



CHALLENGES TO ANTIRETROVIRAL ADHERENCE AMONG MSM AND LGBTI LIVING WITH HIV IN KAMPALA, UGANDA

A scoping study

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ABBREVIATIONS

AGHA	Action Group for Health, Human Rights and HIV/AIDS
AIDS	Acquired Immune Deficiency Syndrome
amfAR	American Foundation for AIDS Research
ART	Antiretroviral therapy
COPECC	Come Out Positive Test Club
ESA	East and southern Africa
FARUG	Freedom and Roam Uganda
HCT	HIV counselling and testing
HIV	Human immunodeficiency virus
HOYMAS	Health Options for Young Men in HIV, AIDS and STIs
HRAPF	Human Rights Awareness and Promotion Forum
LGBTI	Lesbian, gay, bisexual, transgender, and intersex
LVCT	Liverpool Voluntary Counselling and Testing Clinic
MARPI	Most-at-Risk Populations Initiative
MARPs Network	Most-at-Risk Populations Network
MSM	Men who have sex with men
MSW	Male sex workers
NAFOPHANU	National Forum of PLHA Networks in Uganda
PLHIV	People living with HIV
PWID	People who inject drugs
SMUG	Sexual Minorities Uganda
UHRC	Uganda Human Rights Commission
UN	United Nations
UNAIDS	The Joint United Nations Program on HIV/AIDS
VCT	Voluntary counselling and testing
WHO	World Health Organization

SUMMARY

It is now possible for antiretroviral therapy (ART) to reduce viral load to the point where an infected person is no longer, or much less, infectious to others. As a result, 'treatment as prevention' has become the cornerstone of UNAIDS's post-2015 global strategy to end AIDS by 2030. As the expansion of treatment provision continues, and access improves, adherence becomes a determining factor in the impact of ART for both treatment and prevention. HEARD is conducting a number of small scoping studies on challenges to ART adherence in men who have sex with men (MSM) and lesbian, gay, bisexual, transgender, and intersex (LGBTI) communities living with HIV in east and southern Africa (ESA), as key populations in the AIDS response. This report presents findings from a scoping study carried out in Kampala, Uganda, in December 2015. The findings suggest that (double) stigma and criminalisation of behaviour of people living with HIV (PLHIV) in MSM and LGBTI communities cut across almost every perceived challenge to ART adherence as a driving or contributory factor. As a result, indications suggest MSM and LGBTI experience challenges that are similar in type to the general population, but that these population groups experience the challenges more often, more acutely, and with less opportunity to overcome the challenges.

Currently, there is no robust, clinical data on rates of ART adherence among MSM and LGBTI population groups. Within the constraints of this scoping study, findings recommend addressing double stigma and criminalisation underlying challenges to ART adherence for MSM and LGBTI with a human rights approach. Perceptions shared in this scoping study suggest these changes will only occur in the mid to long term so a public health argument should be used to create a more robust health system in the shorter term, able to meet the requirements for ART adherence in the MSM and LGBTI communities within the challenging and changing political and legal, and socio-cultural environment of Uganda. This paper provides an imperative and direction for further research to take forward the provisional findings of this scoping study.

1. INTRODUCTION

The United Nations holds that criminalisation, discrimination, and stigma in society against key populations create barriers to realising their human right to the highest attainable standard of health (UNFPA, MSMGF, and UNDP et al 2015: 7). Further, on 29 September 2015, 12 UN entities (ILO, OHCHR, UNAIDS Secretariat, UNDP, UNESCO, UNFPA, UNHCR, UNICEF, UNODC, UN Women, WFP and WHO) released ‘an unprecedented joint statement’ within which is agreed a ‘failure to uphold the human rights of LGBTI people...have a far-reaching impact on society – contributing to increased vulnerability to ill health including HIV infection’ (UN 2015: 1).

The challenges to antiretroviral therapy (ART) adherence is the subject of an emerging body of research and interest, and ‘key populations’ (men who have sex with men, male/female/transgender sex workers, transgender people, people who inject drugs, and prisoners) have been identified as critical population groups within the AIDS response. A systematic literature review conducted by HEARD in 2015 revealed an extensive knowledge gap in research on challenges to ART adherence amongst HIV positive men who have sex with men (MSM) and lesbian, gay, bi-sexual, transgender, intersex (LGBTI) communities in east and southern Africa (ESA) [HEARD 2015]. HEARD undertook a scoping study in Nairobi, Kenya in August 2015, to explore challenges to ART adherence amongst MSM and LGBTI populations. The outcome report is available from the HEARD website. A second scoping study was conducted by HEARD in Kampala, Uganda in December 2015, enabling a comparative, and more nuanced, analysis which is presented in this report to inform further research.

Similar to the Nairobi study, the Kampala study recorded perceptions of healthcare workers, key population programme officers, and MSM and activists living in Kampala. The report primarily finds that many of the most emphasised challenges to ART adherence experienced by HIV-positive MSM and LGBTI are not unique to MSM and LGBTI populations, but there is a perception that these are more acute and prevalent within the MSM and LGBTI communities. Initial indications suggest criminalisation of MSM and LGBTI-related behaviours, discrimination, and double stigma (from being HIV positive and a member of a key population) may increase the severity of the many challenges to ART adherence for MSM and LGBTI that are otherwise shared with the general population. Further research would need to be carried out to strengthen or confirm these indications.

2. BACKGROUND

The ESA region bears the greatest burden of the global HIV and AIDS epidemic. With only 5% of the world's population, ESA is home to half the world's population living with HIV. Today the region continues to be the epicentre of the HIV and AIDS epidemic, experiencing 48% of the world's new HIV infections among adults, 55% among children, and 48% of AIDS-related deaths (UNAIDS 2013a). From this crisis, countries in the region have emerged as some of the world's leading nations in HIV testing, up-scaling ART coverage, and increasing condom usage. The past five years or so have seen the rise of the 'HIV treatment as prevention'¹ approach, whereby treatment reduces viral load to the point where an infected person is much less infectious to others. Treatment as prevention is a core component of the post-2015 UNAIDS global Fast-Track strategy to end AIDS as a public health concern by 2030. The strategy aims by 2020 to have 90% of all people living with HIV to know their HIV status; 90% of all people with diagnosed HIV infection receiving sustained ART, and; 90% of all people receiving ART to have viral suppression. These targets rise to 95% by 2030 (UNAIDS 2014b).

As access to ART scale-up continues to be at the forefront of programme efforts to prevent new infections and HIV progression, socio-behavioural factors that may affect the adherence of ART become increasingly salient (Cock 2009: 488). For viral suppression, evidence shows optimal adherence to ART is >95%² with studies suggesting that inadequate adherence in resource-poor countries averages 23%, varying considerably by context (Paterson, Swindells, Mohr *et al* 2000; Scanlon and Vreeman 2013: 4). This has led to an exploration in research of the challenges to adherence for PLHIV on ART in the general population within ESA, but, as yet, there has been extremely limited focus on key populations like MSM and LGBTI: '[r]esearch to improve access and adherence among these [key] populations is virtually non-existent in LMIC' (Scanlon and Vreeman 2013: 7). A paucity of research on key populations is problematic because MSM, LGBTI communities, and key populations more generally experience comparatively higher rates of HIV prevalence – up to 19 times greater globally in MSM than for the general population (UNAIDS 2014d: 20). Key populations also typically suffer human rights infringements that undermine their access to, and engagement with, HIV prevention and treatment information and services. Key populations such as MSM and LGBTI are defined as disproportionately affected by HIV in all countries and settings.

The exclusive general population approach to researching and promoting ART adherence repeats similar knowledge gaps of earlier HIV prevention research (UNAIDS 2010: 3; Beyrer, Wirtz, and Walker *et al* 2011: 8). Methodologically, it can be comparatively challenging to research populations that are criminalised, discriminated against and stigmatised in society due to the safety considerations for study participants, the hidden nature of these populations, and a lack of dedicated funding (Beyrer, Wirtz, and Walker *et al* 2011: xxi). Yet, these same issues drive the need to focus on challenges these populations may be facing in ART adherence, and continuing to orientate research at the general population level will result in a lower return on investment in health outcomes (WHO 2014: 7-8), and the human right to the highest attainable standard of health will continue to be beyond the reach of key

¹ Antiretroviral therapy reduces the risk of HIV transmission by up to 96% (UNAIDS 2014a)

² Although >95% adherence is still cited for optimal adherence, more recently research has emerged suggesting lower adherence is required for effective viral suppression using more potent boosted protease inhibitors and nonnucleoside reverse transcriptase inhibitors. Until there is a consensus on optimal adherence to achieve viral suppression and avoid developing resistance, caution is exercised by using the >95% figure for optimal adherence (Kobin, and Sheth 2011: 373; Mitiku, Abdosh, and Teklemariam 2013)

populations. Effective programming for MSM and LGBTI communities must be informed by robust evidence generated through research, and inclusive decision-making. Priorities for research were provided by MSM and LGBTI community activists who attended an amfAR-organised one and a half day meeting to develop an LGBTI research agenda, in partnership with the Gay and Lesbian Coalition of Kenya and the International AIDS Vaccine Initiative (amfAR 2014). The focus of HEARD's research on ART adherence is derived from these priorities.

Kenya was chosen as the first site of the scoping study in part because what little research existed was focused on Kenya and informed our entry point. Uganda was selected because, in contrast to Kenya, research efforts have been stifled by police crack-downs on MSM and LGBTI, and a hostile political environment towards MSM and LGBTI. The only two studies of note examining MSM behaviour in Uganda mention similar challenges: (i) 'The 2008 Kampala arrests prevented us from achieving the target sample size, and the resulting decreased statistical power may have impeded identifying some risk factors for HIV infection' (Hladik, Barke, Ssenkusu *et al* 2012: 8) and; (ii) 'we terminated recruitment early due to unwanted publicity in a national newspaper that threatened confidentiality of participants' (Kajubi, Kanya, Raymond *et al* 2008: 495). The resulting knowledge gap may have contributed to a limited focus on MSM and LGBTI in national HIV programming, as indicated in the National Strategic Plan 2011 – 2015 which stated 'there is insufficient data to warrant ranking [People Who Inject Drugs (PWID) and MSM] high among HIV prevention priorities' (Uganda AIDS Commission, 2012: 15).

Uganda has been experiencing a trend of increasing HIV prevalence from 6.2% in 2005 (UNAIDS 2013b) to a present estimate of 7.3% (UNAIDS, 2014c), although incidence estimates have been on a downwards trajectory in more recent years. Also characteristic of the Ugandan HIV epidemic is a comparatively high estimated prevalence of HIV amongst MSM of 13.7% (Hladik Dr W., Barker J., Ssenkusu J. 2012: 7) and a lack of dedicated HIV response towards MSM and LGBTI populations. Uganda has a penal code criminalising homosexuality which remains virtually unchanged from the inherited anti-homosexuality legislation of British colonial law. This hostile legal environment for MSM and LGBTI is furthermore reflective of norms across the East and Southern African region (except South Africa). In 2009, the Ugandan political leadership discussed strengthening the anti-homosexuality bill, including introducing the death penalty for 'aggravated homosexuality. When the Bill reached parliament in 2013, the death penalty had been amended to life in prison under Western pressure. In February 2014, the Anti-Homosexuality Act was passed then annulled a few months later, in August, by the Constitutional Court on the basis the parliamentary vote was iniquitous. The Act that was briefly voted into law not only outlawed homosexual acts, but also compelled citizens to report suspected homosexual activity to the police, triggering increased levels of prejudice, violence and discrimination against the gay community (SMUG and the National LGBTI Security Team, 2014: 1-20).

The Anti-Homosexuality Act also banned the 'promotion or support of' homosexuality, threatening the viability and work of civil society and non-governmental organisations providing specialised services and support to MSM and LGBTI populations. On 27 November 2015, the NGO Bill 2015 was passed by parliament and affords a greater scope of registration and de-registration powers to The Uganda Registration Services Bureau. LGBTI CSOs are concerned that this was implemented with the intention to prevent LGBTI supportive CSOs

from registering or retaining their registration, indirectly achieving a similar result to the suppression of LGBTI advocacy (promotion) explicitly referred to in the Anti-Homosexuality Act 2013 (HRAPF). It is too early to comment further, as the enhanced powers are yet to be exercised.

3. METHODOLOGY

3.1 Overview

This scoping study was informed by a systematic literature review (HEARD 2015) that revealed an extensive knowledge gap on the challenges to ART adherence among HIV-positive MSM and HIV-positive members of the LGBTI communities in the ESA region. The review found just two studies contributing to research in this area. The first study summarised challenges to ART adherence unique to HIV positive transgender people, but lacked data on comparative rates of ART adherence (Schneiders 2014: 28-9). The second study established an empirical basis, within a limited sample size, for a poorer rate of ART adherence among MSM compared to other high risk adults, but did not explore the reasons for this difference (Graham, Mugo, and Gichuru et al 2013: 1255-65). HEARD's scoping study in Kampala interviewed key informants over a two-week period in December 2015, including sensitised HIV healthcare workers, key population programme officers, a variety of civil society organisation (CSO) executive directors and staff, and MSM and LGBTI activists living in Kampala. Interviews sought to record and understand perceived challenges to ART adherence experienced by MSM and LGBTI populations.

3.2 Key informant selection

Key informants were initially identified through web-based searches of MSM, LGBTI and People Living with HIV (PLHIV) organisations and HIV clinics in Uganda, and via HEARD's involvement with the UNAIDS East and Southern African Think Tank on HIV, Health and Social Justice. Snowball sampling was used to identify further key informants. This scoping study includes perceptions from a range of key informants operating at different levels in different types of organisations including a constitutional body, human rights, LGBTI and HIV advocacy CSOs and networks, HIV positive and negative MSM, MSW and LGBTI members of CSOs, an international non-governmental organisation, a faith-based organisation, and key population and MSM focused clinics. Clinics were targeted that provide HIV voluntary counselling and testing (VCT), and treatment with a key population focus. All individuals and organisations interviewed were based in Kampala, Uganda. 13 interviews were conducted, nine of which involved direct questions on the challenges to adherence, and seven of these nine interviewees could speak authoritatively about MSM and LGBTI.

Table: List of key informants with descriptions

KEY INFORMANT	DESCRIPTION
Sexual Minorities Uganda <ul style="list-style-type: none"> Executive Director Frank Mugisha 	Network established in 2004 comprising 18 LGBTI organizations working to advocate for rights of LGBTI in the policy arena
Most-at-Risk Populations Initiative <ul style="list-style-type: none"> Clinical Doctor Dr Katende 	Free STI, VCT and ART clinic specialised in advice and support services for MARPs including MSM, MSWs and LGBTI
MARPs Network <ul style="list-style-type: none"> F. Kamyia - Youth and Rock Foundation S. Bernard - VINACEF Uganda K. Juliet - Crested Green Lighters A. Beatrice - Transgender Equality Uganda 	Government initiated Civil Society Organization whose purpose is to promote coordinated leadership in HIV prevention among MARPs in Uganda
National Forum of PLHA Networks in Uganda <ul style="list-style-type: none"> Executive Director Stella Kentusi 	National umbrella organization for People living with HIV (PLHIV) established in 2003 to coordinate networks of PLHIV in Uganda
Freedom and Roam Uganda <ul style="list-style-type: none"> Two members (anonymous) 	Unregistered, membership-based organisation established in 2003 to support and advocate for lesbian, female bisexual, transmen and intersex persons
HIV and AIDS support civil society organisation (anonymised) <ul style="list-style-type: none"> Staff member (anonymous) 	A network advocating for improved public health in Uganda. Description limited to preserve requested anonymity
Uganda Human Rights Commission <ul style="list-style-type: none"> Staff member (anonymous) 	Established under the 1995 Constitution of the Republic of Uganda to protect and promote fundamental Human Rights and freedoms in Uganda for sustainable development.
Come Out Positive Test Club. Members: <ul style="list-style-type: none"> Transwoman sex worker Transwoman HIV+ sex worker Transwoman individual 	Provides safe space for transgender and transsexuals who are HIV positive and engage in sex work while living in Uganda
Health GAP <ul style="list-style-type: none"> Executive Director Asia Russell 	An organization of U.S.-based AIDS and human rights activists campaigning for sustainable drug access for people with HIV/AIDS across the globe
DanChurchAid <ul style="list-style-type: none"> Programme Officer for HIV Programming Janepher Taaka 	A Danish church-based organisation with international offices. In Uganda, DanChurchAid focuses on combating HIV & AIDS, among other development issues.
The Action Group for Health, Human Rights and HIV/AIDS <ul style="list-style-type: none"> Executive Director Dennis Odwe 	Health rights advocacy organization dedicated to raising awareness of the human rights aspects of health, and the quality of health and healthcare for all Ugandans
Human Rights Awareness and Promotion Forum <ul style="list-style-type: none"> Executive Director Adrian Jjuuko 	An independent, non-partisan, non-governmental human rights advocacy organization with a focus on marginalised groups
Icebreakers Uganda <ul style="list-style-type: none"> Clinic and Resource Centre Manager 	A civil society organisation established in 2004 advocating and providing resources, advocacy and STI and VCT services to MSM and LGBTI in Uganda

3.3. Data gathering and analysis

Semi-structured key informant interviews were conducted either in individual and group format. Interviews were recorded and transcribed for analysis, and subsequently destroyed due to the sensitivity of the material and protection of confidentiality. Notes and transcriptions were scanned for common themes, especially relating to challenges to ART adherence. As this was a small scoping study, it was not necessary to code or tabulate transcriptions to deduce common themes.

Study limitations - As a small-scale scoping study, findings are indicative only, primarily intended to guide any further research.

4. FINDINGS

4.1 Summary of key findings

Summary of key findings in challenges to ART adherence for MSM and LGBTI populations:

- 1. Inadequate access to food:** Some ARVs must be taken with or after food consumption to support drug absorption to required levels. Doses can be delayed/ missed until people can afford food with which to take the pills.
- 2. Stigma and a lack of social support:** A lack of social support due to stigma resulting from a perceived or disclosed sexuality and HIV status is thought to contribute to worse adherence.
- 3. Fear or experience of stigma at healthcare facilities:** Both the fear of and the lived experience of stigma from healthcare workers on the basis of perceived sexuality breaks down trust in the relationship between health provider and patient.
- 4. Inadequate counselling:** A deficit of on-going counselling support was associated with a reduction in resilience to overcome challenges to adherence facing HIV positive MSM and LGBTI.
- 5. Insufficient access to information:** Information on side-effects, how to take pills, and the importance of adherence needs to become more accessible and relevant to MSM and LGBTI.
- 6. Fears or perceptions of breaches in confidentiality by healthcare workers:** Healthcare workers' concern for confidentiality is driven by the perceived potential of stigma or criminal charges that could result in supporting MSM or LGBTI populations.
- 7. Fear of or experience of ART side effects:** Fears of or experience of negative ART side-effects. Psychosomatic, medication induced, or fears of side-effects can delay ART commencement or cause ART cessation.
- 8. Fear of disclosure via pill taking and storage:** Delaying/missing doses to reduce visibility of ART pill-taking so as to maintain HIV non-disclosure.
- 9. Prohibitive travel costs to clinics:** Public transport costs can be a barrier to collecting ART pills monthly for those living far away, especially to attend sensitised or dedicated healthcare for MSM and LGBTI.

- 10. High pill burden:** Daily regimens for life presents physical and psychological challenges. This can be worsened by TB-coinfection and regimen changes due to stock-outs.
- 11. Alcohol and drug abuse:** Abuse of drugs and alcohol is associated with worse adherence.
- 12. ART stock outs:** Stock-outs occur when clinics deplete their stocks of the regimens they prescribe. This can sometimes reflect a national shortage.
- 13. Loss to follow up:** Due to the necessity to maintain adherence, clinics follow up with patients that miss appointments

4.2 Discussion of key findings

This discussion draws primarily on data from the scoping study conducted in Kampala, supplemented with information generated by the systematic literature review (HEARD 2015) and contextual grey literature.

4.2.1 INADEQUATE ACCESS TO FOOD

The requirement of some anti-retrovirals (ARVs) - such as non-nucleoside reverse-transcriptase inhibitors - to be taken with food appears to be closely followed within the HIV positive MSM and LGBTI communities with six out of seven interviewed respondents reporting this as a significant challenge to adherence. Some of the interview respondents lacked access to regular meals, and some feared the perceived side-effects of taking their ARVs on an empty stomach, and opted instead not to take their medication. The immediacy of unpleasant or painful side-effects appears to be more compelling than the longer-term negative effects of poor ART adherence.

In consideration as to whether access to food affects HIV positive MSM and LGBTI to a greater extent than PLHIV in the general population, it is worth noting that both DanChurchAid and NAFOPHANU also reported this as a key challenge among the general population. All respondents correlated poor access to food with unemployment leading to poverty, a lack of family support, and unstable living conditions. A number of interviewees did assert that employment, family support and living conditions were all generally worse among MSM and LGBTI communities than the general population: 'In the heterosexual community there is a family support mechanism and friends. MSM often don't have [family support], they are alone... The MSM because of discrimination don't have employment' and 'There is no way someone can have enough food when they do not have a job. They used to give out supplements but they haven't for two years now' (SMUG, 2015; MARPs Network members, 2015). Referring to the introduction and subsequent annulment of the Anti-Homosexuality Act in 2014, a clinical doctor at the MARPI clinic pointed out that MSM and LGBTI 'had problems of accommodation and, of course, feeding, and during that time they could not take their drugs well' (MARPI clinic 2015).

4.2.2 STIGMA AND A LACK OF SOCIAL SUPPORT

Interview respondents repeatedly emphasised the important role of social support in ART adherence; 'Evidence shows you're more likely to forget your appointment or treatment if you are depressed, abuse alcohol, or don't have a community of progressive support' (Health GAP 2015). The importance of social support in adherence has official recognition in the 2011/12-2014/15 National Strategic Plan for HIV&AIDS; 'social support and protection plays

a big role in effective national response; it is evident that individuals who have the social support they need are more likely to adhere and comply with complicated schedules of taking their medicine' (Uganda AIDS Commission 2012: 10).

MSM and LGBTI in Uganda who have intentionally or unintentionally disclosed their sexuality often report being excluded from the kind of social support the mainstream population enjoys: 'There is less social support to take medication' (COPTec members 2015); 'I was seen as a different thing at home. I was abandoned. They didn't want to interact with me. When my father died, I did not get any legacy' (MARPs Network members 2015). Conversely, PLHIV within MSM and LGBTI communities in Uganda who have intentionally or unintentionally disclosed their HIV status can experience social exclusion from their sexuality-based community. Double stigma therefore refers to the fear or experience of the mutually reinforcing stigmas of sexuality and positive HIV status; 'an LGBTI person cannot come out to their family about their sexuality, and they cannot come out as HIV positive in the LGBTI community or to your partner – especially if you're depending on your partner for shelter etc.' (Icebreakers 2015). The term 'double stigma' was used by respondents in four separate interviews.

Exclusion from mainstream society on the basis of actual or perceived sexuality can result in a corresponding lack of access to supportive programmes designed for PLHIV on treatment, for example, positive test clubs: 'we lack safe spaces to talk about our challenges' (MARPs Network members 2015); 'There's no support mechanisms for MSM and LGBTI, we need to have more support groups that can encourage each other by sharing stories about taking medication and feeling well or how if you have a problem with the medication, the doctor can change it' (SMUG 2015).

Furthermore, the other side of double stigma means that attempts to replicate those support mechanisms within the MSM and LGBTI communities are also challenged; 'there is a problem of confidentiality of support buddies in the LGBTI community, where support buddies disclose the other person's HIV status in the community' (Icebreakers 2015). 'The impacts of HIV stigma within MSM community is more because it is small – if you are infected, everyone in your community will know' which could lead to the total undermining of a critical social support structure (COPTec members 2015).

The effects of double stigma reduces the access of MSM and LGBTI to specifically HIV stigma coping mechanisms that are available to PLHIV in the general population. This may lend itself to reduced resilience, depression, isolation, non-disclosure, lack of social and family support, missed ART appointments, loss to follow up, and ultimately, worse ART adherence. 'Evidence shows you're more likely to forget your appointment or treatment if you are depressed, abuse alcohol, or don't have a community of progressive support' (Health GAP 2015).

4.2.3 FEAR OR EXPERIENCE OF STIGMA AT HEALTHCARE FACILITIES

SMUG asserts that the fear, rather than experience, of discrimination 'cuts across from MSM who are poor to MSM that are rich. They will not seek treatment, they will stay in their homes. They will resort to self-medication or ask friends' (SMUG 2015). Although the actual experience of discrimination was de-emphasised in this interview, a respondent from AGHA, an organisation that runs sensitisation training for healthcare workers, estimated that 'about two out of ten healthcare workers will discriminate, especially in rural areas' (AGHA 2015).

Perceived and actual stigma was reported to come from the healthcare workers, but also from other patients in the waiting room, especially for people who dress or behave in a way that may reveal their sexuality: 'Of course I think [stigma] happens. You can even see how I am living. People see how I am dressed and they think 'why are they dressed like that?' It still does exist in the clinic.' (FARUG 2015). For those that can hide their sexuality, a fear of stigma can lead to inhibited consultations with healthcare workers: 'If I go to a mainstream clinic, there are a lot of issues I won't say out. I won't say anything that will disclose my sexuality' (COPTec member 2015).

The fear or experience of stigma also raises concerns around a lack of confidentiality that would result in further and wider stigmatisation. For example AGHA noted that many 3 and 4 tier (smaller, local) clinics deviate from guidance on consultation rooms and only have curtain dividers affording little confidentiality from other patients and staff: 'That's why I go [to dedicated healthcare facilities] rather than mainstream clinics' (FARUG 2015). The provision of dedicated healthcare services, therefore, becomes necessary, but the geographically limited availability of these services in Uganda creates other challenges such as travel costs for some MSM and LGBTI in need of ART, further discussed under 'travel' below. On a cautionary note, clinics that focus on key populations should not be assumed free of stigma, as one respondent pointed out 'even at MARPI this is the case because they serve fishermen and truck drivers some of whom are homophobic even if they are a key population' (FARUG 2015).

To adhere to ART it is necessary to attend a clinic every month to collect medication for the following month. If there is a fear or experience of stigma, concerns around confidentiality, and geographically inaccessible stigma-free healthcare alternatives, respondents felt this could contribute to missing appointments and poor adherence. CSOs have responded by creating an MSM-friendly list of healthcare workers, but say that many MSM and LGBTI are hard to reach and are unaware of this list, or even that there are dedicated healthcare alternatives to mainstream clinics. The response by the Ugandan government was described in one interview as 'They say they provide services with no discrimination so there is no need for them to do anything further' (SMUG 2015). The claim to non-discriminatory service provision does not address the related, but separate, issue of stigma discussed here, as it is possible to be subjected to stigma without discrimination and for this to be harmful to adherence. This was identified in four interviews as a formidable challenge to adhering to ART for HIV positive MSM and LGBTI persons.

4.2.4 INADEQUATE COUNSELLING

In four out of the seven interviews in which challenges to adherence were addressed with explicit reference to MSM and LGBTI communities, counselling before and during treatment was stressed as a critical support mechanism underpinning the capacity to cope with other challenges to adherence: 'counselling plays a very big role if done consecutively, not just once or twice' (Icebreakers 2015), and 'Sometimes the doctor doesn't have time to tell us what we need to eat, how to take the drug, they just say take these drugs, these ARVs. The pre-treatment counselling is very important' (MARPs Network members 2015).

The Ugandan Ministry of Health released guidelines for 2005 stating that 'Clinicians, counsellors and pharmacists who provide care to HIV-positive clients should also provide ongoing counselling' (Ministry of Health, 2003; 9). Yet in 2015, interviews revealed a

perception that the reality of counselling still lags behind the national guidelines: 'there are too many people and not enough counsellors so people have to wait a long time and don't have long with counsellors. Everyone is supposed to receive ART counselling. There is a standard for how many people counsellors should see a day. But when there are 300 people outside waiting...there is not enough time' (NAFOPHANU 2015).

The benefits of counselling is perhaps greater for the ART adherence of HIV positive MSM and LGBTI in helping overcome more significant challenges to ART adherence, relative to the general population, as indicatively described in this report. Additionally, the counselling that is available may be less accessible to the MSM and LGBTI communities due to the fears of stigma and breach of confidentiality by counsellors as part of the healthcare profession, as discussed above, and because HIV counsellors are not trained to give advice specific to the challenges and issues experienced by MSM and LGBTI: 'counsellors don't know about MSM issues and [MSM] cannot come far to see specialist counsellors as well. MSM also fear there is a lack of confidentiality from counsellors' (COPTec members 2015).

4.2.5 INSUFFICIENT ACCESS TO INFORMATION

There are two aspects to the perceived deficit in information or the communication of information. Firstly, amongst interviewees there was a perceived need to improve communication of information both about ART, its side-effects, importance of adherence, and regimens: 'Sometimes the doctor doesn't have time to tell us what we need to eat, how to take the drugs... they just say take these drugs, these ARVs' (MARPs Network members 2015). Although this lack of information about ART could affect any person's adherence, it was perceived to affect MSM and LGBTI to a greater degree, because 'the level of ignorance, illiteracy and unemployment is worse amongst LGBTI because they are more likely to drop out of school earlier... health-seeking behaviour in our community is poor...This is because they don't have access to information - there's so much illiteracy' (MARPs Network members 2015). Although the impacts of avoiding clinics due to stigma were not mentioned in connection with accessing information about ART, it may be reasonable to suppose that clinics form an important ART information-point and therefore access to that information would be worse for MSM and LGBTI without alternative points of access provided. Limiting access to information can affect adherence because if, for example, the pills change in colour or shape 'people don't trust it and stop taking it. Health workers don't always explain that the pills are the same' (NAFOPHANU 2015). As members of the MARPs Network said, 'some people don't adhere out of ignorance. You need continual sensitisation'.

Secondly, there is a perception that improvement is required in communicating about the existence, location and how to access dedicated ART services for MSM and LGBTI; 'information is limited about MSM-friendly services, especially to rural LGBTI who do not have good access to the internet' (Icebreakers 2015); 'Most MSM in Uganda don't know about any of the services that exist for them... MSM or LGBT who are not within the community have no idea' (SMUG 2015). This is partly attributed to perception that 'There is no capacity or funding for outreach to take the message further' (SMUG 2015). This is reported as particularly problematic because the government and mainstream clinics do not use their communication channels to raise awareness about specialised services so these services are reliant on the limited capacity of CSOs to reach MSM and LGBTI with this information. Without an

awareness of specialised healthcare facilities, as discussed above, MSM and LGBTI may delay or stop ART so as to avoid unsensitised mainstream healthcare clinics altogether.

4.2.6 FEARS OR PERCEPTIONS OF BREACHES IN CONFIDENTIALITY BY HEALTHCARE WORKERS

Three MSM and LGBTI oriented organisations reported separately that MSM and LGBTI fear healthcare workers will breach their confidentiality in relation to perceived or disclosed sexuality. The reported concerns encompassed doctors, counsellors, clinic support staff, and lay support volunteers. Icebreakers recounted one reported experience of a mainstream clinic that concerned ‘a nurse who called their colleagues to come and look what a transwoman looks like. The transwoman felt they had to leave before they could even get treatment’ (Icebreakers 2015).

Respondents felt that a concern about a lack of confidentiality on the part of healthcare workers was primarily ‘about exposure [of sexuality]. They’re afraid people will come to know about it and eventually will be published in the paper’ (SMUG 2015), which was linked to a ‘fear of being beaten up. They fear the public will get to know and eventually they will be beaten’ (AGHA 2015). A perceived lack of confidentiality was not limited to unsensitised staff at mainstream clinics either; ‘there is a problem of confidentiality of support buddies in the LGBTI community, where support buddies disclose the other person’s HIV status in the community’ (Icebreakers 2015).

SMUG also points out that in addition to a concern of stigma as an outcome of a breach in confidentiality, ‘criminalisation [of ‘unnatural sexual acts’] initially had an impact. There is an ignorance in Uganda about the law where LGBTI think that they are illegal. They fear if they go to the doctors, the doctors will report them to the police. So when people think about it they fear, they don’t go’ (SMUG 2015). When the key populations-focused clinic, MARPI, was questioned about any requirement or pressure to report criminal activity – namely homosexual activity disclosed to them – Dr Katende responded that ‘I can’t. I can’t disclose anything from my patients’ (MARPI clinic 2015).

Although PLHIV in the general population may have fears around healthcare workers’ confidentiality regarding their HIV status, MSM and LGBTI have additional concerns about the confidentiality of their sexuality, aspects of which are also criminalised potentially increasing the fear and thus the challenge of overcoming those fears to see healthcare workers for ART-related matters, not least the monthly appointment to collect ART pills.

4.2.7 FEAR OR EXPERIENCE OF ART SIDE-EFFECTS

The *fear* of side-effects was stressed over the *experience* of side-effects, as a challenge to commencing and adhering to ART; ‘there’s a lot of *fears about the side-effects* of ARVs. People report bad dreams’ (MARPs Network members 2015). This account is closely reflected in another interview: ‘People report bad dreams. That they dreamed of snakes. This is often the fear rather than experience of side effects, though sometimes where there are side effects, I think they could be psychosomatic’ (Icebreakers 2015).

In one interview where the actual experience of side-effects were mentioned, the physical effects were still seen as less significant than the psychological effects: ‘Sometimes when [HIV positive MSM and LGBTI] see even a small side effect they stop taking their medication because they think, well, they are going to die anyway’ (SMUG 2015).

It was unclear from the interviews whether fears or experiences of side-effects are worse within MSM and LGBTI communities relative to the general population. To investigate this further, it would be necessary to explore whether other factors affecting MSM and LGBTI disproportionately may be implicated with fears or experiences of side-effects, such as poor access to information (leading to spurious or exaggerated fears) and insufficient food (worsening physical side-effects) or greater stigma and double stigma (raising the consequences of disclosure via visible side-effects), making it more likely ART will be delayed or adherence stopped to hide HIV status.

4.2.8 FEAR OF DISCLOSURE VIA PILL TAKING AND STORAGE

This challenge to adherence only exists for PLHIV who have not disclosed their HIV status to whomever may typically be around them at the regular time of taking their ARVs. This then becomes a challenge for proper adherence through the practice of non-disclosure: ‘Some people still fear to be seen taking their medication. So you find when they go to spend a few days with their [MSM] partner they are not taking their medication because they do not want to be seen taking it. They haven’t disclosed to them due to fear and stigma. Anywhere public they do not want to take their medication’ (SMUG 2015).

NAFOPHANU also reported this challenge amongst PLHIV in the general population who had not disclosed their HIV status so it is not exclusive, as such, to MSM and LGBTI. Assessing the degree to which the disclosure-linked challenge of pill-taking may be greater within the MSM and LGBTI communities compared to the mainstream community is beyond the scope of this report. It could be ventured that because the MSM and LGBTI communities are relatively small with a high degree of social inter-connectivity and reliance for social support, barriers to disclosure may be greater. This assertion resonates with one interview response: ‘there’s fear if they come out [as HIV positive] in the MSM community, people are not going to associate with them and I think it’s mostly that they will not get sexual partners. And that people will be talking about them. Some MSM disclose [their HIV status] to the heterosexual community but then to the MSM community just keep it quiet’ (SMUG 2015). Icebreakers and COPTec members echoed this perception in a separate interview: ‘If you take the ART in front of a friend you might lose that friend or he won’t go into bed with you’ (COPTec members 2015); ‘it can be hard if in front of friends/family’ (Icebreakers 2015).

4.2.9 PROHIBITIVE TRAVEL COSTS TO CLINIC

Poverty creates a barrier to public transport costs to collect ART pills for those who live far away as patients can only obtain a monthly supply at each visit. Few have access to private transport. Many local (tier 4 and 5) clinics are not licensed to prescribe ART, and as DanChurchAid noted, ‘ART is administered at Health Centres of tier 3 with a radius of 30-50km from each other... Long distances and other related costs in accessing ART, remain a big hindrance in ART adherence in Uganda’ (2015). The challenge of financing monthly travel to a clinic for ART medication is thought to be greater for those living in poverty who are less able to afford the travel, and for those living rurally who typically have to travel further at greater expense than those living in urban contexts.

MSM and LGBTI may be disproportionately affected by the burden of travel costs to attend clinics in two ways. Firstly, as mentioned previously, respondents conveyed a perception that MSM and LGBTI endure greater unemployment and instability which would affect their ability

to pay for travel. Secondly, those MSM and LGBTI who fear or experienced stigma at a nearby mainstream clinic may have to travel much further to find either a LGBTI-friendly clinic or a dedicated service: 'Travel to dedicated clinics is an issue, especially for people living rurally' (Icebreakers 2015). This perception was closely echoed in another interview: 'I think it is likely to be worse in rural areas where there are much fewer dedicated services' (AGHA 2015). Another interview respondent pointed out that 'if mainstream clinics were sensitised to LGBTI needs, it would reduce the travel currently required to get to specialised clinics like MARPI. I knew a person who would come from Jinja to MARPI and sometimes they did not actually have money to get home again' (COPTEC members 2015).

4.2.10 HIGH PILL BURDEN

ART regimens have evolved to reduce the pill burden to as low as a once-daily dosage with a decrease in the number of pills to be swallowed by combining drugs within pills (on a standard ART first-line regimen). Despite these improvements, interview respondents stressed the prospect of swallowing a daily medication that needs to be taken at the same time every day for the rest of a person's life, with strict adherence, is as much a psychological challenge as it is a physical one to some PLHIV: 'they cannot imagine the idea of taking these tablets for the rest of their life' (NAFOPHANU 2015). These psychological challenges were also reported amongst Dr. Katende's patients at the MARPI clinic: 'usually they have problems before they start the ARVs with the fear that the tablets are big or too many, but when they start they take their drugs on time' (MARPI clinic 2015). Furthermore, NAFOPHANU points out that TB-coinfection creates a higher pill burden until the TB is cured, and stock-outs of some ART regimens can force some patients to take child regimens at a higher pill count.

Both members of COPTEC and Dr. Katende at the MARPI clinic cited pill burden as a challenge to adherence for MSM and LGBTI, although emphasis was on the physical difficulty or discomfort experienced swallowing the pills. It is not clear whether the physical or the psychological challenges associated with the ART pill burden differ between PLHIV in the MSM and LGBTI communities and those PLHIV in the general population. An area of exploration could be the impact of poor social support on the psychological barriers to starting life-long medication.

4.2.11 ALCOHOL AND DRUG ABUSE

'Among the known impediments to medication adherence is alcohol use. Studies demonstrate that individuals who take ART and drink alcohol experience more missed doses, medication lapses, and HIV treatment failure' (Kalichman S., Grebler T., Amaral C. *et al* 2012: 399). What is key here is that alcohol abuse does not interfere with CD4 count and medication efficacy, but is shown to decrease adherence due to missed doses, missed appointments, and reduced motivation, increasing the rate of treatment failure. Kalichman S., Grebler T., Amaral C. *et al*'s study concludes that ART adherence is negatively affected, not only by the psychologically disabling effects of alcohol abuse, but also by the permeating misperception that alcohol intake produces a toxic interaction with ART. This leads PLHIV who abuse alcohol or drugs to intentionally skip or discontinue ART.

The assertion here is that adherence suffers not only due to the cognitive impairment from alcohol abuse and drug abuse, but is also, in part, intentionally interrupted by PLHIV due to misinformation. Given that misinformation is more likely where access to correct information

is restricted or challenging, MSM and LGBTI are at particular risk of being misinformed as they may be less able to access pertinent and accurate information relating to their HIV treatment, as discussed in the 'access to information' section above.

There appears to be a gap for empirical data comparing relative alcohol and drug abuse within east and southern African MSM and LGBTI communities relative to respective general populations. One interview respondent expressed a perception that alcohol and drug abuse was higher within LGBTI (and sex worker) communities: 'Most are taking too much alcohol, they're on drugs, and they're smoking. I think this happens more in the LGBTI and sex worker communities' (MARPs Network members 2015). Furthermore, studies examining the association between drug and alcohol abuse and ART adherence *in a sub-Saharan Africa context* are split as to whether they find a significant or insignificant correlation (Morojele N., Nkosi S., Kekwaletswe C. *et al* 2013: 2).

This uncertainty is also reflected within the interviews conducted, in which only two brought up drug and alcohol abuse within the MSM and LGBTI communities as a challenge to adherence (Health GAP 2015; MARPs Network members 2015). One MARPs member expressed that alcohol and drug abuse is high 'in order to get clients or to fit in the community' whilst another said 'sometimes they find it hard to accept their HIV status. That's why they take drugs' (MARPs members 2015). The inconclusive background literature and scoping study feedback on the relative alcohol and drug abuse within MSM and LGBTI communities, and the extent to which this is associated with ART adherence outcomes, obscures the degree to which assertions can be made as to the extent to which this poses a challenge to adherence.

4.2.12 ART STOCK OUTS

Stock outs of ART medication is where a clinic uses up existing supplies (or they expire) without new stock of the same ART medication to replace it. Two MSM and LGBTI-focused organisations and two other organisations interviewed were vocal about the extent of stock-outs in Uganda: 'Sometimes there are stock-outs of ARVs. Some ARVs have been out of stock nationally for six months now' (AGHA 2015). One interview respondent perceived that 'Access to ARVs is still a challenge in rural areas where stock outs are worse' (DanChurchAid). Conversely, stock-outs do not seem to affect MSM or LGBTI dedicated clinics to a greater extent: 'Stock-outs are a problem at the moment in Uganda. Sometimes clinics even refer people to us to get their medications' (Icebreakers 2015). These perceptions are substantiated by stock status reports from the Ugandan Ministry of Health as reported on by The Uganda Network of AIDS Service Organisations (UNASO 2015: 1).

One interview respondent outlined a possible consequence of stock-outs: 'Sometimes, due to stock-out, [PLHIV] have to take children regimens which have more pills' (NAFOPHANU 2015), which can invoke challenges relating to physical pill burden, discussed above. The Executive Director of UNASO further pointed out that if a person on first line treatment stops taking ART as a result of stock-outs, their body will become resistant to first line and they will be required to immediately start on second line treatment, which has a high pill burden (UNASO 2015: 2). As discussed above, it is not clear if a higher pill burden may pose a greater physical challenge for MSM and LGBTI than the general population, but it could worsen the challenges that may already be relatively higher for MSM and LGBTI described under 'fear of disclosure via pill taking and storage'. If this is the case, stock outs may not be experienced

more by PLHBV in MSM and LGBTI communities than the general population but the impact of those stock outs could be greater in the challenges they create for ART adherence.

4.2.13 LOSS TO FOLLOW UP

Although a failure, or an inability, to follow up with patients after missed appointments may be seen as the negation of a support mechanism rather than a challenge to ART adherence, the role it plays is similar to that of social support, the absence of which is commonly dealt with in literature as a challenge to ART adherence.

Two MSM and LGBTI-oriented organisations saw a failure to follow up as a factor in poor ART adherence or ceasing treatment within the MSM and LGBTI communities (AGHA 2015; COPTec members 2015). Reasons given for the perceived lack of follow up include insufficient staffing, a lack of prioritisation, and a greater difficulty in following up with MSM and LGBTI than members of the general population: ‘There is a lack of follow up due to a human resources deficit’ (DanChurchAid 2015); ‘There are targets for following up on HIV positive women and children – but key populations like MSM need to be made a priority too. It affects follow up a lot because LGBTI may not want to say exactly where they stay, and may move around a lot so more time is required to follow up whether they are adhering to their treatment and reduce loss to follow up in these populations’ (AGHA 2015).

Due to a concern for confidentiality and of being reported to the police, some MSM (especially male sex workers) and LGBTI may give false or limited information about themselves. Similarly these populations may live in less stable or less permanent conditions, making follow up more difficult. Conversely, the need for follow up among MSM and LGBTI may be greater in light of the burden of challenges to ART adherence already outlined above. Follow up can provide essential encouragement that may otherwise not be forthcoming, as one MARPs member emphasises: ‘Some doctors even say, it is not my life, it’s yours. It is up to you, I am not going to force you to take it.’ (MARPs Network members 2015).

5. ANALYSIS

This scoping study recorded perceptions from a range of key informants operating at different levels in different types of organisations including a constitutional body, human rights, LGBTI and HIV advocacy CSOs and networks, HIV positive and negative MSM, MSW and LGBTI members of CSOs, an international non-governmental organisation, a faith-based organisation, and key population and MSM focused clinics.

Perceptions converged in some areas and diverged in others, and these have been represented and explored as accurately as possible above. This report is primarily concerned with perceptions of the relative scale, intensity, and type of challenges to ART adherence currently facing PLHIV in the MSM and LGBTI communities in Uganda. In the interest of clarity, it is relevant to note that there is no empirical data on relative rates of ART adherence amongst HIV positive MSM and LGBTI compared to PLHIV in the general population, and such research would be difficult and expensive to conduct on the scale required to be reliable (Graham S., Mugo P., Gichuru E. 2013). Additionally the two perceptions of rates of adherence volunteered in separate interviews within the scoping study were opposing: ‘adherence is not good. That’s why the death rates are still high. The issue of behaviour change is why we have

not made much progress’ (MARPs Network members 2015); this contrasts with ‘some take their drugs late, but most take them on time... they can take their drugs because they come on every visit. The majority are taking their drugs well’ (MARPI clinic 2015).

Framing the report’s discussion of the findings under the headings of political and legal environment, socio-cultural factors, and the health system provides a useful and relevant analytical framework cutting across many of the perceived challenges explored in this report.

5.1 Political and legal environment

5.1.1 THE LEGAL INSTRUMENTS MOST REFERENCED

Legally, the Ugandan Penal Code Act, Cap 120 contains a number of provisions that directly and indirectly criminalise same sex conduct with a maximum penalty of life imprisonment (HRAPF 2015: 24-28). The most recent legal development was the Anti-Homosexuality Act which was briefly enforced, then annulled, in 2014. A greater account of the legal and political background is provided in the earlier Background section, but the penal code and Anti-Homosexuality Act were the most commonly referenced legal instruments by respondents commenting on the effects of criminalisation on the lives of MSM and LGBTI, and their ability to access and adhere to ART.

5.1.2 MERITS OF DECRIMINALISATION AND BEYOND

Almost all respondents expressed a desire for decriminalisation of same sex conduct to precipitate more supportive social and healthcare environments that would improve ART adherence in MSM and LGBTI communities: ‘The government, by changing the law, would be telling everyone that these people [LGBTI] have the right to live’ (COPTec members 2015), and ‘decriminalisation would really be a milestone to reducing discrimination and stigma’ (SMUG 2015). It was also perceived that decriminalisation would additionally lead to improvement at the health systems level, through greater stakeholder engagement: ‘due to criminalisation, LGBT persons were not invited to health planning meetings because they said “we cannot invite criminals”’ (SMUG 2015).

To realise the potential benefits decriminalisation would permit, a respondent from the UHRC indicated that the government would have to go beyond decriminalisation: ‘it is one thing passing a law but discrimination is still existing because society is still not tolerant. Government has to enact laws and mechanisms ensuring the protection of the LGBTI communities – where people can seek redress and record experiences in addition to the UHRC – at the local level, the district level... [and] institutionalise non-discrimination where every institution has mechanisms to ensure non-discrimination’ (UHRC 2015). The need for protective legislation for LGBTI, in addition to decriminalisation, was also emphasised by MARPs Network members, HRAPF, and AGHA respondents, in order to achieve benefits for ART adherence: ‘Once the government passes laws prohibiting discrimination against key populations then we shall be in position to see a change in the environment and the manner in which HIV and AIDS services are provided’ (AGHA 2015). Societal stigma and discrimination, however, will remain a problem: ‘decriminalisation may only bring partial relief, the cultural thing will still be there’ (MARPs Network members 2015). Indeed HRAPF pointed out that there were a greater number of violations against LGBTI when the Anti-Homosexuality Act was annulled than when it was enforced (HRAPF 2015).

5.1.3 RISKS OF DECRIMINALISATION

Although HRAPF still advocates for decriminalisation and protections via the Constitution, this line of thinking led the Icebreakers respondent to report that decriminalisation could actually be detrimental to the adherence to ART of PLHIV in the MSM and LGBTI communities in Uganda: ‘it would remove the [overseas] funding clinics get to provide specialised and dedicated services, which would lower our access to medication. Vigilante violence would increase against LGBTI because there is no law against it so they would take it on themselves to prevent [same sex conduct]’ (Icebreakers 2015). Careful consideration

should clearly be given to the potential for negative impacts from decriminalisation in terms of societal vigilantism, which is strongly linked to reduced adherence (HealthGAP 2015; MARPI 2015) and access to dedicated healthcare services, which would be problematic if stigma and discrimination endured beyond decriminalisation.

5.1.4 POLITICAL WILL AND THE NARRATIVE OF POLITICAL ADVOCACY

Although respondents were not all agreed on the exact nature of the potential effects of decriminalisation, it was clear that respondents perceived that the legal status of MSM and LGBTI impacts in a significant way on many of the challenges to ART adherence identified by the respondents, from societal and healthcare stigma, through to fears around sexuality disclosure, and difficulties accessing information. Indeed, respondents reported some challenges with less obvious links to the criminalised status of homosexuality, such as the most commonly reported challenge – inadequate access to food: ‘Even the relatives who were giving them [MSM and LGBTI] food stopped. Now they start seeing you as something to fear. Because the bill was that whoever deals with them gets sent to jail. [The anti-homosexuality bill] definitely affected their adherence’ (MARPI clinic 2015). Similarly, when respondents were asked about the steps the government should take to improve the adherence to ART of PLHIV in the MSM and LGBTI communities of Uganda, there were differences of opinion around what order legislative and public messaging to reduce stigma should occur in, but respondents converged around their assertion that efforts needed to be directed to building political will to produce legislative change: ‘Law-makers do not come from Mars... they are coming from communities... and they make laws based on their beliefs’ (UHRC 2015). A discourse that combines both human rights and a public health narrative was thought by HRAPF to have the best chances for success.

5.2 Socio-cultural factors

5.2.1 HIGH LEVELS OF STIGMA

Respondents unanimously perceived there to be a high level of societal stigma associated with being MSM and LGBTI in Uganda. Beyond this point of agreement, perceptions were nuanced, as captured in the discussion of stigma, above, regarding the sphere of stigma most emphasised –healthcare facilities, family, or the community; the discrepancy between fears and reality of stigma; levels and areas of discrimination resulting from stigma; the drivers of stigma and; how to reduce stigma. Stigma, similarly to criminalisation, was also perceived to be a factor cutting across many of the challenges reported, from access to food and fears around healthcare confidentiality to travel costs and social support.

5.2.2 IMPACT OF STIGMA ON CHALLENGES TO ADHERENCE

Stigmatising attitudes in Ugandan society towards members of the MSM and LGBTI communities were thought by some respondents to be made worse where those members were disclosed as HIV positive as well. The term ‘double stigma’ was used to refer to this combination of stigmas and recorded as being used by four respondents in separate interviews. The impacts of double stigma on challenges to ART adherence for PLHIV in the MSM and LGBTI communities were perceived to be cross-cutting through many of the challenges reported. A full account of these has been provided in the ‘discussion of findings’ but those of particular note are discussed here.

Stigmatising attitudes towards MSM and LGBTI within the family may be due to a fear of societal shaming, as reported by a MARPs Network member in one interview, and seems often to result in the suspected or known MSM or LGBTI individual to be cast out from their family, sometimes rendering them destitute. This can decrease access to regular meals

required for taking ART because if they do not have an independent income they may not be able to afford food or feel healthy enough to prepare it, and they can no longer rely on relatives to share food with them. The breaking of close family ties also constitutes the crumbling of key pillars of social support, stressed by the Ugandan National AIDS Committee as essential for an effective national response to HIV infections (Uganda AIDS Commission 2012).

MSM and LGBTI people who were interviewed reported perceptions that double stigma occurs within familial, sexual, care, and community relationships. The permeation of double stigma therefore discourages both sexuality and HIV disclosure – worsening challenges where there is a risk of involuntary disclosure of HIV status, notably the challenges of pill burden - taking and storage, fear of side-effects, fear of a lack of confidentiality from healthcare workers, and loss to follow up.

The fear and experience of stigma amongst mainstream healthcare workers was perceived by respondents in five separate interviews to contribute to deterring HIV positive MSM and LGBTI from seeking treatment in clinics due to a fear or experience of being morally judged, discriminated against in treatment, having their confidentiality breached resulting in further disclosure and exposure (also causing a reduced uptake of counselling), and incurring sometimes unaffordable transport costs to access a dedicated clinic.

5.2.3 DRIVERS AND APPROACHES TO REDUCE STIGMA

Respondents were divided on what they perceived to be the drivers of stigma around sexuality, and this informed different approaches to reducing stigma. A discussion of the drivers and approaches to reducing stigma is necessary because, as discussed above, stigma was seen to permeate many of the challenges to adherence reported.

As touched on previously in the discussion of political and legal environment, criminalisation was seen by some respondents to drive stigma and discrimination and therefore decriminalisation should be pursued: ‘Decriminalisation would really be a milestone to reducing discrimination and stigma’ (SMUG 2015); ‘Once you change the law it means that the people’s behaviour, attitudes will change. It’s a question of time, it’s a journey’ (AGHA 2015), and; ‘people would not be able to say what you are doing is wrong, it is illegal’ (COPTC members 2015). Decriminalisation would also open up avenues for recourse and justice, currently perceived as being closed to MSM and LGBTI, when MSM and LGBTI experience breaches of confidentiality, vigilantism, and discrimination. The absence of legal recourse means there is no deterrence to stigmatisation and the discriminatory or abusive behaviours that result from it: ‘Given that [same sex relations] is still illegal, the complaints [to UHRC] are very few. People fear to report it. The people report the violence but not the root cause of it (UHRC 2015).

Other respondents felt the primary driver of stigma towards MSM and LGBTI lay in a lack of knowledge about what it meant to be MSM and LGBTI. The respondent from HRAPF emphasised that in Ugandan society there existed a fear of the unknown coupled with an extensive lack of awareness about MSM and LGBTI. A HRAPF respondent noted that ‘Ugandan people don’t like to talk about sex. They disapprove of anal sex. That’s why homophobia is so high. People don’t know when we are talking about homosexuality we are talking about

people with lives... because you won't get on the radio if you say that. It's actually ignorance – who are these gays and what do they do?' (HRAPF 2015). This was echoed by MARPs Network members: 'It is mostly because they are ignorant about our community. They don't have the information, they didn't grow up knowing we are there. So when they realise they think it is unAfrican' (MARPs Network member 2015). Indeed, preceding decriminalisation, the AGHA respondent suggested the government should 'Scale up community sensitisation to reduce stigma around where LGBTI live' (AGHA 2015).

Socio-cultural factors such as religion, with large populations of Catholics; conservative attitudes around sex and the discussion of sex; a lack of knowledge relating to MSM and LGBTI, and; the reinforcement of criminalisation, were perceived to play roles in stigmatising attitudes that in turn limit access and adherence to ART for PLHIV in the MSM and LGBTI communities in Uganda, by contributing to a wide range of challenges. Economic power was perceived as a key factor affecting the vulnerability of MSM and LGBTI to isolation from family and society as a result of stigma: 'Vulnerability to the detriments of stigma is increased by poverty' (HRAPF 2015). If an individual has a sufficient income, they are not dependent on family for shelter or food so they will not endure these challenges if they are ostracised. Also if they are able to afford safe and secure accommodation in a wealthier area, they will not be as vulnerable to physical attack as someone living in informal settlements (HRAPF 2015). This is especially relevant given the perception shared in separate interviews: 'If LGBTI are unemployed and kicked out from home, where do you think they will get food? Unemployment is worse for LGBTI because they both get fired by gossip, and it is more difficult to get hired' (Icebreakers 2015), with another CSO suggesting 'unemployment is worse amongst LGBTI because they are more likely to drop out of school earlier' (MARPs Network Members 2015).

5.3 Health system

5.3.1 PARTICIPATION IN HEALTH PROGRAMMING

In Uganda's *National Strategic Plan for HIV&AIDS 2011/12-2014/15*, MSM and LGBTI were relegated to a short explanation as to why the plan included no specialised provisions for, or focus on, them: 'There will also be ongoing surveillance of risk behaviours among IDUs and MSM that have potential for upsurge of new infections, but for which there is insufficient data to warrant ranking them high among HIV prevention priorities' (Uganda AIDS Commission 2012). The two studies of significance since 2008 that have tried to survey the MSM population in Uganda, and which would begin to provide this kind of data, found their research efforts frustrated by hostile political developments and social environment, to the point of ending the research prematurely (Kajubi, Kanya, Raymond *et al* 2008: 495 and Hladik, Barker, Ssenkusu *et al* 2012: 7). Although hampered, the research did find an estimated HIV prevalence of 13.7% amongst the MSM population (Hladik Dr W., Barker J., Ssenkusu J. *et al* 2012; 7), whereas there was a reported 7.2% estimated prevalence amongst the general adult population in the same year (UNAIDS 2013b). Although methodological differences in data collection and analysis make the MSM and general population prevalence statistics difficult to compare, such a significant purported prevalence amongst MSM might be expected to spur a greater focus on MSM and LGBTI than is currently the case: 'at the moment they say we cannot include LGBT in our national policies because it is illegal and they have said that before' (SMUG 2015). A journal paper published in 2008 commented that '...we

recognize that the social and legal environment in Uganda and much of sub-Saharan Africa presents a challenge to conducting research and openly offering prevention programs for gay and bisexual men. However, there are pragmatic precedents in public health for reaching out to other populations whose behaviors are illegal’ (Kajubi P., Kanya M., Raymond H. *et al* 2008: 504)

5.2.2 FAILURE TO MEET THE NEEDS OF MSM AND LGBTI

There was a perception of a systematic failure to meet the needs of MSM and LGBTI where they differ from the general population: ‘the health advice provided by healthcare workers is not relevant to LGBTI. Some healthcare workers refuse to work on LGBTI – they say “I have been to medical school all this time and I have never been taught about you”’ (AGHA 2015). Other shortcomings refer to issues within health programming: ‘from a public health perspective, the government has to take those extra steps to ensure the healthcare that is provided is inclusive in the sense that the needs of the LGBTI are put into perspective in programming so that lubricants or whatever they need is mainstreamed into the healthcare package’ (UHRC 2015). For this to happen, the respondent from Icebreakers noted that ‘Government needs to include key populations at the planning table. How can they programme for key populations without the statistics? They do not have the statistics’ (Icebreaker 2015).

5.2.3 FAILURE TO ADAPT TO RAPIDLY CHANGING REQUIREMENTS FOR ADHERENCE

Adherence was perceived to suffer due to the passing and subsequent annulment of the Anti-Homosexuality Act in 2014: ‘most of them [HIV positive MSM and LGBTI] had problems of accommodation and, of course, feeding, and during that time they could not take their drugs well... because the community could fight them, they could do anything to them... Even the relatives who were giving them food stopped. Now they start seeing you as something to fear. Because the bill was that whoever deals with them gets sent to jail. [the anti-homosexuality bill] definitely affected their adherence’ (MARPI clinic 2015). This is relevant to the Ugandan health system because it is clearly not robust against political and legal changes in preserving public health since it did not adapt to the changing needs of the MSM and LGBTI communities to maintain ART adherence. For example, it was reported in one interview that ‘They used to give out [food] supplements but they haven’t for two years now’ (MARPs Network Members 2015). This food programme would have eased one of the greatest challenges to adherence at that time caused by political and legal changes. The perceived lack of responsiveness and attention could be seen as a further failure to meet the specific needs of MSM and LGBTI.

5.2.4 PERCEPTIONS OF, AND CAVEATS TO IMPROVEMENTS

There was a perception of improvement in terms of including members of the MSM and LGBTI communities in national health programming and services: ‘there is progressive reduction in homophobia in society and inclusivity of LGBTI in health programming’ (HIV and AIDS support civil society organisation (anonymised) 2015); ‘MARPI [a clinic dedicated to key populations] is in a government hospital. They never would have used to allow that. No one would imagine we would have a key population facility within a public health facility’ (NAFOPHANU 2015). However, perceptions of improvement were caveated with a suspicion that recent improvements were not motivated to better the health of MSM and LGBTI: ‘There has been

some improvement more recently in the health sector. NAC reach out here and there [to MSM and LGBTI], but you cannot say you want to engage with key African populations but then not publically talk about key African populations' (SMUG 2015); 'They are only doing it because they have to, because they get money to. They do not get money unless they target us' (MARPs Network members 2015).

5.2.5 FUNDING OF DEDICATED HEALTHCARE SERVICES

Where dedicated healthcare provision exists for MSM and LGBTI, it seems to be exclusively funded by overseas donors and agencies with a significant portion reported from PEPFAR and USAID. None of the CSOs or clinics interviewed received funding from the Ugandan State, with UHRC being a notable exception as a constitutional body. Throughout this report the perception of systemic stigma in mainstream clinics has been emphasised as a barrier to adherence, mitigated by dedicated service provision from clinics such as MARPI, and sensitisation training from CSOs like AGHA, Icebreakers and SMUG. The heavy reliance on overseas donors makes the capacity of these CSOs, and the continuation of their programmes and services, perceived as vital to ART adherence within the MSM and LGBTI communities, vulnerable to the shifting priorities or changing constraints of these donors.

5.2.6 MAINSTREAMING HEALTHCARE FOR MSM AND LGBTI

Respondents expressed a desire to mainstream MSM and LGBTI services which would include sensitisation of healthcare workers and stocking of products currently only obtainable at dedicated clinics: 'If services are quality, in terms of hospitality LGBTI get, medicines available, health workers trained to their needs, then definitely LGBTI will be empowered to attend mainstream clinics and this will be more sustainable' (AGHA 2015), and; 'If mainstream clinics were sensitised to LGBTI needs, it would reduce the travel currently required to get to specialised clinics like MARPI' (COPTTEC members 2015). For this to occur, programming would need to involve a greater engagement of MSM and LGBTI stakeholders at various stages of developments and levels. Indeed, a respondent from NAFOPHANU asserted that 'perhaps in the NAC we need a key populations desk like they have in Kenya. Then we can have a person ensuring our communication is right' (NAFOPHANU 2015).

5.2.7 INCLUDING COMMUNITIES RATHER THAN ACRONYMS

Respondents from FARUG were strongly of the perception that lesbians, female bisexuals, transmen, and intersex are consistently marginalised in research, in participation in programming, and in some health services that are supposed to be geared towards MSM, LGBTI, and key populations. Because lesbians, female bisexuals, transmen, and intersex are perceived as low-risk to HIV, 'healthcare workers are dismissive', but respondents asserted that these ignored communities included 'diverse sexuality with multiple entry points for HIV infection...with different health issues and needs' (FARUG 2015).

The perception seems to be that some sexualities such as MSM, gay men, and transwomen are engaged with to a greater degree in programming and have their health needs prioritised over those of lesbians, female bisexuals, transmen, and intersex persons due to perceived relative risk. This could create a situation where some communities that identify with and are identified as members of the LGBTI communities receive no significant inclusion in support and services that would help their particular challenges to ART adherence. This was the

perception from SMUG: ‘Lesbians are totally left out. Totally. No information, nothing. Even within the LGBTI community. With interventions and outreach. Everything. There are no services. FARUG pushed for lesbian services so now Icebreakers have included a programme for lesbians but before that they had nothing’ (SMUG 2015). Further research is required to ascertain the needs of LGBTI, the level of services actually oriented to them, and evidence-based decisions pertaining to their inclusion in health programming and focus.

6. RECOMMENDATIONS FOR FURTHER RESEARCH

1. Further research is needed to build on this scoping study to better understand the linkages between criminalisation, awareness, and stigma directed towards (HIV positive) MSM and LGBTI communities, on the one hand, and greater challenges to ART adherence, on the other.
2. ‘Double stigma’ was a recurring theme of the scoping study. This term describes how a combination of stigmas can interact to exponential negative effect. Further research should examine the relationship between HIV-related stigma and sexuality-related stigma, and the consequences of this ‘double stigma’ for ART adherence.
3. Although challenging – especially in the Ugandan socio-political environment – quantitative research needs to be undertaken on the level of ART adherence within the MSM and LGBTI communities relative to the general population.
4. The relative access to timely and relevant information for MSM and LGBTI versus the general population is perceived to be limited. Further research is therefore required to look at the relevance of ART access and adherence messaging in public and consultations (is it heteronormative), and whether MSM and LGBTI communities have the same ability as the general population to access the information that exists, considering such factors as literacy rates, placement of signs and leaflets, and sources of information.
5. Both the literature review and the pilot study reveal that the narrative of both research and service programming and provision is dominated by MSM, largely to the exclusion of lesbians, (particularly female) bisexuals, transgender (particularly transmen), and intersex people. Therefore, further research is initially required to better delineate what challenges to ART adherence are particular to lesbians, (particularly female) bisexuals, transgender and intersex people, to inform evidence based decision- and policy-making and programming.

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8 GLOSSARY

Antiretroviral therapy or antiretroviral treatment (ART) refers to a triple or more antiretroviral drug combination.

Lesbian is a woman who is sexually attracted to another woman/other women.

Bisexual is used to describe a person who is physically, romantically, and emotionally attracted to men and women.

Discrimination When stigma is acted upon, the result is discrimination that may take the form of actions or omissions. Discrimination refers to any form of arbitrary distinction, exclusion, or restriction affecting a person, usually but not only by virtue of an inherent personal characteristic or perceived belonging to a particular group—in the case of AIDS, a person's confirmed or suspected HIV-positive status—irrespective of whether or not there is any justification for these measures.

Gay The term 'gay' can refer to same-sex sexual attraction, same-sex sexual behaviour, and same-sex cultural identity. In accordance with UNAIDS 2011 terminology guidelines, 'men who have sex with men' has been the preferred term throughout this report.

Gender identity refers to each person's deeply felt internal and individual experience of gender, which may or may not correspond with the sex assigned at birth, including the personal sense of the body, and other expressions of gender, including dress, speech and mannerisms.

Homophobia is fear, rejection, or aversion, often in the form of stigmatising attitudes or discriminatory behaviour, towards homosexuals and/or homosexuality.

HIV-positive A person who is HIV-positive has had antibodies against HIV detected on a blood test or gingival exudate test (commonly known as a saliva test). Synonym: seropositive.

Human immunodeficiency virus (HIV) is the virus that weakens the immune system, ultimately leading to AIDS. Since HIV means human immunodeficiency virus, it is redundant to refer to the 'HIV virus.'

Intersex An intersex person is an individual with both male and female biological attributes (primary and secondary sexual characteristics).

LGBTI is used in preference to 'homosexuals' as this term tends to make lesbians invisible, does not encompass bisexuals and transgender people and may be considered offensive by many gays and lesbians.

Men who have sex with men (MSM) MSM is an abbreviation used for 'men who have sex with men' or 'males who have sex with males'. The term 'men who have sex with men' describes males who have sex with males, regardless of whether or not they have sex with

women or have a personal or social gay or bisexual identity. This concept is useful because it also includes men who self-identify as heterosexual but have sex with other men.

People living with HIV (PLHIV) reflects the fact that an infected person may continue to live well and productively for many years.

Prevalence Usually given as a percentage, HIV prevalence quantifies the proportion of individuals in a population who are living with HIV at a specific point in time.

Sexual orientation refers to a person's capacity for profound emotional, affectional and sexual attraction to, and intimate and sexual relations with, individuals of a different gender or the same gender, or more than one gender.

Stigma and discrimination 'Stigma' is derived from the Greek meaning a mark or a stain. Stigma can be described as a dynamic process of devaluation that significantly discredits an individual in the eyes of others. Within particular cultures or settings, certain attributes are seized upon and defined by others as discreditable or unworthy.

Transgender is an umbrella term for all people whose internal sense of their gender (their gender identity) is different from the biological sex they were assigned at birth. Transgender does not imply any specific form of sexual orientation and may include transsexuals and cross-dressers. They could identify as female-to-male or male-to-female, and may or may not have undergone surgery and/or hormonal therapy.

ANNEX

1: Key informants and interview dates

Key informants	Informant details	Adherence challenges	Interview date
Sexual Minorities Uganda <ul style="list-style-type: none"> Executive Director Frank Mugisha 	Network established in 2004 comprising 18 LGBTI organizations working to advocate for rights of LGBTI in the policy arena.	Direct question and response	01. 12. 2015
Most-at-risk populations Initiative <ul style="list-style-type: none"> Clinical Doctor Dr Katende 	Free STI, VCT and ART clinic specialised in advice and support services for most-at-risk populations including MSM, MSWs and LGBTI	Direct question and response	03. 12. 2015
MARPs Network <ul style="list-style-type: none"> F. Kamya - Youth and Rock Foundation S. Bernard – VINACEFUganda K. Juliet – Crested Green Lighters A. Beatrice – Transgender Equality Uganda 	Government initiated Civil Society Organization whose purpose is to promote coordinated leadership in HIV prevention among MARPs in Uganda	Direct question and response	04. 12. 2015
National Forum of PLHA Networks in Uganda <ul style="list-style-type: none"> Executive Director Stella Kentusi 	National umbrella organization for People living with HIV (PLHIV) established in 2003 to coordinate networks of PLHIV in Uganda.	Direct question and response	07. 12. 2015
Freedom and Roam Uganda <ul style="list-style-type: none"> Two members (anonymous) 	Member based, and unregistered organisation established in 2003 to support and advocate for lesbian, female bisexual, transmen and intersex persons	Contextual and background	07. 12. 2015
HIV and AIDS support civil society organisation (anonymised) <ul style="list-style-type: none"> Staff member (anonymous) 	A network advocating for improved public health in Uganda. Description limited to preserve requested anonymity	Contextual and background	07. 12. 2015
Uganda Human Rights Commission <ul style="list-style-type: none"> Staff member (anonymous) 	Established under the 1995 Constitution of the Republic of Uganda to protect and promote fundamental Human Rights and freedoms in Uganda for sustainable development.	Contextual and background	08. 12. 2015
Come Out Positive Test Club <ul style="list-style-type: none"> Transwoman sex worker (member) Transwoman HIV+ sex worker (member) Transwoman individual (member) 	Provides safe space for transgender and transsexuals who are HIV positive and engage in sex work while living in Uganda	Direct question and response	09. 12. 2015
Health GAP <ul style="list-style-type: none"> Executive Director Asia Russell 	An organization of U.S.-based AIDS and human rights activists that campaign for drug access and the resources necessary to sustain access for people with HIV/AIDS across the globe.	Direct question and response	09. 12. 2015

DanChurchAid <ul style="list-style-type: none"> Programme Officer for HIV Programming Janepher Taaka 	A Danish church-based organisation with international offices. In Uganda, DanChurchAid focuses on agriculture, disaster preparedness, combating HIV & AIDS, & supporting democratic development.	Direct question and response	10. 12. 2015
The Action Group for Health, Human Rights and HIV/AIDS <ul style="list-style-type: none"> Executive Director Dennis Odwe 	Health rights advocacy organization dedicated to raising awareness of the human rights aspects of health, and the quality of health and healthcare for all Ugandans	Direct question and response	10. 12. 2015
Human Rights Awareness and Promotion Forum <ul style="list-style-type: none"> Executive Director Adrian Jjuuko 	An independent, non-partisan, non-governmental human rights advocacy organization with a focus on marginalised groups and a LGBTI legal aid service provider	Contextual and background	11. 12. 2015
Icebreakers Uganda <ul style="list-style-type: none"> Clinic and Resource Centre Manager 	A civil society organisation established in 2004 advocating and providing resources, advocacy and STI and VCT services to MSM and LGBTI in Uganda	Direct question and response	11. 12. 2015

Annex 2: Key findings linked to key informants

Challenge	Description	Reporting rate and origin
Inadequate access to food	Some ARVs must be taken with or after food consumption to support drug absorption to required levels. Doses can be delayed/ missed until people can afford food with which to take the pills	COPTec members MARPs Network members SMUG MARPI Icebreakers AGHA
Stigma and a lack of social support	A lack of social support due to stigma resulting from a perceived or disclosed sexuality and HIV status is thought to contribute to worse adherence	COPTec members Health GAP AGHA MARPs Network members Icebreakers SMUG
Fear or experience of stigma at healthcare facilities	Both the fear and the lived experience of stigma from healthcare workers on the basis of perceived sexuality breaks down trust relationship between health provider and patient	COPTec members SMUG FARUG Icebreakers AGHA
Inadequate Counselling	A deficit of on-going counselling support was associated with a reduction in resilience to overcome challenges to adherence facing HIV positive MSM and LGBTI	COPTec members MARPs Network members SMUG Icebreakers
Insufficient access to information	The belief that information on side-effects, how to take pills, and the importance of adherence needs to become more accessible and relevant to MSM and LGBTI	COPTec members MARPs Network members Icebreakers AGHA

Fears or perceptions of breaches in confidentiality by healthcare workers	A concern for confidentiality on the part of healthcare workers is driven by the perceived potential of stigma or criminal charges that could result	AGHA COPTec Icebreakers SMUG
Fear or experience of ART side effects	Fears or perceived experience of negative ART side-effects. Psychosomatic, medication induced, or fears of side-effects can delay ART commencement or cause ART cessation.	MARPs Network members SMUG Icebreakers
Fear of disclosure via pill taking and storage	Delaying/missing doses to reduce visibility of ART pill-taking so as to maintain HIV non-disclosure	COPTec members SMUG Icebreakers
Prohibitive travel costs to clinics	Poverty creates a barrier to public transport costs to collect ART pills monthly for those living far away, especially to attend sensitised or dedicated healthcare for MSM and LGBTI	COPTec members Icebreakers AGHA
High pill burden	Daily regimens for life presents physical and psychological challenges. This can be worsened by TB-coinfection and regimen changes due to stock outs	COPTec members MARPI
Alcohol and drug abuse	Abuse of drugs and alcohol is associated with worse adherence	MARPs Network members Health GAP
ART stock outs	Stocks outs occur when clinics deplete their stocks of the regimens they prescribe. This can sometimes reflect a national shortage	Icebreakers AGHA
Loss to follow up	Clinics often follow up missed ART-related appointments with phone calls or even home visits in order to maintain patients' adherence	COPTec AGHA

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