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HYGIENE  
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MEDICINE



**Investigating experiences of engagement with HIV  
Treat-all among people living with HIV in Eswatini**

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Thesis submitted in accordance with the requirements for the degree of  
Doctor of Philosophy  
of the  
University of London

April 2019

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## Declaration of originality

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*I, Shona Horter, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.*

Signed:...



...

Date: 29<sup>th</sup> April 2019

## Abstract

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Treat-all involves regular HIV testing and prompt initiation of ART for all those diagnosed HIV-positive, regardless of immunological status, aiming to improve health outcomes and reduce HIV incidence. It is a biomedical and social approach to HIV treatment and prevention, requiring active engagement of individuals. Questions remain as to how Treat-all will be experienced, interpreted and understood by people living with HIV, how ART initiation will be decided upon in the absence of clinical symptoms of disease, and how ongoing engagement with care will be navigated over time.

This thesis aims to investigate how clinically asymptomatic people living with HIV experience engagement with HIV treatment and care under Treat-all, situated within a Médecins Sans Frontières/Eswatini Ministry of Health Treat-all pilot in Shiselweni, southern Eswatini. Research comprised 145 interviews, conducted February 2015 – September 2017, including repeated interviews with 30 people living with HIV, one-time interviews with 28 people living with HIV, and one-time interviews with 31 health care workers. Additionally, observations and focus group discussions were conducted. Data were analysed thematically, drawing upon principles of grounded theory to generate findings inductively from participant accounts. Nvivo 11 aided analysis.

This research highlights the individually varied, potentially complex processes of coming to terms with an HIV diagnosis and deciding when to initiate ART, and the dissonance between biomedical interpretations of treatment necessity and individuals' decision-making processes and treatment readiness. It appears important for individuals to perceive need for treatment, have choice regarding when to initiate ART, to feel ownership over the management of their health and treatment-taking, and to have evidence of the treatment's effectiveness to motivate treatment-taking and engagement with care. Doubts about diagnosis accuracy, treatment need and effect could undermine engagement and cause intermittent treatment-taking. Stigma persists in the context of Treat-all, driving engagement with treatment to avoid symptom development and status exposure, and also undermining engagement and causing treatment-taking fragility.

As settings implement Treat-all, it is imperative to understand, reflect upon and address the views and experiences of people living with HIV, and to ensure programmes meet individuals' needs. This thesis aims to contribute towards this understanding.

## Acknowledgements

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I am grateful to all those who supported this PhD research, and who enabled the completion of this thesis to be possible. Firstly, I want to acknowledge the participants of the research, who were integral and contributed in numerous ways. Thank you for sharing your experiences, for your time, commitment and openness.

I want to extend particular thanks and appreciation to my supervisors, Alison Wringe and Janet Seeley, from whom I have learnt a great deal and who have supported my development as a researcher enormously, including in finding my own voice. Thank you for being so responsive, patient and understanding, and for the wealth of technical input you provided. I am extremely grateful to Sarah Bernays, who inspired me to want to do this PhD, and whose input, guidance and support has been instrumental to both the initial phase of the PhD before she moved to Australia, as well as to our collaborative work since. Thank you to Chris Colvin (University of Cape Town), Nicki Thorogood, Magdalena Harris and Catherine Dodds (London School of Hygiene and Tropical Medicine), for guiding and advising on various stages of this research.

Thank you to MSF for supporting this research, enabling this thesis to be possible. Thank you Iza Ciglenecki, Bernhard Kerschberger, Kiran Jobanputra, Barbara Rusch, and members of the MSF/MoH project team in Eswatini where this research was based. I am particularly grateful to Zanele Thabede and Velibanti Dlamini, whose contributions were manifold. Thank you for being the most amazing “A team”, for all the experiences we shared, and for your tireless work, particularly with data generation. It was a pleasure to work alongside you. Thanks to Beverley Stringer and Philipp du Cros, who have been so influential throughout my career, supporting my growth and development. To my wonderful colleagues and friends in Eswatini, who inspired me in so many ways, and from whom I learnt so much, thank you for sharing life, laughter and vitality with me.

Finally, I am so grateful to my family and friends for the wealth of support. Thank you to my mum for instilling values of humanity and a desire to learn and grow, and my sisters, whose unending belief in me and my ability to finish the PhD helped carried me through the times when I wavered. Thank you to my friends for sticking by me through the ups and downs, for sharing laughs and distractions with me, reminding me of my sense of self beyond the PhD, and helping me to keep pushing forwards.



Photo: Eswatini, author's own

*"I am because we are"*

- Ubuntu

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## Glossary

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Acquired Immune Deficiency Syndrome	AIDS
Anti-Retroviral Therapy	ART
Conference on Retroviruses and Opportunistic Infections	CROI
Focus Group Discussion	FGD
HIV Prevention Trials Network	HPTN
Human Immunodeficiency Virus	HIV
HIV Testing Services	HTS
Lost From Treatment	LFT
Médecins Sans Frontières	MSF
Ministry of Health	MoH
Principal Investigator	PI
People Living with HIV	PLHIV
Pre-Exposure Prophylaxis	PrEP
Research Assistant	RA
World Health Organisation	WHO

## Chapter 1: Introduction

---

Advances in antiretroviral therapy (ART) have transformed the HIV pandemic (De Cock and El-Sadr, 2013), and substantially reduced HIV-related mortality (Reniers et al., 2014). ART offers the potential to improve the health of individual people living with HIV and to prevent HIV transmission, thus having dual individual and public health benefits (Cohen et al., 2011a; INSIGHT START Study Group, 2015; The TEMPRANO ANRS 12136 Study Group, 2015). Since 2015, the World Health Organisation (WHO) treatment guidelines recommend ART for all people living with HIV, at any CD4 count, in recognition of the prevention and health benefits of ART (World Health Organisation, 2015). This “Treat-all” policy for HIV treatment and prevention, also referred to as “Universal Test and Treat” or “Test and Start”, recommends regular, annual HIV testing and immediate offer of ART for all individuals diagnosed HIV positive, irrespective of immunological status or stage of disease. It is hoped that universal HIV testing combined with immediate ART could reduce HIV incidence so substantially as to eliminate HIV as a public health threat (Hayes et al., 2014; World Health Organisation, 2016).

Treat-all, together with new biomedical technologies, including treatment to prevent HIV acquisition, and medical circumcision, has bought the real possibility of ending the epidemic into view (Reynolds et al., 2016; The Lancet HIV, 2015). To facilitate this being realised, UNAIDS set the “90-90-90” targets, which propose that 90% of people living with HIV know their status, 90% of those diagnosed are on ART, and 90% of those on ART are virally suppressed by 2020, to achieve HIV elimination by 2030 (UNAIDS, 2014).

According to UNAIDS, 36.9 million people were living with HIV globally in 2017, of whom 21.7 million were accessing ART, and 70% of people living with HIV reside in Africa (2018). Access to ART has increased exponentially, from 8 million people on treatment in 2010. HIV incidence peaked in 1996, with 47% fewer new HIV infections and 1.8 million people becoming newly infected in 2017 (UNAIDS, 2018). Eastern and Southern Africa represents the world’s most affected region. By 2017, 76% of people living with HIV knew their HIV status, 60% of people living with HIV were on ART,

and 50% were virally suppressed, with almost 50% less mortality than 6 years previously (UNAIDS, 2017).

The cascade of care is used as a standard way of describing and analysing patient behaviour between diagnosis and retention (Fox and Rosen, 2017), viewing patient care as a stepwise progression through a set of stages, where each prior level of engagement supports future engagement in health care services (Wademan and Reynolds, 2016). 90-90-90 targets are based upon key stages of the cascade, HIV diagnosis, treatment initiation and viral suppression, and may be used to evaluate the performance and success of HIV programmes (Levi et al., 2016), distinguishing success and failure in stark biomedical terms (Paparini and Rhodes, 2016). Whereas in reality, engagement with care is rarely experienced as a linear process, and people may engage, disengage and re-engage from HIV services at various times (Skovdal et al., 2017; Wademan and Reynolds, 2016).

Narrowly focusing on the stages of the cascade and on viral suppression as a “goal” that needs to be achieved can detract attention from the broader aspects of HIV as a health and social condition, and from viral suppression as a state that must be maintained over time, thereby requiring continuous patient re-engagement (Paparini and Rhodes, 2016). Throughout this thesis, I use the term engagement to reflect the fluidity of people’s experiences with HIV, and with accessing treatment and care services, aiming to understand this process from the perspective of the individuals who are affected, and considering the broader complexity of individual and social practices that may influence engagement.

This thesis is a study of the lived experiences of people living with HIV, examining how individuals navigate engagement with HIV treatment and care in the context of Treat-all in Eswatini, with fieldwork conducted between February 2015 and November 2017. This research is situated within a Médecins Sans Frontières (MSF) and Ministry of Health (MoH) of Eswatini Treat-all pilot, which was implemented from October 2014, with Treat-all being adopted to national treatment guidelines in October 2016.

Within this research, I focus on the experiences of people living with HIV who are considered clinically asymptomatic, and who would have otherwise been ineligible for treatment at the time, with CD4 counts greater than 500 and WHO disease stage 1 (clinical markers used to distinguish stage of HIV). I consider how disease diagnosis, self-identity, treatment decision-making, and the treatment-taking experience may change in the context of Treat-all, when individuals are increasingly encouraged to initiate ART at asymptomatic stage of disease. Additionally, I explore the perspectives of health care workers involved in the provision of HIV treatment and care services, and the implementation of Treat-all, as well as situating the research within the broader health system context. Throughout this thesis, I refer to people living with HIV as individuals, unless it appears necessary to clarify for the reader, in which case I use the distinction “people living with HIV”. This is in respect of the importance of language in communicating meaning, in an effort to avoid the risk of defining people through an illness label, appreciating that there are other aspects to self and personhood. I have chosen not to abbreviate this term in the body of the thesis, to recognise that using abbreviations to define people can be reductive, dehumanising, and that language also has the potential to contribute towards stigmatisation (Dilmitis et al., 2012; Lytvyn et al., 2017). In some of the published papers comprising the results section, abbreviations have been used in line with journal expectations.

Within this chapter, I describe the background to Treat-all, including the evidence upon which the approach is based and how Treat-all came to be introduced, in particular in terms of the use of treatment for prevention of HIV transmission. I consider the current findings relating to Treat-all implementation, such as the randomised controlled trials in six African countries aiming to measure the effect of increased and earlier ART on HIV incidence, in situating this PhD research. Then, I consider the assumptions underpinning Treat-all, pertinent areas to consider, examine and address within Treat-all implementation, and formulate the rationale to conducting this PhD research. Finally, I briefly outline the study context, describe the research aims and objectives, the role of the candidate and provide an overview of this thesis.

## The advent of Treat-all and HIV treatment as prevention

During the first 15 years of the HIV pandemic, there was no available treatment able to sustainably control viral replication, and CD4 count and clinical stage were used to estimate the degree of immunosuppression and risk of death, upon which clinical decisions were based, for example regarding the management of opportunistic infections (Eholié et al., 2016). The development of combined ART in 1996 transformed HIV prognosis (Gulick et al., 1997; Hammer et al., 1997), seen as “miraculous” and creating hope for the survival of people living with HIV, for the first time in a decade of treatment trials (Kobayashi, 1997). HIV thus went from being a fatal, incurable disease to a chronic condition requiring lifelong treatment (Siegel and Lekas, 2002). However, ART carried toxicity risks, challenges with adherence to lifelong daily medication, and the potential for emergence of drug resistance, particularly with suboptimal adherence. Thus, decisions about when to initiate ART were framed by an avoidance of initiating ART earlier than necessary to spare patients the risks of resistance and toxicity, and ART initiation thresholds fluctuated over the period 1996 to 2014 (Eholié et al., 2016).

In 2009, Granich and colleagues’ mathematical modelling study suggested HIV prevalence could be reduced to just 1% within 50 years through Treat-all (Granich et al., 2009). While mathematical models may offer encouraging findings, empirical data demonstrate their application to a “real-world” context (Hayes et al., 2014). Therefore, when results from the HIV Prevention Trials Network (HPTN) 052 Trial later evidenced a 96% reduction in transmission among serodiscordant couples with ART initiation (Cohen et al., 2011a), this provided exciting evidence in support of the potential for ART to prevent HIV transmission. Until then, trials seen as the “gold standard” for evidencing intervention effect had shown behaviour change interventions did not protect against HIV infection, nor even seem to change behaviour (Corbett et al., 2007; Gregson et al., 2007; Padian et al., 2010). Although the appropriateness of randomised-controlled study design for such socially complex interventions is questionable, the perceived failures of “behavioural prevention”

spurred enthusiasm for biomedical approaches to prevention (Kippax and Stephenson, 2012).

Since the HPTN 052 trial, observational studies have also suggested that ART can reduce HIV incidence (Donnell et al., 2010; Tanser et al., 2013). However, the potential population level impact of Treat-all remains unknown, particularly prior to Treat-all implementation within health systems and the results of trials to prove a causal link between expanded ART access and HIV incidence (Hayes et al., 2014).

The use of treatment for the prevention of HIV transmission has been referred to as the “treatment as prevention” paradigm, grounded on the proposition that bringing treatment to the maximum possible number of people living with HIV will enable enhanced survival for those accessing treatment, and will reduce the chance of HIV being transmitted (Adam, 2011). This has resulted in what Nguyen terms the “remedicalising” of HIV (Nguyen et al., 2011), ideologically driving HIV policy in terms of funding and focus (Bond et al., 2016; Kalichman, 2013). Many believe the potential for treatment to prevent HIV transmission will provide the sought-after solution, “bringing the era of HIV to a close” (Braunstein et al., 2011). The potential for ART to reduce HIV transmission was first applied to the context of preventing vertical transmission of HIV, referred to as Prevention of Mother to Child (PMTCT) Option B+, and throughout this thesis referred to as Option B+. Malawi pioneered the implementation of Option B+ in 2011 (Schouten et al., 2011), and the offer of lifelong ART to all pregnant women was included into WHO treatment guidelines in 2013 (World Health Organisation, 2013). Evidence from Option B+ suggests that retention in care among women initiating ART under B+ is lower than among women starting ART for their own health (Clouse et al., 2014; Knettel et al., 2018; Tenthani et al., 2014), potential circumstances and reasons for which are explored further in Chapter 2.

As mentioned above, increasingly biomedical technologies are being used to prevent HIV transmission or acquisition physically, chemically or immunologically (Vermund, 2014). While the focus of this thesis is Treat-all, and other approaches go beyond the scope of this research, I acknowledge that a combination approach to HIV prevention is recommended in updated 2016 WHO guidelines. Therefore, here I

briefly introduce these approaches. The offer of pre-exposure prophylaxis (PrEP) is recommended to all those diagnosed HIV-negative in populations with an incidence of above 3 per 100 person years, considered substantial risk for acquiring HIV (World Health Organisation, 2016). This follows evidence from 14 randomised controlled trials, with a meta-analysis of ten trials finding a 51% reduction in risk of HIV infection with PrEP compared to placebo (Fonner et al., 2016). However, adherence to PrEP can be challenging and can undermine the potential for the approach (Amico et al., 2013). Additionally, WHO suggests the offer of male circumcision to prevent heterosexually acquired HIV in men (World Health Organisation, 2016), following three randomised trials demonstrating approximately 60% reduction in female-to-male transmission (Auvert et al., 2005; Bailey et al., 2007; Gray et al., 2007). These approaches are being implemented in a range of settings alongside Treat-all.

The long-standing debate regarding when to initiate ART was accentuated by recognition of the preventative benefit ART provides, with calls for the need for definitive data on which to base treatment guidelines (De Cock and El-Sadr, 2013). In 2015, the START and TEMPRANO Trial findings provided “compelling evidence that the benefits of early initiation outweigh any reasons for delay” (Nsanzimana et al., 2015). Both demonstrated a significant reduction in risk of negative health outcomes with early (CD4 count above 500), rather than delayed ART initiation (CD4 count below 350), with 44% and 57% lower risk of severe morbidity respectively (The TEMPRANO ANRS 12136 Study Group, 2015; INSIGHT START Study Group, 2015). Thus these findings, together with evidence of the preventative benefits of ART, spurred the WHO treatment guidelines recommending Treat-all in 2015 (World Health Organisation, 2015).

### Treat-all implementation findings

As of mid-2018, 74% of all low and middle income countries were implementing Treat-all, and WHO anticipates that by the end of 2020, 92% of these countries will have adopted the policy (World Health Organisation, 2018). There are national differences in how Treat-all is implemented, for example in how rapidly ART initiation is recommended following diagnosis, and the sense of urgency with which

the policy is interpreted (Ford et al., 2018a). It remains to be seen how approaches to implementation may translate to how Treat-all is experienced by people living with HIV.

In 2016 the Undetectable=Untransmissible (U=U) slogan was launched by the Prevention Access Campaign, recognising that people with HIV who have a stably suppressed viral load cannot transmit the virus (Leahy, 2018; The Lancet HIV, 2017). Evidence supporting U=U is extensive (for example, Attia et al., 2009; Bavinton et al., 2018; Rodger et al., 2016), and it has been argued that health care providers should routinely communicate this message to all of their patients living with HIV (Calabrese and Mayer, 2019). Nevertheless, there appears to be a moral dimension to treatment as prevention, with people living with HIV holding both the blame for potentially spreading the virus, and the emphasis of responsibility for containing it (Bond et al., 2016). Delaying ART initiation or sub-optimal adherence may also become morally framed in this context (Keogh and Dodds, 2015). Formative research prior to Treat-all implementation in Eswatini described local resistance to the treatment as prevention terminology, due to locally ascribed meanings of treatment concerned with taking responsibility for one's own health rather than relying upon or promoting ART for preventing HIV transmission, instead being framed as Early Access to ART for All (Vernooij et al., 2016).

Although mathematical modelling, the HTPN 052 trial among serodiscordant couples, and observational studies suggest ART reduces HIV transmission, the impact of Treat-all implementation on population-level HIV transmission has not yet been demonstrated. Five randomised trials underway in Southern and Eastern Africa from 2013 to 2020 aim to investigate whether Treat-all reduces HIV incidence. These trials include PopART (HTPN 071) in South Africa and Zambia, Sustainable East Africa Research in Community Health (SEARCH) in Uganda and Kenya, TasP (ANRS 12249) in South Africa, MaxART in Eswatini, and The Ya Tsie Botswana Prevention Programme, the findings from which are summarised in Appendix 1. The preliminary results from these trials are positive, with good uptake of HIV testing, ART initiation and viral suppression. For example, within the SEARCH trial,

retention in care at one year was around 95% (Brown et al., 2017, 2016). However, the link between Treat-all implementation and HIV incidence reduction appears to be more complex. Results from the largest trial, PopART, presented at the Conference on Retroviruses and Opportunistic Infections (CROI) in March 2019, showed that HIV incidence reduced by 30% in Arm B compared to Arm C (standard of care), though Arm B included a PopART intervention according to national treatment guidelines, which adopted Treat-all in 2016. Arm A, which implemented Treat-all from the outset, had a non-statistically significant reduction in HIV incidence of 7% (Hayes et al., 2019). After two years of intervention, the SEARCH trial observational analysis of interim data reported 96% of HIV-positive individuals within the trial communities were diagnosed, 93% of previously diagnosed residents had initiated ART, and 90% of residents with prior ART initiation had achieved viral suppression (Petersen et al., 2017). However, recent incidence results presented at the AIDS conference in 2018 showed that while there had been a reduction in HIV incidence and mortality during the trial period, there was no difference in three-year cumulative incidence between the intervention and the control arms of the trial (Havlir et al., 2018). Findings from the TasP trial presumed the found absence in difference in HIV incidence between the intervention and the control arms to be a result of low rates of linkage to HIV care following diagnosis, with only around 30% of individuals registered at a trial clinic within 6 months of diagnosis (Iwuji et al., 2018).

Botswana appears to be on track for achieving the 90-90-90 targets, with national estimates that in 2015 83% of people living with HIV knew their status, 87% of whom were receiving ART, and 96.5% of whom were virally suppressed, leading to a population viral suppression of 70% for all people living with HIV (Gaolathe et al., 2016). It is hoped that such high levels of viral suppression will translate to a reduction in HIV incidence over time, and ultimately to control of the HIV epidemic (Marukutira et al., 2018). Eswatini has also had promising results, with a recent national survey finding HIV incidence was 44% lower in 2016 than in 2011, presented as the “first direct measure of the national impact of expanded HIV prevention and treatment programmes” at the IAS conference in 2017 (Nkambule et al., 2017).

Thus far, evidence proving an attributable effect of ART on population viral suppression (Larmarange et al., 2018), or a significant difference in HIV incidence between trial intervention and control arms is still awaited (Havlir et al., 2018; Hayes et al., 2019). This could be due to a number of factors, and potential reasons cited within the trial data interpretation include the change in treatment guidelines to national adoption of Treat-all potentially dampening intervention effect (Hayes et al., 2019). Other cited reasons include that men and young people have consistently lower rates of engagement and viral suppression, which could contribute to HIV incidence (Brown et al., 2019, 2017; Gaolathe et al., 2016; Iwuji et al., 2018). Population mobility and sexual networks are purported to influence potential challenges with realising HIV incidence reductions (Gaolathe et al., 2016; Iwuji et al., 2018; Lundgren and Phillips, 2018). Suboptimal linkage to HIV care may undermine the population-level coverage of ART (C. Iwuji et al., 2016; Iwuji et al., 2018; Plazy et al., 2016), with linkage to and retention in care being undermined by poverty (Ayieko et al., 2018). Additionally, current testing approaches largely miss those within the acute stage of HIV infection, with research suggesting that risk of transmission is much higher for those with acute, early infection than for those with established infection (Cohen et al., 2011b).

Importantly, 90-90-90 targets are based on models, underpinned by a range of assumptions, and which do not capture the complexity of factors that contribute to HIV transmission (Gaolathe et al., 2016). These unilinear metrics do not reflect and account for individuals' variation in response to the Treat-all policy and time for treatment readiness, and this divergence should be examined (Kawuma et al., 2018). Successful implementation of Treat-all relies upon the engagement of individual people living with HIV with HIV testing, access to HIV care, treatment initiation, maintained adherence and long-term sustained engagement with care (Ford et al., 2018b; Hayes et al., 2015). However, shortfalls exist at each of these stages, with the potential to undermine the success of Treat-all efforts to reduce HIV incidence (Ayieko et al., 2018; Gardner et al., 2011; Kilmarx and Mutasa-Apollo, 2013; Nachega et al., 2014).

Treat-all is both a biomedical and a social intervention, requiring modifications to behaviour and practice and the active engagement of people and communities, situated within social, cultural and political dimensions (Adam, 2011; Kippax and Stephenson, 2012). Increasingly people initiate ART at earlier, asymptomatic stage of disease, and the time between diagnosis and ART initiation is expedited. The biomedical logic framing Treat-all presumes individuals will adjust their actions once they are educated, when individuals' treatment decisions are situated beyond the biomedical realm (Beckmann, 2013).

### Study rationale

A growing body of evidence has documented that expanding access to HIV testing and treatment within Treat-all has important health benefits for individual people living with HIV, and for the prevention of HIV transmission. However, many aspects relating to how Treat-all implementation will be experienced by people living with HIV, and the social circumstances which surround it, remain unknown. The question is not whether the biomedical technologies are efficacious, but rather how to implement them and how to effectively support individuals to engage with and benefit from them (Reynolds et al., 2016).

Rather than adopting a public health approach that is underpinned by neoliberal notions of individual responsibility, we must recognise the collective nature of epidemics (Henderson et al., 2009), and engage with the lived world of those affected by HIV (Kippax and Stephenson, 2012). The biomedical paradigm risks reducing disease to an abstract physical matter within the realm of clinics, with rigid distinctions between individuals' physicality and the broader social world, abstracting people from their social contexts and the other aspects to self and personhood, which extend beyond the biomedical sphere (Beckmann, 2013; Hickel, 2012).

There may be anticipated and unanticipated factors within individuals' life contexts which could undermine Treat-all interventions from having the desired beneficial effects (Camlin et al., 2016a). Understanding and accounting for such complex dynamics and the contextual, social circumstances which surround HIV and

engagement with care is essential to the success of Treat-all (Reynolds et al., 2016), as is consideration of the behavioural aspects of HIV treatment and transmission (Kalichman, 2013). It is therefore vital that socio-behavioural contexts and dimensions are examined, understood and addressed as integral to Treat-all approaches (Adam, 2011; Keogh and Dodds, 2015; Kippax and Stephenson, 2012; Young et al., 2016).

Individuals who are increasingly being encouraged to initiate ART when clinically asymptomatic may have differing support needs, such as for those who do not feel unwell, who may have fears regarding ART side effects and the potential impact of taking ART on their lives (Camlin et al., 2016a). It is important to consider how interventions such as Treat-all interact with everyday exigencies, including the competing demands of treatment with work, home, family, relationships and other social and lived realities (Adam, 2011). For example, social science research from the context of Treat-all has found that some individuals are not able to engage with treatment and care, despite being aware of the benefits early treatment can bring. This is due to a range of competing priorities and responsibilities which can place pressing demands on life, such as the need to work and earn a living (Bond et al., 2018).

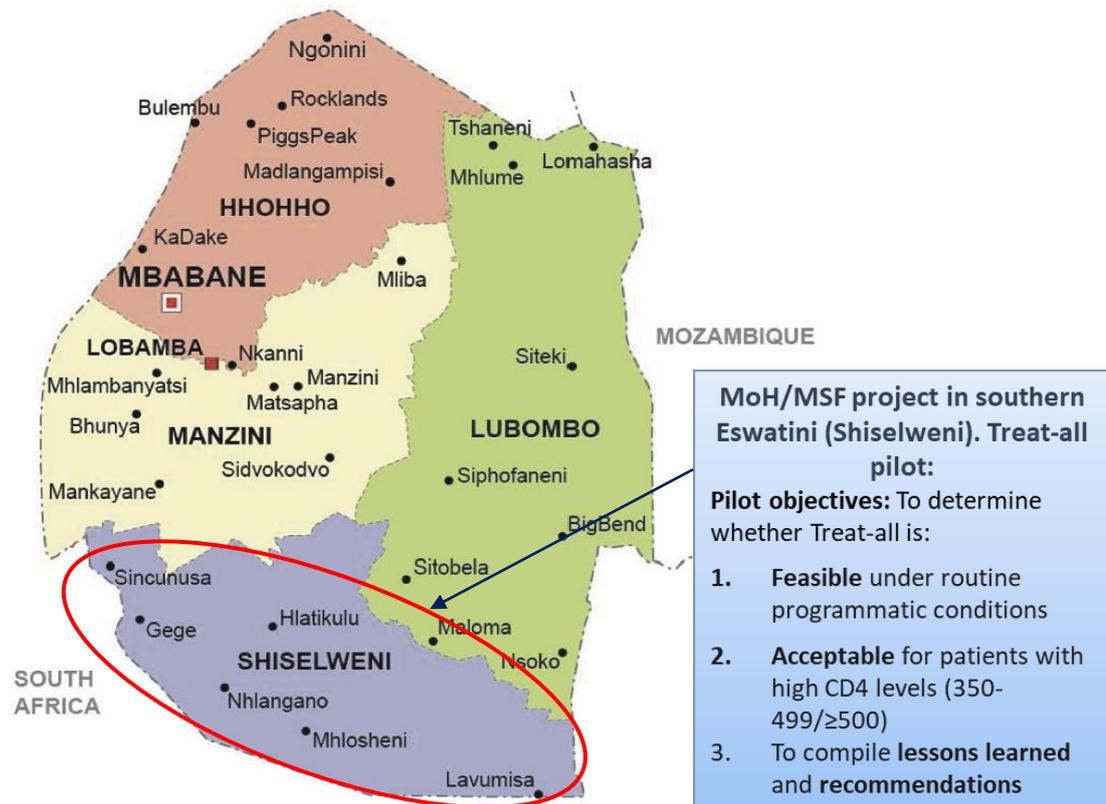
There may be dissonance between clinical guidelines and individuals' interpretation of what constitutes treatment necessity (Kawuma et al., 2018), and behaviours judged as "irrational" such as interrupting treatment or changing doses, instead represent "ways in which people enact agency in the context of their day-to-day needs" (Paparini and Rhodes, 2016, p.506). Under Treat-all, motivations for ongoing engagement with treatment and care may change, as the circumstances surrounding treatment initiation differ from those in the past, when individuals would largely initiate treatment when experiencing symptoms and feeling unwell. Existing evidence suggests that motivation for adherence may be stronger among those who initiate treatment when sick, as illness histories are drawn upon to motivate continued treatment-taking, and improved health and strength create a sense of need for treatment and belief in its efficacy (Bernays et al., 2015; Nam et al., 2008). Initiating ART when in good health may have implications for sustained treatment-taking, as

people living with HIV may not see the benefits of sustained ART adherence if they have not experienced any deleterious HIV-related health effects (Pell et al., 2019), and thereby initiating ART without HIV-related symptoms may undermine treatment-taking (Boyer et al., 2016). However, a study from Treat-all in Eswatini found acceptance of HIV diagnosis to be more important than disease stage on initiation, for sustaining treatment-taking and engagement with care (Pell et al., 2019).

As settings move forward with Treat-all implementation, it is an imperative to understand individuals' views, experiences and broader life context to ensure that support is tailored to meet individuals' needs, so that the benefits of Treat-all can be realised, and engagement sustained over the longer term. This is vital for enabling individuals to experience improved health outcomes. Additionally, it is important from a public health perspective, due to the potential risk of drug resistance developing with inconsistent treatment-taking, which has been highlighted as a critical threat to eliminating AIDS by 2030 (Jena, 2013; Wagner and Blower, 2012; World Health Organisation, 2017a, 2017b). The findings of this thesis aim to contribute towards this understanding.

### Study setting

This PhD research is embedded within an MSF/MoH project in the Shiselweni region of southern Eswatini. The Kingdom of Eswatini, formerly named Swaziland, is a small landlocked country in southern Africa, which borders South Africa to the north, west and south, and Mozambique to the east (Figure 1.1). Throughout this thesis, the country is referred to as Eswatini, and the people of Eswatini as Swati(s). However, as the country's name changed during the research, some results, such as those presented in Chapter 4, and quotes from participants refer to Swaziland and Swazi (for the people of Swaziland).



**Figure 1.1:** Map of Eswatini showing the location of the MSF/MoH project. Source: Ministry of Education and Training, 2018.

Within the Shiselweni project where this research is based, MSF and the MoH have been collaboratively providing decentralised HIV and tuberculosis care since 2007, predominantly at the primary health care and community level. In 2013, the project began a pilot of combination biomedical approaches to HIV prevention, aiming to contribute towards reduced HIV incidence. These approaches included the implementation of Option B+ in 2013, and of Treat-all in October 2014. This pilot aimed to assess the acceptability and feasibility of Treat-all under routine programmatic conditions. At the time the Treat-all pilot began, national treatment guidelines recommended ART for those with a CD4 count greater than or equal to 350, which then changed to 500 during the pilot. Treat-all was adopted to national guidelines in October 2016. More recently (2017) the project also began piloting oral HIV self-testing and PrEP for young women and men who have sex with men.

Eswatini has the highest reported HIV prevalence worldwide, estimated as 27% of adults aged 15 to 49 years, and much higher among women (35%) than men (19%) of

the same age (UNAIDS, 2016). The prevalence peaks at 54% among women aged 35 to 39 years, and at 49% among men aged 45 to 49 years (Swaziland Ministry of Health, 2017). Further information on the study context is presented in the methods chapter (study context section).

### Research aim and objectives

This study aims to examine the lived experiences of people living with HIV, and how engagement with HIV treatment and care is navigated in the context of Treat-all in Eswatini

Objectives:

1. To understand how an HIV diagnosis is interpreted and understood in the context of Treat-all, and how this may influence engagement with care
2. To examine how treatment is perceived and experienced by those who are asymptomatic
3. To explore treatment initiation decision-making
4. To examine how ongoing engagement in HIV care and treatment-taking is navigated over time
5. To generate policy and practice recommendations for consideration of MSF and the Eswatini MoH, including for the national adoption of Treat-all

The research objectives align with different phases of the research, and with results that are presented through papers in Chapters 4-7 (Table 1.1).

**Table 1.1:** Research objectives aligned with research phase and results focus

Research objective	Research phase	Results chapter	Topic focus
Objective 1 and 5	Preliminary phase	Chapter 4	Processing an HIV diagnosis, engagement with HIV care
Objective 3, 4 and 5	Main phase	Chapter 5	ART initiation decision-making processes, sense of choice and ownership influencing engagement
Objective 2, 4 and 5	Main phase	Chapter 6	Perceived need for treatment and evidence of treatment effectiveness influencing treatment-taking
Objective 3, 4 and 5	Main phase	Chapter 7	Stigma framing engagement with treatment and care under Treat-all

### Role of the candidate

I worked with MSF within the MSF/MoH project in Eswatini as a Qualitative Researcher, based primarily in Eswatini, from early 2015 to end 2017. Within my role, I managed several research projects, and responded to operational needs for research support, as well as conducting qualitative research studies. I was the Principal Investigator for the research presented in this thesis. I contributed to the study conception, designed the study, including developing the study protocol and the tools for data generation (Appendix 2). I managed a research team including two research assistants, who I trained and led in qualitative research methods, and who supported implementation of the research throughout the fieldwork. A research assistant acted as an interpreter within field visits and observations that I conducted, for example of community and clinic activities. Research assistants contacted potential people living with HIV participants to arrange meetings to invite study participation and to engage with the informed consent process, under my supervision. I conducted interviews with health care workers, and the research assistants conducted interviews with people living with HIV. Focus group

discussions were conducted by myself and a research assistant. Research assistants also helped with translation and data transcription.

The individuals that participated in this research had received MSF/MoH health care services, either through HIV testing, or through having been registered at one of the clinics in the region. Additionally, health care workers were either employed by MSF or the MoH. As the research was embedded within this MSF/MoH project, MSF primarily have ownership of the data, the research topic aligned with the project priorities (as Treat-all was being implemented, hence the desire for social science research on the topic), and MSF approval was required for the study protocol. However, I was autonomous in my approach to the study design and the methods that I adopted. I also had absolute autonomy in my analysis and interpretation of the results, and my choice for paper topics, or for topics of abstracts to submit to conferences. I reflect further on my positionality and my influence on the process of data generation and analysis in the Methodology chapter (in particular see Reflexivity section). The conferences that abstracts were submitted to depended on MSF support in terms of potential funding of conference attendance.

For each paper included in this thesis, I contributed to data generation, and I led on data analysis, with input to interpretation and analytical thinking from the research assistants. I conducted full data analysis, and then wrote the first full draft of each paper. I collated co-author feedback and made edits to the paper, and submitted each paper as the corresponding author. I liaised with journal editors, responded to reviewer comments, and made any necessary edits to papers before resubmitting for publication.

The work I present within this thesis sits within the discipline of public health, as it concerns the science and art of preventing disease, prolonging life and promoting health through the organised efforts of society (Acheson, 1988). The Treat-all approach for HIV aligns with the public health goals of promoting the biological, physical and mental well-being of all members of society (Detels, 2009), and this research aims to investigate how people experience their health in relation to HIV and Treat-all biologically, socially and psychologically. I therefore also draw upon

the disciplines of Medical Sociology, Anthropology and Psychology, as these disciplines provide important insights towards understanding people's lived experiences with a health condition such as HIV, and experiences engaging with treatment and care services. These disciplines informed the study design, choice of methods, and the theories that I apply in situating and interpreting the research findings, detailed in Chapter 2 and 3.

### Funding

MSF sponsored this PhD research, including providing a scholarship towards tuition fees. As the research was conducted within the MSF project, research costs were covered by the field project including for all logistics relating to interviews and focus group discussions, field worker salaries and required flights, for example to the UK. Conference costs and open access publication charges were also provided by MSF.

### Structure of the thesis

In Chapter 2, I engage with the literature from the fields of health, anthropology, sociology, psychology and HIV. I draw upon empirical findings, theory and concepts to situate Treat-all within existing knowledge and to consider how such knowledge may support the understanding of individuals' experiences with Treat-all, as well as potential evidence gaps. The topics I explore include the HIV normalisation discourse and HIV stigma. I reflect upon theoretical contributions to stigma in defining my own position and interpretation of the stigma process, and I draw upon existing evidence relating to how stigma manifests in the context of HIV and affects individuals' lives and engagement with treatment and care in multiple ways. I consider how stigma may be changing in the context of Treat-all. Then I explore chronic disease diagnosis, how individuals may respond to and process an HIV diagnosis, how this may be experienced in the context of Treat-all and potential implications for engagement with care. I consider treatment decision-making processes and again reflect upon the Treat-all context. Finally, I explore how ongoing engagement with treatment and care may be navigated over time, and what may be unique about this experience for those who are asymptomatic.

Chapter 3 describes the study methodology. Here I outline the epistemological approach underpinning the research, which draws upon interpretive, phenomenological and feminist theories in aiming to understand the world from the point of view of its participants, recognising that there is no single interpretive truth and paying attention to the ways in which the researcher and the researched shape and contribute to study findings. I describe the approaches to participant recruitment, data generation, interpretation of accounts generated through interviews and focus group discussions, and to data analysis. I position the research in the setting of Shiselweni, Eswatini, describing the study context and socio-political information of potential relevance to the research. I describe the methods that I adopted, and finally, I reflect upon the ethical dimensions of the research, including steps to uphold ethical principles and to protect participants from potential harm.

The findings of this thesis are presented through four papers, three of which have been published in peer-reviewed journals and one which has been accepted for publication. The first, published in *Social Science and Medicine*, examines how individuals process an HIV positive result, and what influences their engagement with HIV care following diagnosis, presented in Chapter 4. This paper highlights the individually varied, potentially complex process of coming to terms with, and accepting an HIV diagnosis, which is important for care seeking. The second paper, submitted to *Medical Anthropology* and presented in Chapter 5, uses narrative methods to examine decision-making processes regarding ART initiation and ongoing engagement with care, finding it important for individuals to have sense of choice and ownership over the management of their health and treatment-taking, for supporting their engagement with care. The third paper in Chapter 6, published in the *Journal of the International AIDS Society*, examines how engagement in care is navigated over the longer term, drawing upon a sub-sample of individuals who have been on ART for at least 12 months. Perceiving need for treatment and having evidence of its effectiveness motivated treatment-taking. Those who did not feel unwell at treatment initiation, and who expressed doubts about treatment need and effect described treatment fatigue and experimenting with treatment-taking. The final paper in Chapter 7, published in the *African Journal of AIDS Research*, examines

the influence of stigma on individuals' engagement with Treat-all HIV care. Stigma was pervasive within participants' narratives, and appeared to cause treatment-taking fragility and potentially undermine engagement with care.

Finally, Chapter 8 is the discussion chapter. Here I summarise the overall findings, situated within existing literature and highlighting the novel contribution of this research to knowledge. I reflect upon the approaches taken within the research, and the potential influence of this in shaping the data, including reflexivity to the role of the researcher, the strengths and limitations of the research, steps taken to disseminate the research findings, and recommendations for policy and practice.

The appendices include a table summarising the main Treat-all trial findings, example topic guides for each of the phases of data generation, certificates of ethical approval, and informed consent forms that were used with participants. Presentations (oral and poster) of the study findings that I prepared and delivered at conferences, detailed recommendations for policy and practice from the extensive programmatic feedback report that I wrote for MSF and the MoH, and key findings summary documents are included.

## Chapter 2: Literature Review

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I begin this chapter by considering the positioning of HIV as a “normalised”, manageable chronic condition through increased access to ART. I then examine HIV stigma, in terms of the theoretical construction of stigma, its drivers, causes and potential impacts, how stigma manifests in the context of HIV, and how increasing access to ART, while changing forms of stigma, does not appear to be “normalising” HIV or addressing the fundamental causes of stigma. In the following section, I examine how individuals may process and respond to an HIV diagnosis, drawing upon literature and theory from chronic conditions, and from the sociology of health and illness, to explore how illness can cause changes to identity which people living with HIV navigate and may reconcile. I then examine treatment initiation decision-making processes, considering choice, autonomy, and the importance and influences of perceived treatment necessity for motivating individuals’ engagement with care. I reflect on evidence from the Treat-all context to position this within the experiences of those who are asymptomatic. Additionally, I consider the multitude of rationalities which can influence individuals’ engagement with care, reflecting on patients as socially situated, and with aspects of self and personhood which extend beyond the biomedical realm, and which affect treatment-taking. Finally, I consider extant knowledge that may be applied to the Treat-all context in understanding how ongoing engagement in treatment and care may be navigated over time. This includes how treatment-taking might be motivated in the absence of experiential, embodied evidence of treatment effect through physical improvements, and how ownership and self-management may support determination for continuing with treatment over the longer term.

### HIV normalisation: the biomedicalised framing of HIV

The medicalised normalisation discourse of HIV-as-ART (Bernays et al., 2017) frames HIV as a manageable chronic condition, likened to other health conditions such as diabetes or asthma (McGrath et al., 2014; Moyer and Hardon, 2014). This discourse first emerged as early as 1989, when experts at the fifth annual AIDS conference in

Montreal, Canada described AIDS as a chronic condition (Altman, 1989), as opposed to an acute or fatal one, with the possibility of managing HIV and being able to live with it for a prolonged time period (Bernell and Howard, 2016). The possible management of HIV was presented as akin to cancer or other chronic conditions, through a cocktail of new and existing drugs at the time (Altman, 1989). In 1991, HIV as a chronic condition then appeared in the nursing and medical sociology literature (Nokes, 1991; Siegel and Krauss, 1991). Following the introduction of effective antiretroviral-based therapies in 1996, the view of HIV as a chronic illness became more widely accepted (Siegel and Lekas, 2002).

As chronic illnesses are typically incurable, the goals of medical care are to slow disease progression and manage symptoms (Siegel and Lekas, 2002). The chronic disease paradigm emphasises biomedical disease management, self-care, social normalisation and uncertainty (McGrath et al., 2014). The self-care that is required for successful disease management is considerable, for example requiring individuals to take medications, monitor symptoms and side effects, and eat healthily (McGrath et al., 2014; Siegel and Lekas, 2002). Additionally, chronic diseases can spur identity changes as an individual attempts to integrate the illness into their life (Bury, 1982; Polak, 2017). The identity work and processing that can occur following diagnosis with a chronic disease such as HIV are further explored in the following sections, as are some of the processes involved with self-management. Chronic illnesses necessitate some degree of dependency, for example on medical care or treatment to prevent disease progression, as well as uncertainty about the potential for changes to health status, mortality, or treatment availability in the future (Moyer and Hardon, 2014; Siegel and Lekas, 2002). Adjustment to a new life on ART can therefore pose significant medical, economic and social challenges, particularly in a setting of poverty and treatment insecurity (Rhodes et al., 2009; Russell and Seeley, 2010). In fact, Colvin argues that transforming HIV infection to a chronic condition may actually worsen “the economic vulnerabilisation of people”, due to adherence difficulties, episodic illness, transaction and opportunity costs related to lifelong treatment and the need for sustained investment of public resources to fund treatment programmes (2011, p.2).

The scale-up of ART represents an example of what Biehl termed the “pharmaceuticalization of public health” (2007), which alongside a biomedicalised approach (Clarke and Shim, 2011), highlight an increasing tendency towards relying on biomedical “magic bullets” to treat and prevent diseases (Persson, 2015; Williams et al., 2011). However, the journey towards universal ART access in Africa has by no means been plain sailing. Peter Mugenyi was one of the leaders in advocating for universal access to ART in Africa, and he and colleagues provided ART through a research centre in Kampala, Uganda from 1991. During the 1990s, the high cost of drugs prevented ART from being accessible to more than a privileged few individuals, and there was the sense that providing ART in Africa would not be viable due to pharmaceutical companies’ control over drug pricing, and therefore availability (Mugenyi, 2008). As reflected in Janet Seeley’s book on HIV in East Africa (2014), by 2011, the cost of treatments had reduced due to competition from generic producers and lobbying of activists, and treatment availability has since continued to improve. However, associated treatment costs persist for people living with HIV, such as transport and time off from work required for clinic visits, and poverty undermines individuals’ access to treatment and care (Seeley, 2014).

Within the process of medicalisation, a range of problems, including those previously considered non-medical, or not solely medical, become defined, viewed and treated as purely medical; requiring technical, biomedical solutions and management by biomedical professionals and scientists (Bell and Figert, 2015). The pharmaceutical industry increases in importance and power within medicalisation (Williams et al., 2011), and many countries are reliant upon international donors to fund ART programmes (Whyte et al., 2013). Mattes describes HIV “normalisation” and the medicalised framing of HIV as a “cultural form of social control, in that it creates new expectations for bodies, behaviour and health” (2014, p275). This echoes the work of Irving Zola on how medicine can serve as an institution of social control (1972).

An approach that is solely medicalised risks marginalising the non-medical aspects of living with HIV (Squire, 2010). It does not call for the structural drivers of HIV to be addressed, nor consider the social context that shapes the lived experiences of

people living with HIV (Hickel, 2012; Nguyen et al., 2011). For example, medical anthropologist Paul Farmer describes the “structural violence” driving HIV (Farmer, 2004), whereby existing inequalities and vulnerabilities become embodied through HIV (Hunter, 2010), which biomedicine alone cannot speak to. Didier Fassin shares two narratives connecting the HIV epidemic in South Africa to structural violence, one of President Mbeki linking the spread of HIV to apartheid, and another of a woman living with HIV, who presents and understands her infection as resulting from the structural violence of the township within which she lives (Fassin, 2007). Additionally, a study examining experiences of HIV-related stigma in Eswatini conceptualised women’s rejection from their familial or marital homestead due to their HIV status as a form of structural violence, in light of women’s sexual and socioeconomic vulnerabilities in this context (Root, 2010). Existing evidence from medical anthropological studies demonstrates that there is no simple causal link between biomedicalising HIV and normalising the social and economic realities of the disease (Moyer and Hardon, 2014), and for people living with HIV, medication is not always the easy solution (Zhou, 2016).

The scale-up of ART has been accompanied by a narrative of hope and restitution for the HIV pandemic (Rhodes et al., 2009), and one of the cited benefits of increased access to treatment is that this will further normalise HIV and decrease stigma (Castro and Farmer, 2005). It has been argued that there is the potential for ART to reconceptualise HIV, as a controllable condition rather than a death sentence (Russell et al., 2016a), as a disease “like many other diseases”, and one of many potential causes of death, which counselling messages may facilitate (Russell et al., 2015). However, evidence suggests that ART can serve as an unwelcome reminder of HIV, and a loss of independence and freedom (Persson et al., 2016), and it remains to be seen how this may be experienced by people living with HIV in the context of Treat-all.

HIV differs from other chronic conditions due to its infectiousness (McGrath et al., 2014). In particular, the predominantly sexual nature of HIV transmission raises connotations surrounding morality, and results in the persistence of blaming

attitudes towards people living with HIV (Roura et al., 2009a, 2009b). Therefore, Squire poignantly states that the association of HIV with “transgressive sexuality, particularly for women, will always render it socially pathological” (2010, p409). Existing evidence suggests that HIV continues to be seen as exceptional, in particular in terms of the experiences of those living with HIV, and those providing care and support to individuals living with HIV (Colvin, 2011; Mattes, 2014; Moyer and Hardon, 2014). I will now further explore what contributes to HIV being considered exceptional, the stigma surrounding HIV, how this influences engagement with care, and how forms of stigma may change as access to ART increases in the context of Treat-all.

### HIV-related stigma

#### **Stigma theory and definition**

Historically, stigma theorists have predominantly focused on individual-level stigma, aiming to understand the psychology of the stigmatised person, and the process through which stigma is internalised and shapes behaviour (Kleinman and Hall-Clifford, 2009). Although Erving Goffman’s seminal work on stigma dates from 1963, his framework for understanding and examining stigma is still heavily drawn upon today, and he remains the predominant stigma theorist. For over a decade pre-Goffman, the work on stigma was primarily situated in the fields of psychology and sociology, examining the individual who is disqualified from full social acceptance (for example see Lemert, 1951; and Wright, 1960). Goffman (1963) acknowledged the dearth of work exploring the structural preconditions of stigma, or clearly defining the concept, which he aimed to examine from a sociological, and particularly a symbolic interactionist perspective. Symbolic interactionism considers the construction of meanings through social interaction (Goffman, 1963), where the self is developed and maintained through social relations (Charmaz, 1983).

Goffman considers the psychological and social elements of stigma, viewing it as a process through which identity is socially constructed. He considers the ways in which society categorises people through evidence of their possessing an attribute signifying difference or ‘othering’, or an undesirable difference, with such an

attribute being a stigma symbol. Based upon this, individuals are judged in terms of their relative social value, thus being reduced from “a whole and usual person to a tainted, discounted one” (p12).

Other sociological theorists have also examined stigma from a symbolic interactionist perspective. For example Scheff (1966) proposed a “labelling theory” for mental illness, based on the application of deviant labels leading to changes in individuals’ self-perception and social opportunities. Additionally, Jones and colleagues describe a deviant condition identified by society using the term “mark”, which might define the individual as spoiled or flawed (Jones et al., 1984). These views echo the work of Goffman in considering stigma symbols (e.g. p114) and attributes (1963) in influencing how difference comes to be identified.

Goffman (1963) outlined the distinction between “discredited” and “discreditable” identities. He examines the “social information” that is conveyed by particular stigma symbols, and how an individual may conceal and manage such information in navigating social reality and protecting a social identity which is not perceived as “spoiled” or discounted. Those who are discredited possess an evident or visible attribute, requiring them to devise coping mechanisms to manage the resulting prejudice and discrimination, which can also be referred to as “enacted stigma”. Conversely, conditions which can be hidden from the public eye create discreditable identities, where the main focus is managing and concealing information to “pass” as “normal”, to avoid becoming discredited and experiencing the expected resultant stigma, which can also be referred to as “anticipated stigma” (Goffman, 1963; Scambler, 2009; Steward et al., 2008).

In order for someone to be stigmatised and to possess a discrediting attribute, this requires the existence of a social context which defines the attribute as devaluing (Crocker et al., 1998). It is important to consider the structural conditions that produce exclusion from social life, and that cause someone to be stereotyped and devalued (Parker & Aggleton 2003). Stigma is relational, in that the discrediting attribute is something others affix to the person, rather than it being inherently present (Link and Phelan, 2001). Thereby a rationale is constructed for devaluing, rejecting and

excluding the stigmatised individual (Link and Phelan, 2006). This “language of relationships” (Goffman, 1963) speaks of and to extant social inequality (Alonzo and Reynolds, 1995; Parker and Aggleton, 2003). Additionally, stigma is entirely dependent upon social, economic and political power, required for a stigma component to have weight and influence, and imbuing discriminatory consequences for the stigmatised (Link and Phelan, 2001; Yang et al., 2007). Parker and Aggleton (2003) highlight the importance of considering how people come to be socially excluded, and the forces that create and reinforce such exclusion. They draw upon the work of Foucault and Goffman, in positioning the function of stigma at the “point of intersection between culture, power and difference”, with “culturally constituted stigmatisation (i.e. the production of negatively valued difference)... central to the establishment and maintenance of social order” (Parker and Aggleton, 2003, p.17).

Stigma processes can have a multitude of impacts on the outcomes of those affected, including a dramatic effect on life chances, for example through undermining employment opportunities, housing and access to medical care (Link and Phelan, 2006). An individual with an assigned inferior social status has less power than the non-stigmatised and therefore less access to resources valued by society (Steward et al., 2008), which can affect a range of life domains including social relationships, health and psychological wellbeing (Link and Phelan, 2006). Stigma is said to “reduce the humanising benefits of free and unfettered social intercourse” (Alonzo and Reynolds, 1995, p.304), and can cause chronic stress which has negative consequences for mental and physical health (Link and Phelan, 2006; Yang et al., 2007).

Critiques of Goffman have argued that while it is important to understand the psychology of the stigmatised and the processes through which stigma comes to be internalised and to shape behaviour, this must not be to the exclusion of considering how social life and relationships are changed by stigma (Kleinman and Hall-Clifford, 2009). Some anthropological contributions to stigma theory view stigma as embedded in the moral experience, with moral standing being determined by an individual’s local social world, i.e. the domain within which daily life occurs, and upon meeting social obligations and norms (Yang et al., 2007; Yang and Kleinman,

2008). These approaches aim to focus on the lived, social experience in examining how “stigma decays what matters most to ordinary people in a local world... wealth, relationships, life chances...” (Kleinman and Hall-Clifford, 2009, p418).

Within this thesis, I use the term stigma to refer to a social process occurring in the context of power, where an individual’s difference, condition or attribute is considered unfavourable and linked to negative stereotypes. This definition of stigma is based on the work of Goffman, Link and Phelan, and Parker and Aggleton in particular. I acknowledge that the manifestations of stigma are socially constructed and context specific, and that being judged as possessing a stigma symbol generally results in loss of status, devaluation, and leads to unequal outcomes for the stigmatised individual (Gilbert and Walker, 2010; Goffman, 1963; Link and Phelan, 2001; Parker and Aggleton, 2003; Steward et al., 2008). It is important to examine the ways in which stigma may be experienced and made manifest, as in order for stigma to be addressed, it must first be understood, ideally by examining the perspective of those affected.

### **HIV stigma and judgements of immorality**

HIV-related stigma is widespread, and has been described as debilitating and intrusive (Gilbert and Walker, 2010). Simbayi and colleagues (2007) suggest that HIV could be the most stigmatised medical condition in the world, with negative views towards people living with HIV being common. HIV infection is associated with immorality, with judgements of responsibility for HIV infection, which is assumed to result from “promiscuous” behaviour and immoral conduct, thereby instilling a culture of blame and discrediting of the identities of those living with HIV (Mattes, 2014; Mbonye et al., 2013; Moyer and Hardon, 2014; Simbayi et al., 2007). Fear-driven attributions include those of contagion and death, due to the transmissibility of HIV, and its incurability (Mbonu et al., 2009), which exacerbate stigmatising processes of othering and separation.

When HIV was first identified in the 1980s, one of the dominant narratives surrounding the epidemic was that of vilification and blame for HIV transmission, particularly apparent in the media and public response to then-named “Patient Zero”

in the USA, including that he intentionally transmitted HIV through “promiscuous” sexual behaviour (McKay, 2014). In studying the epidemic in Africa, where transmission was largely heterosexual, one response was to invoke culture to explain transmission (Sovran, 2013), with descriptions of “promiscuity” and “sexual deviance” (Packard and Epstein, 1991), which Sovran argues may have been at the expense of considering the powerful effects of structural factors such as poverty in shaping the epidemic (2013). Such narratives can influence the response to an epidemic, and may have contributed towards how HIV infection came to be interpreted and perceived, including the shame, blame and moral judgements which can surround living with HIV (Caldwell et al., 1992).

Religion may serve to reinforce stigma, rather than promoting tolerance (Kayal, 1992). Stigma can be related to moral and religious beliefs, in which a person is considered sinful or evil (Duffy, 2005), and HIV is often seen as punishment for the sinful behaviour of the affected individual (Alonzo and Reynolds, 1995; Mbonu et al., 2009). As HIV may be socially judged as a punishment for those who have challenged sexual and gendered social norms (Campbell et al., 2011), HIV stigma can thus be seen as central to the establishment and maintenance of social order (Foucault, 1978, 1977; Parker and Aggleton, 2003), and the control of sexual behaviour (Mbonu et al., 2009). In Campbell and colleagues’ (2005) study of stigma and HIV management in South Africa, the link between stigmatisation, the policing of sexuality, and social inequalities are described. The authors suggest that the combination of church teachings with the construction of “traditional culture” serve to “place limits on the sexuality of African women, preserving the patriarchal social relations that continue to dominate in South Africa, despite challenges and resistance” (Campbell et al., 2005, p.809). Manifestations of stigma are exacerbated by fear, ignorance, lack of knowledge, shame, moral judgements and concepts of punishment (Gilbert and Walker, 2010). Thus, such moral and religious beliefs of sin and punishment may serve to further exacerbate the culture of blame and judgement, and feed stigmatising processes which surround HIV.

As HIV-related stigma operates within existing inequalities, gender dynamics can create unique vulnerabilities for women regarding judgements surrounding HIV infection, and in terms of the consequences of stigma, which may be particularly acute in patriarchal settings (Katz et al., 2013; Mbonu et al., 2009). Some women face severe consequences of HIV status disclosure, including abandonment, relationship dissolution and denying access to care, which can be particularly acute where women are financially dependent on their partners, and women may fear violence on their partners discovering their status (Maeri et al., 2016). Additionally, the deleterious judgement of “promiscuity” attributed to HIV infection may be particularly damaging for women (Duffy, 2005), although also described as being of concern for men (Maeri et al., 2016).

In Eswatini, a vast majority of the population identify as Christian (Central Intelligence Agency, 2018). The construction of social value and personhood is closely linked to social respectability, based on a conservative sexual morality (Kuper, 1986), similar to that described in Zimbabwe (Campbell et al., 2011). This influences the type of sexual practices considered acceptable, and frames social stature as dependent upon notions of being a moral, upstanding citizen, threatened by judgements relating to HIV and immorality. There may be dissonance between cultural scripts relating to an “ideal culture”, i.e. the norms that are publicly affirmed, and “real” or lived culture, i.e. the norms that are actually followed by individuals (Chambliss and Eglitis, 2013). In a study examining relationships and HIV risk in Eswatini, participants described an ideal of marriage and monogamy which were equated with social respectability, although many described low rates of marriage in their communities, and having multiple concurrent sexual partners (Ruark et al., 2016). In addition to the health impacts which are described further below, HIV-related stigma influences individuals’ lived experiences in terms of marriage prospects, sexual relationships, having children, all of which can be important aspects of identity and particularly in societies (such as in Eswatini) within which having children is of importance for societal value (Mattes 2014). It will therefore be important to consider how stigma may be experienced by people living with HIV and made manifest in this context.

## **The impact of stigma on engagement with HIV care**

Stigma complicates the prevention, management and treatment of HIV worldwide (Mbonye et al., 2013; Steward et al., 2008), compromising the wellbeing of individuals living with HIV (Gilbert and Walker, 2010), and influencing a myriad of factors. Experiencing HIV stigma can undermine individuals' care seeking, uptake of testing, response to an HIV diagnosis, identity, engagement with care, treatment initiation, adherence and access to support, which have been evidenced extensively in the southern and eastern African context (Ayieko et al., 2018; Katz et al., 2013; Maeri et al., 2016), and which are hereby explored further.

Avoiding a disease label may mean individuals avoid care seeking altogether (Link and Phelan, 2006; Maeri et al., 2016), with clear resultant negative health impacts in terms of morbidity and mortality from delayed access to HIV treatment and care (INSIGHT START Study Group, 2015; Lahuerta et al., 2013; Reniers et al., 2014; The TEMPRANO ANRS 12136 Study Group, 2015). Fear of stigma and inadvertent disclosure on engaging with care, for example through people living with HIV being seen by others at the clinic, can undermine access to HIV services (Gilbert and Walker, 2010; Nakigozi et al., 2013). Additionally, people living with HIV may have feelings of despair, fear of dying, and the anticipation of potential stigma and rejection may lead to non-acceptance of HIV status and avoidance of care seeking (Raveis et al., 1998). The perceived need to conceal may be a strategy that is of particular importance in the asymptomatic phase of infection (Mbonye et al., 2013), when HIV-related symptoms are not visible and therefore enacted stigma can be avoided.

Fear of the potential consequences of a positive HIV test result, including stigma and discrimination, can deter individuals from getting tested (Gilbert and Walker, 2010; Niehaus, 2014). For example in the context of Treat-all in South Africa, study participants described a reluctance to seek clinic-based testing due to confidentiality concerns and fear of status exposure (Orne-Gliemann et al., 2016). Likewise, treatment initiation can also be delayed due to concerns about the difficulty of maintaining a confidential status while on lifelong treatment, also found in the context of Treat-all in Uganda (Mbonye et al., 2016). In South Africa, Moshabela and

colleagues describe people feeling it is “better to die with dignity, than live with shame” of others knowing of your HIV status (Moshabela et al., 2016, p.7).

Stigma can undermine adherence both directly and indirectly. Attempts to hide treatment from others have been described as contributing to treatment interruptions in several studies included in a systematic review (Katz et al., 2013). Additionally, studies from several African settings have described how some individuals may opt to use a clinic far from their home community in order to avoid being seen by people they know while accessing treatment and care, thereby avoiding inadvertent disclosure (Bond, 2010; Gilbert and Walker, 2010; Maeri et al., 2016). This can create challenges for adherence by adding to the burden of treatment and undermining the sustainability of treatment-taking over the longer term, with potential for extensive investment of time and effort to maintain the appearance of health and thereby avoid anticipated stigma (McGrath et al., 2014). Stigma also indirectly affects adherence through reducing access to social support due to non-disclosure. Existing evidence points to the importance of such support for ART adherence, in terms of emotional, financial support, and treatment reminders, particularly from a partner/spouse or family members (Katz et al., 2013).

### **ART access and changing forms of stigma**

ART enables the management of HIV-related symptoms and therefore the potential for HIV status concealment (Abadía-Barrero and Castro, 2006; Roura et al., 2009a, 2009b). Castro and Farmer suggested that increased availability of ART would result in a decline in AIDS-related stigma, based on their experience in Haiti, where they said treatment “decreased stigma dramatically” (2005, p57). However, experiences of living with HIV, and with ART are not uniform (Seeley, 2014). Castro and Farmer’s (2005) findings reflected a context where the majority of individuals engaging with treatment and care were at advanced stages of disease, with symptoms which caused their HIV status to be visible, thereby creating discredited social identities. For those who initiate ART when symptomatic, ART can facilitate a “return to normality” (Beckmann, 2013). Ecks describes how biomedicine can “de-marginalise the suffering individual”, rendering them acceptable to society (2005, p.242). However, Persson

highlights that this is dependent upon patients' compliance with biomedical solutions and fulfilment of their obligations as citizens (2015). Talcott Parsons presents the doctor as the guardian of established order, and as "the embodiment of the "sacred" order of normality" (Parsons, 1951; Turner, 1999, p.174), on whom patients depend for this "normality" to be achieved and sustained.

The ability of ART to resurrect bodies (Colvin, 2011), and to bring people back from the edge of death, has been described as the "Lazarus effect" (Seeley and Russell, 2010; Siegel and Lekas, 2002). These restorative benefits of ART and the concealment of symptoms or stigma symbols could thereby enable the lived experience of stigma to become more manageable, as acts of overt discrimination or enacted stigma are reduced (Beckmann and Bujra, 2010), and as individuals can conceal information regarding their status and have discreditable, rather than discredited identities (Goffman, 1963).

Additionally, the ability of ART to alleviate physical symptoms enables social and economic participation, through which individuals can reconstruct their sense of social value, again countering processes of stigma (Bernays et al., 2010; Campbell et al., 2011; Mattes, 2014). ART has been described as a "technology of invisibilisation" (Mattes, 2014), as it enables the avoidance of visible symptoms and therefore supports status secrecy and the avoidance of stigma (Beckmann, 2013; McGrath et al., 2014; Moyer, 2012). However, although ART may facilitate status concealment, stigma continues to persist (Niehaus, 2014; Russell et al., 2016b), and increased ART access may generate new forms of stigma, linked to social judgements of morality and concerns about treatment hiding individuals' HIV positivity (Roura et al., 2009b, 2009a). Individuals taking ART may "remain mired in conflictual symbolic relationships between the HIV/AIDS people and the untested" (Campbell et al., 2011, p. 1004).

While ART may enable status concealment through preventing the development of HIV-related symptoms, this does not address the fundamental causes or the structural drivers of stigma. For example, ART does not challenge the views which lead to the labelling of difference, stereotyping, separating and devaluing of

individuals with HIV, by individuals or groups with the economic, social and political power to be able to influence such processes (Link and Phelan, 2001). Likewise, ART does not counter the underlying social inequalities which can create vulnerability for stigma and exclusion, such as racism, gender inequality, poverty and class (Link and Phelan, 2001; Parker and Aggleton, 2003; Russell et al., 2016b). Additionally, such concealment requires individuals living with HIV to sustain engagement with HIV treatment and care services and treatment-taking. This carries risks for status exposure, as well as creating dependence on ART programmes, and uncertainty relating to potential changes in health status or treatment availability in the future (Moyer and Hardon, 2014; Siegel and Lekas, 2002).

In the context of Treat-all, increasingly individuals are initiating ART when clinically asymptomatic, with therefore no visible signs and symptoms of HIV, and with discreditable rather than discredited social identities (Goffman, 1963). The *MaxART* Treat-all study in Eswatini found health care workers appropriated HIV-related stigma to encourage patients to initiate ART under Treat-all, in describing the benefits of avoiding HIV status disclosure to the wider community, and in the ability of ART to hide visible signs of illness, an approach which may in fact exacerbate HIV-related stigma (Pell et al., 2019). This evidence highlights the perspectives of health care workers relating to how stigma may be experienced in the context of Treat-all, and it remains to be examined how this may be experienced by people living with HIV. Evidence from Treat-all in Mozambique suggests that severely ill people living with HIV are less likely to fear unwanted disclosure and resultant stigma on engaging with HIV care, due to the priority of regaining health. However, for those who feel healthy, the potential for unwilling disclosure is exacerbated by engaging with HIV services, which can dissuade individuals from treatment initiation and can undermine longer term adherence (Magaço et al., 2019). This therefore warrants further investigation, in examining how stigma may influence individuals' engagement with HIV treatment and care under Treat-all.

## Adjusting to illness: HIV, identity and conceptions of health and ill health

Coming to terms with an HIV diagnosis can be complex and individually varied. Adjusting to “illness” and to changes in identity that such a diagnosis infers may be particularly challenging in the absence of any symptoms or signs of ill health, requiring prevailing conceptions of health and ill health to be reframed. In the following section, I explore extant evidence on the processing of disease diagnosis. I draw upon psychological and sociological theory, particularly relating to the sociology of health and illness and to chronic conditions, to further understand how such a diagnosis may be experienced by asymptomatic people living with HIV in the context of Treat-all, and to consider the potential impact of such processes on individuals’ outcomes and engagement with care.

As described further above (section on the impact of stigma on engagement with care), the fear of potentially being diagnosed HIV positive, and the anticipated stigma for example in terms of social isolation and exclusion that may result, can dissuade test-seeking and access to HIV care (Lindkvist et al., 2015). This is important to address, as HIV testing is the “crucial entry point to effective HIV prevention” (Alsallaq et al., 2013), and timely linkage to medical care can improve individuals’ health outcomes as well as contributing to HIV transmission reduction (Jenness et al., 2012).

### **Processing an HIV diagnosis**

Reactions to health and illness are shifting and contextual (Harris, 2009). However, receiving an HIV diagnosis is frequently accompanied by shock, doubt and disbelief, and an inability to accept the HIV positive test result (Beer et al., 2009a; Nakigozi et al., 2013; Raveis et al., 1998), or to acknowledge and embody the realities of living with HIV (Moitra et al., 2011). A lack of HIV-related symptoms can make it particularly challenging to accept an HIV positive result, as individuals who perceive themselves as healthy may deny the significance of infection (Raveis et al., 1998), and not having symptoms may reinforce disbelief and doubts about being HIV-infected (Beer et al., 2009a; Wringe et al., 2009). This has been found in the Treat-all context in Mozambique, where feeling healthy discouraged treatment initiation among some

individuals who struggled to accept their HIV positive status, associating HIV with sickness (Magaço et al., 2019).

Stigma can exacerbate this process of status non-acceptance, as denial is a defensive response which partly results from avoidance of anticipated HIV stigma (Lyimo et al., 2014), making it difficult to reconcile with (Denis, 2014). Avoidance of anticipated stigma results in the suppression of any thoughts related to living with HIV (Moitra et al., 2011), and can dominate all aspects of behaviour relating to HIV (Lindkvist et al., 2015). Fear of experiencing stigma can result in self-rejection, denial and as a result self-medication and care secrecy (Ajala, 2012). Commonly held views around HIV infection and morality, or “careless” sexual behaviour can mean that individuals who do not identify with this image of who gets HIV therefore do not perceive themselves as being at risk, thereby undermining HIV status acceptance (Skovdal et al., 2011). Views about HIV risk and susceptibility, which are important for status acceptance, can also be influenced by concepts of HIV aetiology. For example extant views that HIV is caused by witchcraft and may be cured by traditional medicine or spirituality can undermine engagement with biomedical care, and may in turn be driven by the stigmatisation of HIV as a sexually transmitted infection, offering a more socially palatable (and therefore less stigmatising) cause of infection (Beer et al., 2009a; Wringe et al., 2009). There can be duality between traditional medicine and clinical biomedicine, and individuals may alternate or combine different approaches. The alluring promise of cure offered by alternative systems and the deterring HIV stigma of being known to take ART can render traditional medicine and spiritual healing particularly appealing (O’Brien and Broom, 2014).

Denial is arguably the most common psychological barrier to initiating medical treatment, as seeking care serves as a reminder of an HIV status that an individual may be attempting to avoid thinking about (Raveis et al., 1998). Denial has been associated with poorer physical and mental health (Kamen et al., 2012), with delayed testing, access to care and initiation of treatment (Ayieko et al., 2018; Lindkvist et al., 2015), and may exacerbate symptoms and cause poor adherence to ART (Moitra et al., 2011).

The concept of denial was first explored psychologically by Sigmund Freud (1856-1939) within the language of defence mechanisms, which were identified as processes the ego applies to avoid the anxiety of a threatening situation (Freud, 1961). Freud presented denial as functional in the short-term, as it allows a patient to avoid an unbearable situation and the feelings which accompany it, however, in the longer term it can lead to pathology including personality disorders. Elisabeth Kübler-Ross (1969) describes the stages of grief that patients go through following a terminal diagnosis, presented as five stages between awareness of serious illness and death. These include denial, which may be accompanied by a sense of “no, not me”, and can last seconds or months; then anger, “why me?”, and bargaining “yes me, but...”, for example where a patient asks for more time. This is followed by depression, which can be reactive and despondent, where the patient mourns the loss that they will inevitably experience with their diagnosis. Finally comes the stage of acceptance, “the miracle is that I am ready to go now, and it is no longer frightening”. Kübler-Ross’s later work (1987) applied this grief model to AIDS, presenting acceptance as an adaptive state, whereby individuals reach a state of peace and resignation to the inevitable. While this applied to the pre-ART era, an HIV diagnosis will likely be experienced quite differently now, but an understanding of these psychological processes may still be of use, and relevant during the roll-out of Treat-all in many African countries. Kübler-Ross highlights the importance of health care workers’ listening to patients, understanding their individual experiences and supporting them on the journey of processing a diagnosis, for example through helping them to express their anger, rather than discounting it or encouraging them to suppress it (Kübler-Ross, 1969).

The stages of grief model has been critiqued for being reductive and presenting emotional adjustment in terms of linear stages that all individuals go through, and based on the assumption that a person is only able to move forward when they have come to terms with the reality of a changed life (Kralik, 2002). It is important to have an understanding of the illness response that prioritises individuals’ experiences, including the complexity and uniqueness of how each person may adjust to living with an illness such as HIV (Telford et al., 2006).

Acceptance of HIV status has been described as willingness to acknowledge infection and its implications for future life, as well as openness to altering behaviours in order to maintain healthy living (Moitra et al., 2011). Accepting a positive HIV test result can take time, and may involve re-testing for HIV to confirm the accuracy of the test result, which McLean and colleagues describe as potentially occurring over months or even years (2017). Where the process of acceptance is accompanied by hope for the future, this may improve individuals' wellbeing, with hope being linked to both self-reported health and directly measured immunological status (Scioli et al., 2012). Acceptance and overcoming stigma are interlinked, with acceptance supporting status disclosure, which in turn can facilitate engagement with treatment and care, and support adherence (Nam et al., 2008). Coming to terms with such a diagnosis, adjusting to illness and the required identity work are explored further in the sections below.

### **Adjusting to chronic illness**

Illness refers to the human experience of disease, which is "an explicitly social phenomenon with both an objective and a subjective reality" (Idler, 1979, p.723). Adjusting to, and learning to live with chronic illness can be a complex process, which involves fluctuation and movement back and forth (Kralik, 2002). There are several theoretical contributions towards understanding a patient's response to chronic illness, which can be considered in the context of HIV within Treat-all. Overall, theoretical work has shifted from "the doctor's legitimation of illness, using the disease model, towards an understanding of the meanings which patients place upon their situation" (Radley, 1989, p.230). Here disease refers to an "abstract, biological-medical conception of pathological abnormalities in people's bodies" (Idler, 1979, p.723). There may be divergence between scientific interpretation of disease, and a person's experiential account of illness, and it is important to look beyond the biomedical perspective to understand how chronic illness is experienced (Telford et al., 2006).

Michael Bury's (1982) work on chronic illness as a biographical disruption is often cited, and has also since been critiqued and adapted (e.g. Williams, 2000).

Biographical disruption relates to the experience of chronic illness disrupting the structures of everyday life and the forms of knowledge underpinning them. The worlds of pain and suffering, which are normally seen as distant possibilities or the struggle of others, must be recognised. Additionally, rules of reciprocity and mutual support are disrupted as an individual becomes increasingly dependent. To make sense of the illness, an individual draws knowledge and meaning from their own biography, and in searching for the cause of the illness one likewise finds its meaning (Bury, 1982). Stages involved in the process include bringing to attention bodily states which are not normally conscious, making decisions relating to help seeking, fundamentally re-thinking biography and self-concept as extant explanatory systems are disrupted, and mobilising resources in facing an altered situation. Several of the aspects of this theoretical construction of chronic illness imply an illness where someone is symptomatic and debilitated as a result, creating increasing dependency on social networks and families, which are not as relevant in the context of HIV Treatment, as increasingly individuals living with HIV are diagnosed when asymptomatic (Bury, 1982).

The critique of Bury's theorisation of chronic illness includes the view that biographical disruption does not account for the possibilities in which illness may already be a central part of one's biography, for example from birth, early childhood, or later life, including so-called "normal crises" (Williams, 2000). Gareth Williams explores the meaning and experience of chronic illness through narrative reconstruction, including how an individual may reify illness and symbolically attempt to "reconstitute and repair ruptures between body, self and world by linking-up and interpreting different aspects of biography in order to realign present and past, and self with society" (Williams, 1984, p.197). Illness may bring about biographical continuity or reinforcement, rather than disruption, particularly in circumstances of hardship and adversity (Williams, 2000), where illness may reinforce components of identity and lifetime illness experiences or struggles.

Chronic illness diagnosis has also been conceptualised in terms of transition, in reflecting the move towards incorporating illness into life, which can be facilitated by

reflective processes and taking action (Kralik, 2002). Transition to living with HIV as a chronic condition may involve quests to regain control, create order and to feel 'normal' again (Russell and Seeley, 2010). The conceptualisation of transition supports reflection on the dynamic aspects of living with chronic illness, a process which is nonlinear, potentially cyclical, convoluted and may occur over a long period of time (Kralik, 2002; Meleis et al., 2000).

In a high HIV prevalence context, such as in southern Africa and Eswatini, risk of exposure to HIV is widespread, and an HIV diagnosis could thereby serve as a biographical reinforcement. However, HIV-related stigma creates a unique context, where it could be more likely that due to the association of HIV with "immoral" and "sexually deviant" practices, the majority of individuals would not associate with the socially normative image of the type of person who gets HIV. Therefore in the context of stigma, even if the HIV prevalence is high, it may still be more appropriate to consider an HIV diagnosis in terms of a potential biographic disruption, as it disrupts the "socially set standards and cultural prescriptions of 'normality'" (Bury, 1982; Williams, 2000, p.50), likely requiring particular work in terms of adjustment and identity.

### **Illness and identity**

Being diagnosed with a chronic illness is said to fundamentally necessitate identity work (Siegel and Lekas, 2002; Telford et al., 2006). Such identity work requires that a person diagnosed with HIV takes on the identity of a chronically sick person, and recognises the long-term nature of the condition, committing to its ongoing lifelong management within the realm of everyday life (McGrath et al., 2014). The former self-image may crumble away as the experiences and meanings upon which previous self-images were built persist to be available, and control over life and the future diminishes, resulting in a diminished self-concept, with loss of self-esteem and self-identity (Charmaz 1983).

Social identity theory suggests that identity rests on the process of social comparison, whereby individuals compare themselves with similar others during social encounters (Exley and Letherby, 2001). In Mead's (1934) analysis of the self, the "I"

and the “me” are differentiated, with the “I” representing the principle of action and impulse and the “me” representing the socialised aspect of personhood. Thereby the self is considered a social being, and it is through social process that a biological being gets a mind, self and rationality (Mead, 1934). Adams describes the “I” and the “me” as “personal identity” and “social identity” respectively (1997). Living with a chronic illness becomes a part of personal identity and social and personal frameworks, with resultant impact on conceptions of self, time, and relationships with others (Roth and Nelson, 1997). Within HIV, both aspects of personal and social identity work may be required, as identities and responses to the epidemic are forged by individuals, which can both reinforce or undermine overarching social and cultural norms (Keogh and Dodds, 2015). An HIV diagnosis necessitates reconstruction of the self, and of the new identity through illness (Fassin, 2007), an ongoing process which may be undertaken within a macro-social context by the individual, family members and health care providers (Roth and Nelson, 1997).

Although less common in the Treat-all era, treatment can still be interpreted as symbolising illness and death. For example, a study examining attitudes towards early ART in Kenya found initiating ART was perceived as signifying the final stage of HIV illness, when one was “nearing the grave” (Curran et al., 2014). Treatment may reinforce an illness label which individuals do not identify with, whereby medicines are seen as an unwelcome reminder of illness (Pound et al., 2005), and patient identity (Siegel and Lekas, 2002). Polak describes the devalued identity of being a pill-taker in the context of statins, with resisting medication being framed as resisting an illness label, and treatment-taking posing a direct threat to a presentable identity (2017).

In the context of HIV, ART may be associated with stigmatising judgements of HIV including immorality, sin and sexual deviance. This could exacerbate the undesirability of associating with such an identity, which on the one hand involves identifying with an illness for which individuals in the Treat-all context may have no symptoms, and which also is aligned with a stigmatised and devalued social identity. Adams and colleagues describe the avoidance of membership of a stigmatised group

in the context of asthma, whereby asthma was reconstructed to enable denial of the label or social identity of “asthmatic”. Asthmatics were viewed as “weak” and “decrepit”, holding problematic repercussions for individuals’ self-concepts in reconciling self-identity with living with asthma (1997). Within HIV, this has been described in terms of concepts of masculinity, with the identity of being “a real man” attributed to physical strength, resilience to illness, responsibility and success in sustaining a family, which an identity of living with HIV may threaten and contradict (Chikovore et al., 2016; Siu et al., 2013; Skovdal et al., 2011). This may change in the context of Treat-all, as the promise of ART prolonging good health may appeal to such concepts of masculinity and strength, potentially motivating test-seeking (Camlin et al., 2016b).

Within this section, I have reflected that adopting the identity of a chronically ill person who must continually navigate and engage in health services may be particularly challenging for those without symptoms of ill health, for whom treatment can reinforce an identity with which they do not identify, and which is stigmatised and socially devalued. As adjustment to illness and identity work may be necessary precursors for committing to ongoing management of health and treatment-taking, it will be important to consider how this may influence the experiences of people living with HIV engaging with treatment and care in the context of Treat-all in Eswatini. For example, in examining whether and how self-identity influences how an HIV diagnosis is processed and decisions to engage with treatment and care in this context.

I will now go on to explore the existing literature on the processes that people living with HIV may go through when deciding upon ART initiation. I will consider how individuals’ identity and conceptions around health and ill health may influence their decisions about treatment necessity, with particular reflection on how this may be experienced by asymptomatic people living with HIV within Treat-all.

### Choice and decision-making regarding ART initiation within treat-all

There may be dissonance between the biomedically framed rationale of Treat-all, which posits that HIV is an imperceptible illness which is made visible only through

a positive test result indicating that an individual is sick, and the rationale framing individuals' conceptions of illness and treatment necessity (Zhou, 2016). It has long been recognised that individuals' perceptions of their own health, illness and symptoms, and decisions regarding their help-seeking are not necessarily congruent with the views held by medical professionals (Bury, 1982). Despite biomedical evidence showing that ART should be initiated immediately following diagnosis in order to achieve its beneficial effects (INSIGHT START Study Group, 2015; The TEMPRANO ANRS 12136 Study Group, 2015), how individuals living with HIV view and experience their decision regarding when to initiate ART may not align with this biomedical rationale (Mbonye et al., 2016). In this section, I will outline and define treatment decision-making, consider concepts of autonomy and choice relevant to Treat-all, how patients may determine treatment necessity and decide when to initiate ART in the absence of HIV-related symptoms, which may be relevant to the research context.

### **ART initiation decision-making processes**

Before considering decision-making processes, and how decisions to initiate ART may be experienced within Treat-all, it is important to first reflect on the concept of choice within health care, and whether and why such choice matters.

Autonomy is one of the principles of health care ethics, along with beneficence, non-maleficence and justice. Beneficence refers to the obligation to provide benefits that outweigh risks, non-maleficence the obligation to avoid causing harm, justice the obligation of fairness in the distribution of benefits and risks, and autonomy refers to the obligation to respect the decision-making capacities of autonomous people (Warnock, 1994). Respect for autonomy is a moral obligation, requiring that individuals are consulted, informed, heard and their agreement obtained prior to medical intervention, i.e. informed consent (Gillon, 1994). Autonomy can be seen as the obverse of dependency (Polak, 2017). Within autonomy, individuals are considered self-determining agents whose decisions and actions are their own, and liberty, power and privacy may be necessary for individuals to develop their own aims and interests (Dworkin, 1988). Thus, a "capacitous individual is entitled to

decide whether or not to accept medical treatment”, even if this decision is considered to be unwise or medically not in their best interests (Cave, 2017, p.529). This may be additionally complicated in a public health context, as there can be dissonance between the public health agenda and an individual patient’s choice. For example, health care workers can experience perceived moral responsibility in the implementation of Treat-all, to reduce the risk of HIV transmission in the community, or to protect an unborn child from HIV acquisition (Vernooij and Hardon, 2013). It will be important to consider how this potential dissonance is experienced, and how it might be reconciled in the Eswatini context.

Within the rationale of autonomy, choice is assumed to be good because it offers individuals autonomy, claiming that by making choices we become in control of our own lives (Mol, 2008). However, Polak argues that “this binary framing fails to represent the complex calibration process people may undertake in resolving the tension between stubborn rejection or passive acceptance of health care worker advice” (Polak, 2017, p. 611). Within the logic of choice, Mol (2008) describes how patients are considered “consumers” and health products “goods”. However, there is a negative starting point with disease, as individuals would prefer not to have it, so it is therefore not a “good” around which they are actively choosing to “consume”. Additionally, actually making decisions about our own care can be difficult, as fear and emotion can cloud judgement, and making rational, objective choices is near impossible when many risks (and in the context of Treat-all, potentially benefits) are unknown and the future is uncertain (Mol, 2008). Mol argues that choice can actually erode good care, and proposes an alternative approach, the logic of care (2008). Here, rather than seeking equality between patients and healthy people, the aim is to establish living with a disease (not ‘normality’) as the standard. The active patient is resilient and flexible, and through caring strives to achieve as much health as the disease allows (Mol, 2008). However, Mol’s perspective on patient choice as eroding good care has been critiqued, and in Uganda and Kenya, Hardon and colleagues found that choice can actually complement good care rather than eroding it (Hardon et al., 2011).

The updated (2016) WHO treatment guidelines state that the decision to accept or decline ART within Treat-all lies with the individual patient, who can also choose to defer, and that health care workers should discuss patients' willingness and readiness to initiate ART with them. I will consider evidence regarding how this decision may be experienced in practice, and what might influence a person's willingness and readiness to initiate ART.

Historically, a paternalistic model of patient care was common. Within this approach, physicians would make decisions in the best interest of the patient, with minimal patient involvement, and the focus being solely the patient's biomedical problems (Byrne and Long, 1976). In this context, patients represent "docile bodies", who submit to medical authority (Foucault, 1977). Within such hierarchical medical systems, it is argued that medical professionals can act to carefully guard their "expert knowledge", holding the power and control, for example over the drug administration on which patients rely (Beckmann, 2013; Russell et al., 2015). Talcott Parsons described a patient's "sick role" as an assigned social position (Parsons, 1951a, 1951b), requiring patients to enter into a relationship of dependency, compliance and cooperation, looking to medical authority with admiration and deference (Crossley, 1998). Parsons argued that asymmetry of knowledge and power in favour of doctors was necessary for an effective practitioner-patient relationship (Parsons, 1975). However, the paternalistic medical model has since been extensively criticised, including for requiring patients' submission to expert medical opinion and blind obedience to doctors' orders (Bader et al., 2006; Childress, 1982). Additionally, the narrow focus on biosociality does not account for the range of social relations that characterise and shape people's daily lives (Whyte, 2009). The term biosociality was introduced by Paul Rabinow (1996), reflecting the construction of sociality based on biological nature, as portrayed and controlled by and through science.

The theory of patient-centred medicine was first introduced by Balint (1964), with a view to consider and understand illness from the patient's perspective, rather than assuming medical practitioners know best. Negotiated care can create a power balance in the practitioner-patient relationship (Goodyear-Smith and Buetow, 2001),

and can improve patient outcomes (Nafradi et al., 2017). This approach has been developed further with the theorisation of person-centred care, which holistically situates patients in their social and biologic entirety, drawing medical attention to patients' personal identities, their subjectivity, environment and social situation, avoiding the reduction of people to disease alone (Ekman et al., 2011; Olsson et al., 2013). Rather than passively receiving health care, the patient is considered an active participant in their care (Leplege et al., 2007).

The model of shared decision-making posits that both health care workers and patients have a legitimate investment in the treatment decision within a collaborative relationship. Here, rights and responsibilities are distributed between both the health care worker and the patient, with "active" forms of patient-hood being recognised, and treatment decisions which explicitly refer to evidence being valued (Charles et al., 1999, 1997). Individuals' decisions are shaped over time by knowledge and encounters beyond the initial medical consultation (Rapley, 2008). People can consult a variety of sources of information, and do not rely solely on medical advice regarding taking medicines. (Pound et al., 2005). Decisions individuals take are rational within the context of their beliefs, responsibilities and preferences, for example, weighing up the costs and benefits of medicine offered in accordance with desired outcomes, which may differ for the patient and the health care worker (Adams et al., 1997; Conrad, 1985).

Decision-making is deeply embedded in, shapes and is shaped by interactions with others. Autonomy can thus be considered as relational (Keller, 1997), with a patient's agency potentially "emerging in and through a web of intersubjectivity and relationality" (Rapley, 2008, p.436). For example, a study examining views towards provider-initiated HIV testing in Kenya and Uganda found it rarely the case that an individual made a choice to accept HIV testing in isolation of other influences. Decisions were socially embedded, and included consideration of the views of family members, partners, religious leaders, friends and others (Hardon et al., 2011). In Eswatini, meanings of treatment offering the potential to prevent HIV transmission, and conceptions of initiating ART early, before one becomes visibly ill, are

“incorporated into existing socialities such as kinship relations, and should be seen in relation to specific local moral worlds” (Vernooij et al., 2016, p.11).

Within this thesis, I take a person-centred perspective, focusing on understanding the illness experience and thought processes informing treatment decisions (Conrad, 1985; Pierret, 2003; Zhou, 2016), aiming to understand this from the perspective of the individual experiencing the illness, whilst considering the broader social, cultural and health system context. I define decision-making as a process involving multiple encounters and interactions with multiple people, and relying on multiple sources of information and knowledge, occurring over a period of time (Rapley, 2008). Patients consider medical advice, and also weigh the possible benefits of treatment against anticipated costs such as of side effects, drug dependence, stigma and clinic attendance (Conrad, 1985; Wringe et al., 2009; Zhou, 2016). Decisions may involve an interpretation of past events, imagining of future trajectories, and judgements in response to changing situations (Zhou, 2016). Additionally, decisions are influenced by structural factors such as education, class, gender and race (Cockerham, 2005). Thus decision-making should be considered based on rationality that is situated (Beckmann, 2013), with the prioritisation of ART and physical health above other areas of life, such as generating an income, securing food, providing for family, or maintaining social position, not always being realistic, achievable or possible. “Many individuals may simply choose not to forefront HIV as the central or defining issue in their lives” (Kielmann and Cataldo, 2010, p.25), and people can have logical reasons for not taking ART (Pound et al., 2005). Thus seemingly “irrational” behaviours such as not taking treatment as prescribed, may be “ways in which people enact agency in the context of their day-to-day needs” (Paparini and Rhodes, 2016, p.506).

### **Treatment readiness**

As outlined above, it can take time to process an HIV positive result, to come to terms with and adjust to illness and the identity work this requires, and to undertake decision-making processes regarding whether and when to initiate ART. In a Treat-

all study in Eswatini, some individuals were described as delaying ART initiation in order to have time to come to terms with their diagnosis (Pell et al., 2019).

When individuals initiate ART before they are ready, this can undermine their subsequent engagement in care (Katirayi et al., 2016), including in terms of adherence (Pell et al., 2019) and retention in care (Cataldo et al., 2017). This is particularly evident in the context of Option B+. For example in Malawi, Tanzania and Uganda, Mclean and colleagues (2017) found that the way in which ART initiation was offered and encouraged during pregnancy could cause some women to “accept” ART before feeling ready, as many women believed HIV testing and ART initiation were obligatory parts of antenatal care. Pregnant women who did not feel ready for treatment described various avoidance tactics, including accepting and then discarding treatment, or stopping treatment once the perceived primary motivation for ART, protecting their unborn child, was fulfilled (McLean et al., 2017). Health care workers can feel a moral responsibility to protect babies from the risk of HIV acquisition, and a professional need to promote and adhere to the public health goals of preventing further HIV infections, which may translate to pressure felt by women who access services during pregnancy to initiate ART quickly (Vernooij and Hardon, 2013). If treatment initiation occurs before individuals are psychologically ready, their capacity to prepare for ART and to sustain engagement with treatment and care may be reduced (Bulsara et al., 2018).

Health care workers can experience pressure to encourage patients to “comply” with treatment policy and programmes, employing various strategies to “convince” patients (McLean et al., 2017). For example, counsellors may attempt to engage clients by “making appeals” or by “prescribing rules for living” (Cawley et al., 2016). Such “rules for living” can include abstinence, condom use, reduction in sexual frequency and number of sexual partners, which may be appropriated by counsellors to encourage individuals’ adoption of healthy lifestyle behaviours, with potential disadvantages and sanctions presented as penalties for breaking such rules (Allen et al., 2011). There may be asymmetries of power between practitioners and patients, which establish order and direct codes of conduct, whereby submissive people living

with HIV who subscribe to rules of engagement are seen as cooperative and rewarded with labels of “good patients”, as opposed to those of “bad patients” (Ondenge et al., 2017). Health care workers may also adopt more extreme measures, potentially using their position of authority to attempt to control patients, for example, with threats of withdrawing treatment and care, including for pregnancy or other health conditions, “if patients are not obedient, passive, and compliant, fashioning a form of subordinated therapeutic citizenship” (Russell et al., 2015, p.2). Health care workers who are trained to convince women to test for HIV during pregnancy can be judged as having failed at their jobs if the woman refuses (Vernooij and Hardon, 2013). Women receiving provider initiated testing during pregnancy in Malawi described not perceiving HIV testing as a choice, but rather as compulsory in order to receive antenatal care (Angotti et al., 2011), and in Uganda HIV testing within antenatal care was described as an “offer they can’t refuse” (Vernooij and Hardon, 2013, p.S563).

A systematic review of Option B+ studies found that newly diagnosed HIV-positive women could feel alienated by perceived pressure from providers to initiate ART immediately following their diagnosis, with some not feeling ready to make a lifelong commitment to ART, and needing time to consider their options (Knettel et al., 2018). While patients may subscribe to medical hierarchy and follow health practitioner advice, individuals are also self-determining agents who challenge and resist the structures of power and domination in modern society, with the potential to resist or rebel from following medical advice as prescribed (Foucault, 1963). Where individuals feel pressured to initiate ART before they are ready, their agency may be enacted through their choices once they leave the bounded domain of the health services. People may assert their agency by refusing to take medication, or by giving health care workers as little information as possible (Telford et al., 2006). For example in Eswatini, women who engage with HIV services during pregnancy can appear to engage with care and initiate ART, then throwing away the medication on leaving the clinic, or delaying their actual initiation until they feel ready (Katirayi et al., 2016).

In the context of Treat-all, the time between diagnosis and treatment initiation is expedited for many people living with HIV. This may cause barriers to treatment initiation to be compounded, particularly for those who do not feel unwell and therefore do not experience the same motivation for treatment as those who initiate when symptomatic, or under previous treatment guidelines (Magaço et al., 2019; Nhassengo et al., 2018). It is important to ensure that programmes still allow for and support individual variation in response to an HIV diagnosis, and time to treatment readiness. Some individuals may benefit from being given more time to accept an HIV positive status, and to receive counselling tailored to their specific needs until they feel ready to initiate ART (McLean et al., 2017).

### **Conceptions of treatment necessity**

Existing evidence from southern Africa describes predominant conceptions of illness as being experiential and embodied. For example, within research on Option B+ in Malawi, health and illness are described by women as experiences they can see and feel, with sickness equated with feeling pain, weakness, weight loss and observable changes in appearance, whereas health is understood in terms of being pain-free, being fat and beautiful, strong, energetic and capable of work (Zhou, 2016).

In the pre-Treat-all era, several studies highlighted the influence of not feeling unwell on undermining engagement with HIV care and treatment initiation (Gold and Ridge, 2001; Govindasamy et al., 2012; Newman et al., 2015). The perceived severity of an HIV infection and its potential consequences may be interpreted based on the presence of physical symptoms, with accordant influence on accessing care (Beer et al., 2009a; Nakigozi et al., 2013; Wringe et al., 2009). Not having symptoms, or feeling able to manage symptoms, have led to treatment being described as “not yet necessary” by people living with HIV in Uganda and Zimbabwe (Kawuma et al., 2018).

Those who feel “normal” and healthy may want to protect that state of being, and treatment-taking can be associated with illness rather than health, with loss of control and autonomy rather than empowerment, and with shame and difference, not normalisation (Pound et al., 2005). This is reiterated by Persson and colleagues (2016),

whose research examining decisions not to take ART in context of Treat-all found that treatment was seen to signify a “loss of control” over one’s condition and life, and an unending reliance on the medical establishment from thereon. Few participants felt the need to initiate ART, due to feeling healthy (Persson et al., 2016). Further, in the context of Option B+ in Eswatini and Malawi, many women have been found to have difficulty accepting treatment when feeling healthy (Katirayi et al., 2016; Kim et al., 2016; Zhou, 2016).

Within the context of Treat-all in Eswatini, many people living with HIV perceive ART as being for the treatment of symptomatic illnesses, which may undermine the perceived need for treatment for those who are asymptomatic, and influence ART initiation decisions (Pell et al., 2018). Additionally, a study examining men’s views about Treat-all in Eswatini found men had concerns about taking treatment while feeling healthy, with one man stating: “I will take ARVs once my body deteriorates, so that I can regain my strength” (Adams and Zamberia, 2017, p.300). This may change as Treat-all becomes more commonplace (Pell et al., 2018). In addition to good health potentially undermining a desire to initiate ART, ART may offer perceived benefits of preserving good health and productivity which can motivate some to want to start even in the absence of symptoms or signs of ill health (Magaço et al., 2019; Pell et al., 2018; Vernooij et al., 2016). The desire to protect good health has been described as a mechanism through which to achieve future roles and responsibilities, and seen as essential for maintaining normalcy and concealment of HIV status, thereby avoiding inadvertent disclosure (through the development of visible HIV-related symptoms), and resultant anticipated stigma (Magaço et al., 2019).

### Navigating ongoing treatment-taking and engagement with care

As explored in the section above on decision-making for treatment initiation, patients may weigh perceived benefits of taking treatment against the costs (Conrad, 1985; Pound et al., 2005), which is also relevant to how treatment-taking is sustained. Additionally, in the section above on conceptions of treatment necessity, I highlight that patients may seek evidence from their embodied experience to determine whether a drug is worthwhile to take (Zhou, 2016). While there is extant literature

from the Treat-all context examining ART initiation, as of yet, there is a dearth of knowledge from Treat-all programmes examining how individuals navigate longer term engagement in treatment and care following initiation of ART when asymptomatic. In this section, I will consider how this might translate to the context where patients are increasingly initiating ART when asymptomatic, to reflect on how treatment-taking may be motivated and navigated over the longer term.

### **Evidencing treatment effect**

Initiating ART when in good health can have implications for treatment-taking, as people living with HIV may not see the benefits of sustained treatment-taking if they have not experienced any deleterious HIV-related health effects prior to starting it (Pell et al., 2019). Therefore, initiating ART without HIV-related symptoms may reduce motivation for treatment-taking (Boyer et al., 2016; Nhassengo et al., 2018). In the past, under previous treatment guidelines, individuals would draw upon illness histories to motivate continued treatment-taking, and improved health and strength with ART created a sense of need for treatment and belief in its efficacy (Bernays et al., 2015; Nam et al., 2008).

Within Treat-all, the costs of taking treatment such as side effects or risks of inadvertent disclosure and resultant stigma may have a greater influence when not balanced against experiential benefits of improved physical health. For example, evidence from Option B+ highlights how side effects may influence women's engagement with care differently within Treat-all than in the past. Women in Malawi who stopped taking treatment said they did so as they felt less healthy after taking ART than they did prior to starting it (Kim et al., 2016). This is reiterated by Renju and colleagues (2017), who found side effects were better tolerated by individuals who had experienced past illness, suggesting that those who initiate treatment earlier, prior to sickness, may not have sufficient motivation to overcome them (Renju et al., 2017).

Where evidence of the treatment's effect is not clearly apparent, patients may alter the course of their treatment in order to evaluate its efficacy, for example through altering the dose or stopping medication to observe the resulting effects (Pound et al.,

2005). Modification of the treatment regimen is particularly common when side effects are troublesome or when patients perceive the medication to be ineffective (Adams et al., 1997). Such experimentation has been seen within Option B+ in Malawi, where having few symptoms and no obvious benefits of treatment led some women to alter their regimens, comparing their health before and after interrupting treatment or adjusting their dose to test the treatment's efficacy. Where there was no experienced physical difference between taking the treatment and not taking it, this could undermine motivation for engagement with treatment (Zhou, 2016). Conrad describes "non-compliance" as a form of "self-regulation", whereby patients take control of their disease management (Conrad, 1985). Rather than there being two types of patient, adherent and non-adherent, or compliant and non-compliant, individuals' perception of treatment can change over time, and many weave in and out of treatment (Zhou, 2016).

Viral load tests may offer evidence of the effectiveness of ART, which could be particularly important within the context of Treat-all, where viral load monitoring results have been found to offer a means through which patients can monitor the progress of their condition (Pell et al., 2019). In fact, some argue that the need for accessible and affordable routine viral load monitoring is crucial for Treat-all implementation, in order to enable individuals to measure their health improvements (Renju et al., 2017).

Until now, viral load monitoring has mainly been used as a tool through which to monitor adherence, rather than as a useful tool for patients' self-management. Blood counts may be used as clinical evidence towards determining whether patients are maintaining their part of a therapeutic deal, at the expense of considering the everyday demands that can affect treatment-taking, when in fact viral suppression is a state that must be maintained, not a goal that needs to be reached (Paparini and Rhodes, 2016). Thereby viral load monitoring may be used as a form of surveillance and control, which Vale describes as being the ultimate "Panopticon", prompting patients to take their treatment as prescribed or to risk discovery and reprehension (Vale et al., 2017).

Foucault highlights the ways in which care can provide an opportunity for control, as the receipt of care may involve submission (Foucault, 1979), illustrating an “inherent dialectic between care and coercion within systems of discipline”, and how those involved in “webs of discipline are also involved in appropriating, re-inventing and resisting techniques of power” (Vale et al., 2017, p.1288). If health care workers use their authority to control patients, they may thereby contribute to fashioning a form of subordinated therapeutic citizenship (Russell et al., 2015).

The medicalised framing of Treat-all can produce pharmaceutical (Ecks, 2005; Persson, 2015) or therapeutic citizens (Cataldo, 2008; Nguyen et al., 2007), as people living with HIV appropriate ART as a set of rights and responsibilities (Nguyen, 2005). Patients are co-opted into rigid conditions that determine treatment access and align their behaviour with what is deemed “appropriate” and “healthy” (Mattes, 2011; Vale et al., 2017). Additionally, power is displaced from the nation-state, which becomes increasingly reliant on donor-funded programmes for sustaining ART provision (Whyte et al., 2013). As therapeutic citizens, people living with HIV become citizens of funded programmes over and above being citizens of their state (Colvin et al., 2010). Through ART provision, people living with HIV may gain increasing awareness of their own rights, which they can seek to extend to other areas of services beyond those relating to HIV (Biehl, 2007; Cataldo, 2008).

Neoliberal biomedical approaches consider patients as physical, biological individuals whose health is their primary priority over which they have self-efficacy and volitional control, when in fact people are socially situated, with other aspects of their personhood (Whyte et al., 2013). Considering patients as “entrepreneurial, free and autonomous individuals capable of caring for themselves” (Beckmann, 2013) may be inappropriate in socially collectivist societies, where functioning social relationships are important for survival (Beckmann, 2013), and where the self is commonly conceptualised as an element of larger social units (Kielmann and Cataldo, 2010). Neoliberal biomedical models view patients as consumers of a product, namely health care (Colvin et al., 2010; Whyte et al., 2013). Their relationships with health services are framed by contractual obligations and expectations which must

be upheld and fulfilled, also referred to as patient responsabilisation (Beckmann, 2013; Whyte et al., 2013).

This approach does not consider people living with HIV as socially embedded, situated within a wider context and with other aspects to their personhood beyond the biomedical realm, and it does not acknowledge the demand and restrictiveness of treatment-taking routines. Treatment may become “the central organising principle” for people living with HIV (Stone et al., 1998, p.589), so overwhelming that individuals “no longer feel in control of their lives” (Pound et al., 2005, p.138). HIV care incurs a range of direct and indirect costs, including relating to the cost of maintaining health, accessing healthy food, and the time required to seek and access care (McGrath et al., 2014). People may have to balance the preservation of a “biomedical” self against a side effect free self that is able to work (Paparini and Rhodes, 2016). Treatment fatigue can also undermine treatment-taking, with participants in Uganda describing over time “becoming tired of ART” and taking “drug holidays” (Bukonya et al., 2019, p.4). Within Treat-all, increasingly individuals will be required to continue with treatment for longer periods of time, with potentially less embodied, experiential evidence of treatment effect. Therefore the burden of treatment and potential for treatment-taking fatigue may increase (Ayieko et al., 2018).

### **Ownership and self-management**

Disease self-management refers to the “ability of the individual, in conjunction with family, community, and healthcare professionals, to manage symptoms, treatments, lifestyle changes and psychosocial, cultural and spiritual consequences of health conditions” (Richard and Shea, 2011, p.261). It involves a range of processes deriving from an individual’s work to sustain wellbeing, to incorporate illness and treatment into life and to maintain a positive worldview in the face of a health challenge (Russell et al., 2016a). Corbin & Strauss (1988) were the first to identify processes of self-management within chronic illness, including tasks of medical management, behavioural management and emotional management. Within this thesis, I define self-management broadly based on three areas identified by Schulman-Green and

colleagues (2012): focusing on illness needs, activating resources and living with a chronic illness. I have explored adjusting to living with a chronic illness, and the identity work this may involve in the section above. What is of particular relevance here is the process individuals undertake to learn about their illness, to take ownership of their health needs, and to perform health promotion activities.

Taking ownership of health needs involves tasks and skills relating to learning about and managing body responses (whether responses to treatment, other triggers, or general health changes in response to the condition), completing health tasks such as keeping appointments, and becoming an expert (Schulman-Green et al., 2012). Acquiring knowledge about HIV and ART can reduce uncertainty, offer hope, and provide individuals with inner strength to carry on, with the possibility of regaining control over health and life feeling attainable (Russell et al., 2016a). Self-management is a complex, dynamic and interactive process (Russell et al., 2016a). In order to integrate illness into daily life, individuals must modify their lifestyle, and may seek normality through balancing the pursuit of meaningful activities with the appropriate level of attention to their illness needs, with the process thus involving complex interaction between illness and life context (Schulman-Green et al., 2012).

Prior to Treat-all, ART could enable a dramatic recovery of health, which could “transform subjectivities and create more empowered HIV patients able to self-manage their condition in a disciplined way” (Russell et al., 2015, p.3; Russell and Seeley, 2010). This will differ in the Treat-all context, where the work required for disease management, which can be ongoing, difficult, expensive and demanding (McGrath et al., 2014), may require new motivations for self-management that are based on health preservation rather than recovery.

Taking ownership of health needs includes developing confidence and self-efficacy for the condition and its treatment (Schulman-Green et al., 2012), which may be an important source of determination for motivating ongoing treatment-taking and engagement with treatment and care. As we have seen from the context of Option B+, where the decision to initiate ART is not intrinsically based, and where individuals may feel coerced to test and take treatment, this can influence their disengagement

from care (An et al., 2015; Wringe et al., 2017). These are important considerations for Treat-all, where maximising individuals' capacity for self-management, ownership of health needs and ability to sustain longer-term treatment-taking and engagement with care may require that people living with HIV have sense of choice and readiness for treatment.

In conclusion, this chapter has outlined the myriad of factors which could influence individuals' engagement with HIV treatment and care in the context of Treat-all, considering existing theoretical, conceptual and empirical evidence relating to chronic diseases, HIV and asymptomatic treatment-taking. This chapter aimed to define concepts which are further explored and drawn upon in the latter chapters of this thesis, and to critically engage with the knowledge base from which I will examine individuals' lived experiences with Treat-all in Eswatini. In summary, I have outlined the basis of HIV "normalisation" discourse in framing the Treat-all rationale and rhetoric, and considered how and why HIV may continue to be considered "exceptional" despite increased and earlier ART access. I define the theoretical basis to stigma's conceptualisation, considering the ways in which HIV is particularly stigmatised and moralised. It remains to be seen how this may translate to the lived experiences of people living with HIV in the context of Treat-all in Eswatini, and how stigma may influence engagement with HIV treatment and care here, which I aim to explore in this thesis.

I have considered the ways in which an individual may psychologically process and respond to an HIV diagnosis, and what this may mean in terms of their lived social context. There may be identity work required for an individual to adjust to the "new normal" of living with HIV, potentially necessary prior to engagement with care and influencing how an HIV diagnosis is processed. In the context of Treat-all, it remains unknown how individuals who do not feel unwell may reconcile with an identity which is stigmatised and socially devalued, with which they may not see themselves aligning, and how this may influence experiences of engagement with care. The literature suggests that the process of HIV status acceptance can support overcoming stigma and may be important for individuals' engagement with treatment and care,

which can be undermined by the absence of symptoms, and which can require time, warranting exploration in the Treat-all context where the time between diagnosis and treatment initiation is expedited. Treatment decision-making processes can involve multiple encounters with multiple people and sources of knowledge, and it may be important for individuals to have experiential, embodied experiences indicating treatment necessity. This thereby indicates potential dissonance between the biomedical logic framing Treat-all, which assumes that individuals will adjust their actions once they are educated, and individuals' conceptions of health and treatment need, which should be investigated.

There are various perspectives regarding whether and why patient autonomy and choice may be important for engagement with HIV care, and on the potential influence of mechanisms of patient control and coercion, which I have reflected upon. There is the potential for conflict between the public health agenda and the individual right to choice within Treat-all approaches, which I will attempt to further consider within this thesis, including in terms of how differing priorities (for example of health services and individuals) may be reconciled. Finally, I have considered existing knowledge relating to how ongoing engagement in treatment and care may be navigated over time. For example, there is evidence suggesting the importance of patients' having evidence of treatment effectiveness for motivating their treatment-taking, and under previous treatment guidelines individuals could draw upon their illness histories prior to initiating ART to motivate continued treatment-taking. There may be need for adjustments to health management and motivation for ongoing treatment-taking in the Treat-all context.

Next, I outline my study methodology, including the epistemological approach, and the methods that I adopted during this PhD research.

## Chapter 3: Methodology

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### Overview

In this chapter, I outline my research approach in terms of the epistemological and theoretical influences which underpin it. I explain the approach taken for participant recruitment; for data generation through in-depth interviews, focus group discussions and observations; the approach to interpreting participant accounts; and data analysis. I describe the study setting of Eswatini, reflecting on information relating to the socio-political context in framing the research. I then describe how I applied the theoretical and epistemological approaches of this research through the methods that I adopted in the preliminary and main phases. Finally, I discuss the ethical considerations relating to various aspects of the research. The aim is to present the theoretical lens through which participants' views and experiences relating to living with HIV and engaging with treatment and care in the context of Treat-all were explored and interpreted. This research primarily draws upon interview data from interviews with people living with HIV, including longitudinal, repeated interviews, and interviews with health care workers. The epistemological approach presented in the following section underpins the approach to data generation and analysis which follow.

### Epistemological approach

It is important to identify and outline the epistemological approach that underpins research as this refers to what is taken to constitute knowledge and its justification (Carter and Little, 2007), and therefore influences the chosen methodological approach and how knowledge is constructed and interpreted. Epistemology can be defined as "a philosophical inquiry into the nature of knowledge", including how beliefs are justified and what a claim to truth can be taken to mean (Alcoff, 1998). The positivist approach posits that "truth" can be objectively measured through value-free research which treats social facts as existing independently of researcher and participant activities (Silverman, 2013). Positivist, experimental sciences are said to be "seen as the crowning achievements of Western civilisation, and in their practices,

it is assumed that “truth” can transcend opinion and personal bias” (Carey, 1988; Denzin and Lincoln, 2013, p4), presuming there is a stable, unchanging reality which can be studied with empirical methods of objective science (Huber, 1995).

Non-positive traditions, on the other hand, view this as a narrow, reductive lens which does not consider the complexity of social reality, and the ways in which interpretations of experience can change and be re-evaluated in different circumstances or with different people (Schwandt, 2000). Qualitative research involves interpretive practices which aim to make the world visible through representation and description, and by exploring lived experience. Within interpretive epistemologies, the knower and known interact and shape each other, and there is no single interpretive truth (Denzin and Lincoln, 2013). Rather, the focus is on understanding the world from the point of view of its participants (Green and Thorogood, 2009). For example, how individuals diagnosed with HIV interpret and understand this diagnosis, and the meaning of treatment for those who do not have symptoms of HIV infection.

This research aligns with the interpretive tradition, and draws upon phenomenological and feminist epistemologies. Phenomenology refers to the study of meaning of experience of a phenomenon for individuals (McCaslin and Scott, 2003), aiming to examine the lived experience of a person or people in relation to a concept or phenomenon of interest, and how people make sense of this experience (Smith, 2004). This research is phenomenological in that the aim is to investigate the lived experiences of people living with HIV, and how Treat-all is interpreted, understood and experienced from the perspective of those affected by HIV and involved with Treat-all. Therefore, people living with HIV who engage with treatment and care services under Treat-all are the main focus of inquiry.

Phenomenology stems from the work of Edmund Husserl (1970) and Maurice Merleau-Ponty (1962), with Husserl positing that human consciousness is the means through which to understand social reality. Alfred Shultz (1967) contributed to developing phenomenology, with his interest in exploring how people process experience in everyday life (the “lifeworld”), valuing the sympathetic understanding

of conscious experiences (Schutz, 1967). Phenomenology has also been linked to symbolic interactionism, which addresses how meanings are constructed by individuals during interactions with others, through social processes (Carter and Fuller, 2016; Denzin, 1987; Smith and Osborn, 2008).

Phenomenology aims to understand and describe individuals' experiences of their everyday world as they see it (Liamputtong, 2013), and to remain as faithful as possible to the phenomenon and the context in which it appears in the world (Giorgi and Giorgi, 2008). Phenomenology is intellectually connected to hermeneutics and theories of interpretation, combining an empathetic hermeneutics (trying to understand what it is like to be living with HIV and offered lifelong treatment from the point of view of participants) with a questioning one (critically examining participant accounts and asking questions relating to the nature of the account and the dynamics that produced it) (Smith and Osborn, 2008). The key focus is how individuals lived through and interpreted situations (Giorgi and Giorgi, 2008). In accordance with an interpretive phenomenological approach, I did not start this research with a predetermined hypothesis, rather I aimed to examine the experiences of people living with HIV with Treat-all broadly, taking an inductive approach to the generation of insights and findings. I then explored emergent findings in the context of existing knowledge and theories, which I explored, tested and investigated further as data generation progressed. I thereby adopted an iterative approach to generation and analysis, which aimed to remain as close to, and as reflective of, participants' voices and perspectives as possible.

Within this research I also draw upon feminist theories regarding knowledge production, valuing researcher reflexivity and considering the power relations that are implicated in various methodological approaches (Oakley, 1998). The impact of the social status and gender of the researcher, the "knower", upon the production of knowledge are acknowledged and considered, including the intrinsic connections between values, politics and knowledge, and the unequal power relations implicated in theories of knowledge (see section of this chapter on power in the construction of knowledge) (Alcoff and Potter, 1993). I align with the feminist perspective that

research should be used in support of advocating for change in practice and policy (Campbell and Wasco, 2000; Deutsch, 2004; Harding, 1987; Oakley, 1998), aiming to generate findings which can inform improvements to service delivery to better align with individuals' needs, and which can inform policy and practice relating to HIV treatment and care more broadly.

### **Approach to participant recruitment**

I adopted a purposive sampling strategy, to include those most able to provide insight to the phenomenon being investigated (Marshall 1996). This sampling approach aims to select information-rich cases for study in depth, to elucidate issues of central importance to the purpose of the inquiry (Patton, 2002). Therefore, people living with HIV in the context of Treat-all in Eswatini are the primary participant group, as these individuals can provide insight into their experiences being diagnosed with HIV and offered ART under Treat-all. Additionally, health care workers involved in Treat-all implementation and the delivery of HIV treatment and care within Treat-all can provide insight into the health provider perspectives on this topic, and health care workers can also draw upon experiences with a wider group of patients.

The study population was stratified to examine particular sub-groups of theoretical importance (Guest et al., 2013), including age and gender. Additionally, sample selection aimed to enable exploration of a diversity of opinions (Guest et al., 2013), by including those with a range of different testing, access to care or treatment-taking experiences (for example those recorded as engaged with care, lost from treatment, or as diagnosed HIV positive but not accessing care). Sampling decisions fluctuated between the aims of covering as wide a field as possible with a range of different perspectives investigated, and of conducting analyses which are deep and rich (Flick, 2014).

Additionally, I adopted theoretical approaches to sampling, whereby the number of participants was decided based upon evidence of data saturation. This was determined based on the iterative process of data generation and analysis (see also section on data analysis), when adding further participants does not result in new

categories, themes or explanations relating to the topic of investigation (Glaser and Strauss, 1967; Marshall, 1996).

### **Approach to data generation**

Various methods of data generation were adopted in this research, including in-depth interviews, focus group discussions and observations. Using a variety of methods enables integration of participants' accounts of phenomena, generated via co-produced interactions during in-depth interviews and focus group discussions, with the interactions, environment, meanings and context of the health services that are observed. The approaches that I adopted for each of these methods of data generation are outlined as follows.

#### *In-depth interviews*

I considered interviews as actively constructed narratives which reflect a particular time and space (Silverman, 2013). The interview itself represents a social encounter, which reflects the "local interactional contingencies in which the speakers draw from, and co-construct, broader social norms" (Rapley, 2001, p.303). As interviews are interactional events, the narrative and meaning is constructed jointly between the interviewer and interviewee (Gubrium and Holstein, 1997; Riessman, 2008; Seale, 1999). With this in mind, and due to the language, racial and background differences between myself and participants, I decided it more appropriate for interviews with people living with HIV to be conducted by same-gendered siSwati speaking Swatis. Both were aged 30-40 years, educated (one having completed high school and one in the process of completing a university degree), and from the capital city, rather than being from the Shiselweni region where the research was conducted. This may have led to them being perceived by participants as having higher socioeconomic status. Reflections on this decision are elaborated in the Discussion Chapter (section: Interview dynamics and data co-production). One trained female researcher conducted interviews with women, and one trained male researcher conducted interviews with men. The decision to have same-gendered interviewers was linked to the patriarchal context in Eswatini, and the sensitive nature of topics being discussed, which included relationships, sexuality, sexual practices, and health. I

conducted interviews with health care workers, largely in English, or in siSwati with the assistance of an interpreter where participants felt more comfortable.

As I was not present for interviews with people living with HIV, this created a certain level of distance from the process of co-construction, from the participants' lived context and from the data. I therefore took steps to try to remain close to the data, including meeting several of the participants at the study finish to thank them for their time and to discuss the study findings. Living in the study context, and visiting communities within which people lived enabled me to have some familiarity with and understanding of the broader social context. I held debriefing discussions with the interviewer after each interview, with detailed field notes subsequently written up. These discussions included reflecting on the environment within which the interview was conducted, and as this was usually participants' homes, a reflection on their home environment and their social circumstances. We reflected on the participant's broader situation including their living environment, potential employment, and relationships. Additionally, we considered the interview dynamics, the methods that were adopted and how the participant might have perceived the interview and the interviewer.

The in-depth nature of the interviews encouraged open discussions, and while being broadly based on topic guides (see Appendix 2), were flexible to participants' language, narrative and allowed the order of topics discussed to develop naturally rather than following a prescriptive, structured order and flow. The interviewer was also familiar enough with the topic guide to be able to ask questions and probe conversationally (Oakley, 1998), which aimed to promote a more natural, informal atmosphere and to ease participants' comfort. The style of interviewing that was adopted aimed to encourage participants to elaborate and provide detailed narratives of their experiences, or "thick descriptions" (Rapley, 2001), including the use of non-verbal and verbal probing. This approach aimed to generate deep insights into participants' understanding and interpretation of their social world (Arskey and Knight, 1999; Gubrium and Holstein, 1997; Roulston, 2010; Silverman, 2001). Oakley highlights the importance of a relationship of mutual trust and reciprocity between

the interviewer and interviewee (1981), which we aimed to achieve through rapport building before the interviews, and also through the longitudinal nature of repeated interviews.

As data generation progressed, topic guides were adapted to further test emerging themes, in line with the iterative nature of data generation and analysis that was adopted (see section on data analysis), and likewise topic guides for the second and subsequent interviews with individuals were devised following analysis of the previous interview with each participant.

Longitudinal, repeat interviews were chosen to assist with the development of trust and rapport between the interviewer and interviewee, aiming to enable access to the multiple layers of participants' narratives, beyond that which is deemed to be socially desirable (and often closely linked to health messaging that is disseminated). Repeating interviews over time also aimed to gain insight into how individuals' accounts of their experience with Treat-all may change over time.

### *Focus group discussions*

Focus group discussions can facilitate an understanding of group norms, providing access to a wider variety of communications than one-to-one interviews (Kitzinger, 1994) and a range of perspectives (Arskey and Knight, 1999), as well as providing access to the interaction between participants (Brocki and Wearden, 2006). Therefore, I decided to include certain focus group discussions within this research, to gain insight into socially normative accounts regarding HIV testing and access to HIV care in the context of Treat-all in Eswatini.

While some sensitive issues may be more readily discussed in group settings, such as dissatisfaction with health service provision (Green and Thorogood, 2009), generally the group environment can inhibit certain people from talking about certain things, particularly for those who may feel hierarchically lower in status, and if a perspective or topic deviates from the group standards (Kitzinger, 1994). With this in mind, and also as confidentiality cannot be guaranteed within a group setting (the researcher cannot control whether other members of the group maintain confidentiality

regarding topics of discussion), I decided not to encourage personal disclosures, for example regarding HIV status, but rather to focus on general perspectives regarding HIV among community members in Shiselweni.

### *Observations*

In this research, I draw upon ethnographic principles, recognising that it is important to understand, examine and consider the social contexts within which findings from interviews and other data sources are produced and used (Atkinson et al., 2001), and for researchers to actively witness the phenomena that is being studied in action (Adler and Adler, 1994).

Qualitative observation is fundamentally naturalistic in essence, and draws the observer into the phenomenological complexity of the world, where connections and correlations can be witnessed as and how they unfold (Adler and Adler, 1994). It has been argued that all social research is a form of participant observation, as we cannot study the world without being a part of it (Hammersley and Atkinson, 1983). Participant observation reflects the inevitability of the researcher's participation influencing what is observed (Flick, 2014). While steps may be taken to mitigate this influence, and to try to observe events in as "natural" a context as possible, it is still important to reflect upon this process within the research. Such observation aims towards an empathetic immersion in daily life and the meaning systems of those studied, which involves gaining access to and immersing oneself in the social world being investigated (Emerson et al., 2001).

The observations offer a view to how Treat-all implementation may be experienced in practice, and to enable insight into the interactions between health practitioners and patients, the information shared, approach taken, and the communication style. This contextualises data generated in interviews and focus group discussions, and aids understanding of the health system and practitioner-patient relationships, including how these might influence patients' experiences with Treat-all, as well as their accounts during interviews.

### *Data capture*

Interviews and focus group discussions were audio recorded following participants' informed consent, which all participants agreed to. Detailed field notes were produced for each interview, capturing information on the interview arrangement and setting, reflecting on the specific time and space within which the interview data were generated, and reflecting on the interview dynamics and methods (including power dynamics and whether certain questions may have been misunderstood). Field notes additionally included a summary of the participant's account, a reflection on emerging themes and areas to follow up on in future interviews, therefore supporting the analytic process beginning from the point of data generation.

Following each interview and focus group discussion, audio recordings were transcribed verbatim, or transcribed and translated where conducted in siSwati, by the same researcher who conducted the interview. For translation, direct translation was used as much as possible, and equivalent translation where not possible to directly translate, which was indicated in the text. This approach aimed to maintain the meaning and integrity of participant's accounts as much as possible. For data quality purposes transcriptions were then checked against the audio recording by a research assistant, and amended where discrepancies between the audio and transcript were identified.

### **Approach to data analysis**

Data generation and analysis followed an iterative process, allowing for emergent concepts, and any potential discrepancies from majority themes, to be further explored (Corbin and Strauss, 2008). Topic guides for later interviews were adapted according to preliminary data analysis, supporting further exploration of emergent themes.

### *Approach to interpreting accounts*

The positivist sciences view interview accounts and their interpretation as invalid and unreliable due to their subjective nature (Golsworthy and Coyle, 2001), and criticisms of qualitative research include that it is "soft" science, or unscientific, being

only exploratory and subjective (Denzin and Lincoln, 2013). However, the interpretivist tradition values interview data *because* it is subjective, and provides insight into how an individual evaluates, makes sense of, and accounts for their reality (Atkinson and Silverman, 1997).

In this research, I consider interview data as a window through which to explore the ways in which participants try to make sense of their world, whereby the researcher is trying to make sense of the participants trying to make sense of their world (Smith and Osborn, 2008). Interview data are considered co-constructed, generating situated accounts that reflect a 'locally produced subject' (the participant) in relation to the interviewer, and reflecting the particular time and space within which the interview occurs (Roulston, 2010). I also pay attention to the researcher role, issues relating to the "outsider" or "insider" status of the researcher and how this might influence the type of account that is generated (Best, 2003; see sections in this chapter: Reflexivity; and Power in the construction of knowledge).

Within this research I consider interview accounts as offering a view on how participants interpret and talk about their life worlds, rather than seeing them as offering a direct view to their experiences. Mazanderani and Papparini describe research interviews as "talking technology", and as performative, rather than representative of people's experiences of living with HIV (2015). In this thesis, interview accounts are taken to reflect how participants interpret and ascribe meaning relating to living with HIV and engaging with treatment and care when clinically asymptomatic, rather than as evidencing what participants actually do. Therefore changes in participants' accounts, which may arise during longitudinal, repeat interviews, are not interpreted as a threat to data accuracy or validity, but rather offer insight to how perceptions and opinions can change over time, and according to circumstance (Walford, 2007). Changes in account offer an opportunity to gain insights into participants' processing of an event or their circumstances, and to reflect on the interview-interviewee dynamic, as participants continually come to re-evaluate and re-position themselves within the interview setting.

### *Data analysis*

I adopt a primarily inductive approach to data analysis, with findings emerging from the data and aiming to remain grounded in participant accounts, rather than having pre-determined hypotheses to then test. Within this research, this followed a cyclical approach of examining emerging themes, re-visiting literature, and then re-visiting the data. The approach to data analysis was primarily thematic, using coding to identify emergent patterns, categories and concepts from participant accounts, and drawing upon principles of grounded theory (Bradley et al., 2007; Glaser, 1999; Glaser and Strauss, 1967), elaborated below.

Initially I read and re-read interview transcripts, and applied open, descriptive coding, with the use of *in vivo* codes which mirrored the words of participants (e.g. “dirty blood”) where possible. This formed the initial approach to analysis in order to try to remain close to the data and to stay true to participants’ accounts, interpretation and description of events (i.e. avoiding my influencing data interpretation with my own pre-conceived ideas about the research or pre-existing knowledge from the literature). This approach aimed to ensure interpretations were grounded in participants’ accounts (Brocki and Wearden, 2006), and to distinguish between the participant’s original account and the analyst’s interpretation (Smith and Osborn, 2008).

Following initial open, descriptive coding, I re-read and analysed transcripts, moving between concrete data and abstract concepts and between inductive and deductive reasoning (Merriam, 2009). On the basis of preliminary analysis of transcripts, I developed a coding framework, which I then developed and refined as analysis progressed. Initially, a subset of transcripts were analysed by myself and the two research assistants, and discussions were held to explore the differing interpretations and emergent codes from each analysis, which also contributed to the developing coding framework as I progressed with full data analysis.

In drawing upon principles of grounded theory, I aimed to build theories inductively through data analysis by creating theoretical categories directly grounded in data (Charmaz, 2008), raising findings to an interpretive, conceptual level (Bradley et al.,

2007; Glaser, 1999). However, I do not claim to have adopted a grounded theory approach in its entirety, as I recognise that it is not possible to fully “bracket off” pre-existing knowledge and theoretical influence, which will influence my interpretation of data, and which helped to guide and situate analytic interpretations. For example, during the research process, findings relating to HIV status secrecy emerged. Many people living with HIV emphasised the importance of others’ not knowing their status, and the described impact this could have on their treatment-taking and engagement with care. Status secrecy was then explored further in subsequent interviews to try to understand why this appeared so important to individuals, and the implications they anticipated from having their status known, as well as to better understand how this affected their lives and influenced their engagement with HIV treatment and care services. During data analysis, extant theories relating to processes of stigma were drawn upon, as these enriched the interpretations and understanding of the findings, and further supported the development of theory grounded in participant accounts.

The principles of grounded theory that I applied include constant comparison within and between cases, ascertaining patterns within the data leading to concepts about it, built into broader theoretical propositions, which can then be evaluated and tested with other comparison groups (Glaser and Strauss, 1967). Additionally, I paid attention to discrepancies from majority themes and exceptions within the dataset, recognising the unique opportunity these can provide for additional insight and understanding to the topic being investigated, as well as the importance of this for validity (Green and Thorogood, 2009).

Analysis involved connecting emergent findings from different data sources, and exploring how these may confer or differ, particularly with how health care worker accounts compare to those of people living with HIV. This provides a fuller picture of the Treat-all experience, as these differing perspectives all have an influence on how services may be implemented, perceived and experienced. Potential contradictions were examined to consider meaning, and to reflect upon the different dimensions of narrated experience that these data sources and methods can capture.

Data generated through interviews and focus group discussions were integrated with the interactions, environment and health services that were observed, with observational evidence enabling participants' accounts to be situated in the lived context. Using various methods of data generation was flexible and iterative, aiming to enable an in-depth, nuanced view to the topic being explored.

Data analysis was manual, with use of Nvivo 11 as an analytic aid, which helped to organise the large volumes of data. Analytic memos were used to aid the development of analytic thought and to track its progress.

In addition to the thematic analysis that I conducted, I also analysed interview transcripts using narrative methods, which aimed to reflect on the extended accounts of participants (rather than their fragmented thematic categories) (Riessman, 2008). This approach focused on participants' stories and how these were told (Green and Thorogood, 2009), providing a richer, more detailed perspective of how participants narrated their experiences being diagnosed with HIV and offered treatment within Treat-all (Flyvbjerg, 2013).

### **Reflexivity**

Sensitivity and paying attention to the ways in which the researcher(s) and the research process shape the data are a crucial part of qualitative research, and are inherent within the co-produced nature of data generation (Mays and Pope, 2000). The nature of research is recognised as co-constituted, jointly produced by participants, researcher(s) and their relationship, and reflexivity to this aims to examine how knowledge is actively constructed (Finlay, 2002). This can be done through bringing the researcher's roles and actions into view, and taking into account the researcher's construction of emergent concepts (Charmaz, 2013). Reflexivity in the form of "confessional accounts" have been common within anthropology and social science (Seale, 1999). However, this approach to reflexivity has been critiqued for being self-indulgent on the part of the researcher, and for displacing the focus of attention from the researched to the researcher (Finlay, 2002). Additionally, focusing on reporting researcher characteristics such as age, gender and ethnicity may appear

arbitrary, not necessarily adding meaning to analytic interpretations of benefiting the reader's interpretation of such analysis (Brocki and Wearden, 2006).

Some argue that a more useful approach may be to consider how a personal aspect, belief or worldview can influence data generation, analysis and contribute to broader research focus and findings (DeVault, 1997). In phenomenology, this can start with trying to make known and explicit pre-existing beliefs and conceptions, for example about the topic of investigation, so they can be "bracketed out" in order that the researcher is fully able to enter the participant's view and understand their lived experience (Husserl, 1970). While it is unlikely that full "bracketing out" can be achieved, within this research I aimed to make visible the researchers' influence on the data as much as possible. Beginning at the point of study conception and design, I reflected upon the questions asked and the approach to data generation and analysis, taking steps to actively remain as close as possible to participants' accounts and to access alternative layers of participants' narratives beyond those deemed to be socially acceptable. For example, through using repeat interviews over time and trying to have interviews in participants' lived context where possible, and through the inductive approach taken to data analysis. At the start of the research (for both the preliminary phase and main, longitudinal phase), I facilitated a team session to discuss our views about the topic, including possible areas or findings we anticipated could emerge. For Treat-all, this included engaging with questions such as would we as individuals want to take lifelong treatment if we were diagnosed with HIV and did not have symptoms, why/why not? What concerns did we have about Treat-all, what benefits did we think it may bring? Also, what do we think about the concept of treatment as prevention? Making these views explicit enabled us to acknowledge, and then park them, trying not to let them influence our interactions with participants and the questions we might ask, but also then being able to explore their presence and influence where it did emerge through data analysis.

Reflexivity was also taken in reflections following each interview, with the use of field notes and debriefing discussions, which included actively exploring and reflecting on interview dynamics and personal feelings about the interview process and the

topics which emerged. Consideration of what is being said, by who and in what context or circumstance included these reflections after each interview and also during data analysis, to explore the way participants referred to the researcher and the type of talk being generated.

Through my experience with previous research in this setting, the potentially contradictory positions as qualitative researchers who are there to confidentially, non-judgementally and empathetically try to understand people's stories and experiences, whilst at the same time being part of an operational research team attached to the health programme could pose challenges. For example, in the past I had noticed an association of the interviewer with the health services, as participants referred to the interviewer as "nurse", and as some narratives appeared to closely reflect the health messages that were disseminated. It could therefore be challenging to access thoughts, views or accounts of experience beyond the surface level. I therefore implemented steps to try to minimise the association with the health system in this research, for example in the way the research was introduced, and our position as working alongside the health services but also independent from them, using language such as "we"/"they" when referring to the health services and reiterating confidentiality. The longitudinal approach with repeat interviews also seemed to help in building a relationship with participants and gaining trust and rapport. However, the researcher will likely have been perceived in a certain way, which could influence the data and the account generated.

As I was working as a researcher within the MSF project in Eswatini during the period of this research, my positionality as a member of the project team may have influenced the research process. I regularly reported and shared research findings with the project and other stakeholders, and also aimed to confidentially and impartially interview health care workers and understand their experiences, which may have been perceived as contradictory. Initially certain health care workers appeared to perceive my role as evaluating their performance, for example during an observation of counselling sessions a counsellor said that I was there to see if they shout at patients. Building rapport, explaining the purpose of the research, interviews

and observations, and emphasising the measures adopted to protect confidentiality (including anonymity and use of pseudonyms) did appear to reassure health care workers. Interview discussions were open, lengthy and in-depth, with health care workers openly sharing challenges they face in their work. However, my positionality is likely to have influenced the nature of discussions and may have dissuaded certain health care workers from sharing critical views or accounts that could be perceived as less socially desirable.

The decision for interviews with people living with HIV to be conducted by same-gendered siSwati speaking Swatis, may enable access to an “insider” perspective, and particularly where participants were of a similar age and socio-economic (including educational) background, this sense of shared understanding could lead to in-depth, open, rich descriptive narrative. For example, in Best’s (2003) work in an interracial context (where the interviewer is a white woman and the interviewees are black women), she examines the interactional nature of the interview in which race meanings are constructed. Here language indicated presumed difference and an “outsider” status of the researcher, which also allowed exploration of what taken-for-granted statements or concepts may mean for the interview participants (Best, 2003).

### **Power in the construction of knowledge**

In line with feminist approaches to research, in this research I aim to minimise and mitigate unequal power relations between the interviewer and interviewee as much as possible (Alcoff and Potter, 1993; Harding, 1987). However, I also recognise that it is not always possible to mitigate power dynamics (Oakley, 1981; Roulston, 2010). It is therefore important to attempt to bring these to consciousness and to actively engage with the ways in which power may influence the co-created data. As taking responsibility for the reproduction of power may be more possible than equalising power, for feminist researchers this involves considering ways to reciprocate the time given by participants (Skeggs, 2001). This is linked to the decision in this research to reimburse participants with a small financial contribution towards their time, and with refreshments provided at each interview and focus group discussion.

The epistemological recognition that all knowledge is situated, partial, contingent and interpretative underpins this research, and the researcher and participants form a collaborative, reciprocal quest for understanding (Skeggs, 2001). However, I also acknowledge that while steps towards collaboration and consideration of power are adopted, the research project is ultimately that of the researcher, and offers my interpretation and voice in addition to trying to reflect the voice of participants (Skeggs, 2001). In the Discussion Chapter (section: Reflection on the approaches taken within the research) I further reflect on how power dynamics may have influenced the data and findings that emerged from this research.

## Study context

The Kingdom of Eswatini is the last remaining absolute monarchy in Africa, with King Mswati III in power since 1986 (Figure 3.1). Eswatini has a dual monarchy, and the king (referred to as *Ngwenyama* meaning lion), represents the father of the nation, ruling alongside the queen mother (*Ndlovukazi* meaning lady elephant), who represents the mother of the nation, with an undefined delicate balance of power between the two (Matsebula, 1976). While all powers centre on the dual monarchy, the use of such powers are restrained by their relationship, by officials whose positions depend upon maintaining the monarchy rather than supporting a particular king, by the local government system and councils of state (Kuper, 1986). The king is responsible for the distribution of land, and he and the queen mother share powers of rainmaking that are necessary for ensuring the fertility of the land (Booth, 1983). A king's successor is not known during the king's lifetime, but is chosen based on the Royal Family Council meeting after the death of a king, by deciding upon who among the queens will be the queen mother, with her son then assuming the heirship (Matsebula, 1976).



**Figure 3.1:** Photos depicting King Mswati III (left) and the annual Umhlanga ceremony (right)

Britain formally controlled the administration of Eswatini from 1903 until independence in 1968, governing the country through the Transvaal in neighbouring South Africa. However, the order-in-council did not define or declare the official status of Eswatini in relation to Britain, so some argue that Eswatini was not legally a “protectorate”, “colony” or “possession” of Britain during this period (Matsebula, 1976). Eswatini was not conquered by force, and the political system was allowed to

continue under the British administration (Kuper, 1986), with the arrangements including an expressed respect for Swati law and custom (Matsebula, 1976). However, there was a longstanding dispute regarding land concessions which predated this period. These concessions, pushed by the British and the Boers, have been described as “economic weapons representing a type of warfare beyond the traditional system... [that included] laws of land ownership that clashed with rights of customary usage... the commerce and banking of an expanding capitalist economy” (Kuper, 1986, p.13).

King Mbandzeni (reign 1875-1889) asserted that he had not sold the land within such concessions, but had simply leased it. However, what has been termed fraudulent activity relating to concession claims led for a push towards two-thirds to one-third land division, whereby Swatis would only have one-third (Matsebula, 1976). There were political killings among the aristocracy regarding the concessions controversy, and by 1893, sales in the UK from companies based on acquired concessions capitalised at £2 million (Booth, 1983). Many native Swati lived on European-owned land and had to perform arduous unpaid services to landowners in order to be able to stay there (Marwick, 1940), thus highlighting the historical race and power dynamics that were present. In 1946, although European people comprised just 1.66% of the population, they owned around half the land, with all major advances in mining, agriculture, industry and commerce being concentrated in these areas, and schools were racially segregated until 1961 (Kuper, 1986).

Eswatini is a small, mountainous country with a population of 1.2 million people. Although classified as a lower middle income country, 60% of the population lives in poverty, of which 38% are in extreme poverty, and income inequality is high (The World Bank, 2018). Historically, the traditional way of life is rural and revolves around subsistence farming, with crops including maize, millet, sugar cane and pumpkins, normally grown in the gardens of familial homesteads (example homestead see Figure 3.2). Food supplies tend to vary seasonally, and many live at a precarious subsistence level (Kuper, 1986). Cattle are the most important livestock, and cattle are attributed to wealth and power (Marwick, 1940). The majority of Swatis

live on Swazi National Land, which is the property of the nation, held by the king in trust and distributed to citizens through chiefs (Matsebula, 1976). Rights to land are secured by allegiance and usage, rather than through purchase or rental, and therefore, wealth generated through such land is communal, and the system strengthens citizens' ties to the monarchy (as well as strengthening its power). Historically, citizens who were deemed to have too many wives or cattle (measures of wealth) were judged as "evil doers" with potential for suspicion of witchcraft and the death penalty. Land rights and fear of witchcraft can prevent economic enterprise and restrain the ambition and ability of citizens (Kuper, 1986; Marwick, 1940).



Photo author's own

**Figure 3.2:** Photo depicting an example Swati homestead

The influx of Europeans and the introduction of money into a primarily subsistence economy created the necessity for other sources of income and opportunities, which challenged the traditional way of life in Eswatini (Marwick, 1940). Advancement was seen as unanimous with education, and increasingly educated individuals sought jobs in urban areas (Booth, 1983). In 2018, the main land use in Eswatini was still pastoral, as well as timber forest (Central Intelligence Agency, 2018). Limited economic opportunity and high unemployment have resulted in widespread dependence on labour migration, with the majority of migrant labourers travelling to neighbouring South Africa for work, including in the mining industry, with such labour migration attributed as increasing HIV transmission risks between partners (Corno and de Walque, 2012; Hickel, 2012).

Traditionalist and conservative values are emphasised in Swati society, with these ideals being consciously promoted as the “guiding ideology of the nation” (Booth, 1983, p.34). Respect and politeness are considered important, generosity can be seen as the hallmark of achievement and the primary virtue of *buntfu* (humanity) (Kuper, 1986, p.30), and Swatis are a peaceful people. The Swatis were one of the few powerful Bantu tribes whose relations with Europeans did not lead them into war, which is seen to partly stem from a powerful tradition against fighting the settling white people, as led by Sobhuza I, and subsequently reinforced by his successor Mswati II. It is said that as the Europeans were never fought, the Swati were never conquered by them (Matsebula, 1976). As society becomes increasingly industrialised, urbanised and with increasing education, many of the traditional social values are being questioned and at times challenged (Booth, 1983).

The importance of social collectivism in Swati society is reflected in the southern African concept *Ubuntu*, which is a philosophy of humanity revolving around lived community and respectful, caring relations with other living beings and the environment (Seehawer, 2018). It is based upon primary values of intense humanness, caring, sharing, respect and compassion (Tarkang et al., 2018), and structures individual consciousness in communitarian terms, serving as an indigenous knowledge system and a collective identity (Root et al., 2017), where the group is prioritised over the individual (Fassin, 2007).

Christianity was introduced to Eswatini in the nineteenth century, with the first chapel and missionary being built in Shiselweni in 1845, where missionaries began to convert Swatis to Christianity, alongside providing broader education (Matsebula, 1976). Christianity is now embedded in society, blending with traditional religion in multiple ways (Golomski, 2014). In 1921, 4% of the Swazi population was listed as Christian (Booth, 1983), which subsequently increased dramatically, and in 2018, 90% of people in Eswatini were said to identify as Christian (Central Intelligence Agency 2018). Traditional religion in Eswatini is spiritual, and recognises a higher power as well as the influence and power of ancestors (Kuper, 1986; Matsebula, 1976). Now many Swatis belong to African Independent Churches, some of which follow Zionist

denominations, emphasising divine healing and prophecy, and which may combine Christian dogma and liturgy with traditional spirituality and custom (Booth, 1983; Kuper, 1986). To explore matters relating to the spiritual world, and in situations requiring deep, esoteric knowledge, *tinyanga* (traditional medicine practitioners, see Figure 3.3) and/or *tangoma* (diviners) may be consulted by individuals (Kuper, 1986), and sickness may be regarded as resulting from spiritual causes rather than natural or physiological (Marwick, 1940).



**Figure 3.3:** Photo depicting example *tinyanga* materials

Swati society is patriarchal and patrilineal, with the patriarchal headman being in control of the homestead, his prestige being enhanced by the size of his family, and with men holding the superior, stronger position socially, politically and legally (Kuper, 1986; Marwick, 1940). Predominant socially constructed gender values celebrate concepts of masculinity connected to physical strength, power and sexual potency, which may be demonstrated through men having multiple sexual partners, and relationships within which condom use can be seen to reduce this potency or strength, as well as reducing pleasure (Ruark et al., 2016). A very high proportion of Swazi girls experience violence and abuse, with 33% having experienced sexual violence, 25% physical violence, and 30% emotional abuse by the time that they are just 18 years of age (UNICEF, 2007). Violence against women causes additional vulnerability for HIV, and women who experience violence are one and a half times more likely to become infected with HIV than those who do not (UNAIDS, 2018). Uptake of male circumcision amongst Swati men is low, with 26.7% of males aged 15 years and older having undergone medical circumcision (Swaziland Ministry of Health, 2017). Low uptake has been attributed to the perceived threat circumcision poses to masculinities and sexual pleasure (Adams and Moyer, 2015).

This study is based in the predominantly rural southern region of Shiselweni. Here, subsistence farming is widely practiced, and the region has been particularly affected by drought in recent years, which has caused food insecurity (Root et al., 2017). Health care is primarily delivered through decentralised services, with two secondary health facilities (in Nhlanguano and Hlatikhulu), and several primary health clinics (Figure 3.4). This PhD research is primarily based in Nhlanguano health zone, which has eight primary health care clinics offering integrated HIV services, and one secondary facility, which offers HIV care within a specific HIV-related care department, as well as being included within antenatal care.



Photo credit: Claire Elise Burdet

**Figure 3.4:** Photo depicting example health facility in Shiselweni

## Methods

### **Study design**

A longitudinal, prospective qualitative study design was adopted in order to examine the lived experiences of people living with HIV, and their engagement with HIV treatment and care services in the context of an MSF/MoH Treat-all pilot in the Shiselweni region of southern Eswatini.

This research comprised of an initial phase of data generation and analysis, which focused on examining individuals' experiences with HIV testing, diagnosis and linkage to HIV care, hereby referred to as Phase 1. Data for phase 1 were generated in February to May 2015, through one-time in-depth interviews with people living with HIV and health care workers, and focus group discussions with community members. Preliminary analysis was conducted during data generation, with more extensive analysis being performed from September 2015, and subsequent write-up and manuscript submission in March 2016. The methods adopted for phase 1 are presented in the following section (Phase 1: Linkage to HIV care), and the results from phase 1 are presented in Chapter 4.

The main phase of the research began in August 2015, with participant recruitment and data generation through repeat interviews with people living with HIV from August 2016 to September 2017, one-time in-depth interviews with health care workers in March to April 2017, and formal observations of community and clinic activities in August to September 2015, and in March 2016. The results from the main, longitudinal phase of the research are presented in Chapter 5, 6 and 7. I was primarily based in the study setting of rural Eswatini from February to May 2015, and from August 2015 to November 2017, which also provided greater contextual familiarity and understanding. Table 3.1 shows a detailed timeline of research activities.

**Table 3.1:** Time line of research activities (data generation and analysis)

Activity	2015												2016												2017												2018												2019			
	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Jan	Feb	Mar	Apr			
Field visit, observations	[Orange bar]												[Orange bar]												[Orange bar]																											
Data generation:																																																				
- One-time interviews with PLHIV	[Light blue bar]																								[Light blue bar]																											
- One-time interviews with HCW																									[Light blue bar]																											
- FGDs with community members	[Light blue bar]																																																			
- Repeat interviews with PLHIV																									[Blue bar: Int. 1, Int. 2, Int. 3]																											
Preliminary data analysis	[Purple bar]												[Purple bar]												[Purple bar]												[Purple bar]															
Feedback/dissemination findings	[Purple bar]												[Purple bar]												[Purple bar]												[Purple bar]															
Extensive data analysis													[Purple bar]												[Purple bar]												[Purple bar]															
Write up													[Dark blue bar]												[Dark blue bar]												[Dark blue bar]												[Dark blue bar]			
Chapter 4 paper submission													[Red bar]																																							
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## **Phase 1: Linkage to HIV care**

Phase 1 of the research focused on examining the experiences of individuals who were diagnosed with HIV through the MSF/MoH provided community-based HIV testing services in Shiselweni, Eswatini, in particular exploring factors influencing their linkage to HIV care. Data were generated through interviews with people living with HIV and health care workers, and focus group discussions with community members. Linkage to care was defined as attendance at a specified referral facility and registration in the pre-ART or ART register within six months of the HIV test date. This phase of the study relates to the first research objective. The following sections outline the participant sampling and recruitment strategy that were adopted, and the methods of data generation and analysis used for this phase of the research.

### ***Phase 1 sampling and recruitment strategy***

Community members who were diagnosed HIV positive between June and November 2014 were identified for recruitment to the study, having been tested through the community-based HIV testing services provided by MSF with the MoH. The community testing register was used to sample participants, which records details of all individuals who are tested for HIV, including their contact and testing information. The initial sample was stratified to include those linked to care (using the recorded pre-ART or ART enrolment date) or not (no pre-ART registration recorded within 6 months of diagnosis). Individuals were then purposively selected to include an equal gender balance and range of ages, and a mix of rural and urban dwellings. Identified participants were contacted by telephone by a member of the research team with information about the study, requesting their participation in an interview at a time, date and location convenient to them.

Health care workers were identified to include those employed in a range of positions involved in delivering HIV testing services, and HIV treatment and care services, and who could therefore provide insight to their experience offering HIV testing and supporting individuals' diagnosed HIV positive to process their diagnosis and link to HIV care. This included members of the MSF community-based HIV testing team,

clinic-based HIV testing staff, nurses, and then-named “expert clients” (now referred to as adherence counsellors; HIV positive lay counsellors involved in post-test counselling, pre-ART sessions and assessing patients’ readiness for ART). All health care workers who were invited to participate in an interview agreed to do so, leading to a sample of 11.

Community members of unknown HIV status were identified through community-based adherence counsellors, so their views on HIV testing and access to treatment and care for HIV positive individuals could be explored and understood. Six to eight members were recruited for each focus group discussion, of the same gender and aiming to recruit those of a similar age, with three focus group discussions were held in total. Table 3.2 shows participant information.

**Table 3.2:** Preliminary phase participant information

<b>Participant information</b>	<b>Number of participants</b>
All people living with HIV	28
Recorded linked to care	14
Recorded not linked to care	14
Total women	14
- 16 to 24 years	3
- 25 to 34 years	4
- 35 to 44 years	4
- 45 to 69 years	3
Total men	14
- 16 to 24 years	2
- 25 to 34 years	4
- 35 to 44 years	3
- 45 to 69 years	5
All health care workers	11
HIV testing counsellor – clinic based	3
HIV testing counsellor – community based	6
Nurse	1
Adherence counsellor	1
All community members	19
Group discussion 1 – women (aged 17-39 years)	6
Group discussion 2 – men (aged 16-30 years)	6
Group discussion 3 – women (aged 19-24 years)	7

### *Phase 1 methods of data generation and analysis*

Interviews were undertaken with the aim of exploring the ways in which experiences with HIV testing, and receiving an HIV diagnosis may be processed, interpreted and understood, and the factors which may influence linkage to HIV care in the context of Treat-all. Interviews with health care workers aimed to explore perspectives on HIV testing, diagnosis and linkage to care. Focus group discussions with community members explored attitudes, views and beliefs surrounding HIV testing and access to HIV treatment and care in this context

Interviews with people living with HIV were held at the individual's home, a private room within the health clinic or a private room within the project office. These were conducted in siSwati by same-gendered Swati researchers, bar one interview with a man which was conducted by a woman. There were some challenges with interview technique and several of the interviews were shorter and less open or in-depth than hoped. This was particularly apparent in interviews with men recorded as not linked to care, which averaged 30 minutes, compared to nearly 60 minutes for women. For those recorded linked to care the interview length was more similar, with mean 45 minutes for men and women. On reflection and analysis of data, it was felt that this was likely linked to an issue with interview technique rather than reflective of "not linked" men's accounts more broadly, and additionally an interview conducted with a "not linked" man by a woman was 75 minutes long. However, it would be difficult to definitively draw conclusions about this, as it could have been influenced by a myriad of factors. The author provided ongoing training and support for interviewing techniques, and regular team meetings were held to discuss and reflect on interviews and potential opportunities for probing and encouraging further discussion and open narratives. The use of open probes was encouraged, including non-verbal such as nodding, use of silence to encourage elaboration, and "mmhmm", as well as questions such as "how did that make you feel?", "what thoughts went through your mind at that time?", "could you tell me more about that?".

Health care worker interviews were conducted by the author, with the majority being held in English (n=9), or in a combination of English and siSwati with the assistance

of an interpreter (n=2) when preferred by the participant. These interviews were held in the clinics where each health care worker was based, during working hours, and averaged 50 minutes.

Focus group discussions were co-facilitated by a Swati research assistant and myself, with the assistance of an interpreter. These discussions (n=3) averaged one hour and 40 minutes, and were based on topic guides with an ice breaker activity at the start (see appendices for example topic guide).

Data were analysed thematically, drawing upon principles of grounded theory (as outlined in section titled: Approach to data analysis above), and using Nvivo 10 as an analytic aid.

### **Main phase: Longitudinal study**

The main, longitudinal phase of research investigating people living with HIV's experiences engaging with HIV treatment and care in the context of Treat-all in Eswatini began in August 2015.

The approach to participant recruitment and the data generation tools were initially piloted with four women. This enabled adaptation of participant recruitment, study introduction and the life history interview tool (see sections on participant recruitment and data generation below). Following this pilot, repeat interviews with people living with HIV were conducted from August 2016 to September 2017 (all but one conducted by June 2017; see Table 3.3). I conducted health care worker interviews in February to March 2017, and observations of clinic and community activities in August-September 2015 and March 2016. 106 interviews were conducted in total, and 13 days of formal observations.

**Table 3.3:** Interview outline for people living with HIV participants

Interview	Date range	No. of participants	No. of meetings
1 – Life history, family and relationships, hopes and aspirations, key life events	22/08/16 – 31/10/16	30*	33
2 – HIV testing, diagnosis, treatment offer and treatment initiation decision-making	17/11/16 – 07/02/17	29	31
3 – Living with HIV, ongoing treatment-taking and engagement with HIV services	25/03/17 – 08/09/17	26	27

\*Certain interviews were conducted over more than one meeting, for example due to length of discussion and available time. 1 participant was lost to follow up after the first interview, attempts were made to contact her but she was not available to arrange another meeting. 3 participants completed 2 interviews and 1 completed 4 interviews.

### *Sampling strategy*

The sampling frame used for participant identification and recruitment was the project patient database for the Treat-all pilot. This was reviewed in April 2016, and an initial sample was prepared that included individuals enrolled into HIV care under Treat-all between the start of the pilot (October 2014) and the end of the pilot (31 March 2016), for potential recruitment to the longitudinal qualitative study. On reviewing the patient database, I selected potential participants to include only those recorded as newly diagnosed with HIV at enrolment to care under Treat-all (within 6 months of enrolment, the majority of whom were diagnosed within 1 month of enrolment). I also selected participants who were registered as having WHO disease stage 1 and a CD4 count  $\geq 500$  at time of enrolment to HIV care, and who therefore would be considered clinically asymptomatic and otherwise ineligible for treatment according to national treatment guidelines in place at the time.

After selecting potential participants on the basis of these criteria, the sample was then stratified for gender and age, to include men and women, young adults (aged 16 to 25 years) and adults (aged 26 to 49 years). Sample selection also aimed to enable exploration of a range of treatment-taking experiences, and therefore those recorded as initiating ART the same day as diagnosis, those recorded lost from treatment (LFT),

those enrolled to care at the beginning of the pilot (October to December 2014) and those enrolled more recently (January to December 2015 and January to March 2016) were purposively selected. LFT was defined as those whose last visit date was 4 months ago or more from time of study recruitment (those considered LFT had last clinic visit date before 30<sup>th</sup> November 2015). 4 months was chosen as many patients stable on ART have 3 monthly refill appointments.

Sample selection reflected the fact that more women than men were enrolled in the Treat-all pilot, there were also very few potential young men due to the epidemiology of HIV in Eswatini (i.e. there are more young women newly infected with HIV than men), and men often access care later in this context. It was therefore expected that the sample would have less men than women, and the goal was a gender balance that reflected the epidemiology of HIV in Eswatini, rather than an equal one. I also decided to not stratify the sample to young men if there were less than five young men available to recruit from, in order to protect individuals' confidentiality, and as it would be difficult to draw analytic conclusions from a small participant sub-group.

Health care worker participants were identified and recruited to include those from all of the nine clinics involved in the Treat-all pilot (Nhlangano health zone), both MoH and MSF staff, and a range of different treatment and care-related positions (such as adherence counsellor, nurse, nurse supervisor and doctor).

### *Participant recruitment*

Once potential participants were identified for recruitment to the study, names and phone numbers for these individuals were obtained by looking up individual patient files at their respective clinic using their unique identifiers (ART number, as the Treat-all patient database only included confidential patient information including ART number and date of birth but not full name or contact information). All people living with HIV enrolled to the Treat-all pilot had consented to being contacted for invitation to participate in a qualitative interview at the time of their consenting to Treat-all pilot participation. However, as this was up to two years ago for some individuals, many did not remember having consented, which we initially discovered during the pilot phase of participant recruitment.

During the pilot phase, an approach to recruitment was tested whereby adherence counsellors at each clinic were approached to act as the gatekeeper, contacting the identified individuals themselves in the first instance to briefly introduce the study and ask for the individual's permission for someone from the research office to contact them to discuss further. Following the pilot, I decided not to continue with this approach. It proved difficult to implement in practice, was time consuming, and it may have also influenced the quality of interview interactions and the data generated, as participants appeared to associate us with the health programme due to the initial introduction coming from a member of staff at the clinic. Practical difficulties that we faced adopting this approach included issues such as adherence counsellors not being provided with airtime to call clients unless for "defaulter" (LFT) tracing, in which case they had to log all such calls, and there were therefore questions around affordability of their calling patients on our behalf. Logistically we were not able to provide additional airtime to all of the adherence counsellors who would be involved in contacting potential participants from each clinic. Additionally, the process of preparing a shortlist of potential participants to contact, giving this to the adherence counsellor from the relevant clinic, subsequently following up and reminding the adherence counsellor and seeking feedback from the calls, and having to prepare an additional list of participants if the initial calls were unsuccessful (including if the number was incorrect or unavailable, or if the patient did not answer) added several additional steps to the process of recruitment than if we were to contact patients ourselves directly, and was fairly time consuming. Adherence counsellors had made suggestions that we instead contact some of the "good" patients that they had more regular contact with and felt it would be easier to engage, which we were concerned may influence the study, particularly as we wanted to purposively try to include those "harder to reach" and LFT. As this approach to recruitment did not seem to improve the quality of interviewer-interviewee rapport, of the data generated, or add ethical value to the recruitment process, we therefore decided not to continue with this approach to recruitment following the pilot.

Therefore, we subsequently decided to adapt the approach to contact potential participants directly, with research assistants' briefly outlining the research and

seeking consent to meet in person to discuss further, or to proceed with an interview if they were comfortable doing so.

### Contact history

The strategy employed for contacting individuals was to call the number listed from their patient file first, and if unsuccessful, to then contact the listed treatment supporter. When contacting the treatment supporter care was taken to avoid potential deductive disclosure, as although this person had been selected and provided to the clinic by the individual, we did not want to make assumptions regarding what individuals had chosen to disclose, and it was important to avoid risk of potential harm. If these were both unsuccessful, in certain instances we then contacted the clinic adherence counsellor to ask if they had any other means of contacting these individuals, such as an updated phone number.

Fifty four percent of individuals who were contacted to invite participation were unidentifiable due to their listed number being unavailable or incorrect. 64% of those contacted agreed and participated, 18% silently refused (agreeing to meet and not attending the arranged appointment, further reflected on in the Discussion Chapter, section: Ethical dilemmas ), 10% were out of the study region, 4% were unwell and unable to meet, and 4% did not have time due to work commitments (Table 3.4).

**Table 3.4:** People living with HIV participant contact history

<b>Participant contact history information</b>	<b>Number of individuals (%)</b>
All women attempted to reach	78
Contactable	31 (40%)
Uncontactable	47 (60%)
Agreed and participated	20 (26%)
Silent refusal	4 (5%)
Out of study area/region (e.g. South Africa)	5 (6%)
Unwell and unable to meet/talk	2 (3%)
All men attempted to reach	31
Contactable	19 (61%)
Uncontactable	12 (39%)
Agreed and participated	12 (39%)
Silent refusal	5 (16%)
Refusal due to work commitments – no time	2 (6%)

For recruitment of health care worker participants, the MSF head of clinical activities was first point of contact, as it was important to respect organisational hierarchy of communication and to fit in with established procedures within the project. He would therefore make initial contact with each of the clinics and would introduce me to staff there, for me to then arrange a convenient time to come back to conduct interviews with various individuals. Interview appointments were then arranged in consideration of what was convenient for each health care worker, as well as project logistics such as car movement schedules for visiting each clinic (some clinics were up to 2 hours' drive away from the project office).

All health care workers who were approached and invited for interview agreed to take part. Arranging interviews at one privately funded clinic proved more challenging than the other clinics, with one health care worker discussion being informal (rather than a recorded interview), one interview quite brief as this individual had limited time available, and one longer (with an MSF employed member of staff there).

#### Study participant information

The final sample included 30 people living with HIV, 29 of whom were interviewed two to four times, and 20 health care workers, who were interviewed once (Table 3.5).

As described in the earlier section on the approach to participant recruitment, the number of participants was decided based upon evidence of data saturation, with an iterative process of data generation and analysis. I interpreted data saturation as being evidenced when adding further participants did not appear to generate new findings relating to the topic of inquiry. For people living with HIV, this was determined based on analysis and reflections on findings emerging from the first interview with participants. I also considered the risk of attrition between first and repeated interviews, with a sample of 30 individuals aiming to allow for the potential for some participants to be lost between interview phases.

**Table 3.5:** Main research phase participant information

<b>Participant information*</b>	<b>Number of participants</b>
All people living with HIV	30
Treatment-taking category:	
On ART	18
Lost From Treatment	12
Enrolment period:	
Early (Oct 2014 – Mar 2015)	13
Mid (Apr 2015 – Sep 2015)	12
Late (Oct 2015 - Mar 2016)	5
Gender and age:	
Women	18
• Young women (17-25 years; average 21)	9
• Adults (26 to 46 years; average 33)	9
Men	12
• Young men (16 to 25 years)	0 (none eligible in patient cohort**)
• Adults (26 to 49 years; average 37)	12
All health care workers	20
Position:	
Nurse supervisor	5
Nurse	8
Adherence counsellor	5
Doctor	1
Employer:	
MoH	12
MSF	8

\*Participant information relates to that recorded on the project patient database at time of recruitment; or for health care workers the positions they identified with during interviews.

\*\* No young men were eligible due to the epidemiology of HIV in Eswatini meaning less young men are infected, and additionally men can access care later.

## **Methods of data generation**

### *In-depth interviews*

The first interview with people living with HIV focused on the participant's life history, establishing rapport, exploring their family background, education, relationships, interests, and key life events. The second interview focused on general health management and experiences accessing health services. Following participants' disclosure of their HIV status, their story regarding past HIV testing experiences; how receiving an HIV diagnosis was understood, interpreted and felt (psychosocially and physically); their experience being offered early ART; their decision-making regarding the initiation of ART; and their experience with HIV-related health services was then explored. Subsequent interviews sought to understand how participants' on-going treatment-taking and engagement with HIV services is navigated over time, identifying and exploring changes in the lived experience of HIV and being on treatment (particularly where ART was initiated when 'asymptomatic'), as well as re-visiting topics explored in previous interviews. Topic guides for subsequent interviews were developed based on analysis of the previous interview for each individual participant, which enabled further exploration of certain areas which had been discussed, greater depth of insight, as well as providing a view as to changes in participants' accounts regarding their experiences. For example topic guides see appendix 2. Interviews with health care workers explored views and experiences relating to implementing Treat-all and providing treatment and care to asymptomatic patients.

### *Interview arrangement and setting*

When requesting to meet with participants, we tried to arrange meetings at participants' homesteads as much as possible, as long as individuals were comfortable with this (Table 3.6). This approach aimed to create a relaxed, informal environment for interview discussions, and to gain insight to the context within which people lived. As Riessman says, "working ethnographically with participants in their setting over time offers the best conditions for story telling" (2008). Where participants did not feel comfortable having interviews held at their homestead, for

example due to lack of privacy or fear of inadvertent disclosure, we avoided the use of clinics as much as possible, to mitigate association with the health programme and to ease participants' comfort, particularly regarding discussions relating to their care and relationship with health care workers. One man was interviewed at the clinic because this was most convenient for him, he was studying in Mbabane and would come to Nhlngano to get his treatment refills, so we coordinated our meetings with him around his visits to the clinic and met him there while he was waiting. As this suggestion was led by him and he was comfortable having the discussions in this environment, it did not seem to negatively impact on the nature of what was discussed. However, it would be difficult to know this definitively.

**Table 3.6:** People living with HIV participant interview location

<b>Interview location</b>	<b>Number of interviews</b>
Homestead	48
Private office room (project office or fixed HIV testing site)	15
Car	9
Outside (e.g. under a tree)	6
Private room at clinic	7
Total	86

Health care worker interviews were all held at the clinic where they worked, during working hours.

For each interview with people living with HIV, individual participants were reimbursed 60 emalangenani (around £3.20) as a contribution towards their time, which was framed as a transport reimbursement (but provided for all participants including for interviews conducted within participants' homes). It was decided to provide this amount to all participants based on consultation with the local research team, as this amount had also been provided in previous research in the setting, and with the same amount provided to all to ensure fairness. Providing this amount to participants was in appreciation of participants' time, and the income generation they may have lost as a result of their time participating in the interview. Additionally, 30 emalangenani was spent on refreshments including a savoury sandwich or stew/meal with meat, a

drink and fruit, provided at each interview. See also section of this chapter: Ethics in research; Avoiding risk of harm to participants.

As interviews with health care workers were held at the clinics where they worked, within working hours, such reimbursements or refreshments were not provided for these interviews.

### *Observations*

I conducted observations of community and clinic-based activities relating to Treat-all implementation, which aimed to provide further understanding and insight into the context of HIV treatment and care service delivery, as well as to the socio-cultural context within which participants were situated. These observations included health talks in various clinics (delivered at the secondary health facility and primary health clinics within Nhlangano) and communities; HIV testing sessions; pre-ART counselling sessions, clinical consultations where ART is offered in the context of Treat-all, routine ART counselling and enhanced adherence counselling sessions (for those with unsuppressed viral load results). I also observed differentiated models of treatment and care, including community ART groups, treatment clubs and treatment outreach.

I conducted observations with a research assistant who interpreted the observed discussions from siSwati to English. The potential influence of language on the quality of observational evidence are reflected in the Discussion chapter: strengths and limitations.

Additionally, I conducted informal discussions with traditional healers including four tinyanga (traditional healer) and one umthandazi (faith healer) in September 2015 and June 2016, with the assistance of an interpreter. These were held because medical pluralism is common in Eswatini, and there are traditional conceptions of health and illness which can both contradict, as well as working alongside, biomedical models. Therefore, I felt it important to better understand the extant alternative health systems, as this was relevant to the accounts of several participants.

I recorded field notes for each session that was observed, including reflections on the setting, what was said, body language and potential interpretations.

### **Methods of data analysis**

For each participant included in the longitudinal research, I analysed transcripts for each of their interviews separately and in succession, comparing emergent themes within an individual interview for each case, and across their different, repeated interviews to explore how these might change over time, and then comparing across the sample of different people living with HIV.

For the narrative analysis component, narratives that I examined included the decision-making processes regarding ART initiation, and navigation of ongoing engagement with treatment and care. Within this approach, I also aimed to maximise the use of longitudinal data, by focusing on the narrative of an individual in each interview, and looking at how this might have changed across the repeat interviews.

An example of the coding framework that I developed during data analysis is included in Appendix 4.

### **Ethics in research**

Ethical issues in research are inextricably linked to views about the ontological and epistemological foundations which underpin it (Murphy and Dingwall, 2001). Within this research, I take steps to adopt both consequentialist and deontological approaches to ethics, considering the potential outcomes of research in terms of the harm or benefit that could result from participation, and how to mitigate risk of harm; as well as considering the rights of participants, including to respect, privacy and autonomy (Murphy and Dingwall, 2001). In the proceeding section I outline the steps which I undertook to uphold these ethical principles within this research. However, these were not exhaustive, and many ethical reflections and decisions continued throughout the research process, rather than occurring prior to or at the start of participant recruitment and data generation. I further reflect upon the ethical dilemmas raised in this research in the Discussion Chapter (section: Reflection on the approaches taken within the research; Ethical dilemmas).

## **Ethical approval**

Prior to study commencement I prepared a study protocol for the preliminary and main phase of research, including informed consent forms for the various participant groups (see Appendix 3), and addressing potential risk of harm and benefit to study participants and communities, which I then submitted to the relevant ethics review boards for review.

For the preliminary phase of research, ethical approval was granted by the Eswatini (then named Swaziland) Scientific and Ethics Committee and MSF Ethics Review Board.

For the main phase of research, ethical approval was granted by the Eswatini Scientific and Ethics Committee, the London School of Hygiene and Tropical Medicine Ethics Review Board, and MSF Ethics Review Board.

## **Informed consent**

Informed consent refers to the principle that individuals should not be coerced, persuaded, or induced to participate in research against their will, rather participation should be based on voluntarism, and on a full understanding of the implications of participation (Green and Thorogood, 2009). Consent is a process, which should be assessed on an ongoing basis, with sensitivity to any changes in participant decision-making capacity (Hewitt, 2007). In post-colonial settings signing a consent form may carry different meanings to the protective intent embedded in western discourse, potentially functioning to establish control and ownership over the information gathered, and to release research institutions from liability (Riessman, 2005), which it is important to consider.

An information sheet was given to all participants, available in siSwati and English, which was also discussed verbally at the first meeting with participants, with the opportunity for questions and further discussion, and offering participants the option of having some time to consider and to reconvene for the interview at a later date. Study information presented the purpose of the study, who was conducting it, why individuals were being requested to participate, and included contact details of the

Eswatini Scientific and Ethics Committee, and the qualitative research office phone number, should participants require further information about the study. Information included the steps taken to try to ensure confidentiality would be protected, also explaining that confidentiality could not be fully guaranteed. Participants were informed that they could withdraw their participation or end an interview at any point, and could choose to not answer certain questions or share information if they wished. Informed consent included provisions requesting consent for oral recording of interviews, explaining that these recordings were for the purpose of wanting to capture everything that was said in the interview, and that these would be securely stored (password protected), and not heard by anyone beyond the research team. For repeat interviews, the consent process was revisited verbally at each interview, reminding participants of the provisions for confidentiality and their rights to withdraw participation.

For focus group discussion participation, an information sheet was given to all participants prior to the discussion, which was discussed verbally. Participants were informed that while being requested to respect each other's confidentiality and not further discuss things that were shared in the group, that this could not be guaranteed by the researchers. Again, steps taken to remove individually-identifying information from study reports and documents were outlined. Verbal consent was requested from all individuals prior to discussion commencement.

It has been posited that signed consent forms may actually jeopardise the confidentiality of participants by making them identifiable (Murphy and Dingwall, 2001), so it is important to consider how informed consent forms will be stored securely and to also discuss with participants where they will keep their information sheet and how they will respond if someone finds it. Within this research, all signed consent forms were stored securely in a locked cabinet in the qualitative research office, which was also locked whenever empty.

Using consent forms which must be signed by participants may not be appropriate for all participant observation research (Punch, 1994). Before observations started, myself and a research assistant were verbally introduced, the research and the

purpose of observations were outlined, and verbal consent was sought from individuals for each observation. If an individual wanted me to leave the observed session at any point, they were encouraged to indicate this, and I would leave without asking any questions (and without any negative implications for them for example in terms of their care). This was emphasised for all counselling and HIV testing sessions. Where not possible to seek each individuals' verbal consent (for example for large group sessions, such as health talks in the community or clinics), the health care worker leading the session would introduce me, explain why I was there and ask generally if people were OK with this.

Although individuals in the study sample had given consent to be contacted for interview at enrolment to the Treat-all pilot, many said they could not remember having consented to this when they were contacted requesting participation in the qualitative research. In consultation with colleagues, I therefore decided to change the approach and introduce the study as focusing on health, so participants could decide if, when and how they disclosed their HIV status to us, rather than us pushing them to discuss something which may be painful and uncomfortable for them. I therefore anticipated that not all participants would disclose their HIV status and planned participant recruitment with this in mind.

Interviews may be filled with conflicting expectations and assumptions, as participants are constructed as sources of social knowledge, and the interviewer may be interpreted as someone who can provide medical knowledge (Riessman, 2005). It was important to clarify our role and position throughout the research, to offer participants signposting or referrals to further information and support, and to provide information ourselves where appropriate. Additionally, the final interview included questions to explore participants' expectations surrounding the research, how they had understood their invitation to participate, their motivations for agreeing to take part, and what they understood would happen with the information they had shared. Participants were asked to reflect on their experience participating in the research, including whether there were any good or bad experiences resulting from their participation. This allowed for more detailed reflection and exploration of

the consent process and participants' experiences taking part in the research (see Discussion Chapter section: Reflections on the research approach).

### **Avoiding risk of harm to participants**

The ethical principles of beneficence and non-maleficence include an obligation that research should result in benefits, and that such potential benefits should be balanced against risks (Beauchamp and Childress, 2001). Additionally, participating in research should cause participants no harm (Hewitt, 2007). Research should be worth doing, in the sense that the results are likely to lead to tangible benefit for patients (Richards and Schwartz, 2002).

Protecting participants from harm includes taking steps to ensure that participant confidentiality is maintained within research, with confidentiality referring to all information that is hidden from anyone not in the primary research team. This includes through anonymity, so that an individual's identity should not be traceable from the data presented about them (Saunders et al., 2014). However, it may be impossible to guarantee complete anonymity to participants in qualitative research, and it is possible that quotations and context could be sufficient information for participants to be identified by themselves or others (Hewitt, 2007).

Within this research I wanted to protect participants' confidentiality as much as possible, which is particularly important due to the sensitive nature of the topics discussed within interviews, and as HIV is a highly stigmatised condition in the study context. Steps taken to protect confidentiality included the use of pseudonyms and avoidance of any individual-identifying information within reports or publications. Additionally, data was stored securely using password protected files, only accessible by members of the qualitative research team. Privacy was also considered within interview settings, requesting somewhere quiet without others present who may overhear discussions, for example in a private room within a homestead. If there were disturbances, such as someone entering the interview space, then the discussion would be stopped and resumed once others left. This was also emphasised to participants during introduction meetings and discussions about interview location.

I took steps to avoid the risk of inadvertent disclosure of participants' HIV status through their participation in the research. This included through paying attention to the association of MSF with HIV, to avoid exposure of participants or potential deductive disclosure within the community when visiting homesteads. The use of an MSF vehicle was discussed with participants when arranging visits, and for most visits, a plain sign saying "social research" was used to cover the MSF logo on the vehicle. Some participants requested that the car not be parked directly outside their homestead, in which case it would be parked somewhere nearby and the interviewer would walk to the interview location. Participants were asked how they would like to introduce the researcher to others that may be present, for example family members at the homestead.

It is important to consider the potential risk of harm to participants from interview discussions themselves, and how to manage and prepare for emotional distress that may arise. The probing nature of interviews has the potential to lead to participants divulging more information than they had planned when consenting to participation (Hewitt, 2007). Attempts to mitigate such risk are reflected in the approach to in-depth interviews adopted within this research (see section Methodology: Approach to data generation: In-depth interviews), which were participant-led and empathetic.

Some say that the process of sharing in interviews may be cathartic for certain individuals (Richards and Emslie, 2000), with findings that participants feel it is good to have someone to talk to (Finch, 1984). However, there is the potential that revealing emotionally sensitive and painful details can cause participants emotional distress (Stacey, 1988). Within this research, the nature of the topic being explored (in particular HIV and relationships) is sensitive and could be upsetting for participants. Attention was paid to how participants appeared to be feeling during discussions. Anyone who became distressed, who raised anything suggesting potential risk of harm, or who appeared in need of further support could be referred for additional psychosocial support and counselling. This would always be discussed with the participant first, and their consent for referral sought. Interview discussions were managed to not start or end with emotive topics, in preparing for interview endings

and avoiding the risk of leaving participants in any emotional distress. Listeners can also be deeply affected by the narratives they hear, with the potential to upset or even traumatise the investigator (Riessman, 2005), and within debriefing sessions following each interview, interviewers were supported with processing any uncomfortable emotions they themselves experienced as a result of the nature of the discussions.

Although rapport is important for participant comfort and openness, this relationship should not be exploitative (Goodwin et al., 2003). Additionally, there may be unintended consequences of growing emotional intimacy (Hewitt, 2007), and participants may experience loss when the study ends and the researcher withdraws (Murphy and Dingwall, 2001). With this in mind, participants were prepared for the study ending in advance of the last interview, and the interviewer checked in during the penultimate interview to ask participants how they felt about the research coming to an end and the next meeting being the final one.

In considering the importance of reciprocity and respect, power dynamics and valuing participants' time, I decided to offer participants a contribution in appreciation of the time they shared during interviews. Some argue that reimbursement is an ethical requirement (Draper et al., 2009), particularly among feminist researchers (Head, 2009). However, it is important to consider the appropriate amount of compensation, which can have differing meaning in different contexts, and if an incentive is too high there is the risk that those on low incomes may feel coerced to participate (Head, 2009). The decision to offer participants a small financial contribution, as well as refreshments, for each interview, was based on consultation with local researchers, knowledge of the study context, and what was feasible within the project resources.

In this chapter, I have presented my epistemological approach, which underpins this thesis, influencing the choice of methods that I adopted, and the study findings that are presented in the following chapters. I have outlined my approach to participant recruitment, to data generation including in-depth interviews, focus group discussions and observations, and to data analysis and the interpretation of accounts.

I described the study context of Eswatini, reflecting on information relating to the socio-political context, which influence and shape this research and frame the findings. I describe the methods that I adopted within the preliminary and main phase of this research, and the steps I took to uphold ethical principles.

## **Chapter 4: “Life is so easy on ART, once you accept it”: Acceptance, denial and linkage to HIV care in Shiselweni, Swaziland**

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## RESEARCH PAPER COVER SHEET

Please note that a cover sheet must be completed for each research paper included within a thesis.

### SECTION A – Student Details

Student ID Number	LSH281543	Title	Miss
First Name(s)	Shona		
Surname/Family Name	Horter		
Thesis Title	Investigating experiences of engagement with HIV Treat-all among people living with HIV in Eswatini		
Primary Supervisor	Alison Wringe		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

### SECTION B – Paper already published

Where was the work published?	Social Science and Medicine		
When was the work published?	January 2017		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	Yes	Was the work subject to academic peer review?	Yes

\*If yes, please attach evidence of retention. If no, or if the work is being included in its published format, please attach evidence of permission from the copyright holder (publisher or other author) to include this work.

### SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	
Please list the paper's authors in the intended authorship order:	
Stage of publication	Choose an item.

**SECTION D – Multi-authored work**

<p>For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)</p>	<p>I contributed to the study's conception. I designed the study, developed the study protocol and designed tools of data generation. I conducted data generation, along with fieldworkers. I analysed the data. I wrote the first draft of the paper, and incorporated feedback from co-authors. I submitted the paper, liaised with journal editors, and made edits following peer review comments.</p>
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**SECTION E**

<b>Student Signature</b>	<i>Jhona Porter</i>
<b>Date</b>	<i>20/03/19</i>

<b>Supervisor Signature</b>	<i>R,</i>
<b>Date</b>	<i>21/03/2019</i>

## Overview

Within Chapter 2, I engaged with existing literature and theory to consider how individuals may respond to and process an HIV diagnosis in the context of Treat-all, when increasingly individuals are offered treatment when asymptomatic, and how this may influence health seeking and engagement with care, which remains unknown. Existing evidence suggests that conceptions of health, ill health and treatment need likely differ and extend beyond the biomedical rationale framing Treat-all, and it is important to consider how this may influence individuals' access to HIV treatment and care. Evidence has highlighted how crucial linkage to HIV care is for individuals to be able to benefit from early treatment within Treat-all, and sub-optimal linkage may undermine Treat-all effectiveness in reducing HIV incidence.

In this chapter, I examine individuals' experiences with HIV diagnosis and linkage to HIV care in the context of Treat-all in Eswatini, to understand what influences individuals' response to their diagnosis, and their access to HIV treatment and care. This paper reflects the preliminary phase of this PhD research, with data generated through one-time interviews with people living with HIV, one-time interviews with health care workers, and focus group discussions with community members, which were conducted in Shiselweni, Eswatini February to May 2015.

The findings presented in this paper highlight the importance of the process of HIV status acceptance for supporting access to HIV treatment and care. Status acceptance can be particularly challenging for those who struggle to identify with an HIV diagnosis, for example through not having physical symptoms or signs of infection, and through conceptions of HIV risk and views about who gets HIV. Support for coming to terms with an HIV diagnosis should be available, adapted to meet individuals' needs, and focusing on status acceptance.

This paper aligns with **research objective 1**:

1. To understand how an HIV diagnosis is interpreted and understood in the context of Treat-all, and how this may influence engagement with care

## Abstract

**Background:** Timely uptake of antiretroviral therapy, adherence and retention in care for people living with HIV (PLHIV) can improve health outcomes and reduce transmission. Médecins Sans Frontières and the Swaziland Ministry of Health provide community-based HIV testing services (HTS) in Shiselweni, Swaziland, with high HTS coverage but sub-optimal linkage to HIV care. This qualitative study examined factors influencing linkage to HIV care for PLHIV diagnosed by community-based HTS.

**Methods:** Participants were sampled purposively, exploring linkage experiences among both genders and different age groups. Interviews were conducted with 28 PLHIV (linked and not linked) and 11 health practitioners. Data were thematically analysed to identify emergent patterns and categories using NVivo 10. Principles of grounded theory were applied, including constant comparison of findings, raising codes to a conceptual level, and inductively generating theory from participant accounts.

**Results:** The process of HIV status acceptance or denial influenced the accounts of patients' health seeking and linkage to care. This process was non-linear and varied temporally, with some experiencing non-acceptance for an extended period of time. Non-acceptance was linked to perceptions of HIV risk, with those not identifying as at risk less likely to expect and therefore be prepared for a positive result. Status disclosure was seen to support linkage, reportedly occurring following the acceptance of HIV status. HIV status acceptance motivated health seeking and tended to be accompanied by a perceived need for, and positive value placed on, HIV health care.

**Conclusions:** The manner in which PLHIV process a positive result can influence their engagement with HIV treatment and care. Thus, there is a need for individually tailored approaches to HTS, including the potential for counselling over multiple sessions if required, supporting status acceptance, and disclosure. This is particularly relevant considering 90-90-90 targets and the need to better support PLHIV to engage with HIV treatment and care following diagnosis.

## Introduction

Timely uptake of antiretroviral therapy (ART) has a considerable effect on individual HIV-related health outcomes and on reducing the likelihood of HIV transmission (Cohen et al., 2011a; Gardner et al., 2011; INSIGHT START Study Group, 2015; Jenness et al., 2012; The TEMPRANO ANRS 12136 Study Group, 2015). The UNAIDS 90-90-90 targets propose that with 90% of people living with HIV (PLHIV) knowing their status, 90% ART initiation for those diagnosed and 90% viral suppression for those on ART, HIV could be eliminated by 2030 (UNAIDS, 2014). Several countries are now adopting 'Test and Start' approaches in light of recent WHO guidelines (World Health Organisation, 2015), whereby providers offer ART for all individuals diagnosed HIV positive, irrespective of CD4 count. High coverage and uptake of HIV testing, linkage to HIV care, treatment initiation, retention in care, and maintained adherence to ART are required for Test and Start to reduce HIV incidence successfully (Gardner et al., 2011; Gardner and Young, 2014; Hayes et al., 2015). However, shortfalls exist at each of these stages (Gardner et al., 2011; Kilmarx and Mutasa-Apollo, 2013; Nachega et al., 2014).

Community-based HIV testing services (HTS) can achieve high uptake, particularly among first time testers, underrepresented groups such as men, and those in early stages of disease (Bassett et al., 2014; Mills and Ford, 2012; Negin et al., 2009; Parker et al., 2015; Tumwebaze et al., 2012; Tumwesigye et al., 2010; van Rooyen et al., 2013; Wachira et al., 2012). Yet, reported rates of linkage to HIV care following diagnosis can be low. Recent findings from the ANRS 12249 TasP trial in South Africa demonstrated just 36.9% linkage to care within three months, among those tested HIV positive by home-based HTS and not in HIV care at the time of referral (Plazy et al., 2016), compared to linkage rates found in Kenya, which were 42% following home-based HTS (Medley et al., 2013).

Factors that can support or undermine linkage to HIV care have been documented, including access barriers such as transport costs and distance to health services (Mills and Ford, 2012), and the perception that medical care is not required in the absence of symptoms (Braunstein et al., 2011; Nachega et al., 2014; Rosen and Fox, 2011). The

reasons for patients' clinic non-attendance may be complex and unintentional, including competing time demands and anticipated harsh provider attitudes (Ware et al., 2013). Authors argue that how people process an HIV-positive result, their subsequent actions and their support needs remain insufficiently understood (Gerdt et al., 2014; Mills and Ford, 2012; Wachira et al., 2012). The need for more research on this topic is increasingly pertinent in light of the move towards Test and Start, with linkage to care presenting a critical gap that could undermine its effectiveness in reducing HIV incidence (C. Iwuji et al., 2016). Swaziland is one of the first countries in sub-Saharan Africa to pilot Test and Start amongst the general population, with a Médecins Sans Frontières (MSF) and Swaziland Ministry of Health (MoH) implementation study in Shiselweni since 2014 and plans for national adoption imminently.

Swaziland has the highest reported HIV prevalence worldwide (31% of 18-49 year olds; Swaziland Ministry of Health, 2012). As part of an MSF/MoH decentralised HIV and tuberculosis care project in the Shiselweni region of southern Swaziland, community-based HTS is one of the services provided. These HTS approaches were recently evaluated and found to have achieved high levels of HIV testing (e.g., 86% uptake reported by a home-based HTS campaign) but with just 34% of those testing HIV positive then recorded as linked to pre-ART care at an HIV care facility within six months of the test date (Parker et al., 2015). Project data suggest that these rates of linkage to care have improved to around 50% since 2015, following the implementation of a range of linkage support strategies. These strategies include individual case management with intensive counsellor follow-up, point-of-care CD4 count, and a buddying scheme, which connects newly diagnosed HIV-positive individuals with a Rural Health Motivator in their community. Yet, it is not exactly known why linkage to care rates improved (or which strategies had the greatest effect), and the factors supporting or hindering individuals' from linking to care following HIV diagnosis are not well understood. It was therefore pertinent to examine individuals' experiences with HIV testing and linkage to HIV care to inform potential adaptation of support strategies to meet identified needs satisfactorily.

## Methods

In early 2015, qualitative research was conducted in Swaziland to examine community member and health practitioner experiences with MSF/MoH-provided community-based HTS in the Shiselweni region, in particular exploring factors influencing linkage to care for those testing HIV positive. Data were collected through semi-structured interviews and focus group discussions.

For the purposes of this study, linkage to care refers to attendance at a specified referral facility and registration in the pre-ART or ART register within six months of the HIV test date as this information is recorded and available through the project linkage to care database. The study area was Shiselweni, southern Swaziland, which includes three health zones: Nhlanguano, Hlatikhulu and Matsanjani.

Full ethics approval was granted by the Swaziland Scientific and Ethics Committee and the MSF Ethics Review Board before study commencement.

### **Sampling strategy and participant recruitment**

A stratified purposive sampling strategy was adopted to identify and recruit those able to provide insight into community-based HTS and linkage to HIV care (Marshall, 1996). The study sample included three participant groups (Table 4.1): Patients who tested HIV positive by community-based HTS interventions (group 1), including those who had linked to care (group 1a) and those who had not (group 1b); health practitioners with knowledge and experience of community-based testing and/or linkage to HIV care (group 2); and members of the communities where the HTS interventions were delivered (group 3, HIV status unknown).

Group 1 participants were selected from a larger cohort of patients in the project's community-based testing and linkage database, including those who had tested HIV positive by community-based HTS between June and November 2014 and either linked to care (using the pre-ART or ART enrolment date) or not (no pre-ART or ART registration recorded) within six months, to explore their experiences with HIV diagnosis and subsequent health seeking. The research team selected patients to include a gender balance and a range of ages, those from each of the three health

zones, and a mix of urban and rural dwellings. A team member contacted identified participants with information about the study, requesting their participation. Interviews were arranged with those who agreed at a time, date and location of their choice, which was either in the patient's home, a private room within the health clinic, or a private room within the project office.

Group 2 participants were recruited to include health practitioners from the community-based HTS team, clinic-based HTS staff, expert clients (HIV positive lay counsellors) and nurses responsible for pre-ART and ART enrolment to explore their views and experiences working with patients during HIV diagnosis and linkage to care. Recruitment of this participant group aimed to give insight into provider perspectives on their rapport with HIV patients and to understand how their views on the social and cultural factors influencing linkage to care may confer or differ from patient accounts.

Finally, group 3 participants (community members from the community-based HTS sites) were recruited for focus group discussions to explore their views on HIV testing and access to HIV services, providing important contextual information through insight into shared perspectives and commonly held views.

Community members were identified through community-based expert clients who recruited six to eight members of their community with unknown HIV status and of the same gender and a similar age.

**Table 4.1:** Characteristics of study sample participants and methods adopted for each

<b>Participant group</b>	<b>Participants</b>	<b>Data collection method</b>
<b>Group 1</b>	Patients diagnosed HIV positive by community-based HTS	Semi-structured interviews ( <i>n</i> =28)
<b>Group 1a</b>	Who are registered linked to care	<i>n</i> =14
<b>Group 1b</b>	Who are registered not linked to care	<i>n</i> =14
<b>Group 2</b>	Health practitioners (with knowledge/experience of HTS and linkage to care)	Semi-structured interviews ( <i>n</i> =11)
<b>Group 3</b>	General community members (HIV status unknown)	Focus group discussions ( <i>n</i> =3, 6–7 participants per group, 19 participants total; 2 with women aged 17–39 years, 1 with men aged 16–30 years)

### Data generation and analysis

Data were generated through semi-structured interviews with patients and health practitioners and focus group discussions with community members in Shiselweni from March to May 2015. Interviews with female patients were conducted by a female research assistant (RA). All interviews with male patients were conducted by a male RA save one, which was conducted by the female RA, and all were in siSwati language. The principal investigator (PI; SH) conducted interviews with health practitioners, with most being in English and two a combination of English and siSwati, with the assistance of an interpreter. Interviews averaged 50 min. An RA facilitated focus group discussions in siSwati, with an interpreter and the PI co-facilitating and taking notes, averaging one hour and 40 min. Interviews and focus group discussions were conducted according to topic guides following written informed consent. The consent process included an informed consent form (discussed verbally), with provisions for confidentiality, data storage and requesting

consent for audio recording. All interviews were transcribed verbatim or transcribed and translated equivalently to maintain meaning and integrity of data.

Data generation and analysis followed an iterative process, with analysis beginning at the point of data generation and participants being recruited until evidence of data saturation, when adding further participants generated no new findings (Green and Thorogood, 2009; O'Reilly and Parker, 2013). Data were analysed thematically using coding to identify emergent patterns, categories, and concepts from participant accounts. Principles of grounded theory were drawn upon including constant comparison of codes within and between cases to raise codes to a conceptual level and generate theory inductively from participant accounts, and through actively seeking discrepancies from majority themes (Bradley et al., 2007; Glaser, 1999; Glaser and Strauss, 1967).

To ensure analytic rigour, interview transcripts were initially analysed by three researchers independently to identify patterns and descriptive codes from participant narratives. These patterns were discussed, results were checked, and an initial coding framework was developed. Full analysis was conducted by the PI with NVivo 10 as an analytic aid, with the initial coding framework being adapted as analysis progressed. Attention was paid to the role of the researcher in shaping data analysis and interpretation, emergent themes were tested by examining exceptions and counter examples, and findings were triangulated by comparing participant groups. Finally, a fourth researcher (BS) reviewed the NVivo project data and coding to enhance validity and minimise researcher bias.

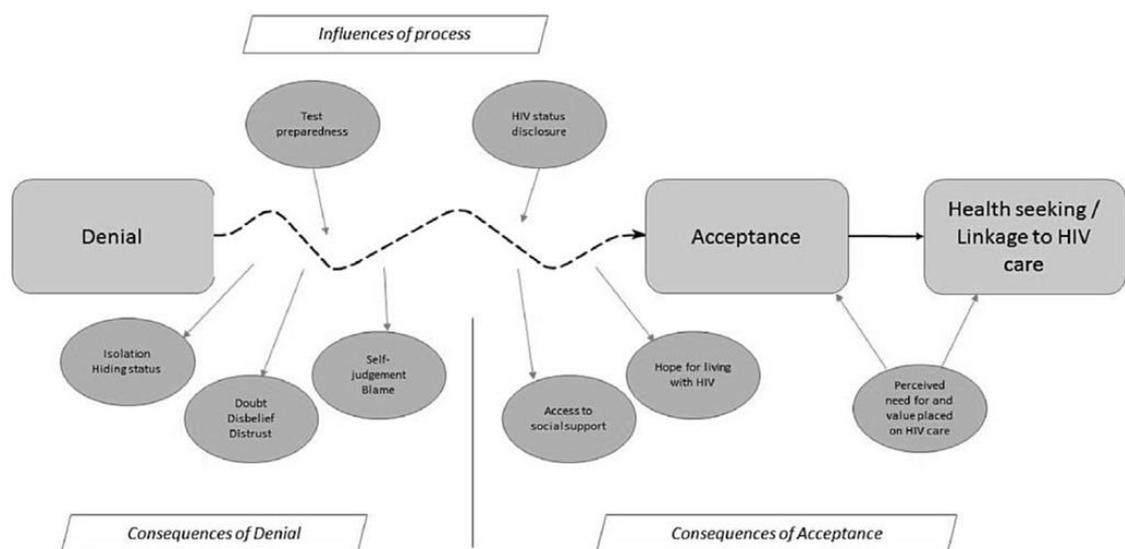
## Results

Thirty-nine interviews were conducted, with 28 patients who tested HIV positive through community-based HTS initiatives and 11 health practitioners (online supplement Tables 2 and 3). Half of the patients were female, and ages ranged from 16 to 69 years. Among the patients identified for recruitment from the project patient database, 52% were contactable, and for those who were non-contactable, there was no telephone number listed on their testing form, the number listed was incorrect, or they are now living outside the study area. For the patients who were contactable

(n=31), 100% agreed to be interviewed; of these, 90% completed the interview, obtaining a final sample of 28. Three focus group discussions were conducted with 19 community members in total.

Of the 28 patients who were interviewed, half of them were recorded as having linked to HIV care and half as not. It is noteworthy that during interview 8 of the 14 'not linked' participants reported having actually linked to care, either to the clinic they were referred to or another clinic elsewhere.

Data analysis led to the identification of several key themes as influencing individuals' linkage to HIV care: (1) processing an HIV-positive result and status acceptance and (2) value placed on health care and the perceived need for HIV care services. Figure 4.1 depicts these themes, as elaborated in this section.



**Figure 4.1:** The process of HIV status acceptance or non-acceptance: influencing factors and consequences.

### **Processing an HIV-Positive result: shock, doubt and disbelief**

Many participants reported experiencing shock after receiving an HIV-positive test result, feeling distressed, and questioning how they were infected and the source of HIV infection. Many struggled to accept the diagnosis, with several doubting or disbelieving the test result.

*'I was refusing to accept the result when they were telling me ... I'm still asking myself how I got infected.'* P06

*'I really cried, I felt pain and was shocked that "oh my word".'* P02

*'When sisi [HTC] told me that I am positive, I just did not believe it. So I stayed for two years, and some people would come to do testing, and I would not test because I was like these people tell lies ... '* P05

Periods of non-acceptance that were described ranged from months to years and had marked consequences for many individuals' mental and physical health, seen as a significant barrier to accessing care.

*'It is what can make someone ill, the fact that they do not accept.'* C06

*'I came back and stayed here at home for almost a year, and I would go to Nhletjeni and get some pills [not ART], and then it later got worse and I lay down.'* C04

Non-acceptance of HIV status was particularly evident among those who had not felt unwell or were not experiencing symptoms, which was reiterated by health practitioner participants. Participants reported confusion over receiving an HIV-positive result and not identifying themselves as being HIV positive because of their expectation that HIV infection comes with common symptoms.

*'If I had got it from him, there would be a difference by now. I would have gotten sick and bedridden, but I just think that I do not know.'* C01

*'I stayed for the year telling myself that they are lying. It means that my mind was acting childish because I would tell myself, how come I am not sick and I do not have any pain.'* P05

Many participants reported undergoing re-testing for HIV to confirm whether the result they had received was true. Re-testing and verifying the HIV-positive result appeared to be an important step in accessing HIV treatment and care and 'taking the necessary steps':

*'I wanted to see if the test was for real. I wanted to see if what we did last time was realistic, and I found that it was realistic ... I found that I am really HIV positive, and*

*that is when I accepted that I am really HIV positive and when I started the ART.'*

C08

*'I was tested, and the result was the same as the one I got before ... and then I decided that I should then go to the clinic ... because I have heard two different people sharing that information with me...'* P11

Still, this could potentially add to participants' confusion, as one participant described receiving discordant results on re-testing:

*'I did not believe that they say now I am positive because you see I had tested just that week, and I tested again, I found it positive, and I tested again the last time and found it negative. It made me think, what is happening. That is what is making me question.'*

C06

### **Perceptions of HIV risk**

Non-acceptance of HIV status was exacerbated by not associating oneself with HIV through judgements about who gets HIV, which shaped a sense of personal risk of infection. The reflections individuals made about their perception of risk for HIV included the described introduction of HIV in Swaziland linked to 'prostitution'; therefore, those who reported few sexual partners felt they were not at risk. Perception of HIV risk continues to have associations with the concepts of morality or social standards despite the generalised HIV prevalence.

*'The way in which HIV was first introduced, that HIV is in those who go sleeping around, so for those who know that they take care of themselves, they are far away from thinking of being HIV positive.'* HP 02.

*'I can say I never got to accept it. What came to me was that I questioned "me and HIV? But I am well behaved".'* P05.

Certain men presented as not identifying themselves with risk of HIV infection, as having multiple partners was seen as a positive and celebrated achievement for men, which they did not associate with the negative connotations of 'promiscuity'. Many men described living a life of Christianity and not believing in sex before marriage,

which could be at odds with the reality of their sexual practices, thereby creating misalignment of their beliefs, religious practices, and HIV risk.

*'I live a life of Christianity. I was very shocked to find that it is there ... when it comes to sex ... [pause] hmm let me say it is possible for me to have gotten it through that because it does not mean that I am this old and I have never, never had sex without a condom.'* C13, male

Those who expected that a positive result could be possible and perceived themselves to be at risk of HIV could accept their status. This was particularly apparent in the accounts of some of the women who suspected HIV exposure through their partner's refusal of condom use or their partner's infidelity, which they felt put them at risk of HIV infection:

*'I found my boyfriend's treatment, and he had not told me that he is HIV positive ... I went to get tested and found that I am HIV positive ... I was expecting it because my boyfriend is HIV positive.'* C08, female

### **Readiness to test and acceptance**

Preparedness for the chance of receiving a positive result and pre-test information appeared to be vital for acceptance of one's HIV status. Participants described their feeling of being able to exert choice in testing as influencing their preparedness for dealing with the result and therefore their likelihood of accepting it. Testing incentives were said to undermine this process, and participants described instances where individuals' motivation to test was the incentive (e.g., a t-shirt), rather than to know their health status, which caused them to go into shock on receiving a positive result.

*'Testing when you want to test and you wish to test, it is better in your spirit because you initiated it, so the results will also not be so hard to accept emotionally.'* C06

*'At the tents sometimes, they give incentives. And because as Swazis, we are hungry, so if there is some incentive, I will now stay behind, but that is not good ... because they want to receive those things but will they accept after that? I do not know.'* FGD

02-P3

HIV-related counselling and information were seen to be crucial in providing support and reassurance that there is life after HIV diagnosis. Some participants reported needing time to process and come to terms with their result.

*'I ended up going for counselling and accepting it. What helped me the most and what I can advise that every person does is to go for counselling because counselling helps a lot; it soothes the soul and makes you able to accept the status you have.'* C08

Individuals' acceptance of their HIV diagnosis and their sense of hope and belief for living with HIV was emphasised through social support and encouragement (which was achieved through disclosure). Participants had seen others with HIV surviving, realised that they were not alone or the minority affected by HIV, and had seen the transformative effects of ART, compared to the past when many had seen people around them dying due to HIV-related illnesses. These experiences enabled individuals to move from questioning where HIV could have come from to accepting and looking towards the future.

*'I accepted my situation because I have seen others surviving with the virus.'* C03

*'I was not scared because there are others I know that are living with HIV ... That is what made me not be nervous, as well as looking at other relatives who have passed on because of it and not being educated about it.'* C06

### **HIV status disclosure and linkage to care**

Non-acceptance was described as a barrier to disclosure of HIV status as the disbelief, perceived stigma, and fear of negative judgement may force the HIV-infected individuals to hide their positive result. Disclosure was seen to help the process of acceptance and support engagement in care and receiving treatment. It enabled access to social support, reassurance, and encouragement, including for treatment initiation decisions, clinic visits, and treatment reminders.

*'I was able to [disclose] after I had accepted ... I told them that I am now someone who is like this. If you see me taking pills, do remind me to take the pills when it is time.'*  
C08

*'I accepted and decided to let them know because I'm going to need their help and I want them to remind me when it's time to take the treatment and also when going to the facility.'* P01

Disclosure could influence linkage to care, with some participants who had not accessed care stating that they were waiting to disclose before going to the health clinic. Participants described how those who feared inadvertent disclosure of their status would struggle to take their treatment consistently because they did not want to be seen taking their treatment. This concern was considered significant enough to deter people from even seeking treatment.

*'I'm waiting to talk to her first before I can go to the clinic.'* C12

*'Some people die because of not telling their relatives. You find that a male person has his friend but is unable to tell them that they are taking treatment, so he ends up hiding the treatment ... they stop taking them because they are scared to tell the lover ... that is what kills them.'* P03

### **Perceived need for and value placed on health services**

The perceived need for and belief in the benefits of health care were seen to influence whether individuals would link to care or not. This was particularly evident where individuals did not feel unwell, they had not experienced symptoms that they associated with HIV, and where they did not accept their HIV status. This belief therefore created the sense that seeking health care was not urgent, and other life needs, such as work, household activities, and responsibilities, have higher priority.

*'I have not gone because I have not even had that cold. I am someone who is working, and I have not felt that I was sick and I cannot even work.'* C01

*'Some would feel strong, see themselves very good, very healthy, so they wouldn't see the reason for coming to the clinic.'* HP 01

For some, avoiding potential imminent health deterioration motivated them to access services even in the absence of symptoms because of the perceived benefits of accessing early care to avoid reaching a 'bedridden state'.

*'Going there when you're bit healthy is better than going there when you're already lying down. This way you can live longer, as if you don't have this thing.'* C09

*'We want life ... it is better to go to the clinic while you still can walk there unlike when you're already sick and bedridden. That is what motivated us.'* P08

Avoiding a 'bedridden state' was not only associated with health benefits including avoiding risk of death, but was also seen in terms of stigma reduction. Participants felt they would be able to maintain good physical health with early access to treatment, thereby preventing them from developing symptoms and being identifiable as HIV positive.

*'I do not want to fall sick and get bedridden ... and be a written book for anyone to read.'* P07

Though ART was described as enabling stigma reduction, some participants felt reluctant to visit health clinics for fear that doing so could reveal their HIV status. They feared confidentiality breaches by health practitioners or of being seen queuing for ART-related services, which could instil feelings of shame. These fears could be particularly influential for those who had not fully accepted their HIV status and who described them as deterring these individuals from accessing HIV care.

*'The minute you sit on the bench, you are engulfed with embarrassment and you feel ashamed, but then you must accept yourself and not worry yourself about whether you see your neighbour or anybody. We are all there to get the treatment.'* P14

Seemingly, socio-cultural norms and expectations relating to men could create difficulties for their accessing health services, which was mainly described by health practitioner participants who stated that males are less involved in all aspects of health services. Furthermore, men were perceived as not wanting to go to the clinic due to its association as being a woman's place, and the expectation that men should be strong and not seek health care.

*'Going to the clinic is something I wouldn't have done except when I'm being driven there in a wheel barrow.'* P06 (male)

*'They are afraid to use hospitals ... Mainly Swazi men ... They don't believe that much in hospitals. They prefer to do some- thing else.'* HP 04

Counsellor attitudes and the approach taken with linkage follow-up were important to patients. When patients felt as though the health practitioner valued their life and wanted them to seek care for their own well-being, it tapped into their sense of valuing and prioritising healthcare. On the contrary, more aggressive approaches when patients felt they were being followed up for the sole purpose of getting them to go to the clinic could undermine their motivation and could cause feelings of disappointment and distrust.

*'She really followed up on me, and called me and called me to ask me and said she loved me very much. She stopped once I went there, and I usually say, aw I thought she loved me but she stopped calling me. She stopped once I went there.'* P05

## Discussion

Our study findings suggest that HIV status acceptance is important for a person's engagement with HIV care and access to social support, quality counselling, knowledge, attitudes, and practices regarding health care. The process of status acceptance was influenced by an individual's awareness that there was a heightened probability they would receive an HIV-positive result. Although past studies describe linkage to care and HIV status denial, as far as we are aware, our study is the first to portray acceptance as a longitudinal process in which supporters can intervene to facilitate individuals' acceptance of an HIV-positive result.

While the exact way in which someone processes an HIV- positive result is heterogeneous and individually defined, certain factors could influence the transition towards acceptance. These include the perception of risk for potential HIV infection, including judgements about HIV; an association of self with images of HIV positivity; and counsellor support offering reassurance, encouragement, and hope for life after diagnosis. Although Swaziland has the highest reported HIV prevalence rate in the world with a generalised epidemic, an association of HIV with 'promiscuity' and 'prostitution' persists. Most participants did not identify themselves with these

behaviours and therefore did not perceive themselves to be at risk. This non-association with HIV risk led many to experience shock and disbelief on being diagnosed HIV positive and made accepting the diagnosis particularly challenging.

Other studies have found non-acceptance of HIV status, often termed as denial, to negatively affect individuals' access to HIV care, ART initiation and adherence (Beer et al., 2009b; Jenness et al., 2012; Lindkvist et al., 2015; Manirankunda et al., 2009; Nakigozi et al., 2013; Nam et al., 2008; Otieno et al., 2010; Stinson and Myer, 2012; Wringe et al., 2009). Reiterating our findings, doubt and disbelief on receiving a positive HIV result are associated with a lack of HIV-related symptoms (Beer et al., 2009b; Nakigozi et al., 2013; Raveis et al., 1998; Wringe et al., 2009), and time can be required to process, come to terms with, and accept an HIV-positive result (Gilbert and Walker, 2010; Raveis et al., 1998). In our study, many reported re-testing for HIV to verify if their result was true, and HIV testing incentives were seen to undermine status acceptance. Denial of HIV status has been linked to poor mental and physical health (Kamen et al., 2012; Moitra et al., 2011). Still, our findings are unexpected, given that shock and disbelief can prevail and prevent PLHIV from accessing HIV care in a setting where HIV knowledge and familiarity is high and where HIV is perceived to be increasingly 'normalised' through increased access to ART, transforming it to a chronic manageable condition (Bernays et al., 2015; Russell and Seeley, 2010).

How individuals respond to chronic diseases, including HIV, are varied and contextual (Bernays et al., 2015; Harris, 2009). Various theories can be applied in understanding individuals' reactions to health and illness, and an HIV diagnosis has been described as a transition (Russell and Seeley, 2010) and biographical reinforcement (Bernays et al., 2015; Carricaburu and Pierret, 1995; Williams, 2000) through reinforcing components of identity and lifetime illness experiences or struggles. Yet, because of commonly held views related to morality and behaviour, an HIV diagnosis in this context appeared to disrupt the 'socially set standards and cultural prescriptions of normality' (Bury, 1982), with a reaction of disbelief and anxiety thus being more common, in line with Bury's (1982) theory of biographical

disruption. The reactions to an HIV- positive result described in our study echo some of the stages of grief that Kübler-Ross described by following a patient's diagnosis with a terminal illness, which include shock, denial, anger, bargaining, depression, and acceptance (Kübler-Ross, 1969). As individuals progressed towards acceptance, elements of transition appeared, with active adaptation to incorporate illness and its treatment to daily life, developing approaches for self-management of HIV and feeling 'normal' again (Kralik et al., 2004, 2003; Russell and Seeley, 2010; Telford et al., 2006). We found that acceptance, disclosure of HIV status, and linkage to HIV care appeared connected. Disclosure enabled support and reassurance, which aided accessing care and cultivated hope (Gilbert and Walker, 2010; Nakigozi et al., 2013; Nam et al., 2008).

The perceived need for and value placed on health services increased individuals' motivation for seeking HIV care. This could be challenged in the absence of symptoms, where the need for health care was less evident, a factor that has been reported previously (Jenness et al., 2012; Nachega et al., 2014; Nakigozi et al., 2013; Rosen and Fox, 2011). However, some participants described learning about the benefits of early access to treatment and care through receiving HIV information linked to the Test and Start pilot and through seeing others with HIV experience health deterioration in the absence of treatment. The avoidance of a 'bedridden state', which could render an individual identifiable as HIV positive, had the potential to be a powerful motivator for accessing care. Yet, fear of health practitioner confidentiality breaches and experiencing stigma on being seen attending a health clinic for HIV-related care were reported, as found by others (Beer et al., 2009b; Nakigozi et al., 2013; Raveis et al., 1998; Tumwebaze et al., 2012; Wringe et al., 2009). In our study, this was particularly prevalent among those who had not fully accepted their HIV status and appeared to be more vulnerable to self-stigma.

### **Limitations**

During initial patient interviews, it was clear that the interviewer was being associated with the medical programme, which subsequently improved following adaptations to the study introduction, such as reiterating the non-association of the

researchers with medical teams. Interviews conducted with male patients recorded as not linked to care were shorter and less in-depth (including less participant open narrative) than those with females (average interview length: 30 min for males vs. 55 min for females, with the exception of one 72-min interview conducted by a female RA). Interviewer technique is likely to have influenced the narratives of these participants, although this could also reflect characteristics of the participant group.

Nearly half of the identified participants for study recruitment were non-contactable because of a missing or incorrect phone number captured during HTS. This reflects the operational challenges with linkage follow-up and may have affected the results, with these participants potentially having different experiences with testing and linkage to HIV care. In addition, two patients (one recorded as not linked and one linked) did not attend the agreed interview appointment, with unknown reasons for non-participation. However, it appears that the themes that emerged were robust and reiterated sufficiently to evidence data saturation. Furthermore, the general participation response rate was good. Although we had requested that focus group discussions be held with community members who were similar in age, two of the groups had a large age range. These differences may have influenced the group dynamics, as younger participants were quieter than older participants, which reflects the social interactions that can be found within wider Swazi society. The generalisability of the study's findings is limited to the concepts presented, which also may not apply in different contexts or settings.

## Conclusions

This research shows that how individuals process an HIV-positive result can fundamentally affect their engagement with health services. Status acceptance enabled access to social support and increased a sense of need for and value placed on HIV services, thus influencing individuals' linkage to HIV care. Although situated within a generalised high-prevalence epidemic setting, many participants in our study did not perceive themselves to be at risk of HIV and struggled to accept a positive result. Being asymptomatic could pose particular challenges for accepting an HIV diagnosis and could create less sense of urgency regarding the need for health

services. Still, there were also perceived benefits from accessing treatment and care early.

Our findings indicate the need to develop and test linkage support strategies that address individuals' needs and facilitate progression to HIV status acceptance. These could include supporting diagnosis preparedness (e.g., through pre-test information), exploring individuals' perceptions relating to HIV risk, and expectations for the chance of receiving an HIV-positive result. Counselling with clear goals is important within programmes to support status acceptance and disclosure. A flexible approach to patient follow-up should be considered, with varied intensity and types of support provided depending on the needs of each individual and with the opportunity for multiple sessions beyond the point of HIV testing if required. For example, certain individuals may require more time to process and come to terms with an HIV diagnosis before engaging in HIV care or initiating ART than others. HIV prevention programmes should consider our finding that HIV testing incentives undermined status acceptance as individuals may be less prepared for a potential positive result.

These findings are particularly important in light of the move towards the adoption of Test and Start approaches in many settings, including in Swaziland. Engaging with how people respond to an HIV test result is critical to the success of these initiatives, given how crucial the processes of HIV diagnosis and follow-up are for patients' access to HIV care. Without addressing specific patient support needs and improving linkage to HIV care, these approaches risk being ineffective in reducing HIV incidence and improving the quality of care to PLHIV.

### **Acknowledgements**

We thank all the patients and staff involved with the MSF/MoH project in Shiselweni who contributed to this study, with particular thanks to Dr. Bernhard Kerschberger, Dr. Inoussa Zabsonre and Thomas A. Obulutsa and to the heads of clinical activities and heads of community activities (MSF Swaziland). Thanks to Alison Wringe (LSHTM) for reviewing the drafts and providing technical input, and to Janet Seeley (LSHTM).

## Appendix A Supplementary data

**Table 4.2:** Patient participant information

<b>Interview Code</b>	<b>Gender</b>	<b>Age group (years)</b>	<b>Health zone</b>	<b>Linkage recorded in database</b>	<b>Linkage reported in interview</b>
P01	Male	25-34	Nhlangano	Linked	Linked
P02	Female	25-34	Hlatikhulu	Linked	Linked
P03	Female	55-69	Matsanjeni	Linked	Linked
P04	Male	16-24	Nhlangano	Linked	Linked
P05	Female	35-44	Nhlangano	Linked	Linked
P06	Male	45-54	Hlatikhulu	Linked	Linked
P07	Female	35-44	Hlatikhulu	Linked	Linked
P08	Male	35-44	Nhlangano	Linked	Linked
P09	Female	35-44	Matsanjeni	Linked	Linked
P10	Male	55-69	Matsanjeni	Linked	Linked
P11	Male	55-69	Matsanjeni	Linked	Linked
P12	Female	35-44	Matsanjeni	Linked	Linked
P13	Male	55-69	Hlatikhulu	Linked	Linked
P14	Female	16-24	Hlatikhulu	Linked	Linked
C01	Female	55-69	Hlatikhulu	Not linked	Not linked
C02	Female	55-69	Nhlangano	Not linked	Linked elsewhere (NATICC)
C03	Male	35-44	Nhlangano	Not linked	Linked outside of region
C04	Male	55-69	Hlatikhulu	Not linked	Linked to agreed clinic (on ART)
C05	Female	25-34	Nhlangano	Not linked	Linked to agreed clinic (on ART)
C06	Female	16-24	Hlatikhulu	Not linked	Not linked
C07	Male	16-24	Matsanjeni	Not linked	Not linked
C08	Female	16-24	Matsanjeni	Not linked	Linked outside of region
C09	Male	35-44	Matsanjeni	Not linked	Linked to agreed clinic
C10	Female	25-34	Nhlangano	Not linked	Linked as agreed and transferred out
C11	Male	25-34	Matsanjeni	Not linked	Not linked
C12	Male	25-34	Nhlangano	Not linked	Not linked
C13	Male	25-34	Nhlangano	Not linked	Linked elsewhere (NATICC)
C14	Female	25-34	Nhlangano	Not linked	Linked and on ART

P=patient. C="not linked" client. NATICC=Nhlangano AIDS Training Information and Counselling Centre

**Table 4.3:** Health practitioner participant information

<b>Participant code</b>	<b>Position</b>
HP 01	HTC (clinic-based)
HP 02	HTC (clinic-based)
HP 03	HTC (community-based)
HP 04	HTC (community-based)
HP 05	HTC (community-based)
HP 06	HTC (community-based)
HP 07	HTC (community-based)
HP 08	HTC (community-based)
HP 09	Nurse Supervisor (MoH)
HP 10	Expert Client (clinic-based)
HP 11	HTC (clinic-based)

HP=health practitioner. HTC=HIV testing counsellor.

## **Chapter 5: Whose choice? The dissonance of biomedical and lived perspectives on HIV treatment-taking in the Treat-all era**

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## RESEARCH PAPER COVER SHEET

Please note that a cover sheet must be completed for each research paper included within a thesis.

### SECTION A – Student Details

Student ID Number	LSH281543	Title	Miss
First Name(s)	Shona		
Surname/Family Name	Horter		
Thesis Title	Investigating experiences of engagement with HIV Treat-all among people living with HIV in Eswatini		
Primary Supervisor	Alison Wringe		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

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Where was the work published?			
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Where is the work intended to be published?	Medical Anthropology
Please list the paper's authors in the intended authorship order:	Horter, S; Seeley, J; Bernays, S; Kerschberger, B; Lukhele, N; Wringe, A.
Stage of publication	Submitted

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<p>For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)</p>	<p>I contributed to the study's conception. I designed the study, developed the study protocol and designed tools of data generation. I conducted data generation, along with fieldworkers. I analysed the data. I wrote the first draft of the paper, and incorporated feedback from co-authors. I submitted the paper and I am the corresponding author, responsible for incorporating peer reviewer edits.</p>
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**SECTION E**

<b>Student Signature</b>	<i>Shona Meze</i>
<b>Date</b>	<i>20/03/19</i>

<b>Supervisor Signature</b>	<i>R</i>
<b>Date</b>	<i>21/03/2019</i>

## Overview

In this chapter, I examine individuals' decision-making processes regarding ART initiation in the context of Treat-all and how sense of treatment choice and ownership over the management of treatment and health influence ongoing treatment-taking and engagement with care. This chapter builds upon the literature that I engaged with in Chapter 2, as well as building on the findings presented in Chapter 4.

In Chapter 2, I highlight the potential dissonance between the biomedical logic framing Treat-all, and the priorities of a public health agenda, with those of individuals living with HIV, who may have differing conceptions of their health and treatment needs. This chapter reflects on this potential dissonance, exploring how individuals experience the treatment offer in the context of Treat-all, and their decision-making processes regarding when to initiate ART. I draw upon theoretical contributions to decision-making presented in Chapter 2, and literature relating to adjusting to illness, identity work, and aspects of self-management, in particular considering how ownership of one's health needs and treatment may support ongoing engagement with care.

The findings in this chapter draw on data generated during the main research phase. I focus on the narratives of four individuals, each interviewed three times, to enable a deep, rich exploration of decision-making and engagement with care accounts. I reflect on data from interviews with health care workers and observations to consider how health care worker perspectives may converge and differ from those of individuals, and how potential dissonance between the health and individual perspectives and priorities may be reconciled.

This paper aligns with **research objectives 3 and 4**:

3. To explore treatment initiation decision-making
4. To examine how ongoing engagement in HIV care and treatment-taking is navigated over time

## Abstract

Treat-all recommends prompt treatment initiation for those diagnosed HIV positive, requiring adaptations to individuals' behaviour and practice. Situated within a longitudinal qualitative study in Eswatini, we examine the choice to initiate treatment when asymptomatic, dissonance between the biomedical logic surrounding Treat-all and individuals' conceptions of treatment necessity, and how ongoing engagement with care may be navigated over time. We reflect on the perspectives of healthcare workers, responsible for implementing Treat-all and holding a duty of care for their patients, demonstrating considerable care and empathy in wanting to support people to achieve good health outcomes. We explore how the potentially differing needs and priorities of individuals and the public health agenda are navigated and reconciled. Rationalities regarding treatment-taking extend beyond the biomedical realm, requiring adjustments to sense of self and identity, and decision-making that is situated and socially embedded. Sense of choice and ownership for this process is important for individuals' engagement with treatment and care.

Antiretroviral therapy (ART) offers individual and public health benefits, with dual roles for HIV treatment and transmission prevention (Cohen et al., 2011a; INSIGHT START Study Group, 2015; The TEMPRANO ANRS 12136 Study Group, 2015). Reflecting this duality, the Treat-all approach is now being implemented in many settings, aiming to improve health outcomes and reduce HIV incidence through the immediate offer of ART following HIV diagnosis (World Health Organisation, 2016).

Treat-all is both a biomedical and a social intervention, requiring modifications to behaviour and practice and the active engagement of people and communities, situated within social, cultural and political dimensions (Adam, 2011; Kippax and Stephenson, 2012). The biomedical logic framing Treat-all assumes that individuals will adjust their behaviour once they are informed about their condition, accordingly engaging with care and with taking daily medication (Beckmann, 2013). This logic reflects the broader “biomedical paradigm”, which we define as the constellation of beliefs, values, techniques and skills shared by members of the health and pharmaceutical community, whereby health is defined in terms of the absence of disease, and experiences and perceived symptoms are reduced to the biological (Ashcroft and Katwyk, 2016).

The biomedical paradigm can be seen as regarding a range of problems through a medical lens (the “biomedical gaze”; Foucault, 1963), requiring technical, biomedical solutions and management by biomedical professionals and scientists (Bell and Figert, 2015), with the pharmaceutical industry holding significant power and importance (Williams et al., 2011). The biomedical gaze stems from Foucault’s conceptualisation of the “medical gaze” separating a person’s identity from their body, thereby constructing patients as medical objects rather than people situated within a social context (Foucault, 1963). Such an approach may risk reducing disease to an abstract physical matter within the bounded realm of clinics, with rigid distinctions between individuals’ physicality and the broader social world, abstracting people from their social contexts and the other aspects to self and personhood, which extend beyond the biomedical sphere (Beckmann, 2013; Hickel, 2012).

Yet, individuals' decisions to engage with ART are situated beyond the biomedical realm (Beckmann, 2013). The prioritisation of ART and physical health above other areas of life, such as generating an income, securing food, providing for family, or maintaining social position, may not always be realistic, achievable or possible (Kielmann and Cataldo, 2010). For example, a study in South Africa and Zambia found some individuals delayed ART initiation following diagnosis due to contradictory priorities of needing to work taking precedence over clinic attendance (Seeley et al., 2018). Thus, seemingly "irrational" behaviours such as not taking treatment as prescribed, may be "ways in which people enact agency in the context of their day-to-day needs" (Paparini and Rhodes, 2016, p.506). Additionally, there can be dissonance between clinical guidelines and lay interpretations of what constitutes treatment necessity (Kawuma et al., 2018). It is thus an imperative that socio-behavioural contexts and dimensions be considered, understood and integrated within Treat-all approaches (Kippax and Stephenson, 2012).

WHO treatment guidelines, updated in 2016, state that healthcare workers should discuss patients' willingness and readiness to initiate ART, with the choice to accept or decline ART lying with the individual patient, who can also choose to defer (World Health Organisation, 2016). Patient autonomy is one of the four principles of healthcare ethics (in addition to beneficence, non-maleficence and justice), i.e. individuals should give informed consent (Gillon, 1994) and have the right to choose whether or not to accept medical treatment, even if this decision is not deemed to be medically in their best interests (Cave, 2017). While presenting important principles, there are competing interests to be reconciled in the practice of bioethics, with claims to universality not necessarily mapping onto the details of everyday life that shape the ethical landscape (Kingori, 2013). The relationship between the action being undertaken (i.e. the "choice" to initiate ART) and the agent (the healthcare worker and the person with HIV) are pivotal in the production of ethical practice and perspectives (Ricoeur, 1992). Within Treat-all, the premise of choice for treatment is presented as singular and linear, whereas choice involves multiple pathways that an individual may take. It is therefore important to understand people's lived

experiences, and how their priorities and concerns may extend beyond and potentially conflict with bioethical principles.

Through the biomedical gaze, health professionals seek rational, objective, measurable indices of health, illness and treatment success, which within Treat-all are namely rates of HIV diagnosis, treatment initiation, and viral suppression. The UNAIDS “90-90-90” targets are the diagnosis of 90% of people living with HIV, ensuring 90% ART initiation for those diagnosed and 90% viral suppression for those on ART (UNAIDS, 2014). However, the unilinear metrics of 90-90-90 do not reflect and account for individual variation in response to the policy and time for treatment readiness, and this divergence must be examined (Kawuma et al., 2018). Healthcare workers may perceive moral responsibility, for example to reduce the risk of HIV transmission to others in the community, or to protect an unborn child from HIV acquisition (Vernooij and Hardon, 2013). However, what will happen when patients’ choices conflict with public health goals, and how will the tension between these potentially differing priorities be managed?

In the context of Treat-all, it is important to consider how the individual right to choice is balanced against the public health good, and how the seemingly straightforward logic employed within healthcare ethics may translate to how Treat-all is implemented and experienced in reality. We aim in this article to critically engage with these questions, through examining the lived experiences of individuals seeking to make choices about when to initiate ART, and the perspectives and experiences of healthcare workers who operate at the heart of this interface.

### **Choice for treatment: extending beyond the biomedical gaze**

Decision-making is deeply embedded in, shapes and is shaped by interactions with others. Autonomy can thus be considered as relational (Keller, 1997), with a patient’s agency potentially “emerging in and through a web of intersubjectivity and relationality” (Rapley, 2008, p.436). For example, a study examining views towards provider-initiated HIV testing in Kenya and Uganda found it rarely the case that an individual made a choice to accept HIV testing in isolation of other influences. Decisions were socially embedded, and included consideration of the views of family

members, partners, religious leaders, friends and others (Hardon et al., 2011). In Eswatini (formerly Swaziland), meanings of treatment offering the potential to prevent HIV transmission, and conceptions of initiating ART early, before one becomes visibly ill, are “incorporated into existing socialities such as kinship relations, and should be seen in relation to specific local moral worlds” (Vernooij et al., 2016, p.11).

Decision-making can be considered as an ongoing event occurring over multiple encounters, and distributed over interactions with a number of different people, forms of information and technologies (Rapley, 2008). Recognising the distributed nature of decision-making may facilitate moving from an overly prescriptive (and simplified) view to a more plausible set of ideas, which capture its complexity (Rapley, 2008), and reflect that decision-making processes are fluid and not necessarily linear.

Following diagnosis with a chronic illness such as HIV, individuals may undertake what can be described as “identity work”, involving a process of coming to terms with their diagnosis and the changes this may instil to their sense of self and their health identity (Exley and Letherby, 2001; McGrath et al., 2014; Roth and Nelson, 1997). Polak describes the identity work involved in individuals’ decisions to take statins, and how resisting medication can be portrayed as a way of resisting an illness label (Polak, 2017). Identity work is also a part of managing a perceived “spoiled identity” (Goffman, 1963), as individuals may take steps to conceal information which can be discrediting, with ART offering the potential to facilitate this through preventing the development of HIV-related symptoms which may render one’s status visible (Horter et al., 2019a). Nguyen proposed the concept of “therapeutic citizenship” (Nguyen, 2005), considering changes in identity that arise through interactions with biomedical authorities, and as people with HIV appropriate ART as a set of rights and responsibilities (Nguyen, 2005). However, ART can serve as a daily reminder of ill health, and those who feel healthy and “normal” may want to protect that state of being, thereby resisting from treatment-taking (Persson et al., 2016). “Many individuals may simply choose not to forefront HIV as the central or defining issue in their lives” (Kielmann and Cataldo, 2010, p.25), and people can have logical

reasons for not taking ART (Pound et al., 2005). Thus seemingly “irrational” behaviours such as not taking treatment as prescribed, may be “ways in which people enact agency in the context of their day-to-day needs” (Paparini and Rhodes, 2016, p.506).

There can be several processes of self-management involved in living with a chronic illness, including adjusting to and accepting the “new normal”, making sense of illness, and adjusting expectations of life and self (Schulman-Green et al., 2012). Schulman-Green and colleagues present taking ownership of health needs as a key component of the self-management process, including learning about and managing body responses, and developing confidence and self-efficacy for managing the condition and its treatment (Schulman-Green et al., 2012).

We build upon the work of Rapley and Schulman-Green to examine how patients in Eswatini decide to initiate ART under Treat-all when considered asymptomatic, and how this may influence their ongoing treatment-taking and engagement with care. We engage with the juxtaposition of the biomedical gaze, which focuses on Treat-all success based on unilinear metrics such as 90-90-90, compared to the lived reality of people’s experiences and choices for engaging with care. Individuals’ choices include more than one potential pathway, albeit taking one that does not involve immediate ART involves resistance to the biomedically prescribed “necessary” pathway. We also situate these findings within extant relevant literature and theory, to interpret and understand patient perspectives on this topic in the context of existing knowledge, and to compare healthcare workers’ perspectives with those of patients.

### Study methods

This analysis draws on data from a longitudinal, qualitative study, conducted in the Kingdom of Eswatini from August 2015 to November 2017. The broader study included repeat interviews with individuals living with HIV enrolled in HIV treatment and care under Treat-all, one-off interviews with healthcare workers, and observations of clinic and community activities relating to Treat-all.

Eswatini is a small, landlocked country in southern Africa, bordering South Africa and Mozambique, with a population of 1.3 million (UNESCO, 2018). It is the last remaining absolute monarchy in Africa. The country grapples with a high HIV prevalence, generalised epidemic. An estimated 27% of adults (aged 15-49 years) are HIV positive, and the majority of transmission is through heterosexual sex (UNAIDS, 2016). The Shiselweni region is a largely rural area in southern Eswatini, where the [institution] and [institution] provide decentralised treatment and care for HIV and tuberculosis. In October 2014, a Treat-all implementation pilot began in Nhlhlangano health cluster of this region, aiming to contribute towards reduced HIV incidence and improved clinical outcomes for PLHIV. Treat-all was rolled out nationally in October 2016.

The broader qualitative study comprised of 106 interviews; including interviews with 29 people living with HIV, who were interviewed between two and four times from August 2016 to September 2017; and 20 interviews with healthcare workers employed in a range of positions relating to the implementation of Treat-all, conducted in March 2017. Thirteen days of formal observations were conducted of clinic and community-based activities relating to Treat-all (including health talks, HIV testing and counselling, pre-ART counselling and adherence counselling for those with unsuppressed viral load results), in August to September 2015, and in March 2016. Broader ethnographic insights were generated through fieldwork conducted by the lead author in Eswatini during the period February 2015 to November 2017. Interviews with healthcare workers and observations were conducted by the lead author, and interviews with people living with HIV were conducted by same-gender siSwati speaking research assistants, supervised by the lead author.

All people living with HIV included in the study were considered clinically asymptomatic and would have been otherwise ineligible for treatment at the time, had it not been for the Treat-all pilot (i.e. CD4 count  $\geq$  500 and WHO disease stage 1). They were all enrolled into HIV care under Treat-all, and were selected to include a gender distribution reflective of the proportion of women to men on treatment, range of ages and treatment-taking experiences (for example, those recorded lost from

treatment, and those on treatment for differing periods of time). Healthcare workers included those employed by [institution] and [institution], from each of the clinics involved in Treat-all implementation (eight primary healthcare and one secondary health facilities), with a range of positions (adherence counsellor, nurse/nurse supervisor, doctor).

For the purposes of this analysis, four people living with HIV were selected to allow a deeper exploration of decision-making and self-management processes relating to individuals' engagement with HIV treatment and care under Treat-all. Focusing on fewer individuals enables greater detail, richness, completeness, and variance, than other analytical approaches that draw upon interviews from a higher number of people (Flyvbjerg, 2013; Prior, 2016). Each of these individuals were interviewed three times over a period of 10 months. The first interview focused on exploring the individual's life story, including their upbringing, key life events, relationships and hopes and aspirations, aiming to build an understanding of the participant's social and lived context, and to develop rapport. Subsequent interviews explored experiences relating to health management, visiting the clinic, HIV testing and diagnosis, ART offer and initiation decision-making, and ongoing treatment-taking and engagement with care. Interviews were conducted in siSwati by same-gendered interviewers, mostly held at participants' homes. Following each interview, field notes were written to capture information including the interview arrangement, setting, and interviewer-interviewee dynamics. These also included a reflection on methods, emerging themes and a summary of the individual's account, thereby supporting the analytic process beginning from the point of data generation. Interviews were audio-recorded following written informed consent, and then translated and transcribed.

These four individuals were chosen for presentation in this paper as their narratives highlight a range of experiences and exemplify the type of experiences reflected in the data more broadly. We also situate their narratives within the broader health system context by drawing upon healthcare worker interview and observational data, examining how various perspectives may confer and differ. Healthcare workers

play a pivotal role in implementing Treat-all, and their narratives can provide insight to the potential tensions and dissonance between public health and individuals' goals. Interview data (transcripts and field notes) were analysed using narrative methods, exploring how language is used to communicate meaning, how individuals construct identities through story-telling, and how accounts can be used to recount, interpret and make sense of past experiences (Riessman, 2008). Additionally, how individuals' accounts of their diagnosis, treatment offer, treatment decisions and treatment-taking might change over time were examined, through analysing decision-making narratives within each interview and longitudinally across repeat interviews for each person.

The Eswatini Scientific and Ethics Committee, the [institution] and [institution] Ethics Review Boards granted ethical approval before study commencement. Pseudonyms are used to protect individuals' confidentiality.

## Findings

### **Zandile: adjusting to illness and ART decision-making**

Zandile is 26 years old and has two young children from two separate relationships. She had hoped both relationships would lead to marriage and had then discovered each partner to be having relationships with other women, who they then went on to marry. She is an educated, ambitious young woman who was training to be a teacher throughout our conversations with her, and hoped to be able to build a home and provide for her mother and her children. According to her clinical record, she was diagnosed with HIV in April 2015 and initiated ART the same day as her diagnosis. This diagnosis came as a shock to her.

How difficult processing an HIV diagnosis can be is apparent in Zandile's narrative. She described herself as being Christian, "well behaved" and never thinking she would have HIV. During the first interview in September 2016, she told us she felt she had 'fallen from Christian values' and appeared to carry a lot of self-blame and shame. She then appeared to come to terms with her diagnosis in the later interviews in January and May 2017. This reflects the challenging processing of emotions that

can occur following diagnosis with a chronic condition, described by Schulman-Green and colleagues, including dealing with the shock of diagnosis, self-blame, guilt and grief, followed by making sense of illness and accepting the “new normal” (2012).

When Zandile described her diagnosis in the first interview it was unprompted, as we had been talking to her about her life story. She said that she “messed up”, and she thinks she should have left her boyfriend before they slept together, but they slept together and she became pregnant. She first attended a clinic for her pregnancy, where she was tested for HIV and tested negative, and then she decided to change clinics as that particular clinic was expensive and she felt that it did not do thorough checks including for STIs, which she wanted. When she changed and went to the health centre her blood was tested, and in the second interview she told us that she was not informed of the results, but was just given a piece of paper, which she did not read. When she eventually saw another nurse and was told that she had been diagnosed with HIV she said: “I felt like the hair on my head is coming off... and as though I would get into a hole and the earth just curves in”. This visceral reaction shows this experience was a fracturing moment in which everything was going to change, a moment of biographical disruption (Bury, 1982; Charmaz, 1983).

She was then advised to go for counselling in a different room. When she got to the counselling room, she said several people were there relaxing and drinking tea, as though they were not expecting her and did not know the situation she was in, which she found difficult. She said:

I am just standing there, and they said I should ask and I didn't know what to ask... I went back there, and the nurse gave me the pills... I was scared... and she said, “if you start them you start for the rest of your life”, and then I got so nervous... really, I felt like I was dying and being buried at that time. They gave me huge containers of pills... and I was carrying a mini bag, it's too small to put everything inside, and people will be looking at me, you see that when you are taking treatment people are looking at you, really I was very low.

Zandile's description of how she felt captures the gravity and shock that accompanied the news of her receiving a positive test result. In the context of Treat-all it may be presumed that a positive HIV test result provides a final confirmation of an existing embodied sense of potential HIV positivity or risk. However, in the absence of symptoms this can be challenging (Kawuma et al., 2018; Persson, 2013), as appeared to be the case for Zandile. HIV does not appear to be a normalised life event, nor does being on ART appear to be considered a normalised state, certainly not immediately, as is evident in Zandile's account. This shows that while HIV testing and ART initiation may be becoming an increasingly routinised process within the healthcare system, at an individual level it can be cataclysmic. The recognition of such a reaction is subsumed within the momentum that is integral to Treat-all.

In the first interview she told us of her hopes that if she tested again at a different clinic maybe they would find a different result, as the testing machines are not the same. She hoped if she spoke to a pastor who she had heard on the Voice of the Church had healed people who are positive, that they could heal her, "I am trying for this thing to move from my body, I do not want it". She also asked us about how far the research was progressing with the possibility for curing HIV, and said she was too scared to ask about this at the facility. She told us that she took the treatment from the facility and hid it in a bush near her home for around 3 weeks, appearing to engage with care to healthcare workers at the clinic, but not swallowing the pills.

Zandile's narrative highlights how difficult processing an HIV diagnosis can be, and there may be identity work involved in coming to terms with and absorbing an identity related to a chronic disease. This identity work may involve adjusting to the shock of an HIV diagnosis and the threat of illness, as well as reconciling oneself to the options available for ensuring good health and keeping the illness at bay. Taking prescribed treatment can be a concretisation and reinforcement of illness rather than health, with loss of control and autonomy rather than empowerment, and with shame and difference, not normalisation (Pound et al., 2005). This is alluded to in Zandile's account, when in her third interview she reflected on her initial decision not to take treatment:

When you go to the hospital and they give you Panadol [pain killer], you do not have to take it again once the headache is gone... but these [ART] that you have to take for the rest of your life, pills every day... and they are this big... no, no, no, I felt like it meant I was really sick.

By the third interview she talked about how she was adjusting to her “new” self and accepting the “new normal” (Schulman-Green et al., 2012), for example she said “I decided to make HIV my friend” and spoke of not letting it have too much influence over her sense of self and her life:

I do not take note of it, I do not give myself time to think that I am positive. When I get angry I do not then have pity and think “oh because I am positive”... I just don’t think about it and dwell on it, it is just something I have put on its own shelf.

This reveals the continuum of identity work that is required in initiating and committing to sustained treatment-taking. Zandile’s perception of treatment appeared to shift over time, from ART initially symbolising illness and therefore being potentially frightening, to later signifying a means to contain the illness and deflate the significance of HIV in her life and identity. Over time HIV may therefore come to be considered contained, rather than signified through ART (Pound et al., 2005). This process of transformation took time and work, and will likely require ongoing work to maintain, rather than representing a fixed state.

Decision-making can be considered as a process occurring over multiple encounters with healthcare workers, and with a range of other people and technologies, as outlined by Rapley (2008). When Zandile narrated her experience of being diagnosed with HIV and offered ART, her account highlighted multiple encounters with healthcare workers even within her first clinic visit. The information she received from providers at the clinic formed part of the knowledge that she was processing towards her decision to initiate ART. She described reflecting on what the healthcare worker had told her, that she would give birth to a positive child if she did not take treatment, which she did not want and which influenced her decision to eventually start treatment, although *‘it was not easy’*.

Before starting treatment, Zandile underwent a process of thinking and seeking information through consulting people and technologies. First, she told us that she spoke to her boyfriend, who assumed that she had discovered her HIV positive status before she had told him of the outcome of the clinic visit herself, which led to her suspecting that he had already known his status and infected her with HIV. She said her boyfriend was not on treatment, and he advised her to re-test elsewhere as her test result may have been inaccurate or untrue. She said that what he told her made her think they were lying at the clinic, hoping he might be right, and that she might be negative, so she said she stayed without taking treatment and continued to think about it.

She described seeking information on the internet, listening carefully to programmes about HIV on the radio and reading about relevant articles in the news. These sources of knowledge all seemed to reinforce the same perspective, that there is no cure for HIV and that treatment is the means through which to prolong health and life.

She then contacted a pastor, seeking advice and hoping he would be able to heal her. When this pastor advised her to follow the advice at the clinic and take the treatment, that is when she said she decided to start the treatment. This highlights how the support of faith networks can provide a confirmatory catalyst for taking up treatment. However, there may be variation in effect of the influence of faith, which in other examples has been described as potentially contradicting engagement with biomedical services (Roura et al., 2010; Wringe et al., 2009).

The words “my whole life” scared me, because I thought now I have to take pills for the rest of my life, when I do not like pills and they scared me too when I looked at them, ha they are so big! So I stayed for some days, or was it weeks... I had just put them there and did not take them. I would listen to “HIV kills”, and I did not have any peace. I called this pastor... because he did not know me... I told him that at the hospital they told me this... and the pastor said “do everything they say at the hospital, we will pray for you”. I said, “so should I take the treatment?”, and he said “take them”. And that is when I started taking the treatment, I started that way.

Zandile's story emphasises treatment decision-making processes as non-linear. If an individual feels forced or shamed into initiating ART, and if genuine patient engagement and consensus is not achieved, there may be greater risk of an individual reversing their decision to initiate treatment, or not digesting ART despite receiving a prescription.

### **Sifiso: taking time to reconcile a sense of self with HIV**

The identity work involved in processing an HIV diagnosis and deciding whether or when to take ART can also be seen in the story of Sifiso. Sifiso is a 29-year-old man who was studying at tertiary level in Mbabane, the capital city, when we met with him. He was recorded by the HIV clinic as being newly diagnosed in February 2015, with a CD4 count of 812, and as initiating ART two months later. However, during interviews with us in September 2016, December 2016 and June 2017, he narrated his HIV diagnosis as having occurred several years earlier. He told us that he initially doubted whether he was really HIV positive and re-tested for HIV as though he was testing for the first time, wanting to confirm whether his HIV diagnosis was accurate or true. He described eventually starting to experience signs, which he later interpreted as indicative of HIV, including weight loss, lethargy (waking up tired), chest pains and coughing. He spoke of this triggering his decision to start treatment, as he did not want his health to deteriorate further. The importance of embodied, experiential evidence of treatment need for initiation decisions is reinforced by findings from other studies with people living with HIV (Kawuma et al., 2018; Zhou, 2016).

The resolution of identity that can be undertaken through engaging with treatment, and that can work to reconcile a spoiled identity is described by Camlin and colleagues in Kenya and Uganda (Camlin et al., 2017). Sifiso's story extends the concept of therapeutic citizenship, showing how this may unravel and be threatened by refusing or delaying ART initiation. This illuminates contrary currents wherein Treat-all is based primarily on a notion of patient compliance rather than patient choice, and there is a thorniness with how healthcare ethics may translate in practice. In this context, taking an alternative route, such as wanting more time before

initiating ART, is characterised as resistance, and could potentially contribute to an additional spoiled identity (Goffman, 1963) through subverting the expected order.

In the second interview, Sifiso said: “I was having doubts that, do I really have it? But then again, I looked at my system that some days I would wake up tired and yet I didn’t do anything, and then I felt it’s time to take the treatment”. In the third interview he went on to say: “When you’re still strong there’s nothing that encourages you to start the treatment... it’s just that you feel you’re still fit... I was still feeling fit and that I can still continue living... but as time goes on you realise that the immune system gets weak and so it needs something to boost it”.

Sifiso’s account of his treatment-taking decisions highlights the importance of embodied, experiential evidence indicating the need and time for treatment. This echoes Conrad’s theorisation of embodied self-regulation, which emerged from his work with epilepsy patients whereby individuals would interpret their physical symptoms and alter the course of their treatment in order to test its efficacy, seeking evidence that the treatment was necessary and effective for motivating their engagement with it (Conrad, 1985). We also describe the importance of individuals having evidence of treatment need and effect for motivating treatment-taking in the broader study context (Horter et al., 2019b). This demonstrates that the act of interpretation based on physical symptoms requires the passing of time for evidence to become manifest and for responsive actions to be taken, which therefore cannot be instantaneous for those who are asymptomatic.

### **Celiwe: the journey to treatment readiness beginning prior to the clinic encounter**

For others, the decision-making process and identity work may have begun before the initial ‘clinic encounter’ at the point of HIV diagnosis, when each individual diagnosed with HIV is then referred for ART. Celiwe is a 19-year-old woman who is married with 2 children. She completed primary school education and works at a textile factory. She was recorded as diagnosed in January 2015, and as initiating ART less than a week later. She described her health seeking as initially being prompted by embodied experiences that something was not right, as she had repeated stomach

ache, diarrhoea, felt weak and had lost weight. This health-seeking process was influenced by different people, in particular her mother who told her she should go to the hospital, and then by the healthcare worker who told her to get tested, and then diagnosed her with HIV.

Although there may be a common epidemiological trend lending towards the anticipation of HIV acquisition, in the context of Treat-all in South Africa for example, acceptance of HIV-testing remains constrained by poor self-assessment of HIV risk (Orne-Gliemann et al., 2016). However, Celiwe describes reflecting back on her lifestyle in conceiving her own HIV risk, which supported her coming to terms with her diagnosis and engaging with treatment. Prior to the initial clinic encounter where she was diagnosed with HIV, she described her processing of past experiences, in light of her current physical symptoms, which led to her thinking she might be HIV positive and feeling prepared for the chance of a diagnosis and the potential need for treatment before she tested for HIV. In the second interview in November 2016 she said:

When you are doing bad things, you don't think of the risk, like when I was in [city] living that life I never thought of it. But when I was sick with stomach ache, it then came back to me that in [city] I was living that life and not even protecting myself, and that is when it dawned on me that it could happen that I too am like this. That is what made it easy for me to test and further accept the treatment.

This decision was also influenced by other sources of knowledge, including observed experiences from her family life, as she had seen someone in her family who she knew had HIV living a "normal" life with treatment. She described the decision to initiate treatment as being her "choice", saying that healthcare workers gave her the space to make her own decision and told her that it was up to her if she wants to start them or not, as her CD4 count is high whereas if it were lower she would be "forced to start them". While she appeared to embrace treatment, she said she quickly accepted her diagnosis and felt ready for treatment; this engagement with treatment appeared to be more about resisting health deterioration and death than a positive "choice":

I am scared that I will become too sick maybe... I think it is better than for me to end up dying and my children are left alone. So it is better for me to take them... I had heard that if you are positive and do not take the treatment you could die... I looked at having a child and if I do not start them and I fall sick and die, who will take care of my child

### **Nobuhle: navigating and resisting engagement with treatment and care**

Evidence suggests that where the decision to initiate ART is not intrinsically based, and where individuals may feel coerced to test and take treatment, this can influence their disengagement from care, particularly found in the context of Option B+ for the prevention of vertical HIV transmission (An et al., 2015; Wringe et al., 2017). This is reflected in the story of Nobuhle, who was diagnosed with HIV during pregnancy. She described testing as “not up to you”, but as a necessity during pregnancy in order to access other pregnancy-related health services. She appeared not ready to test for HIV, and had not been able to adjust to her HIV diagnosis and undergo the identity work described by others. She did not believe her diagnosis, having a high CD4 count and no physical “signs of HIV”, and she felt she was too young to have HIV. In her second interview she described her experience being diagnosed with HIV and offered treatment:

It is the name [HIV], because the CD4 is high and it is just the positive word that is pointing, there are no other signs... I will take them [ART] when I can see that it is now really there... They [HCW] did not ask me, they told me that I will start them [ART] because I am pregnant... They told me that when you are pregnant... whether you like it or not you take the treatment because they say when a baby is found to be positive, you will be arrested

In her first and second interview she told us that she was not taking the treatment, and had stopped taking it after her pregnancy, “because I was doing it for the child, not that I was ready to start taking treatment until I die”. As well as not believing her HIV diagnosis and need for treatment in the absence of any signs of ill health, she also had concerns about taking treatment herself without having disclosed to her boyfriend, fearing the anticipated negative consequences of him potentially

discovering her status through her treatment-taking. However, by the third interview she said she had re-engaged with treatment, re-testing and starting afresh at a different clinic, as she feared the healthcare workers would assume she would stop again if she told them her treatment history and that she already knew her status. She said that she now felt ready for treatment, and did not want to become sick and bedridden, when she felt she may not be able to fully recover. She also described embodied changes including weight loss and feeling as though she was not recovering physically, as influencing her decision to re-engage with treatment:

Instead of recovering, I kept on losing more weight. Only to find that even the CD4 count was less, from what it was, they had dropped drastically... I feel like I am ready now

### **Dissonance between policy and patient priorities: healthcare worker perspectives**

We have seen the complex process that individuals can go through in coming to terms with an HIV diagnosis and deciding when to start ART. However, this is not necessarily reflected or accounted for through the biomedical gaze which measures success of Treat-all implementation based on unilinear metrics, whereby almost all of those diagnosed HIV positive should initiate treatment within a short timeframe.

Healthcare workers' accounts highlight the ways in which providers straddle, and try to reconcile, the differing demands and priorities of patients and public health policy. Healthcare workers unanimously describe a strong desire to support patients to achieve good health outcomes and a positive life with and beyond HIV, demonstrating empathy and flexibility in caring for patients. Their accounts are interwoven with descriptions of their perceived pressure and responsibility to meet targets and to ensure patient "compliance" in successfully implementing Treat-all. Health care workers also recognise that some patients cannot be "convinced", and that they cannot force patients to engage, or to take treatment once they are home.

The regional and national monitoring events at which each clinic's achievements are displayed and judged were described, where questions are asked as to why staff have

not initiated all those who had been diagnosed HIV positive. Healthcare workers described feeling that they must demonstrate their competency in testing and initiating patients, and several appeared to blame themselves and their abilities if they were not able to “convince” patients to “comply”. This echoes Vernooij and colleagues’ finding that healthcare workers felt they would be judged as having failed if a woman refused an HIV test during antenatal care (Vernooij and Hardon, 2013). One clinic nurse told us:

We know that counselling takes time and convincing someone takes a lot of effort. If only the program would allow and not judge us like we have failed. They just make sure that they are following us, just to see what are we doing about it.

Healthcare worker accounts highlighted how this pressure could translate to the messaging they disseminated to patients and their approach in trying to achieve good results, which appeared to be particularly acute for pregnant women, as healthcare workers felt additionally responsible for the health of the child. A nurse at a different clinic explained:

Maybe we are coercing them much... because they are already forced to come to the facility for antenatal care, so when they come for antenatal care, every time they come you have to force them, "you have to start the ART". So they felt no, the best thing is to take the tablets and put them at home so that you will think I'm taking them while I'm not, because they felt they were forced.

This highlights the complexity of healthcare ethics in reality, and how the individual’s right to choice is navigated and balanced with healthcare workers’ trying to encourage and ensure what is “best” for the greater good. The sense of greater good, and the perceived responsibility for upholding and protecting it, may have differing parameters and scales, with healthcare workers potentially feeling responsible for their patients, their community, or the broader community. The wider the scope, the more emphasis can be placed on treatment as prevention, whereas aligning the parameters with an individual patient can heighten the tension in encouraging someone to start treatment even when they are known to not be ready.

This suggests a moral dimension to treatment as prevention, whereby people living with HIV are considered at blame for potentially spreading the virus, and responsible for containing it (Bond et al., 2016), and where delayed ART initiation and sub-optimal adherence may also become morally framed (Keogh and Dodds, 2015).

While patients may subscribe to the hierarchy that exists within practitioner-patient relationships, and follow healthcare worker advice, individuals are also self-determining agents who challenge and resist the structures of power and domination, with the potential to resist or rebel from following medical advice as prescribed (Foucault, 1963). Foucault highlights the ways in which care can provide an opportunity for control, as the receipt of care may involve submission (Foucault, 1979), illustrating an “inherent dialectic between care and coercion within systems of discipline”, and how those involved in “webs of discipline are also involved in appropriating, re-inventing and resisting techniques of power” (Vale et al., 2017, p.1288). If healthcare workers use their authority to control patients, they may thereby contribute to fashioning a form of patient identity which reinforces this hierarchy (Russell et al., 2015). The clinic may offer a space within which healthcare workers can exert their authority and encourage patients to comply, but once patients leave the bounded realm of the clinic their sustained engagement relies on an individual’s agency and commitment to ART.

Biomedical responsibility assumes that individuals will adjust their actions once they are educated, with their rationality being scientifically or biomedically based (Beckmann, 2013). Patients are co-opted into a set of rigid conditions that determine treatment access and align their behaviour with what is deemed ‘appropriate’ and ‘healthy’ (Mattes, 2011), with their inclusion therefore resting on a performance of the deserving citizen-consumer (Vale et al., 2017). Healthcare worker accounts emphasised the importance of patient responsibility, in that patients’ must be responsible for their lives, for their health and treatment-taking. This was also reflected in the approach observed in counselling sessions. Blood tests to monitor patients’ treatment success appeared to also be appropriated as means of ensuring patient “compliance” with treatment-taking, representing a surveillance technology

and mechanism for control, encouraging patients' self-regulation of their treatment-taking to avoid detection (Foucault, 1979). We observed this within adherence counselling sessions, for example when one patient who was presumed to be non-adherent was told that the tests they were going to run (viral load monitoring) would reveal the truth about their treatment-taking.

Healthcare workers talked about how important it was to them to support patients towards achieving the best outcomes possible, and ultimately to live a long healthy life. Many spoke of the emotional toll from working with large numbers of patients, and the difficulties they faced with trying to encourage patients to successfully engage with treatment and care. Several highlighted the importance of patients feeling they had choice and ownership over their health and treatment-taking and asked for more support and understanding from programmes in their performing their work. As one nurse said:

You cannot just give that patient treatment, they would not adhere, it's not their treatment. They need to be on the team, and actually say yes. Because if you push the treatment on them, it becomes your treatment. So, it has to be theirs, they should own it... the whole programme, they should own it, so that they keep their appointments, they take their tablets even.

### **Taking ownership of health needs: How sustained treatment-taking is navigated over time**

Taking ownership of health needs involves learning about one's condition, managing and taking medicines, and becoming an expert (Schulman-Green et al., 2012). Additionally, patients' perceptions of their own capacity for disease management and their beliefs about how much control they have over their health outcomes influence treatment-taking (Nafradi et al., 2017). This highlights the importance of individuals being involved in their treatment and care, taking control, and being "on the team".

Zandile spoke of the treatment-taking routine she established, and adjusting her life, so she is now used to going to the clinic regularly. She appeared to feel a sense of

responsibility for her treatment-taking and for managing her health, drawing upon various approaches to continue to persevere and motivate herself to take it. She spoke with a sense of pride of how she would continue, and “stand up properly and take them”. Sifiso said he felt his life was dependent upon treatment-taking, and it was of utmost importance to “be faithful to them at all times”. He described ensuring he checked the time for taking his treatment, telling himself to take it and focusing on the dreams he wants to fulfil in the future that he feels treatment can help him achieve.

According to Celiwe, this was not always easy. She spoke of “begging” herself to take treatment, using her faith to find strength to persevere and reminding herself of her reasons for taking it (including to avoid death), for example she told us “I just tell myself that by missing a dose I am killing myself”. She said she had many difficulties taking treatment while pregnant, with morning sickness and vomiting, leading to her stopping work so she could have more time to eat and then take the treatment, thereby prioritising treatment-taking over other areas of her life and highlighting the sacrifices being on treatment can require (Beckmann, 2013). She felt able to make this choice because she was supported by her husband and mother, whereas for others this may not be the case.

These findings provide insights into the complex process that individuals can go through in coming to terms with an HIV diagnosis, feeling ready for, and deciding to initiate ART. This process is both temporally and individually varied, and an individual’s priorities may differ from the priorities of the public health and biomedical agenda framing Treat-all care. Healthcare workers describe the ways in which they are confronted with, and try to reconcile these two agendas, recognising the importance, and also the underlying challenges, of achieving targets for testing and initiations, and that some patients cannot be “convinced” to “comply”. Several individuals described the importance of having a sense of choice regarding their treatment initiation, which could potentially influence their ownership over the management of their condition, in turn potentially supporting their motivation for sustained treatment-taking.

## Conclusion

It is important to understand the complexity of the ART initiation decision-making process, which for some may involve multiple encounters, with multiple people and multiple sources of information. Additionally, the identity work and process of adapting to the “new normal” following an HIV diagnosis may take time, and can require embodied, experiential understandings of the need for treatment, additional to the sources of knowledge that may be experienced and received. Some individuals engage with HIV testing services having already begun or undergone these processes and feeling ready for the chance of an HIV diagnosis and lifelong treatment, whereas others need more time, and tailored information to support this journey. Once individuals feel they have come to terms with their diagnosis and have chosen to engage with treatment and care for themselves, the process of ownership of health needs can support and foster determination and self-responsibility to navigate and overcome challenges with treatment-taking, thereby supporting engagement with care over time.

Healthcare workers’ perspectives and experiences should also be considered, in particular in terms of the pressure they may experience to achieve successful Treatment implementation and meet targets for patient “compliance”. Having more understanding of the challenges patients can face coming to terms with an HIV diagnosis, starting and continuing on ART, and the challenges healthcare workers can face in supporting patients on this journey, will hopefully enable an environment conducive towards supportive practitioner-patient relationships and service delivery which is tailored to individual patient needs, as opposed to one which is coercive. Allowing healthcare workers to engage with the logic of different individuals, which for some will involve giving an individual time to consider the benefits of treatment according to their own rationale, could be important for their sustained engagement. Our findings suggest that where patients feel coerced to undertake testing or treatment this may undermine their engagement with care, while conversely choice and ownership may support sustained engagement.

## **Chapter 6: “Is it making any difference?” A qualitative study examining the treatment-taking experiences of asymptomatic people living with HIV in the context of Treat-all in Eswatini**

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## RESEARCH PAPER COVER SHEET

Please note that a cover sheet must be completed for each research paper included within a thesis.

### SECTION A – Student Details

Student ID Number	LSH281543	Title	Miss
First Name(s)	Shona		
Surname/Family Name	Horter		
Thesis Title	Investigating experiences of engagement with HIV Treat-all among people living with HIV in Eswatini		
Primary Supervisor	Alison Wringe		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

### SECTION B – Paper already published

Where was the work published?	JIAS		
When was the work published?	January 2019		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	Yes	Was the work subject to academic peer review?	Yes

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<p>For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)</p>	<p>I contributed to the study's conception. I designed the study, developed the study protocol and designed tools of data generation. I conducted data generation, along with fieldworkers. I analysed the data. I wrote the first draft of the paper, and incorporated feedback from co-authors. I submitted the paper, liaised with journal editors, and made edits following peer review comments.</p>
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**SECTION E**

<b>Student Signature</b>	<i>Jhona Porter</i>
<b>Date</b>	<i>20/03/19</i>

<b>Supervisor Signature</b>	<i>[Signature]</i>
<b>Date</b>	<i>21/03/2019</i>

## Overview

The literature that I presented in Chapter 2, and the findings presented in Chapters 4 and 5 suggest the importance of individuals having evidence of treatment need for motivating their engagement with treatment. Conceptions of health and treatment need that are experiential and embodied may be particularly important in framing individuals sense of treatment necessity, which can be challenging for those without signs or symptoms indicating ill health. Additionally, the literature I engage with in Chapter 2 suggests that such experiential conceptions may also relate to ongoing treatment-taking, with evidence of treatment effect potentially important for motivating continued engagement with it. In the past, illness histories could be drawn upon to motivate ongoing treatment-taking, highlighting the difference treatment made for individuals' health. Under Treat-all, when individuals increasingly initiate treatment when asymptomatic, this difference may be less apparent, and it is important to consider how ongoing engagement will be motivated and navigated in this context.

This paper explores how treatment need is understood in the context of Treat-all, and how ongoing engagement in care is navigated. Findings draw upon a sub-sample from the main phase of research, of 17 people living with HIV who had been on ART for a mean of 20 months, and 20 health care workers. The findings presented in this chapter highlight the importance of individuals' perceiving need for treatment and having evidence of the difference it is making to their health, for motivating sustained treatment-taking.

This paper aligns with **research objectives 2 and 4:**

2. To examine how treatment is perceived and experienced by those who are asymptomatic
4. To examine how ongoing engagement in HIV care and treatment-taking is navigated over time

## Abstract

**Introduction:** Treat-all is being implemented in several African settings, in accordance with 2015 World Health Organisation guidelines. The factors known to undermine adherence to antiretroviral therapy (ART) may change in the context of Treat-all, where people living with HIV (PLHIV) increasingly initiate ART at earlier, asymptomatic stages of disease, soon after diagnosis. This paper aimed to examine asymptomatic PLHIV's experiences engaging with early ART initiation under the Treat-all policy, including how they navigate treatment-taking over the longer term.

**Methods:** A longitudinal qualitative study was conducted within a Médecins Sans Frontières/Ministry of Health Treat-all pilot in Shiselweni, southern Eswatini. The Treat-all pilot began in October 2014, adopted into national policy in October 2016. Participants were recruited purposively to include newly diagnosed, clinically asymptomatic PLHIV with a range of treatment-taking experiences, and health care workers with various roles. This analysis drew upon a sub-sample of 17 PLHIV who had been on ART for at least 12 months, with mean 20 months on ART at first interview, and who undertook three interviews each. Additionally, 20 HCWs were interviewed once. Interviews were conducted from August 2016 to September 2017. Data were analysed thematically using coding, drawing upon principles of grounded theory, and aided by Nvivo 11.

**Results:** It was important for PLHIV to perceive the need for treatment, and to have evidence of its effectiveness to motivate their treatment-taking, thereby supporting engagement with care. For some, coming to terms with an HIV diagnosis or re-interpreting past illnesses as signs of HIV could point to the need for ART to prevent health deterioration and prolong life. However, others doubted the accuracy of an HIV diagnosis and the need for treatment in the absence of symptoms or signs of ill health, with some experimenting with treatment-taking as a means of seeking evidence of their need for treatment and its effect. Viral load monitoring appeared important in offering a view of the effect of treatment on the level of the virus, thereby motivating continued treatment-taking.

**Conclusions:** These findings highlight the importance of PLHIV perceiving need for treatment and having evidence of the difference that ART is making to them for motivating treatment-taking. Patient support should be adapted to address these concerns, and viral load monitoring made routinely available within Treat-all care, with communication of suppressed results emphasised to patients.

## Introduction

Treat-all is being implemented in several African settings, accordant with 2015 World Health Organisation (WHO) guidelines recommending regular HIV testing and immediate offer of antiretroviral therapy (ART) for all those diagnosed HIV-positive, irrespective of immunological status (World Health Organisation, 2015). To contribute towards reduced HIV incidence and the hoped-for elimination of AIDS, Treat-all requires engagement of individual people living with HIV (PLHIV) with HIV testing, prompt initiation of ART and continued lifelong treatment (Baggaley et al., 2015; Gardner et al., 2011; Granich et al., 2013; Nachega et al., 2014). However, shortfalls exist across the treatment and care cascade (C. C. Iwuji et al., 2016; Iwuji et al., 2018; Plazy et al., 2016).

There is extensive research examining adherence to ART in African settings under previous treatment guidelines, highlighting the individual, social and structural factors influencing engagement with treatment and care among PLHIV (Heestermans et al., 2016; Tucker et al., 2017; Vervoort et al., 2007). Motivation for adherence may be stronger when patients are very sick at ART initiation, as the effects of ART in enabling a return to health and strength can create a sense of need for treatment and belief in its efficacy, and past illness experiences are drawn upon to motivate continued treatment-taking (Bernays et al., 2015; Nam et al., 2008). Many of these factors change in the Treat-all context, where PLHIV are initiating ART at earlier, asymptomatic stages of disease, where the time between diagnosis and ART initiation may be expedited, and the length of time on ART may eventually be greater than previously.

Evidence from Prevention of Mother to Child Option-B+ (Option-B+) suggests retention in care among women on Option-B+ is lower than among women starting ART for their own health (Clouse et al., 2014; Knettel et al., 2018; Tenthani et al., 2014). HIV status acceptance, treatment readiness and perceived need for treatment in the absence of symptoms can undermine pregnant and lactating women's retention, with some disengaging from care once their perceived objective of protecting the baby is fulfilled (Cataldo et al., 2017; Katirayi et al., 2016; McLean et al., 2017). While these

findings provide important insights into understanding how asymptomatic PLHIV may respond to ART, the experiences of pregnant and lactating women are likely to differ from those of the general population.

It is important to understand PLHIV's experiences with Treat-all care to ensure programmes correspond to their needs, and can adequately and appropriately support them to engage with treatment and care to improve health outcomes (INSIGHT START Study Group, 2015; Song et al., 2018; The TEMPRANO ANRS 12136 Study Group, 2015). Additionally, from a public health perspective, suboptimal adherence among growing cohorts of asymptomatic patients could lead to drug resistance, which has been highlighted as a critical threat to eliminating AIDS by 2030 (Jena, 2013; Wagner and Blower, 2012; World Health Organisation, 2017b, 2017a). This heightens the importance of understanding how treatment-taking is experienced by asymptomatic PLHIV enrolled in Treat-all care.

We examine asymptomatic PLHIV's experiences engaging with Treat-all care in the Kingdom of Eswatini (formerly named Swaziland), including how treatment-taking is navigated and motivated over the longer term (at least 12 months after initiation).

## Methods

### **Study design**

This paper draws on data that were collected between August 2016 and September 2017, within a longitudinal qualitative study on the experiences of asymptomatic PLHIV enrolled in chronic HIV care under the Treat-all policy in Eswatini.

### **Study setting**

This study took place in the Shiselweni region of Eswatini, where Médecins Sans Frontières (MSF) and the Ministry of Health (MoH) collaboratively provide decentralized HIV and tuberculosis care since 2007, with a Treat-all implementation pilot beginning in October 2014. Eswatini has the highest reported HIV prevalence worldwide, estimated at 35% among women and 19% among men aged 15 to 49 years (UNAIDS, 2016), with heterosexual sex being the main transmission route (Swaziland

Ministry of Health, 2012). Men are generally infected at older age than women, and HIV prevalence peaks at 54% among women aged 35 to 39 years and 49% among men aged 45 to 49 years (Swaziland Ministry of Health, 2017).

The Treat-all pilot project was implemented in the predominantly rural Nhlanguano health zone, with eight primary healthcare clinics (largely rural, offering integrated HIV services) and one secondary health facility (urban, offering HIV care within a specific HIV-related care department or as part of antenatal care). Patient enrolment to the pilot ended on 31 March 2016, with Treat-all then becoming the standard of care in Nhlanguano, and adopted into national policy in October 2016. Within the pilot project, prompt ART initiation was offered on the day of facility-based HIV care registration. Forty-nine per cent of patients initiated on the same day as enrolment to HIV care, and the majority of those who deferred initiated ART at a median of 10 days (Kerschberger et al., 2018). Routine viral load monitoring was available at six months on ART and annually thereafter if results showed viral suppression. Communication of viral load results was prioritized for those with unsuppressed results, who were offered enhanced adherence counselling.

### **Participant recruitment**

PLHIV participants were identified and recruited purposively to include only those recorded as newly diagnosed (within three months of enrolment to care) and considered clinically asymptomatic (WHO disease stage 1 and CD4 count  $\geq 500$  cells/mm<sup>3</sup>), using the Treat-all patient database as a sampling frame. For the purposes of this analysis, we drew upon a subset of the study sample to include those who were enrolled at the beginning of the Treat-all pilot, from October 2014 to June 2015, and who therefore would have been enrolled in at least 12 months at the time of first interview (see Table 1). This allowed examination of longer term, sustained engagement with treatment and care in the context of Treat-all. We anticipated that recruiting young men (aged 16 to 25) would be challenging, as very few young men are infected with HIV in Eswatini, and as men often access treatment and care later in this setting.

Healthcare worker (HCW) participants were sampled purposively, to include those from all the nine clinics involved in the pilot, both MoH and MSF staff members, and a range of different treatment and care-related positions, such as adherence counsellor (HIV-positive peer supporters), nurse, nurse supervisor and doctor (Table 2).

Participants were recruited until data saturation was evidenced, that is, when adding further participants did not generate new findings relating to the particular topic or theme being investigated (O'Reilly and Parker, 2013).

### **Data collection and analysis**

Repeat in-depth interviews with PLHIV participants aimed to gain insight into changes in participants' accounts of their experiences with Treat-all over time, and to build trust and rapport between interviewer and interviewee, enabling access to alternative layers of participants' narratives beyond those participants may deem to be socially desirable. Interviews were based on topic guides and were primarily participant-led, with first interviews focusing on the participant's life history, second their experiences of HIV testing and diagnosis, offer of treatment and experience starting ART. Subsequent interview(s) explored ongoing treatment-taking, and revisited topics explored in earlier interviews to gain greater depth of insight and to explore any changes. Interviews were conducted from August 2016 to September 2017, the majority being held at participant homes, or at an alternative site if preferred.

Interviews with HCW participants explored views and experiences relating to Treat-all implementation and providing treatment and care to asymptomatic patients. These were one-time interviews conducted during February and March 2017, held in the clinics where HCWs worked.

Informed written consent was sought prior to all interviews, including for audio-recording, which was re-visited verbally at subsequent interviews for PLHIV participants. Interviews averaged 80 minutes, ranging from 50 minutes to 1 hour 40 minutes. Pseudonyms are used to protect participant confidentiality.

Detailed field notes were completed for each interview, and audio-recordings were translated and transcribed. Data were analysed thematically using coding to identify patterns, categories and themes that emerged from participant accounts, drawing upon principles of grounded theory to raise findings to a conceptual level (Bradley et al., 2007; Glaser, 1999). Initial codes were organized into a coding framework, forming the basis of continued analysis in Nvivo 11, which was developed and adapted as data collection and analysis progressed. Data collection and analysis followed an iterative process, enabling topic guides to be adapted to further probe emerging themes.

Ethics approval was obtained from the Eswatini Scientific and Ethics Committee, the London School of Hygiene and Tropical Medicine and MSF Ethics Review Boards prior to study commencement.

## Results

### **Study participants**

Selecting those enrolled to Treat-all from October 2014 to June 2015 from the sample, seventeen PLHIV participants were eligible for inclusion in this analysis, including nine women and eight men, with fifteen interviewed three times, one interviewed four times and one interviewed twice. PLHIV participants had been on ART for a mean of twenty months at the time of the first interview, and there was a mean of eight months between the first and the last interview (see Table 6.1). Additionally, 20 HCW participants were interviewed once (see Table 6.2).

**Table 6.1:** PLHIV participant characteristics (n=17)\*

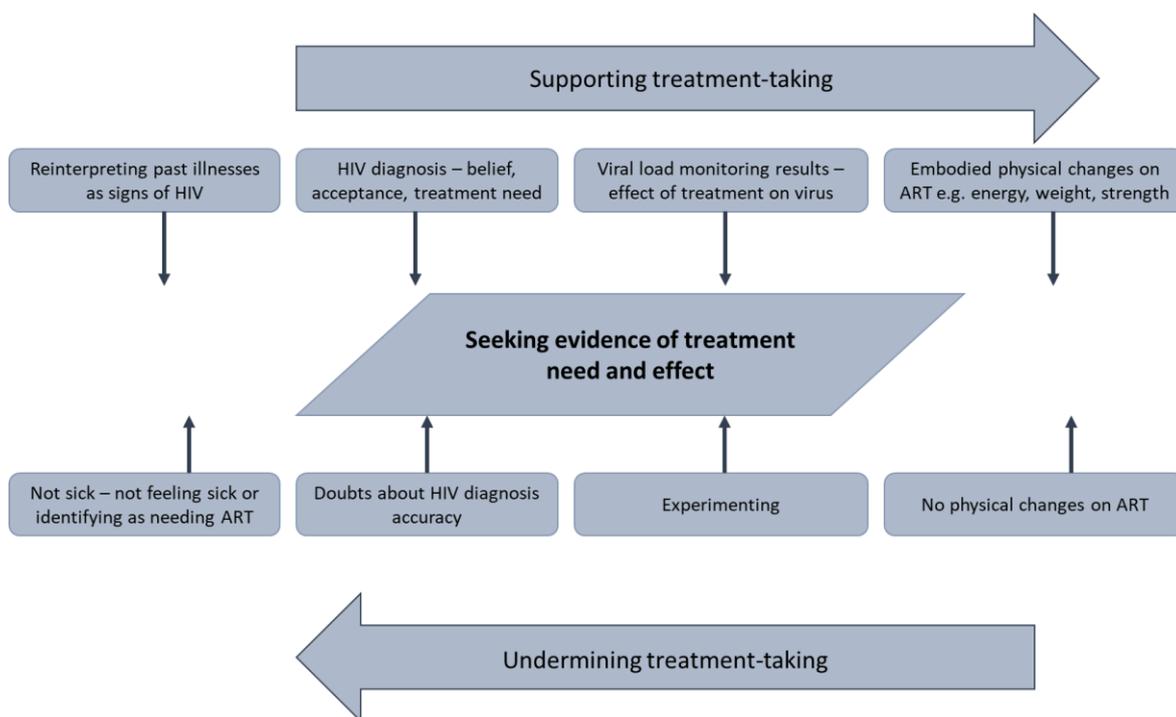
<b>Gender</b>	
Women	9
Men	8
<b>Age</b>	
Young adult:	
- 17-20 years	4 (all women)
- 21-25 years	3 (all women)**
Adult:	
- 26-39 years	5 (1 woman, 4 men)
- 40-49 years	5 (1 woman, 4 men)
<b>Enrolment to Treat-all</b>	
Oct 2014 – Dec 2014	5
Jan 2015 – Mar 2015	8
April 2015 – June 2015	4
<b>Time between enrolment and initiation</b>	
Same day	4
1-6 days	5
7-10 days	1
10 days – 1 month	3
1-3 months	2
4-8 months	2
<b>Treatment category</b>	
On ART	10
Lost from treatment***	7

\* Participant information as recorded on project patient database at time of recruitment. \*\* Young adults (aged 16-25 years) and adults (aged 26-49 years) were purposively included in the sample. No young men were eligible due to the epidemiology of HIV in Swaziland meaning fewer young men are infected, and additionally men can access care later. \*\*\* Lost from treatment defined as those with a last recorded visit date of at least 4 months from time of sample selection (to allow for those with 3 monthly refills)

**Table 6.2:** HCW participant characteristics (n=20)

<b>Position</b>	
Adherence counsellor	5
Nurse/nurse supervisor	13
Doctor	1
<b>Employer</b>	
MoH	12
MSF	8
<b>Facility</b>	
Primary Health Clinic (8 clinics included)	17
Secondary Health Facility	3

Figure 6.1 depicts a summary of the study findings, which are elaborated as follows.



**Figure 6.1:** Diagram of findings relating to seeking evidence of treatment need and effect and their influence on treatment-taking.

### **The perceived need for treatment influencing engagement with treatment and care**

For PLHIV, perceiving need for treatment was important to motivate their taking it. For some, receiving an HIV diagnosis was itself a pointer to the need for treatment: *“I had heard that if you are positive and do not take the treatment you could die. . .”* (Nozipho, woman, 19 years). Although clinically asymptomatic, some participants described embodied signs of HIV which served to warn them of the potential risk of deteriorating health:

*I started taking the treatment because I am afraid of getting sick and even at times I would have headache, and I would think probably it has started.* (Sifiso, man, 41 years)

Some believed that treatment would prolong their life. This was particularly described by men living with HIV, with early initiation of treatment seen as enabling maintenance of strength and productivity, potentially reinforcing notions of masculine responsibility. Additionally, several PLHIV described experiencing physical changes after starting ART, such as increased energy and strength, increased weight and feeling healthier, for example no longer experiencing headaches. This reinforced a sense of value to the treatment and motivated continued treatment-taking:

*It is helping ... because most of the time before I started taking the treatment I would feel that my body is going down, like when you wake up you'd find that the body is very tired most of the time. But then since I started the treatment I feel much better and healthier, and my body is energetic (Mandla, man, 36 years*

### **Doubts about treatment need and effect undermining treatment-taking**

However, not all participants perceived themselves as needing treatment or believed that it could benefit them. Several described doubts about the need for treatment in the absence of symptoms or signs of ill health:

*The CD4 is high and it is just the positive word that is pointing, there are no other signs . . . I will take them when I can see that it [HIV] is now really there. (Zandile, woman, 23 years)*

*Some patients tell you that there is no need, they will start the treatment when they are sick, not now. (HCW15)*

Those who did not experience any changes with ART appeared to doubt its effectiveness and the difference that treatment was making to them, which could undermine their motivation for taking it.

*The problem I have is that I haven't seen the effectiveness of the treatment, because even when I go to the hospital the weight scale doesn't reflect much of a change . . . nothing changed because when I went there I wasn't sick, but I just went there healthy. (Jabulane, man, 31 years)*

These doubts could also change over time, as participants sought evidence of the treatment's effectiveness and interpreted their own experiential changes as suggesting the treatment was working. For example, Jabulane, quoted from his second interview above, went on to interpret his health as improving by the third interview:

*With the pills my brother, the way I see it, they are working because ... I used to have flu every now and then ... that is when I eventually got tested, but then since I started taking the treatment I no longer have such, I don't get influenza and go to the hospital.*

Where doubts about treatment need and effectiveness were present, these appeared linked to PLHIV developing a sense of treatment fatigue over time:

*I used to just get tired and I would sometimes skip some days and not go to collect them . . . there were times I just would be quiet and not take it, not because there is no food or something, I would just feel annoyed that why am I taking this treatment and what is it for? (Khanyisile, woman, 24 years)*

HCW also described such doubts and treatment fatigue as a reason for some PLHIV disengaging from treatment and care:

*After some years . . . you can find that a patient would say 'ahh this treatment, I'm not sick anyway' . . . so they believe they should stop the medication. (HCW10)*

### **Seeking evidence of the treatment's effectiveness**

Almost all PLHIV participants described wanting to see the difference that treatment was making to the virus and their health prognosis. Some also described a desire to hear more about their blood tests:

*I want them to tell me is there something that it is doing, is there a difference. Even now I want them to tell me how my CD4 is doing, my CD4 was this much and now that I am continuing with the treatment, is it making any difference? (Celiwe, woman, 40 years)*

For those who were informed of suppressed viral load results, this appeared to instill a belief in the effectiveness of treatment, which could be particularly important for

those who initiated ART in the absence of symptoms, and which was said to motivate ongoing treatment-taking: “[When told suppressed] it made me to feel free and to continue emphatically taking the treatment, because it means it is working.” (Vusi, man, 49 years)

The role of viral load monitoring as a potentially important tool for supporting adherence among patients who initiate ART when healthy under the Treat-all policy was reiterated by HCW participants:

*These patients are patients who came in healthy, they had no symptoms, so they are going to continue being healthy... they are not going to see what is better for them. So viral suppression is important... it would actually be good to have an initial baseline viral load and then you do monitoring following.* (HCW19)

HCW recognized the importance of time explaining results:

*I can admit and say we don't give that oomph for that time as equal as when the viral load is unsuppressed... yes we don't give that attention, maybe we can strengthen and say yes even if the patient's viral load is suppressed... CD4 count is high... we need to sit with the patient... and try to give the patient a lot of time and understanding.* (HCW09)

Certain participants who were doubtful about the need for treatment and its effectiveness described experimenting with treatment-taking, as a means of seeking such evidence:

*There was a time... when I would think 'haw this thing is not doing anything to me' and then I stopped taking them and there was no sign of it being there... I never used to take them... I was not taking them well and nothing would happen and it would be the same as when I was taking them.* (Nobuhle, woman, 17 years)

## Discussion

This study investigated the experiences of asymptomatic PLHIV engaging with HIV care under the Treat-all policy in Eswatini. Our findings suggest that it is important for PLHIV to have a sense of the difference treatment is making to them, in terms of its influence on their virus and health prognosis. Where PLHIV perceived need for

treatment and believed it was effective in improving their health and potentially prolonging life, this motivated treatment-taking and supported engagement with care. On the other hand, doubts relating to treatment need and effect could undermine engagement.

The biomedical logic framing Treat-all assumes that individuals will adjust their actions once they are educated; however, treatment decisions surpass the biomedical realm (Beckmann, 2013). There can be dissonance between the biomedical rhetoric and lived experiences of those who engage with technologies (Young et al., 2016), including in lay interpretations of what constitutes treatment necessity (Kawuma et al., 2018). In our study PLHIV could gain evidence of treatment effect through experiential, embodied changes with identifiable, physical improvements after being on ART, or through viral load monitoring results showing the impact of ART on the level of the virus. However, some PLHIV had doubts about the need for treatment and its effectiveness in the absence of any symptoms or signs of ill health, which could undermine their engagement and cause intermittent treatment-taking. While others have examined the factors influencing ART initiation among asymptomatic PLHIV within Treat-all (Boyer et al., 2016; Mbonye et al., 2016; Pell et al., 2018), our study builds on these findings and provides insight into the influences on ongoing, longer term treatment taking, after an average of 20 months on ART.

Existing evidence from Eswatini suggests PLHIV can find it difficult to accept ART within Treat-all when feeling healthy, with the belief that ART is for sick people (Adams and Zamberia, 2017; Pell et al., 2018). Experiences with Option-B+ programmes in Southern Africa have found some relate taking ART with being ill or having a low CD4 count, which can undermine asymptomatic pregnant and lactating women's engagement with treatment (Adams and Zamberia, 2017; Katirayi et al., 2016). Pound et al. describe treatment-taking as a concretization of illness, rather than health (Pound et al., 2005). As HIV treatment for preventative purposes within Treat-all transforms HIV from an acute to chronic condition, the symptoms of disease and efficacy of treatment become less apparent (Zhou, 2016). While some participants in our study felt they did not need treatment in the absence of symptoms, others

reinterpreted past illnesses and physical experiences such as fatigue, low energy and weight loss as signs of HIV, which served to warn them of the potential imminent health deterioration without treatment, thereby motivating their engagement with care. Such reinterpretations of past events as indications of HIV were also found by Zhou, and influenced women's ART initiation within Option-B+ (2016), suggesting the importance of experiential, embodied experience in treatment decisions. Certain participants in our study felt that an HIV diagnosis itself pointed to the need for treatment. These findings therefore highlight the ways in which conceptions around health and treatment need are changing within the context of Treat-all, and they may continue to do so as it becomes more commonplace.

Almost all participants in our study wanted to see the positive effect or difference treatment was making to them, seeking evidence of the treatment's effect either through their own embodied experiences or through biomarkers such as CD4 count and viral load, which served as indicators of their health status. Although some researchers have described the value placed on such indicators (Renju et al., 2017), our findings went further by suggesting that viral load monitoring can play an important role in supporting adherence to ART, offering patients a means to view the effect of treatment on the level of the virus. This may be of particular importance in Treat-all contexts where PLHIV are increasingly initiating ART at earlier, asymptomatic phases of the disease. Routine viral load monitoring should be implemented universally as a tool to promote engagement in treatment and care, with communication of both suppressed results, as well as unsuppressed results, being emphasized.

Under previous treatment guidelines, recounting narratives of illness history and comparing pre- and post-ART health could motivate continued treatment-taking (Bernays et al., 2015; Nam et al., 2008) Although PLHIV are now increasingly initiating ART when clinically asymptomatic, findings from Option-B+ suggest that interpretations of physical improvements on ART, in particular falling sick less often, feeling more energetic and therefore more productive can be important for supporting continued treatment-taking (Katirayi et al., 2016; Ngarina et al., 2014;

Zhou, 2016). Certain PLHIV in our study who did not experience any such physical signs of HIV prior to starting ART, changes on ART or viral load results presented doubts about the need for treatment and its effectiveness. This could lead to treatment experimentation, where PLHIV could miss doses of treatment, seeking evidence of its effect. Conrad describes “non-compliance” as a form of “self-regulation,” where patients may alter the course of treatment to test its efficacy (Conrad, 1985), as seen in mothers enrolled in Option-B+ (Zhou, 2016). This is particularly problematic as it poses risks for drug resistance (World Health Organisation, 2017a), suggesting the importance of patients within Treat-all starting treatment when they are ready, when they want treatment and exploring means of addressing their concerns about its effectiveness. PLHIV who had such doubts were also said to be more likely to develop a sense of treatment fatigue over time, where questioning the point of treatment undermines the energy for taking it. This could become increasingly relevant as Treat-all patients are on treatment for longer periods of time.

### **Limitations**

As the Treat-all pilot was implemented by MSF and the MoH, patients may have received more support, including greater availability of viral load monitoring. However, the pilot aimed to examine the feasibility of Treat-all under routine programmatic conditions, and the presence of viral load monitoring enabled unique insight into the supportive value of this tool for patients’ treatment-taking. Though we were able to include PLHIV who had been enrolled in Treat-all care for longer than previously reported, Treat-all was still fairly new at the time of this study. It will be important to examine how these findings may change as Treat-all becomes more commonplace, as well as to examine experiences of PLHIV with Treat-all who have been on ART for longer.

### **Conclusion**

This research highlights the importance of PLHIV perceiving need for treatment and having evidence of the benefits of their taking it, for motivating their ongoing, sustained treatment-taking in the context of Treat-all. Almost all participants described a desire for evidence of the need for treatment and its effect, with routine

viral load monitoring potentially providing this. This could be particularly important for those who initiate ART when asymptomatic, who do not experience the transformative effects of ART and who can have doubts about the value of treatment, which potentially undermine treatment-taking. It is important that programmes consider these findings to adapt patient support, to avoid the risk of PLHIV “experimenting” with treatment-taking which could cause drug resistance to develop. This could include communicating to patients that there may be no notable difference in health status on initiating ART when asymptomatic, and that benefits of early ART include prolonging good health. Programmes should also ensure routine viral load monitoring is included as an integral component of HIV care within the Treat-all policy, with a baseline viral load if possible, and ensuring suppressed results are communicated to patients.

### **Competing interests**

The authors declare that they have no competing interests.

### **Authors’ contributions**

SH was the principal investigator of the study, and with BK and AW conceived and designed the study. SH, ZT and VD collected and analysed data. AW also contributed to analysis and interpretation of data. SH wrote the first draft of the paper, and led on revisions with input from AW and JS. All authors commented on the paper and approved the final version.

### **Acknowledgements**

We thank all the PLHIV and HCW who participated in this study, and who shared their time and experiences with us. We also thank all the MSF and MoH project staff members who supported the implementation of this research. This research was funded by Médecins Sans Frontières.

## **Chapter 7: “I don’t want them to know”: How stigma creates dilemmas for engagement with Treat-all HIV care for people living with HIV in Eswatini**

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\*Horter, S<sup>1,2</sup>; Bernays, S<sup>3</sup>; Thabede, Z<sup>2</sup>; Dlamini, V<sup>2</sup>; Kerschberger, B<sup>2</sup>; Pasipamire, M<sup>4</sup>; Rusch, B<sup>5</sup>; Wringe, A<sup>1</sup>

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## RESEARCH PAPER COVER SHEET

Please note that a cover sheet must be completed **for each** research paper included within a thesis.

### SECTION A – Student Details

Student ID Number	LSH281543	Title	Miss
First Name(s)	Shona		
Surname/Family Name	Horter		
Thesis Title	Investigating experiences of engagement with HIV Treat-all among people living with HIV in Eswatini		
Primary Supervisor	Alison Wringe		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

### SECTION B – Paper already published

Where was the work published?	AJAR		
When was the work published?	February 2019		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	Yes	Was the work subject to academic peer review?	Yes

\*If yes, please attach evidence of retention. If no, or if the work is being included in its published format, please attach evidence of permission from the copyright holder (publisher or other author) to include this work.

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Stage of publication	Choose an item.

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For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	I contributed to the study's conception. I designed the study, developed the study protocol and designed tools of data generation. I conducted data generation, along with field workers. I analysed the data. I wrote the first draft of the paper, and incorporated feedback from co-authors. I submitted the paper, liaised with journal editors, and made edits following peer review comments.
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**SECTION E**

<b>Student Signature</b>	<i>Shara Porter</i>
<b>Date</b>	20/03/19

<b>Supervisor Signature</b>	<i>R.</i>
<b>Date</b>	21/03/2019

## Overview

In Chapter 2, I introduced and defined stigma, and explored HIV-related stigma, including social judgements of immorality and deviance, which may be attributed to HIV infection and people living with HIV. I engaged with the HIV normalisation discourse, which posits that increased and earlier access to ART should enable HIV stigma reduction and HIV management as a chronic condition akin to other conditions such as diabetes. However, evidence suggests that despite increased ART access rendering the signs and symptoms of HIV less visible, people living with HIV may continue to have discreditable social identities, and anticipated stigma prevails. This paper examines how stigma is experienced by people living with HIV in the context of Treat-all, and how it frames engagement with treatment and care.

In this chapter, I draw on data from the main phase of the PhD research. The findings highlight the conflicting forces of stigma, in both driving engagement with HIV care, as individuals want to prevent the onset of HIV-related symptoms which may inadvertently disclose their HIV status to the community, and also undermining engagement with HIV care due to the multitude of risks of status exposure that engagement presents. Intermittent treatment-taking, and disengagement from care were described when the risks of HIV status exposure appeared too great, and maintaining a hidden HIV status appeared a priority over and above preserving good health for health's sake. This suggests that treatment-taking and engagement with HIV care in the context of Treat-all are fragile, as HIV stigma and risks of HIV status exposure require continual navigation by people living with HIV.

This paper aligns with **research objectives 3 and 4:**

3. To explore treatment initiation decision-making
4. To examine how ongoing engagement in HIV care and treatment-taking is navigated over time

## Abstract

“Treat-all” programmes aim to improve clinical outcomes and to reduce HIV transmission through regular HIV testing and immediate offer of antiretroviral therapy (ART) for those diagnosed HIV-positive, irrespective of immunological status and symptoms of disease. Global narratives on the benefits of Treat-all anticipate reduced HIV-related stigma and increased “normalisation” of HIV with Treat-all implementation, whereby HIV is remoulded as a manageable, chronic condition where stigmatising symptoms can be concealed. Drawing on Goffman’s stigma work, we aimed to investigate how stigma may influence the engagement of clinically asymptomatic people living with HIV (PLHIV) with Treat-all HIV care in Shiselweni, Eswatini (formerly Swaziland). This longitudinal research comprised 106 interviews conducted from August 2016 to September 2017, including repeated interviews with 30 PLHIV, and one-off interviews with 20 healthcare workers. Data were analysed thematically using NVivo 11, drawing upon principles of grounded theory to generate findings inductively from participants’ accounts.

Stigma was pervasive within the narratives of PLHIV, framing their engagement with treatment and care. Many asymptomatic PLHIV were motivated to initiate ART in order to maintain a “discreditable” status, by preventing the development of visible and exposing symptoms. However, engagement with treatment and care services could itself be exposing. PLHIV described the ways in which these “invisibilising” benefits and exposing risks of ART were continually assessed and navigated over time. Where the risk of exposure was deemed too great, this could lead to intermittent treatment-taking, and disengagement from care. Addressing HIV related stigma is crucial to the success of Treat-all, and should thus be a core component of HIV responses.

## Introduction

“Treat-all” programmes are being implemented in several African settings, as a prevention and treatment strategy for HIV. In line with recent World Health Organization (WHO) guidelines, regular HIV testing is encouraged and antiretroviral therapy (ART) is offered immediately for those who are diagnosed HIV-positive, irrespective of immunological status and symptoms of disease (World Health Organisation, 2015). Global narratives on the benefits of Treat-all implementation anticipate that earlier and increased access to ART will facilitate the “normalisation” of HIV, where it is considered a manageable chronic condition, and where stigma can be reduced through management of HIV related symptoms enabling HIV status concealment (Abadía-Barrero and Castro, 2006; Roura et al., 2009b, 2009a). Castro and Farmer (2005, p.57) describe this transformation of HIV from a fatal disease to a chronic, manageable one as having “decreased stigma dramatically in Haiti”.

Stigmatisation can be defined as a social process occurring in the context of power, where an individual’s difference, condition or attribute is considered unfavourable and linked to negative stereotypes (Link and Phelan, 2006, 2001). While the manifestations of stigma are socially constructed and context specific, possessing such an attribute generally results in loss of status, devaluation and discrimination, and leads to unequal outcomes for the stigmatised individual (Gilbert and Walker, 2010; Goffman, 1963; Link and Phelan, 2001; Parker and Aggleton, 2003). In his seminal work on stigma, Goffman (1963) outlined the distinction between “discredited” and “discreditable” identities. Those who are discredited possess an evident or visible attribute, requiring them to devise coping mechanisms to manage the resulting prejudice and discrimination, which can also be referred to as “enacted stigma”. Conversely, conditions which can be hidden from the public eye create discreditable identities, where the main focus is managing and concealing information to “pass” as “normal”, to avoid becoming discredited and experiencing the expected resultant stigma, which can also be referred to as “anticipated stigma” (Goffman, 1963; Scambler, 2009; Steward et al., 2008).

A growing body of work has explored the relationship between stigma and taking ART. Mattes (2014) refers to ART as a “technology of invisibilisation”, as it provides an opportunity to maintain status secrecy and to thereby avoid stigma, a concept which is also reflected in the work of other scholars (Beckmann, 2013; Moyer, 2012). However, while ART may enable the avoidance of enacted stigma (Beckmann and Bujra, 2010) and prevent people living with HIV (PLHIV) from being discredited, anticipated stigma can persistently prevail in people’s lived experiences with HIV (Alonzo and Reynolds, 1995). PLHIV remain discreditable, partly due to the potential for symptom development and status exposure, but also because ART does not directly address the structural drivers of stigmatisation (Russell et al., 2016b), such as poverty, gender inequality and racism (Link and Phelan, 2001). Stigma reflects the workings and forms of social inequality, and to properly understand it we must consider how some people come to be socially excluded, and the forces that create and reinforce such exclusion (Parker and Aggleton, 2003). Additionally, ART does not address the fundamental causes of stigma, including the deeply held views of powerful groups that lead to stereotyping and labelling (Link and Phelan, 2001), and Squire (2010, p.409) argues that the association of HIV with “transgressive sexuality, particularly for women, will always render it socially pathological”.

HIV related stigma presents a major barrier to the prevention and treatment of HIV (Mbonye et al., 2013; Stangl et al., 2013; Steward et al., 2008). In African settings, and particularly in Southern and Eastern Africa, stigma has been found to discourage care-seeking (Maeri et al., 2016), and undermine uptake of HIV testing, ART initiation and adherence (Bond, 2010; Genberg et al., 2009; Mbonu et al., 2009; Mbonye et al., 2013; McGrath et al., 2014; Orne-Gliemann et al., 2016; Sengupta et al., 2011). Stigma can undermine adherence and engagement directly, where attempts at status concealment such as hiding treatment or selecting clinics far from home contribute towards treatment interruptions (Dlamini et al., 2009; Gilbert and Walker, 2010; Katz et al., 2013). There are also indirect influences, whereby non-disclosure of HIV status results in lack of social support and treatment reminders (Katz et al., 2013). While this body of research explores stigma and HIV service engagement for symptomatic PLHIV, where the discrediting attributes are made visible by the disease itself, it is

not yet known how this may be experienced by clinically asymptomatic PLHIV in the context of Treat-all, where the discrediting risk is made manifest only through accessing treatment.

Supporting PLHIV to engage with treatment and care is important for individuals' health outcomes, as delayed treatment and suboptimal adherence have deleterious effects on morbidity and mortality (INSIGHT START Study Group, 2015; Song et al., 2018; The TEMPRANO ANRS 12136 Study Group, 2015). Additionally, suboptimal adherence can contribute to drug resistance, which can be transmitted, with resultant population level and individual level risks, and which has been highlighted as a critical threat to eliminating AIDS by 2030 (World Health Organisation, 2017a, 2017b). Without detailed exploration of whether and how stigma is manifested and experienced in this context, it is unknown how it may undermine Treat-all efforts. To ensure stigma is addressed, it must first be understood, ideally by examining the perspective of those affected. In this context, we aim to examine how stigma shapes PLHIV experiences with HIV, and engaging with HIV treatment and care services under Treat-all in Shiselweni, Eswatini (formerly Swaziland).

## Methods

This study is situated within the context of a broader research project that used a longitudinal qualitative design to examine the lived experiences of clinically asymptomatic PLHIV, their engagement with HIV treatment and care, and how these changed over time in the context of Treat-all in Shiselweni, Eswatini.

The study of lived experiences refers to understanding individuals' experiences, choices, and options, and how individuals interpret and make sense of their experiences (Given, 2008; Smith, 2004). This approach aims to understand and describe individuals' experiences of their everyday world as they see it (Liamputtong, 2013), and to remain as faithful as possible to the phenomenon and the context in which it appears in the world (Giorgi and Giorgi, 2008).

## **Study context**

Eswatini has the highest reported HIV prevalence worldwide, estimated at 35% among women and 19% among men aged 15–49 years (UNAIDS, 2016). HIV prevalence peaks at 54% among women aged 35 to 39 years and 49% among men aged 45 to 49 years (Swaziland Ministry of Health, 2017). Most transmission occurs through heterosexual sex (Swaziland Ministry of Health, 2012).

Eswatini is the last remaining absolute monarchy in Africa. Classified as a lower middle-income country, it is a small, largely mountainous country with a population of 1.2 million people. Sixty per cent of the population lives in poverty, of which 38% live in extreme poverty, and income inequality is high (The World Bank, 2018). Limited economic opportunity and high unemployment have resulted in widespread dependence on labour migration, with most migrant labourers travelling to neighbouring South Africa for work (Hickel, 2012). Most people identify as Christian (90%), and the main land use is pastoral, and timber forest (Central Intelligence Agency, 2018). In the predominantly rural southern region of Shiselweni subsistence farming is widely practised, and the region has been particularly affected by drought in recent years, which has caused food insecurity (Root et al., 2017).

In October 2014, a Ministry of Health/Médecins Sans Frontières (MoH/MSF) Treat-all implementation pilot began in the predominantly rural Nhlangano health cluster in the Shiselweni region. This aimed to contribute towards reduced HIV incidence and improved clinical outcomes for PLHIV. The population in Nhlangano largely access HIV treatment and care at primary health clinics. The area has eight primary clinics and one secondary health facility; some people have to travel long distances, often on foot, to reach the nearest clinic. Treat-all was rolled out nationally in October 2016.

## **Participant recruitment**

Participants were recruited purposively to include PLHIV enrolled in the Treat-all pilot programme who were considered clinically asymptomatic and who would have been otherwise ineligible for treatment at the time of ART offer (CD4 count  $\geq$ 500, WHO disease stage 1), and to include a range of treatment-taking experiences (see

Table 7.1). The project patient cohort was stratified for gender and age, to include young people (aged 16 to 25 years) and adults (aged 26 to 49 years). Healthcare workers (HCWs) from the facilities implementing Treat-all (one secondary and eight primary care facilities, not HIV-specific) were purposively recruited to include a range of positions involved in the delivery of HIV testing, treatment and care, and both MoH and MSF personnel. Fieldwork was conducted from February 2015 to November 2017. Identified PLHIV were contacted in June 2016 and invited to participate in between 2 and 4 interviews over a 12-month period, while HCW were invited to participate in 1 interview during March and April 2017.

Attempts were made to contact 107 PLHIV identified for potential recruitment, 55% of whom ( $n = 59$ ) were non-contactable. Of those who were contactable ( $n = 48$ ), 30 agreed and participated, 9 agreed and did not attend the agreed appointment (reason for non-participation unknown), 2 refused due to work commitments limiting their time in the area, 5 were out of the region and 2 were unwell and therefore unable to meet. All HCW who were approached and invited to participate agreed to an interview.

**Table 7.1:** Participant characteristics

<b>Participant information*</b>	<b><i>n</i></b>
<b>All PLHIV</b>	<b>30</b>
Treatment-taking category:	
On ART	18
Lost From Treatment	12
Enrolment period:	
Early (Oct 2014 – Mar 2015)	13
Mid (Apr 2015 – Sep 2015)	12
Late (Oct 2015 - Mar 2016)	5
Gender and age:	
Women	18
• Young women (17-25 years; average 21)	9
• Adults (26 to 46 years; average 33)	9
Men	12
• Young men (16 to 25 years)	0 (none eligible in patient cohort**)
• Adults (26 to 49 years; average 37)	12
<b>All HCW</b>	<b>20</b>
Position:	
Nurse supervisor	5
Nurse	8
Adherence counsellor	5
Doctor	1
Employer:	
MoH	12
MSF	8

\*Participant information relates to that recorded on the project patient database at time of recruitment; or for HCW the positions they identified with during interviews. \*\* No young men were eligible due to the epidemiology of HIV in Swaziland meaning less young men are infected, and additionally men can access care later.

**Table 7.2:** Longitudinal interview time frame

<b>Interview</b>	<b>Date range</b>	<b>Participants (<i>n</i>)</b>	<b>Meetings (<i>n</i>)</b>
1 – Life history, family and relationships, hopes and aspirations, key life events	22/08/16 – 31/10/16	30*	33
2 – HIV testing, diagnosis, treatment offer and treatment initiation decision-making	17/11/16 – 07/02/17	29	31
3 – Living with HIV, ongoing treatment-taking and engagement with HIV services	25/03/17 – 08/09/17	26	27

\*Certain interviews were conducted over more than one meeting, for example due to length of discussion and available time. One participant was lost to follow up after the first interview, attempts were made to contact her but she was not available to arrange another meeting. Three participants completed 2 interviews and 1 completed 4 interviews.

### **Data generation and analysis**

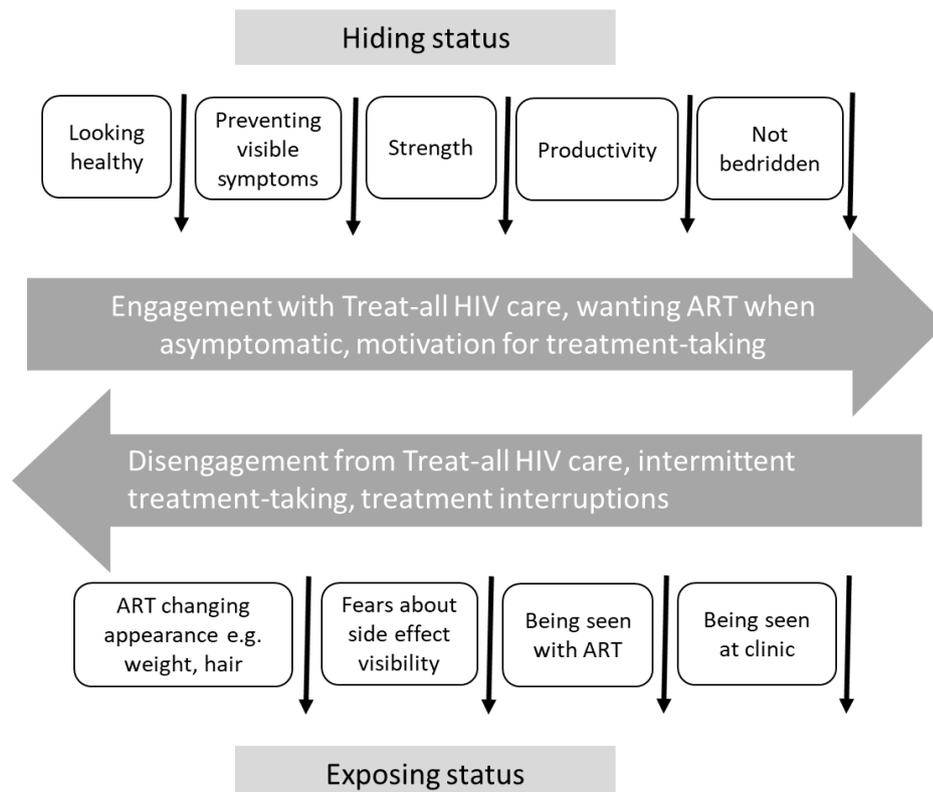
In-depth interviews were conducted to explore a range of topics relating to PLHIV's lives, their experiences of living with HIV, and with treatment and care (see Table 7.2 for a summary of topics). Interviews were based on topic guides but were primarily participant-led, for example, HIV status was not asked about unless participants themselves disclosed their diagnosis (which all participants did). Multiple waves of data generation were conducted to capture changes over time, and also to benefit from developing rapport between participants and the researcher, which produced richer quality data. Data generation and analysis followed an iterative process, with topic guides for subsequent interviews being based on initial findings, to further test and explore particular areas emerging as potentially important. Interviews were conducted in siSwati by same-gendered interviewers, mostly held at participants' homes, or another location of their preference if they felt more comfortable (e.g., fixed testing site in town). The interviews were audio-recorded following participant consent and were then translated and transcribed. Interviews with HCW were conducted at clinics, mostly in English, and explored topics relating to their experiences implementing Treat-all including offering ART to those considered clinically asymptomatic, supporting patients, and related challenges faced by patients and HCW.

Interview transcripts were analysed thematically using NVivo 11, drawing on principles of grounded theory to generate findings inductively from participant accounts and to actively investigate discrepancies from the majority of themes (Bradley et al., 2007; Glaser, 1999; Glaser and Strauss, 1967). Initial coding and themes were discussed collaboratively, with a coding framework developing as analysis progressed. Repeated interviews with PLHIV were initially analysed per round to examine themes across participants' accounts, and then longitudinally to explore how patients' narratives changed over time. Ethical approval was received from the

Swaziland Scientific and Ethics Committee, London School of Hygiene and Tropical Medicine and from MSF Ethics Review Board. Pseudonyms are used in this paper for PLHIV participants, and HCW participants are referred to as HCW, to ensure confidentiality.

## Results

In total, 106 interviews were conducted between August 2016 and September 2017, including 86 interviews with 30 PLHIV (Tables 7.1 and 7.2) and 20 interviews with HCW (Table 7.1). Stigma emerged inductively from participants' accounts of living with HIV and engaging with HIV treatment and care services. Stigma was then explored further in later interviews to gain greater depth of understanding into the ways in which it affected individuals' sense of identity, their interpretation of their diagnosis, and their engagement with treatment and care. HCW interviews also highlighted the ways in which stigma frames and influences PLHIV's engagement with treatment and care in the context of Treat-all. Figure 7.1 shows a summarised depiction of these findings.



**Figure 7.1:** How stigma and status concealment versus exposure influence PLHIV's engagement with HIV treatment and care under Treat-all

## **HIV status concealment to avoid anticipated stigma**

Anticipated stigma was pervasive within PLHIV participant narratives, and almost all described feeling that they must conceal their HIV status to avoid stigma through being singled out and treated differently by those around them. The importance of status secrecy also appeared reinforced through health messaging at the point of treatment initiation and subsequent clinic visits, with some health workers encouraging their patients not to widely disclose their diagnosis.

*When you are HIV-positive you must keep it a secret (Hlobisile, woman (F), second interview).*

*They [HCW] said going around telling people isn't a good thing... they explained this to us at the clinic that we should tell someone who will not go around talking about you (Cebisile, F, third interview).*

Many PLHIV feared the potential negative consequences of having their status discovered. The fears should they be identified as taking treatment included not wanting to be gossiped about, made a mockery of, or to experience social judgement which could result in loss of reputation, social stature and standing, which in turn could impede future relationship and marriage prospects.

*It lowers your value when people point at you for taking the treatment. People will not respect me the way they do now, and they will not treat me the way they treat me now (Nokuthula, F, second interview).*

Commonly held notions of what comprises a good, upstanding citizen, in line with Christian values and moral standards, appeared contradictory to, and threatened by, views about who gets HIV. Most participant accounts included references to the ways in which HIV continues to be abnormal and morally judged, particularly linked to the sexual nature of transmission, and with negative connotations regarding the sexuality and behaviour of PLHIV.

*I wish that people could take AIDS as a common cold, because it can get anyone, not that they take you as an animal, or that you were living a life that is not good, you see (Thandi, F, first interview).*

*Religion comes in, and if you do go to church we don't expect you to be having sex when you are not married, but you are actually having sex, so you can't talk about it (laughs) and then at the same time this is a very small community, so everybody knows everybody. I know you go to church, and if I then know that you are sleeping with this one, it means you are not actually an outstanding Christian if I may say (HCW).*

The impact of such anticipated stigma could be strong and harmful. Some participants described considering suicide, linked to the humiliation, shame and devaluation that could come from having their status known:

*I even wished to kill myself because I had lost so much weight and people in the community were making a mockery of me (Sanele, young woman (YF), second interview).*

### **ART offering the potential to maintain good health and a hidden HIV status**

Initiating ART while still largely asymptomatic and with good general health, offered both risks and opportunity. ART was a means to avoid signs or symptoms of ill health from developing, which could expose one's HIV status. Avoiding HIV visibility appeared more important than maintaining good health itself, with the fear of being identified being more pervasive than the fear of experiencing sickness.

*I should just start taking the treatment while I am still walking on my own, while I am still healthy, and I shouldn't go down but instead I should improve from where I am now... so that I wouldn't lie down and be identifiable and then lose weight and many other things (Vusi, man (M), second interview).*

Maintaining good health, including strength and energy, enabled the maintenance of a sense of normality, being able to work and function as a member of society, contradicting stigmatising processes of "othering" and countering feelings of no longer being a human. This appeared particularly important for men, who described wanting to work and provide for their family, thereby upholding notions of masculinity and productivity.

*When I'm healthy, my family will have something to eat and my children will be able to go to school and they wouldn't have problems... if I might get sick then I think my children will struggle because what they get from me it's something they cannot get from anyone [else] (Mandla, M, second interview).*

Many participants described having seen the effects of delayed ART initiation, for example, with family members or neighbours becoming sick and bedridden, which reinforced their motivation to start treatment before succumbing to these symptoms:

*I saw from my sister, she started them late when she was very sick and I said I do not want to get to that stage, let me start them while I am walking because when you are sick people then start to gossip about you (Sanele, YF, third interview).*

Though all participants were considered clinically asymptomatic, several described experiencing embodied signs of HIV, such as headaches, weakness, lethargy and weight loss, which served to warn them of the potential for imminent health deterioration and therefore HIV visibility without ART. Perceptions of health and ill-health appeared to differ experientially from biomedical definitions regarding the severity of HIV related disease (e.g., those included in WHO disease staging). For some, even receiving an HIV diagnosis pointed to a fragility in their health status, reinforcing their sense of needing to start ART.

*When you haven't tested, you are going to tell yourself that you're okay but once you have things like constant headache and things like that, you must know that those are the signs... We know the symptoms, like if your hair is like it has been licked by a calf... Forget it just go and start taking the treatment, there's nothing you can do (Jabulane, M, second interview).*

*It hurt me... [after HIV diagnosis] you then begin to see yourself that you're not someone who is healthy, you're someone who is sick (Sifiso, M, third interview).*

Health workers also felt that a key driver for PLHIV to initiate ART before becoming symptomatic was the ability of ART to hide their status, relating this to anticipated stigma.

*Usually it is that they don't want to be sick, to be seen by everyone that this one is now sick... once you get sick, be in a wheelchair, they [community members] diagnose you as being HIV positive... there will be rumours all over. They still want their status to be confidential. They test and initiate but are not ready to disclose in public. It is self-discrimination (HCW).*

*[Treat-all] has helped us greatly because if a person is initiated today on ART nobody will see that the person is HIV positive because there are no hair changes and no nothing. By that the stigma... because once the symptoms... manifest, discrimination begins... (HCW).*

In addition, certain HCW alluded to this message being reinforced in pre-ART sessions with PLHIV:

*They eventually want to take them because we tell them: why do you want people to see you that you are sick? Because you could take even when no one is noticing, and you will continue (HCW).*

As well as wanting to initiate ART to ensure HIV status concealment, the perceived need for, and benefit of ART in enabling a hidden status was said to motivate ongoing, continued treatment-taking:

*The thought of stopping treatment never crossed my mind because I am the one who will get exposed if I stop taking them... I respect them [ARVs] a lot they have helped me, if it was not for them, I would also be visible that I am sick, so really I respect them a lot (Welile, F, third interview).*

### **The risk of HIV status exposure undermining engagement with HIV treatment and care**

While many PLHIV appeared motivated to take treatment early to protect a hidden status, engagement with HIV treatment and care services could itself be exposing and therefore discrediting. Almost all participants described fears of being seen at clinics, or having their treatment found:

*When you are going to the hospital you are ashamed, even just walking around you are ashamed because you know that people know that you are positive, and then others*

*will point you using their heads and have names for you, you find that they call you Khumalo [one who takes] (Sanale, YF, third interview).*

Many PLHIV could go to great lengths to hide their treatment, and at times these efforts undermined their capacity to take it. For example, a dose may be missed when others were present to avoid being seen and therefore exposed:

*Sometimes you would find that when the time for taking the treatment comes he is also in the room, so it would happen that I wouldn't take them (Nelisiwe, YF, third interview).*

*I am scared to say 'yey people get out so that I can take my bag and drink my treatment'. I am scared, so I end up skipping, and this makes me stressed (Nontokeko, YF, third interview).*

Participants also reported that they feared the risks of being seen at the clinic while queuing for ART refills. Some described strategies they adopted in order to minimise this risk, including befriending HCW to avoid the need to queue, or choosing a clinic further from their home community to avoid the risk of being seen by neighbours. However, these strategies were often fragile or less convenient, which inadvertently added to the burden and fragility of treatment-taking. This could potentially undermine the sustainability of longer-term engagement with treatment and care. The strategy of selecting a clinic which was further away from home in order to avoid exposure was particularly described by young women and by men, who were less easily able to justify their presence at the clinic by citing an alternative and more socially acceptable reason than, for example, older women.

*I do not want to lie to you [interviewer surname], I have never queued and I feel like I am scared to. I feel like I am not ready to be seen by everyone that I am HIV positive. You see where you sit there, I have never sat there... I just come and go inside (Hlobsile, F, third interview).*

*I transferred from Nhlngano to Big Bend... aunt said I should transfer because people around here know me, so they might know me and see me and be gossiping about me...*

*she said it is better that I go where they do not know me (Thobile, F, second interview).*

Some PLHIV also described times when they turned back from the clinic without collecting their refill due to seeing someone they knew at the clinic and not wanting to be exposed:

*They said because I am pregnant I have to go to the VCT and when I looked at it the Nhlanguano VCT the way it is, I just left everything there and then... it exposes too much sisi... I was like I will be discovered by people I work with... so I was like no ways (Welile, F, second interview).*

*Someone might decide to leave the treatment because there's a relative of mine in the clinic, or the cleaners or something, she knows me and she's going to talk (HCW).*

Although early initiation on to ART was understood to prevent symptom development, some saw ART itself as concomitantly potentially exposing, with fears that treatment side effects could cause physical deformities, changes in weight, hair and skin colour. This is indicative of the dilemma that the prospect of Treat-all posed for asymptomatic PLHIV, as ART could be the catalyst for their status to become noticeable, with treatment related side effects perceived as potentially revealing their HIV to others.

*I do not want to lie, part of me was saying I should take them but another part was saying I shouldn't take them... I am scared of them making a problem of me and I would be like a written book, look at her she doesn't have a big belly anymore, she is finished with a flat ass, you are now written that you are taking treatment you see, I was scared of them, telling myself that they [ART] will expose me (Hlobisile, F, third interview).*

*I thought that the treatment would make me sick and I would be seen by all people because I would've changed so much than what I was before (Lindiwe, F, second interview).*

*I was actually afraid of gaining weight because it was now a common thing that once you gain weight, whether I have told this person or not, but once I gain weight they*

*are going to say I have started taking the treatment... I was really afraid that people were now going to identify me easily (Mandla, M, third interview).*

Maintaining a hidden HIV status whilst engaging with HIV treatment and care services thus appeared fragile. Participant accounts were interwoven with calculations of perceived benefits and risks of treatment-taking and status exposure, which were continually considered and navigated over time. If the risk of exposure was deemed too great, this could cause individuals to disengage from treatment and care services:

*It is not pleasing to be on a treatment for the rest of your life, and also that you can hide it today but for how long? Because there are people that you do not want to know about you taking treatment... you can hide it from them today and tomorrow, but they will end up finding out about it because the hospital is not mine alone (Nontokeko, YF, third interview).*

*When you are talked about, and when you are scared, you may end up saying let me just stop taking this thing. This is what can make people stop taking treatment (Sanele, YF, third interview).*

*I was not collecting them anymore... what was in my mind was that I was scared to tell my boyfriend that it is my time to collect my treatment, I was scared to do that... (Ncobile, YF, fourth interview).*

### **HIV status acceptance countering anticipated stigma**

The extent to which PLHIV's engagement with HIV treatment and care services was framed by avoiding exposure and anticipated stigma appeared to be influenced by their own interpretation of their diagnosis. Only four participants did not mention trying to hide their status, and for these participants, their own acceptance of being HIV-positive and wanting to live seemed to support their overcoming fear of others' judgement, thereby also supporting their engagement with care.

*Whatever situation you go through, what will help is that you accept yourself first, so that you get accepted by other people. When you start having self-stigma [utinyandza wena], then at that time you feel like I am not the same as other people... I accepted*

*myself a long time ago, in the beginning. That is what made me live, that I just accepted myself. I never found myself as different, even if you could come and say "I am not positive", that does not hurt me... I find that we are the same. You can be negative and I know that I am positive, it does not make any difference to me... when they said I am positive so what, there is treatment, they say it helps, I will continue to live (Philile, F, second interview).*

Such acceptance of status could be challenging in the absence of any symptoms or signs of ill health. Some did not perceive the need for ART in the absence of symptoms, questioning their diagnosis or the likelihood of experiencing future health deterioration, and wanting to wait before starting ART:

*I thought for myself that I do not have to take them because I feel okay... maybe when I get sick and I can see that I have to take the treatment (Gcinile, F, second interview).*

*Some... they say they are not ready, they are still fine... they tell you that there is no need, they will start treatment when they are sick, not now (HCW).*

Treat-all could expedite the time from HIV diagnosis to treatment initiation, but for many it appeared important to have time to process and come to terms with an HIV diagnosis, to feel ready for treatment, and for people to know.

*I think it is still processing for me to accept it... I think that after some time I will end up not caring if people know, it is just for now... (Nokuthula, F, third interview).*

*I think that as time goes on I will be alright, I will then accept it... but I do not know yhiii... what can be done... it is still new, just like losing a mother, you keep thinking about her but as the years go by you then forget that she died and I cried at the funeral. So I think I will also be alright (Nontokeko, F, third interview).*

## Discussion

In the context of Treat-all, in a setting with a high prevalence generalised HIV epidemic, stigma was pervasive and influential in participants' accounts of living with HIV, and appeared to strongly frame PLHIV's engagement with treatment and care services. On the one hand, treatment appeared as a pulling force, offering the potential to preserve good health, so that any symptoms which may expose HIV could be avoided. This motivated many PLHIV to want to start treatment early, when considered clinically asymptomatic. However, being on treatment and engaged with HIV care services could also be exposing, and many had fears around being seen collecting refills or having their treatment discovered, which could undermine their engagement. Avoiding anticipated stigma appeared so important that some participants thought of suicide if they were to be discovered living with the virus, and to experience the expected humiliation and devaluation that could result. While there is a wealth of research on HIV related stigma and its interplay with use of HIV services, to the best of our knowledge this is the first study to unpack in detail the ways in which stigma influences asymptomatic PLHIV's engagement with Treat-all.

Status concealment appeared as an information management strategy, through which PLHIV maintain a discreditable identity and avoid becoming discredited (Goffman, 1963). The need to conceal was reinforced by health messaging at clinics, potentially implying that there is something inherently wrong with being HIV-positive (Bernays et al., 2017). Our finding that almost all participants felt they must conceal their HIV status due to anticipated stigma has been shown by others (Alonzo and Reynolds, 1995; Dlamini et al., 2009; Katz et al., 2013). While all PLHIV participants were considered clinically asymptomatic, several described embodied signs of HIV, which served to warn them of the potential for imminent health deterioration and discrediting without ART, and supported their motivations for initiating ART. This also highlights the dissonance between biomedically ascribed markers of HIV (e.g., CD4 count and WHO disease stage) and PLHIV's experiential conceptions of their health and illness.

The ability of ART to alleviate physical manifestations of HIV have led to it being referred to as a technology of “invisibilisation” (Beckmann, 2013; Mattes, 2014), enabling social and economic engagement, and therefore providing PLHIV with a sense of value (Bernays et al., 2010; Campbell et al., 2011; Mattes, 2014). In our study, this manifested in the ability of ART to prevent the development of physical symptoms, rather than alleviate them once present. Other studies describe the transformative and restorative effects of ART when taken by PLHIV who are very unwell, which can then motivate adherence (Bernays et al., 2015; Russell and Seeley, 2010). Our findings that participants were motivated to start and continue taking treatment in the absence of symptoms show how the relationship with ART, and its capacity to conceal HIV, are changing under Treat-all.

While ART can present a technology of “invisibilisation”, some authors have suggested that wider treatment availability can generate new forms of stigma (Roura et al., 2009a). Although being visibly healthy can conceal an HIV-positive status, clinic visits and daily medication use can create privacy concerns and risks of exposure (McGrath et al., 2014; Moyer and Hardon, 2014). Many PLHIV in our study had concerns about the risk of exposure from engaging with treatment and care, which could cause intermittent treatment- taking, interruptions and disengagement from treatment and care. Hiding treatment can lead to non-adherence and treatment interruptions (Dlamini et al., 2009; Katz et al., 2013; Maeri et al., 2016), and in our study several participants described times when they felt unable to take their medication if others were present.

The extensive efforts PLHIV in our study described in order to maintain privacy, such as choosing to attend clinics long distances from their home communities, have been found by others (Bond, 2010; Gilbert and Walker, 2010; Maeri et al., 2016), and as affecting individuals’ ability to remain adherent to ART (McGrath et al., 2014), for example, through increasing the burden of treatment and undermining longer-term sustainability. However, our findings illustrate the dilemma that individuals experience because some perceive that not engaging in treatment, in the hope of continuing to remain asymptomatic, may allow a continued invisibility of their HIV

status for longer. In the past, the risk of exposure from engaging with treatment could potentially be balanced with the risk of exposure from visible signs of HIV before starting ART. In the Treat-all context, where PLHIV were visibly asymptomatic before initiation, these risks of exposure may actually seem greater with treatment-taking than without it, as the risk of developing symptoms in the future are perhaps more abstract and less current than those experienced presently. There is a risk that the effect of this is to delay treatment-seeking. Likewise, while some studies have found that PLHIV may have concerns about visibility linked to ART side effects (Mattes, 2014; Mbonye et al., 2016, 2013; Zhou, 2016), in our study these concerns could influence the cost-benefit weight of ART unfavourably, as treatment may be felt to cause changes to appearance which were more exposing than PLHIV's health before starting. If these perceived risks are not addressed within programmes, this could undermine the success of Treat-all implementation.

Self-acceptance of HIV status appeared to counter stigma, helping individuals to overcome the fear of others' judgement and not to internalise stigmatising attitudes and shame. The influence of HIV status acceptance on PLHIV's engagement with treatment and care in Swaziland is reported elsewhere (Horter et al., 2017). Others have found that status acceptance has supported the choice to live, to overcome fear of stigma and to support adherence (Gilbert and Walker, 2010; Katz et al., 2013; Nixon et al., 2018). We found that some PLHIV felt it could take time to process and come to terms with an HIV-positive result, which may be expedited under Treat-all as the time between diagnosis and treatment initiation can be reduced. This highlights the importance of considering individual patient readiness and acceptance of HIV status within Treat-all and same-day treatment approaches.

Many authors have described the ways in which HIV is associated with immorality and deviant sexual behaviour (Mattes, 2014; Mbonu et al., 2009; Mbonye et al., 2013; Moyer and Hardon, 2014; Roura et al., 2009b, 2009a), with PLHIV therefore being blamed for their infection, and HIV deemed as a punishment for those who have challenged sexual and gendered social norms (Campbell et al., 2011). HIV stigma can thus be seen as central to the establishment and maintenance of social order

(Foucault, 1978, 1977; Parker and Aggleton, 2003) and control of sexual behaviour (Mbonu et al., 2009), which can be reinforced and upheld by religion, with PLHIV being considered sinful or evil (Alonzo and Reynolds, 1995; Duffy, 2005). This is of particular relevance in the study setting, where the population is predominantly Christian, and participation in religious and church activities are an important part of culture and personhood.

Several studies have shown that individuals judged in association with HIV and immorality can experience great shame, indignity and humiliation (Campbell et al., 2011; Gilbert and Walker, 2010; Mbonu et al., 2009; Mbonye et al., 2013). Respectability is an important aspect in the social construction of value and personhood (Campbell et al., 2011), lending understanding as to why several participants in our study who anticipated stigma also contemplated suicide. Our finding mirrors that of Moshabela and colleagues (Moshabela et al., 2016, p.27) in South Africa, where it was felt “better to die with dignity, than live with shame” from being known to be HIV-positive. Additionally, a study conducted in the same region of Eswatini as our study (Shiselweni) reported suicidal ideation following HIV diagnosis and as a result of anticipated stigma (Root et al., 2017). However, there is also a powerful strand of “responsibilisation” which could be emphasised, where initiating ART early allows for continued productivity. This could be particularly effective for men, by appealing to the prevailing discourse of masculinity, which is imbued with the need to provide for their families (Siu et al., 2013). These findings highlight the importance of understanding and considering the social experiences of individuals as integral to the HIV response, and the need to acknowledge stigma and its influence on PLHIV’s lived experiences.

The longitudinal approach that was adopted in our study supported rapport and relationship building between interviewer and participant. This helped with the discussion of sensitive topics such as stigma, and facilitated access to alternative layers of participants’ narratives, beyond those deemed to be socially acceptable. This approach also enabled a greater depth of understanding, and insight to the nuanced ways in which stigma accounts changed over time. These findings are situated within

a specific time and place, relating to a fairly early stage in the Treat-all pilot, where it was uncommon for people who were relatively healthy to be accessing ART, and before national implementation. It will therefore be important to see how these findings continue to evolve as Treat-all becomes more commonplace. While likely to be of relevance to similar contexts, our findings reflect the voices of particular participants in a particular context, and therefore should be considered with this in mind.

### Conclusion

With increased and earlier access to ART in a high prevalence, generalised HIV epidemic setting, stigma persists to frame PLHIV's experiences with HIV, and to shape their engagement with HIV treatment and care. Taking treatment and engaging with care presents both benefits and risks for HIV status concealment, which must be continually negotiated and navigated. PLHIV may be motivated to initiate ART early to remain hidden by avoiding the development of discrediting stigma symbols, i.e. signs and symptoms of HIV. However, engaging with treatment and care itself presents risks of exposure at multiple points, and for some this risk was deemed too great, with decisions to abandon treatment and care being described. Where individuals are engaging with treatment and care as a means to hide their status, this is likely to be fragile, with the risk of non-adherence or disengagement from care.

These findings point to the continued need for efforts to address the root causes of stigma and stigmatising processes where those with HIV are labelled with harmful judgements of difference, deviance and immorality. Regular measurement of community HIV stigma index could be beneficial, and programmes should ensure individual PLHIV are ready for treatment, have accepted their status and are not choosing to take treatment primarily to remain hidden, as this could undermine the sustainability of their engagement. Addressing HIV related stigma is crucial for the success of Treat-all, and should thus be a core component of HIV responses.

## **Acknowledgements**

Thank you to all the participants who shared their time, stories and experiences, which enabled insight and understanding of the influence of stigma on the lived experiences and engagement with treatment and care of people living with HIV, and without whom this research would not have been possible. Thanks to all of the Ministry of Health and Médecins sans Frontières (MSF) project staff who supported this research. Thank you to Janet Seeley (London School of Hygiene and Tropical Medicine (LSHTM)) for input to the research and manuscript write-up, and to Oliver Bonnington (LSHTM) for discussion on framing the findings.

## Chapter 8: Discussion

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Within this chapter, I summarise the overall findings of the research presented in this thesis, reflecting on the contribution to existing knowledge, the novel aspects of these findings, and their relevance for Treat-all implementation. I reflect on the approaches taken within the research, and how my choices may have influenced the emergent findings. I also reflect on the ethical dilemmas that arose during the research, and my response to these. I consider the strengths and limitations of the research, outline the steps taken to disseminate study findings, and propose implications and recommendations for policy, practice and potential areas for future research.

### Overall findings

As I have outlined in this thesis, there are complex social dynamics and contextual circumstances which surround people's experiences with HIV and their engagement with treatment and care (Reynolds et al., 2016). It is vital to examine, understand and address these broader social dimensions as integral to Treat-all approaches (Keogh and Dodds, 2015; Kippax and Stephenson, 2012; Young et al., 2016). However, many of the social aspects surrounding Treat-all implementation remain unknown. In order for people living with HIV to be adequately and appropriately supported to engage with HIV treatment and care and to benefit from Treat-all, their needs and experiences must first be understood (Camlin et al., 2016a). The findings of this PhD research contribute towards this understanding, providing novel insights into the experiences of asymptomatic people living with HIV in the context of Treat-all in Eswatini, highlighting how an HIV diagnosis may be processed, decisions to engage with care and to initiate treatment taken, and ongoing engagement in care navigated over time.

The ways in which individuals respond to and process an HIV positive result may be individually and temporarily varied, potentially extending for a long period of time (Gilbert and Walker, 2010; Raveis et al., 1998). The findings I present in Chapter 4 highlight the importance of the process of status acceptance for engagement with HIV care and treatment readiness, which can be challenging in the absence of symptoms

associated with disease. Individuals may conceptualise health in terms of embodied experiences that can be seen and felt (Zhou, 2016), and within this research, many individuals understood HIV infection as occurring alongside the experience of common symptoms, which an HIV diagnosis alone could not necessarily address.

Feeling healthy may discourage treatment initiation, as findings from the Treat-all context in Mozambique also suggest, with some individuals struggling to accept their HIV positive status as a result, associating HIV with sickness (Magaço et al., 2019). The findings I present in this thesis go further in exploring the process of status acceptance, and considering the various factors which can influence it, presented in Chapter 4. An individual's acceptance of HIV status could be undermined by prevailing judgements of HIV infection resulting from immoral behaviour and "promiscuity", with which most individuals did not identify, therefore not perceiving themselves to be at risk of HIV acquisition. In this context, receiving an HIV diagnosis could disrupt an individual's biography and challenge the social prescriptions of normality (Bury, 1982), despite the high HIV prevalence, and making it all the more difficult for some asymptomatic individuals to accept their diagnosis. It appeared important for some individuals to have time to process and come to terms with an HIV positive result. HIV-related counselling was seen as crucial for providing support and reassurance for the process of HIV status acceptance, as well as broader social support and encouragement.

The biomedical logic framing Treat-all assumes that individuals will adjust their behaviour once they are educated, whereas decisions are situated beyond the biomedical realm (Beckmann, 2013). The findings presented within this thesis highlight the potential dissonance between clinical guidelines and individuals' interpretation of what constitutes treatment necessity (Kawuma et al., 2018). In Chapter 5, I examine the narratives of four individuals, situated within the broader health system context and drawing upon the accounts of health care workers and observational data. These findings further explore the potential complexity of adjusting to an HIV diagnosis and the altered self-identity this may require. Treatment may represent a concretisation or reinforcement of illness (Pound et al.,

2005), and the continuum of identity work that treatment-taking may entail can be particularly challenging for those without symptoms that signify disease. Thus, treatment decisions may be framed within individuals' embodied experiences, which can either provide evidence of treatment need, for example for those who described reinterpreting past illnesses as potential signs of HIV, or lack thereof.

In Chapter 5, I explore how ART initiation decision-making may involve multiple encounters with health care workers, and other people and technologies (Rapley, 2008). For individuals who described having time to undergo this process, and for whom the decision to initiate ART appeared intrinsically based, this could instil a sense of choice and ownership over the management of their health and treatment-taking. Having a sense of ownership of health needs (Schulman-Green et al., 2012) may enable individuals to prioritise treatment-taking, establishing it within daily routines, overcoming challenges and fostering determination and perseverance for continuation. Conversely, for those who may feel coerced to test and to initiate treatment, which appeared particularly relevant to those engaging with HIV treatment and care during pregnancy, this pressure, lack of time and absence of perceived choice could influence individuals' disengagement from care.

The findings presented in Chapter 6 further highlight the importance of individuals having evidence of treatment need and effectiveness for motivating their ongoing treatment-taking, drawing upon a sub-sample of 17 individuals who were registered as having initiated ART a mean of 20 months prior to their first interview. Within Treat-all, conceptions around health and treatment change as HIV treatment is increasingly appropriated for preventative purposes, and the symptoms of HIV and efficacy of treatment are less apparent (Zhou, 2016). In this thesis, certain individuals who had not identified physical signs of HIV prior to initiating ART, and who could not see evidence of improvements with treatment, described having doubts about treatment which could undermine their motivation for taking it and result in intermittent treatment-taking. Some described experimenting with treatment, seeking evidence of its efficacy by missing doses to see if there was any resulting effect. This may pose risks for drug resistance, which can develop through

intermittent treatment-taking (World Health Organisation, 2017a). Understanding the potential reasons for what Conrad (1985) describes as patients' "self-regulation" (i.e. where patients may alter the course of treatment to test its efficacy), will enable individuals' needs and priorities to be addressed and incorporated within programmes. For those who received viral load results, this appeared to offer a means through which the effect of treatment on the level of the virus became visible, thereby motivating continued treatment-taking. Routine viral load monitoring could therefore be particularly important in the context of Treat-all.

Despite hopes that increased and earlier access to ART would contribute to the normalisation of HIV and HIV stigma reduction (Castro and Farmer, 2005), the findings presented in Chapter 7 of this thesis suggest that HIV stigma persists to frame individuals' lived experiences with HIV in the context of Treat-all. Stigma was pervasive in the narratives of people living with HIV, both driving and undermining engagement with HIV care, and suggesting a fragility surrounding treatment-taking in this context. ART may represent a "technology of invisibilisation" (Mattes, 2014), by preventing the development of HIV-related symptoms which could expose an individual's HIV status and discredit their social identity. However, this relates to the avoidance of an abstract future risk, and individuals' identities may remain discreditable (Goffman, 1963). Engagement with treatment and care presents risks for HIV status exposure which individuals continually navigate. For some, this risk appeared too great and was linked to disengagement from care or intermittent treatment-taking. If stigma is not addressed and included as a core component of HIV responses, there is the risk that it will undermine individuals' ability to engage and to sustain engagement with Treat-all care.

Although not a specific focus of the analyses presented in the papers within this thesis, society in Eswatini is patriarchal (see Study context section in Chapter 3), and the gendered context influenced the research findings in numerous ways. For example, for men, engaging with early treatment within Treat-all was seen to allow for continued work and productivity through maintaining good health, appearing to align with predominant constructs of masculinity which celebrate strength and

productivity. Women's accounts alluded to the ways in which they would navigate the patriarchal context, and engaging with HIV treatment and care could pose additional risks for partner abandonment and abuse. The structural drivers of HIV, and the influence of gender on people's lived experiences with HIV in this context warrant further investigation.

Eswatini is predominantly Christian, and the vast majority of the population identify as religious (see Methods: Study context). The religious context also influenced the study findings, for example through shaping perceptions of HIV risk (as described in Chapter 4), and influencing the moral framing of HIV which contributed to stigmatising processes (see Chapter 7). There could be dissonance between social standards of respectability and having upstanding moral stature, aligned with the Christian doctrine, and the complexity of people's lived reality. As HIV was perceived linked to "promiscuity" and "immoral" behaviour, this could make it difficult for individuals' to accept a HIV positive status and the social identity that this inferred, potentially undermining their engagement with HIV treatment and care."

### Reflection on the approaches taken within the research

This section includes aspects relating to reflexivity, paying attention to the ways in which the researcher may be shaping the data, as well as broader reflections on my choices within the research, which may have influenced the findings, including the epistemological approach and the provision of a financial reimbursement or contribution to participants for their time. I also reflect upon some of the ethical dilemmas that were raised within the research.

### **Interview dynamics and data co-production**

In recognition of the co-produced nature of data within interviews, and the role of the interviewer in shaping the data (Gubrium and Holstein, 1997; Silverman, 2013), I had initially wanted to undertake interviews with participants myself. The desire to be present in interviews was so that I could have a direct connection with participants, to facilitate understanding their social circumstances and life world,

which could aid my interpretation of participant accounts within data analysis, and my ability to reflect on the dynamics of data production. However, I also wanted to choose the most appropriate approach in the study setting, to be mindful of potential power dynamics, ethics and participant comfort. Initially, I piloted the approach and conducted one interview with a woman myself. Although I had siSwati lessons twice a week, and was learning the language, I was not fluent enough to conduct an interview in siSwati, so a researcher accompanied me for the interview to interpret. This interview experience raised several concerns relating to ethics and power dynamics. The participant lived in a very rural location, around one hour walk from the road into the hills, and as we walked together through the community to get to her homestead, my presence drew a lot of attention, partly because I was not known to the community, exacerbated by my skin colour and the visibility of this difference. When I discussed this with her, she said it was fine, as people in the community would assume I was from World Vision (charity), or that I was a missionary, which would be preferable to assuming I am from the health services or MSF, to avoid risk of inadvertently disclosing her HIV status. However, the amount of attention was uncomfortable and could have the potential to cause her harm.

The consent process was slower than had been the case for other interviews, and she seemed confused about the research process and in her expectations of what participation may involve. Initially she asked if we were offering her a job, and at first was reluctant about making a time commitment she could not uphold, saying she felt conscious that she could not teach us anything, as her education level is low, before saying she would like to take part. This raised questions about the extent to which she may have felt able to refuse participation, and about her understanding and comfort. Once the interview began, I established good rapport with her, and she appeared comfortable and open. However, there were several allusions to hierarchical power dynamics, which appeared exacerbated by my race. For example, when we arrived, her family members came to greet us, thanked us for visiting and said that as I am powerful and respected (presumed due to my skin colour), now the rain should come.

Following this experience, I wanted to explore this further, and to be led by participants' views, preference and comfort, asking if they would feel more comfortable being interviewed by me (a white woman) or by another researcher (a Swati woman) prior to meeting with individuals. One woman responded by strongly emphasising that she did not want an *umlungu* (white person) coming to meet her, and another responded "*What is it that you really want now that you are bringing this white woman... no please don't bring a white lady to me*". I therefore decided that it would be more appropriate for these interviews to be conducted by same-gendered siSwati speaking Swati researchers, and took other steps to remain close to the process of data generation (as described in the Methods Chapter 3, section: Approach to data generation, p74).

The most important factor influencing the choice of interviewer related to participant comfort and safety. There may also be relative value in the interviewer having either "insider" or "outsider" status (Best, 2003), as described in the methods chapter. It appeared that the "insider" status of the interviewer in having presumed shared experiences and understanding supported participant comfort and openness, which was particularly visible where the participant and interviewer were presumed to be age mates, with a relaxed and open dialogue. Age is said to be the main factor characterising group association in Swati life, and age cohorts are a particularly important means of differentiation among men, with women also identifying with age groups, though perhaps on a less formal and regimented level (Kuper, 1986). For example, one woman who was similar in age to the interviewer said: "*I feel comfortable talking to you... it's like you're my friend*". However, this "insider" status could make it challenging for the interviewer to probe or to make explicit meaning that was presumed to be shared and mutually understood, reflected in language such as "*as you know we men/women...*" and "*as Swatis we are just like that...*"

Where there were differences in age or presumed social status, this could create power dynamics which influenced the interview process. While steps can be taken to mitigate these dynamics, it may be impossible to fully equalise power, and it is important to explore the ways in which they may influence the interview process and

participant accounts which result (Oakley, 1981; Roulston, 2010; Skeggs, 2001). The influence of such dynamics could be seen in certain interviews with young women, who were often reserved and more closed in their responses to questions or probes. For example, one young woman who was 23 years old and recorded as lost from treatment said *“I do not know what how to answer your questions, they are so strong”*. Younger participants often appeared to become more comfortable over time, and the longitudinal approach to data generation likely aided this relationship building.

Differences that participants felt in social status could result from perceived educational differences, social class or status, for example one man said *“I don't understand you since I didn't go that far in school”*. This could potentially result in some reluctance for participants to feel fully comfortable and open to share their views, fearing they may not be appropriate or acceptable. One interviewer's surname shares a connection with the royal family of Eswatini, which could have also created a certain dynamic, respect and formality. The clanship associated with this name holds the highest social level, as lineage with the king is pre-eminent and therefore holds high attributed social status (Kuper, 1986). For example, one man refers to him as *“mntfwanenkhosi”*, which is a surname extension (said in a sign of respect) that directly translates to child/son of the king. This participant would often check in with the interviewer to ask if his responses were appropriate, and said *“in my opinion, and this is not to say that's how it would be, but it's just how I see things”*. These interviews could appear more formal and respectful, with the participant's narratives seeming to be aligned to a narrative deemed to be socially acceptable, and often accordant with the predominant health messaging, for example that having multiple concurrent partnerships is not acceptable.

In interviews with health care workers, which I conducted, there were instances where my “outsider” status as non-Swati may have enabled probing and exploration of topics relating to the “way of life” or the “Swati way”. For example, in allowing deeper exploration of gender dynamics:

*“Swazi traditional men, I'm not sure whether I would say they are very tough or strong or what. Because, myself I don't remember when was the last time I was sick.*

*Not because I'm now somebody who is a nurse, but we are not those people who just get sick anyhow. Yeah, we are just like that." (Clinic nurse, man)*

Additionally, in explaining aspects relating to migration and engagement with care:

***Interviewer:** when you say for us Swazis it's unlawful...you mean it's unlawful for people to move to that side...to South Africa? Could you tell me more about that... what do you mean by that?*

***Participant:** being a Swazi...you are not allowed to do your documents that side... South Africa is another country... it's not your own country where you were born you see... being a Swazi you have to stay in Swaziland. They [patients] are just cheating on their own by relocating there. It's just that we [clinic] are located along the borderline. (Clinic nurse, woman)*

This difference, as well as reassurances of confidentiality, may have created an environment where participants felt comfortable to share views which challenge the dominant, socially normative narrative, for example relating to the political context in Eswatini. This can be seen in the narrative of one participant who spoke openly about problems with the current political system and the wealth inequity, identifying as wanting democracy rather than the monarchy, which was not common in the social context:

*"I think we have got enough money in Swaziland it's just that somebody is enjoying. If people can go to Las Vegas to just buy water to drink, while we are fetching our water from the streams, it means you have got a lot of money if you can travel just to get water from Las Vegas." (Clinic nurse, man)*

It is important to reflect on the potential influences of interviewer-interviewee dynamics, and to consider the relational environment within which data is generated when interpreting and analysing participant accounts.

### **Reflections on the research approach**

As described in the methods chapter, the epistemological approach underpinning this research is phenomenological and interpretive, aiming to understand the

complex world of lived experience from the point of view of those who live it (McCaslin and Scott, 2003; Schwandt, 1994). In examining how engagement with HIV treatment and care may be experienced in the context of Treat-all, I aim to understand how individuals make sense of this experience (Smith, 2004), and I recognise that there is no single interpretive truth (Denzin and Lincoln, 2013). Additionally, as the approach that I adopted was largely inductive, this will have influenced the findings that were generated, as rather than being predetermined, findings emerged from participants' perspectives, and were primarily exploring individuals' interpretation, understanding and experience. While I also considered and explored the broader social and health system context, the primary focus was on individuals' lived experiences, rather than for example being predominantly health system or policy focused. The influence of this perspective can be seen by comparing the findings presented in Chapter 7 on how stigma frames individuals' engagement with Treat-all care, with that of Bond and colleagues (2019). The findings in Chapter 7 demonstrate the ways in which stigma frames narratives of living with HIV and engaging with treatment and care in the context of Treat-all. Bond and colleagues also examine stigma experiences in the context of Treat-all (in Zambia and South Africa), but focus on the environment within health facilities which contributes to the production of stigma experience for people living with HIV, through exploring the spatial organisation of HIV services and material items. These findings both provide interesting insights to HIV stigma in the context of Treat-all, from differing perspectives.

Due to the large volume of data that were generated through this research, further analysis and publications are planned. For example, there were findings relating to how the preventative benefit of ART is understood by people living with HIV, the fact that the vast majority had no knowledge of this benefit, although it was seen as information that could motivate treatment-taking, and reasons for health care workers' reluctance to share this information with individuals. I chose to present findings which emerged most strongly, for example across several participants, and appearing to be influential for lived experience and engagement with care, and additionally, which aligned with the research aim and objectives. Therefore, while

the findings relating to treatment as prevention were interesting, as they demonstrated that this preventative benefit was largely unknown, they therefore did not appear to frame people living with HIV's interpretations of Treat-all or narratives relating to engagement with care. This choice thereby frames the findings presented in this thesis.

The majority of interviews were conducted in siSwati and subsequently translated, which is likely to have influenced the findings to a certain extent. Meanings are embodied in the language of participants (Schwandt, 1994), and within this research I aimed to interpret and represent such meaning in the way intended by participants in their narratives, in order to ground findings within participants' accounts (Brocki and Wearden, 2006) and to authentically present their perspectives as much as possible. However, due to differences in the construction of siSwati and English, it was not always possible to directly translate, and also convey the meaning of phrases or words. Therefore, equivalent translation was used in the instances where there was no word available for direct translation, and to convey meaning, with the original siSwati word indicated in parentheses. When writing the paper included in Chapter 5, on choice and ownership regarding treatment-taking under Treat-all, I had initially positioned findings to consider the extent to which individuals had a sense of choice regarding the decision to initiate ART, and what influenced their experience of enacting choice. In this framing, I was interpreting participants' use of words such as "I *must* take treatment", "I *had* to take it" to infer a potential lack of perceived choice. However, I could not be confident that the meaning behind these expressions was exactly the same in the original siSwati form and in English, and in the accuracy of such interpretations. I therefore decided to instead focus on the decision-making processes, and how participants' narratives described and accounted for the thought and other processes that individuals could undertake when coming to the decision to initiate ART. Some social constructivists consider language as a site of reality construction, and will analyse the minutia of language and accounts to infer meaning (e.g. Best, 2003). While this is a different level of focus to the approach taken within this research, it could be difficult to examine and understand such dynamics due to the added layer of translation creating additional distance and complexity.

## **Ethical dilemmas**

The section on Ethics in research in the methods chapter outlined the steps taken within this research to uphold ethical principles, and in this section I reflect on some of the ethical dilemmas which were faced within the research process, including my decisions and responses to such dilemmas. I recognise that informed consent is a process (Hewitt, 2007). Consenting to participate, understanding the research process and what participation involves is more nuanced than a signature on a consent form, and may change over time. I therefore sought to explore and understand how participants may have experienced study participation. For example, any potential influences the research may have had for them, and how their understanding and expectations about their participation aligned with their experience of it.

A particularly challenging ethical dilemma related to emotive discussions and referrals to psychosocial support for certain participants. The nature of discussions relating to HIV are inherently sensitive, and while certain approaches such as interviews being led by participants and not ending with emotive topics can help protect participants from harm, there is still the possibility of emotional distress. I had planned to have a referral system whereby any participant who was emotionally distressed, in need of psychosocial support, or at risk of harm, would be referred to the psychosocial team, and this would be discussed with the participant beforehand and their consent sought. However, when discussions relate to past or historic trauma, or more complex needs than can be provided for within a predominantly biomedical project, where the mental health support is mainly focused around adherence and support for engagement with health services, this can be challenging. Although I was aware of the patriarchal context in Eswatini from my experience living and working in Shiselweni, I was not prepared for the number of participants who described their experiences with sexual violence and abuse, which particularly related to the life history interviews, as well as to narratives of HIV acquisition. Almost every woman in the study described having experienced some form of violence or abuse, and sexual non-consent was frequently implicit within participants' accounts. This was confronting, and while reflecting broader social

constructs relating to power and gender, was difficult to navigate when forming relationships with individuals who were so open in sharing their experiences. It felt insufficient to listen without being able to act, to offer or refer to specialist support, or to contribute towards dismantling the violent and oppressive social structures which exacerbate violence against women. However, within this project, and the broader study setting, we were limited with the options of support that could be offered.

The research assistants and I identified several participants as being in need of additional psychosocial support, and I had anticipated that being situated within the MSF project would aid the referral process. However, in reality the process was more complicated. There was resistance to what was perceived as the creation of more work for the psychosocial team, and referrals had to fit within the existing operational systems, which were largely based around clinic engagement. For example, one younger woman who was not on treatment or engaging with care was told she would have to go to the clinic to be able to see the counsellor. Eventually we were able to navigate these challenges and establish an agreement with the team to refer certain individuals, but it was not as easy to refer people for additional support as we had hoped.

Responses to the invitation to participate were varied, even among those who agreed to participate, and while the invitation was generally interpreted as a positive opportunity some individuals had concerns about why they had been chosen. For example, one woman said:

*“I asked myself why they chose me, and I’m going to tell you my sister-in-law, because I was asking myself that maybe there’s something I haven’t done alright or maybe God has sent these people to me to ask something which will help them and also help me in the process... like maybe did I make any mistakes? Or is my illness different to the rest? And then I told myself again that no... they want to help us, and it’s not like I have told our king’s secret...(laughter)...and I have since moved myself out of that problem” (Woman, on treatment)*

Several participants had concerns regarding confidentiality and how we had obtained their contact details. For example, another woman describes her fears and confusion when she was first invited to participate:

*“When you called me I was shocked ‘where did this person get my number from and what does she want me to do’, and I asked myself ‘does she not want to expose me to people’... it was my first time hearing of this research you see...”* (Woman, on treatment)

Confidentiality concerns regarding how researchers had obtained participants’ contact information partly influenced the decision to not directly emphasise an HIV focus when introducing the study. Rather, the research was framed as being about health and experiences with health care services in Shiselweni more broadly, and any disclosures relating to HIV were led by each individual participant. I felt uncomfortable with not being fully open and transparent with participants about the HIV focus of research, which could have been unethical, but it seemed most important to not presume participants’ HIV status and to allow such conversations to be led by individuals, rather than by the researchers. Sensitivity around presuming participants’ HIV status or leading with HIV discussions felt particularly pertinent given how stigmatised HIV is in this context.

While most of the individuals who were invited to participate agreed, there were several who appeared positive about the research, and agreed to meet, but who either frequently rearranged or who then didn’t attend the agreed appointment and subsequently became uncontactable. Such participants have been described as “silent refusals”, hesitating to participate without explicitly refusing (Kamuya et al., 2013). Initially it could be hard for researchers to distinguish certain silent refusal participants, particularly those who appeared positive and engaged. For example, there was one man who agreed to meet on several different occasions, but each time asked to rearrange because of work or other commitments. Silent refusals were explored within a study in Kenya, which found that this could be a norm when politely refusing strangers or highly respected individuals, perceiving an outright refusal as being rude (Kamuya et al., 2015). This can raise ethical dilemmas in how to

recognise and respect silent refusal without badgering individuals to participate who may not really want to take part. This also needs to be balanced when trying to recruit harder to reach individuals, for example those lost from treatment, who may need more time and reassurance about what research involvement entails before feeling comfortable to take part. For example, one young woman who was lost from treatment initially appeared as though she may be silently refusing, but when we managed to meet with her to talk through more of what the research would entail, she said she had been concerned that the researcher would try to bring her back to treatment. When this concern was addressed and the participant was reassured by further explaining the confidentiality of discussions, she was then willing to take part.

It is possible that some health care worker participants felt unable to refuse study participation, as a member of the project who was their superior (the head of clinical activities, as outlined in the Methods Chapter, section: Main phase: longitudinal study; Participant recruitment) requested their participation before I could discuss consent and what participation would involve. Health care workers may also have perceived the interview as an evaluation of their performance. Once it was possible to meet with health care workers and discuss the research further with them, most appeared to feel more comfortable. However, some were potentially more open in sharing their views than others, and the views reflected were largely professional.

Taking part in the research appeared to impact on individuals in different ways. Several participants described appreciating having a safe, confidential space to talk about their lives and HIV, with certain individuals saying they had not spoken about their status with anyone else before, and feeling that it was good to talk and to be able to get things off their chest, having a cathartic, comforting effect and described as reducing stress. Research participation also seemed to impact on experiences with HIV for some, for example there were participants for whom interview discussions supported their feeling able to talk more openly about their status, possibly facilitating disclosure beyond the interview setting. One woman said:

*“Talking to you has made me to be able to talk to another person about my life, whereas if you weren’t talking to me, I would feel like it is my chest, my secret to keep and I*

*have to keep quiet and not tell even my friend... I was scared Zet [nickname participant has given the interviewer] but now that I am talking to you I feel like it is just stupid for me to be scared... Because I am talking with you, I am able to talk to someone else [outside of interview] now... hiding it will not work for me.” (Woman, on treatment)*

Certain participants who were lost from treatment also described re-thinking their treatment-taking and engagement with care following interview discussions, as another woman describes:

*“I thought I should start taking them [ART], after you came here, I thought I should start taking them because what if I pass it on to my child...” (Woman, lost from treatment)*

Additionally, the research could offer reassurance that people’s voices were valued, that the government cared for individuals and wanted to hear their views and experiences and incorporate them into health services.

*“Having someone to talk to about my status has helped develop me... there’s something I’m going to learn from you as we talk and I also feel appreciated that we are people as well, and that we are also accepted in the community unlike to feel neglected.” (Man, on treatment)*

*“I think that there could be some change that is instigated especially if I have been abused in some way at the health facility, the research can make a difference in making that change happen.” (Young woman, on treatment)*

Many described taking part because they wanted to help others who may have similar experiences to them, to encourage people to test and to be able to access care. However, there is the potential that this could reflect an expectation which the research cannot guarantee to deliver on, as while this research highlights areas for potential adaptations to policy and practice, I cannot control to what extent these are heard or adopted.

While the longitudinal nature of the research supported relationship building between participants and interviewers, this also requires navigating and warrants

reflection. For some individuals, particularly women, their language and communication reflected a sense of friendship with the interviewer, with some sending Whatsapp messages to say “hi” and to check in between meetings. It felt important to try to put boundaries around this relationship and be clear in terms of expectations, to protect participants from any potential hurt or disappointment, while at the same time appreciating their trust and openness. As participants had been involved in the study for some time, we prepared for the study ending by reminding participants of what participation would involve at each interview, and checking in with how they were feeling about the last interview.

In the methods chapter, I outlined why I decided to offer participants a small financial reimbursement for their time, as well as providing refreshments for each interview. Here I will briefly reflect on how these reimbursements may have influenced the research process. The use of reimbursements appeared to influence certain participants’ attitudes towards research participation in feeling appreciated and more positive towards taking the time to take part than they may have felt otherwise, as one young woman says:

*“I liked the fact that you also get some... [laughing] [money] they do not irritate you for nothing..”* (Young woman, lost from treatment)

While unlikely to have influenced choices regarding participation at the study outset, as reimbursements were not promoted when inviting study participation, these reimbursements may have potentially contributed to motivating continued engagement with the research.

Observations raised unique ethical dilemmas. In sessions that were observed, I would try to minimise my presence as much as possible, to avoid disturbing the flow of the session and individuals’ comfort, for example sitting behind patients or out of their line of view, though it is inevitable that my presence will likely have influenced the interactions that I observed. It was not feasible to form a relationship with all patients or individuals involved in the sessions that I observed, and as I relied upon health care workers to introduce the research, my presence, the purpose of the observation, and to seek individuals’ consent, this created some distance from what was said and

how the research was presented and understood. Certain health care workers seemed to interpret my presence in observing their work as an evaluation of their performance, and one introduced me to a patient as being there to see whether health care workers' shouted at patients. Having more time with health care workers and being able to further explain and reassure them seemed to help with this, but ultimately sharing the research findings with clinics and project staff did involve critical reflection on the services that were delivered, so it may be inevitable that the research would be interpreted as somewhat of an inspection. All individuals were given the choice to opt out of having their session observed, or to ask me to leave at any point. In observing HIV testing sessions, certain individuals were happy for me to observe the pre-test information, but did not want me to be present for the test result. Other than that, all individuals gave verbal consent for observations.

### Strengths and limitations

As this research was positioned within an MSF project piloting Treat-all under routine programmatic conditions, this provides a unique opportunity to explore individuals' experiences with Treat-all at an early stage of its implementation, which can then inform future policy and practice relating to Treat-all. This Treat-all pilot began in October 2014 and had been underway for some time when this research commenced. It was therefore possible to recruit participants who had been enrolled in the pilot for almost two years, and to explore somewhat longer-term engagement. However, some of the findings may change as Treat-all becomes more commonplace. These findings are situated within a particular time and place, relating to a context within which the concept of treatment for HIV when asymptomatic was fairly unfamiliar and not yet the standard of care or incorporated to national treatment guidelines, and should be interpreted with this in mind. Additionally, the HIV services offered to individuals in this context likely included more patient support and routine viral load monitoring than may be included in other settings, due to MSF's support. However, the pilot aimed to investigate the feasibility and acceptability of Treat-all under routine programmatic conditions, with lessons to inform the national roll-out of Treat-all. Feasibility thereby included reflections on

resources (human and financial), and what would be sustainable in contexts beyond the MSF programme. The availability of viral load monitoring provided the unique opportunity to explore participants' perspectives and experiences with this tool.

This research included fieldwork (over the period 2015 to 2017), and the formal and informal observations that this enabled aided my interpretation of interview data and provided a deeper understanding of the broader study context. As observations were conducted with the assistance of an interpreter, this may have resulted in some of the nuance in the use of language, and potential meaning of the words that were used by participants being missed. The longitudinal nature of the research supported relationship building between participants and interviewers, facilitating trust, rapport and comfort and creating rich data that offered unique depth of insight into the lived experiences of people living with HIV within the context of Treat-all. This could have been particularly important for younger participants, who appeared to become more comfortable and open over time. The relationship building that was facilitated by repeat interviews also aided the discussion of sensitive topics, and access to alternative layers of narrative, beyond those deemed to be socially acceptable, and often closely aligned with the dominant health messaging. Repeated interviews allowed for the exploration of changes in participants' experiences over time, reflecting the evolution in perspectives, interpretations and understanding, and the non-static nature of living with HIV and engagement with treatment and care. However, repeated interviews were held after a fairly short period of time (mean 8 months before first and last interview for those who had more than two interviews). The regularity and close time proximity of interviews will likely have aided rapport building, but may have not allowed for many changes in circumstance or experience, for which a longer research time frame with extended spacing of interviews would have been needed.

A range of perspectives are reflected within this research, adding to its value. Individuals recorded as lost from treatment, men and young women are included, whom we know can all have additional challenges with treatment-taking and engagement with care, and whose perspectives are important to understand, in

addition to the perspectives of those who are engaging with care. However, it is still possible that the hardest to reach individuals were not included, and these individuals may be particularly disadvantaged or have unique challenges relating to engagement with HIV treatment and care. Almost half of the identified individuals for study recruitment were uncontactable, due to an unavailable or incorrect telephone number. This reflects the challenges with follow-up of individuals in this context, and these individuals may have had different experiences from those included in the research. There were also several silent refusals, i.e. individuals who agreed to meet but did not attend the appointment, and who then became uncontactable. It was therefore not possible to explore their reasons for non-participation or to reflect their voices within the study findings. It was not possible to recruit young men to the study, as the HIV epidemiology of Eswatini means fewer young men are living with HIV, and men often access treatment and care later than women. There were therefore no young men registered as newly diagnosed and enrolled in the Treat-all pilot who met the study eligibility criteria for CD4 count and WHO disease stage. This will have affected the study findings, in not reflecting their views and experiences.

Due to time and resource constraints I took the decision for audio files to be transcribed directly in English (translated from the audio), rather than being transcribed verbatim and then translated. This is because the same researchers who conducted the interviews also conducted transcription and translation, and it would have taken double the time to transcribe and then translate, thereby delaying data analysis and the time frame for subsequent interviews. Although the original audio files could be referred to during data analysis, and transcripts were checked for data quality, having the siSwati and English transcripts could have facilitated remaining closer to the original use of language.

### Dissemination of research findings

I took steps to disseminate the research findings at local, national and international levels, as follows:

Local dissemination: Throughout the research process, I shared and discussed preliminary findings with the project, largely through PowerPoint presentations and workshop-style discussions. These sessions included presentations to the whole project, sessions held with the research and medical teams, and with counsellors and others in the psychosocial team. Once data analysis was complete, I also returned to the project to share the final findings with members of the project including those at coordination and field teams, and prepared a presentation for sharing findings with the clinic staff and the Ministry of Health. I had wanted to hold sessions at each of the clinics during this visit to share findings with health care workers directly and to seek their views on the findings and potential implications. However, this was not possible due to project constraints. I met with several of the participants at the study end to thank them for their time, to share the key findings with them, to answer any questions they may have and to seek their views on the findings. Within these meetings I offered a contribution of meat and soap to thank participants for their contribution, and prepared a document summarising the findings for these participants, which was translated into siSwati. Unfortunately, it was not possible to meet with all the study participants, but only those who were interested and available. I also prepared a programmatic feedback report with extensive research findings and recommendations for policy and practice, as well as a summary of key findings document (see Appendix 5).

National dissemination: I presented preliminary research findings at several stakeholder meetings with the Ministry of Health and other partner organisations present, in Mbabane, throughout the research process. The programmatic feedback report and summary of findings document were distributed to national partners, and a member of the Ministry of Health was a co-author on each of the papers prepared for publication. I prepared three oral presentations of the research findings, delivered at the Eswatini National AIDS conference in July 2016, with one winning an award.

International dissemination: I delivered an oral presentation on the research findings at the MSF Scientific Day conference in May 2016, with an online audience of around 8,000 people worldwide. I presented a poster at AIDS 2016 in Durban. Additionally,

I orally presented research on viral load monitoring and Option B+ at the ASSHH conference in Stellenbosch in 2015. Three papers have been published in peer-reviewed journals and one has been submitted, which it is hoped will contribute towards dissemination of research findings, all being open access publications.

### Recommendations

The findings presented in this thesis highlight the individually varied, potentially complex process individuals may go through when coming to terms with an HIV diagnosis, deciding when to start treatment, and sustaining engagement in the context of Treat-all, with specific support and informational needs for those who are asymptomatic.

Policy relating to Treat-all implementation should include counselling as integral, with flexibility to tailor support to meet individuals' needs for time and intensity of support, and with specific provisions for supporting status acceptance and treatment readiness. Specifications should be established to allow for some individuals to be able to take more time before initiating ART, without feeling pressured, and highlighting the importance of individuals having sense of choice regarding this process. Stigma should be included as integral to the HIV response, including components of support, as well as consideration for how to tackle stigma at its root. Viral load monitoring should be routinely available and delivered alongside Treat-all, with results communicated to patients to support continued treatment-taking. Results should be communicated for both suppressed and unsuppressed

Within practice, counselling and support should be available for diagnosis and treatment initiation decision-making, tailored to meet individuals' needs for support and time, ensuring acceptance, readiness and sense of choice regarding ART initiation. While this has resource implications, increased support will likely result in a wealth of benefits including improved patient outcomes. Approaches should reflect conceptualisations of health, illness and treatment beyond the biomedical, to address individuals' potential concerns about the need for treatment in the absence of any physical signs of ill health. Areas of focus could include the potential for treatment to preserve good health and productivity, which may be particularly appealing to men

and which can align with dominant conceptions of masculinity and strength. It should be acknowledged that stigma can undermine individuals' abilities to engage with treatment and care, and rather than health messaging encouraging individuals to hide their status, which could reinforce stigma processes, individuals should be supported towards status acceptance and disclosure, as well as with finding ways to navigate the stigmatised environment which surrounds HIV.

The importance of individuals having evidence of the difference that treatment is making for motivating their continued treatment-taking should be recognised within programmes, and steps taken to communicate and to meet this need, including in communicating viral load results as a potential tool to provide this evidence to individuals. Additionally, individuals should be supported to foster a sense of ownership over the management of their health and treatment-taking, with support for their determination and perseverance in overcoming its challenges, and creating a safe space to be able to discuss such challenges without fear of retribution. It is important for health services to be delivered in an environment which encourages openness and support, where patients feel able to come forwards and share their challenges with health care workers without fear of being reprimanded. Programmatic targets should be interpreted with an understanding of the individual variation in responses to Treat-all care, and pressure for health care workers to successfully implement Treat-all should be understood in this context. For example, some individuals need more time to engage with treatment and care, and this does not reflect on the performance or ability of health care workers to convince them.

Further research on the structural drivers of HIV and how this shapes individuals' engagement with treatment and care in the context of Treat-all is warranted, including the fundamental causes and drivers of stigma, which should be better understood and examined in order to consider how stigma may be tackled at its core. Additionally, it is important to consider the experiences of individuals who have been engaged with Treat-all care for a longer period of time, as well as exploring the views and experiences of those experiencing Treat-all once it becomes more established and commonplace. For further recommendations see Appendix 4.

## Conclusion

A body of scientific evidence demonstrates that Treat-all is efficacious for reducing HIV transmission and improving the clinical outcomes of individuals living with HIV (Cohen et al., 2011a; INSIGHT START Study Group, 2015; The TEMPRANO ANRS 12136 Study Group, 2015). However, we have seen from the early findings of Treat-all trials that this does not directly translate to a reduction in HIV incidence at the population level (Havlir et al., 2018; Hayes et al., 2019; Iwuji et al., 2018). The social reality surrounding people's lived experiences with HIV and with engagement in care is complex and nuanced. The biomedical paradigm that considers health as an absence or containment of disease does not account for the multitude of aspects to health, personhood and self, which extend beyond the biomedical (Beckmann, 2013; Hickel, 2012). The findings presented within this thesis highlight the perspectives, priorities and needs of individuals living with HIV in Eswatini, who must be able to engage with HIV treatment and care services in order to experience the benefits of Treat-all, which should be incorporated within the HIV response. Additionally, the findings of this research explore the potential dissonance between the biomedical logic framing Treat-all and individuals' conceptions of health and treatment need, as well as between the priorities of individuals and the priorities of biomedical and public health agendas which frame Treat-all. Understanding these perspectives may help with considering how such differences may be reconciled, and how challenges engaging with treatment and care in the context of Treat-all may be overcome.

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<p><b>TasP</b> <b>ANRS12249</b></p>	<p>South Africa</p>	<p>Cluster-randomised trial of 22 communities in Kwazulu-Natal between 2012 and 2016, aiming to evaluate the feasibility and acceptability of UTT, with 28,419 individuals eligible for inclusion in the trial.</p> <p>Control group ART initiation as per national guidelines, intervention group immediate ART initiation for those diagnosed positive (UTT).</p> <p>Residents were offered home-based HIV testing 6monthly for 2-4 years (depending on the cluster)</p> <p>HIV positive individuals were referred to trial clinics for ART.</p> <p>In the control group national guidelines were initially <math>\leq 350</math> cells per <math>\mu\text{L}</math> and <math>&lt; 500</math> cells per <math>\mu\text{L}</math> from January 2015</p>	<p>Population-level suppression was 75% after 1 year and 80% after 2 years of intervention</p> <p>Of 8,646 observed people living with HIV Jan 2013 – Jan 2016:</p> <p>Population viral suppression increased:</p> <p>Intervention arm: increase of 17% (from 29.0% suppression to 46.2%, <math>p &lt; 0.001</math>)</p> <p>Control arm: increase of 12% (from 32.4% suppression to 44.6%, <math>p &lt; 0.001</math>)</p> <p>This effect was mainly attributable to repeated home-based counselling and testing, with <u>limited effect attributable to ART</u> (explaining the limited difference between trial arms).</p> <p>Null effect observed on cumulative HIV incidence.</p> <p>Concluding changes in ART guidelines alone not sufficient to significantly increase population-level viral suppression.</p> <p>63% trial participants women and 37% men</p> <p>Estimated HIV incidence was 2.11 per 100 person-years (95% CI 1.84–2.39) in the intervention group and 2.27 per 100 person-years (2.00–2.54) in the control group (adjusted hazard ratio 1.01, 95% CI 0.87–1.17; <math>p = 0.89</math>)</p> <p>90-90-90 cascade estimated as:</p>	<p>AIDS 2018 conference presentation: (Larmarange et al., 2018)</p> <p>Publication: (Iwuji et al., 2018)</p>
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<b>MaxART</b>	Eswatini	<p>Stepped-wedge randomised trial, enrolling 3,485 participants from 2014 to 2017 across 14 government health facilities in the Hhohho region, with primary endpoints of retention and viral suppression.</p> <p>The implementation study aimed to determine feasibility, acceptability, clinical outcomes, affordability and scalability of offering early ART to all HIV positive individuals.</p>	<p>91.5% of HIV positive participants knowing their status, of whom 58.0% were on ART, 85.3% of whom were virally suppressed – 49.4% of all HIV positive participants virally suppressed.</p> <p>Presumed absence of difference in HIV incidence between intervention and control due to low linkage to care (only around 30% of individuals registered at trial clinic within 6 months of HIV diagnosis).</p>	<p>AIDS 2018 conference presentation: (Khan et al., 2018)</p> <p>(MaxART Consortium, 2018)</p>
			<p>Under the UTT intervention, 12 month retention was 86% and viral suppression rate 79%, compared to 80% and 4% respectively under the standard of care (control).</p> <p>75% of individuals were missing viral load results at 6 months on ART, and were considered unsuppressed (which could largely account for the difference in viral suppression between the intervention and control arms)</p> <p>Adopting UTT led to improved health system performance</p> <p>Average public sector costs per ART patient-year remain essentially the same under UTT and standard of care (mean cost US\$219 compared to US\$215 respectively)</p>	

<p><b>The Ya Tsie Botswana Prevention Programme</b> (also referred to as Botswana Combination Prevention Programme (BCPP))</p>	<p>Botswana</p>	<p>Pair-matched community-randomized trial evaluating the impact of prevention interventions on HIV incidence in 30 rural/semi-urban communities throughout Botswana, from 2013-2018. Intervention arm: combination prevention including scale-up of annual HIV testing campaigns and UTT, linkage to care, retention in care and adherence support, and male circumcision referral for HIV negative men</p> <p>Comparison arm: enhanced care as per local guidelines</p> <p>Universal ART became standard of care in both arms mid-2016.</p> <p>A random sample of ~20% of households in each community was selected for longitudinal HIV incidence cohort with annual HIV testing and counselling</p>	<p>HIV incidence measured through a sub-sample of 12,610 participants:</p> <p>At baseline, 29% were HIV-infected, of whom 72% were already on ART</p> <p>The intervention resulted in a reduction in HIV incidence of 30% compared to the control, though not statistically significant (incidence ratio 0.69, p=0.09)</p> <p>Annual HIV incidence was measured at 1.35% in 2013</p> <p>Trial results 2013-2015 found HIV incidence estimated at 1.06%</p> <p>90-90-90 cascade estimated as:</p> <p>83.3% of individuals with HIV knew their status</p> <p>87.4% of whom were receiving ART</p> <p>96.5% of whom were virally suppressed</p> <p>Overall, 70.2% of individuals with HIV were virally suppressed</p>	<p>AIDS 2018 conference presentation: (Makhema et al., 2018)</p> <p>Publication: (Statistics Botswana, 2013) (Moyo et al., 2018)</p> <p>(Gaolathe et al., 2016)</p>
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## Appendix 2: Example data generation and capture tools

### Participant Interview 1 Topic Guide – Life History

*Could you tell me your life story, from when you were as young as you can remember?*

*[their story, in their words, open narrative – silent probing and encouragement to continue]*

- **Childhood, upbringing and key life events**
  - What are your earliest memories from your childhood/life?
  - Are there any family stories that were told about you as a baby or a child?
  - Were there certain duties or tasks you had to do as a child?
  - What would you say are some of the key/main events or experiences that have happened in your life?
  - How did these experiences impact or affect you?
- **Family structure**
  - What was your family structure like? Who did you grow up with (at homestead)?
  - What do you remember about [family members described]?
  - How would you describe their personality/characteristics?
  - What do you think you inherited from them?
  - What feelings come up when you think about your parents/grandparents [link to family members mentioned above]?
  - Which people would you say were most influential for you during your upbringing? *Probe role model/ someone looked up to*
- **Area/community grew up in (and now)**
  - What was the area you grew up in like?
  - What was the community like?
  - What role did/does your family play in the community structure? *Probe social position*
  - *Gossip*: What are the sources of gossip in the area? What do people talk about? What do you think about that? Why is that important?
- **Educational experience**
  - What was your experience of school (probe educational level)
  - What was school like for you?
  - What did you like/dislike about it?
- **Hopes and aspirations**
  - When you were young, what did you want your future to be like?
  - What did you want to be or do when you grew up?
  - How does your life now compare to what you imagined as a child?
  - *Probe work and income* – source of income/type of work? Regular income or not?
- **Relationship views and experiences**
  - Could you tell me about your relationships growing up until now?
  - What were these relationships like?
  - If in current relationship, could you describe what your relationship is like/tell me about it?

- What does your partner do for you
- What do you do for [him/her]?
- What's important for you in the relationship?
- If not in current relationship, what do you want for the future?
- *Probe relationship expectations versus reality*
- *Probe what's important versus unacceptable in a relationship*

**Anything else to add? Any questions for me?** *Info for next interview, thanks and close.*

### **Participant Interview 2 Topic Guide**

- **Follow-up from 1st interview**
  - How have things been since we last met?
  - [Probe specific areas discussed in first interview] – *adapt for each participant*

#### **If NOT DISCLOSED:**

- **General health, illness, health management and health seeking**  
*How have you been feeling?*
- *[If necessary probe]: Could you tell me about how you manage your health, and experiences you have had with illness or ill health generally...*
  - Probes:
  - Perceptions around health and ill health/being healthy and being sick, signs of ill health, causes of illness/ill health
  - What's important for good health
  - Main concerns with regards to health
  - Decision-making for approach to take/health seeking e.g. umthandazi versus clinic
  - Views and experiences with health services, accessing health services, managing health
    - Probe traditional med (i.e. when, what, for which health purposes)
    - Probe health clinic (again, when, which clinic, for what health conditions)
  - Which illnesses or health conditions are a particular/main concern here/for you?
  - What do people with TB do to manage their health
  - What about HIV?

#### **If DID/DOES DISCLOSE:**

- **General health, illness, health management and health seeking**  
*How have you been feeling?*

*[If necessary probe]: Could you tell me about how you manage your health, and experiences you have had with illness or ill health generally...*

- Probes:
  - Perceptions around health and ill health/being healthy and being sick, signs of ill health, causes of illness/ill health
  - What's important for good health
  - Main concerns with regards to health
  - Decision-making for approach to take/health seeking e.g. umthandazi versus clinic
  - Views and experiences with health services, accessing health services, managing health
    - Probe traditional med (i.e. when, what, for which health purposes)
    - Probe health clinic (again, when, which clinic, for what health conditions)
- **HIV testing experience**

*Could you tell me about your experiences testing for HIV from the beginning, your story?*

  - Probe testing experience from first testing positive, including potential re-testing, engaging and disengaging or re-engaging with care, what drove testing on each occasion, how were circumstances different e.g. this more recent time to first time
  - Could use health journey tool
  - Probe motivation to test and perception of HIV risk
  - Probe testing circumstances
  - Probe diagnosis and processing result – what thoughts went through your mind at that time, how did you feel then/later?
  - Probe what happened next (after positive result) (e.g. seeking health care, talking to someone about it?)
- **HIV health seeking/management**
  - What did you know and think about HIV before your diagnosis?
  - How felt about living with HIV – feeling well/unwell / identifying self and HIV?
  - Decisions about health seeking (e.g. feel need to access HIV health services / perceived value of health services)
- **ART initiation decision-making**
  - Experience being offered early ART
  - What HCW said at clinic
  - What happened
  - What they thought about it – what went through their mind
  - Probe reasons/motivation for early ART or reasons for reluctance to start ART

- **Changes with diagnosis**
  - *Has anything changed since being diagnosed HIV positive?*
  - *What about after starting ART?*
    - Probe – if changes, why, where did the perceived need for these changes come from? HCW advice versus personal interpretation?
  - General life (including social life, work)
  - How feel about living with HIV/being on ART (physically and emotionally)
  - Hopes, dreams, aspirations (link to interview 1)
  - Relationship(s) (current relationship or future hopes, link to interview 1)
    - Sexual practices

**Topics to probe:**

- **Stigma and gossip**
  - Probe where comes from, meaning and implications – e.g what happens if people talk about you as being HIV positive/on ART, what impact does this have on different areas of life?
  - Gender dynamics e.g. association of HIV with “promiscuity” and how this may impact men and women differently
- **Dirty blood**
  - *[If participant mentions diagnosis and dirty/unclean blood probe the following:]*
  - What does it mean to find blood is dirty? Probe interpretation and implication
  - What would the difference be if blood was not dirty?
  - What causes blood to be dirty or clean?
  - NB: wait for participant to mention dirty/unclean blood themselves first, if no mention: *We have heard some people mention a HIV diagnosis as dirty blood or finding their blood is unclean. Is this something you are familiar with? What do you think about it? What would make someone to have clean or unclean/dirty blood?*
- **HIV status secrecy**
  - Probe where comes from e.g. health messaging? Why felt need to keep secret?
  - What would happen if people found out?
- **Practitioner-patient relationships**
  - Probe what relationship is like with different health practitioners e.g. nurse/counsellor
  - Perceived ability to come forward with challenges?
  - What do/say if things not going so well?
- **Rules of treatment – expectations and responsibilities alongside treatment-taking**
  - Impact on ART initiation and treatment-taking
  - Impact on life / restrictions

- How manage these, what happens if unable to e.g. food security // women and condom use?

End interview:

**Anything else to add? Any questions for me?**

*Info for next interview, thanks and close.*

### **Interview 3 Topic guide**

This example was prepared for participant M06 (interview topic guides were individually tailored for each participant).

- **General Health Concerns**
- **HIV diagnosis, perception of risk, self-identity**
  - Re-visit testing experience
  - Processing diagnosis
  - Perception of risk
  - How he was infected?
  - Views about future, life prospects, fear of death?
  - What do you feel has been taken away from you by HIV diagnosis?
- **Experience with Tx Offer**
  - Last time we met we spoke of your testing experience and being offered treatment, please tell me about that experience?
    - **ART initiation decision-making**
    - Perceived need for tx?
    - Probe concerns/fears – how feel now, how overcame, potential impact on future tx-taking?
  - Motivation to start tx
- **Ongoing Tx taking**
  - Perceived benefits of tx? Views about tx effect?
  - Times when more difficult to take tx?
  - What happens when you have to take the treatment when you are amongst/with other people?
  - Things shares with HCW/counsellor, things doesn't share, views about counselling purpose etc
  - **Counselling-** what is needed, what is counselling to him? What would he like in terms of support?
- **Rules of tx**
  - Why – where these rules come from, why important, what does he think about them, difficulties following? Impact on life? What happens if cannot follow (anticipated consequences)? Talk to HCW about it?
  - E.g. not drinking – impact of this on life
- **Stigma/Gossip/talking openly about HIV/disclosure**
  - Disclosure experiences

- Not wanting many people to know his status? Why?
- Potential impact of hiding status on treatment-taking?
- **HIV transmission, tx as prevention:**
  - Views about relationship with partner
  - Condom use – how he finds using condoms, impact on relationship, times when more difficult? What do if run out?
  - Knowledge about tx as prevention?
  - Some people say tx could reduce chance of infecting sexual partner... is this something you have heard? Views about it? Probe potential influence → tx-taking?
- **Men and health-seeking / clinic visits**
  - Probe more on reasons for differences in health seeking - Why?
  - Why different with him (starting tx with high CD4 count, going to clinic healthy)?
- **Research process**
  - How found being in the study?
  - Positives
  - Negatives
  - Why chose to take part?
  - How compared to expectations
  - Understanding of study purpose and what happens to data?
- **Anything to add, recommendations, questions for me?**

#### Main areas of focus

1. Testing experience and HIV diagnosis
  - a. Motivation to test
  - b. Processing result – acceptance?
  - c. Understanding of HIV infection cause/origin
  - d. Perception of HIV risk
2. Practitioner-patient relationships
  - a. Things he talks to HCW about/not
  - b. Why he doesn't talk to HCW about certain challenges?
  - c. HCW pressuring/threatening/scolding? Consequences of not following rules and advice?
  - d. Rules of tx
  - e. Views about counselling
  - f. What he would like in terms of support
3. Treatment-taking
  - a. Decision to initiate early ART – choice versus obligation (seemed as though felt had to start), fears and concerns
  - b. Challenges with tx taking
  - c. Tx-taking interruptions e.g. missing refill appointments
4. Stigma, hiding status

- a. Is it important to him to maintain hidden status and not be seen on ART? Why? How does he manage this?
- b. Potential impact of this on tx taking? Times where not taken tx because of potential exposure?
- c. Potential impact in future/ongoing tx-taking

Preparation / things to follow up on

- History of testing – ““We are people who are cautious about our health lives and we have been going regularly to the clinics and have been testing after every 3 months” - *Why? Perception of HIV risk? Why felt need to test regularly in past?*
  - He said he tested regularly from being in school (annually since 1998, then 3 monthly since working at factory) – why?
- HIV diagnosis experience – contradictions in account – 1<sup>st</sup> interview says he and his wife had been testing negative then it changed with the second child, that the wife tested during pregnancy and the virus was found. They sat down and talked about it, they accepted because knew virus not transmitted just through sex (seemingly important for acceptance) – thought could have come from getting hair cut in salon. Said shouldn’t wait to get sick and took the pills. Taking them and remind each other to take them every day before going to bed. 2<sup>nd</sup> interview says he tested positive first at Tfokotani and then went straight away to tell his wife, thinks he was infected via kukata...
- Status acceptance? Said he was planning to re-test over Christmas – follow up on this, what exactly was he planning to re-test for? Why? How did this go?
  - *“since I got tested and accepted when I was tested at Tfokotani that the virus is now there and so I have to go and get tested again and maybe the results would come back...since the doctor said I should get tested again because maybe they would say it is there (virus) yet it was just a mistake from their machines and such things happen”. – 2<sup>nd</sup> interview*
- Self-identity – seemed to identify himself as someone who was healthy, taking care of himself, someone who was cautious about health, didn’t feel sick – how does he now identify himself as someone who has the virus?
  - 2<sup>nd</sup> interview: *“As people living with HIV I just wish our government would take care of us just like he is doing to our grandparents, **since we are people who are now vulnerable**, so if she can make sure that we are provided with something so that we can continue being on the treatment”*
- Hopes for a cure? Or a future negative result? Seemed in second interview to be hoping there may have been a mix up with the results and wanted to re-test over Christmas.
- Doubts and distrust? *“since the doctor said I should get tested again because maybe they would say it is there (virus) yet it was just a mistake from their machines and such things happen”*
- Perception of HIV risk – did he perceive himself to be at risk? If so why? Perception of HIV risk and regular testing when said he didn’t have MCP (first interview), then talked about a time where he had several girlfriends in the past in the second interview

- Understanding/description of where he sees HIV infection as having come from
  - re-visit where he thinks he was infected and probe further for more understanding of why he thinks such, could there have been any other way/route of infection/cause?? (contradiction in how he described where he thinks he was infected in first and second interviews, both described non-sexually – why? What does he think about risk of being infected through sex?)
    - First interview said thought infection came through salon
    - Second interview said thought it came through razor with insertion of muti (kukata) on his knees
- Processing result and decision for ART initiation
  - Starting treatment early, not waiting to get sick – why is this important, what thought about this
  - In second interview seemed to say he started ART the same day as testing positive? Check? Contradiction in account – waiting for disclosure and starting with wife?
- Not feeling sick – motivation for treatment, perceived need for treatment, also look at men’s access to clinics generally
- Practitioner-patient relationships – subservience? Seems to do as told by HCW – what does he himself think? Did he feel he had a choice? What might have happened if he had refused treatment?
- Research participation – 1<sup>st</sup> interview he asked permission to miss work for the interview, 2<sup>nd</sup> and 3<sup>rd</sup> interviews took place in the evenings after work – why did he ask permission to miss work the first time and not the others, what did he tell his employers? Did he lose pay for missing work? What did he understand about his participation and choice to take part? Check how he understood who has access to his information that he shared during the study, and why he thinks he was chosen to take part.
- Consulting tinyanga – why does he think he shouldn’t consult tinyanga? He said he would discourage people from consulting tinyanga because it’s not good – why? Where did this understanding/view come from (especially as he is someone who used to consult them in the past)
- Importance of privacy, not wanting to be identifiable – *“it would be better if these people wouldn’t be made to sit where they can be identifiable when they have come to get the treatment for TB and HIV”*

### **Health care worker interview topic guide**

*Could you tell me a bit about yourself and your role?*

*Could you tell me about your best/proudest moment from your time [working as...]*

*Could you tell me a story of where [profession] has been hard for you?*

**Views and experience of EAA pilot**

***Were you involved with the Early Access to ART for All pilot (led by MSF/MOH) in Nhlango? // What was your role in the EAA pilot?***

- Thoughts/views, why implemented, benefits/risks?

T&S: ART for early diagnosed, asymptomatic, high CD4 PLHIV

*What do you think about ART initiation for those with high CD4 counts (e.g. 1000)/who don't feel unwell?*

- How PLHIV respond to offer of early ART?
- How quickly should patients start ART? (*Probe time to process result, readiness*)
- **Why do patients start early ART?** (*Probe pt choice versus following HCW advice*)
- **Why do patients refuse?** When they refuse what reasons do they have/give you?
- What would happen if someone refuses ART? How would you manage this/what would you do? *Probe consequences to pt and to HCW*

*What is your sense of how patients find ongoing treatment-taking amongst those who initiated ART early?*

- Reasons for default
- Reasons for non-adherence
- How manage
- Consequences to patient // to HCW?
- Disclosure – experiences, challenges

*If someone in your family was found to be HIV positive and their CD4 count was high what would you advise them? What would you do if it was you? Why?*

Health messaging – rules of tx

*What is expected of patients, what rules must they follow or what responsibilities do they have?*

- E.g. “taking care of self” less frequent sex, no MCP, condoms
- E.g. no oily food, no chicken skin, no salty food
- E.g. No alcohol, no smoking
- Why, where messaging comes from

Stigma – gossip, hiding status

- What do people say about PLHIV?
- Why some want to hide tx/status?
- Social implications of being seen on ART
- Men vs women
- VCT queuing, privacy, confidentiality – e.g. “rather die than be seen on ART”

Practitioner-patient relationships, patient support

- Are certain types of patients more challenging than others?
- Confidentiality – instances when HCW should disclose a patient's status? When?
- HCW scolding/shouting/forcing? Heard examples? Why...

Gender dynamics – access to health services, health seeking behaviours, communication approach

Anything else to add on topic that we haven't discussed today?

### T&S: Early ART for young people

T&S and HIV transmission – tx as prevention?

*People are continuing to get infected with HIV, what's going on? Why is this? How could this be changed?*

Some people say that they think EAA will be helpful in terms of reducing HIV transmission, what are your thoughts on that? Would you communicate this with patients? Why / why not? How?

National implementation T&S/EAA

*Can you tell me what you know about the national policy to implement test and treat? What do you think about the plan?*

- Thoughts/views, potential challenges, what's needed

### Recommendations

What is needed, ideal world...

Anything else to add on topic that we haven't discussed today?

Any questions for me?

## **Focus Group Discussion Topic Guide**

### Introduction

- Study aim, why invited to participate
- Confidentiality – request that we all respect each other's confidentiality and keep what is discussed in the group within the group – however, confidentiality cannot be 100% guaranteed so please share what you feel comfortable sharing
- Consent
- Introductions – go around in a circle, introduce yourself – your name, age and one thing people would find interesting about you
- Ice breaker – fruit salad

### HIV in the community

- What are the **main health challenges** here?
- What can prevent people from going to the health facility?
- What about HIV, is that a problem here?
  - o Probe HIV prevention, treatment, etc
  - o We have heard stories where one person knows that they are HIV positive, their partner is negative and they refuse to use condoms, why do you think that is? Probe spiteful/purposeful infection
- Who gets HIV? Are certain people more at risk of HIV than others?
- Do people talk openly about their HIV status?
- Is there **stigma**? What does stigma look like/what happens?

- How is HIV **transmitted**?
  - o Probe most common way for HIV to be transmitted
- How do people protect themselves from HIV?

#### Views on HIV testing and counselling

- Where can people go to test? (What options are available for HIV testing here?)
- What do you think about the **different options**?
  - o Probe positives and negatives about each
- What do you know about **community-based** HIV testing?
- What do you think about it?
- **What motivates** people to test for HIV?
- Why do some **people refuse** to test?
- Is there any difference between the people that test and don't test for HIV?
  - o Probe difference – what is known, why is there a difference (e.g. men and women etc)

#### Positive diagnosis and linkage to care

- What should people do after they have tested positive?
- What motivates people who are diagnosed HIV positive to go to the clinic?
- What factors can prevent them from going to the clinic?
- A lot of the people who test positive don't go for their follow-up appointment at the clinic, why do you think that might be?
- How could they be better supported to link/access health clinic or how might these difficulties be overcome?
- What are your views about traditional medicines?
  - o Probe views about muti and how trad approaches may contradict modern medicine seeking

Do you have any recommendations or ideas for how HIV testing and access to treatment and care could be improved? What would make things better in the future e.g. in an ideal world

Do you have anything else to add on the topic before we end?

Any questions for us

Thank participants for their time and remind them that they can approach any of us individually at the end if they have further questions or anything of concern/that they would like to discuss.

## Appendix 3: Ethical Procedures

### Ethical approval certificates

Telegrams:  
Telex:  
Telephone: (+268 404 2431)  
Fax: (+268 404 2092)



**MINISTRY OF HEALTH**  
P.O. BOX 5  
MBABANE  
SWAZILAND

THE KINGDOM OF SWAZILAND

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February 6, 2015

Mr. Bernard Kerschberger  
Principal Investigator  
MSF  
**MBABANE**

**REF:** MH/599C

Dear Mr. Kerschberger

**RE:** Assessing Linkage to Treatment and Care within Community Based Counseling and Testing initiatives in Shiselweni, Swaziland

---

The committee thanks you for your submission to the Swaziland Scientific and Ethics Committee and it has the following comment;

1. The investigators should include provision for assent in addition to consent for the minors who might get involved in the study.
2. This is a MSF study led study but might be worth mentioning role of the MOH as a collaborator, in the research governance structure and roles MOH
3. Identification of HIV + who have not assessed care in 6 months as a challenge was done. However, the researchers do not provide a systematic way of navigating the challenge in an ethical way.
4. Lack of linkage to care is defined by a time period of 6 months after an HIV test. The Researchers also mention the use of the HCW who conducted the test to be one to make contact for recruitment. However, they do not mention limitations of this such as attrition of the HCW and how they will deal with case where a HCW is no longer with MSF.
5. In the exclusion criteria, the researcher mention use of MSF staff assessment and recommendation on those identified as too unwell. The researchers should also state an objective assessment criteria for such cases
6. The researchers should provide a definition for the hard to reach population in the context of Shiselweni (page 10)

A handwritten signature in blue ink, appearing to be 'B. Kerschberger'.

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Ethics Review Board  
Instituted by Médecins Sans Frontières

Dr Micaela Serafini  
Director, Medical Department  
Médecins Sans Frontières  
Rue de Lausanne 78  
Case Postale 116  
1211 Genève 21, Switzerland

19 December 2014

**Re: Ethics approval of *Assessing linkage to treatment and care within community-based HIV counselling and testing initiatives in Shiselweni, Swaziland, version 10, November 2014 (ID 1437)***

Dear Dr Serafini,

Many thanks for your reply to our review of the above-mentioned proposal. We are happy with your answers. We thus approve the protocol for a period of 12 months from initiation of the study. The study must be initiated within the next 12 months. If this is not the case the approval of this protocol is no longer valid. It is your responsibility to ensure that all people associated with this particular research are duly informed about the changes introduced and what has actually been approved.

Any subsequent changes you might wish to make to the project must be notified to the Ethics Review Board for further consideration and approval. Anything that may occur during the research that may affect ethical acceptability of the project, including adverse effects on participants or unforeseen events, must be reported immediately to the Ethical Review Board. We would appreciate receiving the final research report.

We would like to draw your attention to the fact that the ERB will routinely check the reported and published outcome measure(s) against the outcome measure(s) initially approved in the protocol. If the outcome measures published differ from the proposal, the ERB should be consulted beforehand. There may be good reasons for the change, but as any other alteration in the approved protocol it should be assessed on ethical grounds.

We wish you much success with the research.

Yours sincerely,



Doris Schopper  
Chairperson, Ethics Review Board

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**Members of the Ethics Review Board**

Prof Doris Schopper, Chair  
Zurich, Switzerland

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Prof Aasim Ahmad, Pakistan

Prof Angus Dawson, United Kingdom

Dr Amar Jesani, India

Dr Eunice Kamaara, Kenya

Dr Raffaella Ravinetto, Belgium

Prof Lisa Schwartz, Canada

Prof Michael J. Selgelid, Australia

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MINISTRY OF HEALTH  
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SWAZILAND

**THE KINGDOM OF SWAZILAND**

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TO: Dr. Kiran Jobanputra  
Principal Investigator EAA Study  
Medecins sans Frontieres, Swaziland

DATE: 13<sup>th</sup> June 2014

REF: MH/599C/ FWA 000 15267

**RE: Early access to ART for all people living with HIV in Swaziland: An implementation study to feasibility, accessibility and programmatic outcomes of providing ART irrespective of immune status.**

The committee thanks you for your submission to the Swaziland Scientific and Ethics Committee, an Expedited review was conducted.

In view of the importance of the evaluation and the fact that the evaluation is in accordance with ethical and scientific standards, the committee therefore grants you authority to conduct the evaluation. You are requested to adhere to the specific topic and inform the committee through the chairperson of any changes that might occur in the duration of the evaluation which are not in this present arrangement.

The committee requests that you ensure that you submit the findings of this evaluation (Electronic and hard copy) and the data set to the Secretariat of the SEC committee.

*The committee further requests that you add the SEC Secretariat as a point of contact if there are any questions about the evaluation on 24047712/24045469.*

The committee wishes you the best and is eagerly awaiting findings of the study to inform proper planning and programming to use for analysis

Sincerely,

  
**Dr S.M. Zwane**  
PRINCIPAL SECRETARY  
(THE CHAIRMAN)  
cc: SEC members



**London School of Hygiene & Tropical Medicine**  
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**Observational / Interventions Research Ethics Committee**

Miss Shona Horter  
LSHTM

20 November 2015

Dear Shona,

**Study Title:** Exploring Early Access to ART for adults living with HIV in Swaziland

**LSHTM ethics ref:** 10420

Thank you for your application for the above research, which has now been considered by the Observational Committee.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

**Conditions of the favourable opinion**

Approval is dependent on local ethical approval having been received, where relevant.

**Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

Document Type	File Name	Date	Version
Protocol / Proposal	JUN 2014_EAA_MSF SEC_approval	13/06/2014	n/a
Local Approval	JUN 2014_EAA_MSF SEC_approval	13/06/2014	n/a
Protocol / Proposal	JUN 2014_EAA_MSF ERB_approval	30/06/2014	n/a
Local Approval	JUN 2014_EAA_MSF ERB_approval	30/06/2014	n/a
Protocol / Proposal	Ethics protocol updated for LSHTM	29/10/2015	11
Investigator CV	CV Shona Horter 2015	29/10/2015	n/a
Information Sheet	Patient and HP interview consent form	29/10/2015	n/a

**After ethical review**

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the Committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexpected Serious Adverse Reactions (SUSARs) which occur during the project by submitting a Serious Adverse Event form.

At the end of the study, the CI or delegate must notify the committee using an End of Study form.

All aforementioned forms are available on the ethics online applications website and can only be submitted to the committee via the website at: <http://leo.lshtm.ac.uk>

Additional information is available at: [www.lshtm.ac.uk/ethics](http://www.lshtm.ac.uk/ethics)

Yours sincerely,

A handwritten signature in black ink, appearing to read 'John Porter'.

**Professor John DH Porter**  
Chair

Ethics Review Board  
Instituted by Médecins Sans Frontières

Micaela Serafini  
Director, Medical Department  
Médecins Sans Frontières  
Rue de Lausanne 78  
Case Postale 116  
1211 Genève 21, Switzerland

19 October 2016

**Re: Request for ethical approval of amendments to research protocol “Early access to ART for adults living with HIV” in Swaziland: an implementation study to assess feasibility, acceptability and programmatic outcomes of providing ART irrespective of immune status” Version number Version number 11, 9 May 2016 (updated October 2016), ID: number 1336**

Dear Dr Serafini,

Thank you for your e-mail dated 14 October 2016, sending us the investigators’ reply to our review of the planned amendments to this protocol and copies of presentations made in various conferences of the results of interim analysis of this study. The Board is happy that substantial issues raised in the review have been addressed. We approve the latest version of the protocol for one year until 18 October 2017.

Anything that may occur during the research that may affect ethical acceptability of the project, including adverse effects on participants or unforeseen events, must be reported immediately to the Ethical Review Board. We would appreciate receiving the final research report.

We wish you much success with the research.

Yours sincerely

For the ERB,

  
Doris Schopper  
Chairperson

## **Informed consent forms**

### **Part 1: Information for Participants**

The Swaziland Ministry of Health and Médecins sans Frontières (MSF), with the London School of Hygiene and Tropical Medicine (LSHTM) are carrying out a study investigating people's experiences with health services in Shiselweni, aiming to understand how particular health conditions may be managed. These health services and health conditions may include HIV, TB, and family planning, among others.

#### **Purpose of the research**

The purpose of this study is to learn about people's views and experiences with medical services and with managing health conditions. From this we hope to be able to make recommendations about how services might be adapted and improved in the future. As somebody who lives in Shiselweni, and who uses health facilities here, you have been invited to take part in this study to share your views on the study topic, and so that we can learn from your experiences using these services. We are inviting you to participate in this study by taking part in three to four interviews over the next 12 months, each interview will last about one hour. Please read this document carefully and sign below if you agree to take part. If anything is unclear, you would like more information or if you have any questions please feel free to ask.

#### **Benefit and potential risks for the individual and the community**

There will be no direct benefit to you from taking part in the study. However, the information you share will help us to understand how patient support and health services may be improved. Participating in interviews does not carry any direct risks for you as a participant.

#### **Voluntary participation**

Your participation in this interview is voluntary. You may stop at any time without giving a reason, and you may choose not to answer certain questions or discuss certain topics if you don't want to. There is no right or wrong answer for anything that is discussed, we would like to learn about both good and bad experiences for example with the health services. Deciding not to take part will not affect the services you receive in any way, and will not result in any loss of benefits regarding medical treatment. We would like to record the interviews if you consent to this, solely for the purpose of the study, to ensure we capture everything you say.

#### **Confidentiality**

The information given in the interviews is accessible only to those in the social research team: qualified researchers who are trained in confidentiality and are under an oath of professional secrecy. The audio recording will only be heard by the research team, it will be transcribed onto paper and the original recording will be kept securely for no longer than 5 years (when it will be destroyed). All written information collected will be kept privately and anonymously (including password protected storage) so that no one can link anything you say in the interview back to you. As a participant in the study, you have the right to access your recorded interviews if you wish. The researchers will make every effort to ensure that the information you provide as part of this study remains

confidential. Your identity will not be revealed in any publications, presentations, or reports resulting from this research study.

You will be informed of the results of the study through general information provided to the Ministry of Health, through health facilities.

Should you have questions regarding your rights as a participant in the study please contact the Scientific and Ethics Committee of the Ministry of Health (tel: 24047712 or 24045469, on weekdays between 8am and 4pm), or the social research team on 22077477, or at PO BOX 572 Nhlanguano Mccalpine, extension 3, plot 442

**Part 2: Consent form for participants**

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the information sheet above or the explanation given to you please ask the researcher before you decide to take part. You will be given a copy of the information sheet to keep.

Informed consent:

- I have been informed by the undersigned person of the purpose and procedures of the study, and of the possible benefits and drawbacks of my participation.
- Any questions I had about my participation in this study have been answered to my satisfaction. I will receive a copy of the document I have signed.
- I was given enough time to make my decision.
- I am participating to this study on a voluntary basis. I may withdraw at any time without giving a reason and my decision not to take part will not affect my care as a patient, my position or reputation as a community member, or the services that I receive in any way.
- I agree to allow the MoH and LSHTM-MSF researchers, and the Ethics Commissions to see my **anonymised** data, with the understanding that this data will remain confidential.

I, \_\_\_\_\_ consent voluntarily to being a participant of this study

I consent to this interview being recorded

I consent to being contacted for follow up interviews  
(maximum of 4 in total over the next 12 months)

Signed \_\_\_\_\_

Date \_\_\_\_\_

Signature of the researcher: \_\_\_\_\_ Date \_\_\_\_\_

### **Sicephu sekucala: umniningwane welucwaningo**

Litiko letemphilo libambisene naboDokotela lebangenamncele (MSF Switzerland) Kanye ne London School of hygiene and Tropical medicine (LSHTM), benta lucwaningo lolubukete kutsi bantfu bahlangane nani basafuna lusito lwetemphilo eShiselweni, kuzama kucondzisa kutsi khambi lini lesingaphuma nalo kuletingcinamba tetemphilo bantfu labahlangana nato loku kufaka ekhatsi iHIV, TB nekuhlela umndeni, kuletinye.

#### **Injongo yalolucwaningo**

Injongo yalolucwaningo kucondzisa tintfo bantfu labahlangana nato basatfola lusito lwetemphilo nekutsi khambi lini lelingatfolakala. Kuloku sinelitsemba kutsi sitawukhona kuncoma kutsi lolusito lungatfolakala kahle kanjani kute libe sezingeni lelisetulu esikhatsini lesitako. Njenge muntfu lohlala eShiselweni futsi lowusebentisako umtfolamphilo, uyamenywa kutsi ulungenele lolucwaningo ngekuveta imivo yakho kuloludzaba khona sitofundza ngelwati lwakho usatfola lusito lwetemphilo. Siyakumema kutsi ube yincenye yalolucwaningo lapho khona sitawucocisana katsatfu noma kane ngemnyaka, lokucocisana kutotsatsa sikhatsi lesingaba lihora linye. Uyacelwa kutsi ufundzise lomininingwane bese uyasayina uma uvuma kuba yincenye yalolucwaningo. Uma kukhona longakucondzisi kahle noma udzinga umniningwane lowengetiwe noma nje uma unembuto, uyacelwa kutsi ukhululeke ubute.

#### **Lokungaba yinzuzo Kanye nalokungaba yingoti kuwe Kanye nasemmangweni**

Kute lokuyinzuzo lokucondzene nawe ngekuba yincenye yalolucwaningo. Nomakunjalo, Umniningwane lotosinika wona utawusisita kutsi singaba sekela njani bantfu Kanye nelusito lolutfolakala emtfolamphilo kutsi singalenta njani lube nguloluncono eSwatini. Kute bungoti lobungaba khona ngekungenela lolucwaningo.

#### **Kutinikela kwakho**

Kungenela lolucwaningo kuyintsandvo yakho. Ungakhetsa kuyekela kuba yincenye yalolucwaningo noma nini ngaphandle kwekunika sizatfu, futsi ungakhetsa kungayi phendvuli leminyane imibuto noma tihloko uma ungafuni. Kute imphendvulo lengiyo nalena lengasiyo uma sisacoca, ngoba sifise kufundza ngalokuhle nangalokubi usatfola lusito lwetemphilo. Kungenela lolucwaningo angeke kuyitsikamete indlela lotfola ngayo lusito lwetemphilo. Singatsandza kutfwebula lenkhulumo yetfu uma nawe kukulungela, lomtfwebulo sitawusebentisela tidzingo talolucwaningo kucinisekisa kutsi sikutfola konkhe lokushoko.

#### **Kugcinwa kwetimfihlo**

Umininingwane lotosinika wona sisacocisana nawe utawubonwa licembu lebacwaningi kuphela, laba ngebacwaningi labafundzisekile ngekugcina timfihlo baphindze bakufungela loko. Umtfwebulo nawo utolalelwa bacwaningi kuphela bese ubhalwa phansi ephepheni bese loko lokutfwetjuliwe kuyagcinwa iminyaka lesihlanu emvakwaloko bese uyacinywa. Wonkhe umniningwane utawugcinwa uyimfihlo futsi kute lapho khona utawumbandzakanyeka khona. Njenge muntfu lolungenele lolucwaningo, unalo lilungelo lekulalela lengcogco letfwetjuliwe uma ufuna. Bacwaningi batokwenta konkhe lokusemandleni abo kucinisekisa kutsi umniningwane losiniketa

wona ugcineke uyimfihlo. Ligama lakho kute lapho litovela khona uma sekwentiwa imiphumela yalolucwaningo.

Utokwatiswa emittfolamphilo ngemiphumela yalolucwaningo nelwati lolutfolakele ngelitiko letemphilo.

Uma kwenteka uba nemibuto mayelana nemalungelo akho njengemuntfu lolungenele lolucwaningo, ungashayela baka Scientific and Ethics Committee ngephansi kwelitiko letemphilo kuna tinombolo; 24047712 nobe 24055469 ekhatsi neliviki kusuka nga 8 ekuseni kuya 4 entsambama, noma ushayele lihhovisi lebacwaningi kunayi inombolo; 22077477, noma ubhalele ku PO box 572 Nhlango Mccalpine, extension 3, plot 442.

**Sicephu sesibili: Sivumelwano lesingiso**

Siyabonga kutsi uyacabanga kuba yincenye yalolucwaningo. Umuntfu lohlelebisa lolucwaningo kumele akuchazele ngalo lolucwaningo ngaphambi kwekuba uvume kuba yincenye yalo. Uma unemibuto mayelana nalomniningwane lolapha ngetulu, lose uchaziwe, uyaniketwa litfuba lekutsi uyibute leyomibuto yakho kumcwaningi ngaphambi kwekuba uncume kungenela lolucwaningo. Utawuniketwa lipheshana lemningwane kutsi uligcine.

- Ngatishiwe ngulosayinile nge mlomo kanye nangalokubhaliwe ngekwenhloso nemihambo yalolucwaningo, lokuhle nalokubi kwekuhlanganyela kwami.
- Ngifundzile noma ngichazelekile futsi ngevisisa ngalolwati lolubhaliwe. Yonkhe imibuto mayelana nekuhlanganyela kwami kulolucwaningo ngalokwanele iphendvulekile. Ngitawutfolela ikhophi yalencwadzi lengiyisayinile.
- Nginikiwe sikhatsi lesanele sekwenta sincumo.
- Ngitikhetsele mine kuhlanganyela kulolucwaningo. Ngingashiya noma nini ngaphandle kwekubeka sizatfu futsi sincumo sami sekungalungeneli lolucwaningo angeke siphatamise lokuhle mayelana ngekwelashwa kwetempilo kwami.
- Ngiyavumelane ne MoH kanye na MSF kanye nalababeka umtsetfo kutsi babone lwati lolufihlakele ngekucondzisisa kutsi lolwati lutogcinwa lungulolufihlakele.

Mine, \_\_\_\_\_ ngiyavuma ngekutinikela kwami kuba yincenye yalolucwaningo

Ngiyavuma kutsi lengcogco itfwetjulwe

Ngiyavuma kutsi baphindze bangitsintse mayelana netikhulumo letitako

Singceveto \_\_\_\_\_

Date \_\_\_\_\_

Singceveto semcwaningi: \_\_\_\_\_

Date \_\_\_\_\_

## **Part 1: Information for HCW participants**

The Swaziland National AIDS Program and Médecins sans Frontières Switzerland (MSF Switzerland), with the London School of Hygiene and Tropical Medicine (LSHTM) are carrying out a study on Early Access to Antiretroviral Therapy (ART) for all adults with HIV (EAAA) in Nhlngano Health zone.

### **Purpose of the research**

The purpose of this study is to learn about people's views and experiences with EAAA, decision-making for ART initiation, and ongoing treatment-taking in the context of EAA over the long-term. We are inviting you to take part because we would like to learn from your experience with the EAAA pilot, whereby treatment is now offered to all people diagnosed HIV positive, at any CD4 count. We want to better understand your experience working with patients, offering ART to those diagnosed HIV positive and supporting patients with ongoing treatment-taking, including the challenges you might face with this. We are also conducting interviews with patients enrolled in the EAA pilot, who were offered ART at high CD4 counts. From this study we hope to be able to make recommendations about how services might be adapted and improved in the future.

We are inviting you to participate in this study by having an interview that will last about one hour. Please read this document carefully and sign below if you agree to take part. If anything is unclear, you would like more information or if you have any questions please feel free to ask.

### **Benefit and potential risks for the individual and the community**

There will be no direct benefit to you from taking part in the study. However, the information you share will help us to understand how best to implement EAAA/Test and Start in Swaziland, and how health services more broadly might be improved. Sharing your views and experiences will provide a better understanding of the working conditions of your colleagues and yourself. Participating in interviews does not carry any direct risks for you as a participant.

### **Voluntary participation**

Your participation in this interview is voluntary. You may stop at any time without giving a reason, and you may choose not to answer certain questions or discuss certain topics if you don't want to. There is no right or wrong answer for anything that is discussed, we would like to learn about both good and bad experiences. Your decision not to take part will not affect your professional position or the services you receive in any way, and will not result in any loss of benefits regarding medical treatment. We would like to record the interviews if you consent to this, solely for the purpose of the study, to ensure we capture everything you say.

### **Confidentiality**

The information given in the interviews is accessible only to those in the social research team: qualified researchers who are trained in confidentiality and are under an oath of professional secrecy. The audio recording will only be heard by the research team, it will be transcribed onto paper and the original recording will be kept securely for no longer

than 5 years (when it will be destroyed). All written information collected will be kept privately and anonymously (including password protected storage) so that no one can link anything you say in the interview back to you. As a participant in the study, you have the right to access your recorded interviews if you wish. The researchers will make every effort to ensure that the information you provide as part of this study remains confidential. Your identity will not be revealed in any publications, presentations, or reports resulting from this research study.

You will be informed of the results of the study through general information provided to the Ministry of Health, through health facilities.

Should you have questions regarding your rights as a participant in the study please contact the Scientific and Ethics Committee of the Ministry of Health (tel: 24047712 or 24045469, on weekdays between 8am and 4pm), or the social research team on 22077477, or at PO BOX 572 Nhlanguano Macalpine, extension 3, plot 442

### **Part 2: Consent form for HCW participants**

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the information sheet above or the explanation given to you please ask the researcher before you decide to take part. You will be given a copy of the information sheet to keep.

- I have been informed by the undersigned person of the purpose and procedures of the study, and of the possible benefits and drawbacks of my participation.
- My questions about my participation in this study have been answered to my satisfaction. I will receive a copy of the document I have signed if I wish.
- I was given enough time to make my decision.
- I am participating to this study on a voluntary basis. I may withdraw at any time without giving a reason and my decision not to take part will not affect my care as a patient, my position or reputation as a community member, or the services that I receive in any way.
- I agree to allow the MoH and LSHTM-MSF researchers, and the Ethics Commissions to see my **anonymised** data, with the understanding that this data will remain confidential.

I, \_\_\_\_\_ consent voluntarily to being a participant of this study

I consent to this interview being recorded

Signed \_\_\_\_\_

Date \_\_\_\_\_

Signature of the researcher: \_\_\_\_\_

Date \_\_\_\_\_

**Informed Consent form – Focus Group Discussions**

## **PART 1: INFORMATION SHEET FOR PARTICIPANTS**

Assessing linkage to treatment and care within community-based HIV counselling and testing initiatives in Shiselweni, Swaziland.

Principal Investigator: Shona Horter, Qualitative Researcher

Organisation: Médecins Sans Frontières/Doctors Without Borders (MSF)

We would like to invite you to participate in this study because we feel you can give an insight into this area and value your opinion. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you would like to take part or not, it is important for you to understand why the study is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. If anything is unclear, you would like more information or if you have any questions please feel free to ask.

### Purpose of the research

This study is being conducted by Shona Horter on behalf of Médecins Sans Frontières. It aims to understand community members' experiences and views of the community-based HIV counselling and testing that has been provided by MSF in Shiselweni. We would also like to understand the HIV services available here and how people with HIV can access treatment and care, including the barriers they might face. We want to explore this with you so that we can work towards improving HIV services in Shiselweni. Taking part in this research would involve your participation in a focus group discussion which will last around 90 minutes.

### Voluntary participation

Your participation in this research is entirely voluntary. You may stop the discussion at any point and chose not to answer any question you don't want to. There is no right or wrong answer to the questions asked, we would like to learn about both good and bad experiences and hear how we might be able to improve HIV services. The findings of this study can be fed back to you once it has been completed. We will also record the discussion solely for the purpose of the study, to ensure we capture everything that is said.

### Confidentiality

The audio recording will only be heard by the research team and translator. It will be transcribed onto paper and the original audio recording will be destroyed as soon as the study is finished. All written information collected will be kept privately and anonymously. Transcripts of the focus group discussion will only be shared with the researchers in compliance with the principles of data protection e.g. anonymous and password protected format. In the study report it will be ensured that anything you say in the discussion cannot be linked back to you as an individual. While we request all participants of the focus group discussion respect each other's confidentiality and not

share what is discussed more widely, this confidentiality cannot be guaranteed. If you share information during the focus group discussion which indicates risk of harm to yourself, like concerns which would require medical intervention or psychological support, this may require the interviewer to disclose this risk of harm to a member of staff e.g. doctor. This would be discussed with you beforehand and would only be done in order to protect your wellbeing.

Should you have questions regarding your rights as a participant in the study please contact the Scientific and Ethics Committee of the Ministry of Health (tel: 24047712 or 24045469, on weekdays between 8am and 4pm). The Principal Investigator Shona Horter can be contacted on 784081276, or at PO BOX 572 Nhlanguano Mccalpine, extension 3, plot 442

## **PART 2: CONSENT FORM FOR PARTICIPANTS**

Title of study: *Assessing linkage to treatment and care within community-based HIV counselling and testing initiatives in Shiselweni, Swaziland.*

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the information sheet above or the explanation given to you please ask the researcher (Shona Horter) before you decide to take part. You will be given a copy of the information sheet to keep.

Informed consent:

- I have been informed by the researcher (signed below) about the purpose and procedures of the study, and of the possible benefits and drawbacks of my participation.
- Any questions I had about my participation in this study have been answered to my satisfaction. I will receive a copy of the document I have signed if I wish.
- I was given enough time to make my decision.
- I am participating in this study on a voluntary basis. I may withdraw at any time without giving a reason and my decision will not affect my position as a member of staff in any way.
- I agree to allow the MoH and MSF researchers, and the Ethics Commissions to see my anonymised interview data, with the understanding that this will remain strictly confidential.

I \_\_\_\_\_ consent voluntarily to being a participant of this study

Signed \_\_\_\_\_

Date \_\_\_\_\_

## Appendix 4: Findings

### **Recommendations from extensive Programmatic Report**

#### **Practice recommendations**

##### ***1 Testing***

Community: sensitisation and mobilisation to encourage more people to seek tests when asymptomatic, highlighting the potential for a hidden (symptom-free) HIV infection and the benefits of knowing your status. Expanding on the use of radio programmes could be an effective strategy for encouraging individuals to test, as many described such programmes as influencing their test seeking in our study. Messages should highlight that anyone can be affected by HIV, regardless of relationship and health status, and that testing can enable access to treatment. It could also be beneficial to encourage couples testing (ideally prior to pregnancy).

Counselling: Certain individuals can require more support in preparing to test for HIV and processing a HIV positive result than others. Counselling should be tailored to individual's needs, paying particular attention to those testing via provider-initiated testing (or where the test was not individually motivated/sought), to ensure test preparedness and to support HIV status acceptance.

Health system: Allowing/supporting re-testing, as this study suggests re-testing can support individuals in processing a positive result and believing in test accuracy, thus progressing towards HIV status acceptance. It also appears important to consider testing approaches which support couples testing, particularly related to testing during pregnancy, where women can face difficulties and negative consequences of disclosure to their partners. Also new approaches such as HIV self-testing could facilitate this approach, as seen in other settings.

##### ***2 ART initiation***

Community: Potential to expand upon the use of radio programmes encouraging EAA uptake – highlighting the benefits of early ART for enabling maintenance of good health, physical strength, productivity and ability to work. Engaging community leaders and influential people in encouraging ART uptake, which appears to be an effective approach to gaining community members' buy-in. This could be particularly useful for engaging men, through highlighting the benefits of early ART which support concepts of masculinity (physical strength, energy, ability to work and provide).

Counselling: ART readiness – our findings suggest that certain individuals need more time to feel ready for lifelong ART. The psychological process towards ART readiness is individually varied, and influenced by a myriad of factors. Removing pressure from HCW (linked to targets and monitoring), and from patients (aggressive follow-

up approaches, fear of being reprimanded/scolded for delayed access), and keeping the door open so patients can come and discuss, ask questions and access treatment and care when they feel ready may be beneficial for both HCW and patients. This could avoid silent refusals, where patients appear to be initiating ART but do not swallow the pills, and could also avoid individuals from initiating before they are ready and therefore potentially facing challenges with ongoing engagement and adherence, when they may have more doubts about treatment need and effect, and less motivation for treatment-taking. Nevertheless, care must be taken not to delay ART initiation for patients who have clinical reasons to start ART quickly. Counselling should also encourage disclosure, which appears important for access to support, encouragement and treatment reminders. Our findings also suggest that couples testing may support disclosure. Counselling could aim to reassure and address patients' fears about ART side effects, and consider the cost/benefit analysis patients may be undertaking in deciding to initiate ART.

Health system: Ensure privacy and confidentiality within clinics and health service provision, and not differentiating HIV from other health conditions (e.g. different coloured treatment booklet, HIV-specific waiting area). Integrated services, such as those provided via a one-stop-shop approach, where patients can access treatment and care for a variety of health conditions in one room, without others being able to know what they are accessing the clinic for, could be preferable. This may help patients to overcome fears of potential status exposure, which can prevent some from wanting to start ART.

### ***3 Ongoing treatment-taking: adherence and sustained engagement with treatment and care***

Community: Sensitising community members about viral load monitoring, to inform PLHIV that they are entitled to know their viral load results, and can request these from the clinic if they wish, as this can provide evidence of the treatment's effectiveness.

Counselling: Enhancing patient choice, involving patients in decisions relating to their care and fostering a sense of ownership for their health and treatment-taking. Enhancing the potential for viral load monitoring to support adherence – sharing suppressed results with patients, and using this as an opportunity to celebrate achievements, as evidence of treatment effectiveness, and to encourage their continued adherence. Encouraging time and space for discussion and for patients to share concerns and ask questions – so they can access support, encouragement, and reassurance. Ensuring patients know that there are counsellors available at each of the clinics and that they can access support if they wish. Exploring patients' hopes, dreams and plans for the future. Ensuring patients know they can re-engage with treatment and care following a treatment interruption, without being scolded or

reprimanded. Have clear communication to patients about treatment as prevention, to ensure consistent messaging (which is important for honesty, transparency and trust in HCW advice), as well as to build on the potential for this to motivate treatment-taking, as was suggested in our study.

**Health system:** Implementing routine viral load monitoring as a core component of Test and Start approaches. Ensuring adequate and consistent treatment supply, with no shortages or drug stock outs. Considering health staffing – to ensure there are enough staff in clinics to have adequate time with patients, so patients feel able to ask questions, share concerns and access support. Providing staff with ongoing training, skill and capacity building, and constructive feedback to enhance staff motivation. Address the need for emotional/psychological support for staff in their work supporting patients, and to counter staff burnout. Considering EAA-specific differentiated models of treatment and care to reduce the burden of ART for those starting when asymptomatic.

### **Policy recommendations: the national implementation of Test and Start**

Health infrastructure: It is important to address human resource challenges and ensure clinics have adequate staffing, including nurses, adherence counsellors, laboratory and pharmacy technicians. It is also important to facilitate ongoing staff training for skills, knowledge and capacity in managing Test and Start patients. This is particularly important in recognising that Test and Start patients who initiate ART when asymptomatic need tailored support and counselling, due to the absence of an illness history and therefore the greater potential for doubts and distrust relating to the perceived need for treatment and its effectiveness.

Routine viral load monitoring: appears to be particularly important for Test and Start, not only in monitoring treatment success and rates of viral suppression, but also in being able to provide evidence of treatment effect to patients, which could motivate their ongoing treatment-taking.

Drug supply: It is of utmost importance to consider drug procurement systems and mechanisms to ensure consistent drug supply, avoiding any risk of potential treatment shortages, as well as supply of other resources such as those needed for blood tests and patient monitoring. It would not be recommended to initiate increased numbers of patients onto ART, who feel healthy, but who then have to collect refills more frequently or face interruptions in their treatment-taking due to lack of treatment availability. It is also important to ensure patient confidence in the drug supply chain, and reassurance/trust that there will not be drug shortages in the future.

Differentiated models of treatment and care: There could be scope to consider the potential for differentiated models of treatment and care specific to Test and Start, for example a Community ART Group for asymptomatic patients, with tailored counselling messages and mutual support, or a buddying system whereby patients who are not yet ready for ART could be matched with a patient who is ready/on ART and can offer support and encouragement. Such approaches should aim to reduce the burden of treatment to patients, as well as reducing the pressure to health services. This may also mean to enrol patients into community ART with less restrictive criteria, i.e. extending eligibility beyond those who can demonstrate sustained adherence.

## Coding Framework example

Category	Code	Description
Testing experience	Past testing	Descriptions of previous experiences testing for HIV/testing history
	Choice to test	Descriptions regarding extent to which participants felt able to choose to test versus encouraged, descriptions indicating feeling of coercion. Testing during pregnancy.
	- Provider initiated testing	
	- Compulsory testing	
	- Testing incentives	
	Motivation for testing	Why someone decides to test for HIV, encouragement to test
Processing an HIV diagnosis	Concerns about testing	Reasons given for people refusing to test for HIV, fear of being told you are living with HIV
	- Fear about known status	
	Re-testing	Descriptions of re-testing after receiving a positive result
	Dirty blood	Where someone makes reference to 'dirty blood' as being HIV positive
	Test preparedness	Expectation for the chance of a positive result Influence of sense of being prepared on processing result
	Time	Descriptions of time to come to terms with diagnosis
Processing an HIV diagnosis	Perceiving HIV risk	Potential exposure to HIV (cuts, caring for people, braiding hair, unprotected sex, partner infidelity?) Judgements or views about good person/bad person, promiscuity
	- Views about HIV/who gets HIV	
	Non-acceptance	Reactions to an HIV diagnosis which indicate possible status non-acceptance
	- Shock	
	- Stress	
	- Doubt and disbelief	
- Not feeling unwell		
- Stigma – hiding status		
- Self-judgement, blame		
Processing an HIV diagnosis	Acceptance	Factors which may influence/support status acceptance
	- Perceived risk of HIV	
	- Expectation chance positive result	
	- Test preparedness	
	- Counselling	
	- Disclosure of HIV status	

	<ul style="list-style-type: none"> <li>- Support</li> <li>- Hope</li> </ul>	
	Counselling	Descriptions of counselling surrounding test and diagnosis, perceived importance of counselling for supporting process
	HIV information and education	Awareness, understanding, views about HIV
	Confidentiality	Where participants mention confidentiality concerns or the perceived importance of privacy etc for testing
Accessing health care	Perceived need for health care/treatment	e.g. symptoms, diagnosis, how need for treatment is understood/conceptualised
	Attitudes and beliefs about health care	Views about health services and potential benefits, valuing ART for life, potential doubts or scepticism, trust of HCW advice
	<ul style="list-style-type: none"> <li>- Value placed on health care/ART</li> <li>- Trust</li> </ul>	
	Alternative health systems	Beliefs and practices relating to alternative health systems (traditional, faith), how these may contradict, support, influence conceptions of health and engagement with care
	<ul style="list-style-type: none"> <li>- Contradictions traditional medicine and ART</li> <li>- Religious beliefs/faith healing</li> </ul>	
Self-identity and HIV	Symptoms/signs of HIV	e.g. headache/nausea, what is taken to signify HIV or what signs and symptoms are attributed with it
	Identifying as well/unwell	What it means to be healthy or sick, descriptions of seeing self in terms of health
	Associating HIV and death	The death / <i>kufa</i> , imminence of death
	Normalising HIV	ART and Panadol, HIV and influenza, normalising discourse/narratives
	Moralising HIV	Differentiating HIV and other diseases/conditions – transmission
	Uncertainty about the future	e.g. what will happen in 2022 (when government aims to “end HIV”
	The life of treatment, dependency	Dependency on ART/treatment
	Living with HIV	Descriptions about HIV e.g. now like this, now in this situation

	Hope for a cure	Mentioning hoping for a cure or asking questions about this
Treatment initiation decision-making	Treatment offer	How tx is proposed by HCW, health messaging
	- Repercussions with delaying	Understanding of portrayed implications delayed ART e.g. you will die, baby will die, etc
	Choice	Descriptions relating to choice for tx
	- Obligation/duty to act	
	- Valuing health and life	
	Readiness	Time to process result and feel ready for tx, importance of readiness for tx
	CD4 count	Descriptions of CD4 count at ART offer, understanding about CD4 count and treatment-taking
	Situated rationalities	Mentions of weighing up different factors in decision, conflicting priorities
Motivation for starting early ART	Perceived need for treatment	e.g. not feeling sick – questioning need for treatment Described reasons for starting/wanting tx
	Perceived benefits of early ART	Views about possible benefits of early ART initiation
	- Avoiding health deterioration	
	- Not wanting to be visibly sick/bedridden and identifiable HIV+	
	- Belief in treatment effectiveness	
	Familiarity	Observed treatment experiences/effects
	- Seeing effect of starting ART later/when ill	Those who describe having seen people within their family/neighbourhood who were known to be HIV positive and their treatment-taking
	- Seeing others die without ART	
	- Seeing improvements in others on ART	

	Knowledge and understanding relating to EAA	Radio, health talks, knowledge and familiarity early ART
	Seeking information	Examples where individuals have actively sought more information e.g. through internet, consulting peers etc
	Receiving support and encouragement	e.g. seeking advice from family members/friends/others (with disclosure)
Concerns about ART	Fear of side effects	
	- Myths/commonly held views about tx	e.g. treatment eating brain, causing liver damage
	- Fears about becoming identifiable due to side effects	e.g. changes to body shape
	Lifelong treatment	No going back – once start cannot stop, length of tx
	- Young people	
Potential inability to adhere	Concerns about forgetting time to take tx, self-efficacy	
Concerns about future treatment shortages	Better not to start than to start and stop	
- Government goals to end HIV by 2022	Potential implication for those who have started tx, fear	
Being seen on ART	e.g. collecting refills at clinic, being exposed	
Confusion and distrust	e.g. changes in health messaging/treatment guidelines	
Treatment-taking experience	Perceived and experienced benefits of tx	Descriptions of wanting to see changes with treatment, interpretations of such benefits through symptom/perceived health improvements or through VL results
	Doubts relating to tx need and effect	Not seeing/experiencing changes on ART, confusion
	Ownership and self-responsibility	Determination, motivation for treatment-taking e.g. I am the driver of this life
	Treatment-taking routine	Treatment journey, incorporating HIV and ART to life, time for treatment, reminders
	Treatment-taking challenges	Descriptions relating to various challenges faced with treatment which can undermine individuals' ability to take it
	- Forgetting	
	- Hiding tx	
	- Tx interruptions	

	<ul style="list-style-type: none"> <li>- Missing doses</li> <li>- Experimenting</li> <li>- Tx fatigue</li> <li>- Food shortages</li> <li>- Losing hope</li> <li>- Situated rationalities</li> </ul>	<p>Retention in care challenges including silent refusals and silent transfers</p> <p>Situated rationalities refers to conflicting priorities which contradict and can undermine tx-taking e.g. work commitments</p>
Stigma and disclosure	<p>Consequences and manifestations of stigma</p> <ul style="list-style-type: none"> <li>- Gender dynamics</li> <li>- Social implications</li> </ul>	<p>Descriptions including association of symptoms and HIV, feeling no longer a person, discrimination, gossip, isolation or ostracising, shame and embarrassment, implications for social stature and reputation of having known HIV+ status</p>
	<p>Hiding status, secrecy</p> <ul style="list-style-type: none"> <li>- Changing clinic to avoid exposure</li> <li>- Hiding treatment</li> <li>- Implications for engagement</li> </ul>	<p>Avoiding stigma and gossip</p> <p>Descriptions of hiding/not hiding status.</p> <p>Potential implications of hiding status and tx on engagement with care and tx-taking</p>
	<p>Drivers of stigma</p> <ul style="list-style-type: none"> <li>- Association of HIV and stigma</li> <li>- Morality and moralising</li> <li>- Lack of knowledge</li> </ul>	<p>Mention/descriptions of the way HIV was introduced as influencing how it is viewed now</p> <p>Description of lack of knowledge influencing stigma</p> <p>Contradiction Christianity and image of who gets HIV</p>
	<p>Disclosure experience</p> <ul style="list-style-type: none"> <li>- Fear of disclosure</li> <li>- Benefits of disclosure</li> <li>- Perceived importance of disclosure</li> <li>- Disclosure and treatment-taking</li> <li>- Disclosure and status acceptance</li> </ul>	<p>Descriptions of disclosure experience, whether disclosed or not and to who/disclosure circumstances</p> <p>Negative consequences of disclosure – perceived and experienced, concerns about disclosure.</p> <p>Perceived importance of disclosure and benefits anticipated and experienced. Disclosure-treatment-taking link, and link between status acceptance and disclosure.</p>

## Appendix 5: Dissemination of study findings

### MSF Scientific Day Conference Oral Presentation May 2016

**Early Access to ART in Swaziland:**  
6 month treatment outcomes and patient experiences  
MSF Scientific Day 2016

A new approach to HIV care  
Early Access to ART for all

Shona Horter<sup>1,2</sup>, Médecins Sans Frontières (MSF), Nhlngano, Swaziland  
Bernhard Kerschberger<sup>3</sup>, Alison Wringe<sup>4</sup>, Inoussa Zabsone<sup>5</sup>, Vellorenti Dlamini<sup>6</sup>,  
Sikhathele Mazibuko<sup>7</sup>, David Etooi<sup>8</sup>, Roger Teck<sup>9</sup>, Serge Kabore<sup>10</sup>, Mpumelelo  
Ndingamandla<sup>11</sup>, Barbara Rusch<sup>12</sup>, Iza Ciglenecki<sup>13</sup>

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**Context- Swaziland**

- Population: 1,2 million
- High HIV prevalence: 31% (SHIMS, 2012)
- HIV incidence: 2.38%
- 94% transmission via heterosexual sex

Since 2013, Accelerated ART pilot studies

- PMTCT+
- Early Access to ART for All (EAA; also known as 'test and treat')




**Two EAA pilots in Swaziland, since 2014**

MoH/ CHAI MaxART project in northern Swaziland (Hhohho)

MoH/MSF project in southern Swaziland (Nhlngano):

**Objectives:** To determine whether EAA is:

- Feasible under routine programmatic conditions
- Acceptable for patients with high CD4 levels (350-499/ ≥500)
- To compile Lessons learned and Recommendations



- Design:** A prospective cohort of PLHIV entering HIV care and being offered ART (regardless of any criteria)
- Eligibility:** Non-pregnant adults aged ≥16 years
- Location:** 1 rural health zone (Nhlngano) with 1 secondary facility, 8 nurse-led primary care facilities.



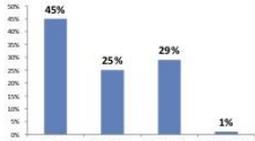
Nurse-led primary care clinic: 'one-stop-shop' TB-HIV care (Shushweni region)



**Mixed method analysis**

- Quantitative:**
  - 6-month retention on ART
  - Predictors of composite unfavourable outcome
- Qualitative:**
  - Examining PLHIV decision-making regarding ART initiation

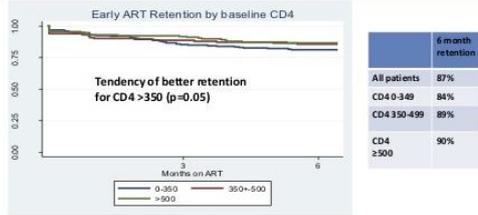
**Baseline characteristics**



625 patients initiated ART

- CD4 ≥500: 29%
- Median age: 33 (IQR 27-42) years
- Newly diagnosed with HIV: 48%
- 68% were women

## 6 month retention in ART care



## Predictors of unfavourable outcome

### Multivariate analysis- Increased LFT/ Death:

- Same day ART initiation (aHR 1.68, 95%CI 1.02-2.79)
- WHO stage III/IV (aHR 2.35, 95%CI 1.41-3.89)
- CD4, health care level, gender, age, known(vs new) HIV+ patient not associated with early treatment outcomes

LFT= loss from treatment

## EAA decision-making process

- Time to feel ready for ART

*'I waited...waited...and waited and then after some time I asked myself why I'm waiting because the time for me to take the treatment has arrived'* (EA.01)

- Autonomy, choice, and patient subservience

*'You have to surrender yourself to what the doctor told you'* (EA11)

*'I was afraid that she might shout at me if I didn't [take ART] because she had told me that I have the virus... It wasn't really my decision...'* (EA10)

## Protecting health and a hidden HIV status

- Fear of deteriorating health and death
- Not wanting to be identifiable as HIV positive motivated ART initiation
- BUT being on ART can also expose HIV status - fragility

*'My tongue, it used to be dry and had a whitish stuff. I knew now HIV is saying if you don't take medication you'll see more signs, we are in this body now...'* (EA12)

*'I thought let me take the treatment with my CD4 count being high as that is going to help me. I shouldn't take them when my face has withered and I'm like a written book that I'm now living with HIV, let me go there now as I am still fresh and I will find myself healthy'* (EA14)

## Conclusions

- EAA can achieve acceptable treatment outcomes – **high crude retention rates in higher CD4 strata**
- Same day ART initiation** needs consideration
- Many desired to initiate ART even when clinically asymptomatic
- Avoiding health deterioration → **avoiding anticipated stigma**
- PLHIV can start ART through **lack of perceived choice**
- Yet to see how these factors play out over longer-term in operational settings



# Thank you



### Acknowledgements-

- Patients and the Community of Nhlanguano Health Zone
- Health workers, Regional Health Management Team
- SNAP (Swaziland National Aids Program)
- MSF
- CHAI (Clinton Health Access Initiative)



For **ZERO** Eliminate HIV infections



## Power, agency and choice: Practitioner-patient relationships in the context of early antiretroviral therapy for people living with HIV in Shiselweni, Swaziland



\*Shona Horter<sup>1,2</sup>, Alison Wringe<sup>2</sup>, Velibanti Dlamini<sup>1</sup>, Bernhard Kerschberger<sup>1</sup>, Inoussa Zabsonre<sup>1</sup>, Sikhathele Mazibuko<sup>3</sup>, Munyaradzi Pasipamire<sup>3</sup>, Barbara Rusch<sup>4</sup>

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### Background

- Médecins Sans Frontières (MSF) and the Swaziland Ministry of Health began a test and treat pilot under routine programmatic conditions in Shiselweni, southern Swaziland in October 2014.
- Here immediate initiation of ART is encouraged for all adults diagnosed HIV positive, at any CD4 count.
- Swaziland is one of the first countries in sub-Saharan Africa to pilot test and treat for all HIV-positive adults.
- A qualitative study was conducted to explore experiences of people living with HIV (PLHIV) with test and treat in Shiselweni, Swaziland.



### Methods

We examined PLHIV's interpretation, understanding and decision-making processes regarding ART initiation under test and treat:

- Participants were recruited purposively from the pilot cohort to include a range of treatment-taking experiences (e.g. those presumed to be asymptomatic, those otherwise ineligible for treatment, and those who had and had not initiated ART)
- 17 in-depth interviews were conducted
- Data were analysed thematically using coding and Nvivo 11
- Principles of grounded theory were applied including constant comparison of patterns and concepts within and between cases, and actively investigating discrepancies from majority themes.

Participant characteristic	n=17
Newly diagnosed HIV positive	14
Pre-ART registered	3
CD4 count >350	12
CD4 count ≤350	5
Male / female	7 / 10

Table 1: Study participant information



### Results

Practitioner-patient relationships appeared to strongly frame and influence PLHIV engagement in HIV care under test and treat, including their autonomy and choice for ART initiation.

- Patients presented subservience in their relationships with health practitioners, describing the need to "surrender to" and "obey" the "law" of health services.
- Many participants felt the need to follow health practitioner advice as prescribed and viewed health practitioners as "experts" who had power and responsibility for their health.

*'They are the ones responsible for my life... you have to surrender yourself to what the doctor told you... I will do anything they tell me to do'* EA11

The power dynamics at play within practitioner-patient relationships could call to question patients' autonomy over the decision to initiate early ART under test and treat.

- Some participants described the importance of their having choice in whether and when to start ART, needing time to process a HIV positive diagnosis and to feel ready for lifelong ART, or wanting to try alternative approaches to boosting their immune system such as eating a healthy diet or using traditional medicine before ART.
- However, certain participants felt pressured by health practitioners and felt unable to refuse ART.

*'I didn't want to start at the time... I told myself that I will try and eat healthy and in my mind I thought I should just boost myself with eating healthy'* EA 04

*'What hurt me on that day was this was a person who doesn't know how to counsel people, who forced me'* EA17

Certain participants would exert their agency in resisting from this power, for example by reportedly agreeing to initiate ART to providers but not swallowing the drugs.

*'When I went in she told me I have the virus and then she asked me if I agree to take the treatment or not and then I told her that I want to think about it first, and then she said it was out of the question for me to refuse taking the treatment because I already have the virus...I then took them... I was afraid that she might shout at me if I didn't... it wasn't really my decision... I never drank them...'* EA10

Considerations for initiating ART were not just described in terms of the treatment itself, but also related to the adjustments that a life on ART entails.

- Responsibilities and expectations that come with treatment-taking were described, referred to by several participants as the "rules of the treatment" – such as not drinking alcohol, having less frequent sex and having a healthy diet
- Participants raised concerns relating to their perceived ability to meet these expectations and to continue with ART, as health messaging strongly dictates that ART is lifelong.

*'They are saying we are supposed to eat a balanced diet...[but] now there are no rains, this year we haven't ploughed anything... nothing would be conducive under this weather. And then you ask yourself how are we going to survive as people taking the treatment'* EA16

### Conclusion

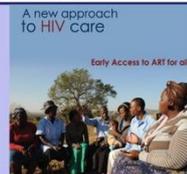
The power dynamics within practitioner-patient relationships can undermine patients' autonomy in their decisions regarding ART initiation under test and treat.

Some patients follow the perceived health service rules and expectations, with many initiating ART accordingly; and others demonstrate ways to resist.

Further research is needed to examine how patients will navigate ongoing engagement in HIV care following early ART initiation, when the decision to start ART and potential motivation for treatment-taking may not be intrinsically based. Health practitioner perspectives and experiences with test and treat should also be examined.

### Policy/practice recommendation:

- > Programmes should ensure patients are supported to make informed choices regarding ART initiation within test and treat, including their readiness for ART, and take care to avoid patients' feeling pressured or unable to choose.



### Acknowledgements

Thank you to the patients and staff involved in the MSF/MoH Shiselweni project.

### Ethics

Ethics approval was obtained from the Swaziland Scientific and Ethics Committee, MSF Ethics Review Board (ERB) and LSHTM ERB.

# Eswatini National AIDS Conference Oral Presentations July 2016

## 1 Linkage to HIV care in the context of Treat-all



**The ART of Acceptance: acceptance, denial and linkage to HIV care in Shiselweni, Swaziland**



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<sup>1</sup>Médecins Sans Frontières (MSF), Ntlangano, Swaziland <sup>MSF</sup> London, UK <sup>2</sup>Swaziland National AIDS Programme (SNAP), Ministry of Health of Swaziland, Mbabane, Swaziland, <sup>MSF</sup>, Geneva, Switzerland  
Contact: mdchv@hango-socialresearch@geneva.msf.org

### Background

- HTS crucial entry-point to HIV treatment and care – **90-90-90 / Test and Start**
- Increased access to HTS should facilitate HIV prevention and treatment
- Early linkage to care** associated with positive clinical outcomes plus preventative benefits
- Community-based HTS initiatives have been effective in reaching those previously untested and underrepresented groups (men, CYP)
- BUT** sub-optimal linkage to care reported

### Study Rationale

- To better understand the barriers and supportive factors for linkage to care – **why do some people link while others do not?**

**Study aim:**  
To examine community members' experiences with the community-based HTS programme, in particular exploring factors associated with linkage (or lack of linkage) to care for those testing HIV positive

### Methods

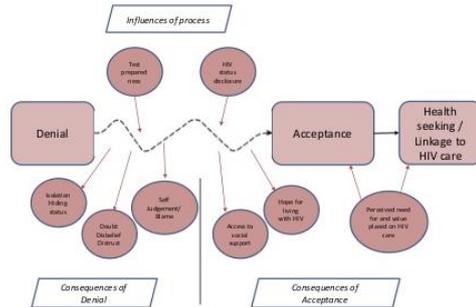
- 39 interviews and 3 focus group discussions held with:

Participant type	Number of participants	Participant info
Clients	28	14 recorded linked 14 recorded not linked, of whom: - 6 report not linked - 4 report linking as agreed - 4 report linking elsewhere 50/50 male/female Age range 16-69 years
Health practitioners	11	HTCs (community and clinic) Nurses Expert clients
Community members (HN status unknown)	3 FGDs (19 participants total)	Young women x 2 Young men x 1

**N.B. over half of 'not linked' participants reported having actually linked during interview**

### A summary of the findings

- How people **processed** an HIV positive result, **accepted or denied** their HIV status **influenced** linkage to care.
- Testing and follow-up approach and process important.
- Status disclosure supported linkage to care.
- Health system factors – approaches of HCW at clinics, queues, lack of privacy/confidentiality.



## Denial

- Shock, stress, anxiety, anger, doubt, disbelief
- Self-stigma, self-judgement, blame
- Potential suicidal thoughts, unsafe sexual practices
- Denial and re-testing for HIV – is it really true?

*'I wanted to see if the test was for real... I [re-tested and] found that I am really HIV positive and that is when I accepted, and when I started the ART' C08*

*'It is what can make someone ill, the fact that they do not accept' C06*

## Denial and non-disclosure

- Those in denial less likely to disclose and therefore access social support (which helps with linkage)
- Also may be more afraid of having to start ART – fear of being identified HIV positive

*'I'm waiting to talk to her first before I go to the clinic' C12*

*'Once you have not disclosed it, the status, it means you are still fighting in your mind. You still have these many unanswered questions: why? Who? When? What? You see, but once we have shared it with someone, it means you've accepted the situation.' HP05*

## Testing process: influences of acceptance/denial

- Readiness for test and result
- Seeing the test being done with own eyes – trust and belief
- Choice to test – undermined by testing incentives

*'Testing when you want to test and you wish to test, it is better in your spirit because you initiated it so the results will also not be so hard to accept emotionally' C06*

*'Some people go [to test] because you know at the tents sometimes they give incentives and because as Swazis we are hungry so if there is some incentive I will not stay behind but that is not good... it is like bribery... because they want to receive those things [they test], but will they accept after that, I do not know' (FGD 02, P03, males)*

## Influences of acceptance/denial process

- Perceptions of HIV risk
  - Judgements about who gets HIV
  - Association of HIV and "promiscuity"
- Expectation of chance of receiving positive results (also linked to symptoms/feeling unwell)

*'I never got to accept it... I questioned - "me and HIV? But I am well behaved"' P05*

*'The way HIV was first introduced, that HIV is in those who go sleeping around... so for those who know that they take care of themselves, they are far away from thinking of being HIV positive' HP 02*

## Support towards acceptance

- Counselling
  - Attitudes, approach
- Time to process result
- Support, reassurance
- Hope and belief for future living with HIV

*'I accepted it because I told myself that I was going to live because they are living' P12*

## Value placed on health care

- Denial and asymptomatic – less urgency
- Acceptance, understanding, belief
- Perceived benefits of accessing early ART
- Avoiding "bedridden state" - stigma

*'Going there when you're a bit healthy is better than going there when you're already lying down. This way you can live longer, as if you don't have this thing' C09*

*'I do not want to fall sick and get bedridden, and be a written book for everyone to read' P07*

## Health system factors

- Losing form – afraid to go to clinic – fear of being reprimanded
- Missing appointment
- Lack of privacy at clinics (especially Secondary HC)
- Queues
- Missing work
  - Especially for those without symptoms, who don't feel unwell – other priorities, health not main concern

*'What held me from going to the clinic on the agreed date was the document I lost as I kept asking myself how am I going to access care without that paper, because this lady emphasised that I should go with the document and then are they going to help me after that...'* C11

## Conclusions

- Acceptance or denial of HIV status fundamentally affected individuals' health-seeking
- Acceptance -> access to support, increased sense of need for and value placed on health care
- Potential need for emphasis on test preparedness (perception of HIV risk), and expectation for chance of a positive result

## Recommendations

- Enhancing pre-test preparedness
  - HIV risk perception – why testing today?
  - Expectation chance 2 results / readiness
  - Reconsider appropriateness of testing incentives.
- Individually tailored post-test counselling
  - Available at multiple points if required
  - Clear aims – supporting acceptance and disclosure
- Consider developing key and direct messaging around the forms used for linkage.



Thank you!



**From Crisis to Opportunity**  
Swaziland HIV/AIDS Conference  
12 - 14 July, 2016

## 2 Stigma and engagement with treatment and care within Treat-all (award won)

**HIV-positive individuals' experiences with Early antiretroviral therapy in Shiselweni: Maintaining health and a hidden HIV status**

A new approach to HIV care

Early Access to ART for all

From Crisis to Opportunity  
Swaziland HIV/AIDS Conference  
12 - 14 July, 2016

\*Shana Horter<sup>1,2</sup>, Velibanti Dlamini<sup>1</sup>, Zanele Thabede<sup>1</sup>, Bernhard Kerschberger<sup>1</sup>, Inausa Zabantse<sup>1</sup>, Sikhathelo Mazibuka<sup>1</sup>, Muryaradi Pasipamire<sup>1</sup>, Barbara Rusch<sup>1</sup>, Alison Wringe<sup>2</sup>

<sup>1</sup> Médecins Sans Frontières (MSF), Nhlanguano, Swaziland; <sup>2</sup> London School of Hygiene and Tropical Medicine, London, UK; <sup>3</sup> Swaziland National AIDS Programme (SNAP), Ministry of Health of Swaziland, Mbabane, Swaziland; <sup>4</sup> MSF, Geneva, Switzerland.

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### Context- Swaziland

- Population: 1,2 million
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Since 2013, Accelerated ART pilot studies

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MoH/ CHAI MaxART project in northern Swaziland (Hhohho)

MoH/MSF project in southern Swaziland (Nhlanguano):

Objectives: To determine whether EAA is:

1. Feasible under routine programmatic conditions
2. Acceptable for patients with high CD4 levels (350-499/ ≥500)
3. To compile Lessons learned and Recommendations



### Study rationale

- Assumed increased access to ART under EAA would **reduce stigma**
- Normalisation of HIV** – chronic disease like any other
- HOWEVER:**
  - We don't yet know what will happen in reality with EAA
  - Including how PLHIV will interpret, understand and experience EAA
  - And how EAA may shape experiences with HIV stigma

### Methods

- 17 in-depth interviews with PLHIV offered ART under EAA
- 13 days of observation – clinic and community activities
- Aim: to examine PLHIV's experiences with HIV testing and decision-making processes regarding ART initiation under EAA
- Ethics approval

Participant characteristic	n=17
Recently diagnosed HIV positive	14
Pre-ART registered	3
CD4 count higher than previous tx eligibility guidelines (>350)	12
CD4 count lower than previous tx eligibility guidelines (≤350)	5
Male / female	7 / 10

### Avoiding health deterioration

- Fear of death
- Familiarity
- Signs of HIV
- HIV diagnosis-duty to act

"Like my sister who is now in a wheel chair she was found to have the virus and her CD4 count was 2 and then when she started taking the treatment she became better but then she still couldn't stand up from the wheel chair..." EAO7

"My tongue, it used to be dry and had a whitish stuff, I knew now HIV is saying if you don't take medication you'll see more signs, we are in this body now..." EAI2

"I was seeing the situation out there and I said to myself I don't want to be killed by something that has been found in me and yet there are pills that can be taken to suppress the virus" EAO1

## Maintaining a hidden HIV status

- Not wanting to be identifiable as HIV positive motivated ART initiation
  - Avoiding development of signs/symptoms associated with HIV

*"I thought let me take the treatment with my CD4 count being high as that is going to help me, I shouldn't take them when my face has withered and I'm like a written book that I'm now living with HIV, let me go there now as I am still fresh and I will find myself healthy"* EA14

## ART Potentially exposing

- Engaging with HIV services – anticipated stigma
- Fear of being discovered on ART
- Fragility

*"If I was amongst those who sit on the benches I don't think I would go there, I would prefer not to take [ART] and I'd rather die because really if you hear people talking saying they saw so and so there... I'm taking the treatment because I am not going to those benches..."* EA12

## Conclusions

- Many participants expressed a desire to initiate ART, even in the absence of symptoms
- HIV diagnosis – duty to act to protect health
- Avoiding health deterioration → **avoiding anticipated stigma**
- ART potential to hide HIV status and also expose - fragility
- Yet to see how these factors will play out over longer-term – ongoing engagement in HIV care

## Recommendations

- Adapt health messaging to target **reducing** stigma (rather than encouraging hiding HIV status)
- Increase tailored patient support towards overcoming anticipated stigma
- Enhance privacy through more integrated health services



Thank you



### Acknowledgements-

- Patients and the Community of Nhlanguano Health Zone
- Health workers, Regional Health Management Team
- SNAP (Swaziland National Aids Program)
- MSF



**From Crisis to Opportunity**  
Swaziland HIV/AIDS Conference  
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**For ZERO** stigma and discrimination  
towards HIV infections

### 3 Practitioner-patient relationships framing engagement with Treat-all care

**Power, agency and choice:**  
Practitioner-patient relationships in the context of early antiretroviral therapy for people living with HIV in Shiselweni, Swaziland

A new approach to HIV care  
Early Access to ART for all

**From Crisis to Opportunity**  
Swaziland HIV/AIDS Conference  
12 - 14 July, 2016

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#### Background: Why early access to ART?

- Treatment as prevention
  - Studies have shown ART can reduce HIV transmission
  - HIV transmission could also be reduced at population level – suppressed viral loads
- Health benefit to PLHIV with early rather than delayed ART
  - Trials have shown lower rates of death and illness with ART initiation at CD4 > 500 compared to <350



#### Two EAA pilots in Swaziland, since 2014

MoH/ CHAI MaxART project in northern Swaziland (Hhohho)

MoH/MSF project in southern Swaziland (Nhlalango):

**Objectives:** To determine whether EAA is:

1. Feasible under routine programmatic conditions
2. Acceptable for patients with high CD4 levels (350-499 / ≥500)
3. To compile Lessons learned and Recommendations

#### Study rationale

- EAA effectiveness requires patient compliance
- Don't yet know what will happen in reality...
- How will PLHIV interpret, understand and experience the offer of early ART?
- How will ongoing treatment-taking and engagement in HIV care be maintained over time without a history of feeling unwell?



**Study aim:**  
To examine PLHIV's experiences with HIV testing and decision-making processes regarding ART initiation under EAA

#### Methods

- 17 in-depth interviews with PLHIV offered ART under EAA
- 13 days of observation – clinic and community activities

Participant characteristic	n=17
Newly diagnosed HIV positive	14
Pre-ART registered	3
CD4 count higher than previous tx eligibility guidelines (>350)	12
CD4 count lower than previous tx eligibility guidelines (≤350)	5
Male /female	7 / 10

#### Findings

- Practitioner-patient relationship framing PLHIV engagement in HIV care under EAA
  - Power dynamics
  - Patient autonomy
  - Choice for ART initiation



MSF Swaziland Project, 2014

## Hierarchy and power dynamics within practitioner-patient relationships

- Obeying the “rules” and “law” of health services
- Health practitioner “expert” advice
- Responsibility to government as well as to health practitioners

*'You have to surrender yourself to what the doctor told you'* (EA11)

*'They are the ones responsible for my life... I will do anything they tell me to do'* (EA11)

*'They told me... we are not forcing you to start taking the treatment because if that's the case then you'll take them and throw them in the pit toilet and in that way you'd be letting the government down'* (EA14)

## Patient autonomy and choice

- Importance of choice – time to process HIV positive result and feel ready for ART
  - Alternative approaches to self-care
- Pressure
- Perceived inability to refuse ART

*'I didn't want to start at the time... I told myself that I will try and eat healthily and in my mind I thought I should just boost myself with eating healthy'* (EA04)

*'What hurt me on that day was this was a person who doesn't know how to counsel people, who forced me'* (EA17)

## Patient resistance from practitioner-patient power dynamics

*'When I went in she told me I have the virus and then she asked me if I agree to take the treatment or not and then I told her that I want to think about it first, and then she said it was out of the question for me to refuse taking the treatment because I already have the virus... I then took them... I was afraid that she might shout at me if I didn't because she had told me that I have the virus... it wasn't really my decision... I never drank them...'* EA10 – 22 year old female

## Expectations placed on patients – life on ART

- “Rules” of ART:
  - Not drinking alcohol
  - Less frequent sex
  - Condom use
  - Balanced diet
- Self-efficacy and volitional control

*'We do follow the rules they gave us but at times we break those rules...'* (EA11)

*'They are saying we are supposed to eat a balanced diet... [but] now there are no rains, this year we haven't ploughed anything... and then you ask yourself how are we going to survive as people taking the treatment'* (EA16)

## Conclusions

- Power dynamics within practitioner-patient relationships can cause patients to follow health advice due to lack of perceived choice
- Patients can feel unable to refuse ART under EAA
- While some patients present subservience and obey health advice, others can resist e.g. by not taking ART
- Yet to see how these factors will play out over the longer term....

## Policy and practice recommendations

- Programmes should support patients to make informed choices regarding ART initiation under EAA
- Need to consider individual patient readiness for ART
- Take care to avoid patients' feeling pressured
- Further research:
  - Practitioner-patient relationships and EAA influence on ongoing treatment-taking
  - Health practitioner perspectives

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**Thank you**



**ZERO**  
AIDS  
DEATHS  
AND DISABILITIES



## Feedback for participants document

### Health Services Research in Shiselweni

*Shona Horter, Velibanti Dlamini, Zanele Thabede, October 2017*

We conducted research in Shiselweni, Swaziland from June 2016 to September 2017, with our partners the Swaziland Ministry of Health, Medecins Sans Frontieres, and the London School of Hygiene and Tropical Medicine. This research aimed to explore people's views about, and experiences with the health services in Shiselweni, to understand how particular health conditions may be managed and to see how health services could be improved.

#### **Key recommendations that have come from this research:**

- The importance of privacy and confidentiality in clinics, patients value integrated services where certain conditions are not considered differently, one-stop-shop approach where all services can be obtained in one room is ideal, using the same colour of treatment booklet for all health conditions if possible
- The need to support and allow for individual patient readiness – everyone takes a different amount of time to feel ready to start treatment, people should feel able to take the time they need, and come to the clinic to discuss and ask questions in the meantime. People should not be shouted at or reprimanded for wanting to start treatment later, or for re-engaging with treatment and care after a gap in treatment-taking.
- Patients would like to be able to have more time with HCW, to discuss any concerns they might be having and to ask questions
- Patients appreciate friendly, open and approachable HCW, who can give them support, reassurance and encouragement
- Patients found routine monitoring blood tests, in particular viral load results, useful for seeing evidence of the effectiveness of treatment. This supported and motivated ongoing treatment-taking. Patients should be able to get their viral load checked routinely and should be given their results when they are available.
- HIV testing: patients should not feel they have to test for HIV, the tests are encouraged but are not forced, people should be given information and then be able to choose if they want to test. Where tests are suggested by HCW a patient should be able to access counselling, information and support – this is your right as a patient, you can ask for more information if you are unclear and can access counselling after the test if you would like it.

### **Key findings:**

The findings presented here relate to services that are provided for HIV, but other health conditions were also discussed and explored in this research, including family planning and tuberculosis.

### **HIV testing**

- Some wanted to test for HIV knowing they could get now treatment at any CD4 count – which actually motivated their testing.
- Many people knew that it is good to test for HIV regularly, even if you don't feel sick or don't see yourself as at risk of HIV specifically, HIV can affect anyone and there are advantages of knowing your status early and then being able to access treatment and care early too.
- Some people wanted to re-test for HIV, to verify if their result was really true. Most who re-tested seemed to find this helped them to accept their HIV status and believe in the test accuracy.
- Some felt that testing as a couple was helpful, and made it easier to disclose and access treatment and care if one or both partners were found to be positive. Testing as a couple meant there was a HCW available to support with the results, and could offer counselling and advice to those with different results – like when one partner tests positive and one tests negative. This was seen to make it easier for the couple to accept each other's results.

### **Starting early treatment:**

- Patients felt there were many benefits to starting treatment early, even without having any symptoms or feeling unwell, including the positive effects early treatment has for health. It was seen that early treatment enables good health, energy, strength and productivity, so people who started early felt able to continue as normal, to work, socialise, have a relationship/get married, and have babies if they wanted to.
- Lots of people said they had seen the effects of starting treatment late or not at all, with many having family members or neighbours who they had seen become very sick, or even die, as a result of late or no access to treatment.
- Treatment was seen as enabling life – it was seen that with early treatment you can live for longer and keep good health. Some felt that if people start treatment late their recovery can be hindered and treatment side effects can be worse
- Quite a few people had fears about treatment side effects. Most people in the study who had side effects said they were not too bad and that they only lasted for a few weeks after starting treatment, until their bodies adjusted to the treatment. Those who were afraid of side effects, or who experienced them, said it was reassuring to know they could go to the clinic at any time and discuss side effects they were experiencing with the treatment. Those

who did report side effects said they were taken seriously by HCW, something was done to help them, and that they then felt better afterwards.

- How long it took people to feel ready to start treatment was really varied. Some went to test already wanting to start ART if the result was positive
- Some people needed more time to come to terms with a positive result, and to feel ready for treatment. Some had concerns about being able to remember to take treatment every day, though most who took treatment said this became easier over time, and that things could help like having a family member who knew they were on treatment and who could help, encourage and remind them to take treatment.
- Talking to someone about a positive test result could be important, as it can enable access to support, encouragement, reassurance, hopes for the future, as well as making it easier to take treatment (without feeling as though it needs to be hidden).
- People said HCW support, as well as support and encouragement from a partner, family members or friends, could really help them to feel ready to start taking treatment and also to continue to take it.

#### **Ongoing treatment-taking:**

- It seemed important to be able to see the difference treatment was making, which could be difficult to identify for those who started treatment when they were not sick. Some had doubts about the treatment's effectiveness, as they couldn't see physical improvements that came about after starting treatment. The blood tests that are taken at the clinic were seen to really help with this, as being able to see that the level of the virus is going down, or that the CD4 count is going up, could help give evidence of the effect of treatment and therefore motivate continued treatment-taking.
- Some people spoke about missing some doses of treatment to see if this had an effect on their body, and because they wanted to see evidence of the need for treatment and its effectiveness. This could be really dangerous, as taking treatment sometimes and sometimes not taking it can cause the risk of drug resistance to develop, which can make it more difficult to find a successful and effective treatment in the future. If you have doubts about the effectiveness of your treatment talk to your HCW about it, or ask them to do a viral load test for you, so that you can make sure that your virus is being kept suppressed by the treatment – this will show you that the treatment is really working.
- Those who felt like they owned their treatment-taking – that they had decided to take treatment for themselves, for their health, and their future, appeared to be more motivated and determined to continue taking it. It seems like it is important for people to feel as though their treatment is theirs, and to want to take it for themselves. This can help people to feel able to prioritise treatment-

taking, and overcome any difficulties they might face, as they know how important the treatment is for enabling a long, healthy life ahead.

- It seemed to help people to have plans, hopes and dreams for the future – thinking about what you want to do and planning how you might be able to achieve your aspirations. Then the treatment could be seen as a tool through which to achieve your dreams, which can make it feel more positive.
- Lots of people said they didn't want to be seen at the clinic collecting treatment refills, as they feared being gossiped about and stigmatised as a result. Many people said they would change the treatment container to avoid the rattling noise pills can make. It seemed really important for clinics to offer privacy, confidentiality and integrated services – which could help people overcome fears of being seen on treatment.
- Some people felt like they didn't have enough time with HCW at clinics, that HCW could seem like they are too busy, with long queues of patients outside, and that they didn't always seem open to hearing patient's questions, concerns, or challenges. This is important and needs to be addressed within the health systems, so that patients feel able to come forwards and talk, ask questions and share – and therefore are able to also access support. You shouldn't feel the need to hide any difficulties you are having, there are counsellors who are available to offer support with overcoming such difficulties, who should be able offer a listening ear, and to help you problem solve.

We would like to say a big thank you to all of those who shared their time, views, experiences and opinions. This research would not have been possible without your contribution. We hope as a result of you sharing your views about health services in Shiselweni, that it might be possible for services to be better adapted to meet people's needs, and to provide support for patients in the future.

## Summary of key findings document

Qualitative research investigating how people living with HIV engage with HIV treatment and care in the context of a Test and Start/Early Access to ART for All pilot in Shiselweni, Swaziland:

### Summary of key findings and recommendations

Shona Horter, October 2017

#### 1. Entry into care – mode of testing

- Motivations for HIV testing:
  - Knowledge of EAA appeared to motivate some to test for HIV: Certain participants wanted to test knowing they could receive ART if tested positive, rather than having to wait for their CD4 count to reach a certain point for treatment eligibility.
  - Several participants said they wouldn't have tested had it not been for HCW encouragement
  - Radio programmes said to encourage many to test, even those asymptomatic and who didn't have specific HIV risk perception – community mobilisation emphasising any one can be affected, encouraging all to know status for healthy, long life.
  - Some also wanted to test for HIV because of signs or symptoms of ill health, or perceiving HIV risk
  - Some felt they didn't have a choice but to test for HIV, and could only access other services e.g. related to pregnancy if they tested, thus in some cases provider initiated tests could be experienced as coercive
- Participants testing for HIV via provider initiated testing potentially needed more support for test preparedness, status acceptance and treatment readiness, highlighting the need for an individually tailored approach
- However, it also appeared that provider initiated testing is a means to reach those who may not otherwise test for HIV, and to encourage access to care
- Our findings emphasise the importance of ensuring patient choice for HIV testing and avoiding mandatory testing, or testing which could be perceived or experienced as coercive. Where the choice and ownership lies with the patient it appears more likely this will also translate to ART readiness, and motivation for adherence (see later sections).

- Re-testing for HIV following a positive result:
  - Many PLHIV participants described re-testing following receiving a positive result, to verify the HIV test accuracy, thus for those who did not believe their diagnosis this could support the process of status acceptance.
  - Some PLHIV participants described re-testing to check their CD4 count (to see whether it had changed over time)
  - Re-testing also appeared as a means to re-engage with treatment and care, as it was perceived easier to test again and start afresh (as though first time tester), than potentially have to confess late access to care and risk being scolded and reprimanded by HCW.
  - Though all participants were recorded on the project database as being newly diagnosed, during interviews several participants described having been diagnosed HIV positive at an earlier point, some several years ago, and re-testing as though for the first time
- Couples testing was seen to enable disclosure

#### Recommendations:

- Community: Enhance community mobilisation approaches such as radio programmes – encouraging testing for all, even if not experiencing any symptoms, encouraging early treatment prolonging life. Also involvement of community leaders in mobilisation – said to be more trusted, respected and influential members who could therefore positively influence care-seeking
- Community: re-examine invitation approach for partner involvement and couples testing? Better for couple to test together before pregnancy than to rely on woman having to disclose to man, and potentially be judged as having brought HIV into the family, with negative ramifications including potentially being shunned or abused
- Counselling: Take care for those testing via provider-initiated tests, ensure test preparedness, patient choice and ability to opt out, even where the test is encouraged for health purposes, where patients feel as though they are choosing to test they may be better able to process and accept a positive result and have more sense of ownership (and therefore motivation) for treatment-taking
- Counselling: Emphasise that it is OK for people to take time to process a positive result and feel ready to come back to care when they want to, rather

than feeling pressured to comply and initiate ART straight away (if not ready/accepted diagnosis), particularly for those who are asymptomatic and with high CD4 counts

- Health system: Avoid “compulsory” testing approaches – or those potentially perceived as coercive e.g. denying access to other health services without HIV test. Re-testing potentially enabling progression towards status acceptance – offer re-tests where possible?

## 2. ART initiation

- ART Readiness:
  - Time for ART readiness varied for different individuals
  - Readiness for ART appeared supported by HIV status acceptance, disclosure of status (and access to support and encouragement therein), support, encouragement and reassurance, counselling, and hope for the future of life with ART
- HCW could feel pressured to “convince” patients to initiate ART and comply, which then led to patients experiencing pressure. HCW pressure was described linked to monitoring information capturing the number of diagnoses versus initiations, which could be judged as a reflection of staff competency. However, in reality HCW cannot control for an individual’s psychological process of readiness, which can be very varied. Due to the experienced pressure to initiate ART, and feeling unable to refuse, some patients would take the treatment home with them and not swallow the pills, thereby silently refusing (whilst appearing to remain engaged with treatment and care).
- The importance of patient choice for ART initiation was highlighted by participants, including wanting to take treatment for self, sense of ownership, valuing health and life, which was seen to support and foster treatment-taking motivation as compared to treatment-taking due to sense of obligation.
- Factors motivating ART initiation:
  - Many wanted to prevent HIV visibility through protecting good health and therefore avoiding development of symptoms that could be seen and judged by community members as indicative of HIV, to avoid anticipated stigma.
  - The advantage of early ART protecting good health and therefore enabling productivity was described, particularly by men, and appeared important for being able to work and provide for family.

- The perceived need for and benefits of treatment, and belief in treatment effectiveness were emphasised by participants as being important for ART initiation:
  - Perceived need for treatment appeared supported by status acceptance, and signs and symptoms that could be seen as indicative of HIV infection.
  - Perceived benefits of treatment were supported by familiarity, i.e. seeing others recover on ART or deteriorate/die without ART.
- Factors undermining ART initiation:
  - Concerns about ART side effects could undermine desires to initiate treatment, with fears of becoming visible through side effects e.g. weight change, lipodystrophy, skin colour changes. Side effects could pose a particular challenge for those who were asymptomatic and therefore could feel worse after starting ART than they did before, which could undermine perceived need for/benefits of treatment and motivation for taking it.
  - It appeared important to PLHIV participants to have access to reassurance and information about side effects – knowing what to expect, knowing they could report side effects to HCW, that they would be taken seriously and something would be done to address any such experiences.
  - PLHIV had concerns about their potential inability to adhere to treatment-taking demands including the required lifelong commitment of treatment, remembering to take ART on time every day, and also to adhere to the “rules of treatment” e.g. healthy diet, no alcohol, no smoking, condom use, less sexual partners. This prevented some participants from feeling able to start ART.
  - Some participants had concerns about the potential for future treatment shortages. Many understood that it was better not to start treatment than to start and stop, due to the risk of resistance developing, and thus this could deter them from wanting to initiate ART. HCW participants also raised concerns about the potential for future treatment shortages with national implementation of Test and Start.
  - Disclosure of HIV status could particularly pose a barrier to treatment initiation for women, with risks highlighted for those testing and initiating ART during pregnancy – it appeared there could be initiation, adherence and retention in care challenges linked to fear of disclosure and hiding treatment, or not feeling

able to take it without partner consent and support. Couples testing was seen to enable disclosure (i.e. where the couple would come and test as though neither knew positive status, with HCW then available to support serodiscordant results if needed). This then was seen to support engagement with treatment and care.

#### Recommendations:

- **Community:** Could build upon the notion that early ART supports concepts of masculinity and productivity – early ART enabling you to stay healthy, strong, energetic and productive. Build on messages encouraging couples testing, ideally before pregnancy, as it appeared easier to test together for disclosure and subsequent access to and engagement with treatment and care
- **Counselling:** Emphasise the benefits of early ART for good health, long life/future and productivity. Provide information on side effects and invite patients to report any side effects, reassuring them that these will be addressed if needed. Consider that patients may be making decisions regarding ART initiation based on risk/benefit analysis – how to address this and reassure concerns?
- **Counselling:** ART readiness appeared influenced by multiple factors, and varied for each individual in terms of time to readiness (with some ready on testing for HIV, and some needing more time) – need to remove pressure to HCW to convince patients to start ART (targets, monitoring etc), and also remove pressure to individual PLHIV; not seeing it as a failure (for HCW or for patient) if patient is not ready for ART, rather keeping door open for patients to come back and talk, even if they are not yet ready for ART. Importance of patient choice, readiness and ownership.
- **Health system:** Integrated services appeared preferable to counter fears of HIV status exposure when accessing treatment and care, importance of privacy, confidentiality, and non-differential treatment of HIV compared to other health conditions. Possible to have treatment booklet for HIV the same colour as for other conditions?

### 3. Adherence and retention in care

- Many wanted to see the difference treatment was making for them, and evidence of the treatment effect, particularly those who hadn't had physical symptoms prior to ART initiation, for whom this could be hard to qualify. This appeared important for their belief in treatment effectiveness, perceived benefits of treatment and need for treatment, which motivated treatment-taking.

- Experimenting – some patients who appeared to doubt the treatment need and effect would experiment by missing certain doses or having a treatment interruption, wanting to see if something would happen that evidenced the treatment need and effect (and testing the likelihood of threatened consequences and repercussions of non-adherence, emphasised by HCW, being realised)
- Belief in treatment need/effectiveness could be supported by viral load monitoring, which appeared particularly important for those with no physical symptoms prior to ART initiation, who can struggle to see treatment effect. Others felt that weight changes or gaining strength and energy could be an indication that treatment was working.
- Ownership and self-responsibility for treatment-taking appeared important for motivation and determination. Patients who chose to take treatment for themselves and their health, and had a sense of ownership, appeared more driven to overcome challenges and prioritise treatment over other areas of life, such as work commitments which could otherwise contradict treatment
  - There appeared less motivation for treatment-taking where the ART initiation decision was not intrinsically based (i.e. taking treatment because perceived have to/obligation/no choice rather than taking for self, health, life)
- Wanting to take treatment to live, having hopes, aspirations and plans for the future appeared to support and motivate treatment-taking
- Importance of treatment support – including emotional support (e.g. encouragement, reassurance), practical support (e.g. treatment reminders), and financial support (e.g. money to get to the clinic). Counselling, being able to talk to HCW and receive ongoing encouragement appeared particularly important
- Insufficient time with HCW was raised as a potential challenge, with many participants feeling unable to share challenges and concerns with HCW, and ask questions. Where HCW appeared friendly, open, approachable, trustworthy and to have time for dialogue this seemed to help PLHIV feel able to discuss their questions and concerns, which in turn enabled access to support for their continued treatment-taking

- There appeared to be inconsistent messaging around Treatment as Prevention. Many PLHIV participants said they have heard of the concept, mainly through community, radio or informal channels. Most presented limited understanding and most said they did not believe in TasP and sexual transmission, though there appeared consensus that ART could reduce the risk of infecting a baby with HIV. There appeared contradiction between HCW advice, messages around risk of reinfection, unprotected sex causing unsuppressed viral loads, and the need to always use condoms. Most HCW participants said they were not comfortable telling patients about TasP. However, the contradictory messaging could potentially cause distrust in HCW advice if not careful – some PLHIV described trusting HCW advice (that TasP is not true) over other channels. This could also present a missed opportunity, as many said TasP would motivate treatment-taking, and many in serodiscordant relationships had concerns about transmitting HIV to their negative partner.
- Fear of status exposure undermining adherence and engagement with treatment and care:
  - Hiding treatment potentially leading to non-adherence (not taking tx when others are around, not accessing treatment support and reminders due to non-disclosure)
  - Hiding status potentially leading to disengagement or treatment interruptions e.g. if people from community present at clinic – individuals may not proceed to wait/queue and collect refill
  - Importance of integrated services, non-differential treatment for HIV, avoiding identifying factors e.g. not using different coloured treatment booklet, treatment containers making noise

#### Recommendations:

- **Counselling:** At present, the counselling emphasis is for those whose viral load results are unsuppressed. Many felt viral load monitoring could provide evidence of treatment effectiveness and could motivate treatment-taking, it therefore could be important to inform patients of their suppressed results, celebrating their achievements and reinforcing treatment-taking continuation.
- **Counselling & community:** Treatment as prevention communication should be reconsidered. Not communicating the preventative benefit of treatment to patients could be a missed opportunity, as it was said to have potential to motivate treatment-taking. Also not informing patients about TasP could

undermine their trust in HCW, as the inconsistency in messaging could be seen as a form of limiting information to exert control.

- Counselling: create space for patients to share their concerns and ask questions, encouraging discussion and exploring patients' hopes, dreams and plans for the future.
- Counselling: emphasising patient ownership, involvement of patients in their care – feeling responsible for their health and treatment-taking
- Health system: importance of viral load monitoring – need to ensure systems are in place to incorporate routine viral load monitoring as a core component of Test and Start/EAA, ideally for baseline and routine thereafter. Also need to ensure sufficient resources (including staffing) to communicate results to patients.
- Health system: staffing shortages, particularly described in terms of the nurse to patient ratio: resources, including clinics having sufficient space/rooms for consultations, drug procurement and supply chain to ensure no risk of shortages/stock outs.