of male circumcision in preventing HIV acquisition in circumcised men, concerns are raised about the potential of 'disinhibition' amongst circumcised men resulting in increased sexual risk behaviour (Kalichman *et al.* 2007).

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In microbicide trials it is suspected that risk compensation could result in what is sometimes termed 'condom migration' (Foss *et al.* 2003; Minnis & Padian 2005; Short *et al.* 2003) or 'condom replacement' (Smith *et al.* 2005). Women will use the microbicide *instead of*, rather than *in addition* to a male condom, believing that they are protected. Yet, current candidate microbicides are not anticipated to be more efficacious than condoms. Replacing condoms with microbicides could therefore have an unfavourable impact on HIV spread (Karmon *et al.* 2003), although these fears have been somewhat diminished by evidence from modelling data (Foss *et al.* 2003; Smith *et al.* 2005). In trial settings, condom replacement is a particularly critical ethical issue in terms of ensuring participant safety, although reported condom use often increases owing to the intensive counselling received by trial participants (Family Health International 2008, 37; Malow *et al.* 2000; McCormack *et al.* 2001).

Even though MDP participants believed that PRO 2000 was effective, this was on very different terms to those of the drug developer, trial designers and researchers. PRO 2000 was designed as an HIV prevention technology that ultimately failed to show efficacy against HIV acquisition. Yet, women participants reinvented the gel as a technology that cleansed the body, encouraged vaginal hygiene, reinvigorated the body, and promoted intimacy within relationships and sexual satisfaction. From their perspective, PRO 2000 was a successful intervention. Many women said they were sad when the trial ended; they asked us: "Where are we going to get our gels now?"

CHAPTER 3
TALKING ABOUT TECHNOLOGIES

Technologies are not only experienced; they are a locus of representation. Conversations about condoms and gels permeated Johannesburg. Infused with meanings, rumours, narratives and dialogues about HIV prevention technologies have been understood as commentaries that express inherent experiences and truths about relationships between medical practitioners and medical subjects (Briggs & Mantini-Briggs 2004; Landecker 2001; van der Geest 2005; Whyte *et al.* 2002). Anthropologists have looked to narrative accounts[13] as a means of escaping the ubiquity of biomedical interpretation and empowering the perspectives and experiences of patients (Garro & Mattingly 2000; Hunt 2000; Kleinman 1988; Thomas 2008). Stories are expressive perlocutionary acts that can be employed strategically to simultaneously comment upon the lived world, as well as an idealised one. As Ochs and Capps (1996, 22) write: "Narratives situate narrators, protagonists, and listeners/readers at the nexus of morally organized, past, present, and possible experiences." In so doing, narratives affirm, negotiate, and contest social relations and hierarchies.

What tales of condoms and microbicides circulate through Johannesburg and what do they tell us? Throughout sub-Saharan Africa, tales of medical interventions and technologies have produced accounts of the malicious creation and spread of lethal diseases such as HIV, blood theft, clandestinely inflicted sterility, and the trade in, or theft of, body parts (Geissler 2005; Kaler 2009; Niehaus & Jonsson 2005; Scheper-Hughes 1996). Given the documented responses to previous medical research conducted in sub-Saharan Africa, we anticipated that similar narratives of harm were likely to appear in Johannesburg. As predicted, community members did recount rumours in which pharmaceuticals and medical procedures were portrayed as a tool through which malicious whites infected participants with HIV. Although often dismissed by medical researchers as misunderstandings, myths, or urban legends, anthropologists frequently assert that these statements persist, in part, because they reflect, negotiate, and contest contemporary concerns and anxieties. Tales of lethal medical interventions and pharmaceuticals can be regarded as a form of everyday protest - a weapon of the weak that is capable of articulating complex accusations (Geissler 2005; Kaler 2009; Newton *et al.* 2009; White 2000; Youde 2007).

While community narratives have the potential to comment on global relationships between medical researchers and subjects, we believe that tales of harm should not be reduced to a single sentiment or meaning. As we spoke to more and more township residents, we realised that tales of lethal technologies were not uncontested and did not exist in isolation. Instead, they were part of a larger series of complementary and contradictory narratives that explicitly addressed themes of gender, cash, social reproduction, morality and medicine. In some narratives, men were cast as promiscuous and resistant to wearing condoms. In others, women were portrayed as engaging in unprotected or risky sex for money. In still other narratives, those using the gel were depicted as virtuous volunteers, selflessly contributing to the advancement of science. Although each narrative was popular, none were universally endorsed. Some individuals made firm assertions, some speculated, and others reported the assertions and speculations of others. Consequently, the power of these tales lay in their articulation rather than their 'truth'. Rather than presenting a single uncontested perspective, HIV prevention narratives became a vehicle through which a variety of concerns were articulated and negotiated. As Treichler (1999, 126) writes: "Diverse voices, then, represent not diverse accounts of reality but significant points of articulation for on-going social and cultural struggles." Through tales addressing the role of medical technologies in South Africa, longstanding debates were unambiguously invoked via popular themes of economy, gender, and social reproduction. Reviewing each narrative in turn, we argue that condoms and microbicides are a vehicle through which on-going debates are continued regarding wealth, personhood and the 'spiritual insecurities' of post-colonial South Africa. Rather than being victims, community members were actively debating and shaping changing social, cultural, economic and political contexts.

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LETHAL TECHNOLOGIES

As medical researchers debate the origin and spread of HIV/AIDS pandemic, South Africans marshal social, economic, medical and historical evidence to explain how an incurable and deadly disease suddenly appeared, only to disproportionately affect black Africans. While a number of accounts currently circulate throughout the country, many popular narratives focus on conspiracy – a hidden plot to carry out a harmful act. One widely recorded rumour states that HIV was secretly and intentionally created as a tool of genocide (Epstein 2007; Niehaus & Jonsson 2005; Stadler 2003). Like many with whom we spoke, a female Sowetan asserted, "This [HIV/AIDS] is something that came from white people." Organisations

and individuals thought to support white interests were especially implicated. Some blamed Wouter Basson, the former head of the country's secret chemical and biological warfare project, Project Coast, during the apartheid era, while others accused the American government and the CIA.

HIV diagnostic and prevention technologies were considered to be one way through which the virus was maliciously spread (McNeill 2009). One woman explained, "Most people think things like condoms that are made by white people are the things that give black people diseases." We were repeatedly told that condoms were contaminated with disease-causing agents, notably HIV. As proof, individuals noted that despite the widespread distribution of condoms – a technology lauded for its ability to prevent HIV transmission – a great many people continue to contract the disease. Consequently, condoms available free of charge were blamed almost exclusively. One man commented, "The reason why you get condoms free is because they know that they infect people and spread HIV with condoms." In many cases, the lubricant that was specifically identified as containing pathogens. Another man commented, "Other people are asking themselves why condoms are oily – the lubrication that you get from condoms – and what kind of oil are they using. What about if it has infections…?" In an attempt to answer these questions, individuals conduct informal experiments. These most often consist of either filling a condom with water or unrolling a condom and immersing it in water. During such experiments, a noticeable film formed on the surface of the water, in which those present claim to discern worms, viruses or other pathogens.

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Tales of white malice, purposeful infection and the danger of HIV prevention technologies also suffused discussions of microbicide gels. Reflecting a common sentiment, a 28-year-old participant stated, "There are people who are saying that … white people are trying to kill blacks through the [gel]." Like condom narratives, some residents asserted that the gel distributed by the MDP 301 contained AIDS or deadly worms. Marshalling evidence to corroborate these accusations, individuals remarked that other microbicide trials had also put their participants at risk. Many had seen media reports regarding the Zambian Cellulose Sulphate trial, which was suspended after higher rates of HIV infection appeared amongst those using the product as compared to those randomised to the placebo. Several months after joining the trial, a 30-year-old participant reported, "My partner is supportive but since yesterday – after hearing that there were people who were using the gel and they became HIV positive – he started to

panic saying, "You see that gel of yours!' He does not trust it [the gel] anymore."

Trial procedures such as financial reimbursements and blood draws were also subjects around which narratives of harm were structured. As stipulated by the Medicines Control Council of South Africa, all trial participants received R150 (US$21) per clinic visit. Over twelve months, a total of R1 800 (US$258) would be collected for clinical appointments alone. Medical staff stressed that these payments were reimbursements for travel expenses, not fees for participation in the trial. However, actual travel costs were far lower than the sums being distributed. This discrepancy led many to speculate about the 'real' purpose of these payments. In some instances, reimbursements were said to be a 'bribe' intended to discourage participants from complaining about any 'side-effects' that resulted from gel use. In others, monetary compensation was explicitly linked to the threat of death. When asked about community views of the MDP 301 during a focus group discussion, one man volunteered:

> The people who stay next to me are scared because someone came here [to the MDP 301 clinic]. I mean the time the research had just started and when they tested her they found that she is HIV positive. Then after three days she started to become very sick and then after that she died. So, people are scared because they said when you come here they tell you your status, then give you R50, and the next day after drinking a cold drink that you bought with the money that they give you, you die.

Through discussions with people on the streets of Soweto and Orange Farm, we learned that some residents warned one another that any funds received as a result of trial participation would actually be used to 'buy your coffin'. As one 41-year-old woman succinctly noted during an interview, "They say you will die for the sake of getting R150."

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Another persistent narrative concerned the sale of blood. Accounts of blood selling were so widespread in Soweto and Orange Farm that community members nicknamed the microbicide trial clinic 'money for blood' (IsiZulu: *imali ye gazi*). Residents alleged that women enrolled in the trial received cash reimbursements as payment for blood that was drawn as a routine part of clinic visits.[14] Although the informed consent process included an explanation of these procedures, many participants felt that the amount of blood taken for testing and storage was excessive and potentially dangerous. Rather than a resource that could be easily replenished, blood was considered to be a substance that existed in limited quantities within the body. Once blood was depleted, health and wellbeing would be compromised. One

32-year-old woman commented, "Someone had told me that she knew someone who was participating in this study and they drew so much blood from her that she ended up weak." A few participants also reported that non-participants asserted that trial blood draws would lead to death.

Not only was the health of the community in jeopardy as a result of the blood draws, the 'payment' was thought to be inadequate. One older participant noted in an interview that "I have heard some women participating in the study saying that the money is too little because the blood taken in the clinic is too much." We were told in other participant interviews that women received only 'a little' money because the clinic staff were profiting from the sale of trial blood. As proof, one participant cited the expensive new cars that the clinic doctors drove through the poor township. Similar to the assertions of trial participants, residents also stated that R150 constituted only a small portion of the total funds that the clinic received. The bulk was thought to be appropriated by trial staff. In these narratives, the clinic was portrayed as endangering the lives of trial participants while simultaneously deriving profit from reselling their blood.

POSTCOLONIAL RELATIONSHIPS

Through medical interventions and technologies, the 'long conversation' between colonisers and colonised is continued (Comaroff & Comaroff 1991). From the introduction of colonial medicine and its portrayal of black bodies as fundamentally diseased, medical narratives have been suffused with social meaning (Comaroff 1993; Comaroff & Comaroff 1992; Saethre & Stadler 2009; White 2000). For decades, the disenfranchisement and segregation of the black population in South Africa was justified through the language of health. The Public Health Act of 1919, South Africa's first national health measure and one that would remain until 1977, advocated racial segregation as a means of arresting the spread of disease (Phillips 1990). Throughout the interwar years, as black migration to white urban centres swelled, health officials argued that a large metropolitan black population would lead to poor sanitation and increased rates of illness, justifying stricter influx controls (Comaroff & Comaroff 1992, 229; Jochelson 2001). While black people suffered from high rates of infectious disease, whites did not.

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At the same time that the apartheid system was being dismantled, the AIDS pandemic attracted more attention in South Africa and bore a family resemblance to these

previous scenarios. We were asked: "Do you remember the time we had the first vote and white people were not dying? Very few white people had AIDS." As township residents watched their family and friends succumb to the new disease, they did not, and still do not, see white people sharing that experience. Similar to earlier public health measures, those spearheading education campaigns and interventions appeared to be wealthy, white and (increasingly) foreign.

Situated within a postcolonial context, narratives of white malice, contaminated pharmaceutical products, and blood selling are made much more meaningful and credible (Geissler 2005; Kaler 2009; Niehaus & Jonsson 2005). Tales of Wouter Basson or of the CIA creating HIV as a biological weapon reflect a suspicion resulting from a long history of white oppression in South Africa. Products distributed free of charge, such as condoms and gels, were thought to be made specifically for black people. Several individuals noted that not only did white people refrain from using free condoms, but they also escaped high rates of HIV infection. One man asserted that the only safe condoms were those sold in stores. Transcending technology, stories about condoms and gels often linked economy, pathology and race. Similar to stories of contaminated condoms and gels, those of 'coffin money' and blood selling couple historical relationships with everyday observations, to link cash with injurious and exploitative procedures. These narratives reconfigure the relationship between researchers and researched by constructing a counter-epistemic community through which historical and contemporary relationships between 'poor Africans' and 'wealthy whites' can be expressed and critiqued.

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Bracketed by a continuing history of inequality, economic domination, and repressive public health, South Africans express a genuine reality – black people are disproportionately suffering the effects of AIDS, access to free condoms does not seem have slowed the epidemic, clinical trials have been proven hazardous, and meanwhile doctors continue to drive expensive vehicles. Examining rumours of organ stealing, Scheper-Hughes (1996, 9) writes, "The stories are told, remembered, and circulated because they are fundamentally, *existentially* true."

But responses to medical technologies and practices are not 'merely' critical commentaries on exploitation. They embody the deep personal, economic and social anxieties that suffuse the postcolonial world. Since the apartheid era, South Africa has experienced a rise in 'spiritual insecurities' (Ashforth 2005) and 'occult economies' (Comaroff & Comaroff 2000; Comaroff & Comaroff 1999), in which

harmful magic is employed to achieve monetary benefit. Exemplifying this trend, witchcraft is an acute source of concern throughout the nation. Much more than a system of explanation, witchcraft represents a fundamental threat to the social and moral structure of society (White 2000). However, witchcraft is not the only means through which these concerns are given voice. Sharing many of the themes found in witchcraft accounts, tales of medical interactions also provide a series of narratives through which spiritual insecurities are similarly negotiated.

Analogous to rumours concerning blood draws for HIV testing, the immoral exchange of blood for wealth and the misfortune that results from it are recurring themes in witchcraft narratives. Witches are accused of deviously taking innocent people's blood, giving it to witch familiars, and receiving cash in exchange (Bähre 2002). Although money is gained through these transactions, it is portrayed as 'unproductive and sterile', failing to benefit the wider society (Niehaus 2000, 50). These illicit exchanges threaten the very fabric of family and sociality. While blood is considered a vital bodily fluid, it also embodies notions of personhood. Conceptualised as the comingling of a man's white blood and a woman's red blood, the transfer of fluids during sexual intercourse is essential to the constitution of individuals and their relationships to one another (Thornton 2008). These exchanges acquire social legitimacy through the payment of *lobola* or bridewealth. *Lobola* is given for a woman's 'blood' or reproductive potential. In this way, blood and cash are necessary components to ensuring social continuity. If these transactions are perverted or hijacked – for instance when blood is stolen for profit – the foundation of society is put at risk.

Incorporating condoms, microbicides and medical procedures into longstanding narratives, spiritual anxieties permeated accounts of 'coffin money', blood selling and lethal medical technologies.

Incorporating condoms, microbicides and medical procedures into longstanding narratives, spiritual anxieties permeated accounts of 'coffin money', blood selling and lethal medical technologies. One participant's male partner reported that his close friend, with whom he had grown up in a rural homeland, believed microbicides were 'white people's witchcraft': "He said white people are bewitching them; they have put other people's sperm in the applicator and the woman inserts them inside her vagina so when a man have sex with the woman they do so on top of the other person's sperms." Other community members also noted the similarity between narratives of witches stealing blood and medical administrators selling blood.[15] We were told that medical staff resembled witches 'thirsty for their own child's blood' and blood draws were proof that the microbicide trial staff engaged in witchcraft. These statements not only stress the oppression of Africans at the hand of foreign

powers, they do so by invoking representations of an irreplaceable and priceless resource – lifeblood – without which health, self, and procreation would collapse (Stadler & Saethre 2010). As in narratives of illicit blood transaction, the alleged presence of foreign sperm in the gel endangers a legitimate exchange and undermines relatedness. Because wealth obtained at the expense of social reproduction can only lead to death, women who used the gel were said to buy their coffins.

CHEATING MEN AND DISHONEST WOMEN

Although portrayed as potentially lethal in some narratives, in others condoms are transformed into signifiers of fidelity and commitment.

Although portrayed as potentially lethal in some narratives, in others condoms are transformed into signifiers of fidelity and commitment. Monogamous HIV-negative couples, we were told, had no need to use condoms. Consequently, fidelity was often invoked to justify a lack of condom use. One woman commented, "My partner says that he cannot use a condom with me because we are staying together and there is no another person that he has sex with besides me." While in some cases foregoing condoms was a decision made by both partners, in others, it was not. When one partner wished to introduce condoms into a stable relationship, often the other viewed this act as indicative of promiscuity. A young woman from Johannesburg recalled:

> So, I talked to him and I said, 'What about for the sake of our health that we start using a condom whenever we have sex?' And he went like, 'What, are you crazy?' He said to me, 'Why don't you tell me the truth that you have found someone else because now you are more sexually active out there and that is why you are coming up with excuses that we use a condom. You know I am faithful to you and you are faithful to me so, why should we use a condom.' So, I tried to explain to him, but it was hard and I ended up not knowing what to say or how to express it. He then said to me, 'Why do you suddenly want us to use condoms, we are faithful to each other or are you cheating on me?' He also said that he is also taking a risk by having sex with me without using a condom, but he is doing it because he trusts me. He indicated that I trusted him [in the past] and he wanted to know why there is a sudden change now. So, I do not know whether I have done the right thing or what, but sometimes I regret saying it.

This narrative demonstrates the difficulties that many people in relationships encounter when advocating condom use. South Africans are well aware of the association between promiscuity and condoms. One male resident of Johannesburg summed it up in a focus group:

> I think the challenge with the condom is that the condom was made as if it's specifically for naughty people. Like someone here said that if you are going to have a girlfriend outside your regular

> relationship you can use it, but at home you cannot use it. Now it's like if you have a condom we comment that you are naughty.

Many people felt that suspicions of infidelity were indicative of a general lack of trust between partners. One partner did not have faith in the other's assertions of monogamy. This led to tensions between partners, as well as tensions between genders. As one man succinctly commented, "At the end, we do not trust each other."

A lack of trust resulted in two gendered discourses. The first blamed men as almost universally resistant to wearing condoms and, as a result, endangering the lives of women. A male Orange Farmer commented, "You know, us men, we are naughty when we have sex out there and then when we return home we do not use a condom and that is when we infect our partners." While some men engaged in this narrative, it was women who were the most adamant in their assertions about men's culpability. Claiming that men doubted the existence of HIV, they were incapable of monogamy, they wrongly believed that condoms contained HIV, and they routinely deceived women about their sexual activities, women invoked male attitudes and propensities regarding condoms to label men as ignorant, promiscuous, naughty, irresponsible and 'uncivilised'. In some instances, these statements were contrasted with positive ones regarding the behaviour of women. One woman said, "I can be faithful to my partner but you can never be sure about a man." Given this lack of trust, women expressed a desire for men to wear condoms but acknowledged that this choice was largely in the hands of their partners: "I tell him about the advantages of not cheating and the disadvantages of cheating. But he is the one to make the final decision." Considering the risk that many women felt they were taking, subjugation and sacrifice were common themes. We were told, "Men do not like to use a condom, that is why us women sacrifice. There is no one who sacrifices like women…"

Many people felt that suspicions of infidelity were indicative of a general lack of trust between partners.

Parallel to portrayals of cheating men were narratives casting women as greedy. Young unmarried women were regularly depicted as using men only as a means to access cash. Although these women were not referred to as 'prostitutes' (*magosha*) because they did not 'stand in the streets', they were nevertheless accused of relentlessly pursuing money and, in the process, transforming love and relationships into a commodity. A female Orange Farm resident noted:

> When they see money they pretend as if they love, meanwhile there is no love… Yes, there is someone who has a boyfriend that has money and she loves him because he has money. There are people who are close to that person and they

> tell you that he has money and he can give you money. You find that she does not love the guy but she wants his money. She even says he is ugly but he has money.

While concealing their greed from partners, women confided in others. In Soweto, some women referred to their boyfriends as 'ATMs' or 'checkbooks' (Wojcicki 2002a, 360). Valuing money over health, these women were said to refrain from asking a man to wear a condom if he gave her enough money, endangering her own health and that of her future partners. Greedy women were also cast as jealous and malicious. When discussing women who engaged in sex for money, one man commented, "They sometimes get jealous if you and your wife live happily together. This outside one knows already that she's sick she's got these gonorrhoea and such. The next thing she's infected you and you get into trouble with the lady of the house. So it's best just to use the condom."

Depicting women as greedy, deceitful and licentious, trial participation was marshalled as evidence of moral weakness.

Narratives of covetous women also suffused discussions of the gel. While tales of 'money for blood' and 'coffin money' portrayed women as victims of white malice, community residents expressed little sympathy for their plight. Depicting women as greedy, deceitful and licentious, trial participation was marshalled as evidence of moral weakness. The 'real' reason that women joined the trial – risking their health and their lives in the process – was a selfish desire for 'money all the time' and 'fashionable clothes'. These trial participants were cast as lazy, young, self-centred and untrustworthy – accessing cash without participating in the wage labour market, and then concealing their gel use as well as reimbursements from their partners.[16] Men and women of all ages made these statements. Many suggested that women accessing the trial for cash also engaged in sexual relations with numerous men.

Women charged with joining the trial solely as a means of obtaining cash were often accused of 'dumping' their gels. Gel dumping was described by a 32-year-old participant as follows: "A person will go into the [bath] room for hours, squeezing the gel out so that they hand over an empty applicator. Then they lie and say they used it. They are not using the gel. They are only coming here for money." Although none of the women we interviewed admitted to disposing of the gel, many stated that they had met or heard tales of gel dumpers. While sitting in the waiting room, one participant reported hearing another divulging that she had discarded the contents of five applicators. Whereas gel dumpers confided in other women, they attempted to conceal their actions from trial staff and their partners. In an effort to avoid discovery, some gel dumpers were thought to discard the gel in the 'long grass' and other secluded

locations. In one case, a participant described a woman who pretended to insert the gel in front of her partner as a means of concealing her dishonesty.

Similar to other narratives involving the insatiable desire for cash, accounts of gel dumpers implicated young, greedy, deceitful, promiscuous women. After participating in the trial for six months and commenting positively on the gel, one 36-year-old woman noted, "The majority of people dumping the gel are young people and those who did not disclose to their partners. They are only interested in money." In one Orange Farm focus group discussion comprised individuals not enrolled in the trial, a male noted that "[participants] come here because they want money." A female responded that many of these women are not in monogamous relationships and dump their gels. She added, "It is not right because they are just playing with RHRU [the trial coordinators]." Gel dumping was also said to be 'naughty' and fundamentally irresponsible because it endangered the scientific process. If the trial closed due to a lack of positive results, participants told us, it would be the fault of the gel dumpers.

Medical narratives not only reflected notions about relationships between white researchers and black subjects; they also formed part of a larger conversation concerning gender

GENDERED RELATIONSHIPS

Medical narratives not only reflected notions about relationships between white researchers and black subjects; they also formed part of a larger conversation concerning gender. Stories of cheating men and dishonest women mirror widespread dialogues regarding the changing relationships between men and women. Since the 1970s, sub-Saharan Africans have expressed concern over the growing independence of urban women, and the link between sexual relationships and monetary ones. Accounts of women engaging in 'transaction sex' have been increasingly documented by researchers (Harrison *et al.* 2001; Hunter 2002; Jewkes *et al.* 2003; Kaufman & Stavrou 2002). These narratives are often understood as a reflection of changing economic and gender relations (Cornwall 2002; Kaler 2006; Wojcicki 2002a, 2002b). As early as 1895, when the Kruger government introduced a £2 flat tax to be paid by all African males, cash has been a tool to encourage migrant labour (Gilomee 2003, 294). While mine workers took home cash to rural regions, family relationships were restructured as men were separated from their wives, children, herds and land for extended periods. Just as crucial, *lobola* payments shifted from cattle to cash (Murray 1981). Although men possessing steady work were now afforded the opportunity to choose a

wife without relying on the approval and resources of family members, those that did not have work faced an extended bachelorhood. Over the years the price of *lobola* rose alongside the cash economy, leading an increasing number of men to complain that taking a wife and starting a family were becoming ever more costly and prohibitive (Kaler 2006).

As men postponed matrimony, women obtained cash – in part – through transactional sex, which was often portrayed as the antithesis of *lobola*. Instead of remaining a virgin until the wedding night, the desire for cash was thought to motivate women to engage in premarital sex with a variety of partners. Once married, wives could be prompted to either deceive or divorce their husbands in the hopes of gaining greater resources from another man. Whereas *lobola* cemented procreative relationships, money gained from feigning love was thought to profit the individual rather than the collective. Women were said to purchase commodities for their sole use, such as fashionable clothes or perfumes. Associated exclusively with the female gender, these items did not, and could not, benefit the entire family. Money acquired via sex was often depicted as a threat to 'traditional' gender and family relations. During a focus group discussion with women from Orange Farm, all four present condemned 'selling your body' as immoral and stressed that it resulted in promiscuity and infidelity. Immediately after making these statements, the women contrasted this with *lobola*, which was 'good' because it demonstrated that 'your parents looked after you.' A force that is 'expressive and transformative' (Cornwall 2002, 971), commoditised relationships rearticulate and reshape gender and family interactions.

The changing relationships between women and men inform condom and gel narratives.

The changing relationships between women and men inform condom and gel narratives. When discussing men's reluctance to wear condoms, women remarked that their partners could justify their decision by invoking *lobola* payments. A Johannesburg woman said, "He paid *lobola* and even though he has not finished paying yet, that is the thing that tells him that he is my husband and I must not tell him to use a condom." Other women echoed these views: "Let's say that my boyfriend pays *lobola* for me and marries me. If I should even raise the condom issue, he will tell me that he didn't just ask for me from my family, he married me properly." While condom discourses invoke trust and fidelity, they also reference – either explicitly or implicitly – money paid for women either through *lobola* or transaction sex. Condom narratives and practices express meaning within a larger gendered economy.

Given the convergence of female participants, sexual activity, and cash reimbursements, the MDP 301 also became incorporated into existing gender dialogues. Framed by a wider unease regarding women's access to money via premarital sexual relationships, participation in the trial became a focus around which these notions were expressed. While older participants in stable sexual relationships were portrayed as honest and moral, young single participants were thought to be greedy, deceitful and promiscuous – terms similar to those used to describe women who sold their bodies to men. In these instances, the MDP 301 seemed to assume the characteristics of an illicit male lover, who provided women with a clandestine income but could also be deceived. Greedy participants were accused of 'playing with' RHRU, much like they supposedly did with their boyfriends. Instead of feigning love or hiding infidelity, trial participants cheated by dumping the gel, lying to clinic staff and then boasting to friends. Interestingly, community members asserted that women dumped gel in the long grass, where illicit affairs are thought to be conducted. Dumping the gel, like engaging in transaction sex, was portrayed as benefiting the individual while harming the collective by placing the success of the trial at risk and threatening the development of a pharmaceutical that could conceivably benefit millions of African women. Through these accounts, the MDP 301 was transformed into a vehicle for conveying local gender concerns regarding who should be having sex and for what reasons.

PREVENTION AND POWER

Stories of lethal technologies, cheating men, and dishonest women led some community members to confront women using the gel or to confront men who refused to wear condoms. Trial participants reported being taunted for selling their blood to the clinic, accused of enrolling in the study for remuneration, and attempting to infect others with HIV. Faced with these indictments, women taking part in the MDP 301 – as well as their male partners – reframed these discussions by highlighting their own agency and questioning the accuracy of popular narratives. Dismissing accounts of HIV-laden gels, bribes and 'coffin money', some women claimed that these stories were the result of ignorance and misinformation. Despite news coverage of the Zambian Cellulose Sulphate trial and the concerns of her partner, a participant mentioned earlier did not believe that the MDP 301 was putting her health at risk. She commented, "You know when we talk like this we must know that the media lies sometimes or exaggerates things. They add inaccurate information to get

Stories of lethal technologies, cheating men, and dishonest women led some community members to confront women using the gel or to confront men who refused to wear condoms

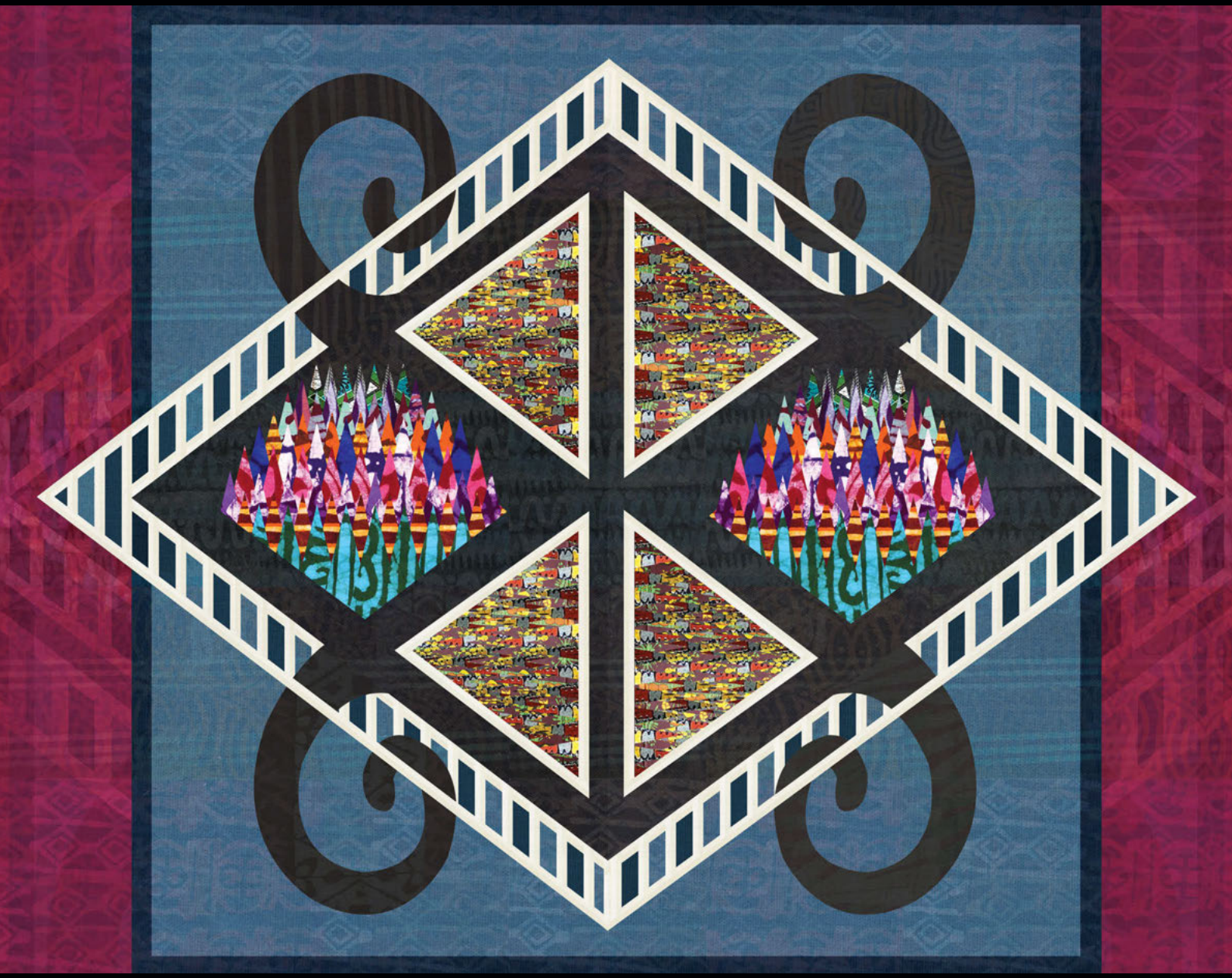
people's attention." Similarly, the 32-year-old woman who had been told that blood draws led to ill health, enrolled in the MDP 301 trial despite these tales because "the girl was lying". Individuals using neither the gel or condoms were repeatedly cast as basing their opinions on hearsay and supposition, rather than on fact and experience. The man who had equated the MDP 301 with witchcraft was described as "an uncivilised person who does not believe in this science stuff." Men that refused to wear condoms claiming that they were infected with HIV were similarly dismissed as ignorant and 'uncivilised'.

While rumours of harm were rejected as uninformed and unfounded, individuals who failed to employ measures to prevent contracting HIV were depicted as indolent, irresponsible, promiscuous and jealous. We were told, "You know other people just want bad things to happen to them. How can you allow your partner to have sex with you without using a condom even if you can see people are dying?" A primary theme in these counter-narratives was HIV status. An unwillingness to use condoms or to join the trial was equated with an unwillingness to be tested for HIV. These individuals were sometimes referred to as 'cowards', 'lazy' and 'not doing anything in their life or about their health'. One woman commented, "I think [condoms] prevent HIV, it's just that people do not want to use it. You can find people who have sex with many partners – that is why other people think condoms don't work." Fear of condoms, the gel or HIV testing was marshalled as proof that some community members were promiscuous and, as a result, could not be trusted. After participating in the trial for only a month, a woman commented, "Some say that the gel will infect women with HIV/AIDS because they are paying women who are using the gel. And I do not believe what they are saying because they know that they have multiple partners and that is why they say all these things."

Although trial participants criticised women that chose not to join the MDP 301, they also condemned fellow participants who enrolled simply for financial benefit.

Although trial participants criticised women that chose not to join the MDP 301, they also condemned fellow participants who enrolled simply for financial benefit. We were told that it was 'wrong' for women to 'waste' the gel by dumping it. After spending a year in the trial and regardless of her concern that the clinic had been 'taking too much blood' from her, one participant noted:

> I have noticed that many of them joined the study because they like the reimbursement. And I tell them I joined the study without the knowledge of the reimbursement and I did it because I wanted to be part of the study. And some of them dump the gel because they only need the money that they get from the study.



A clear distinction was made between women who had joined the trial for the reimbursements and those that had not. We were told that for some the trial was 'like a job', but others were 'volunteering'. When we asked a focus group of seven participants in Soweto how they would respond if the cash payments were discontinued, one told us, "I did not come here for money, we are here for our safety." This statement was echoed by others in the room. Declarations such as this were common in focus group discussions and in-depth interviews. Rather than being motivated by cash, women reported that they enrolled for the security of knowing their HIV status and receiving regular physical examinations.

For the majority of 'volunteers', medical procedures were viewed as an important method through which their wellbeing was monitored.

For the majority of 'volunteers', medical procedures were viewed as an important method through which their wellbeing was monitored. In these narratives, blood draws – although sometimes still a source of anxiety – were recast in positive terms. One participant commented, "Yesterday they took ten bottles of blood and I asked myself, 'What are they are going to do with my blood?' Then I told myself that maybe my blood was good, that was why they took ten bottles." Because participants possessed 'clean' or uninfected blood, some asserted that the trial donated their blood to health facilities and private individuals for transfusions. Blood collected in the clinic was 'going to work for someone who is sick' and 'helping people'. We were told that the reimbursements were intended to purchase food and other items that would nourish participants and replenish their blood.[17] Instead of being used to buy luxury feminine items, reimbursements were conceived as an exchange that benefited those in need, rather than a payment in the strict sense. In this narrative, cash for blood was portrayed altruistically. In addition to aiding those who required clean blood, women asserted that their involvement in the MDP 301 could potentially benefit people around the world. If the gel was found to be efficacious, it could prevent millions of other women from contracting HIV. During the Soweto focus group of seven women that was discussed in the previous paragraph, another participant added:

> People talk too much about the gel because it's not them using it. When they are testing the gel on us, it's what we want. It is true when they say we are taking risks – so what? I am proud of what I am doing because I want to see if this gel works so it can help many people. That is why at the end I tell myself that I am a lifesaver and I feel good about it.

Rather than casting doubt on the motivations of all participants as greedy and avaricious, women enrolled in the trial portrayed their motivations as selfless and moral.

AGENTIVE RELATIONSHIPS

Accounts of preventative technologies challenged the notion that individuals employing HIV prevention technologies posed a fundamental threat to society, while simultaneously addressing divisions and tensions between trial women and the local community. Whereas some residents depicted trial enrolment as an indicator of greed, deception, promiscuity and immorality, participants invoked their HIV-negative status to contest these claims. Popular themes of malice, gender and cash were reconfigured to portray non-participants as ignorant, jealous, malicious and potentially HIV positive. When confronted by community members asserting that she would die 'for the sake of getting R150', one woman responded, "I tell them that I am better because I know my health and I am even aware of my HIV status." These assertions functioned as a powerful declaration, particularly in a nation where people living with HIV are often stigmatised (Mills 2006; Petros *et al.* 2006; Robins 2006). Stressing that gel use was contingent upon remaining HIV negative, enrolees demonstrated their own health and morality, while calling into question that of others. As one young participant from Orange Farm commented, "We are different because if you join the study it means you are responsible about your life. So those ones who did not join the study, they do not care about their life."

Concerned for the collective good rather than for individual profit, 'volunteers' acknowledged that they were willing to take risks in an effort to contribute to the testing and development of HIV prevention technologies.

Although women asserted that some individuals enrolled in the trial for monetary rewards, these statements were contrasted with beliefs regarding 'volunteers' and 'lifesavers', which portrayed the activities of the speakers as largely beneficial. Concerned for the collective good rather than for individual profit, 'volunteers' acknowledged that they were willing to take risks in an effort to contribute to the testing and development of HIV prevention technologies. Similarly, blood sale was transformed from a dangerous and selfish act into a long-term productive relationship between the providers of medical technologies and the recipients. Stating that they purchased foodstuffs rather than fashionable clothes or perfumes, trial participants emphasised that reimbursements were used to potentially nurture an entire family. Like *lobola*, 'donating' blood at the trial clinic was framed as an instance in which the exchange of cash for blood engendered legitimate bonds. Women's insistence that they were involved in a reciprocal relationship with the clinic – a cyclical flow of lifesaving blood for blood-renewing cash – transformed what some viewed as an amoral act of consumption into a model example of social and procreative relations. Instead of

attacking the very basis of relatedness, women claimed to be engendering life, health and personhood through their use of the gel.

Standing in stark contrast to tales of lethal technologies, those of virtuous volunteers significantly reframed the relationship between medical researchers and clinical trial participants. Rather than exploitative enterprises, medical interventions are depicted as ultimately constructive. Imparting a variety of resources to its participants, the MDP 301 trial allowed women to assert claims regarding their probity and agency. By enrolling in the trial, women were able to monitor their health, obtain access to cash that was not controlled by men, and become valued contributors to medical research. Participants remarked that clinical trials made affluent, white and foreign medical professionals dependent upon poor black women (Saethre & Stadler 2010). The MDP 301 study allowed women to invert global relationships while simultaneously restructuring local narratives of gender, cash and sex.

Imparting a variety of resources to its participants, the MDP 301 trial allowed women to assert claims regarding their probity and agency.

In addition to the discursive power of remaining HIV negative, women were able to use their health status to justify their own agency in relationships. While some women spoke about sacrificing for men, others urged them not to compromise, as their health was at stake: "Women have to be strict and tell their partners that without condoms, then there will be no sex. No sex, no play!" Gender norms could be challenged – at least verbally – when health concerns were invoked. Despite these entreaties, many women were unable to convince their partners to use condoms, leading some to employ deception. Nervous about her health, one woman said, "When I feel like we use a condom I just tell him that I am about to menstruate. That is how I trick him to use a condom." Menstruation acts as an important natural process through which dirt is removed (Jewkes & Wood 1999; Leclerc-Madlala 2002), resulting in a belief that menstrual blood is potentially polluting (De Heusch 1980; Hammond-Tooke 1981; Ngubane 1976; Niehaus 2002; Pauw 1990). Wishing to avoid all contact with menstrual blood, men wear condoms to protect themselves. Modifying this strategy, women also invoked gel use to prompt men into using condoms. Misleading her partner by telling him that she would be using the gel for five years instead of only one, she said:

> I am doing this because I am thinking of my own health. I feel I had a weapon to use in the house so that he can use a condom. I told him that they gave me the gel and it is supposed to be used with a condom. So, I told him that so that we can continue to use a condom … I thought that if I told him that I had finished using the gel, he may stop using a condom.

While rumours of condoms infected with HIV allowed men to resist the accusation that male sexuality was 'irresponsible' (Stadler 2003, 364), concerns over the safety of the gel were used by women to prompt condom use. Narratives of lethal – or at least potentially polluting – technologies were actively and strategically invoked to ensure that another technology – condoms – were used. Transcending a static utilitarian function, HIV technologies can be imbued with a multiplicity of meanings, which are routinely manipulated and negotiated.

Although unanticipated by its inventors, HIV prophylaxis technology itself encouraged community members to create signification. Introduced to support female autonomy in HIV prevention, microbicide gels were designed as a technology that could be used without the tacit knowledge of a sexual partner (Bell 2003; Mantell *et al.* 2006). In a setting where 'HIV risk' is often equated with 'multiple-partner sex', microbicides can appear to be a technology for promiscuous women. Not only do microbicides address sexual norms, their ability to be concealed also restructures overtly gender relations. Assuming that some women would choose to hide their utilisation of a microbicide gel, the MDP 301 trial did not require participants to inform their partners of their enrolment. Consequently, it is hardly surprising that the trial became a locus around which narratives of women's agency were debated. Through the process of witnessing, discussing and participating in the trial, residents of Orange Farm and Soweto fashioned the MDP 301 trial into a tool through which on-going social processes and insecurities were affirmed, debated and contested. While the MDP 301 study was successful in providing women with pharmaceuticals and reimbursements that could be concealed from men, in so doing it ignited fears that gender relations and social reproduction would be fundamentally challenged. In considering that microbicide technology was developed to aid young unmarried women, it is ironic that the residents of Orange Farm and Soweto often equated sincere trial participation with stable sexual relationships and disclosure to partners. The different significations of microbicide gels – and medical technologies and interventions generally – highlight the importance of anthropological research within medical settings, particularly in regard to issues of recruitment, adherence and acceptability.

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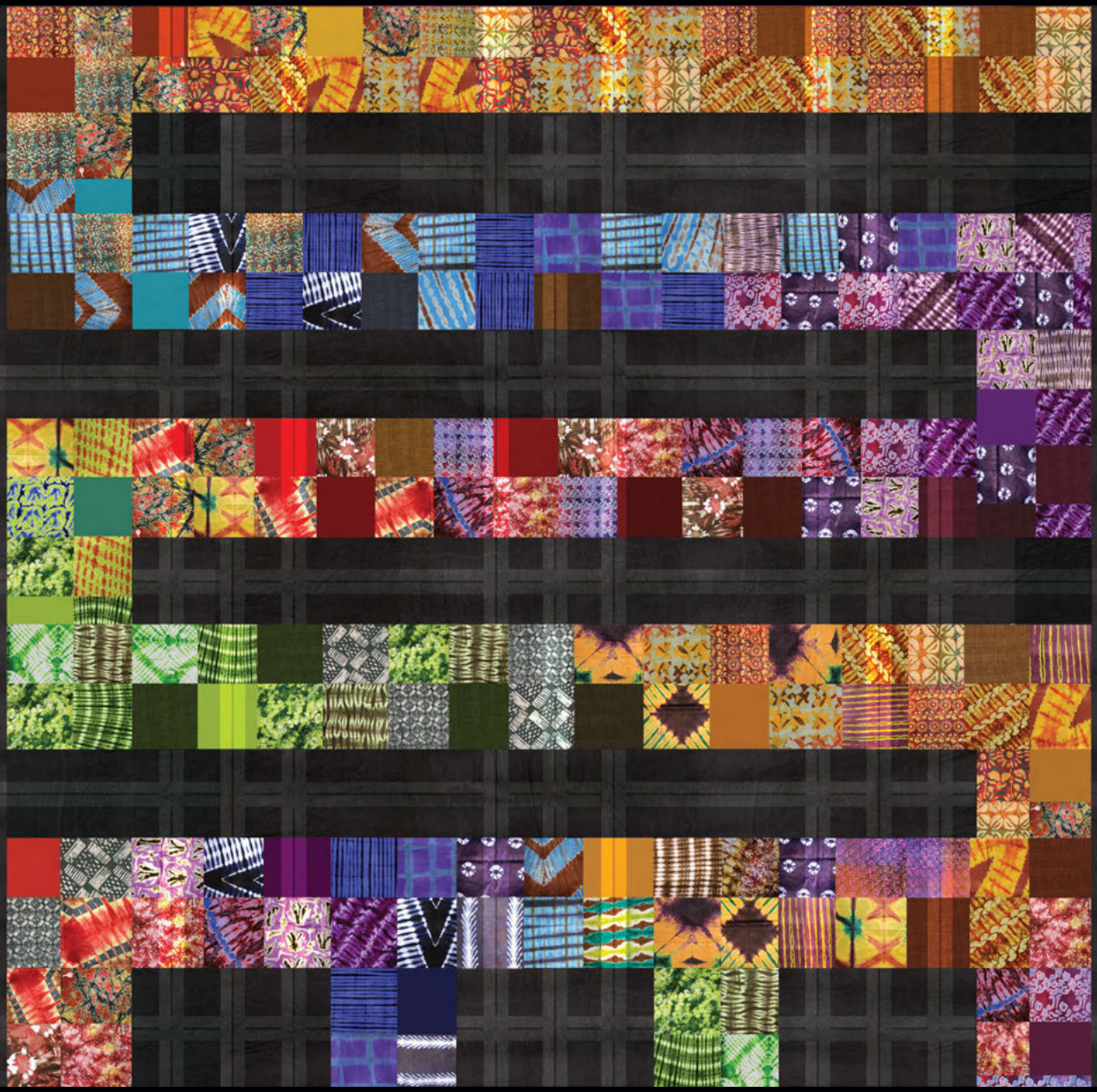

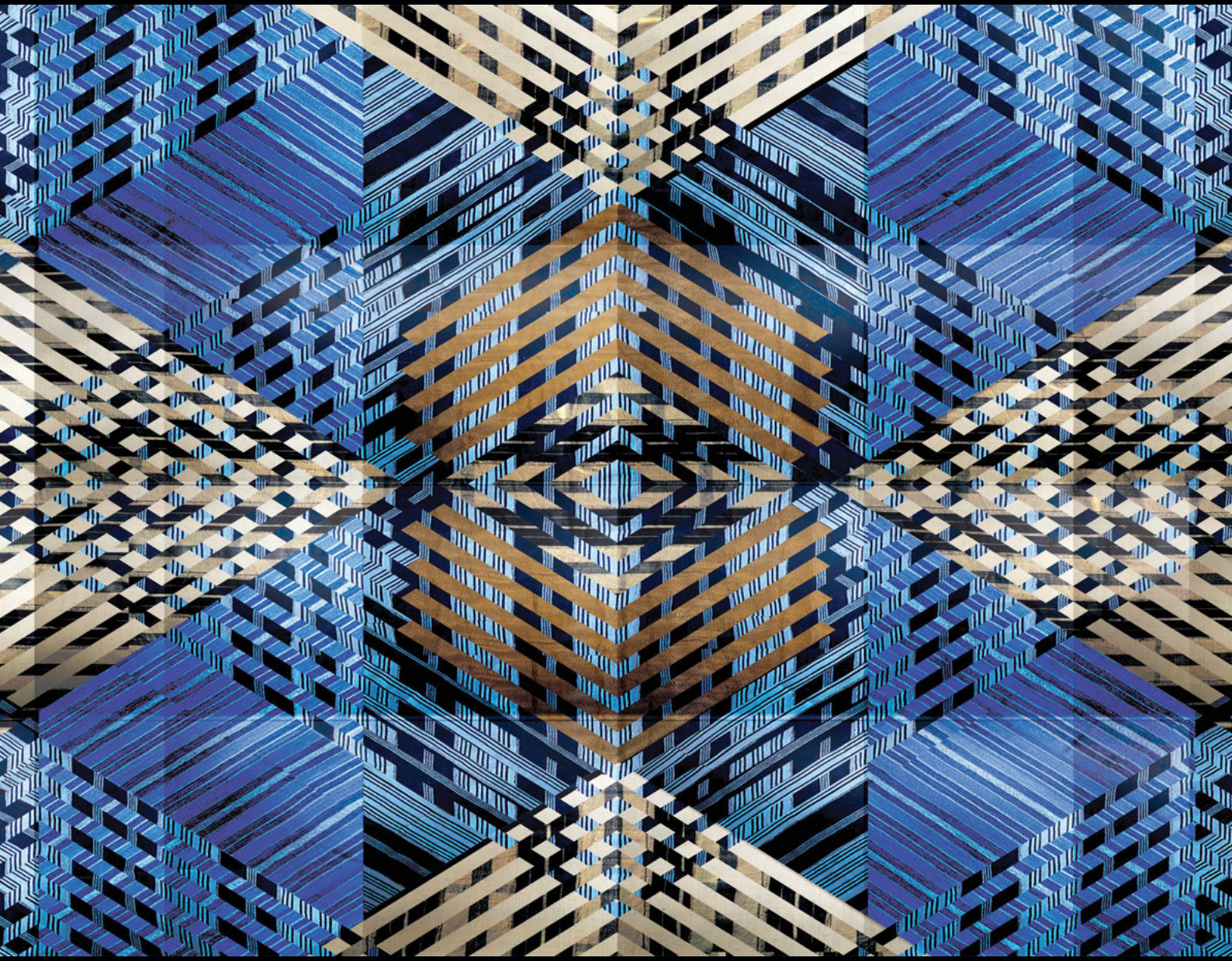

CHAPTER 4:
TRANSNATIONAL MEDICAL MEANINGS

Pharmaceuticals have increasingly become one of the most effective tools to battle disease. However, for many people living in the developing world, the availability of drugs is limited. Although treatments exist for diseases such as HIV, malaria and tuberculosis, their high cost restricts use. The World Health Organization (2004) estimates that over one third of the world's population is denied regular access to medicine. Hoping to increase life expectancy in developing nations, the distribution of pharmaceutical products and other medical technologies has become a global health priority. In many settings, access to medication is equated with improved health outcomes. This is particularly true during an epidemic. Currently, sub-Saharan Africa has the highest number of AIDS cases in the world, while South Africa has the distinction of being the African country with the largest population of HIV-positive people. An estimated 5.4 million of 48 million South Africans are infected with HIV, a total population prevalence rate of 11 percent (Dorrington *et al.* 2006). Consequently, a great deal of work has been undertaken to determine and document the main factors that contribute to the spread of HIV in South Africa. Sex with multiple partners, unprotected sex, transaction sex, violence and poverty structure individual's vulnerabilities to HIV infection (Gilbert & Walker 2002; Harrison *et al.* 2001; Hunter 2002; Jewkes *et al.* 2003; Kaufman & Stavrou 2002; MacPhail & Campbell 2001; Wojcicki 2002a).

Neatly quantifying disease and claiming to accurately describe the reality of the HIV/AIDS pandemic, statistics are employed to naturalise difference and motivate action. Lea (2008, 119) asks, "Why do 'we' know about being healthy? Because 'we' are structurally enabled to produce and consume the information; we know about the risks, and in a liberal politic, access to information equates to power to act." The result of these actions – prevention policies, condom initiatives, and clinical trials – portray illness and those most at 'risk' in a circumscribed manner. Examining the rhetoric and reality of development initiatives in Lesotho, Ferguson (1990) asserts that policy documents homogenise and delineate peoples and nations. Countries are portrayed as having geography but not

history; government but not politics. Similarly, strategies seeking to address HIV in sub-Saharan Africa tend to focus on popular conceptions of African-ness, while forgetting the complexity of lived experience and everyday meanings. In some instances, medical interventions, such as clinical trials, have been portrayed as unethical and harmful. Thought to be controlled by multinational pharmaceutical companies based in the North, medical research in the global South has increasingly come under fire for enrolling vulnerable populations.

While acknowledging critiques of international medical practice, it is important to recognise the power of individuals in South Africa to evaluate these interventions and technologies on their own terms. Just as medical research creates and propagates social meaning, so too do the people who utilise the results of that research. As condoms and gels are employed (or not employed) in people's everyday lives, these technologies acquire their own unique signification. In some cases, these meanings could be quite different to those intended by medical professionals. In this final chapter, we explore the ways in which medicine and medical technologies are employed to construct and perpetuate social categories. We assert that in epidemics, risk and hope play vital roles in the conceptualisation and development of medical technologies. Finally, we revisit the ways in which residents of Johannesburg understand and experience these technologies.

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COLONIALISM, MEDICINE, AND CULTURE

For centuries prior to the HIV/AIDS pandemic, Africans and African sexuality have been exoticised by European explorers, researchers and scientists. Treichler (1999, 207) notes that "little known sexual practices" have been "a long-standing obsession with Western observers of Africa and other 'exotic' cultures." As early as the 18th century, Africans were associated with deviant sexual practices (Gilman 1985). By the 19th century, some scientists and race theorists were asserting that the peoples of Africa comprised a species that was distinct genetically from other humans (Stillwaggon 2003, 816). Throughout the Victorian era, African sexuality was described as wild, animal-like, exotic, irrational and immoral (Gausset 2001, 510). Sexual aberrations were seen to be symptomatic of the social and physical afflictions that were believed to plague an entire continent and its people. Black bodies were associated with 'degradation, disease, and contagion' (Comaroff 1993, 306). These themes continue to play a role in research dedicated to understanding both the origin of HIV/AIDS and its impact upon the continent.

In the 1980s, when researchers were seeking to find the origin of HIV, some popular theories also incorporated themes of blackness, aberrant sexuality and disease. Initially, both Africa and Haiti were considered possible environments that fostered and spread HIV. In each case, theories explaining the mechanism through which the virus 'jumped' from animals to humans tended to focus on exotic cultural practices. Karpas (1987) asserted that sexual practices involving the use of monkey blood in the Rift Valley region could be responsible. It was even suggested that perhaps Africans had sexual intercourse with monkeys (Sabatier 1988, 50). In Haiti tales of exotic voodoo rituals, such drinking animal blood, were theorised as yet another way that the virus could have entered the human population (Farmer 1992; Shannon *et al.* 1990). In the case of both Haiti and sub-Saharan Africa, black bodies, disease and culture were inextricably linked. Although initially there was little scientific data to support these claims, the allegations were disseminated in both scientific and popular publications. As the years progressed and medical and epidemiological data regarding HIV became better understood, themes of deviant sexuality, disease and culture continued to permeate behavioural explanations regarding the high prevalence of HIV in sub-Saharan Africa (Marshall 2005).

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Just as there has been a long tradition of associating sub-Saharan Africa with deviant sexuality and disease, the concept of culture has historically been used to delineate and emphasise difference. In each case, this difference is explained by appealing to factors that are largely beyond the control of the individual – biological hierarchy versus cultural conditioning. Malik (1996, 159) writes, "Culture seemed to provide a mechanism whereby the particularities of a people could be conveyed unchanged from generation to generation and one, moreover, which suggested an explanation for the seemingly immutable differences between different social groups." Consequently, the concept of culture was used to effectively account for human variation in a way that biological theories of the time could not. Stocking (1982 [1968], 265) notes that the new anthropological concept of culture "provided a functionally equivalent substitute for the older idea of 'race temperament'." Although championed to bring an end to racial theories, culture became a new medium through which differences could be explained. In a South African context, Macleod and Durrheim (2002, 788) comment, "In the place of biological 'scientific' racism, we have a 'new racism' in which 'culture', 'tradition' and 'ethnicity' perform the work previously achieved by the category of 'race'." They note that South African research publications assume that black individuals are

motivated by culture in a way that white people are not. Furthermore, it is primarily 'troubling' behaviours that are attributed to culture.

Within the context of HIV/AIDS research, culture continues to be a marker of difference in much the same way (Bibeau & Pedersen 2002; Briggs 2005). Many behavioural explanations also highlight 'troubling' behaviours, notably sexual practices, and then attribute these proclivities to culture. Such an approach succeeds not only in linking culture and race but also culture and illness. Mirroring earlier views of Africans as sexually deviant and diseased, behavioural explanations that focus on culture as one of the leading contributors to the high rates of HIV in sub-Saharan Africa, provide scientific and medical proof that African culture is not only different, it is pathological. As Briggs (2005, 276) writes, "Using liberal languages of multiculturalism, cultural features are pathologised by linking them to notions of biomedical causation." Through HIV/AIDS research publications and a health discourse of risk behaviour, social categories that are based on historical and ideological representations of the Other become naturalised and accepted as scientific fact.

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Disease and medicine have been, and continue to, be powerful ways of explaining the world. Medical narratives often reflect social ones, particularly in colonial and post-colonial environments (Bibeau & Pedersen 2002; Crandon-Malamud 1993; Marshall 2005; Treichler 1999). These social meanings become particularly evident in epidemics, which Fassin (2007, 32) characterises as "moments of truth when both knowledge and power are put to the test." Uncovering rather than inventing, epidemics create a space through which social beliefs and attitudes are laid bare. Furthermore, medical narratives and interventions aimed at eradicating health inequalities can play a pivotal role in articulating an identity for citizens (Briggs & Mantini-Briggs 2004). The portrayal of African culture as dangerous and biomedical intervention, such as condoms or anti-retroviral therapy, as efficacious, both constructs and reinforces ethnic and racial boundaries between white and black. Consequently, while it is possible to medically identify the risk factors involved in HIV transmission, the way in which these factors are portrayed – in terms of individual behaviour that is the result of culture – are far from neutral.

THE PROMISE OF TECHNOLOGY

While routinely cast as culture-free, biomedicine is thought to provide efficacious solutions – pharmaceutical products,

medical technology and best practice protocols – to combat the health threats posed by local beliefs. Consequently, biomedicine has been characterised as a "culture of no culture" (Taylor 2003). Nonetheless, biomedical protocols, practices and diagnoses are increasingly viewed as reflecting and constructing social categories, identities and norms. Activities and rituals such as the prescription of pharmaceutical products at a doctor's office or washing hands prior to surgery can be viewed as sacraments, physical instantiations of belief (van der Geest 2005). Through the process of transforming health and illness into moral categories, we are taught who we are and how we should behave.

Biomedicine has been characterised as a "culture of no culture".

Biomedicine has become increasingly linked to technological innovation and practice. As medicine expands its knowledge of the human body and disease, it does so through sophisticated equipment and machinery. Examining the 'biotechnical embrace', Delvecchio Good (2007) notes that technology plays a critical role in the acceptance of medical paradigms and perspectives. On one hand, medicine is embracing. Through the use of diagnostic techniques and treatment protocols, technologies become routinised. On the other hand, medicine is embraced. Accustomed to the use of biotechnologies, patients often invest hope in experimental treatments. Rather than seeing the use of medical technology as impersonal or alienating, it is perhaps more accurate to view it as capable of embodying and shaping notions of who we are.

The use of ventilators, CT scans, in vitro fertilization and genetic testing are becoming ever more commonplace. Now a standard diagnostic technique, ultrasounds have reconfigured notions of pregnancy. While mothers-to-be experience the embodied changes that accompany pregnancy – gaining weight, swollen breasts, the movement of the foetus – ultrasound images have become just as much a part of pregnancy in North America and Europe. What began as fuzzy black and white images viewed during an appointment have been transformed into three-dimensional photographic renderings that can be distributed to family and friends. Browsing social media such as Facebook reveals parents creating accounts for unborn children and posting ultrasound images as their first photos. Much more than a tool for visualising the foetus, the role of ultrasounds in maternal bonding has been evaluated (Taylor 2008). Identifying the sex of the child prior to delivery, ultrasounds bequeath an identity of either male or female. This informs decisions regarding purchasing, such as what colour clothes to buy. Ultrasounds have been transformed from a diagnostic instrument, into one that imbues personhood. Furthermore, this identity is firmly grounded within existing social, cultural, economic and political contexts.

Examples of expanding technologies, condoms and microbicides similarly act as tools through which identity is negotiated and reconfigured. As the HIV/AIDS pandemic continues, condoms and microbicides embody hope. If used correctly, condoms will prevent the transmission of HIV. Consequently, public health campaigns invariably focus on the distribution and use of condoms. Nevertheless, in many regions of the world, such as South Africa, condoms are not regularly worn. A great deal of research has sought to address why a technology that has been proved to prevent illness is not being utilised. Lack of condom use has been explained in terms of a patriarchal 'culture' in which women's well-being is subsumed by men's desire, whereas rumours of HIV in condoms are dismissed as superstition and ignorance. Often blaming the disuse of condoms on cultural causes, health professionals have attempted to alter this behaviour through education programmes. Pamphlets, billboards and television advertisements repeatedly stress the importance of condom use. Like ultrasounds, condoms, and discourse surrounding them, constructs identities.

Examples of expanding technologies, condoms and microbicides ... act as tools through which identity is negotiated and reconfigured.

Tied to notions of the responsible and rational citizen, the use of HIV prevention technologies embodies morality. On speaking with a nurse whose task was to interview women about their use of condoms, she remarked she was careful not to be judgemental. She added that if a woman hesitated when answering, it was often because condoms were not worn. The nurse commented that in these cases she would ask, "Have you been naughty?" Charged with avoiding blame, the nurse nevertheless engaged in a discourse of morality when interviewing women about their sexual practices.

Developed as a response to the widespread disuse of condoms, microbicides are also pregnant with meaning. Although not conclusively proven to reduce the likelihood of HIV transmission, microbicides nevertheless embody hope. Developing a technology that women could control and use covertly would seemingly circumvent men's indifference to prophylactics. This technology is seen as a way in which the barriers posed by culture could be successfully surmounted. As a result, a great deal of financial and medical resources has been devoted to developing and testing microbicides. DelVecchio Good (2007) asserts that it is through experimental treatments and the 'political economy of hope' that a medical imaginary is created. She notes that a lack of empirical efficacy can be largely ignored in favour of an anticipated outcome. Playing a kind of medical 'what if', new technologies are created and tested in the hopes that one day they will prove effective. This is particularly true within the context of medical crises and pandemics (Petryna 2006).

As health initiatives often portray condoms and microbicides as a tool of biological salvation, many people in Johannesburg echo these narratives. Women, in particular, discussed condoms as an effective method of preventing HIV. Many microbicide trial participants similarly viewed the gel as having the potential to arrest the spread of the disease across the continent. Nevertheless, these narratives were not universally accepted by the residents of Johannesburg. Rather, a range of rumours, stories and musings permeate everyday interactions. Although condoms and microbicides can be portrayed as a means of preventing HIV, they have also been implicated as a tool through which infection is purposely transmitted. In these accounts, biotechnologies are transformed into vehicles of death. Rather than being mere misunderstandings, narratives of lethal biotechnologies reflect the contemporary environment, including the presence of largely white and increasingly foreign health professionals, changing gender and family roles, and the function of cash in social reproduction. Transcending medical dialogues, these concerns are reflected in anxieties over spiritual insecurities throughout South Africa.

While biotechnologies acquire meaning through the social contexts that surround them, the actual experience of their use also impacts the ways in which individuals interpret their efficacy. Unlike pills or many other pharmaceuticals, use of these biotechnologies requires negotiating latex and applicators. Furthermore, condoms and microbicides are objects that are utilised in very personal ways during very intimate moments. Sexual intercourse is closely associated with pleasure, affection, health, physical reproduction and social reproduction. Consequently, condoms and microbicides are thought to impact on each of these factors. But these meanings are not arbitrary. Through physical experiences of blockage and flow, condoms and microbicides become incorporated into existing beliefs regarding health, illness and fertility.

While biotechnologies acquire meaning through the social contexts that surround them, the actual experience of their use also impacts the ways in which individuals interpret their efficacy.

Etkin (1992) notes that side-effects which a health professional might dismiss as a proximal cause could be interpreted experientially by those using the drug as primary, and therefore proof of efficacy. For some individuals, vaginal discharge was not simply a side-effect, but was evidence of the cleansing properties of PRO 2000. Similarly, by preventing semen from entering the vagina, condoms could be cast in the role of inhibiting flow, and therefore dangerous.

Replicating discussions that cast medicine as authoritarian and controlling, there has been a tendency to view clinical trials as corporate enterprises that victimise their participants. Littlewood (2003, 256) suggests many medical

anthropologists have transformed the relationship between doctors and patients into that of colonialists and the Other. Rather than producing a single narrative with a single meaning, condoms and microbicides functioned as a wellspring of resources – conceptual and financial – which was exploited and manipulated. Employing common themes with shifting meanings, both use and non-use were a source of alternating criticism and power. We suggest that the globalisation of biotechnology should not be viewed simply, and unproblematically, as a project that is solely created and controlled by Western organisations, or that medical narratives are invariably, and continually, structured around the reified dichotomies of doctor/patient, global/local, victimiser/victimised, and coloniser/Other. Although these themes were present in narratives and experiences of some Johannesburg residents, others focused on gender, witchcraft, morality and marriage. Consequently, understandings of condoms and microbicides should encompass not only local views of the global but also local views of the local. These technologies are imbued with signification, dynamically negotiated by community members, and, as a result, actively transformed into local entities.

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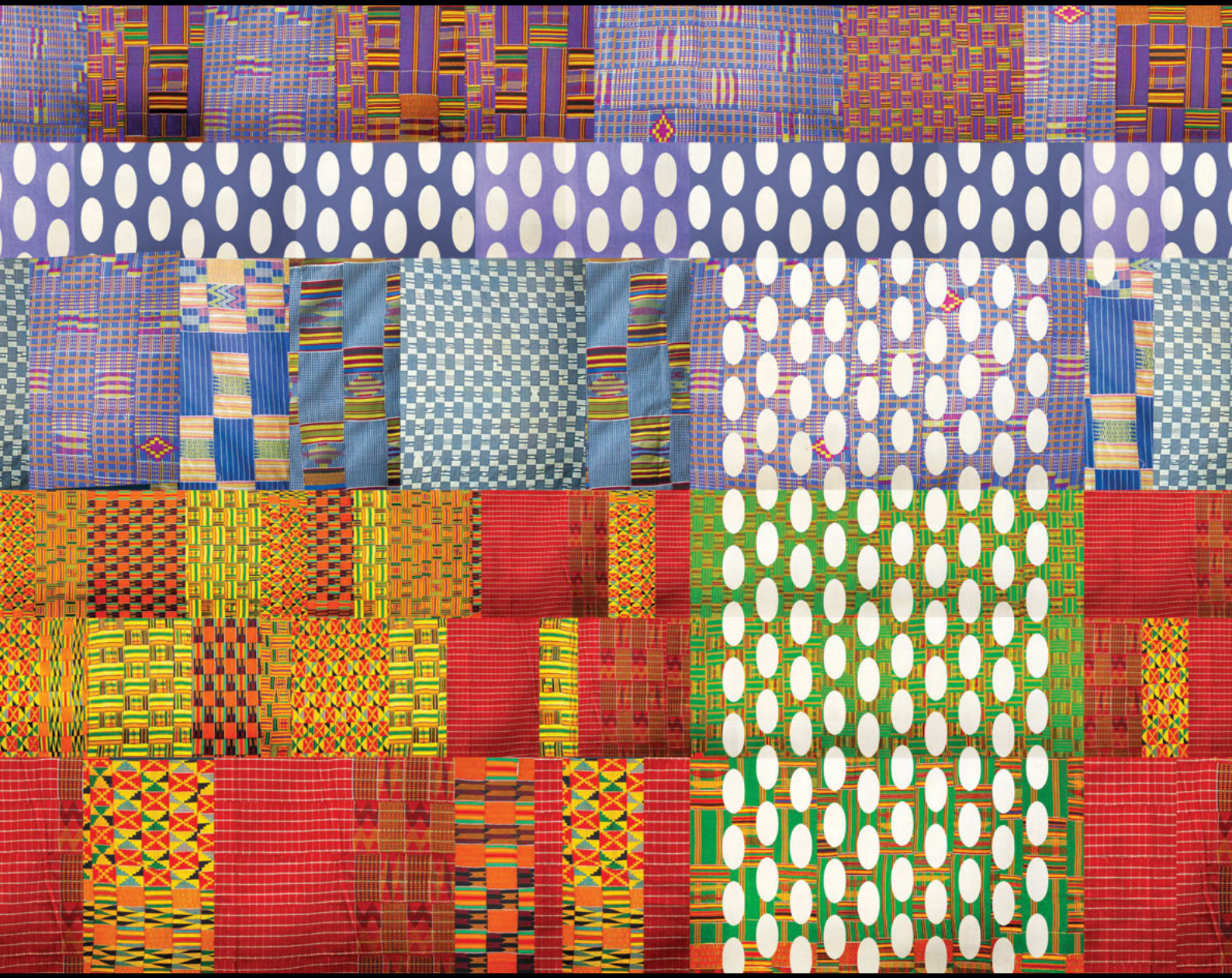


Endnotes

1 All researchers who have contact with participants or participant data are required to hold certificates in Good Clinical Practice (GCP).

2 Microbicides are topically applied chemical agents that may be suspended in gel, embedded in a polymer ring or a sponge and inserted into the vaginal tract. They function by disabling pathogens or preventing their entry into host cells by interfering with cell surface receptors (McCormack *et al.* 2001). Most recently, microbicides have included antiretrovirals such as Tenofovir, a drug used for treating AIDS patients.

3 Sobo's (1995) research amongst inner city women in the US focused on the social and economic context of women's everyday lives in understanding their denial of personal HIV risk and their resistance to condom use. She argued that risk denial is encouraged by AIDS education messages that recommend condom use in the context of 'multiple partners', 'casual sex' or 'unfaithful lovers'. Women invest in a 'monogamy narrative' characterised by love and trust.

4 United Nations International Conference on Population and Development (ICPD) 5-13 September 1994, Cairo.

5 All trials are regulated by a Data Safety and Monitoring Board (DSMB) that regularly views the data and makes recommendations. The primary concern is protecting the safety of trial participants and assessing the scientific merit and validity of the trial.

6 The DSMB review on 17 November 2011 recommended that VOICE stop evaluating Tenofovir gel, because there was no difference in effect between the Tenofovir gel and placebo gel in preventing HIV infection among the women in those two groups. The HIV incidence rates in the two groups were nearly identical – 6.1% in the placebo gel group and 6% in the Tenofovir gel group (Microbicide Trials Network 2011).

7 The chemical compound, PRO 2000, is suspended in a gel and inserted vaginally using a pen shaped applicator prior to sex. Participants were told to insert the gel within one hour preceding sex and to avoid washing immediately after sex.

8 Permission to conduct the research was granted by the University of the Witwatersrand Human Research Ethics Committee (Reference 050108).

9 Choice condoms were launched in 2004 as a rebranding of the government condom, repackaged in bright yellow and blue and with the slogan 'No Choice, No Play' designed to appeal to young, sexually active South Africans (www.rrtmedcon.com/choice.htm).

10 There has been some debate on whether or not to provide condoms and counselling to microbicide trial

participants and the effects this could have on the outcomes of trials (Potts 2000).

11 A national survey published in 2002 reports that almost a quarter (24.7%) of females and a third (30.3%) of males used a condom during the last sexual intercourse (Shisana & Simbayi 2002). More recently, significant increases have been recorded particularly amongst young people (Shisana *et al.* 2009).

12 The gel was randomised to a 2% and a 0.5% concentration of PRO 2000.

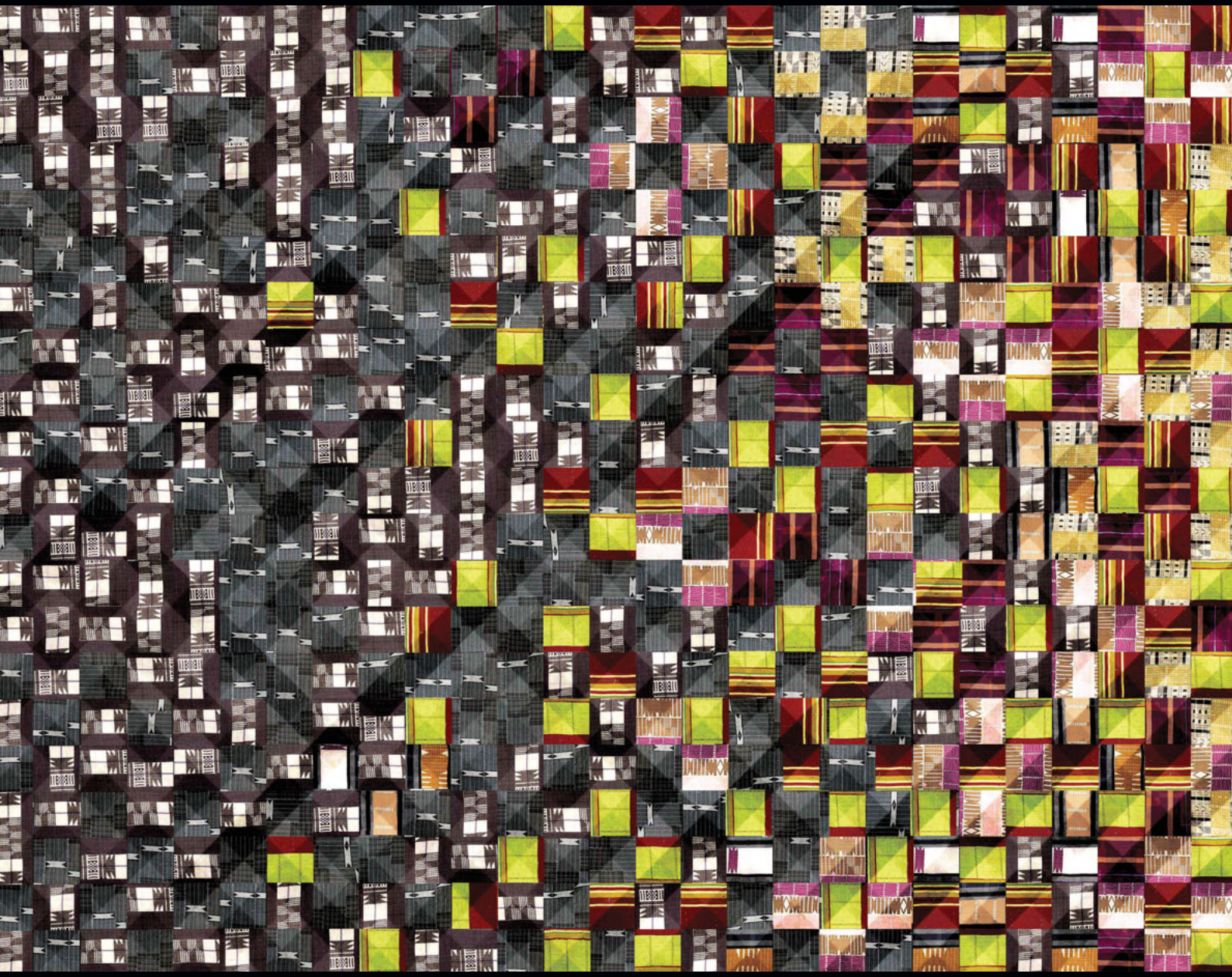
13 For the purposes of this article, we use 'narrative', 'story', and 'tale' as synonyms. We acknowledge that some researchers consider these distinct concepts, where narrative refers to the representation of discourse and story refers to the events that the narrative relates (Garro & Mattingly 2000, 12).

14 Venous blood draws took place at regular intervals – at least five times throughout the study – and blood was tested for HIV (8.5ml), syphilis and herpes simplex (5ml), while an additional 15ml was collected for storage. The first 500 women had a further 15ml of blood taken for full blood counts, liver function, kidney function and clotting tests.

15 White (2000, 18) notes that blood-selling rumours in East and Central Africa were derived from witchcraft beliefs.

16 Some women did conceal remuneration from their partners. While we have no quantitative figures, we believe that these women were in the minority.

17 As with other narratives, statements such as this express an idealised notion rather than strict realities. While many participants reported using reimbursement to purchase a range of products and services that assisted their households, including food, basic household articles, children's clothing, transport to seek work and school fees, others did acquire luxury items for themselves.



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Appendix

TIMELINE OF MICROBICIDE P2 AND P3 TRIALS

Year	Trial	Country	Population
1987-1990	Nonoxynol 9 Sponge	Kenya	Female Sex Workers
1994-1996	Nonoxynol Film	Cameroon	Female Sex Workers
1996-1998	Nonoxynol Gel	Kenya	Female Sex Workers
1996-2000	Nonoxynol Gel	South Africa, Thailand, Benin, Cotê d'Ivoire	Female Sex Workers
2004-2006	SAVVY (C31G) Gel	Ghana	High Risk Women
2005-2007	Cellulose Sulphate Gel	Benin, India, South Africa, Uganda	High Risk Women
2004-2006	SAVVY (C31G) Gel	Nigeria	High Risk Women
2004-2007	Cellulose Sulphate Gel	Nigeria	High Risk Women
2004-2007	Carraguard Gel	South Africa	Sexually Active Women
2005-2008	0.5% PRO 2000/5 Gel	Malawi, South Africa, Zambia, Zimbabwe, USA	Sexually Active Women
2005-2008	Buffer Gel	Malawi, South Africa, Zambia, Zimbabwe, USA	Sexually Active Women
2005-2009	0.5% PRO 2000/5 Gel	South Africa, Zambia, Uganda, Tanzania,	Sexually Active Women
2007-2009	1% Tenofovir Gel	South Africa (KwaZulu-Natal)	Sexually Active Women
2009-current	Tenofovir 1% Gel, Tenofovir Disoproxil Fumarate Tablet and Emtricitabine/Tenofovir Disoproxil Fumarate	South Africa, Uganda, Zimbabwe	Sexually Active Women
2011-current	Tenofovir 1% Gel	South Africa	Sexually Active Women

Sources: (Padian *et al*. 2010)

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Centre for the Study of AIDS

The Centre for the Study of AIDS (CSA) is located at the University of Pretoria. It is a 'stand-alone' centre which is responsible for the development and co-ordination of a comprehensive university-wide response to AIDS. The Centre operates in collaboration with the deans of all faculties and through interfaculty committees, to ensure that a professional understanding of the epidemic is developed through curriculum innovation and through extensive research.

Support for students and staff is provided through peer-based education and counselling, through support groups and through training in HIV/AIDS in the workplace. The CSA, in partnership with the Campus Clinic and staff at Pretoria Academic Hospital, offers a full antiretroviral rollout with counselling, testing and treatment. A large number of student volunteers are involved in the various CSA programmes, as are many community groups, ASOs and NGOs.

To create a climate of debate and critique, the CSA publishes widely and hosts AIDS forums and seminars. It has created web and email-based debate and discussion forums and seeks to find new, innovative, creative and effective ways to address HIV/AIDS in South African society.

Together with the Centre for Human Rights and the Law Faculty at the University of Pretoria, the Centre has created the AIDS and Human Rights Research Unit. This research unit continues to conduct research into the relationship between AIDS and human rights in Southern African Development Community (SADC) countries, is engaged in the development of model legislation, conducts research in AIDS and sexualities and sexual rights, and is involved in the placement of interns in various sub-Saharan parliaments and with parliamentarians, to strengthen the role of parliaments and governance. In collaboration with the Faculty of Education, the Education and AIDS Research Unit has been established.

The *AIDS Review*, published annually since 2000, addresses major aspects of the South African response to the HIV/AIDS epidemic. *Review 2000*, written by Hein Marais and entitled *To the edge*, addressed the complex question of why, despite the comprehensive National AIDS Plan adopted in 1994, South Africa had one of the fastest growing HIV

epidemics in the world. *Review 2001*, written by Tim Trengove Jones and entitled *Who cares?*, dealt with the levels of commitment and care – in the international community, in Africa and in South Africa. *Review 2002*, written by Chantal Kissoon, Mary Caesar and Tashia Jithoo and entitled *Whose right?*, addressed the relationship between AIDS and human rights in eight of the SADC countries and how a rights-based or a policy-based approach has determined the ways in which people living with HIV or AIDS have been treated and the rights of populations affected.

Review 2003, written by Vanessa Barolsky and entitled *(Over) extended*, evaluated age, demographic changes and changing family and community structures. *Review 2004*, written by Kgamadi Kometsi and entitled *(Un) real*, looked at the dominant images of men in society and focused on masculinities in the South African context. *Review 2005*, written by Jimmy Pieterse and Barry van Wyk and entitled *What's cooking?*, focused on the impact of HIV and AIDS on agriculture, and the politics of food access and production. Also in 2005, an extraordinary *Review*, *Buckling*, written by Hein Marais, and dealing with the impact of HIV and AIDS on South Africa, was published. *Review 2006*, written by Jonathan Jansen and entitled *Bodies count*, looked at HIV and AIDS in the context of education, race and class. *Review 2007*, written by Patrick Eba and entitled *Stigma(ta)*, addressed the background to and impact of AIDS-related stigma. *Review 2008*, written by Carmel Rickard and entitled *Balancing acts*, looked at the ways in which public health and human rights have often been pulled into tension in dealing with HIV and AIDS and other related health issues.

AIDS Review 2009, *Magic*, authored by Isak Niehaus and Fraser McNeill, looked at uptake of ARVs and the forces that come into play which determine how people and communities respond to the 'magic' of treatment – the physical effect on the body, as well as 'supernatural' effects.

AIDS Review 2011, *(B)order(s)*, written by Vasu Reddy, looked at how sexuality is understood and constructed and the ways in which barriers are erected around people's experience of sexuality and how sexual identity, preference and practices are viewed in the dominant heteronormative society and how this affects HIV and AIDS work.

In 2012, the second extraordinary *AIDS Review*, *Third degree*, examined various ways in which tertiary institutions could be, and are, responding to the HIV and AIDS

epidemics. *AIDS Review 2012, Off label*, discusses biomedical technologies for HIV prevention with particular reference to microbicides in clinical trials.

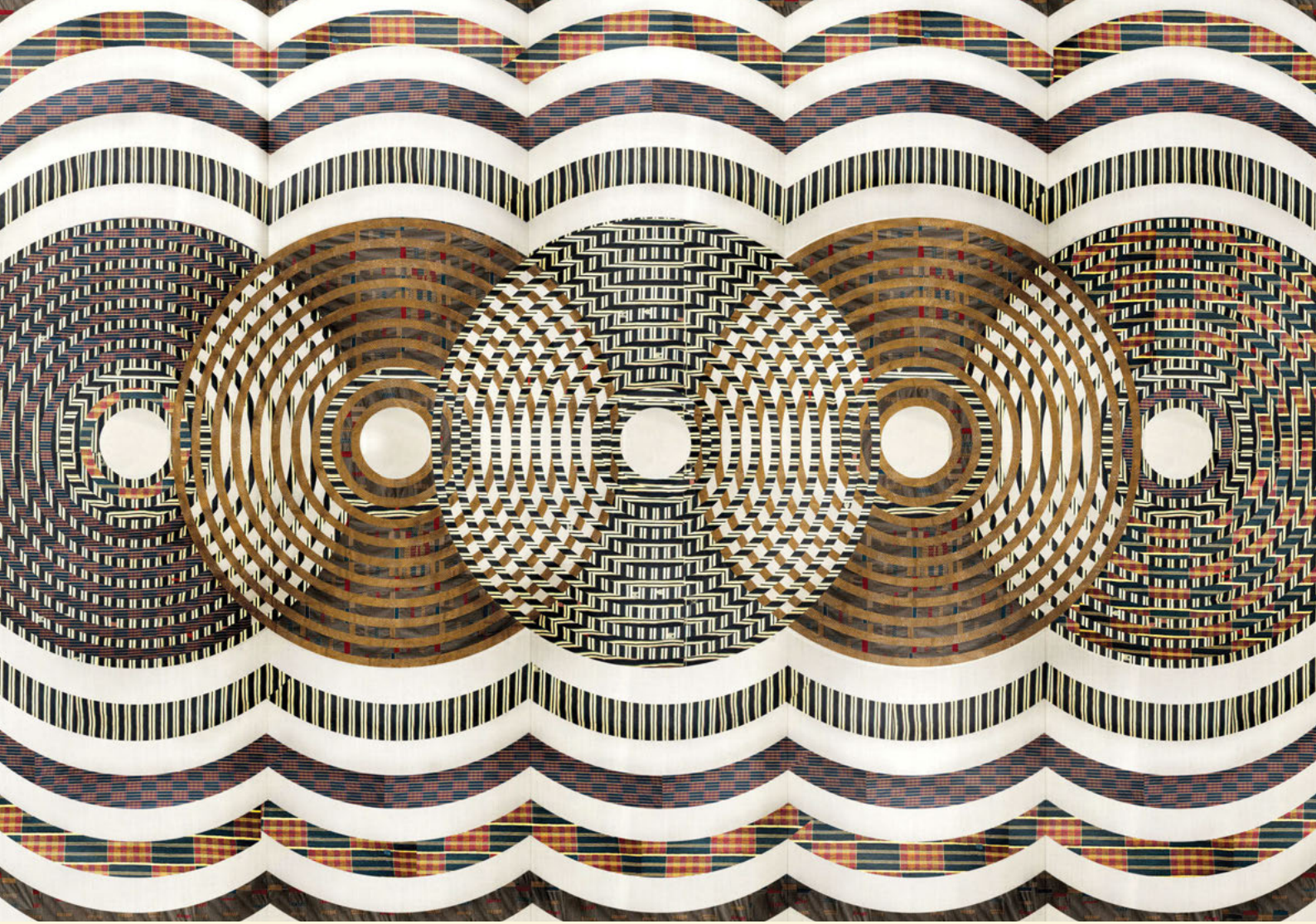
The CSA operates in consultation with an advisory reference group – TARG – comprised of university staff and students from faculties and service groups, as well as community representation. The CSA has furthermore developed a close partnership with a number of Southern and East African universities through the Future Leaders @ Work Beyond Borders initiative, as well as the Imagined Futures programme to develop university-based responses that address the needs of students and staff living with HIV and AIDS.

Amongst other partners, the CSA works closely with the SADC PF based in Windhoek on model legislation and issues of criminalisation, and has interns placed in other African universities. Through an extensive community-based programme in Hammanskraal paralegal and community-based health and human rights workers are trained and supported. The CSA also has two stigma projects in Hammanskraal, through which it works with magistrates, the police and other agencies on issues of HIV and AIDS-related stigma.

CONTACT DETAILS

Centre for the Study of AIDS
University of Pretoria
Pretoria 0002, Republic of South Africa

T: +27 (12) 420 4391
F: +27 (12) 420 4395
E: csa@up.ac.za
www.csa.za.org



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Centre for the Study of AIDS
University of Pretoria
Pretoria 0002, Republic of South Africa

T: +27 (12) 420 4391 | F: +27 (12) 420 4395
E: csa@up.ac.za | www.csa.za.org