The Proposed "Mandatory Testing and Disclosure Act": An Unjustified and Unnecessary Violation of Rights

A submission to the Yukon Department of Justice
and Members of the Legislative Assembly

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1. About the Canadian HIV/AIDS Legal Network

The Canadian HIV/AIDS Legal Network (www.aidslaw.ca) promotes the human rights of people living with and vulnerable to HIV/AIDS, in Canada and internationally, through research, legal and policy analysis, education and community mobilisation. The Legal Network is Canada's leading organization working on the legal and human rights issues raised by HIV/AIDS.

The Legal Network is a national non-governmental organization with over 100 members across Canada and around the world, the majority of which are community-based AIDS service organizations. The Legal Network has been involved in extensive government, community and international consultations regarding a wide range of HIV/AIDS-related legal and policy issues. HIV testing and disclosure issues have been a key aspect of the Legal Network's research and analysis for many years. This includes extensive work specifically on the issue of compulsory HIV testing.

A body of research and analysis by the Legal Network, including several publications, has addressed a number of issues that are relevant to the debate regarding the proposed *Mandatory Testing and Disclosure Act,* including:

- *Testing of Persons Believed to Be the Source of an Occupational Exposure to HBV, HCV, or HIV: A Backgrounder (2001)*;[1]
- *Occupational Exposure to HIV and Forced HIV Testing: Questions and Answers* (2002), based on the background;[2] and
- *Undue Force: An Overview of Provincial Legislation on Forced Testing and HIV* (2007).[3]

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," presenting 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.

The Legal Network supports measures to prevent the spread of HIV, including for workers such as police officers, firefighters, ambulance attendants, paramedics and those providing emergency assistance (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

[1] 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). 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 www.aidslaw.ca/testing.

[2] T de Bruyn. *Occupational Exposure to HIV and forced HIV Testing: Questions and Answers*, Canadian HIV/AIDS Legal Network, 2001. Available via www.aidslaw.ca/testing.

[3] Available via www.aidslaw.ca/testing.

and protect the rights of people living with HIV and those vulnerable to HIV infection.

However, legislation that authorizes compulsory blood testing is not a measure needed to prevent the spread of HIV, nor is it necessary to ensure quality HIV testing, counselling, care, treatment or support for those exposed to the risk of infection. Furthermore, compulsory blood testing is not a measure that respects and protects the right of people living with or vulnerable to HIV infection. Therefore, this submission sets out our position as to why legislation authorizing the forced testing of people for HIV should not be enacted in the Yukon. In the event that the Department of Justice decides to proceed with this legislation nonetheless, this submission also includes an appendix of recommended revisions that we believe are necessary in order to make the bill more balanced.

2. HIV testing: the "three C's"

Both globally and within Canada, human rights-based responses to HIV/AIDS have been broadly endorsed.[4] Practically speaking, this means that human rights principles and protections should be at the heart of all policy decisions related to HIV testing. The "three C's" approach has become the accepted rights-based approach to HIV testing, shown to be effective and endorsed by the expert technical agencies of the United Nations.[5] The principles of the "three C's" approach are:

- HIV testing may only occur with specific **informed consent** voluntarily given. This requirement derives from the human right to *security of the person* – that is, being able to control what happens to one's body – as well as from the *right to information* which is an integral part of the right to health.[6]

- **Pre- and post-test counselling** of good quality must be provided with every HIV test. This counselling gives effect to the *right to information* and is essential for both promoting the mental health of persons getting tested and protecting public health more broadly by helping to prevent onward transmission of HIV. Good quality counselling is of particular importance for people who may not otherwise get appropriate information on HIV/AIDS.

[4] E.g., see *Leading Together: Canada Takes Action on HIV/AIDS 2005-2010* (Ottawa: Canadian Public Health Association, 2005); *Counselling Guidelines on HIV Testing* (Ottawa: Canadian Medical Association, 1995); *International Guidelines on HIV/AIDS and Human Rights*, 2006 Consolidated Version (Geneva: UNAIDS & Office of the UN High Commissioner for Human Rights, 2006); *UNAIDS/WHO Policy Statement on HIV Testing* (Geneva, June 2004).

[5] The Voluntary HIV-1 Counseling and Testing Efficacy Study Group, "Efficacy of voluntary HIV-1 counselling and testing in individuals and couples in Kenya, Tanzania and Trinidad: a randomised trial," *Lancet* 2000: 356: 103-12; *UNAIDS/WHO Policy Statement on HIV Testing* (Geneva, June 2004).

[6] *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act*, 1982, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c. 11, at s.7; *International Covenant on Civil and Political Rights*, 999 U.N.T.S. 171, Articles 9 and 19 [ICCPR].

- **Confidentiality** of HIV test results, and even of the fact that someone has sought to be tested, must be protected. The confidentiality of medical tests derives from the *right to privacy* and is a central element of ethical medical practice.[7]

Compulsory testing is directly antithetical to the spirit of the rights-based approach embodied by the "three C's" approach to testing. The principles of informed, voluntary consent and confidentiality of test results are necessarily disregarded by legislation that forces a person to submit to blood test under court order.

3. Compulsory testing and disclosure legislation is unnecessary and unwarranted

a) Overestimating the risks of transmission and under-appreciating the alternatives to forced testing

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, including legislation authorizing forced testing for blood-borne infections. Effective legislation must be informed by the best available medical and scientific evidence, and a commitment to respecting and protecting human rights.

Transmission of blood-borne infections

The bodily fluids capable of transmitting Hepatitis B Virus (HBV), Hepatitis C Virus (HCV) or HIV are:

- blood (including serum, plasma and all biological fluids visibly contaminated with blood);
- breast milk;
- pleural, amniotic, pericardial, synovial and cerebrospinal fluid;
- uterine/vaginal secretions and semen; and
- saliva (Note: saliva on its own may transmit *only* HBV; if saliva is contaminated by blood, it may also transmit HCV and HIV).[8]

Transmission of HBV, HCV or HIV can occur when one of the aforementioned bodily fluids comes into contact with:

- tissue under the skin (e.g., through a needle stick or cut), which is called a percutaneous exposure;

[7] *Canadian Charter of Rights and Freedoms*, ss. 7 and 8; ICCPR, Article 17.

[8] HBV, HCV and HIV can *not* transmitted by feces, nasal secretions, sputum, tears, urine or vomit, unless they are visibly contaminated by blood.

- mucous membranes (e.g., through a splash to the eyes, nose or mouth), which is called a mucotaneous exposures; or
- non-intact skin (e.g., skin that is chapped, scraped or afflicted with dermatitis).[9]

The factors that influence the risk of infection from a single exposure include:

- which virus is involved;
- the type of exposure;
- the amount of bodily fluid involved in the exposure; and
- the amount of the virus in the source person's bodily fluid at the time of exposure (e.g., the amount of HIV in the blood is higher in the initial stage of HIV infection and in the final stage of AIDS; it can also be reduced to the point of being undetectable through successful antiretroviral treatment).[10]

Exposure to blood containing HIV or other blood-borne virus carries the greatest risk and is, therefore, the focus of the information that follows. (The very small risks are considerably lower in the event that exposure is to some other bodily fluid.)

HIV: Risk of transmission

The risk of infection from a single *percutaneous* exposure to blood from someone who is known to be HIV-positive is 0.3% (1 in 300).[11] In other words, there is a 99.7% probability that any such exposure will not lead to infection. This kind of direct, under-the-skin exposure to contaminated blood presents the greatest risk of transmitting HIV.

The risk of infection for *mucotaneous* exposures to blood from someone who is known to be HIV-positive is estimated to be about 0.1% (1 in 1000). The risk of transmission is even lower if the HIV-positive source person is taking anti-retroviral drugs (because they reduce the amount of virus in the blood).

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

Given these very low risks, it is not surprising that there has only ever been one case of confirmed occupational transmission of HIV in Canada. It involved a health-care worker not wearing gloves who sustained a puncture wound involving a patient in the late stage of AIDS (when bodily fluids have elevated concentrations of HIV) and who did not seek post-exposure treatment. There

[9] Contact with intact skin or clothing is not a significant exposure.

[10] Injuries that are deep, involve a device that is visibly contaminated with the source person's blood, involve a needle that has been placed in the source person's vein or artery, and/or involve a source person with terminal illness are associated with a higher risk of HIV transmission in health-care workers suffering occupational percutaneous exposure to HIV-infected blood. DM Cardo et al., "A case-control study of HIV seroconversion in health care workers after percutaneous exposure," *New England Journal of Medicine* 337:21 (1997): 1485-1490 at 1487.

[11] As estimated by The US Centers for Disease Control and Prevention (CDC) and the BC Centre for Excellence in HIV/AIDS. See, e.g., Centers for Disease Control and Prevention, *Updated U.S. Public Health Service guidelines for the management of occupational exposures to HIV and recommendations for Postexposure Prophylaxis*, *MMWR* Vol. 54 No. RR-9 (September 30, 2005), p. 2.

have also been two probable cases, both involving laboratory workers working with contaminated blood. Given the availability of protective devices (e.g., goggles, gloves, safety-engineered needles), this type of exposure would not be expected today.

There is little data on occupational exposures among emergency responders (e.g., firefighters, ambulance attendants, police and correctional staff). The Chief Medical Officer of Health for Ontario, however, 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.[12]

HIV: Post-exposure treatment

Exposure prevention must remain the primary strategy for reducing occupational exposures, and further reduces any need for resort to compulsory testing laws. Where exposures to HIV do occur, if *post-exposure prophylaxis* (sometimes referred to as PEP) is indicated in order to reduce the risk of infection, it will consist of treatment with two or three anti-retroviral drugs for a recommended period of 4 weeks. The degree of risk incurred in the exposure determines whether or not post-exposure prophylaxis is appropriate and if so, what regimen. PEP is only appropriate where a "significant exposure" has occurred *and* either the source person is known to be HIV-positive or the HIV-status of the source person is unknown and other risk factors are present. For maximum effectiveness, post-exposure prophylaxis should be initiated as soon as possible after exposure, and ideally within 2 to 4 hours.[13]

Roughly three-quarters of those taking post-exposure prophylaxis experience side effects. The most common are nausea, malaise or fatigue, headache, vomiting and diarrhea. These symptoms can often be managed with medications or by modifying the dose interval (i.e., administer a lower dose more frequently). Side effects may result in time off work for individuals taking PEP and are a principal reason for not completing the full course of post-exposure prophylaxis.[14]

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[12] 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.

[13] Animal studies suggest that post-exposure prophylaxis probably is substantially less effective when started more than 24 to 36 hours following the exposure. Available data indicate that post-exposure prophylaxis for humans exposed in non-occupational settings is less likely to be effective if initiated 72 hours or later post-exposure: 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) (January 21, 2005), online: www.cdc.gov/mmwr/PDF/rr/rr5402.pdf. Note that there is little available data on the effectiveness of PEP in cases of occupational exposure, however some studies on primates, a small case-control study of occupational exposure among healthcare workers in the U.S., and data from studies on the prescription of antiretrovirals to prevent mother-to-child transmission all support the use of PEP as a means to reduce the risk of HIV infection following an exposure: E. Hamlyn & P. Easterbrook, "Occupational exposure to HIV and the use of post-exposure prophylaxis," *Occupational Medicine* 57 (2007): 329-336 at 330.

[14] A substantial proportion (17% - 47%) of healthcare providers taking PEP after occupational exposures to HIV-positive sources in the United States did not complete the full 4-week course of therapy because of side

HBV: Risk 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 be offered this vaccine. Many members of the general public have also received this vaccine or have developed a natural immunity to HBV as result of exposure.

HBV: Post-exposure treatment

If the exposed person has not been vaccinated against HBV, the post-exposure 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 resulting receiving HBIG have been rare.[15] Vaccination is recommended for any exposure regardless of the source person's HBV status and should begin as soon as possible (preferably within 24 hours and no later than 7 days).[16] HBV vaccination helps prevent HBV infection in the exposed person and also protects against infection in the event of future exposures.

HCV: Risk of transmission

The risk of infection from a single percutaneous exposure to HCV-infected blood (i.e., the occupational exposure with the highest degree of risk) is estimated to be 1.8%. The risk of infection following mucotaneous exposure to HCV-infected blood is not known exactly, but is believed to be very small. Statistically, the risk of infection following exposure to blood from a person whose HCV status is unknown will be even lower.

HCV: Post-exposure treatment

There is no post-exposure prophylaxis for exposure to HCV nor is there a preventive vaccine. According to the US CDC's most recent guidelines on managing occupational exposures, however, HCV "is not transmitted efficiently through occupational exposures to blood."[17]

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effects: US CDC, *Updated U.S. Public Health Service guidelines for the management of occupational exposures to HIV and recommendations for Postexposure Prophylaxis* (2005), p. 4.

[15] US CDC, *Antiretroviral Postexposure Prophylaxis After Sexual, Injection-Drug Use, or Other Nonoccupational Exposure to HIV in the United States* (2005), p. 5.

[16] *Exposure to Blood: What Healthcare Personnel Need to Know*. CDC Department of Health and Human Services (updated July 2003).

[17] US CDC, *Antiretroviral Postexposure Prophylaxis After Sexual, Injection-Drug Use, or Other Nonoccupational Exposure to HIV in the United States* (2005), p. 6.

b) Exaggerating the benefits that compulsory testing legislation can provide to exposed persons

Forced testing legislation such as that being proposed in Yukon is supposed to benefit people potentially exposed to HIV, HBV and HVC by providing information regarding the source person's HIV, HBV or HCV status. This information 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, breastfeeding infants); and
>
> (3) to alleviate anxiety about the possibility of infection.

Each of these is an important consideration. Persons who have been exposed to blood or other bodily fluids need accurate information and support in order to access their degree of risk, make appropriate treatment and prevention decisions, and deal with anxiety. However, as outlined below, these purported benefits of forced testing legislation are subject to important qualifications. In order to design an effective and appropriate response to occupational and non-occupational exposure, these limitations on the benefits that forced testing can deliver must be taken into account.

The rare circumstances in which compulsory testing offers any benefits to an exposed person

The benefits of legislation authorizing compulsory testing only exist in those circumstances where:

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

A significant exposure can be defined as a percutaneous injury or the contact of mucous membrane or non-intact skin with a potentially infectious bodily fluid or tissue.[18] Significant exposures are dramatically reduced by the widespread adoption of standard universal precautions (including the provision of adequate sharps containers, training of workers and the use of protective equipment such as gloves, eye wear and safety-engineered needles that automatically sheath or retract after use), which has led to a marked reduction in needlestick and other injuries over the last two decades.[19] If there has not been a significant exposure, testing the source person offers no benefits to the exposed person.

[18] Hamlyn and Easterbrook, p. 330.

[19] Ibid., p. 329.

When an exposure does occur, the source person is not always available to be tested. Where the source person is available for testing, it has been established that in the overwhelming majority of cases of occupational exposure, the source person consents to testing.[20] Forced testing legislation is therefore unnecessary in the vast majority of cases. In some rare cases the source person may refuse to be tested, but we submit that evidence of a significant problem should be required before we step onto the slippery slope of passing legislation that authorizes forced blood tests. In most cases, appropriate and sensitive pre-test counselling and guarantees of confidentiality to the source person may well achieve better results for the exposed person than pursuing a forced test.

Making decisions about post-exposure prophylaxis

When a significant exposure does occur, various factors should be taken into account in order to decide whether to take PEP. The source person's serological test results may provide useful information and if available, should be taken into account, as should other information such as the source person's risk factors, the nature and extent of the exposure, and the source person's treatment history using anti-retroviral drugs, if available.[21]

In cases of possible HIV exposure, the decision as to whether to initiate PEP must be made immediately or within a few hours. It is unlikely that it will be possible, within that short timeframe, to comply with the procedural safeguards set out in the proposed legislation (such as arranging a judicial hearing to obtain a warrant, a safeguard which is required to justify the infringement of a constitutionally-protected right in the circumstances),[22] provide appropriate pre- and post-test counselling to both the exposed person and the source person, draw a blood sample from the source person, and then deliver the test results.

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[20] This information was presented by various members of and witnesses before the House of Commons Standing Committee on Justice and Human Rights with regard to Bill C-217 (the proposed federal "Blood Samples Act" that was ultimately rejected), including by the Member of Parliament who 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. For example:

- The House of Commons Committee that examined Bill C-217 heard testimony from an Alberta physician specializing in infectious diseases that approximately 99% of source patients consent to being tested in cases of occupational exposures to health care workers in hospitals: 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.
- In the first six months of study by the Canadian Needle Stick Surveillance Network, 83% of known source persons agreed to be tested: S Onno, Oral presentation at the 9th Annual Conference of the Canadian Association of Nurses in AIDS Care, 2001.
- It has been reported that in one hospital in British Columbia with over 1,700 significant exposures, all but two source people agreed to be tested; in Ontario, none of 2,600 refused to be tested: 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.

[21] See: US CDC, *Updated U.S. Public Health Service guidelines for the management of occupational exposures to HIV and recommendations for Postexposure Prophylaxis* (2005).

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

The decision whether to initiate PEP will therefore almost always be made based on an analysis of risk factors, the type of expose and any information voluntarily provided by the source person.

Some people choose to discontinue post-exposure prophylaxis if the source person tests HIV-negative. While an HIV-negative test result 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 source person might be within the "window period," having been infected but not yet registering as such on the test.[23] The possibility of a "window period" is particularly relevant if the source person has recently engaged in "high-risk" activities, such as sharing drug-injection equipment or having unprotected sex.

Knowing the source person's status is not necessary for treatment decisions in the event of a possible HBV exposure; vaccination is recommended in the event of a possible exposure for anyone who has not already been vaccinated. There is no preventive vaccine against HCV nor is there a known effective post-exposure prophylaxis. Compulsory testing legislation offers little benefit, therefore, in making decisions about PEP regarding HBV and HCV.

Preventing secondary transmission

A person who has potentially been exposed to a blood-borne infection may need to take precautions in order not to infect others in the event she or he is infected. Persons exposed to HIV should be counselled about safer sex practices and about advising their sexual partners of the potential risk of transmission. They should also be informed about other activities that pose a risk of transmission (e.g., sharing drug consumption equipment). They should refrain from donating blood, plasma, organs, tissue or semen. Women should be counselled about possible risks to the infant if exposed to HIV *in utero*, during labour and delivery, and through breast milk. Temporary behaviour modifications can and should be undertaken until an exposed person can determine whether or not he or she has seroconverted — none of this requires, nor should it be dependent on, forcibly testing the source person without consent.

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. He or she should refrain from donating blood, plasma, organs, tissue or semen.

[23] For a description of different testing technologies available for HIV, HCV and HBV see N. Constantine, et al. "HIV Antibody Assays", *HIV insite*, May 2006, online: http://hivinsite.ucsf.edu/Insite?page=kb-00&doc=kb-02-02-01. See also 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.

None of HIV, HBV or HCV is casually transmitted; therefore an exposed person need not change his or her behaviour beyond what is mentioned in the preceding paragraphs to prevent secondary transmission.[24]

Alleviating anxiety of the exposed person

A person who has experienced a significant occupational exposure to blood or bodily fluid (and potentially blood-borne pathogens) will no doubt experience anxiety. This anxiety is likely to persist until he or she has definitively tested negative for HBV, HCV or HIV, which may take up to six months.[25]

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. Knowledge of the source person's HIV test result may be a double-edged sword with respect to the anxiety felt by the exposed person. In cases where the source person tests *positive* for HIV, this information will only *increase* the exposed person's anxiety during the waiting period, although the risk of infection remains very low, as outlined above.

Providing appropriate counselling and information to the exposed person is likely more important than testing in order relieve the exposed person's anxiety. Counselling can and should be done without resort to compulsory testing. Many exposed police officers, fire fighters, health care workers and good Samaritans believe that they are at much higher risk of infection than the circumstances of their exposure indicate, or do not fully understand window periods and what the test results mean. This misinformation is a tremendous source of anxiety to exposed persons and it is fully avoidable. If any legislative action should be taken, it is to ensure that workers and others who are exposed to bodily fluids are guaranteed timely, accurate information and counselling and support while taking

[24] Emergency responders have been quoted in the media stating that they are afraid to hug and kiss their loved ones following potential exposures. Such statements, which are not based on real risks of transmission, contribute to misinformation amongst the public. That any emergency responder would refrain from hugging or kissing their loved ones to prevent secondary exposure only underlines the need for comprehensive education on HIV transmission and prevention. See, e.g.: C. Sanders, "Firefighters' union supports quick-testing bill," *Winnipeg Free Press* (on-line edition), 29 April 2008: "He carried with him the burden that he may have contracted something and is unknowingly carrying it and possibly passing it on to his loved ones…. Imagine being scared to hug your kids or kiss your wife.",

[25] The majority of people who become infected with HIV seroconvert (which means they begin to produce specific antibodies in response to the presence of the virus) within the first 3 months following exposure, and often within the first few weeks. Ninety-five percent will have seroconverted within 6 months following exposure. Therefore, if this has not happened by 3 months, or certainly by 6 months, following the exposure, the chances of seroconverting beyond that point are practically nil. Using early-generation HIV tests, HIV antibodies can be detected within 6 to 12 weeks after infection (the time period prior to tests being able to detect the antibodies is what is referred to as the "window period"). Some newer tests however are able to detect antibodies as early as 1.5 to 3 weeks after infection. See: N. Constantine, "HIV Antibody Assays", and C. Major, "HIV testing – the nexus of technology and sociobehavioural intervention", plenary presentation at Ontario HIV Treatment Network Annual Research Conference, November 2008.

PEP — including, if needed, time off work without loss of pay — in circumstances where this is indicated.

4. Compulsory testing and disclosure legislation unjustifiably violates human rights

a) The 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 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.[26] 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. Respect for persons — the ethical imperative — requires that each person is valued and treated as an end in himself or herself, not merely as means to the ends of other people.

The principle of informed consent is explicit in HIV testing guidelines within Canada and internationally. Moreover, the Canadian Medical Association's *Code of Ethics* advises physicians that "[i]f a service is recommended for the benefit of others, as for example in matters of public health, inform the patient of this fact and proceed only with explicit informed consent or where required by law."[27]

b) Human rights concerns under the *Charter*

Forced testing raises numerous human rights concerns under the *Canadian Charter of Rights and Freedoms*. 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.

<u>The rights to liberty, security of the person and physical privacy</u>

Forcibly subjecting a person to a medical procedure without consent infringes security of the person. To have your blood drawn against your express wishes represents the quintessential harm against which the *Charter* right is intended to provide some protection. 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.

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[26] *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).

[27] *CMA Code of Ethics*, (Update 2004), para. 23.

The proposed legislation provides that a source person who refuses to comply with an order to provide a blood sample for testing is guilty of an offence. It thereby would criminalize a person for asserting their legal right to bodily integrity and informed consent. Furthermore, if the aid of peace officers is used to compel testing in the face of a refusal to comply with the court's order, further infringements of both liberty and security of the person would ensue in forcibly detaining a person and drawing blood.

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 person's blood from a person who holds it subject to a duty to respect the dignity and privacy of that person."[28]

The Court had said previously in one of the leading cases on section 8 of the *Charter*,[29] 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."[30] The Supreme Court has since reiterated: "That physical integrity, including bodily fluids, ranks high among the matters receiving constitutional protection, there is no doubt…"[31]

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 his or her will and provide the test results to a person claiming to have been exposed to a risk of infection.[32] In this case, a woman sought an order that the man accused of sexually assaulting her provide a blood sample for HIV testing.[33] The order was refused. The court, a Quebec trial court, expressly referred to the Supreme

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[28] *R v Dyment*. In this case, 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.

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

[30] *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.

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

[32] There have been other cases in which a request for a testing order has ultimately been agreed to by the accused, so the issue of the constitutionality of forced HIV testing has not been judicially analysed in those cases.

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

Court's decision in *Dyment* and noted that forced testing raises serious *Charter* concerns.

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 of those circumstances, 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.

Forced blood testing legislation such as that proposed for the Yukon would authorize medical tests on people without their consent, 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. Under this legislation, an accident victim found unconscious by the roadside could be ordered to be tested for HIV, HCV and/or HBV if an emergency responder came into contact with the victim's blood. Someone injured in a domestic assault could be compelled to be tested for these viruses if a healthcare worker accidentally stuck him or herself with a needle while treating her injuries. Any patient receiving health care services could be the subject of an order for compulsory testing.

The violation of physical privacy and bodily integrity is compounded by a violation of psychological integrity by removing for the source person the option to decide whether and when to get tested in accordance with his or her own personal circumstances.

The right to 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 to release personal information.[34] While most people consent to testing in circumstances of occupational exposure, there are indeed good reasons why someone may not wish to be tested or to have his or her test results revealed to the exposed person. The loss of confidentiality about something as significant as HIV status can produce a whole range of negative consequences.

Stigma and discrimination related to HIV/AIDS remain a reality in Canada.[35] Discrimination in employment, services, accommodation and membership in

[34] [1990] 1 SCR 30 at 46.

[35] See: Info sheets: "HIV/AIDS and discrimination", T. de Bruyn, *HIV/AIDS and Discrimination: Final Report*, Canadian HIV/AIDS Legal Network, 1998; and T. de Bruyn, *A Plan of action for Canada to reduce HIV/AIDS-related stigma and discrimination*, Canadian HIV/AIDS Legal Network, 2004. All these documents are available on-line via www.aidslaw.ca/discrimination.

social or professional associations persists for people known or perceived to be HIV-positive (or to have hepatitis). A victim of domestic assault who tests HIV-positive faces the prospect that public health authorities would notify his or her partner of the possible past exposure, exposing the assault survivor to further risk of violence.

The confidentiality afforded in forced testing legislation can never be more than illusory.[36] The very purpose of forced testing legislation is to inform an exposed person of the source person's serostatus. Even if the legislation states that the exposed person and those who are involved in carrying out responsibilities under the legislation (e.g., public health officer, health care worker, lab technician) are not allowed to disclose this information to others, this is likely to be unenforceable in practice. The invasion of the source person's privacy would be particularly acute in a smaller community.

Evidence of someone's HIV-positive status can also become evidence in court proceedings. Once the source person's status is known, that information is compellable under oath. 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.[37] 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).

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. Experience to date indicates media interest in reporting cases of occupational HIV exposure of police officers and emergency responders. An application made by an emergency responder for a compulsory testing order could attract media attention and risks leading to the publication of the names or other identifying information about the source person. In most cases, there is no effective, accessible remedy for privacy violations.[38]

Rights violations cannot be justified

In the leading *Oakes* case,[39] the Supreme Court of Canada set out the requirements for justifying legislation that infringes *Charter* rights under the provisions of section 1 of the *Charter*:

[36] S. 14 of the Draft "Mandatory Testing and Disclosure Act".

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

[38] See generally *Privacy Protection and the Disclosure of Health Information: Legal Issues for People Living with HIV/AIDS in Canada*, Canadian HIV/AIDS Legal Network, 2002-2004, online via www.aidslaw.ca/privacy.

[39] *R v Oakes*, [1986] 1 SCR 103.

- 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 (step 1 of the *Oakes* test). However, the forced testing legislation proposed for Yukon would fail each of the remaining steps required to justify a violation of *Charter* rights.

Assuming that this proposed legislation is intended to protect emergency responders from infection and provide them with peace of mind in the face of the risks they face, for the reasons we have laid out above about the limitations of compulsory testing, it is *not* rationally connected to, nor does it achieve, the legislative objectives.[40]

With respect to the third step of the test, we submit that forced testing legislation 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 may 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.

[40] After-the-fact testing for HIV, HBV or HCV does not protect against the occurrence of exposures, nor does it make workplaces safer environments. Furthermore, 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 initiating post-exposure prophylaxis. As for addressing anxiety post-exposure, if emergency responders are provided with accurate information about HIV, HBV and HCV transmission and the risks involved in different types of exposures, as well as appropriate counselling, treatment and support services, there would be little more "peace of mind" to be gained from a forced testing procedure.

Finally, we submit that the requisite proportionality between objectives and infringement of *Charter* rights is not adequately demonstrated. The benefit to the exposed person is limited, and the potential negative consequences to the forcibly tested person are significant; this is therefore not a proportional response. Workers who risk exposure to blood-borne pathogens deserve a more considered, comprehensive response from legislators which offers them real protection against infections to which they may be exposed. This view is shared by various leading associations of health professionals have criticized this sort of legislation as "not warranted" or "unjustified."[41]

5. Consistency in the law is an important policy consideration

Proposed legislation such as the Draft "Mandatory Testing and Disclosure Act" also raises the issue of consistency in the law, which is desirable as a matter of public policy. This legislation would authorize the compulsory testing of a source person in the event that an emergency responder 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 in any circumstances. Surely, as a progressive, democratic society, this is not an avenue we would wish to pursue.[42]

6. Conclusions and recommendations

Forced testing legislation, as is being proposed in the Yukon, offers few benefits to emergency responders potentially exposed to HIV, HBV and/or HCV in the course of their duties, but raises serious constitutional concerns.

As detailed in this submission, legislation of this sort is a flawed response to the real anxiety and health concerns of those potentially exposed to blood-borne infections. Misinformation about the true risks of infection and the limited benefit of test results compelled under legislation of this sort often motivate calls for legislation of this sort. Legislators therefore must avail themselves to the best

[41] 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.

[42] This question was raised by representatives of Justice Canada before the House of Commons Standing Committee with respect to similar forced testing legislation, which legislation that Committee ultimately recommended not proceed: 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.

available medical and scientific evidence regarding communicable diseases – their prevention, transmission risks, and related human rights issues.

The rights of source persons deserve protection, and the very real negative consequences that can flow from compelled blood testing should give legislators pause when confronted with this draft bill. Testing source persons' blood without consent, as contemplated in the forced testing legislation, is not a balanced, effective response to this issue. An approach that offers real HIV prevention and support, and protects the human rights of everyone involved represents a more constructive and useful alternative.

Given the limited benefits and considerable risks posed by this policy approach, the Canadian HIV/AIDS Legal Network urges the Government of the Yukon to withdraw, and all Members of the Legislative Assembly to oppose, this legislation.

Appendix 1
Recommended Revisions to Draft "Mandatory Testing and Disclosure Act"

The Canadian HIV/AIDS Legal Network urges the Government of the Yukon to withdraw this legislation and all parties in the Legislative Assembly to oppose such. In the event that it is passed nonetheless, we encourage you to adopt the following revisions.

Recommendation #1: Limit scope of application of law

Section 2(1)(a) states that an individual may apply for a testing order if the individual has come into contact with a bodily substance of another individual in one of the circumstances listed in (i)-(iii). This formulation is much broader than is justified.

The only bodily fluids capable of transmitting HBV, HCV or HIV are blood (including serum, plasma and all biological fluids visibly contaminated with blood); breast milk; pleural, amniotic, pericardial, synovial and cerebrospinal fluid; uterine/vaginal secretions and semen; and saliva. (Note: saliva on its own may transmit *only* HBV; if saliva is contaminated by blood, it may also transmit HCV and HIV.) The Act should define "bodily substance" to reflect these limitations (s.1).

Furthermore, a forced testing order should never be issued unless a significant exposure has occurred. A significant exposure is a percutaneous injury or the contact of mucous membrane or non-intact skin with a potentially infectious body fluid or tissue. The provisions should be revised to permit an application only in the event of a significant exposure and a definition of "significant exposure" should be added to s.1.

Recommendation #2: Allow forced testing orders against emergency workers and others

The same justifications for allowing forced testing order when emergency responders are exposed to bodily fluids apply when another person is exposed to bodily fluids of an emergency responder. In order to ensure consistency in the law, the following provisions should therefore be added to the list contained in section 2(1)(a)(i)–(iii) of circumstances that trigger the right to apply to the court for a testing order.

> (iv) while receiving emergency health care services or emergency first aid from that individual; or
>
> (v) while that individual is performing any other prescribed function;

Recommendation #3: Require baseline testing of the exposed person

Section 3 states that for the purposes of preparing the medical practitioner report, a medical practitioner *may* require the applicant to submit to an examination, testing, counselling or treatment. This should be revised to read "… a medical practitioner must require the applicant to submit to an examination, testing and counselling, unless in the

circumstances of the case, submitting to an examination, testing and counselling is impossible."

Recommendation #4: Ensure a thorough medical assessment of risk while protecting confidentiality

The following provisions should be added to **section 3** in order to ensure that: a) the most accurate medical risk assessment possible is presented to the court; b) that the confidentiality of the source person is protected as much as possible; and c) to inform decisions about the appropriate course of PEP, where PEP is appropriate:

> (2) Where possible or practicable the medical practitioner completing the medical practitioner report should seek information on a confidential basis from the source person to inform the assessment of the risk of infection. Any information provided to the medical practitioner by the source person,
>
> (a) shall be provided on a voluntary and confidential basis, and
>
> (b) must not be disclosed to the applicant without the source person's written consent.
>
> (3) In order to assist in obtaining information from the source person that will assist the medical practitioner in assessing the risk of infection, the medical practitioner must inform the source person that any information that the source person provides will not be disclosed to the applicant, and will only be disclosed, if relevant, to the judge presiding over an application for a testing order.
>
> (4) The medical practitioner's report must be submitted directly to the court and only released to the applicant if the court determines that it contains no confidential information from or about the source person.[43]

Recommendation #5: Ensure consideration of other potential harms to source person of forced testing

Section 4(1)(d) prohibits taking a sample from the source individual if it would endanger the source individual's life or health. The harms associated with denying someone the right to determine when and how he or she is tested, and to control who knows this sensitive confidential personal health information, goes far beyond endangerment of life or health. This provision should, therefore, be amended to include consideration of other substantive harms such as mental anguish and a reasonable apprehension of violence or discrimination.

[43] In the alternative, the law could require that the medical practitioner seal the medical practitioner report and that it be submitted to the court by the applicant with that seal unbroken.

Recommendation #6: Ensure counselling accompanies testing of source person

Section 6(1) lists several requirements of the health professional who takes the blood sample from the source person. Added to this list should be that they provide pre- and post-testing counselling in accordance with accepted professional standards.

Recommendation #7: Minimizing infringement of confidentiality; ensuring counselling for exposed person

Section 8(1)(a) provides that a copy of the test results shall be provided to the applicant and the applicant's medical practitioner. The results should be provided only to the applicant's medical practitioner, and the medical practitioner should provide counselling in accordance with accepted professional standards to the applicant when revealing the test results. Disclosure of the source person's personal medical information should always be as minimal as possible.

In addition, **section 14(1)** on confidentiality should explicitly prohibit the applicant from revealing any personal health information about the source person should the applicant come to know such information.

Recommendation #8: Limit prescribed diseases

Section 17 (a) allows the Commissioner in Executive Council to make regulations specifying the communicable diseases for which the Act applies. In these regulations, there is no need to include HBV because of the highly effective vaccine and post-exposure treatment for those who have not been vaccinated, which is recommended irrespective of the source person's status. Similarly, HCV should not be included, as there is no post-exposure prophylaxis option — knowing the source person's HCV status therefore can serve no purpose in making decisions regarding such prophylaxis.

Recommendation #9: Mitigate harshness of penalties

Section 18 outlines the penalties for contravening the Act. The Act should clearly designate two separate offences, firstly an offence for breaching the confidentiality guarantees and a second offence for failing to cooperate with a forced testing order. Given the severe harms that can result to a person living with HIV, HBV or HCV from the disclosure of that information without their consent, the fine for breaching the confidentiality guarantees should be significant.

Recognizing that there may be many good reasons why a person is unwilling or unable to comply with a forced testing order, as well as the violations of their rights to security of the person and privacy that are implicated in compulsory testing and disclosure, the fine for this second offence should be minimal, to a maximum of three days' worth of further fines for continuing offences.