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Acts of Service

HIV-AIDS & SOCIAL WORK RESEARCH

HIV- Testing and Beyond
Exploring Perceptions, Behaviours and Experiences

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Acts of Service

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Key Terms: HIV testing, test readiness, voluntary testing, mandatory testing, provider initiated testing, impact of diagnosis, post test experiences, test resistance, psychosocial effects of diagnosis

1. RESEARCH PROBLEM AND JUSTIFICATION

This research project seeks to investigate perceptions and experiences of HIV testing in order to fully understand the range of psychosocial factors that impact upon individuals both in preventing HIV transmission and in seeking treatment. In particular, the study aims are to examine perceptions and experiences of test services from contemplation through to receiving test results and the psychosocial impact of diagnosis, dealing with disclosure and, accessing treatment.

The project was established against a backdrop of international calls for a global emphasis on 'scaled up' testing (World Health Organization (WHO) and United Nations (UNAIDS)) as a primary means of reducing the prevalence of HIV infection. In examining what needed to be implemented to achieve scaled up testing in Trinidad and Tobago and through a preliminary literature review of culture/country specific factors, a number of psychosocial issues were identified. These include: perceptions and attitudes, exhibited behaviours by those conducting tests, the implications of a positive diagnosis and fears associated with disclosure. Additionally, the literature suggests that a major issue in promoting test-seeking behaviour is whether the outcome of testing will result in access to treatment, whether there is a realistic chance of prolonged life or whether these steps will *not* improve the quality of life overall for HIV positive persons. In countries with limited access to free antiretroviral treatment, HIV-testing and "knowing one's status" may actually be perceived as a further burden for the individual since *knowing* but not having support in handling this knowledge or being unable to access treatment to prevent the development of AIDS may have little overall benefit to the person concerned. In Trinidad and Tobago, where antiretroviral treatment is free (and in theory at least, universally available), it has been acknowledged by some medical practitioners that should *all* the persons in need of ARV's actually seek treatment, the health services may not be capable of effective delivery. These factors indicate that any drive to further increase HIV testing will need to be matched by improvements in ARV access, monitoring & ongoing psychosocial support.

There is a considerable body of international literature on HIV-testing and on experiences of diagnosis and treatment; however there have been no such studies carried out in Trinidad and Tobago. Little is known within the country about the experiences of persons who have tested for HIV and have had to deal with the impact of a positive diagnosis, disclosure issues or challenges they may have faced in accessing or adhering to treatment. The 'scaling-up' of HIV testing and universal access to anti-retroviral treatment in Trinidad and Tobago are recognised as important national objectives in HIV prevention at the policy level. However it is clear that information on the factors that contribute to test-resistance and the post-test experiences of persons who have been diagnosed HIV-positive is needed in order to ensure that policy can be translated into effective prevention and treatment services. In order to stimulate South-South cooperation in relation to knowledge-sharing on the psycho-social implications of HIV-AIDS, the project has been established as an international study, involving a review of studies on HIV-testing (primarily from Africa) and field work in two countries: Trinidad and Tobago and Kenya, East Africa. It is planned to include a third country: South Africa

(Kwazulunatal) at a later stage. It is hoped that the international dimension of the study will result in the identification of cross-national/cross-cultural lessons for policy and social work practice.

Based on this rationale, a two-stage research project was established:

- Stage I To investigate perceptions, attitudes and experiences in relation to different HIV-testing models
- Stage II To examine the psychosocial implications of post-test experiences in culture-specific contexts.

2. RESEARCH AIMS

The aims of the study are to:

- Identify testing models, procedures, attitudes and behaviours which *promote* or run *counter* to human rights and which *contribute to* or *confront* stigma and discrimination
- Understand the links between testing and sustained health promoting behaviours
- Understand the psychosocial effects of receiving a positive diagnosis
- Understand the factors that are taken into account in the decision to disclose or not to disclose
- Examine the psychosocial factors that impact on treatment accessibility and adherence

3. METHODS

The project utilises a triangulated approach in that several methods of data collection will be used.

Stage One: *The Investigation of Perceptions, Attitudes and Experiences in Relation to Different HIV-Testing Models*

Objectives:

- a) To review research on HIV testing models, procedures, attitudes and behaviours
- b) To identify models which *promote* or run *counter* to human rights and which *contribute to* or *confront* stigma and discrimination
- c) To examine links between testing and sustained health promoting behaviours

This aspect of the study will be based on a review of studies conducted primarily in Africa on different models of HIV-testing.

(This stage of the project was carried out over the period March-May 2007 – the report of the review together with a summary of the key messages and recommendations are presented in Section Eight of this document).

Stage Two: *The examination of the psychosocial implications of post-test experiences in culture-specific contexts*

Design										
Literature Review										
Sample Identification - Kenya										
Conduct Field Work - Kenya										
Sample Identification - Trinidad										
Conduct Field Work - Trinidad										
Data Input and Analysis										
Write up Report										
Submit Final Report										
Activity	Feb/March	April	May	June	July	August	Sep	Oct	Nov	Dec

6. ETHICAL PROTOCOL

This research project explores experiences of persons affected by HIV; a group of persons who are negatively impacted by stigma and discrimination. The conduct of the research will be based on clear ethical standards which emphasise and assure confidentiality, privacy, anonymity and informed consent. Ethical adequacy of the research will also be assured through ensuring that the research outcomes are geared towards policy reform and that the participants are not exposed to detriment or harm.

The project will be carried out in accordance with the UWI Research Ethics and Protocols document as follows:

1. The aims and objectives of the research will be clearly explained to all participants and stakeholders.
2. All participants will remain anonymous
3. Data will be kept confidential in a secured location
4. Each participant will be allocated a code name or number, and actual names and other personal identifiers will not be used
5. The data will only be seen by researchers
6. Due to the sensitive subject of the research, and the possibility that during interviews topics may be brought up that produce psychological stress, trauma, or fear of physical violence or detection (such as HIV+ status, undocumented

- status, sexual abuse, prostitution and homosexuality), the researchers will be trained social workers
7. Supervision and guidance will be provided by the Sondai Project Research Director
 8. Informed Consent will be based on the following principles:
All participants in the project (e.g., interviewees, survey informants, practitioners, agency representatives) will be informed of:
 - The nature of the research (goals and objectives, etc.);
 - The research methodology to be used;
 - Any risks or benefits;
 - Their right not to participate, not to answer any questions, and/or to terminate participation at anytime without prejudice;
 - Their right to anonymity and confidentiality;

The project will allow for any of the following methods of obtaining informed consent:

- a. Informed consent form: an informed consent form will be provided for use by the researchers. This would detail the principles outlined above, and require the participants' signature
- b. Letter: Where the traditional informed consent form is not appropriate (e.g., interviews with practitioners or representatives of an organization, etc.), the researcher will seek permission through a letter inviting them to participate. This letter will incorporate the principles of informed consent outlined above
- c. Verbal statement: In some instances, where written communication is not feasible, researchers will relay the principles outlined above verbally.

7. MANAGEMENT

The Sondai Management Team operating within the remit of The Social Work Unit at The University of The West Indies, St. Augustine Campus, is the executing group for the project and will be responsible for ensuring the timely execution and implementation of the project in line with project objectives. These responsibilities include:

- Budget management
- Project implementation
- Compliance with project objectives and ethical protocol
- Project monitoring
- Supervision of research staff
- Timely reporting

Research Team

The research team will comprise the Research Director for the Sondai Project, two Research Assistants, and a postgraduate student. The Research Director is responsible for:

- Defining the conceptual scope of research and research methodologies to be employed;
- Approval of all research instruments;
- Implementation and monitoring of research
- Quality assurance of research

- Supervision of data collation and analysis
- Supervision and oversight of preparation of research reports
- Analysis of all findings from all components of the research and the preparation of the final research report.
- Compiling and editing the project report, and for producing a publishable manuscript at the end of the project
- Ensuring maximum policy linkages

RESEARCH TEAM

Dr. Adele Jones, Research Director, Sondai Project
 Tracie Rogers (MPhil Student), Research Assistant
 Maud Mthembu, Research Assistant
 Postgraduate Student (TBA)

8. FINDINGS FROM STAGE ONE

HIV TESTING: MESSAGES FROM RESEARCH

8.1 Introduction

The descriptive phrase 'scaled-up' frequently appears in contemporary research and activist discourse in relation to HIV testing and counselling; it denotes a clear thrust towards a large scale, concentrated approach to promoting testing behaviours. The argument for scaled up testing proceeds along the course that universal testing will be equivalent to every individual being aware of his/her status and this universal sero-status knowledge will produce unprecedented advances in prevention and medical treatment access behaviours.

Testing is conceptualized as the gateway to care and treatment - the first point of access in attempting to address the epidemic. The consensus of the literature reviewed is that testing should be the foremost priority in combating the HIV pandemic and some commentators indicate that universal testing might impact all spheres of HIV related policy and service provision, be this antiretroviral access, stigma, discrimination, the effect of the epidemic on economic and political realities or implications of globalization. While there is a lack of overall consensus amongst researchers and policy makers that universal testing will produce these ripple effects there is general agreement that the behaviours and attitudes which exist around testing are not conducive or supportive to the achievement of universal testing.

This literature review explores studies into HIV testing conditions across Africa, the US and the Caribbean and investigates strategies, innovations and test taking behaviours. In bids to increase accessibility and utilizations of testing services, a range of innovative approaches to testing have been implemented meeting with varying levels of success. These innovations are discussed in view of the implicit and explicit statements they make about testing attitudes and behaviours. The 'routinizing' of testing is also explored with attention to its potential to inhibit as well as promote test taking. The review explores the divergent postulations and arguments which will guide future policy throughout the world on testing and counselling.

8.2 Evolution of Testing and Counselling

Terminology

Throughout the evolution of HIV testing and counselling new terms have been introduced in the literature, and these terms are sometimes used broadly and other times incorrectly. In the literature the term Voluntary Counselling and Testing (VCT) and Testing and Counselling (T&C) are sometimes used interchangeably and yet in other incidences there is a clear demarcation. VCT itself has come to mean many things however, in its original conceptualization VCT was intended to mean HIV testing which was requested by the client as opposed to testing ordered or recommended by a clinician for diagnostic purposes.

In the conceptualization of VCT, pre-test and post-test counselling was prescribed to prepare the client for the testing process as well as receiving the results, with the latter focusing on either risk reduction or psychosocial adjustment to living with HIV. VCT was formulated as a point of entry for prevention, care and treatment. Promotions of VCT are most rigorous in East and Southern Africa mostly in urban areas but are beginning to target rural areas. In Kenya, VCT programmes have started in a major refugee camp, and two programmes exist in south Sudan. VCT sites are found in a variety of settings and can be integrated into the services of health facilities, stand alone or free standing as in mobile units or in community-based sites.

Inception of Testing

HIV testing first became available in the US and Western Europe between 1985/1986 and was introduced to the rest of the world thereafter. Miller, De Cock & Zoysa (2005) point out that the 'western ideology' regarding testing, its approach and methodology, was exported indiscriminately to Africa and other parts of the world. An appreciation of testing and counselling, its very structure and how it came to function as it does presently, necessitates an understanding of the climate in which VCT was developed in the US and Western Europe. Miller, De Cock & Zoysa (2005) explains the atmosphere and 'western ideology' which shaped the fundamentals of testing as follows:

...the concepts of anonymous testing, need for counselling, confidentiality and patient autonomy over test-taking. However, the US & Western Europe was at that time facing "focal epidemics and overall low HIV prevalence", high stigmatization of affected risk groups (specifically Men who have Sex with Men and injecting drug users), lack of understanding and the understanding of HIV and AIDS as a short term illness resolving in death. There were two main thrusts driving VCT at the time, prevention of widespread mandatory testing and the introduction of VCT to prevent persons at risk from donating blood as a means of learning of their serostatus. (p4)

It was from this tradition that the precepts of the 3 C's: *Confidentiality*, *Counselling* and informed *Consent* was born. These principles have continued to inform the approach to HIV testing in most parts of the world. Anecdotal reports of what actually occurs in many settings often differ from this theoretical approach.

In the 1980's in the US and Western Europe, the structure of pre-test and post-test counselling and the emphasis of the voluntary nature of testing was shaped by the overarching concerns of the day: homophobia; stigma; lack of information; novelty of the

virus and its course. The major argument for a movement away from the rigid structure of VCT is that these conditions are somewhat altered and that there is a need to shape testing services to better reflect the needs of the population. At the time of the establishment of VCT, HIV was not of epidemic proportions however, the situation is now changed and many countries are facing a pandemic. Given present day circumstances, there is need to reconsider the very underpinnings of testing and counselling as originally conceptualised. Before exploring these arguments further, this review will consider the principles of current counselling and testing protocols.

Terms, Definitions and Models of Testing

UNAIDS/WHO (UNAIDS/WHO Policy Statement on HIV Testing, 2006) recommend that the following four types of HIV testing be clearly distinguished:

1) *Voluntary counselling and testing* – this is person-initiated HIV testing to learn of one's HIV status and is provided through voluntary counselling and testing. Pre-testing counselling may be provided either on an individual basis or in group settings with individual follow-up. UNAIDS/WHO encourage the use of rapid tests so that results are provided in a timely fashion and can be followed up immediately with a first post test counselling session for both HIV-negative and HIV-positive individuals.

2) *Diagnostic HIV testing* is indicated whenever a person shows signs or symptoms that are consistent with AIDS-related illnesses to aid clinical diagnosis and management. This routinely includes HIV testing for all tuberculosis patients as part of their routine management.

3) *Provider-Initiated testing* is a routine offer of HIV testing by health care providers where individuals are:

- Assessed in a sexually transmitted infection clinic or elsewhere for a sexually transmitted infection - to facilitate tailored counselling based on knowledge of HIV status or,
- Assessed in the context of pregnancy - to facilitate an offer of antiretroviral prevention of mother-to-child transmission or,
- Assessed in clinical and community based health service settings where HIV is prevalent and antiretroviral treatment is available (injecting drug use treatment services, hospital emergencies, internal medicine hospital wards, consultations etc.)

Explicit mechanisms have been deemed necessary in provider-initiated HIV testing to promote referral to post-test counselling services emphasising prevention, for all those being tested, and to medical and psychosocial support, for those testing positive. The basic conditions of confidentiality, consent and counselling apply but the standard pre-test counselling used in VCT services is adapted to ensure informed consent, without a full education and counselling session. The minimum amount of information that patients require in order to be able to provide informed consent is the following:

- The clinical benefit and the prevention benefits of testing
- The right to refuse
- The follow-up services that will be offered and
- In the event of a positive test result, the importance of anticipating the need to inform anyone at ongoing risk who would otherwise not suspect they were being exposed to HIV infection

- For provider-initiated testing, whether for purposes of diagnosis, offer of antiretroviral prevention of mother-to-child transmission or encouragement to learn HIV status, patients retain the right to refuse testing, i.e. to 'opt out' of a systematic offer of testing.

4) *Mandatory HIV screening* is touted by UNAIDS/WHO for all blood that is destined for transfusion or for manufacture of blood products. Mandatory screening of donors is required prior to all procedures involving transfer of bodily fluids or body parts, such as artificial insemination, corneal grafts and organ transplant. UNAIDS/WHO does not support mandatory testing of individuals on public health grounds, however mandatory testing has been implemented in many countries throughout the world in military settings and for immigration and insurance purposes.

Many countries require HIV testing for immigration purposes on a mandatory basis and some countries conduct mandatory testing for pre-recruitment and periodic medical assessment of military personnel for the purposes of establishing fitness. In response to the latter, UNAIDS/WHO recommendation is that such testing be conducted only when accompanied by counselling for both HIV-positive and HIV-negative individuals and referral to medical and psychosocial services for those who receive a positive test result.

The Human Rights Watch (2005) have highlighted the controversial proposed policy in Peru which calls for mandatory testing for pregnant women:

...the proposed reform to law 26626 ... pits children's rights against women's human rights. The connotation of these arguments, put forward, amongst others, by the president of the congressional health commission, Daniel Robles, is that any woman who values her right to consent or not to HIV testing is failing her moral duties to her future child. This is a false dichotomy. One need not violate a woman's human rights in order to protect those of a child, or to reduce the risk of HIV transmission to infants. By switching to mandatory HIV testing during pregnancy, Peru would be abandoning a voluntary testing approach that was never properly implemented.

<http://hrw.org/english/docs/2004/05/14/peru8584.htm>

International agencies report that in Peru, voluntary HIV counselling and testing programs have not received the support they need to function adequately. While international agencies insist that voluntary testing is more likely to result in behaviour change to avoid transmitting HIV to other individuals, many governments have snubbed this notion insisting that in their cultural context, mandatory testing is the optimal approach. Concerns about mandatory testing are based on ensuring human rights-based approaches to testing and counselling.

8.3 Ensuring a Rights-based Approach to Testing and Counselling

There is a pronounced fear that scaled up T&C will equate to mandatory testing and an undermining of the individual's right *not* to know their HIV status. The right not to know ones' HIV status seems in direct contradiction of the objective of universal knowledge of serostatus, but UNAIDS, WHO and other related bodies have taken the task of promoting *both* advocating universal testing as well as ensuring a rights-based approach to testing. It is around this point that views about T&C diverge – the major point of

contention being conflicting human rights. Running parallel to the individual's right not to know their status are the rights of the citizenry to be protected: a case in point being the example in Peru where policy makers are advocating that the rights of children should supersede the rights of pregnant women.

UNAIDS and PAHO have made clear statements that the voluntariness of testing must remain at the heart of all HIV policies and programmes, both to comply with human rights principles and to ensure sustained public health benefits (UNAIDS/PAHO Policy statement 2004). Miller, De Cock & Zoysa (2005) argue that this may have been relevant in the 1980's in the context in which VCT was set up, however, the realities of a pandemic require a different approach.

Much of the literature also argues that it is human right to have access to systems which address the implications of a positive test result, including non-discrimination and access to sustainable treatment and care. The tensions around testing are highlighted when advocates and activists point out that there needs to be not only a sustained focus on 'scaled up' ART but that laws and policies to deal with stigma and discrimination must also be scaled up. The argument that increased testing must be met with increased capacity for treatment is a dominant theme throughout the literature.

Taking a provocative stance, Miller, De Cock and Zoysa (2005) argue that "individual liberties (may) have been excessively prioritized and ... well-meaning attempts to protect individual rights, combined with lack of funding, have resulted in massive infringement of communities' rights, now burdened by high rates of disease, death, orphanhood and poverty" (p4). The authors argue that individual liberties have been excessively prioritized and are not relevant to the current realities of the pandemic which exist in Africa; they advocate for less restrictive testing procedures and innovations which may result in universal testing (for example, self-testing):

The use of self-testing with rapid tests, such a test in the bedroom before engaging in sex with a new partner, exemplifies challenges. This could avert many new HIV infections, and the logical question is why the average citizen is prohibited from using such a test. Persons who are found to be HIV negative "win" in this context; the person found to be HIV positive in this setting would have risks of losing a great deal—the relationship, privacy, and perhaps even safety. The risks of coercion and violence are present for individuals, especially women, but overall incidence might reduce. The cost/benefit ratio is debatable, but could well fall on the side of benefit to society (Miller, De Cock and Zoysa (2005, p7).

Miller, De Cock and Zoysa (2005) make the assertion that if the current level of the pandemic facing Africa existed in Western Europe or United States, there would be a "radical shift [in testing policies], with an aim to introduce universal testing, premarital testing, routine diagnostic testing, etc so that every citizen knows his/her serostatus, and this is the basis of prevention and care lifelong". (p7)

Nonetheless, the UNAIDS/WHO policy position is that:

The reality ... [of]... stigma and discrimination continue to stop people from having an HIV test. To address this, the cornerstones of HIV

testing scale-up must include improved protection from stigma and discrimination as well as assured access to integrated prevention, treatment and care services. The conditions under which people undergo HIV testing must be anchored in a human rights approach which protects their human rights and pays due respect to ethical principles (UNAIDS, 2006).

The rights-based approach to HIV testing and counselling means that: persons have a right to know or not know their HIV status; HIV testing must be voluntary, the decision to test or not to test must be based on an understanding of accurate, objective and relevant information; post-test counselling & services must be available; confidentiality must be protected; non-discrimination in service delivery should be ensured; and testing and counselling must be scaled up, eventually leading to universal access.

Models for HIV Testing

There have been innovative approaches to testing which seek to increase accessibility and de-stigmatize T&C while also upholding tenets of a human rights approach. The WHO (2005, p45) produced 'Scaling-Up HIV Testing and Counselling Services: a toolkit for programme managers' and summarizes HIV testing and counselling approaches as follows:

Model 1. Individual pre-test and post-test counselling and HIV testing (classic model, used by most free-standing VCT sites).

Model 2. Group information, opt-in individual pre-test counselling, and individual post-test counselling.

Model 3. Group information, opt-out individual testing, and individual post-test counselling for persons who are seropositive or are seronegative.

Model 4. Group information, opt-in couple/family pre-test counselling, individual/couple/family post-test counselling (shared confidentiality model).

Model 5. No pre-test information, screening/testing (with possibility of opting out), individual post-test counselling for persons found to be HIV-positive (screening of STI attendees, drug-treatment programme attendees and women attending antenatal clinics).

Model 6. Mandatory HIV testing.

Model 7. Counselling without testing.

Home-based Testing & Community-based Testing is a new approach that has met some success in some African countries where uptake using conventional VCT methods has been slow and where test-takers have often not returned for their results. Wolff et al (2005) in a study entitled, 'Evaluation of a Home-Based Voluntary Counselling and Testing Intervention in Rural Uganda' reported that:

Despite concerted efforts over 10 years to improve access to VCT services, less than 10% of participants in an annual serosurvey in rural southwest Uganda return to get their HIV results on an annual basis, and only 20% had ever received their results under the existing facility-based system. A pilot study of home delivery of HIV test results increased uptake of HIV results 3 to 4 times or more for both sexes and all age groups. In a qualitative investigation carried out after the intervention study, the relative popularity of home VCT and reasons for low uptake

under the facility-based system were explained by a combination of personal fears, service constraints and social barriers to access.

Home delivery was predictably preferred in terms of travel time, distance and effort required to obtain results. While home delivery of results was no faster than facility-based delivery, it guaranteed they would arrive as soon as they were available without the risk of finding results were not yet available. It was found that participants felt no overt or implicit pressure from the Programme and very few refused to receive the results they had requested, and none of those interviewed regretted their request afterwards.

Uganda has received acclaim for uniquely addressing the stigma surrounding HIV/AIDS on a national policy level. Research, advocacy and public discussion of the problem has been welcomed. In the site of this VCT pilot study, the targeted individuals were recipients of continuous HIV education outreach efforts for over a decade. The fears of being identified as HIV-positive discouraged study area residents from asking for their test results. Getting results at home allowed area residents to know their status without the risk of it being disclosed to others in the process.

Whether similar results would be reproduced outside the unique conditions of a long-term study cohort is debateable. At the time of this study, antiretroviral therapy was not available through the study programme, though early access to routine treatment through the programme was cited by participants as an advantage of knowing their status. Despite some apparent benefits, home VCT is an expensive option for an intervention whose efficacy and social consequences are not known.

Wolff et al (2005) forward the following generalizable lessons that might be learned from the study for all VCT programmes:

- (1) Low uptake of VCT should not necessarily be interpreted as lack of interest in knowing results.
- (2) Home counselling appears to work better for most people in this setting, but others will continue to prefer clinically-based VCT, while others such as young people might prefer more anonymous settings away from both home and clinic.
- (3) Convenience is important, but must be balanced against social stigma considerations. Dedicated HIV counselling centres should be located away from busy centres or allow unobserved access. Particularly in rural areas where full anonymity is not feasible under any system of delivery, efforts to scale up VCT services should take advantage of integrating testing into other services that provide clients a safe pretext to visit. Ultimately, efforts to disguise VCT services through home delivery or integrating VCT into other health services may succeed precisely because they pander to the existing stigma surrounding HIV/AIDS. Breaking the silence around testing and encouraging public disclosure of the act of testing itself (but not necessarily individual HIV test results) might address the root problem of HIV stigma that still persists even in relatively progressive environments such as Uganda. Perhaps the relative success in getting people to know their status by routinizing of testing in Rakai, or encouraging entire families to

test in the Mukono example, really lies in taking away the stigma attached to HIV testing itself

Couples-oriented testing

In the aforementioned study in Rakai, Uganda, participants were able to request VCT, as individuals or couples, either at the time of interview, or during the inter-survey period. Couples were encouraged to receive their HIV results together, and those who opted not to receive counselling were encouraged to share their test results with their partners. In keeping with the Ugandan Government's HIV testing policy, test results were not disclosed to partners without prior written consent. The literature highlights many issues that arise with couple oriented testing. While studies show that couples-oriented testing is generally viewed positively, there has been a low demand for the service in African countries in which it has been offered. Glick (2005) points out some barriers to couples-oriented testing:

- African women lack the power to bring their partners to test
- The cost (social and emotional) of testing are higher than testing singly since there is a chance of sero-discordant results, exposing external relationships that the other partner may not be aware of

8.4 Routinizing Testing

Throughout the literature the term 'routine testing' has been ascribed different meanings. For example in some contexts 'routine testing' means everyone in a given setting or circumstances is tested without regard to individual consent. In US 'routine testing' refers to the routine offering of voluntary testing to all patients, with consent obtained but no pre-test counselling.

In the Outcomes Paper of the 2005 Symposium on HIV Testing and Human Rights implemented by the Canadian HIV/AIDS Legal Network, activists, researchers and PLWHA stated that there is "urgent need for a greater understanding of the practical reality of what constitutes "routine-offer" approaches, how informed consent is or is not included, and such factors as what motivates some people to be tested or not." This outcomes paper describes the struggle of the participants of the symposium to arrive at a consensus of the meaning of the term:

"Routine offer of testing" is also regularly used, but its meaning is not always clear. There seems to be general consensus that it means everyone in a given setting or circumstance is routinely offered an HIV test, and the term itself suggests that testing remains "opt-in" (i.e., testing proceeds only if consent is expressly given, preferably in a truly voluntary fashion and informed based on quality pre-test counselling). However, sometimes the term "routine offer of testing" is used in ways that suggest that, following the offer, testing proceeds on an "opt-out" basis. It is important to know if "routine offer of testing" means testing in the absence of refusal or testing only with affirmative consent. While these terms are sometimes used without clearly stated definitions, they generally involve departures, to varying degrees, from the VCT model, particularly those approaches to HIV testing that would eliminate or modify individual informed consent, and truncate or eliminate counselling, or restrict counselling solely to post-test counselling tailored to the test result."

Concerns around routine testing

Several studies indicate that routine testing may lead to increased numbers of persons getting testing however this argument is tempered by understandings that

...the number of tests is not an adequate indicator of benefits. If people are unprepared for testing or for disclosure of their status, and are inadequately counselled at the time of testing, adverse consequences of testing — for which some persons tested will be unprepared — will likely also rise along with numbers tested. Among these potential consequences are abandonment by family members, violence, abuse and psychological depression. Simply measuring the number of people tested does not capture either the experience of HIV testing or that of people who may be at risk of adverse outcomes” (Canadian HIV/AIDS Network, 2005).

Routine testing and counselling is forwarded as an attempt to normalize the process. By extension there is a view expressed that ART can help to ‘normalize’ HIV. Other commentators disagree and point out that access to ART does not mean universal access and that the burden of the virus is still borne disproportionately by certain groups of PLWHA e.g. women. The question “*is it legitimate to “normalize” HIV and end “AIDS exceptionalism”*” is raised by the Canadian HIV/AIDS Network (2005) and it is argued that HIV-related illnesses can not yet be considered “normal” therefore it may be premature to attempt to normalize any process associated with it, such as HIV testing.

In Phillips, A. and Fernyak (2000) ‘The Cost-Effectiveness of Expanded HIV Counselling Testing In Primary Care Settings: A First Look’, current C&T practices in the US are outlined as consisting of a mixture of routine testing, the use of risk histories, face-to-face counselling by physicians, and testing that occurs because of patient request. There were two primary conclusions. First, routine testing was the most cost-effective option under the baseline assumptions because: (i) testing alone was inexpensive; and (ii) more infected people were identified. However, there are ethical and feasibility concerns about routine testing, including the possibility of false positive results, the implications of testing without pre-test counselling, and the concern that routine testing might discourage high-risk patients from seeking care and would become mandatory testing. If testing becomes more routine, the long history of ‘HIV exceptionalism’ may erode along with its advantages and disadvantages. The ‘best’ approach may vary between settings and decisions about which approach to use and can be based on other factors such as patient and provider preferences.

“Routine-offer” approaches may lead to an increase in the number of tests given, but that increase may not be the most important outcome. People who are unprepared to be tested and unsupported in dealing with the consequences of disclosure of their HIV status may suffer depression, abandonment, violence and other severe outcomes that may be mitigated by VCT approaches. Critics of VCT often fail to acknowledge that in many settings VCT has not been adequately funded or promoted. It is unlikely that any move to make HIV testing more routine will address the real or perceived deficiencies of VCT

Assumptions around Readiness for Testing

Fylkesnes et al (1999) in a population-based HIV survey in Zambia examined the factors affecting readiness for VCT and found that readiness was very low and makes the assertion that this equals low demand. These researchers found that there was a low

proportion of persons who volunteered to be tested for the purpose of knowing the result. They found “a striking gap between what people think is a good idea and how they actually respond when services are made available”. Approximately 9% of the initially willing participants actually showed up for testing and counselling.

Such a poor response appeared in a population where less than 7% reported to have ever been HIV tested, where factual knowledge about HIV was found to be good and where about 50% perceived themselves to be at risk of being infected and worried about being infected (p14).

The researchers attributed low readiness to the following factors:

- Benefits from VCT being limited to medical care, there is no other reason to access results other than medical care. If care is perceived as unimportant or unavailable, then test take up is negatively affected
- Quality aspects of VCT - in particular concerns about confidentiality, have a negative influence on use of the service.
- Individuals who have already taken an HIV test are heavily influenced by past accessibility of VCT and by the acceptability of the services provided.
- Length of time one has to wait for results – there is a considerable lag between pre-test and post-test counselling primarily because there are delays in receiving results
- Higher rate of utilization of the service in rural areas than in urban areas. Possible influence of sociocultural factors and higher degree of stigma. This difference can also be attributed to the use of counsellors from outside of areas in rural communities and local counsellors in urban settings – possible effect on confidentiality

8.5 The Arguments & Counter Arguments for Disassembling VCT

Resource & Time Intensive

The major argument against VCT has been that it is resource intensive and time-intensive and therefore is counterproductive to bringing testing to scale and therefore impedes efforts to scale up treatment. Counter arguments are fuelled by the assertion that it is not clear that increased testing will be matched by increased access to treatment in many settings. Advocates of VCT argue that there have been no serious investigations about how to streamline VCT in order to address these issues. It may be possible to ensure confidentiality, consent and counselling in alternative models of VCT, rather than only seeing these components as barriers. Different populations require different approaches to testing and there should be a focus on creating more varied approaches instead of attempting to eliminate VCT altogether (Canadian HIV/AIDS Legal Network, 2005).

Poor Utilization Rates

Poor utilization rates are another major argument against VCT. Many studies support this argument, repeatedly highlighting that there are key barriers to use of the service. Applying the structural model of health behaviour (Cohen, Cribner, & Farley, 2000) explored VCT knowledge and practices in rural South Africa (Mabunda, 2006). The structural model of health behaviour builds on ecological theory, the key factor of which is that environmental or structural factors are major determinants of individual behaviour. This model changes the environment's structural context in which behaviour exists. The goal of structural interventions is to change the behaviour of the entire population or

community. There are four factors that constitute a structural model of health behaviour that affects the population:

- (a) availability and accessibility of consumer goods
 - (b) physical structures
 - (c) social structures and policies
 - (d) media and cultural messages
- (Cohen et al., 2000).

This model was appropriate for this study because the questions were designed to unravel what is the perceived availability and accessibility of VCT services and what are the factors that influence utilization of the services (are there any physical barriers, social factors, or media messages that affect the utilization of services?). According to this framework, there are four factors that constitute a structural model of health behaviour, and participants were asked questions related to all four areas as identified in the framework. The questions used to collect data in this study were open ended so that participants could talk about any factors or issues related to VCT and the four areas.

Data analysis revealed four major themes:

1. Participants know about VCT services and are aware of availability of VCT services at the local clinics
2. Participants know about the availability of VCT services, but half of them have not been tested
3. The radio and health care personnel (clinics and doctors offices) are the main sources of information about the availability of VCT services
4. Participants do believe that there are benefits in participating in VCT services.

This study had many limitations and yielded little information as to the perceived barriers to utilizing the services however, it *did* support other findings that awareness of the availability of VCT is not positively correlated with the use of the service.

Traditional Counselling Format is Ineffective

Miller, DeCock & Zoysa (2005) offer the critical observation that with Africa's high incidence rate and scarcity of counsellors and health care workers, the argument for providing counselling (risk reduction counselling specifically) in the traditional format of VCT is a "commendable "but unrealistic goal. The authors argue for the recognition that VCT is having a 'shallow impact' on populations in most countries in Africa:

Although an incentive has been the technical advancements that Africa is presently benefiting – namely in the form of rapid testing which has addressed the distrust and low likelihood of return to collect results shipped in from an outside laboratory. An inhibitor of growth and change in some African countries has been the interests of laboratory technologists and technicians resisting allowing non-laboratory personnel (e.g. counsellors) performing testing sitting protection of professional status and work. Miller, de Cock & de Zoysa forwards that "many of the available rapid tests are as simple to administer as a home pregnancy test or a blood glucose test... (p5).

The National Centre for HIV, STD, and TB Prevention, U.S. Department of Health and Human Services included the following statement in its revised guidelines for the provision of counselling:

In the proposed guidelines, the provision of counselling at the time of disclosure of results will not change from current practices for persons who test positive for HIV. Furthermore, the guidelines will continue to recommend linking those who test positive to care and prevention services. However, prevention counselling (i.e., pre-test counselling with the development of a risk reduction plan, and post-test counselling for HIV-negative persons) will not be required in conjunction with HIV screening programs in health care settings. Several studies have shown that both patients and providers often perceive prevention counselling as a significant barrier to testing in medical settings. Because of time constraints and other considerations, when conventional counselling and testing are recommended for health care settings, most patients receive neither...Additionally, data from the National Health Interview Survey indicate that, by the mid-1990s, the U.S. population exhibited high levels of knowledge about HIV, HIV testing, and risk factors for HIV transmission. Emerging data suggest that singling out HIV testing is likely to perpetuate the stigma surrounding HIV testing. ...At the federal level, the Ryan White CARE Act requires counselling before testing of HIV disease. This provision, which was added by the Ryan White Care Act Amendments in 2000, is not consistent with CDC's proposed recommendations for HIV testing in health care settings. While this requirement was consistent with CDC recommendations at the time, qualitative data now show that prevention counselling may not always be appropriate or feasible (such as during episodic or acute care visits) and can serve as a barrier to testing CDC 2006, <http://www.hhs.gov/asl/testify/t060426a.html>.

The Importance of Existing Components of VCT- Implications for Disclosure

A study carried out in Dar es Salaam Tanzania, Mamam et al (2003) describes the experiences of 245 females attending VCT in terms of how HIV serostatus was disclosed to sexual partners. The study demonstrated the value of incorporating disclosure as a crucial element in pre-test and post test counselling. It highlights the importance of preparing women specifically for the disclosure process. Without VCT there is no structured, professional source of this type of support and the fears of partner and community reaction can vary from mild to extreme.

In a qualitative study in Zimbabwe describing the informational, social and emotional needs and problems of newly diagnosed seropositive persons attending public health services, comprehensive pre- and post-test counselling were found to be an essential preparation for coping effectively during and immediately after testing. It was found that the availability of supportive counselling beyond this first phase was essential to assist clients with needs and problems which will appear over time. The aim of pre and post-test counselling was to prepare clients to make an informed decision about being tested, and to deal with the results in a constructive manner. Eighty of the 96 patients had undergone pre- and/or post-test counselling by the research team; 16 others had been referred for further counselling after diagnosis elsewhere. Criteria for selection in the study were: age >15 years, living no more than 25 km from town, and being symptomatically seropositive short of having clinically-diagnosed AIDS. This sample can be considered to be reasonably representative for seropositive persons attending urban public health services in Zimbabwe. The key finding of this study which promotes the use of VCT as essential is that 72 of the 96 (75%) seropositive persons invited to continue counselling accepted which suggests that this service meets a demand. This is

a significant occurrence especially given the level of denial and repression reported by these persons during the post testing phase.

Role of counsellors

In this study in Zimbabwe it was found that counselling for PLWHA was extremely valuable for gaining social support from family, partners and employers by correcting misconceptions and defusing irrational fears, blame and anger. In both marital and family relationships the presence of a counsellor facilitated the discussion of 'shameful' sexual subjects, and the difficult subject of planning for a future with more advanced HIV-related illnesses. Additionally, the assistance of counsellors was often sought for help in medical, practical and economic problems. Counsellors often "functioned as a 'relay station' in organizing comprehensive care adjusted to clients changing needs, by bringing PLHA and their families in contact with appropriate sources of support in the community and health care system" (p345). The following findings are noteworthy:

Sixty-two of the 72 PLHA who accepted ongoing counselling disclosed their HIV status to at least one other person. Twenty-five of 32 married PLHA in ongoing counselling took the difficult step of disclosing to their spouse. In contrast more than half of PLHA who refused further counselling intended not to tell anyone of their diagnosis. Some were married or engaged to be married. Twelve of the 72 clients broke off contact with their counsellor when they began to deny or disbelieve the diagnosis during a period of protracted good health. This carried the risk of a return to unprotected sex. Analysis of transcripts of pre/post-test and further counselling sessions revealed that newly diagnosed seropositive PLHA had a host of social, emotional, and informational needs, which often seriously impeded their capacity to make constructive use of the knowledge of their HIV status. Pre- and post-test counselling also allowed the counsellor to identify clients in need for crisis intervention (p347).

Subjective and Objective Knowledge of HIV/AIDS & Testing Behaviours

Phillips (1993) in a study on subjective knowledge of AIDS and HIV testing, investigated the association of objective AIDS knowledge (scores on objective questions) and subjective AIDS knowledge (self perceptions) and the association of both objective and subjective knowledge with the use of HIV Testing. The study found that

- There was a moderate correlation between objective and subjective knowledge
- Subjective knowledge was significantly associated with testing
- Objective knowledge was not significantly associated with testing

Phillips suggests that studies must attempt to measure both objective and subjective knowledge when analyzing VCT and or other preventative behaviours since one measure alone can produce misleading results. The author notes that one of the reasons accounting for the failure of previous studies to observe a consistent link between knowledge and preventative behaviours may have been the use of objective structured questionnaires that do not capture underlying attitudes about that knowledge. Phillips reminds us that knowledge may be 'a necessary but insufficient' reason for behaviour change:

...this study suggests that what people perceive they know may be more important than what they actually know (p1462).

Stigma, Testing and Counselling

Stigma is frequently cited in the contemporary literature on HIV as a major reason to account for the difficulties in increasing HIV testing. This has become a 'popular' explanation for the low take-up of VCT and the rise in incidence rates. Castro & Farmer (2005) in an article on clinical practice in Haiti suggest however, that while AIDS-related stigma clearly needs redress, there is little evidence that stigma stands as a ranking obstacle to treatment in poor countries and that a more significant issue is the fact that less than 5% of people with advanced AIDS in these countries have access to HARRT. The authors question the understanding of AIDS-related stigma and seek to assess the relationship of stigma to HIV prevention and care. A structural violence conceptual framework for understanding AIDS-related stigma, informed by Goffman's seminal work on stigma is forwarded. The definition of stigma is given as "the identification that a social group creates of a person (or group of persons) based in some physical, behavioural, or social trait perceived as being divergent from group norms". There is a premium placed on the value of analyzing stigma in terms of relationships as opposed to individual traits and attributes. The social violence framework begins by forwarding that all societies are shaped by large-scale social forces that define structural violence; these include racism, sexism, political violence and other social inequalities 'rooted in historical and economic processes that sculpt the distribution and outcome of HIV/AIDS'. Social violence predisposes certain groups to vulnerability by shaping the risk of infection, rate of disease progression, access to counselling, diagnosis and effective treatment and by extension this type of violence determines who suffers from AIDS-related stigma and discrimination. A second framework for analysis is offered – a biosocial framework which draws on conventional epidemiology and 'complimentary re-socializing disciplines in which the patient's voices and experiences can be heard and documented'. The authors use the aforementioned frameworks to analyze a case study of a Haitian man in a rural setting who deals with the stigma and discrimination associated with his HIV diagnosis after successfully responding to ART:

The Haiti project already demonstrates that individuals who can access effective care are the most likely to get an HIV test, which supports social theories on the social discourse on illness. The introduction of antiretrovirals has had a profound impact on the demand for voluntary counselling and testing.

Castro and Farmer forward that since the 1998 introduction of the first free comprehensive AIDS program at their rural clinic the demand for these services have quintupled despite the continued existence of stigma and discrimination.

8.6 Improving VCT Compliance and Accessibility

The trend of rapid testing was introduced to increase testing, receipt of results and treatment access/compliance. The literature reveals that rapid testing has affected VCT significantly. There have been continuous efforts to improve VCT compliance & accessibility including:

- Result notification and counselling by phone
- Rapid HIV testing
- Home testing and delivery of HIV test results

(Studies in rural Rakai district, Uganda, show that home delivery of results increases utilization of VCT (Matovu et al 2005)).

International organizations, researchers and policy groups involved in designing and improving VCT services operate on the assumption that VCT will relieve the anxiety of 'not knowing'. However the literature (particularly in African studies) indicates that there is little anxiety produced by not knowing and that instead, the high prevalence of HIV-AIDS in developing countries has created a fatalism (more akin to 'knowing' or assuming a high likelihood of infection) among many segments of the population.

In Zambia, Fylkesnes et al (2000) noted that higher educational groups were more likely to test. This was not supported by (Matovu et al, 2005) however, who observed in a Ugandan study that educated individuals had a significantly lower VCT acceptance rates compared to those with no education - this suggests a need to encourage VCT among the better-educated participants (p 509).

8.7 Self-testing as the Way Forward

Miller, De Cock & Zoysa (2005) offer the following:

Concerns exist against home testing or self-testing, based on anxieties regarding subsequent coping of those who discover themselves to be HIV infected by such procedures. There is currently available a simple, rapid HIV test which can be performed using oral fluids. Collection of the sample, performing the test, and interpreting the results could be done by almost anyone who is literate. When this test is demonstrated to the average non-medical person, one of the first questions is "Can I have one to take home?" Implementation of such technologies, with appropriate levels of information, identified referral pathways and follow-up interventions should be designed to assess, empirically, their impact." (p6.)

Miller et al (2005) argue that the use of self- rapid-testing (as could be used before sex with a new partner, for example) may potentially avert many new HIV infections, and question why such tests are not promoted. They point out that while persons who are found to be HIV negative "win" in this context; the person who is HIV positive may face considerable risks: the relationship, privacy, and perhaps even safety (the risk of coercion and violence may be present, especially for women). Miller et al point out that while the balance between costs and benefits would need to be carefully considered, the overall incidence of infection would probably be reduced with general benefits at the societal level (p7).

8.8 VCT and Behaviour Change

In a study in Pune, India, in which T & C was offered at a STD Clinic which also included individual counselling and condom provision, Bentley et al (1998) found that:

....ongoing counselling reinforced desired behaviours and aimed at sustaining those changes over time did have a positive outcome with a large proportion of the men recruited for this study. However, counselling and testing, which provides information about HIV transmission and serostatus, is not sufficient for changing behaviour for

the majority of the individuals seen in these clinics in India, as is the case in many other communities struggling to meet the challenge of the AIDS pandemic. Social and cultural factors, like poverty, lack of access to condoms, low self-efficacy of most Indian women to negotiate condom use, and belonging to marginalized or stigmatized communities (such as CSW), make it difficult for individuals to fulfil the intention to change behaviour . The ultimate goal of HIV prevention efforts must also focus on efforts to change the behaviours and norms of entire communities (Bentley et al 1998).

8.9 Repeat Testing

Leaity et al (2000) examine the characteristics of repeat and first-time HIV testers, considering their implications for HIV test counselling. This study, implemented in London found no significant differences in the frequency of unprotected penetrative sex between repeat and first-time testers with the exception of gay men with a history of three or more previous HIV tests, who reported elevated levels of high-risk sexual behaviour. For many people, repeat HIV testing has become part of a risk reduction strategy to establish sero-concordance with a regular partner. HIV test counselling provides the opportunity both to address high-risk behaviour and to reinforce personal risk-reduction strategies. This study is consistent with the normative shift in testing behaviours in western societies where repeat HIV testing has been “integrated into a personal sexual health strategy by many people rather than being a consequence of high-risk behaviour alone” (Leaity et al 2000, p551). It is noteworthy that the majority of repeat testers received a repeat HIV negative result. Another trend noted among gay male repeat testers was a higher likelihood to report increased high-risk exposure to HIV. The authors noted that this finding is consistent with contemporary research and went further to outline implications for post-test counselling with this population: post-test counselling should be an opportunity to challenge risk taking behaviours, identify trends and discuss personal strategies for risk reduction. The authors call for a problem identification approach in HIV test counselling geared toward each individual's risks and their reasons for seeking an HIV test.

8.10 Evaluation Studies on HIV VCT

Glick (2005) provides a critical review of the evidence of VCT effects on behaviours from evaluations conducted in African settings. The following findings were highlighted:

- Risk-reducing behaviour change tends to be greater among individuals who test positive than those who test negative. One exception to this in Uganda found that reported condom use had risen in both negative and positive persons, however, the share of HIV-negative persons who were sexually active also increased
- Couple counselling was more effective/successful than individual counselling (i.e. resulted in greater behaviour change); sero-discordant couples who test together adjust their behaviours. (Note: this may be because of cultural/gender roles in which men commonly make sexual decisions and therefore this may be a mode of risk-reduction for men.) In some cases individual testers also reported risk reduction.

Limitations of these studies

These studies commonly use single-group pre-test and post-test design and are based on self-reported behaviours that assume that any change in behaviour is attributed to the intervention. Changes in behaviour may in part reflect general changes over time rather than as a result of intervention. Furthermore, the results may reflect self-selection into

VCT of individuals who are predisposed to make such changes. The costs of using VCT (in this case referring to psychological or social costs rather than monetary costs) were probably quite high. Given this barrier, the VCT site or study may have drawn in individuals who were not representative of, and whose response to the intervention may differ from, the target population for the VCT program. There was one randomized study noted which is well recognized in public health literature since it demonstrates the cost effectiveness of scaling up VCT in Africa - however it was noted that:

The randomized trial does ensure stronger internal validity, meaning that it provides reliable estimates of the effect of VCT on those who volunteer, the “effect of treatment on the treated.” But external validity—the credibility of the findings as indicators of efficacy for the target population in general—may be weak Glick (2005).

In addition to the limitations highlighted above, other concerns are that follow up periods in many cases are too short (often only a few months) to gauge long-term behaviour change. The author makes the point that none of the studies attempted to measure key behaviour change variables and that evaluations have not paid attention to aspects of the counselling process. Glick poses that:

It would be of interest to know whether interventions that explicitly incorporated constructs such as self-efficacy or behaviour change skill acquisition are more effective, or whether the key benefit of VCT is simply that it provides information on one’s status that can be used to adjust behaviour (2005).

Test-taking decisions are complicated matters. Glick, drawing from studies performed throughout Africa, identifies several behavioural models to explain test-taking decisions and further suggests that randomization over “communities rather than individuals is offered as the best way to provide direct estimates of average program outcomes in the target population for VCT, incorporating both uptake and efficacy and sidestepping the problem of self-selection into treatment” (2005, p347)

8.11 CONCLUSION

In ‘Towards the close of AIDS in Africa: The Future Scenario of voluntary counselling and HIV testing’, Miller, De Cock & Zoysa identify the major issues for consideration as:

- Need for national policies on HIV testing in the context of medical services
- Pre-marital testing
- Partner notification
- The concept of aiming for universal knowledge of serostatus

(Miller, De Cock & Zoysa, 2005)

These authors list critical certainties for addressing AIDS in Africa. These are not specific only to Africa however and there are some important messages that have cross-cultural and cross national significance. In rolling out HIV-testing and universal access to treatment in Trinidad and Tobago (objectives of the National Strategic Plan on HIV/AIDS) the evidence emerging from Africa provides an important foundation for country-specific research into HIV testing. The literature review points in particular, to the need to investigate the following:

Critical Certainties:

- i. Where people perceive testing to be associated with social 'punishment' and perhaps legislative, occupational and other forms of disadvantage, they will not come forward to learn their HIV status
- ii. Continued advances in testing technologies will make HIV testing ever easier to perform, inexpensive, and feasible in non-traditional settings, including the home

Areas requiring future research

This literature review highlights a need for further research into:

- Testing processes and experiences
- Understanding of reasons for seeking or not seeking HIV testing
- The experiences of counselling and testing under different approaches
- Understanding of test takers of the concept of informed consent and the concept's relevance in different cultural contexts
- The experiences of people who have been tested when they were really not ready for testing
- Health-seeking behaviours, including the behaviours of vulnerable populations (e.g. who comes to health facilities, who is not coming? what factors contribute to testing readiness)
- Stigma and discrimination including against persons who refuse testing
- The impact of the criminalization of HIV exposure on seeking testing
- The interpretation of policies
- Post-test experiences: dealing with the impact of a positive diagnosis, facing disclosure (who to tell, what & when), accessing and dealing with the effects of treatment

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