

Legislation to Authorize Forced Testing for HIV In the Event of Occupational Exposure: An Unjustified Violation of Human Rights

A submission to the Government of Manitoba

August 2005

Introduction

The Canadian HIV/AIDS Legal Network ("Legal Network") understands that the government of Manitoba has received proposals encouraging it to enact legislation authorizing the forced testing of people for HIV and other diseases in situations of possible occupational exposure. The Legal Network wishes to take this opportunity to comment on this subject. It is our understanding that proposals under consideration are largely based on the Uniform Law Conference's draft *Uniform Mandatory Testing and Disclosure Act* (the "*Uniform Act*").¹ We have prepared these comments accordingly.

As a matter of human rights, the Legal Network supports measures to prevent the spread of HIV, including for workers such as police officers, firefighters, ambulance attendants and paramedics, Good Samaritans (collectively referred to as emergency responders in this submission) and health care workers. The Legal Network also supports access to quality HIV testing and counselling, and access to care, treatment and support, for those who may be exposed to the risk of HIV infection, whether occupationally or otherwise. Finally, we support measures that respect and protect the rights of people living with HIV/AIDS and those vulnerable to HIV infection.

This submission sets out our position as to why legislation authorizing the forced testing of people for HIV should not be introduced by the government of Manitoba.

Legislation authorizing the forced testing of people for HIV (i.e., without a person's informed consent), such as the *Uniform Act*, does not represent an appropriately balanced policy response to the issue of occupational and non-occupational exposures to HIV. Forced testing legislation remains a flawed approach that does not adequately respect and protect human rights. Forced testing legislation is an example of a situation where a legal "quick fix" is not the best solution to a complex problem. Workers who risk exposure to blood-borne pathogens such as the Hepatitis B and C viruses and HIV deserve a more considered, comprehensive response from legislators, a response that would help ensure the human right to safe and healthy working conditions is fulfilled thereby offering real protections for such workers.² Moreover, ensuring access to adequate information, counselling, support and treatment in the event of an exposure is more beneficial to emergency responders and represents more a constructive and useful alternative.

It should be noted at the outset that Manitoba currently has a comprehensive protocol and guidelines to manage occupational and other exposures to blood and body fluids, last revised in November of 2003.³

¹ Uniform Law Conference of Canada. *Uniform Mandatory Testing and Disclosure Act* (Draft and Commentary). 2004.

² The right to just and favourable conditions of work, including safe and healthy working conditions, is set out in the *International Covenant on Economic, Social and Cultural Rights*, Article 7(b). Canada has ratified this treaty.

³ Integrated Post-Exposure Protocol: Guidelines for Managing Exposures to Blood/Body Fluids. Manitoba. November 2003, at s 2. Available at <u>www.gov.mb.ca/health/publichealth/cdc/fs/ipep.pdf</u>.

About the Canadian HIV/AIDS Legal Network

The Canadian HIV/AIDS Legal Network is a national organization engaged in research, education and policy development on legal issues related to HIV/AIDS. The Legal Network promotes the human rights of people living with and vulnerable to HIV/AIDS, in Canada and internationally. We have 250 members across Canada, approximately half of whom are community-based organizations with an interest in HIV/AIDS issues.

The Legal Network has been involved in extensive government, community and international consultations regarding all issues related to HIV/AIDS. Issues relating to HIV testing and disclosure have been a key aspect of the Legal Network's research and analysis for many years. In 1998, we produced *HIV Testing and Confidentiality: Final Report*, containing an extensive analysis of various aspects of Canadian law and policy in these two areas. In 2000, we produced *Rapid HIV Screening at the Point of Care: Legal and Ethical Questions* that addressed numerous questions related to the introduction and use of rapid HIV test kits in Canada.

We have also undertaken extensive work on the issue of compulsory HIV testing. In 2001 we produced *Testing of Persons Believed to Be the Source of an Occupational Exposure to HBV, HCV, or HIV: A Backgrounder.*⁴ In 2002, based on the *Backgrounder*, we produced *Occupational Exposure to HIV and forced HIV Testing: Questions and Answers.*⁵ In February 2002, the Legal Network appeared before the House of Commons Standing Committee on Justice and Human Rights on Bill C-217, the proposed "Blood Samples Act", and presented written and oral submissions highlighting the serious human rights issues raised by the legislation. On the Standing Committee's recommendation, the Bill did not proceed.

⁴ T de Bruyn. *Testing of Persons Believed to Be the Source of an Occupational Exposure to HBV, HCV or HIV: A Backgrounder.* Canadian HIV/AIDS Legal Network. 2001. A copy of the *Backgrounder* accompanies these submissions. Unless otherwise indicated, data and studies referenced in this brief are drawn from that document. Please refer to the *Backgrounder* for citations to the original sources. The *Backgrounder* is available on-line via <u>www.aidslaw.ca/Maincontent/issues/testing.htm</u>. Please not that French versions of Legal Network documents are available via <u>www.aidslaw.ca/francais/accueil.htm</u>.

⁵ T de Bruyn. *Occupational Exposure to HIV and forced HIV Testing: Questions and Answers*. Canadian HIV/AIDS Legal Network. 2001. Available via <u>www.aidslaw.ca/Maincontent/issues/testing.htm</u>.

1. Risks and management of occupational exposures

It has become apparent over the years – including in testimony before the House of Commons Standing Committee that ultimately recommended against proceeding with forced testing legislation at the federal level – that there remains a great deal of misinformation about HIV, the risks of transmission through occupational exposures, and what should be done in the event of such exposures. Too often, such misinformation fuels calls for ill-conceived responses such as legislation authorizing forced testing for HIV and other blood-borne pathogens such as the Hepatitis B and C viruses. A proper understanding of the basic facts is vital when considering whether such proposals are warranted or justified; legislation should be informed both by a commitment to respecting and protecting human rights and by the best available medical and scientific evidence.

As noted in the Manitoba *Integrated Post-Exposure Protocol*, "[b]ody fluids presenting risk for blood-borne disease transmission are: most importantly blood; also semen, vaginal secretions, cerebrospinal fluid, synovial fluid, pleural fluid, pericardial fluid, amniotic fluid and peritoneal fluid; other body fluids (e.g., urine or vomitus) only if there is visible blood; or laboratory specimens containing HCV, HBV, or HIV."⁶

It is significant to note that HIV, the Hepatitis B virus and the Hepatitis C virus are *not* transmitted by feces, nasal secretions, sputum, tears, urine and vomit unless these bodily substances are visibly contaminated by blood. Saliva that is not contaminated by blood can only transmit the Hepatitis B virus.

1.1 HIV

Risk of transmission

Almost all available data on the risks of occupational transmission of HIV comes from exposures in health-care settings. The US Centers for Disease Control and Prevention and the BC Centre for Excellence in HIV/AIDS have estimated that the **risk of infection from a single** *percutaneous* **exposure (i.e., under the skin through a needle stick or cut) to HIV-infected blood is 0.3% (1 in 300). In other words, 99.7% of such exposures do not lead to infection.** This kind of direct, under-the-skin exposure to contaminated blood presents the most significant danger for transmission of HIV.

The risk of infection is lower for *mucotaneous* exposures to HIV-infected blood (i.e., to mucous membranes through a splash to eyes, nose or mouth), at about 0.1% (1 in 1000). If the HIV-positive source person is taking anti-retroviral drugs, the chance of infection is lowered further, because the drugs reduce the amount of virus in their blood (even to the point where the virus is clinically undetectable).

The risk of transmission from an exposure to intact skin is estimated to be lower than 0.1%.

⁶ Integrated Post-Exposure Protocol: Guidelines for Managing Exposures to Blood/Body Fluids, at s 2.

If the HIV status of the source person is unknown, statistically the chance of infection from any exposure is lower still.

Given these very low risks, it is not surprising that there have been two probable cases, and only one definite case, of occupational transmission of HIV in Canada since the beginning of the epidemic. The two probable cases involved laboratory workers working with contaminated blood, one in the early 1980s (before HIV was identified) and one working with cultured virus during research activities. The one definite case was that of a health-care worker not wearing gloves who sustained a puncture wound involving a patient in the late stage of AIDS (when body fluids have elevated concentrations of HIV) and who did not seek post-exposure treatment with anti-retrovirals.

There is little data on occupational exposures among emergency responders (e.g., firefighters, ambulance attendants, police and correctional staff). One study of police officers in the United States found that one-third of exposures reported by police officers were "significant." These exposures were rarely percutaneous or mucotaneous exposures to blood (most exposures were to non-intact skin), but when they were, they occurred in circumstances where precautions were not an option or would not have been effective. Of the identified source persons, 94% consented to HIV testing. None of the police officers in the study were infected.⁷

More recently, the Chief Medical Officer of Health for Ontario told a committee of that province's legislature that there have been no documented cases of "emergency services workers" (meaning police officers, firefighters and ambulance attendants) acquiring blood-borne pathogens occupationally in Ontario or in Canada.⁸

Post-exposure treatment

Following an occupational exposure to HIV, if *post-exposure prophylaxis* (sometimes referred to as PEP) is indicated, it will consist of treatment with two or three antiretroviral drugs for a recommended period of 4 weeks.⁹ The decision whether to recommend or offer post-exposure prophylaxis depends on assessing the degree of risk incurred in the exposure. In the Manitoba *Integrated Post-Exposure Protocol* confirming that a "significant exposure" has occurred is the starting point for assessing whether to administer post-exposure prophylaxis for HBV, HCV or HIV. A "significant exposure" is defined as "an injury during which one person's blood or other high-risk body fluid comes into contact with another person's body cavity; subcutaneous tissue; or non-intact, chapped, or abraded skin or mucous membrane".¹⁰

Ideally, post-exposure prophylaxis should be initiated as soon as possible after exposure. Manitoba's *Integrated Post-Exposure Protocol* states that prophylaxis

⁷ R Hoffman et al. *Occupational exposure to human immunodeficiency virus (HIV)-infected blood in Denver, Colorado police officers.* American Journal of Epidemiology 1994; 139(9): 910-917.

⁸ Dr Colin D'Cunha, Chief Medical Officer of Health for Ontario. Submission to the Standing Committee on Justice and Social Policy, Legislature of Ontario, 4 December 2001.

⁹ US Public Health Service (Centers for Disease Control and Prevention). Updated US Public Health Service Guidelines for the Management of Occupational Exposures to HBV, HCV and HIV and Recommendations for Postexposure Prophylaxis. *MMWR* 2001; 50 (No. RR-11) (29 June 2001). Available at <u>www.cdc.gov/mmwr/PDF/RR/RR5011.pdf</u>. [Hereinafter "CDC Guidelines"].

¹⁰ Integrated Post-Exposure Protocol: Guidelines for Managing Exposures to Blood/Body Fluids, at s 2.

should be started "ideally within 2 to 4 hours".¹¹ Animal studies suggest that postexposure prophylaxis probably is substantially less effective when started more than 24 to 36 hours post exposure, however the interval after which no benefit is gained from post-exposure prophylaxis for humans is undefined. Available data indicate that post-exposure prophylaxis for humans in the non-occupational setting is less likely to be effective if initiated 72 hours or later post exposure.¹²

There are side effects for roughly three-quarters of those taking post-exposure prophylaxis. The most common are nausea, malaise or fatigue, headache, vomiting and diarrhoea. According to the US Centers for Disease Control and Prevention, these symptoms can often be managed with anti-nausea or anti-diarrhoea medications that target these symptoms without changing the regimen. In other cases modifying the dose interval (i.e., administer a lower dose more frequently) may help with adherence to the regimen. However, not all side effects can be adequately mitigated and may result in time off work. Side effects are also a principal reason for not completing the full course of post-exposure prophylaxis. Adverse side effects usually cease when treatment is stopped.

1.2 Hepatitis B

Risks of transmission

A preventive vaccine for HBV is available, and those vaccinated are at virtually no risk of infection. All emergency responders and health care workers should, as a matter of occupational safety, be offered this vaccine as a truly protective measure against an occupational hazard. Many members of the general public have also received this vaccine or have developed a natural immunity to HBV as result of exposure.

Post-exposure treatment

If the exposed person has not been vaccinated before the exposure, the postexposure prophylaxis will consist of hepatitis B vaccine and possibly hepatitis B immune globulin (HBIG). HBV vaccination is safe, and reports of any serious adverse effects receiving HBIG have been rare.¹³ In addition to helping prevent HBV infection if the person has been exposed, vaccination benefits the exposed person in the event of future exposures.

¹¹ Ibid. at s 11.2.

¹² US Public Health Service (Centers for Disease Control and Prevention). Antiretroviral Postexposure Prophylaxis After Sexual, Injection-Drug Use, or Other Nonoccupational Exposure to HIV in the United States. *MMWR* 2005; 54 (No. RR-2) (21 January 2005). Available at www.cdc.gov/mmwr/PDF/rr/rr5402.pdf

¹³ Ibid. at 5.

1.3 Hepatitis C

Risk of transmission

There is no preventive vaccine for HCV. However, according to the US Centers for Disease Control and Prevention's most recent guidelines on managing occupational exposures, HCV "is not transmitted efficiently through occupational exposures to blood."¹⁴ The risk of infection from a single percutaneous exposure to HCV-infected blood – the highest degree of occupational exposure – is estimated to be 1.8%. The risk of infection following mucotaneous exposure is not known exactly but is believed to be very small.

Post-exposure treatment

Unfortunately, there is no post-exposure prophylaxis for exposure to HCV.

¹⁴ Ibid. at 6.

2. What benefits might compulsory testing legislation offer to exposed persons?

There are three benefits for people exposed to HIV, HBV or HCV that are said to flow from legislation such as the *Uniform Act*. Information about the source person's HIV, HBV or HCV status is said to benefit the exposed person because it can be used:

(1) to inform the exposed person's decisions about post-exposure prophylaxis;

(2) to inform the exposed person's decisions about precautions to prevent secondary transmission to others (e.g., sexual partners); and

(3) to alleviate anxiety about the possibility of infection.

Each of these is an important consideration and exposed persons need accurate information and support following occupational exposures. However, the purported benefits of forced testing legislation such as the *Uniform Act* in these three areas are subject to important qualifications. These qualifications must be taken into account both in assessing the balance of benefits and harms that such legislation carries and in the interests of ensuring exposed persons are given the information they need.

2.1 Limited number of circumstances in which compulsory testing legislation would offer any potential benefit

First, it must be remembered that the benefits of legislation authorizing compulsory testing only exist in those circumstances where:

- there has been a significant exposure to the risk of infection;¹⁵
- the source person is available to be tested; and
- the source person does not consent to testing.

It should be remembered that most of those who are likely to be occupationally exposed to HBV have likely already received a very effective preventive vaccine. This means there will be few cases in which an occupational exposure to HBV will carry any significant risk of the exposed person being infected. In the case of HCV and HIV, it would only be those cases of occupational exposure to blood (and not fluids such as saliva, sputum, urine, etc) that could be considered a significant exposure. This means that it is a much smaller subset of cases of occupational exposure where there might be a great enough concern about the risk of infection to even consider testing the source person.

Furthermore, it has been established that in the overwhelming majority of cases of occupational exposure, the source person consents to testing.¹⁶ The study previously

¹⁵ Note that in the case of HBV, if the exposed person has already received the very effective preventive vaccine, there will be few significant exposures that would carry any appreciable risk of the exposed person being infected.

¹⁶ This information was presented by various parties to the House of Commons Standing Committee on Justice and Human Rights with regard to Bill C-217, including by the Member of Parliament who

mentioned of exposures among US police officers reported that 94% of source persons consented to testing. The House of Commons Committee that examined Bill C-217 heard testimony from an Alberta physician specializing in infectious diseases that in the case of exposures to health care workers in hospitals, approximately 99% of patients consent to being tested, leading him to point out that if the only exposures were occupational in the health care setting, he would not be in favour of this type of legislation.¹⁷ In the first six months of study by the Canadian Needle Stick Surveillance Network, 83% of known source persons agreed to be tested.¹⁸ Elsewhere it has been reported that in one hospital in British Columbia with over 1,700 significant exposures in the hospital and in emergency rooms, all but two people agreed to be tested; in Ontario, none of 2,600 refused to be tested.¹⁹

There is no evidence that source persons are frequently unwilling to provide a blood sample for testing. The available evidence is to the contrary. It may well be that in some cases the person refuses, but we submit that stronger evidence of a significant problem should be required before we step onto the slippery slope of passing legislation that authorizes testing people for HIV without their consent, particularly when there are limited benefits to the exposed person (as is discussed more fully in the following sections).

In the vast majority of cases of occupational exposure forced testing legislation serves no purpose.

2.2 Making decisions about post-exposure prophylaxis

<u>HIV</u>

The person occupationally exposed to HIV must make a decision as to whether to initiate post-exposure prophylaxis. The question is: Does testing a source person for HIV offer such a benefit to the exposed person (in the handful of cases where there has been a significant exposure and the source person does not consent to testing) that it justifies overriding other important rights of the source person, with the attendant harms, in all of the circumstances currently covered by the broad language such as that found in the *Uniform Act*?

introduced the bill. See: Hon. Chuck Strahl, Member of Parliament. Evidence to the House of Commons Standing Committee on Justice and Human Rights, 12 December 2001.

¹⁷ Dr Steven Shafran, Professor of Medicine, Director of Infectious Diseases Division, University of Alberta Hospital. Evidence to the House of Commons Standing Committee on Justice and Human Rights, 14 June 2000.

¹⁸ S Onno. Oral presentation at the 9th Annual Conference of the Canadian Association of Nurses in AIDS Care, 2001. For discussion, see *Backgrounder*, at 7.

¹⁹ Dr Chris Archibald, Chief, Division of HIV/AIDS Epidemiology and Surveillance, Department of Health. Evidence to the House of Commons Standing Committee on Justice and Human Rights, 27 February 2002. Dr Archibald was testifying before the committee in relation to Bill C-217, the proposed federal "Blood Samples Act."

While the effectiveness of post-exposure prophylaxis for HIV has yet to be fully proven, there is good indirect evidence and theoretical support for its use in appropriate circumstances. Current medical advice is that it should ideally be initiated within a matter of hours after the exposure. But it is highly unlikely that in such a short period of time it will be possible to arrange a judicial hearing to obtain a warrant (which procedural safeguard is required to justify the infringement of a constitutionally-protected right in the circumstances),²⁰ draw a blood sample from the source person if the warrant is obtained, and then receive test results.²¹ Under Manitoba's *Integrated Post-Exposure Protocol*, HIV-negative test results are available within 24 to 48 hours.²² In any event, even if these test results were to be obtained within a matter of a few hours – either through some extremely expedited process or the use of "rapid tests" on-site – we must remember that testing the source person provides only some of the information needed to answer the exposed person's question about whether or not they are at risk of infection and should initiate post-exposure prophylaxis.

With respect to rapid tests, it should also be noted that these are *screening* tests only – they do <u>not</u> provide the confirmed test results currently available using laboratory procedures that consist of repeated testing using different kinds of tests. In fact, they are designed to be over-sensitive so as not to miss any possible case of HIV infection. The result is that many initially positive test results using rapid tests are in fact false positives. For example, recent annual statistics for Ontario showed that two-thirds of all initially positive results turned out to be false positives upon further confirmatory testing.²³ A similar ratio has been reported for tests conducted at various sites in Alberta.

What is being proposed is to authorize compulsory HIV testing when, in the short period of time during which it might be of any possible benefit, the information that would be available is an unreliable test result. The exposed person is still confronted with decisions about post-exposure prophylaxis. If the source person were to test HIV-positive on one of these rapid tests, obviously this might encourage the person to decide they definitely need to take the post-exposure prophylaxis regimen. Who, upon receiving that initial positive result, which could very well be an inaccurate or false positive result, would want to take the risk of forgoing the drug regimen if there has been what they consider a significant exposure?

As has been noted, some people choose to discontinue post-exposure prophylaxis if the source person tests HIV-negative. Even if the source person tests HIV-negative, while this provides some reassurance, it does not rule out the possibility that the source person (and by extension the exposed person) might still be HIV-infected. The

²⁰ See e.g., *R v Dyment*, [1988] 2 SCR 417 at 438.

²¹ Receiving an order for testing under legislation such as the *Uniform Act* is not an expedient process. The exposed individual must apply to the superior court of the province in question and must present evidence of the circumstances of the case (in the form of an affidavit) as well as a physician's report. See *Uniform Act*, s 3.

²² Integrated Post-Exposure Protocol: Guidelines for Managing Exposures to Blood/Body Fluids, at s 12.1.

²³ See R Elliott, R Jurgens. *Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Montreal: Canadian HIV/AIDS Legal Network, 2000. Available at www.aidslaw.ca/Maincontent/issues/testing/finalreports/tofc.htm.

source person might be within the "window period", having been infected but not yet registering as such on the test.²⁴ The window period is indeed a moving target, and advances in testing technology have reduced it significantly, but it remains a concern which the exposed person needs to understand.

The window period is particularly relevant if the source person had recently engaged in high-risk activities, such as sharing injection equipment or having unprotected sex. If this fact were known to the exposed emergency responder or health care worker – as it might well be in some circumstances, such as the police officer stuck with a needle in the course of searching someone incident to their arrest – he or she would no doubt be concerned about possible infection. However, in the case of a recent potential infection, concern about the possibility of a "false negative" test would be greatest.

The source person's test result can provide useful information for making decisions about post-exposure prophylaxis, and if available is one factor that should be taken into account in making decisions about post-exposure prophylaxis. Other information such as risk factors of the source person, the nature and extent of the exposure, the source person's previous treatment history using anti-retroviral drugs should also be taken into account in the decision whether to initiate post-exposure prophylaxis. However, this additional information is often not available and, where this is the case, the limits of the test results need to be fully appreciated.

HBV

Given the availability of a highly effective preventive vaccine, and post-exposure prophylaxis that carries no appreciable risk of harm, knowing the person's HBV status is not necessary for treatment decisions. This, therefore, is not a compelling rationale for compulsory testing of the source person for HBV.

<u>HCV</u>

There is no preventive vaccine against HCV, nor is there a known effective postexposure prophylaxis. In the absence of such medical options, testing the source person cannot assist with decisions about stopping or starting post-exposure prophylaxis, meaning this is not a compelling rationale for compulsory testing of the source person for HCV.

2.3 Preventing secondary transmission

<u>HIV</u>

Persons exposed to HIV should be counselled about safer sex practices and about advising their sexual partners of the potential risk of transmission, as well as counselled about avoiding other activities (e.g., sharing needles) that pose a risk of transmission. Women should avoid becoming pregnant until reasonably sure they are not infected (based on a negative HIV test result at 3 months, or 6 months at the

²⁴ For a description of different testing technologies available for HIV, HCV and HBV see *Backgrounder*, at 15 -18.

outside), and if already pregnant, should be advised of the use of anti-retroviral therapy and other interventions to considerably reduce the chance of transmitting the virus to their child during gestation or labour/delivery. If relevant, women should also be counselled about the risks of breast-feeding and advised about alternatives. All of these represent temporary modifications to behaviour and can be undertaken whether or not the source person's HIV status is known.

HBV & HCV

A person exposed to blood infected with HCV or HBV need not take any special precautions to prevent secondary transmission during the follow-up period (such as modifying sexual practices, or refraining from becoming pregnant or breastfeeding). They should refrain from donating blood, plasma, organs, tissue or semen.²⁵ Knowing the source person's HCV or HBV status is not necessary for this. Preventing secondary transmission is, therefore, not a compelling rationale for compulsory testing the source person for HCV or HBV.

2.4 Alleviating anxiety of the exposed person

A person who has experienced a significant occupational exposure to blood (and potentially blood-borne pathogens) will no doubt experience anxiety. This anxiety is likely to persist until he or she is outside the window period and has tested negative for HBV, HCV or HIV. As the Legal Network's *Backgrounder* indicates, there are various kinds of tests available for these three viruses:²⁶

- Nucleic acid tests (which test directly for virus) can detect HBV in the exposed person as early as 23 days following infection, HCV as early as 12 days after infection, and HIV as early as 11 days after infection.
- Antibody tests can detect HBV infection 60 days after infection, HCV as early at 70 days after infection, and HIV as early as 22 days after infection.

Since the *Backgrounder* was published in 2001, there have been a number of advances in testing technology.²⁷ Such advances are capable of reducing the window period during which viruses are undetectable, meaning that the time the exposed person must wait before being tested to determine if they are "in the clear" is also potentially shortened.

The majority of people who are exposed to and as a result become infected with HIV do so within the first few weeks or first 3 months following exposure. Ninety-five percent will have seroconverted within 6 months following exposure. Given the very small risks of occupational infection even with percutaneous exposures to blood

²⁵ CDC Guidelines, at 23.

²⁶ For a description of different testing technologies available for HIV, HCV and HBV see *Backgrounder*, at 15 -18.

²⁷ See e.g., S Stramer et al. Detection of HIV-1 and HCV infections among anti-body negative blood donors by nucleic acid-amplification testing. *New England Journal of Medicine* 2004; 351(8): 760-768; J Barletta. Lowering the detection limits of HIV-1 viral load using real-time immuno-PCR for HIV-1 p24 antigen. *American Journal of Clinical Pathology* 2004; 122(1): 20-27; F Hecht et al. Use of laboratory tests and clinical symptoms for the identification of primary HIV infection. *AIDS* 2002; 16(8):1119-1129.

known to be contaminated with HIV (i.e., estimated at 0.3% likelihood), if the exposed person has not seroconverted by 3 or certainly by 6 months following the exposure, the chances of them seroconverting beyond that point are evidently exceedingly small indeed.

There is no question that receiving a source person's *negative* test results for any of HBV, HCV or HIV can relieve some of the anxiety of the exposed person (and their loved ones) about possible infection, as it means it is statistically less likely that they have been infected as a result of the exposure.²⁸ (Of course, as already noted, it is possible that the negative result is a false negative if the source person is in the window period before HIV is detectable by standard tests.)

Knowledge of the source person's HIV test result, while having some value for decisions about post-exposure prophylaxis, may be a double-edged sword with respect to the anxiety felt by the exposed person as they wait for their own test results following an exposure. In cases where the source person tests *positive* for HIV, this information will only *increase* the exposed person's anxiety during the waiting period. The point is simply that, as with the other benefits said to flow from knowing the source person's status, the claimed benefit of alleviating anxiety is a qualified one. The limited benefits to be gained from knowing a source person's HIV status must be kept in mind in considering whether the human rights violations inherent in forced testing can be justified.

Ensuring that appropriate counselling and information is provided to the exposed person is as important as testing in achieving the goal of relieving the exposed person's anxiety. This can and should be done without resort to compulsory testing. There have been too many reports of exposed police officers, fire fighters, health care workers or good Samaritans believing that they are at much higher risk of infection than the circumstances of their exposure indicate, or not fully understanding the extent of time required for follow-up testing during which they may still test positive. This is a tremendous source of anxiety that is fully avoidable, and must be addressed through ensuring access to accurate, quality information. With respect to HIV, awareness of the truly small nature of the risks – and in industrialized countries the very small number of emergency responders (zero in Canada) or health care workers (1 definite, 2 probable in Canada) who have been infected through occupational exposure – is information critical to relieving the anxiety of exposed persons.

²⁸ In the case of the exposed person already vaccinated against HBV, providing adequate information to the exposed person about the effectiveness of the preventive vaccine should go some considerable distance toward alleviating concern following exposure, meaning the anxiety-alleviating value of knowing the source person's HBV test result is much less significant.

3. Concerns about compulsory testing legislation

The qualified benefits offered by compulsory testing must be weighed against legal and ethical concerns based on values Canadian society considers important. In this regard, the Legal Network raises three concerns regarding compulsory testing legislation such as the *Uniform Act*:

- the disregard for the ethical and legal principle of informed consent;
- unjustified infringements of Charter rights; and
- the inconsistency, from a public policy perspective, of imposing compulsory testing on source persons of emergency responders, and not *vice versa*.

3.1 Legal and ethical doctrine of informed consent

Forced testing violates the legal and ethical principle of informed consent.

The legal doctrine of informed consent reflects the fundamental ethical principle of respect for persons and their autonomy. The Supreme Court of Canada has repeatedly recognized that a person cannot be subjected to medical procedures without his or her informed consent.²⁹ This requirement has also been codified into statute in many provinces, and forms a part of the codes of ethical conduct for all health care professionals. This includes their bodily and psychological integrity, and it includes their right to privacy with respect to their own medical information. (Privacy rights are examined in section 3.2, below.)

Respect for persons – the ethical imperative – requires that people be treated as ends in themselves, not merely as means to the ends of other people. The qualified benefits of forced testing, noted above, are not sufficient to justify this ethical violation.

In 1995, Health Canada convened a national conference that established a consensus on guidelines for a protocol to notify emergency responders when they may have been exposed to an infectious disease.³⁰ In 1996, Health Canada convened a meeting establishing a protocol for managing exposure to HBV, HCV and HIV among health-care workers.³¹ Both reiterated that informed consent must be obtained for testing the source person.³²

 ²⁹ Reibl v Hughes, [1980] 2 SCR 990; see also: Hopp v Lepp, [1980] 2 SCR 192; Ciarlello v Schacter, [1993] 2 SCR 119; Malette v Shulman (1990), 37 OAC 281 (CA); Fleming v Reid (1991), 82 DLR (4th) 298 (Ont CA); Videto v Kennedy (1981), 33 OR (2d) 497 (CA).

³⁰ Health Canada. A national consensus on guidelines for establishment of a post-exposure notification protocol for emergency responders. *Canada Communicable Disease Report* 1995; 21(19): 169-175.

³¹ Health Canada. An integrated protocol to manage health care workers exposed to bloodborne pathogens. *Canada Communicable Disease Report* 1997; 23 (Suppl 23S2): 1-14.

³² A discussion paper written by ULCC member Prof. Wayne Renke argues that the Health Canada protocol is ineffective because its disclosure provisions are not broad enough to cover all cases of occupational exposure. However, this approach ignores the fact that Health Canada has rightly adopted an informed consent approach to situations of occupational exposure. See W Renke. *Communicable*

The Manitoba *Integrated Post-Exposure Protocol* emphasizes voluntary testing and the informed consent as basic principles.³³

3.2 Human rights concerns under the *Charter*

Forced testing legislation such as the *Uniform Act* raises numerous human rights concerns under the *Canadian Charter of Rights and Freedoms*. In our submission, the state violates the *Charter* if it authorizes HIV testing without consent. In particular, it infringes the rights to liberty and security of the person (section 7) and the right to be free from unreasonable seizure (section 8). A person's right to privacy is reflected in both of these constitutional guarantees. We look at each of these considerations below. We then address the question of whether these infringements of constitutionally-guaranteed human rights can be justified.

Liberty and security of the person

First, forcibly subjecting a person to a medical procedure without their consent amounts to an infringement of their security of the person. If the state is to exercise its coercive power in this way to infringe basic human rights, it must have a strong justification for doing so. Under the *Charter* the state must show that a violation of the right to liberty or security of the person is consistent with the basic principles of our legal system and is demonstrably justified in our free and democratic society.

Second, under legislation such as the *Uniform Act*, the person who refuses to comply with a court order to provide a blood sample for testing is guilty of an offence and liable on summary conviction. Thus, the legislation criminalizes people for asserting their legal right to bodily integrity and informed consent.³⁴

Furthermore, legislation such as the *Uniform Act* permits medical officers of health to enlist the aid of peace officers to compel testing in the face of a refusal to comply with the court's order.³⁵ Peace officers are entitled to use reasonably necessary force to enforce the law. The infringement of both liberty and security of the person are evident.

Physical privacy and bodily integrity

The Supreme Court ruled has ruled, in the Dyment case, that

the use of a person's body without his consent to obtain information about him invades an area of personal privacy essential to the maintenance of human dignity... [T]he protection of the *Charter* extends to prevent a police officer, an agent of the state, from taking a substance as intimately personal as a

³⁵ Ibid. s 12.

Disease Exposure and Privacy Limitations: Issues Paper. Uniform Law Conference of Canada. 2003. Avalable via <u>www.ulcc.ca</u>.

³³ Integrated Post-Exposure Protocol: Guidelines for Managing Exposures to Blood/Body Fluids, at ss 6, 7, 11.

³⁴ Uniform Act, s 21.

person's blood from a person who holds it subject to a duty to respect the dignity and privacy of that person."³⁶

In *Dyment*, police had obtained without patient's consent a sample of free-flowing (not drawn) blood obtained by a physician treating a man involved in an automobile accident. The Supreme Court ruled this was an unlawful seizure in breach of section 8 of the *Charter*, and that the violation of the man's privacy interests were not minimal.

The Court had said previously in one of the leading cases on section 8 of the *Charter*,³⁷ and reiterated in *Dyment*, that the function of the *Charter* "is to provide...for the unremitting protection of individual rights and liberties" and that a major purpose of the constitutional protection against unreasonable search and seizure is the protection of the privacy of the individual. Furthermore, that right "must be interpreted in a broad and liberal manner so as to secure the citizen's right to a reasonable expectation of privacy against governmental encroachments."³⁸ The Supreme Court has since reiterated: "That physical integrity, including bodily fluids, ranks high among the matters receiving constitutional protection, there is no doubt…"³⁹

There has been only one reported case in Canada directly considering the question of whether a court may order HIV testing of a person against their will, with that information provided to a person claiming to have been exposed to a risk of infection.⁴⁰ In *Beaulieu*,⁴¹ a man accused of sexual assault was brought before the court and the woman whom he had allegedly assaulted sought an order that he provide a blood sample for HIV testing. The court in that case, a Quebec trial court, expressly referred to the Supreme Court's decision in *Dyment* and said that forced testing raises serious *Charter* concerns. The court refused the order.

Taking bodily samples without consent is clearly the exception in Canadian law. Indeed, the *Criminal Code* only allows it in two carefully limited circumstances – that is, testing for alcohol when there are reasonable grounds to believe an offence of impaired driving has been committed, and for the purpose of DNA analysis relating to a prosecution for certain designated serious offences. In both those cases, the infringement of privacy has been deemed justified in the interests of law enforcement once reasonable grounds exist for believing a person has engaged in criminal wrongdoing.

Legislation such as the *Uniform Act* would authorize medical tests on people without their consent and without any requirement that there be at least a *prima facie* case of wrongdoing. Compulsory testing could be ordered for a person who has not been arrested or charged with any criminal or quasi-criminal offence – e.g., a person lying

³⁶ R v Dyment.

³⁷ Hunter v Southam, [1984] 2 SCR 145 at 155.

³⁸ *Dyment*, at 426. In the earlier case of *R v Pohoretsky*, [1987] 1 SCR 945, the Court stressed the seriousness of a violation of the sanctity of a person's body as an affront to dignity.

³⁹ R v. Colarusso, [1994] 1 SCR 20 at 53.

⁴⁰ There have been other cases in which a request for a testing order has ultimately been agreed to by the accused (e.g., in the case of Paul Bernardo), so the issue of the constitutionality of forced HIV testing has not been judicially analysed in those cases.

⁴¹ R c. Beaulieu, [1992] AB No. 2046 (Cour du Québec – Chambre criminelle).

by the roadside after being hit by a car. Under the *Uniform Act*, an accident victim found unconscious by the roadside could be ordered to be tested for HIV, HCV or HBV. Someone injured in a domestic assault could be compelled to be tested for these viruses. Any patient receiving health care services could be the subject of an order for compulsory testing. Failing to comply with an order is a summary offence punishable by a fine of up to \$2000 or a prison sentence of up to 6 months.⁴²

Psychological integrity

The violation of physical privacy and bodily integrity is compounded by a violation of psychological integrity. The *Uniform Act* allows the source person to decide whether or not to be informed of their test results.⁴³ However, it nonetheless removes from them the option to decide whether and when to get tested. People should not hesitate to call police, paramedics or firefighters for assistance out of fear they could end up getting tested for HIV without their consent.

The *Uniform Act* provides that an application for a testing order "must be made on three days' notice to the source individual." However, this cursory attempt at procedural fairness is checked by the following sub-section, which allows the application to proceed without notice if the applicant satisfies the court that "in the circumstances of the case, giving notice... within a reasonable time is impossible or impracticable."⁴⁴

Informational privacy

Two years after the *Dyment* decision, the Supreme Court ruled in the *Duarte* case that the *Charter* protects the right of an individual to determine for himself or herself when, how, and to what extent they will release personal information about themselves.⁴⁵

Because most people (as submitted above) would consent to being tested in the event of posing such exposure to an emergency responder or health care worker, it may be hard for many to imagine why someone might refuse testing. But there are indeed good reasons why people do not wish to be tested. The loss of confidentiality about something as significant as HIV status can produce a whole range of negative consequences.

Stigma and discrimination related to a disease like HIV/AIDS are a reality in Canada.⁴⁶ People who admit simply to being tested for HIV (even where negative) have been denied insurance; certainly the person who tests positive will likely be unable to obtain certain private insurance coverage in the future. Discrimination in employment,

⁴⁴ Ibid. s 3.

⁴⁵ [1990] 1 SCR 30 at 46.

⁴⁶ See: (1) Series of info sheets on "HIV/AIDS and discrimination"; (2) T de Bruyn. *HIV/AIDS and Discrimination: Final Report*. Canadian HIV/AIDS Legal Network. 1998; (3) T de Bruyn. *A Plan of action for Canada to reduce HIV/AIDS-related stigma and discrimination*. Canadian HIV/AIDS Legal Network. 2004. All documents are available on-line via <a href="http://www.aidalaw.ao/Maincontext/incontext/aidalaw.ao/Maincontext/aidalaw.

http://www.aidslaw.ca/Maincontent/issues/discrimination.htm.

⁴² Uniform Act, s 21. See also Criminal Code, RSC 1985, c C-46, s 787.

⁴³ Uniform Act, s 10(1).

services, accommodation, and membership in social or professional associations persist for people known or perceived to be HIV-positive (or to have hepatitis). The victim of domestic assault who tests HIV-positive faces the prospect that public health authorities would be required to notify his or her partner, who may also be their abuser, of the partner's possible past exposure.

The *Uniform Act* contains important provisions aimed at providing some measure of confidentiality protection for the source person tested against their will. However, it is questionable whether the protection afforded by such provisions can ever be more than illusory, for four reasons.

First, evidence of someone's HIV-positive status can find its way into evidence in court proceedings. While the *Uniform Act* prohibits the use of the test results certificate as evidence in a civil or criminal proceeding (other than in accordance with the *Act*),⁴⁷ this is of limited practical benefit. Once the source person's status is known, that information is compellable from them under oath in another proceeding. A province does not have the constitutional jurisdiction to declare evidence inadmissible in a criminal proceeding. Consequently, provincial legislation authorizing forced HIV testing could result in evidence that could be used against a source person in a criminal proceeding -- a violation of the constitutional right against self-incrimination.⁴⁸ Such an outcome would compound the original violations of the source person's constitutional rights to liberty, security of the person and privacy (including the right to be free from unreasonable search and seizure).

Furthermore, the *Uniform Act* allows a judge to order that a witness disclose information made confidential under the legislation, after merely "consider [ing]... the probative value of the information to be disclosed and the invasion of privacy of the person who is the subject of the information."⁴⁹ So the fact that the certificate with the source person's test results is not admissible is irrelevant. (There are also no provisions in the *Uniform Act* requiring that the certificate with the source person's test results be destroyed.)

Second, the *Uniform Act* only requires confidentiality with regard to information (e.g., identity and HIV test result of the source person) that comes to a person's knowledge "in the course of carrying out responsibilities pursuant to this Act or the regulations."⁵⁰ Those who carry out responsibilities pursuant to such legislation are those such as a public health officer, a peace officer, a "qualified health professional" and a "qualified analyst". Requiring confidentiality on the part of these parties is important. However, while these are the only persons who have a legal obligation of confidentiality under such legislation the result of an HIV test ordered under the legislation will be known to other people.

Under the *Uniform Act* the source person's identity and HIV test result are communicated to the exposed person – indeed, this is the entire *raison d'être* of such legislation. Significantly, there is nothing in the legislation that prevents the exposed person from disclosing the source person's identity and medical information to whomever they choose. One can understand the desire to share this information with

⁴⁷ Uniform Act, s 10(2).

⁴⁸ The constitutional right against self-incrimination is based in sections 7, 11(c) and 13 of the *Charter*.

⁴⁹ Uniform Act, s 18(2).

⁵⁰ Ibid. s 17(1).

family, friends and co-workers with whom the fact of the initial exposure has likely already been discussed. Those people will, in turn, likely discuss this information with others, with the result that the source person's HIV-positive status could become much more widely known. The invasion of the source person's privacy would be particularly acute in a smaller community.

Nor is there anything that would prevent media from reporting on a person's identity and HIV status after they had been forcibly tested for the virus, an outcome that could be more likely if the issue of a testing order were disputed before the courts, thereby attracting media interest. In reality, it is practically impossible to legislative any effective confidentiality protection for the source person who has been forcibly tested for HIV, just as the law will be able to do little to protect against HIV/AIDS-related stigma that will follow.

Third, the draft legislation undermines the confidentiality provision altogether by providing numerous exceptions, including very open-ended provisions permitting disclosure when "ordered by the minister for the purpose of protecting the public health" or "in prescribed circumstances."⁵¹ Such wide open exceptions to the confidentiality obligations that are already of limited effect raise further concern about the deleterious impact of this kind of legislation on the source person who is forcibly tested for HIV.

Finally, the *Uniform Act* prescribes no criminal penalty, nor does it create any civil cause of action, for breaching confidentiality. Even if it did, such provisions would likely be of little practical value. Two decades of experience show that breaches of confidentiality are commonly experienced by people living with HIV, particularly in small or closely knit communities, and that the consequences can be devastating. In most cases, there is no effective, accessible remedy.⁵²

Prior judicial authorization dubious as a safeguard for Charter rights

The Uniform Law Conference emphasizes the fact that the *Uniform Act* would require prior judicial authorization by the provincial superior court for compulsory testing orders (although recognizing that some jurisdictions concerned with issues of expediency or practicality in bringing such applications may wish to allow them to be heard by provincial court judges). Commentary accompanying the draft legislation states that "[t]he use of a judge as decision-maker guarantees independence and impartiality or neutrality."⁵³ Certainly it is important that there be some such scrutiny of the legitimacy of the request before people are subjected to testing without their consent. Yet the safeguard of prior judicial authorization does not adequately protect every *Charter* right implicated.

The requirement of judicial authorization does not necessarily address concerns about the right to privacy. Experience to date indicates media interest in reporting cases of occupational HIV exposure of police officers and emergency responders. An application for compulsory testing under legislation such as the *Uniform Act* would likely attract media attention. The *Uniform Act* does not require that media refrain

⁵¹ Uniform Act, s 17(2).

⁵² See generally *Privacy Protection and the Disclosure of Health Information: Legal Issues for People Living with HIV/AIDS in Canada.* Montréal: Canadian HIV/AIDS Legal Network, 2002-2004.

⁵³ Uniform Act, ss 2, 3.

from publishing the names or other identifying information about the source person in the course of reporting of the court proceeding, or any provision requiring the court hearing the application to order such a publication ban or other protections for the source person's or exposed person's privacy.

Furthermore, the *Uniform Act* contemplates that the requirement to notify the source person of an application for a testing order may be dispensed with if giving notice is "impracticable".⁵⁴ This opens the door to an agent of the state (i.e., a court) issuing orders allowing for forced testing of people for diseases without giving them a chance to oppose the order.

Rights violations cannot be justified

In the leading case of *Oakes*,⁵⁵ the Supreme Court has set out the requirements for justifying legislation that infringes *Charter* rights under the provisions of section 1 of the *Charter*:

- the objective to be served by the measures infringing the right must relate to concerns that are "pressing and substantial in a "free and democratic society";
- the measures must be fair and not arbitrary, carefully designed to achieve the objective in question, and rationally connected to that objective;
- the measures should impair the Charter right as little as possible; and
- there must be proportionality between the effects of the limiting measure and the objective - the more severe the infringement of the right, the more important must be the objective.

We agree that protecting people against occupational and non-occupational exposures to blood-borne pathogens, and helping them deal with the aftermath of such an exposure, are pressing and substantial concerns. This is why the Legal Network supports, as a matter of workers' human rights, measures to prevent or reduce the risks of occupational exposures in the first place, and to prompt and adequate information, counselling, support, accommodation and treatment in the event that exposures do occur.

However, we submit that forced testing legislation such as the *Uniform Act* fails each of the remaining three steps in the *Oakes* test under section 1 of the *Charter*.

The *Uniform Act* is not rationally connected to, nor does it achieve, the legislative objectives. After the fact testing for HIV does not protect against the occurrence of exposures involving emergency responders and health care workers. It does not make workplaces safer environments. Providing emergency responders and health care workers with a procedure to test a source person for HIV does not ensure that the source person's HIV status can be definitively determined during the time in which this information is crucial for making a decision about post-exposure prophylaxis (ideally within 2 to 4 hours). On the contrary, assuming that an order could be obtained in this short time frame, as a matter of medical fact the results from a rapid

⁵⁴ Ibid. s 3(3).

⁵⁵ *R v Oakes*, [1986] 1 SCR 103.

test are not confirmed test results currently available from laboratory facilities. As for addressing anxiety post exposure, providing emergency responders with basic information about HIV transmission, accurate information about the risks involved in different types of exposures, and appropriate counselling resources Various leading associations of health professionals have criticized this sort of legislation as "not warranted" or "unjustified,"⁵⁶ and the Chief Medical Officer of Health for Ontario, while supporting the intention behind such legislation, considers that it does not realize its goals.⁵⁷ We have noted in detail above and in the *Backgrounder* that the rationale for authorizing compulsory testing for HCV and HBV is not borne out by the medical and scientific evidence.

We submit that forced testing legislation such as the *Uniform Act* impairs *Charter* rights in considerably more than a minimal fashion, for the reasons set out above, including:

- the application of physical force to conduct a medical procedure without consent;
- the invasions of physical, psychological and informational privacy represented by compulsory testing;
- the practical impossibility of legislating adequate protection for the confidentiality of the test results of the person subject to compulsory testing, or of creating any effective remedy once the damage of testing without consent has been done;
- the potential negative ramifications that will or will likely follow for the person who tests positive (particularly for HIV) as a result of compulsory testing; and
- the viable alternatives for managing occupational (and non-occupational) exposures that seek to address many of the concerns and needs of exposed persons without infringing the constitutional rights of alleged source persons.

Finally, we submit that the requisite proportionality between objectives and infringement of *Charter* rights is not adequately demonstrated. The commentary accompanying the *Uniform Act* states that the Act as a whole is premised on the notion "that the individual and social interests in the health of exposed individuals (and those who might in turn be infected by them) warrant limiting the privacy interests of source individuals." But a more fundamental point is that such infringement of constitutional rights – liberty, security of the person, privacy (including freedom from unreasonable search and seizure), and possibly even the right against self-incrimination – is not warranted if it is unnecessary to achieve the legislative objectives. If the benefit to the exposed person is limited, and the potential negative consequences to the forcibly tested person are significant, laws based on the *Uniform Act* are not constitutionally justifiable. Workers who risk exposure to blood-borne pathogens such as the Hepatitis B and C viruses and HIV deserve a more considered, comprehensive response from legislators, a response that would help ensure the human right to safe and healthy working conditions is fulfilled thereby offering real

⁵⁶ As set out in the *Backgrounder*, at 25 to 31, the groups include Canadian Nurses Association, the Canadian Association of Nurses in AIDS Care, and the Canadian Medical Association.

⁵⁷ Dr Colin D'Cunha, Chief Medical Officer of Health for Ontario. Submission to the Standing Committee on Justice and Social Policy, Legislature of Ontario, 4 December 2001.

protections for such workers.⁵⁸ Moreover, ensuring access to adequate information, counselling, support and treatment in the event of an exposure is more beneficial to emergency responders and represents more a constructive and useful alternative.

3.3 Consistency in the law: an important policy consideration

Proposals such as the *Uniform Act* also raise the issue of consistency in the law, which is desirable as a matter of public policy. The *Uniform Act* would authorize the compulsory testing of a source person in the event that an emergency responder or health care worker is exposed in the course of their duties, or if a Good Samaritan were exposed in the course of assisting another. But what if the emergency responder or health care worker exposes the other person to the risk of infection? The same rationales about obtaining information to make post-exposure prophylaxis decisions, prevent secondary transmission and alleviate anxiety would surely apply in those circumstances. We are faced, then, with the prospect of authorizing the compulsory testing of emergency responders, health care workers and Good Samaritans – or, indeed, authorizing compulsory testing following any significant exposure of one person by another. This question was raised by representatives of Justice Canada before the House of Commons Standing Committee with respect to Bill C-244, the precursor to Bill C-217 that the Committee ultimately recommended not proceed.⁵⁹ It remains a question with respect to the *Uniform Act* or similar legislation.

⁵⁸ The right to just and favourable conditions of work, including safe and healthy working conditions, is set out in the *International Covenant on Economic, Social and Cultural Rights*, Article 7(b). Canada has ratified this treaty.

⁵⁹ Yvan Roy, Senior General Counsel, Criminal Law Policy Section, Justice Canada. Evidence to House of Commons Standing Committee on Justice and Human Rights, 13 June 2000.