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HIV Testing and Counselling: Policies in Transition?

Research Paper prepared for the
**International Public Health Dialogue
on HIV Testing and Counselling**

Toronto, August 17, 2006

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TABLE OF CONTENTS

Acknowledgements	ii
Introduction	1
SECTION ONE	
Historical background and how we got to where we are now	3
Overview	3
Brief history of HIV testing and counselling policies	5
Quarantine and isolation	6
Mandatory reporting.....	7
Surveillance and case reporting	7
Contact tracing/partner notification.....	7
Confidentiality	8
Screening.....	8
Mandatory testing.....	8
Informed consent	8
Stigma and discrimination	9
Disclosure of serostatus	9
AIDS exceptionalism.....	10
Current policies and new approaches	10
Legislation on HIV testing.....	14
Social and structural barriers to testing and counselling	15
Historical development: a range of national responses.....	19
Sweden	19
Great Britain	19
United States.....	20
AIDS surveillance	20
Dialogue with at-risk communities	20
Voluntary HIV antibody testing, including anonymous testing	21
Partner notification	21
Opposition to VCT.....	21
HIV Prevention Community Planning Councils	22
Prevention for Positives	22
Canada	22
National response.....	22
Counselling and testing services	23
Anonymous testing and counselling	24
Perinatal testing and counselling	26
Rapid testing technologies	27
Cuba	27
SECTION TWO	
What is known about the number of people unaware of their HIV status ..	28
Overview	28

Global estimates.....	29
Using estimates for monitoring.....	30
Methods used to estimate the number of people unaware of their HIV status	30
Country estimates	30
Canada	30
Cuba	31
European Union (EU) countries	31
United States.....	31

SECTION THREE

Policies in practice: Addressing the issues in 2006.....	34
Overview	34
Special population approaches	35
Sexually active women	35
Young people	37
People Who Use Injection Drugs	38
Men who have sex with men	39
Minority men who have sex with men.....	40
People who are transgendered or transsexual	41
Aboriginal/First Nations/Indigenous communities	41
People of ethnic and racial minorities	42
People in rural communities	43
Migrants, refugees, and internally displaced persons.....	43
People living with mental illness	44
Lived experiences of people living with HIV	45
Receiving counselling and testing	45
Issues for people living with HIV.....	46
Rapid testing technologies	47
This paper now turns to a discussion of new technologies and approaches for increasing the proportion of people who receive testing and counselling, including rapid testing technologies, Nucleic acid amplification testing, and provider-initiated testing and counselling (PITC)	47
Description and use.....	48
Negative results.....	49
Confirmation of reactive results	49
Quality assurance	49
Counselling, confidentiality, and informed consent.....	49
Point-of-care versus home testing	49
Advantages.....	50
Increased uptake.....	50
Lower failure rate for returning for results	50
Use in low resource settings and community outreach programs	50
Client confidence in test results	50

Issues	51
Counselling, confidentiality, and informed consent.....	51
True informed consent under conditions of duress	51
Quality assurance	51
Staff capacity	51
New approaches to testing and counselling.....	52
Detection of acute infections using nucleic acid amplification testing.....	52
Using rapid testing in community outreach programs	52
Description and use	52
Benefits	52
Issues and concerns	53
Provider-Initiated Testing and Counselling (PITC)	53
Description and use	53
OPT-in versus opt-out PITC.....	54
Benefits of PITC	54
Issues and concerns about PITC	56
 SECTION FOUR	
Association of counselling and testing modalities with behavioural change and reduced HIV transmission	58
Overview	58
Effect of HIV counselling and testing on behavioural change	59
Research on counselling modalities used with testing	60
Partner notification	63
Factors affecting counselling and testing	64
Health provider attitudes	64
Health provider characteristics.....	65
Patient characteristics and acceptance of counselling and testing.....	66
Use of opinion leaders and social networks.....	66
Mass communication	67
Offering incentives for testing and counselling	68
Linking testing and counselling to care and treatment	68
 SECTION FIVE	
Gaps in knowledge	69
The test	69
The process	69
The context	70
Conclusions	71
References	72

HIV TESTING AND COUNSELLING: POLICIES IN TRANSITION?

INTRODUCTION

Two growing bodies of evidence contribute to the importance of reaching a greater portion of people who are HIV positive, but do not know their status. First, people with HIV can greatly benefit from treatment that is initiated before they develop physical symptoms of HIV disease. Second, people who know they are HIV seropositive are more likely to adopt safer sexual and/or injecting drug practices in order to protect their partners from becoming infected. When people know their serostatus and have access to care and information, they are better able to cope with the diagnosis; manage their illness; prevent transmission to others; and live satisfying and healthy lives (Ontario Ministry of Health, 1995).

In considering approaches to reaching people unaware of their HIV status, two populations need to be taken into account: people who do not know that they are infected because they generally do not access testing, and people who may have been tested, but tested negative because they are in the acute phase of infection, prior to seroconversion. Due to the high level of infectiousness during acute infection, approaches that increase the efficiency of identifying those in the acute phase could potentially have a significant impact on the epidemic. Increasing testing rates among people who generally do not access testing, however, is a much greater challenge, as will be described in this review.

There are several different approaches to HIV testing and counselling. Public health decisions regarding these approaches need to consider a range of factors. Universal screening has not been considered cost-effective in low-

prevalence parts of a population, given the resources required to administer all aspects of HIV testing and counselling. Moreover, even in large-scale testing, the low percentage of false-positives has usually been deemed too high. The alternative, targeting at-risk people for testing and counselling, has had varying results but always leaves some proportion of seropositive people unidentified. As testing and counselling become more affordable and available and the known advantages of increasing HIV testing and counselling begin to outweigh the disadvantages, old assumptions are being questioned and new approaches are being considered.

It will be crucial for these approaches to be grounded in sound public health practice that respects, protects, and fulfills human rights norms and standards. The voluntary nature of testing must remain at the heart of all HIV policies and programs to comply with human rights principles and to ensure sustained public health benefits.

The purpose of this background paper is to set the stage for a dialogue about the issues related to testing and counselling. Section One provides the historical background regarding HIV counselling and testing primarily in middle- and high-income countries. It discusses the ethical, social and legal contexts within which the predominant model, voluntary counselling and testing (VCT) often with partner notification, has developed.

Section Two briefly outlines what is known about the number of people unaware of their HIV status, providing some figures from countries that have calculated its possible magnitude.

Section Three describes how counselling and testing is currently being done. Special populations who are vulnerable to both HIV and HIV-related stigma and discrimination are discussed. New counselling and testing approaches including rapid testing and provider-initiated testing and counselling are also discussed. Section Four summarizes the body of knowledge that has developed regarding the effectiveness of counselling and testing including cost-effectiveness modeling. Section Five outlines some of the areas in which further research would help close the gaps in knowledge about how to reach people unaware of their HIV status.

As the focus of this paper is HIV testing and counselling as it relates to people unaware of their HIV status,

the paper will primarily be concerned with reaching individuals through their contact with health care systems and through other more community-based approaches. The issues regarding the testing and counselling of pregnant women in order to prevent perinatal transmission are presented because much of the research related to screening has been in the context of perinatal testing and counselling. The primary focus of this paper, however, is HIV testing and counselling as it relates to reaching people who do not have easily identifiable institutional affiliations.

SECTION ONE: HISTORICAL BACKGROUND AND HOW WE GOT TO WHERE WE ARE NOW

OVERVIEW

Over the past 25 years of addressing and coping with the epidemic, many lessons have been learned that can inform the challenge of reaching people unaware of their HIV status. Public health and human rights concerns, as well as the development of optimal strategies for resolving the apparent differences between the two, have dominated much of the ethical and legal policy dialogue over the course of the first two decades of the epidemic. Specific issues regarding testing and counselling have included whether to use traditional public health measures such as quarantine, mandatory reporting, contact tracing, and universal screening; how to monitor the epidemic; how to respond to unwarranted public and community fear of HIV; and how to protect the rights of those who are infected and assure their well-being and care. The development and incorporation of new technologies and treatments have also significantly affected the development of policies related to counselling and testing for HIV infection.

Against this backdrop, the standard approach to HIV testing that evolved during the first two decades of the epidemic includes counselling whenever individuals are tested, voluntary testing with explicit informed

consent, and strict protection of the confidentiality of test results. The UNAIDS/WHO Policy Statement (2004) describes the elements of what has become an internationally accepted approach to HIV testing. It also introduces new approaches to expand the identification of people infected with HIV, such as provider-initiated testing and counselling (PITC). The statement has been included on page 18 of this paper.

The history of counselling and testing in specific countries demonstrates how various aspects of the challenge have been addressed. Early in the epidemic in Sweden, for example, the expectation that individuals' responsibility to society include knowledge of their HIV status led to a policy of encouraging anyone who might be exposed to HIV to get tested. By contrast, in Great Britain, the belief that it is each person's individual responsibility to take the necessary precautions to avoid infection led to a policy of discouraging widespread testing. In the United States, the involvement of all the major stakeholders in the public health dialogue (public health officials, communities at risk of infection, health care providers, representatives of the blood bank industry, etc.) led to intense debate that accompanied the evolution of testing and counselling policies. In Canada, with a national advisory committee established early to guide regional policy-making, a range of provincial responses have been developed. Cuba's approach was one of containment.

BOX 1.1: HISTORICAL BENCHMARKS

- 1981: The first cases of opportunistic infections and cancers suggesting a new disease syndrome, are reported. Active case-finding and surveillance point to a blood-borne transmissible agent (spreading both sexually and through needle-sharing) causing immunodeficiency.
- 1982: Based on the epidemiological evidence that the pathogen is blood-borne recommendations are issued to prevent hospital and laboratory transmission.
- 1983: The first cases of perinatal transmission from mother to infant are reported.
- 1983: The etiologic agent is identified. After several attempts to name the virus, the scientific community finally agrees to call it the Human Immunodeficiency Virus (HIV).
- 1985: The ELISA test is developed and approved by the U.S. Federal Drug Administration (FDA) for use in screening blood. Blood is screened in the U.S., (March), Germany (April), Netherlands and Sweden (June), Italy (July), Belgium, Finland, France, Greece, and Norway (August), Denmark and Portugal (September), Britain (October), Switzerland (November), and Japan (Hamers, 1996).
- 1987: The first antiretroviral drug, Zidovudine, is developed.
- 1993: The female condom is available for use in the U.S.
- 1994: Pediatric AIDS Clinical Trials Group Protocol 076 demonstrates that a three-part regimen of Zidovudine monotherapy can reduce the risk for mother-to-child transmission by nearly 70%.
- 1996: Combination antiretroviral therapy becomes available, vastly improving the disease trajectory of HIV infection.
- 2002: The FDA approves the first rapid HIV test for point-of-care use.
- 2004: UNAIDS/WHO policy statement on VCT is published.

BRIEF HISTORY OF HIV TESTING AND COUNSELLING POLICIES

After its development as an antibody test, ELISA became widely used for surveillance, blood screening, medical diagnosis and as part of HIV prevention programs both in public health and community-based settings. Pre- and post-test counselling became a standard part of administering the test: pre-test counselling occurs when blood is drawn and post-test counselling is provided when clients return in two weeks for their test results.

Stigma related to getting the test or being seropositive, fear of exposure in the community, prioritizing other health and social needs above learning HIV status, and fear of learning one is HIV-positive have all been given as reasons for avoiding HIV testing.

In the late 1980s, the WHO's Global Program on AIDS developed recommended guidelines for counselling and testing, as well as curricula for training health care providers and others. The linkage of testing with both pre- and post-test counselling has remained an essential principle of HIV antibody testing. As the policies evolved, the term Voluntary Counselling and Testing (VCT) became widely used to make

clear that individuals should be able to choose whether to be tested, without pressure or coercion.

Within the context of a voluntary counselling and testing approach, countries took different approaches to HIV testing, some encouraging much more widespread testing than others (see the discussions of Sweden and Great Britain below). A key and significant finding of different approaches to testing and counselling is that countries with widespread promotion and uptake of HIV testing and counselling have longer periods of time between first diagnosis of HIV infection and the diagnosis of AIDS. In 1996 in Sweden, a country with widespread testing and counselling, the median time from HIV diagnosis to AIDS was 6 years, compared with Great Britain, a country which did not promote testing and counselling, where the median time was less than 3 years (Danziger, 1999).

Uptake of VCT differed widely in countries and among at-risk communities, even in countries with dynamic testing and counselling programs. Stigma related to getting the test or being seropositive, fear of exposure in the community, prioritizing other health and social needs above learning HIV status, and fear of learning one is HIV-positive have all been given as reasons for avoiding HIV testing. People who might benefit from testing and counselling may not seek testing in the first place and many other people do not return to learn their test results. While some at-risk individuals return often to be tested, others avoid testing entirely. Many people, especially women, did not know they were at risk as they were unaware of their partner's sexual involvement or drug use with other people.

Antiretroviral therapy dramatically improved the clinical outcomes of HIV infection, particularly when it became evident that intervening earlier in the disease trajectory was optimal. This strengthened one objective of HIV testing and counselling - to make care available to people who are seropositive. In recent years, the goal of having more people learn of their serostatus has encouraged more discussion with the growing evidence that people who know they are HIV-positive are more likely to take precautions to protect their partners than people who do not know their serostatus (Marks, 2005). The importance of this for HIV prevention is enhanced when the value of antiretroviral therapy in reducing a person's viral load is factored in.

As the AIDS epidemic unfolded, public health officials in various national and local health departments worked to develop appropriate policies to address the issues of disease control and prevention. In some democratic countries, major stakeholders engaged in dialogue, at times heated, regarding the policies being considered. Where gay communities were well organized and active, they played an important part in the discussions. The primary controversy was whether to utilize a traditional public health approach to AIDS requiring measures such as reporting and contact tracing as in other sexually transmitted infections and quarantine as in tuberculosis, or whether this approach would "drive the epidemic underground." Some countries opted for compulsory disease control measures and some for seeking voluntary cooperation by people with AIDS, and later by people infected with HIV. According

to an analysis by Baldwin (2005), the resulting variation in public health policy was more closely related to the strictness of each country's traditional disease control policies than to its relative social conservatism or liberalism.

When the ELISA test for HIV antibodies was first approved for blood and blood product screening, its implementation was also fraught with controversy regarding possible misuse of information (Bayer, 1989). There was disagreement about whether and if so, how to inform individuals whose donated blood was seropositive and whether the test was even cost-effective (this last question was posed by the blood-banking industry itself). This controversy continued as testing began to be used for determining the HIV status of people for purposes other than blood and blood product screening.

Some of the critical issues related to testing and counselling are highlighted below, with more discussion in later sections. While many issues address the potential for adverse effects of testing, some issues, if resolved appropriately, can result in positive outcomes.

QUARANTINE AND ISOLATION

The initial impulse of many, including the general public and health care institutions, was to isolate people with AIDS. As the routes of transmission were quickly identified, it became clear to public health officials early in the epidemic that protection from blood and certain other body fluids was necessary, but that isolation or quarantine of infected individuals was an overreaction based on fear of what is an entirely preventable disease.

MANDATORY REPORTING

Many countries required physicians to report information on all diagnosed cases of AIDS either by name or unique identifier for the purpose of monitoring the epidemic. Some countries used the information for contact tracing. A smaller proportion of countries, and states or provinces within countries, have required physicians and/or laboratories, or both, to report all positive HIV antibody tests to public health authorities. Some public health officials and consumer advocates expressed concern that mandatory reporting of test results by name would reduce the willingness of people in vulnerable populations to seek counselling and testing. There has also been concern that mandatory reporting by name could result in human rights violations in some countries and among some vulnerable populations.

SURVEILLANCE AND CASE REPORTING

The distinction between collecting information for the purpose of surveillance (monitoring the course of the epidemic) and for the purpose of partner notification (contacting individuals who might have become infected) was often muddled in policy discussions related to reporting. Some in democratic countries argued that without effective treatment (such as there is with tuberculosis), no disease control objective could be achieved by mandatory reporting of people by name with a disease transmitted by voluntary behaviours and that surveillance should be conducted without personal identifiers. In fact, many epidemiologists argued that the best scientific surveillance involves systematic random unlinked testing

within a population (Nicoll, 2000) rather than monitoring based on HIV test results from individuals voluntarily seeking testing and counselling, especially if unduplicated repeat testers could not be accounted for.

Despite its epidemiological weaknesses, however, monitoring of reported HIV tests has been very useful. In monitoring results of voluntary testing, the uptake rate directly affects the aggregated data. The higher the intensity of HIV testing among at-risk groups, the more cases will be diagnosed and potentially reported. The question of unique identifiers arises even when reporting is not mandatory. In Europe, HIV results are mostly reported with unique identifiers, not with names. Moreover, in some countries, reporting is routine and the completeness is high, even though it is not mandatory. In general, in high income countries, computerized systems and case identifiers now enable people who test more frequently to be only counted once (Hamers, 2003).

CONTACT TRACING/ PARTNER NOTIFICATION

For advocates in communities at risk, the distinction between public health systems with 1) mandatory contact tracing by public health officers obliged or allowed to detain individuals and 2) voluntary partner notification that could be conducted by the individual, their physician, or a public health officer, was not a subtle one. In both cases, the value of identifying and testing sex or drug-injecting partners of seropositive individuals for prevention counselling has been augmented by the importance of identifying all people who are HIV

positive so that they can benefit from health and social supports that include antiretroviral treatment.

CONFIDENTIALITY

Reporting and contact tracing, by definition, compromise the confidentiality of the patient's medical diagnosis. Moreover, because HIV is transmitted through behaviours that are stigmatized in many societies and illegal in some, confidentiality of medical information has been considered paramount by health providers and consumer groups alike. Nevertheless, this issue has required continuous reinforcement in agency and institutional policies as well as education of health care workers and communities because confidentiality is often breached both within institutions and in communities (Surlis, 2001; Klosinski, 2000). Furthermore, even when confidentiality is assured, the perception that information may not be confidential can deter people from seeking testing and counselling.

SCREENING

On a larger scale, the only way to identify everyone infected with HIV is to screen the entire population. Reasons for not doing so include the high cost and the possibility of false-positive and false-negative results when screening for a disease of low prevalence in the general population. In addition, concerns exist regarding informed consent and confidentiality related to a disease whose diagnosis may be associated with discrimination, legal sanctions, and psycho/social distress. Finally, questions remain about how frequently one would have to screen the population to effectively identify

people as they become infected. Conversely, reasons for conducting universal screening include the value of early detection for monitoring, treatment, and prevention.

MANDATORY TESTING

Mandatory HIV testing in some situations is required in most countries. For example, HIV screening for blood, blood products and before organ donation is recommended by UNAIDS/WHO and is commonly required in national HIV policies, often legislatively. Many countries apply universal screening to people in certain institutions such as the military or prisons, or those undergoing certain evaluations, such as immigration or applications for insurance. Because of the risk of discrimination against people who are seropositive, some countries have prohibited mandatory testing legislatively. This continues to be an important human rights issue related to HIV. UNAIDS does not support mandatory testing on public health grounds, and recommends to countries that all HIV testing be confidential, subject to the provision of informed consent, include pre- and post-test counselling for both HIV-positive and HIV-negative individuals, and that those testing positive be referred to medical and psychosocial services (UNAIDS, 2004).

INFORMED CONSENT

The informed consent of the person being tested has generally been considered essential in HIV testing to ensure that the person: (1) understands what the test means; (2) is prepared for potential positive results; and (3) provides permission to be tested (UNAIDS/WHO, 2004). Along with informed consent, pre- and post-test

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counselling has typically been built into HIV testing practices. Some agencies or jurisdictions have developed special procedures such as the signing of a written consent form so that surreptitious testing of persons does not occur. One of the current policy issues being debated is how involved the consent process should be. Some have actually advocated that consent for HIV testing become implicit in consenting for care rather than requiring additional provision of information or discussion (DeCock, 2002). Others continue to argue that informed consent must involve both explaining the meaning of the test and eliciting specific consent in order to prepare the patient for the emotional, social, and medical consequences of a potential positive test result. The prevention value of counselling and testing becomes lost if people do not receive counselling that gives them the tools for changing their risky behaviours (Csete, 2006). This position on informed consent for testing is based in human rights law,

which asserts that the security of the person includes the right to have control over what happens to one's body and the right to receive information (UNGA, 1966).

STIGMA AND DISCRIMINATION

All the preceding issues point to the central theme of potential adverse repercussions associated with having a positive HIV antibody test. These include negative attitudes and reactions (stigma), and actions that impinge on an individual's legal rights (discrimination) by significant others and family, informal social networks, social institutions such as health care services or places of employment, and the state. Repercussions have ranged from social or physical isolation, physical or emotional violence, and incarceration or deportation. (see Special Population Approaches and Lived Experiences of People Living with HIV in Section Three for more detail). Many argue that because the stigma of HIV continues to result in discrimination, particularly against people marginalized within society, protections continue to be necessary, especially those integrated into counselling and testing programs as such protections seek to promote the benefits as well as reduce the actual and perceived risks of seeking testing (Csete, 2006; Heywood, 2004).

DISCLOSURE OF SEROSTATUS

How strongly to encourage people to disclose their serostatus to the different people in their lives has been an issue among health care providers. The obvious benefit of disclosing HIV status to sexual and injecting drug-using partners is to enable them to protect themselves from exposure or to encourage them to get tested. Fear

of rejection or judgment can prevent many people with HIV from disclosing to partners as well as to other family members or members of their support networks (Sandelowski, 2004; Medley, 2004; Zea, 2005). This deprives them of the benefits experienced by many who are open about their status, including emotional and social support, a greater ability to plan for the future, as well as a reduction in the social isolation and shame they may feel when coping with the diagnosis in isolation.

AIDS EXCEPTIONALISM

The term “AIDS exceptionalism” has been used to describe the policies by which AIDS is treated differently than other diseases (Bayer, 1991). Exceptionalist policies have their roots in the concern for the protection of people from stigma and discrimination in a time when public fear of AIDS was high and there was no HIV antibody test or effective treatment for AIDS. The term can also be used to describe phenomena such as special funding streams, separate clinical care, fast-track approval of new drugs, and the involvement of civil society in the development and implementation of new policies and programs. In many ways, addressing AIDS “exceptionally” has broken new ground for how other diseases are dealt with, through the intense response of the public health community as well as within communities most affected by HIV. The exceptionalist approach to HIV policy has become less dominant as the importance of engaging people with HIV in care and prevention has increased (National Research Council, 1993). Some are advocating changing many of the current standard policies in the effort to increase uptake of

testing (De Cock, 1998). Others argue that specific protections should remain in place to ensure that testing and counselling continue to be voluntary with informed consent and the explicit right to decline, without risking denial of services (de Bruyn, 2005; Wolf, 2004).

CURRENT POLICIES AND NEW APPROACHES

Most middle- and high-income countries have standard policies supporting voluntary counselling and testing, sometimes targeted to people at higher risk of HIV infection, as well as the offering of HIV testing and counselling to people in medical settings who may be at risk. Nonetheless, given the growing importance of identifying a higher proportion of those who do not know their HIV status, the standard approaches are being revised. UNAIDS/WHO issued a policy statement in 2004 (see Box 1.2) reasserting the importance of maintaining three key elements for all voluntary counselling and testing (VCT): confidentiality, counselling, and informed consent. This policy statement also advocates for scaled-up services, changes in how provider-initiated testing and counselling is delivered, and the use of new technologies.

One recommendation of this WHO/UNAIDS policy is that pre-test counselling be provided in group settings with individual follow-up in order to streamline the counselling process. Another recommendation, designed to speed up the process of providing test results, is to use rapid test technologies (see Section Three for a description of these technologies).

A third recommendation, relating to provider-initiated testing and counselling (PITC) in health care settings, is to offer the HIV test to all patients in certain clinical settings (see Box 1.2) along with pre-test counselling that is less involved than the standard counselling session recommended in VCT. According to WHO, the pre-test counselling or information session should provide all the required amount of information to ensure informed consent such as the benefits of testing, the right to refuse, the availability of follow-up services, and the need to inform anyone at ongoing risk of infection if the test is positive. The provider must still be able to refer the patient for post-test counselling and ongoing needed services, including HIV treatment.

A fourth recommendation of the WHO/UNAIDS policy is to have patients opt-out of PITC rather than opt-in. With the opt-in approach, which has been the standard of care, health care providers offer all patients the opportunity to receive testing and counselling and only provide it if the patient says yes. With the opt-out approach, also known as PITC with the right to decline, HIV testing and counselling are included in the battery of medical procedures and all patients

are informed that testing and counselling will be performed unless they refuse to be tested. The opt-out approach is more controversial. Some argue that when the opt-out approach is used in medical settings, true informed consent for HIV testing and the voluntary nature of testing are eroded.

Throughout the epidemic, advocates and public health experts have articulated the importance of obtaining people's cooperation in changing the voluntary behaviours that transmit HIV, resulting in the policies described above as "AIDS exceptionalism." As more and more countries review their approaches to HIV/AIDS testing and counselling, it will be important to do so in such a way that protects and promotes the human rights of individuals so that those at greatest risk of being HIV-positive feel safe learning their status. Programs targeting people who do not know their HIV status need to continue to focus on maintaining confidentiality, informed consent, counselling, as well as ensuring access to the health services required by people living with HIV. Only in this way will it be possible to scale up efforts and reach people unaware of their HIV status.

The Context

As access to antiretroviral treatment is scaled up in low and middle income countries, there is a critical opportunity to simultaneously expand access to HIV prevention, which continues to be the mainstay of the response to the HIV epidemic. Without effective HIV prevention, there will be an ever increasing number of people who will require HIV treatment. Among the interventions which play a pivotal role both in treatment and in prevention, HIV testing and counselling stand out as paramount.

The current reach of HIV testing services remains poor: in low and middle income countries only 10 per cent of those who need voluntary counselling and testing have access to it. Even in settings in which voluntary counselling and testing is routinely offered, such as programs for prevention of mother-to-child transmission, the number of people who avail themselves of these services remains low in many countries. The reality is that stigma and discrimination continue to stop people from seeking out HIV testing.

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. Young people require special attention to their needs through the provision of confidential and youth friendly health services. Public health strategies and human rights promotion are mutually reinforcing.

The conditions of the '3 Cs,' advocated since the HIV test became available in 1985, continue to underpin principles the conduct of testing for HIV. Such testing must be:

- *Confidential*
- Be accompanied by *counselling*
- Conducted only with *informed consent*, meaning that such consent be informed and voluntary

In many low and middle income countries, the primary model for HIV testing has been the provision of *client-initiated* voluntary counselling and testing services. Increasingly, *provider-initiated* approaches in clinical settings are being promoted, i.e. health care providers routinely initiating an offer of HIV testing in a context in which the provision of, or referral to, effective prevention and treatment services is assured. To reach people in need of treatment, tens of millions of tests will have to be conducted among those who may have been exposed to HIV.

UNAIDS/WHO recommend that the following four types of HIV testing be clearly distinguished:

1) Voluntary counselling and testing

Client-initiated HIV testing to learn one's HIV status provided through voluntary counselling and testing remains critical to the effectiveness of HIV prevention. UNAIDS/WHO advocate for the effective promotion of knowledge of HIV status among any population that may have been exposed to HIV through any mode of transmission. 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

Diagnostic testing occurs whenever a person shows signs or symptoms that are consistent with HIV-related disease or AIDS in order to assist clinical diagnosis and management. This includes HIV testing for all tuberculosis patients as part of their routine management.

3) Routine offering of testing by health care providers (Provider-initiated testing and counselling)

Routine offering of testing by health care providers should be made available to all patients being:

- assessed in a *sexually transmitted infection* clinic or elsewhere for a sexually transmitted infection in order to facilitate tailored counselling based on knowledge of HIV status
- seen in the context of pregnancy in order to facilitate an offer of *antiretroviral prevention of mother-to-child transmission*; and
- seen 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) but who are asymptomatic

Explicit mechanisms are necessary in provider-initiated HIV testing to promote referral to post-test counselling services emphasizing prevention for all those being tested and 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 simply 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
- 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

UNAIDS/WHO support mandatory screening for HIV and other blood borne viruses of all blood that is destined for transfusion or for the 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 do not support mandatory testing of individuals on public health grounds. Voluntary testing is more likely to result in behaviour change to avoid transmitting HIV to other individuals. Recognizing that many countries require HIV testing for immigration purposes on a mandatory basis and that some countries conduct mandatory testing for pre-recruitment and periodic medical assessment of military personnel for the purposes of establishing fitness, UNAIDS/WHO recommend that such testing be conducted only when accompanied by counselling both for HIV-positive and HIV-negative individuals and referral to medical and psychosocial services for those who receive a positive test result.

Available at: http://data.unaids.org/una-docs/hivtestingpolicy_en.pdf

LEGISLATION ON HIV TESTING

Early in the epidemic, several European countries passed legislation to safeguard blood supplies and to require compulsory reporting of AIDS to public health authorities (Mann, 1992). Since then, legislation has been passed around the world for a wide range of purposes. Laws in some countries are designed to protect people with AIDS and HIV from discrimination and harm, but the purpose of laws in other countries is to protect people who are uninfected from HIV infection.

A 1997 UNAIDS/WHO update of legal instruments provides a picture of various national laws dealing with HIV infection and AIDS. Of 191 member states, information was available from 121 countries, representing 85% of the world's population (D'Amelio, 2001). According to this update, 17% of the world's nations have legislation protecting people with HIV from discrimination and those nations only represent 5% of the people living with AIDS worldwide. On the other hand,

11 countries (representing 25% of the world's population) require that people with HIV be quarantined, isolated, or coercively hospitalized. Sixty percent of the 121 responding countries reported having laws or regulations requiring that all AIDS diagnoses be reported to authorities, and 31 countries required reporting of HIV infections (all but one also required AIDS reporting). Of 72 countries requiring reporting of HIV or AIDS cases, 24 explicitly required confidentiality regarding reporting, generally by means of coded or anonymous reports. Forty-two percent reported legislation requiring that donated blood be screened for HIV.

Twenty-seven percent of the 121 countries had legislation focused on vulnerable people, including commercial sex workers, men who have sex with men, people who inject drugs, immigrants, prisoners, health care personnel, and people who have received blood or blood products (D'Amelio, 2001). Most of the laws listed were concerned with mandatory screening, prohibition of certain risk activities (such as donating blood), or requiring people to participate in HIV

prevention programs (e.g., needle-exchange programs for people who inject drugs).

The social and structural barriers that contribute to HIV risk also increase people's vulnerability should they seek counselling and testing and be found to be HIV-positive.

A final finding of the report was that 9 out of the 121 countries required all pregnant women to be either tested or offered HIV testing. Three countries required premarital HIV testing, and two required HIV screening of all hospital patients. It is important to note that this study was conducted on information submitted in 1997, which has most likely changed since then. In addition, it only reflects the situation of countries that have reported to the Directory of Legal Instruments Dealing with HIV Infection and AIDS (D'Amelio, 2001).

As of 2000, 30 states in the U.S. had laws criminalizing at least some behaviour that could transmit HIV (Burris, 2000). Some laws are so broad as to make anyone who engages in unsafe sexual or needle-sharing behaviour without informing the partner liable for prosecution. One consequence of such laws is to lessen confidence that public health and medical records will remain confidential, having a chilling effect on the willingness of marginalized people to be tested. Health department records have actually been sought, and at least in one case obtained, to prove a person's positive HIV status in court.

SOCIAL AND STRUCTURAL BARRIERS TO TESTING AND COUNSELLING

The social and structural barriers that contribute to HIV risk also increase people's vulnerability should they seek counselling and testing and be found to be HIV-positive. These barriers include poverty, racism, and gender inequality; the sexual "Code of Silence;" the stigma of HIV/AIDS; misperceptions regarding risk factors; and lack of leadership (IOM, 2001). Each barrier becomes part of the context in which HIV testing and counselling efforts succeed or fail. Thus each also becomes an opportunity to enhance prevention programming if contextual and structural issues are addressed. Specifically, increasing the willingness of individuals to be tested requires addressing these barriers so that HIV testing becomes desirable rather than risky. In particular, policymakers must assert the importance of human rights as the basis for HIV policies (see Box 1.3).

Poverty creates conditions that contribute to an individual's fear of testing for HIV. For example, women raising children may be afraid their children will be taken from them or that they will lose their housing or source of income. People who leave their families to seek work may no longer be able to cross borders into countries where jobs are available (Haour-Knipe, 1996). People with mental health issues or addictions that make them unable to work full time may find themselves living in poverty and may also become too socially marginalized to take advantage of HIV counselling and testing.

Each barrier becomes part of the context in which HIV testing and counselling efforts succeed or fail.

HIV-related stigma is a result of various factors including homophobia, prejudice against people who use injection drugs, rigid ideas about sexuality, racism, and fear of contagion.

The implications of the social inequities of racism and gender inequality for counselling and testing is that both the perceived and actual negative social repercussions can deter people from obtaining HIV tests and seeking needed services. Although race often refers to a social concept, not a biological or scientific one, the health and epidemiological disparities by race that are associated with HIV/AIDS in Europe and North America make it especially important to address the issues of race as they pertain to HIV testing and counselling (FCHR, 2006). The same factors that make people of ethnic and racial minorities more vulnerable to HIV transmission, such as limited economic and educational opportunities and often generations of social marginalization that contribute to poverty, also prevent them from seeking HIV testing and counselling thereby exposing them to additional stigma and discrimination if found to be HIV-positive.

Gender inequality has also had a consistently profound effect on the course of the HIV epidemic in countries around the world. Women's low social and legal status has contributed to vulnerability to poverty and to HIV. Women are often afraid to be tested because of the implications of being HIV positive, such as the impact on reproductive choice (being

coerced into having an abortion or being sterilized), confidentiality (having the test results divulged within the family or community), and stigma and discrimination (being shunned or forced to relocate by family, losing custody of children) (Chase, 2001). Nonetheless, women may not have a choice about being tested. In India, consent is often obtained from the husband or mother-in-law rather than from the woman herself. If a pregnant woman has an HIV positive test, the husband is called and the results shared with him. In Ukraine, the physician usually expects to make the decision to test without consulting the patient.

A "sexual code of silence" seems to exist in societies around the world, leading to a community's denial of the possibility of sexual transmission in its midst and to reject HIV prevention and education programs, including counselling and testing programs (IOM, 2001). In this atmosphere, health care providers are not provided the training needed to assess sexual histories and they lack the comfort to frankly discuss risk behaviour, causing them to miss opportunities to offer HIV testing to many people who could have benefited from knowing their HIV status.

HIV-related stigma is a result of various factors including homophobia, prejudice against people who use injection drugs, rigid ideas about sexuality, racism, and fear of contagion. The social risk associated with HIV has been described as having two components: 1) the threat, that is, the attitudes and behaviour that threaten social harm to a person with a disease; and 2) the perception of risk, that is, the attitudes and beliefs about the threat among those who are associated with the disease (Burriss, 2000).

Whether the threat is physical or emotional, stigma has been shown to drive those perceived as vulnerable underground. In a survey of men who have sex with men, 68% of those who were HIV positive but unaware of their status had neglected to get tested in the preceding year because they were afraid of learning their status versus 34% of those who were HIV negative. People vulnerable to HIV including men who have sex with men, commercial sex workers, homeless youth and migrant workers may also choose not to get tested as they may face discrimination or physical harm or even deportation if determined to be HIV positive. In the same survey of men who have sex with men, 35% of the unaware HIV-positive respondents chose not to get tested in the past year because they were worried others would find out the result compared to 14% of the HIV-negative respondents (CDC, 24 Jul 2005).

Discrimination against people with HIV includes denial of housing and health care, loss of employment, and physical violence. Laws have been passed against HIV-related discrimination but they cannot protect against the many social risks of HIV, such as being shunned by a faith community or abandoned by a spouse. A metasynthesis of qualitative studies on stigma in HIV-positive women found that both perceived and enacted stigmas were pervasive in the women's lives, and that HIV-related stigma was compounded by the fact that they were women (Sandelowski, 2004). Women's protective measures were largely attempts to control information in order to preserve their social relations and maintain their moral identities.

Misperceptions regarding risk factors may also cause people to fail to recognize whether they are actually at

risk for HIV (IOM, 2001).

Misperceptions are often generated within communities that deny the reality of HIV in their midst, contributing to ongoing stigma as well as continued risky behaviours. Individuals may believe they are at risk from casual contact, increasing their fear of people living with HIV. Those who do not consider themselves in a "high risk group" often assume themselves to be at low risk and therefore engage in riskier behaviours (Dolcini, 1996). They also may not seek counselling and testing, leaving them without proper care and leading to continued exposure of their partners.

Lack of leadership, or political will, is often identified as a problem that constrains HIV prevention efforts. The endorsement and promotion of HIV testing and counselling by respected community leaders (politicians, educators, spiritual leaders) can have a dramatic effect on a community's willingness to seek or agree to testing. For example, the mayor of Washington, DC, which may have a 4% prevalence of HIV infection, launched a citywide campaign in June 2006 with the goal of having 400,000 men and women between the ages of 14 to 84 years get tested for HIV (KFF, 2006). Drawing on civic leadership, he appointed hospital presidents, business leaders, physicians, AIDS activists and community leaders to the Mayor's Task force on HIV/AIDS, who at the opening event announced that they all had been tested.

War and civil disorder can cause social disruption and can lead to significant power imbalance between individuals. Under these conditions, typical protections related to counselling and testing, such as confidentiality, laws against discrimination, and laws against mandatory testing, frequently disappear.

BOX 1.3: ENSURING A RIGHTS-BASED APPROACH

The global scaling up of the response to AIDS, particularly in relation to HIV testing as a prerequisite to expanded access to treatment, must be grounded in sound public health practice and also respect, protection, and fulfilment of human rights norms and standards.

The voluntariness of testing must remain at the heart of all HIV policies and programs, both to comply with human rights principles and to ensure sustained public health benefits. The following key factors, which are mutually reinforcing, should be addressed simultaneously:

1. Ensuring an *ethical process for conducting the testing*, including defining the purpose of the test and benefits to individuals being tested; and assurances of linkages between the site where the test is conducted and relevant treatment, care and other services, in an environment that guarantees confidentiality of all medical information;
2. Addressing the *implications of a positive test result*, including non-discrimination and access to sustainable treatment and care for people who test positive;
3. Reducing *HIV/AIDS-related stigma and discrimination* at all levels, notably within health care settings;
4. Ensuring a supportive *legal and policy framework* within which the response is scaled up, including safeguarding the human rights of people seeking services;
5. Ensuring that the *health care infrastructure* is adequate to address the above issues and that there are sufficient trained staff in the face of increased demand for testing, treatment, and related services.

UNAIDS Global Reference Group on HIV/AIDS and Human Rights

Available at: http://data.unaids.org/una-docs/hivtestingpolicy_en.pdf

BOX 1.4: REFRAMING THE DISCUSSION FROM BARRIERS TO CONDITIONS

A policy to increase testing and counselling among people who do not know their serostatus, regardless of its specific components, will succeed only if it creates a climate in which people with and at risk of HIV have:

- 1) the opportunity to obtain testing and other services;
- 2) the information necessary to assess and fulfill their needs;
- 3) the motivation to use the information and take up the opportunity; and
- 4) the confidence to run the real and perceived risks entailed in doing so.

Source: Adapted from Burris, 2000

HISTORICAL DEVELOPMENT: A RANGE OF NATIONAL RESPONSES

SWEDEN

Sweden was the first country to enact national legislation related specifically to AIDS, passing a law in 1983 requiring that suspected and confirmed cases of AIDS be reported (Mann, 1992). The legislation placed AIDS under the jurisdiction of Sweden's laws regarding venereal and other transmissible diseases passed in 1919 and 1968. Under these laws, individuals with STIs were required to undergo medical examination and treatment. If they did not follow the physician's orders they could be detained and isolated as well as forced to receive treatment. Physicians were required to conduct contact tracing, and contacts were required to undergo medical examination and treatment. Infected people could be punished for having sex with others (Baldwin, 2005).

In 1988, a more explicit law was passed requiring those who think they might be HIV-infected to seek testing. If seropositive, they must have regular medical checks and if they admit to engaging in unsafe behaviour, the treating physician is required to report them to the authorities who have the power to place people in isolation. With this law, seropositive people must inform their sexual partners and must use condoms for penetrative sex (Danziger, 1999).

As soon as the HIV antibody test became available, mass media was used to encourage people to get tested. By 1991, 5.5 million tests had been performed in a country with 8.6 million people. In Swedish culture a high value is placed on the well-being of society, with less emphasis on the

freedom of the individual. Thus individuals are expected to assume a high level of social responsibility; Danziger (1999) attributes the widespread acceptance of testing and restrictive laws to this social value.

GREAT BRITAIN

When the HIV antibody test became available in Great Britain, it was primarily employed as a diagnostic tool rather than a prevention strategy. It was advertised or promoted only in clinical settings such as genitourinary medicine or antenatal clinics, and used for the purpose of determining HIV status rather than for HIV prevention. Danziger describes the British concept of HIV prevention as being "the shared responsibility of both HIV-positive and HIV-negative people. According to this view, effective prevention requires safe behaviours among people who are infected and among those who are or may be at risk of infection. . . . Thus, it follows that effective prevention does not require widespread testing to identify who is and who is not infected" (Danziger, 1999, p. 294). In fact, it was argued that widespread testing would divert scarce resources from prevention strategies believed to be more effective. Another reason for not promoting testing included the continued problem of discrimination against people with HIV in areas such as housing and health insurance. Following discussions on HIV testing in Britain, both the Department of Health and the Terrence Higgins Trust recommended that individuals be fully informed of both the potential harms and benefits of testing in order to make their own decisions (Danziger, 1999).

In Great Britain, voluntary confidential testing is available in clinical settings but has not been widely utilized. A recent large,

stratified probability sample survey in Great Britain found that 32.4% of men and 31.7% of women had been tested for HIV, and over half were tested when giving blood. Excluding blood and perinatal screening, 9% of men and 4.6% of women had obtained voluntary confidential testing within five years, one-fourth in general practice settings. One third of people using injection drugs and men who have sex with men have been tested in the past five years (McGarrigle, 2005). In Northern Ireland and Scotland, the number of new diagnoses of HIV infection was higher in 2004 than ever before, and in Scotland this was due largely to increased testing among antenatal and genitourinary medicine clinic attendees (HPA, 2005). For men who have sex with men, voluntary counselling and testing in genitourinary medicine clinics increased to 79% in 2004 (HPA, 2005).

The promotion of VCT to people attending a genitourinary medicine clinic can be assessed by monitoring the proportion of individuals whose HIV infection could have been diagnosed during their attendance but who left the clinic remaining unaware of their HIV infection (HPA, 2005). Among men who have sex with men, this proportion fell from 63% in 2000 to 44% in 2004, and among heterosexuals, from 52% to 35%. Of those who did not receive VCT, at least 44% of men who have sex with men and 52% of heterosexuals are known to have been offered but declined an HIV test. Of those who refused testing, 5.8% of men who have sex with men and 0.7% of heterosexuals were HIV-infected (HPA, 2005).

UNITED STATES

AIDS surveillance

When the first cases of opportunistic infections, cancers, and other conditions were reported in 1981, the Centers for Disease Control (CDC) began working with local health departments to conduct informal surveillance of this strange new disease syndrome. Initial reporting began with an epidemiologic case definition and active surveillance and investigation of cases. AIDS officially became a reportable disease relatively easily under the state and local health department requirements governing the reporting of communicable diseases. State-level reporting of AIDS cases was name-based but confidential. All case reports were sent to the CDC, with unique identifiers rather than names and this national system of surveillance was used to monitor the epidemic.

Dialogue with at-risk communities

From the beginning an active dialogue emerged between public health officials, health care providers, and leaders of the most visible affected community — the gay community — regarding the civil rights of the infected and the protection of others from becoming infected (Bayer, 1989). In anticipation of the development of an antibody test, concerns were aired that potential lists of HIV-positive people would be circulated to exclude people from employment or insurance coverage. Thus when the test was finally licensed, many of the policy issues and controversies had already been discussed in intense debates, both in the public health and the gay communities.

Voluntary HIV antibody testing, including anonymous testing

In 1985, when the test to detect HIV antibodies was developed and licensed, the U.S. Public Health Service recommended that it be used only to screen blood and plasma collected for transfusion. Concern that individuals might donate blood in order to learn their serostatus, however, led the agency to also fund alternate test sites. By the end of 1985, 874 alternative test sites had been established nationwide by 55 state and local health departments through \$10 million in federal funds managed by the CDC. In that first year, 79,083 people were tested free of charge and 17% were antibody-positive (Valdiserri, 1997). Anonymous testing was also made available at some testing sites in order to ensure that fear of stigma and discrimination would not stop people from coming forward to be tested.

Partner notification

As a condition of funding, the CDC requires that state and local public health jurisdictions establish standards and procedures regarding partner notification and that they make good-faith efforts to notify spouses of persons known to be HIV positive (West, 1997). Both patient and provider referral mechanisms are commonly used, with health departments offering some additional level of services to assist clients in notification of their partners. Some programs focus their efforts on specific groups of people (e.g., women, at-risk communities).

Opposition to VCT

Resistance to widespread voluntary testing and counselling continued following the initial testing

experience. The Association of State and Territorial Health Officers initially stated that beyond blood screening and research, the HIV test was of little use because of the risk of false positive results and the unknown prognostic significance. The Health Departments in Philadelphia, Chicago, and New York challenged the public health grounds for funding alternative test sites, where people could be tested either confidentially or anonymously. The New York City health commissioner refused to establish alternative test sites in the city, which was an epicentre of the U.S. epidemic. The largest gay organizations initially discouraged gay men from getting tested (Bayer, 1989). Opposing conservative forces advocated the use of traditional disease control measures such as the screening of high-risk group members, names reporting, contact tracing, and legal restrictions on the sexual activities of seropositive individuals.

Colorado became the first state to require reporting of positive HIV test results by name. The controversy over whether collecting HIV test results was useful for surveillance purposes became muted as more states established reporting systems, some by name, some by unique identifiers.

A similar level of controversy erupted in relation to the testing of pregnant women. Until the success of Zidovudine in preventing perinatal transmission, many opposed the routine or mandatory testing of pregnant women. Fears of coerced abortions spurred reproductive rights advocates to oppose antenatal HIV testing. However, with the realization that many women did not know they were at high risk of HIV infection, the policy shift to routine testing became commonplace among states.

HIV Prevention Community Planning Councils

Throughout the 1980s, the CDC decided how federal prevention funding would be allocated to the individual states. In the early 1990s, however, an external evaluation determined that more local flexibility was needed in order to specifically target local communities at risk (Valdiserri, 1997). The CDC initiated a new system of planning and priority setting based on the collaboration of community representatives, public health officials, and AIDS service organizations. HIV Prevention Community Planning Councils were established to decide how monies would be allocated for HIV prevention. In some cases, this led to decreased funding for counselling and testing as money was allocated to other interventions such as street outreach. In other cases, at-risk communities felt that too much funding continued to be allocated to health departments for counselling and testing rather than being provided to community-based organizations.

Prevention for Positives

In the third decade of the epidemic, prevention experts began a major initiative to increase the number of people aware of their HIV-positive status and to assist them in reducing HIV transmission to others by adopting and sustaining HIV risk reduction behaviours (IOM, 2001; Jansen, 2001). The CDC launched a new strategy called the Serostatus Approach to Fighting the HIV Epidemic (SAFE). While behavioural interventions for people living with HIV were being tested, a campaign was also launched to motivate and train health providers to address prevention with their HIV seropositive patients.

CANADA

National response

Although public health is primarily within the purview of each province and territory in Canada, a national committee (the Federal/Provincial/Territorial Advisory Committee on AIDS – FTP AIDS) was established to produce in-depth policy and program analyses on emerging HIV issues through the sharing of information and accessing of necessary expertise. The results of these analyses have informed provincial, territorial and federal jurisdictions in policy and program development. Furthermore, numerous AIDS service organizations and province-wide AIDS networks sprang up at the community level to address the crisis and to dialogue with public health agencies.

The Canadian Guidelines on Sexually Transmitted Infections from which provinces and territories adapt their policies include the following recommendations (Health Canada, 1998):

- Testing
 - Any physician can order an HIV test.
 - Testing should only be carried out with the consent of the person being tested.
 - HIV-antibody testing should be offered to any person with risk behaviour or at risk, any person with clinical or laboratory clues suggestive of HIV infection, or any person who requests it. Explain clearly the nature of the test AND provide appropriate pre- and post-test counselling.
 - In all provinces and territories, a physician does not have to supply the name of the person being tested but in some jurisdictions, the

physician is required to report the name of the individual to public health officials (nominal reporting) if the test results are positive.

- Non-nominal and/or anonymous testing (patient does not reveal identity; result is only given to the person tested) is available in many jurisdictions.
- AIDS is reportable by name.
- Partner notification must be undertaken in all cases of AIDS and HIV infection. Local public health authorities are available to assist with partner notification and help with referral. The treating physician is responsible for ensuring that partner notification is initiated.
- All children born to mothers who are, or may be, HIV-infected must be evaluated.
- At time of diagnosis, review and monitor prevention practices, and identify barriers to prevention practices and the means to overcome these.
- Extensive pre- and post-test counselling guidelines describe the optimal information and process to be followed.

From the beginning, Canada has generally leaned toward creating an environment of easily-available voluntary counselling and testing rather than mandatory testing, and a social justice and human rights perspective has usually prevailed in policy discussions. Similar to other federally organized countries (e.g., the U.S. and Germany), however, the provinces and territories have a range of policies on the various issues posed by HIV. Alberta, British Columbia, and Ontario provide contrasting examples of the provincial policy responses to key HIV issues as discussed below.

COUNSELLING AND TESTING SERVICES

In British Columbia, the vast majority of positive HIV test results are from hospital or community medical settings with the second source being public health clinics. The BC Division of Sexually Transmitted Disease/AIDS Control operates an ambulatory clinic, a Prevention Street Program in the downtown eastside of Vancouver, and an Aboriginal Program, Chee Mamuk, which provides education to Aboriginal communities and organizations in British Columbia. HIV tests are conducted on request at sexually transmitted infection clinics. In medical settings, a physician usually conducts pre- and post-test counselling, whereas in public health clinics a public health nurse often provides the service. Partner notification options are provided to patients during post-test counselling, including to notify their partners themselves, to be assisted by the providers, or to request assistance by the health department which is provided by a public health nurse.

The majority of HIV counselling and testing in Ontario is conducted confidentially within physicians' offices. Providers have the option of ordering the HIV test non-nominally if the patient requests, that is, using a unique identifier rather than the patient's name. As in British Columbia, patients are given a choice of ways of notifying their partners by providers. If the test is ordered with the patient's name, the health department follows up positive test results, first with the physician and then with the person who is seropositive.

In Ontario, the sexually transmitted infection clinics and local public health units are an important part of

the HIV testing program, and many offer anonymous testing. Both nursing staff and public health workers provide HIV counselling and HIV testing is offered to all patients (routine opt-in testing). The person can select nominal, non-nominal, or anonymous testing, or to not take the test at all.

In Ontario, three to four percent of all testing is done anonymously, but the rate of anonymous seropositive tests is twice the rate of positive tests reported nominally and non-nominally (Ontario Ministry of Health).

In Alberta, HIV counselling and testing is offered throughout the province, including public health sites, at sexually transmitted infection clinics in three cities, some regional health authority family planning clinics, and some physicians' offices (Personal communication, Dawn Krahn, Communicable Disease Manager, and Pamela Miller, Blood Borne Pathogens Nurse Consultant, Alberta Health and Wellness).

ANONYMOUS TESTING AND COUNSELLING

Anonymous testing and counselling was a controversial topic in the early years of the epidemic, advocated in the high-incidence provinces of Ontario and Quebec as a means of providing people who might not seek testing with access to a less risky form of HIV testing. The purpose of offering it was to ensure that people could

learn their serostatus without risking that the confidentiality of positive test results might be breached. While public health officials in other provinces strongly opposed providing the option, anonymous testing and counselling gained traction and has become one of the most important forms of HIV testing in Canada (Personal communication with David Hoe, former Senior Policy Advisor with the Public Health Agency of Canada, 2006). The Hassle Free Clinic in Toronto developed counselling guidelines for anonymous testing that provide highly respected guidance for anonymous testing and counselling (Ontario Ministry of Health, 1995).

In Ontario, three to four percent of all testing is done anonymously, but the rate of anonymous seropositive tests is twice the rate of positive tests reported nominally and non-nominally (Ontario Ministry of Health). Anonymous testing is conducted at 36 sites, including community health centres, public health units and sexually transmitted infection clinics across the province, and the Ministry of Health is expanding the number of sites. The Hassle Free Clinic provides full-time anonymous testing to men and women, and a significant portion of the anonymous testing occurs there, especially for men who have sex with men.

Before staff can provide anonymous testing and counselling they must receive training through the Ministry of Health. Thus the Ministry also provides annual update training in a commitment to maintaining the quality of the counselling that is provided. Because complete pre- and post-test counselling is only ensured at anonymous test sites, people who call the HIV hotline looking for a test site are often encouraged to consider anonymous testing over confidential

testing to begin with, so that they receive the information and support they need whether the results are negative or positive. The anonymous testing process is considered “a holding zone” in Ontario (Frank McGee, AIDS Coordinator of the Ontario Ministry of Health). It provides people who might avoid HIV testing an opportunity to find out whether they are HIV-positive and then to “sit back and decide what next steps are appropriate, including when to enter into health care.” In post-test counselling people are told to expect that they will need to be re-tested nominally when they enter care and to document their medical condition.

The anonymous test sites are an essential component of Ontario’s outreach to marginalized at-risk persons who do not know their serostatus, which is one reason why the Ministry is expanding the sites. Many anonymous test sites have dynamic working partnerships with community-based social service agencies serving specific groups of people and with AIDS service organizations. Some are street-involved programs serving people such as homeless youth and individuals who use injection drugs. Anonymous test site staff often go to partner agencies (including street outreach) to provide pre-test counselling. When a person finally comes to the anonymous test site for testing (often accompanied by a staff person from the social service agency), the pre-test counselling continues and the post-test counselling is extensive. The concept of one-stop-shopping is inherent in how agencies work with vulnerable people.

In Ontario, whether people return for their test results is considered an important measure of the quality of

counselling and testing. If people feel welcomed and well cared for during the pre-test counselling process (which may last more than one session), they are more likely to return for test results. The rate of return is very high at the anonymous test sites, but a more extensive formal evaluation is also planned.

According to Frank McGee, “It is a myth that there is no partner notification associated with anonymous testing.” Discussions about the importance of notifying sex and drug-using partners begin during pre-test counselling and continue during post-test counselling for persons who are seropositive. Anonymous test site counsellors offer their own assistance as well as that of the health department in notifying partners (as with all partner notification, people can be notified without being told who provided their names).

When British Columbia instituted HIV reporting in 2003, a compromise was developed that provides an alternative to anonymous testing. Health care providers were given the option of reporting non-nominal HIV test results, creating a unique identifier if the patient requests. This option prevents a positive HIV-test result from being associated with the patient’s name. Mandatory HIV reporting was instituted in British Columbia with the option of non-nominal reporting. This system was evaluated after the program was in place for two years and the small breaches of confidentiality that occurred do not appear to have harmed patients (Personal communication with Steven Smith, British Columbia Ministry of Health, July 2006).

In Alberta, HIV testing is available at sexually transmitted infection clinics in Calgary, Edmonton, Fort McMurray and at some family planning clinics in the province; if the test is positive, it becomes reportable nominally (Personal communication with Dawn Krahn, Pamela Miller). HIV reporting became mandatory in 1998 (Jayaraman, 2003).

PERINATAL TESTING AND COUNSELLING

Perinatal HIV testing and counselling is another issue with varying policies among the provinces. It is routine in British Columbia and Ontario on an opt-in basis. This means the woman must say yes to an offer of HIV testing as opposed to opt-out testing in which the test is done unless the woman refuses. Health care providers must provide HIV counselling and offer HIV antibody testing to all pregnant women and those planning pregnancies. The HIV test is voluntary and can only be done with informed consent. The test is also conducted nominally using her name and health card number.

When perinatal testing is offered in Ontario, however, a woman can decline nominal testing and choose to be tested at one of Ontario's anonymous HIV testing sites (Ontario Ministry of Health). In this case, only the woman receives the result and no one, including her health care provider, will know her test result unless she discloses it. It is a woman's option to tell her health care provider the results of her anonymous test and it is the physician's option to document the test result. If a woman requests treatment, the provider discusses retesting nominally with her in order to have a documented positive HIV-test result in the patient's record.

When the Ontario Ministry of Health enacted routine opt-in perinatal testing in 1998, a working group of providers, public health representatives, community-based groups, and researchers was convened to develop strategies to support the policy. The interventions that were implemented targeted health care providers, local public health staff, and women. They included the following:

- A counselling checklist and brochure were sent to physicians in 1999, 2002, and 2003. (Ontario Ministry of Health, 2003) and an analysis of local testing rates was sent to all 36 provincial Medical Officers of Health (2000).
- Physicians who did not order an HIV test for a patient were sent a memo recommending prenatal HIV testing when the other laboratory results were sent to them.
- A multi-media campaign was conducted to provide the public with information about the importance of HIV testing for pregnant women (2004).

As a result of this series of interventions, the rate of perinatal HIV testing in Ontario went from 34% (prior to the routine opt-in policy) to 88% in 2005 (Personal communication, Frank McGee, AIDS Coordinator of the Ontario Ministry of Health). The lesson learned was that a high rate of HIV testing for pregnant women can be achieved through voluntary opt-in testing using multiple approaches to promote the intervention. In fact, the Perinatal Working Group of Ontario finds that overall the rates currently being achieved are as high as some jurisdictions using the opt-out approach (Personal correspondence, Lynne Leonard, PhD, University of Ottawa, Ottawa, Canada). Dr. Leonard

thinks that the important factor in increasing testing rates is the quality and content of pre-test counselling. Not only should HIV testing be offered to all women of child-bearing age in order to enable them to make informed reproductive choices prior to becoming pregnant, they should be counselled about the benefits of HIV testing for their own health as well as for the baby's health. She contends that the HIV test is not a routine test to be conducted lightly; rather it has implications for a woman for the rest of her life. Women, especially women experiencing the stresses of pregnancy, need pre-test counselling in order to be prepared for a positive test.

In Alberta, perinatal counselling and testing is offered on an opt-out basis (routine testing with the right to decline). As of 1998, the provincial policy is that all pregnant women should be tested for HIV as part of routine prenatal care, unless they choose not to be tested. The overall goal of Alberta's opt-out screening program is to ensure that the majority of pregnant women residing in the province of Alberta have access to HIV screening as part of routine prenatal care.

In 2000, the Alberta Medical Association and Alberta Health and Wellness commissioned an independent evaluation of the implementation and short-term outcomes of the Alberta Routine Prenatal HIV Screening Program (Alberta Medical Association, 2001). The final evaluation found that the vast majority of pregnant women are being tested prenatally for HIV. The proportion of pregnant women who declined testing decreased from 4.0% in the first year of implementation of the screening program to 2.4% in the second year of the program. While

the majority of health care professionals reported that they always (83.1%) inform women that HIV testing during pregnancy is routine, only 67.1% reported that they always informed women that they have the choice to decline.

RAPID TESTING TECHNOLOGIES

Laboratory tests are licensed at the national level in Canada. Two rapid tests were licensed and subsequently removed from the market because of defective manufacturing, and as of December 2005 one test has again been approved for use in Canada. Private physicians are able to purchase and use the tests, but as of August 2006 no provincial governments have funded the use of rapid testing in public health clinics. Only the Hassle Free Clinic in Toronto uses rapid tests, where they are being tried on an experimental basis. There is a great deal of discussion in Canada about rapid testing, and public health officials are considering the approach.

CUBA

Soon after the antibody test was developed, Cuba began a program of mandatory screening of all sexually active people to identify and quarantine those who were HIV seropositive, "thereby creating a system of medical preventive detention" (Mann, 1992). Contact tracing and HIV testing of sexual partners of people with HIV were conducted, and all seropositive individuals were confined to sanatoriums. Although in detention, people continued to receive salaries, pursue educations, allowed home visits, and received high-quality nutrition and medical care. By 1991, 75% of the population had been screened and by 1993, 12 million

tests had been conducted in a country with a population of 11 million. The government spent 15 to 20 million dollars annually on HIV care in the 1990s, including antiretroviral therapy and other medical care, nutrition and housing (Hansen, 2003; Santana, 1991).

Although the Cuban government lifted the quarantine in 1994, half of all seropositive people were still living in the sanatoriums in 2003, which continue to be used as transitional counselling and housing facilities. In 2002, HIV prevalence in Cuba was reported to be only 0.03%. Since the 1990s however, tourism from abroad has been a mainstay of the economy, including sex tourism. This, as well as other factors such as poverty caused by the economic crisis of the early 1990s, the prohibition on unofficial community-based health activism, and a lack of perceived vulnerability due to the success of Cuba's HIV prevention campaign, may all be contributing factors in the health ministry's announcement in 1997 that Cuba's HIV infection rate was rising (Hansen, 2003). Cuba has been held up as a success story in curbing HIV, but the relative effects of various potential contributing factors — quarantine, mandatory testing, contact tracing, the island's social/political isolation, living standards that eliminated abject poverty and social inequality, and universal access to preventive medical care — have yet to be studied (Hansen, 2003).

SECTION TWO: WHAT IS KNOWN ABOUT THE NUMBER OF PEOPLE UNAWARE OF THEIR HIV STATUS

OVERVIEW

Obviously, the only way to actually identify every person with HIV infection is to test the entire population. Because few countries have opted for this strategy, the serostatus of a certain proportion of asymptomatic people is unknown both to themselves and to public health authorities. The challenge is to reach these people for the dual purposes of engaging them in care and assisting them in preventing further transmission. Increasing the uptake of HIV testing and counselling requires different strategies depending on the subpopulation that is being targeted.

Data on the proportion of people with HIV who are undiagnosed are scarce. In addition, the task of estimating a country's overall HIV prevalence and incidence is difficult because these vary within different subpopulations of people, such as men who have sex with men and people who use injection drugs. To identify the number of people unaware of their HIV status, epidemiologists have applied various methods to estimating the total number of unknown seropositives (Archibald, 2004; Glynn, 2005). Direct methods require testing the entire universe under consideration, which is not considered realistic. Indirect methods to estimate the number of people unaware of their HIV status on a population-based, national level make calculations based on other sets of data. The validity of the estimates depends upon the accuracy of the data.

Nonetheless, making calculations over time provides a means of monitoring the effectiveness of counselling and testing programs and can also be used to monitor the effectiveness of providing care.

The overall global situation is that 85% to 90% of the estimated 38 million people living with HIV are undiagnosed and therefore cannot benefit from treatment or counselling to prevent further spread of HIV (Archibald, 2004).

GLOBAL ESTIMATES

The number of people unaware of their HIV status varies greatly in different parts of the world (see Table 2.1). In addition, specific factors are associated with the proportion of undiagnosed cases such as the older the study, the higher the proportions as the

availability of testing has increased in recent years; developing countries, where testing is less available, generally have higher proportions than developed countries; at-risk subpopulations tend to have higher proportions than estimates in general populations; and within at-risk populations, youth and minorities tend to have higher proportions of persons who do not know their serostatus.

While the proportion of seropositive people who are unidentified is estimated to be as low as 14% in Cuba and 12% to 20% in Sweden - two countries with robust testing and counselling programs - the proportion in low income countries with poorly resourced programs can be as high as 90% to 95%. The worldwide proportion is estimated to be 85% to 90%. The overall global situation is that 85% to 90% of the estimated 38 million people living with HIV are undiagnosed and therefore cannot benefit from treatment or counselling to prevent further spread of HIV (Archibald, 2004).

TABLE 2.1: GLOBAL ESTIMATES OF UNDIAGNOSED HIV INFECTION

Region	Approximate percent undiagnosed	Number prevalent infections in millions*
Sub-Saharan Africa	90-95%	25
East Asia	90-95%	0.9
N Africa, Middle East	85-95%	0.48
South and Southeast Asia	85-95%	6.5
Eastern Europe, Central Asia	75-85%	1.3
Caribbean	75-85%	0.43
Latin America	65-75%	1.6
Western Europe	30-35%	0.58
Oceania	25-35%	0.032
North America	25-30%	1.0
Global total	85-90%	37.8

* Estimates at end 2003, UNAIDS (Archibald, 2004)

USING ESTIMATES FOR MONITORING

The estimated number of undiagnosed seropositives reflects the size of the population that is of most interest for both prevention and care programming (Archibald, 2004). Therefore, this number or proportion can be used as an impact indicator both to assess the extent of coverage by care programs and the effectiveness of prevention programs in reaching people at risk (Archibald, 2004). Narrowing the gap between those in need and those receiving treatment indicates increased impact. Moreover, activities that reduce the proportion of undiagnosed people contribute to HIV prevention, and improving the ability and willingness of individuals and communities to know their HIV status assists in monitoring progress toward that goal. In fact, the figure of the estimated number of undiagnosed seropositives would be a valuable supplement to the Global Fund Monitoring and Evaluation Toolkit. For example, it could enhance the utility of indicators such as the percentage of people aged 15-49 years of age who have requested HIV tests and received results. Nonetheless, a program can have high testing rates with many remaining undiagnosed in the community.

METHODS USED TO ESTIMATE THE NUMBER OF PEOPLE UNAWARE OF THEIR HIV STATUS

Various methods have been developed to calculate the proportion of people living with HIV who are unaware of their HIV status (Archibald, 2004).

The direct method compares self-reported HIV status with results of laboratory tests conducted at the same time. The difference between

the two numbers is the number of unknown seropositives. Although the number is accurate within the sample, in a convenience sample or group of voluntary testers, how representative this method is with respect to the overall population is usually problematic.

The anecdotal method uses unsupported statements regarding number or prevalence. While the estimate may be based on extensive knowledge of the populations in question, if it is not based on data, it remains the subjective opinion of the public health official.

The indirect method depends upon calculating separate estimates of HIV prevalence in the population of interest and of the number of diagnosed HIV-positive individuals in that population who are still alive; the difference is the number of people who do not know their HIV status (Archibald, 2004; Glynn 2005). With the indirect method, the accuracy of the calculation depends upon the accuracy of the component estimates themselves and there is often no detail regarding various at-risk groups within the larger population.

COUNTRY ESTIMATES

Estimates have been made of the proportion of people of unknown HIV status for selected countries. Some of these estimates are described below (see also Table 2.2 and Table 2.3).

CANADA

In 2005, the estimated number of Canadians with HIV or AIDS who did not know their status was 15,800 or 27% of 58,000 people living with HIV or AIDS (Boulos, 2006). Targeted studies provide a direct measure of

the proportion of individuals with HIV who are undiagnosed in various sub-populations. In the most recent phase of the I-Track survey of injecting drug users conducted at selected centres across Canada, 22.9% reported that their HIV status was negative or unknown whereas blood testing indicated they were HIV positive (Unpublished data, Public Health Agency of Canada, 2006). A targeted study among men who have sex with men in Montréal indicated that in 2005, 23% of the men who tested positive for HIV were previously unaware of their infection (Lambert, 2006). These targeted populations are likely more aware of their risks of infection and thus may have higher rates of testing and lower proportions undiagnosed compared to other sub-populations.

CUBA

According to statistics, 14% of people with AIDS were unknown to the Health Authority before they developed symptoms of AIDS. Based on a mathematical model, the number of seropositive people in Cuba who do not know their status is estimated to have risen from 174 in 1991 to 401 in 2000 (Hsieh, 2002). Estimates using a different mathematical model calculated the proportion to be 20-30%, rising from 316 in 1991 to 446 in 1999 (Hsieh, 2002; de Arazoza, 2000).

EUROPEAN UNION (EU) COUNTRIES

Estimates of the number of people unaware of their HIV status for the EU are available for half of the countries and ranges from 12-20% in Sweden to over 50% in Poland. Other countries include Denmark at

15-20%; the Czech Republic at 20-25%; France at 30%; Germany at 25-30%; Latvia at 50%; the Netherlands at 40%; Slovakia at 20-30%; and the UK at 35%, (range of 29-39%). Among men who have sex with men who are seropositive in the UK, an estimated 34% (range 27-43%) were unaware of their status in 2004 (HPA, 2005). Overall, it is estimated that around 30% of the EU population is unaware of their HIV status. (Unpublished data, Hamers F, 2006).

UNITED STATES

An estimated 30% of people living with HIV or AIDS in the U.S. did not know their status in the late 1990s (Sweeny, 1997). In 2003, this figure dropped to 25%. Calculating between 850,000 and 950,000 HIV-positive people in the U.S. at that time, it is estimated that approximately 180,000-280,000 people were unaware of their serostatus (Fleming, 2003). In 2005, that estimate remains steady with 25% of approximately one million people living with HIV or AIDS in the U.S. not knowing their status (CDC, October 2005).

The proportion is apparently higher among men who have sex with men. In a national survey of randomly selected sites where men who have sex with men meet socially, the HIV prevalence was 25%. Of that 25%, a full 48% did not know they were seropositive. Moreover, the proportion who were unaware of their status was highest in men younger than 30 years old, those who were non-white (64% were black, 18% were Hispanic), and those in cities other than San Francisco (CDC, 24 June 2005).

TABLE 2.2: ESTIMATED PROPORTION OF PEOPLE LIVING WITH HIV OR AIDS UNAWARE OF STATUS

COUNTRY	PREVALENT PERSONS WITH HIV/AIDS	UNAWARE OF STATUS Range; (Number) Percent of total
Canada in 2005 ¹	(58,000)	27%
European Union ²	(700,000)	30%
Denmark ³		15-20%
Czech Republic ⁴		20-25%
France ²		30%
Germany ⁵		25-30%
Latvia ⁶		50%
Netherlands ⁷		40%
Poland ²		>50%
Slovakia ⁸		20-30%
Sweden ⁹		12-20%
United Kingdom ¹⁰ in 2004	(58,300)	(19,700) 34%
U.S. in 2003 ¹¹	925,000-1,025,000	164,000-264,000
(Using 2 different calculation methods)		18-26%
	1,039,000-1,185,000	252,000-312,000
		24-27%

- 1 (Boulos, 2006)
- 2 Personal correspondence, Françoise Hamers, European Centre for Disease Prevention and Control (ECDC)
- 3 Personal correspondence, Susan Cowan, Serum Staten Institute
- 4 Personal correspondence, Maria Bruckova
- 5 (Robert Koch Institute, 2005)
- 6 Personal correspondence, A Ferdats, AIDS Prevention Centre
- 7 Personal correspondence, Eline Op de Coel, RIVM
- 8 Personal correspondence, Danica Stanekova, Slovak Medical University
- 9 Personal correspondence, Anders Blaxhult, Slovak Medical University
- 10 (HPA, 2005)
- 11 (Glynn, 2005)

Table 2.3: HIV prevalence, %; HIV infected persons aware of serostatus; HIV tests performed annually per 1000 population; and HIV testing peaks and practices in the European Union + Switzerland

	HIV testing routinely offered												
	2005 Estimated prevalence	Estimated ¹ HIV infected people aware of their serostatus	HIV tests in 2004**	National Policy for Testing Pregnant women	Pregnant women	Hospital patients except TB	TB patients	STD patients	IDU	Youths <25 years	MSM	Partner notification of sexual contact	% HIV infections diagnosed through partner
Austria	12 000	NA	86	U	NA	NA	NA	NA	NA	NA	NA	NA	
Belgium	14 000	20-25%	52.6	No	Yes	No	Yes	Yes	Yes	No	No	No	
Czech Republic	1 500		31.5	U	Yes	No	Yes	No	Yes	Yes	Yes	Yes	10-50%
Cyprus	<500		81.8	NA	NA	NA	NA	NA	NA	NA	NA	NA	
Denmark	5 600	15-20%	24.4	S	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10-50%
Estonia	10 000		45.5	U	NA	NA	NA	NA	NA	NA	NA	NA	
Finland	1 900		25.5	U	NA	NA	NA	NA	NA	NA	NA	NA	
France	130 000	30%†	75.9	U	Yes	No	No	No	No	No	No	No	
Germany	49 000	25-30%	26.7	U	Yes	No	No	No	No	No	No	No	
Greece	9 200		1.7	No	Yes	No	No	No	Yes	No	No	No	
Hungary	3 200		11.2	No	NA	NA	NA	NA	NA	NA	NA	NA	
Ireland	5 000	NA	5.7	U	Yes	No	No	No	No	No	No	No	
Italy	150 000	25%‡	NA	No	NA	NA	No	Yes	Yes	Yes	No	No	
Latvia	10 000	50%	36.8	U	Yes	NA	NA	NA	NA	NA	NA	NA	
Lithuania	3 200		17.5	U	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	<10%
Luxembourg	<1000	NA	32.2	NA	NA	NA	NA	NA	NA	NA	NA	NA	
Malta	<500	NA	15.6	S	Yes	No	Yes	Yes	Yes	Yes	No	No	<10%
Netherlands	18 000	40%	NA	U	Yes	No	No	No	No	No	No	Yes	unknown
Norway*	2 500	15%	40.4	U	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	<10%
Poland	25 000	>50%	3.2	U	NA	NA	NA	NA	NA	NA	NA	NA	
Portugal	32 000	NA	50.5	U	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Slovenia	<500	20-30%	17.4	U	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	10-50%
Slovakia	<500	NA	11.1	No	No	No	Yes	Yes	Yes	Yes	No	No	
Spain	140 000		NA	U	Yes	No	No	Yes	Yes	Yes	No	No	
Sweden	8 000	12-20%	NA	U	Yes	Yes	No	No	Yes	Yes	No	No	10-50%
Switzerland	17 000		44.5	NA	Yes	No	No	Yes	Yes	Yes	Yes	Yes	
UK	68 000	30%	NA	U	Yes	No	No	Yes	No	Yes	No	No	
TOTAL	715 300	approx. 30%											

U= universal; S= selective; NA= data not available; No= no national policy
 * Switzerland and Norway are not part of the European Union
 † per 1000 of population
 ‡ figure among HIV infected persons with STI
 § Data sources: Chartres, UNAIDS, EuroHIV, University of Ghent for pregnant women, apparent discrepancies between national peaks and routine testing of others arise from the fact that testing may be routinely offered while there is no national policy (e.g. Belgium) and the converse may also be true

TABLE 2.3:

SECTION THREE: POLICIES IN PRACTICE: ADDRESSING THE ISSUES IN 2006

OVERVIEW

The two main focal points of efforts to reach people who are unaware that they are HIV positive are targeting these efforts towards special populations of people at higher risk and further developing innovative testing and counselling strategies. This section first describes the efforts directed towards communities at risk for HIV and reviews the experiences of testing and counselling by people living with HIV. It then moves to discuss and analyze the new technologies and approaches for increasing the proportion of people who receive testing and counselling. These innovative approaches include rapid testing technologies; methods to detect people with acute infection before they develop HIV antibodies; the use of rapid testing in community outreach programs; and provider-initiated testing and counselling (PITC). The bulk of attention is paid to PITC, which is the intervention being implemented in a number of settings using different approaches. The benefits and potential unintended consequences of PITC, especially routine PITC with the right to decline, are discussed.

The people who are most vulnerable to HIV require targeted interventions that address the specific needs of each unique culture or social group. For example, gay men and people who use injection drugs may have language and priorities that are specific to their communities. Culturally sensitive outreach is an important element contributing to the capacity of many programs to make meaningful

connections with and gain the trust of the people to whom they wish to provide health services. In addition, for many vulnerable groups of people, HIV prevention may need to involve support services to assist with survival needs such as housing, education, and income generation. Even in HIV prevention programs targeting the general population, a multiplicity of approaches must be used in order to reach the diverse range of people infected with HIV. Finally, in some sense, people who are HIV-positive are a special population by virtue of their serostatus, and are vulnerable to the same stigma and personal fears of all others who share their diagnosis. These issues must be addressed to make it possible for some people to come forward and be tested.

The people who are most vulnerable to HIV require targeted interventions that address the specific needs of each unique culture or social group.

Historically, a large proportion of the resources for HIV prevention has been devoted to a package of interventions that include pre- and post-test counselling, HIV antibody testing, referral to prevention and care services, and, sometimes, contact tracing or partner notification. The interventions are variously called voluntary counselling and testing or voluntary confidential testing (VCT), counselling and testing, and counselling, testing, referral, and partner notification. However, these interventions by themselves have never identified all people living with HIV.

Public health prevention experts recommend the development of a comprehensive package to support VCT, including biomedical, psychological, and social interventions. Possible interventions include behavioural change activities, harm reduction activities, social marketing and mass media campaigns, sexually transmitted infection screening and treatment, post-exposure prophylaxis, antiretroviral treatments to prevent perinatal transmission, and at some point in the future, vaccines and microbicides (Auerbach, 2004). Thus, throughout the world, VCT is usually part of an array of approaches, some of which are especially helpful in relation to vulnerable people for whom a comprehensive approach is even more necessary. While this paper does not address the array of interventions that can and should complement testing and counselling, they must be acknowledged as the context in which all testing and counselling ought to occur, even when conducted within clinical settings.

SPECIAL POPULATION APPROACHES

In this review of approaches to special populations at risk for HIV, this section discusses the issues of key populations who are more vulnerable to HIV infection and describes some interventions and approaches being used to reach them. The concept of vulnerability in the context of HIV/AIDS "...means to have limited or no control over one's risk of acquiring HIV infection or, for those already infected with or affected by HIV, to have little or no access to appropriate care and support. Vulnerability is the net result of the interplay among many factors, both

personal (including biological) and societal; it can be increased by a range of cultural, educational, demographic, legal, economic and political factors." (UNAIDS)

SEXUALLY ACTIVE WOMEN

ISSUES

Countries almost universally target women for HIV testing through perinatal services in order to prevent HIV transmission. There is wide variability as to whether this HIV testing also includes counselling, the informed consent of the woman and is conducted confidentially. Women may also be the focus of special HIV prevention programming through reproductive health services, primary care, or community-based programs. For women of childbearing age, who are sexually active or who are commercial sex workers, the issue of gender inequality must be taken into consideration as a potential cultural variable contributing to their vulnerability not only to HIV infection but also to stigma and discrimination associated with the disease.

A study of stigma and prevention of perinatal transmission in India, Ukraine, Burkina Faso, and Zambia found that women were subjected to stigma due to gender, seropositive status, and due to being HIV-positive pregnant women or mothers (Chase, 2001). Uniformly throughout the study, stigma was directed towards women more extensively than towards men. Stigma caused women to avoid being tested for HIV, and once they were known to be HIV-positive, reduced their choices regarding health care and family life and reduced their quality of life. Moreover, women were tested without their knowledge within the health care systems. In India,

women found to be seropositive were coerced into terminating their pregnancies. In Ukraine, it was reported that physicians terminated pregnancies at their own discretion with no consultation of the women. A separate study of stigma in Ukraine also found that despite strong human rights protections for people with HIV in national policies (including that HIV testing requires informed consent and counselling), pregnant women were tested for HIV without their consent and the results provided to husbands and other family members without permission (HRW, 2006). Moreover, pregnant women were not provided information about or access to antiretroviral therapy, apparently in an attempt to coerce them into having abortions. Some women who were provided antiretroviral therapy reported being required to pay for it despite a national law stating that people with HIV should receive treatment free of charge.

On an interpersonal level, gender inequality in cultures and lack of protections within the legal system can cause women to be unable to protect themselves from others within their families as well as in their social networks. They may either be unable to obtain an HIV test without their husband's permission or be forced to be tested (Chase, 2001). Violence against women is an extreme but common consequence of gender inequality, and can be HIV-related. If women demand that their male partners use condoms or try to reject sexual advances they may be subject to domestic violence and rape. Gender inequality makes women more vulnerable than men if they are known to be seropositive, with the risks including being blamed, beaten, or abandoned. In a review of studies regarding disclosure of serostatus in

developing countries, the majority of women who disclosed their HIV status to their partners described supportive reactions, but between 3% and 15% said their partners had a violent reaction (Medley, 2004). In a survey of women in Tanzania three months after they received testing and counselling, the women who were HIV positive reported more violence from their current partners than the women who were HIV negative (Maman, 2002).

Women's inequality also contributes to their economic dependence on men and inability to make decisions regarding their own sexual and reproductive lives. In many countries, women are not equal to men in regard to property rights, inheritance rights, marriage and divorce, access to the legal system, and protection under the law (UNDP, 1995). Women have access to fewer jobs, at lower pay, than men. Women receive much less formal education than men, further reducing their economic opportunities. In addition, there is a correlation between education and HIV vulnerability: girls 15 to 18 years of age enrolled in school were found to be over five times less likely to have HIV than those who had dropped out (UNAIDS, 2005).

Moreover, HIV is biologically more easily transmitted to the receptive partner, which is the woman in a heterosexual relationship. Women who have sex with women are often thought of as not being at risk for HIV, but they are vulnerable to HIV in the same ways as other women: some lesbians have sex with men and some use injection drugs. In addition, HIV can be transmitted from woman to woman during sexual activities that involve exchange of body fluids (Baeten, 2005; Kwakwa, 2003).

PROGRAMMING

HIV prevention programs targeting women often include activities that assist women to learn negotiating skills, improve their self-esteem, and establish greater economic security. At a policy level, structural changes such as enactment of laws giving women more economic control of their lives and development of community education programs to stop domestic violence are considered aspects of HIV prevention. In addition, research has focused on developing barrier methods that are under the control of the woman. The female condom, for example, is now promoted widely by HIV prevention programs and intensive research is being conducted to develop microbicides to kill or block HIV in semen from infecting the woman. Availability of these new technologies could shift the paradigm regarding counselling and testing, perhaps increasing the value of universal testing for women. With more effective ways to protect themselves from HIV, women might have greater motivation to know their status in order to either remain negative or, where positive, to protect their partners and children. Furthermore, to deflect the attitude of blame towards pregnant women living with HIV, whose offspring are at risk of becoming infected, suggestions have been made to stop using the term 'prevention of mother-to-child-transmission' (PMCT or PMTCT) and begin using the term 'prevent perinatal transmission' (PPT) (de Bruyn, 2005).

To protect women from adverse effects of perinatal testing so that they can safely protect their unborn children from HIV infection, the recommendation has been made that women be told the following (Wolfe, 2004):

- The rationale for prenatal HIV testing;
- The psychosocial risks of HIV testing, particularly the risk of violence; and
- Their testing decision will not adversely affect their prenatal care or legal rights.

YOUNG PEOPLE

ISSUES

In general, adolescents are developmentally vulnerable to HIV. For example, the importance of peer approval, a developing sense of self and sexuality, gender, education levels and early life experiences all influence adolescent sexual behaviour. Youth who are at higher risk include those who are street involved or homeless as well as economically disadvantaged children who need to help support their families. Jurisdictions vary in whether adolescents require parental permission to obtain HIV tests if they are under the age of majority.

PROGRAMMING

Programs to reach adolescents usually require special outreach that addresses their particular developmental needs and take into account their interests and concerns. Gaining the trust of youth can be challenging and take time. For at-risk youth who are homeless, incorporating counselling and testing into other comprehensive social services is usually necessary. Prevention programming may use group discussion, practice of HIV prevention negotiation and skills-building. Opinion leaders, social networks, and peer counsellors are used with youth.

PEOPLE WHO USE INJECTION DRUGS

ISSUES

Societies throughout the world stigmatize people who use injection drugs as well as people with a wide range of addiction problems. Furthermore, in many countries the use of narcotic and other mind-altering drugs is illegal. For these reasons, people who use injection drugs may not seek counselling and testing and, in fact, they may avoid health care and social welfare agencies and institutions altogether.

Stigma and discrimination against people who use injection drugs has been documented in health care services as well as in communities. In a study in Ireland of the experiences of hospitalized people with HIV, those who were drug users perceived more stigma and judgment from nurses than other people with HIV. For example, respondents reported that nurses blamed them for their illness and made disparaging remarks when they requested pain medication (Surlis, 2001). In Ukraine, where injection drug use is a major factor in the spread of HIV, people who use drugs report that they frequently face police violence and abusive treatment in the health care system (HRW, 2006). Ukrainian service providers as well as persons who use drugs report avoiding drug treatment and other services because official registration requirements can lead to being exposed to the police, losing employment, and being mistreated in hospitals.

The issues of addiction often include physical and mental health issues and poverty. All of these issues are compounded in countries in which use of narcotics is a criminal offense. The multiple issues confronting the people

who use injection drugs contribute to their social marginalization and economic instability.

PROGRAMMING

Approaches to prevention for drug users incorporate special efforts to gain their trust. Interventions include client-centred counselling about safer sex as well as drug-using behaviours, programs to address their multiple immediate needs, and strategies to overcome structural barriers to care (Downing, 2000). A number of intervention strategies have been demonstrated to be effective in reducing drug-related risk behaviours, especially when conducted within the context of network strategies that focus on changing community norms regarding risky drug use and sexual behaviours (Metzger, 2003).

Counselling and testing programs for people who use injection drugs often have street outreach teams that provide harm reduction interventions. In a four-year study of people who use injection drugs, HIV incidence went from 8.4 per 100 person-years to 2.4 per 100 person-years following a street outreach intervention using peers for HIV prevention (Wiebel, 1996).

Harm reduction is a strategy that is often integrated with prevention, treatment and law enforcement. This approach encourages individuals to take incremental steps in protecting themselves from the harmful effects of

Counselling and testing programs for people who use injection drugs often have street outreach teams that provide harm reduction interventions.

injecting drugs. The objectives of harm reduction programs include preventing the transmission of HIV and other blood-borne pathogens; providing health promotion and prevention information; and connecting highly vulnerable and marginalized groups of people to health and social services, including addiction treatment programs. Needle exchange is an important harm reduction intervention in which a person's used needles are exchanged for sterile needles so that they are not shared with others. The implementation of needle exchange programs is widespread and there has been much pressure to change the laws preventing these programs in countries in which possession of injection equipment is criminalized. Countries as different as the U.S. and Ukraine have established needle and syringe exchange programs.

For opiate users, substitution treatment with methadone or buprenorphine has been shown to be effective in reducing or stopping drug use. The two interventions that are documented to be effective in reducing both risky behaviours and HIV incidence among people who inject drugs are needle exchange programs and drug treatment (Auerbach, in press).

MEN WHO HAVE SEX WITH MEN

ISSUES

Pervasive homophobia has added stigma to AIDS because from the beginning AIDS was perceived by many as a "gay disease." Men who have sex with men continue to experience stigma and discrimination because of their sexual orientation, particularly in jurisdictions in which homosexuality is illegal, which creates

a significant barrier to testing and counselling. Conversely, in many countries where homosexuality is accepted, urban men who self-identify with the gay men's community are at an advantage in having the benefit of well-developed outreach, education, and HIV prevention programs that target them. A high proportion of gay men already recognize the higher risk of HIV, and therefore take advantage of gay-sensitive testing and counselling programs.

An issue in the third decade of the epidemic, however, is that even among well-informed communities of men who have sex with men, the rates of seroconversion have begun to rise. One suspected reason is the perception that widespread use of antiretroviral treatment has reduced the risk of becoming infected. A meta-analysis of studies of sexual risk behaviour and antiretroviral treatment found that individuals who believe that antiretroviral treatment reduces HIV transmission or who are less concerned about engaging in unsafe sex if such treatment is available, are significantly more likely to engaging in unsafe sexual behaviour (Crepaz, 2006).

Men who have sex with men who do not self-identify as gay or who are not connected with the gay community, including many who are in heterosexual relationships, are less likely to protect themselves and have historically been more difficult to reach for testing and counselling.

PROGRAMMING

Prevention interventions for men who have sex with men include informational literature that is gay-friendly, outreach by peer educators into venues frequented by men who have sex with men, workshops for support and for skills-building, and

Involving members of the targeted community in planning and development is critical to the success of prevention programs.

programs that use opinion leaders and social networking. For example, the STOP AIDS Project, founded in 1984, operates a community organizing project for self-identified gay and bisexual men in San Francisco to reduce HIV transmission and promote dialogue among HIV-positive gay and bisexual men about their role in reducing transmission. Programming includes special outreach teams as well as programs for individuals who may not be integrated into the gay men's community, such as Black men who have sex with men. More information is available at:

<http://www.stopaids.org/>. and http://ari.ucsf.edu/programs/policy/pwp_resources/USCA12.pdf. Few programs exist for men who have sex with men who also engage in heterosexual activity.

MINORITY MEN WHO HAVE SEX WITH MEN

ISSUES

Men who have sex with men who are also in an ethnic or cultural minority in the larger society have the challenge of being a minority within two different communities. Within their ethnic or cultural communities they are often stigmatized as gay men and within gay communities they experience racism. Assumed to be reached by HIV prevention programs targeting the community of men who have sex with men, this group of at-risk people may be completely overlooked despite HIV

prevalence figures significantly higher than among men who have sex with men in general.

A qualitative study of HIV-positive Black men who have sex with men in New York City identified three important themes that have an effect on the ability of health care providers to engage in meaningful discussions with them (Wheeler, 2005). First, the health provider was identified as the most important or possibly only link to information about HIV treatment and prevention. The social isolation of men who choose not to disclose their sexual preference or their HIV status limits their access to information and support. Second, respondents stated that being able to communicate honestly and openly with their providers was critical to being able to translate information and make behavioural changes to prevent further HIV transmission. A trusting relationship was not necessarily dependent on being of the same race/ethnicity. Third, prior experiences with health care providers and health systems play a role in how respondents approached their care. They found it difficult to overcome past experiences with health providers and to learn to build collaborative relationships regarding prevention and care.

PROGRAMMING

Prevention interventions for minority men who have sex with men need to be ethnically and culturally appropriate as well as sensitive to the issues of men who have sex with men. Involving members of the targeted community in planning and development is critical to the success of prevention programs.

The African-American Men's Health Study, for example, was a randomized trial of a community-based, HIV risk

reduction intervention targeting African-American homosexual and bisexual men (Peterson, 1996). The training materials used in the three 3-hour sessions were designed to be culturally relevant for this specific audience. The themes of the sessions were self-identity and development of social support; AIDS risk education involving activities such as the AIDS jeopardy game; assertiveness training; and behavioural commitment. In the last activity, participants shared strategies they had used for risk reduction and made verbal commitments to change their risk behaviours. Participants were randomized into the three-session intervention, a shortened one session intervention, and a wait-list control group. Participants in the three-session intervention group greatly increased their safer sex behaviours. At 18 months, rates of unprotected anal intercourse in that group had fallen from 45% to 20%. Comparatively, men in the single session group showed only slight rates of behavioural change, and men in the control group showed no change in risky sexual behaviour.

PEOPLE WHO ARE TRANSGENDERED OR TRANSSEXUAL

ISSUES

People who are transgendered or transsexual, whether they have undergone sex reassignment surgery or not, often live within very closed and marginalized communities and can be stigmatized even within gay and lesbian communities. Therefore, outreach to individuals for counselling and testing or other HIV prevention interventions is especially challenging. Risks to members of the transgendered communities include not only HIV

infection, but substance abuse and other health issues, including difficulties related to the sex change hormones they may be taking.

PROGRAMMING

Community involvement and empowerment are important components of HIV prevention efforts (Bockting, 1999). Programs must provide transgender-sensitive outreach, education, and services. For example, a program for transgendered women in San Francisco, developed with community input created a safe space for education and services, including HIV prevention workshops, general health promotion, and referrals to substance abuse treatment programs and other services in the community (Nemoto, 2005).

ABORIGINAL/FIRST NATIONS/INDIGENOUS COMMUNITIES

ISSUES

People who are of Aboriginal descent (in Canada also known as First Nations people, and including people who are Inuit and Metis, and in the United States known as American Indians or Native Americans, and including Alaska Natives and elsewhere as Indigenous peoples), have experienced a long history of oppression as the original peoples living in the Americas who were displaced by European colonization. Their communities are vulnerable to HIV because of underlying problems of poverty, drug and alcohol abuse, domestic violence, and other health problems. Men who have sex with men are often a stigmatized minority within both their native communities (as men who have sex with men) and the gay men's community (as First

Nations people). A high proportion of Aboriginal people now live in urban areas where First Nations community services are not easily available.

Conversely, those who live in rural areas or on reserves or reservations often lack the desired confidentiality of HIV status that is possible in cities. In Canada, Aboriginal persons represent 3.3% of the Canadian population and yet an estimated 9% of all incident HIV infections in 2005 (D Boulos, P Yan, D Schanzer, RS Remis, CP Archibald, 2005). Injection drug use is the predominant risk factor among First Nations people in Canada (64%) and the age of infection is younger than in the general population. In the U.S., Native Americans have the third highest rate of infection (FCHR, 2006).

PROGRAMMING

HIV prevention programs for First Nations people should be developed by the communities themselves with cultural specificity. Indigenous ways of perceiving and behaving must be incorporated into the conceptual and theoretical frameworks for programs (FCHR, 2006). The bridging of traditional medicine and western medicine already happens within communities, and this sort of innovation must occur in HIV prevention programs. An example of a program that grows out of the community itself is the Indigenous People's Task Force in Minneapolis, Minnesota. The program has a peer education/theater program for youth, trains women as peer educators who offer services such as safer sex house parties for women, and provides anonymous HIV testing in the program's offices (IPTF, 2006).

PEOPLE OF ETHNIC AND RACIAL MINORITIES

ISSUES

From the beginning of the epidemic in Europe and North America, the prevalence of AIDS and HIV has been significantly higher among certain ethnic minorities than among majority white populations, even in groups at higher risk of HIV such as men who have sex with men and people who use injection drugs. This trend is associated with the demographic disparities in health and economic status that are related to discrimination against people in certain minorities within society. In the U.S., for example, the incidence of HIV is much greater among African Americans and Hispanics who have higher levels of poverty and poor health, than among white people. In addition, racism has manifested itself in the AIDS epidemic when society has identified and discriminated against entire ethnic or cultural groups of people as being a potential source of HIV transmission. When this happens, racism compounds the stigma of HIV, increasing the perceived risks of getting tested for HIV among many people who are ethnic and racial minorities. In the UK, data indicate that fears of testing positive and of HIV-related stigma and discrimination are key factors making people in migrant African communities reluctant to obtain voluntary confidential testing and counselling (HPA, 2005). Many people have characteristics of two or more special populations with the compounded issues that entails.

PROGRAMMING

Outreach and testing and counselling programs are most successful when they are run by people from each ethnic community and are situated

within the community. Programs must be culturally specific as well as culturally sensitive. In planning programs, communication between HIV experts and the people within communities affected by HIV is critical (FCHR, 2006). Focusing on areas of particular concern to affected and infected persons lays the groundwork to establish appropriate priorities and create meaningful, realistic program goals. Addressing the structural issues underlying higher HIV risk among people in minorities is an essential component of community and national planning for HIV prevention.

PEOPLE IN RURAL COMMUNITIES

ISSUES

Issues related to counselling and testing in rural communities have to do with geographic isolation and fear of unwanted disclosure in small, close-knit communities. Moreover, high rates of poverty in rural areas increase vulnerability to HIV. Many prevention services are only available long distances from where people live; transportation and ongoing support can be difficult. Men who have sex with men may avoid social hostility and violence by hiding their sexual orientation and living a primarily heterosexual lifestyle (Williams, 2005).

Issues related to counselling and testing in rural communities have to do with geographic isolation and fear of unwanted disclosure in small, close-knit communities.

PROGRAMMING

Offering both anonymous testing and assurances of confidentiality in other counselling and testing programs can improve motivation to obtain HIV testing. Some HIV prevention programs provide funding for transportation to health centres or provide mobile services in rural communities. For example, in the southern U.S. state of Mississippi, a Mobile Medical Clinic travels to rural communities to provide a range of primary health care services, including free HIV testing and counselling (Bowen, 2006).

MIGRANTS, REFUGEES, AND INTERNALLY DISPLACED PERSONS

ISSUES

People who have migrated from their homes, for economic or political reasons, and from rural to urban areas within one country or across national borders, are often especially vulnerable to discrimination and to factors contributing to HIV transmission, in their new communities. They may be called migrants if they have emigrated, refugees if they have fled over borders from disaster or conflict, and internally displaced persons if they have fled their homes but remain within the country. The stigma of HIV has been conferred on entire ethnic groups or nationalities, as when people from Haiti were considered a “high-risk group” in the U.S. early in the epidemic. People from high-incidence regions, for example people from Africa, may still experience discrimination based on society’s perceptions of possible HIV risk. Many countries, including the U.S., require all immigrants to be screened for HIV and deny entry to those who are HIV-positive.

Programs targeting migrants must be based on the universal right to know HIV status rather than on any notion of specific risks (Burgi, 1996).

All countries in the EU have laws protecting individuals from discrimination due to race, religion, and political ideas, and prohibit the collection of data for such purposes (DelAmo, 2004). The EU surveillance system collects information on country of origin but no information on race or ethnicity, which are considered irrelevant categories for disease control purposes. Even with these protections, HIV surveillance within various communities is difficult: AIDS rates in migrant communities may be overestimated because undocumented migrants, the most deprived and vulnerable, are more likely to be in the numerator than in the denominator of statistics. Clandestine migrants are most likely to be untested and avoid prevention and care services because they fear being identified and deported (Carballo, 1996). Language differences, lack of official legal status of asylum-seekers that may limit access to health and other services, the stress and family disorganization that often accompany being uprooted, and poverty may all contribute to people not accessing HIV counselling and testing services.

PROGRAMMING

Programs targeting migrants must be based on the universal right to know HIV status rather than on any notion of specific risks (Burgi, 1996). Moreover, only a participatory, community-based, prevention program, coordinated by people who belong to the targeted communities and involving as many

key persons and community peer-educators as possible, will be accepted. In Switzerland, the national AIDS prevention strategy included outreach to various migrant communities (including people with guest worker status and asylum-seekers) based on the following principles: messages and measures were adapted to the cultural characteristics of each ethnic group; information and motivational activities were focused on self-help and peer education; existing structures and channels of information were used and built upon; and any form of stigmatization of an 'immigrant risk group' was avoided (Burgi, 1996). American HIV prevention initiatives that target migrant workers along the U.S.-Mexican border use peer educators, advertise testing sites on popular radio stations, and offer counselling and testing at border stations and bus stops where people cross regularly to go to work.

PEOPLE LIVING WITH MENTAL ILLNESS

ISSUES

In countries without well-developed service structures for people living with mental illness, such as the U.S., people who suffer from mental illnesses are more vulnerable to HIV infection because of structural issues, including poverty and homelessness, high-risk sexual activity and drug use, as well as social marginalization (Weiser, 2004). These issues affect their ability to make healthy choices and maintain their health. In addition, a number of individuals are dealing with both addiction and mental health issues. Because people living with mental illness are not perceived as a group as being at high risk of HIV, they are often not tested for HIV or targeted for HIV prevention.

For HIV prevention to be successful for people living with mental illness, programs must be incorporated into comprehensive support services that address the multiple factors that create vulnerability to HIV. Low threshold addiction services that enable people to receive health services while not being substance-free are essential given the inter-connectedness of mental illness and substance use. Individuals conducting HIV testing would benefit from sensitivity training around working with people living with mental illness.

Because people living with mental illness are not perceived as a group as being at high risk of HIV, they are often not tested for HIV or targeted for HIV prevention.

LIVED EXPERIENCES OF PEOPLE LIVING WITH HIV

People who are living with HIV have played an essential role in shaping HIV prevention and care policies and programs from the local to the international level. Their voices can inform the dialogue about how best to reach people unaware of their HIV status because they have lived the experiences of being either respected or stigmatized in their communities, and of receiving supportive or inadequate counselling and testing. They know what would have enhanced their ability and willingness to learn their serostatus sooner.

The experience of receiving counselling and testing has been explored with people who are living with HIV. One study (Worthington, 2002) determined people's preferences during the process:

- Access and availability - convenience, physical accessibility, familiarity;
- Structure of the service - privacy, short wait, comfortable waiting room, continuity of service provider from session to session, well-informed provider;
- Technical aspects - provision of clear and complete information, being formally asked for permission to take blood without feeling pressured, providing informed consent (having all questions answered), being confident blood samples and files would not be misplaced/mislabeled, receiving results in person, having time to process the information;
- Cognitive interpersonal process - decision-making support regarding test-taking during pre-test counselling, personalized HIV risk information during pre- and post-test counselling, and the opportunity to ask questions; and
- Socio-emotional interpersonal process - a personally warm and respectful service provider, sensitivity to client risk beliefs, emotional state, personal situation, and ethno-cultural background and spiritual beliefs, emotional support and referrals for further support.

They know what would have enhanced their ability and willingness to learn their serostatus sooner.

In a study of patients who had received positive HIV test results at STI clinics, over 80% felt that learning one's seropositive HIV status was beneficial (Kilmarx, 1998). Benefits included being able to prevent HIV transmission (reported by 1/3), obtain medical care (1/3), take better care of oneself (1/3), plan for the future (10%), get off drugs (10%), and obtain more social services (10%). Forty-four percent identified possible harmful results, including becoming depressed (1/3), discrimination (5%), and reduced sexual activity (5%).

On the other hand, many people have not had satisfactory experiences in receiving HIV test results. In a study of women with HIV in Toronto, half the women reported they received only post-test counselling and 43% reported receiving no counselling at all. Two women were told their results over the telephone and one received the message which was given to her husband (Jackson, 1997). In a European study of people living with HIV, 19% of respondents reported they experienced feelings of rejection when they were told their test results, and over half felt the support they received was inadequate (Schrooten, 2001).

The fear of stigma and discrimination has kept many from seeking HIV testing. According to a woman in Burkina Faso, "A woman will never decide to do the testing. If she finds herself HIV-positive, she is signing three deaths: psychological death, social death, and later physical death. Don't you think that is a lot?" (Chase, 2001).

ISSUES FOR PEOPLE LIVING WITH HIV

People who are HIV-positive face many stressful issues in living with HIV. Stressors include coping with a

life-threatening chronic disease; managing their health as well as their care and treatment; making decisions regarding disclosure to family members and members of wider circles in the community; and living in a world that stigmatizes and discriminates against people with HIV. The stressors may exacerbate alcohol and drug use, causing disinhibition that leads to other risky behaviours. In a large U.S. study entitled *HIV Costs and Service Utilization Study* (HCSUS), rates of heavy drinking were twice as high among people in treatment for HIV disease as rates in the general population (Galvan, 2002).

Stigma and discrimination against people living with HIV are well documented. The potential for hostility from intimate partners and others to whom they disclose their serostatus is a reality for many. Of the people interviewed in the HCSUS study, 20% of women, 11.5% of the men who have sex with men, and 7.5% of the heterosexual men reported experiencing physical harm since they had been diagnosed, and nearly half of the violence was attributed to their being HIV-positive (Zierler, 2000).

Women experience more stigma and discrimination than men, as discussed in the earlier section on issues of sexually active women. In a metasynthesis of research on stigma experienced by women with HIV, 80% of the studies sampled contained findings pertaining to stigma. The key finding "was that stigma is virtually synonymous with the experience of HIV infection in women. ...For these women, living with HIV infection meant living with the fear and the hurtful effects of stigmatization." (Sandelowski, 2004, p.124).

The fear, as well as very real possibility of negative reactions from partners, family, social networks, and larger society, reduces the willingness of people living with HIV to disclose their status to others. This not only limits their ability to protect partners from potential exposure, but also deprives them of needed social and emotional support. In a review of studies conducted in developing countries, the fears about disclosing status to partners expressed by women living with HIV (many of whom were pregnant) included rejection, discrimination, accusations of infidelity, divorce, social isolation, violence, shaming the family, worrying others, and being accused of being the source of the disease (Medley, 2004). In the actual outcomes reported by women if they did disclose, these fears were born out, although many also reported positive responses to disclosing. In another review of 17 studies of disclosure to sex partners by HIV-positive men, perceived efficaciousness and the expectation of a positive outcome were associated with disclosure (Sullivan, 2005).

Interpersonal factors influencing whether individuals disclosed included partner support, emotional investment in the relationship, and ability to communicate about safe sex.

Because of the importance of ongoing medical care and support, the ability to communicate with and trust their health care providers is a critical issue for people living with HIV. A survey of people with HIV in Latvia found that many worried about their physicians not respecting their confidentiality, and that confidence in confidentiality was a basic prerequisite for building trusting patient-physician relationships (Sauka, 2000).

Much has been written about both the positive and negative experiences of people living with HIV. In

communities around the world, it has been the presence of community-based programs that provide support to people living with HIV that has made it possible for some people to come forward and tell their stories so that others would know they were not alone. These public voices of people living with HIV have been the most powerful means of sensitizing communities to the realities of HIV; reducing stigma; and increasing the social support that is available for persons with HIV. These voices are also most likely the most effective invitation to people who do not yet know they are living with HIV.

RAPID TESTING TECHNOLOGIES

This paper now turns to a discussion of new technologies and approaches for increasing the proportion of people who receive testing and counselling, including rapid testing technologies, Nucleic acid amplification testing, and provider-initiated testing and counselling (PITC).

These public voices of people living with HIV have been the most powerful means of sensitizing communities to the realities of HIV; reducing stigma; and increasing the social support that is available for persons with HIV. These voices are also most likely the most effective invitation to people who do not yet know they are living with HIV.

BOX 3.1: RAPID TESTING TECHNOLOGIES

- Particle agglutination assays:
 - *Time*: 10 to 60 minutes or more
 - *Procedure*: Results are interpreted visually, requiring subjective interpretation.
 - *Requirements*: Most are used with serum or plasma, but some use whole blood. Reagents may require refrigeration.
 - *Cost*: From US\$2 to US\$4
- Immunoconcentration (flow through) devices:
 - *Time*: 5 to 15 minutes
 - *Procedure*: The specimen flows through a porous membrane which immobilizes HIV antigens and is then absorbed into an absorbent pad. A dot or line visibly forms on the membrane when a signal reagent is applied. Several steps are usually required (the addition of specimen, wash buffers, and signal reagent).
 - *Requirements*: Many are used with serum or plasma, some have a filter or initial dilution step that allows use of whole blood. Refrigeration is usually required.
 - *Cost*: From US\$4 to \$US12
- Immunochromatographic (lateral flow) strips:
 - *Time*: 20 minutes or less
 - *Procedure*: Antigen and signal reagent are both incorporated into a nitrocellulose strip. Many require only a single step. Specimen is applied (usually followed by a buffer) to an absorbent pad or diluted in a vial of buffer into which the test device is inserted. The specimen migrates through the strip and combines with the signal reagent. The appearance of a visual line indicates a positive test. A procedural control is also usually included, so that a visual line only at the control site (and not at the test site) indicates a negative result, a visual line at both sites indicates a positive result, and lack of a visual line at the control site indicates an invalid test. Some tests can differentiate between HIV-1 and HIV-2.
 - *Requirements*: Whole blood, serum, or plasma; some can be used with blood from finger-sticks and with saliva or oral fluids. No additional equipment or refrigeration. Most test strips encased in a plastic cartridge.
 - *Cost*: Usually less than US\$10

Source: Branson, 2003

DESCRIPTION AND USE

A number of rapid tests have been developed that can detect HIV antibodies in whole blood, saliva or urine (over 60 as of 2003). Most are in kits that include the reagents and require no additional equipment. Because no laboratory processing is needed, the test can be conducted at the point of care, often producing a result in 20 minutes (see Box 3.1 for a description of three different rapid testing assay formats).

Rapid tests now have sensitivities and specificities comparable to enzyme immunoassays (EIA). As with the EIAs, the predictive value varies with HIV prevalence and is lower in low-prevalence populations. This is because with fewer true positives a higher proportion of reactive tests are false positive (Greenwald, 2006a).

NEGATIVE RESULTS

A single non-reactive test is considered antibody-negative. Due to the window period between infection and the development of antibodies, however, persons who were exposed to HIV in the three months prior to testing should be counselled to return for a repeat test in three months if the test is not reactive.

CONFIRMATION OF REACTIVE RESULTS

As with the EIA, when rapid tests are used for point-of-care screening purposes, confirmation of reactive results is necessary. In high income countries, the Western blot or immunofluorescent assay is normally used for confirmation, requiring blood to be drawn and sent to a laboratory and the patient to return for results. In low and middle income countries WHO recommendations are more likely to be followed, which involve confirmation with a second rapid test that uses different antigens or a different platform and that demonstrates appropriate levels of specificity and sensitivity (WHO, 2004). This can be done in parallel format (two tests simultaneously) or serially (if reactive, the confirmatory test is done).

QUALITY ASSURANCE

Because test accuracy is critical, standard operating procedures must be instituted and an external quality assessment process must be in place wherever rapid tests are used (WHO, 2004; Greenwald, 2006a). WHO recommends using three complementary methods to assess all programs: an on-site audit to observe that all standard operating procedures are adhered to, records are maintained correctly, and staff perform correctly; distribution of test samples for spot checking of testing; and blinded

rechecking of selected specimens in a reference laboratory. External controls should be run by each new tester on each new lot of test kits; on each new shipment of kits received; and, at periodic intervals depending on the volume of testing done at the site (Greenwald, 2006a). In the U.S., four tests have been licensed by the Food and Drug Administration (FDA). Two are categorized as moderate in complexity and must be performed in laboratories that meet personnel, supervision, quality assurance, and proficiency testing standards. The other two rapid tests have received CLIA (Clinical Laboratory Improvement Amendments of 1988) waivers, meaning that persons with no formal laboratory training can perform the tests outside a laboratory. In order to purchase the tests, however, facilities must register with the CLIA program as laboratories and follow the manufacturer's instructions (Greenwald, 2006a).

COUNSELLING, CONFIDENTIALITY, AND INFORMED CONSENT

The underpinnings of testing and counselling, the three C's, continue to be essential components of testing with rapid tests (WHO, 2004). In addition to the information provided with other forms of HIV testing, counselling associated with rapid testing involves an assessment of whether the person is prepared to receive test results in the same session, understands the meaning of the test results and if they would be willing to return for a confirmatory test in the event of a reactive test.

POINT-OF-CARE VERSUS HOME TESTING

The popularity of the rapid test is that it would be available over-the-counter for self-testing like a home pregnancy test. Rapid testing for point-of-care use, however, has standard algorithms

to ensure that appropriate counselling and laboratory procedures are followed and these algorithms could not be implemented for self-testing in a home testing situation. In the U.S., two home testing kits were licensed by the FDA in 1996 that involve the collection of blood by individuals who then send it to a laboratory and receive the results and counselling by telephone (Wright, 2006). Home testing continues to be a controversial intervention. Concerns include the fact of false positives and false negatives, the need for confirmation of positive results, quality assurance, and the lack of face-to-face counselling and support. These are all part of why home testing has not been licensed in many countries and why a test kit has not been licensed that would provide immediate results in the home.

ADVANTAGES

Numerous advantages have been identified for the use of rapid testing rather than the standard enzyme immunoassays.

INCREASED UPTAKE

Providing same-day results improves testing uptake compared to traditional enzyme immunoassays testing, which requires a two-week turnaround. For example, a randomized, controlled trial compared different types of HIV tests and counselling at outreach programs for people who use injection drugs and for men who have sex with men. With oral fluid testing and rapid blood testing, significantly more people received test results than with traditional HIV testing (Spielberg, 2005).

LOWER FAILURE RATE FOR RETURNING FOR RESULTS

Providing same-day results resolves the problem of clients not returning later to receive test results and post-test counselling. In VCT and antenatal clinics, as many as half of people tested with the enzyme immunoassays do not return for their results (Branson, 2003). Even with rapid tests, wait times can affect whether clients obtain their results. A study of rapid tests in emergency departments found that when the mean wait time was 48 minutes, 20% of patients left compared to 55% when the mean wait time was 107 minutes (Kelen, 1999). Even in countries in which reactive tests require returning for confirmatory results, rapid testing has increased the return rates (Kelen, 1999).

USE IN LOW RESOURCE SETTINGS AND COMMUNITY OUTREACH PROGRAMS

Many rapid tests can be used at sites without laboratory equipment (e.g., centrifuges), refrigeration, electricity, water, or transport to laboratories (WHO, 2004). Thus the kits can be used in street outreach settings, rural areas, and low resource settings. When used for mobile HIV testing in Zimbabwe, 98.8% of the people tested chose to receive their test results on the same day (Morin, 2006). Many had not obtained testing before because of the location of the test site (20%) and inconvenience of the hours the test site was open (25%).

CLIENT CONFIDENCE IN TEST RESULTS

Conducting the test during the clinical or counselling session can increase the client's confidence in the test result. The client can see that the test was done with no possibility of being mislabeled or changed with another specimen (Branson, 2003).

Rapid testing introduces complexities into the process of counselling and testing, especially when one is aiming to ensure that protocols are followed and high standards of quality are met.

COUNSELLING, CONFIDENTIALITY, AND INFORMED CONSENT

The 3 C's are already well established in VCT programs in which trained counsellors provide testing and counselling services. In these venues, the use of rapid testing can be introduced with additional training about the testing process itself. When introduced into clinical settings in which HIV testing has not previously been performed, it may be more difficult to maintain appropriate and adequate counselling, to assure strict confidentiality, and to obtain true informed consent. Even with enzyme immunoassays outside of designated HIV testing clinics with trained staff there is much testing that occurs without counselling and informed consent (Van Casteren, 2004; de Bruyn, 2005). In addition, there is concern about whether sufficient support would be provided to those with a reactive test whose blood is drawn and who must return for results of a confirmatory test (Elliott, 2000). Finally, there is a continuing concern about people having sufficient "decision time or thinking time" when taking a rapid test (WHO, 2004). With up to a two-week waiting period for EIA test results, individuals are able to reflect on and prepare for the potential positive test results. The lack of decision time is of particular concern in venues where people are coming for other services, such as sexually transmitted infections or tuberculosis treatment, and had not previously planned to be tested for HIV.

TRUE INFORMED CONSENT UNDER CONDITIONS OF DURESS

While rapid testing provides tremendous benefits in emergency situations, such as when an untested woman is in labour, most democratic countries as well as UNAIDS/WHO maintain that testing in these circumstances should always be voluntary with informed consent. There is concern as to whether a person under duress, such as a woman in labour, is able to receive all the information needed to make an informed decision, including the purposes of testing, available treatment and support, and the possible consequences of receiving a positive test result (de Bruyn, 2005).

QUALITY ASSURANCE

If sufficient regulation does not occur within a jurisdiction, there are concerns about quality control, including whether only appropriately trained personnel are authorized to do the test, whether confirmatory tests are conducted, and whether standards and procedures are established and followed for quality assurance.

STAFF CAPACITY

Concerns here arise over whether a site has sufficient personnel capacity, including adequate training and expertise both in conducting the rapid test and in counselling the persons being tested. In addition, if confirmatory results will be done by Western blot or IFA, the agency must have staff qualified to draw blood.

NEW APPROACHES TO TESTING AND COUNSELLING

DETECTION OF ACUTE INFECTIONS USING NUCLEIC ACID AMPLIFICATION TESTING

Nucleic acid amplification testing (NAT), a test for HIV-RNA, can be used to identify HIV- infected individuals early in the infection process before antibodies have developed, during what has been called the “window period.” Developed in 1999, NAT detects viral RNA in blood during the initial acute phase of HIV infection (Pilcher, 2005).

NAT is used to screen-donated blood, but in the past has been considered too expensive to be used in most other circumstances as a screening test. It can be used, however, in a cost-effective manner with pooled batches of specimens that have tested negative, in order to detect HIV in blood from individuals in the “window period.” HIV-RNA levels are very high in individuals during the acute phase of infection resulting in a higher potential of HIV transmission (Cohen, 2005). Thus, identifying individuals during this period has great potential for reducing HIV transmission.

NAT technology has been applied in state and local health departments in the U.S. to identify people in the acute infection phase, and to initiate their notification. The potential benefit of this approach was illustrated by a one-year study comparing the diagnostic performance of standard HIV antibody tests with retesting of antibody negative samples using NAT in state-funded sites in North Carolina (Pilcher, 2005). Out of 109,250 tests, 108,667 were antibody negative and among these, 23 acute HIV infections were detected using NAT (an additional two were false-positive). When individuals were notified of

their results (74% within 72 hours after test results became available), 21 initiated special medical care and 20 were prescribed antiretroviral therapy, including a pregnant woman whose child was HIV-negative. Furthermore, 48 sexual partners received counselling and 18 of these were HIV-positive, newly detected in five individuals. In another at the San Francisco City Clinic study, 11 acute HIV infections were detected over an eight-month period, for a prevalence rate of 36 per 10,000 (Patel, 2006). The diagnostic yield of HIV- positive individuals was increased by 10.5%. Many local health departments are beginning similar programs, including public health in Baltimore, Maryland, which has the fifth-highest number of AIDS cases in the US.

USING RAPID TESTING IN COMMUNITY OUTREACH PROGRAMS

DESCRIPTION AND USE

Rapid testing technologies greatly expand the potential for increasing uptake of HIV testing and counselling. This is especially true in community-based settings designed to reach individuals who are unaware of their HIV status, in particular marginalized people without easy access to health care settings.

BENEFITS

With various provisions and WHO guidelines in place, studies have found the use of rapid testing in community outreach settings feasible for a number of reasons. First, it increases the rates of testing and rates of learning test results. In a study conducted in Zimbabwe, for example, where free anonymous mobile VCT was provided in marketplaces, the demand for

testing often exceeded the capacity of the researchers to provide testing and counselling (Morin, 2006). Another study of on-site counselling and rapid HIV testing in drug treatment programs in the U.S. found that test results were provided to all but one of 735 persons (Keenan, 2001). Compared with the fact that 48% of persons tested at publicly-funded VCT programs failed to return to learn their test results in the U.S. in 1998, the study's 99.9% rate of learning serostatus is a great improvement.

The use of rapid testing in community outreach settings is also more effective in accessing populations with higher rates of HIV infection compared to clinic-based test sites. Again in Zimbabwe, a study of the use of rapid testing and counselling in workplaces showed that it achieved a mean test rate by site of 51% when testing was conducted onsite compared to only 19% when testing was provided offsite using vouchers (Corbett, 2006). Street-based or mobile use of rapid testing and counselling has the potential to reach people at higher risk of HIV than point-of-care testing. In the aforementioned study of mobile testing in Zimbabwe, outreach in the two community settings identified a higher rate of HIV-positive people (29%) than the proportion identified at clinic-based sites in Harare (17%) (Morin 2006). The authors speculate that areas of high migration are likely to yield higher rates of HIV infection.

ISSUES AND CONCERNS

Concerns regarding the use of rapid testing technologies in community-based settings have to do with the potential for mismanagement and abuse. Even in highly controlled institutional situations, there is documentation of people being tested

with EIAs or receiving rapid testing without counselling, informed consent, or protection of confidentiality (Van Casteren, 2004; Schrooten, 2004; Chase, 2001; Surlis, 2001; Klosinski, 2000). (For further discussion, see Issues and Concerns about PITC under Provider-Initiated Testing and Counselling outlined below). In settings without strong policies requiring counselling, informed consent and confidentiality, with few resources for personnel training, and with less structure or opportunities for quality assurance and monitoring, these risks may be higher.

PROVIDER-INITIATED TESTING AND COUNSELLING (PITC)

DESCRIPTION AND USE

HIV testing and counselling that is offered by health care providers in the context of medical services is called *Provider-Initiated Testing and Counselling (PITC)* to differentiate it from client-initiated counselling and testing that is offered in dedicated voluntary counselling and testing centres.

In some health settings, providers conduct an HIV risk assessment with each patient, and if any potential exposure to HIV (through sexual activity, drug use, history of transfusions, etc.) is noted, they would offer HIV counselling and testing. Key to this system of testing is assessing the person's level of risk. In other settings, HIV counselling and testing is offered by providers to all their patients rather than only to those assessed as being at risk. This strategy has been used with pregnant women, in settings in which a higher proportion of individuals are at risk than in the general population, such

as sexually transmitted infection clinics, and in geographic areas of high HIV prevalence. PITC is being examined in both high and low prevalence countries as a strategy for promoting more widespread testing and counselling for patients seen in a variety of settings, such as genitourinary medicine and sexually transmitted infection clinics, tuberculosis clinics, emergency and urgent care departments, community-based clinics, and sites where people who inject drugs receive treatment.

OPT-IN VERSUS OPT-OUT PITC

PITC is currently being delivered using both opt-in and opt-out approaches. The opt-in approach provides a routine, universal offer of testing to all patients, but the test is only done if patients indicate that they would like an HIV test. The opt-out approach incorporates HIV testing into standard clinical workups and patients are informed that the test will be done unless they decline. This is also called routine testing with the right to decline. Both strategies are being studied. The first use of PITC for routine testing with the right to decline (opt-out testing) was with pregnant women, among whom it has been widely promoted as an intervention to help prevent perinatal transmission. Recommendations for routine testing with the right to decline continue to stipulate that testing be offered voluntarily with the person's informed consent, but the amount of counselling is reduced (UNAIDS/WHO, 2004). Rather than pre-test counselling, patients are provided with information to make an informed decision about being tested, such as the benefits of being tested and the right to refuse (see Box 1.2).

BENEFITS OF PITC

PATIENT ACCEPTANCE AND INCREASED UPTAKE

The most important advantage of the PITC strategy is that it increases uptake of testing and counselling. Studies indicate that a high proportion of patients find PITC an acceptable intervention. In a sexually transmitted infection clinic in the U.S., for example, HIV was added to the tests offered to all patients, who were informed at registration and given an informed consent form to read and sign (Campos-Outcalt, 2006). Each person who signed the form was provided counselling during the clinical encounter (which consisted of answering the patient's questions regarding the test and providing general prevention information). Sixty-eight percent of patients accepted testing, and 5.6% of those tested were seropositive.

A study of routine testing at a genitourinary clinic in the U.K. also demonstrated that patients will accept HIV testing and counselling when it is offered (Lee, 2005). A population-based study in Botswana indicated that most people (82%) were extremely or very much in favour of routine testing (Weiser, 2006). Respondents felt a policy of routine testing would decrease barriers to testing, and violence towards women (55%), and increase access to antiretroviral therapy (93%).

In a rural hospital in Uganda, when opt-out HIV testing was introduced into the antenatal clinic program and the maternity ward to prevent mother-to-child transmission, acceptance of testing and counselling in the antenatal clinic was 97% in both women and their accompanying men, and in the maternity clinic, acceptance was 86% in women and 98% in their

accompanying men (Homsy, 2006). The change resulted in an increase in detection of HIV infections of 12%. When opt-out testing and counselling was introduced into perinatal care services in Botswana, the proportion of women tested went from 75.3% to 90.5% (CDCP, 2004).

The implementation of an opt-out prenatal HIV testing policy has resulted in a significant increase in the number of women being testing for HIV infection in Canada (Jayaraman, 2003; Walmsley, 2003; Mossman, 2002). In Alberta, in the month immediately following the adoption of opt-out prenatal HIV testing, the testing rate increased by 28%. Over the following two years (1999 and 2000), the average annual percent increase in the number of HIV tests among females was 1.4%. (Jayaraman, 2003).

Many guidelines now recommend that all pregnant women be offered HIV testing on an opt-out basis based on the increase in testing rates associated with this approach. Since many women who test positive do not perceive that they have risk factors and might decline testing, the approach has enabled an increase in the prevention of perinatal HIV transmission. It must be noted however that in Ontario, Canada, the opt-in testing and counselling policy for pregnant women delivers results comparable to most opt-out policies.

INCREASED TESTING AMONG PEOPLE WHO DO NOT KNOW THEY ARE AT RISK

Many people, especially women, who do not know they have been exposed to HIV, would neither seek out testing nor be offered testing based on a risk assessment. In one study of women with HIV, 90% did not know they were at risk for HIV before they were tested (Jackson, 1997). In the U.K., which had a recommended

opt-in policy in antenatal clinics, 560 pregnant women were surveyed (Campbell, 2003). Only 23% had an HIV test while 77% declined. Women who declined did so because they did not feel they were at risk for HIV. Their responses to the knowledge questions indicated that they had poor understanding of HIV transmission.

DECREASED STIGMA ASSOCIATED WITH BEING TESTED

One argument currently being advanced is that when testing and counselling are offered to everyone, individuals do not feel singled out as “at risk” for HIV. Thus, the stigma of being tested will be lessened if everyone is offered the test and many people are tested. In one patient survey, 60% of respondents felt that routine testing would reduce the stigma of getting tested (Weiser, 2006). Interviews with most persons tested anonymously in a mobile VCT program in marketplaces in Zimbabwe mentioned the stigma of being tested as a factor discouraging HIV testing (Morin, 2006). While the above studies point to the importance of addressing stigma, there is insufficient evidence to support the hypothesis that routine testing reduces stigma and discrimination.

IDENTIFICATION OF PEOPLE WITH HIV EARLIER IN THE DISEASE PROCESS

An obvious benefit of PITC is that increasing the amount of testing in medical facilities increases the likelihood of diagnosing people earlier in the disease process. In a comparison of people who were tested for HIV in hospital settings and those who were tested in outpatient settings on a routine basis in the U.S., 79% who tested positive as inpatients were diagnosed with AIDS, while only

26% who tested positive as outpatients had AIDS (Greenwald, 2006b). The authors conclude that routine testing identified individuals in outpatient settings who would not otherwise have been diagnosed.

While most experts agree that all HIV testing should be voluntary, the element of choice is different when a person initiates testing at a VCT program and when a person seeks medical services and is then offered testing.

ISSUES AND CONCERNS ABOUT PITC

CHOICE AND INFORMED CONSENT

The issue of whether appropriate informed consent will be obtained is a key concern regarding opt-out counselling and testing. HIV testing and counselling in the context of health care services is different from dedicated VCT programs in health departments and community-based settings. While most experts agree that all HIV testing should be voluntary, the element of choice is different when a person initiates testing at a VCT program and when a person seeks medical services and is then offered testing. In Belgium, where general practitioners can perform HIV tests without legal restrictions on patient consent “it is well known that diagnostic HIV testing without informed patient consent is unethical and against European guidelines” (Van Casteren, 2004). Nonetheless, in an eight-year survey of PITC in Belgium, at least 35% of general practitioners

performed at least one non-consensual HIV test (Van Casteren, 2004). A large-scale survey of the experience of people with HIV in Europe found that 14% were tested without their consent (Schrooten, 2001).

Despite recommendations by UNAIDS, WHO, and many national health ministries that PITC be voluntary with informed consent, some countries, such as Peru and Singapore, have instituted mandatory HIV testing of pregnant women (de Bruyn, 2005). Even in countries in which prenatal HIV testing is not mandatory, it can be coercive. Indeed, some cases may involve pressuring women not only to be tested but also to terminate pregnancies and to be sterilized if they are HIV positive. Women have reported these experiences in key informant interviews in India, Zambia, Ukraine, and Burkina Faso (Chase, 2001). In this four-country study of stigma, women in Ukraine reported being tested without their consent as well as having their pregnancies terminated against their will by physicians. In addition, nurses would disclose HIV test results to others in the community, causing women to be subjected to abuse, rejection and abandonment.

COUNSELLING

As PITC becomes the standard of care in busy clinics, there is a risk that not only informed consent but also counselling, even post-test counselling will be lost to other priorities. In a survey of clients seen at two London genitourinary medicine clinics, 92% of respondents indicated they wanted to know the results of their laboratory tests (Patel, 2006). In a move toward greater efficiency, however, nearly one fourth of London clinics would only inform clients of positive results. In a

survey of 1,366 people with HIV in Europe, over half of respondents reported they did not receive adequate support when they were told their test results (Schrooten, 2001). Fifteen percent were informed that they were HIV- positive over the telephone or by mail. Of those who were told the results in person, the clinical visit lasted longer than 20 minutes for only 30% of the respondents. For 35% of them, the visit was between 10 to 20 minutes, and for 26%, the visit lasted less than 10 minutes.

A significant concern about opt-out testing is that a certain proportion of people tested do not return for their test results. One interpretation is that individuals may be uncomfortable refusing to be tested, and simply vote with their feet. Another interpretation is that because they did not arrive with the intention of obtaining an HIV test, their motivation to return for results is not high. A third interpretation, and certainly one that applies in developing countries and/or remote locations, is that logistics, primarily the difficulty of travel, make returning to a clinic prohibitively difficult. In Botswana, where testing rates of pregnant women increased by 15% in the first month after the institution of opt-out testing, many women never learned their HIV status because their perinatal care and deliveries occurred in remote

communities (Weiser, 2006). In rural Malawi, when opt-out testing was instituted in a program to prevent mother-to-child transmission, 95% received testing and counselling and only 1% refused testing. Because 87% of deliveries occurred at peripheral sites, the loss to follow up by delivery was 68% (Manzi, 2005). Only 45% of HIV-positive mothers and 34% of babies received the prophylactic ART protocol, Nevirapine. As mentioned above, rapid testing technologies may alleviate the problem of not returning for test results.

Another concern expressed by many about opt-out perinatal counselling and testing is that sufficient counselling may not occur. In a Canadian tertiary care centre in which routine opt-out PITC was instituted, the staff expressed concerns regarding the capacity to handle the burden of counselling (Gruslin, 2001). An interdisciplinary approach was taken in which the specialized team of physicians, nurses, social workers and psychologists were all incorporated into the counselling process. The initial step was the institution of a departmental policy, followed by an educational session for all professional staff. An informational brochure was developed for patients, providing an additional staff tool.

SECTION FOUR: ASSOCIATION OF COUNSELLING AND TESTING MODALITIES WITH BEHAVIOURAL CHANGE AND REDUCED HIV TRANSMISSION

OVERVIEW

Some modalities for conducting voluntary HIV counselling and testing have been studied more extensively than others. This section examines what is known about the impact of counselling and testing modalities on behaviours associated with preventing transmission, testing rates, and where possible, rates of HIV transmission.

In a review of the literature, two key findings stand out as having a bearing on policy regarding testing and counselling. First, PITC has been shown to increase the number of people tested, and PITC with the right to decline has been associated with the highest proportions of individuals tested (Anderson, 2005; CDCP, 15 Nov 2002; CDCP, 26 Nov 2004). This strongly suggests that the changes in HIV- testing policy that are currently being discussed and studied could significantly lower the proportion of people with HIV who do not know their serostatus. However, as was discussed in Sections One and Three, stigma and discrimination continue

to be issues for people with HIV. The reports of persons being tested without consent in settings where informed consent is a prerequisite attest to the difficulty of maintaining protections within medical institutions.

testing and counselling have been shown to be an effective intervention for risk behaviour change primarily for individuals who learn they are seropositive.

The second finding is that testing and counselling have been shown to be an effective intervention for risk behaviour change primarily for individuals who learn they are seropositive. In numerous studies, people change their behaviours after learning they are HIV-positive (Marks, 2005; Weinhardt, 1999). Conversely, counselling and testing individuals who learn they are HIV- negative, unless they are in a relationship with someone who is HIV-positive, do not seem to lead to significant changes in risk behaviour (Weinhardt, 1999). This finding emphasizes the value of establishing a supportive, non-stigmatizing environment for people living with HIV. Within this context, it becomes equally important to provide HIV clinical care in which each person can develop an ongoing, trusting relationship with the health care providers.

"Ultimately it is essential to bear in mind that no single HIV prevention program, particularly a relatively brief intervention such as HIV CT, should be expected to directly lead to the initiation and maintenance of behaviour change among all participants. Motivating individuals to change their HIV risk behaviours is best achieved by comprehensive efforts that provide for repeated intervention contacts across multiple settings using a range of intervention strategies and messages. The ultimate goal of these efforts should be to change the behaviours and norms of entire communities in a manner that will perpetuate the reinforcement of HIV risk-reduction and help-seeking practices of at-risk community members." (Wolitski, 1997, p. 65)

The challenge of establishing effective counselling and testing modalities to generate changes in behaviour or reduce the incidence of HIV is due in large part to the fact that human behaviour does not exist in a vacuum. Research primarily focuses on discrete interventions under controlled conditions and most of what is presented in this section is the result of randomized controlled trials. What is now needed is outcomes-based research that can examine the interrelationship of interventions and conditions that contribute to individual and collective behaviour.

EFFECT OF HIV COUNSELLING AND TESTING ON BEHAVIOURAL CHANGE

A review of 35 studies published between 1991 and 1997 assessed the scientific data regarding the ability of HIV counselling and testing to motivate changes in risk-related practices and to promote help-seeking behaviour (Wolitski, 1997). The most consistent evidence of beneficial effects was with heterosexual HIV-serodiscordant couples. In addition, persons who learned during counselling that they were HIV seropositive were more likely to adopt risk-reducing practices than persons who learned they were seronegative. Methodological weaknesses and wide variations in study populations limited the ability of the authors to come to strong

conclusions. Just over half the studies provided positive evidence that HIV counselling and testing could motivate the adoption of risk-reducing practices, but the other studies did not. In many studies, the target population itself seemed to be an important factor in success. Studies differed dramatically in the amount of education and counselling that accompanied testing, reducing the value of their comparison.

A meta-analysis of 27 published studies of HIV counselling and testing interventions promoting reductions in sexual risk behaviour concluded that HIV counselling and testing can facilitate behavioural change among individuals found to be seropositive as well as among serodiscordant couples, but is not an effective primary prevention strategy for uninfected individuals (Weinhardt, 1999). The review found that those who were seropositive and discordant couples reported more behavioural change (reduced unprotected intercourse and increased condom use) than those who learned they were HIV-negative. In fact, HIV-negative participants reported no more change in sexual behaviour than participants who were not tested at all.

A more recent systematic review of the literature conducted to examine the risks and benefits of HIV screening concluded that the benefits of screening outweigh the risks (Chou, 2005). The methodology did not provide a

definition for screening, but the term seemed to refer to HIV testing in a health care setting, with a risk assessment conducted in conjunction with testing followed by counselling about risk reduction and other relevant topics for those found to be seropositive. The review addressed a series of questions designed to examine various components of the screening process, one of which was testing plus counselling interventions. In about half of a group of randomized trials, counselling that was tailored to participant needs or was more intensive was associated with greater reductions in risky behaviours than standard or less intensive counselling, but counselling methods varied greatly across trials (Rotheram-Borus, 2004; Rotheram-Borus, 2001; Wingood, 2004; Fogarty, 2001; Kalichman, 2001).

In terms of drug injecting behaviour, cross-sectional studies found that HIV-positive people who use drugs reported less risky behaviours than untested or HIV-negative people who use drugs (Desenclos, 1993; Schlumberger, 1999; Celentano, 2001). In a randomized clinical trial and a prospective study, counselling and testing was not associated with decreased drug behaviours but in two other randomized clinical trials more intense counselling reduced drug use behaviours to a greater extent than standard counselling (Rotheram-Borus, 2004; Margolin, 2003).

A systematic review of the literature found that no clinical trials compared counselling and testing with an absence of testing and counselling on the rates of HIV transmission (Chou, 2005). The review does, however, cite a U.S. study of serodiscordant heterosexual couples, which documented no seroconversions in 193 couple-years of follow-up after receiving counselling and which

reported a reduction of risky behaviours. An African study of serodiscordant couples found a seroconversion rate of six to nine per 100 person-years in uninfected women with HIV-positive partners compared to a rate of 22 per 100 person-years in uninfected women whose partners were untested. In two observational studies, testing and counselling was associated with a decrease in STIs in seropositive individuals and with an increase in those who were seronegative. In two randomized clinical trials, more interactive counselling was more effective than standard counselling in reducing STI rates in women with HIV and in seronegative heterosexual persons. The number of new HIV infections was too small to detect differences in HIV rates.

While many of the components of counselling and testing interventions have been studied and evaluated, little is known about the actual effect of the testing itself on HIV transmission rates. Much of the research has been conducted in perinatal screening, one of the first settings in which HIV testing was utilized in a routine fashion. In this unique setting, however, testing is followed by a discreet medical intervention (receipt of antiretroviral agents), restricted in time and place. Thus, this does not inform programs or research evaluating the effect of testing on other transmission modalities.

RESEARCH ON COUNSELLING MODALITIES USED WITH TESTING

The type and range of counselling interventions is broad and complex in terms of factors such as theoretical underpinnings, professional skills and level of training of the counsellors, amount of time and number of sessions required, and location of service delivery. A review of the

concepts, goals, and techniques of different counselling approaches being used in the U.S. identified five tasks of counselling - relationship building; risk assessment; dissemination of information; behavioural change; and emotional and coping support (Sikkema, 1997). The authors found that no HIV counselling and testing program was actually able to achieve all of the tasks. In-depth interviews with Canadian health care providers who give HIV test results identified the following five best practices considered to be important: ensuring information and education for HIV risk reduction; individualizing risk assessment; ensuring test results are given in person; providing information and referrals; and facilitating partner notification (Myers, 2003). Other necessary but non-HIV-related practices included building trust and rapport; maintaining professional boundaries; ensuring a comfortable, safe environment; ensuring confidentiality; imparting a nonjudgmental attitude; and self-determination.

A review of HIV prevention programs for heterosexuals assessed 32 programs, each with a comparison group (Rotheram-Borus, 2000). The authors identified three types of interventions that resulted in changes in risk behaviour, the most common being counselling interventions that are based on social cognitive theories and that focus on improving HIV-related knowledge, attitudes, and practices. Such counselling interventions have had different results in different settings. The second type of intervention, the treatment of sexually transmitted infections, used biological markers as indicators of success. In sexually transmitted infection clinics, counselling interventions led to changes in risk behaviours in both

the treatment and control groups, suggesting that the process of conducting a risk assessment can lead to short-term change. In addition, single-session counselling in sexually transmitted infection clinics led to reduced rates of sexually transmitted infection for 6 months compared to negative results from single-session counselling in other settings. The third type of intervention found to be effective was pre- and post-test HIV counselling.

A randomized controlled trial of HIV prevention interventions varying in intensity found that both a workshop intervention (with skills training) and a community-level intervention (with skills training and engagement in neighbourhood-based HIV prevention activities) produced and maintained reductions in two measures of sexual risk behaviour (Sikkema, 2005). The control (an education-only intervention) was not as effective as either the workshop or community-level intervention, and furthermore, the community-level intervention was found to be more effective than the workshop intervention. The authors conclude that changes in behaviour require environmental and normative supports to maintain the changes over a sustained period of time.

A large-scale randomized clinical trial also determined that didactic counselling did not increase self-reported condom use or decrease rates of sexually transmitted infections as well as brief or enhanced counselling (Kamb, 1998). Conducted in STI clinics in five U.S. cities, this study compared two interactive counselling interventions with a control involving provision of standard educational messages. The brief counselling intervention consisted of two 20-minute sessions. The first session was a discussion of the HIV test

result, risk assessment, identification of barriers to risk reduction, and negotiation of an acceptable and achievable risk-reduction plan, and support for patient-initiated behavioural change. The second session involved progress made in the behavioural change and discussion of barriers, facilitators, and longer term risk reduction. The enhanced counselling intervention was conducted in four sessions, the first being 20 minutes and the last three being 60 minutes. The first three sessions involved addressing self-efficacy, attitudes and perceived norms regarding condom use. HIV test results were given at the third session, and concluded with a behavioural goal-setting exercise in which the participant selected an achievable risk-reduction step. The fourth session involved developing a longer term risk reduction plan.

A meta-analysis of studies comparing high-risk sexual behaviour among people who are either aware or unaware that they are infected with HIV found that the prevalence of high-risk sexual behaviour is reduced substantially after learning they are HIV-positive (Marks, 2005). This finding has supported the recent focus on identifying people who are not yet aware of their HIV seropositivity and on developing prevention programs for people who are HIV- positive.

A systematic review of studies of HIV prevention interventions for people living with HIV determined that the interventions associated with efficacy in reducing sexual risk behaviours had the following characteristics (Crepaz, 2006):

- based on behavioural theory
- focused specifically on HIV transmission risk behaviours (more than 2/3 of sessions)

- provided skills building (e.g., correct condom use, problem-solving)
- delivered by health care providers or professional counsellors
- delivered to individuals on a one-to-one basis
- delivered in an intensive manner (more than 10 sessions or 20 hours total)
- delivered over a long duration (greater than 3 months)
- delivered in settings where people with HIV receive services
- addressed a myriad of issues related to coping with one's serostatus, medication adherence, and HIV risk behaviour.

Another meta-analysis of randomized controlled trials of sexual risk reduction interventions for persons living with HIV examined interventions according to the type of risk reduction objective (Johnson, 2006). For those using condom use as a risk reduction behaviour, the interventions were more successful with younger rather than older participants, with participants who were not men who have sex with men, and if the interventions included not only information but also motivational and behavioural skills components (rather than only one or the other). For trials using reduction of number of sexual partners as risk reduction behaviour, there was no change in behaviour based on the interventions compared to participants in the control group.

Finally, drug treatment is a modality that has been shown not only to decrease risky behaviours that lead to HIV infection but also to reduce HIV incidence (IOM, 2001; Auerbach, 2006). Programs for opiate addiction using methadone as substitution treatment have been most widely studied in this regard, but

buprenorphine is also now widely used. A prospective study of people who use injection drugs and who are addicted to opiates documented an HIV seroconversion rate of only 3.5% in persons in continuous drug treatment over the 18-month period compared to a rate of 22% in the people who remained out of treatment during that time (Metzger, 1993).

PARTNER NOTIFICATION

Partner notification inevitably involves a balancing of the individual right to privacy and autonomy with the broader public health prevention ideal, and that, on the whole, those involved voluntarily choose to cooperate with partner notification.

Notifying the sexual and drug-using partners of people who are HIV-positive can be an important means for identifying more people who are HIV-positive but may not know their status. In addition, reaching and educating those who are not yet infected enables them to prevent infection. Partner notification also has the potential to be an effective tool in identifying newly seroconverted individuals. According to numerous studies cited by the European Partner Notification Study Group, one in four people not previously known to be positive and who are tested during partner notification efforts is found to be HIV-antibody positive (EPNSG, 2001). The Concerted Action on HIV Partner Notification was established in Europe in the middle 1990s to document the process of partner notification, emphasizing current partners and recent seroconverters. The study found that half of the newly HIV-diagnosed IPs had a previous negative HIV test, with 60% having seroconverted in the last two years. The review also determined that the

health care worker who informed the person of the positive test results, defined as the index health care worker or iHCW, is key in gaining the willingness of the person to provide information on partners (EPNSG, 2001). A follow-up review of the partner notification process for 356 newly diagnosed persons with HIV in six European countries found a higher yield of HIV diagnoses among recent seroconverters (38/100 or 38%) than among persons who already knew their HIV status (52/190 or 27%) (EPNSG, 2001). Given the potential for higher transmission rates due to high viremia in recent seroconverters, the authors propose new strategies to improve case-finding in this population: prioritization for notification of partners of recent seroconverters; strengthened surveillance for HIV diagnoses, augmented surveillance for future HIV diagnoses in at-risk partner notification-untested individuals and for their recurrence in other partner notification networks; simple worksheets for more careful computing of seroconversion date using last seronegative HIV test; and new partial-identifier measures to alert potential and past sexual partners of newly HIV-diagnosed individuals who are unable or unwilling to assist in partner notification.

Partner notification in the United States is highly variable in its success, depending not only on the program, but also on the demographics of the persons interviewed. A national review of programs found that HIV partner notification programs interact with a minority of persons with HIV (Golden, 2004). Health departments often depend upon referrals from physicians or clients. Of the jurisdictions that responded to the study, only one third of newly diagnosed persons with HIV were interviewed for partner notification (of the jurisdictions that

responded to the study). Partner notification was most successful among people who use injection drugs and heterosexuals. Another study found that one half of physicians surveyed reported HIV- positive results to the health department, while one third instructed the patient to do so and to provide the health department with partner information. Only 9% to 16% of health providers reported information on partners to the health department (St Lawrence, 2002).

A review of the research on partner notification of people with HIV identified the following five key findings (West, 1997):

- people with HIV are generally cooperative in identifying at least some of their sex partners;
- sex partners who are notified by the person with HIV or the health department usually seek HIV testing;
- referral by the provider is probably more effective than referral by the person with HIV, particularly for individuals with multiple sex partners;
- sex partners often have not known or been clear about their risk of HIV; and
- the rates of seropositivity among sex and drug-using partners of people with HIV are high, ranging from 5% to 56%.

A program being tested in the U.S. is patient-initiated STI/HIV partner notification through the Internet. It enables individuals to send e-mails to past contacts either personally or anonymously through an informational website. Launched in 2004, the San Francisco site receives 750 visits a day and 36% of the persons who receive e-mails click through for more information on STIs and test sites. Internet Sexuality Information Services

(ISIS) is a non-profit organization that provides an eCard notification service, inSPOT (www.inspot.org), in a growing number of U.S. cities, as well as in Romania.

FACTORS AFFECTING COUNSELLING AND TESTING

A review of articles looking at rates and determinants of counselling and testing acceptance in a range of health care and other facilities found that high acceptance rates were associated with factors that include protection of confidentiality; counselling and testing offered routinely rather than as an option; and an attitude in health providers that counselling and testing are of benefit to the person (Irwin, 1996). Lower acceptance rates were associated not only with persons having been tested before and having fears about positive test results, but also with informed consent being explicit.

Other factors affecting counselling and testing include the following:

HEALTH PROVIDER ATTITUDES

Research on health provider attitudes towards HIV testing, much of which has been conducted in relation to perinatal HIV testing, suggests that attitudes have an important impact on whether health providers offer patients HIV testing. A random survey of perinatal providers in Ontario, Canada found that although less than half were aware of Ontario's policy of offering HIV testing to all pregnant women regardless of risk, 85% generally offered or ordered HIV testing for all pregnant women (Guenter, 2003). The strongest predictors of high prenatal HIV testing rates in Ontario, where opt-in counselling and testing are used, were attitudes and practices that favoured a routine approach to testing and placed

little emphasis on informed consent. While 76% of the perinatal providers believed counselling should accompany testing, 44% did not agree that women should have a choice about being tested, and 72% felt HIV testing should be similar to Hepatitis B testing, which is usually done routinely without counselling or consent. Twenty percent of those surveyed reported ordering the test for all women without giving them an option, and 65% offered the test to all women. Six percent offered no HIV testing to any women, while 10% offered testing to selected women. Most did not perceive much risk associated with testing. While 62% anticipated moderate to high anxiety while the woman waited for test results, only 28% thought a positive result would cause her difficulty obtaining medical care and 24% believed simply having a test done could result in being denied life insurance. Generally, midwives perceived more risks associated with HIV testing than physicians and agreed more strongly than physicians about providing information and choice.

those who felt that the local prevalence of HIV justified universal counselling were ten times more likely to routinely offer screening, after controlling for provincial policy or regional HIV prevalence.

A Canadian survey of physicians and obstetricians found that the existence of provincial recommendations was a strong predictor of whether physicians offered HIV testing routinely to all patients. This was true even after controlling for reported prevalence

and for physicians' perception of whether HIV prevalence in their own practice justified universal counselling (O'Connor, 2002). Three factors had important effects on health provider behaviours. First, those in provinces with routine screening or a formal policy to offer or recommend screening were almost six times more likely to routinely offer screening. Second, those who felt that the local prevalence of HIV justified universal counselling were ten times more likely to routinely offer screening, after controlling for provincial policy or regional HIV prevalence. Third, physicians in regions with higher HIV prevalence were significantly more likely to agree that universal counselling was justified. In another study conducted prior to the provincial recommendation of universal prenatal HIV counselling and screening in Ontario, a tertiary care centre was able to increase prenatal HIV counselling and screening rates from 13% to 72% by implementing a departmental policy of offering counselling and testing routinely and providing patient information (Gruslin, 2001). The departmental policy initiated HIV counselling (by nurses, residents and attending physicians) and voluntary testing of antenatal patients.

HEALTH PROVIDER CHARACTERISTICS

Health provider characteristics are also associated with whether patients accept PITC. In a perinatal setting, both the time that was spent counselling patients and the individual HIV counsellor best predicted which women would agree to be tested (Sorin, 1996). The health care providers of women who declined testing in perinatal settings in Alberta, Canada under an opt-out approach tended to be female, midwives, non-obstetrical medical specialties, and

general practitioners (Wang, 2005). In a large-scale survey of prenatal care providers in four different areas of the U.S., 95% to 99% of respondents reported that they offered HIV testing to all pregnant women, but the average percentage of their patients actually tested ranged from 64% to 89% (Anderson, 2005). Reporting that all patients were tested was positively associated with how strongly testing was encouraged and specifically encouraging testing of women thought to be at low risk. In some areas, lower rates of universal testing were reported among obstetric physicians and residents, and nurse-midwives than among family practice physicians and residents.

The strong focus on perinatal screening to prevent mother-to-child transmission throughout the 1990s has increased HIV testing of pregnant women. Health providers have not been as concerned with offering testing to other patients. A national survey of physicians in the U.S. found that only one fourth screened women or men for HIV, although 30% of physicians screened pregnant women and 81% of obstetricians and gynecologists screened pregnant women (St Lawrence, 2002).

PATIENT CHARACTERISTICS AND ACCEPTANCE OF COUNSELLING AND TESTING

Patient characteristics have been found to have effects on acceptance of PITC. In a study of women offered HIV testing on an opt-in basis at a London antenatal clinic, the intent to be tested was most strongly associated with (1) the woman's perception that the test would benefit her, her partner, and the midwife; (2) being young; (3) being single; and (4) not understanding well how HIV is transmitted sexually (Meadows,

1993). In a study of Canadian women receiving prenatal care in clinics using the opt-out approach (routine testing with the right to decline), only 1.5% of women declined (Wang, 2005). Age was a factor as women who declined tended to be older. In addition, the rate of non-acceptance was double among First Nations women, especially when under the care of male health providers. In-depth interviews with another cohort of Canadian women about their experiences of HIV screening in pregnancy revealed that patients have a wide range of opinions and reasons for being tested or not, suggesting that an individualized approach is important (Katz, 2001).

A review of the literature regarding rates and determinants of acceptance of counselling and testing in a range of settings found that rates varied widely, even in settings which were similar (Irwin, 1996). Persons at higher risk of HIV were more likely to accept counselling and testing than persons of lower risk. Factors associated with acceptance included personal perception of risk, acknowledgement of risk behaviours, assurance of confidentiality, the presentation of counselling as "routine rather than as optional," and the health provider's belief that counselling and testing would benefit the client. Factors associated with refusal included fear about coping with positive results, prior testing, and the need for explicit informed consent.

USE OF OPINION LEADERS AND SOCIAL NETWORKS

In contrast to most outreach and HIV prevention efforts that focus on personal factors to facilitate behavioural change, one set of approaches capitalizes on the social context within which the person

functions to provide motivation and reinforcement. Working with social networks and opinion leaders has been found useful with groups of people who tend to be close-knit and who have a well-developed culture, such as men who have sex with men, people who use injection drug users, and youth.

The social network technique, recently pilot tested in the U.S. in community-based organizations, uses clients of an agency who are either at risk for HIV or already HIV-positive (CDC, 24 Jul 2005). These individuals (recruiters) are trained and then asked to contact other members of their social group (network associates) whom they assess as being at risk and likely not to know their HIV status in order to encourage them to access counselling, testing and referral. In all, the pilot test was based in nine sites that worked with 133 recruiters who were able to reach out to an additional 814 people (network associates) to be counselled and tested. The recruiters were 60% male, 32% female, and 8% transgender. Seventy-seven percent were seropositive and 16% were HIV- negative but at high risk. Sixty-six percent were non-Hispanic black and 26% were Hispanic. Forty-one percent were heterosexual at high risk, 29% men who have sex with men, 11% were both men who have sex with men and people who use injection drugs and 9% were heterosexual injection drug users. The outcome of counselling and testing of the network associates revealed that 82% were HIV- negative at high risk, 10% were HIV- negative at low or unknown risk of becoming infected, 6% were newly identified as HIV-positive, and 2% had already been diagnosed seropositive, and 1% did not have results available. The group of network associates recruited by transgendered people and men who

have sex with men had the highest prevalence of HIV infection: men who have sex with men/injection drug users (26%), transgendered persons (20%), and men who have sex with men (16%).

MASS COMMUNICATION

Media campaigns (posters on buses and billboards, radio messages, advertisements in community papers, public statements by politicians, popular singers, or other opinion leaders) have been used in many places to promote counselling and testing. A review of studies evaluating mass media interventions to promote VCT and sustain test-seeking behaviour was conducted in order to assess the effect of mass media interventions and to identify the most effective forms of this type of intervention for general and specific target populations (Vidanapathirana, 2005). Only two randomized controlled trials, three non-randomized controlled studies, and nine interrupted time series met the criteria for inclusion in the final analysis. The meta-analysis concluded that mass media interventions for promotion of HIV testing “showed significant immediate and overall effect.” No long-term effects were seen.

Two targets of mass media campaigns in the U.S. have been rural communities and migrant worker communities. In rural Georgia, for example, AIDGwinnett used public information (announcements on minority radio stations) and website publicity to expand awareness of testing services, with one particular community being Hispanic migrant workers (HAB, 2006). In addition, mapping technology was used to identify the high-risk areas to target. Counselling and testing were then offered in nontraditional venues, outreach workers went to high-risk

venues, and incentives were offered such as provision of rapid testing supplies to clients and give-aways. In the first year of the program, the number of people received counselling and testing at local sites increased by 900 people.

OFFERING INCENTIVES FOR TESTING AND COUNSELLING

Financial incentives can increase the motivation of patients to complete the process of testing and counselling. This can be particularly useful if patients are being referred elsewhere for testing and counselling. In a study conducted in an urban emergency department in the U.S., patients were offered \$US25 to get tested at the outpatient HIV counselling and testing office in the hospital (Haukoos, 2005). During that time, 23% of referred patients completed counselling and testing compared to only 8% during the control periods when no money was offered.

LINKING TESTING AND COUNSELLING TO CARE AND TREATMENT

An important motivation to be tested for HIV should be to obtain treatment. In a study of nearly 200 people entering primary care, 39% had received a positive HIV result one year ago and 18% had tested positive over five years ago (Samet, 1998). It is important to create links so that people who receive testing and counselling have access to appropriate and affordable care and treatment. See the meeting report and background paper for a meeting entitled *Linkage and Integration of HIV Testing, Prevention, and Care Services* convened by the Forum for Collaborative HIV Research on this topic at: <http://hivforum.org/publications/publications.htm>.

SECTION FIVE: GAPS IN KNOWLEDGE

Further research is needed in a number of areas to develop testing technologies that can be applied in a variety of circumstances to identify the optimum methods for conducting counselling, testing, and partner notification with people who are marginalized or most vulnerable to infection, and to better understand the circumstances under which people who do not know their serostatus can be reached.

THE TEST

New technologies are needed:

- for rapid testing
- for confirmation
- for low resource settings

For resource-limited settings, clarity is needed regarding:

- their similarities and differences
- availability
- feasibility under a variety of circumstances
- parameters for quality assurance/quality control

Realistic quality assurance protocols need to be:

- developed
- evaluated (especially for remote or community-based settings)

Modes of rapid testing need to be better understood:

- differences in acceptability of modes of testing (oral versus fingerstick versus venipuncture) in various populations
- skill levels that are optimal for each test

Educational programs for training (rapid) testers need to be:

- developed
- piloted
- evaluated
- disseminated

Operational research is needed for:

- use of nucleic acid - based testing (NAT) for detection of acutely infected individuals
- use of testing in settings where new prevention approaches are being rolled out (e.g. circumcision)

THE PROCESS

Obtaining informed consent:

- What is the nature of informed consent?
- What is the meaning of informed consent in various marginalized and vulnerable populations?
- What is the meaning of informed consent in patients under duress (for example, in labour; during treatment for trauma; in conflict settings)?
- What factors or behaviours on the part of health providers can be construed as coercive, supportive, or stigmatizing?
- What are the ethical implications of the use of financial or other incentives to increase numbers completing the testing and counselling process?

Provision of testing and counselling:

- How are existing models of testing and counselling experienced by people who are socially marginalized and most vulnerable to infection?
- Why is testing and counselling not an effective primary prevention strategy for people who learn they are uninfected?

- How can testing and counselling be changed to become a more effective strategy for those testing HIV negative?
- What are the most effective counselling approaches and what is their relationship to changes in behaviour?
- What are the differences between how people experience opt-in and opt-out counselling and testing?
- How can we best document/track adverse consequences of opt-out testing in specific populations?

Prevention for positives:

- What are motivating health seeking behaviours?
- Do different amounts and qualities of pretest and post-test counselling result in differences in risk reduction with people who are HIV positive (Project RESPECT)?
- What is the impact of HIV treatment optimism, the Internet and “serosorting” vis-à-vis the next generation of prevention interventions for people living with HIV?

Partner notification:

- What models are most effective for motivating people who are HIV-positive to contact their sex and drug-using partners?
- What models of health provider/patient collaboration achieve the highest level of follow-through?
- What are the characteristics of partner notification programs that have the confidence of people living with HIV and high rates of counselling and testing among their contacts?

- How can public health systems best support, strengthen and stimulate high rates of partner notification followed by testing and counselling?
- What are the types, extent, and frequency of unintended effects of partner notification, such as violence to women or disruption of personal relationships? What are the risks of not being notified?

THE CONTEXT

- How does the complex interaction of personal, social, and political factors impinge on counselling, testing and partner notification?
- What are effective measures for intervening in HIV risk behaviours at the individual, group, structural and societal levels?
- What are the effects of manipulating structural factors (e.g. campaigns to reduce gender inequality and stigma, laws to prevent discrimination, programs to reduce poverty) on counselling, testing and partner notification?
- What are the best ways to support health providers so that they are able to conduct effective and supportive counselling?
- Why are racialized communities (ethnic minority communities) at increased risk for HIV infection?
- What is the role of both unrestricted access to care (e.g. in countries with universal health care) and restricted access to care in reaching people unaware of their HIV status?
- Regarding prevention for people living with HIV, there are several areas that require further research. These include a more complex examination of the determinants of health; an inquiry into the range of

complementary interventions that broaden the capacity to effect change, as well as the sustainability of such interventions; studies into what is required as both a minimum and an optimum for health providers to deliver prevention interventions, including the quantity and quality of resources; and research into the possible adverse consequences of increasing effective prevention interventions.

CONCLUSIONS

There is still much to be learned about reaching people unaware of their HIV status. From a public health perspective, a clearer understanding of and sensitivity to the needs of

populations vulnerable to HIV will assist in creating environments in which it is both safe and beneficial to receive counselling and testing. In questioning and seeking out new approaches to testing and counselling, and in all efforts to streamline policies and systems, it will be crucial to identify ways to harmonize human rights and public health best practice. In addition, refining and applying new technologies to reducing barriers to testing and counselling will only enhance accessibility. Reaching individuals unaware of their HIV status requires, most of all, focusing on their needs and fears about not coming forward to be tested.

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